

Nelson Marlborough District Health Board

Health and Hospital Services Needs Assessment for People with a Disability: A Report informed by Providers and Consumer Representatives

July 2009

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1 EXECUTIVE SUMMARY

Purpose

Nelson Marlborough District Health Board (NMDHB) recognises their accountability in defining the prevalence and incidence of health services needs for people with a disability residing in Nelson Marlborough. This includes finding out how health and hospital services are provided to and experienced by, a person with a disability. Mental health services and services to children have been covered recently in other reviews by NMDHB, therefore, this report includes those with the following disabilities: those with an intellectual disability, physical disability and sensory disability and people 65 years of age or older with a disability.

Method

Information for this report was collated from census data (Statistics NZ 2006 Census), existing literature, key stakeholder and consumer interviews conducted utilising focus groups or, one on one interviews.

Results

There are approximately 15,000 people in Nelson Marlborough reporting having a severe or moderate disability.. Those with physical disabilities being the most common type of disability in adults, particularly mobility disabilities amongst the elderly. Disability prevalence in Nelson Marlborough is likely to minimally increase until 2011, at which time a dramatic shift in the over 65 age group due to aging baby boomers, could significantly impact on the number of people with disabilities in the region. Using current prevalence of disability in this age group, by 2026, Nelson Marlborough estimates it may have roughly 32,000 people with disabilities, of which half would be over the age of 65.

While the delivery of current health and disability services in Nelson Marlborough are of a good range and quality, there is no evidence that a distinction is made for people with disabilities for access to these services as systems and processes are designed in a similar way for all. However analysis of information from the process undertaken in this report found this disadvantages a person who has a specific need relating to an intellectual disability, a physical disability and a sensory disability and for older people with a disability which results from life-long disability as well as age-related disability.

All disability groups identified that cost was a main barrier for access to many primary and community services particularly General Practice (GP). Care co-ordination and advocacy were raised as key areas that needed to be developed and were noted to be of high importance by consumers that were interviewed.

Primary, community and hospital providers identified the sheer number of older people needing services, their vulnerability in a system that is not designed to meet their needs and considered to be ill equipped to expand into the future without major systems changes.

Conclusion

Making sure that people with a disability are able to receive appropriate facilitation and get

a personal health action plan if they want one requires all stakeholders to work together to develop a local model and implementation strategy. Section 6 outlines specific feedback that can be used by service providers and planners to make some useful changes for all people with a disability who need health and hospital services.

We suggest that specialist stroke services and dementia services need to be further explored and developed within Nelson Marlborough particularly to manage the projected increase in need as the number of elderly increases into the future.

It is suggested that this report assist in supporting the development of individual health action planning and facilitation through the following:

1. Leadership to support better health for people with a disability. Leadership must ensure that measures are in place to check performance on disability equality and plans to improve health and hospital service delivery for people with a disability.
2. Data and knowledge management opportunities should be included to provide the information to support the planning, funding and development of a range of coordinated services to improve the overall health of people with a disability.
3. Funding should focus on ensuring improved health outcomes through ensuring that local systems work effectively to improve the health of people with a disability as well as support their families and care-givers. Where feasible agencies with expertise in disabilities should be utilised to deliver interventions that promote better health.
4. As part of regular 'health checks', primary and community care providers should ensure that people with a disability receive access to the type and level of care they require to maintain, improve or manage their health.
5. Accessible health information should be provided to people with a disability to assist them to self-manage their general health along with their disability.
6. Robust systems should be in place to capture and act on issues relating to patient experience and complaints.
7. Hospitals should ensure that interpreters are available for those who need and/or require them and that processes support 'patient-centric' care processes.
8. Hospital admissions should be accompanied by discharge planning that takes due regard of the 'special' needs of the patient with complex functional disabilities including the need for convalescent, rehabilitative and supportive care once they return to their home.

2 INTRODUCTION

2.1 Purpose

NMDHB wants sustainable health and disability services that both support the principle of an inclusive society and meet the needs of current and future generations of people. This report will give a picture of disability prevalence and incidence in Nelson Marlborough and will describe how health and hospital services are provided to and experienced by, a person with a disability. We propose that the existing stigma and discrimination experienced by people with disabilities has affected their access to health and hospital services and that this has resulted in worse health status similar to that experienced by Maori, other ethnic minorities and those with lower socio economic status^{1,2}.

This health and disability services needs analysis for people with disabilities (report) covers a vast client group which includes those with a intellectual disability, a physical disability and a sensory disability and people at or over age 65 with a disability. The report excludes services to children and mental health service as each has been covered in other recent NMDHB reports.

2.2 Definition of Disability

According to the NZ Disability Strategy (2001), individuals do not have disabilities. Rather, they may have physical, sensory, neurological, psychiatric, learning, or other impairments. The Strategy states, "*Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have*".

2.3 Limitations

Limitations of this report result from the difficulty to access useful local information on the nature and prevalence of disabilities and the size of the group being included. Not all providers and consumer representatives were able to attend the focus group meetings when invited.

2.4 Method

Information for this report was put together from census³ data, existing literature from national strategy documents, incident reviews and published articles, key stake holder and consumer interviews.

Use of a survey was considered but due to time constraints for those who might be requested to complete a survey, and the desire to not influence or restrict the feedback, focus group meetings were selected as the way of gaining qualitative feedback. Focus group meetings of service providers and consumer representatives were held to gain a picture of how health and hospital service is provided to and experienced by those people with a disability in NMDHB (see Appendix 1).

¹ J,S, Crowley.,2006 www.kaiseredu.org web access 18-03-09

² M,A, Nosek.,D,K Simmons(2007) People with Disabilities as a health disparities population *Californian journal of Helath Promotion* vol5pp68-81 Web accessed google 18-0309

³ <http://www.stats.govt.nz/census/default.htm>

A consistent format in seeking the information through a facilitated interview methodology was used.

