Disability Support Services in New Zealand

The service user survey

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Contents

List of Tables and Figures

Executive Summary

The Ministry of Health (MoH) has a number of initiatives aimed at improving the quality of life for some specific population groups. These are informed by the New Zealand Health Strategy and several other key strategies including in particular the New Zealand Disability Strategy, the Positive Ageing Strategy and the Health of Older People Strategy. The New Zealand Disability Strategy presents a long-term plan for changing New Zealand from a disabling to an inclusive society.

The quality and safety project

The quality and safety project was initiated by the MoH to investigate issues within the disability support service sector. These issues focused on enhancing the delivery of high quality and safe support services to disabled people throughout New Zealand, both in the community and in residential settings.

In 2003, the MoH contracted the University of Auckland to investigate disability support from the service provider's perspective and a second piece of work from the support worker's perspective. This third study has sought to ascertain the service users' perspective.

This project had three principal aims:

1.   development of a service user profile; using data from the Client Claims Payment System (CCPS)

2.   exploration of quality and safety issues impacting on service users

3.   determination of the service users' perceptions of service provision.

These latter two aims were addressed through a series of focus groups with service users from mainstream disability support service providers and hui/fono with Māori or Pacific service providers.

Service user profile

- CCPS data captured all invoicing for the month of June 2004.

- The majority of services invoiced were for older service users receiving home based support or carer support services.

- Around 56% of all service users had a primary age-related impairment.

- Physical impairment was reported as the primary impairment for 19.7% of all service users.

- Intellectual impairment was reported as the primary impairment for a large proportion of younger service users (52.4% of service users aged 15–44 years, 37.6% of those aged less than 15 years).

Regional differences were also considered between different District Health Boards (DHB). While DHBs had relatively similar proportions of service users by age, each DHB had a unique composition of support services accessed.

For those who received non-residential services, 80% received home support in the form of domestic assistance or personal care.

Nearly half a million hours of home support were invoiced in the month of July 2004.

This equated to five hours of domestic assistance and/or 13 hours of personal care on average per week.

Quality and safety issues for service users

The mainstream focus groups and Māori and Pacific hui/fono enabled the researchers to explore issues of support services with those who received them. It should be noted that due to time and budget limitations, the scope of this phase of the project was limited to participants across four DHBs:

1.   Counties Manukau for mainstream focus groups

2.   Waikato for mainstream focus groups, Māori hui and Pacific fono

3.   Canterbury for mainstream focus groups, Māori hui and Pacific fono

4.   Southland for mainstream focus groups.

Participants in the focus groups and hui/fono were those using home-based services.

A disability advocate, contracted by the MoH, worked in conjunction with advocacy groups and disabled people across the four nominated DHBs to identify focus group participants and organise the 10 mainstream focus groups.

There was a mix of urban and rural participants in all DHBs. In particular, in both Waikato and Canterbury a combined total of 12 participants travelled for over an hour to attend a focus group

presenting service user views from small New Zealand communities.

Of the 80 participants, 25 (31%) identified themselves in the over 65 home-based support category; 43 (54%) participants identified themselves in the under 65 home-based support category; 12 (15%) participants identified themselves in rehabilitation/ habilitation category, of these, nine also listed themselves as receiving home based support in the under 65 group.

Risks to service users' safety

Physical safety was an area of concern and fear for many participants and generated much discussion.

- Service users described scenarios, such as being left in their wheelchair all night, or isolated in bed without access to food or toilet facilities because the support worker did not show up.

- The majority felt that an underlying cause was poor communication (or lack of communication) between needs assessors, support workers and the providers.

- Poor hygiene, food preparation and safety practices by support workers were seen to be as a consequence of a lack of training combined with a lack of understanding of what it is like to be disabled.

Many of the perceived difficulties with the current Health and Disability support services centred on the support workers themselves. While service users were realistic about the current difficulties with turnover and retention they felt that it did not mean that they should receive care which lacked respect and dignity.

- Many participants stated they did not feel sufficiently safe to raise concerns as they felt they might be labelled as 'difficult'.

- Turnover and lack of continuity of support workers were a great concern for service users. Turnover was viewed by participants to be directly linked to poor pay and poor working conditions.

- One service user felt that the low pay was reflective of society's attitude towards home care support workers and service users.

- Many service users felt that the needs assessors were too reliant on family members to either fill the gaps or supplement the services provided.

- Services users expressed concern about the 'burden' of their disability on their families financially, emotionally and physically.

Service users' perceptions of support services

The residing impression by the service users, in relation to current service delivery, was it was inadequate and made them feel devalued. The term 'second class citizen' was brought up often by the different focus groups.

- A recurrent theme was the lack of respect by support workers that the home in which care was being delivered was in fact the service users 'home'.

- They felt that the trust developed between the user and worker plus the rules of the home should be respected.

- The service users felt the reason this occurred was due to their lack of involvement in decision making.

- Impact of cultural differences on service delivery was not seen to be considered.

- Participants noted that once a service is put in place there is little follow up and service users felt relatively powerless to make changes.

- The lack of information on entitlements and the ongoing 'battle' to receive their entitlements was seen to be a significant problem.

- 'Choice and control' was a major recurring theme and service users commented that they had none or very little control over their lives. For example, what they would like to wear and when they want to go to bed.

Focus group participants were reasonably unanimous in their perceptions of what would make for quality support services. It would involve:

- client-centred, flexible services with a back-up support system

- access to quality information

- appropriately trained support staff who would be monitored

- funding to secure the quality support required for disabled people and the elderly to live lives of their choice in the community.

1 Introduction

This report outlines service users' feedback on quality and safety issues with regards to health and disability support workers. The report covers people of all ages who required support to carry out daily activities and to participate in the community. A further two reports have explored:

(i) the perceptions of disability support service provider organisations; and

(ii) the perspectives of support workers.

Gaining information from all three perspectives will aid future decisions on improving the safety and quality of support services. The three reports (service user, support worker and service provider) were commissioned by the Ministry of Health (MoH) who contracted the research to the University of Auckland. It was anticipated that the outcomes of these reports will inform the MoH in providing recommendations on a policy and purchasing framework for disability support services. The project is based on the goals set out in the New Zealand Disability Strategy and the Health of Older People Strategy.

The disability support provider sector offers services to a wide variety of individuals. This research was focused on home-based support services (including personal care and/or household management support) for both service users aged under 65 and those aged over 65. In addition, service users' perspectives from rehabilitation or habilitation services were also sought. The views

of Māori and Pacific Island disability support service users' were gathered through hui and fono respectively.[1]

1.1 Definitions

In this report, the term 'service user' will be used to describe the person receiving a disability support service. The phrase 'service user' is often used interchangeably with 'consumer' or 'client'. 'Consumer' is a term used more in countries where the person is likely to choose and direct the services they receive. Although 'consumer' is occasionally used, client-directed services are not common in New Zealand.

Further, the MoH is moving towards using terminology that reflects 'supporting' older people and disabled people rather than 'caring' for them. Although 'caregiver' was identified as the most commonly used term to describe those who provide personal care and domestic help (Parsons et al 2004), the term 'support worker' will be used throughout this report to reflect the new direction of the MoH.

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[1] This analysis does not include any data from residential service users, nor from mental health service users.

2   Methods

2.1   Research aims and objectives

This project has three principal aims: firstly, the development of a service user profile; secondly, the exploration of quality and safety issues impacting on service user and; thirdly, the determination of the service users' perceptions of service provision. The topics discussed in focus groups were developed by the research team with input from the MoH and were aligned with the study research questions.

2.2   Research questions

Focus group discussions were structured in order to address the following questions:

1.   What are the risks to the safety of service users and what causes those risks from the user perspective?

2.   What are the issues that service users have with the safety and quality of the services they receive?

3.   What are the service user perceptions of what would improve the safety and quality of the services they receive?

4.   What are the service user views on the services they receive from the provider organisations?

2.3 Population group

The target population group was users of disability support services in New Zealand. The demographic information was gathered using the Client Claims Payment System (CCPS). However, for focus groups and hui/fono, due to time and resource limitations, the sampling was a smaller population. The MoH indicated that for the quality and safety project, home-based support, rehabilitation/habilitation and Māori and Pacific perspectives were needed to add to the extensive research already undertaken with disability support service users.

Four DHBs were selected for the focus groups, hui/fono and drawn from the DHB regions as indicated in Table 1.

Table 1: Sampling

DHB	Service user survey data sources			
	Mainstream focus groups	**Hui**	**Fono**	**Client Claims Payment System (CCPS)**
Counties Manukau	✓			
Waikato	✓	✓	✓	National (all 21 DHBs)
Canterbury	✓	✓	✓	
Southland	✓			

2.3.1 Rationale for DHB selection

The four DHBs provided a mixture of urban and rural locations and represented both the North and South Islands. Over 50% of persons with disabilities are over the age of 65 (Statistics NZ 2001) and three of the DHBs (all except Counties Manukau) contained at least the national average of persons over the age of 65. Counties Manukau was included as it was a DHB with a large Pacific population (20.5% vs national average of 6.2%). Waikato was selected to ensure representation of Māori as it has a higher proportion by head of population (Statistics NZ 2001). Canterbury was also included in the hui and fono, as the Māori Development Unit, in the Disabilities Services Directorate identified this area as having unique issues of service delivery for these ethnic groups. Namely, a large number of service users, and a small number of Māori and/or Pacific disability support service providers. Southland provided additional data from another South Island area, with a wide geographical spread and low population density, creating particular challenges for the funding and delivery of adequate support services.

It should also be noted that given the limitation of focus groups, hui/fono to four DHB regions, generalising results from these to the total population of support workers should be undertaken with caution. Table 2 presents the summary statistics for these four DHBs. The percentage of persons with disabilities was recorded in the Disability Survey 2001 but Transitional Health Authority boundaries were used, making a DHB comparison not possible.

Table 2: Justification of sample selection

DHB	Data from service provider survey				Population class[2]	% of 65+
	Home-based support services	Residential services (65+)	Residential services (<65)	Respite care services		
Canterbury	13	38	35	33	1, 2, 3	13.4
Counties Manukau	5	11	8	5	1, 2, 3	8.7
Southland	3	3	4	1	1, 2, 3	12.5
Waikato	9	19	20	22	1, 2, 3	11.9

2.3.2 Sampling framework

The disability support services sector offers support to a wide variety of individuals and this heterogeneity was reflected in the project. Sampling occurred at two levels:

1. Eighty service user participants in 10 focus groups were contacted through both advocacy groups and through consultation with disabled people across four DHBs, as outlined in Table 1. In addition, a further 24 participants were involved in Māori hui and Pacific fono. The total number of service users who participated was 104.

2. Broad data (as prioritised by MoH) was collected on all service users across 21 DHBs using the MoH CCPS database.

The framework also ensured representation of the four main service user groups outlined in Table 3.

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[2] 1 = Main urban area, 2 = Secondary urban area, 3 = Minor urban area or rural area.

Table 3:   Service user sampling

1.   Under 65 home-based support services
2.   Over 65 home-based support service
3.   Rehabilitation and habilitation services
4.   Māori and Pacific Island disability support services

2.4   Study design

The data collection sources are summarised in Table 4.

Table 4:   Data collection

Population group	Mainstream focus groups	Hui	Fono	All New Zealand disability support service users
Service user data	77 participants plus three written	Two, a total of eight participants	Two, a total of 14 participants	Client Claims Payment System (CCPS) 88,170 client claims

2.4.1 Sample sizes in qualitative research

Much of the data in the service user survey was of a sensitive nature. Service users were asked to discuss the risks they experienced when receiving support services, and their experiences as a user of disability services in general. Small focus groups were determined to be the most appropriate form of data collection, considering both the support some service users needed to discuss these topics, as well as the difficulty some had in communicating using other modalities.

Quantitative research requires sufficient sample sizes to assure that results can be generalised to the population of interest. The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size (Patton 1990).

Sample size in qualitative research depends on many factors, and sampling usually will continue until the point of redundancy, "In purposeful sampling the size of the sample is determined by informational considerations. If the purpose is to maximise information, the sampling is terminated when no new information is forthcoming from new sampled units" (Lincoln and Guba 1985, p.781). The sampling of service users needed to satisfy both the redundancy of information and represent as wide a range of disabilities and geographical settings possible.

2.4.2 Mainstream focus groups

As mentioned earlier, due to the short time frame in which the data had to be collected as well and the nature of the research questions, focus groups were deemed to be the most appropriate data collection method.

A disability advocate, contracted by the MoH, worked in conjunction with advocacy groups and disabled people across the four nominated DHBs to identify focus group participants and organise the 10 mainstream focus groups. Over 191 organisations and individuals were contacted by the disability advocate. Each of these organisations and individuals were asked to both identify eligible participants and to pass on to their contacts, information about the focus groups. Electronic

databases, such as the NZCCS[3] Information Service and WEKA[4] were used to identify potential organisations. A number of internet lists were also utilised to facilitate contact with potential participants and to post information about the research. DPA[5] Nationally, the Quality and Safety Sector Reference Group, the Office for Disability Issues 'Key Consumer Organisations' contacts and many 'key' organisations were approached with the goal of identifying eligible participants. While this 'Spider-web' approach (the advocate's contacts contacting their contacts who contact their contacts etc) is not infallible, with the limited time available to contact participants in each DHB area, it was believed to be the most effective. Indeed, feedback from participants indicated that many had been told about the research a couple of times from different sources. As evidence of this, one individual was contacted seven times!

Another aspect of the recruitment process was to contact eligible participants through access with other disabled people rather than only through an organisation. The justification for this was to minimise the number of participants who could have been preselected by an organisation possibly selecting which clients they would approach. Once an eligible participant made contact

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[3] NZCCS is a provider of support and services to people with physical disabilities. They also act as advocate for the rights of disabled people. Founded to help New Zealand children following two polio epidemics early last century, CCS now works in partnership with over 5000 children and adults with physical or multiple disabilities and their families and whānau. Services are provided nationally through 16 integrated branches around the country. CCS employs more than 500 staff and is assisted by over 2000 regular volunteers.

[4] WEKA is New Zealand's disability information web site, for people with disabilities, their families, whānau and caregivers, health professionals and disability information providers.

[5] DPA (New Zealand) is an umbrella organisation representing people with disabilities, the organisations involved in advocacy on their behalf and service providers. DPA is a national assembly, which encompasses people with all types of disabilities, including physical, sensory, intellectual, psychiatric, neurological and age-related.

with the disability advocate, their contact details were recorded along with identifying the group that most matched their circumstances (eg, home-based support over 65). Any specific needs that the participant may have in order to attend the focus group were identified at this stage. The disability advocate then sent to each enrolled participant a copy of the four questions that were to be discussed during the focus group as well as details of the time and venue of their specific focus group.

The focus groups represented a mixture of service users, over and under 65, and those receiving rehabilitation/habilitation services. Focus groups were held at a time and place (normally an appropriate community venue) that was accessible to participants stated needs. For example, some were held at the weekend as participants worked during the week, at another focus group, an outside toileting area for guide-dogs was arranged. The focus groups were held during late July and early August 2004.

The focus groups were facilitated by an experienced disability advocate, contracted by the MoH. An experienced researcher from the University of Auckland made a written record of the discussions during the focus groups. Prior to commencement, informed consent was obtained from all participants. The consent form was written in plain English, was available on disk for participants who used speech software, was available in large print and at every focus group the consent form was read out and any questions answered. NZSL[6] interpreters were employed where participants had indicated the need for an interpreter.

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[6] New Zealand Sign Language (NZSL) is the natural language of the Deaf community in New Zealand. NZSL is a visual-gestural language, which conveys ideas by signs, facial expressions, body language and lip patterns and has its own grammar, rules and sentence structures, which is different from English or Maori.

The facilitator outlined the purpose of the focus groups and used the four previously stated questions to guide discussion. In order to accommodate the needs of a diverse community, on one occasion a focus group was held specifically for people with an intellectual impairment. At another focus group a large percentage of the participants were Māori with the meeting starting and ending with a karakia.

Focus groups lasted up to two hours and involved between five and 16 people. Care was taken to ensure that the needs of all participants were met, and at times, service users chose to be accompanied by their own support person. When necessary, additional support staff were employed by the researchers to assist with the specific needs of participants. All focus group participants were provided with refreshments and offered $20 cash as koha.

