

PACIFIC PEOPLES' EXPERIENCE OF DISABILITY

A paper for the
PACIFIC HEALTH AND DISABILITY ACTION PLAN REVIEW



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PACIFIC HEALTH AND DISABILITY ACTION PLAN**

Acknowledgements

The Ministry of Health would like to acknowledge the contribution of Dr Siale 'Alo Foliaki, Philip Beilby (Pacific Information and Advisory Support Services Trust), Juliet Elworthy (Office for Disability Issues), Daniel Te'o (Royal New Zealand Foundation for the Blind), Cherie Hannam and Faimafili Tupu (Accident Compensation Corporation) to the development of this paper.

Within the Ministry of Health, the development of this paper was led by Dr Debbie Ryan and Julie Hynes (Pacific Innovations and Capability), Natalie Thomsen (Pacific Policy and Strategy team), Manase Lua (Health and Disability National Services Directorate) and former Ministry of Health staff Fliss Curtis and Tessa Buchanan. Advice was provided by the Disability Policy team and other staff of the Ministry.

Citation: Ministry of Health. 2008. *Pacific Peoples' Experience of Disability: A paper for the Pacific Health and Disability Action Plan Review*. Wellington: Ministry of Health.

Published in February 2008
by the Ministry of Health
PO Box 5013, Wellington, New Zealand

ISBN: 978-0-478-31708-4 (Print)
ISBN: 978-0-478-31709-1 (Online)
HP: 4545

This document is available on the Ministry of Health's website:
<http://www.moh.govt.nz>



MANATŪ HAUORA

Foreword

Talofa lava, Malo e lelei, Kia Orana, Taloha Ni, Fakalofa Lahi Atu, Ni Sa Bula Vinaka, Talofa, Kia Ora, Greetings

This is one of a series of papers prepared for the review of the Pacific Health and Disability Action Plan and represents another step towards the development of a Pacific health evidence base. *Tupu Ola Moui: Pacific Health Chart Book* in 2004 brought together much of the available data and identified indicators that could be used for monitoring Pacific health. Its development also highlighted the comparative inaccessibility of quality information about Pacific health. These papers bring together much of the published information relevant to Pacific health and a more complex picture is emerging about the significant influence of determinants and risk factors on Pacific health; and the role of the health system in addressing Pacific health need. The evidence from the papers confirms the importance of action in two directions to achieve Pacific health gain and reduce inequalities: one, intersectoral action to improve the determinants of health status and two, improved health system responsiveness to Pacific peoples to reduce inequalities.

The information about Pacific peoples' experience of disability is limited and there seems to be no independent research or case studies in spite of the evidence that 11 percent of Pacific people have a disability. The available information suggests that Pacific people experience difficulty negotiating the complexities of the disability support system. This includes the needs assessment process and recommended support services. There is also some concern that little is being done to develop a better evidence base about Pacific children and youths' experience of disability and how they and their families can be better supported. Improving disability support services for Pacific people needs to be an expectation of the health system.



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Executive Summary

There is limited information available about Pacific peoples' experience of disability, and few sources of reliable data. Differing definitions of disability across surveys and service areas further complicate the picture. This paper attempts to describe the current situation, drawing on the most recently published information. The following is a summary of the main points.

Eleven percent of Pacific people in New Zealand in 2006 had a disability. Of these, three quarters were adults and one quarter were children. Physical disabilities are the most common type of disability experienced by Pacific people, followed by other disabilities and then sensory disabilities. In 2001, a greater proportion of disabled Pacific people had severe disability than disabled non-Pacific people (24 and 12 percent, respectively). Disease or illness is the most common cause of disability for both Pacific adults and Pacific children.

Disabled Pacific people are less likely to have received a needs assessment than non-Pacific people with disability: in 2001 8 percent of Pacific adults with disability had received a needs assessment, compared with 15 percent of non-Pacific adults. That year nearly half (48 percent) of Pacific adults with disability received some kind of help with everyday activities from other people, compared with 39 percent of non-Pacific adults with disability. Some reports suggest that disabled Pacific people often do not continue on after needs assessments to access the recommended support services. Reasons for this may include lack of co-ordination between disability providers and health services, and the difficulties experienced navigating a complex disability support system.

A much higher proportion of disabled Pacific people live in the most socioeconomically deprived areas compared with disabled non-Pacific people (72 percent and 42 percent, respectively). This makes it important that they access financial assistance for their disability costs, which might otherwise have to be either neglected or prioritised over other basic needs. Some evidence suggests that financial assistance is not getting through; for instance, parents or caregivers of disabled Pacific children are less likely to receive the child disability allowance than parents or caregivers of disabled non-Pacific children (11 percent compared to 19 percent). Pacific people also claim ACC at a lower rate than the non-Pacific population (45 percent of the rate of the general population).

Pacific children have similar rates of disability as non-Pacific children, but the most common types of disability within each group are different. Pacific children have higher rates of deafness and asthma, while non-Pacific children have higher rates of all other disability types. The youthful age structure of the Pacific ethnic group means that the number of Pacific people with disabilities will probably increase as more young people – who already have a higher prevalence of some disabilities – enter the ages most prone to disabling injuries and illnesses.

Some disabled Pacific people and their families may experience discrimination. Positive family and community attitudes to disability, and community support for families and individuals with disabilities, need to be encouraged and developed. This may also provide career opportunities for disabled Pacific people themselves, who are in an ideal position to share their experiences and knowledge of disability.

Introduction

This paper stands alone, but also forms part of a series of papers prepared for the review of the *Pacific Health and Disability Action Plan* (PHDAP). The other papers in the series cover Pacific child health, Pacific youth health, promoting healthy lifestyles and preventing chronic diseases among Pacific peoples, Pacific peoples and health care services, improving the quality of care for Pacific peoples, and Pacific peoples and mental health.

This paper considers the PHDAP priority area ‘Promote participation of disabled Pacific peoples’. The paper brings together information and knowledge about Pacific peoples’ experience of disability, identifies issues and inequalities, and draws conclusions about Pacific peoples’ experience of disability in New Zealand.

Definition of disability

There are various definitions of disability, and often overlapping categories of disability. For example, most children who use technical aids are also defined as having a chronic condition. This has led to some difficulties in interpreting and reporting survey results (Ministry of Health 2004).

For the purposes of this paper, the Ministry of Health’s disability definition in *Tupu Ola Moui: Pacific Health Chart Book* will be used: ‘As a population measure “disability” refers solely to the functional and/or role limitation experienced by the population’. Functional limitation is then defined as ‘requiring the assistance of another person or a complex assistive device to carry out everyday routines’ (Ministry of Health and Ministry of Pacific Island Affairs 2004).

The Ministry of Health’s disability definition used in determining who is eligible for Ministry-funded disability support services (DSS) is that a disabled person is a person who has been identified as having:

A physical, psychiatric, intellectual, sensory, or age-related disability (or a combination of these), which is likely to continue for a minimum of six months and result in the reduction of independent function to the extent that ongoing support is required (Ministry of Health 2007a).

The above are examples of medical models of disability, which see disability as the result of a physical condition that reduces quality of life and causes the individual disadvantage. The focus is on curing and managing illness and disability, and improving functionality to enable people to live a ‘normal’ life.

Ministry-funded disability services are also underpinned by a social model of disability – the basis of the approach taken in the New Zealand Disability Strategy. Social models of disability recognise that individuals can have different impairments (physical, sensory, psychiatric etc) but these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are not impaired. Disability relates to the interaction between the person with impairment and their environment. It has a lot to do with discrimination, prejudice and exclusion by society.

The diverse Pacific cultures have various ways of defining disability. However, in general the way Pacific peoples see disability is different from the way non-Pacific people do, particularly in explanation of the origins and root causes of disability. Like the general New Zealand population, Pacific peoples understand disability from a medical perspective, where a disabled person is one who has a physical, sensory or intellectual impairment. However, some Pacific peoples tend to identify different reasons for or causes of disability, which are not biomedical but either religious or cultural. A general Pacific perspective of disability is described in detail in Appendix 1.

Disability policy context

The policy context for issues relating to disabled Pacific people is provided by two overarching documents: the *New Zealand Disability Strategy* (NZDS) (Minister for Disability Issues 2001) and the *Pacific Health and Disability Action Plan* (Ministry of Health 2002).

New Zealand Disability Strategy

The NZDS is the key strategic framework for disability development and advancement in New Zealand. It is a long-term plan for changing New Zealand into an inclusive and non-disabling society in which disabled people will be integrated into community life on their own terms, their abilities will be valued, and their diversity and independence will be recognised (Minister for Disability Issues 2001).

Objective 12 of the NZDS is to promote the participation of disabled Pacific people. This objective seeks to promote opportunities for disabled Pacific people to participate in their communities and to access disability services. The NZDS also recognises that disabled Pacific people should receive an equitable level of resources that are delivered in a culturally appropriate way (Minister for Disability Issues 2001). Appendix 2 of this paper provides a summary of the NZDS.

Pacific Health and Disability Action Plan

The PHDAP sets out the strategic direction and actions to improve the health outcomes and participation of Pacific peoples, and to reduce inequalities between Pacific and non-Pacific peoples (Ministry of Health 2002). ‘Promote participation of disabled Pacific peoples’ is one of the priorities identified in the PHDAP.

Goal 6 of the PHDAP is ‘To deliver disability support and health services that will enable disabled Pacific peoples to participate fully in their communities’, and builds on the NZDS. Goal 6 is supported by two objectives:

1. to increase access to and the quality of disability support services
2. to encourage Pacific communities to consider disability issues and perspectives and further their own understanding of disability through the development of community-based plans for disability issues (Ministry of Health 2002).