3 DEMOGRAPHICS OF THE NMDHB TOTAL POPULATION

Nelson Marlborough district (district) had an estimated population of 134,500 as of 30 June 2007. This is spread, reasonably evenly, between the three local authorities namely Tasman Region, Nelson City and Marlborough Region.

The Nelson Marlborough district is expected to grow only by about 0.5% per year for the next 25 years, with the largest growth occurring in the Tasman Region. The district has a significant number of people living in rural areas

The district has a smaller percentage of Māori (8%) than the New Zealand average (15%), but Nelson Marlborough's Māori population is expected to increase proportionately more than the national average over the next 10 years.

3.1 Māori

There are both quantitative and qualitative differences between the Māori and non-Māori experience of impairment and disability that reflect wider inequalities. Māori experience higher rates of single and multiple impairment in all age groups and more severe impairment at younger ages and overall. Further, disabled Māori are represented as more socioeconomically deprived and have higher unmet needs for disability support services and special equipment.

In 2006, the disability rate for Māori (17%) was lower than the disability rate for European (18%). However, this is skewed by the fact that the local Māori population is much younger than the European population. It is more appropriate therefore that the rates should be compared by age groups. For each age group, Māori have a higher disability rate than others.

Māori also experience an earlier onset of age-related disease and impairment. The higher proportion of young people in the Māori population means that the majority of Māori with disability (63%) were aged less than 45 years. Māori prevalence of functional impairment increased with age, from 13% for those aged 15–24 years, to 22% for the 25–44 year age group, to 34% for those aged 45–64, and 61% for Kaumātua aged 65 years and over. For example, Māori women aged 45 years and over have a significantly higher rate of functional impairment caused by disease/illness than non-Māori, similar to the profile expected for the non-Māori 65 and over age group.

Nearly all Māori living with disability (99%) lived in households and less than one percent lived in residential facilities.

With the exception of learning impairment, Māori adults are over-represented in each major functional impairment category. The most common types of functional impairment experienced by Māori adults are mobility, hearing, and agility impairments. The most

common cause of impairment for both Māori and non-Māori was disease/illness.

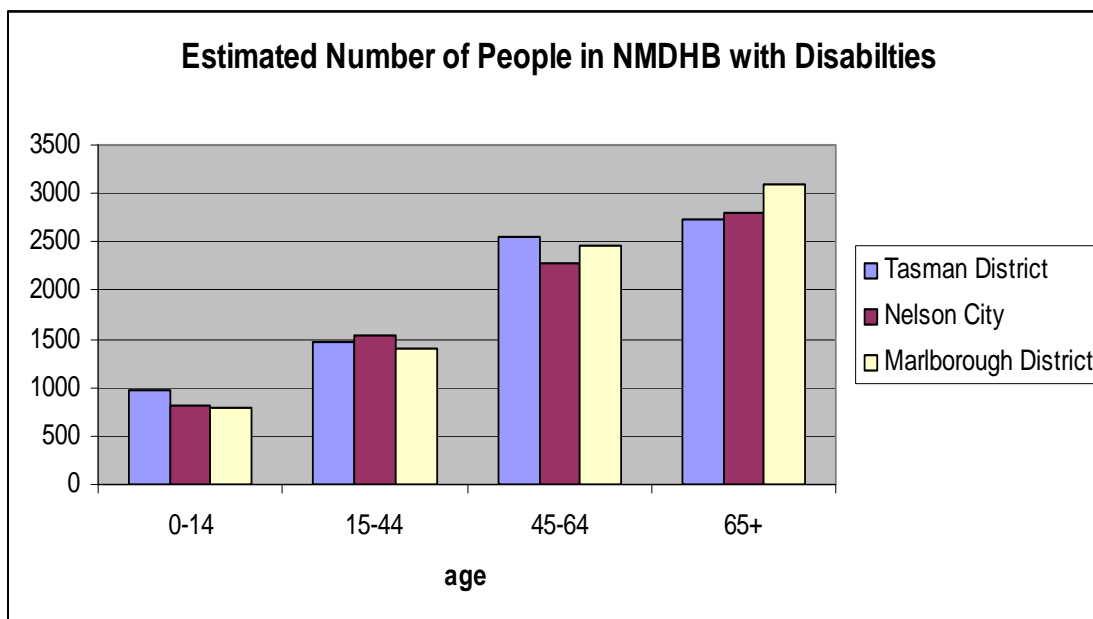
Disabled Māori living in households have indicated higher levels of unmet need for health services (23% compared to 14% for non-Māori) and transport costs (17% compared to 7%). Māori reported less usage of disability-related equipment (23% used equipment compared to 31% of non-Māori), despite more severe disability. Māori also indicated a greater unmet need for special equipment (15% compared to 11% for non-Māori)⁴. This is consistent with Māori concerns that there are insufficient assessment, treatment, and rehabilitation services to meet Māori needs⁵.

3.2 **DISABILITY INCIDENCE AND PREVALENCE**

3.2.1 **Prevalence of disability**

In 2006, an estimated 17%, or just less than one in five of New Zealanders had a disability, rising to 45% of those 65 years of age and older.

Extrapolating the national rates of prevalence to the Nelson Marlborough region⁶, about 23,000 people, including about 2,500 children, have a disability out of a total regional population of 130,000 in 2006.



