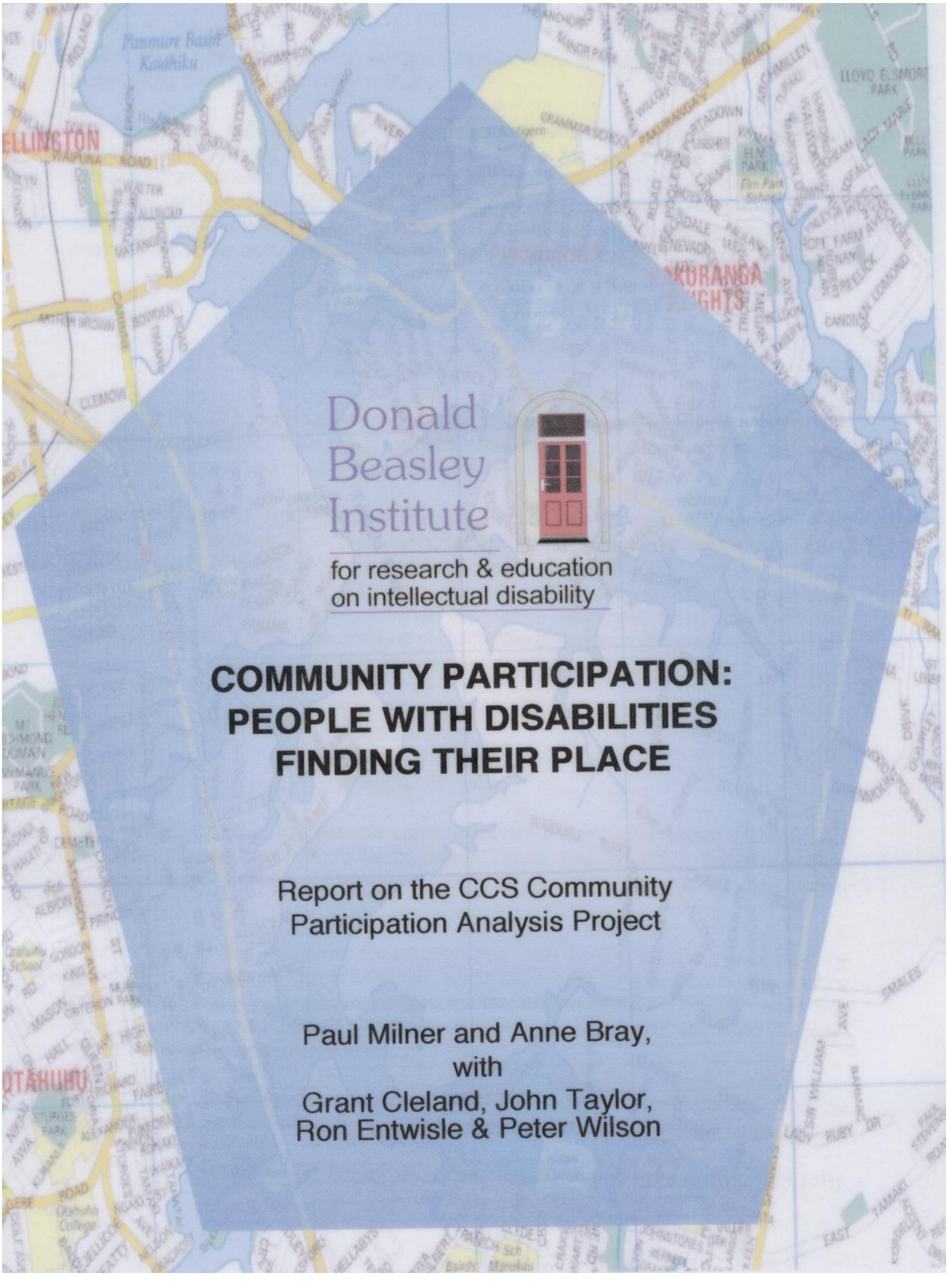

Donald
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on intellectual disability

COMMUNITY PARTICIPATION: PEOPLE WITH DISABILITIES FINDING THEIR PLACE

Report on the CCS Community Participation Analysis Project

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with
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The Community Participation Analysis Project and this Final Report was made possible by the love and labour of many.

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Paul Milner, Anne Bray, Grant Cleland, John Taylor and Ron Entwisle.

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EXECUTIVE SUMMARY

Chapter 1: Introduction

In 2003 the Ministry of Social Development gave money to CCS to do a *"participatory action research project."* The aim of the project was to develop some shared understandings of community participation and ways to support people with disabilities to take part in community life. The project was to actively involve CCS Service users and staff to explore:

- the actual experiences of service users and their support staff compared to current government and CCS definitions of community participation;
- the negative and positive experiences of people with disabilities;
- the implications for people who use, staff and fund disability support services.

CCS contracted the Donald Beasley Institute to do this research project.

Two government policy documents set out the principles that disability support services are required to follow. The stated aim of the ***New Zealand Disability Strategy*** is to guide New Zealand towards a non-disabling society. The goal is for people with disabilities to be able to say they live in "*a society that highly values our lives and continually enhances our full participation."*

Pathways to Inclusion sets out what the government sees as the future direction of vocational services. The aim of the policy is to increase the participation of people with disabilities in employment and other forms of community participation.

This chapter explored recent ideas about "community". These ideas about "community" include the inter-related aspects of place, people and a sense of belonging. Thinking about communities having all three aspects means that it is too simple to think of community as a location or place or that it is the opposite of segregated settings.

Places have many different attributes that influence how people experience them. These can include whether they are public or private spaces, how physically or socially accessible they are and how familiar or unpredictable they feel. Because of the way places vary people react to them differently. In some settings people experience a sense of place that involves a strong emotional attachment. In others people only experience a community presence. People appear to feel a sense of belonging to places where they experience supportive social relationships.

People with disabilities often find it difficult to occupy socially valued community roles or participate in decisions that affect their lives.

Current understandings of community participation may not pay sufficient attention to the **Social Model of Disability,** which describes the community's role in creating disability. People with disabilities are often required to fit into their communities, rather than changing communities so they can accommodate all citizens.

Chapter 2: Method: How the Project Was Carried Out

A participatory action research model was requested by CCS. Service users, staff and the research team worked together to gather information and to reflect about the implications of what people said about the way they participated in their communities.

Ethical approval for the research was obtained from five Regional Ethics Committees before the research began.

Invitations to participate in the study were sent to service users in five CCS regions. People could take part in focus groups and/or individual interviews. Nineteen service users contributed to four focus groups in four regions. Four of these individuals also gave an individual interview. Nine other people gave individual interviews.

The ages of the people with disabilities ranged from 25-56 years. They had an average age of 39 years. Seventeen men and 11 women with disabilities took part. Most people described themselves as European. One Pacific Islander and two Maori service users chose to take part and one person did not nominate an ethnicity. There was a variation in the length of time people had been supported by CCS. The average time spent as a service user was 16.9 years, but most people had been receiving support for either less than 6 years or more than 18 years. The amount of support provided by CCS to participants was fairly evenly distributed between historical support (0 hours) and more than 20 hours per week.

CCS vocational staff from two regions were invited to take part in a focus group to provide staff feedback to the Draft Report. Seventeen staff from across the spectrum of CCS services took part. The 13 women and four men who participated were mostly aged between 31-50 years and most had worked for CCS for less than 5 years.

A preliminary analysis of the data was sent to all participants in a Draft Report for their feedback. Once their feedback had been analysed and the report amended, a Preliminary Report was considered further by representatives of National CCS and the Research Team prior to the final report being completed.

Chapter 3: How People with Disabilities Participate in their Communities

Community Activities: What people do.

People participated in their communities in many different ways. Most people's activities included a mix of involvement in informal networks like family, organized community activities, and segregated (disabled only) activities.

Almost all of most people's time was spent at home or in a Vocational Centre. Very few people had paid jobs. No one participated in more than six different types of activity beyond the home. Men and women tended to do different types of activities.

Most people participated in the community with other service users or support staff. Some people liked going out in groups: others did not.

People who had the most disabled friends were also the most comfortable in being in the community, and went to more places. People were most comfortable asking for help from someone who knew them.

Although everyone wanted to be more involved within the community beyond the Centre, many still wanted to participate with other disabled people in community settings where they felt vulnerable.

The places where people felt most valued and comfortable were: family, church, shopping, work, and continuing education.

Activities taking place from Vocational Centres tended to be fleeting and irregular, rather than sustained and on-going. Most activities took place in public spaces, where money was exchanged.

Many people were undertaking training courses. Most people enjoyed these, but some saw them as inappropriate or time-wasting and not leading to jobs.

There was a lot of similarity among the group in their range of activities, and people often felt they did not have much control over what they did and when they did it.

Community relationships: Being with other people

Most people had few friends, with staff and family often identified as key people in their lives. Being with people changed activities into **social** events. Friendships were mostly around the contexts in which people participated, and these different friends rarely met with other friends. A lack of resources and support often made it hard for people to keep friendships going.

To meet with other members of the community, people had to go out: the community seldom came **in** to the disabled person's setting. Some people had managed to make contact with others without having to go out, by the telephone, radio talkback, and the internet.

Unfortunately people were doubly disadvantaged because the best way to make friends and become connected is through friends and contacts you have already.

Anyone’s involvement in their community depends on the places where people are familiar and feel comfortable and the “pathways’ or ways that people connect with these places and people. We can use this model to think about supporting people to participate in their communities. (Chapter 3 has a story and a diagram at the end which illustrates these ideas).

Chapter 4: An Analysis of Community from the viewpoint of People with Disabilities

What is community?

People with disabilities initially described “the community” as a place “out there”, somewhere different to home and apart from a segregated service. These public places “out there” included disabled and non-disabled people. Some people felt that being “out” in the community gave a political message about the rights of people with disabilities to be part of the community. Being in places that were separate from the wider community was sometimes associated with isolation and boredom. The wider community was seen as offering the **potential** for friendships and a more interesting life, but changes were needed in community attitudes and behaviours towards people with disabilities.

These initial ideas about community, however, did not adequately portray the richness and diversity of people’s experiences. Ideas about “community”, from the perspectives of people with disabilities also need to be considered within the complexity and variety of their individual, daily lives.

The Complexity of Life

The complex and varied experiences of people with disabilities showed that being “out” in the community could be a very negative experience. On the other hand, being part of a separate, disabled-only “community” was often a very important and positive part of people’s lives. People needed to feel safe, supported and valued when they went into “outside” community settings. Relationships with other people with disabilities were greatly valued. These findings show that **it is simplistic to assume that “the community”, as it is now, will meet all the needs of people with disabilities for the experience of community.**

The central notion of the community as a “place” needs to be expanded to consider the varied characteristics of different places, and what these mean to people with disabilities.

Attributes of place

The overlaps and blurring of boundaries between public and private spaces helps us to understand the experiences of people with disabilities. The priority of **how people are treated over where** they spend their time is a critical finding. This finding should guide policy and its implementation in practice, in both community development at the wider level, and in the provision of individualised disability support services. So what are the characteristics that people with disabilities value in their lives – whether they are involved in public or private spaces, "the community" or "segregated services"? The next section will describe these characteristics.

Valued characteristics of spaces/places

The characteristics of places that were valued by people with disabilities were: self-determination, choice, and personal control; a social identity – being known and accepted; being able to contribute, reciprocal relationships; psychological safety and comfort; and positive expectations. People with disabilities advised others to be assertive and persistent in pursuing their own goals. So, if people with disabilities act on this advice, **and** "the community" supports self-determination, promotes a positive social identity, and enables people with disabilities to contribute to their communities – what will be the outcome? The ultimate outcome of these valued characteristics is a sense of membership – in communities, and "the community".

Chapter 5: Employment and Family: Contexts for Community Participation

Employment

People with disabilities identified employment as extremely important to them and saw a job as a critical part of community participation. However, none of those interviewed had a job of more than three hours a week. People's work was a source of pride and social identity, as well as increasing a very low income. Volunteering was valued more highly than sheltered work. Without any employment people sometimes felt isolated and this could lead to depression. Work provided opportunities to meet new people and to contribute to the community.

Having a job was of most importance to people with more severe, multiple disabilities but they were the least likely to be given support to work.

A few people saw other aspects of their life as more important than employment, and valued their "free time".

People did note that employers could be discriminatory and some were not aware that discrimination on the grounds of disability was against the law. People who were older felt doubly disadvantaged.

Many people felt that their education had not prepared them adequately for employment.

Family

People's families were one of the most important places of "community" for most people. Family was connected to the idea of "home", a place where people belonged and where their disability was irrelevant.

Family members **knew** them, they shared the whole story of their lives. They provided a place of psychological safety – a safe place to return to.

Families provided emotional and sometimes material resources for people. They also created opportunities to widen people's social networks.

The primary source of intimacy and emotional support in people's lives came from their families. They also enabled the person with a disability to contribute in a reciprocal way to others whom they cared about.

Families provided the continuous long-term relationships that professionals and support workers cannot provide.

Proximity to their families appeared to influence people's willingness to try new things, to venture out. People who had stayed in contact with a supportive family tended to participate in a wider array of community activities, and had a stronger sense of personal control.

Support services should consider how they can support people to stay close to their families. Families can also provide valuable knowledge and models of support for service providers.

Chapter 6: Individual Stories

It is not possible to summarise these four stories.

Chapter 7: CCS Staff Respond to Views of Service Users

Seventeen CCS staff discussed the Draft Report in two focus groups. Staff feedback included both a staff perspective and, for some staff, a personal perspective as a person with a disability.

In general, staff found the ideas and experiences from service users were familiar to them. They confirmed the importance of employment, and, while not wanting to set people up to fail, staff also affirmed the right of people to have another chance. They noted that some people chose other avenues for participation, instead of employment.

Staff agreed that there is a danger of stereotyping and low expectations of people with disabilities, by parents and/or staff.

Support for inclusion in the community was noted as sometimes requiring long term support and considerable coordination.

Staff challenged themselves about the degree of real choices for CCS service users. Some felt that there was a danger that people could be “pushed into” community participation, when this was not their choice. The value of spending time with other people with disabilities was also confirmed.

Staff expressed frustration with what they saw as an overemphasis on “quantitative outcomes”, when process and other ways of spending time were seen as critically important to people with disabilities.

Some staff felt that some service users may have been “spoon-fed” ideas about community vs segregation. They felt that people sometimes repeated the philosophy, but, in actuality, had often had very negative experiences in community settings.

Staff were very concerned about current gaps and limitations in available services, particularly for young people leaving school.

Other issues raised were the limits on availability of wheelchairs and other technology, and the lack of access to support at weekends and holidays.

The danger of increasing isolation as a result of current service trends was raised. Lack of choice in housing would also increase isolation.

Some staff felt there were differences between older and younger service users, due to differences in their educational experiences.

There was some critical comment on current government strategies, and the needs assessment and service coordination process.

The limitations of transport were seen as posing enormous barriers to community participation.

Staff noted the vital role of advocacy in their work. Staff reflected on what the views of people with disabilities implied for their own skills and qualities as support staff.

Other issues were discussed, including, educating the community' lifestyle plans; the low value placed on support staff; staying on at school until age 21.

Finally, staff noted the difference in the way service users defined community in terms of "what it is **not**", whereas no staff defined it this way.

Chapter 8: What Helps and Hinders Community Participation

Introduction

The research has shown how the **experience** of community is more about people than places. Bricks and mortar, "segregation" or "integration" were not as important as how people were treated, wherever they were. Attachments to people grow into attachments to places. When asked about "the community", however, people with disabilities talked initially about the places where they spent little time – "out there". Being "out there" was seen as valuable because it offered opportunities for new experiences, and a valued social identity. People also talked about other "communities of choice" in which they experienced acceptance and affirmation. Even though everyone's story was different, there are conclusions which can be drawn about what hinders and helps community participation.

Barriers to Community participation

From the research findings we can identify a number of barriers to community participation for people with disabilities. These barriers can be grouped into personal, service, community and policy barriers.

Personal barriers include:

- the lack of friends;
- a lack of personal and social confidence;
- unwillingness to complain;
- low expectations and the protectiveness of family.

Service barriers include:

- limited imagination;
- inadequate communication support;
- the use of time;

- the quality of support time;
- a perceived lack of transparency;
- problems with individualized planning;
- collective vs individual participation;
- the availability of services.

What helps Community Participation

What helps community participation includes addressing all the barriers. The following areas appear to be particularly important:

- access to technology that erodes the distance of space;
- supporting and sustaining friendships;
- supporting relationships with families;
- finding employment;
- promoting a sustained and regular presence;
- having safe places to return to;
- giving people real choices;
- having a participatory presence in services.

Chapter 9: Implications for Policy and Practice, and for People with Disabilities Themselves

This final chapter sets out some implications of this research for people with disabilities, for CCS and other service providers, and for policy makers.

Implications for people with disabilities

People with disabilities involved in this research challenged and encouraged others to be strong, increase control of their own lives, and strive to achieve their own goals. They urged people with disabilities to make sure their voices are heard in their own lives and in the planning and organization of services. They stressed the need to value each other and to work together to gain a stronger political voice.

Implications for CCS, and other service providers

The strong desire of people with disabilities for employment suggests that more resources and expertise may need to go into this area.

Community participation is complex and involves the whole of life, implying that supports need to be designed to meet the needs of individuals, rather than organizations.

Services need to be sensitive to the needs of people with disabilities to feel physically and psychologically safe when they go into unfamiliar community settings.

Closing vocational centres, as part of a move towards community integration, needs to be undertaken with care. They clearly meet some important needs for some people with disabilities. It is critical that such closures do not have unintended consequences, such as increased isolation and no way for people with disabilities to spend time together. People with disabilities should be fully consulted and involved in any service changes.

Other ways of increasing community participation, such as bringing the community in to people's lives, could be explored.

Some disabled people could benefit from personal development courses and counselling, to help them to move on from traumatic and hurtful experiences in their lives.

Services need to consider how to support people to make friends and sustain longterm friendships.

Autonomy, personal control, and reciprocity are agreed service principles, but there is a challenge to make them more of a reality within support services.

Implications for policy

Community participation requires an Intersectoral approach at policy and funding levels, which can be translated into the actual level of service delivery.

The physical environment and lack of transport continue to be significant barriers to community participation and require concerted attention.

Community participation is an ongoing process, not a simple outcome and goal. This fact raises questions about the appropriateness of current funding and accountability processes.

The appropriateness of the **goals** of "Pathways to Inclusion" are confirmed in this research, but the implementation of the Strategy needs a critical review. Community participation is not a programme, and "community" cannot be simply conceived as a place, or places, where people do things.

Coordination of supports is an important part of community participation, but a lack of clear responsibility and current structures often prevent effective coordination.

Individualised funding is one possible avenue to consider in addressing these issues.

Poverty, or inadequate income, poses enormous barriers to community participation for many people with disabilities.

Finally, achieving the goal of the New Zealand Disability Strategy requires changing the community itself. There is an urgent need for a public education and awareness campaign to begin to address the prejudice, intolerance, and sometimes hostility, experienced by some people with disabilities.

CHAPTER 1

INTRODUCTION

The origin of this Project

In 2003, the Ministry of Social Development provided funding to CCS to undertake a "participatory action research project into the community participation of adults with physical disabilities". The aims of the project were to develop some shared understandings of "community participation", and to describe effective ways to support people with disabilities to participate in their communities (CCS Project Brief, 2003). The project was to increase knowledge or evidence about community participation and to actively involve CCS service users and staff in the project.

The research was to explore:

- current government and CCS definitions of community participation in the light of the actual experiences of CCS service users (people with disabilities) and staff;
- describe the experiences – positive and negative – of people with disabilities themselves;
- set out some implications for: the people who use CCS support; the people who provide that support; and the people who fund that support (individuals, CCS, and the Ministry of Social Development).

CCS contracted the Donald Beasley Institute in Dunedin to undertake this research project. The Donald Beasley Institute is a national disability research institute, which is a non-profit, independent organisation, governed by a Trust Board. (The next chapter describes how the research was carried out).

The research project was not supposed to look at services which are designed to support people with disabilities to find jobs, live with dignity in homes of their choice, or participate in leisure and recreation. However, these boundaries for the Project were continually broken by the people with disabilities who took part. Their experiences of life and community participation do not fit into "funding streams" or "policy definitions".

Why focus on "community participation"?

The New Zealand government has outlined its guiding principles for all its actions as they affect New Zealanders with disabilities in the New Zealand Disability Strategy (2001). People with disabilities were strongly involved in the development of this important document. The longterm goal of the strategy is for people with disabilities to be able to say that they live in

> *"a society that highly values our lives and continually enhances our full participation".*

The strategy has a number of underlying values including the following:

- we move forward from exclusion, tolerance and accommodation to a fully inclusive and mutually supportive society;
- disabled people are integrated into community life on their own terms – equal opportunities are assured but individual choices are available and respected;
- the abilities of disabled people are valued, not questioned;
- interdependence is recognised and valued, especially relationships between disabled people and their families, friends, whanau and other people who provide support;
- the diversity of disabled people, including their cultural backgrounds, is recognised, and there is flexibility to support their differing aspirations and goals;
- community-based services ensure that disabled people are supported to live in their own communities and institutionalisation is eliminated.

(Minister for Disability Issues, 2004: Progress in Implementing the New Zealand Disability Strategy, 1 July 2002 to 30 June 2003).

The New Zealand Disability Strategy sets out 15 objectives. The objectives most relevant to this Project are:

1. Encourage and educate for a non-disabling society.

3. Provide the best education for disabled people.

4. Provide opportunities in employment and economic development for disabled people.

7. Create long-term support systems centred on the individual.

8. Support quality living in the community for disabled people.

9. Support lifestyle choices, recreation and culture for disabled people.

15. Value families, whanau and people providing ongoing support.

Another important Government strategy was also launched in 2001, called "Pathways to Inclusion". This policy provided the future direction for vocational services for people with disabilities. This policy seeks to achieve one or both of the following outcomes for people with disabilities.

- To increase the participation of people with disabilities in employment.

- To increase the participation of people with disabilities in their communities.

The Ministry of Social Development contributes towards the cost of disability support services which focus on achieving these two outcomes. A typical service specification for the purchase and provision of vocational services states:

> *Community Participation may be an outcome in its own right when an individual is not seeking work; it may be a means of 'stair-casing' an individual towards employment; or it may complement employment (for example, when an individual is waiting for a supported employment placement and requires services to retain skills and motivation, or when a person is in part-time employment because of the nature of their impairment, and requires alternative services while not working to sustain their ability to work.*

Services which receive funding from government (as a contribution towards the costs of services) under this policy are expected to work towards the following:

- provision of similar opportunities (to other people at that stage of their lives or age group);

- achievement of valued social roles;

- employment support and skill development;

- individual focus;

- decision-making and choice;

- services which reflect the distinctive needs of Maori;

- services which meet the distinctive needs of Pacific Peoples;

- participation and inclusion in the life of the community, in training and/or in employment, … where appropriate and possible, these activities should take place in 'ordinary' places (the 'mainstream');

- quality services.

Services are not supposed to focus on the provision of respite for the family, care, or therapy, although respite may be a secondary outcome, and “care” may be a necessary component of supporting the person to access activities or training.

But what **is** “community participation”? What is “the mainsteam”? What is “community”? Is it a **place?** Does it have to be away from places that include people with disabilities?

What is “community participation”?

This section draws extensively from a recent literature review of community participation for people with intellectual disabilities (Bray & Gates, 2003). Much of the research covered in this review includes people with **developmental** disabilities, a term which includes many people with physical and/or multiple disabilities.

The concept of “community” itself is highly debated and the focus of a considerable body of theoretical discussion. For the purposes of this project, it is sensible to use a “commonsense”, general concept which views “community” as a geographical place which includes the ordinary and varied activities of other citizens. It may also be seen as including sub-communities and “communities of interest”, such as “community groups”.

In the field of disability research, “community” is typically presented as the opposite of segregation or isolation in “special” facilities or services which only include disabled people and those who are paid to support them.

A number of definitions of “community” include the three inter-related components of **“Place, people, and a sense of belonging”** (Bell & Newby, 1974; Wellman & Leighton, 1979; both cited in Walker,1999). This multifaceted concept is helpful in the context of this project, as it avoids a narrow view of community as simply a location which is **not** an institution (Walker, 1999). From the point of view of adults with disabilities, therefore, simply conceiving of “community” as a place or location, cannot address the issue of “community participation”. However, this 3-part model of community provides a useful framework. Do adults with disabilities have “a sense of place” in the community? Are they involved in a variety of social networks? Do **they** feel a “sense of membership or belonging? to a community or communities?

The concept of “place” can also be examined in more detail. (Relph,1976, cited in Walker, 1999) pointed out that “place is just not the ‘where’ of something; it is the location plus everything that occupies that location seen as an integrated and meaningful phenomenon.” In considering “place”, we can consider to what extent adults with disabilities occupy places designated for that group, rather than places which are used by the general public.

A further useful distinction is between public versus private places. For example, there is an increasing tendency for people to spend more leisure time in private rather than public spheres. It has been suggested that we derive our sense of community through private connections more than through broad community-based connections and involvement.

“Community participation” is conceived to involve more than mere “community presence.” It would also be unrealistic to expect all individuals to participate comfortably in every conceivable community context. No person, non-disabled or disabled, experiences universal acceptance or rejection in community places or contexts. Everyone feels accepted and welcome in some places and rejected and unwelcome in others.

Taylor, Bogdan and Lutfiyya, (1995), (cited in Walker,1999) note that the actual **experience** of “community” is complex and dynamic, and is composed of both negative and positive experiences. They also described a continuum of community participation, ranging from mere “community presence” to a “sense of place”, involving a positive attachment or identification with a place (Agnew & Duncan, 1989; Cloke, Philo & Sadler, 1991; Eyles, 1985; all cited in Walker,1999).

A further dimension of community is the notion of a political entity, as well as a geographic and psychological sense of place and belonging (Abraham, 1989; Baron & Haldene, 1992; Wilmot & Thomas, 1984; all cited in Myers, Ager, Kerr & Myles, 1998). Past conceptions of “community” have tended to be based on monocultural and traditional values, and failed to reflect the variety of communities to which we actually belong. People move between numbers of different communities to reflect different aspects of their lives and this enhances their choices and experiences.

There is a general agreement that an essential component of the **experience** of community is a personal feeling of belonging. A sense of belonging also includes experiencing support and greater control over one’s life (Biklen, 1983). It is clear, therefore, that “community participation” must involve participation in the “**social** life of the community through a growing network of personal relationships” (O’Brien, 1987). For a positive experience of community participation, adults with disabilities need to be able to be involved in various community places and activities free from discrimination and abuse from other community members (Menard, 1997).

Community participation also requires a consideration of the various valued roles that individual community members fill e.g. tenant, citizen, volunteer, employee, parent (Broderick, 1996). Adults with disabilities may play few roles, and these may be roles which imply dependency and lack of community contribution. For example, the roles of “client” or “resident” (of a particular facility) are not usually perceived as valued roles of community members. The roles available may be significantly created and maintained by the type of support services provided for adults with disabilities.

Ryan (1997) relates community participation to citizenship which she describes as “about a person’s capacity to fully participate in all dimensions of social, political and community life” (p. 19). She goes on to note that such participation must include participating in decisions which affect our lives. Thus community participation is an

active process, not a passive one. When adults with disabilities are placed in the role of mere service consumers, they will not be seen as “citizens actively engaged in community life” (p. 20).

Support services have also been charged with the responsibility for enabling people with disabilities to enjoy a ‘quality of life’, characterised by “community participation”. O’Brien (1987) identified five core service accomplishments or outcomes, in services for people with disabilities:

- having a community presence in the ‘ordinary places that define community life’;
- having the opportunity to make choices both at the level of day to day decision making and more fundamental life choices;
- having the opportunity to develop the competencies and skills to be able to undertake functional and meaningful activities;
- being accorded respect;
- participating in the social life of the community through a growing network of personal relationships (O’Brien, 1987).

There have also been concerns raised that the concept of community participation and the values implied within it, have not paid sufficient attention to a social model of disability, which identifies and challenges the community’s role in the construction of disability. An uncritical notion, for example, that “the community” does not need to change, (to address the goal and process of community participation), should be strongly challenged. Simply trying to “fit” adults with disabilities into existing structures and community activities, without addressing issues of discrimination, devaluation, and rejection – is bound to fail.

Some of the assumptions inherent in some concepts and empirical research also deserve serious reflection. For example, why are relationships and friendships between adults with disabilities seen as somehow less desirable or less valuable than relationships with non-disabled people? Surely an “inclusive community” also **includes** all adults with disabilities? Are the issues of personal choice in danger of becoming subsumed uncritically to an overly simplistic ideology?

In summary, research into the community participation of adults with disabilities will need to examine the following components of community participation:

- **Where** do adults with disabilities spend their time?
- **What** do they do in these places?
- **Who** do they do things with?

- **What social relationships** and networks do they have?

- Do they feel they **belong** – in various places, activities, and social groups?

- Are they perceived by others as **community members?**

- What **roles** do they fill in the community?

- What are the **barriers** to their participation in community(ies)?

- What do **people with disabilities themselves say, if we really listen?**

Summary:

In 2003 the Ministry of Social Development gave money to CCS to do a *"participatory action research project."* The aim of the project was to develop some shared understandings of community participation and ways to support people with disabilities to take part in community life. The project was to actively involve CCS Service users and staff to explore:

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CCS contracted the Donald Beasley Institute to do this research project.

Two government policy documents set out the principles that disability support services are required to follow. The stated aim of the ***New Zealand Disability Strategy*** is to guide New Zealand towards a non-disabling society. The goal is for people with disabilities to be able to say they live in "*a society that highly values our lives and continually enhances our full participation."*

Pathways to Inclusion sets out what the government sees as the future direction of vocational services. The aim of the policy is to increase the participation of people with disabilities in employment and other forms of community participation.

This chapter explored recent ideas about "community". These ideas about "community" include the inter-related aspects of place, people and a sense of belonging. Thinking about communities having all three aspects means that it is too simple to think of community as a location or place or that it is the opposite of segregated settings.

Places have many different attributes that influence how people experience them. These can include whether they are public or private spaces, how physically or socially accessible they are and how familiar or unpredictable they feel. Because of the way places vary people react to them differently. In some settings people experience a sense of place that involves a strong emotional attachment. In others people only experience a community presence. People appear to feel a sense of belonging to places where they experience supportive social relationships.

People with disabilities often find it difficult to occupy socially valued community roles or participate in decisions that affect their lives.

Current understandings of community participation may not pay sufficient attention to the **Social Model of Disability,** which describes the community’s role in creating disability. People with disabilities are often required to fit into their communities, rather than changing communities so they can accommodate all citizens.

CHAPTER 2

METHOD: HOW THE PROJECT WAS CARRIED OUT

The aims of the Project

The Donald Beasley Institute expanded on the original aims of the research, restating them as follows:

- to provide a critical analysis of the process and goal of community participation in the light of the research literature, policy, and specification statements, and the actual experience of service users in CCS (adults with physical disabilities identified by CCS);
- to describe the meanings and experiences of service users in the area of community participation;
- to obtain reflective feedback from CCS staff on the implications of the critical analysis and views of service users;
- to present individual stories of positive experiences of community participation;
- to suggest general principles of best practice emerging from the project as a whole.

The research method used

The research method which CCS requested for the Project was “participatory action research”. This model of research involves active participation in the research by key stakeholders, and a strong focus on seeking ways to improve practice. The emphasis is on a collaborative approach in which everyone works together to gather and analyse relevant information, and to reflect on its implications.

Action research typically involves a series of cycles – asking questions, seeking answers, reflecting, changing practice, evaluating changes – which are repeated. Throughout the process researchers and practitioners work together as a “collaborative community of researchers” (Carr & Kemmis, 1986; Kemmis & McTaggart, 2000).

This Project was constrained by its short timeframe and limited budget, but the key elements of participatory action research were retained as follows:

- The Project Team included a majority of researchers with personal experience of impairment and disability.

- The Team included a representative of CCS as the service provider.

- The major emphasis was on seeking direct input from adults who used CCS services about their experiences and interpretations of “community participation”.

- CCS staff were involved in reflecting on the initial findings, as a critical part of the action research cycle.

- All participants – people with disabilities and CCS staff – were given the opportunity to provide feedback on the draft Report.

- Individual stories were created jointly by people with disabilities and a researcher.

- Representatives of the National CCS Team were involved before and throughout the Project, for feedback, reflection and input.

Planning for the Project

Ethics review: The first step in undertaking the research involved seeking ethical review and approval of the proposed research. The Research Team first met with the CCS Kaumatua and retained contact with him and the Whanau group to ensure that the planned processes were appropriate and met Treaty obligations.

Ethics applications were sent to five Regional Ethics Committees in each of the proposed areas of the research. The Ethics Application, including information sheets and consent forms, is included in Appendix 1.

This multicentre process is currently required for health and disability research which takes place in more than one locality. (The process will change in 2005, when only one review will be required, from a new national committee). With the five Ethics Committees all meeting on different dates and the intervening Christmas period, obtaining ethical approval from all five committees took four months. These delays inevitably affected the planned timeframe for the Project.

CCS Regional Coordinators. CCS appointed a staff member as Regional Coordinator in each region in which the research was to occur. These coordinators undertook all the organizational details of inviting participants, organizing venues, ensuring support for participants, hosting the Research Team, etc. Without this valued, critical support, the Project would not have been possible.

Who was involved? Invitations to CCS service users were distributed in five CCS regions by the Regional Coordinators. People with disabilities were invited to participate in focus groups and/or individual interviews. Those who were interested in participating returned completed interest forms directly to the Donald Beasley Institute.

The original intention was to hold seven focus groups and individual interviews with ten individuals. The purpose of the focus groups was for service users to discuss their own perceptions and experiences of community participation, within a safe environment. Each focus group was facilitated by an experienced member of the Project Team, with a second member keeping a record of the discussion. Ground rules for each Focus Group provided a framework for discussion (Appendix 2).

The Regional Coordinators undertook all the organisational tasks for the focus groups and individual interviews, including arranging venues and transport. These tasks were a crucial component of the overall Project.

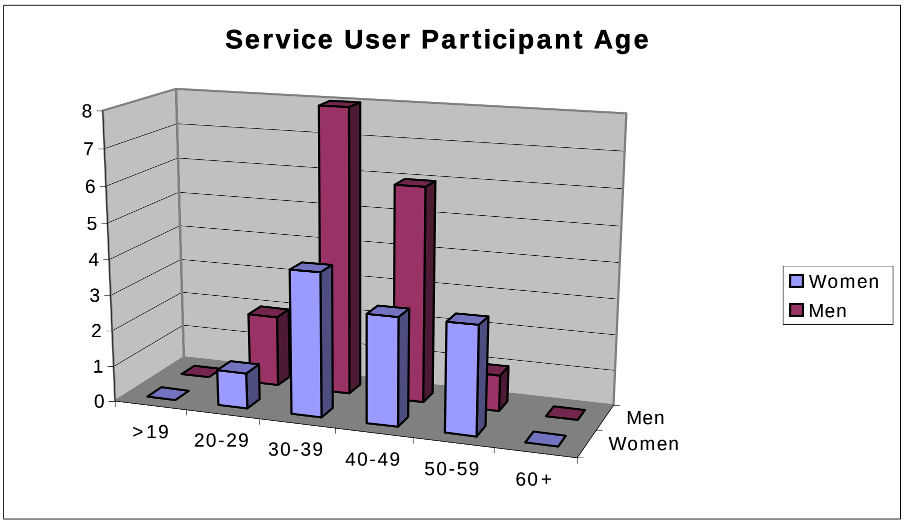
Nineteen people with disabilities took part in four focus groups in four regions. Four of these people also gave individual interviews. Nine other people gave individual interviews only. These 28 service users were fewer than the Project had hoped to include, but their contributions have provided a wealth of information.

As noted in the Project aims, the individual interviews were originally seeking “positive” stories, in order to identify positive contributors to best practice. However, the Ethics Committee pointed out that individuals should be free to tell their whole stories, which may also include negative experiences. This expanded aim was included in the information sent to participants.

Age and gender of participants

The ages of the 28 participants ranged from 25 to 56 years, with the average age being 39 years. The average age of the women was 41 years, slightly older than the men who had an average age of 38 years. There were 17 men and 11 women involved in the focus groups and interviews (Figure 1).

Figure 1. Service User Participant Age



The individual interviews were all undertaken by members of the Research Team, and were taped and transcribed. The transcriptions were returned to the interviewees to check for errors or omissions. Interviewees could also change or delete any passages.

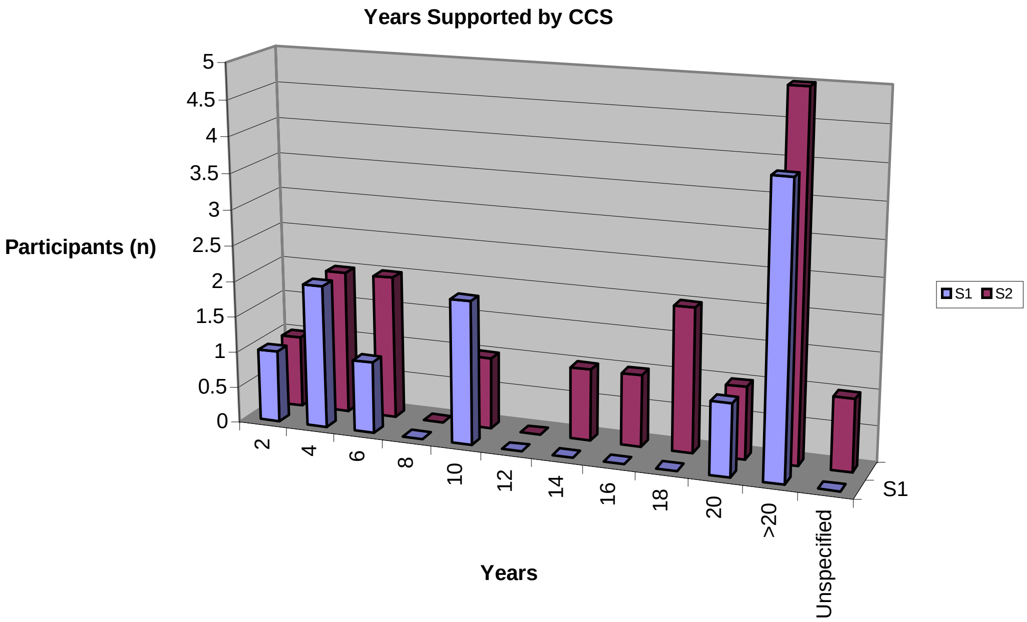
Ethnicity

Most participants described themselves as European. One Pacific Island and two Maori service users chose to participate. One person did not nominate an ethnicity category.

Length of service use

The length of time participants had been using CCS services ranged from between less than one year, up to having received support for forty-two years. The average time spent as a service user of CCS was 16.9 years, but there was a bi-modal clustering of participants at either pole of the distribution with a slightly higher number of participants using CCS for less than six years and another cluster who had used the service for most of their life (Figure Two).

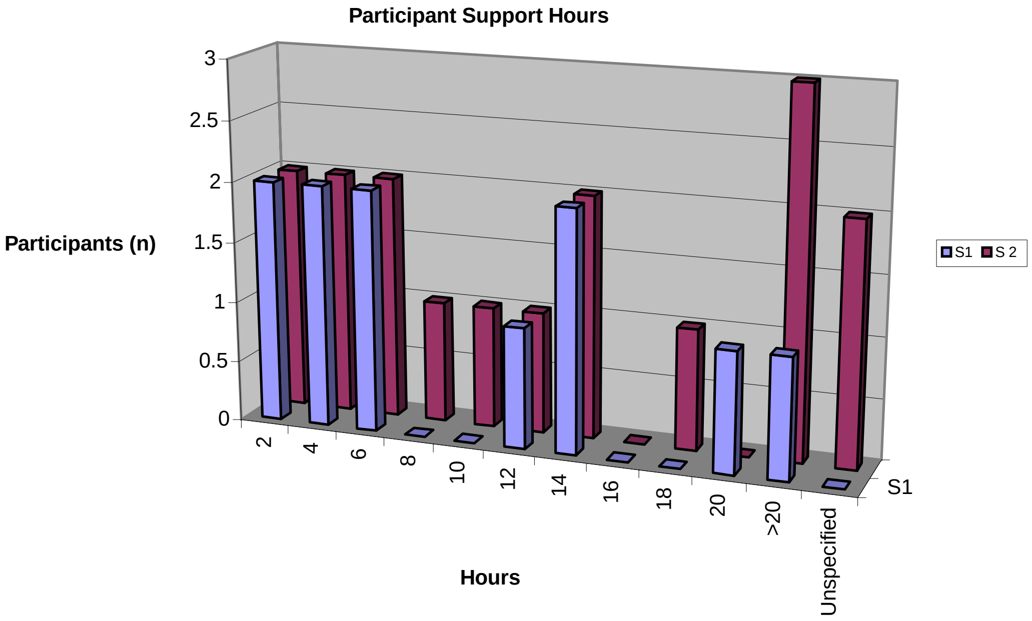
Figure 2: Number of Years Participants had received support from CCS



Support hours received

The spread of hours participants received support from CCS was much more uniform. Support varied from historical support (0 hours) to up to thirty-five hours. The average number of support hours for the group was 9.7. Given the small population size and the spread of support hours, it is difficult to tell whether participants who chose different forms of participation also differed in personal characteristics. (Figure 3).

Figure 3: Support hours received by participants.



Analysis of information from the focus groups and individual interviews with people with disabilities.

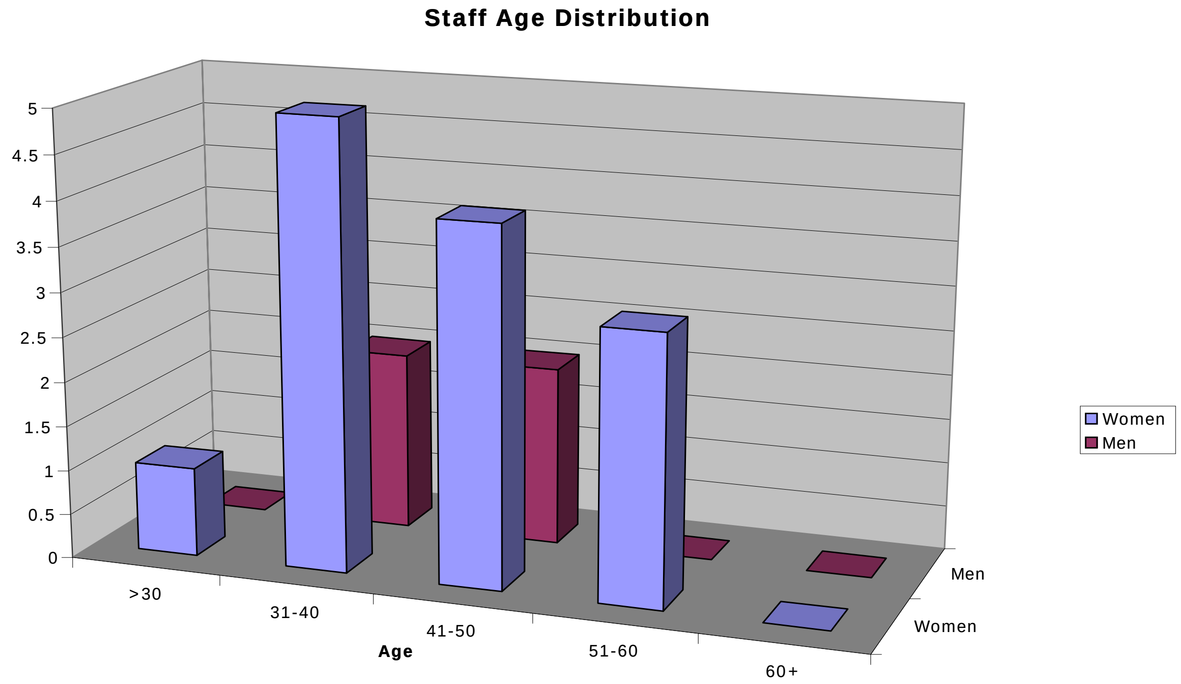
All of the data were read and re-read by at least two researchers on the Project Team. Researchers identified common themes and issues which emerged from the data itself. This was a detailed and iterative process involving reflection and discussion between and among the researchers. Paul Milner took primary responsibility for the in-depth analyses of the data and the restructuring of the information into the explanatory models and categories outlined in this Report.

The initial analysis of the data was considered and reflected on by the whole Research Team. A final presentation of this initial analysis then provided the basis for the staff focus group discussions (Appendix 3).

Staff focus groups

CCS staff who worked in CCS Vocational Services in two different CCS regions were invited to take part in focus groups to provide feedback on the initial analyses. Seventeen staff participated in two focus groups, 11 in one group, and 6 in the other group. Thirteen staff were women and four were men. These staff were mostly aged 31 to 50 years (Figure 4).

Figure 4: Staff age distribution



	>30	31-40	41-50	51-60	60+
▢ Women	1	5	4	3	0
■ Men	0	2	2	0	0

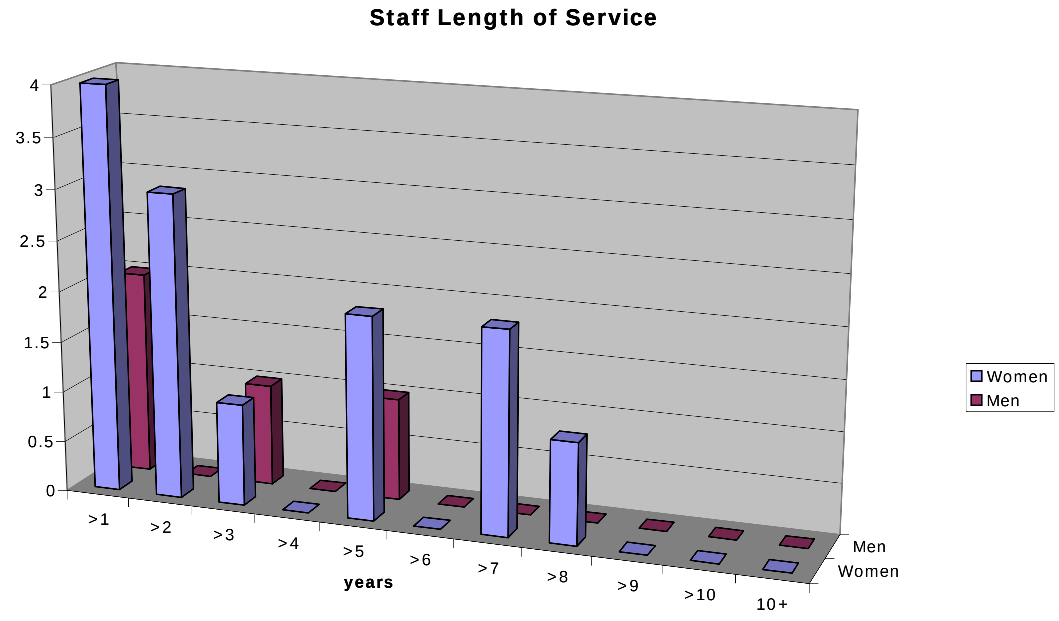
The staff involved undertook a wide range of roles in CCS services.

Table 1: Staff job titles

Job Title	n
Community Support Worker	3
Transition/Employment Consultant	3
Tutor	1
Support Coordinator	2
Supported Living Coordinator	2
Team Coordinator	1
Vocational Support Worker	1
Volunteer Coordinator	1
Whanau Support Worker	1
Community Access Coordinator	1
Service Manager	1

Most staff involved in the focus groups had worked for CCS for five years or less. The average length of service for women was 3.5 years and for men, 2.5 years (Figure 5).

Figure 5: Staff length of service



	>1	>2	>3	>4	>5	>6	>7	>8	>9	>10	10+
🟦 Women	4	3	1	0	2	0	2	1	0	0	0
🟥 Men	2	0	1	0	1	0	0	0	0	0	0

Following confirmation of staff intention to participate, each staff member was sent an initial analysis of the data from the focus groups and interviews with people with disabilities (Appendix 3).

Each staff focus group was facilitated by a member of the Research Team. One focus group was also attended by a second researcher. Written notes and transcriptions of the discussion provided the feedback data from CCS staff.

The data were examined for common themes and critical points made by staff, in relation to the purpose of the research. An initial analysis of this data, in terms of main points, was part of the draft report which went to all participants for feedback (see next section).

Final steps in the process

A final draft of the Report was sent to all participants – service users and staff – for feedback and comment. A structured feedback form and outline of the Report detailing what was in each chapter and the state of completion of each chapter was also enclosed with the draft Report (Appendix 4). Summaries of Chapters 3, 4, and 5 were also included for those who did not wish to read the longer chapters.

Feedback was received from 15 people with disabilities (54%) and five staff (29%). The first question in the feedback form asked how the Report should refer to the non-staff participants. As the majority of both people with disabilities and staff preferred the term “people with disabilities”, that is the predominant terminology used in this Report. Appendix 5 provides a summary of the feedback received, which was overwhelmingly supportive of the presentation and analyses of the data. Individuals also added further comments/additional data. These are also provided in Appendix 5. Useful suggestions were also made about ensuring the accessibility and wide dissemination of the final Report.

The completed Draft Report was then considered by representatives of the National CCS Team and the whole Research Team before publication.

Summary

A participatory action research model was requested by CCS. Service users, staff and the research team worked together to gather information and to reflect about the implications of what people said about the way they participated in their communities.

Ethical approval for the research was obtained from five Regional Ethics Committees before the research began.

Invitations to participate in the study were sent to service users in five CCS regions. People could take part in focus groups and/or individual interviews. Nineteen service users contributed to four focus groups in four regions. Four of these individuals also gave an individual interview. Nine other people gave individual interviews.

The ages of the people with disabilities ranged from 25-56 years. They had an average age of 39 years. Seventeen men and 11 women with disabilities took part. Most people described themselves as European. One Pacific Islander and two Maori service users chose to take part and one person did not nominate an ethnicity. There was a variation in the length of time people had been supported by CCS. The average time spent as a service user was 16.9 years, but most people had been receiving support for either less than 6 years or more than 18 years. The amount of support provided by CCS to participants was fairly evenly distributed between historical support (0 hours) and more than 20 hours per week.

CCS vocational staff from two regions were invited to take part in a focus group to provide staff feedback to the Draft Report. Seventeen staff from across the spectrum of CCS services took part. The 13 women and four men who participated were mostly aged between 31-50 years and most had worked for CCS for less than 5 years.

A preliminary analysis of the data was sent to all participants in a Draft Report for their feedback. Once their feedback had been analysed and the report amended, a Preliminary Report was considered further by representatives of National CCS and the Research Team prior to the final report being completed.

CHAPTER 3:

HOW PEOPLE WITH DISABILITIES PARTICIPATE IN THEIR COMMUNITIES NOW

Community activities: what people do

People participated in their communities in many different ways. For some people, CCS services constituted their entire social universe, but for the most part, people's activity included a mix of involvement in segregated programmes, organised activities in community settings and activities that occurred within informal social networks.

Most people reported spending almost all of their time in one of two places, either home or a vocational setting – A Vocational Centre, Day programme, or training course.

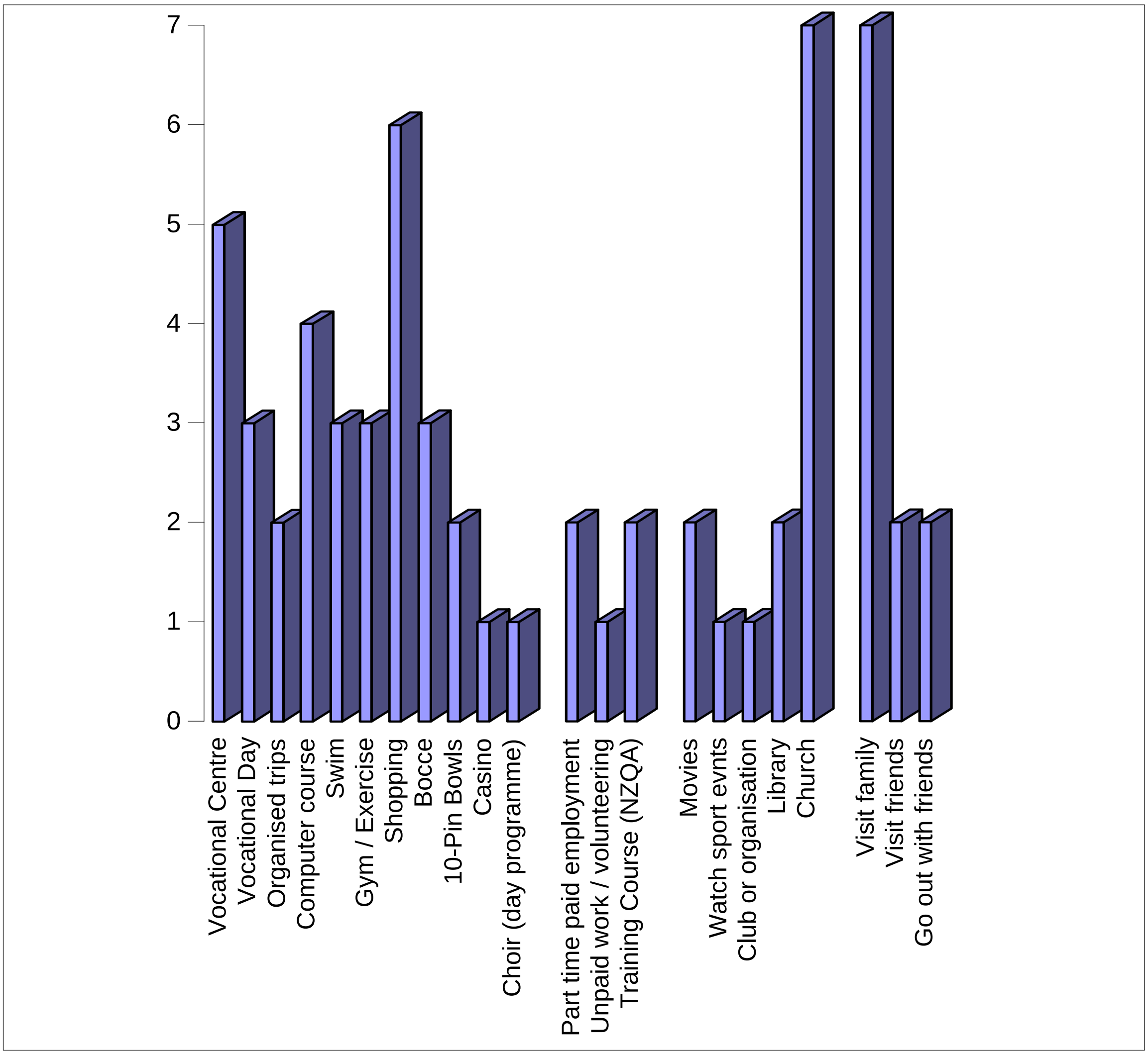
It was rare for people to spend any significant time in paid employment. For example, of those that volunteered individual interviews, only one person was employed on a regular basis, and no-one was employed for more than three hours a week. Most people were either unemployed, doing a course, or volunteering their labour.

Almost all of the different ways that people engaged with the community occurred from a base of home or a vocational centre. For people with severe or multiple disabilities, the vocational centre day programme was typically the focus of their community participation. For them, most of their activities and valued interpersonal relationships were supported by their involvement with some form of centralised day programme (Figure 6).

A number of questions in interviews and focus groups attempted to tease out the range of ways that people participated in the community. Figure 6 shows the number of times a particular form of engagement was mentioned by someone as being part of their own life activities. This graph gives a general flavour of the life-spaces of the people who spoke to us.

The activities recorded in Figure 6 are **all** of the ways people said that they participated. No individual volunteered more than six different types of activity beyond the home. People generally had a small life-space and few contexts in which to be either visible or involved within the community.

Figure 6: The activities people named in individual interviews.



One of the consequences of a limited life-space and limited individual support was that many people spent long periods on their own. Many were bored and any activity beyond the home was a welcome change.

> *Interviewer: How often do you (go to the Vocational Centre)?*
> *Mary: About eight hours (a week)*
> *Interviewer: What do you do the rest of the time?*
> *Mary: Sit here and watch TV.*
> *Interviewer: I noticed when I came in you were playing cards on the computer.*
> *Mary: Yes, when I am bored.*

Every woman who was interviewed also reported a number of hours in craft activities.

> *Interviewer:…are there any other good things you would like to tell me about that has happened to you…some activity or something you have done recently.*
> *Wendy: I could say my knitting.*
> *Interviewer: Do you like knitting?*
> *Wendy: I love it.*
> *Interviewer: What do you enjoy about it, what's a good thing?*
> *Wendy: Just watching it grow, I mean it might have to come undone in the end but it is always enjoyable.*

Men tended to go to the gym. They never mentioned handcrafts as a chosen activity. However both the gym and handcrafts were activities that participants experienced pleasure from seeing progress: whether row by row or weight by weight.

The other gender difference in activities was a tendency for younger males to more readily embrace new forms of participation, especially social events that took place at night – like going to the pub or catching an evening movie. These activities were regarded as having truly crossed the threshold of inclusive participation, but were also, coincidentally, the time people were **least** able to access support staff.

Many people appeared to have been socialised to see disability as a deficit, and there was anecdotal evidence, from staff especially, that women of an older generation felt stigmatised by disability.

Most people we spoke to participated in the community either in the company of other service users or accompanied by professional support staff. Some enjoyed going out with other service users on organised community activities.

> *Interviewer: What are your hobbies, what are you really interested in? You said Colouring. What else are you interested in?*
> *Kelly: Art.*
> *Interviewer: Have you been to the Art Gallery?*
> *Kelly indicated yes.*
> *Interviewer: How did that happen?*
> *Kelly: They got a special handicapped bus which is really fun.*

Other people disliked being in groups either because they felt their individual needs were swamped, or it was difficult to communicate meaningfully. Some people disliked being out in a group of people with disabilities because they felt being identified as "disabled" led to being understood by the community in ways that they felt did not describe them. For Marie, being cast as part of the disabled community impeded her ability to break free of it, because of the way people in the community responded to her once the ascription had been made.

> *Interviewer: Is there a disabled community?*

> *Marie: Yes, but it gets you trapped. It is one community but it is the wider communities that I want to be in.*
> *Interviewer: What is it about being in the disabled community that actually makes it more difficult to get out?*
> *Marie: People's opinions. People's way of thinking about you.*

Karen illustrated her point with the common experience of being ignored and talked over, or of staff interceding on her behalf. She felt these practices prevented her from engaging directly with her community.

> *When I go shopping, the shop person usually talks to the other person. That's an embarrassment.*

People did not feel the same about being in the community with other people with disabilities when they had chosen the activities. People enjoyed being with others whom they trusted and who understood them because of similar life experiences. They felt that being with other people helped to reduce their apprehension to try new things because of a lack of self confidence or fear of community hostility.

> *Trevor: I like people to come to the gym with me.*
> *Interviewer: Why do you like that?*
> *Trevor: Somebody you trust and you don't have people stare at you.*

Perhaps as a consequence, people who had the largest number of disabled friends also were most comfortable in being in the community and engaged in the widest range of places in their community.

> *I just like trying to get out into the community and (with) people I can associate with – with disabilities, different disabilities… (I feel comfortable when) out in the community – at a party or something like that and I have a friend there.*

Certainly, shared spaces and experiences make it easier to establish friendships.

> *Marie: I have one friend, Michelle. Yes, I see her on and off.*
> *Interviewer: How did you meet Michelle?*
> *Marie: She did the nanny course and people kind of gave her a hard time too…She was a bit older too… maybe that was it.*
> *Interviewer: And maybe a bit of empathy?*
> *Marie: Yes.*

People were also more comfortable to ask for assistance from someone who knew them and was not threatened by such a request.

> *If you have a problem it is not so hard for you to go to someone who can explain (understand) what is going wrong for you.*

Even though the bulk of people's activities took place either in segregated settings or in the context of service use, these forms of participation should not be devalued as <u>not</u> constituting others' concept of "community participation". Although participants expressed a universal desire to be more involved with the community beyond segregated settings, many chose to participate with other people with disabilities in environments where they felt vulnerable. Examples included: swimming; the gym; training courses; and the pub. These places featured prominently in the activity patterns of the people with disabilities who were interviewed.