Government agencies

In total there are 11 agencies that fund support services for people with long-term disabilities. The following are some of the key government agencies that have responsibilities for service provision and other support for people with disabilities, including disabled Pacific people. Other involved agencies include Housing New Zealand Corporation, District Health Boards and the Accident Compensation Corporation (ACC).

Office for Disability Issues

The Office for Disability Issues is located in the Ministry of Social Development. The role of the Office is to ensure that government agencies ‘keep faith’ with the NZDS by promoting the participation and inclusion of disabled people in New Zealand society (Office for Disability Issues 2007). The Office provides a focus on disability issues across government, leads cross-sector policy, and provides support to the Minister for Disability Issues.

Under the New Zealand Public Health and Disability Act 2000, the Minister for Disability Issues is required to report to Parliament on progress implementing the NZDS. The Office regularly issues reports on the actions that government agencies have taken to implement each objective of the strategy.

Ministry of Health

The Health and Disability National Services Directorate (HDNSD) of the Ministry of Health is responsible for the planning and funding of disability support services, which includes providing policy advice to the Minister and Associate Ministers of Health on Pacific disability outcomes and accompanying support services. The overarching focus of the disability group within HDNSD is to give better support to disabled people, and to their families and whānau, based on the philosophy of the NZDS to value disabled people and enhance their participation in their families and communities. HDNSD also fund support services for people under age 65 years who have physical, intellectual or sensory disability. The 2007/08 budget for HDNSD funding of long term disability support for this group is \$839 million (GST exclusive).¹

The key policy work in progress under the NZDS reported by the Ministry in 2006 includes:

- implementing the Access to New Zealand Sign Language interpreter policy and other measures to remove language barriers for deaf people
- establishing a Consumer Consortium of disabled people to provide advice and input into the HDNSD's planning and activities
- providing more home-based support so that disabled people can remain living in their homes and communities
- running a twice-yearly forum with community organisations to enable disabled people to have input at the development and evaluation stages of the policy process
- ensuring that all breast and cervical screening services are responsive to disabled women (Office for Disability Issues 2006).

Ministry of Social Development (Work and Income)

Work and Income, a service of the Ministry of Social Development, delivers financial assistance and job-seeking support to disabled people in the form of the disability and child disability allowances and the sickness and invalids benefits. These are discussed later in this paper in the section on assistance with disability expenses.

As part of meeting its objectives under the NZDS, and in response to feedback from people receiving sickness and invalids benefits, the Ministry of Social Development has developed the Sickness and Invalids Benefits Strategy, which aims to broaden and strengthen the support offered by Work and Income to sickness and invalids benefit recipients, including supporting people who want to move into employment to reach this goal (Ministry of Social Development 2007).

¹ See the 'Disability Services and Support' section below for further details on the support available and funding arrangements.

Sources of information

This paper has drawn from two main sources of information: *Living with Disability in New Zealand* (Ministry of Health et al 2004), and the *Auckland Pacific Disability Research Report* (Ministry of Health 2005).² *Living with Disability in New Zealand* extracts relevant information from two Statistics New Zealand surveys in 2001: the Household Disability Survey and the Disability Survey of Residential Facilities. Where available, updated figures from the 2006 Household Disability Survey have been used.

The 2005 Research Report, along with the report *Capital Support in the Lives of Pacific Peoples with Disabilities* (Ne'emias 2003), provides both quantitative and qualitative information on Pacific people's experience of disability, and recommends future areas of action.

Although there is only limited information and evidence available, this paper attempts to profile Pacific peoples' experience of disability in New Zealand. With this caveat, cultural perspectives, and the use of support services are also discussed.

² From this point on this is referred to as 'the 2005 Research Report'.

Pacific Peoples and Disability

In 2006, 24,800 Pacific people living in New Zealand had a disability. This was 3.8 percent of the entire disabled population. Pacific peoples had a disability rate of 11 percent, which was lower than the rate for Māori (17 percent) and European (18 percent). Ninety-eight percent of disabled Pacific peoples lived in households and 2 percent lived in residential facilities (Statistics New Zealand 2007a).

Health expectancy of Pacific peoples

Health expectancy has two components: life expectancy (survival) and disability (functional limitation), representing the ‘quantity of life’ and ‘quality of life’ dimensions of health, respectively.³ Independent life expectancy (ILE) refers to the number of years on average that a person can expect to live independently, free of disability requiring assistance. Table 1 shows how long, on average, Pacific people can expect to live with disability that requires assistance.

Table 1: Health expectancy of Pacific people and the total New Zealand population

	Pacific people		Total NZ population	
	Male	Female	Male	Female
Life expectancy at birth	71.5 years	76.7 years	76.3 years	81.1 years
Years expected to be lived with disability requiring assistance (DRA)	9.7 years	13.6 years	11.8 years	13.5 years
Ratio of years expected to be lived with DRA to life expectancy (%)	13.6	17.7	15.5	16.6
ILE at birth	61.8 years	63.1 years	64.5 years	67.6 years

Source: Ministry of Health and Ministry of Pacific Island Affairs 2004

Pacific males can expect to spend a smaller proportion of their lives living dependently than the New Zealand and Pacific female populations. However, Pacific males’ ILE at birth is also lower than that of the New Zealand and Pacific female populations. This is a consequence of the lower life expectancy of Pacific males in general, and is consistent with Pacific population demographic projections (Statistics New Zealand 1999).

Prevalence of disabilities

Adults

In 2006 there were an estimated 18,700 Pacific adults with disability living in New Zealand. This equates to 75 percent of Pacific people with a disability, compared with 90 percent for European/Other disabled people and 71 percent for disabled Māori people. The disability rate for Pacific peoples was lower than for Māori and slightly lower than for European/Other across all age groups.

The proportions of men and women among disabled Pacific adults were similar to those for disabled adults from other ethnic groups: 46 percent male and 54 percent female for disabled Pacific adults, compared with 41 percent and 59 percent for European/Other and 44 percent and 56 percent for Māori (Statistics New Zealand 2007a).

³ The term ‘quality of life’ makes no negative assumptions as to the life experiences of those with disabilities.

The percentage of Pacific adults with disability in the 65 years and over age group (16 percent) was noticeably lower than the percentage of European/Other adults in the equivalent group (38 percent). Conversely, the percentage of Pacific adults with disability who were aged 15–44 years was noticeably higher than non-Pacific adults in the same age group (33 percent compared with 19 percent) (Statistics New Zealand 2007a). These differences in prevalence across age groups reflect the younger age structure of the Pacific population, which in 2006 had a median age of 21 years compared to 36 years for the total population (Statistics New Zealand 2007b).

Children

In 2006 it was estimated that there were 6100 Pacific children⁴ with disability living in New Zealand households. Twenty-five percent of Pacific people with a disability were children, compared with 10 percent of European/Other people with a disability. This reflects the higher proportion of children in the Pacific population.

Fifty-four percent of disabled Pacific children were male, which was slightly lower than European/Other Māori disabled children (both 60 percent male) (Statistics New Zealand 2007a).

Disability type

Adults

Physical disabilities (mobility and agility) were the most common type of disability reported by Pacific adults, followed by other (eg, speaking, learning, remembering) sensory (hearing and vision) disabilities. Sixty-four percent of disabled Pacific adults had a physical disability, 41 percent had other disability and 35 percent had a sensory disability (Statistics New Zealand 2007a). This was slightly different to the pattern in the total population, where mobility (66 percent) was also the most common disability type; however it was followed by sensory (42 percent) and then other (39 percent) disabilities.

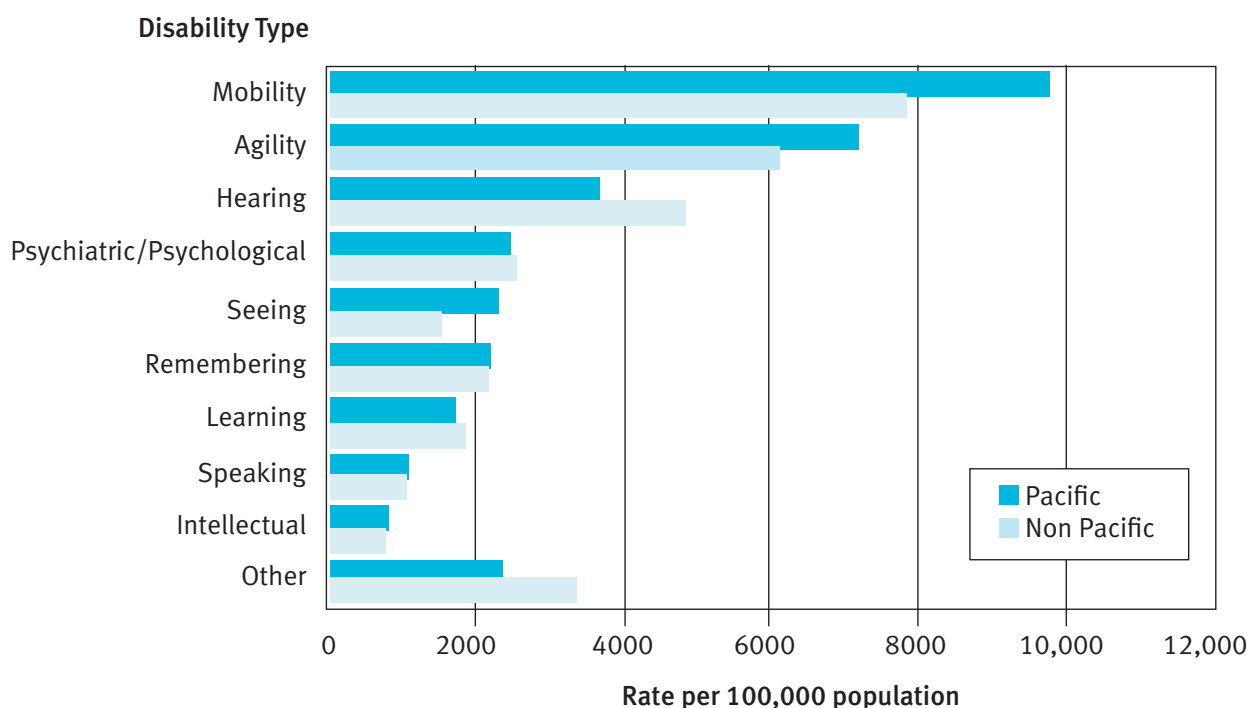
It is estimated that eight percent of the total Pacific adult population had physical disabilities. This was lower than for the total New Zealand population, which had a physical disability rate of 12 percent of disabled adults (Statistics New Zealand 2007a). In 2001, 43 percent of disabled Pacific adults had a mobility disability as their main disability, while 10 percent had an agility disability and 11 percent had a hearing disability as their main disability. Mobility disability was the disability most commonly reported by Pacific adults as having the greatest effect on limiting their everyday activities (Ministry of Health et al 2004).