⁴ Ministry of Health 2004

⁵ Macdonald et al 2002

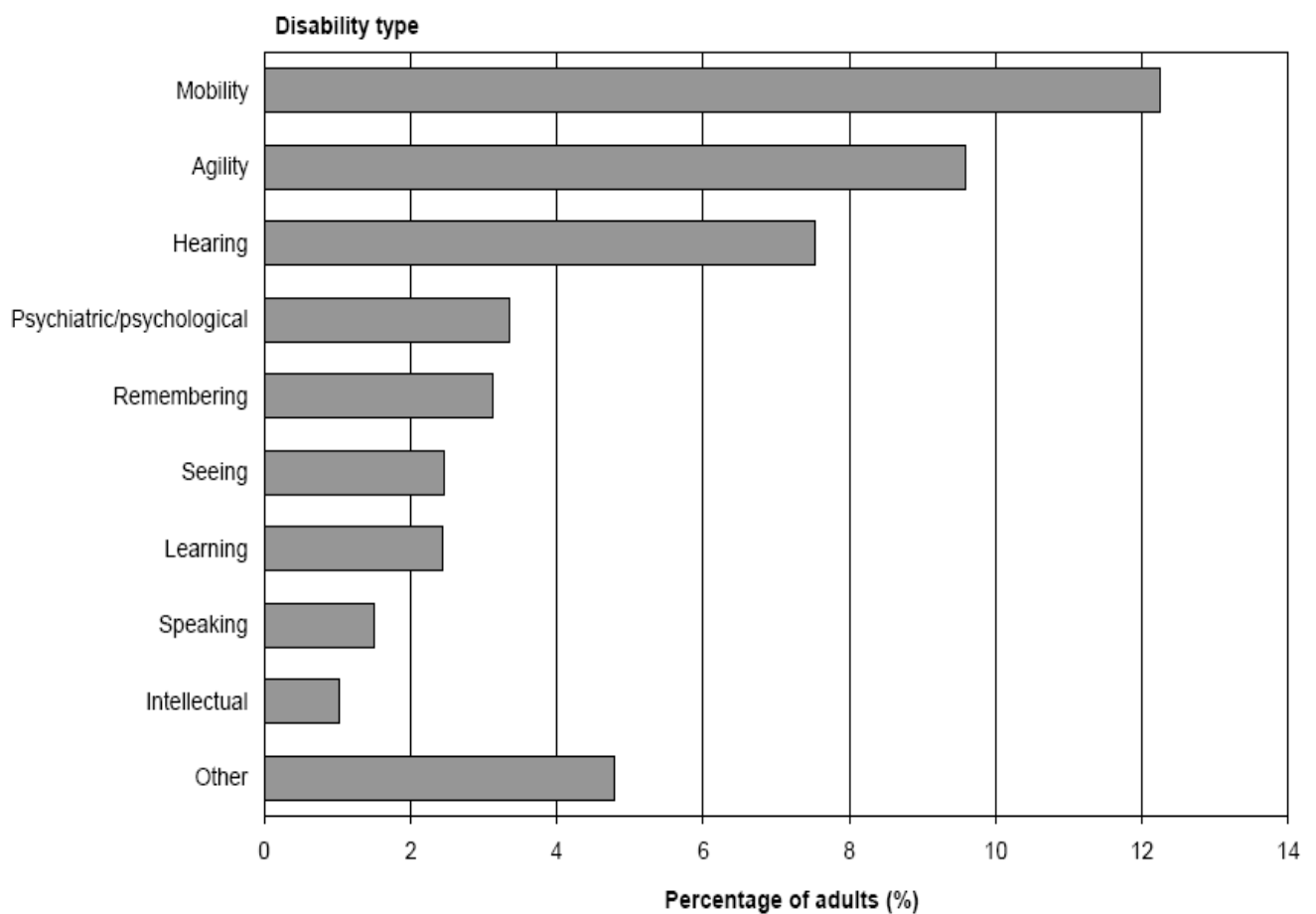
⁶ Results from the 2001 survey suggest the disability prevalence in the South Island was higher than the national average, with 27% of South Islanders having a disability compared with a national average of 20%. The South Island also had the highest age standardised rate of disability at 19,400 per 100,000. As such, the national prevalence estimates may be slightly lower than the actual rates for several South Island DHBs, though these have not yet been calculated for the 2006 survey.

3.2.2 Type of disability

Physical disabilities were the most common type of disability in adults, particularly mobility and agility disabilities among the elderly. Difficulty walking affected about two-thirds of those surveyed. Hearing disability was the most common sensory disability.

Mental health disabilities were also common.

This is illustrated in the graph on the following page
Percentage of adults living in households experiencing different types of disability, 2001.

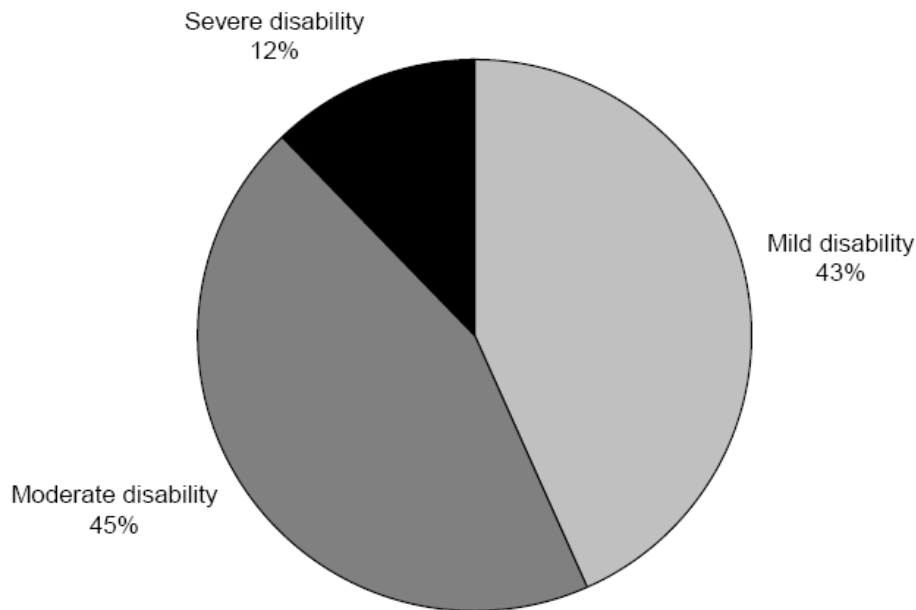


3.2.3 Severity of disability

Over half of people with disabilities had a severe or moderate disability, equating to roughly 15,000 people in Nelson Marlborough with a severe or moderate disability.