A narrow range of "inclusive" forms of participation were the activities people most commonly named as a form of participation. These activities were: membership of a church group; sustaining a family identity through visits to parents or siblings; going shopping; employment; volunteering and continuing education (Figure 6). These contexts appeared to be places where people felt most valued and/or comfortable. They were also the most free of service culture and were forms of association where disability was incidental to membership.

These places were also where people had spent the greatest amount of discretionary time. In contrast, the forms of activity that radiated from vocational settings, were characteristically infrequent and fleeting. Going for walks, trips to the library, museum, or art gallery, the occasional swim, trip to the movies, or going to town to shop and have a coffee – these activities were ephemeral and provided fewer opportunities for people to build an identity through sustained presence.

Most activity shaped by service delivery also tended to take place in public spaces, where money was the main form of exchange. People "purchased" community engagement. As a consequence they had limited access to private social worlds and limited opportunity to contribute to relationships in a reciprocal way, other than through a financial transaction. Here again, forms of community participation supported by services differed from those most valued by people. Reciprocity and interpersonal intimacy were the currency of family, spiritual and educational/work relationships.

Relative to other people the same age, a large number of people with disabilities appeared to be undertaking training courses. Nearly a third of those interviewed were enrolled in a computer course, with others completing vocational training, work skills programmes or health and wellbeing courses. Most people enjoyed these courses and lamented the limited range of opportunities to continue with their education.

> *Support worker: Last year Louise did a Health and Wellbeing course, and you really love education, and you actually made some really good friends on the course. There is not a lot out there (anymore) because Louise has done the human services course… some years ago.*

Some people, however felt insulted by being placed in courses they believed to be inappropriate and others expressed cynicism about the number of courses and training programmes they had completed without a genuine commitment to finding real employment.

> *What we are finding here, just quietly, is that perhaps it becomes like a baby sitting service instead of a training service.*

Despite the wide variations among people, there was a remarkable similarity among their activities. Authorized forms of participation, like craft-work, 10-pin bowling, boccia, the gym and visits to the library, museum or shopping centre, featured prominently (Figure 6). There were a few spectacular exceptions like duck shooting or watching a local rugby league club, but these were a part of an individual's lifestyle that came from the family or personal interests of people before they were disabled.

People generally felt that they were not able to exercise a great deal of influence over either the timing or the sorts of activities that took place in service settings.

> *On Wednesdays we go out if it's fine and if it's wet we stay in.*
>
> *Interviewer: …you were telling me before (that) you get to choose what you do - you were saying you do a plan or something about your day, how does that work, Kelly?*
> *Kelly: Well basically like you go out, or if you don't do what you get told, you get told off basically, but no they basically want you out in the community.*

Only one person said that they belonged to a club or organization. Even then, it was a furtive membership that she had kept secret from all her other friends.

> *Don't laugh, I collect spoons.*

This limited range of participation existed even though participation in community groups was officially encouraged. People therefore had limited avenues for self-expression or for getting involved again in activities they had done before. Their lives were also limited largely to receiving rather than contributing to the lives of others and the community.

> *Interviewer: Do you belong to a surf club? The Surf Lifesaving Association of Australia – what about here in Dunedin? Do you belong to a surf club, Board Riders or…*
> *Adam: N O.*
> *Interviewer: Would you be interested?*
> *Adam: Y E S*
>
> *Interviewer: Now, you said you were interested in (Country) music, Louise. How does this find expression?….Do you go out and see country music?*
> *Louise: No.*

Community relationships: being with other people

Most people considered that they had few friends. Staff and family were more frequently identified as the key people in their lives

> *Interviewer: So who are your friends?*
> *Stuart: Haven't really got them – I have only got two.*

> *Wendy: Well, I like to get out and meet people, get to know people, and people can get to know me. I have said to the Polytech students, if there is anything you want, give me a ring. I have even given them my number but there is nothing out there. I wish I could get out more….meet more people, get other people interested in me.*

> *Louise: I am going out to visit.*
> *Support person: …from what I know of you, she is the first person outside of the staff, immediate family that you have….gone and visited on a friendship basis.*

Yet to most people, being with other people was more important than where these activities took place.

Louise hated being in groups. Part of the reason she resented groups was that she almost never had time alone with anyone unless she gate-crashed an office or met someone whilst out in public. And yet, when offered a one-to-one relationship in the form of individualised support from home, her preference was to be around people.

> *Interviewer: Which is more important, being in a place with other people (or) having the (one-to-one) support you want taken to your home? Being with people? (Louise is nodding), Isn't that interesting!*

Being with people changed the meaning of activities to become **social** events. Even though Trevor walked most days to relieve his boredom, what he really wanted was someone to walk with.

> *Interviewer: ….is it having somebody help you to think about what you would like to do, would that help?*
> *Trevor: No. I need somebody to help me to come and walk with me – come for walks.*

Furthermore, the friendships people did have were largely limited to the contexts in which they participated. Invariably their relationships were restricted to a few disconnected islands of contact. People from “one island” vary rarely met the inhabitants of the other islands in the archipelago.

Kelly, for example, said that she had a huge pool of friends. She was atypical in that she felt other service users were her best friends, and, in common with others, never escaped the ambit of service culture. She had no able bodied friends other than staff and had limited contact with her family. She appeared to love meeting other service users at the day centre and organised disability events like Boccia and 10-Pin bowling, but none of her friends rang for a chat, stayed over or arranged to meet her anywhere other than where they ordinarily would. From her side, Kelly never rang them either.

> *Interviewer: You really like going out for lunch?*
> *Kelly: Yes.*
> *Interviewer: How do you get there?*
> *Kelly: By handicapped bus.*
> *Interviewer: Who do you go with?*
> *Kelly: Some (Vocational Day Programme) staff.*
> *Interviewer: What about all those friends you listed before; Graham and Tessa and Hone……do you ever meet those guys?*
> *Kelly: No…..I just know their names basically, that’s about it.*
> *Interviewer: Are you friends with anyone else in (the) services you use?*
> *Kelly: Oh, yes.*
> *Interviewer: Do you go anywhere outside of work…..how do you stay in touch with those guys? Do you ring? Does anybody ring you, Kelly?*
> *Kelly: No…I meet them at work.*

The separation of people’s social networks into discrete islands of time and place was true for more independent people too. When asked who her friends were, Marie nominated one person that she had met on a course. She saw her less and less now the course had finished. Marie also considered her work colleagues to be friends. But her two groups of friends were destined never to meet as they were bound to their respective social contexts.

> *Interviewer: Do you have friends, who would your friends be?*
> *Marie: I have one friend, Michelle, yes, I see her on and off.*
> *Interviewer: How did you meet Michelle?*
> *Marie: She did a nanny course…..*
> *Interviewer: …..do you count the people that you work with at school as well?*
> *Marie: Yes.*
> *Interviewer: So do you have any contact with them outside of that?*
> *Marie: No.*

People also found it difficult to sustain friendships, lacking the resources or support to close distances of time or space. Any support available was arranged around typical working hours, rather than the number of hours that would match all sorts of community opportunities.

As would be true for all citizens, people who participated in the study had to go out to engage the community. What did appear to be different was the extent to which this was obligated. Seldom did the community ever come to people with disabilities in the familiar places where they were comfortable. People had few visitors either to their vocational centre or at home. The segregated nature of the places in which many people spent most of their time, meant that they rarely engaged the public from positions of greater knowledge or cultural familiarity. As a consequence, being in the community usually required an act of **migration**.

> *Interviewer: How do you stay in touch with your brother Trevor?*
> *Trevor: Ring them up.*
> *Interviewer: How many are in New Plymouth?*
> *Trevor: Three.*
> *Interviewer: And do you go and see them all or do they come and see you?*
> *Trevor: I go and see them. One lives down there.*
> *Interviewer: …how do you get down?*
> *Trevor: Walk there.*
> *Interviewer: That's great. Do they come and see you in your house?*
> *Trevor: No.*

Some people had, however, found ways to invite the community that were not tied to actual places. The telephone had a huge degree of significance to many people because it was often the most reliable conduit to the world of relationships outside. Mastery and control of the phone assumed great importance.

> *Interviewer: What things are you proud of, Louise?*
> *Louise: Me ringing you. (Interviewer phoning Louise)*
> *Support person: Communication over the phone because some people find that really difficult…..*
> *Interviewer: Oh right, (that) I understood you…… That's good. So would you like bit more of that? Of being understood.*
> *Louise: Yes.*

And later in the same conversation.

> *Interviewer: Control is an interesting word to use, the ability to not control, I did like the fact that when I rang you Louise, they put me straight through to your phone…. they were respectful enough that nobody thought to answer for you Louise, that was good.*
> *Louise: Yes.*
>
> *Support Person: You have just got into a new room with your own phone, you didn't have that previously. Although they would have always put you on the phone but it is pretty good having your own extension really.*

Barbara’s first response when asked to tell the interviewer what the good bits about her life were, stressed a new independence through using the phone.

> *I am living on my own. I do as much as possible. I am learning to ring a taxi.*

Some people had engaged with their community by monitoring its daily rhythms, like when people left to go to work, and where the school kids would hang out after school. Others engaged with a changing world through the television and radio talk back shows. One person spoke about creating his own website to bring people to him around his special interest in plants. Another person dissolved the distance of space through a chat room and was optimistic he was on the cusp of a new chapter in his life.

> *I have got a friend I have been talking to for nine months and I am hopefully moving up to the West Coast – to get married.*

People with limited life-spaces were doubly compromised because the most effective way to increase connections in the community was to already be connected. The wider people’s social network was and the more places they went, the greater their exposure to the new people and new places from which new forms of community participation might grow.

Louise’s visits to her only friend began because they had met while doing the same course at Polytech. The path that led to Marie’s becoming a teacher’s aide began after she had built a rapport with someone from Special Education Services whilst on placement, and ended by her being recommended by a teacher at the school where she was volunteering. Stuart had found his way to a computing course because of a conversation he had had at physiotherapy.

> *Interviewer: So basically what happened was, you were getting physio and someone talked about this place where they do computer courses?*
> *Stuart: I got here half an hour early so I decided to go for a walk and the lady said, you can use the computer.*

Often it was linkages like these and through informal networks that people were best able to sustain a community presence. The disparity in the size of John and Janet’s informal support network meant that their access to their respective communities was very different.

John lived in his own flat. He has recently moved to a small rural community, and although he does get a few, structured support hours, it was his informal support network that kept him engaged and feeling safe in his community.

> *….fortunately my next door neighbour, Mary, she gives me a lift there and back because it's quite a long way on the other side of town…..I can pretty much look after myself. Sometimes I need some help but I was fortunate to meet my good friend Meghan who helps me out whenever I need some help or if she is unavailable then I just call Sue next door or someone at the church.*

Janet lives in a large rest home. All of her supports come from the formal support services. Janet eloquently describes the position of vulnerability she is placed in because paid staff are her only link to the community and the lifestyle she wants for herself.

> *I have learnt patience…..(it's) very frustrating. I get sick of looking at four walls, but hey, doesn't everyone, so it's just a matter of keeping my cool….. The hardest bits are when you haven't got staff to take you where you want to go……(*barriers are) *mainly staff because there is not enough staff and three hours is not enough for me….. I wish I had more so I could get out more, meet more people, get other people interested in me.*

Representing people's forms of community participation

In the 1960s, American sociologist, Kevin Lynch suggested that the way people come to know, navigate and act in their communities depends on their "mental map" of where they live. Although everyone's is unique, he believed that they all shared some common features. Amongst those were "Nodes" and "Pathways." Lynch described "Nodes" as centres of attraction and activity that people knew more intimately and felt more comfortable in. "Pathways," were the familiar routes and ways that people used to connect their network. It is a good way to think about people's community participation because it gives us a model of the range and types of activity people engage in. It also gives us a useful frame of reference for thinking about the ways that certain places or Nodes become attractive to or are hostile to people with disabilities and what helps or hinders their passage.

People's mental maps are different because their lives are different. Pamela's story below is not one person's life, but a blending of some of the stories we heard. It is a simplification and is not the picture of any actual person, but it does summarize many of the themes we found when service users spoke to us.

Pamela's Story

Home and the Day Centre are the two places where Pamela spends most of her time. During the week she journeys between them by taxi. In the weekends, visits to her sister have become an important and highly valued routine. None of her friends or family ever come to hang out at Pamela's house.

Once a week Pamela goes shopping. She loves looking in the shop windows but always goes to the same coffee shop in the mall because she is familiar with what to do, and the shopkeeper now knows her and has taken the time to understand her speech.

A team leader at her service suggested to Pamela that she might like to volunteer to work in a kindergarten. This is a “job” to Pamela and it is the first one she has ever had. Even though it is only 3 hours a week, her work is the thing Pamela is most proud of. When Pamela introduces herself, she always tells people she works in a Kindy.

Pamela plays Boccia every Wednesday in a group organised by her Day Centre. Sometimes she goes for “walks” with other clients, but doesn’t like going out in a big group. It makes her feel somehow different to other people.

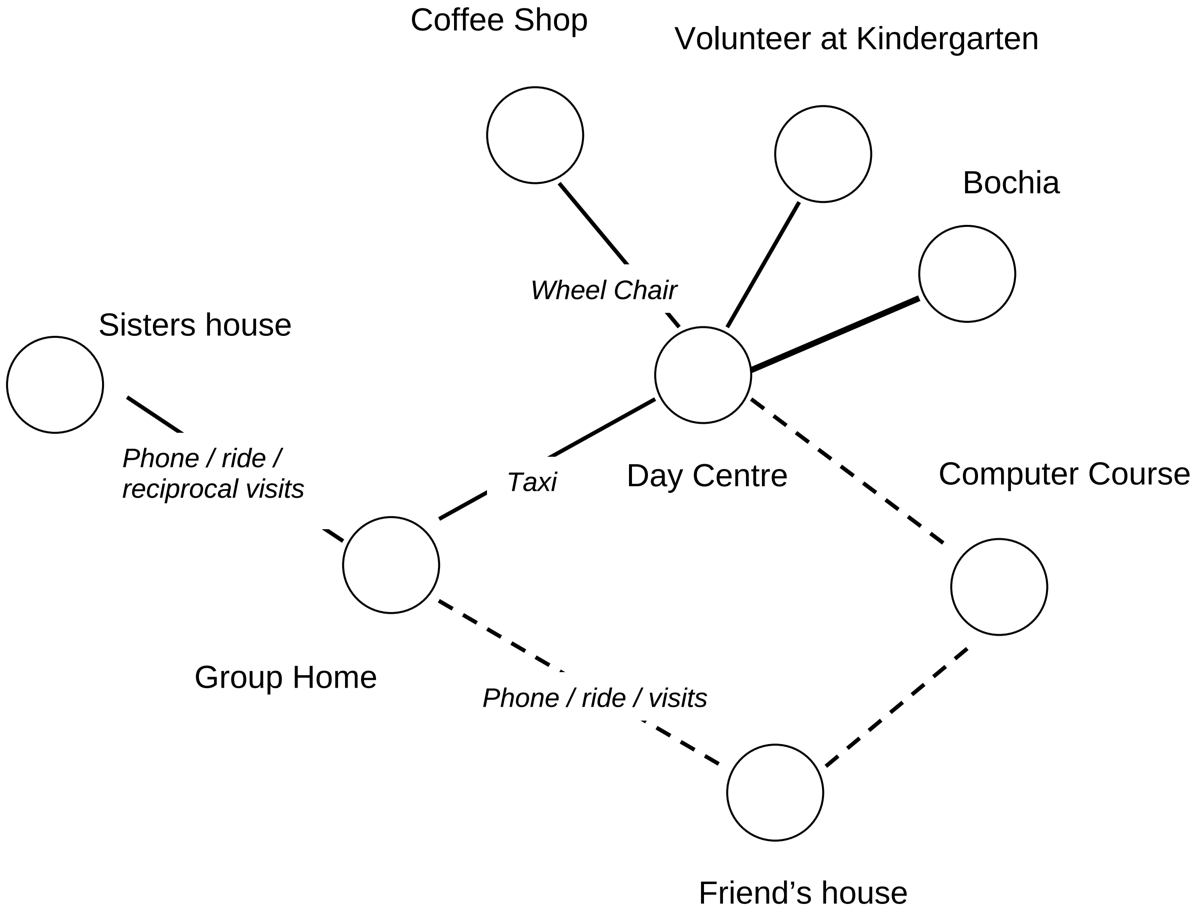
Once a week is “community participation.” Staff at the Vocational Centre have a few things organised, and sometimes when staff are bored they will go out in the fresh air. Even though Pamela is free to chose whether she wants to go or not, she said she would like to decide when and where and who she goes out with.

Pamela used to do a “computing for free” course and loved being with other people and learning new things. She got used to the stares after a while and she had met a friend there. They kept in touch on the phone for a while and her friend had taken her to a different coffee shop a couple of times. Once the course finished though it was difficult to keep in contact and she hasn’t heard from her lately. Pamela wishes there were more opportunities to continue with her education.

Pamela said she did not belong to any organised clubs or anything like that. Knitting and colouring and other handicrafts was what she liked to do for fun and she liked getting the newsletter from her service.

Pamela rated her level of community participation as quite high and said that on the whole she was happy with her life (although she really wished she had some friends to go out with). She seemed to reach this conclusion by comparing her present life to her past, as well as to the potential for greater isolation given her disability. Pamela was a bit reticent to discuss any other hopes she held for herself, and trusted that her support staff would know what she needed. But she loved working on the project.

Figure 7: Pamela's Life-space



Summary

Community Activities: What people do.

People participated in their communities in many different ways. Most people's activities included a mix of involvement in informal networks like family, organized community activities, and segregated (disabled only) activities.

Almost all of most people's time was spent at home or in a Vocational Centre. Very few people had paid jobs. No one participated in more than six different types of activity beyond the home. Men and women tended to do different types of activities.

Most people participated in the community with other service users or support staff. Some people liked going out in groups: others did not.

People who had the most disabled friends were also the most comfortable in being in the community, and went to more places. People were most comfortable asking for help from someone who knew them.

Although everyone wanted to be more involved within the community beyond the Centre, many still wanted to participate with other disabled people in community settings where they felt vulnerable.

The places where people felt most valued and comfortable were: family, church, shopping, work, and continuing education.

Activities taking place from Vocational Centres tended to be fleeting and irregular, rather than sustained and on-going. Most activities took place in public spaces, where money was exchanged.

Many people were undertaking training courses. Most people enjoyed these, but some saw them as inappropriate or time-wasting and not leading to jobs.

There was a lot of similarity among the group in their range of activities, and people often felt they did not have much control over what they did and when they did it.

Community relationships: Being with other people

Most people had few friends, with staff and family often identified as key people in their lives. Being with people changed activities into **social** events. Friendships were mostly around the contexts in which people participated, and these different friends rarely met with other friends. A lack of resources and support often made it hard for people to keep friendships going.

To meet with other members of the community, people had to go out: the community seldom came **in** to the disabled person's setting. Some people had managed to make contact with others without having to go out, by the telephone, radio talkback, and the internet.

Unfortunately people were doubly disadvantaged because the best way to make friends and become connected is through friends and contacts you have already.

Anyone's involvement in their community depends on the places where people are familiar and feel comfortable and the "pathways' or ways that people connect with these places and people. We can use this model to think about supporting people to participate in their communities. (Chapter 3 has a story and a diagram at the end which illustrates these ideas).

CHAPTER 4

AN ANALYSIS OF COMMUNITY FROM THE VIEWPOINT OF PEOPLE WITH DISABILITIES

Introduction

This chapter analyses and reports the views of those people with disabilities who agreed to be interviewed and/or took part in focus group discussions. The actual words of those people themselves are quoted extensively, to present their voices in all their colour and variety, and to ensure that the analyses are clearly grounded in their contributions.

In some places, the interviewer's voice is also quite extensive and may give an impression of leading questions or statements. While this may have occurred occasionally, what it reflects primarily is the communication challenges faced by some people with disabilities. Their responses may be limited to body language and yes/no, or a limited number of predetermined replies, or a very slow and laborious spelling out of replies. The quotations themselves cannot show what was actually happening in the interview or focus group, in terms of the significant role that body language and facial expression also played in the dialogue.

A further validation of the transcribed interviews was the opportunity given to every person to check their own interview and to make any deletions, changes or additions to present what they had said accurately.

Individuals' real names have been changed to pseudonyms to protect their anonymity, as have the names of other people referred to in the interviews. Where people have used identifiable names of places or organisations, (apart from CCS), these have been removed also.

The chapter is structured to reflect a progression from a simple notion of "community" to a very rich picture of the complexity and variety of the lives and views of these people with disabilities.

The first section looks at ideas about what "community" means, and therefore what "community participation" is, or is not.

Following this beginning discussion, the complexity of people's lives and ideas are explored, challenging a simple dichotomy of "community" and "not community". The place of "segregated services" in people's lives is described – from their perspectives.

The following section shows how distinctions between public and private spaces, or "the community" and other settings, is frequently blurred, and what happens in those places is the most important thing to people with disabilities.

Finally, people with disabilities outline what they see as the most valued characteristics of spaces or places – wherever they are.

What is "community"?

Defining "community" and describing what it is and what it is not has been a challenge to both academic theorists and ordinary citizens. Although many people assume that the meaning of "community" is widely shared and understood, many factors, both cultural and personal, result in variations in meaning. Similarly, the people with disabilities interviewed in this project also defined "community" in various ways, involving ideas of **people, places, activities, and purposes.**

The notion of **community involving people** is expressed in the following comment:

> "*Being amongst friends, being out and about, being in public."*

Both personal relationships and general presence among "the public", who may not be known to the person, are suggested in this quotation.

The idea of "**place**" was emphasized strongly by many people who talked about "getting out and about." Participation in the community was seen by most of the people with disabilities who were interviewed as involving a **journey,** from known places to those less familiar. Community participation was seen as "being out there" and not "being in here".

> *"Getting out and about"*
>
> *"Being out of the home with people"*
>
> *"Out having fun"*
>
> *"Getting out and about. Do I need to be more precise?"*

In their attempts to define "community" academic writers often focus on the way that community is **actually experienced.** The places typically nominated by people as part of their community include **key characteristics** such as **familiarity, predictability, being known,** and **feeling valued.**

These characteristics ensure a sense of belonging to communities which are further reinforced by shared valued and customs, and reciprocity among community members.

Service users' initial ideas of community contradicts accepted understanding of the way community is experienced, placing an emphasis on public places which were often **conceived as "somewhere else**", rather than where the people with disabilities perceived themselves to be.

> *All around us is the community. It is anywhere that isn't home, and not the Centre as well.*
>
> *Being out of home with others.*

There was a tendency for people to **define community in terms of what was not seen as part of "the community".** Thus a person's home, or private space was not perceived as part of "the community". Being at home was not the same as being "in the community". For some people, "home" represented a place over which they had little choice or control. In contrast, "the community" was seen as a space or place that offered a prospect of **liberation** from the confines of home. These ideas are illustrated in Louise's comments:

> *Louise: Hello, my name is Louise and I live in an old person's home. My interests are…..*
> *Interviewer: … if I was introducing myself I might say that I lived in P… because I chose to be there, and I think it says something about me as a person…. Did you choose to be in an old person's home?*
> *Louise: No.*
> *Interviewer: If you had the choice of being in an old person's home or not, would you choose to be there?*
> *Louise: No.*
> *Interviewer: Why is it not for you?*
> *Louise: All old people.*

Home was also associated with boredom and isolation for some people. The community, in contrast, was perceived as offering the potential for company and self fulfilment through **relationships.**

> *Interviewer: Trevor is sitting in his armchair and has everything he needs within arm's reach – the TV remote, snacks, phone – and his birds are right by his side. It looks as if you spend some time in that chair?*
> *Trevor: Yes, I go to sleep all the time.*
> *Interviewer: Are you tired, or bored, or what's happening for you?*
> *Trevor: Bored half the time. There is nothing to do.*
> *Interviewer: What if, rather than go to the Centre, someone supported you from home and went for walks with you from here? Would that be better?*
> *Trevor: No.*
>
> *I went flatting… on my own, and it was going well for a while. And then I felt I was stuck indoors, because I couldn't get — I had limited movement . I could only walk small distances, and I felt as if I was isolated – it was, just I was*

> *stuck inside. I felt I had gained my independence, but when it all boiled down to it, I hadn’t – I had no one around me to communicate with.*

Just as the person’s home was not seen as part of “the community”, service users also **tended to view the vocational centre or sheltered workshop as not part of the community**. The same types of feelings were described, feelings of “being stuck”, or “hemmed in”. The segregation of both settings from “the community” was often noted.

> *… it seems like you are all in the same group. You are not being accepted. No one knows you from outside of that group. You’re stuck.*

Some people described the centre as being **a community in itself**, but with a difference:

> *It **is** a community – but it is a closed-in community. We are all closed in to one big room.*

For many people with disabilities, their home and the vocational centre were key points of reference in their daily lives, but neither was seen to be settings which gave them **a community presence.** Moreover, being within such a **service** setting for a long time was seen as the opposite of “community” and a long way from being “out there”.

The reasons for these perceptions are complex, however, and sometimes appear contradictory.

Firstly, service users are familiar with current service values, policies and assumptions about “the community” versus “segregated services”. Within these discourses, public spaces are typically presented as the “correct” location of “community”, “community participation”, and “integration”. Involvement with other people with disabilities in separate places, except for self-advocacy, is often implied to be undesirable or of lesser value or achievement. Service users, therefore, **may be reflecting these more general values or judgments**, rather than their personal views.

Secondly, the segregated setting also appeared to represent a place where people had **limited personal control** over what happened there. Alongside this lack of personal power and control, went a lack of control over the “disabled identity” which was attached to the segregated setting.

There was a great deal of variation among people with disabilities in their views on these issues. For some, a segregated living or vocational setting implied a **“disabled” label or identity**, which was seen as negative, and not the way they saw themselves. Louise rejected the “old persons’ home” as not reflecting anything about herself and what she valued about herself. Some service users felt similarly about support being tied into “disabled only” settings. At the same time, some people

supported other service users' desires to keep their vocational centre open. They saw differences among service users as a justification for this advocacy.

> *All of the handicapped need help except Alistair and me. We're all right.*

The "disabled" identity equated for many the experiences they had undergone as a result of their disability. These included discrimination in employment, low expectations, lack of imagination, feelings of exclusion and being treated differently. The end result was a **strong rejection of being cast in a "disabled identity" by others, which did not reflect their own views of their "true selves".** These descriptions illustrate the social model of disability which underpins the New Zealand Disability Strategy. While this "model", or way of conceptualising disability, is most familiar to academic theorists, these people with disabilities speak about the realities of their experiences of social oppression and their rejection of these experiences or judgments of themselves as individuals.

So why was "the community", which was the site of many of these oppressive experiences, seen as offering valued opportunities that segregated, service settings could not offer? For many service users, **"the community" was a space able to be occupied by both disabled and non-disabled people**. It was also the site of positive experiences for many people. It was a place which **could** provide a sense of acceptance, being recognised, and affirmed – at the level of **public life.**

> *Being out for us – it's acceptance.*
>
> *The community is about getting out there and getting accepted for who we are.*
>
> *I feel lucky because when I go out, I am accepted. People know who I am and my chair is not a big deal. I love it when people wave and toot to me.*
>
> *It's pretty cool when I go out because I'm accepted – mostly from women saying "Hi" to me. I will stop and chat to them.*

For most able-bodied people, "acceptance" in public places is a "given", and not even thought about. Any form of rejection would be inconceivable. The experience of some people with disabilities is very different, implying that **changes in community attitudes and behaviours could bring enormous improvements in the daily lives of people with disabilities.**

There was also a stronger, political motivation for being "out there", among some people with disabilities. Being out in public was important in its own right. People with disabilities saw **the need to occupy public spaces as a political statement**, demonstrating their right to be there.

> *Interviewer: What's the most important thing your support can do for you?*

> *Alistair: Meeting people in the community – WE ARE HERE!*

Some individuals made deliberate decisions to take actions to reaffirm their right to be in the public spaces of the community:

> *Helen described how she repeatedly walked through the local alleyway in which a group of young boys congregated after school. She saw their "funny looks" as a challenge to her right to be in the community.*
>
> *Adam talked about the importance of being alongside members of "the public" in his local gym. He used the example of two opposing forces in weightlifting to talk about the oppression of able-bodied people's preconceptions of disability. With each visit to the gym he experienced greater freedom to move his limbs against the force of gravity. In addition, his presence in the gym also challenged the community to open its boundaries to accept people with disabilities.*

Changing the community itself was a common theme in the responses from a number of people with disabilities who had experienced **exclusion and marginalisation**. Helen and Adam both saw their own presence and actions as moving the community towards an acceptance of disability, within community settings in which such acceptance had been absent before.

Experiences of exclusion rather than inclusion in community settings were sometimes overt, with the person's right to be in the community explicitly rejected.

> *Helen… He used to pick on me and my ex-flatmate because he was an ex-Sunnyside patient and I was disabled. He said that I should be locked up in Templeton.*
> *Interviewer: … when you talked about your right to be in the public, you seemed to be saying you proved your right by having relationships with people without disabilities, and that was a source of pride. I'm not sure, is that right?*
> *Helen. Yes.*
> *Interviewer: I mean, I wondered if that was because people had patently said to you that you don't have that right.*
> *Helen. Yes.*
> *Interviewer: A history of people saying the community does not belong to you?*
> *Helen. Yes.*
> *Interviewer: Who is saying that?*
> *Helen. Nearly all able bodied people are saying it.*
> *Interviewer: You feel that people make that value judgment?*
> *Helen. Yes.*

Some people with disabilities contrasted their segregated lifestyles with those of non-disabled people of the same age in “the community”, and described their own **aspirations to have the same experiences and opportunities**.

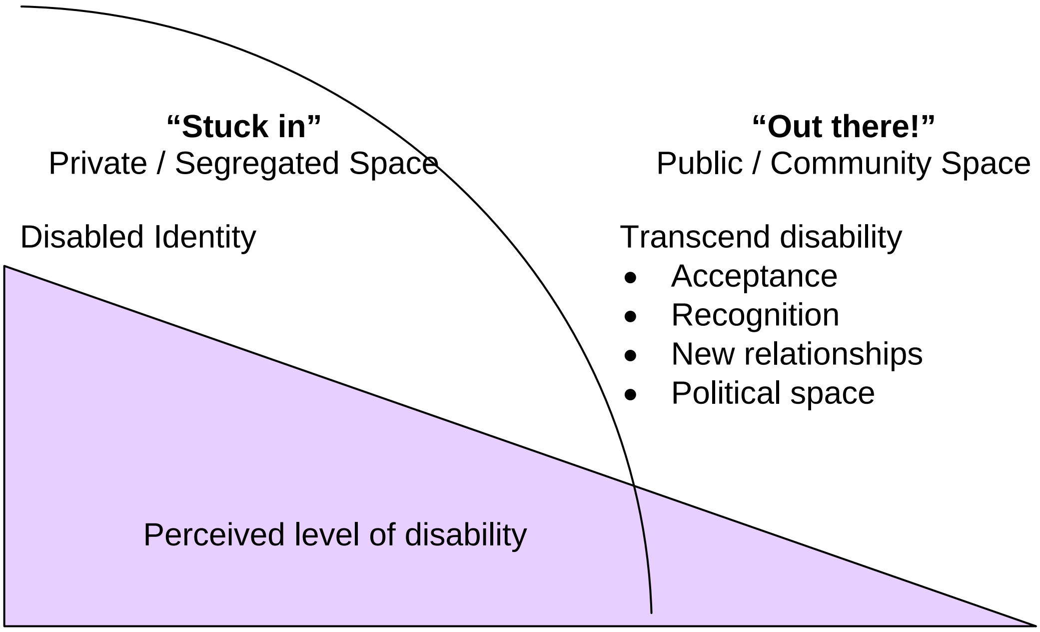
> *Interviewer: Are there things that you wish you were doing that you are not currently doing?*
> *Marie. .. Yes… going out at nights and meeting people – meeting people my own age. I have some friends that are a lot older than me and they have got families of their own. I want to meet people my own age, and maybe get out there and meet someone so I can move away from my grandparents and wasting their time and build a life of my own with somebody else… maybe start a family and things like that. I want to get out there! I don’t know how because I have never been in that situation, I have never gone through the stage of…*
> *Interviewer: … a group of girlfriends?*
> *Marie. Yes, a group of girlfriends.*

Among some people with disabilities, living an ordinary life – with everyday patterns of experience, among able-bodied people in “the community” – had almost become a **measure or yardstick of their value as a person**. There was an assumption that someone’s level of disability could be measured by their level of engagement or immersion within communities of able-bodied people.

> *Some people like Fred and Barney will only go so far.*
>
> *Alison. … I have seen it with this 22 year old disabled female. She has been in an institution and has no community skills whatsoever. She does not know how to communicate with anyone except her peers.*
> *Interviewer: Why is there a difference between communicating with peers and communicating with the public? Why is it such an important difference?*
> *Alison. Why? Because they know how to talk with their peers but they do not know how to communicate with the public.*
> *Interviewer: Do you count yourself as a person of the public or do you see yourself as separate from the public?*
> *Alison. … I see myself with the public.*
> *Interviewer: Are you also this other person’s peer?*
> *Alison. … That’s a hard question to answer.*

Figure 8 below illustrates the contrasts emerging from the views of people with disabilities about “the community” – how to define it – and how this contrasts with the private, segregated settings in which they also spend time.

Figure 8: “What is the community”?



Summary

People with disabilities initially described “the community” as a place “out there”, somewhere different to home and apart from a segregated service. These public places “out there” included disabled and non-disabled people. Some people felt that being “out” in the community gave a political message about the rights of people with disabilities to be part of the community. Being in places that were separate from the wider community was sometimes associated with isolation and boredom. The wider community was seen as offering the **potential** for friendships and a more interesting life, but changes were needed in community attitudes and behaviours towards people with disabilities.

These initial ideas about community, however, did not adequately portray the richness and diversity of people’s experiences. Ideas about “community”, from the perspectives of people with disabilities also need to be considered within the complexity and variety of their individual, daily lives.

The Complexity of Life

As those interviewed began to describe their lives and the various ways in which they participated in their communities, the simple dichotomy between the community as inclusive, public places and the “non-community” of segregated services became a lot more blurred. Even though most people said they were usually accepted by the community, they still recounted incidents of prejudice and hostility. Some individuals continued to experience some community spaces as **intimidating and isolating**. Sometimes there was an **intolerance** of the accommodations that need to be made for different bodies.

> *I get a lot of stares because of the way I look and the way I stand. I don’t usually get smart remarks and things like that because I can stand up for myself and answer them back. . . Say like when I go get a taxi and things like that, because it takes time for me to get into the taxi, and if the driver is not that hot… they kind of get frustrated waiting for me to get into the taxi … I get a few looks from the shopkeepers (too) because it takes time for me to pull the money out of my pocket and sometimes I drop money and things like that. It is hard for me to pick it up, bend down and things like that, so I feel, when I go into a shop and do drop my money, I feel real frustrated. It hurts me real bad.*

At other times, the stigma and frustration centred around **communication breakdowns**, when other people do not make an effort to adapt to a person’s communication differences.

> *Interviewer: Do you feel part of the community, Trevor? … you are saying “No”?*
> *Trevor: No, I don’t understand half of the time.*
> *Interviewer: Do people take the time and help you to understand things?*
> *Trevor: No.*
> *Interviewer: Where are you thinking about when you say that, Trevor? The people you meet in the street? In the shops? Or…*
> *Trevor: I get angry at them.*
> *Interviewer: Because they don’t understand?*
> *Trevor: I get angry at them.*

For a number of people with disabilities, teenagers or young children were the source of particular reactions. Many people described being **teased** by them.

> *Say you go up town or the street and you get a bunch of teenagers start to make fun of you.*

Some people had developed creative strategies to cope with teasing and enable them to continue to get out and about.

> *… as long as I have my headphones on, I don't hear them.*

Reminiscing about **school experiences** revealed difficult experiences for some people, particularly at high school. The developing awareness of being different in later childhood/early adolescence was also a difficult time.

> *Christopher: When I was at school, everybody else was normal. It was really difficult, but in some ways I felt it made me grow up quicker.*
> *Interviewer: What was difficult about it?*
> *Christopher: Oh, just teasing-wise. I was the only disabled person wherever I went at school so… it was back in the seventies and eighties.*

School experiences had resulted in a serious loss of self esteem for some people, a loss which they continued to struggle to recover. Marie described how much of her community was unknown to her because she avoided places that might expose her lack of worldly experience, or require some self-disclosure. She needed to know how to act in public settings because of a fear of judgment that she saw as stemming from the way she was treated at school.

> *Marie: Well I go to church on a Saturday night, but that would be about all, because I find back when I was younger, after I went back to school the kids were pretty hard on me. I would say things and people would laugh at me and I had no hair at one stage and they used to make fun of me… Those things just stuck with me because they hurt. It stopped all my confidence and self esteem in myself.*
> *Interviewer: The Warehouse is OK, but the Coffee Shop isn't?*
> *Marie: I feel uncomfortable because I am doing it on my own and I am scared to get out there and give it a go. I am scared they will judge me – that is it, they will judge me.*
> *Interviewer: So contexts where you have to show more of yourself as a person – is that more frightening?*
> *Marie: I am scared of what people are going to think of me, because it goes back to when I was younger and I felt people were always thinking – what kind of person I was.*

Practical difficulties with accessing all parts of community life were also barriers to community participation. Having to ask for help made some people feel vulnerable and uncomfortable.

> *… going to the supermarket – you can't reach things; you ask for help. Sometimes people will help you and sometimes people will just ignore you and walk past.*

People needed to feel safe, supported and valued when they went into the community. Fear and a lack of confidence in public settings posed major barriers to participation. Support staff can make an important contribution in this area.

Marie spoke about "unfurling her social wings" at a "girls' night", organized by her Supported Living Service. Although she was apprehensive, she felt able to go because of the faith she had in her support staff. She said she knew that her support staff always accepted her "for who she was".

> *Marie: Mandy sent out the invitations… and I thought, I liked her, so I thought, yes, I will go along and see what it's like.*
> *Interviewer: What I think you just said was that you felt safe with Mandy. Is that right?*
> *Marie: Yes, I could trust her. I felt I could trust her.*

Even though some people with disabilities tried to distance themselves from "**the disabled community"**, that same community was **acknowledged as making a valuable and essential contribution.** John saw other people with disabilities and professionals working with them as an essential part of piecing his adult life together, after becoming disabled from an accident.

> *John:. … Yes, well, with other people that are like-minded, that's another thing. With other disabled people … perhaps that was something I did wrong… perhaps I should have worked with disabled people before, so I could see a similarity of how things worked.*
> *Interviewer: So being with disabled people has helped you feel some sort of identity with them?*
> *John:… Yes, it's a thing I should have done a lot earlier. If something goes wrong, there are a lot more people that can prop me up. Everybody (here) has been trained professionally to cope with stress and disabled problems, so we have got the benefit of both. There is always people to turn to.*

The importance of relationships among service users can be obscured or not appreciated when it is not recognised that valued elements of "community" can be found within "segregated" settings. Examples of care, respect, and valued relationships were often described. They were also evident during the focus groups, as service users would quietly fetch sandwiches for others, write name badges, and prompt others with less confidence to talk about their contributions to the community.

Service users demonstrated how they were often unconsciously involved in each other's field of support and network of relationships. For many people with disabilities, the vocational centre was the hub of their "social wheel". Important relationships with support staff were forged there, and for many people, their most significant friendships had developed in that setting.

> *Well, I think we all met at CCS!*

A sense of belonging and membership in this setting illustrates the centrality of the Vocational Centre in some people's lives.

> *Interviewer: So what places do you feel a sense of belonging? Where do you feel it's right to be?*
> *Jane: Centrepoint, CCS.*
> *Interviewer: What gives you that sense? How do you know you belong?*
> *Jane: Don't ask me! I just know I do.*

In a setting in which greater levels of intimacy had developed, people were able to disclose more of their private selves, share a joke, express their fears, and add value to the lives of other people.

> *Interviewer: You said before that you would go five days if you could. What are the good things about being there? Do you feel like they know you?*
> *Trevor: Yes.*
> *Interviewer: What other things are good about going there?*
> *Trevor: We go to have a cup of coffee in the morning. I make everyone a cup.*
> *Interviewer: You get to do things for other people. Is that important?*
> *Trevor: Yes.*
> *Interviewer: What else?*
> *Trevor: Talk to them.*
> *Interviewer: Who do you like talking to?*
> *Trevor: Naomi and Helen.*
> *Interviewer: So, they are staff there?*
> *Trevor: Yes.*

A support person (with a person at her interview) expanded on the disabled person's description of her contributions and relationships at the Vocational Centre.

> *Support person: (talking to the interviewer and to Louise). Well, Louise will pop in – I mean, sometimes it's an interruption … but it's really fun. We have these…. She will pop in and she will say something, and often it's a joke and makes us laugh. Or we are joking about not getting what you're saying, so we make a joke and we all laugh. And other times it's really important stuff that we're just doing in passing – that's how this relationship is built up that we're able to… I really actually enjoy our conversations because sometimes things are getting a bit rough and you wheel in for a joke…*
> *… And I suppose the other side of that is that you know that you can come in, because sometimes things get really hard going for you, and you just need someone to let it out to, and you can just come in our office and let it out. And that just makes you feel a bit better as well. I don't know, that's my assumption.*
> *Interviewer: Well, especially if it's not happening at home as well… How many other places could you actually do that sort of stuff, Louise? Is there anywhere else?*
> *Louise: No.*

Another service user described how people came to her to ask what is happening, and for advice.

To some the Vocational Centre was a place to flirt, with friendships confined to that setting – not necessarily by choice.

> *Interviewer: Have you got any friends there? Who would be your friends?*
> *Peter: The girls.*
> *Interviewer: Do you ever meet them anywhere besides CCS?*
> *Peter: No, no.*
> *Interviewer: Why's that?*
> *Peter: They don't come to my house!*

Vocational centres were **familiar and predictable spaces that provided a high degree of psychological safety.** As one service user said, "I know it inside out". Because of the time spent over quite long periods "hanging out" at the Centre, a number of service users felt that the Centre was the key focus and basis of their social identity. As well as their familiarity with the Centre and the people there, they also felt "known inside out". One service user said that it was almost as if people at the Centre had ESP (extra-sensory perception). They could anticipate his needs and let him know about things they thought he might be interested in. Service users **valued the staff's knowledge of community resources and opportunities**, particularly when this knowledge resulted in support that matched individuals' personal goals and aspirations. This **sensitivity to service users** was particularly important in the understanding and responsiveness of staff to the way each disabled person managed their own disability and its effects.

Rachel sometimes felt disoriented and afraid in unfamiliar places. She derived great comfort from being with people who knew this and could anticipate when this might happen. Sandy described similar feelings with regard to her epilepsy. For Mary, it was the staff members' skill and sensitivity to her personal care needs that was important. **The everyday and ordinary nature of these needs means that they can become an invisible part of essential supports**.

For service users with disabilities that affected **communication**, being among people who were committed to making sure they understood the disabled person's unique communication was very important. Such a **responsive commitment** was rarely found within the external "community". Many service users, during their interviews, mentioned the struggle they had in getting people to see them as a person and not a disability.

Self-image or identity is significantly influenced by the reflections of ourselves from other people. For these people with disabilities, the most significant messages came from the people around them and how they treated them.

> *If you want to understand me, I need to talk. It's easier to talk so I am feeling more comfortable.*

Even services did not always "get it right", however, and some people with disabilities complained of not being listened to, and not being given sufficient time to express themselves. Adam was intelligent, incisive, playful and fiercely independent. However, the only tools for him to express himself were his right hand on an alphabet board and subtle head movements. Having a conversation with Adam took time and concentration, for both parties. Adam communicated letter by fingered letter. Adam's interviewer fed back to him what he had been telling him, to ensure accurate communication.

> *Interviewer: Adam and I were just talking in the way that you do when the tape is turned off… One of the significant barriers for Adam is the fact that in order to know what he is thinking, or in order for him to be able to communicate effectively what he wants, including seeing the "true" Adam, takes time… and that often service staff are incredibly busy. And he feels a sense of frustration and that his ability to communicate is compromised by the business of other people. Is that OK?*
> *Adam: Yes.*
> *Interviewer: Could I have put it better?*
> *Adam nodded, indicating no.*

Samantha used a programmed Delta Talker as her primary means of communication. She expressed her frustration with the Talker as her range of "messages" was limited to what was already programmed into her talker, and her ability to use and combine these to say something new or unexpected. She tended to avoid situations where she was unable to communicate effectively because she felt that she then became invisible.

> *Interviewer: Do you like going out in a group of people with disabilities? (Samantha is unequivocally saying "No").*
> *Samantha: No.*
> *Interviewer: Right, why?*
> *Support person: Can I make an assumption and say that you really enjoy someone who you can work with or be with on a one-to-one, who can communicate. But you don't get that in a group; you are kind of lost – communication gets lost. So that would be particularly around those sorts of reasons for you?*
> *Samantha: Yes.*

So for a significant number of service users who had difficulty with conventional communication, the Vocational Centre was where they could be assured of motivated communication partners who could enable them to express themselves.

In contrast, the lack of willingness to persevere in communication interchanges, was characteristic of the community outside the Centre. Trevor noted his difficulties in understanding, and how this was addressed in his relationships with support staff. Within these relationships he also felt safe enough to express a range of emotions, including frustration.

> *Trevor: I don't believe in the community – sometimes I get angry, they tell you what to do.*
> *Interviewer: Do you sometimes get angry at the Centre too?*
> *Trevor grins.*
> *Interviewer: Do they sometimes tell you what to do?*
> *Trevor: (grinning): I don't hear them.*

Katie had no verbal communication and used a combination of sign and head movement to express herself. In describing the nuances of Katie's communication her support person commented:

> *It takes an awfully long time to pick up on Katie's commands and for Katie to feel comfortable – well, both of us really.*

Despite aspirations to be "out there", the Centre provided a place where disability was unremarkable and adjusted for – a rare situation in the wider community. Within the Centre, people with disabilities could share common life experiences, be unremarkable, and engage with people who saw beyond their disabilities to their individuality. For many people with disabilities, therefore, people's rights to choose between public and private spaces, according to their individual needs, were important to preserve.

For some people, the Centre provided a place of respite from other environments. For Louise it meant being away from the Rest Home. For Trevor, it was a welcome relief from the boredom of having no friends and nothing to do. The Centre was a destination away from home that gave life a purpose and required effort to reach, breaking the unchanging rhythm of life. For Patsy, the Centre encompassed all the relationships and activities that she held dear. For others, it was a respite from always being different.

Manu, who was enjoying training to be a social worker at his local Polytechnic, spoke about his deliberate decision to take computer classes with disabled peers.

> *Manu: … and the people running it are CCS, we are all more comfortable because we all have disabilities and that. If I go to other courses, everyone is abled people and it is a bit of a barrier for me after all, I don't know, I'm just gonna feel…*
> *Interviewer: So does it take you a while to start to feel OK or do you never quite feel OK?*
> *Manu: Yes, I get used to it because I know things are going to be different for abled and disabled people and I am going to get a lot of stares because they wouldn't know what is wrong with me.*

> *Interviewer: So being in a place like this is quite good, isn't it, from what you are saying?*
> *Manu: I can be comfortable.*
> *Interviewer: You can be comfortable and just get on with the learning.*
> *Manu: Yes.*
> *Interviewer: So you are also saying that there is a place for Centres such as this where people with disabilities can come along and just relax and be themselves…*

Stuart described working alongside other people with disabilities as an important part of his personal development.

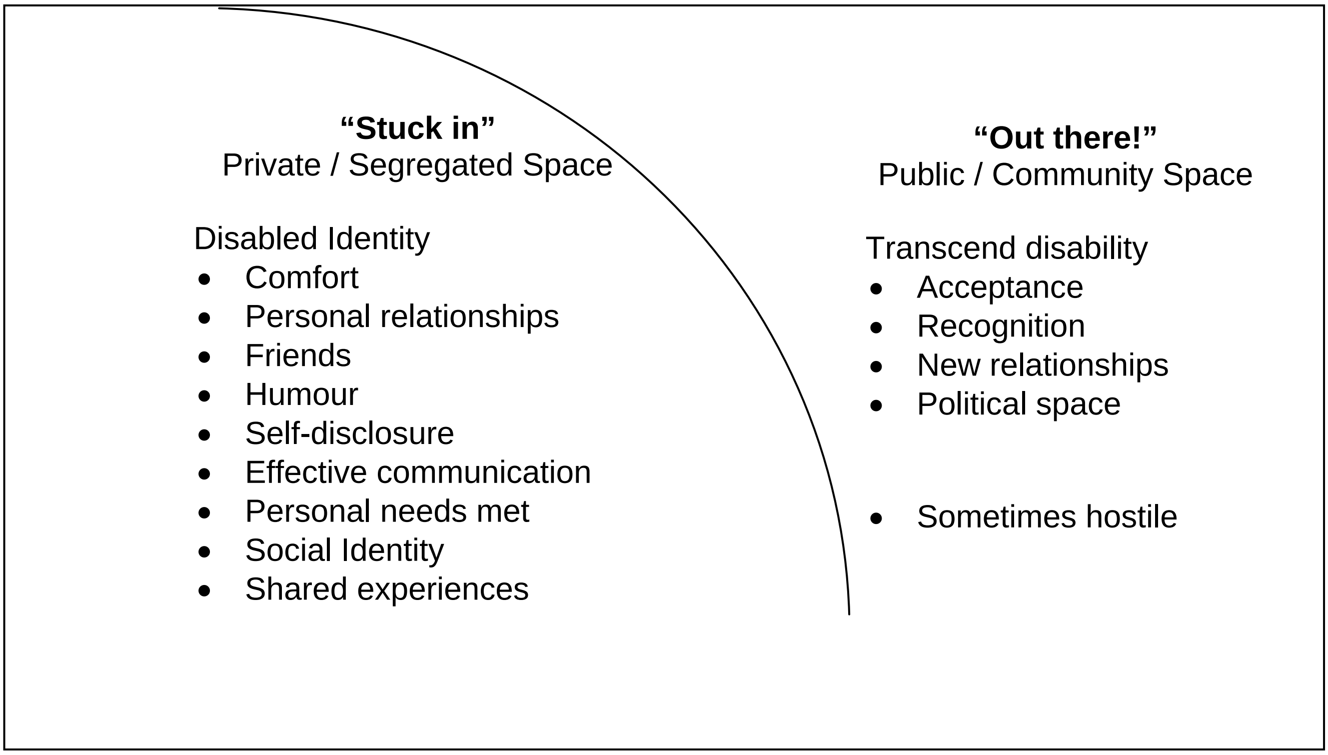
> *Finally I have found something that I enjoy doing, but it has only been because, like I said, before when I have come back and I have looked, and I have been with other disabled people, and I have said to myself, "I recognise the disability kind of in myself" and I said, "Grow up and move on." It is just part of that personal struggle that I guess we all have.*

Those people with disabilities who were the most actively involved in the community appeared to make least use of the Centre. However, as would be expected, those that did use it expressed concern at the thought of its disappearance.

> *Interviewer: Would your life be better or worse without going to the Centre?*
> *Kelly: Worse.*
> *Interviewer: Why worse?*
> *Kelly: Because I wouldn't have anything to do.*
> *Interviewer: What if people came to your home and supported you to go out and do things in the community from home? Would that be better or worse?*
> *Kelly: Well, I started doing that and then gave up on it.*

The contrast between "the community" and "the Centre" (segregated service setting) has now become more complex, when we listen to the complexity and variety of individuals' experiences. Figure 9 summarizes this more complete picture.

Figure 9: The complexity in the contrasts: “community” versus “Centre”



“Stuck in”
Private / Segregated Space

Disabled Identity
- Comfort
- Personal relationships
- Friends
- Humour
- Self-disclosure
- Effective communication
- Personal needs met
- Social Identity
- Shared experiences

“Out there!”
Public / Community Space

Transcend disability
- Acceptance
- Recognition
- New relationships
- Political space

- Sometimes hostile

Summary:

The complex and varied experiences of people with disabilities showed that being “out” in the community could be a very negative experience. On the other hand, being part of a separate, disabled-only “community” was often a very important and positive part of people’s lives. People needed to feel safe, supported and valued when they went into “outside” community settings. Relationships with other people with disabilities were greatly valued. These findings show that **it is simplistic to assume that “the community”, as it is now, will meet all the needs of people with disabilities for the experience of community.**

The central notion of the community as a “place” needs to be expanded to consider the varied characteristics of different places, and what these mean to people with disabilities.

Attributes of place

The notion of “community” was often expressed indirectly in ways that transcended geography and the inclusive/segregated dimension. Most people’s lifestyles combined involvement in segregated programmes, organised activities in community settings, and informal social networks. **Ultimately, what mattered to people most was not where they participated, but how they were treated when they were there.**

Some people described being made to feel disabled in inclusive community settings – public impatience with uncooperative bodies, the “disability ghetto” at the rugby, challenges when facing groups of teenagers. One person described being part of a fitness programme at a gym in town. Although the gym was open to the public, he was expected to complete the programme in a separate area in the gym. He described **feeling like an “outcast”.** He said that he felt worse in this integrated setting than in another fitness programme that was organised and well supported by CCS. Thirteen people with disabilities did the programme together in the main gym area. A supportive climate evolved within the group, providing security for each individual. Perhaps because of this, other gym members interacted freely with them.

However, people also described being made to **feel disabled in segregated settings** too, especially when they felt **disrespected** or not in control.

> *Interviewer: Are there places you won’t go?*
> *Trevor: Not (Sheltered workshop).*
> *Interviewer: Why wouldn’t you go there?*
> *Trevor: Same jobs all the time. They don’t listen. I don’t like (service provider) either.*
> *Interviewer: What is it about those two places?*
> *Trevor: They’re too bossy.*
> *Interviewer: And you like to be able to choose what you do?*
> *Trevor: I say I do my own rules. I am going to stick to my own rules. I don’t get to tell you what to do.*

Another service user said:

> *I used to go to (sheltered workshop) but I got picked on all the time.*

One support staff member explained about a residential service:

> *… someone is playing the radio loudly and you can’t get to sleep, and someone leaves the light on in the corridor, or just those little irritating things that if you could control you would – living in your own place you just wouldn’t … you would have control of those things.*

But some people with disabilities also had pride in how they could contribute within a Vocational Centre: Trevor’s coffee making; Andrew’s pride at being consulted by peers; Helen’s teaching staff computing skills; and Louise’s role as a disability awareness educator. These achievements were so personally significant that geography (the place they occurred in) was irrelevant.

Sometimes people with disabilities make choices to use services which would be called “segregated”, for their own unique reasons. Helen had made a deliberate decision to leave her flat to live in a Rest Home with elderly people. She decided to trade her independence for a living situation in which her disability “disappeared”, and she was treated the same as everyone else.

> *Interviewer: … but there are people who will say that an old persons’ home is an institution?*
> *Helen: But not where I live, because we have got elderly and disabled living in the same place, and we are treated as equals.*
> *Interviewer: So there are two things: the first is that you are not relating exclusively with people with a physical disability – that makes it a community; and two, you are treated like an equal – there is no difference in the way you’re being treated. That’s it?*
> *Helen: Yes.*

People with disabilities spoke about the good things that were happening in their lives, volunteering stories of personal growth and increased independence.

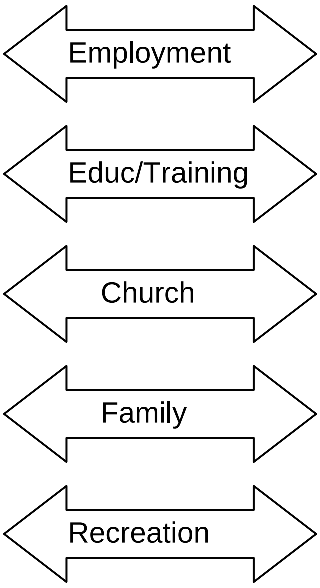
> *I am living on my own. I do as much as possible.*
>
> *Well, mainly just been flatting on my own… I used to flat with people and now I’ve been a lot more independent – been flatting on my own for eight or nine years and it’s been really good. Learning to look after myself and getting away from the parental side of things, the folks and that. So, no, that’s been really good.*

People spoke about how they participated in and/or contributed to a number of community settings and groups. These included employment, education, church or choir, family, and recreation. These places were found in both public and private settings, blurring the boundaries between “out there” and “in here” (Figure 4). The most important things for those people’s involvement were their experience of acceptance, recognition, and new relationships. Their presence also made a “political statement”, but within a space that was safe and accepting. These were places that people valued and continued to participate in, and they combined the valued parts of being in the (public) community with the valued experiences often found in “segregated” settings. Figure 10 illustrates this “coming together” of public and private spaces, from the perspectives of people with disabilities and their daily lives.

Figure 10: Public and private spaces in the community

“Stuck in”
Private / Segregated Space

Disabled Identity
- Comfort
- Personal relationships
- Friends
- Humour
- Self-disclosure
- Effective communication
- Personal needs met
- Social Identity
- Shared experiences



“Out there!”
Public / Community Space

Transcend disability
- Acceptance
- Recognition
- New relationships
- Political space

- Sometimes hostile

Summary

The overlaps and blurring of boundaries between public and private spaces helps us to understand the experiences of people with disabilities. The priority of **how people are treated over where** they spend their time is a critical finding. This finding should guide policy and its implementation in practice, in both community development at the wider level, and in the provision of individualised disability support services. So what are the characteristics that people with disabilities value in their lives – whether they are involved in public or private spaces, “the community” or “segregated services”? The next section will describe these characteristics.

Valued characteristics of spaces/places

1. Self-determination

The degree to which people had control of making their own decisions affected how they perceived community participation. Choosing what, when, and where they did things was very important to them.

> *Don’t tell me what to do. Talk to me quietly.*

For Trevor, the prospect of getting a job – which **he** had initiated and sought support for – was a source of pride and excitement.

> *Trevor: I’m getting a cleaning job anyway, a cleaning job.*
> *Interviewer: Trevor is showing me a newsletter.*
> *Trevor: Saw it in the paper.*
> *Interviewer: You saw it in the paper.*
> *Trevor: Yes!*
> *Interviewer: So what did you do after that?*
> *Trevor: I took it to CCS. She rang up for it. They gave me a form there.*
> *Interviewer: That was good that you felt able to do that. Have you looked for many jobs?*
> *Trevor: First time! I hope I get it. I applied for it.*

Trevor also talked about times when his personal choice or preferences were not to the fore.

> *Interviewer: How would you describe yourself? What do you like doing?*
> *Trevor: Working on cars. Boccia – I’m not keen on boccia.*
> *Interviewer: Who decides what you are going to do in the day? You were saying that you go swimming and you play boccia…*
> *Trevor: CCS do it for me.*
> *Interviewer: How about fixing cars? You said fixing cars was your hobby?*
> *Trevor: No.*

The most highly valued forms of community participation were usually those that people had chosen themselves – such as Trevor’s job, Louise’s relationship she had developed with the lady in the Lotto shop, John’s choice of living situation – carving their own niche in their communities. People liked to be where they could determine what they did.

> *Interviewer: Janet, tell me what you feel good about in your life?*
> *Janet: I can eat when I want to, I can go to bed when I want to, and I can stay in bed when I want to.*
> *Interviewer: And what other things are good?*
> *Janet: I can do my washing. I can have a boyfriend. I’ve actually had two boyfriends.*

People disliked being in places where their autonomy was undermined. They expressed frustration at the absence of control and lack of predictability. Sadly, some people rationalised their powerlessness as an inevitable consequence of needing support in their daily lives.

> *Interviewer: Do other people… have a different idea of what you want?*
> *Wendy: Yes, but they have to accept it.*
> *Interviewer: Too bad if they don’t. Do you find you get frustrated with that?*
> *Wendy: Yes I do, because one day I’m told I’m going out and the next minute they tell me I’m not.*
> *Wendy: So there is a bit of control, in a sense?*
> *Lorraine: Yes.*

> *Wendy: So how could you avoid that?*
> *Wendy: No, because I need support. If the chair tips up there's no way I can…*

Thus, for some people, their disabilities were perceived as the reason for the lack of choice in their lives – about where they went, and what happened when they were there. Their disabilities meant they were denied the range of options available to non-disabled people. "Being disabled" explained their marginalisation and constrained their ability to live self-determined lives, compared to other citizens. For some people with disabilities, these perceptions may heighten the salience and perceived value of employment and other forms of participation in the community, and their sensitivity to segregated settings.