The 2005 Research Report also found that among Pacific clients on the Needs Assessment and Service Co-ordination (NASC) databases,⁵ the most common form of disability was physical disability (37 percent). However, the second most common category was intellectual disability, rather than sensory as found in the Household Disability Survey (PIASS 2005). This is likely to be a consequence of either different disability definitions or the modest sample population sizes.

⁴ People aged under 15 years.

⁵ NASC agencies assess disabled people's needs and direct them to their required disability support provision - see the 'Disability services and support' section below.

Figure 1: Age-standardised rates of different disability types for Pacific and non-Pacific adults living in households, 2001⁶



Source: Statistics New Zealand 2001

Just over half of all disabled Pacific people (52 percent) had more than one disability. Older Pacific people (65 years and over) were more likely than younger Pacific people to have severe disability and more than one disability (Ministry of Health et al 2004).

Mobility disability

The 2001 Household Disability Survey defined mobility disability as having difficulty or being unable to:

- walk 350 metres without resting
- climb stairs
- carry an object weighing less than 5 kilograms
- move from room to room, or
- stand for longer than 20 minutes.

Mobility disability was the most common disability reported by Pacific adults. Pacific adults had a higher age-standardised rate of mobility disability (9800 per 100,000) than non-Pacific adults (7800 per 100,000).

Pacific adults aged 65 and over had the highest rate (45,800 per 100,000) of mobility disability of all Pacific adults. Pacific women reported more mobility disability than Pacific men. In particular, Pacific women aged 65 years and over had noticeably higher rates of mobility disability (50,500 per 100,000) than Pacific men aged 65 and over (39,400 per 100,000) (Ministry of Health et al 2004).

⁶ If individuals reported more than one disability type, they were counted in each applicable disability type category.

Agility disability

Agility disability was defined in the 2001 survey as having difficulty with or being unable to bend, dress, grasp, cut own toenails, reach, cut food, or get in and out of bed. Agility disability was the second most common type of disability reported by Pacific adults. Pacific adults had a higher age-standardised rate of agility disability (7200 per 100,000) than non-Pacific adults (6100 per 100,000) (Ministry of Health et al 2004).

Hearing disability

Adults were defined as having a hearing disability in the 2001 survey if they had difficulty hearing what was being said in a conversation, and this difficulty had lasted longer than six months and could not be fully corrected by use of a hearing aid. Hearing disability was the third most common type of disability reported by Pacific adults, although Pacific adults were less likely (with an age-standardised rate of 3600 per 100,000) to have a hearing disability than non-Pacific adults (4800 per 100,000).

Pacific adults had higher rates of hearing disability at a younger age than non-Pacific adults, but older non-Pacific adults had higher rates of hearing disability than older Pacific adults. Pacific adults aged 65 and over had the highest rate (13,400 per 100,000) of hearing disability of all Pacific adults (Ministry of Health et al 2004).

Children

In 2001 the most commonly reported types of disability among Pacific children were chronic conditions / health problems (3100 per 100,000), disability necessitating the use of special education (2200 per 100,000) and hearing disability⁷ (2000 per 100,000) (Ministry of Health et al 2004). Prevalence data is not routinely collected in New Zealand for congenital disabilities such as spina bifida and Down syndrome, intellectual disabilities, or other disabilities diagnosed in childhood such as cerebral palsy and autism, so these can not be dealt with here. The paper on child health discusses in detail the chronic conditions that affect Pacific children (Ministry of Health 2008).

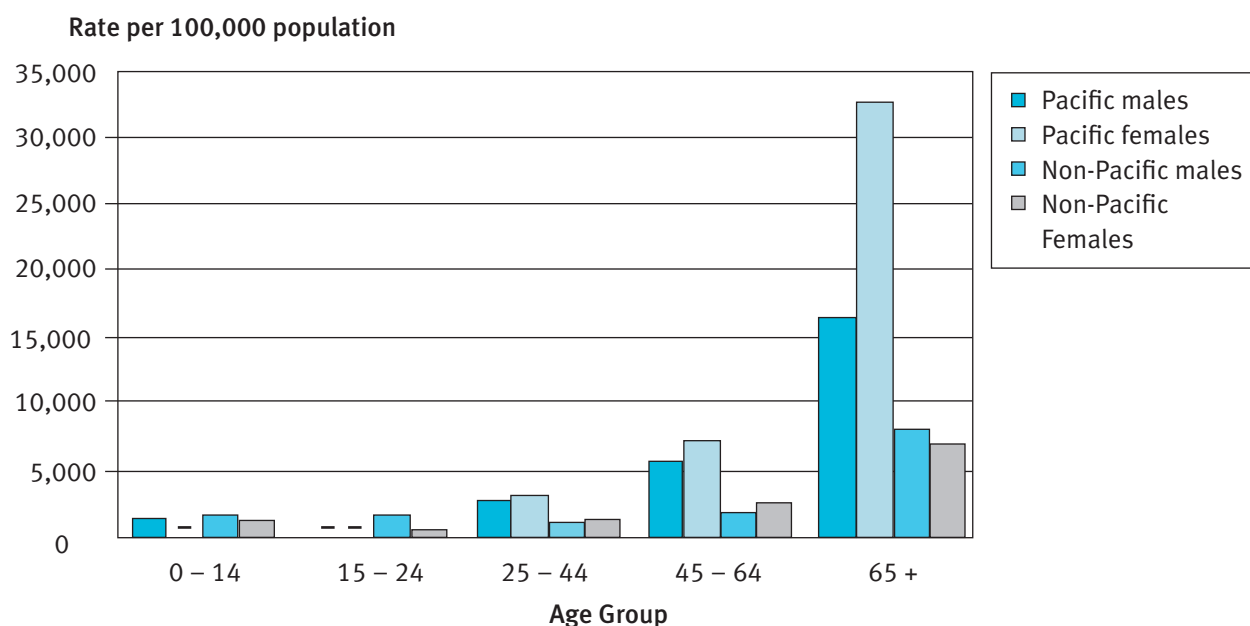
Disabled Pacific children were more likely to have uncorrected deafness or trouble hearing, long-term emotional difficulties, or severe asthma. Pacific children reported higher rates of deafness and asthma than non-Pacific children, although non-Pacific children reported higher rates for all other disability types (Ministry of Health et al 2004). The higher prevalence of hearing disability among Pacific children is reflected in the proportion of students attending the different types of special schools: in 2005, 12.4 percent of Pacific children in special schools were in schools for children with hearing impairments, compared with 6.4 percent of Māori children and 3.8 percent of European children (Ministry of Education 2006a).

Severity of disability

Forty-four percent of disabled Pacific people reported having mild disability, which was similar to the proportion of non-Pacific people (43 percent). A smaller proportion had moderate disability children with non-Pacific people (32 and 45 percent, respectively), but a greater proportion had severe disability compared with non-Pacific people (24 and 12 percent, respectively) (Ministry of Health et al 2004).

⁷ For children, hearing disability includes all those who use a hearing aid.

Figure 2: Rates of severe disability among Pacific and non-Pacific people (adults and children) living in households, by age and sex, 2001*



Source: Statistics New Zealand 2001

* A dash (-) in a column indicates that the percentages were too small to report (estimated frequencies outside the 70 percent relative sampling error cut-off point).

The discrepancies between ethnic groups depended on age. Pacific adults aged 65 and over were almost three times more likely than non-Pacific adults in the same age group to have severe disability (25,900 and 7700 per 100,000 respectively). However, Pacific children had slightly lower disability rates for all three severity levels (mild, moderate and severe) than non-Pacific children (Ministry of Health et al 2004).

Pacific women aged 65 and over were twice as likely as Pacific men aged 65 and over to have severe disability (32,700 and 16,700 per 100,000, respectively). Pacific women in this age group were also over four times more likely than non-Pacific women to have severe disability (32,700 and 7200 per 100,000) (Ministry of Health et al 2004).

In the 2006 survey, 24 percent of Pacific adults with disability had high support needs, which was higher than for all disabled adults (16 percent).