2.4.3 Hui and fono

It was recognised by the research team and the MoH that Māori and Pacific service users accessed support services both from mainstream and Māori or Pacific health support service providers. Further, Māori and Pacific service providers tend to deliver services across the disability spectrum. Given the nature of the discussion that was likely to be generated, hui and fono were identified as the most appropriate data collection methods to explore issues facing the workforce. Hui and fono can be seen as the Maori and Pacific equivalents of focus groups, that is a meeting of a number of individuals who have come together to discuss a topic of common interest. In Canterbury DHB, one hui and one fono were held. In Waikato, one hui and one fono were planned, but at the request of the service users, the two meetings were combined. The hui and fono were held at community

venues identified as having appropriate facilities for the service users. The meetings lasted around two hours and involved up to 10 service users. The hui were led by a kaumatua from the University of Auckland, and facilitated by experienced Māori and Pacific researchers. Written records of discussions were collected by a trained research assistant. Refreshments and $200 koha were offered to all participants.

Recruitment of participants in Canterbury was managed by a disability advocate in that area, who made use of existing relationships and links to contact Pacific and Māori disability support providers, advocacy groups and community groups. From these communications a two day period with two times, one morning, one afternoon was recommended, where service users could attend hui or fono and express their views on the topics. A venue was chosen in an area of Christchurch that had a relatively higher Pacific and Māori population. The conference rooms used were part of a Māori community health centre and so had ideal amenities for disabled people. The disability advocate and the researchers also accessed Pacific service users through connections with Pacific health researchers in the local university.

Recruitment in Waikato was achieved through consultation with a local Māori health provider. The provider has various health and social services for Māori, including kaumatua and kuia in their homes and on marae. They were able to contact a number of service users, and also had an appropriate venue that the researchers were able to use.

As mentioned earlier, a kaumatua from the University of Auckland accompanied the researchers and lead the hui with appropriate karakia. Another member of the research team had extensive

experience with Pacific peoples and was able to acknowledge and accommodate the cultural needs of Pacific service users.

2.4.4 Client Claims Payment System (CCPS)

When a disabled person requires support services, the first step is a formal assessment of their needs by the Needs Assessment and Service Coordination Agency (NASC). The NASC assesses the client's needs, and if necessary will allocate a service to assist the client. The NASC also prepares a manual Needs Assessment Form which drives the Client Claims Payment System (CCPS) system. Invoices from service providers are checked against the client's allocated support services, and then paid. The data presented in this section of the report is based upon this invoice data.

The researchers developed a set of questions based upon the NASC data entry fields. As the data were required in a relatively short period of time, coordinating the extraction of information from NASC national data was not possible. It was possible however to access information from the CCPS system.

The data collected were CCPS invoicing information for the calendar month of June 2004. Where invoicing for a service fell outside of that period, the service user's information would not have been included, even though they were using services during that time. The reader should bear in mind that it represents the invoicing for funding of services, rather than the actual services themselves. It included invoicing for Mental Health residential support services, Age related support services, and support services for disabled people.

2.5   Coding and analysis

Notes from the focus groups, hui and fono were typed up and analysed. A general inductive approach was employed to allow dominant and significant themes to emerge (Thomas and Hodges 2003). The process began with several close readings of the interview transcripts by two members of the research team. Key concepts and themes by which the data could be examined and referenced to the objectives were then identified and other significant emerging issues noted. The researchers then began independently identifying text segments containing meaning, and assigning them to the appropriate relevant categories. Data from the CCPS were supplied as database sheets and summative analysis undertaken as appropriate.

2.6   Ethics

A multi-centred ethics application was submitted to The Auckland Regional Ethics Committee and permission to proceed was obtained prior to commencement of data collection.[7]

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[7] Ref no: AKX/04/06/152, WAI/04/06/048, CTR/045/06/, STH04/08/10.

3 Results

3.1 Introduction

The results chapter is broadly organised into two sections. The first relates to the numerical data from the CCPS database and the second the qualitative data emerging from the focus groups and hui/fono. Given the nature of the CCPS data, the most appropriate means to illustrate trends is through tabular presentation with descriptive statistics, where as the qualitative data from the focus groups is most appropriately organised through presentation of dominant themes with supporting quotes.

3.2 National service user demographic data

Key points

- Support services for 88,170 service users were invoiced in June 2004.

- The percentage of service users per DHB approximated the 2001 census of percentage of population per DHB, with some exceptions.

- Just over 73% of service users were over the age of 65.

- Ethnic identity was a complex issue, it appears that around 79% of service users were of European descent.

3.2.1 Demographic overview

As described in the previous section, the CCPS was used to develop a national 'snapshot' of disability support service users. Table 5 describes the number of service users recorded by invoicing in the month of June 2004. These are presented by

DHB. Canterbury had the largest number of service users, nearly 21,000, representing over 13% of the national total. The right hand column provides the percentage that each DHB contributed to the total number of people resident in New Zealand on the census night, 2001. Many DHBs produced similar percentages, a notable exception being Waitemata, with 6% of service users in June 2004 and 11.3% of the population in 2001.

Table 5:   Service users by DHB

DHB	Number	Percent	2001 census
Auckland	7,170	8.1%	9.9%
Bay of Plenty	5,087	5.8%	4.7%
Canterbury	14,388	16.3%	11.5%
Capital & Coast	4,868	5.5%	6.5%
Counties Manukau	5,467	6.2%	9.8%
Hawke's Bay	3,450	3.9%	3.8%
Hutt Valley	2,682	3.0%	3.4%
Lakes	1,984	2.3%	2.7%
Mid Central	4,538	5.1%	4.1%
Nelson Marlborough	4,071	4.6%	3.4%
Northland	2,627	3.0%	3.8%
Otago	6,566	7.4%	4.6%
South Canterbury	2,267	2.6%	1.4%
Southland	3,610	4.1%	3.0%
Tairawhiti	443	0.5%	1.2%
Taranaki	2,464	2.8%	2.7%
Waikato	6,320	7.2%	8.4%
Wairarapa	908	1.0%	1.0%
Waitemata	5,407	6.1%	11.3%
West Coast	1,416	1.6%	0.9%
Whanganui	2,239	2.5%	1.7%
DHB unavailable	198	0.2%	
Total	**88,170**	**100%**	**100%**

CCPS records the service user's year of birth and from this an approximate age in years was calculated by subtracting that number from 2004. These results were further reduced to the categories seen in Table 8. The first two groupings adheres to Statistics NZ procedure, while the final group of '65+' was divided into '65–74' and '75+'. This allows the data to be discussed in terms of divisions commonly used in gerontology literature, where '65–74' represents the 'younger older person' and the '75+' representing the 'older older person'.

When the service users were analysed by these age groups, it appeared that in all DHBs the largest group of service users was those aged 75 or older, with a national average of around 61%. When all those aged 65 years and older are included, this national average grows to just over 73%. Tairawhiti was a notable exception where, with the smallest number of service users, a large number of 15–44-year-olds were also reported (23.4%, versus the national average of 9.1%).

Table 6: Age groups by DHB

DHB	Age group (years) (as % of DHB)					Total (n)
	<15	15–44	45–64	65–74	75+	
Auckland	4.9	6.4	8.4	11.5	68.8	7,170
Bay of Plenty	3.6	7.7	8.6	14.4	65.7	5,087
Canterbury	7.5	9.9	8.9	11.6	62.1	14,386
Capital & Coast	2.1	12.1	14.3	12.5	59.1	4,867
Counties Manukau	7.9	14.2	11.3	12.7	53.9	5,467
Hawke's Bay	0.6	12.7	15.0	13.2	58.5	3,450
Hutt Valley	2.0	9.7	11.6	14.0	62.8	2,682
Lakes	3.0	8.3	9.7	15.7	63.4	1,984
Mid Central	1.2	13.0	16.3	12.8	56.8	4,538
Nelson Marlborough	1.1	8.9	12.0	13.3	64.6	4,071
Northland	8.3	9.8	11.1	13.8	57.1	2,627
Otago	7.3	11.3	12.1	13.9	55.4	6,566
South Canterbury	7.5	9.0	10.9	11.9	60.8	2,267
Southland	8.6	12.4	9.6	13.0	56.4	3,610
Tairawhiti	12.9	23.5	13.3	6.5	43.8	443
Taranaki	3.2	8.6	9.5	12.8	65.9	2,464
Waikato	4.6	10.7	10.3	13.4	61.0	6,320
Wairarapa	2.5	9.8	15.4	12.7	59.6	908
Waitemata	9.4	9.5	7.7	10.7	62.6	5,407
West Coast	6.6	10.9	11.6	18.0	52.8	1,416
Whanganui	0.4	8.1	12.8	17.5	61.2	2,239
DHB unavailable	8.6	41.9	29.3	8.6	11.6	198
Total	**5.3**	**10.3**	**10.8**	**12.9**	**60.7**	**88,167***

* Three services did not have date of birth data available.

Further analysis of the basic demographic data provided gender information, with is presented in Table 7. The majority of younger service users were male, while older service users were female. This trend is illustrated in Figure 1.

Table 7:   Age of service users analysed by gender

Age group (years)	Gender						Total	
	Male		Female		Unknown			
	N	%	N	%	N	%	N	%
<15	2,921	63.0	1,553	33.5	163	3.5	4,637	100
15–44	4,098	44.9	4,616	50.6	409	4.5	9,123	100
45–64	3,544	37.1	5,445	56.9	576	6.0	9,565	100
65–74	3,685	32.4	6,914	60.9	757	6.7	11,356	100
75+	13,344	24.9	36,851	68.9	3,291	6.2	53,486	100
Total	**27,592**	**31.3**	**55,379**	**62.8**	**5,196**	**5.9**	**88,167**	**100**

Figure 1:   Percentage of service users by age group
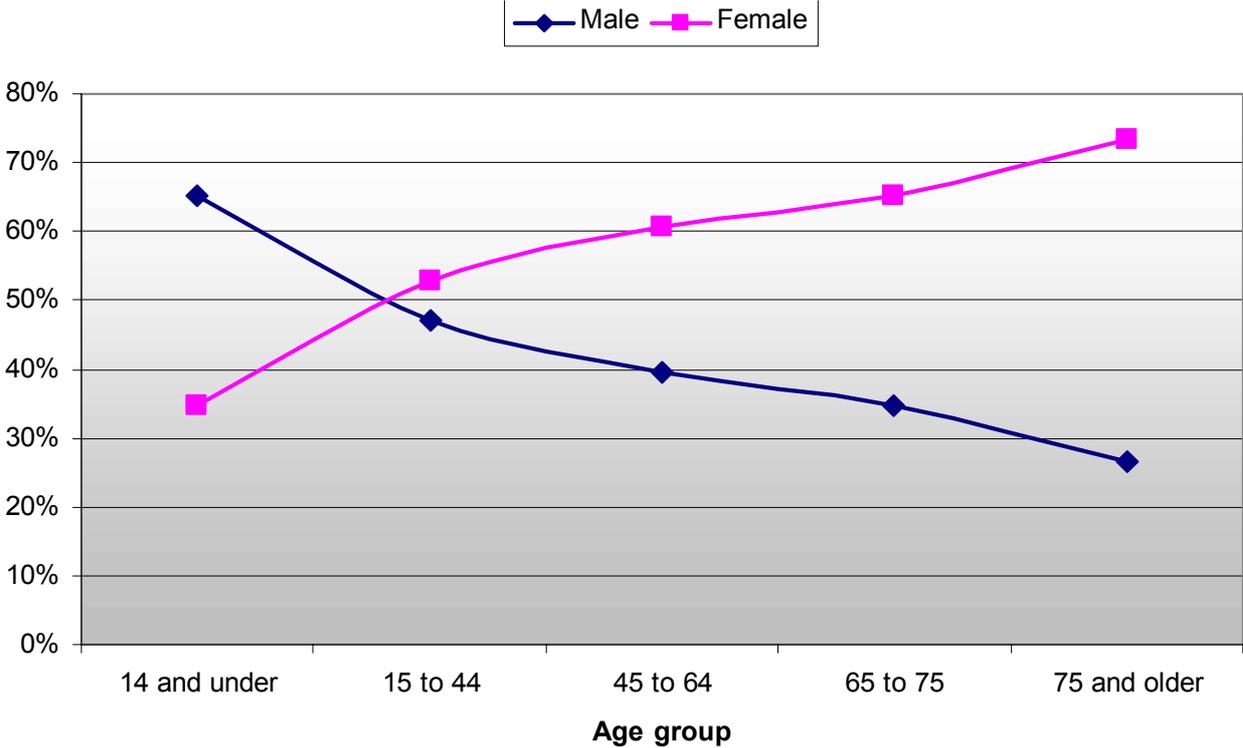
Ethnicity was reduced from 30 categories, to those presented in Table 8. The table provides the percentage of each ethnicity within the DHB. The last column provides the total number of service users in the DHB, while the last row provides the total number of clients within the ethnic group. Note that 'Of European descent' was a category combining 'NZ European, European Not Further Defined', 'European' and Other European'. The category 'European' presented below comprised of 'Dutch', 'English' and 'Irish' categories.

Table 8:   Ethnicity by DHB

DHB	Ethnicity (as % of DHB)								Total (n)
	Of European descent	NZ Māori	European	Pacific	Asian	Indian	Not stated	Other	
Auckland	69.0	4.4	0.4	5.6	1.8	1.4	14.4	3.0	7,189
Bay of Plenty	82.9	10.9	0.1	0.2	0.1	0.2	2.8	3.0	5,040
Canterbury	87.9	2.3	0.1	0.4	0.4	0.1	4.3	4.5	14,483
Capital & Coast	75.0	3.3	0.0	2.0	1.3	0.6	10.8	7.0	4,919
Counties Manukau	61.9	9.7	0.3	8.9	1.3	0.8	14.0	3.0	5,415
Hawke's Bay	71.8	7.8	0.0	0.5	0.1	0.0	12.2	7.5	3,366
Hutt Valley	73.5	4.3	0.0	1.6	0.9	0.5	11.0	8.2	2,679
Lakes	76.3	14.7	0.0	1.2	0.3	0.1	5.6	1.9	1,972
Mid Central	78.5	4.9	0.0	0.4	0.3	0.2	6.4	9.3	4,527
Nelson Marlborough	85.4	2.2	0.0	0.1	0.1	0.0	9.4	2.8	4,029
Northland	61.7	12.8	0.2	0.2	0.2	0.2	20.3	4.4	2,617
Otago	91.3	1.7	0.0	0.4	0.2	0.0	3.6	2.8	6,631
South Canterbury	75.3	2.0	0.1	0.5	0.1	0.0	19.3	2.7	2,260
Southland	89.7	4.2	0.1	0.4	0.1	0.0	4.2	1.2	3,593
Tairawhiti	62.1	25.5	0.9	0.2	0.2	0.2	5.6	5.2	462
Taranaki	87.8	5.9	0.1	0.0	0.3	0.0	2.8	3.0	2,415
Waikato	81.8	8.1	0.1	0.7	0.4	0.3	5.7	2.9	6,268
Wairarapa	84.4	6.1	0.0	0.8	0.3	0.0	2.1	6.2	897
Waitemata	79.4	3.7	0.4	2.7	1.1	0.7	7.9	4.0	5,388
West Coast	89.4	2.7	0.1	0.2	0.0	0.0	6.1	1.5	1,391
Whanganui	75.4	7.2	0.0	0.4	0.0	0.1	12.6	4.3	2,237
No DHB data	67.5	12.8	0.0	1.7	0.0	0.0	13.7	4.3	117
Total %	**79.6**	**5.4**	**0.1**	**1.6**	**0.6**	**0.3**	**8.2**	**4.2**	**87,895**
Number	**69,975**	**4,745**	**110**	**1,425**	**489**	**291**	**7,212**	**3,648**	

3.2.2 Residential settings

> **Key points**
> - Around 31% of service users received support in a residential setting.
> - Over 90% of service users aged 44 or younger received services in community residential settings.
> - Over the age of 65, most support services were delivered in rest home or hospital settings.

The CCPS database recorded the type of service location of service users as residential or non-residential. Of the total number of services users represented by the CCPS data, 31.4% received care in a residential setting (n=27,720 of the 88,170 services users who were included in the residential and non-residential data).

Table 9 gives the breakdown of residential setting service users by age. The following definitions provide an indication of the differences between the three types of residential services:

- **Rest home:** General accommodation with personal care and domestic support provided to satisfy the daily living requirements of the client, usually for those over the age of 65.