The issue of resources and the way supports were provided were also raised by some people with disabilities. One of the issues was **control over the resources needed to participate** in the community.

> *Interviewer: OK, so (you're) waiting for money for you to be able to go out and do more?*
> *Mary: Yes.*
> *Interviewer: Would you need support with contacting (friends and taxis) or can you do that yourself?*
> *Mary: If I had the numbers I could.*

Mary had also experienced pressure not to get involved in some activities of her choice.

> *Mary: Well, my brother thinks that I should have an easy job, I like doing things around the house. They don't think I would be able to handle it out there.*
> *Interviewer: And why don't you want to do what he thinks?*
> *Mary: I'm old enough to do what I want!*

Services themselves were seen to exercise control of resources and routines.

> *Interviewer: So who decides what you are doing in the day?*
> *Trevor: CCS do it for me.*
>
> *Interviewer: What messages would you give services…?*
> *Wendy: The staff, they sometimes have workshops and so far I have not been asked. As I said, I can sing, I can weave, I can knit. You make the odd mistake.*
> *Interviewer: People don't come and ask you to be involved in things, do they?*
> *Wendy: No, because of my sight.*
> *Interviewer: But that's… I mean – don't you find that frustrating?*
> *Wendy: No I don't, because if they don't come to me, how do I know they are out there?*

> *Maxine: I try to mix with different people because I see these people every day.*
> *Interviewer; Do you look forward to that?*
> *Maxine: Yes, but that's only one day a week – I wish it was longer.*

Control by other people over certain aspects of their lives also affected the ability of people with disabilities to undertake or maintain their participation in the community.

> *Interviewer: And this house, you said in the earlier group, was too far from where you wanted to be. Is that correct?*
> *Janet: Yes. But Mrs B. was very concerned I went home too much. So they put me where I am.*
> *Interviewer: They put you where you are because they were concerned that you would go home to your mother's place too often if you were closer to her?*
> *Janet: Yes.*
> *Interviewer: However you would like to be closer to your mother's place and closer to the shops and things as well?*
> *Janet: Yes.*
> *Interviewer: Are you able to change where you live now?*
> *Janet: I have been trying for 10 years but it is not an easy solution. It's a nice house, but it's not where I want to be.*

If services control decisions about the life of a person with a disability, there is a danger that services define what "community" is to be for that person, and where its boundaries are drawn. Some people with disabilities also noted how services themselves can be constrained or have "community" defined for them, by imposed outcome measures or definitions from funders or policy makers, of "community participation".

> *Well, basically, like, you go out, or if you don't do what you get told, you get told off basically. But no, they basically want you out in the community.*

> *… they always take me to the museum. I only get six hours' support a week and it all gets (used) up doing those sort of things.*

> *They take us to the art gallery when they are bored. They feel good because we've been out in the community, but they didn't bother to ask us whether we really wanted to be there, or how it felt for us.*

It was not that some people did not enjoy organized activities like visiting museums or art galleries. But for others, feeling coerced into activities without personal choice or control, was experienced as demeaning and disabling. Marie felt that it was more harmful to her if she was not allowed to try, than it was if she tried and did not succeed.

> *Marie: Well, they wanted me to do the… we talked about getting me out doing something and I went and did a Wider Horizons course, and for my ability at*

> *the start I felt it was really downgrading. I knew about personal hygiene, I knew how to keep myself clean and all that.*
> *Interviewer: So did you stay with the course?*
> *Marie: I stayed there even though I really hated it. But I vowed and declared that I wasn't going to do – let them push me into doing something else like that…*

While people often felt that they had to conform to a fairly circumscribed lifestyle because of their disabilities, some people still described how they resisted imposed authority, often in subtle ways.

> *Stuart: She (recreation officer) said you are only allowed to do one session.*
> *Interviewer: You are only allowed to do one session?*
> *Stuart: Yes. I always get there early so I can do both.*
> *Interviewer: That's a good idea.*

Some people, like Adam, asserted their own responsibility to make their own decisions, rejecting what they perceived as the limited expectations of other people.

> *Interviewer: What have you done (about finding work)?*
> *Adam: B R A I N (spelled out).*
> *Interviewer: Use your brain? … Whose responsibility is it to find work, Adam?*
> *Adam: M E.*
> *Interviewer: … you are displaying a – you know, like a real sense of autonomy about your life… what led you to this view that it was your – is it your responsibility exclusively?*
> *Adam: Y E S.*
> *Interviewer: … can you say in what ways…?*
> *Adam: M Y C H A I R.*
> *Interviewer: Your chair oppresses you? Your chair is an inanimate object, how does your chair oppress you? Is it the value judgements that come from being in the chair, is that what you are saying?*
> *Adam: Y E S.*

In addition to the importance of autonomy and self-determination, people with disabilities stressed their need to have a "social identity", to be known and understood, within the various places in which they were involved.

2. Social Identity

Everyone aspires to be known and accepted for who they are. Many of the people with disabilities interviewed expressed this universal aspiration when they described their pleasure in being recognised, acknowledged and accepted in public spaces by a range of people.

People with disabilities may not have the same opportunities as others to experience this affirmation of their social identity. Firstly, they often have fewer friends, a limited range of “life spaces” with a smaller range of social contacts, and a proscribed set of relationships. These limitations also inhibit easy access to a range of private social spaces which are part of what we call “community”. All of these experiences help us to develop a well-rounded social identity and a more fully informed understanding of ourselves.

Secondly, the general community may fail to see past the disability to what O’Brien (2003) has called “the light of someone’s being”. So even when people with disabilities go into “the community”, this positive affirmation may not happen – in fact, the person may experience the opposite – a negative reflection of “self”.

Some of the people interviewed spent most of their days enveloped in a service culture, which also provided almost all of their relationships. Staff were frequently identified as providing the most highly valued interpersonal relationships. They were often the ones who were perceived as “knowing them best”. They knew their life story, they were the recipients of disclosures about quite intimate and personal matters, and they were often the friends to share a joke with.

> *Interviewer: Can you say who they are, are you OK to say what relationships you really value?*
> *Louise: Naomi and Fiona (Support Staff at the Vocational Centre).*
> *Support Person: What about… generally the people who work here and (old person’s home) you like Tracy at (old person’s home). She is the manager, and some of the staff there you like.*
> *Louise: Yes.*
>
> *Interviewer: So who are your friends?*
> *Stuart: Haven’t got them – I have only got two.*
> *Interviewer: Who are they?*
> *Stuart: Further down the road, … the neighbours they ring up occasionally. Not much.*
> *Interviewer: … have you got any other people you consider to be friends?”*
> *Stuart: My care-giver.*

These interpersonal relationships with staff are conventionally constrained by the service context. Friendships cannot stray far from professional boundaries imposed by the staff role. Relationships can never be completely free of the defined roles of “support recipient” and “support provider”. Such a relationship is also one of unequal power and imbalance in the areas of self-disclosure, reciprocity, and intimacy.

> *I wanted my caregiver to come in with me but she didn’t.*

But staff also often provided the person’s only route or conduit to their community.

> *Interviewer: … would you rather be going to the casino with staff, or with friends or family?*
> *Mary: Friends and family.*
> *Interviewer: In an ideal world?*
> *Mary: Yes.*

The struggle by people with disabilities to be seen as people, beyond their disability, was also described. Adam, who named his chair as a source of oppression, forced the interviewer to recognise and engage with the person he knew he was **before** his accident.

> *Interviewer: So what barriers have you had to overcome, why has your brain been so important?*
> *Adam: INGENUITY.*
> *Interviewer: Right. That ingenuity is a barrier, or ingenuity is what has kept you so…*
> *Adam: INGENUITY IS A BARRIER*
> *Interviewer: So the lack of ingenuity"*
> *Adam: Yes.*
> *Interviewer: The lack of ingenuity on whose part Adam?*
> *Adam: YOURS.*

Before his accident, Adam was a surf lifesaver and could do almost anything he wanted to, including flying. The interviewer spoke to a man in a chair, while Adam fought to make visible the surf lifesaver (see Adam's story, in Chapter 6).

Familiarity and being known in places in the community affected where people went. Louise bought her Lotto ticket from the same shop each week. Over time she had established herself as an identity in that setting.

> *Louise: I haven't won the big one yet!*
> *Interviewer: Do you always go to the same Lotto store?*
> *Louise: Yes.*
> *Interviewer: What makes you go there?*
> *Louise: They know me there.*

Whether people felt known also appeared to affect their assessments of the degree of their community participation.

Helen rated her degree of participation highly. For six months of the year, Helen was sometimes completely immobile. When she was not, she tutored people in computer skills. The yardstick she used to measure her level of community participation was the extent to which she was a familiar social identity in the community around her.

> *Why did I pick an 8 (out of 10)? (Because) all the shopkeepers around the (suburb) have got to know me!*

There were specific community spaces that enabled people to build social identities over time, due to their continued presence – family, work, church, centres of learning, and some recreational settings. Some people with disabilities made a deliberate choice to be involved in settings that gave them the best opportunities to meet new people in a safe environment (Figure 10).

> *I help out at the 10-Pin Bowling Centre, and that's a good way to meet lots of people, and get to know people. And you get recognised. Not for your disability, but for who you are.*

On a few occasions, disabled people spoke proudly of their influence on changing other people's attitudes and the general culture within community settings: Michael described how the camaraderie among their group of disabled men and women at the gym influenced the friendliness of other gym members. Another group of young men described how the atmosphere at a particular pub had changed over time as they were gradually accepted and included as fellow patrons of the pub.

Acceptance within communities was not the ultimate goal for some people with disabilities who stressed their need to **contribute** within their communities as well.

3. Reciprocity and contribution

> *Wendy: Doing value is more important to me.*
> *Interviewer: Doing things for you or others?*
> *Wendy: Doing things for others makes me feel real.*
> *Interviewer: Do you get many opportunities to do that?*
> *Wendy: No.*

This desire to contribute, to have reciprocal relationships, was applied to all interpersonal relationships. Reciprocity was the glue that bound friendships together.

> *Janet: … I have got a male friend and he has got a car.*
> *Interviewer: So you go out with him?*
> *Janet: Yes. In return I give him a cup of coffee… he takes me for a drive if we don't go to physio. And last week we went to the waterfront and he put my chair in the car and we got out and went for a little walk.*

People also wanted some reciprocity in their relationships with informal and formal support people.

> *Rose and Karen and Terry are my helpers if need be. I help them when I can, they help me where they can, so… as long as the staff know that I am out there. I am always willing to help. I am not one just to sit and do nothing.*

The identities that are imposed on people with disabilities – service user, client, recipient of support – imply dependency and infer low social value. An emphasis on reciprocity challenges these imposed identities. As well as contributing in direct ways, people also emphasized the need to "humanise" their support relationships. When talking about their support staff, people tended to emphasize their personal rather than professional characteristics. Having a more equal relationship with staff which involved an ebb and flow of giving and receiving, was simply an example of the same reciprocity that people with disabilities sought in their other relationships.

For people with disabilities, however, their efforts for balanced relationships could be thwarted in a number of ways. Firstly, they typically had very few material and physical resources at their disposal. This lack of practical resources limited their contribution to relationships within both private and public community spaces and kept people in a dependency relationship.

John lives in his own flat and is currently training for a career in horticulture. He described some of the challenges of a very limited budget.

> *… I have had a chance, which is good, to work at the domain, and chances to work at the university and things like that. I have just come back from the Botanic Gardens… but I would say, for me, transport would be the most difficult thing. Just trying to get rides off everybody, being on time and having to - it's difficult having to rely on other people when they have got their own lives themselves… If I take the cab for so many weeks, I have got to look at my budget and I have got to say to myself, well can I allow myself $50 or $30 a week just getting to the job? … I was looking for somebody who can maybe drop me home or pick me up. Yes, I find that difficult, but people have been really friendly in that regard, they realise that's the most difficult thing.*

Typically, the resources brought by people with disabilities to relationships were personal gifts of acceptance, humour, and individuality. These contributions, due to their less tangible nature, can be unrecognised by **both** giver and receiver in a relationship. Within the uneven power relationship in support services, people with disabilities can conceive professional support as a "gift". An alternative model is to view support staff as the "employees" of people with disabilities whose support they have purchased, However, this conception is not very common among people with disabilities who access Centre-based services.

In addition to contributing within interpersonal relationships, a number of people with disabilities wanted to contribute within the broader community, particularly those who were more independent. For example, Derek described his efforts to contribute within his community:

> *A lot of people are helpers and I am a helpee. I can try to help out in some way wherever I can, like whenever I go out I am on constant litter patrol, like cleaning up rubbish on my way into town and back. I like to look on that as my community service sort of thing.*

Marie was proud of her work as a teacher's aide in an inclusive school setting, supporting a young boy with special needs. She was paid to work for one hour, three days a week, but chose to work three hours at a time instead. She gifted this extra time, but acknowledged that she also gained from this situation.

> *Work gives me friendship with the children, confidence, a sense of achievement in watching them grow, and pride that I might be making a difference in someone else's life. In many ways it repairs the damage that I felt was done by the lack of encouragement I felt at school.*

Marie believed that she brought a unique asset to her work – a special empathy – as a consequence of her experience of being disabled in an inclusive school setting. Using that experience to support and protect other children from negative experiences helped her to move forward and develop personal strength.

Some people also described how their unique experiences enabled them to make a special contribution to their community. Sometimes their experiences of marginalisation helped them to understand other people in similar positions in society.

> *Interviewer: … you are studying to be a Youth Worker…?*
> *Manu: Yes. That's what I am studying at the moment.*
> *Interviewer: And how are you finding that?*
> *Manu: I find it quite interesting. Some of the things they teach you, I have sort of experienced some of it as how I grew up and people around me.*
> *Interviewer: So you think you have got something to offer the course?*
> *Manu: Yes, I do.*
> *Interviewer: What sort of things?*
> *Manu: I don't know, talking to young people, and trying to give them the right balance.*
> *Interviewer: Learn from your mistakes?*
> *Manu: Yes, learn from my mistakes. Well, I think I have got experience, because I have experienced life as a young fella and I can share a few of those disadvantage – what do you call them? I just want to give back to young people, and pointing out the right paths instead of going the other paths.*

Living life with a disability was also a valuable asset for educating other members of the community about disability. Louise was a Disability Awareness Educator. She, and a small group of other CCS service users, would visit primary schools, tertiary courses and other public and private organizations. Their aim was to lift community consciousness of disability issues. It was her first paid job and she liked the money! She also loved getting out and meeting new people in new places. Louise said that they hadn't been going out much lately. She missed the money and the chance to challenge people, but what she also missed was the fact that those moments when she sat in front of the audience was one of the few times that she was able to engage her community from a position of greater expertise and authority.

Most people have an affinity for familiarity, for liking the places, situations, and people they know best. When an environment is familiar it is also predictable, we know its social conventions, and we can relax more.

4. Psychological Safety and Comfort

When Trevor went for a walk, he chose a familiar route. He stopped to survey the neighbourhood from a chair outside his local dairy. He had developed the habit of sitting in that chair for a number of reasons. He knew the shopkeeper and would sometimes get a cup of coffee. He also liked to “keep an eye” on the predictable happenings in his neighbourhood. He and the shopkeeper had come to know each other, had shared information about themselves, and learned how to interact with each other.

> *Trevor: I walk down the road.*
> *Interviewer: Have you ever sat on another seat or is that the one you always seem to end up on?*
> *Trevor: The shop one there.*
> *Interviewer: Why did you choose that shop?*
> *Trevor: They give you a coffee.*
> *Interviewer: … they know your name (nod) and where you live (nod). Is that important?*
> *Trevor: All right. The joker who lives here, it’s his ex wife!*
> *Interviewer: Do they get on?*
> *Trevor: No. (grins).*

Marie’s scooter was only ever parked outside a few shops in her community. She would avoid the places where she had no experience of social interaction. Larger stores, like the Warehouse, presented no problem, as she felt anonymous and knew how to act. More intimate or unfamiliar settings, such as a pub or a coffee shop, were intimidating places for Marie.

For some people, the time of day was also part of familiarity and feeling safe. A few people described feeling uncomfortable being out at night. For some this was not the common fear of being out at night, but the practical difficulties of navigating around their community. But for many, who had very limited experiences of being out and about, it was the unfamiliarity of the situation that was the major barrier.

> *Marie: I have no way of getting out into the community at night because I don’t drive a car and taxis are too expensive and I am too scared.*
> *Interviewer: … I have never really thought about the difficulty of night time really. And is that, like the psychological difference about night as well – because it is dark and…*
> *Marie: Yes, it’s –*
> *Interviewer: Well I am wondering too whether it’s because it’s unfamiliar…*
> *Marie: Yes, it is unfamiliar, I am not used to it. I haven’t done it before.*

Not going out at night heightened some people's feelings of difference. For most adults, who work during the day, the social life of the community and community events happens in the evening. For many people with disabilities, being restricted to the provision of support during the day prevented them from participating in this part of normal community life.

The physical environment itself could also pose barriers to feeling comfortable and able to venture out.

> *Interviewer: Where are the community settings that you feel uncomfortable?*
> *Mary: Restaurants. They don't make enough toilets for disabled people with wide enough doors. They should make them wider. Also outside the shops all around town.*

The community itself was seen by some as unwelcoming and, sometimes, even hostile towards difference, resulting in fear and avoidance of community settings.

> *… now, it's just personally within myself. I don't feel like I'm free to join in the community because people just make fun of me.*

These feelings and fears were not characteristic of everyone. In contrast, some people felt they were accepted everywhere. One person felt that his disability had resulted in a wider circle of friends, as he had consequentially met a lot of nice people. What was reported by everyone, however, was the need to have some places where they felt at ease and completely themselves.

Marie found comfort in a group of old friends that she had known for years, and in membership of the "Spoon Club". In these two settings her disability was irrelevant. She enjoyed familiar company who shared common interests. Interactions were familiar and predictable. She described these settings as "refuges from the world of judgment and isolation", or her "halfway houses" – between being "in here" and "out there".

The one community setting that most people felt offered support and safety was the disabled community. For John it was a matter of "like-mindedness". Sharing with other people with disabilities made them better able to support each other. For Manu, he valued the fact that his difference disappeared amongst a sea of "different" bodies. Other people enjoyed the emerging disability culture, with its self-effacing, sometimes subversive sense of humour, a shared ideology, and mutual encouragement. These features were most often discussed by those people who were actually the most active participants in their communities. Going places with friends played a significant role in reducing fears and lack of self-confidence.

> *Stuart: Going as a group, you get the support, and if you get stuck you can ask someone in the group to come and help…*
> *Interviewer: Do you feel like you can talk to people more?*

> *Stuart: Yes. When you go by yourself, you don't talk to people… you feel isolated.*
>
> *Liz would be good to flat with because she is a bit more outgoing than I am, which might make me more prepared to have a go at a few things.*
>
> *Being with someone makes it much easier. I have been to the pub twice. Both times with Erica. Once we went up to get a drink and the barmaid asked us what we would like and we said a lemonade. She asked us if we had ever tried a lemon lime and bitter. Erica said she didn't drink alcohol, but I said I would give it a go. It was my first drink. Because both of us don't put ourselves out there too much we spent most of the night watching.*

Another source of psychological safety for some people was being confident that their individual needs would be understood and responded to appropriately. With these basic issues taken care of, people with disabilities could engage more fully with the community. This assurance could come from friends, or from family or professional support people.

> *That ratbag! Vern takes me to the shops because I have to have somebody with me in case I take a turn. He knows what I want to do or keep an eye on me is what I mean.*
>
> *Interviewer: You feel good about yourself.*
> *Mary: Yes, because I have got friends that can be there for me if I need them.*
> *Interviewer: So what makes community participation so comfortable for you?*
> *Mary: All the things they keep an eye on and what I need.*

Related to the issue of psychological safety was the common problem of dealing with other people's low expectations of people with disabilities.

5. The role of expectations

Low expectations were perceived as one of the most disabling barriers to community participation. Finding opportunities to "prove oneself" was a recurring theme in interviews. The community at large had such limited expectations of and for people with disabilities that they felt they had to show their competence as a form of resistance. Examples of these low expectations of others, were found in all facets of their lives, including school and family.

> *One time after a parent interview, they (parents) came home and they said to me – one teacher thought I was trying too hard, I was setting my goals too high…*

Janet experienced others' expectations when she decided to move out of the special residential institution where she had been placed.

> *Janet: I was at (Special residential institution) for 20 years and one day the matron told us which of us wanted to flat outside. She wasn't very happy when I showed up to the meeting… in fact she was bloody angry.*
> *Interviewer: Why do you think she reacted that way?*
> *Janet: Because she thought I couldn't manage socially on my own.*

Mary's brother tried to persuade her not to seek employment because he did not "think I would be able to handle it out there."

Marie felt that she had been subject to low expectations within her family.

> *They had me wrapped up in cotton wool and I couldn't break free… I wanted to prove myself and try to show them that I can. I am not useless. They made me feel as if I was useless, they were telling me you can't do this.*

Marie pointed out how a person's personal confidence could be undermined by denying her the dignity of discovering her own limits. She talked about enrolling in a Health Foundation Course, in defiance of people who told her she would not be able to manage the course.

> *I came to realise that I just didn't have the strength. But it was important that I discovered this for myself. If I hadn't tried I never would have known and stopping me would have damaged my confidence more than not succeeding.*

In contrast to Marie's experience, Derek felt that having lower expectations of himself had contributed to his sense of contentment, although he acknowledged that his life was now fairly full. He had recently moved into a new flat and was living independently. He had a girlfriend and a large, informal support network that included family, friends, neighbours, and fellow church members.

> *I am pretty content at the moment. I think those with lower expectations are more likely to have their expectations met – but that doesn't mean to say I am aiming low, I am just quite happy with where I am and what I am doing at the moment. When I start to get a bit sick of it, hopefully I will move on and do other things.*

The information gained from interviewing these people with disabilities identified three significant influences on their expectations of themselves: family, personal experience of life, and the disability community.

Families played a critical role in affecting individuals' sense of agency, or feeling that they have the power and ability to control their own lives. Sometimes it was the struggle against familial expectations which resulted in a strong will to take control.

Marie described her life as a struggle to reclaim her self-esteem, by showing her family what she was capable of through various forms of community participation.

> *Marie: … my school report card, they would look at them and put them in my bag. One term I got a bad report card, but what pissed me off was that Mum and Dad didn't take any notice of those, I wanted them to make me feel wanted and to feel loved … they always went on at my brother how they wanted to see an improvement.*
> *Interviewer: Would they ever say the same thing to you Marie – I want to see an improvement?*
> *Marie: … they didn't even bother. They looked at it, signed it and told me to put it in my bag… after that I told myself that I was going to set my own goals for myself. That doing my best and I tried to achieve more than my best because I felt nobody wanted me.*

Many families had held the same expectations for their disabled children as for their siblings. Adults from these families typically expressed a greater feeling of agency, or autonomy and control of their own decisions. Nathan is a young man with cerebral palsy. He lives in a flat with other men with disabilities, drinks with them at the pub, loves his job as a postman, and was eagerly looking forward to the duck-shooting season. He had a supportive family who expected nothing less of him, and he echoed his family's expectations and approach to life:

> *If I want to do it, I will do it! Because I'm outgoing.*
>
> *People know who I am and my chair is no big deal.*
>
> *You're always going to get some people…*

When asked to rate his level of participation on a scale of 1 to 10, Nathan's response was, "Why have you stopped at 10?"

A second influence on expectations were people's experiences of life, with this vividly illustrated by people who had acquired their disabilities from an accident, after living life as an able-bodied person. Adam saw his life as severed in two by his accident, with contrasting expectations in these two segments of his life. He described himself as having been "murdered" by his fall from a train. His fall had taken away many of his personal resources necessary for survival. All he had left to protect himself from others' low expectations and lack of imagination was his "B R A I N". This was his only defence against the limited horizons and controlled lifestyles that he felt other people with disabilities had assimilated.

> *Interviewer: … (where) do you find that prejudice and lack of expectation…"*
> *Adam: Y O U*
> *Interviewer: Yes – I don't know how to read that. Really what you are talking about though is the battle not to be prejudged. Is that fair? Have I got that right?*
> *Adam: Y E S.*

> *Interviewer: So how much of your life do you spend fighting against that, like is that a significant part of your identity?*
> *Adam: Y E S.*

Finally, people with disabilities influenced each other's expectations through processes of mentoring and encouragement. Marie's choice of a more adventurous flatmate helped her to extend the boundaries of her community. John acknowledged that being with other people with disabilities had been the catalyst for personal growth and moving forward in his life. Stuart experienced a sense of common purpose with the other people with disabilities in his gym group.

> *Interviewer: So everyone is there for the common goal of doing this activity.*
> *Stuart: I quite like (it) that they help you…*
> *Interviewer: There was support (and) people challenging you to do better?*
> *Stuart: In the Tuesday classes, pushing the…*
> *Interviewer: So that was a bit of a philosophy?*
> *Stuart: Yes.*
> *Interviewer: So there was a common goal really to push the boundaries with each other.*

Those people interviewed were asked what advice they would give to other people with disabilities. The messages are remarkably similar, given the many differences – in ability, age, gender, and personal circumstances – in the group. Almost all of the advice encourages other people with disabilities to struggle against the barriers to ordinary forms of participation, particularly the low expectations of other people and of society generally (Table 2).

Table 2: Advice Participants Gave Other People with Disabilities.

Mary	“If you are sure you can do it, give it a go.”
Marie	“…go out there and give it a go. And don’t let anybody stand in your way. I’ve had people stand in my way, and it’s taken a long time to overcome.
John	“Never give up basically, always have a dream…”
Derek	“Just hang in there. My favourite Latin phrase is Non legite carborundum, which mostly translates to ‘don’t let the bastards grind you down, which just seems like, keep on keeping on and don’t give up”’
Stuart	If you can’t do things through the normal channels go around and keep fighting until you get what you want. Don’t give up.”
Adam	“GYM. Move your body.”
Kelly	I would advise them to be happy, not sad. What else – be more outspoken and not be sensitive about it. Not lock yourself away
Janet	“Try and make yourself as independent as possible.”
Manu	“Try not to be so dependent would be the main thing….Keep it real.”

Summary

The characteristics of places that were valued by people with disabilities were: self-determination, choice, and personal control; a social identity – being known and accepted; being able to contribute, reciprocal relationships; psychological safety and comfort; and positive expectations. People with disabilities advised others to be assertive and persistent in pursuing their own goals. So, if people with disabilities act on this advice, **and** “the community” supports self-determination, promotes a positive social identity, and enables people with disabilities to contribute to their communities – what will be the outcome? The ultimate outcome of these valued characteristics is a sense of membership – in communities, and “the community”.

Membership: the essence of “community”.

The outcome is a sense of belonging and membership. Belonging is also an outcome that develops over time, through being involved in shared activities in shared places.

Marie divided her friends into “older” and “new” ones. Her “older” friends were a group of women she had met at a camp when she was first diagnosed with cancer.

She had stayed in touch with them for nearly twenty years, and even though she did not originally volunteer them when asked who her friends were, it was this group of women that she described as a “refuge (of) companionship, guidance and support”. She spoke with real affection about “having grown up alongside their families” and how she now stayed with or visited extended family. Marie and her “older friends” were bound by a reciprocated care for each other that had a long and shared history of time and place.

Identity continuity, and membership in communities were illustrated in many different ways. Adam’s wall was decorated with surf lifesaving medals. Family photos were prominent. Trevor named his budgies after himself and his favourite sister. People also adopted the “cultural badges” of local community places, proudly wearing workplace or company logos.

Membership also includes shared knowledge and intimacy that only comes from being involved in a group over a period of time. Jenny described knowing her Vocational Centre “inside out”. Trevor chose his seat outside the shop, because he and the shopkeeper shared some knowledge of each other’s private lives. Adam’s relationship with Jock was founded on their common love of surfing. The group of young men who went to the pub together enjoyed the fact that they had become part of the “bar-scape”, and were comfortable with the cultural conventions in that particular place.

A significant number of people were members of religious or fellowship groups, both inclusive ones and some specifically for people with disabilities. Membership in these communities involved what one person called “the open arms of fellowship”, and shared beliefs and customs which transcended differences.

Community membership often relies more on shared interests or beliefs and not physical attributes. Marie spoke about her membership of a Spoon Club. To the other members, Marie’s knowledge of cultural etiquette, resources, and ability to trade spoons – were far more important than her disability. Marie was equal in every respect to other Club members.

This notion of equality as an essential aspect of membership was important to those interviewed. Helen mentioned it in relation to her decision to move into an elderly care setting because she was treated as an equal with all other members of that “community”. John emphasized it in describing his experiences in the gym, and how, as an individual, he had been treated as an “outcast”, rather than a gym member. He said

> *… get other people to try and treat disabled people as independent, see them as yourself, or just try to treat them as normal… people treating you the same as everybody else. That would be my message.*

Membership of the community of people with physical disabilities, with its own emergent culture, was also important to a number of people. For John, Manu, and Cameron, this membership had been a catalyst for personal growth, greater support, and shared insights. All members of this group had experienced discrimination and incidents of hostility in the wider community. They shared common experiences and humour around incidents such as “being marooned when puddles got deep enough to short batteries”. They encouraged each other to stay as independent and physically active as possible.

None of the service users who were interviewed called for people with disabilities to determine their own culture per se, rather, the strongest forms of resistance to stereotyping discussed, was in opposing lack of understanding and low expectations by others. A few staff (who were also disabled) did express the view that people with disabilities needed to become more visible, celebrating difference in a similar way to other marginalised groups.

Being a member of a specific group also brings with it certain shared cultural understanding and shared goals which are not usually known to “outsiders” in the wider community. Bonds among members can be reinforced by being an “insider”. Trevor did not really enjoy Boccia as an activity, but what he did like was travelling to places with the team, bound together by a common purpose. Helen talked about participating in her Spoon Club as a “secretive activity” which she believed other people her age would see as “nerdy and old-fashioned”. Within the club, however, the members all shared a common interest – whatever other people thought of it.

Membership of community, in its richest sense, was highly valued by those interviewed in relation to the key settings of family, employment, church or other “faith” groups, and some organized recreation. These were the places where people were most likely to experience acceptance and true membership – participation in their community.

The two areas which have been mentioned but not explored in depth in this Chapter are those of employment and family. Because of their high salience to those interviewed, these areas will be further discussed in the next chapter.

CHAPTER 5:

EMPLOYMENT AND FAMILY: CONTEXTS FOR COMMUNITY PARTICIPATION

The one issue on which people spoke with a unified voice was the importance of employment to them. Wanting to work was a universal aspiration. Most saw employment as the gateway to legitimate forms of community participation. Such was the desire to work, some people saw employment as the **equivalent** of participation rather than one possible way to engage with the community.

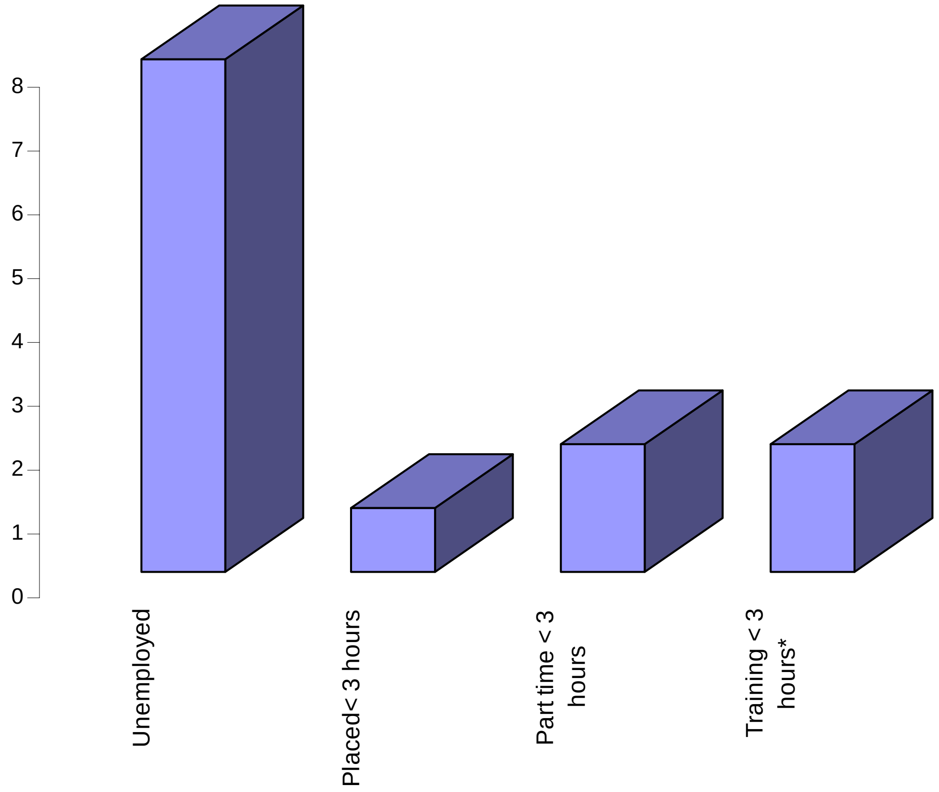
> *Interviewer: And what does community mean to you, when I say the word ‘community’, what do you think?*
> *Kelly: It means jobs and that’s it.*

One person believed the activities that she did at her vocational centre did constitute work, because she was directed to do tasks and it fulfilled an important social function in her life. For the most part, however, people made a discrimination between activities and “real work” and aspired to be in real employment.

> *Well, I am really sorry I have not had a good job… actually I would like to get a job… a real job like answering phones or doing typing or something like that… I want to get a damn job!*

None of the people with disabilities interviewed were in full time employment. The majority of people we spoke to were either unemployed, placed (in work experience) or volunteered their labour. For example, of those people interviewed, only two were employed in part-time work. One person worked for 3 hours a week and another extremely infrequently. Figure 11 describes the employment situations of the thirteen people who gave individual interviews. The distribution is somewhat misrepresentative as there are some people who fit in more than one category. For example, neither the person who was placed in an unpaid position, nor the person who was doing less than one hour’s paid employment per week were recorded as also being unemployed. The reason for doing this was that those people themselves felt they **were** employed.

Figure 11: Employment situation of people with disabilities who were interviewed



For those who had paid employment, or who **considered** themselves to have a job, their work was a source of great pride to them.

> *The most important way I participate (in the community) is through school. I am working as a teacher aide, helping a child with a learning disability.*

Kelly was placed in a community kindergarten. Despite not being paid, she considered this to be work, and of her job she said;

> *Kelly: I watch the children play, I do things in the water, watch them play in the water, watch them play on the sand – on the outdoor equipment and I bring them their drinks…*
> *Interviewer: Do you enjoy being around the kids?*
> *Kelly: Yes – I do.*
> *Interviewer: It was the first thing you said to me when I came in, so I was wondering whether you are proud of being there?*
> *Kelly: Yes, I am actually proud of working at the kindy, I would never stop or give up.*

People’s jobs were often the first thing they spoke about as they began to explore community meanings. Louise could not speak clearly. She communicated with the aid of a pre-programmed Delta Talker. The most used button on her talker was Louise’s introduction of herself. Louise had, very infrequently, been part of a group of service users who would visit community settings to educate people about disability issues. Despite it being pretty irregular work, Louise still wanted her work to feature strongly in her personal introduction. Her most used button said:

> *I am Louise. I live in a residence for the elderly. My interests are music, laughing and talking with my friends and being out and about town. I have worked for awareness education for quite a number of years.*

Louise’s aspiration to be understood through her employment was not uncommon. In one Focus Group, every person introduced themselves to the group by direct reference to their employment or volunteered labour.

> *My name is Tony and I work at the Warehouse on Wednesdays and Thursdays.*

One person noted that one of the good things about a job was that it was easy to construct an identity around. Many people came to interviews proudly wearing their work uniforms or other signs that they were incorporating their employment role as an important dimension of how they saw themselves and wanted others to see them. Most people who were employed identified their job when asked what was good about their lives.

Many reasons were cited for the importance of employment. One of the things that people valued most about work was their pay packet. Everyone reported that they had low incomes and their lack of material resources was itself seen as one of the most significant barriers to other forms of community participation. Getting paid therefore was extremely important and made a considerable difference to stretched incomes. However, even though financial reward was highly valued, people’s remuneration seemed also to be a significant way of acknowledging the individual’s contribution. The sense of inclusion and appreciation communicated by his pay was of value to David.

> *David: I get paid!*
> *Interviewer: What does that mean for you?*
> *David: That they are happy with my job and that I have a really good boss and that I have done a really good job.*

Volunteering was also rated more highly than sheltered work which was seen by many as exploitative. The fact that workshops received the person’s Disability Allowance and then returned some of it as a “wage” also complicates this whole issue.

Employment also developed people's skills and expanded their competence. Learning new things in a real situation was stimulating to some people.

> *Interviewer: What do you like about your work?*
> *Kelly: Well, it's a challenge sort of, work I guess.*

Once people had been employed, they found adjusting to being unemployed or coping with non-work hours very difficult.

> *… I am not used to sitting around… I was getting up at 6 o'clock in the morning. Sometimes I would get up thinking I was going to work, then I had to stop and say I am not working any more and I had to go through all of that.*

> *… I get paid for three hours a week. One hour every three days – but I love my work and do the whole morning each of the three days I am there (3 unpaid hours each day). The alternative is to be at home and since working I get bored with myself at home doing nothing.*

John believed that the sense of isolation and the absence of purpose in his day that he experienced when unemployed were the root cause of a struggle with depression. He suggested this may well be the same for other people with disabilities.

> *John: … if you are just sitting down on the benefit starting at the four walls and you don't want to get out, and you don't want to do anything with your life, it can be a terrible trap. Especially with disabilities, I find a lot of people are like that, you don't want to be caught in traps like that.*
> *Interviewer: Right, and the trap is just with nothing to do.*
> *John: Well, just existing, do you know what I mean?… It's easy to fall into a trap like that, you get upset and you turn on other people kind of thing… I got into a state where I suffered from depression.*

People who had jobs said that one of the most important things about employment was that it gave them the opportunity to meet people. They also valued being in a more equal role and the relationship of co-worker and colleague.

> *In my work – I am working with the public!*

> *I am waiting for work experience which gets me out meeting people.*

Being involved with the public from a position which offered expertise or services was thus highly valued and contrasted with people's roles in other settings. In addition, being chosen for a job builds a person's self-esteem and guarantees entry into a common culture, with common objectives and common membership of communities beyond disability.

A number of people with disabilities expressed the view that being selected and accepted within the culture of a workplace permitted them to "recast" themselves.

Marie spoke directly of the value teaching held for her as evidence that she was able to transcend the disabling effects of low expectations.

> *Marie: Teaching is a very positive thing for me.*
> *Interviewer: What is it that is so good about it?*
> *Marie: Getting out there. I feel as if I have been shut away… People always said I couldn't do it and it's as if I'm proving to myself and to them that I can do it.*

For others it was an important proof that the world of work existed beyond the treadmill of preparation and endless courses which were supposed to "get them ready" to participate in the community.

> *It's saying – so that's why I try to do a course. Every year I say to myself, well you must study something else because I haven't had much luck in this (course). I would be stuck if it wasn't for this place (horticultural training)… every year I say to myself… not more study and I do another course – so this has been a real bonus for me.*

In western culture, paid work represents one of the most potent symbols of adding value to the national culture. Employment also afforded people the opportunity to add value to the lives of other members of their local community. Marie had chosen teaching as a vocation, specifically because of the

> *… sense of achievement in watching them (children) learn and grow and pride that I might be making a difference in someone else's life.*

Manu had chosen to train as a social worker for similar reasons:

> *(my) ultimate goal is to get a job working with young people and giving some stuff back.*

However, Adam's succinct statement – "Y O U W O R K" – made to the interviewer reminds us that we need to recognise that the value of work is a general value shared by all members of society, not something "special" among people with disabilities.

Some of those interviewed did not appear to have such strong desires to have a job. The importance of employment appeared to be strongly associated with people's degree of disability. **Having a job was of most importance to people with severe, multiple disabilities.** People who were more independent and had more control in their lives were often more ambivalent about work. **So those who valued work most highly were also those who had had the most limited access to employment**.

Louise's only experience of employment was with other service users in her role as an awareness educator for CCS.

> *Interviewer: Are there things that you would like to be doing that you are currently not doing?*
> *Louise: Yes. Work! More work.*
> *Interviewer: So other than your awareness education, have you done any other work?*
> *Louise: No.*

Kelly had done nothing other than her two hours a week, unpaid placement at the kindergarten. Delivering a community newspaper for less than $10.00 a week was Trevor's only other employment. Finding employment was extremely important to Louise, Kelly and Trevor.

> *Trevor: I'm getting a job anyway, a cleaning job… Saw it in the paper.*
> *Interviewer: Have you looked for many jobs Trevor? Is this the first time you have done it?*
> *Trevor: First time. I hope I get it.*

Unfortunately, services which aim to support people with disabilities to find and retain employment tend to target people with less severe disabilities, and those like Louise, Kelly, and Trevor are often expected to be involved only in other forms of community participation. The generally held perceptions that people with more severe disabilities cannot work also results in a denial of the training, skill development and work experiences that could increase their work opportunities. This leads to a "vicious circle" of denial of participation in a highly valued community activity.

Ironically, the centres that appeared most successful at finding employment for service users were smaller services that reported making a deliberate effort to "blur the boundaries" and promote flexibility around the differing contracts related to "community participation" and "supported employment". Employment was viewed as one dimension of a holistic vision of service users' support needs with the right to employment taken to be a universal right. An expectation that employment was also universally achievable was an important axiom of service delivery that had been assimilated by service users. At one Focus Group most of the participants were employed, including service users with multiple disabilities, and those that were not believed they would also find employment.

Although every individual was unique, some people who strongly believed in their own right to make decisions or who had been employed previously prioritised other needs over employment. To Adam his "free time" and the prospect it offered for self-expression was a much more precious commodity. Sarah concurred, suggesting that living with disability was difficult enough and that other more intangible forms of participation were more likely to advance her quality of life, than paid work.

> *Employment was the last thing I put on my goal plan, but it was the only thing my support worker talked about! I think services should be looking at all the other things like having fun and making new friends.*

Volunteering was one way that a number of participants sought to replicate the benefits of work. Volunteering got people out of home and enabled them to meet new people in new places. Often they worked with a team of volunteers on a project.

> *I enjoy it. I enjoy being around people. And if there is a group that I am volunteering for and there is an opening for a job, they could see that I was interested.*

Exposing oneself to other networks sometimes did result in paid work. Marie's employment as a teacher aide came about as a consequence of her voluntary work at the school.

> *I went back voluntary this year as a teacher aide because I had nothing else to go to and it was getting me out and about in the community and I have got (now 3 hours) a week paid work out of it.*

A number of people expressed a view that finding work was more difficult for people with disabilities. Sometimes people perceived employers to be overtly discriminatory.

> *Well, is there jobs out there for us? No – because employers don't like employing disabled people.*

Some people assumed that being treated differently on the grounds of disability was culturally acceptable, and did not seem to be aware that such discrimination was against the law.

> *I don't know whether they would accept anyone with an disability in a bank, or something like that.*

Others felt the fact that school had left them unprepared for employment, and a subsequent lack of educational qualifications or work experience made it difficult to compete in the labour market.

> *… one of the sticking points for me is job experience.*

> *Probably not having School C – for jobs (is the barrier to employment).*

Older participants also believed that their disability had the effect of doubly disabling them by facing discrimination on two grounds – disability **and** age. Fifty years of age seemed to be perceived as the ceiling to employment opportunities.

> *Janet: Well, I'm really sorry I have not had a good job.*
> *Interviewer: Do you think this is a possibility for you?*
> *Janet: No… I'm in my mid fifties.*

> *Interviewer: So is it (employment) something you would like to be doing in the future?*
> *Stuart: Well, once you are over 50, it's hard to get jobs isn't it?*

Some people with disabilities were unsure about whether it was reasonable for employers to make accommodations for disability. The inaccessibility of work spaces because of physical design was mentioned, but more often anecdotally. People were also concerned about finding employers who understood some of the more invisible aspects of disability, like tiredness or inability to concentrate for long periods. Suggested solutions to these real difficulties were job sharing and "glide time". Just as the built environment has been designed for able-bodied people, so have many other aspects of work, but discrimination is easier to identify in the inaccessibility of physical environments.

Some people with disabilities expressed a strong desire to initiate and lead the process of finding employment. A perceived lack of transparency and not knowing where they stood frustrated people and undermined their confidence. As discussed previously, what had ignited Trevor's imagination about the prospect of finding employment as a cleaner was that **he** had taken the initiative and initially felt in control of the process.

The second time we saw Trevor was at the Focus Group, nearly two weeks later. He was still hopeful. He recounted to the group how he had seen the job in the paper and had taken it to his support worker who was going to ring. But his excitement had ebbed because he no longer knew what was happening.

> *Interviewer: What is going to happen next?*
> *Trevor: I'm going to have to wait – for a year.*

The world of employment was like an exotic foreign country to some of the people we spoke to. The difficult and hidden route there and its stringent entry criteria all added to the mystique, and those that had made fleeting visits returned with stories of untold riches.

Summary

People with disabilities identified employment as extremely important to them and saw a job as a critical part of community participation. However, none of those interviewed had a job of more than three hours a week. People's work was a source of pride and social identity, as well as increasing a very low income. Volunteering was valued more highly than sheltered work. Without any employment people sometimes felt isolated and this could lead to depression. Work provided opportunities to meet new people and to contribute to the community.

Having a job was of most importance to people with more severe, multiple disabilities but they were the least likely to be given support to work.

A few people saw other aspects of their life as more important than employment, and valued their "free time".

People did note that employers could be discriminatory and some were not aware that discrimination on the grounds of disability was against the law. People who were older felt doubly disadvantaged.

Many people felt that their education had not prepared them adequately for employment.

Family as a context for participation

Everyday understandings of "community" tend to emphasise the geographic and not the experiential attributes of place. Perhaps as a result, families have tended to be overlooked as sites for community participation. However, as people began to describe to us how they had become involved in activities and what forms of community interaction they valued the most, family kept weaving its way into their stories.

As we saw earlier, visiting family was the activity most often named by people who gave individual interviews (Figure 1), and for many participants, visits to parents and siblings, were a regular and highly valued punctuation to their week. To Louise and Janet, they were amongst the things that they most valued about their lives.

> *Interviewer: Have you got family Louise?*
> *Louise: Yes.*
> *Interviewer: Here in New Plymouth?*
> *Louise: Yes.*
> *Interviewer: Do you stay in touch with your family?*
> *Louise: I am going out Saturday.*
> *Support Person: You do that on a regular basis don't you, is it every Saturday?*
> *Louise: Yes. My sister at home.*
>
> *Interviewer: Are there other good things about your life Janet?*
> *Janet: Yes. I go to see my mum on the weekends. Sometimes I stay.*

Paradoxically, Louise describes the experience as one of "going out" **and** of "going home", of leaving home to go home, suggesting that for her, family visits served two important functions. They broke the normal rhythm of life to a degree that visits represented an event of social significance. And, being with her family connected Louise to a place where she knew she belonged. To both women, their family was the only place they described experiencing a sense of belonging, free of the culture of disability.

Ordinarily, family membership is a birthright. The people we spoke to found various ways to give expression to the importance of that birthright. Family photos were propped up on dressing tables or hung from bedroom walls. Weeks were organised around family visits, and conversations were laced with talk about the waxing and waning of family relationships. One of the most powerful metaphors for the importance of staying close to his family came from Trevor. Two of the most precious things to Trevor were his budgies. He had two that shared a cage within arms' reach of the chair at the epicentre of his room. The blue one Trevor had named after himself and the green one he named "Pip," after his favourite sister.

> *Interviewer: Trevor is just going through his address book.*
> *Trevor; I get on with her (showing interviewer)*
> *Interviewer: You get on with Pip, the one you have named your bird after?*
> *Trevor: Yes*
> *Interviewer: And is she the sister that lives close..*
> *Trevor: I don't get on with Helen.*
> *Interviewer: You don't?*
> *Trevor: But we stay in touch……We never get on, me and the oldest there.*
> *Interviewer: You get on like budgies in a cage – I was just thinking that's you and Helen in there.*
> *Trevor: PIP!*

In people's minds family appeared to be thought of a little like we think about important places in our lives. If we think of **"place"** as **centres of felt value,** family could be seen to be one of the most important **places** in peoples' lives.

Chinese geographer Yi-Fu Tuan has written extensively about people's attachment to places. He suggests that certain places come to have personal meaning to us through the steady accumulation of sentiment that occurs over time (Tuan, 1977). The imagery Tuan invokes is one of a sequential laying down of emotional connections with places and times, that will be most easily understood by the people we shared them with.

Trevor shared a number of histories with his family. He and Pip and Helen and his other siblings shared a biological history that meant there was an embodied recognition of each other. They could see themselves in each other's hands and eyes and mannerisms. They also shared a social history. Trevor shared a collective understanding of the subtleties of family rituals, the idiosyncrasies of each other's character, and times and places where he and his brothers and sisters had demonstrated their love for each other. These were insights and understanding that it was difficult for interviewers or anyone beyond the community of Trevor's family to penetrate.

Such was the power of personal history, people and places he no longer had access to, continued to shape the hopes Trevor held for himself. Speaking of the continuing resonance of his childhood memories and of a connection to place forged through a relationship with his grandfather, Trevor reflected;

> *Interviewer: What would you wish for yourself?*
> *Trevor: I want to go away and have my own crib (bach).*
> *Interviewer: You like the idea of having your own crib?*
> *Trevor: Doing up my own crib.*
> *Interviewer: Did you have a crib when you were a boy?*
> *Trevor: My grandfather.*
> *Interviewer: Your grandfather – where was it?*
> *Trevor: At Pilots Bay.*
> *Interviewer: I know Pilots Bay. When was the last time you went to Pilots Bay?*
> *Trevor: I don't know. When I was younger.*

When people began telling us about the importance of their family, most spoke simultaneously about the impact that they had in their everyday lives. This involvement mitigated some of the ways they were disabled by the **absence** of similar forms of support. Belonging to a family was important to participants for a number of reasons.

- They offered a continuous narrative to their life. People **felt known** by their families.
- Proximity to family offered **psychological safety.** Family was a safe place to return in crisis and an ever-present location from which to push out and contest barriers.
- Belonging to family meant **access to collective resources** and other networks.
- Families appeared to seed a sense of **personal agency**.
- They offered a **source of intimacy** and affect that made support from families different.
- They were also a place that reciprocally **received** care and concern.

These various aspects of family importance will be explored in more detail in the rest of this Chapter.

Family as a reservoir of identity

Trevor was almost fifty. For all of those years he had sought out and maintained contact with his family. His "brainy" sister Pip was especially important and he turned to her whenever he needed advice or reassurance. What appeared to make Pip especially trustworthy in Trevor's eyes, was that over time, she had supported him in ways that communicated to Trevor that she knew what was important to him. Pip had acquired the knowledge that underscored Trevor's trust by knowing him over a long stretch of time. Disability writers have recently begun acknowledging the psychological safety that people with disabilities can experience through the continuity of family relationships. Writing about the important role many families play in the lives of people with learning disabilities, McConkey (1994) observed that *“families offer the emotional security that a constantly changing workforce of professionals can not offer” (p. 7).*

To Adam, who believed his train accident had severed him from his identity, the sense of autobiographical insideness that his family provided had added poignancy. Against a forever changing backdrop of support, Adam’s family was a primary reference point for his personal history. Of all the people currently in Adam’s life, only his family knew him prior to his fall. Cues to reminiscence, held by the family, like shared memories, or moments captured on film were probably important touchstones given Adam’s desire to make visible that identity (see Adam’s Individual Story). He was certainly keen to show the interviewer a photograph of the potter’s studio he had helped build for his mum, which must have been an important shared, tangible monument to Adam’s love for his family. As valuable as they may have been, however, it was the seamless narrative that they gave to Adam’s life that appeared to make them such an important resource. Adam’s mother described once writing a brief biography with Adam to ensure that staff had the understanding of his life, of the person he was struggling make transparent. Similarly, because of their greater insight, Adam and his family were more able to respond to each other in ways that reflected how they knew they saw themselves.

Family as a place of psychological safety.

The length of time over which family relationships stretched was important in other ways too. For almost all of the people who spoke to us, family was the context in which they had accumulated the most shared experience. Family relationships stood in stark contrast to most other forms of membership, which were typically much more fleeting or temporally bound. Many people with disabilities find friendships hard to sustain (Bray & Gates, 2003) and family relationships typically remain the most stable in the lives of people with disabilities (Carnaby,1998; Kennedy C. H., Horner R. H. & Newton S. N., 1989). The men and women we spoke to underlined the importance of family by describing them in the following ways. Marie said of her grandparents that “***They were there when I needed them,”*** and Manu echoed the sentiment when he said of his whanau, ***“ a few family members have helped me out (over the years) They were always there for me.”*** Of his family, John would say, ***“Our family is very close. We have always been close.”***

To John, Marie and Manu their families were safe and supportive places to dwell.

Tuan (1977) believes that family is in fact **the first place we come to know**. In a sea of unstable impressions, it is the geography of our mother’s face that we first learn to recognise. Over time, our parents become the focus of felt value and infants grow increasingly attached to them in much the same way that we will later become attached to other places.

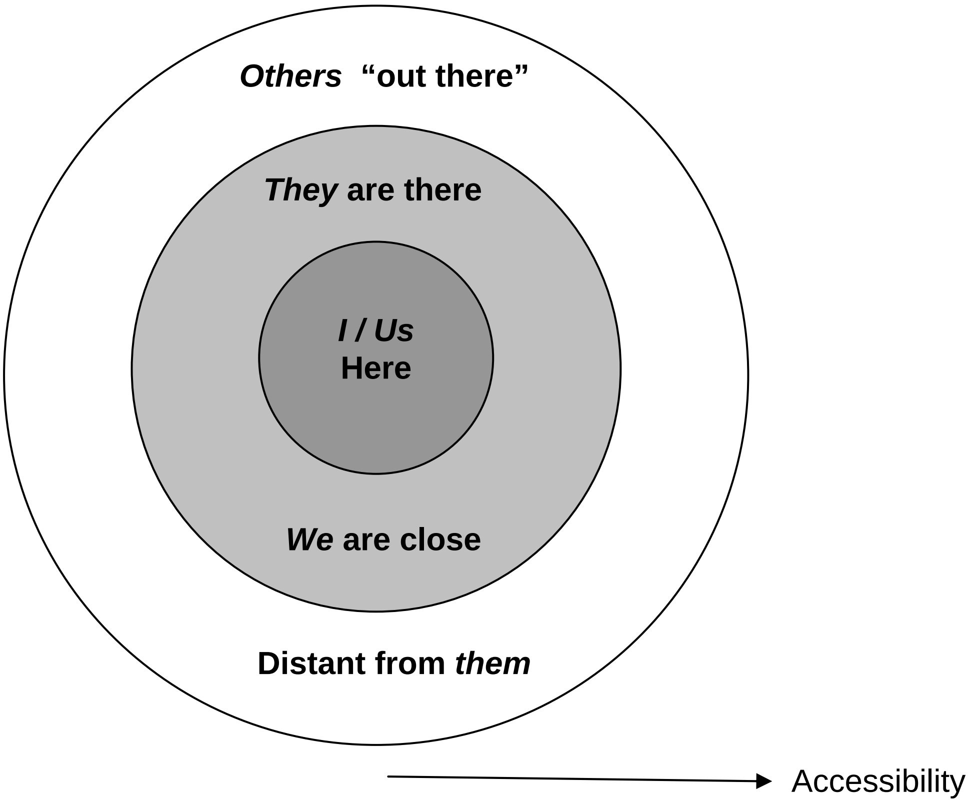
There is general agreement that, towards the end of the first year of an infant's life, they participate in a process of forming attachments to familiar people who display "sensitive responsiveness" to their need for care and stimulation (Ainsworth, 1979; Atwool, 2002). Attachment figures, like parents, then become a secure base from which an infant will push out to explore their world. In much the same way we leave home to explore the world, an infant cycles between drawing nearer or pushing further away from their parent's side. The more hostile the environment, the nearer infants draw and the more reticent they are to push out too far from their parent's side (Konner, 1972). With immediate access however, a strange world holds few fears. Just like our attachment to places in adulthood, attachment figures acquire the status of stability and permanence (Tuan, 1977). It also seems clear that children form an inner representation of the parent-child bond and this "inner working model" of attachment becomes an important part of an infant's adult personality. Access to sensitive responsive care in infancy appears to influence the expectations we have about the availability of support in other relationships in later life. When parental care is not reflectively sensitive to an infants needs, they can form ambivalent or avoidant forms of attachment that act as a model for later relationships. Inner working models of attachment shape the expectations we have of others and can in turn influence our feelings of self worth and agency (Atwool, 2002; Bowlby, 1969; Sroufe, 1988).

When Marie and Manu spoke about the value of their families, they described the importance of knowing that they continued to have access to secure relationships in times of stress or personal crisis. They were safe and supportive places to return to. Marie and Manu also used the language of physical distance when they described their families. They were "**there"** for them and they were "**close"** to them, suggesting association between the language of physical and interpersonal proximity.

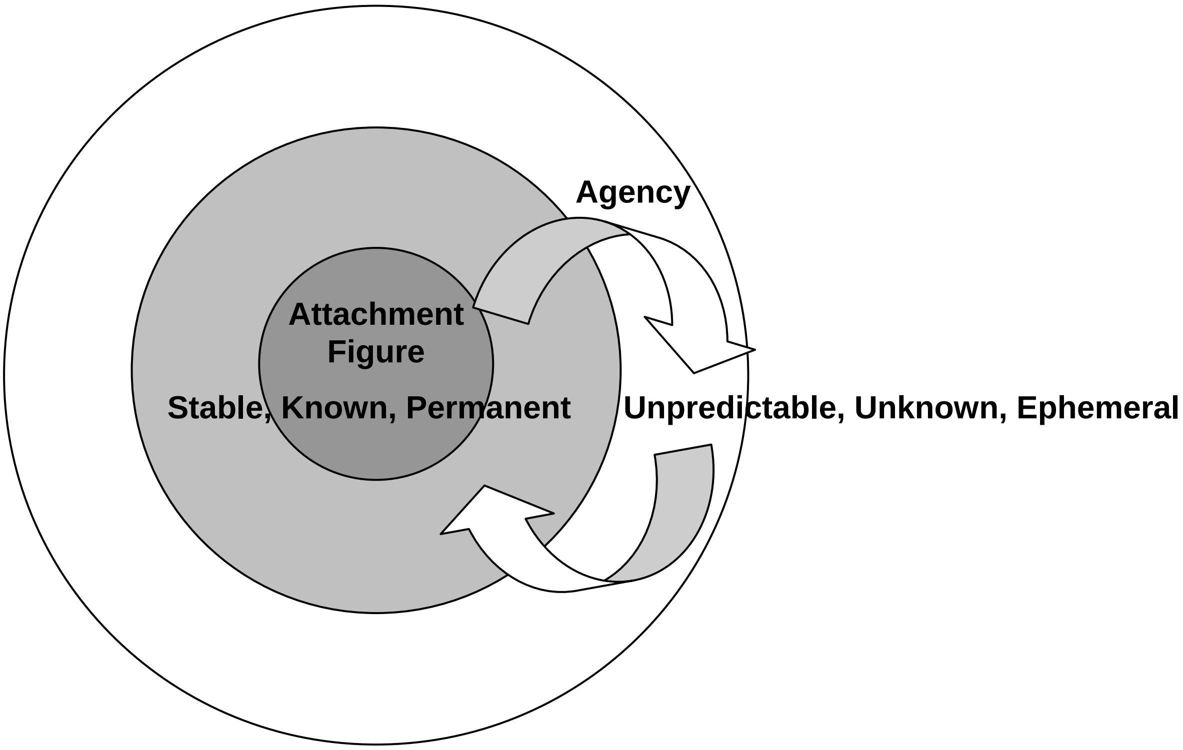
Tuan (1977) suggests that we can use a common language for physical and interpersonal proximity because what we mean by distance, is distance from self. Humans, he argues measure all things in relation to where they are (anthropocentric). Distance, therefore, is a measure of how accessible the resources we value are to us. Because people are so important, the language of physical distance and intimacy have become intertwined. The way we use personal pronouns and spatial descriptors vary in predictable ways depending on how accessible people and places are to us (Figure 12). We take this shared language with us when we push out from and return to the people and places we are attached to and feel safe in.