Causes of disability

The main individual causes of disability for Pacific people were disease or illness (41 percent), accident or injury (23 percent), congenital condition (13 percent) and ageing (11 percent) (Ministry of Health et al 2004). Disease or illness was the most common cause of disability for Pacific adults, followed by accident or injury. In Pacific children the most common cause of disability was disease or illness, followed by congenital disability (Ministry of Health et al 2004).

Adults

Among Pacific adults, the most common cause of disability was disease or illness (with an age-standardised rate of 6400 per 100,000), followed by accident or injury (3800 per 100,000) and ageing (3000 per 100,000). The least common cause of disability among Pacific adults was congenital condition (1100 per 100,000). Overall, the causes of disability were similar for Pacific and non-Pacific adults.

Pacific women were more likely than Pacific men to have a disability caused by disease/illness or ageing. In contrast, Pacific men were more likely than Pacific women to have disability caused by accident or injury (Ministry of Health et al 2004).

Diabetes is an acknowledged leading cause of premature mortality and disability for Pacific people, causing significant disability through heart disease, stroke, blindness, kidney failure, and lower limb amputation.⁸ Pacific people have over 2.5 times the national average of lower limb amputation, and have vitrectomy⁹ rates over five times the national average (which may not even be proportionate to need) (Ministry of Health and Ministry of Pacific Island Affairs 2004).

Children

Among Pacific children, disease or illness (3500 per 100,000) was the most common cause of disability, followed by congenital conditions (2300 per 100,000). The rate for disease or illness was the same for Pacific and non-Pacific children, but non-Pacific children were twice as likely as Pacific children to have a congenital disability (4600 per 100,000 compared with 2300 per 100,000) (Ministry of Health et al 2004).

⁸ See other PHDAP Review policy papers for discussion of the determinants and risk factors for chronic disease. Injuries are discussed in the 'Accident Compensation Corporation' section below.

⁹ Vitrectomy is the surgical removal of the vitreous gel between the retina and the lens (which is often the result of eye disease).

Disability Services and Support

Disability support services (DSS) are funded through two different mechanisms, based on the age of the clients. DSS for people under 65 years of age are funded directly by the Ministry of Health, while funding for those 65 years and over¹⁰ is the responsibility of District Health Boards (DHBs). There is a wide range of types of DSS, including home-based support, respite and carer support, equipment and other environmental supports, and community residential support (Ministry of Health 2007a).

Needs Assessment Service Co-ordination providers (NASCs) are organisations contracted by the Ministry of Health to work with disabled people to help identify their needs and outline what disability support services are available. They allocate Ministry-funded support services and assist with accessing other supports (Ministry of Health 2007c). Disabled Pacific peoples' use of the NASC process is discussed below.

Disability Information Advisory Services (DIAS) provide independent information and advice to disabled people and their families, caregivers, providers and the general public on both Ministry and non-Ministry funded DSS, including:

- support and advocacy groups
- NASC organisations and other community information
- specific information relating to particular disabilities (Ministry of Health 2007b).

There is currently only one Pacific DIAS, which is located in Auckland. Although Pacific people are currently able to access Pacific or mainstream DSS in Auckland as required, the situation in Wellington and the rest of the country is less clear.

Needs assessments

Disabled Pacific people are less likely to have received a needs assessment than non-Pacific people with a disability and to know about services such as the total mobility scheme, but more likely to know about allowances such as the accommodation supplement (Ministry of Health et al 2004).

Adults

A needs assessment is a process in which all of a person's care and support needs for everyday living are identified and prioritised by a needs assessor, with input from the client, the client's family, and/or support people who have contact with the disabled person. The actual process of the assessment can vary depending on how much material has to be collected (Ministry of Health et al 2004).

After assessment, a service co-ordinator is appointed and appropriate ways of meeting the disabled person's needs are identified. This may include finding respite care, household assistance and/or day care (Rescare New Zealand 2006).

A needs assessment should be undertaken once each year to ensure the appropriate treatment or service is maintained (Ministry of Health et al 2004). In 2001, 8 percent of Pacific adults with disability had received a needs assessment, compared with 15 percent of non-Pacific adults. Half of Pacific adults with disability in 2001 indicated they had not had a needs assessment recently (within 12 months) because they did not know about them. In comparison, 34 percent of non-Pacific adults with disability had not had a needs assessment recently because they did

¹⁰ Disability support for people aged 50-64 years with health and disability needs 'close in interest' to older people is also funded by DHBs.

not know about them (Ministry of Health et al 2004). The 2005 Research Report found that the majority of Pacific clients found out about NASC agencies through friends, family and the radio.

Data from the two main NASC agencies in Auckland suggests that access to needs assessment services has improved since 2001.¹¹ The 2005 Research Report found that Pacific people in Auckland were accessing needs assessments at a much higher rate than the total population. The greater concentration of advocacy services and disability providers in Auckland (particularly for Pacific people) may have increased disabled Pacific peoples' awareness of the availability of disability support services. It is important to note, however, that this high uptake of NASC services does not necessarily mean the clients will go on to access the DSS they need.

A project was undertaken in Wellington in 2003 to see why so few Pacific people accessed the Capital Support NASC service, whether disabled Pacific peoples' needs were being met, and whether the services were culturally inclusive. The project found that there was a general lack of knowledge among Pacific people of the availability of DSS services that could be accessed through the NASC. The project also questioned whether key Pacific competencies were being met consistently, such as the ability to communicate in a culturally inclusive manner, to respect older people, and to respect Pacific cultural practices, and found that there was a need for regular reassessment and client follow-up (Ne'emias 2003).

Children

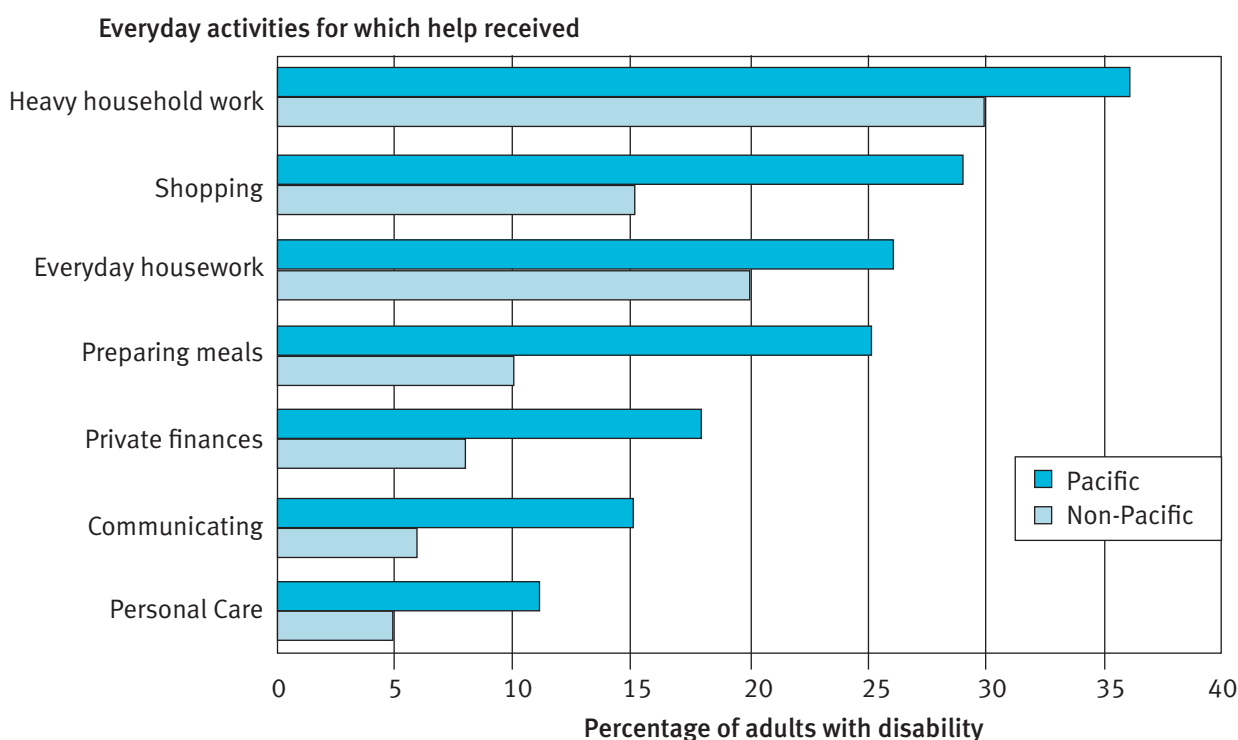
In 2001, 11 percent of Pacific children and 15 percent of non-Pacific children with disability had received needs assessments. Not knowing about needs assessments was more common among the parents or caregivers of Pacific children with disability (47 percent) than among the parents or caregivers of non-Pacific children with disability (35 percent) (Ministry of Health et al 2004).

Types of assistance received

Compared with non-Pacific adults with disability, Pacific adults with disability were more likely to receive help with everyday activities such as meal preparation, shopping, housework, managing private finances, personal care and communication (Ministry of Health et al 2004). In 2001 nearly half (48 percent) of Pacific adults with disability received some kind of help from other people with everyday activities, compared with 39 percent of non-Pacific adults with disability (Statistics New Zealand 2001). This help may have been received from family, friends and others, or from a DSS provider.

¹¹ The two NASC agencies in Auckland (Taikura Trust and Access Ability) cater for people with ongoing disability aged under 65 years, and NSD has noted that they struggle with data collection. Approximately 15 percent of the total Auckland NASC clients are Pacific, compared to 13 percent of the total population (0–64 years).