- **Community residential:** Accommodation, personal care and domestic support for those younger than 65. This includes residential facilities for younger adults with intellectual or cognitive impairments, or those with physical disabilities who require the additional level of care provided in a staffed residential facility.

- **Hospital:** Provides general accommodation with a higher clinical component of care and support for daily tasks of living. A registered nurse is required to be available on site at all times.

Table 9: Residential service users analysed by age

Age	Type of residence						Total number
	Rest home		Community residential		Hospital		
	Number	% of age	Number	% of age	Number	% of age	
<15	7	5.6	112	89.6	6	4.8	125
15–44	50	1.3	3,463	92.5	229	6.1	3,742
45–64	478	15.2	2,025	64.3	648	20.6	3,151
65–74	1,415	52.9	263	9.8	995	37.2	2,673
75+	10,211	56.6	101	0.6	7,714	42.8	18,026
Total	**12,161**	**43.9**	**5,964**	**21.5**	**9,592**	**34.6**	**27,717**

For those service users aged 44 or younger, over 90% were in community residential care. As shown later in Table 15, most of these service users had either physical or intellectual impairments. For those aged 45–64 the spread across residential services remained higher in community residential settings (64.3%), but a higher representation in rest home and hospital level services was also apparent. For those aged 65 or older, a smaller percentage remained in community based residential care with most in rest home or hospital institutions.

Table 10 breaks down the residential service users by DHB. Some regional variation was apparent and to some extent these could be influenced by the regional variation of age groups. For example, Whanganui had the highest percentage of rest home

based service users (58.5% vs a national average of 43.9%). When the age groups of this DHB are assessed, it had a higher proportion of 65–74 and 75+ service users than the national average and a lower proportion of <15 service users.

Table 10: Residential service users analysed by DHB

DHB	Type of residence						Total number
	Rest home		Community residential		Hospital		
	No.	% of DHB	No.	% of DHB	No.	% of DHB	
Auckland	1,460	46.5	435	13.9	1,245	39.6	3,140
Bay of Plenty	548	43.2	242	19.1	478	37.7	1,268
Canterbury	1,971	48.9	705	17.5	1,355	33.6	4,031
Capital & Coast	513	31.4	432	26.4	691	42.2	1,636
Counties Manukau	688	34.7	674	34.0	621	31.3	1,983
Hawke's Bay	475	44.6	309	29.0	280	26.3	1,064
Hutt Valley	327	34.9	203	21.6	408	43.5	938
Lakes	273	46.4	100	17.0	215	36.6	588
Mid Central	622	40.4	229	14.9	689	44.7	1,540
Nelson Marlborough	387	35.3	341	31.1	367	33.5	1,095
Northland	397	48.1	170	20.6	259	31.4	826
Otago	887	48.9	432	23.8	495	27.3	1,814
South Canterbury	214	47.3	96	21.2	142	31.4	452
Southland	391	49.9	150	19.2	242	30.9	783
Tairawhiti	141	47.3	103	34.6	54	18.1	298
Taranaki	466	54.2	136	15.8	258	30.0	860
Waikato	884	42.5	590	28.3	608	29.2	2,082
Wairarapa	164	48.2	82	24.1	94	27.6	340
Waitemata	912	41.6	388	17.7	892	40.7	2,192
West Coast	116	49.6	25	10.7	93	39.7	234
Whanganui	325	58.5	125	22.5	106	19.1	556

Total	12,161	43.9	5,967	21.5	9,592	34.6	27,720

3.2.3 Non-residential settings

Key points

- Around 70% of service users received care in non-residential settings, such as their own home.

- Two service categories accounted for most services: home support 79.9% and carer support 16.1% of all non-residential services invoiced.

The majority of service users in the CCPS database were receiving services in non-residential settings. Non-residential settings refer to community-based settings such as a person's home and services that assist in the delivery of care. Definitions for the non-residential services are provided below. These definitions further indicate that CCPS is an invoicing database, as they refer to the type of service rather than the delivery setting.

- **Home support:** Support services in a person's home, providing personal care and assistance with household chores.

- **Carer support:** A flexible relief service that enables the fulltime care giver to take subsidised time away from their responsibilities. Carer support is a casual, short-term service with a fixed value.

- **Supported independent living (SIL):** Service user lives in their own accommodation, and receive assistance like shopping, cooking etc, to help them live in the community, similar to home support.

- **Ageing in place:** The client has been assessed as requiring Rest Home level of care, and the client elects to stay a home

and receive a variation of Home Support known as Ageing in Place.

- **High and complex:** Inter-relationship between physical, cognitive and social/emotional states that produce complex support needs. For example, enabling the socialisation of a person with a physical disability and a cognitive impairment.

- **Respite:** A higher level of carer support fully funded and coordinated. Tends to be a more formal arrangement with regular respite periods and fully funded to the cost required.

- **Day programme:** A designated day care facility that provides social activities and support at a centralised location that the client comes to.

Table 11 shows the breakdown of age groups into non-residential services. Percentages refer to the proportion of service users with a non-residential service within the total of that age group. For all non-residential service users, 'home support' and 'carer support' dominated the invoicing classifications with a combined total of 96%, comprising 79.9% for home support and 16.1% for carer support.

Table 11: Non-residential services by age

Non-residential service	Age group (years)					Total
	<15	**15–44**	**45–64**	**65–74**	**75+**	
Home support	30.2%	42.9%	64.1%	85.0%	92.5%	79.9%
Carer support	66.0%	41.9%	27.3%	12.0%	5.7%	16.1%
SIL	0.1%	7.6%	3.7%	0.4%	0.2%	1.2%
Ageing in place	0.0%	0.0%	0.0%	0.1%	0.1%	0.1%
High and complex	0.0%	0.1%	0.0%	0.0%	0.0%	0.0%
Respite	3.7%	2.6%	0.8%	0.3%	0.4%	0.9%
Day programme	0.0%	4.9%	4.2%	2.2%	1.2%	1.8%

	100%	100%	100%	100%	100%	100%
Total						
N	**4,524**	**5,324**	**6,281**	**9,056**	**37,946**	**63,131**

When the non-residential data was analysed by DHB, regional differences were not particularly apparent. Tairawhiti notably had a much lower level of home support and higher level of carer support than the national averages (11.7%and 42.2%, vs national averages of 80% and 16.2%, respectively).

Table 12: Non-residential service users analysed by DHB

DHB	Non-residential service type (% of DHB)					Total (n)
	Home support	**Carer support**	**SIL**	**Respite**	**Day programme**	
Auckland	84.0	11.7	0.2	0.8	3.4	4,111
Bay of Plenty	88.7	8.5	0.4	0.7	1.8	3,799
Canterbury	80.8	15.7	0.6	1.0	1.9	10,360
Capital & Coast	63.4	30.4	3.8	1.5	0.8	3,299
Counties Manukau	81.3	15.9	0.6	0.6	1.7	4,316
Hawke's Bay	71.0	24.8	2.4	0.6	1.2	2,436
Hutt Valley	74.9	18.8	3.1	1.4	1.8	1,646
Lakes	88.7	8.0	0.9	0.1	2.4	1,440
Mid Central	72.5	24.1	2.5	0.7	0.3	3,021
Nelson Marlborough	76.0	20.3	3.0	0.6	0.1	2,912
Northland	85.8	10.4	0.3	0.5	3.0	2,888
Otago	83.0	13.7	0.4	1.3	1.5	4,688
South Canterbury	80.0	13.8	1.1	1.3	3.8	1,588
Southland	82.7	13.4	0.4	1.0	2.5	2,518
Tairawhiti	11.7	42.2	13.3	25.0	7.8	128
Taranaki	83.5	13.5	0.3	0.6	2.1	1,600
Waikato	85.8	11.5	0.4	0.2	2.1	4,174
Wairarapa	60.5	28.4	6.5	3.7	0.9	570
Waitemata	82.9	15.5	0.0	0.5	1.2	4,884
West Coast	88.6	8.7	0.7	0.3	1.7	877
Whanganui	68.8	28.0	2.2	0.2	0.8	1,705
DHB not available	29.7	1.4	23.4	6.9	38.6	145
Total	**80.0**	**16.2**	**1.2**	**0.9**	**1.8**	**63,105***

* 32 service users received Ageing in Place, five received high and complex care and these were all omitted from the table.

3.2.4 Funding

Table 13 shows the division of funding between DHB and MoH. The current division indicates the devolution of disability support services funding in October 2003 when DHBs took over the bulk of the funding from the MoH. The payments being made through CCPS were funded by both DHB and MoH. Mental health services, outside the brief of this report are however included in this data. The mental health portion of Home Support and Carer Support for the Southern region was paid through Disabilities Services Directorate funding, and so appears within the MoH funded portion below.

Table 13: Source of funding analysed by DHB

DHB	DHB funded		MoH funded		Total
	Number	**%**	**Number**	**%**	**Number**
Auckland	5,572	77.7	1,598	22.3	7,170
Bay of Plenty	3,846	75.6	1,241	24.4	5,087
Canterbury	11,135	77.4	3,253	22.6	14,388
Capital & Coast	3,452	70.9	1,416	29.1	4,868
Counties Manukau	3,516	64.3	1,951	35.7	5,467
Hawke's Bay	2,039	59.1	1,411	40.9	3,450
Hutt Valley	2,084	77.7	598	22.3	2,682
Lakes	1,474	74.3	510	25.7	1,984
Mid Central	3,101	68.3	1,437	31.7	4,538
Nelson Marlborough	3,035	74.6	1,036	25.4	4,071
Northland	1,809	68.9	818	31.1	2,627
Otago	4,468	68.0	2,098	32.0	6,566
South Canterbury	1,630	71.9	637	28.1	2,267
Southland	2,562	71.0	1,048	29.0	3,610
Tairawhiti	217	49.0	226	51.0	443
Taranaki	1,836	74.5	628	25.5	2,464
Waikato	4,548	72.0	1,772	28.0	6,320
Wairarapa	630	69.4	278	30.6	908
Waitemata	3,909	72.3	1,498	27.7	5,407
West Coast	933	65.9	483	34.1	1,416
Whanganui	1,722	76.9	517	23.1	2,239
Total	**63,518**	**72.2**	**24,454**	**27.8**	**87,972**

3.2.5 Primary disabilities

Key points

- Percentage of service users with age related impairments increase with age.

- An increase in physical and sensory impairments also occurred as age increased.

- Intellectual impairments more highly represented by those used the age of 65.

- Percentage of service users with a Personal Health impairment much greater in Northland and West Coast DHBs.

Tables 14 and 15 provide a breakdown of service users by primary disability. When looking at the percentages of service users by disability in each age bracket, as expected there is an increase in the rate of age-related impairments. This increase is also to be noted in physical and sensory impairments. Intellectual and psychiatric impairments were more highly represented by those 65 years old or younger.

Table 14: Primary impairment by age

Primary impairment	Age group (years) (% of disability)					Total
	<15	**15–44**	**45–64**	**65–74**	**75+**	
Age-related	0.1	0.1	1.2	13.1	85.6	49,626
Intellectual	18.1	49.7	25.4	4.4	2.4	9,629
Personal health	20.2	12.7	16.3	17.5	33.4	3,828
Physical	8.9	10.0	21.1	16.0	44.0	17,411
Psychiatric	22.2	36.5	24.9	7.5	8.8	2,330
Sensory	3.9	9.8	14.6	10.5	61.3	563
Not available	0.1	24.4	33.3	15.1	27.0	4,780*
Total	**5.3**	**10.3**	**10.8**	**12.9**	**60.7**	**88,167**
N	**4,637**	**9,123**	**9,565**	**11,356**	**53,486**	

* The high number of invoices where the impairment was not known or recorded has been noted as an area for further investigation by the CCPS data management team.

Table 15 provides an analysis of each age group by primary impairment. As expected, those aged 14 and under had mostly either intellectual or physical primary impairments, although personal health and psychiatric also had substantial numbers. In the 45–64 age group, 38.4% had a primary physical impairment, with around a quarter having an intellectual impairment. For those aged 65 and older the majority had either an age-related or physical primary impairment.

Table 15: Age by primary impairment

Primary impairment	Age group (years) (as % of age)					Total (as % of total)
	<15	15–44	45–64	65–74	75+	
Age-related	0.7	0.4	6.0	57.3	79.4	56.3
Intellectual	37.6	52.4	25.5	3.8	0.4	10.9
Personal health	16.6	5.3	6.5	5.9	2.4	4.3
Physical	33.3	19.1	38.4	24.6	14.3	19.7
Psychiatric	11.2	9.3	6.1	1.5	0.4	2.6
Sensory	0.5	0.6	0.9	0.5	0.6	0.6
Not available	0.1	12.8	16.7	6.4	2.4	5.4
N	**4,637**	**9,123**	**9,565**	**11,356**	**53,486**	**88,167**

Table 16 provides primary impairment data analysed by DHB. Some marked variations can be seen, with Northland and the West Coast DHBs for example, appearing to have a much greater percentage of service users with a 'personal health' primary impairment (22.8% and 26.1% respectively, versus the national average of 4.3%). Such variations may be indicative of population differences between areas. The West Coast with a coal mining history for example, may have a higher number of individuals with COPD (Chronic Obstructive Pulmonary Disease), CORD (Chronic Obstructive Respiratory Disease) or emphysema. Without more extensive research and analysis, it was not possible to provide any conclusive reasons for the regional variations noted.

Table 16: Primary impairment analysed by DHB

DHB	Primary impairment (% of DHB)							Total n
	Age-related	Intellectual	Personal health	Physical	Psychiatric	Sensory	Unknown	
Auckland	68.8	8.8	2.2	16.8	0.4	0.3	2.7	7,170
Bay of Plenty	49.5	9.8	0.7	38.4	0.5	0.3	0.8	5,087
Canterbury	71.5	9.2	2.5	10.5	5.9	0.0	0.3	14,388
Capital & Coast	36.1	13.2	4.4	26.5	0.7	1.9	17.1	4,868
Counties Manukau	47.0	14.9	3.5	25.6	1.2	0.2	7.5	5,467
Hawke's Bay	46.5	11.4	3.8	18.6	0.9	1.8	17.0	3,450
Hutt Valley	64.8	11.7	1.0	9.0	0.5	0.4	12.6	2,682
Lakes	46.5	9.7	1.2	40.8	0.4	0.4	1.0	1,984
Mid Central	52.3	8.7	2.0	15.2	0.7	1.3	19.7	4,538
Nelson Marlborough	38.9	10.2	1.2	34.3	0.9	3.1	11.4	4,071
Northland	45.3	11.3	22.8	16.8	1.9	0.3	1.7	2,627
Otago	62.2	11.1	9.1	8.7	7.9	0.5	0.6	6,566
South Canterbury	64.7	8.5	10.6	9.7	6.1	0.0	0.4	2,267
Southland	63.2	8.4	11.5	10.6	5.6	0.6	0.2	3,610
Tairawhiti	41.8	42.7	1.4	12.4	1.4	0.0	0.5	443
Taranaki	31.6	12.2	2.0	50.4	1.4	0.8	1.5	2,464
Waikato	52.9	14.6	0.8	29.2	1.3	0.3	0.8	6,320
Wairarapa	49.0	15.0	0.6	16.7	0.1	1.1	17.5	908
Waitemata	64.0	11.4	3.4	15.8	1.4	0.1	3.8	5,407
West Coast	56.2	4.0	26.1	7.5	5.6	0.0	0.6	1,416
Whanganui	57.3	8.0	0.5	14.8	0.4	1.2	17.7	2,239
Total	**56.3**	**10.9**	**4.3**	**19.7**	**2.6**	**0.6**	**5.4**	**88,170**

3.2.6 Home support services

Key points

- Domestic assistance was delivered to around 47,152 service users per week, during July 2004.

- Personal care was delivered to around 16,609 service users per week, during July 2004.

- On average, this equated to five hours of domestic assistance per service user, and/or 12 hours of personal care per service user.

- Some regional variation was noted, but no noticeable extremes.

- Data indicated a very wide variation in the number of respite care days invoiced by DHB.

- Around 582 service users were represented in the respite day's data, and accounted for 8250 respite care days in total, an average of 14 days each.

Table 17 provides an analysis of domestic assistance and personal care provided during July 2004. The data were based on the number of service units delivered weekly. The total number of service users and the number of service hours delivered was reported for both domestic assistance and personal care.