Figure 12 The Shared Language of Proximity and Attachment
Spatial Descriptors and Personal Pronouns

Spatial Descriptors and Personal Pronouns



Bowlby's Attachment Theory



Trevor's budgies seem an appropriate metaphor for the psychological comfort that can be derived from being close to family. It found expression in the adult lives of many of the people we spoke to.

To some, the proximity of family had important practical consequences. Maria's grandparents had taken her in when she felt unable to cope and Trevor visited his sister Pip whenever he had something on his mind he needed to talk through. To others though, simply the security of knowing that their family was an accessible source of support was what they valued, even if it was not required.

> *Interviewer: What are some of the things that have helped you get where you are?*
> *John: I think mainly just confidence and stability with my family. I have got all the family in (the same place) where I am living now, they are all five minutes away and that's been really good. If something happens I can call them up and they are always there to help me out – and I don't need any. I haven't had any major difficulties with my disability.*
> *Interviewer: So family has been really important?*
> *John: Yes. Our family has been very close, we have always been a close family so I think that is what you need if you have any problems.*

Proximity to family did appear to **influence peoples' willingness to venture out** in a way that is anticipated by Tuan (1977) and Bowlby's Attachment theories (Figure 12). John had even made a deliberate decision not to stray far from his family because being close enabled him to be more confident with lifestyle choices.

> *But I never got to the overseas travel side of things. I never got to do that. So I stayed here, close to the family and started again, if you like, doing something brand new, something completely different.*

Sometimes people needed to move to close the distance between themselves and their families.

> *I was just sort of going along for the ride and this is where I ended up, largely thanks to Dad. He decided to move here first and bought the farm. And he invited me to come down here and I had a look and liked the place and I decided to move down here.*

However, sometimes both physical and affective distances were difficult to close.

> *Kelly: I used to stay with my mum and dad when I was two*

> *Interviewer: So you haven't been with your mum and dad since you were two. Is that right?*
> *Kelly: Yes because they live in Manapouri – Te Anau sorry. They live in Te Anau and that's a long way away. I was seeing my counsellor for grieving about my parents. But I still think of them a lot. I still wonder how they are going. I was only saying she got pregnant by mistake. I don't mind talking about it now because I'm old enough to handle it.*

> *My family have deserted me. Mum died about eight years ago and I haven't seen the family since… think they are scared of what to do if I get crook. They just steer clear. But I'm not worried.*

Families as a material resource

People's lives were complex. As a consequence it was impossible to find simple correlations, but there did appear to be differences in the range and type of activities people participated in and their physical and interpersonal closeness to members of their family. **People who had stayed in contact with a supportive family tended to participate in a wider array of community activities.**

In addition to the psychological comfort that being close to family afforded some people, families were also an important material resource. They broadened people's community by providing points of entry to other networks and exposing them to new opportunities.

Sometimes a family connection knew of work that was going.

> *Trevor: I used to work cleaning the office and delivering Weekenders.*
> *Interviewer: How did you get that job?*
> *Trevor: My sister-in-law.*

Sometimes familiarity meant they saw new possibilities, including different vocational paths.

> *I would be pretty stuck if it wasn't for this place here…..it's been a real turning point and the weird thing was, I only found out about this place from the Ellerslie Flower show. My father went through, I wasn't even there and he said it might be something you would be interested in and just picked up a pamphlet from this place.*

It was often parents who linked people to services. Mary's family had helped her to find her home, and three different vocational services to break up a week otherwise spent there. Siblings and extended family were important too. Family traditions were perpetuated by younger generations and age peers were often responsible for introducing people to new activities and new friends.

In one focus group, people enjoyed one participant's barely bridled enthusiasm for the start of the duck shooting season, because that was his, much loved family's tradition. Manu enjoyed being with his whanau at the marae and on the sidelines watching his local league team. There was no ceiling to the age at which family members could introduce people to new places or potential friends.

> *I knew Dale from about when Nana got me into swimming I guess. She is in a home now. She can't talk very well. You have got to yell at her, it's quite frustrating really*.

It was family that people felt most able to turn to when financial resources were stretched too thin to meet their needs.

Because of the way people's lives were configured, including the absence of many other forms of participation, for many people, their families were the only conduit they had to new places and new people outside of service provision. Trevor's experience was typical of a significant number of people that spoke to us.

> *Interviewer: Do you go and do things with other people?*
> *Trevor: No.*
> *Interviewer: I get a picture that beyond CCS, there isn't anybody you meet aside from family really.*
> *Trevor: I play Boccia.*
> *Interviewer: Have you been out of town, other than with the Boccia team?*
> *Trevor: No.*

Trevor's family were an oasis of membership in an otherwise fairly desolate community and there were good practical reasons for him to stay sensitive to the waxing and waning of relationships within it.

> *Interviewer: Who helps you get the things that you want in your life?*
> *Trevor: Ring them.*
> *Interviewer: If you wanted to do something, who would you ring?*
> *Trevor: My sister.*
> *Interviewer: Are there other people who have been useful to you Trevor?*
> *Trevor: No.*
> *Interviewer: What about the other dreams you have for yourself, who would you tell those to?*
> *Trevor: My sister.*
> *Interviewer: Your sister. Why would you pick your sister?*
> *Trevor: Because she is brainy.*

Interviewer: Does she listen to you?
Trevor: She listens to me any way. Close, closer there.

Family as the catalyst to personal agency

People who had managed to maintain good relationships with their families also **expressed a greater sense of agency** (or personal control) about their own lives. Regardless of their level of disability, people in this group tended to believe that they (and not others) were responsible for their lifestyle. They were also more likely to expect to participate equally in the life of their community. Many of those who were dislocated from their family were reticent about expressing personal hopes and aspirations and saw their quality of life as dependent on the efforts of others. The stories of the people we spoke to hinted at possible explanations for this relationship

Not only did people report that it was easier to challenge themselves and disabling community barriers when family represented a safe place to return, parents were often acknowledged as instrumental in seeding their expectations around community participation. Many people said that when they had been at a low ebb, their social world was shrinking or they had unwittingly begun a slide towards surrendering their sense of autonomy, it had been family members who had challenged them.

> *Interviewer: Who have been key people for you?*
> *Mary: Mum and Dad…they didn't want me to sit on my butt and do nothing, which is what I was doing.*
>
> *Interviewer: Who are some of the key people that have helped you get where you are now?*
> *John: I would say my parents mainly, just with the confidence value of things…*
> *Interviewer: Whose responsibility was it to make sure you got what you wanted?*
> *John: I think it comes back to myself. That's why my parents are always pushing me…..I have got a bit of get up and go you know – there are always people behind you saying this is what you can do and they offer you things , advice and things like that, but I think that it is always up to the individual.*

Those people who appeared to be out and about more, also said that their attitude was nurtured by families, and that they expected nothing less. Many had taken their less authorized lifestyles to services and were helping to change the attitudes of others around them.

Conversely, people who told us that that they had had limited access to affirming expectations suggested that this had contributed to poor feelings of self worth, an absence of confidence and a self reinforcing reluctance to engage in new forms of community activity. Kelly had sought professional counselling as part of her struggle to come to terms with feeling estranged from her parents. Stuart described his lack of access to family as being *"deserted."* Marie too, spoke at length about the struggle she had had to escape the consequences of low self-esteem in the absence of affirming parental expectations. When asked about the value of her work as a teacher's aide, Marie responded the following way.

> *Getting out there more – I feel I sort of have been shut away because I have been too scared to give anything a go…. People always said I couldn't do it, and it is as if I am proving to myself and to them that I can. My Mum and Dad always put me down and said I can't do it, you can't do that, you can't do anything…….they had me trapped….wrapped in cotton wool and I couldn't break free. I needed some space.*

Marie appeared to be doubly compromised by the ambivalence she felt towards her family. Perhaps as a consequence of the way she had internalised familial relationships, Marie viewed the world as a sometimes hostile and judgmental place (see Marie's story). Consistent with Bowlby's attachment theory, she did not generally expect her community to be a supportive place. Marie therefore faced what she believed to be a hostile environment without the comfort of many safe places to return to. When asked what settings or places in the community she would avoid, or didn't feel comfortable in Marie said*, "being at home with my parents."*

As real as Kelly and Stuart and Marie's experiences were, they were not the norm. The majority of people we spoke to were committed to sustaining linkages to family because they were so highly valued.

Families as an origin and destination for intimacy

A number of key characteristics about family relationships made them important to people. Not only did they offer an unbroken narrative of their lives that was largely absent in other supportive relationships, that narrative was punctuated by moments of affection and love. The emotional depth to family relationships was expressed in a myriad of different ways. We can be fairly confident that they were perceived of as different, because the language changed. When people spoke about their families they used personal pronouns like "us" and "we" and "our" and descriptors that emphasised proximity like "close" and "warm." Evidence is emerging that the feeling of being understood and the ways that it is both **aquired and communicated** through interpersonal intimacy changes the experience of being supported.

In a recent study Mirfin-Veitch, Conder and Bray (2004) interviewed women with multiple disabilities about the experience of receiving intimate and personal care. The women that they spoke to distinguished between support provided by a family member and the experience of receiving support from a service. What made the difference, they said, were differences in the emotional depth of exchanges between themselves and the provider of care. An absence of affect contributed to a negative perception of the intimate and personal care these women received from residential support services and this was contrasted with relationships where love and affection were known to be the emotions that underlay support.

In ways that echoed the autobiographical importance of Adam's family, one woman, Mirfin-Veitch et al's (2004) interviewed made the comment.

> *Well it was different because she was my mother and she understands me better and I could explain myself better and she understood exactly how I felt and she had a different understanding of me all together.*

And another said;

> *Person: Well mum basically made sure I was clean and fed. I'm not saying [residential service provider] doesn't."*
> *Interviewer: So what made it different.*
> *Person: She loved me. She's my mum.*

Families were not only a source of love and affection, they, (family relationships) were sustained by receiving it too. Many of the people we interviewed spoke with great pride about their ability to support and express love for members of their own family. Sometimes their life experience, including living with impairment, made them uniquely qualified for this role.

> *Manu: I would like to help troubled kids….. for example the young generation in my family – there are a couple of them there…..troubled young fullahs and my older family members, they don't know how to help them…..so they turn to me because I have been through it.*
> *Interviewer: So you have that role in your family anyway, helping people sort problems out?*
> *Manu: Yeah. So I can call on my experience to talk to them and see what happens in the family and they can take that on or not, its up to them. But if they need help, all they have to do is ask you know.*
> *Interviewer: And is that successful?*
> *Manu: Not always. Not always.*

In Chapter 4 we saw how adding value to the lives of others was important to many of the people we spoke to. We also saw how most people had sought to humanise all of their interpersonal relationships through acts of kindness and consideration and how they had sought to sustain valued relationships through reciprocity. Families were similarly bound together and in the quote below, Manu captures the spirit of a universal belief that in the act of his giving, was the gift of receiving.

> *I just decided to help the whanau……it helped me out a bit.*

None of this is unique to people with disabilities. All people seek to affirm their identity through family linkages. We all use them as stable bases to which we return in times of crises and then push out from to explore new horizons. We all seek to draw from the wellspring of love and emotional intimacy in the moments that we do return. And we are all bound to our families through the sense of mutual obligation that comes with belonging.

Two things appeared to be slightly different for the people we spoke to however. Firstly, the community was often a hostile and disabling environment for them to be in, increasing the need for empowering sources of support. And secondly, the degree of marginalisation from other communities that appeared to follow as a consequence meant that family was one of the few contexts for participation that had the characteristics that they described as being key attributes of place. People's families were the places where they were most likely to experience self determination, a chosen social identity, reciprocity and contribution, psychological safety and comfort, affirming expectations and a sense of membership.

Family was one of the few places participants were connected to other people in ways that were completely divorced from disability. Rather than being consumers of support, their roles were different. "They" were daughters, brothers, aunties, clan and whanau. Rather than being one step removed, as in the disequitable power relationship between client and professional, families understood each other as "us," and "we" and "our."

The stories people told about their families invite services to reflect on two particular aspects of the way that they go about facilitating community participation: whether current practice is as effective as it might be at permitting people to stay close to the resource that their families can be; and whether professionals themselves have something to learn from the changing ways that families support their children throughout their lives.

Do services help people stay close to their families?

Fratangelo, Olney & Lehr (2004), make the point that the centrality of services to many people's lives can sometimes inadvertently crowd out other, more natural communities. We saw that when people had limited access to informal support networks, like family, they tended to be involved in fewer and more proscribed forms of community participation. We also saw that the greater the number of networks that people had access to, the more likely they were to generate new forms of activity. A more worrying way to frame this finding is that, the more fully immersed people were in professional services, the harder it seemed to be for them to forge new relationships with people and with places.

Participants themselves described feeling *"trapped"* and *"stuck in"* service settings. When paid individuals are perceived to be experts or have access to privileged knowledge, the chances of people being listened to and gaining entry into alternative communities is further reduced.

A collective belief that people with disabilities are somehow so different from the communities into which they were born, that their needs can only be humanely met by trained professionals, is the logic that underscores all forms of institutionalised segregation. Although much has been written about the way community understandings of people with disabilities have altered over time in ways that reflect the world view (paradigm) of the dominant professional group (Hatton, 1998), little has been written about the ways that services have come to influence the way that families see their children.

Ferguson (2002) argues that professional models of care have always extended into the living rooms of families. In a review of narratives written by parents, Ferguson and a colleague wrote, *"The most important thing that happens when a child with disabilities is born, is that a child is born. The most important thing that happens when a couple become parents of a child with disabilities is that they become parents"* (Ferguson & Asch, 1989). And yet, they would later conclude that, looking over the history of professional responses to the birth of children with disabilities, *"disability"* overwhelmed all other considerations (Ferguson, 2002). The consequences of disabilities were consistently understood to be tragic and immutable. During the first half of the twentieth century, "family indolence and degeneracy," were seen as the primary cause of disability, with vulnerable children removed from families into the safer arms of professional services. In the second half of last century, professionals reversed their underlying assumptions, emphasising how children with disabilities inevitably damaged the families into which they were born. Children were again removed, this time into the safer arms of professional detachment.

The level of professional intrusion was more dramatic for the families of children born with intellectual disabilities, but the same logic is to be found in the stories of some participants.

In her individual story Janet began by reflecting;

> *I was born in Dunedin in October and at first they thought I was a perfect baby. Mum and Dad were thrilled. I was their first child. My father was a dentist and Mum stayed home with me. But as I developed it became clear that I was having problems……I was about a year old when I was taken to see a doctor. He said I was spastic and I would never have a normal life. He said I should be sent to a place in Australia where they could look after me. Luckily Mum would have none of it. She wanted to look after me at home and this is what she continued to do.*

Even in adult life, professionals thought it beneficial to keep Janet from her family.

> *I had been there [residential service] about 10 years when the matron asked for people who were interested in living more independently in the community, to attend a meeting. I turned up. The matron wasn't happy with this. In fact she was bloody angry. She didn't think I could manage the move. She said to me "you will never get out of here." She also thought that because I went home to my parents most weekends on my scooter, I shouldn't move out in case I became a nuisance to them. Eventually I did move in to my own Housing New Zealand two-bedroom house. Unfortunately the matron still wanted to have it her way. When my mother was in hospital, she arranged for me to move into my present place. This is a nice house, but it was chosen so I was not too near my mother…..My mother was furious when she found out.*

There was also some evidence that the people we spoke to had assimilated professional values about their need to access specialised knowledge.

> *Christine: I can't go out. I have to have somebody with me in case I have a turn.*
>
> *Interviewer: Can you go to the shops or …….*
> *Kelly: No, not by yourself*
> *Interviewer: Why do you think that is?*
> *Kelly: Because I am capable of doing things but they like to keep an eye on me.*
> *Interviewer: How do you feel about that?*
> *I feel all right about it….because if something happens to you and that person's in hospital and the staff doesn't know about it, they would get the blame.*

People were sometimes sensitive to the "burden" they potentially posed to families. Flowing with the current tide of an ideology that emphasises the virtues of independence Marie worried that;

> Living with my grandparents sometimes feels like I am a burden to them.

Mary's two favourite places were op shops and the casino. She almost always went with staff, even though she would have preferred to go with her family or friends.

> *Interviewer: (When you go to the op shop and) the casino, who do you go with?*
> *Mary: Somebody from here.*
> *Interviewer: Again, that's staff members from here that go. Have you got any friends who could support you in that respect?*

> *Mary: My brother. My Uncle. One of my nieces if she wanted to.*
> *Interviewer: Would you prefer to be going to the op shop with staff or with friends and family?*
> *Mary: Friends and family.*
> *Interviewer: So what can help that happen for you?*
> *Mary: I would probably try and get help with enough money hopefully so I could go out more at lunch……….*
> *Interviewer: You would like to go out with friends and family more often – and one of the ways in actually being able to do that would be to invite them to lunch (but) at the moment you feel that what prevent you from doing that is that you don't have the money to do that?*
> *Mary: That's right.*

For Mary, doing the things that she wanted, with the people that she wanted to do them with appeared to be contingent on two things: her service recognizing the opportunity implicit in inviting her family to lunch; and an understanding that helping her to find the resources would make the experience more comfortable for her. A clearer understanding of the things that Mary contributed to her family, and supporting her to find ways for to reciprocate care that were less dependent on material resources, may have helped Mary too.

The people we talked to never spoke about the need for services to empower their families. Privileging the voice of families over service users would have left Marie and Brenda hostage to the over-protectiveness they sought to break free of. **People spoke of the need to carve out their own identity and fought to sustain autonomy and independence.** What their stories suggested was that people's families represented *"places"* of such potential value to people with disabilities that services ought to explore the potential benefit to people of dissolving barriers to participation in the same way they looked to integrate people in all other community settings.

What have services got to learn from families?

One of the most important attributes of family was that they absorbed, as well as radiated emotional support. The reciprocity that characterized many family relationships is easiest to achieve in settings where people have a valued social role (Kennedy, Horner & Newton, 1989). In this and in other respects, the cultures of family and of service support seemed to diverge. Whereas people were expected to contribute within families, and often reported pride at the contributions they made , it did not appear to be so easy for them to add value within the services they used. Denial of the ability to do this was most important to those for whom service provision was their social universe.

The people we spoke to knew that reciprocity was what bound people together, and appeared to expend great energy in trying to achieve it in their interpersonal relationships (see Chapter 4). One of the most consistently reported findings, however, is that, families typically remain the most stable relationships in the lives of disabled people. Most other relationships tend to be difficult for them to sustain. (; Bray & Gates, 2003; Carnaby,1998; Kennedy et al, 1989; Horner, Newton & Stoner 1984). Some researchers suggest that this finding is explained by the fact that, whilst giving and receiving is the life-blood of families, disabled people find it hard to do this in other communities (Kennedy et al, 1989) .

Whereas families put an emphasis on inter-dependence, services stress the need to build towards greater independence. Carnaby (1998) suggests that the fear of casting people with disabilities as dependent, has sent the rhetoric of service provision scurrying to the opposite extreme of the agency-dependency continuum, without pausing to recognise that **needs and dependencies are characteristics of all lives.**

We have already discussed how the professional divide between service user and service provider inhibits reciprocity and is characterized by an uneven distribution of power, information and intimacy (Chapter 4 & 5). Using professional control to emphasize services to advance individuals further along the continuum of independence might inhibit the formation of relationships **between** people with disabilities too. Many of the people we spoke to saw integrated settings as the only legitimate contexts for community participation and relationships with non-disabled people as a more powerful indicator of community acceptance (See Chapter 3). In service settings, staff seem to be the foci of service users' interactions (Holland and Meddis, 1993). Whilst some participants who were immersed in service settings named other service users as friends, most of the people spoke of lives of social dislocation.

Our findings that having a group of disabled friends appeared to increase people's confidence in community settings, is consistent with others that suggest that people with disabilities express greater satisfaction with their friendships and relationships when they have a greater number and proportion of other people with disabilities in their social network (Robertson, Emerson, Hatton, Kessissoglou, Hallam & Lineham; 2001). In their interviews with CCS service users Chai, Colquhoun, De Alwis, Johnston, Muttaiyah & Tripp (2002) found that people who were more actively engaged with other people with disabilities, expressed greater levels of satisfaction with their level of community participation. Together these studies suggest there is much to gain by services recognising and acknowledging through support practice, the potential that the disabled community has to meet its own needs

Participants in the present study were also more likely to volunteer staff as their most valued relationships. Here again, it is difficult to avoid concluding that the inability of service users to occupy valued roles or to participate equally within service culture may have led them to perceive service professionals to be a more significant personal resource.

During the 1990s Steven Carnaby attempted to stimulate debate around the delivery of support to disabled people by contrasting the ideology of residential services in London with those he observed in Milan, Italy (Carnaby, 1997; Carnaby; 1998). Although his work focussed on the lives of people with intellectual disabilities, the high degree of similarity between the mechanisms of service delivery for all people with disabilities make his observations universally interesting.

The point of difference that so interested Carnaby was that, whereas services in London emphasised individual choice making and independence as core philosophic values, Milanese providers took the family as their model for support delivery. Services in Milan therefore stressed interdependence and peer support as key principles. Independence was still valued, but it was seen to be a consequence of people having developed sufficient levels of esteem and confidence through **peer support** (Carnaby, 1998). Carnaby suggested that conventional community services tend to assume that a community presence was sufficient for service users to feel engaged with their community. The reality, he believed, was that this was not the way that it was being experienced. If social integration was failing in practice, Carnaby suggested that accepting that people with disabilities were able to add greatly to the quality of life of members of their **own** community was a good place to start.

Milanese support culture attempted to tap the comfort, self esteem and sense of self that people said they gained from spending time with people with whom they shared similar opinions, skills and life experiences. The alternative, Carnaby (1998) pointed out, was that the process of social integration teaches people to only value communities of dissimilarity. He thought that by putting interdependence at the heart of service delivery and by valuing a group’s shared history, **integration could become a group strategy** rather than an individualistic one.

In his comparative analysis of the lifestyles of London and Milanese residential service users, familiar contrasts emerged. Milanese tenants spent more of their leisure time together. They were more likely to name other tenants (with whom they spent the most time) as best friends and reported few conflicts. Tenants in London were more likely to name staff as their friends and were more likely to report conflict between themselves and other service users. Milanese tenants were more likely to interact with their neighbours and when they spoke about the people they shared their life-spaces with, they used the descriptor “we” in contrast to London service users who said “I,” (Carnaby, 1998).

In recent years disabled people have themselves ignited a revalorisation of disability (Gleeson, 1999). Recognising and valuing the unique and affirming culture of disability, including reappropriating the formally disparaging term “crip” has been the cornerstone of a renegotiation that is currently taking place within the community about the identity of disability. People with disabilities and the community at large are awakening to the value they add to the lives of all citizens. Collective organisation has always been at the root of social change. Unless it is allowed to penetrate service culture, many people who continue to experience discrimination and unequal access to opportunities and power are denied a strategy used by many other marginalised communities to improve their circumstances. Non-disabled people and support services also deny themselves the opportunity to learn from and be supported by people with disabilities too.

In his analysis of the service culture of Milanese providers, Carnaby (1998) also observed that, emulation of the family as a model for service delivery extended to Italian service providers speaking openly about the need to provide a *"loving presence."* We are coming to understand that intimacy changes the experience of being supported (Mirfin-Vietch, et al, 2004). In this project, people said that psychological safety is experienced through affective proximity. People in support services sought to humanise their relationships with staff through moments of intimacy. In spite of this knowledge, professional reflection about whether "love" had a place in the vocabulary of service provision would be contentious indeed.

Of all the people we spoke to in the study, only one person headed a family. Robert had come to New Zealand from Kenya four years ago. His mother-in-law had helped to pay, but the real price was having to leave his wife and daughters behind in a refugee camp. He had arrived full of optimism, hoping to get a job and send money back home to his wife so they could all come and live in New Zealand. He also had family here to help with his support and maybe some new friends. Since then, his family had left for Australia and Robert's sense of isolation was compounded by his inability to find work. He felt he was making no progress with immigration and did not know where to turn. Lacking money, Robert had no way to reunite his family. Robert lamented his inability to get close to the place that was his family.

> *I love my wife and my daughters, I never enjoy… No one loves me like my wife and daughters.*

<u>Summary</u>

People's families were one of the most important places of "community" for most people. Family was connected to the idea of "home", a place where people belonged and where their disability was irrelevant.

Family members **knew** them, they shared the whole story of their lives. They provided a place of psychological safety – a safe place to return to.

Families provided emotional and sometimes material resources for people. They also created opportunities to widen people's social networks.

The primary source of intimacy and emotional support in people’s lives came from their families. They also enabled the person with a disability to contribute in a reciprocal way to others whom they cared about.

Families provided the continuous long-term relationships that professionals and support workers cannot provide.

Proximity to their families appeared to influence people’s willingness to try new things, to venture out. People who had stayed in contact with a supportive family tended to participate in a wider array of community activities, and had a stronger sense of personal control.

Support services should consider how they can support people to stay close to their families. Families can also provide valuable knowledge and models of support for service providers.

CHAPTER 6

INDIVIDUAL STORIES

"*Our lives are storied. Were it not for stories, our lives would be unimaginable; we could not make sense of the times we live. Stories make it possible for us to overcome our separateness, to find common ground and common cause.*

To relate a story is to retrace one's steps, going over the ground of one's life again, reworking reality to render it more bearable. A story enables us to fuse the world without and the world within. In this way we gain some purchase over events that confounded us, humbled us, left us helpless. In telling a story we renew our faith that the world is within our grasp.

Any story is like a vessel shaped from wet clay under a potter's hands. In its roundness, containedness and completeness it provides the consoling illusion that life has meaning. And just as a clay vessel bears tell tale traces of the potter's hands, so too, every story carries the personal imprint of the storyteller. "

Michael Jackson (1997)
The Blind Impress

Adam Robinson

Interviewer: So what barriers have you had to overcome, why has your brain been so important?
Adam ‘I’ ‘N’ ‘G’ ‘E’ ‘N’ ‘U’ ‘I’ ‘T’ ‘Y’
Interviewer: Right. That ingenuity is a barrier, or ingenuity is what has kept you so……
Adam: ‘I’ ‘N’ ‘G’ ‘E’ ‘N’ ‘U’ ‘I’ ‘T’ ‘Y’ ‘I’ ‘S’ ‘A’ ‘B’ ‘A’ ‘R’ ‘R’ ‘I’ ‘E’ ‘R’
Interviewer: So the lack of ingenuity?
Adam: Yes
Interviewer: The lack of ingenuity on whose part Adam?
Adam: ‘Y’O’U’R’’S’
Interviewer: My ingenuity! The lack of my ingenuity?
Adam: ‘K’E’E’P’S’ ‘M’E’ ‘T’H’I’N’K’I’N’G’

Meeting each other

On 21 April 1991, eighteen year old, Adam Robinson fell from a Sydney suburban train. He was heading for work on one of the notorious “old red rattlers” when he pitched forward through the carriage door and out of his world.

Adam had already lived a full life. At 17 he moved to Australia, figuring the bright lights of Sydney was the place to start. There, he found work in a tyre shop, but the beach was to become Adam’s domain. New Zealand performance poet, Gary McCormick wrote of his beach about the same time, (that it was)

“Place. It was our place! Everything began and ended there. Discovering that place, that corner, against the backdrop of the windswept cold sea was the beginning of the separation.” And of surfing*, “Surfing is a solitary act. You have to learn to physically take command. You make a mistake and you are on your own. Fishermen, sailors, boat builders – people who spend a lot of time around the sea are made different by it. As if in their minds, the broad expanse of ocean has created a pool of light – an openness which will not be shut. Against which the minor sorrows of birth and death are like tiny lifeboats bouncing up and down.”* (Hunt & McCormick; 1995)

The sea had a hold of Adam. If he wasn’t paddling for one of the waves that still curl around the Terrigal headland, he might otherwise be found on duty or in the club house. Adam was a Terrigal Surf Lifesaver, well practiced at pulling others from peril. He was strong and powerful and had a muscular approach to life. By 18 he was also an accomplished pilot, equally comfortable in a helicopter or fixed wing aeroplane. There was, in fact, very little Adam couldn’t turn his hand to.

As we sat to discuss how to write his story, Adam gave me a newspaper clipping. Someone had enlarged and framed the article, but Adam had tucked it away in his wardrobe. The article was headed ***"Life-guard swims against the tide."*** What drew you in to the story was a photograph of a young man in a wheelchair, embraced by the beautiful woman he was two weeks from marrying before he stepped on to a Sydney suburban train one evening in April.

I met Adam twice. The first time was to interview him for the project. As it turned out, Adam was already waiting for me in his room. I thought it may be Adam behind the pane, but rapped on the door beside a brass plaque that announced I had arrived at Nazareth House. A staff person greeted me warmly and guided me on, past the coffee tin filling with cigarette butts, and down the hall to Adam's meticulous single bedroom at the north end of a community residential group home. Seven other physically disabled men and women lived with Adam at Nazareth House. Adam greeted me with his eyes. He was keen to tell me his story, and we quickly established, in ways that echoed the eight year old communication diary he later showed me, that he was chairbound because of a ***"train crash, went off, fell"*** After the accident, Adam had been in a coma for nine months. Such was his brain injury that Adam needed to reconfigure the neural pathways that had previously articulated his body. He still has problems assembling his words, and does not talk. He does, however, have good control of his head, which he uses to let you know if you are on or straying too far from his track. He has sufficient mastery of his left arm to be able to raise it to his eye-line and to inch a finger across an alphabet that sits beneath the tray of his wheelchair. Letter by letter his finger spells out a fierce independence and incisive intellect.

The aim of the interview was, in broad terms, to capture how someone with a physical disability experiences their community. When the door to his room closed on us the first time, our roles reversed. All I had to make sense of this new situation was able-bodied preconceptions, an interview schedule and Adam's alphabet board. None of these were particularly useful tools to bridge the gulf between our two realities. Confronted with the gap, it was me that felt un-sure-footed and Adam was in turns, patient, playful and hostile towards my clumsy efforts to cross it.

As he must have done a thousand times before, Adam made me conscious of the discriminatory way I framed him by forcing me to sit opposite a surf lifesaver and not a man in a chair.

Freedom of movement was a recurring theme in our interviews. It was important to Adam in ways my body had not sensitised me to. To Adam, his was the only medium he had for self-expression. Physical progress and greater freedom of movement was akin to an act of reclamation. Towards the close of the interview, however, the gym had become a wider metaphor for us both. The reclamation of Adam Robinson, appeared to come from his resistance to two forces. A growing weight stack and the press of prejudice from a community no longer able to penetrate the persona of disability well enough to see him clearly. Adam named the source of his oppression as ***"My** [his]* ***Chair,"*** and the barrier to personally meaningful engagement within the community as being ***"Your** [the interviewer's]* ***imagination."***

The interview transcript that follows, begins with Adam's attempt to make me see him as he sees himself and in quick succession, the struggle I have to understand his friend Jock in anything other than the language of disability, an assumed right to be nosey and surprise that Adam had previously piloted aircraft.

The impression I got of Adam over those two afternoons was of someone who wanted to pull as much of his former self into his future. Adam appeared to want to face the stretch of time ahead of him with as much of his "pre-accident" identity as he was able to carry. The walls of Adam's room now carried his lifesaving medals as well as other artefacts that sign-posted membership of other communities he belonged to in other times.

The ways in which the community reacted to Adam after his accident was what appeared to underscore his determination. Adam has lived two lives. One in which he fashioned an identity through the lifestyle choices he made and another in which he believes he has had a disabled lifestyle imposed upon him. The only protection Adam has against the later is to make more transparent the former.

I would not leave unscathed. Adam swiftly put me in my place about the difficulty I also had seeing past his chair. It was not just in the way I floundered to ask the sorts of questions I would think appropriate to ask a non-disabled person. I came to see it, in my proclivity to keep up barrage of good humour. And in the way, I felt inclined to steer the conversation down paths that might lead to some personal resolution or of an accommodation to an impaired reality by Adam.

When I look back, none of this was really for Adam's benefit. I think I framed and treated Adam in precisely these ways to dampen my own disquiet. The second time we met, Adam described himself as being ***"murdered"*** by his accident. That his fall had extinguished the person he felt himself to be and left him with a casting that was impossible to fill with the resources he had available. Adam's provocative invocation of a carcass was a reality that I sought to abstract.

I needed Adam to author a story beyond that confounding and humbling accident. I wanted Adam to renew a faith that life continued to have meaning through the roundness and completeness of a continuous narrative. And therefore I silently urged him to embrace disability to protect me from the possibility that his one false step was the beginning of a separation of Adam from himself and of himself from me. Being part of a generic cohort of disabled men and women, somehow seemed more comforting and understandable than the pain and injustice of being Adam Robinson, surf lifesaver.

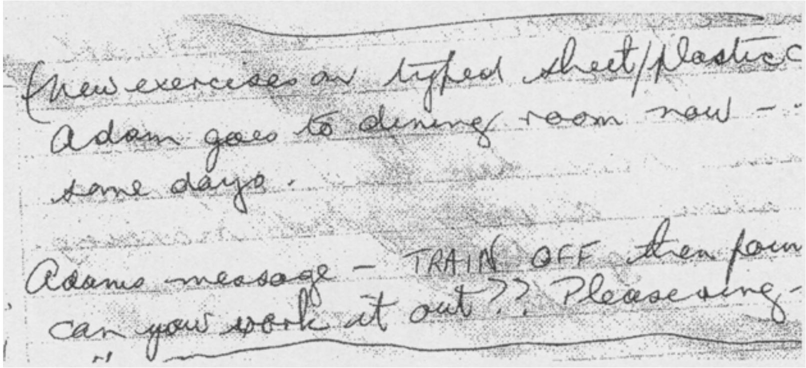
As I left the last time, one of Adam's support staff helped wheel him to tea. Adam directed her to close the curtains because it was getting dark outside and she paused patiently by Adam's doorway as he turned out the light. In between she made him laugh with a quip about his "porno moustache" and leaving the sliding doors open so that the women of Mosgiel could find their way into his bedroom. I smiled too, and put the framed photo of the Terrigal Lifeguard and his beautiful fiancé towards the back of his wardrobe.

Adam

Adam’s Interview

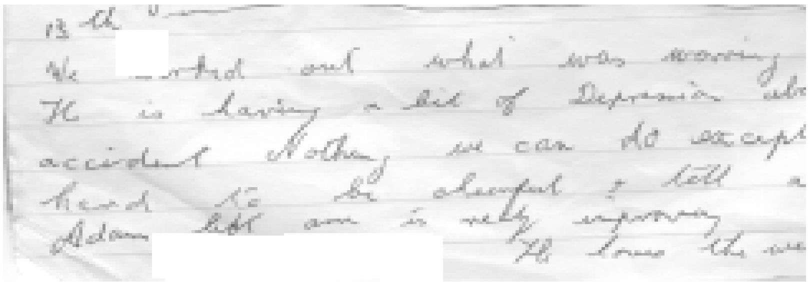
Interviewer: They are quite broad questions Adam, so we will see how we go with them. The first question was around how would you describe yourself, what are the good things about your life.
Adam: COOL.
Interviewer: You describe yourself as cool. Right, okay, if I had to describe this cool guy to one of my friends what interests would I say, what would I say that you are interested in, Adam?
Adam: SURFING.
Interviewer: Surfing, is that right - I have just started. You are pointing at something - the medal? Surf life saving association - Adam is pointing to a certificate and he has got the bronze medallion for surf life saving. Did you surf?
Adam: YES.
Interviewer: And did you do life saving as well?
Adam: YES.
Interviewer: Do you get out to watch the surfers very much now?
Adam: YES.
Interviewer: Where do you go - there is not much surf at Mosgiel. Do you get out to St Clair? Adam is nodding. How big was your board, Adam, what size board did you have?
Adam: FIVE FOOT
Interviewer: A small one, you must have been pretty good. I have a monster mate, I have just started on this nine foot one Malibu. I have been practising in the shallows and haven't been able to ride it out the back yet but I can get up on it. It is slow, it takes a long while to learn, doesn't it.
Adam: Mmmm
Interviewer: How long did you surf for? When did you start, how old were you when you started surfing?
Adam: 17
Interviewer: The medal is Australian - are you from Australia?
Adam: N0
Interviewer: Is it Australasian, is that what it is - no it says Australia. but you got it here?
Adam: WE WENT TO AUSTRALIA.

Communication Diary 12 & 13 February 1996



(New exercises on typed sheet/plastic c
Adam goes to dining room now –
some days.
Adams message – TRAIN OFF then poin
can you work it out?? Please ring-

(New exercises on typed sheet/plastic cover) Adam goes to the dining room now – feeds himself some days. Adam’s message – TRAIN OFF then points to himself.
Can you work it out?? Please ring me

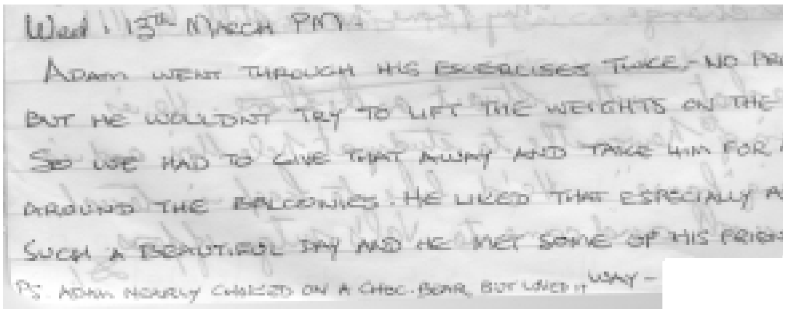


13th
We [redacted] worked out what was worrying
He is having a bit of Depression ab
accident Nothing we can do except
hard to be cheerful & tell a
Adam left arm is really improving [redacted]
He loves the we

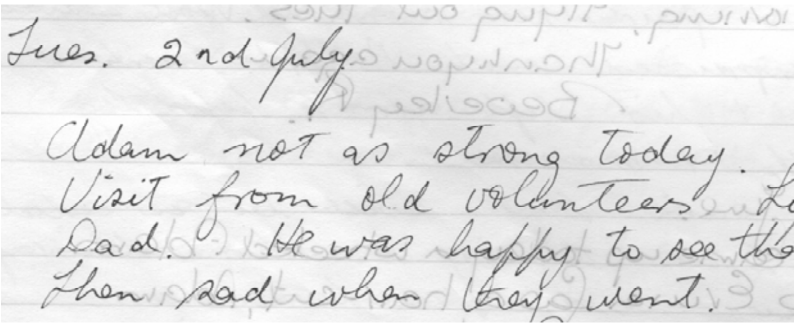
We worked out what was worrying Adam. He is having a bit of depression about his accident. Nothing we can do except try very hard to be cheerful and tell a few funnies. Adam’s left arm is really improving. He loves the weights and pulleys

Interviewer: How many - to live? Do you get to many places now, Adam, have you been overseas since?
Adam: NO
Interviewer: Can I ask you how you ended up in a chair?
Adam: TRAIN CRASH WENT OFF … FELL
Interviewer: I am right with train, am I right with an accident?
Adam: YES
Interviewer: How old were you then?
Adam: 18
Interviewer: You had only just started surfing. What other things were you interested in before the accident Adam?
Adam: FLYING.
Interviewer: Flying - you flew - amazing. Anything else?
Adam: FISHING.
Interviewer: So what about now, what are your interests now? There's surfing.
Adam: FAME.
Interviewer: So how do you stay involved in those things, Adam, how do you stay involved with surfing?
Adam: JOCK
Interviewer: Who is Jock - a friend - is he a family friend? How did you meet Jock?
Adam: I WAS HOUSE
Interviewer: You were a flat mate in his house - he was a staff person?
Adam: NOSEY
Interviewer: I am just being professionally nosy, Adam, is he a staff person - have I got that right?
Adam: NO
Interviewer: He lived in this house. A service user?

Communication Diary 13 March & 2 July, 1996


Wed. 13th MARCH PM
ADAM WENT THROUGH HIS EXERCISES TWICE – NO PR
BUT HE WOULDN'T TRY TO LIFT THE WEIGHTS ON THE
SO WE HAD TO GIVE THAT AWAY AND TAKE HIM FOR
AROUND THE BALCONIES. HE LIKED THAT ESPECIALLY A
SUCH A BEAUTIFUL DAY AND HE MET SOME OF HIS FRIE
PS. ADAM NEARLY CHOKED ON A CHOC-BEAR, BUT LOVED IT WAY –

Adam went through his exercises twice – No problems. But he wouldn't try and lift the weights on the machine. So we had to give that away and take him for a ride around the Balconies. He liked that especially as it was such a beautiful day and he met some of his friends on the way. Adam had a choc. bear and loved it.

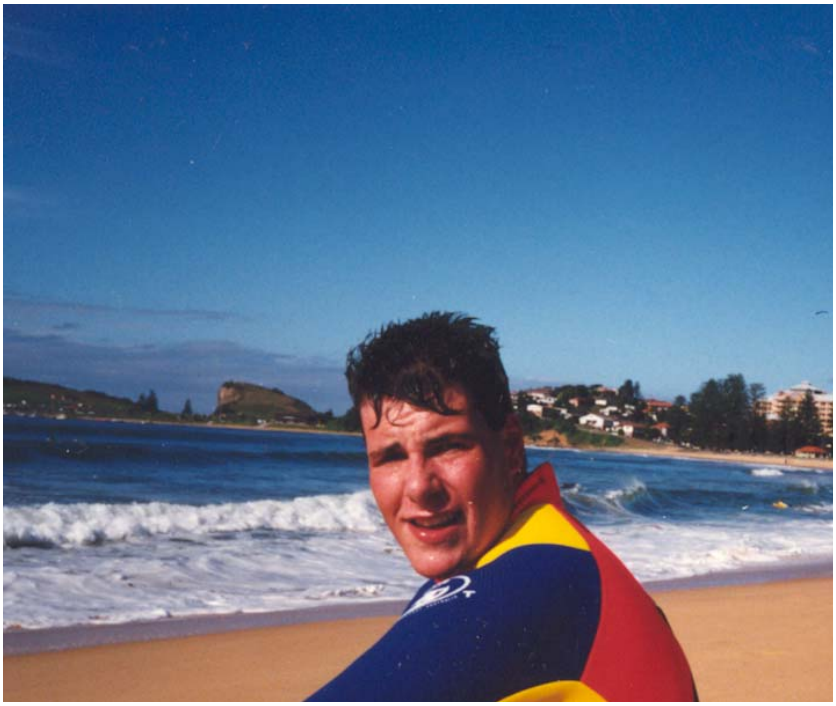

Tues. 2nd July
Adam not as strong today.
Visit from old volunteers.
Dad. He was happy to see th
then sad when they went.

Adam not so strong today. Visit from old volunteers. He was happy to see them then sad when they went.

Adam: NO
Interviewer: Just somebody that lived here. Adam is kind of grinning at my perplexed look really, I am trying to figure this out. Friend
Adam: YES
Interviewer: How often do you see Jock - once a week, more than once a week - how many times a week?
Adam: HE IS STILL HERE.
Interviewer: So how do you and Jock get about?
Adam: VAN.
Interviewer: Does Jock drive?
Adam: NO
Interviewer: So he is not a service user, you said no, not a service user - oh he is, he is a resident here at the house. So you and Jock go and do these things together

- right I think I have got it. Okay so what places do you go Adam, where do you go, like if you had to describe your normal week - what sort of things do you do out in the community?
Adam: MONDAY.
Interviewer: What do you do on Monday?
Adam: I GO TO MOSGIEL TO THE COMPUTER COURSE.
Interviewer: Anything else, so you go in there - how many hours do you do there?
Adam: FOUR.
Interviewer: On a Monday
Adam: YES
Interviewer: Any other ways that you are involved in the community at all Adam?
Adam: DUNEDIN.
Interviewer: You go to Dunedin - how often? How many times a week?
Adam: ONCE MAYBE TWICE.

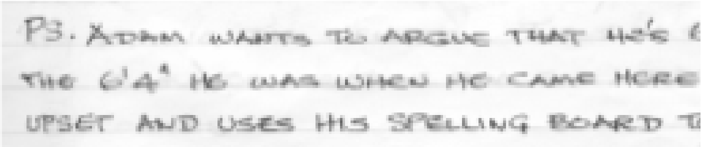
Adam at Terrigal



Interviewer: And what do you do in Dunedin?
Adam: SURF.
Interviewer: Can you still swim Adam?
Adam: YES.
Interviewer: Do you actually go for a surf or watch or…
Adam: NO.
Interviewer: You watch.
Adam: YES.
Interviewer: Do you belong to a surf club? The Surf Life Saving Association of Australia - what about here in Dunedin, do you belong to a surf club, board riders or…
Adam: NO.
Interviewer: Would you be interested?
Adam: YES.
Interviewer: Do you swim?
Adam: YES.
Interviewer: How often do you swim, do you get swimming very much?
Adam: YES.
Interviewer: How does that happen Adam?
Adam: POOL.
Interviewer: How do you get there, if you were to say to me now, Paul, I felt like a swim, can you go for a swim like that, can it happen like that? You just tell somebody here? And that would happen for you Adam.
Adam: YES.
Interviewer: Great, you phone a taxi. Okay, any other things you do Adam?
Adam: BRAIN TEASERS.
Interviewer: Is that like a night or a club or something, how do you do your brain teasers? A magazine?
Adam: DIGEST.
Interviewer: Does that come in the mail?

Adam: YES.
Interviewer: I can tell whenever you are grinning at me, I have mucked it up. So how do you get your brain teasers? This is my brain teaser? Is my brain teaser to guess what else you do in the community? That's my brain teaser. I can see - library, do you go to the library?
Adam: YES.
Interviewer: How often does that happen?
Adam: WHEN I FEEL LIKE IT.
Interviewer: That's my ignorance really Adam, like I had assumed that because of your physical disability it would be hard for you to get out and do these things - are you quite mobile in your chair, like can you get about much in your chair?
Adam: NO.
Interviewer: So it always involves the taxi.
Adam: YES.
Interviewer: But you seem to be saying to me that you can do these things whenever you have the idea. Is that right, have I got that right?
Adam: YES.
Interviewer: And does that happen because of the staff here, or does that happen because support from outside of the house helps you do that?
Adam: WHEN I FEEL LIKE IT.
Interviewer: I was just thinking, the phoning of the taxi, are you able to do that? Can you phone a taxi?
Adam: NO.
Interviewer: I don't know why I assumed any different Adam, eh, that's my prejudice, and it is nice to run up against it really.
Adam: YES.
Interviewer: Do you think your freedom of spirit and your teaching me a lesson right now has happened because of your independence and youth, do you see it like I mean I have done two focus groups now and a lot of the people that I have spoken to in the focus groups, their horizons aren't very broad. You seem to be a fairly free spirit before the train accident, the surfing and the flying, do you think that's been a - that's shaped who you are - that sounds like a silly question now that I hear it out of my mouth but when I have been around, I have seen some people living fairly authorised lifestyles and in a lot of ways shaped by their service, so what's been important to you? Like I mean I am getting a sense that you have got a service that actually has listened to you. That's been important
Adam: NO.
Interviewer: How have you managed to maintain such independence then Adam?
Adam: BRAIN.
Interviewer: Adam is pointing to his brain. So what barriers have you had to overcome, why has your brain been so important?
Adam: INGENUITY.

Communication Diary 8 May, 1996


PS. ADAM WANTS TO ARGUE THAT HE'S
THE 6'4" HE WAS WHEN HE CAME HERE
UPSET AND USES HIS SPELLING BOARD

P.S Adam wants to argue that he is 6'6 instead of 6'4. He was when he came in here – he gets quite cross and uses his spelling board to let us know.

Interviewer: Right. That ingenuity is a barrier or ingenuity is what has kept you so …

Adam: INGENUITY IS A BARRIER.

Interviewer: So the lack of ingenuity

Adam: YES.

Interviewer: The lack of ingenuity on whose part Adam?

Adam: YOURS.

Interviewer: My ingenuity, the lack of my ingenuity.

Adam: KEEPS ME THINKING.

Interviewer: I feel good and properly put in my place. Right Wicked, so that's your primary - my lack of it, yes, that's your primary barrier.

Adam: AND IF DOLLARS.

Interviewer: Which is interesting, you are not saying, like it's not mobility,

Adam: NO.

Interviewer: I mean I have only just met you Adam. Is my ignorance or my lack of ingenuity worse or better than most people that you strike.

Adam: BETTER.

Interviewer: I am assuming that you have given other people just as much of a dressing down that I got,

Adam: YES.

Interviewer: What about the community, the public at large, is that

Adam: NO.

Interviewer: Right, so I think it is really difficult because I don't know how broad your friendship field is, like your friendships of value, do you have many Adam?

Adam: YES.

Interviewer: So where would you meet - here in the house, I am just trying to get a feel for where, where are they? How did you meet these people, have you sustained friendships through your childhood or have some of them dropped off or - and how important have they been - that's three questions all in one. And how important have they been in conquering that lack of imagination of ingenuity or whatever. That was three questions.

Right okay, we will go from backwards to front - have you managed to sustain friendships from your…

Adam: YES.

Interviewer: Where did you grow up Adam?

Adam: CLYDE.

Interviewer: And is your family still in Clyde?

Adam: MY MUM

Interviewer: Do you have brothers and sisters - ?? still in Clyde either so you must have shifted from Clyde

Adam: YES.

Clyde: Outside the potters studio

Interviewer: In your teenage years

Adam: YES.

Interviewer: Did you go to university?

Adam: NO.

Interviewer: Did you work?

Adam: YES.

Interviewer: What did you do?

Adam: TYRE.

Interviewer: Tyre service locally owned and operated - was that you, your business?

Adam: NO.

Interviewer: You worked there?

Adam: YES.

Interviewer: Me too, well kind of - So you worked in the tyre place and then shifted to Dunedin.

Adam: AUSTRALIA.

Interviewer: Of course, that's where you surfed. See I am nervous about these things. Now we talked a little bit about barriers and you said a lack of imagination, which is appropriate in communication, it implies a lack of imagination into it and the expectation too I guess in a way isn't it.

Adam: YES.

Interviewer: But whose ears do you find that prejudice and lack of expectation, who is missing their ears.

Adam: YOU.

Interviewer: Yes, I don't know how to read that you, honestly, really what you are talking about though is the battle not to be prejudged isn't it, is that fair, have I got that right?

Adam: YES.

Interviewer: So how much of your life do you spend fighting that, like is that a significant part of your identity, you spend fighting that prejudgement?

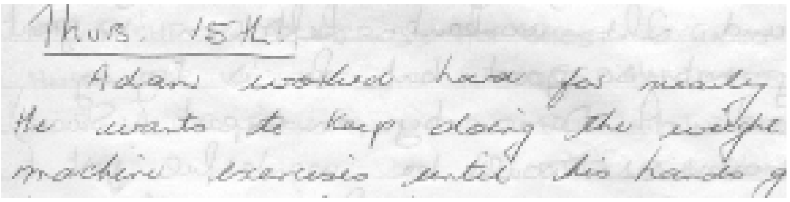
Adam: YES.

Interviewer: See the other thing that I was interested about from hearing the stories from people with disabilities and that terrible language that you have got to describe yourself, is that they occupy space or their community in some ways is a political statement in order to prove they have a right to be there. Do you - does that cross your consciousness or is that something that is important to you or…

Adam: YES.

Interviewer: So as an able bodied person, that is a thought that I would never have. Like are there places that are more

Communication Diary 15 February 1996



Thurs. 15th

Adam worked hard for nearly

He wants to keep doing the weight

machine exercises until his hands g

Adam worked hard for nearly two hours. He wants to keep doing the weight machine exercises until his hands go red

important to them and why is that? Like if it is a political statement of right, which places are most important to be in as a statement of right.
Adam: MAYBE I MOVING
Interviewer: I am not sure I follow, like it's important, moving is important - in what sense, Adam?
Adam: MOVING BODY
Interviewer: Do you mean you are moving your physical body, that's important for you?
Adam: YES.
Interviewer: See I've - you have thrown me because I thought when we were talking about a political statement I wondered whether some people kind of -
Adam: GYM.
Interviewer: It's important to be there and moving your body in the gym. Important for you personally or important for the people that are pumping iron beside you? Is that important too?
Adam: YES.
Interviewer: I've got it. Why is it important for them Adam?
Adam: TO MOVE THEIRS.
Interviewer: Do you use any system of planning or like lifestyle planning or…
Adam: YES.
Interviewer: Is it useful?

Adam: YES.

Interviewer: Useful in that - can you explain to me how it is useful or do you want me to have a go and you can… okay, is it useful in as much as you feel as if you are able to describe to people your kind of hopes and aspirations and hold them accountable to it.

Adam: YES.

Interviewer: How often do you use it? Is it like an annual plan or a six monthly plan or do you get a chance to do it regularly?

A

Family

ewer: So it seems to me that you are a pretty independent guy, I don't have one, and I have always kind of wondered about that. One of the first lessons I got taught, I used to work in a service supporting people with intellectual disabilities. Someone challenged me by saying well, when have you done your job good enough that I don't need one of these any more. In some ways he was talking about, the problem with these is that you are deaf and that communicates to me a lack of self-determination about my life. Would life be okay without it Adam, better or worse?

Adam: NO.

Interviewer: Life wouldn't be better without it. Is it because that formal system of planning allows you to hold the service accountable?

Adam: YES.

Interviewer: That's interesting, so this man and you have come to the same question from different polarities. Well if you don't mind me saying that that actually communicates to me, that actually says to me that you are vulnerable without it. Would that be fair?

Adam: YES.

Interviewer: You think you are vulnerable to people's deafness without it.

Adam: YES.

Interviewer: Do you think the temptation for services would be to not listen without that? Are there any other tools that help you in that way, Adam, like any kind of formal service tools, or what are you - aside from your intellect, that is something you have got to protect you that this man didn't have, he had an intellectual disability, he was written off because he was easily labelled and pigeon holed. Aside from your intellect and imagination, Adam, what other tools are useful to yourself for staying active, or staying like in just achieving your lifestyle that you are looking for?

Adam: GYM.

Interviewer: You are talking about physical though, I am kind of talking about - yeah this is all about your body, I am talking about, I suppose I shouldn't write that off, I suppose that's important too like the ability to maintain as much physical independence, it sounds as if it is incredibly important to you.

Adam: YES.

Interviewer: I missed that eh, as an able bodied person I missed that too. The other thing I was kind of thinking more about, you are telling me your body is a tool. Okay, that's the first time I have had that answer. So like what else is important, like the role of friends,

Adam: YES.

Interviewer: Family

Adam: YES.

Interviewer: Brothers and sisters

Adam: YES.

Interviewer: Are they nearby Adam?

Adam: YES.

Interviewer: How do you stay in contact? Do they visit?

Adam: PHONE

Interviewer: They ring you regularly. Have you ever used communication device or anything like that?

Adam: NO.

Interviewer: They are not useful to you, no. I suppose they are more limited in terms of communication too, most of them. And people don't have to work so hard to understand as well I guess maybe, I don't know, is that true. I am thinking about the delta talkers

Adam's brother

and things like that.
Adam: NO.
Interviewer: Support services, are they up there with family and friends in terms of …..
Adam: YES.
Interviewer: My experience of that is that it is actually people and human relationships rather than services that are important - is that your experience?
Adam: MAYBE, HALF IN HALF.
Interviewer: Are there parts of your community, Adam, that you feel are inaccessible to you?
Adam: NO.
Interviewer: It's just a problem to be solved too. Were you there? Has that always been the way?
Adam: YES.
Interviewer: I mean there are places in the community that I feel uncomfortable. I am a bit of a sociophobe. I am kind of antisocial and there are places in the community that I experience a level of discomfort, is that true for you?
Adam: NO (very strongly)
Interviewer: See I am not sure that that's typical, Adam. I am not sure that that's typical of all of us. Like I think you are going to have to put me in my place again sometime soon. But like was that something that you had to come to terms with or is that part of…
Adam: AT TIMES.
Interviewer: But on the whole now, you feel - like I was talking about - do you still have to come to terms with that? Can you tell me what it is that you are coming to terms with?
Adam: MOVING.
Interviewer: That it's the physical barriers, like inaccessible because of physical barriers. Is it getting better? Like do you find most people are - like building design and that…….
Adam: YES
Interviewer: Are there any places that you are precluded from going to now, like if transport - transport seems to be improving like with mobility taxis and in Dunedin there are buses that I think you can even get your wheelchair on. Is that true? Do you find?
Adam: YES.
Interviewer: Like what about psychological barriers, there are places – it's funny, isn't it, I was reading from one person that they were talking about going to see games of rugby and as an able bodied person I kind of always looked at the fact that often you would see people with wheel chairs in the best seats and there was also a degree of envy about that. But I did that because I hadn't thought about it. Some people kind of describe those settings as a ghetto, like a disability ghetto and it was just kind of non inclusive because it meant that people were separate from being - they were visibly treated as different and segregated, like are there psychological barriers.
Adam: YES.
Interviewer: And it's something that you would feel sensitive to?
Adam: YES.
Interviewer: See some places would see it as enlightened. Do you work, are you working now?

Adam: NO.
Interviewer: Would you like to?
Adam: YES.
Interviewer: Do you think that's a reasonable expectation?
Adam: YES AND NO.
Interviewer: Can we tease that out - in what way yes? Like you were talking about before that I imprisoned you by my lack of imagination and creativity, right - like are work places like that too?
Adam: YES.
Interviewer: And is the no part of it you feeling as if although work places have got a long way to go to accommodate that they are - they have got a right to be productive. What was the no bit about, you went yes and no, what was the no bit about?
Adam: REPEAT
Interviewer: I said would you like to work and you said yes and I asked if it was a reasonable expectation to be able to work and you went yes and no - and I was just wondering what the no was about?
Adam: FREE TIME.

Interviewer: Your free time is precious. Okay, see a lot of people, see you - isn't it funny, people kind of think people with disabilities are this great big homogenous group forgetting that they are as different as everybody else but I will tell you what I have seen, in my jaundiced prejudiced world view is that a lot of people look at employment as a form of validation. That they transcend disability through working.

Adam: YOU WORK.

Interviewer: Yes, I do, but I would never think of it as a term of validation or a right. I would actually like free time. Like it is not about, my working isn't about - I don't know, I do get some status out of it, you're right and it is important to my identity, you are right again. If I am reading you right, but to me it's about - it's not about a form of validation in as much as I have to prove anything or demonstrate my citizenship by working, I don't think of it in those terms. I see some people with physical disabilities who felt marginalised and segregated in a way that the job was about proving equality really.

Adam: YES.

Interviewer: I mean I don't know whether this is right or wrong, I am not sure that its true for you, Adam because I think it is your intellect and creativity that has freed you up from having to feel like that and the fact of your former life too, isn't it?

Adam: YES.

Interviewer: Your surfing and your flying and your working and your family have all sustained an identity that means you don't have to think that way. Is that fair?

Adam: YES.

Interviewer: We had a question therefore what would your advice be to people with disabilities - what would you tell other people?

Adam: GYM.

Interviewer: That's the answer. What is it that - why? Why is that so important, I have only been once? What is it so important about your gym?

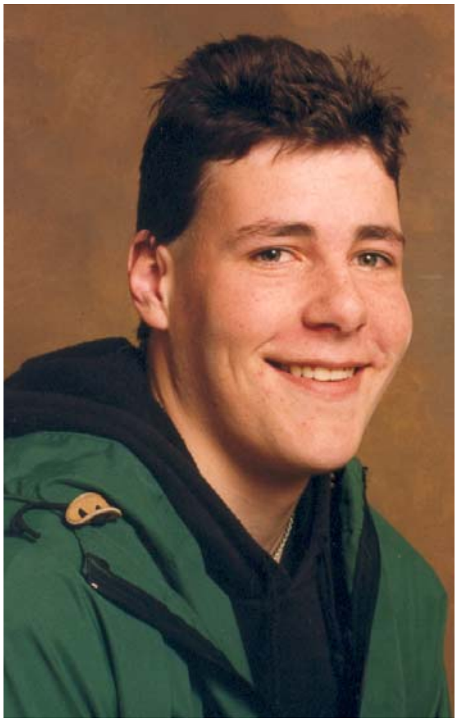
Adam: TO MOVE YOUR BODY.

Interviewer: So on one level that's an incredibly simplistic thing to say, do you know what I mean, Adam, like I can move my body, like it almost - so self-evidently simple that you wouldn't think to say it but is there a - I am looking for - are there any other things that you are able to move by being there. Like is it about moving your mind as well, is really what I am fishing for.

Adam: YES.