Figure 3: Percentage of disabled Pacific and non-Pacific adults living in households who received help for everyday activities, 2001



Source: Statistics New Zealand 2001

There were age-based differences in levels of assistance received. Seventy-two percent of disabled Pacific people aged 65 and over reported receiving help from other people with everyday activities, compared with 56 percent of non-Pacific disabled people in the same age group (Ministry of Health et al 2004). The parents or caregivers of 14 percent of Pacific children with disability needed help with their child’s personal care or with household work related to their child having a disability, compared with the parents or caregivers of 13 percent of non-Pacific children with disability (Ministry of Health et al 2004).

Health service use

Adults

Pacific adults with disability were as likely as non-Pacific adults with disability to have consulted a family doctor in the previous 12 months. They were less likely to have seen health professionals such as nurses, dentists, opticians and medical specialists, but more likely to have consulted a traditional healer or Pacific (or Māori) health worker (Ministry of Health et al 2004).

Approximately two-thirds of Pacific clients are at the medium to high levels of support package allocation (SPA), which means they require a lot of support and assistance. Table 2 shows how Pacific and non-Pacific adults with disability use various types of health services.

Table 2: Use of health services in previous 12 months, Pacific and non-Pacific adults with disability

Type of health service consulted	Pacific (%)	Non-Pacific (%)
Family doctor or other GP	87	86
Saw nurse without seeing doctor at same time:		
• all adults with disability	27	32
• disabled adults 25–64 years old	25	32
• disabled adults 65 and over	22	32
Chemist or pharmacist	70	74
Dentist/dental nurse:		
• all adults with disability	31	36
• disabled adults aged 45–64	19	33
Physiotherapist	15	18
Medical specialist:		
• all adults with disability	30	41
• disabled adults aged 45–64	32	45
Counsellor, social worker or psychologist	10 ¹²	13
Eye specialist:		
• disabled adults aged 45–64	18	26
• disabled adults 65 and over	16	3
Traditional healer¹³:		
• all adults with disability	7	2
• disabled adults aged 45–64*	10	-
• disabled adults 65 and over*	10	-

Source: Ministry of Health et al 2004

* Not available for non-Pacific

An estimated 500 Pacific adults with disability were living in residential facilities such as rest homes, private hospitals and long-stay residential units. This was just 2 percent of disabled Pacific people. An estimated 400 (80 percent) Pacific adults with disability living in residential facilities were aged 65 and over (Ministry of Health et al 2004).

Youth

Forty percent of Pacific clients on the Auckland NASC databases are under the age of 25. Sixteen percent are Pacific youth with disability (aged 15–24), which is higher than non-Pacific adults in the same age group (7 percent) (PIASS 2005). However, this again reflects the younger age structure of the Pacific population (Ministry of Health et al 2004).

¹² This smaller proportion of consultation occurred in each age group.

¹³ According to Sui Ne’emia, alternative health options, including traditional Pacific healing, are seen by Pacific people as the most desirable services for physical wellbeing, particularly for stroke and musculoskeletal conditions, and for older people and family members with a disability (Ne’emia 2003).

Table 3: Use of different types of health services in previous 12 months, Pacific and non-Pacific youth 15–24 years with disability

Type of health service consulted	Pacific (%)	Non-Pacific (%)
Chemist	56	54
Medical specialist	17	30
Counsellor	12	23

Source: Ministry of Health et al 2004

Younger people with disabilities are likely to have the same health needs as the rest of the population, but require greater links across sectors, such as housing, education, transport and vocational support (Ministry of Health 2003). Further research and investigation are required to determine needs, the demand for support services, appropriate models of care and assistance, and facilitation.

Children

Fifteen percent of Pacific children with disability were reported to have some type of unmet need (eg, a need for family help with personal care or household work because of the child’s disability). This was similar to the rate for non-Pacific children (17 percent). Pacific children with hearing impairments seemed to be continuing through to adulthood without getting support such as cochlear implants/assistive equipment (PIASS 2005). However, recent improvements in Pacific children’s failure rates for school hearing tests, if sustained, should begin to resolve Pacific adult hearing problems in future. Table 4 shows the relative rates of health service use by disabled Pacific children.

Table 4: Use of different types of health services in previous 12 months, Pacific and non-Pacific children under 15 with disability

Type of health service consulted	Pacific (%)	Non-Pacific (%)
Family doctor or other GP	91	87
Chemist	68	61
Eye specialist	9	19
Used special hearing equipment	~ 3	~ 3

Source: Ministry of Health et al 2004

Use of equipment and technology

Pacific adults with disability were less likely to use all types of equipment to assist them in their daily lives than non-Pacific adults with disability (21 percent compared with 30 percent). In particular, Pacific adults with disability were less likely to use hearing-related equipment than non-Pacific adults with disability (Ministry of Health et al 2004).

Table 5: Use of equipment/technology, Pacific and non-Pacific people with disability

Use of some kind of equipment or technology	Pacific (%)	Non-Pacific (%)
All people with disability	21	30
Disabled males 65 and over	49	56
Disabled females 65 and over	46	52

Source: Ministry of Health et al 2004

The equipment most commonly used by disabled Pacific people is equipment to help with mobility, which is used by 14 percent of disabled Pacific people, followed by equipment for seeing (6 percent) and for hearing (4 percent) (Ministry of Health et al 2004). In general, those aged 65 and over are more likely than those in other age groups to be using these types of assistive equipment (Cornman et al 2005).

In the 2005 Research Report, the Visone Community Trust reported that Pacific people were experiencing long delays in obtaining approval for equipment funding or subsidies, which may be contributing to the low uptake of equipment (PIASS 2005).

Current initiatives

The Lu’i Ola Auckland Disability Plan (Fitzgerald and Associates 2007) is an intersectoral project involving the Ministry of Health, other central government agencies, and Auckland metropolitan city councils and District Health Boards. Lu’i Ola aims to better serve the needs of disabled Pacific people in the Auckland metropolitan area. The plan was developed in close consultation with an advisory group made up of DSS consumers and providers. A list of the organisations involved and the key outcomes sought by the Lu’i Ola plan are listed in Appendix 3.

Implementation of the plan focuses on co-operation and collaboration through the establishment of intersectoral groups in the areas of training, communications, service review, assessment, information and housing. Each intersectoral group will analyse the needs within its focus area in more detail and define future directions for action (Fitzgerald and Associates 2007).

The Capital and Coast and Hutt Valley DHBs’ current Pacific Disability Scoping Project aims to address the lack of information on Pacific DSS needs and to determine the level of need for such services in the Wellington metropolitan area. The project will also identify the status of the Pacific disability workforce in the Wellington area and their characteristics (gender, ethnicity, qualifications) to ensure future service provision is better able to meet the needs of Pacific disabled people.

Assistance with Disability Expenses

Financial assistance is available to disabled people in the form of the disability allowance, child disability allowance, and sickness and invalids benefits (all from Work and Income) and accident compensation (from the Accident Compensation Corporation). Various other allowances are also available from the Ministry of Health to meet large costs for specific needs such as home and car modification (Statistics New Zealand 2007c).

It is important that disabled Pacific people obtain available benefits such as these, because Pacific people have much lower socioeconomic status and higher deprivation levels than many other population groups and this disparity is even more pronounced for disabled Pacific people. People with disabilities have extra expenses for items and services relating to their disability (such as medication, modified transport and aids), which they may be unable to afford. It may therefore come down to a choice between purchasing needed disability-related items or services, and other necessities of life (PIASS 2005).

Socioeconomic status of disabled Pacific peoples

Almost three-quarters (72 percent) of disabled Pacific people reported living in the most socioeconomically deprived areas (NZDep2001¹⁴ 7–10), compared with 42 percent of non-Pacific people with disability. In comparison with NZDep2001 1–3 these areas are relatively economically and socially deprived (relatively low incomes high dependence on means tested benefits, high unemployment rates, high proportion of single parent families, few households with assets, high prevalence of crowded housing and low levels of home ownership).

The 2005 Research Report examined the percentage of Pacific clients of Taikura Trust (a NASC agency in Auckland) by NZDep2001 deciles. The researchers found that, when broken down by ethnic group, almost 65 percent of Pacific clients lived in the most deprived areas, compared with less than 20 percent of European and Asian clients. The findings also demonstrated a much more even distribution of people across the NZDep2001 deciles for the European and Asian populations than for the Pacific population.

More than half (55 percent) of Pacific adults with disability were not in the labour force, which was a higher proportion than for Pacific adults without disability (31 percent), but consistent with non-Pacific adults with disability (56 percent) (Ministry of Health et al 2004).

As is the case for the Pacific and non-Pacific populations as a whole, Pacific adults with disability were less likely to have post-school educational qualifications than non-Pacific adults with disability. Compared with disabled non-Pacific adults, disabled Pacific adults were:

- less likely to own or partly own a home and more likely to pay rent for accommodation
- less likely to drive their own motor vehicle and more likely to use taxis and buses for short trips every day
- more likely to receive a community wage, sickness benefit or accommodation supplement, or to hold a Community Services Card (Ministry of Health et al 2004).

¹⁴ NZDep2001 is an index of deprivation that reflects aspects of material and social deprivation. It applies to a small geographic area rather than to individual people. The scale of deprivation ranges from 1 to 10, where 1 represents the least deprived areas and 10 the most deprived areas in New Zealand.