Table 17: Home support services analysed by DHB

DHB	Home support service				Total	
	Domestic assistance		Personal care			
	Number of service users	Number of hours	Number of service users	Number of hours	Number of service users	Number of hours
Auckland	3,486	15,835.4	1,194	14,961.3	4,680	30,796.6
Bay of Plenty	3,066	17,000.5	1,074	18,820.1	4,140	35,820.6
Canterbury	8,665	30,211.5	2,634	15,682.4	11,299	45,893.9
Capital & Coast	1,838	15,193.6	708	15,788.0	2,546	30,981.6
Counties Manukau	3,422	15,128.3	1,164	19,329.9	4,586	34,458.1
Hawke's Bay	1,589	11,954.3	752	20,342.8	2,341	32,297.0
Hutt Valley	1,097	7,439.3	402	7,715.3	1,499	15,154.5
Lakes	1,161	9,514.6	480	9,863.5	1,641	19,378.1
Mid Central	1,990	21,174.0	698	12,597.5	2,688	33,771.5
Nelson Marlborough	2,081	14,691.3	548	7,323.0	2,629	22,014.3
Northland	2,280	7,912.0	818	8,916.0	3,098	16,828.0
Otago	3,641	15,712.2	1,285	10,877.1	4,926	26,589.3
South Canterbury	1,134	4,424.4	490	3,602.9	1,624	8,027.2
Southland	1,813	6,633.4	696	4,891.4	2,509	11,524.8
Tairawhiti	2	34.0	13	66.5	15	100.5
Taranaki	1,211	5,217.1	409	4,182.8	1,620	9,399.9
Waikato	3,037	15,038.4	1,242	17,411.5	4,279	32,449.9
Wairarapa	296	2,200.5	145	2,814.5	441	5,015.0
Waitemata	3,429	13,237.5	1,286	12,440.3	4,715	25,677.7
West Coast	780	5,678.1	213	1,908.7	993	7,586.8
Whanganui	1,098	8,456.5	337	6,573.5	1,435	15,030.0
DHB unknown	36	133.2	21	196.1	57	329.4
Total	**47,152**	**242,819.7**	**16,609**	**216,304.9**	**63,761**	**459,124.6**

Table 18 provides a summary of the data illustrated in Table 17. Here, the average number of hours of home support per service user was reported by DHB. Again, some regional variation was noted. Nationally, those receiving domestic assistance were provided with five hours of support services, while those receiving personal care received 13 hours per week. The total national average for all service users was 7.2 hours of service per week.

Table 18: Average hours per week of home support services, analysed by DHB

DHB	Home support service (average hours per week)		Total (average hours per service user)
	Domestic assistance	Personal care	
Auckland	4.5	12.5	6.6
Bay of Plenty	5.5	17.5	8.7
Canterbury	3.5	6.0	4.1
Capital & Coast	8.3	22.3	12.2
Counties Manukau	4.4	16.6	7.5
Hawke's Bay	7.5	27.1	13.8
Hutt Valley	6.8	19.2	10.1
Lakes	8.2	20.5	11.8
Mid Central	10.6	18.0	12.6
Nelson Marlborough	7.1	13.4	8.4
Northland	3.5	10.9	5.4
Otago	4.3	8.5	5.4
South Canterbury	3.9	7.4	4.9
Southland	3.7	7.0	4.6
Tairawhiti	17.0	5.1	6.7
Taranaki	4.3	10.2	5.8
Waikato	5.0	14.0	7.6
Wairarapa	7.4	19.4	11.4
Waitemata	3.9	9.7	5.4
West Coast	7.3	9.0	7.6
Whanganui	7.7	19.5	10.5
DHB unknown	3.7	9.3	5.8
Total	**5.1**	**13.0**	**7.2**

3.2.7 Respite care

Table 19 records the number of respite days invoiced during June 2004. Because of the nature of respite care, a client can claim in the same week as the service delivery, or even six months later. Currently there is no time limit which prevents HealthPAC from excluding the claim, so if the claim is very late but the client has unclaimed eligibility, then the service will be processed. For this reason, presenting the total number of respite days by DHB could be potentially misleading. Canterbury, for example, had a total of 2197 respite days invoiced during the month, where the median value was 315 days per month in total per DHB.

Table 19: Total number of respite days invoiced, analysed by DHB and age group

DHB	Age group (years)					Total
	<15	15–44	45–64	65–74	75+	
Auckland	16	83	564	57		720
Bay of Plenty	179	136				315
Canterbury	10	143	55	397	1592	2197
Capital & Coast	487	230				717
Counties Manukau	19	109	243			371
Hawke's Bay	76	148				224
Hutt Valley	143	341				484
Lakes	12					12
Mid Central	108	114				222
Nelson Marlborough	105	25				130
Northland	48	32		3		83
Otago	88	42		63	420	613
South Canterbury	8	26	9	29	26	98
Southland	55			56	254	365
Tairawhiti	215	210	14			439
Taranaki	5	61				66
Waikato	12	86				98
Wairarapa	270	47				317
Waitemata	10	100	413	116		639
West Coast				34	77	111
Whanganui	5	24				29
Total	**1871**	**1957**	**1298**	**755**	**2369**	**8250**

Table 20 below provides the number of service users represented by the respite day data in Table 19. This does not take into account the number of days claimed, just the actual number of service users. From this data it would appear that respite care is most common for those aged 44 years or under, and those aged 75 or older. Again, Canterbury DHB had a significantly greater number of client claims, 110, while the average number of clients across all DHBs was 10.

Table 20: Number of clients claiming respite days

DHB	Age group (years)					Total
	<15	**15–44**	**45–64**	**65–74**	**75+**	
Auckland	4	6	16	2		28
Bay of Plenty	15	9				24
Canterbury	3	10	5	31	110	159
Capital & Coast	28	20				48
Counties Manukau	4	8	7			19
Hawke's Bay	7	10				17
Hutt Valley	17	17				34
Lakes	1					1
Mid central	11	9				20
Nelson Marlborough	14	5				19
Northland	9	4		1		14
Otago	9	5		3	32	49
South Canterbury	1	4	2	1	5	13
Southland	4			5	22	31
Tairawhiti	19	11	2			32
Taranaki	2	7				9
Waikato	3	6				9
Wairarapa	14	6				20
Waitemata	4	6	12	2		24
West Coast				3	5	8
Whanganui	1	3				4
Total	**170**	**146**	**44**	**48**	**174**	**582**

3.3 Focus group and hui/fono demographics

In total, 80 service users from mainstream services and 22 from Māori and Pacific services provided the data for analysis. This comprised 77 focus group participants and submissions from three further service users for whom written participation was the most appropriate way to accommodate their needs. Table 21 provides a breakdown of participants by DHB.

Table 21: Focus group participant demographics

DHB	Male	Female	Total
Canterbury	14 and 2 written	11	27
Waikato	10	14	24
Counties Manukau	4 and 1 written	3	8
Southland	7	14	21
Total	**38**	**42**	**80**

An unavoidable and sudden change to the originally scheduled date for the focus groups in Counties Manukau, and potentially the low number of home-based support services, may have accounted for the low number of participants in Counties Manukau. In addition, the disability advocate received less support from organisations in this area than in the other three. There was a mix of urban and rural participants in all DHBs. In particular, in both Waikato and Canterbury a combined total of 12 participants travelled for over an hour to attend a focus group presenting service user views from small New Zealand communities. Twenty-five participants identified themselves in the over 65 home-based support category and 43 participants identified themselves in the under 65 home-based support category. Of the 12 participants who identified themselves as

rehabilitation/habilitation category, nine also listed themselves as receiving home based support in the under 65 group.

Table 22: Participants analysed by DHB and service group

DHB	>65 years	<65 years	Rehabilitation/ habilitation	Total	Pre-enrolled
Counties Manukau	4	3	1	8	15 (rescheduled)
Waikato	8	17	0	25	31
Canterbury	5	14	8	27	30
Southland	8	9	3	20	21
Total	**25**	**43**	**12**	**80**	**97**

While specific hui were also held, there were 12 Māori participants over the four focus groups. Participants identified with a range of impairments including, visual impairment, head injury, dementia, hearing impairment, physical impairment, intellectual impairment, deaf and blind, epilepsy, stroke, and other medical conditions. Further to this, some older persons identified their need for services as being the result of the 'ageing process'. Parents, family, whānau and guardians were also participants. While the age of participants was not asked, often this information was volunteered. Of those who stated their age, the oldest was 87 and the youngest a parent of a two-year-old.

3.4 Mainstream service users

3.4.1 Introduction

The focus group participants discussed their experiences as disability support service users. They provided extensive information regarding issues of quality and safety in service delivery, as well as identifying the source and nature of physical and non-physical risks. Participants also gave their thoughts and opinions about the service provider organisations they had contact with. After analysis of the discussion transcripts the following themes were identified:

- the needs assessment procedure

- the support workforce, need for training, recruitment and retention

- risks to service users' safety, both physical and non-physical

- how support service delivery impacts upon the service user's family service users' relationship with the service providers and their experiences with bureaucracy

- service structure and accountability

- disability awareness in the workforce and the community

- the importance of promoting and supporting independent living.

These themes will be discussed herein.

3.4.2 Needs assessment

Key points

- Focus group participants indicated that there was often a long delay before the assessment.

- The participants also believed that the assessment procedure sometimes under-estimated need, and did not take into account the impact on the disabled person's family.

An assessment of a disabled person's needs precedes the allocation and delivery of any disability support services. It is carried out by an approved Needs Assessment and Service Co-ordination (NASC) agency.

The needs assessment process was identified as an issue for many service users. There were concerns about the delay prior to being assessed, the mismatch between service users' expectations and the actual service hours allocated. Participants identified a delay before assessment of approximately six weeks for the under 65 age group, and this increased to up to three months for those in the over 65 age group. The need to get a general practitioners (GP) referral further contributed to the delay. The 65+ service users, in particular, spoke of how this long wait and their ongoing 'battle [against] weariness', can lead to a loss of self-worth.

Participants reported that assessment outcomes did not always match their needs. For example, the husband of a service user noted the brief assessment process did not capture the extent of his wife's needs or those of their family. He could not leave her alone without a support worker, because 'she frets'. As a result of this stress, the husband 'was not getting enough sleep' and felt that there was 'a serious risk to their relationship and his health'.

A support worker who was present who knew the pair well, said the husband 'was very stressed out', and she was 'very frightened for the two of them' (Waikato, over 65).

Service users reported that the impact of disability on family and whānau was an integral element of the needs assessment process. Presently, Māori providers were seen to be the only ones doing so. A proper assessment required a detailed analysis of the person's needs, incorporating their family, culture and religion. Some participants went further and suggested that the assessments should be undertaken in conjunction with the family.

Concern was also expressed around the fact that some assessors relied too much on the family to provide support. For example, the father of a service user, from a sole income family, was told by an assessor to give up his job and sell his work vehicle in order to get a vehicle better suited to the user. Another felt that there was an expectation that she would leave her job in order to become her husband's full-time carer.

Service users felt the support they received should be tailored to their individual needs. As such, support workers' job descriptions should be based on the needs assessment of each client rather than the service provider's agenda. It was also suggested that the needs assessor meet regularly with the service provider and their support staff, to discuss a work plan according to the service user's assessment. Flexibility of service delivery and awareness of changing needs were issues that were often raised in the focus group discussions.

Participants reported that there should be more accountability from service providers to ensure that the outcomes of the assessment were delivered. For example, if a needs assessor identified that a service user was entitled to 12 hours, then the provider should ensure that 12 hours of care is delivered.

Participants also voiced their concerns regarding the credibility and qualifications of some assessors. A parent of a service user felt that the needs assessment process was unfair and that the assessor had 'favourite families'. This person felt the assessors should be monitored and that the support should be consistent and fair to everyone. A mother of a disabled two-year-old child was told by her needs assessor that the child was no more dependant than any normal two-year-old, despite her child being non-expressive and unable to walk.

Other discussion centred on the appropriateness of current assessment criteria. For example, in a situation where a participant was 'flatting' with another service user, only one of them received a NASC assessment because they were in 'shared accommodation'. The service user felt this was 'a need that should be addressed' (Waikato over 65).

3.4.3 The support workforce

Support worker training

> **Key points**
> - Service users reported that the low level of training was seen to be a factor of many physical and non-physical risks, as well as affecting the quality of the services delivered.
> - Recruitment and retention of the support workforce was seen to impact upon the quality of staff and safety of services delivered.

Participants stressed the need for support workers to be skilled and knowledgeable. In many cases, it appeared that the only training for new inexperienced support workers was on-the-job buddying with experienced support workers. Service users were very concerned about this lack of training and the safety issues that it created. One described the emotional and physical stressors endured when her support worker dropped her on the floor. Service user participants suggested that handling clients should only be undertaken following proper training, to prevent injury to both the client and support worker. Participants noted that an injured support worker also required time off work and impacted on the service user's care.

Personal care was another area many users felt training was lacking. Some support workers did not seem to have 'an understanding of these things – particularly hygiene'. As a consequence of this lack of training, service users often found themselves in the position of having to 'train' their support worker themselves. The high turnover amongst support workers just added to this frustration. In an attempt to overcome some of these problems service users felt that there should be opportunities for them to have formal input into any training of support workers, in particular with respect to lifting.

A need was expressed for training in basic home help, to establish quality control and a standard of care amongst support workers, as some workers 'can't even poach an egg'. In addition, it was felt that support workers needed to be aware of 'boundaries'.

> "Carers need to keep their personal issues at home as that is not appropriate work behaviour."

It was felt that trained and better paid workers would improve the quality of care, but at this stage, there was little incentive to undertake training:

> "Support workers here have no reason to train as they have to pay for it and do it in their own time. In addition their uniform, travelling time and travel costs should be funded. This would improve quality for clients" (Canterbury under 65).

Participants also noted the lack of training given to family members who were providing support. Service users felt family members should also be trained in the specific needs of the client. Both service users and family members were thought to be at risk.

> "Family help [being] available stops the support worker coming in but it would be nice to know the correct way of lifting. This is a safety issue because if they are doing it wrong for a long period it will eventually result in an injured carer" (Canterbury over 65).

One service user said her provider had confided in her that they don't bother to train everyone, only those workers who they think 'will be good'.

Support worker quality

Key points

- New support workers required time to get to know the service user.
- With frequent changes of staff, the participants found that a lot of their energy was used to re-establish rapport, and with lesser trained staff, instructing them on their duties.
- Some participants sometimes felt responsible for training their support worker themselves.

The majority of service users saw the roles that support workers undertook as being essential for disabled people, but were concerned about the quality of the work force, especially for home-based support. Other service users felt there was a lack of commitment on the part of support workers. This was reflected in a number of ways, including the standard of care provided. For example, some service users spoke of having eaten food that was 'off' because the support worker had failed to remove expired food items from the fridge. Others believed some workers perceived their job as a 'holiday' and did the bare minimum, or less, this was more apparent in new or relief workers.

Other service users commented on how the quality of support services was compromised by the support worker not being able to communicate proficiently in English. For one parent of a service user this meant being unable to leave the support worker alone with their child, as the child was not able to communicate their needs. Still other service users reported that theft by support workers was a significant problem, with many having lost money, personal property and even home appliances. Service users described how support workers not turning up or being unavailable put extra stress on themselves, and often their family. A service user told of how she:

> "spent the night on the toilet because the carer did not show up" (Canterbury over 65).

Another described how:

> "My caregiver went away for Christmas and never came back. Six months later I was sent a new carer who had been sent straight to me from her job interview with the provider; she had no skills and no training" (Canterbury under 65).

Service users who were positive about their support workers had often had them for many years and had formed a mutual, caring relationship. One support worker always said to her client, 'make sure you lock the front door after I leave', and would then wait to make sure the user did it. Another service user reported having 'an awful lot of laughs' with her support worker. Participants acknowledged that a lot of the work was practical and hands-on, but that 'aroha' (love) was important. Workers do not do the work for the money; they do it for the love; however users felt:

> "[The] system's taken advantage of that and it has been exploited for years now" (Canterbury over 65).

Service users wanted to be able to choose their own support workers. One user, living in an IHC supported living flat, had felt 'disempowered' as the workers had been unsuitable. However, she had since been able to choose her own support worker:

> "She is wonderful. We go line dancing and to the movies. She has a good heart. She knows my needs and she is honest" (Canterbury under 65).

One service user also related his experience with 'Able Tours' (provides recreation excursions for disabled people):

> "The experience was great. The main carer knew what to do when I had a massive epileptic fit. And the carers have fantastic personalities. It was wonderful and has been great for me. Now I go places and do neat things. It has opened up my life" (Canterbury under 65).