Interviewer: And the bit about your mind that you have to free, well here

Adam (before the moustache!)



we go, is it about that being non disabled - I am not even sure that's what I mean, I mean like to the limits of your potential you don't accept the disability persona, is that what you are moving?

Adam: YES.

Interviewer: But you found that as - how long have you been going to the gym?

Adam: 8 YEARS.

Interviewer: Can I ask how old you are, Adam, is that okay?

Adam: 32.

Interviewer: So I just kind of think 18 minus 32 - so that's 14 years in a chair and 8 years at the gym. I mean I don't know whether I am picking up right, but that act, not the library, not going to watch the surfing, not those other things that you listed that you are involved with, the gym is the most significant of all of those.

Adam: YES.

Interviewer: And was it a watershed, like eight years ago, was that some kind of psychological watershed as well or am I reading way too much into that?

Adam: NO.

Interviewer: It was that psychological watershed. That's fascinating, do you think it would work the same for me if I went to the gym?

Adam: TO MOVE YOUR BODY.

Interviewer: What advice would you give services?

Adam: GYM.

Interviewer: You would take them all off to the gym - for themselves, do they need a dose of it or is it for … You know you said about work, it was a reasonable expectation that you would quite like to work, have you taken any steps to find work, Adam, have you taken steps?

Adam: YES.

Interviewer: What have you done?

Adam: BRAIN.

Interviewer: Use your brain - that's pretty ambiguous though, where do you look for work, let's have another go at the question, whose responsibility is it to get you work, if you wanted to work, whose responsibility is it to find work Adam?

Adam: ME.

Interviewer: I see such a huge variety in that, that's not the answer that I get from some people with disabilities. What led you to that view,. What led you to the view that it was your - is it your responsibility exclusively?

Adam: YES.

Interviewer: Right, see that is fiercely independent. And it is helping in the same way - isn't that interesting - the same way that pushing that bar or that weight is the same act isn't it, it is about pushing against - I was going to say a force back the other way which is the same way as saying oppression really isn't it. Is that fair, like do you feel, academic or people with pointy heads like me like to talk about the way people with disabilities are oppressed, do you feel oppressed?

Adam: YES.

Interviewer: Right, can you say in what ways, how do you experience

Adam: MY CHAIR.

Interviewer: Your chair oppresses you, this is an inanimate object. How does your chair oppress you? Is it a value judgement that comes from being in the chair, is that what you are saying?

Adam: YES.

POST INTERVIEW

Interviewer: Adam and I were just talking in the way that you normally do more freely when the tape recorder is off and we were talking about one of the barriers, one of the significant barriers for Adam, is the fact that in order to know what he is thinking or in order for him to be able to communicate effectively what he wants and to see the true Adam takes time and we were talking about time being a barrier and the fact that often in services staff are incredibly busy and he feels a sense of frustration that his ability to communicate is compromised by the business of other people. Would that be fair - is that Okay, could I put that better?
Adam: YES.
Interviewer: Anything else, have we missed anything out?
Adam: NO.

Terrigal Lifesaving Club: Surfing mates

Marie Meikle

"To me life is just starting now"

Marie Miekle (4 June 2004)

Marie and I are sitting in the Invercargill Library. We have just finished a coffee, during which we were talking about the process of re-creating yourself. The conversation grew from our efforts to think of some way to begin her story. I suggested we start with the coffee. Even though Marie has lived in Invercargill for more than 10 years, she had never been in to a coffee shop here and didn't know where she would like to sit to start writing. Marie said she would like to begin her story with the fact that twenty years ago, no one expected her to be here to be making choices like these. Somehow the two ideas seemed connected to us by Marie's beginning to live life afresh through new experiences.

I haven't done anything like this before. Hi, I am Marie.

I am 28 and come from a family of four. I grew up in Mataura, which is a country town in between Gore and Invercargill. Not a lot ever happened in Mataura. Its two main attractions were the Freezing Works and two paper mills. They are all closed now. I lived in Mataura because my father worked at the Freezer.

I went to Mataura Primary School. Up until the age of nine, I was an average student having an average childhood After nine, my life changed for the worst, no it didn't…… well yes, it did change for the worse but twenty years later I am reclaiming it. In 1985 I was diagnosed with a cancerous melanoblastoma brain tumour. I spent three months in Dunedin Hospital fighting for my life. The doctors gave me a life expectancy of just 18 months. I take courage from still being here. I have beaten the odds and fought against something life threatening.

After the operation, returning to a normal life has been a different sort of struggle for me. While I was in hospital, I was in an adult environment with no young people to interact with.

When I returned to Mataura, I felt I didn’t fit in. Socially, there seemed to be a barrier between me and ones my own age. I had spent so long with adults that I didn’t know how to act like a child any more.

I missed so much of my school education too. I constantly fell behind and couldn’t keep up. Back then, teachers didn’t have the time to go over what I had missed, and looking back, I feel like I haven’t got all the knowledge that I needed to help me in my adult life.

At school, I felt I was at a different level of development to those my own age. This was especially during my teenage years. I never got the chance to be an adolescent woman. My hairpiece and my slipping behind, made me different in the eyes of my peers. Different can quickly become distant. I felt isolated and alone and without any friends to talk to, I was the only one who knew how I was feeling.

At home, on the other hand, I felt wrapped in cotton wool. Because I had been so sick, my parents thought I needed protection from the outside world. Life always seemed to lie beyond the barrier of family and I didn’t know how to break through without hurting my mum and my dad. The glue that held me bound was their low expectations for me. *My mum and dad used to put me down a lot. When I got my school report card, they would look at it and give it straight back to me to put in my school bag. One time after a parent interview they came home and said, one teacher thought that I was trying too hard. I was setting my goals too high. The following term I got a bad report card. But what pissed me off was that my mum and dad didn’t take any notice of it. I wanted their reaction to the report cards to let me know I was wanted and loved. They always went on to my brother about how they wanted to see an improvement in his report card, so this is what I tried. I got bad report cards, and they didn’t even say anything. They just signed it and told me to put it in my bag. From then on I decided to set my own goals for myself. [Interview transcript 29/04/04]*

I stayed at school all the way to the end of the seventh form, but left knowing I wanted to continue to learn. What I really wanted to do was to help those that had helped me in the past. I had been helped all my life by other people, in the sense that I wasn't supposed to be here. I had also been labelled as forever needing help, but I wanted to return something to the community. Nurses and doctors had given me a new life. There had to be something special about me for people to have given me that. That special something I thought had to mean giving back to people not as fortunate as me.

I wanted to train as a nurse. I kept getting it drummed into me though that I wouldn't amount to much and I couldn't do it. A life on the benefit was all other people forecast for me. I rejected this future and needed to find out for myself. At a school careers evening I had already tucked a foundation health course pamphlet into my back-pack which I later used to enrol at Southland Poly-tech. I began the course in 1993, but came to realise that I just didn't have the strength, but it was important that I discovered this for myself. If I hadn't tried I never would have known and stopping me would have damaged my confidence more than not succeeding.

Despite struggling, I stuck with it and graduated. That year, however, we spent time learning how to care for children. I discovered I had an interest in children, so the following year I did a New Zealand Nanny Certificate at Polytech. There was an article in the local newspaper about a day care centre opening in Gore. I went along to the meeting and talked with the lady who asked me to come back for an interview and I got a part time job working a few hours a day as a child-care minder. It was my first paid employment and I felt like I was finally "out there" doing something I wanted. I had achieved it myself. I loved being around the children, being in a caring role, and ended up living briefly with one of my workmates.

Today I live with my grandparents in Invercargill. I have been there for nearly two years now. Before that I tried flatting. *My thinking at the time was that I would be more independent. It went well for a little while, but in the end I felt stuck indoors.*

Because I had limited mobility I couldn’t get out much and I ended up feeling isolated. I had gained my independence, but when it all boiled down to it, I hadn’t because I was stuck in doors. I had no-one to communicate with. [transcript 29/04/04 p7]

I think similar things about my involvement in the community. Although I do a few things I don’t really feel connected to my community. I have no real relationships with people out there and support doesn’t seem to help you find them.

When you think of community you think of it being a single thing. Really it is made up of a whole lot of different communities all doing different things.

The most important way I participate is through school. I am working as a teacher aide, helping a child with a learning disability. I get paid for three hours a week. One hour every three days – But I love my work and do the whole morning at school each of the three days I am there. The alternative is to be at home and since working I get bored with myself at home doing nothing. Work gives me friendship with the children, confidence, a sense of achievement in watching them learn and grow and pride that I might be making a difference in someone else's life. In many ways it repairs the damage that I felt was done by the lack of encouragement I felt at school.

I got the job by volunteering. In my correspondence course I had to find work experience for two terms. I approached Waihopai School - but I chose to do a whole year. And before that even, I volunteered as a "help," at a local Kindergarten. While I was there, I met someone from Special Education Services who had come to monitor the child's progress She was talking about teacher aiding and I got the idea that I might look into it further.

Saturday is church day, but don't count that as being in the community. I know other people would say it is part of the landscape of the community but I just come and go from Church. Faith is a personal thing and is part of my family's weekly ritual. It is just something you do and doesn't involve others. I keep to myself. Being in the community to me means being in relationships with people that involve disclosing something of your real self. Church is a private thing.

I feel the same way about things like going to town, or shopping. I am on my own and not sharing anything of myself. Every now and then I go into town. Friday is a spare day for me so it's usually a Friday that I end up going to town. I live at the north end of Invercargill, near the end of the railway tracks and it would be impossible for me to get about without my mobility scooter. My limited mobility determines the amount of time I spend in town because you only have a certain amount of power in the battery before it runs down. You would be most likely to find my scooter parked at the Warehouse, Farmers and the $2.00 Shop. The cheap shops! You would never find it outside of a coffee shop or anywhere flash. The difference between those sorts of places and the Warehouse is not just about not having a lot of money, it's because some places are busy and you don't stick out. I can hide myself and I don't feel so exposed in big, familiar places. I would never go to more intimate stores by myself. I guess I know the outside of Invercargill, but not much of its inside.

In the places I really want to go, you can't be invisible. In the coffee shops, pubs and restaurants I don't really know how to act. I am so self-conscious that knowing how to react in different places is really important. Being with someone makes it much easier. I have been to the pub twice, both times with Donna. Once we went up to get a drink and the barmaid asked us what we would like and we said a lemonade. She asked us if we had ever tried a lemon, lime and bitter. Donna said she didn't drink alcohol but I said I would give it a go. It was my first drink. Because both of us don't put ourselves out there too much, we spent most of the night watching.

When Paul asked me how many friends I had, I could only think of Donna. I met Donna doing the Nanny course. She is a lot like me. What I first noticed about her was that she seemed to find it hard to fit in with the others too. We really started to get to know each other when we were paired up in class. I hardly see Donna at all now because I am working. We keep in touch on the phone though and I have stayed over at her place a few times.

As we talked I realised I actually had another set of friends. There is a group of older women that I have stayed in touch with for nearly twenty years. I met them at Camp Quality, which was a camp for children who had been diagnosed with cancer. I divide my friends into two groups. The "older ones" and the ones around my own age. Over the years these women have given me companionship, guidance and support. I value their friendship and have grown up alongside their families. It has been with these women that I have felt accepted and loved and safe to share my feelings with. They do not judge me but guide me and I am able to relax and be my real self.

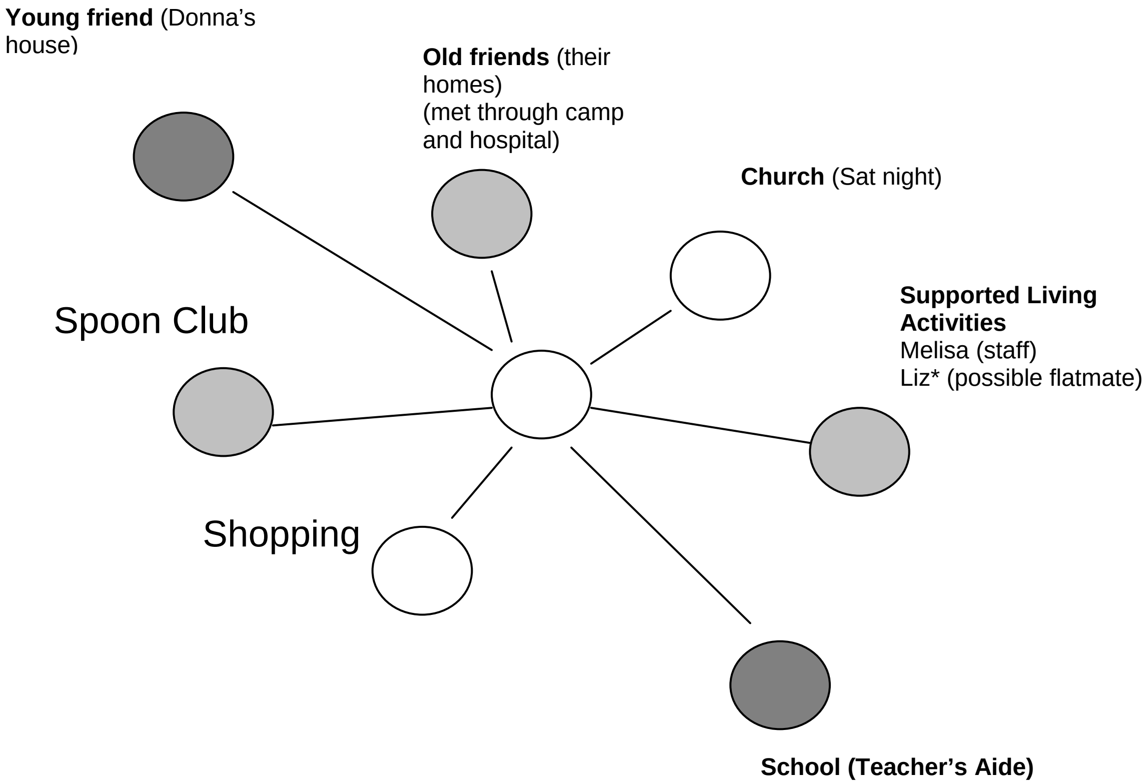
Why I think I make the distinction between young and old friends is that I am less sensitive to the reaction of the group of older women. I can be as different as I like and it doesn't matter. I am a little fearful still of the judgements of people my own age.

One thing I would feel uncomfortable about letting people my own age know about is my spoon collection. I just know they would think that it is pretty nerdy and old fashioned. I have got over 2000 spoons. I started collecting for my Brownie badge. My great aunt started me off by giving me my first spoon. It all started from that one spoon! Over the years family and friends have all added to my collection and even though the number of us collecting is dwindling fast, there is still a small group who meet once a month to talk and trade stories and spoons. Each spoon in the collection has a meaning, either of a place I have been or of others who have given them to me.

My old friends and the spoon club are the communities that are special to me. They are refuges. Safe places from the world of judgement and isolation. But like most refuges, they are hidden halfway houses between being in the private places of your life and exposed and fully out there. It would be really nice if I could find these qualities in all the different places that make up being in the community – so that it could be whole.

The other way that I have just begun to be connected to the community is through a branch of CCS called Supported Living. A group of young people from CCS get together to do different things. We have had a girl's night out where we covered our faces with make-up and ate fish and chips, and another day went to a movie. Melissa from CCS would send out invitations to a few of the younger girls and I thought, well, I get on with Melissa and I liked her, so I thought yeah, I will go along and see what it was like. It was the trust I had in my relationship with Melissa that made it ok for me. I'm not sure whether I would go out with the other women without her, even now. I didn't need to fear that Melissa wouldn't accept me.

Figure One: Marie’s Community



○ **“In There”**
“ Not in the community. My things. The things I do on my own. Places I don’t usually mix with other people in the community. Often activities not really decided by me. They might be family rituals or things I don’t think say all that much about me. I don’t really disclose anything of my true self.”

◍ **Communities within the Community**
“Part of the community.. Some of the clusters of different sorts of community. Refuges of acceptance but hidden and furtive for fear of judgment. It’s a carry-over from when I was younger and people my own age constantly put me down. I’m too scared to let my true feelings about them be known…… with them, I am able to be me.”

● **“Out There”**
“Being in the community. Roles and identities that I would choose for myself. Feel as if I am not judged. Giving back to the community what I missed out on. Places where I feel no matter what I say, it is important to them. They are interested in me.”

There is still much more that I want to achieve by becoming involved within my community.

I would love to find ways to be less dependent on other people. Living with my grandparents sometimes feels like I am a burden to them and I would like to move into my own place. Not by myself this time, but with other people, my own age. I have met someone through CCS Supported Living who is also interested in flatting and we are waiting for something to become available. Liz* would be good to live with because she is a bit more outgoing than I am, which might make me more prepared to have a go at a few things.

I would also like to be a bit less dependent on my Grandparents for transport. It is hard though. The public transport is not great, taxis are expensive and even though I have a car licence, I don't feel confident driving.

I would really love to get out and about more, especially with a group of friends my own age. If I could unlock some of my inhibitions I might also be able to liberate myself from always worrying what others might be thinking about me.

I would like to travel some more. When I was in Dunedin having my tumour removed, I struck up a relationship with one of the nurses and we have written ever since. She moved to Canada, and eleven years ago I wrote to her and said I was coming over. It would be nice to catch up with her again and some of the other professionals I have stayed in touch with.

It is hard to prioritise which is most important because it is really hard to pick out which ones I can make real and which ones are just dreams. They might all be possible.

Support might be what makes the difference. It doesn't matter where it comes from. It can be from any of the communities I am involved with because it is not where support comes from that is important, it is how you feel it. You only feel like you are being supported when you know it comes from someone believing in you. You need to be with people that believe in you. Even push you a little bit further than you thought was possible. I have spent a good part of my life trying to recover from people's lack of belief in me and to push out beyond what they thought I would amount to.

Support also only feels like support when you are being listened to. On occasions I have been put where other people thought it was right for me to go, even though I didn't really want to be there. Because CCS felt it was important to get me out doing something, I was steered into doing a Wider Horizons course. I felt it was really downgrading. I knew about personal hygiene and how to keep myself clean and care for myself. I really hated it and vowed and declared I would not let them push me into doing something else like that. You can’t decide for people. You have to talk it over with them and keep an open mind.

Flatting was a similar situation. Some services think that being by yourself is the pinnacle of independence. Independence does not mean being on your own. Independence to me means being in control.

So long as I can keep control, the way I am feeling now is that I have got a second chance at life. I have come such a long way in the past twenty years. I don’t want to waste another minute.

Janet’s Story

It’s been a long, hard journey - but a good one!

I have been thinking about my life ever since I first met you and you asked me about what I did. It caused me to think back on all the things that I have done. And now I’m sitting in my own flat with a friend to help me, reflecting on my journey.

My name is Janet and I was born in Dunedin in October. At first they thought I was a perfect baby. Mum and Dad were thrilled. I was their first child. My father was a dentist and mum stayed home with me. She was very good to me and spoiled me. But as I developed it became clear that I was having problems. One thing that was a problem was that it was very hard for me to eat. I hated mealtimes because I couldn’t swallow, my neck muscles just wouldn’t work properly.

I was about a year old when I was taken to see a doctor. He said I was spastic and I would never have a normal life. He said I should be sent away to a place in Australia where they could look after me. Luckily my mum would have none of it. She wanted to look after me at home and this is what she continued to do.

We stayed living in Dunedin for another 3 years. In that time my mum devoted herself to looking after me and to trying to get me to walk. When I was 4 we left Dunedin and moved to Auckland. My father had been doing extra study in Dunedin and changed from being a dentist to being a doctor. He did this because he wanted to help me. He wanted to learn more so he could do that. In Auckland he got a job at Greenlane Hospital where he was a registrar for three years. That is why we moved to Auckland.

We lived in a flat and mum took me to Auckland hospital three times a week for speech therapy and physiotherapy. It was hard but they managed to get me up walking on my feet. Just a few steps. I was seven by the time I could do this.

The next thing that happened was my father got a job in Thames, so we moved there. In Thames there was no physiotherapy or other things that I needed. I only stayed there for 6 months. After that time I had to go and live in Rotorua at Queen Elizabeth Hospital where there were the services my parents wanted me to have. There were over 20 other children with disabilities living there. They came from all over New Zealand. I lived there for four years. When I moved there I was really homesick. I stayed homesick most of the time, on and off. Mum and Dad used to come and visit me every three or four months. Each time they came I wanted them to take me home. I didn’t go home for a visit though for two years. Then I could go home for holidays in May, August and Christmas. We all went home at Christmas.

At Queen Elizabeth Hospital we had to get up at 6 o’clock every morning – even on the weekends. We had to dress ourselves and strip the beds, fold the blankets and sheets and put them on a stool by the bed. This took me about 1 1/2 hours every day. Once this was done we would then go into the passageway and put on our shoes. Only then did we get breakfast – weet-bix, toast and milk. The toast was always hard and cold. I think they must have cooked it at night!

During the week we went to the classroom for school and on the weekends we just played in the playroom all day. Every weekday I would go to the physiotherapy for 1 hour, from 9 – 10, before I started school. While I was there I learned to read, I learned to dress myself, and I learned to walk better. By the time I was ten I could walk – but I hated being there.

Before I moved to Queen Elizabeth Hospital from Thames, my mum had my first sister. She had to travel back to Auckland to have her. She was just a few months old when I left and it was to be quite a few years before I got to know her. My second sister was born 3½ years later while I was still in Rotorua.

Five years after we first moved to Thames my father started to train as an ear, nose and throat specialist. This had to be done back at Greenlane, so I moved with the family back to Auckland. Even though it was wonderful to leave the hospital, living with my family again was very difficult at first. One thing was I had to share a room with my next youngest sister. She was only four and like a typical four year old she was into everything. Eventually it got easier. I didn't have to get up until 7am during the week and could sleep in until 9am on the weekends!

While we were in Auckland I went to Carlson School. That was the school for children with cerebral palsy in Epsom. I was only there for about seven months before we left on a boat to go to England. We left so my father could study in England. The boat was a cargo ship for transporting lamb. We had to go down to Wellington and from there to Lyttelton where we boarded the ship. On the trip out to England I remember my two sisters really acted up. One was five and the other about 18 months.

We were in England for two years while my father was studying to be an ear, nose and throat specialist. When my father was free we would go out sightseeing. We saw a lot of England that way. One day I'd love to go back.

While we were in England I went to a really up market school for children with all types of disability. It was like a normal school and I could do more there than at Rotorua or at Carlson. We did our lessons in the morning and in the afternoon we had cooking lessons and handcrafts.

When we were about to leave England we spent six weeks touring the Continent by car towing a caravan. We had a great time even though everywhere we went it was wet.

We moved back to Auckland after that and I have been here ever since. I lived at home with my family and I went back to Carlson school until I was 18. From there I went to the Dadley Foundation for three years. This was a real disappointment because they put me in a dayroom with other very disabled people. It was a sheltered workshop where we did menial things like packing pegs. They would test us to see how fast we were and sometimes you could get a better job if your score was good enough. If they thought you were really good they would look for a job for you outside. They never suggested I should do this and I really wanted one. My father was very angry with this too because he thought I could do a simple job somewhere else.

I went to another place in Mt. Eden where disabled people could work after the Dadley Foundation. This was for older people and wasn’t any better. While I was there they lost all their work contracts and there was nothing to do. I didn’t stay there very long – just a couple of years.

A few years after I started at the Dadley Foundation I left home and moved to the Laura Ferguson Trust Home to live. They had some clustered flats and I lived in one of those. Each flat had its own bedroom and bathroom and there were communal laundry and dining facilities. I ended up living here for over 20 years.

At first I was happy. I learned to cook and to take care of myself so I could live independently. Later on it became too big and then I didn’t like it so much. I never felt all that social at Laura Ferguson. I had been there about 10 years when the matron asked for people who were interested in living more independently in the community, to attend a meeting. I turned up. The Matron wasn’t happy with this. In fact she was bloody angry. She didn’t think I could manage this move. She said to me “you will never get out of here.” She also thought that because I went home to my parents most weekends on my scooter, I shouldn’t move out in case I became a nuisance to them.

There were some good things at the Laura Ferguson home. One good thing was the socials. We used to have a secretary/manager who helped with these. He would always make sure we had a good time. He used to encourage us to drink. And he used to encourage us in other ways too! We were always careful to make sure Matron didn’t know too much.

Another really good thing happened after I had been at Laura Ferguson for about five years. I had my first trip into the community by myself. I had a good friend called John, who is still my friend. He asked me if I wanted to go to the shops as he sometimes took a friend of mine. He offered to take me but I was too nervous. I thought that people would not be able to understand the way I speak. After a few weeks and lots of reassurance from John I went with him. He stood back when I was in the shops so that the shop assistants would talk directly to me. I found that they could understand what I wanted, which was a huge relief to me. We continued this way for close to a year. Finally I felt confident enough to go on my own. By now I had a scooter so, at age 27, I went into the community to go shopping by myself for the first time ever.

On another occasion I had a friend who didn’t want to go out with her boyfriend anymore so she suggested he take me out. Well, we did go out and we hit it off pretty well. We continued to see each other for a further two years. On the first night out we went around the waterfront and to see a movie. Other times we might go out for a meal or to ‘64 Club,’ which was a club for disabled people. We continued to have pretty good parties back at Laura Ferguson which got us into some trouble!

Eventually I did move out into my own Housing New Zealand, two-bedroom house. Unfortunately the Matron still wanted to have it her way. When my mother was in hospital she arranged for me to move into my present place. This is a nice house but it was chosen so I was not too near my mother. When I was told about it I was told that if I didn’t take it my name would go to the bottom of the list and it might take years before I would get the chance again. So I took it even though it was not where I wanted to be. My mother was furious when she found out.

I really like my place and I love being able to live independently. The only problem is it is too far from the shops and from my mother. Also the people who live around me are all very different from me so it is hard to feel like I fit in. I have tried for 10 years to change houses but because I already have a house I am very low priority with Housing New Zealand. I still firmly intend to move to where I want to be. I don’t really know how to make this happen but I have a friend who may be able to help.

When I first moved into my flat I used to have people come in and help me with just about everything: the washing, cooking, shopping and cleaning. Now I can do most things myself. I still get the home support people to drop me off at the shops and they wait for me and bring me home.

These days, I don't go to a centre or workshop. Instead I spend my time doing a whole range of things. I go to the gym, I do craft – especially embroidery, I still go to physiotherapy, I go out with my current boyfriend and sometimes I go shopping. I am also learning the computer. I think a computer would be good for writing letters, making birthday cards and I could use it to help with communication. Once I get competent at using one I would like to get one – perhaps a laptop would be best.

One thing I would like to do more of is travelling. Every now and again I go to Australia to visit my youngest sister but I would love to go back to the UK and to Europe. I like to see new places, meet new people and have the different experiences that travelling brings – although I'm not so sure about the different food.

I enjoy what I do and I think I am really lucky, but I wish I had had the opportunity to get a job. I think it is too late for me now because of my age. I am not all that keen to start at this stage of my life but it is a big regret for me. I think I would have liked to work in a sewing shop. I enjoy meeting people, I like sewing and I like to help. I think I could have been good at that. It really stinks that I had no job.

I like to be in the community. I find it very challenging but I never want to go back to an institution. It is a challenge to do things. It takes me much longer than other people. I do find that most people are good at taking the time to help me and to understand what I want. But it is hard to access places. They are just not designed for people in wheelchairs. Also transport can be difficult and expensive. This certainly limits what I can do and where I can go. That is a reason I want to move.

Things haven't come easily for me. I am generally happy with my life but I have had to work very hard and to be very patient. If I didn't have the support of my parents and sisters, and a few other people, I might not have been able to get to where I am. Along the way I have learned a few important things. One important thing is to share things – even things like sharing something special to eat with someone.

I have learned through my life how important it is to make friends. Having friends means you have someone to talk to, to do things with, have a cup of coffee together, and you can help each other. I think friends keep you connected to the community and stop you being lonely. One special friend I have is Robert. I met Robert just over a year ago. He is now my partner. He has a car and he takes me for little drives to see things. He takes me shopping, and we have coffee together. It is good as it gives companionship, friendship and being together.

My message to others is to make sure you do everything properly. Don’t give up - keep trying until you have got what want. And parents of disabled people should never give up on their child. They should keep making sure they get the best for them.

Michael Turner

I don't have a problem doing activities with other people with disabilities. I wouldn't mind going to the local gym on my own, but not if I feel like an outcast

Michael Turner is 51 years old, lives independently in the community with his dog Charger and loves to keep fit. He has Cerebral Palsy and leads a very active lifestyle. Most of his week is spent out there participating in the community. Since his interview Michael has joined the CCS Local Advisory Committee and access group. His story is a summary of the key points that Michael wanted to say from his interview.

Michael tell me about the good bits about what you are doing in your life
I go to the gym twice a week and I go to swimming at the Burwood Hospital Physio Pool once a week at the moment. A second session starts again next week at the pool so that's good. That helps me with balance and stuff like that and gives me something to do. I get bored sitting at home. I also enjoy going to the gym. That gets me the most motivated and also helps build my fitness and energy up.

The Pro Fitness gym session was arranged through CCS and the exercise class at the Avonside Church Hall and swimming pool was arranged by me. I wanted something to keep my body going. The exercise class and swimming are easy to get to and don't cost a fortune.

I do some computer classes each week at the Alan Bean Centre at Burwood Hospital. These are on Monday and Friday afternoons after gym. We just go down there and muck around on the computer. This is a polytech course that is run at the Allan Bean Centre. The teaching occurs on Monday and Friday and we have free time on Saturday to catch up on the course and emails. .

The good thing about the Alan Bean Centre is that if you get stuck they help you. I tried computing for free at polytech but they didn't help you when you got stuck. I can get more support at the Alan Bean Centre because there are fewer people in the classes, than at polytech. I would put my hand up for support and they would just ignore you! I would also like to go to the movies. My caregiver has offered to take me but at the moment this hasn’t come off.

How many hours a week are you involved in community participation?
Four days and on Tuesday I also go grocery shopping. I probably do about three to four hours per day.

Who do you do these activities with?
People who go swimming have something wrong with them and go to Physio. The computer course tends to be for people with disability or for people in the hospital. The gym class is with other people with disability involved with CCS and the exercise class involves people in the local community.

When you go to the gym class at Pro fitness, do you do this with other people who go to the gym?
We have to walk through the foyer and the main gym to get to the room where we do our gym class. This room is off to the side and away from the main gym area. As we walk through the foyer and main gym, the other people don’t talk to you – they just ignore you! The staff are the only people that seem to talk to us mostly.

Before I found out there were CCS classes I used to go to a gym in New Brighton which I arranged. Unfortunately they changed owners and they moved the gym upstairs which meant I had to find another gym. They used to help you and I felt part of the gym. I also used to go to CCS classes at the YMCA and they used to help you too. About 12-13 people went to the YMCA class and everyone talked and joked with each other and things like that. But I go to Pro Fitness and only three or four go and hardly anyone seems to talk to each other. The YMCA class was really enjoyable, and that was stopped.

You go to Pro Fitness, it’s not as enjoyable because people don’t talk to you apart from staff.
We are in another room which is not part of the main gym and I feel like an outcast! When we were at the YMCA I used

to get there early because people used to talk to me because we were just part of the gym. You would sit down and anyone that came into that gym used to talk to you.

When you go to the Avonside Church Hall to do the exercise class, who goes to that?
Lots of old people from around the neighbourhood. I saw it advertised in the paper and I made enquiries about it, told them that I had a disability and they said, “Yes come along”. I went to another exercise class before that at the Woolston Community Centre, but decided not to go back after a few sessions. Their attitudes towards me were really negative. They treated everyone badly. No one would talk or joke or anything, they just ignored each other. That negative feeling starts to get you down after a while. At Avonside, everyone might be 90, but they are very happy people and talk to one another, help you and stuff like that!

You are doing some activities with people with disabilities and other activities with non disabled people. So who are your friends?
I haven't really got them - I have only got two. Neighbours further down the road - they ring up occasionally, not much – it’s getting further and further apart. I also have my caregiver. She goes to Pro Fitness with me occasionally. I have also got to know another guy with a disability at the Alan Bean Centre computer classes. He’s got Cerebral Palsy like me.

How did you get involved with the CCS programmes?
I saw them advertised in the newsletter at CCS. I have been a member of CCS since about 10 I think and it is only in the last four or five years that they have been getting in touch. The recreation officer use to get in touch with me. Since she has left it has gone downhill. When you go swimming, no one is in charge anymore. There is no one there to coordinate it or talk to you when you go swimming. When you go to the gym at Pro Fitness there is not enough support to be able to help you do the exercises, so you can reach your potential. If you ring up CCS, you get the answer phone. They don’t seem to answer my messages. When CCS had recreation staff it was really well coordinated.

Last year I asked for support and I had to wait and wait. I had a bit of a back injury, needed some help with personal care, tried to get that arranged with my key worker and nothing happened. I eventually complained to the manager and I still got nowhere. So I contacted a member of the consumer advisory group and that’s when I finally made some progress. I tried two or three times to make complaints through the staff channels and when that didn’t work, I went through the consumer advisory group. I feel like some CCS staff don’t listen.

What are the hardest bits about community participation?
Dealing with the negative attitudes. Places where it is hard to get in and out of. My lack of money and the fact that many activities are out of my price range. Gyms that tend to be more accessible tend to be more expensive. Not having the people or support to go to activities. I don’t like going into crowds of people. Feeling more isolated because I can’t ride my bike any more. It’s too dangerous for a disabled person to go out at night after 5pm.

So what helps you get the things that you really want?
When I want something I keep pushing until I get it. If I can't get it I have another crack at it. I have three cracks at it and if I can't get it after three cracks I go out and try something else.

So what sort of support helps you get what you really want?
It depends on what you want. If I want something that I feel I need support from CCS it has got a lot harder - you don’t know who to go to or who to ask. At times it has been really good, and at other times it's been not so good.

It was good when CCS had more recreation staff. They would tell you what you needed before you needed it, they would arrange things that we needed. Now no one is in charge, you can't go and see them to tell them what you want. I don’t even know who to contact when something is wrong.

In the past the recreation staff were really good about letting you know about stuff. They almost had ESP and knew what your needs were. They also used to push you into things and challenge you to do things. Now there is nothing like that!

You would ask for things and they would try to get it for you. They would arrange things, provide transport and subsidize the cost of the programme. The difference between the support I got previously and what I get now is I don’t hear from them, you don’t know who to contact, it is not coordinated, and more of the cost has been put on to me or is going to be put on to me.

I want more support at the gym, more sessions and help with the cost of programmes. I would like to be doing a lot more gym sessions than CCS are currently willing to arrange and the time that the Pro Fitness class is on stops a lot of people who previously went to the YMCA from doing this class.

My enthusiasm also really helps! However CCS are trying to break up people going to activities as a group. They want us to do more individually and I don’t think it works! When they try to stop these sorts of groups you end up going on your own. It doesn’t work because there is no one there to help you if you get stuck and no one talks to you. You end up feeling like an outcast.

Going as a group you get more support, and if you get stuck you can ask someone in your group to come and help you. Whereas if you are by yourself you have to wait for someone to come. When you haven't got support in fact, that really places limitations on what you can do. When you go by yourself, you don’t talk to people, they don’t talk to you and you can feel isolated especially when you’re in a separate room like at Pro Fitness.

When we were at the YMCA, you went as a group, but you were part of the gym and you felt like you were part of it. At Pro Fitness you just feel like you’re not there! It’s like having a foot in the door and you can't open the door any further because a foot stands on it. I don’t feel part of the community of Pro Fitness. It’s like taking a child to a lolly shop and then telling them that they can’t touch the lollies.

So Michael, what would make you feel not like an outcast?
Keep the groups going. Have someone in charge that you can talk to when there is a problem. People talking to me.

In an ideal world would you like to be able to go to Polytech to do your computer courses?
No, because the classes are too big - one to twenty. You don't get enough support. At Burwood, one to one support is available. When I was at Polytech I had to hang about, wait, wait and wait, cough and they would just ignore me.

What makes community participation easier?
People who have been able to anticipate what my needs are, what I might be interested in and let me know, helped me with things like transport and the cost of programmes and made sure that I have got really good support so that I am able to actually do the activity and that is not affected by a lack of support. They should also make sure everything works and is not the reject equipment for people with disability to use. Also make sure that people think about the setting. One of the really cool things about the YMCA was being part of the gym, with a group of people where you could get good support and you had mates that you could talk to. There was also a common goal really to push the boundaries with one another. It is also helpful if CCS staff can be a link to work through physical access and support issues with the community activity.

I don't have a problem doing activities with other people with disabilities. I wouldn't mind going to the local gym on my own, but not if I feel like an outcast, have no one to talk to or are not able to get the support that I need. I like group activities because everyone is kind of there for the enjoyment and the common goal of doing this activity.

Do you feel part of the local community?
Sometimes. When people put graffiti on the outside of my house, I have kids knocking on my front door and you go and answer it and they are not there and my neighbours ignore me, I don't feel part of the community. When the neighbours

talk to me, I go out together with other people and get good support, I feel part of the community.

What are some of the things that you would like to do in the future?
I would like to get a new house which is easier to move around. I would like to be doing more at the gym and with computers. I have got ideas that I don't think I could do - ten pin bowling, use my bike again. I am going to have a crack at driving a car soon and I would like to try volunteer work, through the volunteer centre – gardening or woodwork

Do other people have a different idea of what you want?
Yes – Pro Fitness and CCS. The Alan Bean Centre is quite good because they ask you what you want and if they haven't got it, then they will try and arrange it all and do something about it. My caregiver asks me what I want and she helps me achieve it. With CCS it goes in one ear and out the other. They don't follow up on stuff.

So what message would you like to give to support services?
Figure out the needs and support when it is wanted. I want them to be providing more support, more information, letting me know about opportunities and to be easier to contact. They should be listening to us, hearing what we want, friendly and easy to talk to. There should be good access to information about activities. In an ideal world I would like to be involved with activities like my YMCA experience.

What message would you give to other disabled people?
Don't give up on what you want. If you can't do things through the normal channels go around and keep fighting until you get what you want. Don't give up. It is really important that disabled people get off their backsides and push themselves into things they feel they can't do. It is our responsibility to identify what we want.

CHAPTER 7

CCS STAFF RESPOND TO VIEWS OF SERVICE USERS

Introduction:

The views of service users, as expressed in individual interviews and focus groups, were summarised and this preliminary analysis was the focus of staff feedback (see Appendix 3).

Two focus groups were conducted with 17 CCS staff in two different regions. Staff were sent a copy of the Preliminary Draft Report to read before meeting as a group with one of the research team.

Staff provided very valuable feedback on this Draft Report, and also offered important insights on some areas that had received little comment from disabled people. As some staff also had disabilities, some of their comments also reflected their personal experiences.

The main points emerging from the staff focus groups are outlined in the rest of this chapter with examples taken directly from the focus group discussions.

1. “No surprises”.

In general, staff were familiar with the ideas and experiences expressed by people with disabilities, as they had heard them directly before – from service users and/or their families. Some staff expressed surprise at the lack of complaints or criticism from the service users who were interviewed.

> *… we didn’t learn anything we didn’t already know. We knew all that stuff. We have seen it and we have been told it…*

However, as discussion went on, staff identified some areas that did challenge their assumptions: that those people with more disabled friends tended to participate more in the community; that what was important was **how** they were treated not **where** they were involved; and the strength of the desire for employment.

2. Employment.

Staff confirmed the value of employment as an important avenue to: financial security; friendship; self-esteem; becoming part of the adult world; and opening up other opportunities for community participation.

> *I have got a young man in his 30s who works for a fruit and vege merchant and he has made friends with one of the guys there. And there are now posters now going up around the work place and things like that, and they have something in common they talk about. And it is really good to see he is*

> *making friends. What I see is, from just my viewpoint, the participation value of someone being in work is tremendous, because it opens up all those other doors as well and gives them the financial security that they can go out and do things. They are not reliant on the benefit any more, or if they are it is only partly, and just the whole self esteem issue for them, it goes through the roof, it is great.*

Some staff were concerned that disabled people were not “set up to fail”.

> *… it comes back to what I said before about realistic expectations because we play god a lot. We do, we play god and we also set people up for failure because we make these big plans you are talking about and then we biff them in the bottom drawer.*
>
> *Having said that, and this is being people’s advocate, I think one thing we need to be really careful of, is not setting people up to fail, and that is giving people realistic goals to aim at, at that point in time. I think people get out there and they say “what would you like to do?” “I would like to be a mechanic.” But you know, they don’t have the skills to even read the manuals at that time, so it is really damaging to go out there and say “sure you can be a mechanic.” But you have got to actually plan it and make achievable chunks so that people can actually achieve their goals otherwise you just set people up to fail.*

Others pointed out that failure should not be seen as final; people should be given other chances because we all fail at times. Staff also noted that some people chose not to work but pursued other life activities, such as sport, or voluntary work.

> *To put it another way, some of them – the most adjusted people I know with a disability, they don’t want to work because for them getting by in a way is hard work and so having a job just compounds their disability. So what they have done is, they have got a lot of their worth and value through sports. I know a lot of people that travel, made a career out of sport but because they don’t’ get paid for it, a lot of their work is voluntary and it allows them to have worth, to have all the things that we are talking about, but not having to balance their body on a 9 to 5 basis.*

3. Stereotypes and low expectations.

Staff agreed that these are a danger and we can all be guilty of these at times. They noted that overprotection can sometimes occur – by parents and/or staff.

> *… it can make life a lot more difficult because they are prepared to make the choice about what they can do. Although I can talk about it and say, “these are my concerns, and you have got to be able to manage those, and can you*

> *do that," and they can say "yes," and I can say, "that's fine." It is giving them the opportunity to make a mistake or stuff it up or whatever.*

4. Support for inclusion in community.

Staff noted that some people require a lot of support to participate in community activities, both practical and psychological. It is hard for staff to pull together all sources of support – both informal and formal – as such coordination takes time and resources that are often not available. Staff also noted that support may need to be long term, rather than "tailing off" and leaving the person without needed support or assistance.

> *How else do you create the community if you do not build a relationship with people, if you do not know how to ask or engage people in conversation.*

5. Choice.

Some staff challenged themselves about the degree of real choices available to people using CCS services. They asked whether staff really listen to what people want, or whether it is what others say they **should** want.

> *… especially to listen to what they want, not what the powers that be say they want or what we feel – but we really look, it is a great thing, it has to come in an informed way from that person. It is their choice in life.*

The message from disabled people about the importance of **how** they are treated (when they are in various settings) was discussed. Some staff felt that there needed to be a balance in what some felt was a "push to community participation". People should also be able to choose to associate with other disabled people.

> *… what is important is that people have a choice.*

> *… it is about sharing with people who have the same life experience as yourself, and we all do it.*

> *… he said, "I just like to be amongst people I can relate to… sometimes I just feel the need that I have to come back and get centred again."*

> *I think that idea of individual levels, what do they want, having that time with them, that time to get to know the person, get to know where they are going, what it is, where they are at and to be able to support that person to go the way they want to go. They are getting mixed up with what we have got, what our thoughts are, our expectations, our conceptions, our assumptions that we have made on behalf of these people about where they are going to go, and I am sure we get a moment and we act on it. And I think the other project for me that is important is that … how important it is to actually treat people just*

> *as people. Okay, they have disabilities, but really, you just treat them like you treat anybody. Have that same expectation. They have the same aspirations that everybody else does. It is an arbitrary difference in terms of disability matters.*

6. Focus on outcomes.

Staff were frustrated with how the current focus on "outcome measures" of community participation do not match what disabled people are saying. They felt driven by "outcomes" and the "bean counters", when the process of moving into the community, and "small things", like sitting and talking together – may be more valued by disabled people themselves.

> *We are driven by outcomes as well, they won't admit it but the MSD contract is for a given number of people, we have to have an outcome.*
>
> *… with disability, I believe we should be teaching people how to think. Education should be for people with disabilities, let's teach you how to think because we are going to teach you how to problem solve, how to run your own life, how to carry yourself, all the things we talk about…*
>
> *… one of my big frustrations with the service from CCS and other services I have worked in, we're so outcome focussed and when you are doing community participation (which is what I am doing), how do you measure that outcome – when some people might just want to go down to the local coffee shop and get a cup of coffee. Some people might want to join a club, some people might want to get some work, it is so varied. But my boss, and I have to say to my boss quite a lot, what is the outcome here?*
>
> *…because it isn't wasted time. You are actually valued in that community participation and it is not something we talk about enough, because the "bean counters" out there cannot measure the outcome. And that's fair enough, because we need to justify our time, we need to justify our wages, and we need to get some sort of measurement of what our outcomes are. But we also need to measure the fact that sitting talking and doing things and working alongside people in the community in whatever form they want to be is a bloody good outcome.*
>
> *… also the point of getting someone in work is getting through the Winz report. Some offices are absolutely brilliant. Some offices it is an impediment to work. You have just got to use the drip technique that will slowly wear away and get through. Just a drip, drip, drip, drip and that's what is working.*

7. Over-emphasis on community vs segregated services?

Some staff questioned the degree to which some service users have been “spoon-fed” ideas about community vs segregation, and suggested that these are not necessarily always their own views or values.

> *But sometimes that’s actually the culture I have been in, like in terms of staff in organisations have actually given those definitions of things like community to people, so that’s a big influence. Able bodied people haven’t been in that environment to get told that stuff, but it is being put upon people in a workshop, or whatever it is, it is being spoon fed to them so that’s how they perceive it.*
>
> *It is other people’s perceptions. And people go off on their own tangents, and I know the member that comes to us, often it is not their point of view, and you know it is not, you know that someone has been at them. Often it is not a very pro-active encouragement to get out there or to see things they might do, but the person using the power, and they can always sense very easily the people who can help them and a lot of people abuse that power.*
>
> *I reckon that, I just think that it is empathy. It is getting inside the person’s shoes and looking at it from their perspective. It is not simple, and guys don’t use empathy, and I think who are we to say “you should be doing this or no, you are not doing that.” It is to give them the tools… support people and work with them and go with them. It may end up being something they thought that they could, and at the end think, “no, I can’t actually do this.” But it has to be their reality that they can’t do it, it is not for me to say no, you can’t do this.*
>
> *There is a place for segregated activities, there is a place for people to be integrated… when I am meeting people, I always ask them questions – where do you see yourself? What are your interests? Who do you want to be mixing with?*
>
> *I mean as a disabled person, I don’t get it why the government has got such a … bee in its bonnet about the segregated thing. I mean, sometimes I choose to mix with people with disabilities and sometimes I don’t, and I mean, that’s the same for every culture. I just don’t get it, why make such a big issue about it… the crux is that they have the choice, it is themselves that is taking the control and making that choice.*

Staff took note of the difficult times and unpleasant experiences of disabled people in community settings and the hard work involved in being there. They understood why some people preferred to be in a setting with other disabled people, at least for some of the time; where people can be themselves and experience a sense of community.

8. Serious limitations in available services.

Staff expressed significant concerns about the situation of young people leaving school, with no plans, sitting at home with nothing to do, and long waiting lists for any services to lead to employment or other options.

> *… I would say the hardest area, the part I don't like about my job is where I get a call from a parent of a school leaver, because I come out more disillusioned than when I go in, because they have tried all the options that I would have been going to try, and they have got nothing. And I put referrals through to other agencies – I just get them back – sorry – won't even take them on a waiting list. So it is like – I don't want to go and visit them because I can't offer them anything.*
>
> *… somebody I have just been to visit, that the young school leaver is just at home all day, every day, and that's their life. That's Mum going to work and leaving them at home all day because they left school at the end of last year.*
>
> *…I have got others that have a plan but haven't really been accepted, or haven't found anywhere because there is the long waiting lists.*
>
> *… you can be waiting six months to a year…*

Another area of concern was the limits placed on accessing wheelchairs and other technology, unless people were in full time study or work. Such restrictions can seriously impede a disabled person's ability to participate in the community.

> *I have got a client exactly like that. Because she can walk around her house holding on to the furniture, she is not eligible for a wheelchair. Therefore she can't go out to the community because she lives in a rural area where trucks go by and no footpaths, and the wind of them blows her over because she hasn't got good balance. So she can't go out.*
>
> *… it's almost like saying to the disabled person, if you are not studying and you are not working, you are of no value.*

Another barrier was the lack of access to support at weekends or on public holidays – further restricting community participation.

> *… the client I went to visit couldn't go to her own brother's 21st because she can't get a taxi at that time on a Friday night, because all the wheelchair taxis are doing the dialysis run, or they have worked long enough hours because they do the school run, and then they don't want to work any more hours.*
>
> *The issue of taxis is a real issue, it is huge! To get a taxi – it impacts on people's lives.*

> *The taxi firm dictates to people who use wheelchairs… how often they can go outside the front door.*
>
> *My sister-in-law works for an agency and she gets told that she is not allowed to go and visit the client on public holidays. And if she chooses to, she has to write down that she hasn't gone on a public holiday…*

9. Dangers of isolation.

Staff were concerned about the isolation of some disabled people and how service trends could increase this, rather than reduce it. For example, moving into an independent living situation can mean that the person can no longer access day services. People can become isolated and invisible in their homes. Closing vocational centres could result in people no longer being able to be with friends.

> *… for many people, because of our workloads we are not able to spend that time that each individual needs, and so how do we ensure people aren't isolated. Because unless they are in contact with people they are out of so many different loops.*
>
> *… once you are isolated, you are also invisible.*

Another problem was the lack of choice in housing; disabled people may have to accept what they are offered, somewhere away from their community contacts and networks.

> *… one of the issues for them was when they wanted to live independently, they took the first house that was offered because it was so hard to find a house. But then often the house wasn't where they wanted it to be, and then they didn't have a chance to change it…*
>
> *… I went to Housing New Zealand, and the lady behind the counter said, "But I have shown them three houses." But the fact that they are not in the suburbs they want didn't seem to be important to the lady in Housing New Zealand.*

Isolation from other disabled people can also prevent the development of "disability pride", when disability is part of membership in a community, not a stigma.

> *… when is the last time we have been proud of our disability you see, and I raised this the other day, but it is something that I have been thinking quite a lot about and that's really interesting to me because it is about role models as much as anything but it is also very natural. You will find that someone who likes dogs will hang out with a dog club.*

10. The variation among service users.

Staff noted significant differences between older and younger service users, and between those who had experienced segregated versus inclusive education.

> *We and most of the older people find it a great difference between the younger members and the older members. The younger members, it is not a problem, we suggest getting out there and they are out there; the older members – it is a bit more difficult to break through the fence and it has taken a long, long time. It has taken tears, it has taken everything for her to gain the confidence and think ah, maybe I can, if someone will come with me to do that.*
>
> *I have people on my books who are telling us they are really keen to work. When it comes to crunch time, for one reason or another, they back out. And I have come to a conclusion all by myself, is I have two types of clients on my books. There is the slightly older client who is over aged 25 who has come through the older system which created the model of dependency. Then there is the newer client who has been through the mainstream process of school and what have you, they are keen to work.*

The education system was seen as often failing in its role – young disabled people were not taught how to think, and emerged with no plans or expectations for their adult lives, and little self-confidence.

> *What I perceive to be the lack of expectation and education around people with disabilities. If we were in, for want of a better word, a special unit, and your expectations around what you would do when you leave school are quite separate in me, who was mainstreamed and just assumed (maybe naively), but all my friends were getting jobs, and I totally assumed that's what would happen to me. But the people that didn't have that experience, when they leave the education system, the expectations on what happens now, or the fact that they leave the education system with no formal qualification says a lot about our education system at the moment.*

11. Government policies.

Some staff felt that the New Zealand Disability Strategy failed to acknowledge the effects of severe impairment on some people's lives. This failure can then translate into inadequate levels of support and a lack of flexibility in meeting individuals' needs.

The NASC process was also seen by some as overly invasive, often unrealistic, and failing to lead to appropriate supports and services for some people.

> *I think the whole system is naff, it's totally ridiculous! A total stranger rocks up and starts asking you complex questions about all areas of your life, which can go on for three or four hours.*
>
> *… I just found it so degrading. I can speak up for myself, I am assertive, here's this total stranger asking me about… and I am thinking… what's it got to do with them anyway.*

12. Transport and accessibility

The limitations of transport were seen as posing enormous barriers to community participation for many people. The problems included cost and limited hours of availability of wheelchair taxis. There are also still major problems in access to the physical environment, requiring major changes in attitude and accountability, (in terms of meeting legislated standards).

> *… had to work really hard to find an accessible venue in (city) … it was a really hard job to find, because what people said were accessible – when they were sighted, they weren't for power chairs.*

13. Advocacy

The vital role of advocacy was noted by staff. While empowerment and self-advocacy were promoted, staff noted that service users often did not know what they didn't know; lacked self-confidence; sometimes suffered depression; often don't complain because they don't want to cause trouble, or were afraid of losing services.

> *We inform them – you know these are your rights; there is a complaints procedure; there is a Health and Disability Advocate. "no, no, I don't want to cause trouble, because these are the people who are providing the funding".*
>
> *…"And they might take away what I have already got," and I would have heard that even twice in the last week.*
>
> *… often, if you have been institutionalised, it is ingrained in you that you don't complain anyway, because you have to be grateful for what you have got.*
>
> *… we are trying to empower our client base to be able to do that for themselves and yet it so often doesn't work.*

14. Staff qualities needed

Staff reflected on what disabled people had said and what this meant for their own practice. They saw the following skills and qualities as necessary.

- empathy, looking at things from the person's perspective;

- giving people the tools to do things for themselves;
- not saying "No" but letting people try and find out what they can and cannot do;
- trust;
- respect;
- honesty;
- rapport;
- taking time to get to know people, and supporting them the way they want to go;
- treating disabled people as people – with the same aspirations and expectations;

> *I think given the choice, one I think would be that they are forming new relationships, not with paid people or carers or people they meet in the community setting, whatever that is, that there are in relation to other people, to new people.*

- not "playing God";
- following through on plans;
- giving up power and empowering service users through relationships with them, to where they say " I don't think I need you any more".

> *… a client of mine who I have been seeing every week since I started work at the beginning of the year, said to me yesterday and it was a sad moment but it was a happy moment, was "I don't think I need you any more," and I said "great, but you know how to contact me don't you," and he said, "yes." And the level of confidence from when I started working with this person to now three months down the track is absolutely brilliant. So they have taken the power back and have become stand alone and their employment and everything else – they have got a very supportive employer I might add.*

15. Other additional issues

- the need to educate the community – employers, schools, the wider community;
- the danger of work experience becoming long term and exploitative;
- should "lifestyle plans" be part of services? This is not part of an ordinary life for other people;
- the low value placed on support staff in society – low pay and status;

> *There is a real shortage of carers, they are so low paid.*
>
> *Because the carers are not valued, they are not seeing it as a career path. It's a role you usually only (consider) when you have little other option.*

> *There is a huge shortage of carers, especially male carers.*

- young people staying at school so they can access aids (wheelchairs) and therapy;

  > *And that's another reason why they stay at school. Because while they are at school they can access wheelchairs quickly, and the therapy, and when you leave school that totally stops.*
  >
  > *… while you are in education you can still access easily… speech therapy, physio…*

16. Thoughts on community and community participation

At one Focus Group a staff member noted that while service users often defined "community" in terms of what it is **not**, no staff defined it in that way. Maybe this was because staff were "already there". Also, for **staff**, a disability service is a **workplace** i.e. a community setting?

In the words of staff, community is:

> *a sense of belonging*
>
> *being treated as an equal*
>
> *individually determined*
>
> *(it's) about saying, I am ordinary; I have a disability but I am still an ordinary person that wants to do ordinary things in ordinary places… I need your support to feel ordinary. To me, it is not denying the disability, it is just saying that disability is ordinary, there is nothing special about that.*

Summary

Seventeen CCS staff discussed the Draft Report in two focus groups. Staff feedback included both a staff perspective and, for some staff, a personal perspective as a person with a disability.

In general, staff found the ideas and experiences from service users were familiar to them. They confirmed the importance of employment, and, while not wanting to set people up to fail, staff also affirmed the right of people to have another chance. They noted that some people chose other avenues for participation, instead of employment.

Staff agreed that there is a danger of stereotyping and low expectations of people with disabilities, by parents and/or staff.

Support for inclusion in the community was noted as sometimes requiring long term support and considerable coordination.

Staff challenged themselves about the degree of real choices for CCS service users. Some felt that there was a danger that people could be “pushed into” community participation, when this was not their choice. The value of spending time with other people with disabilities was also confirmed.

Staff expressed frustration with what they saw as an overemphasis on “quantitative outcomes”, when process and other ways of spending time were seen as critically important to people with disabilities.

Some staff felt that some service users may have been “spoon-fed” ideas about community vs segregation. They felt that people sometimes repeated the philosophy, but, in actuality, had often had very negative experiences in community settings.

Staff were very concerned about current gaps and limitations in available services, particularly for young people leaving school.

Other issues raised were the limits on availability of wheelchairs and other technology, and the lack of access to support at weekends and holidays.

The danger of increasing isolation as a result of current service trends was raised. Lack of choice in housing would also increase isolation.

Some staff felt there were differences between older and younger service users, due to differences in their educational experiences.

There was some critical comment on current government strategies, and the needs assessment and service coordination process.

The limitations of transport were seen as posing enormous barriers to community participation.

Staff noted the vital role of advocacy in their work. Staff reflected on what the views of people with disabilities implied for their own skills and qualities as support staff.

Other issues were discussed, including: educating the community; lifestyle plans; the low value placed on support staff; staying on at school until age 21.

Finally, staff noted the difference in the way service users defined community in terms of “what it is **not**”, whereas no staff defined it this way.

CHAPTER 8

WHAT HELPS AND HINDERS COMMUNITY PARTICIPATION

Introduction: Pulling it all together

Focussing on how people experience community showed how attachment to place develops from human relationships. Families and friends can be seen as sites of community participation in their own right. If there was a common theme to what we were told, it was that bricks and mortar were not important. It was not whether the setting was deemed to be segregated or not that really mattered – it was the **way that people experienced places that affected whether they felt a sense of inclusion**.

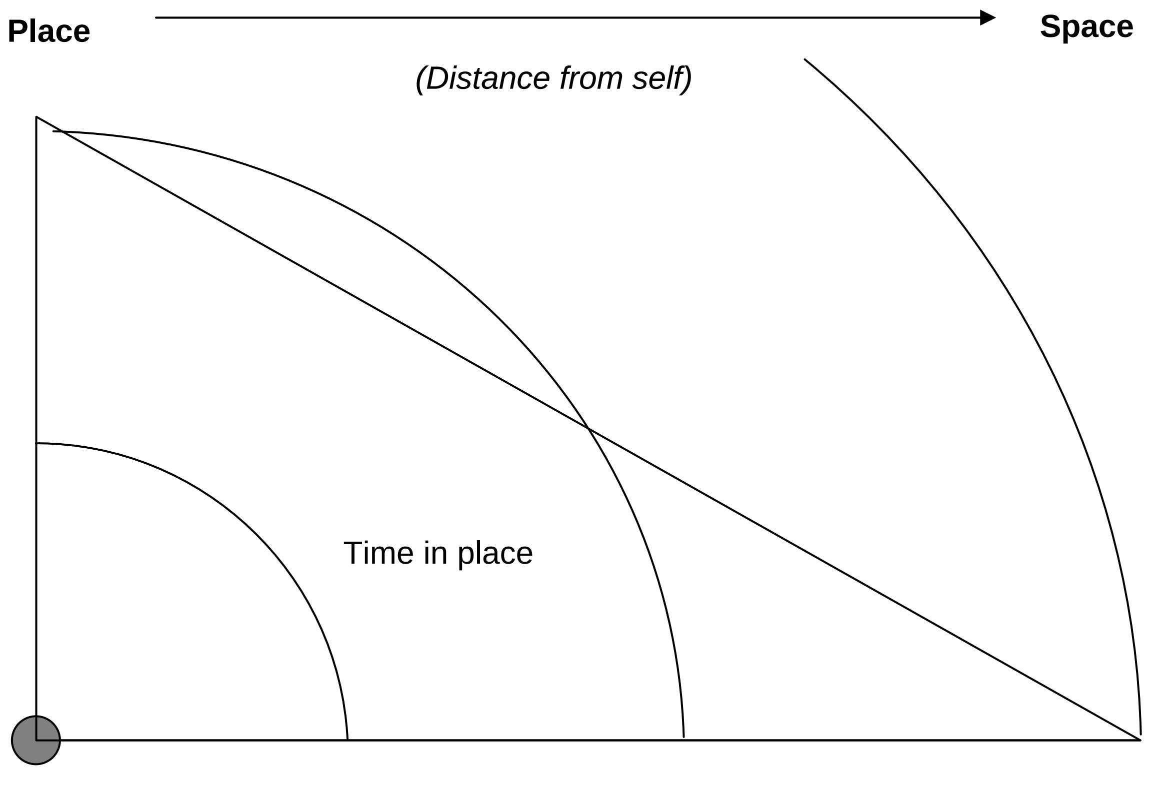
Relationships to people and to place were inextricably interlaced. **All of the characteristics of place that participants said led to a feeling of community participation were yardsticks that measured the quality of their interpersonal relationships when there.** The ability to choose activity; to experience an affirming social identity; to be engaged in relationships of reciprocity where one had a valued role; to feel safe and comfortable; and, to experience a sense of membership and belonging to a group that expected and reinforced ones right to participate; – all describe attributes of human exchange that may or may not occur within the culture of particular community places.