This is illustrated in the pie graph on the following page.

3.2.4 Severity of disability in people (adults and children) living in households, 2001



As might be expected, age-specific rates for severe and moderate disability were highest in the older age groups and lowest in the younger age groups.

Survey results show roughly 2% of all people in households had severe disability. This meant they required daily help from someone else for tasks such as bathing or preparing meals.

However, in the 75 and over age group, the rates of both moderate and severe disability (10,600 per 100,000) were nearly double the rate in the next youngest age group; 11% of people aged 75 and over had severe disability. People with severe disability were very likely to be living within the community, with nearly four out of five people with severe disability lived in households rather than in residential facilities.

3.3 Age

Older people were substantially more likely than younger people to experience disability, with just 9% of adults aged 15-24 having a disability, compared with 87% of people aged 85 and over. In 2006, one third of people with a disability were over the age of 65.

Approximately 8,500 elderly people in Nelson Marlborough have a disability, mainly in the nature of restricted mobility or frailty. As the proportion of the population over 65 is projected to rise significantly in the next two decades, this higher prevalence of disability is predicted to result in higher need for appropriate housing and support services. The most common causes of disability for those 65 and over were physical and age-related disabilities.

Nearly three quarters of people receiving support in the region have been identified as

having age related disability as their prime disability.

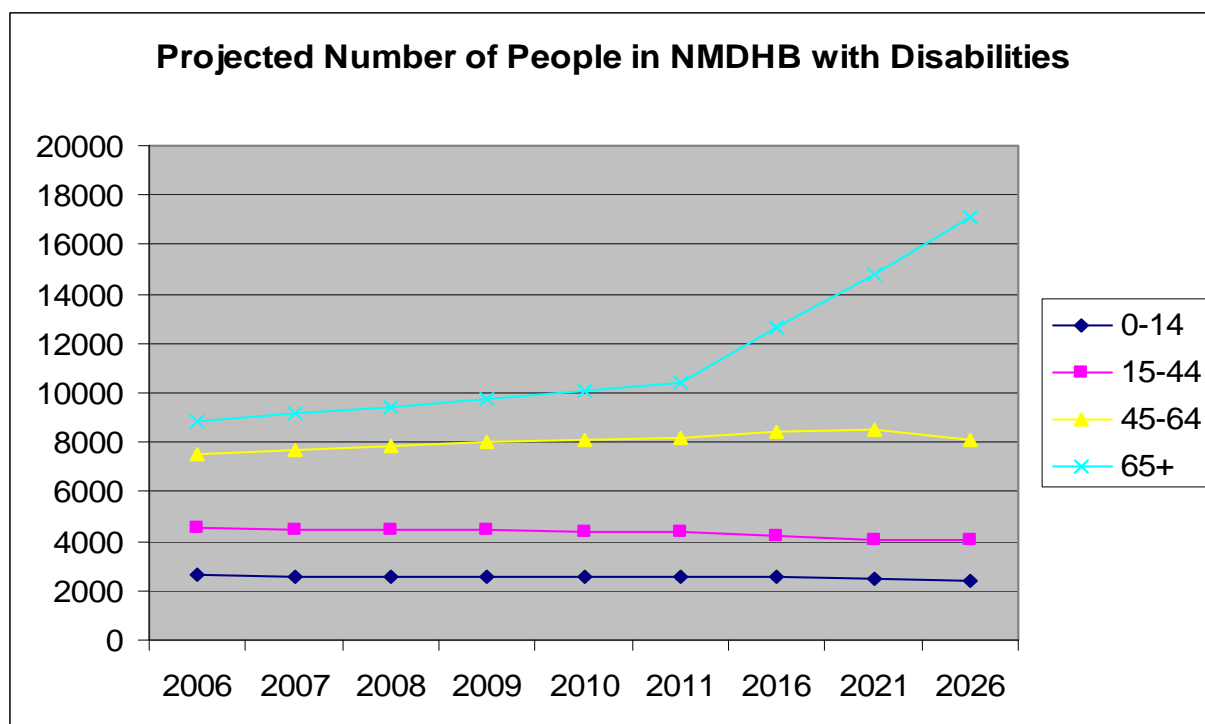
3.4 Projections

Ministry of Health reports suggest a decrease in prevalence of moderate disability over recent decades, although this is less evident in the Australasian surveys they studied. They conclude that prevalence of severe disability is unlikely to increase in New Zealand and will probably stabilise or even decrease.

3.4.1 Percentage of people with disability (survey results 1996, 2001, 2006)

Age group (years)					
	0–14	15–44	45–64	65+	Total
1996	11%	12%	25%	52%	20%
2001	11%	13%	25%	54%	20%
2006	10%	9%	20%	45%	17%

Based on the disability prevalence from the 2006 survey, the number of people with disabilities in Nelson Marlborough is likely to steadily increase until 2011, at which time a dramatic shift in the over 65 age group could significantly impact on the number of people with disabilities in the region. By 2026, Nelson Marlborough is estimated to have roughly 32,000 people with disabilities, 17,000 of which would be over the age of 65.



4 PROVIDER AND CONSUMER THEMES

The overall feedback from providers and consumers is that services are delivered in an appropriate manner and of a good range and quality; however there was a range of feedback that will be useful for providers to address when considering continued service development.