Work and Income

Disability allowances

The disability allowance reimburses disabled people for ongoing additional costs directly related to their disability. The amount paid is not set, but depends on the actual costs a person faces (Work and Income 2007). The allowance is also income tested, meaning that disabled people on benefits or working but with low income can qualify for assistance. To qualify¹⁵ a person must meet the definition of disability; ie, reduction in independent function lasting longer than six months and to the extent that the person requires ongoing help with normal living tasks or treatment by a registered health professional (Statistics New Zealand 2007c).

The child disability allowance is paid to the parents or guardians of children requiring constant care and attention because of severe disability. It is an income-tested supplementary allowance administered by Work and Income and provided as a reimbursement of costs. Parents or caregivers of Pacific children with disability (11 percent) are less likely to receive the allowance than parents or caregivers of non-Pacific children with disability (19 percent) (Ministry of Health et al 2004). When they do receive it, they tend to receive significantly lower rates than non-Pacific beneficiaries (Howell and Hackwell 2003). Given the preference of Pacific families to care for their disabled children, this discrepancy is significant.

Sickness and invalids benefits

People who are temporarily off work or working less than usual due to sickness, injury, pregnancy or disability can receive the sickness benefit. The invalids benefit is available to help meet living costs for people who are permanently unable to work due to sickness, injury or disability. To qualify for the invalids benefit a person must be permanently and severely restricted in their ability to work, meaning their sickness or disability is expected to last at least two years or they have a terminal illness and are not expected to live longer than two years (Statistics New Zealand 2007c). Both benefits require medical assessment and certification of a person's inability to work before they will be granted a benefit and regular reassessment in order to continue receipt (Work and Income 2007).

Between 1996 and 2002 the number of sickness benefit recipients who were Pacific people increased by 16 percent, compared to increases of 7 percent for Māori and 8 percent for Europeans.¹⁶ All three of these ethnic groups had a median duration of around four months spent on the sickness benefit, and similar proportions were still on the benefit after five years. While Pacific people, Māori and Europeans all had similar duration profiles, there were marked differences in their main reasons for exiting the sickness benefit.

Pacific people were more likely to exit due to travel and family obligations overseas, Māori were more likely to transfer to another benefit, and Europeans were twice as likely to cancel due to finding employment (Wilson et al 2005).

15 Standard Work and Income qualification criteria apply (New Zealand citizen or resident, ordinarily resident in New Zealand, not receiving other assistance such as ACC) to all of the disability allowances, sickness and invalids benefits. Some additional criteria regarding length of residency also apply for sickness and invalids benefits.

16 The increase for the 'Other' ethnic group was much greater (73 percent) and they spent longer periods on the sickness benefit than the rest of the ethnic groups. However, this is thought to reflect the fact that the 'Other' category for sickness benefit includes recent migrants who do not yet meet the residency criteria for the invalids benefit (Wilson et al 2005).

From 1996 to 2002 the number of Pacific people receiving the invalids benefit increased by 86 percent, while the number of Māori recipients increased by 73 percent and European recipients by 55 percent. During this period there was little difference in increase in people coming on to the invalids benefit: for Māori the increase was 50 percent, for Pacific people 43 percent. The higher increase in overall numbers of Pacific people is partly due to the fact that the periods that Pacific people stay on the invalids benefit have lengthened, while the durations for Europeans and Māori have stayed stable. Māori and Pacific people generally stay on the invalids benefit for shorter periods than do Europeans, mostly due to higher mortality rates among Māori and Pacific recipients. Eighteen percent of Māori and Pacific men compared to 12.7 percent of European men who were granted the invalids benefit in 1996/97 died within five years of their entry, and the difference was even greater for women (Māori and Pacific five-year mortality 1.5 times that for Europeans) (Wilson et al 2005).

Accident Compensation Corporation (ACC)

In the Pacific population, approximately 23 percent (compared with 32 percent for all New Zealand) of disabilities arise from an accidental cause, which includes the late effect of injury (Ministry of Health and Ministry of Pacific Island Affairs 2004). Forty-one percent of the total disabled population are disabled as a result of work-related accidents and injuries (Ministry of Health et al 2004).

ACC is a Crown entity that provides no-fault personal accident insurance for all New Zealand residents. ACC covers the costs of injury, including primary medical care fees, support in the home and income replacement. Pacific people have lower ACC claim rates compared to the total population (Ministry of Health et al 2004), but this may be due to lack of knowledge. Koloto and Associates Ltd (2005) found that 21 percent of Pacific people surveyed had not heard of ACC and had little or no understanding of ACC and its services.¹⁷ Many of the clients who self-refer or are referred by other agencies to DIAS have relationships with ACC. Clients eligible for ACC are generally ineligible for Ministry of Health-funded DSS services and Work and Income benefits.

ACC visits

The percentage of ACC-related visits by Pacific people to primary health care providers is similar to that of the total population. However, Pacific females only visit primary health care providers for ACC-related matters half as much as the total female population. Visits to a primary health care provider are almost four times as likely to be ACC related for Pacific males compared with Pacific females (Ministry of Health and Ministry of Pacific Island Affairs 2004). The reasons Pacific females are less likely to visit doctors for ACC claims is a potential area for further investigation.

ACC claim rates

In general, Pacific people claim at a lower rate than the non-Pacific population, making new entitlement claims at only 45 percent of the rate of the general population. Pacific claimants tend to be young and are more often male (70 percent compared with 61 percent) than claimants from the remainder of the population. They have a higher proportion of sporting and work injuries and fewer non-earner claims.

The discrepancy between ACC-related visits and claim rates is an area that could be considered for further investigation. With similar visit rates across ethnic groups, there should be correspondingly proportionate rates of ACC claims to ACC-related primary care visits. This discrepancy could be

¹⁷ A total of 575 Pacific people were surveyed.

accounted for by different injury distributions, or it may reflect greater barriers experienced by Pacific people in the claims process (Ministry of Health and Ministry of Pacific Island Affairs 2004).

Serious claim rates

Although the number of serious injury claims by Pacific people is similar to that of the general population, Pacific people make up a much smaller percentage of ongoing serious injury claims in any one year. The duration of injury claims is therefore less, and it is possible that the claim process presents a barrier to Pacific people (Ministry of Health and Ministry of Pacific Island Affairs 2004).

Koloto and Associates Ltd noted that there was a need for Pacific people to become more informed about the types of injuries that entitle them to apply for, and receive, ACC support. Recommended strategies to encourage Pacific people to use ACC services included:

- arranging community meetings about ACC
- translating ACC information into Pacific languages
- encouraging employers to provide information about ACC to their employees and ensure the information is accessible
- using existing groups (such as churches) to promote services (Koloto and Associates Ltd 2005).

Discussion

Severity of disability

The high rate of severe disability in the disabled Pacific population (particularly for Pacific females) must be considered in relation to access to support services and management of disability. Pacific people living with disability appear to be requesting and receiving support only if the disability is very severe, as is evident in the Pacific clients on NASC databases and their levels of support (PIASS 2005). In addition, disabled Pacific people are more likely to require specific services and resources to continue managing their disability due to the high and complex needs related to severe disability. For example, the higher rate of assistance the disabled Pacific population receives may be an indication of the higher rate of severe disabilities (which require greater support) rather than a higher inclination to seek and receive assistance.

Differences in service and support uptake

From the available information, there appear to be disparities between the Pacific and total population in the uptake of needs assessments, access to support services after assessments, and access to equipment and technology. In addition, Pacific people are presenting with higher rates of severe disability than non-Pacific people (gender inclusive), which may reflect a failure to detect and manage chronic disease (Ministry of Health et al 2004). This does suggest that disabled Pacific people may not be receiving the same quality of care as the total population.

There is a role for primary health organisations to link with disability support services, particularly as evidence suggests that disabled Pacific people tend to visit their general practitioner before seeking other assistance (Ministry of Health et al 2004).

Needs assessments

It is difficult to draw definite conclusions about differences in the uptake of needs assessments because the sample sizes are too small to be statistically significant (Ministry of Health and Ministry of Pacific Island Affairs 2004). In addition, the majority of disabled Pacific people in Auckland appear to have a higher-than-average uptake of needs assessments. This is noteworthy because most of the disabled Pacific population reside in Auckland, although those that are not registered on the NASC databases will not be included in this rate (PIASS 2005). Nonetheless, in future it will continue to be important to encourage more disabled Pacific people to utilise needs assessments, as receiving appropriate services and support options depends on these assessments, especially the identification of everyday needs (Ministry of Health et al 2004). Anecdotal information also suggests there are some areas of the needs assessment approach and process that could be improved.

There may be a structural or systemic issue with the preferred ‘assessment as a transaction’ approach, in comparison to a case management approach that may make it easier to understand and navigate the available services. Pacific communication styles and culture favour trust-based relationships. For example, Pacific people may not want to appear ‘greedy’ if in need of specific resources, and assessors may determine from short interviews that there is no need for an increase in the current level of funding or service provision. This outcome can result in poor service and a poor working relationship with disabled Pacific individuals and their families. NSD is currently introducing a Pacific cultural competencies framework for Ministry-funded NASC providers, which may begin to resolve some of these issues for disabled Pacific people and their families.

Support service access following needs assessments

The uptake of disability support services by disabled Pacific people is higher than for disabled non-Pacific people (Ministry of Health et al 2004). However, the 2005 Research Report identifies one of the main problems for Pacific people as being access to the appropriate DSS following needs assessments. Long waiting periods between applying for a needs assessment and receiving it, confusion about the processes for accessing DSS, and the role and function of many of the services are some of the issues described (PIASS 2005). It is unclear from available information whether needs assessors undertake follow-up assessments to ensure that clients are receiving the recommended services. Poor levels of DSS uptake are often the result of insufficient information, advice and support, which may suggest an enhanced role for DIAS (P Beilby, personal communication, June 2006).