Over time, therefore, attachments to people become the cornerstone of attachments to place. So intertwined are people and places that they share a common vocabulary of distance. When valued and accessible, both were said to be **close.** Conversely, people and places beyond easy grasp or understanding were described as **“out there’**” and **“distant.”** The vocabulary of attachment and interpersonal association changes in a predictable way too. **We embrace our closest relationships within the inclusive pronoun “us**.” Radiating out from an individual, slightly less close relationships are understood sequentially as **“we”** and “**they”** and ultimately on to **“them”** and **“others”** for people at greatest interpersonal distance.

The language we use illustrates the discriminations we make between the people that populate our lives and the places we meet them in (Figure 13). How we use particular descriptors depends on the context. The boundaries are fluid because they are relational. From a “big picture” perspective all people and places can be considered to be part of an individual’s community. All people share a common humanity. We have in common attributes, aspirations and threats unique to humankind. At finer levels of discrimination, however, we find a myriad of ways to be different from each other and an equal number of ways to indicate and celebrate our diversity.

We make the discriminations we do, because people and places meet different needs, depending on how accessible they feel to us. The changes we make in the way that we describe people and places is also related to differences in their function (Figure 13).

Figure13: The changing value of space



	“In There”	**Community of choice**	**“Out there”**
Spatial Attributes	• Familiar • Predictable • Exercise control • Free from scrutiny • Express personality • Personal and communication needs met	• Chosen activity • Social Identity • Reciprocity and valued role • Psychological safety and comfort • Participatory expectations • Membership and belonging	• Unpredictable • Acceptance • Recognition • New relationships • New places • New identities • Political space
Personal Pronouns	• I • Us • Our	• We • They	• Them • Others • Non-disabled
Spatial Descriptors	• Here	• There • Close	• Out there • Distant

The relationship between time spent in places and attachment to them tends to be self- reinforcing.

When we asked what "community" meant, however, people first emphasised the places where they spent the **least amount of time**. A simple dichotomy was drawn between being "stuck in" largely segregated settings and "out there," in places and with people they believed were less accessible to them. It is tempting to conclude that the differences apparent to people as they compared their life-spaces to the roles and activities engaged in by their able bodied peers might have contributed to the perceived importance of more distant community spaces. Certainly, these places were valued for different reasons. Being "out there" seemed to be about meeting people's need for new experiences. It was for forging new identities through new relationships. Recognition and acceptance was what people sought and the community was seen by some as a political space to be publicly colonised**. In the language of social distance, most people wanted to be "them," and not "us."**

As we began to explore further though, there did seem to be people and places occupying the no-man's-land between the polarities of place and space. Important institutions appeared able to straddle the gap. Employment, some training courses, church, people's families and some recreational activities were highly valued because they incorporated elements of each (Figure 5). When we examined employment and the family as contexts for participation, a different set of attributes emerged as being important. These sites tended to be participants' **"communities of choice."** Here they looked to experience an affirming social identity. Relationships were bound by systems of reciprocity and mutual support. In these communities, people experienced the psychological comfort, not only of being known, but also of being understood as a member. Disability was usually incidental to membership. Within these communities people were valued for the skills and attributes they brought, and an expectation existed within these contexts, that they participate in advancing the welfare of the community. These were the communities about which people sought to describe their belonging through the various symbols of membership. We saw it in the pride people took in their work uniforms, the medals and photos that hung from bedroom walls, in the naming of pets and in the way they introduced themselves to us (Figure 13).

Marie's Story

To find a way to tell her story, Marie began by trying to situate the different sorts of activities she participated in, along her own "in there - out there" continuum (Figure 14). The way Marie described experiencing each of her different forms of community participation did seem to be strongly influenced by how accessible they felt to her.

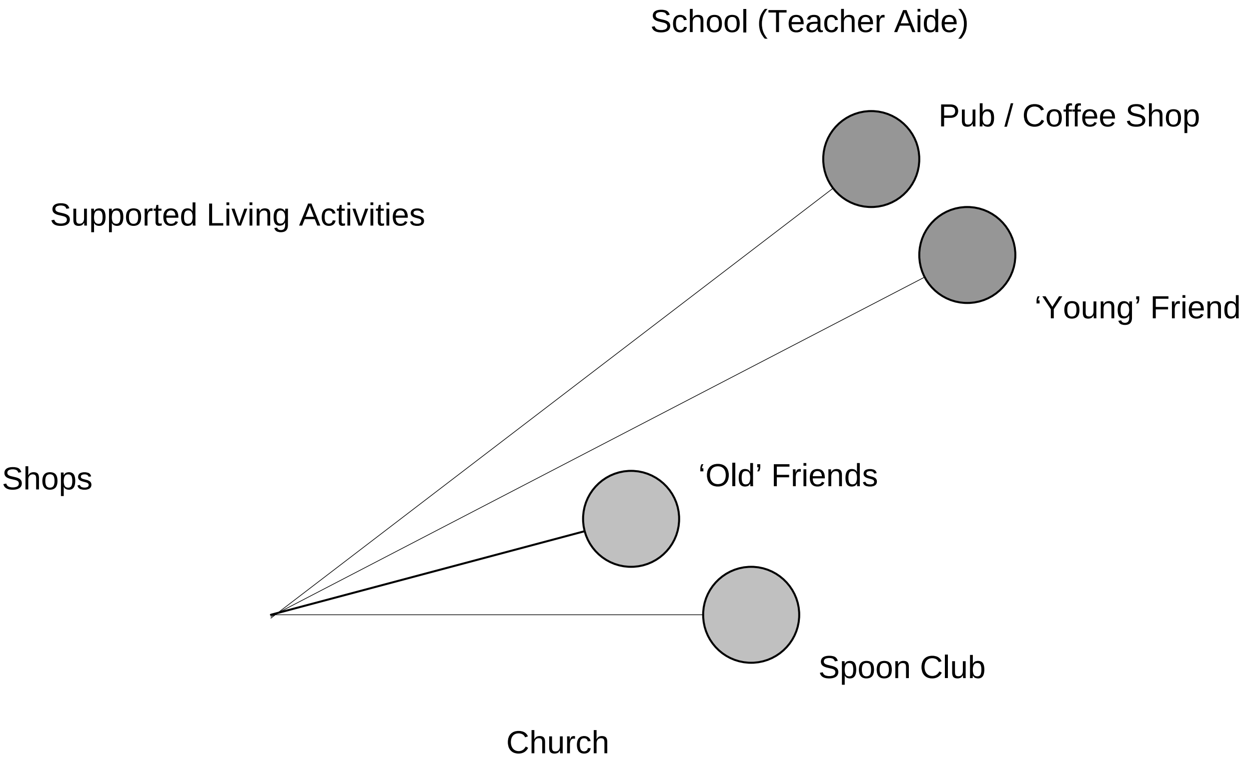
Marie said that her Grandparents' home was currently the centre of her community. The shops that she visited regularly and the church her family attended each Sunday were the places that she said were most accessible to her. These were the places where she had spent the most time. They were familiar and predictable and Marie felt safe and relaxed when there. As a consequence of the time Marie had spent in these communities, she had acquired an identity that was pretty much uniformly recognized by other community members. Having participated in events that shaped the collective identity of her family and church communities, she had become incorporated in their social history. It was in these places that Marie felt almost completely liberated from the scrutiny and judgement she believed she exposed herself to in unfamiliar community settings.

Marie's inclusion of the shops in this closer zone is interesting. It seems inconsistent with the idea that "proximity," and greater time in place tends to be associated with the accumulation of sentiment and attachment. When Marie talked about visiting the Warehouse and Farmers however, it was the psychological safety of her anonymity and her familiarity with the environment and its customs that led her to point her scooter in their direction. Conversely, Marie expressed great love and affection for her grandparents. In spite of her attachment, however, one of the characteristics that Marie said all of these contexts shared was that they didn't *"say anything about me,"* and that the more ritualistic character of her engagement meant that *"I don't really disclose anything of my true self."*

What Marie appeared to be saying was that, in spite of these places meeting a need for psychological safety and membership, her lack of control over culture within these contexts meant that it was difficult for her to fashion new identities . Marie wanted the opportunity to author a new history. She begins and ends her individual story by saying what presently excited her was the feeling that she stood at the threshold of a new life (See Chapter 6: Marie Meikle). Marie wanted to discover and say new things about herself and to do that, she needed the freedom and unpredictability of new people and places. She was desperate to *"get out there"* to "*prove"* to herself and to others that she could re-create herself. She was equally worried, however, about her ability to surmount the enormous barrier that a lack of self confidence and her social experience represented.

Marie said three activities symbolized her recent determination to get out there. Her work as a teacher's aide was the first thing Marie volunteered as being good about her life. She valued it so highly partly because it met the desire she had to give something back to her community.

Figure 14: Marie's view of her community



"In There"

- *Not in the community*
- *My things-things I do on my own*
- *Places I don't mix with the community*
- *Rituals*
- *Things I don't think say anything about me*
- *I don't really disclose anything of my true self*

Community of choice

- *Part of the community*
- *Chosen activities*
- *People who know me and care about me*
- *Refuges were I am accepted*
- *Hidden communities for fear of judgement*
- *I am able to be myself*

"Out there"

- *Being in the community*
- *Roles and identities I would choose for myself*
- *Places I prove I can do things*
- *Giving back to the community what I missed out on*
- *Places where what I say matters*
- *People are interested in me*
- *Sometimes frightening places where I worry about being judged*

But her ability to add value to the life of the young boy she had a special empathy for, had a wider symbolic value. As Marie passed through the Waihopai School gate, she went to a role she had chosen for herself. Part of its attraction was that what she felt she left outside was an expectation that this sort of participation would be unattainable. She felt it helped her to recast herself. Marie's "young friends" were similar in many respects. Both were new roles. Marie said in her interview that she had never had a group of friends her own age and spoke about how this had stopped her from trying new things and learning the social etiquette of her generation. Attempting to form relationships with her peers was similarly both exciting and hazardous. Part of what made it scary was that Marie had to step beyond the shadow of anonymity and declare these forms of participation as personally meaningful. The pub and the coffee shop remained as places Marie felt she still had to conquer. Places where you were exposed to the possibility of new relationships represented the "inside" of a community Marie said she only knew the "outside" of. She had been to the pub once, with a friend for company and courage, but they were still foreign places to Marie.

There were communities that Marie had been a member of for much longer. She had begun collecting spoons when she was still young and had belonged to a spoon collecting club for a number of years. Marie was one of a dedicated, but dwindling group of women who meet regularly to swop their spoons and life stories. She had also stayed in touch with another group of women she described as her "old" friends. She had originally met them at camp when she was recovering from her cancer operation and still visited them over a decade later. Some of the women had children of their own and Marie described growing up alongside them within an extended field of care. These were the last communities Marie spoke about. It was as if they had become covertly assimilated into her own sense of self. These were the places that Marie would write were *"special (places) to me…Safe places from the world of judgement and isolation,"* They were *"half way houses between being in the private places of your life and exposed and fully out there."* What Marie said made them special was that they were people who accepted and loved her for who she was. Her confidence in those relationships gave her the ability to be a little bit different too, safe in the knowledge that she was not going to be quickly judged.

No stories were the same. Adam, Marie, Janet and Michael had lived very different lives. Their contributions to this report are but a small taste of the enormous diversity that is sometimes represented as the experience of people with disabilities. We found subtle differences in the activity patterns of each and every person we spoke to.

As different as the day to day lives of people were, however, they could be said to participate in different communities because **dissimilar personal histories had led them to read and interpret their community in divergent ways.** Nevertheless, there are some valuable conclusions we can draw about barriers to community participation, and what helps people to be part of, and experience "community".

Summary

The research has shown how the **experience** of community is more about people than places. Bricks and mortar, “segregation” or “integration” were not as important as how people were treated, wherever they were. Attachments to people grow into attachments to places. When asked about “the community”, however, people with disabilities talked initially about the places where they spent little time – “out there”. Being “out there” was seen as valuable because it offered opportunities for new experiences, and a valued social identity. People also talked about other “communities of choice” in which they experienced acceptance and affirmation. Even though everyone’s story was different, there are conclusions which can be drawn about what hinders and helps community participation.

Barriers to community participation

Personal barriers

The lack of friends.
One of the most universally expressed forms of marginalisation was from the limited social networks of people with disabilities. Almost everyone we talked to said they had few friends and lacked opportunities to make new ones. John, Mary and Robert all said they only had one other friend and Wendy had left a trail of phone numbers that no-one ever rang . It was worse for some. Louise’s support person had known her for three years. During the course of her interview she remarked that the visit Louise was about to make was the first time she had gone out to meet someone on a friendship basis in all those years.

The absence of friends meant a denial of the gifts of friendship. Many participants spent long hours doing little and attributed this to the pointlessness of doing things by yourself. Being with somebody changed the nature of activities. Despite loving country music Louise would not go to a concert because “(there was) no one to go with.” And Trevor didn’t want support – he just wanted someone to walk with.

Being with other people also seemed to mitigate the fears that people expressed about being in some community settings. Marie lamented the fact that she had never had a group of girl friends with which to brave new frontiers like the pub, or boyfriends, or to learn the etiquette of new cultures through collective (in)experience.

Few friends and limited contexts for meeting them also denied people intimacy and the prospect of relationships of great interpersonal depth. It frustrated the desire people had to “do value,” and left them feeling barely visible.

> *For them to know me, they would need to get me in to a situation where I can talk about my life. As I said, I can sing, I can weave, I can knit”*

Dislocated lives and support that failed to prioritise the quality of interpersonal relationships as a service outcome meant that there was a lack of integration to community participation. People had ‘islands” of friendship that seldom intersected. Few people had friends visit them. Friendship invariably meant a journey to other people’s places.

An important consequence of participants’ restricted friendship field was the lack of access they had to other networks and the possibility for expanding participation through them.

Lack of personal and social confidence

Marie’s lack of self esteem and the fear she had of judgement because she was visibly different could be generalised to a number of other people we spoke to. Marie’s story documents her attempt to recover confidence that had been undermined by incidents she found humiliating. Sensitivity to exposing oneself to similar situations made the community less accessible to her and to others.

Going there with someone people trusted made a difference. The faith Marie had in her support person gave her the confidence to try new things that were happening in the Supported Lifestyles Programme. Being with other people with disabilities who were sensitive to support needs also seemed to influence the range of activities people were engaged in.

A lack of confidence in the skills needed to negotiate novel or unpredictable situations could stop participation. Sometimes, knowing what to do in an environment was all that was required

Unwillingness to complain

Unwillingness of service users to speak out about service issues and not wanting to complain for fear of compromising support occasionally limited both the range and frequency of participation. Wendy had “learnt patience” as she waited for people to help her make things happen. Stuart spoke with some frustration about the lack of progress he was having with his request for personal assistance. The normal aspirations of non-disabled peers like employment, home ownership, finding friends, beginning relationships, contemplating parenthood or heralding the mid life crisis with a new and dramatic recreational pursuit usually found their way to the surface of people’s conversations, but appeared to be indefinitely postponed.

> *Mary: Maybe they would help me get a place where I can hopefully live…”*

> *Interviewer: What support do you need from CCS?*
> *Mary: I suppose someone else as well as me discussing what I would like to happen.*

The dreams and aspirations that seldom surfaced were those that were immediately achievable. It was as if people were reticent to take control of their support. During the process of consultation that took place prior to the design of this project, one of the members of the advisory group used the analogy of an umbilical cord to describe his support. They (his support workers) were his conduit to the community, but he needed to take care of them, because damaging the cord disrupted the flow of nutrients he received. One of the consequences of top down service delivery can be that support can be perceived as a gift, passed from a professional provider to a vulnerable recipient (Duffy, 1996). When support arrives as a gift, it becomes very difficult to complain about when it is late or not what the person really wanted.

Low expectations and the protectiveness of family

Marie said of her parents that *"They had me wrapped in cotton wool and I couldn't break free, I needed some space."* A number of other people also recounted stories of having to break free of familial protectiveness. Trevor found it amusing that he could go to the pub, but his sister had forbidden him from playing the pokies there. Mary recoiled at her brother's suggestion that she find an easy job. She interpreted it as her family "not thinking I can handle it out there," and asserted her right to make up her own mind up about it. Families appeared to exert a very powerful influence over people's agency or sense of personal control. Their expectations influenced both personal autonomy and personal expectations. Supporting families to reflect on their role may advance participation for some people with disabilities.

Marie also reminded us of her right to fail when she said that she would have found it more damaging to her confidence to have been denied the chance to do a training course, than to have discovered for herself that it was too physically demanding. In their focus group, staff said that people deserved the right to fail more than once. They expressed the view that services needed to give people more than one opportunity to succeed. They felt this was especially true in employment.

Service Barriers

Limited imagination.

Some people reported that their lifestyle was also limited by the imagination of supports and lack of belief in their potential. The need people had to "prove," themselves through activity was a recurring theme in interviews and focus groups. Adam's fierce independence was one of the few tools he has to deflect the prejudgements he described having to constantly battle. He named "ingenuity" as his primary barrier, both in terms of seeing past his chair and in supporting him to approximate the lifestyle he had had prior to his accident. Doubt about Janet’s ability to manage in a flat had seen her guided away from living independently. People with multiple disabilities were routinely steered towards community participation as the most appropriate form of engagement when **they** expressed the greatest desire to find employment.

People appeared to live fairly authorized lifestyles with forms of participation that appeared to be drawn from the staple diet of disability activities like 10-pin bowling, handicrafts, swimming and the ubiquitous boccia. Participants clearly enjoyed these forms of recreation, but equally appeared not to have been supported to stray far from the traditional menu of activities. Like most other participants, Trevor played boccia. He didn’t particularly like it but it was “something to do.” He liked meeting other people there and it gave him the only chance he had to get out of town on a trip. What he really wanted to do though was to fix cars, do up cribs, have someone walk to with, meet a girlfriend, have people visit him and to see Pilot’s Bay again.

Inadequate communication support

The people we spoke to who faced challenges in being understood tended to perceive communication difficulties as a deficit in other people’s understanding. Time and patience was essential for them to feel comfortable identifying their hopes and aspirations to others. It was also a prerequisite to them feeling as if they were known and understood. Sometimes busy staff were able to offer neither.

Adam ended his interview by discussing how the business of others limited his ability to express both who he was and what he hoped for himself. When the tape recorder was turned off the final time, his interviewer wheeled Adam back to the lounge where he sat silently to watch a re-run of James Bond. After completing the roster of morning activities Adam’s staff were taking a break outside in the sun sharing the highs and lows of their week over a cuppa.

Part of Adam’s difficulty was that he had a fairly primitive form of communication to work with. Staff who knew him well could quickly decipher his shorthand and the subtle differences in Adam’s expressions. However, they could do little to speed the progress of Adam’s finger across his alphabet board and he needed someone present to make his thoughts transparent. At the other extreme, Louise had a fairly fancy delta-talker. For her, technology was a double edged sword. Her talker permitted Louise to have information stored that she thought it important to communicate, but her spontaneous communication was limited to the buttons on the pad. Neither Louise nor her immediate support staff had any idea how to re-programme the machine.

The world of communication was even smaller for one person who participated in a focus group. His cerebral palsy had left him with a very small repertoire of controllable movement. At one point in his life, a language therapist had taken the time to map the range of movement he had in his hands and within those parameters, they had devised a sign alphabet. There were, however, only two other people in the entire universe able to speak the same language, none of whom he met in the course of an ordinary day.

In this day of technology explosion, it is appalling that people with disabilities are denied access to individualised communication technology.

The use of time

One of the most disturbing findings was the pervasiveness of boredom. Most of the people we spoke to described spending long hours doing nothing. Mary had eight hours of support which she divided between three vocational day centres. She said she spent the rest of her time watching television and playing card games on the computer when she got really bored! Trevor walked to break up his day and Wendy hung out for her Polytech days to come around.

People worried about the effect that these unstimulating stretches of time were having on their wellbeing. They made Wendy cross.

> *"It's hard, very frustrating. I get sick of staring at four walls, but hey, doesn't everyone – so it's just a matter of keeping my cool."*

John told us that isolation had resulted in an apathy or depression that he had found difficult to escape from. In words that echoed Wendy's, John suggested that his experience could be generalised to other people with disabilities.

> *… if you are just sitting down on the benefit staring at the four walls and you don't want to get out, and you don't want to do anything with your life, it can be a terrible trap. Especially with disabilities, I find a lot of people are like that, you don't want to be caught in traps like that.*

In the absence of other forms of support, participants saw some of the responsibility lay in their lack of support hours or staff time.

> *It's mainly staff, because there is not enough staff and three hours is not enough for me.*

Limited informal support and staff availability did not only significantly influence people's ability to get out and about, limited access to staff also made it difficult for people to access the service they wanted. John was looking for extra job training. When asked whether he was using *"Accomplish"* to help his search John replied that:

> *I put my name down, but [they] have been quite busy lately. [They] did say that they know me, that [they] recognise me and all that sort of thing, but when there is 12 other clients we haven't sat down yet……that's the next couple of weeks I think when they will be doing that."*

Inflexible support was also limited in its usefulness because set hours failed to recognise that it was often in the small and unanticipated moments that people most needed support. It also failed to acknowledge or harness the spontaneity of life. Opportunities to participate came unexpectedly and could not be rostered.

The quality of support time.

It was not just the amount of time, but what happened in that time that people thought was critical. Influential American disability theorist John O'Brien talks about the sorts of relationships that lead to good support being constructed as "wasted time." Time spent hanging out talking about the seemingly unimportant stuff actually makes people who they are. Busy staff, institutional practice and programmes that see being out in the community as a service outcome can all eat into people's special time by being deemed to be "wasted" or "unfunded" time.

The intimacy of interpersonal relationships with family and friends happened in the space between activities as much as it did by doing things together. This appeared to be the support that people valued most highly and the majority of participants spoke of trying to humanise their support relationships this way. Louise gatecrashed offices to achieve it, and her support person spoke directly about how these moments had added layers of trust and mutual understanding to their relationship.

> *Support person: Sometimes it's an interruption to our work, but it is really fun…..she will pop in and she will say something and often it is a joke and makes us laugh or we are joking about not getting what you are saying so we make a joke and we all laugh and other times it is really important stuff that we are just doing it all in passing. That's - I kind of see - that's how this sort of relationship is built…. I really actually enjoy our conversations because sometimes things are getting a bit rough and you will come in for a joke…….*
> *sometimes stuff gets really hard going for you, and you just need someone to let it out to, and you can just come in our office and let it out and that just makes you feel a bit better as well, I don't know, that's my assumption.*

Louise, who was submerged in disability services, said that her vocational centre was the one place that she was able to have this sort of relationship. Other participants found it equally difficult to find people that had the sort of time or inclination that let them sit down and talk about their lives. Wendy identified it as absent from all the forms of participation she engaged in, and of her support Mary commented:

> *"Well, I wish they had more time to sit down and say, hey, let's go somewhere."*

A perceived lack of transparency

Another common criticism from the people we spoke to was of a lack of transparency about what was or was not happening for them. Many seemed unsure whose role it was to pursue or unearth opportunities, and in the vaccum of responsibility, often little happened. John was unsure when he would be contacted about training opportunities, Stuart waited for news about his personal care and Manu assumed that someone from CCS would let him know what options were available to him when his computing classes closed down. In a similar vein, Mary didn't know what had happened after she had expressed a desire to work and Trevor, who had taken the initiative and found a cleaning job he liked in the newspaper, said he had no idea when he might hear more about it. Perhaps a year, he thought.

Stuart believed that part of the reason for this lay in the fragmentation of services. He reported that things had got worse of late, for him. Previously Stuart had worked with one person he described as knowing him so well that the way she was able to anticipate his interests or support needs led him to suspect she had ESP. Now he said he *"didn't know who to go to or who to ask."* Staff also reported that it was difficult for them to coordinate the range of formal and informal supports that people often required in order to participate in community activities.

There was also a broader lack of clarity about the respective roles of service user and provider. Professional ideology emphasised autonomy and self determination, implying that people were at liberty to shape supports to meet their individual lifestyle aspirations. Professional support culture, however, sometimes communicated a retention of professional power and control, with service users unable to exercise any leverage over the delivery of support. The danger was that each could easily form a view that community participation was primarily the responsibility of the other partner in the relationship.

Problems with Individualized Planning

Most of the people we spoke to lacked any sense of ownership over any formal planning process. In spite of the investment made by staff, almost all of the people we spoke to were either unaware of a system of individualized planning or found them of limited use. Marie and Mary were typical of many who were unaware of their service plan. For some, a failure to deliver tangible progress toward the things they really valued had undermined their faith in the process. One person in a focus group described them as "sandcastles which took little to knock over." She said it was nearly time for her annual review and suggested(by saying that she needed to get it up to inspection standard), that she saw her plan as a service tool rather than a blueprint for her to guide her support. For others like Trevor, it was clear that either his real aspirations for participation had somehow missed his plan or that if they had, had failed to significantly influence the delivery of his support.

> *Interviewer: Does anyone sit down and talk with you about the sorts of things that you might like to do?*
> *Trevor: No.*
> *Interviewer: What about fixing cars. You said that was something you would like to do. Does anyone help you plan……?*
> *Trevor: No.*
> *Interviewer: Where I used to work we had to sit down with people and help them write a plan so that I had to talk to them about what they wanted to do with their lives. Have you used anything like that?*
> *Trevor: No. No…I would like to go to Aussie though. I would like to go for a holiday.*

Life appeared to happen outside of people's plans, especially life changing events. Cameron moved towns after an invitation from his Dad. John had discovered his vocation via a pamphlet picked up by his dad, and a stray conversation in a gym had led Stuart to his computing course. Opportunities were as fleeting as people's aspirations, and participants tended to find the planning process too cumbersome to capture either.

> *Stuart: I plan for myself.*
> *Interviewer: Tell me a bit more about that. You are quite adamant about that.*
> *Stuart: Yeah, those things that I plan are useful, but can fall to bits before (I) get there.*
> *Interviewer: So rather than spending a huge amount of time planning you would just like to organise it and go and do it?*
> *Stuart: Yes.*

Adam was an exception, however. He appeared to have invested heavily in his plan. He believed it was one of the few ways he had to hold his support accountable to his dreams. Adam indicated that he felt vulnerable to the "deafness" of other people without it and said he reviewed his plan regularly in order to sustain its relevance.

It was not that people disliked the idea of planning. Even those who believed they were not engaged in any formal process thought it would be useful. Therefore, having the flexibility to support service users' systems of planning that were meaningful to them would seem to offer a real prospect of advancing truly individualized forms of community participation.

A number of people we spoke to said that their disability meant they typically had to plan more than other people to make things happen. Helping people to fashion systems of planning more responsive to their personal circumstances would therefore seem to make more sense. Furthermore, participants also said they wanted to solve their own problems, rather than have staff short circuit the process because they felt a responsibility to have answers. Service user ownership of the planning process might also have the effect of affirming their right to resolve their own problems

Collective vs Individual Participation

There appeared to be no clear consensus about whether people felt participation was made easier or more preferable when they went out with individual support or in a group. Some, like Kelly loved going out in groups. Louise, on the other hand, disliked it because she felt that given the difficulties she encountered communicating, too many others drowned out her voice. Many were sensitised to being publicly identified as one of a group of people with disabilities and felt it was easier to negotiate an identity in public if people were given the opportunity to meet them as individuals. Others disliked it because they felt it singled them out as being different. And yet it was often when they were with other people with disabilities that participants reported feeling most comfortable. Being with other people with disabilities also appeared to mitigate fears some had about being in public. People who named more friends with disabilities appeared to go out more to a wider range of community settings. People made a clear distinction, however, between the experience of being in the community doing things with people they chose to be with, and the experience of being there without being able to make that decision.

The availability of services

During one of their focus groups, staff expressed a concern that serious limitations existed in available support services, particularly for young people leaving school. They said that in some places long waiting lists for available services existed, leaving young men and women isolated at home with nothing to do.

Community Barriers

Discrimination in employment

In a report produced recently for the Equal Employment Opportunities Unit of the New Zealand Human Rights Commission, the authors concluded that people with disabilities represented “one of the most disadvantaged groups in the current New Zealand labour force,” (Mintom and True, 2004). In spite of public sector initiatives, the **unemployment rate for people with disabilities has in fact increased** by 19.5% between 1996/7 – 2001. In 2001 only 43.6% of all working age people with disabilities participated in the full or part time labour force compared to 69.8% of their non disabled peers.

The people we spoke to lived marginalised lives. Despite a universal aspiration to work**, no-one we spoke to appeared to be in paid employment for more than three hours a week.** To those that had part time work, it was a source of great pride. To those without, it was a source of deep regret. As she reflected on her life Janet thought that, at fifty, her chance at employment had now gone and lamented, *“Well I am really sorry I never had a good job.”* Younger participants were less philosophical. Mary summed up their attitudes best:

"I want to get a damn job!"

Given its importance to them, people experienced their separation from the world of employment as discriminatory. Consistent with a survey conducted by the State Services Commission in 2001, participants felt the public sector to be hostile to the efforts of disabled people to find employment. Of her chances to find the sort of work she wanted Mary remarked *"I don't know whether they would* ***accept*** *anyone with an impairment in a bank or something like that."*

People were concerned about finding employers who understood some of the less visible consequences of impairment like fatigue or difficulty concentrating for long periods. The inflexibility of the labour market to make accommodations for unconventional bodies, however, meant that people were typically denied access to any form of employment.

The benchmark set by the New Zealand Disability Strategy for a fully inclusive society is one that "highly values the lives of all citizens and enhances their right to full participation." Of all the people we spoke to, employment was the most highly regarded form of participation by people with severe or multiple disabilities. Paradoxically, theirs was the cohort most likely to be steered away from employment as an achievable outcome.

Limited Income

One of the consequences of a lack of access to employment was having to cope with limited material resources. In 2001, nearly half (48.9%) of all people with disabilities in New Zealand reported annual personal incomes of $15,000 or less (Statistics New Zealand, 2001). People with disabilities are doubly compromised by low incomes because coping with disability is often expensive.

Most people were forced to use taxis to access their community because of the absence of usable forms of public transport. People reported having to think carefully about how many times they could go out. The drain that this put on their financial resources simultaneously shrunk their life-space and limited the sorts of activities they were able to participate in.

John had allowed himself $30 - $50 dollars a week for transport. This was a significant amount of his weekly income, but his course placement was offsite, which meant he had to travel to and from work each day. John had no choice but to ask his work mates for assistance. Low incomes placed people like John in positions of dependence in ways that impinged upon their personal relationships. Mary, for example, said she was reticent about inviting her family and friends out because she didn't have the money to pay her way. Poverty also limited access to sometimes ordinary forms of participation which were made extraordinary by disability. Few people appeared to have travelled.

Stuart wryly observed that sometimes it was the expense of inclusive settings that preserved their exclusivity. When he was looking for a gym, stairs were an important consideration, second only to price. Money, he said was the problem because "*the gyms that tend to be more accessible tend to be more expensive."*

People not covered by ACC were seriously compromised. Stuart and Adam had been injured overseas and consequently were not covered by ACC. In addition to their ordinary expenses, Stuart and Adam had to meet their own accident related costs. For Adam it put an electric wheel chair or communication technology beyond his reach. Adam's ability to navigate his world and escape his own thoughts were therefore reliant on the willingness of others.

Community hostility

As people told their stories, most recounted incidents of public intolerance and taunting. Some, like Manu, were able to weather the stares and the comments because they either felt confident enough to stand up for themselves or able to accept it as part of the broader tapestry of human nature. To others however, the fear of judgement and of being made fun of made parts of their community inaccessible. A participant in one of the focus groups reflected, " ….now it's just personally within myself – I don't feel I am free to join in the community because people just make fun of me." Whether participants' fears were real or imagined was immaterial. Perceiving the community to be an unsafe place was sufficient in and of itself to influence their patterns of engagement.

People appeared to be especially sensitised to the younger, teenage cohort when in public and the experience of being different at school appeared to have been difficult for many. Marie described having to piece together confidence lost in school years and the need to get over a fear she subsequently had of forming relationships with age peers. Chris said the teasing he endured at school had made him "grow up fast," and contrasted the experience of being different at school in the 70s and 80s with a more recent discovery he had had about feeling a shared identity with other people with disabilities. An inclusive educational setting, it seemed, was not always experienced as an inclusive school culture.

Community antipathy was sometimes less overt. Trevor felt it when people made little attempt to understand him, and described avoiding those places for fear of becoming angry. Manu disliked the pressure he felt from shop assistants and taxi drivers who failed to appreciate that sometimes things took longer with a less cooperative body.

Lack of educational opportunities

A number of people said they wanted to continue with their education, but found it hard to find appropriate courses. Many felt that their schooling had left them unable to compete in the labour market and saw education and training as a way to enhance their attractiveness to employers. Their concerns were reflective of the broader disabled community. People with disabilities tend to be educationally disadvantaged (Mintrom & True, 2004). In 2001 less than half (48.6%) of the population of people with disabilities had attained school or post- school qualifications compared to 66.3% of able-bodied people. Tertiary Institutions were amongst the most receptive to people with disabilities. Disability Information Services on campus and access to communication technology and reader-writers were highly valued.

Those who did not see tertiary education as an option, said that there was very little in the way of opportunities for them to continue to learn, other than vocational or life-skill based training. It was not just the chance to learn that they missed. Educational settings were one of the contexts for participation that sometimes provided the attributes of place that people said gave them a real sense of inclusion. Many participants had formed friendships and gained a sense of belonging and camaraderie in educational settings.

People were wary, however, of stepping on to a treadmill of courses that never seemed to take them closer to employment.

The built environment

Informed by the Social Model of Disability, the New Zealand Disability Strategy understands "disability" to be *"the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.*" Interestingly, none of the Strategy's 15 Objectives deal explicitly with the accessibility of the environment to people with disabilities, and yet transport and the disabling characteristics of the built environment appear to have most easily captured the attention of the disabled community and statutory authorities alike.

The people we spoke to were no exception. Everybody described the frustration they experienced at being excluded from ordinary forms of participation as a consequence of having to live in an environment constructed for the able-bodied. Stairs and curbing, cobbles and doors and aisles in shops that were too small, had all prevented people participating freely in their community. But it was not just about getting in and out of places. Having to ask if people could reach items from shelves in the supermarket, needing to take a support person because it was impossible to reach the buttons in the casino, worrying if there would be an accessible toilet in the restaurant you had been invited to, and being unable to lift one's eyes to greet people in the street for fear of missing something that could up-end you – these also changed the experience of participation itself.

Whilst most people were satisfied with the accessibility of their own homes, they did say that it was often difficult to get into their friends' homes. People typically sustain their relationships by visiting. Family and friends seldom came to participants' homes. Given the significance of interpersonal relationships in facilitating community participation, supporting service users to resolve issues of access to the people they know and like may greatly improve their quality of life.

Transport

Like many people with disabilities, public land transport was the only autonomous means of transport available to the people interviewed. The lack of an accessible and available public transport system was a major impediment to their access to employment, training, recreational and all other community activities. High floors, difficult egress, narrow aisles, impossible gaps between the seats, unsettling gait, and insensitive drivers made buses a challenge few would contemplate. Both Trevor and Manu had fallen exiting from a bus and would no longer use them. People were therefore reliant on mobility taxis or support services to get them into the community. As discussed above, the cost of taxis seriously curtailed access and in most centres people had to book, or risk long waits if they were to go anywhere at all.

People with disabilities often find themselves in suburbs that had originally sprung up to house a newly mobile middle class. Cars meant town was within easy reach and suburbs were left bare of shops, pubs, theatres and other public facilities. Whereas people historically met, married and fought with people from their own geographic community, human relationships now take place over distance too. They tend to be drawn from communities of interest rather than of place and our neighbour is often a stranger to us.

For people who are less mobile, their resultant lack of proximity to community resources and to communities of interest limits the forms of participation available to them. It was not such a problem for those living in smaller towns like Milton, "Milton is refreshing compared to Dunedin……Dunedin was harder because it was bigger…..it's much easier to get around and the people are much friendlier." People in larger urban centres were most at risk from being isolated from people and amenities. Manu said of Auckland " you need a car which I find is a bit of a downer…. It's just because Auckland is such a big sprawled out sort of a place." The increasing separation of home from work and forms of recreation put great pressure on the ability people had to stay involved in activities.

Being close to sources of support also gave people a sense of psychological safety. Even though John almost never needed any help, he gained great comfort and confidence from knowing his parents were both five minutes away and a ready source of support. Trevor too liked the fact that his sister was within easy walking distance. When he went to indicate where she lived, he stretched his hand, out as if were possible to touch her. *"We have always been a close family, so I think that's what you need really."*

Policy and policy implementation barriers.

Quantifying outcomes

If there is a unifying theme to the stories people told, it is that participation and inclusion and all the other ideological cornerstones to service delivery only make sense in the context of actual experience. They are qualitative outcomes, at best poorly understood and at worst subverted by an emphasis on quantitative assessment. People **felt** a sense of belonging to communities and they **experienced** being valued by them. No valuable knowledge could come from counting where or when or how often people were in community settings. What was important was knowing whether they felt included or valued.

The people we spoke to told us they wanted the right to choose forms of community participation that were available to every other New Zealand citizen. Many people expressed outrage at their degree of marginalisation from fairly mainstream cultural expectations. **They all wanted to be out there!** But time and again, we saw people feel most included and most valued in settings that could be considered an example of the segregation of people with disabilities. People described feeling most peripheral and devalued in inclusive contexts and most alone in the pursuit of an imposed understanding of independence. People's experiences were as individual as their stories. Privileging their voices made it possible to hear how they experienced and interpreted their community and what they wanted to draw from it.

During that dialogue participants suggested that the imposed focus on measurable service outcomes muffled their voice and limited the flexibility service providers had to respond imaginatively to the things they **really wanted**.

The pressure to generate "community experiences," or to "staircase individuals towards employment," and to quantify them as hours beyond a service centre in the quarterly reporting template, impacted on the lives of participants in a variety of ways.

Many people spoke about **having** to go out, and of their pattern of weekly activities being determined by the service. Kelly's response was typical of many.

> *Kelly: Well basically like you go out, or if you don't do what you get told, you get told off basically, but no they basically want you out in the community.*
> *Interviewer: They want you out there? Who decides where you go to Kelly? How does that happen?*
> *Kelly: Well, we have got goals and books and stuff - so basically you've got to remember to ask what they are doing or…….?*

Most of the people who used the service centre regularly reported that their ability to determine the direction of their support was restricted to highly circumscribed moments of choice like which of a range of predetermined activities they would like to participate in, not what, when where and who they went out with.

Kelly's intimation (that her "goals and books and stuff," were really a service tool and not a way for her to direct her support) was echoed by others who, as we saw above, thought they needed upgrading to inspection standard, or like Trevor, who believed they were a poor approximation of their real aspirations.

All organizations will periodically incline towards meeting their own imperatives. Without the ability to influence support delivery, people with disabilities are exposed to the risk that their apprehensions, as well as aspirations may become submerged by professional ideas about what is in their best interest.

Marie described two incidents where she suggested that her quality of life had been affected by the pressure she felt to respond in ways consistent with the need for services to generate quantifiable outcomes. It is unclear whether she had led the process of finding a flat. However, her eloquent description of her limited mobility and social isolation meant that whereas she "*thought she had gained independence, when it all boiled down she had actually lost it."* This is a salutatory reminder of the danger of putting ideology ahead of lived experience. A little later in the interview, Marie spoke again about how her conventional way of responding had steered her towards a course that she had mixed feelings about enrolling in and the consequences of not feeling listened to.

> *"Well they wanted me to do the - we talked about getting me out doing something, and I went and did a Wider Horizons course and for my ability at the start I felt it was really downgrading, I knew (about) personal hygiene, I knew how to care for myself and keep myself clean and all that. I stayed there even though I really hated it. But I vowed and declared that I wasn't going to do - let them push me into doing something else like that."*

John too spoke about the pervasive view that the treadmill of courses was the best way to moderate the reality of lives left empty by unemployment or of other meaningful forms of participation.

Having people out in the community as the only appropriate outcome frustrated a sense of participation in the impact that it had on the activity patterns of service users. The pressure to get people out of centres mitigated against the kind of "purposeless" activity that Louise described as so important to her. What Louise valued was the honesty and intimacy she shared with staff and other people she saw as **members of her disabled community**. The imperative, however, was to push her away from personally meaningful relationships, towards people and places she knew less well.

People also said that planning took more time for people with disabilities, but that it was central to a sense of ownership of their lifestyle. In addition to being a skill, able to be generalised to other situations, the problem solving and anticipation that preceded an event could be more meaningful than the event itself. And yet this did not count as a form of participation.

The ways that people were deemed to have participated also inhibited genuine community formation. Pushing people to the gardens for some fresh air, or fleeting visits that looped through a cycle of civic amenities like the library and the museum, the art gallery and the mall only ever gave people a community presence. They had no opportunity to form relationships that might lead to the sorts of attachment to people that underscore genuine experiences of belonging and membership. People could not be clearer about the relationship with the wider community they most sought. What they wanted were friends.

And finally, keeping an eye on “placement” numbers seemed to underpin the drafting of service users into “Community Participation” or “Supported Employment” Contracts. This occurred despite the fact that the very same contracts emphasised the need for providers to ensure that “all participants will have equal opportunity to access the services according to their needs and irrespective of disability”, and that employment appeared to be most important to people with multiple disabilities.

Lack of choice with housing

Where people live has major implications for their ability to participate in their community. Topography, proximity to amenities, the physical characteristics of the neighbourhood, accessibility to family and friends, the culture of neighbouring and distance to public transport –all influence the accessibility of the community to people with disabilities. The lack of appropriate housing stock can seriously interfere with people’s ability to control all of these variables.

Some local authorities have also been slow to acknowledge that the low incomes, limited mobility and social isolation endured by many people with disabilities represents an equivalent need to other groups for whom they provide subsidised housing.

Failures in the Education System

The disparity in educational attainment discussed above was reflected in a pervasive view that school had left many of the people we spoke to, ill prepared for an adult life. Marie’s comment that that her teacher had cautioned her parents that she ought not to try so hard, and set her goals a little lower, was consistent with a general perception that people with disabilities were not expected and therefore challenged to reach equivalent educational standards

Writing about the way being identified as a person with a disability had affected her education, Simone Aspis has suggested that poor learning outcomes for people with disabilities happen because the way they are taught, following the imposition of the label, makes them a self fulfilling prophesy (Aspis, 1999). She cites Trent (1995) who said that labelling people who did not fit professional understandings of learning ability affected their lives:

> *"(T)his categories coherence derives primarily from the exclusionary treatment of its members and the services delivered to them on the basis of their categorization."*

People worried that their lack of academic achievement and subsequent inability to continue to learn, as well as an inability to build a record of employment, made it difficult for them to compete in the labour market. John's comments were typical of those expressed by others

> *John: Because of my disability I hadn't had a lot of training, I was always the second or first person to be told to move on.*
> *Interviewer: And the next time it becomes harder to get a job again does it?*
> *John: Well, it makes it worse because what is your c.v. looking like. It is saying - so that's why I try to do a course, every year I say to myself, well, you must study something else because haven't had much luck in this.*

Some of the people we spoke to also said their school had not played a major part in teaching them more general life skills. Parents appear to have been key people in supporting people to learn the skills required for independence in the community.

The need for extensive public education

One of the barriers that people continued to return to in their conversations with us was of the reticence of the general public to engage them. Many experienced public social distance as stigmatising and expressed frustration that closing the gap was contingent on attitudinal changes within the non-disabled community. These were changes that they could do little to influence. One person said of the public's apprehension to speak with him, that he *"just wished they would say hello*. *We don't bite!"* Stuart described the experience of being estranged from public conversation in the gym and making him feel like *"an outcast."*

People attributed public reticence to their lack of exposure to people with disabilities and fears they had about an inability to communicate or anticipate their needs. The people we spoke to were more than happy to assist other people to acquire the skills they felt they needed. Valuing the contribution of people with disabilities to advance their own affairs had led to one of the more creative service initiatives we observed. Service users in one centre were employed as Disability Awareness Educators to lift community appreciation of disability issues.

Disparaging social imagery does not help either. In an era seemingly obsessed with body image, oppressive cultural stereotypes like the helpless or heroic cripple can undermine self-esteem, entrench social prejudices and deny people with disabilities the complex and enriching reality of their multiple social identities (Gleeson, 1999).

Inclusive education may help to displace ignorance and increase the ability of a coming generation to see people beyond disabilities. In the interim, the State could do much to erode stereotypes and change the status of people with physical disabilities within the national community through public awareness campaigns similar to the Mental Health, “Like Minds, Like Mine.”

Support mismatch with community rhythms

The lack of access people had to support at night, during the weekends and on public holidays meant that it was more difficult to get out into the community at precisely those times when community members ordinarily met each other or were involved in recreation. People who were employed or engaged in voluntary work could not meet colleagues “out of hours” and it was impossible for people who required attendant support to participate in the normal rhythms of community life other than in a group or with the assistance of informal sources of supports. People did not appear to have much control about the configuration of their support from week to week.

Staff turnover

The low status of support work, its poor remuneration and a failure of many to feel as if the things they valued about their work were appreciated meant that staff turn over in support services is a perennial problem. For people with disabilities this can mean the perpetual loss of relationships they value and a continuing need to educate staff to their support needs and preferences. Furthermore, the sort of support that people wanted was grounded in a knowledge of themselves that had accumulated over time. Trust in staff also strongly influenced people’s inclination to try new activities and to meet new people.

Summary

From the research findings we can identify a number of barriers to community participation for people with disabilities. These barriers can be grouped into personal, service, community and policy barriers.

Personal barriers include:

- the lack of friends;
- a lack of personal and social confidence;
- unwillingness to complain;
- low expectations and the protectiveness of family.

Service barriers include:

- limited imagination;
- inadequate communication support;
- the use of time;

- the quality of support time;
- a perceived lack of transparency;
- problems with individualized planning;
- collective vs individual participation;
- the availability of services.

Community barriers include:

- discrimination in employment;
- limited income;
- community hostility;
- lack of educational opportunities;
- the built environment;
- transport.

Policy and policy implementation barriers include:

- how “outcomes” are measured;
- lack of housing choice;
- failure in the education system;
- the need for extensive public education;
- support mismatch with community rhythms;
- staff turnover.

What helps community participation

The people we spoke to were neither passive nor defeatest about the barriers to participation they faced. All had considerable experience at circumventing obstacles and their stories and suggestions offer much to those seeking to be more active in the community. The list that follows is not exhaustive (and could include removing all of the barriers outlined above) but rather gives a flavour of the sorts of things people told us had helped them.

<u>Access to technology that erodes the distance of space</u>
One of the greatest barriers people faced was the tyranny of distance. Impairment often decreased physical mobility, which was further compromised by limited access to usable and/or affordable transport. Technology that made people and places more accessible were valued highly. Louise had just had a phone installed in her room and her new found ability to make and receive calls was one of the things she most liked about her life at the moment. Many people stayed in regular contact with their

families over the phone. Robert was waiting anxiously to see if an application he had made for a computer would be successful. He was looking forward to seeing his own language, getting news from home and most of all, being able to email his wife and daughters. Some had found communities and even relationships in chat-rooms and others had used cyber space to reconnect with their past. In the course of writing his story, Adam discovered the Terrigal Surf-lifers website and signed their guest-book to let old friends know they were still important to him. Many of the people we spoke to had taken computer classes but few seemed to have ready access to a computer in their own homes.

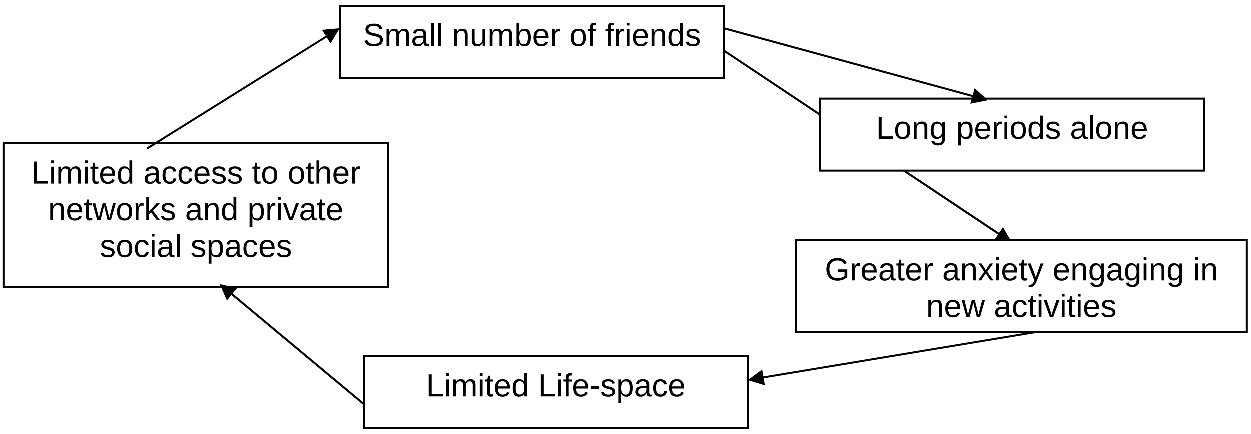
Supporting and sustaining friendships

In the previous section we identified that one of the clearest messages people gave us was that they wanted more friends. We also discussed how being with people changed the nature of participation and made it easier to try new activities. Friends were also important because the feelings associated with interpersonal relationships accumulated over time to become attachment to places.

Having a wide circle of friends had important practical implications too. The greater the number of networks people had access to, the easier it was for them to generate new forms of participation. Conversely, having few friends limited opportunities to expand participation (Figure 15).

The most obvious way to expand a limited life-space is for services to support people to make and sustain meaningful friendships. At a recent Supported Living conference, Pat Fratangelo (2003) suggested that having friends was so important that the primary function of support services should be to find, nurture and finally relinquish people into communities that love and believe in them.

Figure 15: The consequences of having few friends



People’s stories gave good cues about how to begin. **Valuing friendships between people with disabilities** ought to be somewhere near the top of the list. People told us that not only was it easier to relax around others who had shared similar life experiences, sometimes it was nice not to always be different. Other people with disabilities were often better at anticipating needs or were less threatening to ask assistance from. The people who had the largest number of disabled friends also appeared to do more things. For some, being around people with disabilities had profoundly altered their perspective on life and there appeared to be an emergent consciousness of the unique and affirming culture of disability. Prioritising non-disabled relationships devalues and may limit access to the benefits of belonging to a community of peers, including the collective organization required for people with disabilities to challenge discrimination and improve their circumstances. In focus groups the care and thoughtfulness of those involved suggested a strong seam of community lay beneath the surface. Disturbingly, many people with disabilities had themselves also formed a view that non disabled relationships were in fact preferable, and proof of an ability to transcend disability!

Three strategies are suggested by peoples’ stories as potential ways to promote friendships. Firstly, it is important to find ways to bridge the disconnected islands of contact that people had with others. Increased contact might be through inviting workmates out for social events, or having friends and family over for tea. People also said that few people came to visit them. Secondly, bringing the community **to** people through visits, and engaging them where people with disabilities feel empowered and comfortable, may also increase their access to private rather than public social spaces. Finally, supporting people to find creative ways to add value to, or participate in relationships of reciprocity may also erode the awkwardness some felt about their inability to contribute in conventional ways. Many were doing so vicariously. Helen stayed engaged with her community by monitoring its rhythms. She checked to see who had congregated at the neck of the alleyway and watched to make sure elderly residents were up and active. Recognising and exploiting the quiet ways people contributed to relationships, and finding opportunities for people to express the value of their interpersonal relationships, should be the business of support too. One person said she had found a good friend by using a “buddy programme,” but didn’t know if any existed in her town.

Supporting relationships with families

For a number of participants, their family appeared to represent a potent but undervalued resource. We found that the support (or otherwise) of family relationships appeared to exert a powerful influence over people’s disposition towards their disability. Being engaged with family also increased the breadth and frequency of people’s involvement in community activities, personal agency and the expectations they had about their lives. Family was the source of some people’s most intimate and valued relationships and the place where they were most likely to be able to reciprocate intimacy and care. Because family relationships tended to outlast all others, they were often a reservoir of personal identity that people could return to.

Supporting service users relationships with their families can be problematic for services, especially when it exposes service users to unwelcome protectiveness or the limited aspirations of parents. Supporting people to make their own decisions about their relationship with family, including supporting them to remove impediments to access, however, could do much to facilitate greater community participation as well as improve the quality of life of people with disabilities.

Finding employment

Wanting to find employment was a universal aspiration. Unemployment was almost equally pervasive. Those that had part-time employment were proud of their jobs and had incorporated their employment roles into their sense of who they were. Marginalisation from the world of work denied people precious income, the chance to meet people in socially valued roles, a sense that they were contributing members of society and most importantly, a community of colleagues. The inflexibility of workplaces to accommodate different bodies in their physical design, and through work-place initiatives like glide-time or job sharing, discriminated against people with disabilities. Challenging discrimination and supporting employers to recognise the attributes brought by people with disabilities to the labour market would greatly enhance community participation for the population most marginalised from employment in New Zealand (Mintrom & True, 2004). Challenging the service system with the basic premise that **all** people with disabilities had the right to seek employment would also benefit those that most wanted to work. People with multiple disabilities were the most emphatic about their desire to find employment, but paradoxically, were most likely to be steered towards alternative forms of participation.

The people we spoke to said one of the most helpful things they had found was support that was grounded in their ability to do things. Some experienced this when they were encouraged to contemplate new forms of participation that extended their perceived limits. Staff, on the other hand said that people needed chances to try again, if their employment or activity did not work out the first time. The combination of these two attitudes would seem to be ideal touchstones to guide the **process** of supporting people to gain employment.

A sustained and regular presence

People were quick to identify forms of participation they liked and tended to spend most discretionary time in the places they had an affinity for. People also tend to become attached to places as a **consequence** of spending more time there. We seem to be hardwired to like things we see more often, but a sustained and regular presence also permitted people to become acculturated to places. Places became familiar and comfortable when people could read and interpret the social customs and conventions that operated there. They themselves gained the chance to become a recognised and ultimately a known part of the "*landscape*" of a location. Interaction with other people they met there began the process of laying down emotional connections that would accumulate to form a sense of belonging. We saw this happen at many levels. At one end, people expressed it in the love of their families and of the places they had shared. We saw it also in the gravitational pull of Louise’s Lotto shop and the seat outside Gordon’s dairy.

All of the forms of community participation that people said they valued most highly were places where they had acquired a social identity that threaded its way through the social history of a community. Although getting people out for “community participation” was a welcome diversion from the normal rhythm of life for many people, the fleeting and ephemeral presence it gave people with disabilities was unlikely to seed any real sense of participation or membership. As Manu had done with his Polytech course and Marie was doing with her teaching, finding the things that people were passionate about and returning regularly to the places where they could be experienced offers a better prospect of supporting people to transform community spaces into places of belonging.

Having safe places to return to

Many of the people we spoke to thought of community participation as a process of discovery. Community was perceived to be “out there,” beyond the circumference of their everyday life. The need to feel safe in a community that was sometimes perceived to be hostile was a recurrent theme. To do this people said they needed to be with people they knew they could trust. Marie told us that liking and trusting her support worker was what had persuaded her to accept an invitation to a girls’ night out. People also said that it was easier to take risks and explore their community if they knew they had ready access to support or safe places to return to. Even though he did not often need them, John said the comfort of knowing the support of his parents was readily available meant that he felt more able to try new activities. For a variety of reasons, vocational settings had become a safe place to return to for many. For Louise, the relationship she had with staff gave her somewhere to turn when things got rough. To others, their service settings were one of the few places where they were able to access people who were committed to understanding what they had to say and were practiced and comfortable at meeting their support needs.

Giving people real choices

Woven through the stories of many of the people we spoke to was a sense of frustration at the inability they had to exercise control over decisions that affected their lives. Louise did not want to live where she did. She felt she had little or no influence over the setting of the rest home and said it communicated nothing of value about her. Like Louise, Janet had waited all of her adult life to live somewhere she had chosen, and Wendy had learnt patience because staff were too busy to take her to the places she really wanted to go.

People’s lifestyles appeared to be skewed towards the traditional fare of vocational services and participants suggested that their ambivalence towards the lifestyle planning process was rooted in its failure to deliver real aspirations. They were also suspicious that planning represented a service tool and not a genuine attempt to support them to author their own life story. Compared to others, Trevor was fairly quick to volunteer his dreams. There seemed to be no plans, however, that looked likely to take him closer to working on cars or cribs. It seemed improbable that he would make it to Australia or even dangle his feet over the side of one of the boatsheds at Pilots Bay. Similarly, he did not know what had happened about the cleaning job he had found in the paper. Instead Trevor contented himself with his Boccia, long walks and a new literacy course he was keen to give a go.

Autonomy and the right to make choices was important to people. Adam's fierce determination to retain control over his life and Janet's pleasure at the freedoms she had, were indicative of a broader valuing of autonomy. Staff too were keen to emphasise the importance of preserving people's ability to make choices and they made genuine efforts to incorporate it into their practice. However, disparities in control over the resources and culture of service settings did appear to constrain people's ability to be self- determining. Generally the autonomy of participants within service settings seemed to be restricted to artificial moments of choice, like indicating which one of a pre-determined set of activities they would like to do. Many participants spoke of continually having to say things until services listened to their desire to choose what, when, where and who they did things with.

Having a participatory presence

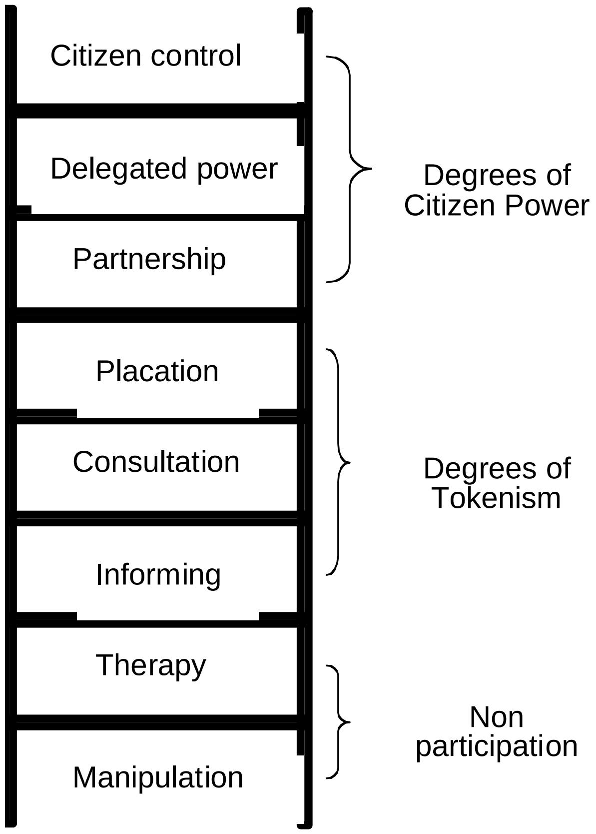
A circumscribed ability to make choices was indicative of the limited opportunity service users had to participate in the culture of their own services.

The benchmark set by the New Zealand Disability Strategy to determine whether progress had been made in transforming New Zealand to a non disabling society is for people with disabilities to be able to *"say that they lived in a society that highly values our lives and enhances our full participation."* The imperative to bring about meaningful participation is further underscored by the stated aims of Pathways to Inclusion.