The feedback is presented in a priority order, commencing with feedback that relates to all the groups first and the most common themes first. Feedback for each specific group is presented next, again in priority of the theme received. The disability group falls in alphabetical order commencing with intellectual disability, older people with a disability, physical disability and sensory disability.

4.1 Universal Themes From Across the Disability Spectrum

Cost

Cost was the number one barrier raised for accessing GP services by all groups' particularly urgent after-hours medical care. Some consumers stated '*...will go to ED as it is free*'

4.1.1 Advocacy

Care co-ordination and advocacy was a key theme. People with complex cases find it hard to access information about '*where to go*' for services. A person with a complex disability often needs someone who can guide them through the system. Advocacy and care continuity was reported as lacking for those who need social support, financial guidance and basic life essentials.

These people report an assumption amongst providers that family are willing/able to take this role but some consumers feel their family will force them to make a decision that they may not be happy with. Also some people have no family or their family lives out of this district so there is no easily available family.

Whilst there are many brochures available, information about what to expect next or where to go for certain services is difficult to locate.

It is difficult for primary and community care as well as hospital providers to keep up with what support groups are available for people with disabilities, and how to access them. They report there are several points of entry and very little standardised information is provided.

Providers reported that to access services, people or their families have to be '*out there*' all the time. They have to know what is available and then fight to get it. '*If you know what you can have and fight for it you get it*'. Many felt that as a rule older people don't want to be a bother and just choose to battle on

4.1.2 Information and Format

There is plenty of information around and much of it is well designed. However, some information is provided in print that is often difficult to read (*'too small'*) and quite wordy. People state that the print on appointment cards is also often too small and some ink is faintly stamped with e.g. telephone contact instructions.

4.1.3 Hospital Outpatient Appointments

In Nelson, most focus groups felt that outpatient appointments are not co-ordinated between different clinicians and/or imaging diagnostic services (x-ray), particularly as part of the hospital outpatient visit. Often a visit for an x-ray and an outpatient appointment are on different days and each may involve a wait. Waiting long periods in the waiting room is difficult and people feel worn out by the time they return home. Times for appointments are often not suitable for people travelling from a rural area. This included hospital day surgery times with older people getting up at 4am or 5am to arrive for an early morning appointment.

Providers acknowledged that an inappropriate appointment time wastes a person's time but also that of any family who may be taking time off work to be with them. Hospital staff are finding that Employers are not as happy as they used to be to allow absences for family issues. Nurse leaders suggested some appointment times would be better scheduled later in the day e.g.4-7pm.

4.1.4 Transport

Transport is difficult particularly for those who are physically unable independently to enter a car or bus. For some people using an ambulance is the only way they can travel. This may result in long awaited and planned appointments having to be cancelled and rebooked due to the ambulance being unavailable due to an emergency call out. The lack of co-ordination of outpatient appointments, plus the inappropriate appointment times for rural people compounds the problems with transport.

4.1.5 Disability Awareness

Disability Awareness is about challenging attitudes and personal understanding about disability so disabled people can be part of the community like everyone else. Providers report there is some knowledge of the disability strategy among managers but not frontline staff, additionally there is limited awareness of what it is like for a person with a disability. It is difficult to get support staff to attend unpaid 'disability awareness' training.

Health staff primary and hospital providers were not aware of the availability of the Health and Disability Commissioner's DVD, **Making it Easy to Do the Right Thing** - Disability Responsiveness Training'.

Support Works was the only provider who reported offering disability awareness training to staff.

4.1.6 Adjusting to a Disability

There is a lack of counselling for people to adjust to and/or cope with a disability including the need often for grief counselling. Whilst there are some counselling services available these are not for adjusting to a disability or for parents of a child with a disability being assisted to manage.

4.1.7 Equipment

Focus group members advised that equipment through ENABLE is very difficult to access and can often take months leaving at risk consumer, carer and support worker safety. The ENABLE process was described as cumbersome, not user friendly and not supportive. One community group reported they have given up on ENABLE and now fund raise for the pieces of equipment that their consumers need.

Housing modifications for people with a physical disability can frequently take 6 months or longer. Delays with bathroom modification makes showering a challenge for the person, carer and support worker.

4.2 Intellectual Disability

4.2.1 Community Services

In identifying health needs and checking access and uptake of health initiatives by people with intellectual disabilities focus groups advise that it is important to include access to services provided by dentists, opticians, podiatrists and pharmacists as well as other community providers.

4.2.2 Primary Care

Providers and consumers report that access to a broad range of services is good and works well when accompanied by a carer. Consumers feel that waiting for long periods in the waiting room *'is not good'*. One consumer reported that he needs clear instructions from the doctor about what to do with a prescription. Written and clear instructions about going to the pharmacy would help him.

4.2.3 Hospital Services

Providers and consumers feel that services are available when needed. Consumers report that being in hospital is a scary experience. The person is alone and traumatised, they need someone to tell their story about best way to manage usual activities and the things that are important e.g.: *'he likes Mickey Mouse and if he has it all the time will be calm'*.

Support services providers report that when a consumer is in hospital, there is an expectation from hospital staff that the community carer will provide showering, meal assistance and other personal care. Support Providers reported that often when a person with a intellectual disability is in hospital, hospital staff are not aware of the abilities of the

person and their usual routine. Hospital staff may feed a person who is able to feed themselves.

Hospital providers report that it is important for all people to have a support person with them when in hospital particularly a familiar face with knowledge of the individual has been known to enhance their recovery.

Hospital staff report that support workers used to be available when someone was in hospital but this is happening less often, as some providers are less accommodating. One provider organised support workers to attend a client in hospital and then sent an account to the hospital department for this service although this had not been negotiated and agreed.

Good information with a detailed care plan, particularly if it can be informed by an Occupational Therapist, makes a big difference to a person returning to their usual ability level.