The ideal support worker was seen to be compassionate, patient, respectful and understanding of service users' needs. Quality support workers were perceived as 'friends' by service users, and

trust was also seen to be essential for a good bond between service user and support worker.

> "My support worker is wonderful. I have no complaints. It is nice when you get a good carer; it helps you appreciate life" (Southland over 65).

Workforce recruitment and retention

Key points

- Low staffing levels could lead to delay in service provision.
- Successful service delivery depended on a stable workforce and continuity of care.
- Poor remuneration of staff was seen as indicative of how society undervalues disabled people.

A lack of adequate staff was highlighted by many service users. They noted the prominence of caregiver advertisements in the situations vacant columns of the newspapers:

> "They are so desperate for workers because there needs to be better pay, [if they] valued staff and [it was] a more attractive option, then people will want to do it" (Canterbury over 65).

Low staff numbers meant some service users waited long periods before receiving support services. Participants noted that the delay often meant a decline in their health, and so more work for the support worker to undertake when they did start providing support services. Many service users complained of high staff turnover and the 'chopping and changing' of support workers. Service users felt the key to a successful support service was a stable workforce and that continuity of care was necessary for trust to develop between the service user and the support worker.

To this end, turnover was seen as a large problem because 'you do get used to someone and then they are gone'. It is hard on both the user, who has strangers turning up without warning at their homes and on the worker, as it takes time to build up a rapport between service users and support workers.

> "I had a great carer, but she wanted to pick up more hours, so she was taken away from me and given to another; it was so unfair" (Counties-Manukau under 65).

> "It must be scary for some of the workers, not knowing clients, especially when personal care is involved" (Southland over 65).

Participants also believed that many support workers saw the job as a 'fill in', due to poor pay and the lack of a career path. 'Pay peanuts, get monkeys' was a popular comment made during focus groups.

> "You can tell the ones who are there just for the money or those who actually have the heart for it. And unfortunately, when you get people who are committed, the system takes advantage of them. They are undervalued and underpaid" (Canterbury over 65).

Many participants voiced the belief that both workers and service users saw poor remuneration as indicative of how society undervalues disabled people in their community:

> "The wages for carers are reflective of society's attitude towards support workers and service users" (Waikato under 65).

3.4.4 Risks to service user safety

Key points

- Physical and non-physical (eg, emotional, cultural) risks to service users' safety were discussed.
- Lack of training and insufficient supervision were two factors seen as responsible for these risks.
- Lack of support services late at night and on the weekend were highlighted by participants.
- Lack of trust was identified as a non-physical factor that affected the service users overall feeling of safety.
- Breaches of client confidentiality were cited as another source of non-physical risks.

Service users also discussed risks to their safety. These included physical risks such as bodily injury as well as non-physical risks such as psychological or emotional discomfort. Many of these issues were seen as related to the lack of training in the support workforce. Physical risks occurred when support staff did not carry out tasks properly, or where not present when the service user needed them. One service user noted that:

> "Some of the girls have long fingernails, which pinch the skin and break it; this can cause damage and worse, cross infection" (Counties-Manukau under 65).

Such an incident showed a lack of training, but also indicated insufficient staff supervision. It was felt by participants that underestimating the level of support and care put the user at risk. If one service user had the appropriate service in the first place, she would not have injured herself and then required ACC funding as well as her original disability funding.

Participants also felt uncomfortable about the lack of care provided late at night and in the weekends, with one commenting he had not had care in the weekends for six months and was reliant on family and friends for help.

"What about weekends? People don't just get better" (Canterbury rehabilitation/habilitation).

"At night you need carers. It would be nice if carers were more flexible" (Canterbury under 65).

A lack of adequate resources was identified by some service users as a physical safety issue. Centralised services caused one blind user to be without a stick for five days, after his stick broke.

"I felt very unsafe without it. Mobility was impossible as it would have been very unsafe. Also, then the public doesn't realise your blind" (Canterbury over 65).

Non-physical risks identified by the participants included trust, privacy and confidentiality. Trust of their support worker was often raised in the focus groups as a factor that impacted on their overall feeling of safety. While many users felt they could trust their support workers, others did not, but often had to provide them with a house key out of necessity. Such situations left the service user feeling unsafe in their own home. Emotional safety was also not helped by the high turnover of staff.

"Changing in front of a stream of constantly changing workers causes undue stress and a loss of dignity" (Counties-Manukau under 65).

Lack of confidentiality was also identified by participants as another risk. Some reported that support workers would discuss service users with their own (support worker's) family. This lack of confidentiality was especially distressful for those in smaller rural communities, where service users felt that the whole town knew what went on in their house. Disclosure of information was a complex issue, with one service user commenting:

> "It is not only carers who talk about clients – providers sometimes 'warn' workers about clients. Clients have a right to personal privacy" (Canterbury under 65).

Some female users were assigned male support workers, and experienced embarrassment and emotional distress. Another client's support workers made her feel uncomfortable when she was menstruating:

> "Workers complain about this and it makes me really uncomfortable because it is unnecessary and makes me feel awkward. They do silly things like wear three pairs of gloves and say I should be wearing nappies" (Counties-Manukau under 65).

Service users had similar problems with respite care workers as they had with their own support workers. Some users mentioned a lack of training and poor quality but also suggested because it was only for a short time, they considered it less problematic.

3.4.5 Impact on family

Key points
- Service users believed that the support service system was too reliant on family to fill gaps in service delivery.
- Support roles were sometimes taken up by inappropriate family members.
- Family members were not seen to receive equitable funding for the support they gave.
- Some service users felt 'shame and guilt' about the pressures they felt had been forced on their families.

As well as risks to their own safety, participants discussed the impact of poor quality services on family and friends. Service

users believed that the support service system was too reliant on the goodwill of individuals, to fill service gaps. Participants felt the government was unaware of the significant role taken by family and friends supporting disabled people. Service users felt family were 'burdened and affected' and 'not paid to step in and pick up the slack' of poor quality support.

> "There is an assumed fallback on family and friends due to the lack of resources" (Canterbury under 65).

Participants said that support roles were sometimes taken up by family members who are not capable. Grandparents were used as caregivers for young children, but some service users felt this was possibly taking advantage of the grandparents' difficulty in saying 'no'.

Participants considered funding was inequitable in the case of family support. Family members were not funded equally as support workers and one user's husband was not paid at all to be her caregiver. In addition, another user noted that she lost her home help when she started living with her partner. Another user and her partner felt embarrassed because it was assumed in the legislation that her partner would provide for her financially, but this was not the case. Inequitable funding was seen by users as 'oppressive' and 'endangering family and personal relationships' (Waikato under 65 rehabilitation/habilitation).

The families of service users reported the inflexibility of service delivery, particularly in respite care, did not enable them to 'have a life'.

> "My life should not be so affected by this. I am not responsible for what happened to him. There needs to be a system that can help and support both the client and their partner" (Canterbury rehabilitation/habilitation).

Families of service users recounted the significant change of lifestyle that resulted from having a family member with disabilities, and the difficulty they had in coping with this. Some service users felt 'shame and guilt' about the pressures they felt had been forced on their family. The wife of a service user described the approach she had to take with her husband due to his emotional state:

> "Pride and self-esteem is so important and if I hadn't been careful, he may have just given up" (Canterbury rehabilitation/habilitation).

Some users mentioned their concern about a perceived new rule in which personal care support workers were no longer allowed to give their clients medication. Service users were concerned that the outcome on this would be greater reliance on the family.

> "It is scary being a client. Often it is a completely new world for a client and also the family as well" (Canterbury over 65)

3.4.6 Service providers and bureaucracy

Key points
- Assertive service users feared punitive actions from providers.
- Some service users reported that complaints procedures were difficult to access.
- Dealing with complaints created stress on the family as well.

As well as the impact of service delivery, service users also identified issues with the service providers. Some participants spoke of being 'blacklisted' or 'left out in the cold' if they were too assertive or 'bolshy' with their provider.

"When families complain, providers get nasty. If you raise an issue with a provider there is the fear that the service will be withdrawn. Perception and fear is everything" (Counties-Manukau under 65).

Furthermore, users noted the difficulty in taking a complaint beyond the provider and the fear that the provider could 'terminate the client's contract.' Users felt there was inequality between the rights of the provider and user. Many service users described the effort to get support services as a 'battle'. Service users related the difficulty they had 'to trust other people' due to 'constantly being let down'. The protracted process of applying for support services meant that:

"Providers have to build up clients self worth because they are so degraded from dealing with government red tape" (Canterbury over 65).

This process resulted in the loss of 'pride' of service users and the feeling that they were a 'burden':

"Being disabled feels like a punishment; like you're not worth or valued enough to give help to" (Waikato under 65 rehabilitation/habilitation).

One parent of a user was in an ongoing 'court battle' with ACC. Their family has three 'special needs children' and have so much ACC documentation they spend '40 hours a week' on paperwork alone and 'the stack is 26 inches high,' for just one child. The family felt exhausted from battling the current system:

"It feels like your being cut off by everyone, which can cause huge emotional issues and result in things like a broken marriage. It is really hard on the families or partners of users. You lose friends because you can't socialise; it's not like you can just get a babysitter" (Canterbury rehabilitation/habilitation).

Participants felt like 'second-class citizens' and becoming 'financially crippled' due to their partner, their child or their own health. Lack of communication between themselves and their provider or government departments, and emotional and financial stress were seen to be 'breaking up families'.

> "People need to live in a good, supportive environment in order to recover. People need to have independence and individualised choice and pride" (Canterbury rehabilitation/habilitation).

3.4.7 Service structure and accountability

Key points

- Service users reported that the process needs to be more client-centred.

- Some suggestions of coordination of services in a 'one-stop shop' or using a key worker model of service delivery.

- Rigid service delivery was seen to inhibit service user's integration into the community by limiting their access to employment or social interactions.

- Many reported a difficulty in accessing information on entitlements to services.

Participants felt there was a lack of communication between the varying government departments and service users and further that government departments were not held accountable for the quality of care. Service users felt the Government needed a shift of focus and philosophy and to ask the question:

> "What do people with disabilities want to do?" (Counties-Manukau under 65).

There was a consensus amongst participants that the whole process needs to be more client-centred. Participants suggested that all those involved in the continuum of care should come together for one meeting per client, preferably in the service user's home. Another suggestion was for a national organisation or department, 'a one-stop shop' which would be less stressful for clients and families. Alternatively, participants suggested a 'key worker' model of service co-ordination. It was commented by participants that the focus of current agencies was not on client satisfaction or needs and was often not compatible with a user's needs or desires. Many service users described the current service was inefficient and felt they would be better off if they could employ their own staff.

> "Why do users have to go to a service provider to employ staff? It is so insulting! Why can't each individual get a payment to employ their own worker? Users would then be able to pay workers better and be able to employ workers with better qualifications and training if necessary" (Counties-Manukau under 65).

Service users suggested fluctuating funding, where they would be given so many hours of support per year, allowing them the 'flexibility and choice as to the delivery time and service.' This would give service more independence regarding their care. Service users felt strongly there was also a lack of communication and accountability from disability support service providers. Contracts meant nothing and despite asking to see their contract, users were 'fobbed off.' Some service users felt contracts and job descriptions of providers should be easily accessed on the internet as they are taxpayer funded. Respondents felt there were no procedures in place for raising concerns or issues regarding the quality of care for the service user. Some service users said that staff and co-ordinators were difficult to get hold of or would refuse to take calls. Respondents felt frustrated by the

lack of service provider choice and the 'battle' they faced trying to get service.

> "You have to 'get on' with people to get resources; it is a balancing act between being headstrong and accommodating in order not to upset people" (Canterbury over 65).

Users noted that their usual feeling from dealing with government departments was 'let down and disgruntled'. Service users noted how hard it must be for elderly people to speak up in the manner necessary. High on the service user's wish list was to:

> "Eliminate the waiting list and priority list making a joke of 'service provider' – they are supposed to provide service" (Canterbury over 65).

Service users felt at the mercy of support services and were often given false hope, wrong information, left waiting or forgotten about.

> "Support services came for the first time six weeks after one user left hospital [which was] two days after he died" (Canterbury rehabilitation/habilitation).

Services users believed that everyone with disabilities needed financial help and questioned what they saw as wide disparities in funding between service users. One respondent currently received no financial assistance because ACC and Health were in disagreement over who should fund him. Some believed family break ups were encouraged due to differences in funding assistance. One wife of a user recounted that only if they were divorced would he be able to get income support (Canterbury rehabilitation/habilitation).

Throughout the focus groups, participants highlighted the lack of input they had in deciding when and for how long support workers would provide services. One participant commented that he could not get a support worker to come before midday, meaning he could not work until after that, and this had impacted on his 'quality of life'. Another wanted four hours home help but was given two hours home help and two hours shopping by the provider. When he asked for a change he was given a 'veiled threat' from the provider, but in the end they worked it out. There was also thought to be little communication between support workers and providers, resulting sometimes in confused job descriptions for workers or confused users. If there were problems, participants believed they should be sorted out by the provider and not left for the user to deal with, which can make them uncomfortable.

> "Constructive comments are better coming from the service provider than from the client" (Counties-Manukau over 65).

Service users felt monitoring of the agency and the support worker by an independent body would be beneficial for the quality of care they received. Participants believed that monitoring would also enhance the communication between all three parties; providers, workers and users. Service users noted they were not always aware if the quality was sub-standard due to their disability (eg, visual impairment). Many participants felt supervision of staff and service user feedback would increase the quality and continuity of work.

Respite care was considered 'badly needed', but the amount given was believed to be inadequate by many service users. A support worker spoke of a service user's grandmother who was

given only 15 days respite care, due to the lack of organisations providing care and relief, which she found very stressful:

> "She is an 80-year-old looking after a 15-year-old. Of course she can't handle it, but it is difficult to access other services to help with this kind of issue" (Waikato over 65).

Service users found it difficult to obtain information on what they were entitled to. Often this was compounded by misinformation from health care workers:

> "Support workers and organisations need to be very clear about the differences between ACC and health, as I found the situation quite embarrassing as did the support worker" (Canterbury rehabilitation/habilitation).

Participants also suggested entitlements could be 'simplified, clear and equitable' and offered in 'plain English'. Many respondents felt general confusion about what they were entitled to and the differences between hours of care provided were great, even in the same regions. One user was provided with seven days of personal cares while others in the same group were only allocated three days. Moreover, some users paid for their home help, while other users were provided with certain hours. Users felt entitlements were more 'who you know than what you know' (Southland over 65).

Some users also expressed difficulty accessing information and entitlements from service providers, including information on social outings and activities. Participants thought it would be good if there was a field officer or key worker who could assist in determining their entitlements. Participants believed complaints, including theft, were not taken seriously enough by the provider organisations and were not always acted upon. If complaints were made against a support worker the worker often continued

to work for the provider, but for another user. Participants saw this as passing the problem on to someone else, and a safety issue. Service users believed that providers did this because they are so short-staffed.

3.4.8 Disability awareness

Key points
• Service users reported that support workers often lacked adequate knowledge of the disabilities that the service users experienced.
• Service users suggested greater promotion of disability awareness in the community

"It is time to stop patronising disabled people. There have been so many discussions and still users live in appalling conditions" (Canterbury under 65).

Users commented on support workers' lack of disability knowledge. One participant found herself constantly educating new support workers about her disability, despite it being relatively common. Service users suggested all support workers take part in a disability awareness training scheme, perhaps run by users. This would enable users to be more proactive in the training process. Some service users felt disability awareness should also extend to the service infrastructure.

"Disability feels very isolated and there is a huge lack of understanding. It is not easy to explain your disability. The MoH needs to be working with the Human Rights Commission in this area. Having to see so many people and constantly describing your disability and limitations is horrible" (Waikato under 65 rehabilitation/habilitation).

Service users related their desire for greater disability awareness in the wider community:

> "Disabled people find it hard to mix with people that don't have disabilities" (Canterbury over 65).

Users suggested more community awareness for disabled people, in the manner of the 'mental health ads'. Some participants found that people did not realise they had disabilities because their disability was not visible. It was felt that at times this could result in injury to a user.

3.4.9 Independent living

Key points

- Personal choice and independence were seen to be essential components of service users' lives.

- Service schedules were seen to suit the provider and support worker rather than the service user.

- Lack of suitable employment opportunities were noted.