The people we spoke to spent most of their time in service settings. In this respect they were similar to a significant number of other people with disabilities. In spite of this fact, **service culture appears to pay little attention to a responsibility to facilitate meaningful participation within its own walls**, on the grounds that this would be better achieved in inclusive settings. Given that the level of experience of how to effectively support people with disabilities ought to be higher in support services than in the general community, this could be seen as puzzling.

People told us over and over again, that it was not place that mattered. Whether a location was deemed to be segregated or inclusive was largely immaterial to them. What mattered was how they experienced places and in particular how they were treated there. Key attributes of place flagged to them whether they were a valued and participatory member of a community. These included: whether activities were freely chosen and whether they retained an ability to exercise control over their own decision making; whether they were involved in relationships of reciprocity because they occupied valued roles; whether they had an affirming social identity and were included in the social history of a community; whether they felt at ease and safe; whether the community expected them to participate in collective decision making and contribute to its welfare; and whether they sensed they belonged as an equal member.

Figure 16: Sherry Arnstien's Ladder of Participation



If people with disabilities have a right to expect to find these attributes in communities outside of service settings, should they not also have an equivalent right to anticipate them inside as well?

Furthermore, if we are satisfied that it is ethical to run the ruler of the Social Model of Disability over the community at large, is it not also appropriate to expose support services to the same measure, to see in what ways disability services "disable" service users?

Duffy (1997) suggests that one of the main reasons why services have not been so successful at integrating people with disabilities into the community is that their own system of service delivery fails to recognise their own inherent power to control the lives of people they aim to serve. Duffy believes that services can threaten the autonomy of individuals by presuming they have the right to make decisions on behalf of an individual. The dangerous consequence is that service providers and not people with disabilities come to define what support is appropriate and when they have done an excellent job. He proposes that a better alternative is to ground support in an assumption that that each and every person is a citizen of their community. The change in thinking Duffy (1997) advocates sounds easy. Trying to give effect to the principle, however, unmasks how entrenched systems of service delivery can become.

In his exploration of how to support disabled children to participate in their service planning, Kernohan (2002), borrowed a model that Arnstien (1969) used to describe citizen involvement in planning processes in the United States. She called it the ladder of participation (Figure 16). The ladder describes different forms of citizenship according to the level of participation that members of a community have in decision making processes. It is a good yardstick against which to measure the participatory presence of community members. Given the centrality of services in the lives of many people with disabilities, it may offer a useful template for services to consider how close service users are to exercising degrees of citizenship **within** their own support service community

There was a good deal of variation in the degree to which people's lives were intertwined with support services. For some, service culture represented the largest part of their material and social worlds. For others the vocational centre was an important enclave that met needs that the wider community failed to meet (see Chapter 4). Louise chose to be there rather than all other places. She was first to arrive and last to leave. For many people vocational services represented a beacon of supportive friendship and stimulation in an otherwise boring and isolated life-space. For others it represented their best chance of gaining access to other communities.

What remained consistent, however, was the lack of influence that service users had over the culture of their support service. Suspending people in dependent roles made them vulnerable in a number of other ways. Firstly, people's lifestyles depended on the imagination and industry of support staff. Adam attributed the difficulty he had finding a lifestyle similar to the one he had prior to his accident to the lack of INGENUITY of others. This, he said was his main barrier. Adam implied a lack of imagination also meant that people found it difficult to see beyond his chair. He felt being cast as disabled changed the way people treated him and fought to resist disabling expectations.

Secondly, being relatively powerless and occupying the passive role of recipient of support meant that it was hard for people to add value to the service communities they lived in. Professional boundaries held at bay people's efforts to humanize relationships through reciprocity. Being powerless within the culture also left people exposed to waves of service ideology that swept through. "Inclusion" was the last of a recent set and appeared to have been widely interpreted to mean two things: a prioritising of inclusive settings and of non disabled relationships. Listening to Allison as she told us how she was enjoying life so much more after moving from her flat to an old person's rest home, or John as he explained how he had learnt to accept and enjoy himself after working alongside other people with disabilities in his vocational setting, or Marie as she recounted how she thought she had gained independence by moving to her own flat when in reality she had lost it, provided a cautionary warning of the dangers of putting professional ideology ahead of an understanding of the lived experience of people with disabilities. The diversity of people's stories suggested that no single service principle or approach could be universally appropriate.

Many participants told us they were unsure about the fate of their vocational settings and the implications that would have for them. In one regional centre, participants said they had successfully opposed the closure of a vocational setting, but on the whole, people did not feel as if they had been consulted about the process. The ideology that drove the closure of segregated settings, appeared to them to belong to others.

People were not resistant to the ideal of being better integrated with the wider community. In fact they embraced it. But they did not want to lose what they had without knowing it could be replaced in community settings. Their caution is understandable. Most people used vocational services because the community had historically failed to meet their needs. People worried about being isolated in the community, isolated both from accountable and empathetic support and from other people with disabilities.

> *John: Well, I think we should keep as many of these type of places as long as we can. I don't think it is justifiable to chuck people out into the community, even if we are not disabled …..*
> *Interviewer: … and this place helps you get the job?*
> *John: It does. You know I would be stuck if it wasn't for this place.*

> *Interviewer: Because you come here for computer classes eh?*
> *Manu: Yes, that's what I was doing today.*
> *Interviewer: And so if they close you think you might be a bit stuck for learning computers. And they are talking about doing it fairly soon is it?*
> *Manu: Pretty soon, I'm not quite sure.*
> *Interviewer: Did they ask your guy's opinion about that?*
> *Manu: …my tutor - she did ask me what am I going to do if this place closes down and I said oh I don't know. Maybe I can go to another computer course but that costs money at some places. I don't have that financial security.*
> *Interviewer: So you still think it is quite a valuable sort of setting to have computer classes in a place like this?*
> *Manu: Yes, …..we are more comfortable with because we all have disabilities and that. If I go to other courses everyone is abled people and it is a bit of a barrier for me after all, I don't know…..I can be comfortable.*

People's apprehension about the loss of vocational centres was also rooted in a fear of the loss of a place and people they had become attached to. For people like Pamela, the vocational centre was the hub of their social world. It was the epicentre of valued friendships and almost all of her activities radiated out from it. It was also an important destination away from the isolation of home. Without a clear picture about how some of the attributes of place would be replicated in the community, people like Pamela were fearful about losing service centres and sensed they were being "pushed" into community activities when they were not convinced it was what they wanted.

Conclusion

The barriers that people with disabilities say make it difficult for them to participate fully in the life of their community have different origins. Most of the barriers people face are environmental and outside the person. Aspects of service, community and political culture act to disable people with impairments by frustrating their efforts to participate fully in the life of their communities. Society has been slow to acknowledge the ways in which it acts to marginalise people with disabilities. This can in part be explained by the historical pervasiveness of medical models of disability which located disability in the body or pathology of a person and stressed a need for impairment to be remedied, cared for or cured. The aim of intervention was to remove disability by changing the person, with a key focus on rehabilitation, and normalising the individual so they better fit into their community. The social model of disability challenges this view by placing a person's impairment in the context of the social and environmental factors which create disabling barriers to participation in society. It also follows, therefore, that the major responsibility for removing barriers and promoting community participation rests with "the community" itself.

Summary

What helps community participation includes addressing all the barriers. The following areas appear to be particularly important:

- access to technology that erodes the distance of space;
- supporting and sustaining friendships;
- supporting relationships with families;
- finding employment;
- promoting a sustained and regular presence;
- having safe places to return to;
- giving people real choices;
- having a participatory presence in services.

CHAPTER 9

IMPLICATIONS FOR POLICY AND PRACTICE, AND FOR PEOPLE WITH DISABILITIES THEMSELVES

This research project has been a demanding and exciting journey for the whole Research Team, and also for some of those who took part in sharing their experiences. Some of us have been challenged to re-examine current service philosophies and how these are translated into the provision of support for people with disabilities.

In this chapter, we identify some of the implications of the increased knowledge and understanding which we have gained from the research.

The first section summarizes the implications or messages from the Project for people with disabilities.

Implications for people with disabilities

The 28 people with disabilities who made the major contribution to this research provided challenges and encouragement to other people with disabilities. They emphasized the need to believe in yourself and to challenge other people's low expectations. Part of being strong and developing greater self-esteem was seen to lie in striving to increase control of their own lives, including looking after their bodies and becoming as independent as possible.

People with disabilities also stressed the importance of knowing what their rights are – as a citizen of new Zealand, and as a consumer or user of health and disability support services.

People with disabilities stressed the need to be actively involved and in control of any plans that are made about their lives and the way they are supported. They stressed how important it is to make sure their voice is heard and their ideas and preferences are supported. It was particularly important for people with disabilities to ensure that they are consulted about and involved in any proposed changes to services.

People with disabilities strongly emphasized the value of employment – as a source of self-esteem, increased income, opportunity to contribute, and friendship. People with disabilities who want a job should persist in seeking the support they need to find and keep a job they like.

People with disabilities have a lot to offer each other – shared experiences, understanding, encouragement, friendship and intimacy, mentoring, and role models. They should value these relationships and seek the support they need to maintain and sustain their friendships and relationships in "communities" of people with disabilities. The old saying “charity begins at home” is relevant here. There are many ways of contributing and adding value to “the community” – including contributing within “communities of interest”.

People with disabilities can also gain a stronger political voice and role in their service organisations through group advocacy.

The next section is addressed to CCS as an organisation, and to CCS staff. Many, if not all, of these implications will also be relevant to other organisations that provide vocational services for people with disabilities.

Implications for CCS, and other service providers

The desire for employment

This research has implications for the **design of support services** and how these supports are structured to deliver what people with disabilities have said they want. Almost all the people with disabilities in this research wanted a job. **Are enough resources and expertise being directed towards Supported Employment services? Is there discrimination in eligibility for these services?**

Supported Employment was originally developed to provide real work for people with severe disabilities, including those with intellectual disabilities. An extensive research evidence base exists on which to base successful services (Bray, 2003). A training programme, recognised qualification, and lead organisation (ASENZ) are available in New Zealand for support staff.

Supported Employment was never designed to be a “quick fix” or “job placement” programme. It was particularly focused on supporting people on a longterm basis, using natural supports in the workplace, when this became possible. Unfortunately, these requirements for ongoing support are not always recognised by policy makers or funders.

The complexity of community participation and the provision of support

A further implication from this research arises from the clear message that “community participation” is much more broad and complex than going out for lunch, or visiting the museum. Community participation is about the whole of life, 24 hours a week, 7 days a week. Support for community participation is typically restricted to typical work hours (9.00 – 5.00), Monday to Friday. **Support needs to be designed around the needs and preferences of individuals, not the needs and convenience of organisations.**

The need for psychological safety

While greater independence is a goal of many people with disabilities, they also **need to feel physically and psychologically safe when they move into unfamiliar community settings.**

Sometimes this safety can be provided by formal support, sometimes other people with disabilities can provide the psychological safety required. People with disabilities have often experienced hostility, teasing, lack of acceptance, and danger in public community settings; they should not be “forced” into experiences which they do not want or for which they do not feel adequately prepared or supported.

Closing vocational centres?

While closing vocational centres may be seen by some as an indicator of a successful move away from segregation to community participation, this is an unduly simplistic viewpoint. As people with disabilities have explained in this research, community participation is not simply being “out there”. People with disabilities value having a place to go to where they feel safe, supported and accepted and where they can spend time with friends. **If there is nowhere accessible to meet, how will people with disabilities have these important needs met?** For example, simply finding an accessible venue for a focus group of six people to meet was a challenge in some areas. The cost of enabling these six people to get to this venue was $300.

The possible outcomes of “having nowhere to go” are isolation, boredom, lack of personal support, loneliness, and depression, particularly for those people who are in part-time work or who do not choose or are unable to work. Furthermore, for people with high needs for personal support in their daily lives, these needs will still need to be met whether people attend a Vocational Centre or not. The everyday and ordinary nature of these needs means that they can become an invisible part of **essential** supports. If people with disabilities are not somewhere where these supports are available, **they need to have the support (and the physical facilities necessary) with them wherever they are.** It is important that changes in service configuration are made very carefully, that people with disabilities are fully involved in any changes and that changes lead to greater experience of community, not a loss of such experience.

A final structural implication relates to the whole issue of community location. Community participation should not be limited to people with disabilities going “out”, it could also include **bringing the community in to people’s lives. Why do vocational centres have to be only for people with disabilities?** Maybe it would be possible to change some of these Centres into **“community centres”.** What are the needs of the local community? How might these needs be met within a Centre? Are there ways that people with disabilities could contribute towards meeting these needs (e.g. computing classes for beginners)? Is there a local need for a meeting place for young parents? For older people? For other ethnic minority groups? A coffee shop? Could people with disabilities be involved in undertaking a local community assessment to see what needs there are and how some might be met through sharing the use of the Centre?

Support services for personal development

Another issue relates to the **kind of support services** that are provided to support community participation. Some people with disabilities who took part had undergone stressful and traumatic experiences which had had longterm effects on their self-esteem and ability to try new experiences. Some of them were also not comfortable about being assertive about their wishes and preferences within the sphere of services. These issues suggest the need for services such as **personal or group counselling and assertiveness training**. For some people, dealing effectively with the past and learning skills for the present and future would provide a firm basis for people to move forward into more challenging lives. **Are such services currently funded as part of preparing for community participation and work?**

Supporting the development and maintenance of friendships

A further need that emerged strongly is that of **making and sustaining friendships.** For people who may have little experience of friendship, services may need to consider **ways to support people with disabilities to experience reciprocal and longterm friendships,** including friendships among themselves. Services will need to identify the personal and practical barriers faced by individuals and plan how to reduce or remove these barriers.

Making autonomy, personal control and reciprocity a reality

An issue that emerged strongly from the research is that of **personal control.** The rhetoric of **choice for individuals with disabilities needs to become a reality.** As pointed out earlier, if services control decisions about the life of a person with a disability, there is a danger that services define what “community” is to be for that person, and where its boundaries are drawn. Another implication allied to the issue of control is the need to promote a more equal and reciprocal relationship between staff and people with disabilities. Many people with disabilities view staff as their friends. **Do staff view people with disabilities as their friends?** People with disabilities want to be able to **contribute to these relationships.** They want their expertise and knowledge valued. They want support to share this expertise with others, to contribute towards problem-solving and encouragement of others – both staff and people with disabilities – within this particular “community of interest”. These ideas **pose challenges to traditional “professional-client” role boundaries** which may need re-examination if services are to move towards more of a “partnership” model.

In order to move forward, building on the knowledge and understanding gained from this research, there are very significant implications for policy at a national level.

Implications for policy

The need for an Intersectoral approach

This research has demonstrated that **community participation is a "whole-of-life" reality** for people with disabilities. As such, it calls for an **intersectoral approach at the level of policy and funding.** The research showed how a decision made in one sector e.g. Housing, could impact significantly on whether and how an individual could participate in her community. With the current government focus on examining an intersectoral approach to needs assessment and service coordination, an **intersectoral approach to the actual provision of supports** is a logical progression.

As Litvak and Enders (2001) point out:

> *Barriers between professions, differences in funding streams, and compartmentalization of disability services are major stumbling blocks to achieving integration and responding to changes in the circumstances of individual disabled people (p.712).*

The inaccessible physical environment

The continuing barriers of inaccessible places and expensive or non-existent transport prevent the community participation of many people with disabilities. Ensuring that existing legislation regarding standards for access is adhered to is clearly needed.

The absolute necessity of accessible public transport and subsidised, available private transport is shown clearly in this examination of the lives of people with disabilities. At present, people on the lowest incomes have to pay for the most expensive mode of transport.

A process, not an outcome

Community participation is encompassed within the ultimate goal of the new Zealand Disability Strategy, "a society that highly values our lives and continually enhances our full participation". It is not a single outcome that can be the responsibility of one government ministry. **Community participation is an ongoing process, not a simple outcome or goal.**

“Pathways to Inclusion”

The strategy document, “Pathways to Inclusion”, signalled a significant new direction for vocational services, with its strong emphasis on participation in employment and communities. The strategy recognised that an important way for all adults to participate in communities was through paid work in real jobs. This research confirms that most people with disabilities share this goal, but all are not currently being supported to actively pursue it, even though this key point emerged in consultation around the strategy.

Unfortunately the new Strategy appears to have been implemented as though there are two distinct areas of life, types of support services, and therefore separate funding streams – employment and community participation. In fact, **employment is actually a part of community participation** for people with disabilities. Community participation is about their whole lives – not a programme to be involved in three times a week for two hour slots. It is essential to consider how a change in one type of support service may have unintended consequences in people’s lives.

This research suggests **the need for a review of how “Pathways to Inclusion” is being implemented, particularly in terms of how funding, contracting, and accountability is currently structured.** There may be problems in how the Strategy has been interpreted and implemented. The Strategy itself is clearly supported by this research. It is clear that people with disabilities often need support for employment **and** support for other forms of participation in communities, and these needs cannot be arbitrarily divided into separate groups. Furthermore, **community participation should not be translated into simple notions of place, with a rejection of the provision of places where people with disabilities can be together.** Where vocational centres have closed, it is important to examine how the various support needs of people with disabilities are now being met, and whether there are any unforeseen negative outcomes for their lives.

Coordination of supports

A further implication for policy is in the area of **coordination of supports to ensure that people with disabilities can participate in all the various communities that they wish to be involved in. Where does the responsibility for this coordination lie?** The current system of Needs Assessment and Service Coordination is not resourced to meet the practical, ongoing needs of people with disabilities for coordination of support that were identified in this research. In fact, these needs were best met when services “blurred the distinction” between employment” and “community participation” and took a more, whole-of-life approach. **The more separation there is of funding streams, location of support, identities of support staff – the greater the need will be for scarce resources to go into service coordination and form-filling.**

One way to reduce the complexity of coordination is to combine resources into an **individualised "funding package"** which is then controlled and used by the individual (with a disability) to purchase the individual supports s/he prefers. However, individualised funding approaches can be too burdensome for some individuals, and their success relies on the availability of appropriate support services to buy.

> *Consumer choice and control of one's supports helps guarantee the best fit possible between the person and the environment, assuming that the supports needed are available and accessible. When resources are limited, when professionals have to be case or resource managers as well as service providers, and when people with disabilities are unaware of support possibilities or choices, "best fit" is an elusive goal (Litvak & Enders, 2001, p. 713).*

Governments are traditionally reluctant to provide resources directly to consumers to control their own supports, assuming that this would lead to widespread abuse by or of people with disabilities. However, Litvak and Enders (2001) cite research that shows that "**services provided in this way are less expensive because they do not require the enormous operating costs of government-monitored, -administered, and – managed services**" (p. 715).

Poverty

Another significant barrier to community participation is **inadequate income.** This barrier was particularly evident in transport around the community and people's ability to contribute to reciprocal relationships. **This issue of poverty deserves closer research and policy attention.**

The need to change the community itself

A final implication for policy and funding is found in the frequent stories of people with disabilities about **hostility and rejection in community settings.** The aim of the New Zealand Disability Strategy for a "new society" requires a significant change in public attitudes and behaviour. The public education and awareness campaign in the area of mental illness – "Like Minds, Like Mine" – illustrates the importance and value of such programmes. This research highlights the need for a similar **comprehensive public education and awareness campaign by government about the value, rights and contributions of people with disabilities.** Such a campaign needs to be divorced from particular organisations or services, where public education is too often tied to fund-raising.

The last words in this research report must go to one of the people with disabilities who shared their experiences and knowledge with the researchers.

> *Support might be what makes the difference. It doesn't matter where it comes from. It can be from any of the communities I am involved with because it is not where support comes from that is important, it is how you feel it. You only feel like you are being supported when you know it comes from someone believing in you. You need to be with people that believe in you. Even push you a little bit further than you thought was possible. I have spent a good part of my life trying to recover from people's lack of belief in me and to push out beyond what they thought I would amount to.*

Summary

This final chapter sets out some implications of this research for people with disabilities, for CCS and other service providers, and for policy makers.

Implications for people with disabilities

People with disabilities involved in this research challenged and encouraged others to be strong, increase control of their own lives, and strive to achieve their own goals. They urged people with disabilities to make sure their voices are heard in their own lives and in the planning and organization of services. They stressed the need to value each other and to work together to gain a stronger political voice.

Implications for CCS, and other service providers

The strong desire of people with disabilities for employment suggests that more resources and expertise may need to go into this area.

Community participation is complex and involves the whole of life, implying that supports need to be designed to meet the needs of individuals, rather than organizations.

Services need to be sensitive to the needs of people with disabilities to feel physically and psychologically safe when they go into unfamiliar community settings.

Closing vocational centres, as part of a move towards community integration, needs to be undertaken with care. They clearly meet some important needs for some people with disabilities. It is critical that such closures do not have unintended consequences, such as increased isolation and no way for people with disabilities to spend time together. People with disabilities should be fully consulted and involved in any service changes.

Other ways of increasing community participation, such as bringing the community in to people's lives, could be explored.

Some disabled people could benefit from personal development courses and counselling, to help them to move on from traumatic and hurtful experiences in their lives.

Services need to consider how to support people to make friends and sustain longterm friendships.

Autonomy, personal control, and reciprocity are agreed service principles, but there is a challenge to make them more of a reality within support services.

Implications for policy

Community participation requires an Intersectoral approach at policy and funding levels, which can be translated into the actual level of service delivery.

The physical environment and lack of transport continue to be significant barriers to community participation and require concerted attention.

Community participation is an ongoing process, not a simple outcome and goal. This fact raises questions about the appropriateness of current funding and accountability processes.

The appropriateness of the **goals** of "Pathways to Inclusion" are confirmed in this research, but the implementation of the Strategy needs a critical review. Community participation is not a programme, and "community" cannot be simply conceived as a place, or places, where people do things.

Coordination of supports is an important part of community participation, but a lack of clear responsibility and current structures often prevent effective coordination. Individualised funding is one possible avenue to consider in addressing these issues.

Poverty, or inadequate income, poses enormous barriers to community participation for many people with disabilities.

Finally, achieving the goal of the New Zealand Disability Strategy requires changing the community itself. There is an urgent need for a public education and awareness campaign to begin to address the prejudice, intolerance, and sometimes hostility, experienced by some people with disabilities.

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Appendix 1: Ethics Application

NATIONAL APPLICATION FORM FOR ETHICAL APPROVAL OF A RESEARCH PROJECT

PART I : BASIC INFORMATION

Protocol number and date received (for office use only)

1. Full project title

Community Participation Definition Analysis Project

2. Short project title (lay title)

Community Participation Project

3. Lead Principal Investigator's name and position

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	E-mail	Donald.Beasley@stonebow.otago.ac.nz

5. Lead investigator's qualifications and experience in past 5 years (relevant to proposed research)

Full time researcher in the area of disability, particularly intellectual disability. Doctorate in Education and Dip.Grad (in Law & Ethics). Supervisor of six doctoral students. Experienced in research involving direct contact with disabled people, their families and staff.

6. Co-investigators' name(s) and position(s) or, if multicentre, Principal Investigator at each site

A	Paul Milner, Donald Beasley Institute, Dunedin
B	Ron Entwisle, Maxeq Investments Ltd, Wellington
C	Grant Cleland, Creative Solutions, Christchurch
D	John Taylor, Tautoko Services, Paremata

7. Address of co-investigator A

Paul Milner	Work phone No.	03-479-8080
Donald Beasley Institute P.O.Box 6189	Emergency No.*	
DUNEDIN	Fax	03-479-2162
		paul.milner@stonebow.otago.ac.nz

8. Address of co-investigator B

Ron Entwisle	Work phone No.	04-801-7657
Maxeq Investments Ltd 244/20 Hankey Street	Emergency No.*	
WELLINGTON	Fax	04-801-7658
	E-mail	ron@blm.co.nz

9. Address of co-investigator C

Grant Cleland	Work phone No.	03-332-1898
Creative Solutions P.O. Box 12-137 Beckenham	Emergency No.*	
CHRISTCHURCH	Fax	03-332-1892
	E-mail	grant@creativesolutions.co.nz

10. Address of co-investigator D

John Taylor	Work phone No.	06-368-2611
Tautoko Services, Suite 10, 99 Mana Esplanade	Emergency No.*	025-652-4527
Paremata	Fax	
WELLINGTON	E-mail	Tautoko2@xtra.co.nz

*** See appendix 1 also, for two additional Team Members.**

(* option for Committee's information only)

11. Where this is supervised work

11.1 Supervisor's name	N/A
Position	
Day time phone number	
11.2 Signature of supervisor (where relevant) Declaration: I take responsibility for all ethical aspects of the project	

12. List any other New Zealand Ethics Committees to which this project has been submitted and attach their letters of approval where available

Auckland, Canterbury, Manawatu/Whanganui, Nelson/Marlborough, Otago, Southland, Wellington

13. I wish the protocol to be heard in a closed meeting

☐ Yes ☑ No

If the answer is yes, provide reason why you wish it to be heard in a closed meeting

14. Proposed starting date (dd/mm/yy)	15 January, 2004
15. Proposed finishing date (dd/mm/yy)	15 July, 2004
16. Duration of project (mm/yy)	6 months, 2004
17. Proposed final report date (mm/yy)	15 July, 2004

PART II : PROJECT SUMMARY

1. Multicentre proposals

(Important: read the guidelines, Appendix 1)

1.1 Is this a multicentre study? **(if no, go to question 2)** ☑ Yes ☐ No

1.2 If yes, name the primary ethics committee for New Zealand	Otago

1.3 Has the protocol been submitted to any other ethics committees in New Zealand? (If **yes**, attach copies of relevant correspondence) ☑ Yes ☐ No

1.4 Who is the lead investigator or institution in New Zealand?	Dr Anne Bray Donald Beasley Institute
1.5 List the other New Zealand sites involved	Invercargill, Dunedin, Christchurch, Nelson or Blenheim, Wellington, Palmerston North, Auckland

1.6 Have the Principal Investigators from secondary sites agreed to participate? N/A ☐ Yes ☐ No
(attach copies of signed Part V Declaration for each site)

1.7 If the study is based overseas, which countries are involved?	N/A

2. Gene Studies

Does this research involve any gene or genetic studies? ☐ Yes ☑ No

If **yes**, complete section 16.

3. Scientific Assessment

Has this project been scientifically assessed by independent review? ☑ Yes ☐ No

If **yes**, by whom? (name and position) A copy of the report should also be attached	Assessed by researcher on CCS National Management Team. No written report.
If **no**, is it intended to have the project scientifically assessed, and by whom?	

4. Data and Safety Monitoring Board (DSMB)

3.1 Is the trial being reviewed by a data and safety monitoring board? ☐ Yes ☐ No
If yes, who is the funder of the DSMB? N/A ☐ Sponsor ☐ HRC

5. Summary

Give a brief summary of the study (not more than 200 words, in lay language)

This small, collaborative study has been commissioned by CCS New Zealand, and is funded by a grant from the Ministry of Social Development. CCS provides support services for adults with physical disabilities to participate in the community.
The aims of the project are:

- To provide a critical analysis of the process and goal of "community participation" in the light of research literature, policy and specification statements, and the actual experience of service users in CCS (adults with physical disabilities identified by CCS).

- To describe the meanings and experiences of service users in the area of "community participation".

- To obtain reflective feedback from CCS staff on the implications of the critical analysis and views of service users.

- To present individual stories of positive experiences of "community participation".

- To suggest general principles of "best practice" emerging from the project as a whole.

The researchers will conduct seven focus groups and ten individual interviews with CCS service users, and two focus groups with CCS staff.

The study uses a qualitative, participatory approach, involving reflective feedback from all participants on a draft analysis of the results.

PART III : PROJECT DETAILS

SCIENTIFIC BASIS

1. Aims of Project

1.1 What is the hypothesis/research question(s)? (state briefly)

As this is qualitative research, there are no hypotheses. The research questions are as set out in the aims under 5, i.e.

- How do adults with physical disabilities experience and define "community participation"?
- What sort of support do they value to enable them to participate in the community?
- How do CCS staff respond to the information from service users in terms of their own experiences?
- What principles of "best practice" can be drawn from the findings?

1.2 What are the specific aims of the project?

- To provide a critical analysis of the process and goal of "community participation" in the light of research literature, policy and specification statements, and the actual experience of service users in CCS (adults with physical disabilities identified by CCS).

- To describe the meanings and experiences of service users in the area of "community participation".

- To obtain reflective feedback from CCS staff on the implications of the critical analysis and views of service users.

- To present individual stories of positive experiences of "community participation".

- To suggest general principles of "best practice" emerging from the project as a whole.

2. Scientific Background of the Research

Describe the scientific basis of the project (300 words maximum). Where this space is inadequate, continue on a separate sheet of paper. *Do not* delete page breaks or renumber pages.

The project tender described the research as "participatory action research". The research method was thus designed within this methodology and the time and resources available for the project. The study involves active participation in the research by key stakeholders i.e. adults with physical disabilities who use CCS services, and CCS staff. This methodology also has a strong focus on seeking ways to improve practice.

The emphasis is on a collaborative approach in which everyone works together to gather and analyse relevant information, and to reflect on its meaning and implications. Action research typically involves a series of cycles – asking questions, seeking answers, reflecting, changing practice, evaluating changes – which are repeated. Throughout the process researchers and practitioners work together as "a collaborative community of researchers" (Carr and Kemmis, 1986; Kemmis & McTaggart, 2000). The research data will be qualitative, gathered from focus groups and interviews and will be analysed from a view point of people's lived experiences and interpretations (phenomenology) (Holstein & Gubrium, 1994).
The methods proposed for this research are constrained by the short timeframe and the limited budget. However, the key elements of participatory action research have been retained as follows:

- the project team includes a majority presence of researchers with experience of impairment and disability;
- direct involvement in the team of a representative of CCS as the service provider;
- a major emphasis on seeking the direct input from adult service users about their experiences and interpretations of "community participation";
- the inclusion of staff reflection on initial findings, as a critical part of the action research cycle;
- inclusion of three specific points for involvement of National CCS during the Project – for feedback, reflection and input.

3. Participants

3.1 How many participants is it intended to recruit?	Participants will include: CCS service users: 73 CCS staff: 20
3.2 How will potential participants be identified?	Through CCS records, by CCS staff
3.3 How will participants be recruited? (e.g. advertisements, notices)	Written information sent by CCS directly to potential participants.
3.3.1 Where will potential participants be approached? (e.g. outpatient clinic) If appropriate, describe by type (e.g. students)	Posted to home address, or given to potential participants by CCS staff person in each branch.
3.3.2 Who will make the initial approach to potential participants?	Information sheet from researcher and access to local CCS coordinator.
3.3.3 Is there any special relationship between the participants and the researchers? e.g. doctor/patient, student/teacher	No

3.4 Briefly describe the inclusion/ exclusion criteria and include the relevant page number(s) of the protocol or investigator's brochure

CCS service users will be recruited from the 499 adults with physical disabilities who use CCS services which have been funded to provide "community participation". CCS staff will be those who work in CCS vocational services which include "community participation" services. Adults who have no way to communicate their views will be excluded, as participation relies on communication. Participants must also be 18 years of age or older.

The service users' focus groups and interviews will include those people who use services in:
Invercargill, Dunedin, Christchurch, Wellington, Nelson or Blenheim, and Auckland.
CCS staff will come from branches in Auckland and Christchurch.

3.5 If randomisation is used, explain how this will be done

Sampling Procedures
From potential participants who respond, samples will be chosen to represent maximum variation in age and gender, within the requirements of location, as set out in 3.4.

4. Study Design

4.1 Describe the study design. Where this space is inadequate, continue on a separate sheet of paper. *Do not* delete page breaks or renumber pages.

The study is a qualitative, participatory action research study. It is focussed on a particular group and aims to improve practice in that setting. Draft analyses are fed back to stakeholders for reflection and comment (see 2 for further details).

Data will be collected through 7 focus groups and 10 individual interviews with CCS adult service users (adults with physical disabilities). (See Appendix 2 for outline of focus groups and Appendix 3 for interview outline). Two focus groups will also be held with CCS staff who work in vocational services. The content of these focus groups with staff will depend on the findings from the data obtained by service users. Focus group data will come from a written record of the discussions by an observer from the research team. Individual interviews will be recorded and transcribed.

Data analyses will focus on both content (actual experiences) and interpretations of that experience. Common experiences and themes will be identified.

Some individual interviews will be written up as "stories" where the interviewee gives consent for this. These "stories" will highlight positive experiences and "best practice" in providing support to adults with physical disabilities.

The data analyses will also be informed by a literature review on "Community Participation", undertaken in 2003 by the Principal Investigator for the National Health Committee.

4.2 How many visits/admissions of participants will this project involve? Give also an estimate of total time involved for participants.

Participants will only be involved in a face-to-face interaction on one occasion. They will also receive a draft report for feedback and comment. A structured response form will be designed for this feedback.

The total time involved for each participant (whether in focus groups or interviews) will be approximately three to four hours.

4.3 Describe any methods for obtaining information. Attach questionnaires and interview guidelines.

The methods used for obtaining information are: focus groups of 8-10 people; individual interviews, and written/audio feedback on a draft report. (See Appendices 2 & 3).

4.4 Who will carry out the research procedures?

The focus groups and interviews will be undertaken by the Co-Investigators who are all experienced in running focus groups, interviewing, and interactions with disabled adults. Two of these investigators have physical disabilities and experience of disability services, and the other two have extensive experience of working with disabled people in disability support services.

4.5 Where will the research procedures take place?

The focus groups will occur in accessible venues separate from CCS services. The interviews will take place in a venue chosen by each interviewee.

4.6 If blood, tissue or body fluid samples are to be obtained, state type, use, access to, frequency, number of samples, total volume, means of storage and labelling, length of proposed storage and method of disposal.

N/A

4.7 Will data or other information be stored for later use in a future study? ☐ Yes ☑ No

If yes, explain how

4.8 Will any samples go out of New Zealand? N/A ☐ Yes ☑ No

If so where, and for what purpose?

5. Research Methods and Procedures

5.1 Is the method of analysis : ☐ quantitative ☑ or qualitative?

If the method of analysis is qualitative, go to question 5.2.

If the method of analysis is **wholly or partly quantitative**, complete the following :

5.1.1 Describe the statistical method that will be used

5.1.2 Has specialist statistical advice been obtained? ☐ Yes ☐ No

If **yes**, from whom?

(A brief statistical report should be included if appropriate)

5.1.3 Give a justification for the number of research participants proposed, using appropriate power calculations.

5.1.4 What are the criteria for terminating the study?

5.2 If the method of analysis is **wholly or partly qualitative**, specify the method. Why is this method appropriate? If interviews are to be used include the general areas around which they will be based. Copies of any questionnaires that will be used should be appended.

The method is wholly qualitative. As the focus of the research is to explore and understand individual's experiences of "community participation", qualitative methods are the most appropriate. Copies of the Outlines for the focus groups and individual interviews with adults with disabilities are attached as Appendices 2 and 3.

6. Risks and benefits

6.1 What are the benefits to research participants of taking part?

The research participants will benefit from the opportunity to discuss their experiences and perceptions in a safe situation and with people who are not directly involved in their support. The opportunity to do this in a group situation may also be rare for some of these disabled adults. Their views and contributions will be highly valued and may influence the quality of service they receive in the future.

The staff participants will also benefit from the opportunity to reflect on what is learned from the disabled adults, and to bring a staff perspective to discussions of "best practice', within a safe environment which assures confidentiality.

6.2 How do the research procedures differ from standard treatment procedures?

N/A

6.3 What are the physical or psychological risks, or side effects to participants or third parties? Describe what action will be taken to minimise any such risks or side effects.

The physical wellbeing of participants will be assured by the selection of an accessible, safe venue by the local CCS staff person appointed to make all the organisational arrangements in each area.

Each disabled person will be allowed to bring a support person or persons with them to focus groups and interviews. We will ask that any support person is not a CCS staff member, to ensure that participants feel free to talk about their own experiences of support.

It is possible that individual participants may have upsetting or painful experiences to relate and this could be upsetting to them or to other participants in the group. Each focus group will be facilitated by one of the co-investigators, and a second co-investigator will also be present at all times. Each co-investigator has extensive experience with disabled people, and will be skilled enough to provide appropriate support and direction to participants. The presence of chosen support persons for vulnerable individuals will also prevent or alleviate these possible risks.

6.4 What arrangements will be made for monitoring and detecting adverse outcomes?

Having two experienced co-investigators present at each focus group will assist in monitoring the participants for any discomfort. The presence of chosen support people for some individuals will provide added safeguards for people who lack confidence or may be distressed.

The individual interviews will be at the disabled person's chosen venue, and they can also bring a support person, if they wish.

6.5 Will any potential toxins, mutagens or teratogens be used? ☐ Yes ☑ No

If **yes**, specify and outline the justification for their use

6.6 Will any radiation or radioactive substances be used? ☐ Yes ☑ No

Note: If any form of radiation is being used please answer the following. If no, go to question 6.8

6.6.1 Under whose license is the radiation being used?

6.6.2 Has the National Radiation Laboratory (NRL) risk assessment been completed? ☐ Yes ☐ No

If **yes**, please enclose a copy of the risk assessment, and the contact name and phone number

If **no**, please explain why

6.7 What facilities/procedures and personnel are there for dealing with emergencies?

N/A

6.8 Will any drugs be administered for the purposes of this study? ☐ Yes ☑ No

If **yes** is SCOTT approval required? ☐ Yes ☐ No

Has SCOTT approval been given? (please attach) ☐ Yes ☐ No

7. Expected outcomes or impacts of research

7.1 What is the potential significance of this project for improved health care?

This project will contribute towards improved disability support services in two ways:

- by providing a critique from disabled people's perspective of current government strategy and definitions of "community participation",

- by identifying positive support practices which are valued by disabled people, to promote "best practice" in CCS and other disability support services.

7.2 What is the potential significance of this project for the advancement of knowledge?

This project will add to the international literature on the community participation of disabled people – a primary strategic goal in Western societies and in UN Declarations, and in the development of a new UN Convention on the Rights of Disabled People. The Principal Investigator has also recently reviewed the international literature in this field for the National Health Committee and this review will inform this research.

7.3 What steps will be taken to disseminate the research results?

The research will be disseminated in various ways by the researchers, the commissioning organisation (CCS) and (possibly) the funder (Ministry of Social Development). The Institute will present the research at one of its regular seminars and at relevant national seminars or conferences (e.g. DPA National Conference). The Principal Investigator will also submit at least one article to a peer-reviewed journal.

PART IV: BUDGET AND USE OF RESOURCES

8. Budget

8.1 How will the project be funded?

Through a grant to CCS from the Ministry of Social Development.

8.2 Does the researcher, the host department or the host institution, have any financial interest in the outcome of this research? Please give details.

No. The funding merely covers the operational costs of the research.

8.3 Will the researcher personally receive payment according to the number of participants recruited, or a lump sum payment, or any other benefit to conduct the study? If so, please specify:

No.

8.4 What other research studies is the lead investigator currently involved with?

- "The effects of the closure of Kimberley Centre". Funded by Ministry of Health.
- "A pilot project establishing a Network for Carers of disabled people with high and complex needs". Funded by the Ministry of Health.
- "Intimate and personal care", funded by Lotteries Health Research.
- "The development of identity in disabled children" funded by Marsden.

9. Resource Implications

9.1 Does the study involve the use of healthcare resources? ☐ Yes ☑ No

If **yes**, please specify:

9.2 What effect will this use of resources have on waiting list times for patients i.e., for diagnostic tests or for standard treatments?

N/A

10. Financial Costs and Payments to Participants

10.1 Will there be any financial cost to the participant? Give examples including travel.

No. All travel for participants to and from venues will be organized by CCS.

10.2 Will the study drug/treatment continue to be available to the participant after the study ends? ☐ Yes ☐ No ☑ N/a

If **yes**, will there be a cost, and how will this be met?

10.3 Will any payments be made to participants or will they gain materially in other ways from participating in this project? ☐ Yes ☑ No

If **yes**, please supply details

11. Compensation for Harm Suffered by Participants

(refer to Appendix 3 of the Guidelines)

Is this a clinical trial under accident compensation legislation (see form guidelines) ☐ Yes ☑ No

If **yes**, please answer the following:

11.1 Is the trial being carried out principally for the benefit of a manufacturer or distributor of the drug or item in respect of which the trial is taking place? ☐ Yes ☐ No

(a) If the answer to 11.1 is **yes**, please complete **Statutory Declaration Form B** and answer questions 11.2, 11.3 and 11.4

(b) If the answer to 11.1 is **no** please complete **Statutory Declaration Form A**

11.2 What type of injury/adverse consequence resulting from participation in the trial has the manufacturer or distributor undertaken to cover? (please tick the appropriate box/es)

	Yes	**No**
a) any injury (mental or physical)	☐	☐
b) only serious or disabling injuries.	☐	☐
c) only physical injuries	☐	☐
d) only physical injuries resulting from the trial drug or item, but not from any other aspect of the trial	☐	☐
e) physical and mental injury resulting from the trial drug or item, but not from any other aspect of the trial.	☐	☐

f) any other qualification (explain)

11.3 What type of compensation has manufacturer or distributor agreed to pay?

	Yes	**No**
a) medical expenses	☐	☐
b) pain and suffering	☐	☐
c) loss of earnings	☐	☐
d) loss of earning capacity	☐	☐
e) loss of potential earnings	☐	☐
f) any other financial loss or expenses	☐	☐
g) funeral costs	☐	☐
h) dependants' allowances	☐	☐

11.4 Exclusion clauses:

	Yes	**No**
a) Has the manufacturer or distributor limited or excluded liability if the injury is attributable to the negligence of someone other than the manufacturer or distributor? (such as negligence by the investigator, research staff, the hospital or institution, or the participant).	☐	☐
b) Has the manufacturer or distributor limited or excluded liability if the injury resulted from a deviation from the study protocol by someone other than the manufacturer or distributor?	☐	☐
c) Is company liability limited in any other way?	☐	☐

If yes, please specify

12. Information and Consent

Consent should be obtained in writing, unless there are good reasons to the contrary. If consent is not to be obtained in writing the justification should be given and the circumstances under which consent is obtained should be recorded. Attach a copy of the information sheet and consent form. **(See Appendix 6 for Information Sheets and Consent Forms)**

12.1 By whom, and how, will the project be explained to potential participants?	By written information, and, if required, by the local CCS staff person attached to the research team. Consent procedures will also be reviewed with the person before each interview. A freephone number is also provided, for contact with the Principal Investigator.
12.2 When and where will the explanation be given?	Through written information to individuals, and this will be reviewed again at the venues for focus groups and interviews.
12.3 Will a competent interpreter be available, if required?	Yes.
12.4 How much time will be allowed for the potential participant to decide about taking part?	Two weeks.
12.5 Will the participants be capable of giving consent themselves? - if not, complete Part VI	Yes.
12.6 In what form (written, or oral) will consent be obtained? If oral consent only, state reasons.	Usually written, but audiotaped oral consent may be given where a person cannot write due to a physical disability. Adults who have no way of communicating their views will not be invited to participate.

12.7 Are participants in clinical trials to be provided with a card confirming their participation, medication and contact phone number of the principal investigator? **N/A** ☐ Yes ☐ No

13. Confidentiality and Use of Results

13.1 How will data including audio and video tapes, be handled and stored to safeguard confidentiality (both during and after completion of the research project)?	Written notes and/or audiotapes of focus groups will be stored after immediate use by each Co-Investigator, in a locked filing cabinet at the Donald Beasley Institute. Audiotapes and transcripts of individual interviews will be stored in the same way.
13.2 What will be done with the raw data when the study is finished?	The tapes will be wiped and transcripts and written summaries stored in a locked filing cabinet at the Institute.
13.3 How long will the data from the study be kept and who will be responsible for its safe keeping?	Five years. The Principal Investigator.
13.4 Who will have access to the raw data and/or clinical records during, or after, the study?	Access to the raw data will be limited to members of the Research team and the transcriber.
13.5 Describe any arrangements to make results available to participants, including whether they will be offered their audio tapes or videos.	Individuals will receive copies of interview transcripts. If they want a personal narrative written from this, they will receive a copy. All

participants will receive a draft and the final report on the Project.

13.6 If recordings are made, will participants be offered the opportunity to edit the transcripts of the recordings? ☑ Yes ☐ No

13.7 Is it intended to inform the participant's GP of individual results of the investigations, and their participation, if the participant consents? ☐ Yes ☑ No

If **no**, outline the reasons: The study is not relevant to the person's health care.

13.8 Will any restriction be placed on publication of results? ☑ Yes ☐ No

If **yes**, please supply details: Only to the extent that CCS has the right to view any proposed research articles before publication.

14. Treaty of Waitangi

14.1 Have you read the HRC booklet, "Guidelines for Researchers on Health Research involving Maori"? ☑ Yes ☐ No

14.2 Does the proposed research project impact on Maori people in any way? ☑ Yes ☐ No

14.3 Explain how the intended research process is consistent with the provisions of the Treaty of Waitangi

CCS does provide services to Maori and employs Maori staff. Appropriate processes for participation and protection of Maori have been developed, in partnership with the group in 14.4.

14.4 Identify the group(s) with whom consultation has taken place, and attach evidence of their support

CCS National Whanau Te Waka Whakapakari (see attached letter, Appendix 4).

14.5 Describe the consultation process that has been undertaken **prior** to the project's development

Consultation was undertaken through CCS' own established processes.

The Research Team met face-to-face in Wellington with CCS National Team members and Haimona Tawha, CCS National Taura whiri, to develop appropriate processes for Maori participation. This meeting was followed by a teleconference among three of the Research Team, Haimona Tawha, and another member of CCS Whanau group. An agreed protocol was then circulated to other members of the CCS National Whanau group by Haimona Tawha. (See Appendix 5 for agreed protocol).

14.6 Describe any ongoing involvement the group consulted has in the project

CCS National Whanau group members will be involved at each location, and at two planned feedback meetings at national level, during the project.

14.7 Describe how information will be disseminated to participants and the group consulted at the end of the project

A draft report will be circulated to all participants for feedback. All participants will be sent copies of the final report.

15. Other Issues

15.1 Are there any aspects of the research which might raise specific cultural issues? ☐ Yes ☑ No

If **yes**, please explain

15.1.1 What ethnic or cultural group(s) does your research involve?

Adults with physical disabilities and CCS staff – will not know before recruitment.

Describe what consultation has taken place with the group prior to the project's development

As the outline of the Project was developed before the Research Team was commissioned, this was not possible. However the details of the Project have been developed involving adults with physical disabilities (researchers on the team) and CCS staff at National level. (Maxeq Investments Ltd is also the research and consultancy arm of DPA, the national organisation of disabled people).

15.1.2 Identify the group(s) with whom consultation has taken place and attach evidence of their support

See above.

15.1.3 Describe any ongoing involvement the group consulted has in the project

N/A. See 15.1.1.

15.1.4 Describe how you intend to disseminate information to participants and the group consulted at the end of the project

All participants will receive a copy of the final report. Dissemination will also be undertaken to all major advocacy and disability service organisations in New Zealand. Dissemination will involve members of the Research Team and/or CCS National Team staff.

16. Genetics Check List

16.1	Does the proposed research study involve use of products made by genetic modification, analyses of DNA or clinical genetics? If it does not, proceed to question 17.	☐ Yes ☑ No
16.2	Have you read, and does your research comply with, the Guidelines "Ethical considerations relating to Research in Human Genetics? *Applicant responses to these questions may initiate a request from the Ethics Committee for more detailed information.*	☐ Yes ☐ No
16.3	Will the study involve administration of any products produced by genetic modification, other than licensed medicines?	☐ Yes ☐ No
	If yes, has approval from GTAC been obtained?	☐ Yes ☐ No
	If yes please describe.	
16.4	Information on Samples :	
16.4.1	Is tissue or body fluid samples for DNA analysis to be taken for :	*(tick all boxes which apply)*
a)	immediate analysis	☐ Yes ☐ No
b)	storage for future analyses	☐ Yes ☐ No
c)	analyses outside New Zealand	☐ Yes ☐ No
d)	analyses by individuals or organisations other than the study investigators	☐ Yes ☐ No
16.4.2	Describe processes for storage and disposal of samples taken for DNA analyses	
16.4.3	Up to what point would withdrawal of the sample or the data at the request of the participant be possible?	

16.5 Is personal and health information from individuals and DNA analysis to be linked? ☐ Yes ☐ No
If yes, please describe how confidentiality will be assured.

16.6 Are samples to be obtained from Maori? ☐ Yes ☐ No
If yes, please describe any relevant issues additional to Section 16.4.1

16.7 Will the study involve participant contact with a clinical geneticist? ☐ Yes ☐ No
If yes, please provide :

- the name of the clinical geneticist, and
- describe the purpose

16.8 Will provision be made where appropriate for genetic counselling? ☐ Yes ☐ No
If yes, please describe the process.

17. Ethical Issues

17.1 Describe and discuss any ethical issues arising from this project, other than those already dealt with in your answers?

In line with a participatory action research model the Research Team includes two disabled members from CCS itself – a member of the CCS National Team (Peter Wilson) and a local service user (Malcolm Cameron). Their inclusion aims to increase their knowledge and understanding of research, in order to promote leadership and professional development of disabled people, in line with the New Zealand Disability Strategy. Equally, their contributions are highly valued, for their immediate and current experience of a CCS service provider, and a service user. They will not facilitate any focus groups or undertake any interviews. Each of them will act as an observer and/or recorder for some focus groups. Each of them will be part of the Research Team in terms of reviewing data and contributing to its interpretation and analysis. They will be bound by the same standards of confidentiality as all other members. Malcolm Cameron is also on the Advisory Group for another Institute research project. Peter Wilson is not in a direct support role in CCS, nor does he have direct responsibility for any staff who may participate.

Thank you for your assistance in helping us assess your project fully

Please now complete:

- **the declarations (Part V)**
- **a drug administration form (if applicable)**
- **Form A or B relating to accident compensation**

PART V: DECLARATIONS

Full Project Title Community Participation Definition Analysis Project

Short Project Title : Community Participation Project

1. Declaration by Principal Investigator

The information supplied in this application is, to the best of my knowledge and belief, accurate. I have considered the ethical issues involved in this research and believe that I have adequately addressed them in this application. I understand that if the protocol for this research changes in any way I must inform the Ethics Committee.

NAME OF PRINCIPAL INVESTIGATOR (PLEASE PRINT): DR ANNE BRAY
SIGNATURE OF PRINCIPAL INVESTIGATOR:

DATE: 11 NOVEMBER, 2003

A separate declaration will be required for each multi-centre site, signed by the principal investigator for that site.

2. Declaration by Head of Department in which the Principal Investigator is located or appropriate Dean or other Senior Manager

I have read the application and it is appropriate for this research to be conducted in this department I give my consent for the application to be forwarded to the Ethics Committee.

NAME AND DESIGNATION (PLEASE PRINT): DR ANNE BRAY, DIRECTOR
SIGNATURE: INSTITUTION: DONALD BEASLEY INSTITUTE
DATE: 11 NOVEMBER, 2003 DESIGNATION: DIRECTOR

- ***Where the head of department is also one of the investigators, the head of department declaration must be signed by the appropriate Dean, or other senior manager.***
- ***If the application is for a student project, the supervisor should sign here.***

3. Declaration by the General Manager of the Health Service in which the research is being undertaken (if applicable) N/A

I have reviewed the proposal for cost, resources, and administrative aspects and issues regarding patient participation and staff involvement. The proposal has my approval subject to the consent of the Ethics Committee.

NAME OF GENERAL MANAGER (PLEASE PRINT):

SIGNATURE: INSTITUTION:

DATE:

FORM A

DECLARATION OF ELIGIBILITY OF A CLINICAL TRIAL FOR CONSIDERATION OF COVERAGE UNDER ACCIDENT COMPENSATION LEGISLATION

Instructions: This form is to be completed and the statutory declaration signed by the applicant. It should be forwarded to the primary Ethics Committee together with the documents seeking ethical approval for the proposed study.

If the study is a multi-centre proposal, this form should only be sent to the primary committee.

The information provided must be sufficiently detailed to enable the Ethics Committee to be satisfied that the proposed research is not conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the research is carried out.

The provision of this information will enable the ethics committee to be satisfied that participants in the clinical trial will be considered for coverage under accident compensation legislation, for injury caused as a result of their participation in the research.

DETAILS OF PROPOSED RESEARCH STUDY

- Title of research project:
- Name of Research Director/Investigator:
- Is the Investigator a Registered Health Professional — Yes No *tick or circle as appropriate*
- Location/s of proposed study:
- State number of participants:
- Organisations providing support ($ or "in kind") for the direct and indirect costs of the research.

Please provide names of organisations and the type of support provided.

- Relationship of proposed research to the pharmaceutical industry or other company involved in health research. Please describe the involvement of industry in your proposed research, and provide details of support to be received from them.

STATUTORY DECLARATION:

I____________________(name, of town/city)__________________ solemnly and sincerely declare that as director of the proposed research, the proposed study is not conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is carried out.

And I make this solemn declaration conscientiously believing the same to be true and by virtue of the Oaths and Declarations Act 1957.

Name (please print)	Signature	this day of

before me

Name (please print)	Signature

A Justice of the Peace, or
A Solicitor of the High Court
or other person authorised to take a statutory declaration.

Warning: Please note that it is an offence under part VI subsection 111 the Crimes Act 1961 to make a false statutory declaration.

Note: Applicants conducting a research study which is conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is carried out should complete Form B.

FORM B

DECLARATION OF PROVISION OF COMPENSATION FOR INJURY FOR PARTICIPANTS IN A RESEARCH STUDY FOR A PHARMACEUTICAL COMPANY OR ANY OTHER COMPANY INVOLVED IN HEALTH RESEARCH

Instructions: This form is to be completed and the statutory declaration signed by the applicant. It should be forwarded to the appropriate Ethics Committee together with the documents seeking ethical approval for the proposed study and appropriate assurance from the pharmaceutical company or any other company involved in health research.

The information provided must be sufficiently detailed to enable the Ethics Committee to be satisfied that:
- the proposed research is conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the research is carried out;
- participants in the proposed research project will receive an acceptable level of compensation from a Pharmaceutical Company or any other company involved in health research in the event of injury to participants resulting from their involvement in the proposed research study.

DETAILS OF PROPOSED RESEARCH STUDY

- Title of research project:
- Name of Research Director/Investigator:
- Location of proposed study:
- Number of participants:
- Organisations providing support ($ or "in kind") for the direct and indirect costs of the research. Please provide names of organisations and the type of support provided.
- Relationship of proposed research to the pharmaceutical industry or other company involved in health research. Please describe the involvement of industry in your proposed research, and provide details of support to be received from them.
- Details of Compensation to be provided to participants in the event of injury. Documents signed by the sponsoring Pharmaceutical Company or other company involved in health research must be attached.

STATUTORY DECLARATION:

I____________________(name, of town/city)__________________ solemnly and sincerely declare that as director of the proposed research, the proposed study is conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is carried out, and that in the event of injury arising from their participation in the research, an appropriate level of compensation, in line with the *New Zealand Researched Medicines Industry Guidelines on Clinical Trials - Compensation for injury resulting from Participation in Industry Sponsored Clinical Trials,* will be provided by ____________________ (name of Pharmaceutical Company or another company involved in the research project) as detailed in the attached documents.

And I make this solemn declaration conscientiously believing the same to be true and by virtue of the Oaths and Declarations Act 1957.

Name (please print)	Signature	this day of

before me

Name (please print)	Signature

A Justice of the Peace, or
A Solicitor of the High Court
or other person authorised to take a statutory declaration.

Warning: Please note that it is an offence under part VI subsection 111 of the Crimes Act 1961 to make a false statutory declaration.

Note: Applicants conducting a research study which is not conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the research is carried out should complete Form A

INFORMATION REQUIRED FOR TRIALS INVOLVING ADMINISTRATION OF DRUGS CURRENTLY REGISTERED IN NEW ZEALAND.

Trade name of drug:

Chemical name of drug

Pharmacological class:

Brief details of any special features:

(E.g., long half life, receptor selectivity)

Recommended dose range:

Form of administration in the study:

Known or possible interactions with non-trial drugs the participants may be taking:

Side effects and adverse reactions:

PART VI: WHEN A PARTICIPANT IS UNABLE TO MAKE AN INFORMED CHOICE

To be completed when one or more participants in a project will likely not be able to make an informed choice about whether to take part. ***Do not complete this section if all participants in the study will be competent to make an informed choice and give informed consent themselves.*** Refer to the Guidelines for information about children in research.

1. Will any of the participants have a person with them who is available and entitled to make an informed choice on their behalf if they themselves are unable to do so.

yes ☐
no ☐

If yes, that person can make a proxy informed choice for the potential participant. Include an appropriate consent form for that person legally entitled. (Note: Where possible the incompetent person should also orally consent to the level of his or her understanding.)

If no, complete section 1.1

1.1 **Is there any person interested in the potential participant's welfare who knows the participant (eg family member/friend/whanau) and is willing and available to express a view as to what the potential participant would choose were he or she competent and fully informed about the study.**

yes ☐
no ☐

If yes, include an information sheet for the family member/friend/whanau statement as per page 24.

Please note: if it is appropriate that there be wider consultation with family, then this should be encouraged

If no, complete section 1.2

1.2 Explain why it is not possible for a potential participant to make an informed choice and why it is not possible for a proxy choice to be made or for a person interested in the potential participant's welfare to state what the participant would choose if he or she was competent and fully informed.

2. What would be the risks to the participants of taking part in this study?

3. Could the research be carried out on people who are able to consent

yes ☐

no ☐

4. Explain why approval is being sought to use this participant/population/.patient group.

5. What is the potential health interest for the group of patients/population of which the participant would be a member?

(to be on letterhead)
(include the Lay Title at the top of each page)

STATEMENT BY RELATIVE/FRIEND/WHANAU

Lay Title ______________________________

Principal Investigator ______________________________

Participant's Name ______________________________

I have read and I understand the information sheet dated ____________ for people taking part in the study designed to ______________. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I believe that ________________________ (participant's name) would have chosen and consented to participate in this study if he/she had been able to understand the information that I have received and understood.

I understand that taking part in this study is voluntary and that my relative/friend may withdraw from the study at any time if he/she wishes. This will not affect his/her continuing health care.

I understand that his/her participation in this study is confidential and that no material which could identify him/her will be used in any reports on this study.

I understand that the treatment will be stopped if it should appear to be harmful. **(if applicable)**

I understand the compensation provisions for this study. **(if applicable)**

I know whom to contact if my relative/friend has any side effects to the study or if anything occurs which I think he/she would consider a reason to withdraw from the study.

I know whom to contact if I have any questions about the medication of the study.

This study has been given ethical approval by the __________ Ethics Committee. This means that the Committee may check at any time that the study is following appropriate ethical procedures.

I believe my relative/friend would agree to an auditor appointed by the sponsoring pharmaceutical company and approved by the __________ Ethics Committee reviewing my relative's/friend's relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study. **(if applicable)**

I/my relative/friend would like a copy of the results of the study. **YES/NO**

I believe my relative/friend would agree to his/her GP being informed of his/her participation in this study **YES/NO**

Signed: ______________________ Date ______________________

Printed Name: ______________________________

Relationship to Participant: ______________________________

Address for results : ______________________________

STATEMENT BY PRINCIPAL INVESTIGATOR

I (name of investigator) declare that this study is in the potential health interest of the group of patients of which (name of participant) is a member and that participation in this study is not adverse to (name of participant)'s interests.

(if applicable)
I confirm that if the participant becomes competent to make an informed choice and give an informed consent, full information will be given to him/her as soon as possible, and his/her participation will be explained. If the participant makes an informed choice to continue in the study, written consent will be requested and if the participant does not wish to continue in the study, he/she will be withdrawn.

Signed: ______________________________ Date ___________________________
Principal Investigator

(If applicable at a later stage)

I _________________________ (participant) having been fully informed about this study agree to continue taking part in it.

Signed: ______________________________ Date ___________________________
Participant

STATEMENT BY INDEPENDENT CLINICIAN

I confirm that participation in the study is not adverse to ___________________ (participant)'s interests.

Signed: ______________________________ Date ___________________________
Clinician

Printed Name : ____

Appendix 1: Additional Research Team Members

Appendix 2: Outline of Focus Groups with Service Users and Ground Rules

Appendix 3: Outline of Individual Interviews with Service Users

Appendix 4: Letter from CCS National Taura whiri

Appendix 5: Agreed Protocol to ensure culturally appropriate processes and participation for Maori service users and staff

Appendix 6: Information Sheets and Consent Forms

Appendix 1

Additional Research Team Members

Two other members have been co-opted onto the Research Team in line with the aims of "participatory action research":

- Peter Wilson, CCS National Services Manager
- Malcolm Cameron, service user, CCS Dunedin.