4.3 Older People

4.3.1 Primary Care

Providers report that access to GPs is difficult. Some older people find that their GP is too busy for them as the GP does not have time to listen to all their concerns in the time he/she has available. Some GPs in Marlborough have closed their books. Providers believe the role of primary care is important. The practice nurse role is very important and they are more accessible than the GP. The practice nurse knows the alerts for a particular person and is proactive in instigating when a check is needed to see a GP. Some GP's have control over what nurses are allowed to do for the patients. The practice nurse needs to know when/how to refer to Support Works and be able to navigate through the system for people. One provider suggested that consideration be given of a system of funding arrangement for primary care nurses that could manage those with ongoing condition and access GP when needed.

Along with cost, transport is also a barrier as hardly any GPs do home visits. A significant barrier is around urgent after hour's primary care both for people in their own home – travelling from Richmond or Wakefield to Nelson; but also those in rest homes. Also, there are no after hour's GP visits so sometimes the older person presents to the Emergency Department (ED) as a result. This is not desirable for the older person or for the ED.

There continues to be a stigma attached to having a dementia. Many community providers feel that GPs lack the knowledge for dementia medication management, and that some GPs lack assessment skill for dementia.

In Marlborough, dementia patients are not referred by GPs to specialist care or the Alzheimer's society. Some GPs are also not aware they can refer the older person directly to Support Works for an assessment. As a result there can be a long delay in necessary support being accessed. Early choices and access are important to manage the older person.

Golden Bay has few services for persons with dementia. Appropriate assessment for a person with both an intellectual disability and dementia is even more difficult to access.

Access to podiatrists is a major concern with many of the comments being '*not enough*' and '*the cost is too high*' creating barriers. Most providers and consumers felt that a large number of older people do not need a podiatrist as a result of a foot problem but they are not able to bend or do not have the dexterity to use clippers. There is therefore little opportunity for safe foot care for those who are not at high risk for complications. A toe nail clipping service from other providers such as Practice Nurses or care support workers who have been trained to do so would be of benefit to some people. In Marlborough there are registered nurses in the community that provide a good service at a very reasonable cost.

There is poor follow-up in the community for people who have had a stroke. In some cases there is professional input from a physiotherapist or occupational therapist for a few weeks after discharge and then nothing. Providers and consumers feel it is hard to access allied health services in the community for more than one visit for perhaps equipment but then nothing for an ongoing need. Hospital Allied Health staff affirm that the staffing levels do not permit a greater community service being delivered.

The cost of hearing aids and of reading glasses was raised by older people as a problem and consumers and providers agreed that dental care was not accessed at all due to similar cost barriers.

4.3.2 Hospital Services

Getting into the hospital through ED is very difficult with long delays causing those who are elderly anxiety. This has been shown to add to their problems. Lack of information about their condition and the reason for the wait is worrying for the elderly.

Another reason that older people fair worse is that hospitals are increasingly geared to getting a person in and out as soon as possible. Nurses indicated '*we do not provide any convalescent services*'. In Marlborough there are possibly 1-2 people a week who need a period of time, possibly as long as three weeks, to get back on their feet. Older people take longer to recover from acute and elective health events.

All the hospital geriatricians acknowledged that it is a challenge for older people in the hospital environment particularly with the pressure for throughput and not having enough beds to enable recovery. There is little time to deal with those frail older people with functional impediments such as mobility issues and confusion. There are problems encountered on acute wards which certainly could be improved if they had more resources. There is a style of care and a way of looking at people that is a consequence of more medical sub-specialisation, with professionals looking at a single problem rather than at the whole person. Fragmentation results from the lack of poorly coordinated services by a range of providers. There is pressure to move people out of hospital and consumers and providers both indicated that discharge planning is not ideal.

The physical environment is also not good for managing older people suffering from

confusion. The ward is noisy and leads to the older person becoming more disorientated.

Community providers say it is very worrying for people with dementia as hospital services do not cope well with their needs. Patients with dementia who go into hospital get stressed due to just being *'in hospital'*, and hospital staff will often call the family member caregiver to come out in the night to try to calm the person. They need more care than a usual older person and often there is a three day period where one to one care is needed to keep a person safer or to keep them at a lower level of service delivery, for example post operative confusion. Hospital providers state that *'the only option we have is to sedate them to get them off to sleep and it does cause problems'*.

All providers and consumers reported that discharge information is limited and not all patients get a copy of their hospital discharge summary. There is often a difference between the yellow medication card and the medicines they are discharged on. There is often little or no warning of their discharge from hospital which is compounded when it is at the end of the week with notification to the follow-on care provider. Often, there may not be a support worker available to attend the person over the weekend. Community providers feel there is poor understanding of community support services by the hospital staff.

The advocate for people with hearing impairment who live alone feels there should be mechanisms in place so that they should get a copy of the client's appointment. A nominated advocate is necessary to assist with ensuring the appointment is written up, to advise the client they will be collected and what will happen.

4.4 Physical Disability

Providers felt there is poor access to community rehabilitation including access to a community psychologist and access to adjustment counselling. There is also disparity of services funding between the DHB, MOH and ACC. The rhetoric is that it is meant to be cheaper at home but this is often not the case for the person with the disability. Also, some diagnostic conditions don't qualify for disability support funding.

4.5 Sensory

The Deaf Association of New Zealand (Inc.) report that the Deaf culture is quite unique. The Deaf see themselves as a separate cultural group within the overall national culture - just as Maori and Pacific are unique cultures. The word *Deaf* spelt with a capital D is a noun that denotes a culture and a community. The use of sign language as one's first language is the main characteristic of people who identify with this culture and community. Spelled with a small d, deaf is an adjective which refers simply to hearing loss - e.g. deaf children means children with impaired hearing who may not yet have had contact with the Deaf community.