- Service users also suggested a greater emphasis on enhancing support for encouraging activities of daily life such as personal care and cooking.

Participants recognised that personal choice and independence were essential components of their lives. The New Zealand Disability Strategy identified equal opportunity and individual choice as the means by which disabled people achieve community integration on their own terms (Dalziel, 2001).

Some participants perceived a lack of respect from support workers and felt they would have liked to be more in control of their life and decisions, to have independence and pride.

"Workers don't ask me when I want to go to bed, I just get told, and even if I am watching a programme, it doesn't matter. It is so degrading" (Canterbury under 65).

Participants believed that service schedules were usually determined by the provider or support worker and that the user was expected to fit in around them. Service users reported that services should not be governed by funding but by need. One user spoke of the difficulty she faced if she wanted to be out later then 10 pm, as her support worker went to bed. If she did stay out, her mother, suffering from arthritis, had to put her to bed.

"Organisation and workers have the mentality that it is not normal for those in residential [care] to be out doing things. Normalisation is a joke. They don't allow for growth. They don't allow you to be an individual… Organisations don't provide individual services for users" (Counties-Manukau under 65).

Many participants expressed difficulties finding appropriate employment. Issues included users not being able to find work and work places with inadequate facilities for their impairments. A small number of participants lost their jobs when partial funding for their salary was no longer available. One user wished to start a business from her supported living home, which she felt would assist her in getting personal care. The manager of the home did not allow this. Working was considered to be good for the self-esteem and users felt this was an area that needed to be addressed.

"The Ministry of Health need to understand that service providers should be a precursor to other things like working or community involvement. There needs to be a philosophy shift; why is it that disabled people live within the community? And what do disabled people want to do?" (Counties-Manukau under 65).

In addition to more employment opportunities, service users suggested that their needed to be a greater emphasis on enhancing their activities of daily life, such as personal care, cooking, life skills and cleaning. Participants acknowledged the vital role that support workers played in their lives. A good support worker allowed a service user to feel 'confident and independent in situations'.

> "The ideal would be if the client could be functional, independent, safe, and personal cares were delivered by a support worker who is trained in their needs" (Canterbury rehabilitation/habilitation).

Service users emphasised the need for good quality support workers, who encouraged the service user to gain independence and to avoid conflicts.

> "The more independent clients can be and then they can reach their potential" (Canterbury under 65).

3.5   Māori and Pacific service users

The hui and fono discussions centred on the following four topics:

1. Service users' views of the services they are currently receiving.

2. Issues the service users have regarding the safety and quality of the services they are receiving currently.

3. Service users' perceptions of what would improve the safety and quality of the service they currently receive.

4. The risks to the safety of service users and what causes these risks.

Each group was asked to make comments about the issues that concerned them in relation to the services they receive, and how they believed the services could be improved.

3.5.1 Service users' views of the services they are currently receiving

> **Key points**
> - Māori district nurses identified as a highly valued and successful service for Māori service users.
> - There was a perception that individualised funding would help service users gain control of their lives, especially for younger service users.
> - Most Māori users generally felt that really there were not enough workers to embrace and look after the many and varied needs of the users.
> - Most Pacific participants expressed some sense of satisfaction with the services provided, although areas of concern were also discussed.
> - A number of Pacific service users felt there was little respect and understanding of cultural issues from providers.

Māori service users

As depicted in the following quote, some service users felt that the services currently being provided:

> "Were less connected to consumers ... they lacked a kaupapa ...."

The service users who were visited by Māori District Nurses (DN) felt that the services were very good. They identified the Māori DNs as being multi skilled and were really appreciative of the way the nurses connected them (the users) to more GP visits and

other assistance as required. In addition, these users also received home help once a week, as well as if necessary, a visit by a specialist nurse, such as a diabetic nurse. It was strongly emphasised that having a Māori DN who understood cultural issues and boundaries was particularly helpful and preferred by Māori users.

The participants noted that there had been a number of surveys carried out by the MoH and they expressed the need for the results to be available to all individuals involved. This not withstanding, a general feeling of lethargy and disdain towards research was expressed; in particular, one individual appeared quite distraught when voicing this point.

Discussion and debate surrounded the need and desire for personalised funding, as this was strongly identified as being better suited to the particular needs of the individual users, in particular the younger disabled persons who want more control and independence in their lives. The hui participants strongly recommended that the MoH re-introduce this option.

They felt MoH needed to understand disability issues more from their perspective. For example they needed to understand that disabled people were ordinary people who led ordinary lives. This meant that if workers turned up at mid day to complete personal cares with the disabled person, how were they supposed to hold down a normal 9–5 job? Arriving late to work would not be tolerated by bosses for very long, hence the disability becomes a stumbling block to having a normal working life.

Such things did not align with the MoH "Pathways to Inclusion" policy for disabled people. Hui participants felt that the MoH does not seem to be fully aware of the needs of disabled people, in particular with respect to the various levels of independence amongst service users. For example, a number of disabled young adults did not leave their parents' homes because they could not bath themselves.

> "A lot of disabled young people can't leave home, because they are not independent enough to do so ... they don't have the choice to do so ... so, growing up doesn't mean much to them, this creates its own problems ..."

Furthermore, one young service user highlighted that the rules pertaining to bathroom alterations were very specific. For example, only one full bathroom alteration is provided for an individual over their lifetime, which consequently ties a young disabled person to their family home. Furthermore, there is tendency for disabled children to be kept at school as long as possible because of the lack of employment opportunities for disabled people. As highlighted by one service user, such flaws in the system breed a certain degree of complacency and lethargy. As such, it was requested that these needs be addressed for the benefit of the users and their families.

The younger service users who were present at the hui felt that they should be given the appropriate support in order for them to live independent lives, comparable to that of non disabled people. One young disabled user felt she was getting a very raw deal from the health sector. As she described it, she felt she was on a merry-go-round and unable to get off, and what she really needed was an advocate to support and guide her through the system.

Many of the users in Canterbury stated that often care workers did not turn up in the weekends, they had been told that it was because of the a low number of workers available to work over the weekends. One user stated that she doesn't use Māori workers because they often did not turn up to work, using non Māori was far more satisfactory to her. Most users generally felt that really there were not enough workers to embrace and look after the many and varied needs of the users.

Pacific Island service users

Most Pacific participants expressed some sense of satisfaction with the services provided. However the group discussed the poor quality of care provided by support workers and not just necessarily Pacific workers. This caused much distress for Pacific service users and their whānau. An elderly Pacific person, who had cared for her husband following a stroke, initially refused services for two years stating she had such distrust of the support workers. When she did agree to have services, particularly personal care, she felt a number of the workers lacked the basic skills to care for her husband. When asked how she dealt with this situation she stated that she:

"Told them off and ordered them to leave."

She felt that many of the workers had no training and generally it was up to her to train them. However, she did notice a big difference in the quality of care when this was provided by a registered nurse.

The discussion expanded, and views and opinions regarding cultural needs were explored, a number of the users felt there was little respect and understanding of cultural issues from providers. For example, a number of participants talked of male support workers being sent to wash female service users and vice versa. This was considered an assault on the culture of the Pacific people.

Sometimes the participants felt unaware of what the providers could offer, particularly when trying to access services that were more culturally appropriate. In times of great need the users required urgent x-rays and medicine which they could not afford. In one region, the Pacific people were the lowest socioeconomic group, and they felt this further disadvantaged them. One user related a distressing story about the lack of medical attention and support offered. He broke down and cried when he described the stress that had caused him personally and his family. One older disabled Pacific person stated that in her culture it was common to give up services even though they were very much needed. Clearly this was done for cultural reasons alone:

> "I was receiving services but was told by [a] more senior member of my family more needy people require services so despite my own needs I gave up the services."

3.5.2 Issues service users have regarding the safety and quality of the services they are receiving currently

Māori service users identified some safety risks, but a number of participants felt it was not appropriate to give their honest opinion on such issues.

Pacific service users highlighted appropriate communication as important for the delivery of safe and quality services.

Māori service users

The Māori service users expressed strong feelings regarding the need to protect and provide safe services for them. This was more strongly expressed in the South Island meetings. The main concern appeared to be the need for easy access to services required that meet all their needs, both physical and cultural. Some participants indicated an unwillingness to contribute to this discussion. When asked why, they said:

> "It is very difficult for them (the users) to give their honest opinion because they felt uncomfortable and it was seen as not at all culturally appropriate."

Safety for one participant meant needing her family with her when support workers visited her home. She stated that she only felt safe when her family were around, however, at the time of the hui, her family were away in Australia and she was feeling very insecure. She has not stopped the services, but she felt a little unsafe and unsure of herself during this time. When asked how this could be improved she thought that if her worker was a Māori she would be much more comfortable having them in her home.

When asked to discuss the quality of services provided, many of the users felt that the time allocated to undertake domestic assistance was never enough: 'they always felt short-changed'. They felt the quality of services provided was lacking and often left them in the situation of having to complete tasks that were often unsafe such as climbing on stools to clean windows, changing lightbulbs.

Pacific Island service users

For Pacific people one of the main issues concerning safety and quality related to the need to understand what the rights of disabled people were when receiving support services. One of the users stated that Pacific people come from an oral [communication] background and it takes much longer to absorb the written word because of this. For those users where English was a second language this was even more difficult and consequently they often felt short-changed with the services being provided either because they weren't what they wanted or they were lacking in some way.

'Talking cross-culturally' was how several users described this misinterpretation. The language of the Pacific is full of metaphors and generally it was difficult to express themselves in English. When discussing personal matters, including bodily problems, it became very frustrating because they found it difficult to put into words that the palangi (white person) could understand. The group agreed that for most Pacific people the challenges in their life were complex and difficult to understand. They expressed much sadness because of this fact.

Funding was raised as a key issue relating to safety and quality. Participants felt the way in which service providers were funding ultimately impacted on what and how services would be offered to users. Solutions to this problem were offered, examples of these included training budgets for workers, this way the users felt reassured that support workers would be better trained. For some participants, disability was seen as just part of life. For example, stiffening joints was seen as a normal part of ageing. Consequently, many felt that this lack of disability awareness had prevented them from accessing services they found they were actually entitled to. For some younger disabled people, transport

difficulties impacted on the safety and quality of care and it was suggested that if these difficulties could be resolved, they would be much more independent.

3.5.3 Service users' perceptions of what would improve the safety and quality of the service they currently receive

Key points

- Māori service users reported that cultural training for providers and support staff would help improve the safety and quality of support services.

- Respite care was provided as an example of services delivered in a culturally inappropriate form, as whānau are separated by the process.

- Consultation with disabled Māori and Pacific people in the policy and decision making was suggested.

- Younger Māori felt that current age-based criteria prevented access to services they saw as beneficial.

- Pacific service users noted the high turnover of support workers made them feel uncomfortable receiving support services.

- Improving Pacific users' understanding of their access to services and methods of communication were vital for improving support services.

Māori service users

The general consensus of the group was that all support workers and senior staff needed to undergo cultural training to better meet the needs of Māori service users. Attempts to provide cultural training was either non existent or largely superficial. It was also felt that there should be a requirement that such training be ongoing. For some of the younger disabled users they would prefer their whānau not to be care givers, so that whānau could

be whānau and caregivers (support workers) could be separate. This they felt would prevent whānau members from becoming worn out and stressed by having to provide all personal cares to a person. Furthermore, users felt that when using respite care it should be allocated in such a way that the whānau could be together at this time, rather that being separated, which they felt was a very non-Māori way of providing respite care. They wanted the option of having a support worker with them while the whānau was on holiday together. Without doubt, the service users felt the whānau needed to be supported better for it to shoulder the responsibility of looking after family members with disabilities. However, many participants expressed the preference of having whānau was close by.

Participants felt that there was a need to include Māori and Pacific disabled persons in all levels of policy and decision making in the MoH and disability sector. The users felt this would improve the processes of consultation and communication between the MoH and Māori with regards their health issues. One user said that there was:

> "Very poor consultation process with Māori on health issues."

There was some acknowledgment that improvements in recent years have benefited Māori disabled people but that gaps in provisions specific to individuals still needed attention. The users in one North Island town praised the type of health clinic they were attending agreeing that for them it fitted their cultural needs extremely well. They considered a wellness/holistic model which included mixing with others as very important to their mental well being. As one user stated:

> "[I] feel lighter after I have come here."

In addition, she had stopped taking her Prozac since going to the wellness clinic and had felt so much better. Others described it as a place of belonging an excellent coming together. Many talked about the aroha, they felt when they went there – "here we knit, weave and eat together".

One key theme that emerged throughout hui was the importance of touch (wairua). When support workers provided services the Pakeha way, they 'cut the culture off' by not providing this touch therapy. One user who had experience of therapeutic massage stated:

> "There is a need for the human touch; otherwise recovery takes that much longer."

For the younger members the hui, they felt a concern that they sometimes did not meet the criteria to attend certain groups, as they stated everybody is different and there is a need to access services that suit the person's needs rather access to certain services being determined by the age of the user. It was believed that if appropriate and timely support was available, the situation would improve.

Pacific Island service users

For many of the Pacific people attending the fono, there was a general feeling about the high rate of support worker turnover; users felt that they had to put up with meeting 'strangers' all the time. Generally users felt insecure when new workers kept coming to attend to them.

> "It is not nice to be naked in front of a stranger."

Furthermore, participants reported that safety could be directly improved if Pacific health providers could communicate with clients in a language they could understand. They felt this would enable them to better understand their options and should ideally happen in their own homes with family support around them. The users felt one of the main ways to improve quality for Pacific people was to provide support that was driven by cultural needs. They all agreed this would have made a big difference, as one user stated:

> "Services would only be improved once workers have clear idea of cultural needs."

Central to improving quality for many of the Pacific service users was a need to understand processes (eg, who to see for what and how to access an advocate if they have some difficulties). The users felt it would be preferable that this person be a Pacific professional. A number of the younger disabled users of services felt that health services need to work smarter. For example, information technology (IT) systems that would allow different organisations to share information and so enhance the coordination of services. For the users in the South Island, methods of communication were felt to be pivotal to the improved quality of services. Many of the group felt this needed to be delivered through different mediums, including the church as well as radio. There are 14 radio stations for Pacific peoples in the Canterbury region and participants agreed that this was an excellent forum in which to share information between users and providers. The key theme to improve quality clearly appeared to be the need to develop appropriate processes to ensure better understanding between users, providers and support workers.

3.5.4 What are the risks to the safety of service users and what causes these risks?

Māori service users

A lack of understanding of the cultural needs of service users was a key theme. The service users felt that if support workers had regular cultural training, they would feel so much more comfortable and at ease and more willing to receive the supports they often so desperately needed. They felt that this would ensure a more equal partnership, which they felt would be more trusting and sustainable over time. Participants reported that at times the workers were sent away from user's homes with little or no explanation about the reason why, which left the service user feeling bad and perhaps the worker feeling inadequate.

The service users stated that they did not want to inform the workers what the problems were and stated they often felt some feelings of whakama (shame) in having to do this. Furthermore, there was no explanation given to the service providers either which often left the family providing cares after this total breakdown in communication. The consequence of this often stretched the relationship in the family and services where often not reinstated until crisis point had been reached.

Pacific Island service users

The Pacific service users found that the telephone was a major barrier to communication as for many, English was their second language and as a result this was cited as a major risk factor for this group. Firstly the users were unable to understand information such as worker's timetable when service providers phoned and secondly they felt totally inadequate using the phone to communicate issues around services. They felt entirely

powerless in this situation and often sent workers away rather than bothering to find some effective way to communicate with the service providers or workers. For users who had had some experience with cultural specific services they generally felt much safer and confident. However, as some users indicated all the users were not receiving services from such providers.

Whānau support and caring comprised a large part of the discussion. Two main themes were identified. Firstly, a lack of, or limited family support because of migration or work commitments left the clients feeling very vulnerable as many were not able to speak English to understand or discuss their support needs. This was given as the reason to refuse or stop services. One of the younger users in Waikato commented that this caused a 'closing down on personal systems'. Secondly, a number of Pacific users felt the risks to safety where compounded because in reality they did not really understand the term 'disability' it was totally foreign work to them.

3.5.5 General comments

Both the Pacific and Māori groups identified similar concerns regarding the lack of tikanga when providing them with services. The group felt there was a complete disregard for this in the everyday care provision. Both groups wanted workers who had been trained well and could provide the support they needed following best practice recommendations. If this practice could not be provided they felt that for themselves and the families it put a lot of unnecessary pressure to try to manage to care for sometimes very disabled service users with little or no support.