These team members represent the viewpoints of the two groups of participants – service users and staff. Their role will be to act as advisers, to fulfil an observer and/or recorder role at some focus groups, and to receive some experiential training in disability research. This latter role is in line with fostering leadership among disabled people, and developing the workforce of disabled researchers, as promoted in the New Zealand Disability Strategy.

Appendix 2: Outline of Focus Group procedures and questions

CCS – Community Participation Definition Project

Focus Groups' Schedule

Below are general instructions for conducting the focus groups for users of CCS services, and a list of discussion topics.

Preparation

1. Work with the local CCS coordinator to ensure that the following has happened. It will be these people's jobs to organise meeting details.
   - Make contact with the local Whanau group person in advance, to arrange for karakia and ensure that you are familiar with any local tikanga that is relevant to the group.
   - Ensure that an accessible and relaxing, non-CCS venue has been booked and physically checked out.
   - The meetings are planned for approximately 90 minutes followed by a light refreshment. (Most meetings to occur in the afternoon.)
   - The venue has white board or other equipment you may need.
   - The room is set out with (tables and) chairs in a circle or rectangle so all participants can see each other and their support person, and to facilitate recording.
   - A pool of non-CCS support people is available should it be needed for any participants for personal needs or for communication assistance.
   - Invitations have gone out to all relevant service users in the area.

2. Prior to the meeting contact Donald Beasley to book recording device if wanted. (The meeting won't be transcribed but this may help recorder's memory.)

Beginning the meeting (Each meeting will begin and end with karakia)

1. Provide people with name tags that are easily readable by all
2. Welcome people and explain the purpose of the research
3. Clarify the length of the meeting, what will happen and refreshments to follow
4. Go over the ethics of the research: confidentiality, voluntary participation, contribution will not affect their service. Remind them this is research and is not a CCS review.
5. Let people know they will get a copy of the outcome of the draft report to comment on, and the final report if they want one.
6. Check people are OK to be there

7. Talk about 'house-keeping' details: toilets, emergency procedures, available support, etc
8. Go over list of ground rules and check acceptability to the group
9. Do a quick round of self introductions

Discussion topics

Throughout this discussion, ensure that there are regular summaries of the discussion to ensure people are kept together. It will also be important to use plain language and concrete examples to explain concepts.

1. **What does the word 'community' mean?**
    - Could introduce this by talking about previous research indicating for some people it is about a place, a feeling of belonging, being with other people to do things with.
    - Use a brainstorming session to gather people's definition

2. **What are the ways people participate in their community?**
    - What does 'participate mean?
    - What are the range of ways people participate?
    - What do you do for fun, recreation or entertainment?
    - Are you involved in clubs or groups?
    - What does it mean to 'contribute'?
    - Where do you do things/ what sort of activities?
    - Who do you do things with?
    - Who are your friends?

3. **What are some of the things that help or hinder participation?**
    - What are some of the barriers to participation?
    - Does planning help you?
    - What planning tools have you used and which were the most useful?
    - What works when you are being supported?
    - What makes you feel good about being in the community?
    - What things make you feel uncomfortable in the community?
    - Do you feel part of your local community?

4. **What do you really want?**
    - What helps you get the things you really want?
    - What are the barriers to you getting what you really want?
    - Are you happy doing recreation and leisure things or would you rather be employed?
    - If you would rather be employed, what steps are you making towards it?
    - Whose responsibility is it to make sure you get what you want?
    - How did you come to this conclusion?
    - How have you achieved what you wanted?

  - Do other people (friends, family, carers, society) have a different idea of what you want?

Finishing the discussion

- Check that everyone has had a chance to say what they wanted to.
- Provide an overall summary of key points from the discussion.
- Thank everyone for their time and valuable contributions
- Explain what happens next, and their future feedback on the draft report.
- End with karakia.

Appendix 3: Outline of Individual Interviews

CCS – Community Participation Definition Project

Semi-structured Individual Interviews

The individual interviews will need to occur in a pre-arranged location where the person feels comfortable. They may take up to 2 hours and will be recorded.

Individuals will need to be reminded of:

10. The purpose of the research
11. The length of the meeting
12. Go over the ethics of the research: confidentiality, voluntary participation, contribution will not affect their service. Remind them this is research and is not a CCS review.
13. Let people know they will get a copy of their interview to change or add to.
14. Let people know they will get a copy of the draft report to comment on, and the final report if they want one.
15. Check people are OK to be there and if they need anything not already arranged.

Interview questions/ prompts

1. Tell me about the good bits of what you are doing in your life?

2. How did you get to where you are in your life?

3. What helped?

4. What had to be overcome?

5. What were the hardest bits?

6. Who were the key people who helped you?

7. What do you feel good about in your life?

8. What message would you give to other disabled people?

9. What message would you give to support services?

10. What other possibilities could you have tried?

11. Whose responsibility was it to make sure you got what you wanted?

At the end of the interview, ask: "Would you like your story written up to give other people ideas on how to support people to have a good life?" Explain that this could be either with their own name, or with some bits changed to protect their privacy.

Appendix 4: Letter from CCS National Taura Whiri

NEW ZEALAND
CCS

Dr Anne Bray: Director
Donald Beasley Institute
Research & education on Intellectual Disability
PO Box 6189
Dunedin

Ph: 0064-3-4798080
FAX: 03-4792162

Re: A contract by CCS to Donald Beasley Institute and collaboratively with
Maxeq Investment Ltd
Creative Solutions
Tautoko Services

This letter is to confirm a meeting between CCS and the above Researchers. Seeking a process of cultural appropriate consultation for researching the meaning and experiences of community participation for CCS service users identifying "current best practice" within service delivery

First meeting with all parties held Friday the 24th October CCS National Office Wellington, and another being a conference call on Tuesday the 4th November with the CCS National Whanau Te Waka Whakapakari committee chairperson.

That CCS Maori, will provide the appropriate support necessary to involve consumers that choose to take part, and that such support will reflect local tikanga. .

Such process is to include the right of choice by the consumer to nominate who should be present, when and where the interviews would take place.

For any further information please feel free to contact me.

(07) 8382744.
(1274) 868663. Mobile.

Haimona (Simon)Tawha
CCS National Taura whiri

A BETTER FUTURE FOR PEOPLE WITH DISABILITIES
86-90 Vivian Street, PO Box 6349, Marion Square, Wellington. Telephone (04) 384 5677, Facsimile (04) 382 9353
E-mail: ccsno@actrix.gen.nz

Appendix 5
Agreed Protocol to ensure culturally appropriate process and participation for Maori service users and staff

Dear Simon, Maudine, John, & Peter,

Thank you for your helpful contributions at our teleconference today.

From my notes taken at the meeting, we agreed on the following:

- Simon will consult with other members of the Whanau group who could not be at the meeting, to ensure that we have addressed all concerns.

- Simon will fax me a letter by Monday 10th 5.00pm, confirming our consultation over the research processes, to include with our Ethics Application.

- All clients (including Maori clients) who wish to bring a support person or persons with them to focus groups or interviews will be told they are welcome to do this.

- Interviews with clients will all be held at the client's choice of venue.

- All focus groups will begin and end with karakia. The local Whanau group member (or Regional Coordinator) will arrange for this to happen.

- As there are no CCS Whanau group members in the Wellington, Palmerston North and Nelson areas, Simon will accept responsibility for these areas, to ensure that local tikanga is respected.

- Simon will send Anne a list of Whanau group members and their contact details.

- Each researcher will make contact with the appropriate Whanau group member before undertaking focus groups in that area.

I hope my notes were accurate. Many thanks for you advice and help.

Warm regards,

Anne Bray

Appendix 6: Information Sheets and Consent Forms

- Information sheet for service users (adults with physical disabilities who use CCS services.
- Participant Interest Form: Service Users
- Consent Form: Service Users (Individual Interviews)
- Consent Form: Service Users (Focus Groups)
- Information Sheet: CCS Staff
- Participant Interest Form: CCS Staff
- Consent Form: CCS Staff

Information Sheet for Service Users
(Adults with physical disabilities who use CCS services)

Community Participation Project

What is this study about?

This study has been commissioned by CCS to learn from adult service users about "community participation". CCS wants to find out what "community participation" means for service users, and how CCS can provide the sort of support that service users want.

CCS has asked an independent research organisation – the Donald Beasley Institute – to carry out this study to ensure that it is objective and people feel free to give their views.

Who can take part in the study?

Adults who use CCS Community Participation services can take part, as long as they have some way of communicating their views. Adults will also need to be at least 18 years of age.

What do we want people to do?

There are two different ways you can choose to take part:

- in a <u>group</u> interview and discussion with other service users (about 7 other people)

OR

- in a face-to-face interview where you talk about your experiences of community participation to one of the researchers. For these interviews, we want to hear about positive experiences and how staff can provide good support. These positive examples can then help CCS to improve its services across New Zealand.

Will the information I give you be kept private?

The focus group and interview information will be kept private and will be used for this study only. It will only be seen by members of the Research Team.
The Research Team is:

Dr Anne Bray
Paul Milner
Ron Entwisle
Grant Cleland
John Taylor
Peter Wilson (CCS National Team)
Malcolm Cameron (CCS service user, Dunedin)

Peter Wilson and Malcolm Cameron will not know who takes part in individual interviews, and your name will not be on any interview records that they might study.

When we write about the study or talk about it when it is completed we will not use your name or any other information that may identify you. However, if you want to present your experiences as a positive story with your name on, you can choose to do this. You would also approve this story first.

What happens if I don't want to be involved in the study?

It is entirely your choice whether or not you take part in the study. If you do not want to be involved in the study, don't do anything. We have not seen your name and address and will only contact you if you contact us first. Whatever you choose to do, it will not affect the services you receive from CCS in any way.

What happens if I would like to be involved in the study?

Please fill out the Pink Form attached to this Information Sheet and post it back to Anne Bray in the Freepost, addressed envelope, within two weeks.

What happens if I want to take part in the study but I am not selected?

We would like to include everyone who wants to take part, but we may not be able to because we only have the resources for a limited number. If you are not selected, it is not because we don' t think you have anything important to tell us, but simply because we may not be able to talk to everyone we would like to.

However, we will send everyone who replies a draft report for you to comment on, and you will also receive a copy of the final report on the study.

What happens if I am selected?

One of the researchers will write to tell you and enclose a Consent Form. You will then need to read this carefully and sign it. Post the Consent Form back or bring this with you to the focus group or interview. We cannot include you in the study without your full, informed consent.

What do I do if I have any questions?

If you have any questions you can contact Dr Anne Bray or Paul Milner at the Donald Beasley Institute. The freephone number is

0800 878-839

or Donald Beasley Institute
P.O.Box 6189
DUNEDIN

There will also be a CCS staff person in each CCS branch who will be able to answer practical questions about being involved.
The person in your branch is ______________________________

If you have any concerns about the study and want to talk to someone outside CCS and the Research Team, you can contact a Health and Disability Advocate.
The contact nearest you is:

____

Adult service users: Participant Interest Form

Your name ______________________________

Your home address ______________________________

____

Your telephone number ______________________________

Your email address (if you have one) ______________________________

Which CCS Branch do you use? ______________________________

I would like to take part in the Community Participation study.

Please tick one or both of the choices below

- I would like to take part in a focus group with other service users ☐

I have a positive story to tell about my experiences of community participation, and I would like to be interviewed ☐

Please tell us a little about yourself

Are you a man or a woman? Man ☐ Woman ☐

How old are you? ______________

For how many years have you used CCS services? ______________

How many hours per week (approximately) do you receive CCS services for? ______________

What method of communication do you use?
(Please tick whichever apply)
Speech ☐

Sign ☐

Communicate device ☐
Please describe____

Do you need an interpreter to assist you with communication?

Yes ☐

No ☐

Thank you for your time.

Remember to post this form back within two weeks if you want to take part.

Service Users' Consent Form: Individual Interviews

If you want to take part in the study, please read this form very carefully, then sign at the end and return it in the envelope provided.

1. I understand that being part of this study means being part of a research project.

2. I have read or have had read to me the information about this study on community participation for adults with physical disabilities.

3. I understand the information I have been given and I have had a chance to talk about the study with a researcher, if I wanted to.

4. If I wanted to, I have been able to ask questions and I am happy with the answers I have been given.

5. I understand that taking part in the study is voluntary (my own choice) and that I can stop taking part in the project at any time.

6. If I do stop taking part in this study I understand that this will not affect the quality of the services I receive now or in the future from CCS.

7. I understand my participation in the research is confidential and that my name will not be used by the research team when they write about this project.

8. I have had enough time to decide whether or not I wish to take part in the study.

9. I understand that my participation in this study will involve me being interviewed by a researcher about my experiences of community participation and that interview will be tape recorded.

10. I understand that I can ask to have the tape recorder turned off at any time during the talk.

11. I understand that the discussions the researcher and I will have during the interview will be used as information for the study.

12. I know that the researchers may also take notes during the interview.

13. I know that I have the chance to check what I have said during the interview, and that I can make changes at this time.

14. If I give written responses to the interview questions I understand that these answers will be used as information in the study.

15. I know that I can bring a support person or whanau with me if I wish.

16. I understand that I will receive a draft report on the study findings, to comment on.

17. I understand I will receive a copy of a final report on the findings of this study, and that there will be a delay between my taking part in the study and receiving the final report.

18. I know that if I have any questions or worries about my right as a participant in this study, that I contact a Health and Disability Services Consumer Advocate. The telephone number is ________

19. I know I can contact Dr Anne Bray or Paul Milner at the Donald Beasley Institute if I have any questions about the study and that I can ask questions at any time during the study.

The toll free number~~s~~ is: **0800 878 839**

20. I know that a local CCS staff person has been appointed to ensure that all the practical arrangements have been made so I can take part in the research.
This person is____
______

Please fill in:

Your name ____
______

Your signature ____

Date ____

Service Users' Consent Form: Focus Groups

If you want to take part in the study, please read this form very carefully, then sign at the end and return it in the envelope provided.

1. I understand that being part of this study means being part of a research project.

2. I have read or have had read to me the information about this study on community participation for adults with physical disabilities.

3. I understand the information I have been given and I have had a chance to talk about the study with a researcher, if I wanted to.

4. If I wanted to, I have been able to ask questions and I am happy with the answers I have been given.

5. I understand that taking part in the study is voluntary (my own choice) and that I can stop taking part in the project at any time.

6. If I do stop taking part in this study I understand that this will not affect the quality of the services I receive now or in the future from CCS.

7. I understand my participation in the research is confidential and that my name will not be used by the research team when they write about this project.

8. I have had enough time to decide whether or not I wish to take part in the study.

9. I understand that my participation in this study will involve me taking part in a group with about 7 other CCS adult~~s~~ service users, The questions and discussion will be about what community participation means to us, and about our own experiences.

10. I understand that notes will be taken of the group's discussion, and it may also be audiotaped to provide "back-up" to the notes.

11. I understand that the group discussion will be used as information for the study.

12. I understand that I can ask for anything I say in the group <u>not</u> to be recorded.

13. I know that I can bring a support person or whanau with me if I wish. I understand that these persons cannot be CCS staff members, and cannot take part in the discussion, except to support me.

14. I understand that I will receive a draft report on the study findings, to comment on.

15. I understand I will receive a copy of the final report on the findings of this study, and that there will be a delay between my taking part in the study and receiving the final report.

16. I know that if I have any questions or worries about my right as a participant in this study, that I contact a Health and Disability Services Consumer Advocate. The telephone number is _____

17. I know I can contact Dr Anne Bray or Paul Milner at the Donald Beasley Institute if I have any questions about the study and that I can ask questions at any time during the study.

The toll free number is: **0800 878 839**

18. I know that a local CCS staff person has been appointed to ensure that all the practical arrangements have been made so I can take part in the research.
This person is_____________________________________

Please fill in:

Your name _____________________________________

Your signature _________________________________

Date ____

Information Sheet for staff

Community Participation Project

What is this study about?

This study has been commissioned by CCS to learn from adult service users about "community participation". CCS wants to find out what "community participation" means for service users, and how CCS can provide the sort of support that service users want.

CCS has asked an independent research organisation – the Donald Beasley Institute – to carry out this study to ensure that it is objective and people feel free to give their views freely.

Who can take part in the study?

Adult service users from five different CCS regions have already provided their input through focus groups and individual interviews. This has resulted in an interim report on these findings.

CCS staff who work in Vocational Services providing support for community participation are now being invited to take part. Staff from two different CCS regions are being invited to help identify 'best practice' in providing support for community participation, and any other implications from the service users' responses.

What do we want people to do?

Those staff who choose to be involved will

- read and think about the interim report which will be sent to them one week before the focus group,

- take part in a focus group with about 6 other CCS staff from that region, to give feedback and discuss the findings in the interim report.

Will the information I give you be kept private?

The information from staff focus groups will be kept private and will be used for this study only. The records of discussion will only be seen by the independent researchers on the Research Team. These people are:

Paul Milner
Ron Entwisle
Grant Cleland

John Taylor

When we write or talk about the study when it is completed, no staff name or CCS region will be used. Individual staff contributions in the focus groups will not be able to be identified.

What happens if I don't want to be involved in the study?

It is entirely your choice whether or not you take part in the study. If you do not want to be involved in the study, don't do anything. We have not seen your name and address and will only contact you if you contact us first. Whatever you choose to do, it will not affect your employment at CCS in any way.

What happens if I would like to be involved in the study?

Please fill out the Yellow Form attached to this Information Sheet and post it back to Anne Bray in the Freepost, addressed envelope, within two weeks.

What happens if I want to take part in the study but I am not selected?

The focus groups will be limited to 6-10 staff. We would like to include everyone who wants to take part but may not be able to.

However, we will send everyone who replies a draft report for you to comment on, and you will also receive a copy of the final report on the study.

What happens if I am selected?

One of the researchers will write to tell you and enclose a Consent Form and an Interim Report to read. Please read the Consent Form carefully, sign it, and post it back or bring it to the Focus Group with you. We cannot include you in the study without your full, informed consent.

You will be informed as to where and when the focus group will be held. CCS will treat the 2-3 hours involved as part of your paid employment.

What do I do if I have any questions?

If you have any questions you can contact Dr Anne Bray or Paul Milner at the Donald Beasley Institute. The freephone number is

0800 878-839

or Donald Beasley Institute
P.O.Box 6189
DUNEDIN

There will also be a CCS staff person in each CCS branch who will be able to answer practical questions about being involved.
The person in your branch is ____

If you have any concerns about the study and want to talk to someone outside CCS and the Research Team, you can contact a Health and Disability Advocate.
The contact nearest you is:

____

CCS staff: Participant Interest Form

Your full name: ______________________________

Your home address: ______________________________

Your telephone number: ______________________________

Your email address (if you have one): ______________________________

Which CCS branch do you work in? ______________________________

The following information will help us to select a range of CCS staff:

What is your current position/title? ______________________________

How many service users do you support in community participation? ______________________________

____

How long have you worked for CCS? ______________________________

Which age group are you in?(*Please tick*)

Under 30 years	☐
31-40	☐
41-50	☐
51-60	☐
61+	☐

Thank you for your time.

Remember to post this form back within two weeks if you want to take part.

CCS Staff Consent Form

If you want to take part in the study, please read this form very carefully, then sign at the end and return it in the envelope provided.

1. I understand that being part of this study means being part of a research project.

2. I have read or have had read to me the information about this study on participation for adults with physical disabilities.

3. I understand the information I have been given and I have had a chance to talk about the study with a researcher, if I wanted to.

4. If I wanted to, I have been able to ask questions and I am happy with the answers I have been given.

5. I understand that taking part in the study is voluntary (my own choice) and that I can stop taking part in the project at any time.

6. If I do stop taking part in the study I understand that this will not affect my employment at CCS in any way.

7. I understand my participation in the research is confidential and that my name will not be used by the research team when they write about this project.

8. I have had enough time to decide whether or not I wish to take part in the study.

9. I understand I will be sent a report to read in preparation for the focus group.

10. I understand that my participation in this study will involve me taking part in a group with 5-9 other CCS staff. The questions and discussion will focus on the findings in the report I would have read.

11. I understand that notes will be taken of the group's discussion, and it may also be audiotaped to provide "back-up" to the notes.

12. I understand that the group discussion will be used as information for the study.

13. I understand that I can ask for anything I say in the group <u>not</u> to be recorded.

14. I understand that I will receive a draft report on the study findings, to comment on.'

15. I understand I will receive a copy of a final report on the findings of this study, and that there will be a delay between my taking part in the study and receiving the final report.

16. I know that if I have any questions or worries about my right as a participant in this study, that I can contact a Health and Disability Services Consumer Advocate. The telephone number is ________

17. I know I can contact Dr Anne Bray or Paul Milner at the Donald Beasley Institute if I have any questions about the study and that I can ask questions at any time during the study.

The toll free number is: **0800 878 839**

Please fill in:

Your name ______________________________

____

Your signature ______________________________

Date ______________________________

Appendix 2: Focus Group Ground Rules

FOCUS GROUP GROUND RULES

1. Be here on time.

2. Keep what is said in the group to yourself. This means keep it confidential. You cannot tell anyone outside the group what other people in the group said.

3. Try not to interrupt when someone else is talking. “One at a time”.

4. Listen to each person speak, and think about what they are saying.

5. Take the opportunity to give your views about the topics being discussed.

6. Value everyone’s ideas even if you don’t agree with them yourself.

7. Support people cannot talk unless they are interpreting for the person they are supporting.

Appendix 3: Preliminary Analysis for Staff Focus Groups

CONFIDENTIAL DRAFT; PLEASE DO NOT COPY OR DISTRIBUTE

CCS Preliminary Analysis

What is "community?"

"getting out and about"
"being out of the home with people"
"out having fun"
"out there, being accepted for who you are"
Getting out and about. Do I need to be more precise."

1. When people spoke to us about what community meant, they almost always emphasised getting out. Participating in the community was seen by many as a journey from known places to less well known. It was about being "out there" rather than "getting in there"
2. Sometimes it's easier to define something by saying what it is not. Because of the way most people saw "community participation," the places that they viewed as <u>not</u> being part of the community varied in a fairly predictable way. Although many people were proud of their home, most believed home was not part of the community. The important exception was when people lived independently in their own flat and saw their independence as an important sign of citizenship of their community. The community was not generally thought to be found in a Vocational Centre and even fewer believed it was being in a Sheltered Workshop.
3. This is not the way academics have thought about community. Theorists have focused on how people "experience" community and argue that the "places" most people nominate as their community tend to have a number of important characteristics. These include familiarity, comfort, predictability, being known, feeling valued. These are said to underscore a sense of belonging to communities. They contrast this with "anomie" or the sense of freedom, unpredictability and anonymity of "space." This suggests that being in the community carried other meanings and functions for many participants. (4,5,6,7)
4. One of the reasons may have been participants' sensitivity to the segregation of these settings. The home and Vocational Centre/Workshop were where many residents spent a good part of their time. Because they are places for people with disabilities only, some people saw them as the opposite of being in the community and used metaphors like, "*feeling stuck*" or *"hemmed into these places,"* where *"no one knows you from outside that group."*
5. Not surprisingly therefore, many peoples' definitions of community included notions of it being a place from which to draw a sense of "acceptance." A key characteristic of "community" was seen to be that it represented a space occupied by people with and without disabilities. Great pleasure was often derived from being recognised and embraced in public. "I love being about, everyone waves..." or "I feel lucky because I am accepted when I go out, although it might be different for others because I am always out there," were common sentiments.

6. Many people also saw the community as a place where people were able to transcend disability *"and be accepted for who you are."*
7. And finally, being out in public was seen by some participants as important in its own right. Public "spaces" became political spaces that through occupation and public visibility people felt they demonstrated their right to be there. By "being out there" they pushed against the weight of personal and public prejudice.

But, but, but.....is this it!

8. We can be quite confident that this is not the whole story for a number of reasons.
    a. Peoples' definitions of community usually wove their way back to stressing that it was about doing things with other people.
    b. The need to feel safe, supported and valued were important when people went out, and conversely, fear and the lack of confidence emerged as important barriers to participation .
    c. The "places" people returned to and valued were those places that they were familiar with, were recognised, felt treated with respect, liked and valued.

9. It was not where people participated that was important to them, it was how they were treated when they were there.
10. People could be made to feel "disabled" in inclusive community settings. For example, one person described being part of a service led fitness programme at a gym in town where they were expected to complete the programme in a separate room from the main gym area. They described this as making them feel like an "outcast" This person described feeling worse off in an integrated setting and contrasted it with another CCS programme which was well supported and organized by CCS were 13 people with disabilities completed a fitness programme together in the main gym area where other gym members interacted with them and they had the security of each others' company.
11. The sorts of things people described as characterizing good community participation, irrespective of the context, included being treated as an equal, getting the support required to show one's potential, having relationships based on respect and mutual friendship, meeting new friends, being told about opportunities and being challenged to try new things.
12. Some people felt segregated settings like the Vocational Centre offered them more and liked being in programmes with other people with disabilities because they felt they got better support, greater opportunities and more effective coordination of services.
13. The vocational centre was highly valued by some participants, because they were places sensitive to their individual needs.
    a. Important relationships were forged and maintained there (most often with staff)
    b. A greater level of intimacy meant people were able to disclose something of their private selves. Participants were able to share a joke, add value to others lives, express their fears and so on.
    c. They were known and predictable spaces "*I know it inside out*"
    d. They had a social identity there.

    e. They were immersed in a caring environment that they were equally able to contribute to through relationships of reciprocity.
    f. They were able to communicate more effectively and have their intimate and personal support needs met in comfort (psychological safety)

14. Vocational Centres were important to some as a destination away from home that required purposeful effort to get to and which broke the ordinary rhythm of life. When asked directly, many participants wanted support to come from their vocational service rather than be delivered exclusively to them at home.
15. Participants who were more actively involved in the community however, appeared to make least use of a centre.
16. Similar to the way that participants initial responses to the definition of community obscured the ways that settings like the vocational centre were sometimes valued, participants didn't seem to acknowledge the significance of other service users. And yet, a community was quietly expressed during the Focus Groups in the way that people would fetch sandwiches, those who were able unassumingly write name badges and people who were more confident quietly prompted others about the ways that they knew them to contribute or participate. Participants appeared to be unconsciously bound up in each others field of care.
17. People that reported gong out more often and to more places also seemed to have the largest number of disabled friends. This is consistent with research that has found that people with disabilities who report the greatest level of satisfaction with their lives also have the highest number of disabled friends.
18. Different places within the community appeared to meet different needs. Public spaces were important to occupy, gain a sense of recognition, expose oneself to the potential of forming new relationships and have fun in, whereas private settings were important as locations of psychological comfort and self-disclosure.

What ways do people participate in their communities?

1. People participated in their communities in many different ways. For most people, activity included a mix of involvement in segregated programmes, organised activities in community settings and informal social networks. However, most identified support staff, family and carers and other people with disabilities they met through shared service use as the key people in their lives. These were also the people they were most likely to do things with. Most considered they had few friends.

Getting a handle on forms of participation

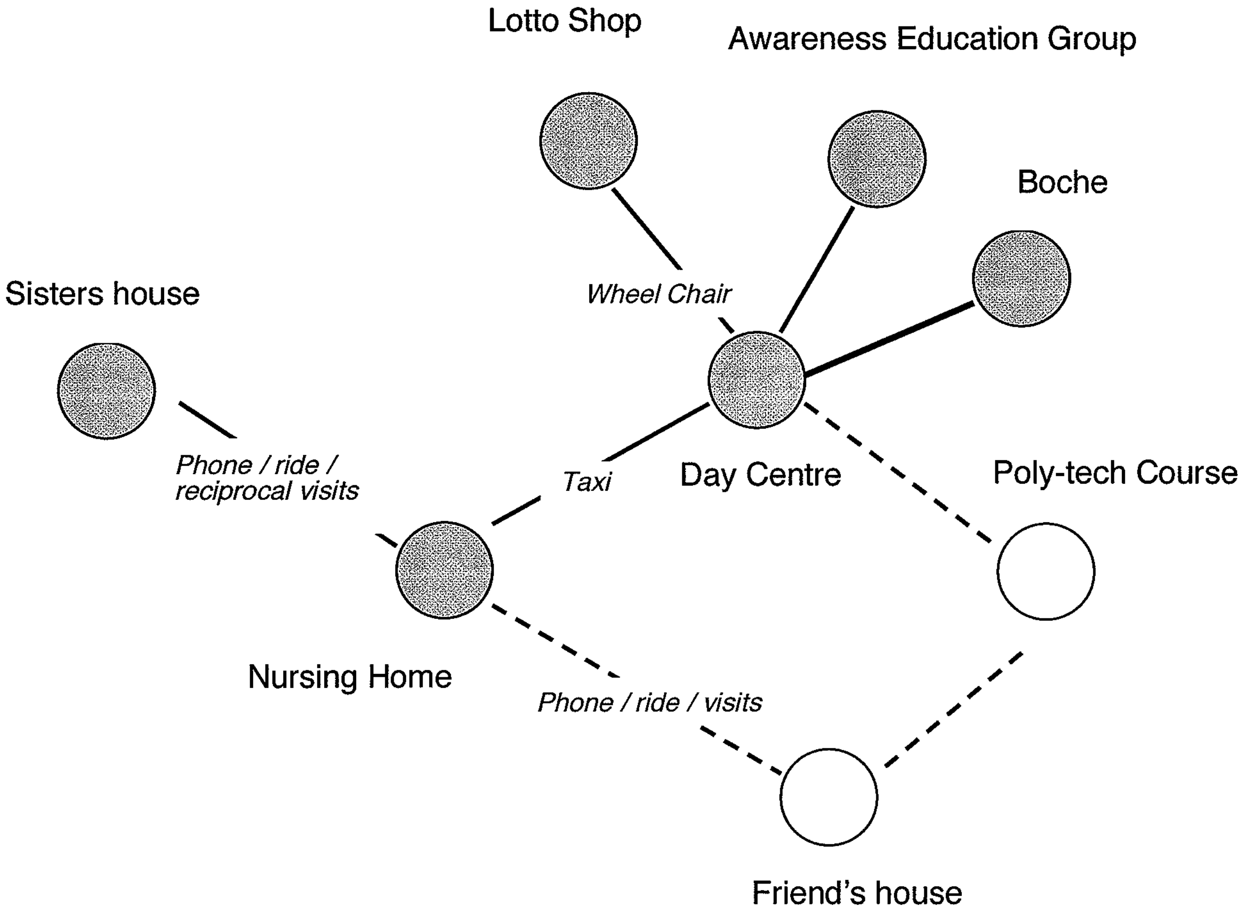
In the 1960s, American sociologist, Kevin Lynch suggested that the way people come to know, navigate and act in their communities depends on their "mental map" of where they live. Although everyone's is unique, he believed that they all shared some common features. Amongst those were "Nodes" and "Pathways." Lynch described Nodes as centres of attraction and activity that people knew more intimately and felt more comfortable in. And "Pathways," to be the familiar routes and ways that people used to connect their network. It is a good way to think about people's community participation because it gives us a model of the range and types of activity people engage in. It also gives us a useful frame of reference for thinking about the ways that certain places (Nodes) become attractive to or are hostile to people with disabilities and what helps or hinders their passage their (Pathways)

People's mental maps are different because their lives are different. Pamela's story below is not one person's life, but a blending of some of the stories we heard. It is a gross simplification and is not representative of all participants, but it does illustrate many of the themes we found when service users spoke to us.

Pamela's Story

Home and the Day Centre are the two places that Pamela spends most of her time. During the week she journeys between them by taxi. In the weekends, visits to her sister have become an important and highly valued routine. Once a week Pamela will go out to the Lotto shop for her ticket. She always goes to the same one because the shopkeeper now knows her and has taken the time to understand her speech. A team leader at her service invited Pamela to join a number of other clients who visit schools and workplaces to educate them about disability issues. It is the first paid employment she has ever had, and even though it is irregular it is one of the things she is most proud of in her life. When Pamela introduces herself, she tells people she is an Awareness Educator. Pamela also plays Boche every Wednesday in a group organised by her Day Centre and she says she sometimes goes for "walks" with other clients from the Day Centre, but doesn't like being in the community in a big group. She says she would like to choose when and where and who she goes out with. Pamela used to do a Health and Wellbeing

Course at Poly-tech, and even though she felt it was it was a little beneath her, she loved being amongst people and learning new things. She met a friend there who she used to phone and occasionally had a coffee with. Once the course finished it was difficult to keep in contact and she hasn't seen her since. Pamela wishes there were more opportunities to continue with her education. Pamela said she did not belong to any organised clubs and said that solitary activities like handicrafts was what she liked to do for fun. Pamela rated her level of community participation as quite high and said that on the whole she was happy with her level of inclusion (Although she really wished she had some friends to go out with). She seemed to reach this conclusion by comparing her present life, to her past as well as to the potential for greater isolation given her impairment. Pamela was a bit reticent to discuss any other hopes she held for herself and didn't really know about her service plan or feel that any system of formal planning had been especially useful.



Pamela story has been put together from little bits of everybody's conversation. Although not real, her life is reflective of many of the themes to emerge from our dialogue with service users.

2. For some, the Vocational Centre was the foci of their participation. Most of their activities radiated out, or were supported by it it.
3. Even though they enjoyed them, many participants' activities appeared to reflect more authorised forms of participation. 10-Pin Bowling, Boche, Gym and needlecraft featured strongly as forms of participation. There were some noteworthy exceptions (duck shooting, surfing, internet dating, watching league). However, these tended to be activities that had happened outside of service provision. (family interests, lifestyles prior to impairment or private interests)
4. Family, organised religion and work were extremely important and highly valued sources of inclusive participation
5. The forms of activity that were most highly valued and participants sought to sustain, were those in which they felt they had a positive or valued role and/or were known. Pamela was proud of her work and kept returning to the Lotto shop because she had built a relationship with the person over time.
6. Participants frequently mentioned a desire to contribute or add value to their community. One person described it as *"doing value."*

"doing value"

Y "Doing things for others makes me feel real."
R Do you get many opportunities to do that?
Y "No"

"A lot of people are helpers and I am a helpee. I try to help out in some way whenever I can, like whenever I go out I am on constant litter patrol, like cleaning up rubbish on my way into town and back. I like to look on that as my community service sort of thing"

In a literature review of research that has looked at the community participation of people with intellectual disabilities, Anne Bray makes the point that 'service user" 'client" 'disabled" or "recipient of support" are identities that imply dependency and limited social currency. People's desire for employment and to find other ways to contribute to their community might reflect aspirations to find alternative ways to make themselves known because of the way they have been cast and treated.

7. Nodes were contagious. The more you had the more you were likely to catch by exposure to other people's networks.
8. Community participation did not always occur in a public places. Some of the most meaningful forms of engagement were placeless and included, use of the internet, pride at mastering the phone, immersion in the rhythms of the neighbourhood, inviting friends/family home or the community in to the vocational centre, belonging to a hobby club/special interest and being kept in touch by newsletters and exchange.

9. Friendships, for most, appeared to be restricted to the contexts in which they participated.
10. Friendships also tended to be fleeting because they were difficult to sustain.

It is people, it is people, it is people.

Pat Fratangelo runs a Supported Living Service in Chicargo. At a recent Supported Living Conference in New Zealand, she provocatively stated that the role of services was to find, nourish and relinquish people to communities that love and believe in them.

Almost all service users said that community meant *"being with others"* and their stories spoke of the importance of human relationships to *"getting out there."*

11. Participants who had the largest number of disabled friends appeared to have the widest array of places where they engaged with their community.
12. A possible reason for this was that, going places with friends appeared to play a significant role in mitigating fears of community hostility and or of lack of self-confidence. Some liked going out in groups, but there appeared to be a difference between meeting a group of disabled friends socially and going with a group from a vocational centre or with staff. Participants were wary of forms of participation that would lead to a disabled identity.
13. It was often people's informal networks that meant they could take a role in their community.

Janet and John's Story

John lives in his own flat. He has recently moved to a small rural community, and although he does get a few, structured support hours, it is his informal support network that keeps him engaged and feeling safe in his community.

"....fortunately my next door neighbour, Mary, she gives me a lift there and back because it's quite a long way on the other side of town.....I can pretty much look after myself. Sometimes I need some help but I was fortunate to meet my good friend Meghan who helps me out whenever I need some help or if she is unavailable then I just call Sue next door or someone at the church"

Janet lives in a large rest home. All of her supports come from the formal support services. Janet eloquently describes the position of vulnerability she is placed in because paid staff are her only conduit to the community and lifestyle she wants for herself.

"I have learnt patience.....(it's) very frustrating. I get sick of looking at four walls, but hey, doesn't everyone so its just a matter of keeping my cool..... The hardest bits are when you haven't got staff to take you were you want to go......" (barriers are) *"mainly staff because there is not enough staff and three hours is not enough for me..... I wish I had more so I could get out more, meet more people, get other people interested in me."*

What helps or hinders participation?

The people who spoke to us were able to name a great range of barriers to participating in their community. Most barriers (perhaps not surprisingly) were environmental and related to the design or behaviour of people that didn't make accommodation for their impairment. Naming barriers outside of one-self, can imply a lack of control over the institutions that shape one's life and a belief that others are more able to alter personal circumstances.

Service Users identified a range of barriers to participation that could be classified as Community, Service or Personal Barriers.

Community Barriers

1. Limited income (benefit) and limited opportunities to earn additional income
2. Discrimination in employment
3. The inaccessibility of friends' houses
4. Community hostility or the fear of being made fun of. *".....now it's just personally within myself. I don't feel like I am free to join in the community because people just make fun of me."* Some participants were especially sensitised to young/teenage cohort.
5. A perceived lack of appropriate opportunities for continuing education.
6. Problems of mobility, such as the availability and cost of taxis, physical barriers like stairs, lack of alternative forms of public transport, puddles!
7. Proximity to community resources. Because of the imperatives of "normalisation" people with disabilities often find themselves in suburbs that had originally sprung up to house a newly mobile middle class. Motorcars meant town was within easy reach and communities were left bare of shops and pubs and theatres and other public facilities. Relationships take place over distance now too. They tend to be drawn from communities of interest rather than place and our neighbour is often a stranger to us. *"Milton is refreshing compared to Dunedin.... Dunedin was harder because it was bigger.....its much easier to get around and the people are much friendlier."*

Service Barriers

8. Lifestyles limited by the <u>imagination</u> of supports and <u>lack of belief</u> in potential (participants frequently returned to the theme of needing to prove themselves) Low expectations were found to be universally disabling.
9. Communication: barriers to communication tended to be perceived as a deficit in understanding. For people with communication difficulties time and patience was essential for them to feel comfortable identifying their participatory hopes and aspirations.

10. It wasn't just time but what happened in that time that participants' thought was critical to being known and shaping the course of their lives. Influential American disability writer, John O'Brien talks about the sorts of relationships that lead to good support being built on "wasted time." Time spent hanging out talking about the seemingly unimportant stuff that really make you who you are. Busy staff, institutional practice and programmes that see being out in the community as a service outcome can all eat into peoples "wasted time." In various different ways, people described this as a barrier to the sorts of community participation they wanted. One person commented *that "....for them to know me, (I need to be somewhere) so I can talk about my life,"* and another *"Well I wish they had more time to sit down and say, hey let's go somewhere"*
11. Some non-verbal participants seemed to struggle with primitive forms of communication and self-expression.
12. A number of participants expressed the view that you had to keep asking to get the things you wanted.
13. The absence of ownership of planning processes: despite the contractual obligation on services to engage service users in a form of support planning (and the investment made by services and support staff), most participants were unaware of any system of planning and those who were, typically found the process of limited use. One person, however, invested heavily in his plan, believing it to be one of the ways he was able to hold the service accountable to his aspirations.
14. Participants also identified the need to plan more than other people to make things happen. Rather than have staff solve their problems for them, people wanted staff to help them solve their own. Services can often short circuit this process when they assume it is their responsibility to have answers or believe the are likely to reach them faster.

Personal Barriers

16. Lack of confidence
17. Unfamiliarity with community settings (social skill set)
18. Lack of friends, constrained life-space and difficulty gaining access to other people's networks, lack of integration or continuity between "islands" of community participation.

What helps

1. Access to technology that erodes the distance of space. The internet, telephone and texting
2. Buddy programmes
3. Work and volunteering
4. Faith in participants' ability and sometimes, being pushed to try new things
5. Finding your way into other people's networks
6. Friends
7. A supportive family; the support (or otherwise) of family appeared to exert a very powerful influence over people's attitudes towards impairment, the level and breadth of community involvement, the horizon of possibility and responsibility for one's lifestyle
8. A good self image (and often reaching some form of personal resolution around one's impairment)
9. Valued roles
10. A sustained and regular presence in community settings
11. Honestly discussing barriers and fear and coming up with strategies for dealing with them. For example, when the group discussed the fact that some people avoided places for fear of public reaction others volunteered the ways they used to quieten the same fear.

The importance of employment

1. Perhaps the clearest finding was of the importance of employment to participants. Wanting to work was a universal aspiration and those that did, took great pride in their work. People's jobs had become incorporated into their sense of who they were (no different to the able bodied community)
2. Employment appeared to be valued as signposting membership of communities beyond disability. It was equally valued as source of precious income, gave pleasure, and seemed to offer participants their best opportunity to interact with the public (in a valued role).
3. The benefits of being engaged in volunteering were perceived by most to outweigh the cost of not being rewarded materially for their labour
4. The segmented approach to Government Funding appeared to steer people with more severe, multiple disabilities towards forms of community participation alternative to employment. Paradoxically, employment appeared to be most important to this cohort. Less disabled participants were more likely to be more ambivalent towards work (valuing time and opportunities for expression through lifestyle more highly)
5. The centres that appeared most successful at finding employment for service users blurred the boundary between MSD and Supported Employment Contracts.
6. People wanted more transparency about how to find work and how services were helping them to do so.

Appendix 4: Structured Feedback Form

FEEDBACK FORM ON THE DRAFT REPORT ON COMMUNITY PARTICIPATION PROJECT

Please give us your comments under each of the questions.

At the end there is space for you to add any other comments.

1. **How did you take part in the project? Please tick all of the ways you participated.**

   Service User Focus Group ☐

   Service User Individual Interview ☐

   Staff Focus Group ☐

2. **How Should the Report refer to CCS service users (as a group)?**

   We have used a variety of terms in the Report. We want you to tell us which you prefer. Please tick the one you prefer:

   Disabled people ☐

   People with disabilities ☐

   People with impairments ☐

   Impaired people ☐

   Service users ☐

3. **Chapter 3: How people with disabilities participate in their communities now**

   This chapter reports on what we were told by service users.

   Are you happy with how this has been written up?

   Yes ☐ No ☐

Do you have any comments on this chapter?

Please list any improvements we could make:

Chapter 4: An analysis of community participation from the viewpoint of people with disabilities

This chapter also reports on what service users told us. Much of the chapter is in their own words.

Are you happy with how this has been written up?

Yes ☐ No ☐

Do you have any comments on this chapter?

Please list any improvements we could make:

____

____

____

____

Chapter 5: Employment and family: Contexts for Community Participation (Family section not yet written)

Are you happy with the Employment section of this chapter?

Yes ☐ No ☐

Do you have any comments on this chapter?

____

____

____

Please list any improvements we could make:

____

____

____

____

Chapter 6: What helps and hinders being part of communities?

Are there any points we have missed out?

Yes ☐ No ☐

If you have answered 'yes', please list those points here.

Chapter 8: The challenges of community participation: Views of CCS staff.

Have we covered the important points raised in the Staff focus groups (only staff can answer this!).

Yes ☐ No ☐

If no, please list points not covered.

Chapter 9: implications for policy and practice, and for people with disabilities themselves.

People with disabilities themselves

Have we identified the most important implications?

Yes ☐ No ☐

If no, please list other implications.

CCS and other service providers.

Have we identified the most important implications?

Yes ☐ No ☐

If no, please list other implications.

Policy and policy implementation

Have we identified the most important implications?

Yes ☐ No ☐

If no, please list other implications.

____

____

____

____

____

____

Other comments

Please add any other comments you wish to make about these chapters of the Draft Report. We value your feedback – this is your Report.

____

____

____

____

____

____

Please post your completed form **and** the Draft Report back to us in the stamped, addressed envelope before Monday, 2 august.

Thank you very much for your contribution to this Report.

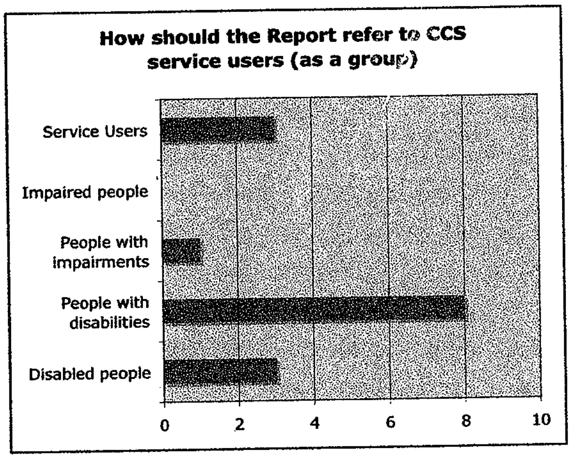
Anne, Paul, Grant, John, Ron & Pete.

Appendix 5: Summary of Feedback to the Draft Report

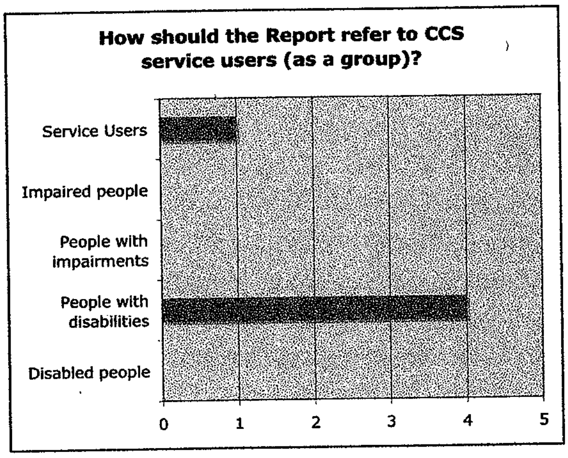
SUMMARY OF FEEDBACK TO THE DRAFT REPORT ON COMMUNITY PARTICIPATION PROJECT

How should the Report refer to CCS service users as a group?

People with disabilities

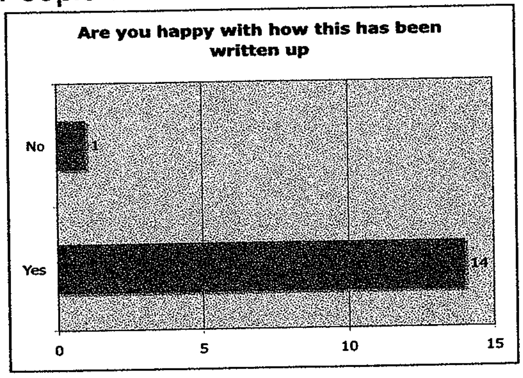


Staff



Chapter 3: How people with disabilities participate in their communities now

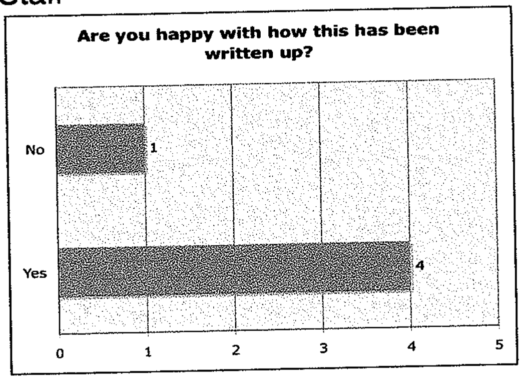
People with disabilities



Comments

- No (comments) but I'd still like a job. I want to get off the benefit
- Should be more employers willing to employ disabled people
- Should include sports events + competition also attending marae based events
- Making friends is really hard – Would like more friends in the community. Like coming to CCS but enjoy community activities
- I suggest that service providers stay committed, consistent, understanding etc Human values. There's always room for improvement, putting them into practice is the key.

Staff

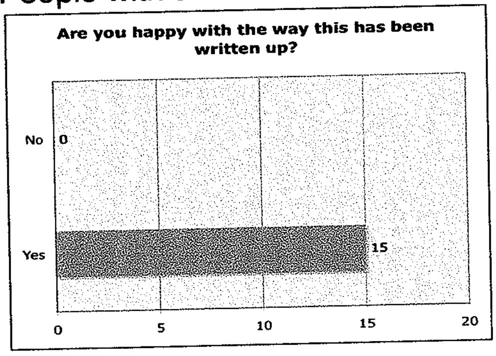


Comments

- Very comprehensive + detailed. More visual aids eg graphs (would be useful)
- My main concern is the language used. It needs to be made simpler. It is written using language that can be understood by a select group of "professionals." The long words and abstract phrases detract from the meaning.....These are not highly technical ideas/concepts. For example; "small life-space" & "limited life-space." "contribute to relationships through a financial transaction" People 'purchased' community engagement"

Chapter 4: An analysis of community participation from the viewpoint of people with disabilities

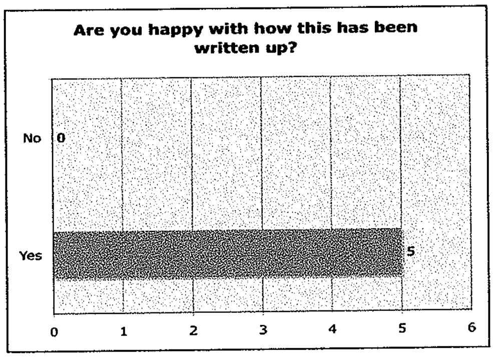
People with disabilities



Comments

- People in the community should practice talking to disabled people as we are the same as everyone else + don't bite
- Unable to read it
- I like my community – everyone is very nice
- I feel that being part of the disabled community is very important as this is where my support and friends are.
- Organisations or individuals who provide service and support be equipped and prepared to practice sensitivity and understanding
- Add in to give someone the chance to work outside – after work experience give them a job
- More feelings in the documentation. Ie How people were affected by community attitudes
- I can use the trains, but can't get on buses. Taxis are my most used transport – but cost prohibits my getting out more, especially to sports events.

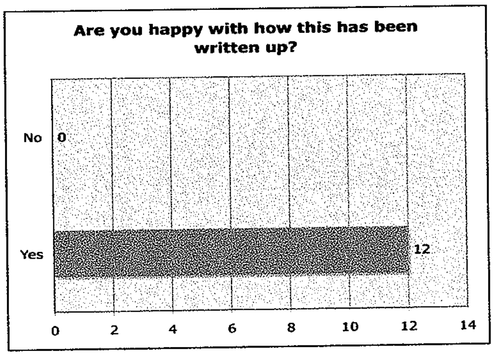
Staff



Comments
- Good to have peoples' comments
- Summarize more coz there is a lot to read

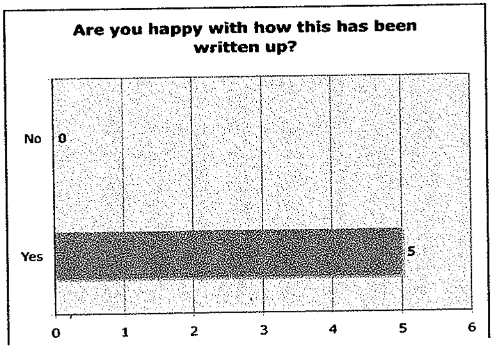
Chapter 5: Employment and family: Contexts for Community Participation (Family section not written yet)

People with disabilities



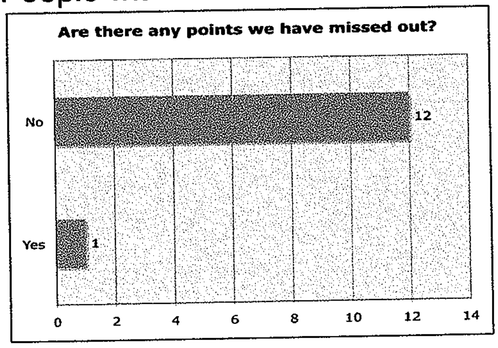
Comments
- I would love to get a job but find it very hard to get employers to consider someone in a wheelchair
- Hard to get a paying job in the community
- There should be more on offer in the community from employers. Employers can provide barriers by not being more flexible
- There's not enough opportunities in the community towards disability. Employers or Government may have to look at their attitude. Re-think their ways on how to extend job (paid) or work for people that have limitations but strengths in other ways.

Staff



Chapter 6: What helps and hinders being part of communities?

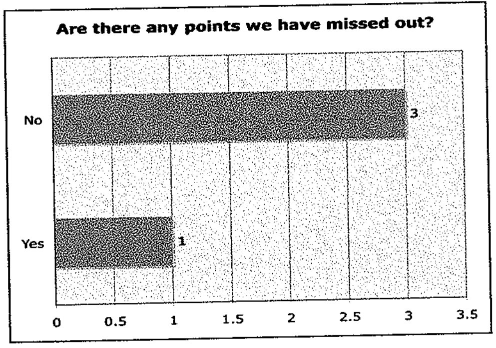
People with disabilities



Comments

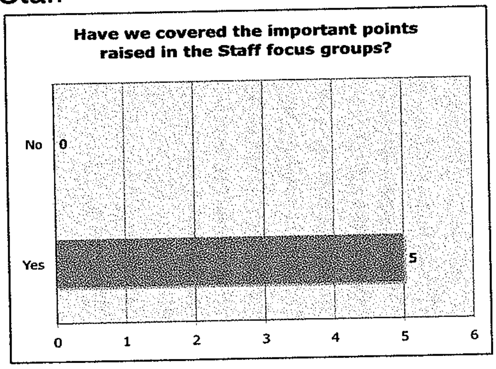
- Vision impaired – increased difficulty. Costs – stopping participation. Transportation – stopping participation. Time involved for community participation – Time to explore community. Some shops inaccessible

Staff



Chapter 8: The challenges of community participation: Views of CCS staff

Staff



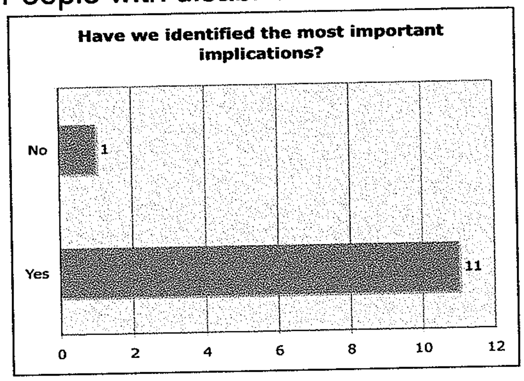
Comments

- This was an honest account of information that was shared. Well written up.

Chapter 9: Implications for policy and practice, and for people with disabilities themselves

People with disabilities themselves

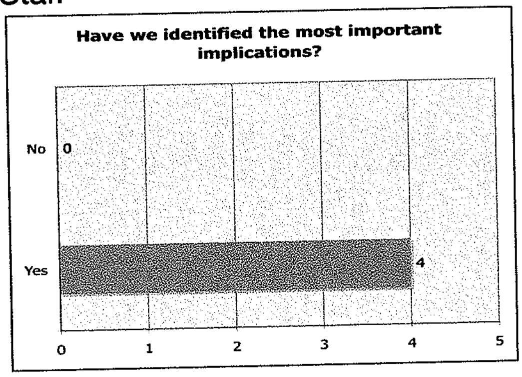
People with disabilities



Comments

- Electric chairs – Footpaths can be bumpy and not very accessible making it difficult to get from A to B.

Staff

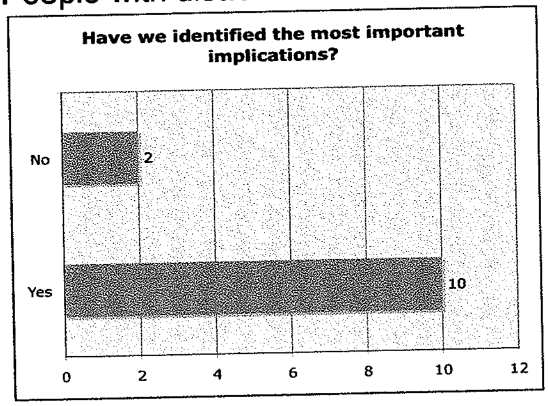


Comments

- (Yes covered the most important implications) I presume these implications will be extended / explained in more depth?

CCS and other service providers

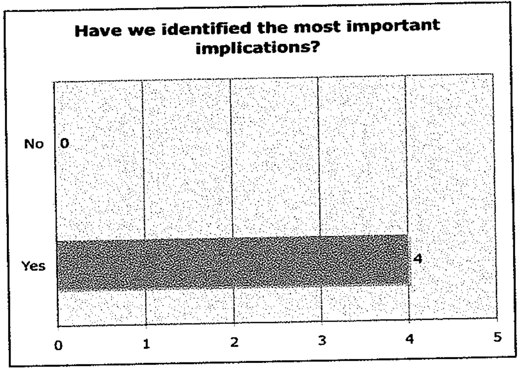
People with disabilities



Comments

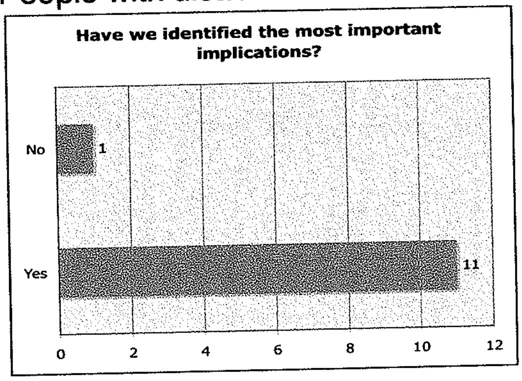
- Disabled people need more support to find a job
- CCS needs to look at what the individual needs and can do, give a trial, see what the person can do, not just make assumptions – make sure people get a fair go

Staff



Policy and policy implementation

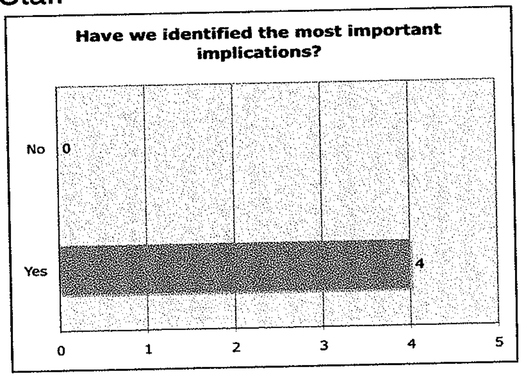
People with disabilities



Comments

- Don't really understand the NZ Disability Strategy, Pathways so it was hard to grasp the implications of policy
- I am supported by staff in the community. But more 1-1 staff needed. Resources are low! NZ Disability Strategy did not follow through with funding.

Staff



Other Comments

People with disabilities

- I live in a residence with other people. This is a good idea for people who need support and company. I think there should be more places like where I live!
- A lot of difficulties has been identified that hinder individuals or families in the (disability sector) community. However it is attitudes and lack of understanding from the community creates barriers. Ignorance is another barrier, interaction and contact in the environment breaks down those barriers. Being able to participate & mixing with people with difficulties (Disability) & informing the wider community that barriers (some) are temporary. Work together as a whole for mutual benefits & maximising strengths.
- What happened to the criticism I put in my interview.
- Be nice to see some real jobs and something come from this report!
- Feel sad for those who cannot find right employment
- I like to see it happening asap
- Will the report be available in larger print

Staff

- This report was very comprehensive and took a huge amount of time to work through. I gave it as much time as was possible. It was very clearly presented and read as an honest reflection of the work as it was carried out. The entire report is very well written and easily understood. The language used is appropriate, sensitive and clearly defines circumstances and situations. It makes for very in-depth and interesting reading.
- A great piece of work. It has made me question where is the voice of the consumer? Thank you.
- Enjoyed reading the quotations. I can put the comments into context and gain a bigger picture of the individual situations, due to experiencing some insight into the issues during my day to day work. Is this going to be possible for those who do not have that hands on contact? I'm aware of the feelings behind some of the comments due to others sharing with me. I'm not sure if the emotional pain / upset comes through as strongly as it is for some?
- Would be helpful to put the summary pages in the front sections. Try to make the layout a little easier to read ie graphs, pictures etc not just words. In the conclusion say who will the report go to & what meanings / changes the contents will have. Do you need a brail or pictorial version? May be useful.