This means a person who is Deaf and unable to read written English relies on NZ sign language (NZSL) as the way to communicate. Written information such as in a brochure is like a foreign language. Spoken format with NZSL interpretation is needed and could be provided in a DVD format. This awareness is not present for many frontline workers in the community and hospital services.

4.5.1 Primary and Hospital Services

Front line hospital services' staff indicate they are unaware of the person with a sensory disability such as the blind or deaf. Whilst the written record may contain an alert about the sensory impairment, a lot of communication may have occurred before the record is accessed. Appointment bookings and attendance information is not being delivered in an appropriate manner and as a result there is occasions when appointments have been missed. In the Primary area it is possible to put an alert on the electronic file so that a flag is raised to alert staff.

NZSL interpreter service for a health appointment is funded by the MoH and needs to be arranged ahead of time as the interpreter has to be flown in from another centre. There have been instances when this has been arranged for a Deaf person however at times the health provider has refused access for the interpreter to be present. Providers report that when a consumer requests a NZSL interpreter, staff have responded that *'the budget does not allow for this service'*. This lack of knowledge of how the interpreter service should be accessed has caused frustration and embarrassment for consumers.

Consumers feel that some health staff have poor use of language particularly relating to sensory disability such as using inappropriate statements like *'do you see what I mean'*, to a blind person. Consumers and community providers report that language has implications for Deaf consumers using mental health services. The example given was of a Deaf consumer being asked *'have you been hearing voices?'*

4.5.2 Awareness

A two hour deaf awareness training is provided by the Deaf Association but many primary and hospital providers have not organised this training. Community providers are the main groups to undertake this training.

5 DISCUSSION

There is congruence in the feedback received from consumer representatives, primary providers and hospital service providers which is striking. The impression is that health and support services are of a good range and quality but there is no distinction for disabled people - the systems and processes are designed in a similar way for all. This presents a disadvantage where a person has a specific need relating to intellectual disability, older people with a disability, physical disability and sensory disability. The feedback from the focus groups aligns with the feedback from other health needs assessments including, long term conditions,⁷ Maori health, and health of older people. The majority of feedback from providers highlighted the difficulties for older people; this is significant as by 2026 based on current prevalence for older people, Nelson Marlborough is estimated to have roughly 32,000 people with disabilities, 17,000 of which would be over the age of 65.

Providers described the system as being designed to respond well to those with an acute

⁷ Meeting the Needs of People with Chronic Conditions, National Health committee 2007; Health of Older People Strategy, Ministry of Health 2002; Maori Health, Mental Health, others?

condition. This has led to short, episodic type interventions from a myriad of providers. For many people with a disability, particularly older people, there is a need for more time for assessing all the factors that impact on staying well and functioning independently. Providers and consumer representatives agreed that there was not enough time allocated to do this well, particularly in general practice. There is scope for developing a more integrated 'slow stream' intervention that is nurse led and includes case co-ordination. Most providers reported that disability awareness training is not provided.

The fragmented nature of the system is a challenge and difficult for most health professionals to understand which compounds the problems for disabled people. Getting information when it is needed is difficult and often only those who are tenacious are able to 'push through' and find out about what services might benefit them. A mechanism for accessing information from various providers (and sometimes other sectors like voluntary or social service agencies) would be useful.

The cost of accessing some services including primary medical care was raised by every group. Particularly after-hours medical cost and the difficulties of travelling to a doctors appointment. Podiatry was routinely reported as very high cost and only 'a diabetic' could access a subsidised service. Most felt that a safe foot care service for those with low risk of complications but who are functionally unable to bend or use clippers, should be provided at low cost and perhaps included in the range of care and support in the community services.

Making sure that people with a disability are able to receive health facilitation and get a 'personal health action plan' if they want one requires all stakeholders to work together to develop a local model and implementation strategy. It requires commitment from funders and providers, particularly those in community, primary care and hospital settings.

Progress is also dependent on a fundamental shift in practice for service providers to develop more inclusive, community-based support and make best use of skills and resources.

We should also be reminded that person-centred approaches and person-centred planning have to be at the heart of any approach. Local plans should clearly account for the needs and wishes of local people and their families and the work required to bridge sectors, settings of care and manage change.

Similarly, health action planning and health services facilitation cannot be seen as isolated processes and much of their effectiveness and success depends on good collaboration between individuals at all levels in the health sector from funding to provision to one-to-one support. Local partnerships are a key mechanism for getting all stakeholders together.

This report has also found there are two areas in particular that need further development and implementation in light of what has been highlighted by the focus groups of service providers and consumers in this report.

They are:

1. The continuum of Stroke services delivery
2. The continuum of Dementia services delivery

It is suggested that this report assist in supporting the development of individual health action planning and facilitation through the following:

1. Leadership to support better health for people with a disability. Leadership must ensure that measures are in place to check performance on disability equality and plans to improve health and hospital service delivery for people with a disability.
2. Data and knowledge management opportunities should be included to provide the information to support the planning, funding and development of a range of coordinated services to improve the overall health of people with a disability.
3. Funding should focus on ensuring improved health outcomes through ensuring that local systems work effectively to improve the health of people with a disability as well as support their families and care-givers. Where feasible agencies with expertise in disabilities should be utilised to deliver interventions that promote better health.
4. As part of regular 'health checks', primary and community care providers should ensure that people with a disability receive access to the type and level of care they require to maintain, improve or manage their health.
5. Accessible health information should be provided to people with a disability to assist them to self-manage their general health along with their disability.
6. Robust systems should be in place to capture and act on issues relating to patient experience and complaints.
7. Hospitals should ensure that interpreters are available for those who need and/or require them and that processes support 'patient-centric' care processes.
8. Hospital admissions should be accompanied by discharge planning that takes due regard of the 'special' needs of the patient with complex functional disabilities including the need for convalescent, rehabilitative and supportive care once they return to their home.