Cultural competence frameworks and Pacific models of care are an emerging response to improving Pacific peoples' access to the appropriate Pacific health and disability service. For instance, cultural competence is a component of the *Pacific Health and Disability Workforce Development Plan 2004*, and HDNSD have introduced a Pacific cultural competencies framework for workers in the disabilities sector. However, the best approach for the future may be to develop navigation systems to steer disabled Pacific people and their families through the complex disability support services and remove barriers to existing services (Siale Foliaki, personal communication, July 2006).

Use of equipment and technology

Fewer disabled Pacific people use assistive equipment compared to disabled non-Pacific people (Ministry of Health et al 2004), although these figures do not appear to be statistically significant. It is important to encourage the use of equipment to ameliorate disability and support participation in society (Ministry of Health and Ministry of Pacific Island Affairs 2004; Minister for Disability Issues 2001), and the reason for Pacific peoples' comparatively low uptake of equipment is not clear.

Pacific families' response to assistive equipment or services may reflect their views about treatment as well as family circumstances. Anecdotal information suggests that some families prefer to provide the support required themselves, such as lifting their family member rather than obtaining a wheelchair (PIASS 2005). This may be the result of limited household space, a lack of awareness that services exist to make homes more wheelchair accessible, or cultural preferences.

Low rates of equipment use are also a consequence of the high proportion of Pacific families living in rental housing, which limits the extent to which they can contemplate or make modifications for better access. For example, 32 percent of disabled Pacific people own their own home, compared to 58 percent of non-Pacific adults with disability (Ministry of Health et al 2004).^{18,19} Competing economic priorities for the family (including meeting basic needs) may also be a factor in the uptake and purchase of assistive equipment. This may be an issue for disabled Pacific people because, as we have seen, 72 percent live in the most socially deprived areas, compared to 42 percent of disabled non-Pacific people (PIASS 2005).²⁰

18 Housing NZ is currently working to generate more accessible state-owned homes for people with disabilities, but this project is long-term and so immediate effects may not be large. Housing NZ also offers an advisory service to assist disabled people with the requirements for modifying homes they own or rent.

19 The 2005 Research Report found that higher rates of deprivation reduced Pacific peoples' options for housing, which in many cases prevent independent living.

20 See the earlier section on assistance with expenses for further information on deprivation and the socioeconomic status of Pacific peoples.

Pacific population demographics

The youthful age structure of New Zealand's Pacific population means that the number of disabled Pacific people will most probably increase when all these young people start entering the ages most prone to disabling injuries and illnesses – particularly as the Pacific population already has a large contingent of children with disabilities. For this reason, the future demand for support services from the adult population may be different from the current demand. This ageing of the Pacific population provides another reason for the need for culturally aware, disability-focused initiatives.

Youth

There is very limited information available about disabled Pacific youth and their need and demand for services, assistance received, uptake of support services, and appropriate models of care. This may warrant consideration, because anecdotal information suggests that disabled Pacific teenagers are most at risk of sliding into a vacuum of inactivity after leaving their special-school environment. It is possible that a pattern of inactivity could begin that continues into adulthood and affects later participation and inclusion.²¹ Community-run day programmes for the elderly (eg, arts and crafts, exercise, cooking and music programmes) have historically been very successful. It may therefore be worthwhile to support Pacific community initiatives with disabled youth, particularly if such programmes help social connectedness with employment and recreation opportunities (PIASS 2005).

Encouraging young people and their families to network may also help overcome isolation, and provide a safe environment for discussion, information sharing and mutual support. A community-driven network of Pacific youth with disabilities may be a way to ensure that disabled people, and youth in particular, do not drop off the radar of DSS and community services – particularly if the network helps disabled Pacific youth to feel supported, encourages advocacy, and provides relevant disability service navigation and information.

Available information also tends to suggest that Pacific youth with disability have lower rates of health service use than non-Pacific youth with disability (Ministry of Health et al 2004). However, further investigation is required to determine whether this is an issue of access barriers, family circumstances (such as ability to meet the cost of travel to appointments) and/or preferences.

Children

Pacific children do not appear to have significantly higher rates of disability than non-Pacific children after the demographic differences in population structures are accounted for (Ministry of Health et al 2004). However, there may be significant issues arising from the compounding effects of disability on Pacific children's already low educational achievement rates, and the level of engagement of Pacific families with DSS. Children with disabilities have reported that their disability has led to educational disadvantage (Ministry of Education 2006b) and low school attendance rates (Masino and Hodapp 1996). These outcomes may be more detrimental or apparent in Pacific children because their school achievement levels are already significantly lower than those of non-Pacific students, regardless of disability (Ministry of Pacific Island Affairs 2000). Pacific children (18 percent) with disability are also less likely than non-Pacific children (39 percent) to have been professionally assessed to determine their developmental and educational needs.

²¹ Establishing programmes that support the need for initiatives for disabled Pacific youth is one of the recommendations that emerged from the 2005 Research Report.

Investigation into the impact of disability on Pacific children and their families would be worthwhile, as would an examination of the attitudes and beliefs about disability held by friends, families and the church.²² Further investigation could explore options for engaging with other disabled people and their families from a young age to help them understand and manage disability, obtain access to appropriate DSS and benefits, and undertake the necessary planning for life to prevent later dependency. The high rate of general practitioner consultation by Pacific families may also be a reason to explore the potential for PHOs and DSS providers to become better co-ordinated.

Forty-one percent of Pacific people living with disability report disease or illness as the cause of their disability, which is much the same as the non-Pacific population rate of 40 percent (Ministry of Health et al 2004). Pacific people (regardless of disability) also demonstrate disproportionately higher rates of chronic disease (particularly diabetes and cardiovascular disease, which are inter-related) than the total population (Counties Manukau DHB 2005). Diabetes is a recognised major contributor to disability, associated with mobility and sensory disability (Gregg et al 2002).

The rate of disability in the Pacific population is probably a reflection of the high diabetes burden. In particular, the late detection and/or poor management of diabetes are causally related to disability, in that the consequence of late treatment of diabetes includes limb amputations and blindness. The chronic disease burden may also increase as the Pacific population begins to move into the older age groups, where chronic disease is more prevalent (Gregg et al 2002).

Encouraging PHOs to refer people with serious chronic disease to disability providers and advocacy services may be a useful way of educating people at high risk about disability and disability management, and available support and services. The PHDAP review process will also focus on reducing the chronic disease burden for Pacific people (eg, diabetes, ischaemic heart disease, cancer, respiratory disease). It is assumed that a reduction in the rate of chronic disease will have a similar flow-on effect on the rate of disability prevalence.

Cultural perspectives and attitudes to disability

Some Pacific people continue to believe that a person's impairment is the result of an affliction or curse brought about by their own (or their parents' or ancestors') marital infidelity, breach of tapu or sin (PIASS 2005). In addition, certain words denoting disability in Pacific languages have negative connotations. For example, in the Samoan language a blind person is commonly referred to as 'tau aso', meaning 'your days are numbered'.²³

Discrimination can come from all parts of the Pacific community, including the church, and stems from the notion that disabilities are linked to divine punishment. The church plays a major role in the life of most Pacific families and is often a centre of support, so it can become a source of distress or embarrassment for many disabled individuals and their families.

HDNSD have identified stigma (negative mind sets and stereotypes towards people with disabilities) as a significant problem in Pacific families and communities. Experienced Pacific disability practitioners consider that Pacific people in general have a long way to go in terms of addressing and changing these entrenched stereotypes, attitudes, and beliefs regarding people with disabilities. The increasing number of Pacific people born and educated in New Zealand is expected to contribute, in time, to a more inclusive attitude towards disability and to reduce traditional prejudices.

Ministry of Health initiatives to address the problem of disability stigmatisation have included

²² This concept is discussed further in the section on cultural perspectives below.

²³ See Appendix 1 for further information on Pacific perspectives of disability.

funding a pilot Pacific disability awareness promotional campaign, similar to the Like Minds Like Mine mental health campaign. This campaign first aired on Radio 531PI in November 2005, and was continued through to June 2006. This campaign, as part of the NZDS, has contributed towards improved disability awareness in the Pacific community of Auckland. HDNSD is currently developing a proposal to explore the potential for continuing the campaign, including the potential for a national roll-out.

Workforce development and labourforce participation

There is a very low representation of Pacific people throughout the disability workforce,²⁴ and so the development of a Pacific health and disability workforce is an integral part of efforts to improve health and disability outcomes for Pacific people in New Zealand (Ministry of Health 2004). There are various strategies, including the *Pacific Health and Disability Workforce Development Plan*, which will hopefully help address some of the workforce issues, such as under-representation and supply in the Pacific disability sector. The NZDS also identifies a need to develop and train a disability workforce for Pacific people, so that they can act as providers of disability information and services in their local communities (Minister for Disability Issues 2001).

Anecdotal information has indicated that disabled Pacific people are in need of advocacy, and favour trust-based relationships, particularly with people who have undergone similar life experiences. One suggestion has been to encourage disabled Pacific people to join the disability support services workforce as advocates and mentors, because they bring a greater understanding and personal perspective of the disabled client having undergone similar life experiences. Services also tend to be more effective for disabled Pacific clients when a disabled person is taking an active role in providing information, making decisions, and giving advice on how to navigate the complex disability service system (Ministry of Education 2006b).