4   Key Outcomes and Discussion

4.1   Introduction

The previous section has highlighted the main themes emerging from the service user focus groups and hui/fono as well as the demographic data derived from the Client Claims Payment System (CPSS). The proceeding section draws on both sources of data to explore the meaning of quality and safety from a service users' perspective. In particular, the risks to the service user are examined in the light of both the findings arising from the current study as well as from the international literature. Direct quotes are again employed to support the risks and outcomes presented herein. The views of Māori and Pacific service users were gathered both through the focus groups and through the hui and fono. Those attending the focus groups tended to be receiving services from mainstream providers, where as those attending the hui and fono received input from Māori and Pacific providers respectively. Although there are many similarities between Māori and Pacific people's experiences of receiving services from mainstream and Māori and Pacific providers, there are also numerous differences. With this in mind, the views of Māori and Pacific service users are considered both within the main body of the discussion presented here as well as a distinct section.

4.2 The service user demographic profile

The CCPS offered an interesting source of information concerning disability service users across New Zealand. Whilst it has provided valuable data, the limitations should be considered. The data represented the invoicing activity for disability support services processed during the month of June 2004, and in the case of home support service data, July 2004. It does not represent the actual services or service users within that month, but the invoices paid for. It should also be noted, as mentioned earlier that CCPS is an evolving database system. While it accesses data from the Needs Assessment and Service Co-ordination (NASC) database, not all of the data captured in the NASC process is passed into CCPS. As CCPS undergoes further development, its capacity will be enhanced to provide a wider range of data on the demographics of, and services used, by disabled people throughout New Zealand. It would seem reasonable to suggest that such technical development would greatly enhance accurate monitoring of current services, as well as providing data for the future development of services. While bearing in mind the limitations mentioned, it is possible to utilise the results of the CCPS database queries outlined in the previous section to present a profile of disabled people in New Zealand. The spread of service users by District Health Board (DHB) represented by CCPS data was reasonably consistent with census 2001 data. As there will be some differences between the 2001 census and the 2004 data presented, no further analysis would be appropriate.

It was apparent from the data that disability services were provided to a wide range of service users, in terms of age, ethnicity and other criteria. The CCPS database provided information on age by indicating the number of persons born in the same year. That is, it does not have a distinct line of data for each service user, just summative information for all those with the same birth year. It was evident that a number of data entry errors were contained within the age field, as 39 service users were reported as having a birth date prior to the year 1900, including one bi-centenarian born in 1800. Such errors were not unexpected, and while exclusion of these points would be preferable, it was not possible to determine a clear cut year at which data entry could be clearly be called 'error'. The collapsing of the ages into summary groups made the data more manageable, reduced any real effect from such erroneous outliers, and did provide age groups to use across other variables. From the reclassification of ages into groups, it was ascertained that the majority of service users were over the age of 75.

Ethnicity proved to be a more challenging piece of data to analyse, as the 30 categories in the CCPS database were not easily collapsed into broader groups. The use of the ethnic descriptor 'European' was particularly common, without any further information regarding whether that was for 'NZ European' or born in Europe. Therefore, the ethnicity data should be treated with some caution. However, only 5.4% of service users were indicated as being Māori, which would place them well below the national average per head of population of around 12%. The 'not stated' category represented over 8% of all service users, so it may be that some proportion of these were Māori. While the vast majority of service users appeared to be 'Of European descent', a wide diversity of ethnic backgrounds was also apparent with service users of many ethnicities being identified.

The bulk of support services provided during the month of June 2004 were in non-residential settings, with just under 70% of service users in this category. The CCPS 'non-residential' category included home based services, and some services that were not specifically attached to a type of residence, such as associated travel costs. However, two categories, 'home support' and 'carer support', accounted for more than 95% of all non-residential invoicing. These are both home-based support activities, as they require services to be delivered in the house where the disabled person lives. The previous information confirms that the majority of service users received support in their own home environment. An interesting trend appeared to be that the prevalence of home support increased with the age of the service user, while carer support decreased. A high level of care support may suggest that support care for younger service users tended to take the form of informal respite care for parents and other informal caregivers. In the 45–64 age bracket, the 27.3% of 'carer support' provided probably indicated respite care to give spouses or adult children a break. In the older two age brackets for those 65–74 and then 75+, carer support drops back further as home support increases. This may indicate both the mortality of spouses and the decline in their ability to perform the support tasks for their family.

Primary impairments recorded by CCPS reflected the majority of service users were classified as having age-related or physical primary impairments. Service users with intellectual impairments were predominantly under the age of 65. Separate data was provided to analyse home support services delivered during July 2004. In that one calendar month, just over 4.5 million hours of home support services, both domestic assistance and personal care, were provided in the community. The summary of average

hours per service user confirmed that personal care tended to take more hours per week on average (five) than domestic assistance (two). Domestic assistance was far more prevalent with 47,152 service users receiving domestic assistance, as opposed to 16,609 for personal care.

4.3   Service user perspectives

A 'battle' was how many of the service users in this study portrayed their life. Participants frequently described how the impact of being disabled not only affected them but their family as well. The clear message from participants was that coping with being disabled was a daily issue and therefore having good support systems in place was essential. However, for many of the service users in this study, having support systems in place was not necessarily making their daily lives easier. The majority of the participants in the focus groups felt they had been or were in situations in which they felt their safety was at risk: emotionally, physically and culturally.

4.3.1 What are the risks to service users?

Key points

- The first key outcome details the risks pertaining to the safety of service users.
- What causes those risks?
- What issues do service users have around the safety and quality of the support services they receive?

Service users' perceptions of risk

Risk of injury or illness to service users

- Risk of emotional and psychological distress for service users.

- Risk of unmet needs.

- Risk of theft or abuse of service user's possessions.

- Cultural risks.

Some service users described scenarios in which they had been left in difficult situations such as, being left in their wheelchair all night, left on the toilet all night or isolated in bed without access to food or toilet facilities because the support worker did not show up, nor did any replacement.

> "Clients life at risk because of inadequate care and support" (Christchurch, rehabilitation/habilation service user).

> "Spent the night in my wheelchair because support worker did not show up" (Christchurch, over 65).

A support worker not turning up places some service users at risk of physical harm, such as dehydration due to lack of access to fluid or falling due to trying to move themselves. The reasons given by participants for why a support worker may not turn up varied, but a majority felt that an underlying cause was poor communication (or lack of communication) between needs assessors, support workers and the providers. Kroll, Beatty and Bingham (2003) found poor service user provider communication can place the user at risk for not receiving appropriate care. Other participants felt that even if a support worker communicated their absence to providers, there is a shortage of support workers available to provide a back-up service.

Fear of serious injury arose when the service user's usual support worker had been replaced with some one who did not know how to provide the appropriate care, due to the support worker not receiving appropriate training.

> "Shower floor is slippery and I have to tell the support worker, but you have to feel safe enough to tell her" (Christchurch, under 65).

> "If a staff member can't lift you properly they can hurt themselves or us" (Counties-Manukau, under 65).

Participants voiced concerns about being dropped or injured while being lifted. The overriding perceived cause regarding this risk was the lack of training of staff. Service users repeatedly associated issues such as poor lifting techniques with poor training.

> "Carers are trained, by the passing of knowledge from old carers. This is a huge safety issue. There is no programme around and no training available to spinal patients to show how they should be cared for" (Christchurch, over 65).

Lack of training in correct lifting techniques can lead to support workers injuring their back, resulting in them being away from work, and temporary staff having to be arranged. It also can lead to service users themselves being injured which can lead to hospitalisation, or an increase in the amount of care needed.

Participants spoke of support workers who cleaned bathroom areas and then used the same cloth for cleaning food preparation areas. A number of blind participants talked of becoming ill after eating out of date food that their support workers had not checked and others spoke of pressure sores developed as a result of lack or insufficient monitoring by support workers.

"Clients are vulnerable and very at risk; this would not be tolerated in hospital. Girls have long fingernails, which pinch the skin and break it; this can cause damage and worse cross infection" (Counties-Manukau, under 65).

(Blind participant stated: "Several times I have eaten food out of the fridge that is off or mouldy – this is a really important part of the support workers job description" (Christchurch, under 65).

Improvement in service user's physical safety can be achieved by disability support providers providing appropriate training to support workers and the means for support workers to be able to attend the training. This was discussed in some depth in the workforce survey report.

Risk of increased emotional and psychological stress for service user

Many service users described feeling ground down with coping with their allocation of care and the frustration with dealing with needs assessors and providers.

"You get sick of being a burden" (Hamilton, under 65).

Participants of focus groups stated they did not feel sufficiently safe to speak up about any concerns as they felt they might be labelled as difficult. There was stress balancing between being assertive and yet accommodating, which led to emotionally feeling frustrated with the system. The fear of being a client was a familiar emotion, although the cause behind this varied from physical fear, as discussed previously, to a vulnerable and emotional unsafe fear.

"It is scary being a client" (Christchurch, over 65).

"Felt very unsafe and uncomfortable, so afterwards I told my mum" (Invercargill, rehabilitation/habilitation).

One such example given by a participant was when a support worker took the participant to their 'boy friend's' house. While individual examples represent anecdotal evidence, the repeated recounting of being fearful or vulnerable was not. Perceived causes by participants suggested that support workers had little or no accountability and that the 'client' was not regarded as being important.

It was strongly stated by participants that delays between assessment and the provision of equipment and services were a significant safety and quality issue. Delays repeatedly lead to deterioration in service user's physical wellbeing, which lead to services being inadequate by the time they arrived. This was particularly so for the fail elderly who if they had received timely assistance may have eliminated the need for more intensive support.

> "People don't feel safe enough to speak up"
> (Christchurch, over 65).

Every user voiced how vulnerable and anxious they became when they had changes in support workers. Participants described strangers turning up at their door saying they were their new support person. There were no phone calls introducing service users to their new support worker. One participant reported that they were visited by eight different support workers in ten days. Another reported how her support worker had gone to the agency that morning to ask for a job and was sent directly to a service user. Concern was expressed over how this support worker could have had police checks, appropriate training and an orientation to the service user's needs prior to commencing work. The issues surrounding recruitment and retention of the support workforce has been extensively studied in the previous reports and quite clearly issues such as this are indicative of the very high

staff turnover rates reported by the disability sector (39% for home-based, 29% for residential).

Staff turnover and lack of continuity of support were a great concern for service users. Gaps in provision of support and support workers unfamiliar with service user's particular needs can lead to inadequate care. For example, a support worker unfamiliar with the importance of monitoring pressure sores may exacerbate the development of pressure sores, which in turn may lead to hospitalisation. Turnover was viewed by participants to be directly linked with poor pay and poor work conditions. In the Providers Report and in the Support Workers Report (Parsons et al 2004) employment terms and conditions was also identified as a major issue, leading to increases in staff stress, and an attempt to 'cut corners' in service delivery. One service user felt that the low pay was reflective of society's attitude towards home-based support workers and service users. Training of support workers was seen as important and many felt that the current work force was not trained and lacked many skills; including what they determined were basic, such as house cleaning and hygiene cares. However, service users felt that lack of pay and incentives did mean that support workers were less inclined to want to undertake training. On the other hand, hiring workers with no or minimal qualifications or skills simply because they are the only people willing to do the jobs will not result in adequate support (Wilner and Wyatt 1998).

Risk of unmet needs

Another recurrent area of concern related to the initial NASC process. Many participants commented that:

- the needs assessment was not holistic and failed to take into account the service user's family, including their culture and religion

- those participants with children who required services felt there was a lack of understanding of the needs of the child and the rest of the family

- this study indicated that for many of the service users, the needs assessment was failing them in that the procedure was undertaken too quickly and did not take in to account their needs and requirements. The final assessment outcome did not match the need. This finding is supported by a study undertaken in South Auckland in 2004, which reported that service users in general found the needs assessments not thorough and that certain key issues were not discussed, such as: the needs of the individual regarding services required and hours allocated (Gundersen-Reid et al 2004).

The current study also highlighted the perception of service users that the NASC process had little accountability and further they questioned the credibility of many of the assessors. Some doubted whether the assessor was qualified to do the assessment and felt they lacked an understanding of their needs. The overall impression was that the current system shows little consideration for the fact that disabled people are individuals with their own particular needs (Gundersen-Reid et al 2004). Service users felt that the needs assessment should be less prescriptive and take into account more the individual needs of the user. This is in line with the New Zealand Disability Strategy, Objective 15, which states that needs assessment processes are to be holistic and take into account the needs of the family and individual (Dalziel 2001) as well as the Evidence Based Guideline around assessing older people (MoH 2003). How well some needs assessors and providers are achieving this objective is difficult to ascertain, yet

from the focus groups involved in this study there seems to be a number of perceived short falls in current procedures.

The perceived inequality of the needs assessment and thus service provision was repeated at a number of focus groups. Two older women with similar perceived needs said:

> "I have a support worker to shower me seven days a week" ... whereas the other reported ... "ooh, you lucky thing, mine showers me three times a week" (Invercargill, over 65).

The difference between rural and urban services was also discussed, again highlighting inequalities.

> "It feels like the Government is trying to get everyone to move to a city. There needs to be consistency throughout" (Hamilton, under 65).

There was also a recurring theme relating to poor or inadequate communication, highlighted repeatedly by service users complaining that they were given wrong information, and had long waiting periods for equipment and waiting for support workers to arrive.

> "Service user left hospital, six weeks later a support worker came, and came again two days after he had died" (Christchurch, under 65).

> "What about weekends? People don't just get better" (Christchurch, rehabilitation/habilitation).

These unmet needs placed increased stress on service users, as well as increased risk of neglect or harm. Many service users suspected that a likely reason for such issues was as a result of support worker stress, though many also noted that the system

was inequitable, with some clients being given more support than another with perceived similar needs.

Repeatedly throughout the focus groups came examples of support workers skill base not matching the needs of the service user. For example, a non-English speaking support worker was allocated to a child with communication difficulties or of the support worker who was unable to read or write in English being assigned to a blind participant, who identified that an essential and agreed need was assistance with food shopping, which required someone to read the list and identify products on the shelf. Such inappropriate matching up of support workers and service users was repeatedly discussed in various focus groups.

Risk of abuse or theft of service user's possessions

Service users are often vulnerable to theft of personal property. Theft was repeatedly brought up by focus group participants as a major issue, which led frequently to a lack of trust between the service user and support worker. Participants felt that the need to employ workers in a climate where they were a scarce commodity overrode the desire to obtain appropriate references for staff. One participant spoke of the incident when she reported a theft to the service provider and later found that the worker remained employed with the provider but for a different client.

> "If you're blind you can't see somebody take anything, so you can't really say anything" (Christchurch, under 65).

A number of participants could not see any way of preventing theft, while others were adamant about the need for provider agencies to undertake closer monitoring, better recruitment and listening to clients that raised concerns about specific support workers.

Risk to service user's family emotional, financial and physical wellbeing

Many service users felt that the needs assessors were too reliant on family members to either fill the gaps or supplement the services provided. Services users expressed concern about the 'burden' of their disability on their families financially, emotionally and physically.

> "Emotional and financial stress can break up families."

> "Families are exhausted. Fighting for funding. Feels like you are cut off from everyone, causes huge emotional issues, can result in broken marriage" (Christchurch, rehabilitation/habilitation).

> [Partner of service user] "I am faced with impossible choices ... [partner cries, unable to finish sentence]" (Hamilton, over 65).

> "There was an expectation that I would leave my job and become my husband's full-time carer" (Christchurch, under 65).

Service users were concerned about the extra work involved for family members. The causes of this was perceived by all focus groups to be a mixture of waiting times for services, poor quality or inflexible services and the sense that families 'should' be there. The extra workload placed on the family may contribute to physical, financial and emotional risk. Several over 65 participants raised the concern that grandparents were being left to look after their disabled grandchildren while at the same time trying to care for their own needs.

> "I am an 80-year-old looking after a 15-year-old. Of course I can't handle it, but it is difficult to access services to help" (Hamilton, over 65).

Over 65 participants reported that they were feeling pressured by their own children to care for the grandchildren, as the parents were finding the work/family life balance precarious, which was confounded by the inability to find high quality support workers.

Cultural risks

Cultural issues were minimised, or appeared to be ignored by service providers, according to some participants.

> "Had whānau worker up north. When moved found that the whānau worker for the whole of the South Island was in Wanganui. What a load of rubbish!" (Christchurch, over 65).