Pacific men aged 25-44 years with disabilities have a much higher rate of non-participation in the labourforce than non-Pacific men with disabilities (37 percent and 18 percent respectively).²⁵ These figures suggest that there is some potential for Pacific males with disabilities to participate in the workforce, although there may be issues of skills and qualifications, and the disability-friendliness of New Zealand work environments. For example, if past experience has been limited to factory employment, it may be more difficult to find a post-disability career match.

24 Appendix 2 of the Pacific Health and Disability Workforce Development Plan notes that there is no available data on the estimated number of disability support needs assessors, regardless of ethnicity.

25 Pacific women of working age with disabilities have a higher rate of non-participation in the workforce than Pacific men of working age with disabilities (59 percent compared to 50 percent, respectively).

Conclusions

This paper considers the available information about Pacific disability in New Zealand. The information suggests that Pacific people have similar rates of disability, relative to the total population, but experience barriers to accessing support services – particularly in receiving regular and follow-up needs assessments, disability support services, access following assessments, assistive equipment, and ACC services. In addition, this paper discusses the severity of disability and the relationship between the chronic disease burden and Pacific peoples' disability rate. It also considers the limited information on Pacific children and Pacific youth. The proposed areas for improvement are as follows.

Pacific children

There is limited information and research available on Pacific children's experience of disability, including the effects of disability and its impact on children and families (PIASS 2005). Disability may pose a particular problem for Pacific children because they already tend to be more susceptible to poorer health outcomes and may also be subjected to disability-associated discrimination (PIASS 2005).

Pacific youth

There seems to be a gap in knowledge about, and initiatives and/or programmes for, disabled Pacific youth. The best option for disabled Pacific youth may be to encourage the development of community-based programmes and/or networks to provide a safe environment for discussion and to promote advocacy. However, further investigation is first required to determine what the needs are, what demand there is for services, and what would be the appropriate models for distributing relevant information and support, and for providing suitable facilitation.

Support services

Living with Disability in New Zealand reports that access by Pacific people to needs assessments and their use of equipment are at a lower rate than for the total population (Ministry of Health et al 2004). Another important issue appears to be access to the appropriate DSS after needs assessments (PIASS 2005). The current passive delivery model for delivering DSS has, until recently, failed to address socioeconomic realities, and places the burden of responsibility for follow-up on disabled people and their families.

Potential solutions may include:

- improved collaboration between needs assessment agencies, disability support services, and primary health organisations
- improved navigation systems for disability support services
- movement towards a more relationship-based case management approach.

These approaches should improve health outcomes for disabled Pacific people and their families, and they also tie in with the PHDAP objective 'To increase access to, and quality of, disability support services'.

Workforce development

The disability support workforce has been identified as requiring urgent development (Ministry of Health 2004). Encouraging disabled people to play a more active role in disseminating information and in providing advice and advocacy seems to be a good way to promote available services and mutual support. It also offers opportunities for disabled Pacific people to participate in the labourforce.

Options for Future Work

Based on the information presented in this paper, the following options for future work are proposed for further consideration and discussion.

Improvements in service delivery and quality of care

1. Investigate options for more relationship-based advisory and advocacy approaches to help Pacific people to navigate the available disability support services.
2. Encourage providers and the disability workforce undertaking training to improve cultural competence so that they better understand Pacific people's perceptions and experiences of disability.
3. Develop career pathways that attract disabled Pacific people to join and progress within the disability workforce.
4. Introduce targets for Needs Assessment and Services Co-ordination to report against; for example, set a target percentage of clients to have re-assessments to check on their uptake of services following their initial assessments.

Synergies with primary health organisations

5. Investigate the synergies and co-ordination between needs assessment agencies, disability providers and mainstream primary health organisations, and how these work for Pacific people, and make improvements as indicated from this investigation.

Community-based initiatives

6. Establish more community-based initiatives to help overcome isolation and provide a safe environment for discussion, information sharing and mutual support.

Research and evidence to inform service development

7. Research the experiences of disability of Pacific disabled children and youth and their families, and appropriate models of care.
8. Describe Pacific family and community attitudes towards disability, and the influence of traditional beliefs and attitudes.
9. Examine the issues that disabled Pacific people and their families face when navigating the disability support service system.
10. Identify the workforce needs of disabled Pacific people and the barriers to entering and re-entering the workforce.

Appendix 1: Pacific Perspective of Disability

The Pacific definition of disability is different from the definitions held by non-Pacific people. That is, the origins and root causes of the disability are explained differently. According to Hukau and Bray (2000, as cited in Statistics New Zealand 2001) Pacific people rationalise disability from two main perspectives: biomedical and social.²⁶

From the *biomedical* perspective, Pacific people understand disability to mean that a person has a physical, sensory or intellectual impairment. In short, there is a visible manifestation of disability that defines certain people as disabled and others as not. This is consistent with the view of non-Pacific people. However, the difference in a Pacific person's case lies in the explanations for disabilities. Their reasoning tends to be either from a religious (eg, disability as a punishment from God) or cultural standpoint (eg, disability as a curse due to a family transgression).

From a *social* perspective Pacific people see disability as an effect of living within a culture that is different from their own. In this perspective, the key issues from a public health point of view are therefore communication (eg, being unable to adequately communicate in English because it is a second language), racial (eg, racial discrimination) or socioeconomic (eg, lack of income or money).

The different causal attributions of disabilities tend to result from a difference in cultural upbringing. Bearing in mind that concepts like culture and family are central tenets of Pacific values, there is a need to consider the significance of social models of care, such as family members encouraging disabled Pacific people to participate in society and be independent rather than dependent. The importance of these Pacific models of care is becoming increasingly recognised, as indicated by the Pacific Health and Disability Workforce Development Plan. A core goal of this plan is to promote Pacific models of care and cultural competence. Pacific people prefer a competent and qualified disability support service that specialises in Pacific models of care, and this preference is being increasingly recognised by providers and government officials.

The different cultural definitions of disability and cultural issues/barriers signify that any treatment or rehabilitation that advances the re-entry and participation of disabled Pacific people into the community must be treated differently from strategies for non-Pacific people. When developing strategies for disabled Pacific people, the factors that must be considered as having the potential to influence participation or the use of services are: the importance of assistance from family members; any potential self-blame or embarrassment Pacific people may be feeling; and communication or socioeconomic differences.

²⁶ The biomedical and social perspectives discussion is also presented in the Living with Disability in New Zealand publication (Ministry of Health et al 2004).

Appendix 2: New Zealand Disability Strategy

The New Zealand Disability Strategy (NZDS) is the key strategic framework for developing and advancing disability services. Underpinning the NZDS is a vision that New Zealand will be inclusive when people with impairments can say they live in, ‘a society that highly values our lives and continually enhances our full participation’.

The NZDS outlines 15 objectives to achieve this vision.

1. Encourage and educate for a non-disabling society.
2. Ensure rights for disabled people.
3. Provide the best education for disabled people.
4. Provide opportunities in employment and economic development for disabled people.
5. Foster leadership by disabled people.
6. Foster an aware and responsive public service.
7. Create long-term support systems centred on the individual.
8. Support quality living in the community for disabled people.
9. Support lifestyle choices, recreation and culture for disabled people.
10. Collect and use relevant information about disabled people and disability issues.
11. Promote participation of disabled Māori.
12. Promote participation of disabled Pacific peoples.
13. Enable disabled children and youth to lead full and active lives.
14. Promote participation of disabled women in order to improve their quality of life.
15. Value families, whānau and people providing ongoing support (Minister for Disability Issues 2001).

The following action points are included under Objective 12 (‘Promote participation of disabled Pacific peoples’).

- Increase access to, and quality of, both Pacific and mainstream service providers that deliver disability services to disabled Pacific peoples, their families and communities.
- Support disability workforce development and training for Pacific peoples, by training Pacific peoples as providers of disability information and services for their local communities.
- Encourage Pacific communities to consider disability issues and perspectives and further their own understanding of disability through the development of community-based plans for disability issues.
- Support training and development of trilingual interpreters for deaf people.
- Ensure the Ministry of Pacific Island Affairs undertakes a leadership role in promoting the participation of disabled Pacific peoples (Minister for Disability Issues 2001).

Every government department is also required to develop an annual NZDS implementation work plan that specifies the actions the department will take to implement the strategy.

Appendix 3: Lu'i Ola Plan Ownership and Goals

The Lu'i Ola Auckland Disability Plan was launched in March 2007 by the Associate Minister of Pacific Island Affairs. Lu'i Ola is an intersectoral plan aimed at improving service provision for disabled Pacific people in the Auckland metropolitan area.

Participating agencies

Accident Compensation Corporation

Auckland City Council

Manukau City Council

Waitakere City Council

Auckland DHB

Counties Manukau DHB

Waitemata DHB

Ministry of Education

Ministry of Social Development

Ministry of Health

Ministry of Pacific Island Affairs

Housing New Zealand

Specific outcomes sought

The following nine Lu'i Ola goals were informed by and are consistent with the findings in the 2005 Research Report.

1. All of the government agency workforce is culturally competent to work with Pacific disabled people.
2. Pacific service providers are competently providing services as needed by the sector.
3. The Pacific communities and workforce are well informed of disability and available services.
4. Shared consultation processes for agencies with Pacific communities are in place.
5. Increase Pacific attendance at service reviews.
6. Shared assessment occurs where possible.
7. A virtual (telephone) central point of contact for all government agencies is available to disabled Pacific people and their families.
8. A personal navigation service is available for disabled Pacific people and their families who require further support.
9. Housing modification and equipment processes are streamlined (Fitzgerald and Associates 2007).

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