> "I felt uncomfortable with the Pakeha worker and thought she was after my husband" (Hamilton, over 65).

When cultural issues were considered, participants reported that it was just as much a battle for culturally appropriate services as it is for any of the other services. Māori participants attending focus groups (as opposed to the hui or fono) always chose to bring their whānau support person with them. On most occasions when a Māori participant described their feelings on quality and safety, the support person acknowledged that they were not aware of how unsafe their whānau member felt, and were prompted to want to follow issues up with participants later.

Conclusion of risks

Whilst risk of injury, illness and emotional distress to service users has been articulated by participants, it has also been outlined that there are significant risks to families and whānau of service users and this can not be underestimated. There seems to be a risk that the scale of, and indeed escalating dissatisfaction with disability support services may mean that public and media scrutiny of health and disability support services is likely to increase.

4.3.2 What are service users' perceptions around the services they receive?

Improving the quality of the services that support workers deliver

Many of the perceived difficulties with the current Health and Disability support services centred on the support workers themselves.

> "The ideal would be if the client could be functional, independent, safe and personal cares were delivered by a support worker who is trained in his needs" (Christchurch, under 65).

> "The ideal caregiver is compassionate, patient, respectful and understanding of patients needs" (Invercargill, over 65).

> "Flexible support worker that does what a client wants or needs and a client individualised system" (Christchurch, rehabilitation/habilitation).

A number of the service users gave examples of good quality of care and talked about how the support workers became significant people in their lives. There is no doubt that many support workers provide high quality services. However, given the preponderance of quality issues and concerns raised within the focus groups around services that were delivered, it is likely that the self-selective nature of the sample selection may have meant that those service users with more negative experiences chose to attend.

Poor pay was viewed to lead to poor quality. Despite requesting that workers receive more pay, there is an expectation that the quality of care should also be raised.

> "Just because you have a disability it doesn't mean you should have to lower your standards" (Invercargill, over 65).

> "It should be about making the worker feel valued, increase the wages of the worker so the quality is better" (Christchurch, rehabilitation/habilitation).

Problems were perceived to be based on poor knowledge and understanding of the client base.

The perceived impact of training on quality

Many service users felt that quality and safety could begin to be addressed by simply educating support workers about disability specific issues (Kroll, Beatty and Bingham 2003). Another area regarding safety was poor lifting techniques, which is surprising as in the workforce survey (Parsons et al 2004) this was seen to be a mandatory training session. However, it was noted by service users that in the community setting, physically locating support workers for in-service training were difficult. Service

users felt that training of support workers was important as they felt that it would lead to better quality of care. Service users also felt that the workers should be paid to attend training. It is well documented in the literature that staff training is needed to ensure quality of care, quality of life, and resident safety (Cowan et al 2004, Dupler and Crogan 2004, Davies et al 1999). In relation to types of training required, service users felt that there needed to be more emphasis on personal care, domestic care and catering to individual needs.

> "You don't need qualifications to get a job as a support worker, but you should have to" (Counties-Manukau, under 65).

> "Support workers play an intricate part. If you have to discuss issues it is great if the worker has an understanding of the client and their needs. This allows the client to feel confident and independent in situations" (Christchurch, over 65).

> "The lack of trained caregivers is definitely a safety issue" (Hamilton, under 65).

Having a greater understanding of the disability movement and what life was like as a disabled person would greatly improve quality of care. Literature on independent living and the disability movement supports this finding (Beatty et al 1998a, Beatty et al 1998b, Benjamin et al 2000, Mattson Prince et al 1995).

Quality monitoring structures

Monitoring of service and support workers was seen to be inadequate.

> "Carers sit on their bums and watch TV or make phone calls" (Counties-Manukau, under 65).

It would seem that once a service is put in place there is little follow-up and service users felt relatively powerless to make changes, they simply had to accept what was on offer with little recourse.

"Not easy to make a complaint beyond the provider" (Counties-Manukau, under 65).

Many attributed these problems to poor monitoring by service provider organisation. They felt this was further reinforced by the fact that staff could not be replaced even with a number of weeks notice and the delay from assessment to service delivery.

"Clients need continuous, constant care necessary for trust between the client and the worker. There needs to be support worker back-up in case of worker illness etc" (Christchurch, rehabilitation/habilitation).

"(There should be) monitoring of both the agency and the support worker by an independent body. Supervisors should be checking the quality of the service. Clients might not know if the workers are doing it properly (eg, blind service users). Checks should be done regularly by the organisation but realise they don't have the funding" (Christchurch, under 65).

"Would like providers kept under stricter controls of quality and monetary. Make sure service providers are meeting the needs they are contracted to meet; this should be done by the Ministry of Health" (Hamilton, under 65).

Access to quality information

The lack of information on entitlements and the ongoing 'battle' to receive the entitlements was voiced to be a significant problem.

"How are you supposed to find out information?" (Christchurch, rehabilitation/habilitation).

Policy papers clearly outline the need for streamlining the entitlement procedures (Dalziel 2002, MoH 2002, MoH 1998) yet the reality for service users is that this is an area fraught with difficulties. Despite many policy documents advocating that service users need to be better informed, it appears this is still an area that needs more work (Dalziel 2001, Dyson 2002). The initial concern for service users begins at the set up phase of service allocation. There was a generalised view that the problems start with a lack of information about entitlements. There also seems to be a noted discrepancy between Accident Compensation Corporation (ACC) and health services. However, the over riding impression was a lack of understanding and knowledge of what they were entitled regardless of funding stream.

> "Hospital care was superb but ACC – huge difference."

> "No communication between government departments. Why can't they meet you in one meeting? That way it would be more client centred and flexible."

> "I have no funding because ACC and Health are fighting over who should fund me" (Christchurch, rehabilitation/ habilitation).

Such situations led to users feeling frustrated and disempowered when attempting to deal with the different government agencies.

> "[Service users] need to have a voice within the community because clients talk amongst themselves about things. Staff can learn lots of things, when you get everyone together to discuss and expand on issues. It is necessary for the whole community to 'own' the issues" (Christchurch, under 65).

Quality of service user directed services

Clients would like more support because it enables them to live the life that they want. Recurring words were, 'choice', 'quality' and 'needs based'.

> "Important that everyone understands the more support clients get the more independent they can be and then they can reach their potential. More staff to support clients, as it is a very big task to know whether or not clients can do something and it is important clients are able to learn from support staff. Clients need help not just with their disabilities – it is often hard for clients to speak up and they need help with that. They need support workers to learn about their own rights and to learn about jobs" (Christchurch, rehabilitation/habilitation).

Internationally, there has been a significant shift in how care is being provided in the home. The independent living movement and advent of politically strong advocacy groups is an example of this. The concept of independent living revolves around self-direction, empowerment, not being dependent and interdependence (Gundersen-Reid, Isbister and Parsons 2004, MoH 2002). Even though the MoH (2002) supports the principles of independent living and deinstitutionalisation it appears from the service users perspective that more action is needed to support this.

> "People need to live in a good, supportive environment in order to recover. Not be sent off to a rest home alone. People need to have independence, individualised choice and pride" (Christchurch, rehabilitation/habilitation).

In the MoH Disability Support Services report, 'Increasing participation and independence' (2002), it is documented that the current regulatory system and Standards New Zealand are developing standards for home and community-based support services. How well these standards are being implemented is worthy of further investigation as from a users perspective there appears to be a number of failings in the system.

Many of the objectives set out in the Disability Strategy encourage choice and control for disabled people (Dalziel 2001). The National Advisory Committee on Core Health and Disability Support Services stated that when individuals are empowered to make choices and take control of their destiny, they will feel valued and be able to participate fully in family and community life (Naylor and Lardner 1994, p.10). The service users would like to see these sentiments mirrored in practice beginning with the needs assessment and service co-ordination.

> "Māori providers are interested in not just the client but the whānau as well. It is important/essential that family and whānau are considered in needs assessments and by workers. It totally affects all the family and their quality of life" (Christchurch, over 65).

It is clear that many service users in the study wanted more thorough needs assessment, which takes into account the needs of the individual. Individual needs are currently considered in the assessment process, though it appears that it is either inadequate or too inflexible. In the Disability Support Services report, Building on the New Deal (1998), the need for an effective needs assessment process and service co-ordination is discussed. The report mentions the need for further work on expanding diversity and range of services to cater for the diverse needs and preferences of disabled people.

The issue about choice and control is that current service users do not perceive themselves as having any or very little control. Choice from what they would like to wear to when they want to go to bed.

> "One worker told her client she has to go to bed at nine o'clock or not at all" (Christchurch, under 65).

> "It would be great if clients could get funding to employ their own support workers. Focus of agencies not compatible with where we are at. ACC needs to be more client focused and have client satisfaction on the top of their list, rather than giving case managers bonuses for getting people off ACC" (Christchurch, under 65).

There seems to be a clear request from users to be more involved in decision making and to be shown more respect in their ability to do this. Self determination is documented in current literature to be necessary for people's wellbeing (Stroman 2003, Deci 1980). Self-determination refers to issues related to choice and control: is concerned with freedom to decide for one's self whether to be in control or not (Deci 1980). Independence is about autonomy and self-determination, but does not imply doing things by oneself (Hawker 2004). Even though many users mentioned the desire to hire and direct their own care literature does show that most clients need support services from a service provider in order to self-direct support services (Flanagan et al 1998, Nadash 1998, Sabatino and Litvak 1992).

Baird (2003) in a concept paper for the MoH stated that the key outcomes of the service provider is that it be a more flexible responsive service: that support client choice, works in partnership with clients and family/whānau, provides increased client satisfaction, decreases dependency on services. Continuity

of care is also an important aspect in providing an effective service. It was clear that many service users had been significantly affected by the current high turnover rates in community care (Parsons et al 2004). From the service users perspective there seemed to be a correlation between continuity and quality of care. Feldman (1993) found that improved worker retention will increase continuity of care and this has been found to benefit both worker and service user.

Recommendations from service users

Focus group participants were reasonably unanimous in their perceptions of what would make for quality support services. It would involve:

- client-centred and flexible services

- a back-up support system

- access to quality information

- appropriately trained support staff

- monitoring of support staff and providers

- service users funded to employ their own staff.

Funding was a feature, but only in order to secure the safe and quality support required for disabled people to live lives of their choice in the community.

4.3.3 What are the quality and safety risks experienced by Māori service users?

Māori beliefs, values and concepts are inherited and practised from generation to generations. Integral to this are Māori views on health which include a holistic approach encompassing the elements of wairua (spiritual), hinengaro (psychological), tinana

(physical) and whānau (extended family). The connection to Māori traditional beliefs is essential to tikanga and indeed the service users stated that it was vital that such a principle of respecting these values was upheld. Many of the issues that have been identified by mainstream users are just as relevant to the Māori users. However, there appeared to be number of positive and negative elements arising from the hui that are unique to this group of service users.

For a number of Māori users, if services focused on Māori and further, reflected Māori values and concepts then general satisfaction tended to be high and culturally safety appeared to be maintained. This ensured that the user and the support worker were working in true partnership and that both respected and valued each other. However, for those users of support services that were unable to develop this relationship with their worker, it became and continued to be an unhappy experience. In order for some of the users to further enhance the key principals of tikanga they sought to have more control over who would provide the services, how they would be provided and be able to generally decide the times of days they wanted to have the support worker visit their home. The solution to this problem inherently lies in the funding of the support services. The ability for the users to purchase their own services clearly would improve the long-term outcomes for most of these users, particularly the younger disabled group. Control in the decision-making process regarding services would not only protect the spiritual wellbeing of the service user, but moreover it would protect the support worker who may at times be out of their depth in both clinical skills and cultural safety.

Cultural safety is an essential aspect of establishing best practice and the only way that this can be achieved is by appropriate

training. While recognising the diversity of Māori, training must therefore be based on a widely accepted Māori world view. Support workers would need to have adequate education in order to develop an acceptable understanding of Māori concepts of health and tikanga. This would encompass the practical aspects of the daily tasks that may be required when supporting people with disability in their own homes. Furthermore, following the implementation of training, consideration would need to be given regarding the ongoing monitoring and evaluating of such a staff training package.

Frequent key issues identified during the hui related to the apparent lack of commitment of workers towards their role. This was particularly an issue on the weekends when staff did not turn up; this often left the users in a very unsafe situation. This perceived and relevant lack of power rendered the disabled person powerless.

For Māori users, both young and old, many felt an unwillingness to complain or seek advice to cover the lack of service provision and relied on the whānau to fill the gap when these incidents occurred. Consequently, whānau members felt extreme pressure on the whānau unit, which often left them overwhelmed. Respect for their elders was often the reasons why they would not seek out service providers and discuss their concerns.

Whānau often felt let down and disappointed by support services. Frequently, their kaumatua and kuia were reluctant to have strangers in their homes and when they finally agreed to services that consequently failed them, they simply returned to providing all the care rather that commence the whole process of trying to persuade their elders to start all over again. This apparent unwillingness to be honest about their situation regarding the poor

service provision would often spiral into general feelings of unhappiness about themselves, their disability and the sense of being totally under-valued as a person.

Exercising and experiencing a holistic model of health (usually in the form of mirimiri or massage) was stated as pivotal to the well being of those individuals who attended the hui. The lack of funding for this type of therapeutic treatment was seen as a serious lack of regard to their culture. For some users, this serious deprivation of alternative health/healing was an unbalanced situation which often impacted negatively on their health.

Most of the services users felt they would have benefited from having an advocate at the outset of seeking services who would not only be able to unbundle the Pakeha speak but continue to be the mediator at times when problems arose, to ensure that service providers and support workers understood the issues. They felt that this would allow some sense of cultural safety between both parties.

4.3.4 What are the quality and safety risks experienced by Pacific service users?

Participants in the Pacific fono indicated a need to enable better access to support services. Affordability and funding were the main barriers identified as preventing their access to services and achievement of a better quality of life. There was a general agreement from participants in the fono that the individual need of the service user was not being taken into account. The need to fund disability support service contracts as well as ensure that Pacific providers received these contracts was highlighted as well. In line with this was the need for Pacific providers, support

workers and service users to be involved in the development of the exact nature of such contracts, so that it will truly reflect the nature of the support services required.

A pertinent point was made in relation to the need for funding to improve the nature of home-based support services (eg, hours per week). There were also concerns expressed by participants regarding the poor standard or quality of services provided by some support workers. When this was the case, family members often had to undertake a lot more, and in some cases help train the workers or just ask them not to return. Support workers in these situations often made the situation worse rather than better. Cultural awareness was highlighted as an area that needed further consideration, both in terms of the service delivery model and for support worker training.

For some Pacific service users, there was a need to identify the services that were available for them, or more simply where to find information on those services. Information needed to be made more accessible to Pacific people, through more culturally appropriate means. For example, it appears to be taken for granted that all homes have phones; this is not the case, yet telephones are extremely important for users to communicate with workers and providers. This is an area that may need further research, as it has implications on issues of access and equity of services by this particular group.

Another uniquely Pacific issue related to the notion of relative need for services between users. It was seen to be not so appropriate to accept services if someone needed more help than someone else. This was a Pacific value; it was seen to be shameful to be asking for assistance for what appears to be a situation not worse than others around. This indicates the need

for assessors to be able to be more discerning of the verbal as well as the non verbal information arising from Pacific service users during assessments.

4.4   Overall conclusions

The vision of the quality and safety project is to improve health and wellbeing for those receiving services from health and disability services and this is to be achieved through enhancing the safety and quality of support service delivery. This study has sought to provide the final piece to the jigsaw and together with the provider surveys and support worker survey contributes to our understanding of the sector.

The analysis of the CCPS data has provided an invaluable demographic profile on those receiving support services, but it was the information arising from the participants in the focus groups, hui and fono that has given rise to the greatest insight into the quality and safety needs of service users. That said, much interesting information was gleaned from the snapshot and it is pertinent to note that the majority of service users were over the age of 65.

Multiple risks and safety issues have been identified, along with recommendations for quality improvement. Analysis of the findings appears to point to a need to establish different funding models, with increased payment and improved training. However, the overriding belief amongst service users was even in the eventuality of increased monitoring, increased training and increased funding, primarily the issues that must be addressed is the fear and vulnerability of being a service user and the belief that service users are 'second class citizens'. The considerable information in this report is due to the willingness of the

participants to contribute to addressing the extensive risks facing service users and the passion to offer realistic quality measures.

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