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National Health Service (NHS) United Kingdom http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4083500

Health and Disability Commissioner website
<http://www.hdc.org.nz/resources/videos>

NMDHB Documents

Chronic Condition framework
Primary Health Strategy
Specialist Health Service of Older People Report
Information Strategy Strategic Plan
Maori Health Strategy

7 Appendix 1

HNA Focus Group Interviews Nelson Marlborough District Health Board

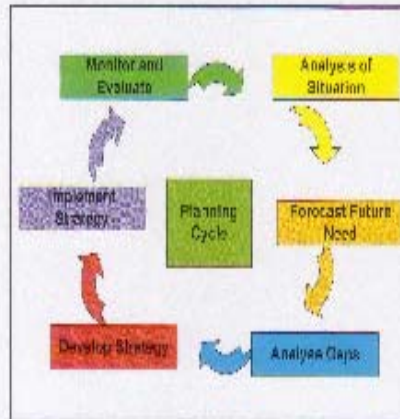
Draft Timetable

<p>Introduction</p> <ul style="list-style-type: none"> ➤ Outline of purpose and objectives of Health Needs Assessment Disability ➤ Brief presentation on Prevalence and Incidence in this district 	<p>Facilitated interviews</p>
<p>Service providers - Older People</p> <p>Age Concern Care and Support in Community Providers Heaphys Home Support, Presbyterian Support, Healthcare of NZ Ltd, Access Homehealth, Maureen Francis, Nelson Nursing Services Aged Residential Care providers(3 Nelson, 3 Marlborough, 1 Motueka) Stroke foundation Arthritis foundation Alzheimer's society Support Works Consumer representatives</p>	<p>Nelson 2 December 08 Marlborough 16 December 08 Motueka 17 December 08</p>
<p>LLD Services</p> <p>NZ foundation for the Blind Hearing Association Deaf Association Care and Support in Community Providers Support Works Neighbour hood Connections Consumer representatives Meredith, Glen Baigent, Ian Tomlinson</p>	<p>Nelson 11 December 08 Marlborough 16 December 08 Motueka 17 December 08</p>
<p>IDSS NZ Care Idea Services People first – Robbie Martin Consumer Representatives x 3</p>	<p>Nelson 9 December 08</p>
<p>GP reps Dave Dixon</p>	<p>Nelson 24 March 09</p>

Maori Consumer representative Ruby Aberhart, Nelson	Nelson 17 February 09
Older Person consumer representative John Brett, Marlborough	28 April 09
Maori Service Providers Marlborough Maata Waka O Te Tau Ihu Trust Te Hauora o Ngāti Rarua Te Rapuora o Te Waiharakeke	28 April 09
Maori Service Providers Nelson/Tasman Te Amo Health Te Awhina Marae O Motueka Te Kahui Hauora O Ngati Koata Whakatu Te Korowai Manakitanga Trust Whakatu Marae Health and Social Services	18 May 09
Hospital Clinical Nurse Leaders Sue Allen, Wairau Lois McTaggart, Lucy Nunns, Maureen Leggatt, Lynne Bary, Stuart Port, Lisa Turner, Lynne Mercer, Sandy McLean-Cooper, Nelson District Nurses Motueka	Motueka 17 December 08 Wairua 27 March 09 Nelson 7 April 09
Allied Health representatives Kit Sidey, Wairau Bella Clark, Hilary Exton, Nelson Physiotherapist, Unit Manager - Motueka	Motueka 17 December 08 Wairua 27 March 09 Nelson 8 April 09
Clinicians/Geriatricians Andrew Wilson Rob Blackbeard, Mike Ball Bobby Clafferty	Marlborough 27 March 09 Nelson 8 April 09 26 May 09
Psycho- geriatric team Mark	26 May 09

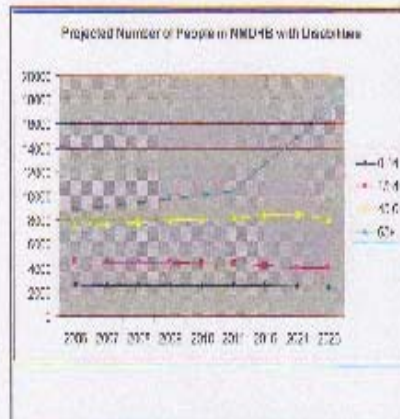
Health Needs Assessment - Disability

NMDHB 2008

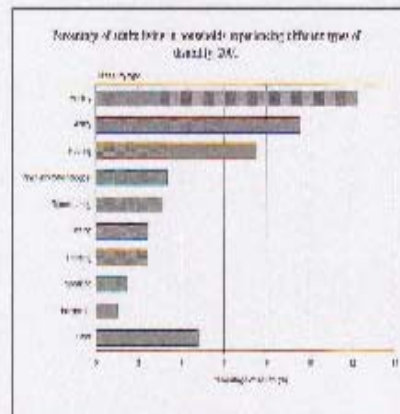
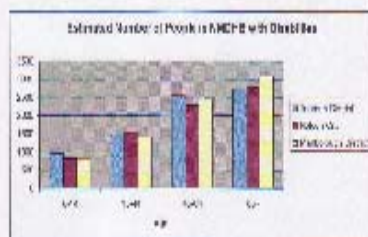


Incidence and prevalence of disability in the Nelson Marlborough district

- Using NZ estimates, we have 25000 people with a disability in our district
- Of these 2500 are children
- Support works provides services to 15329 of these people



Extrapolated from NZ figures



Providers and Consumer Representatives we are talking to

- HOP and Lifelong Disability
- Nelson, Marlborough, Motueka, GB, Wairarapa, Picton
- HOP - Age concern, HBSS, ARC reps, Stroke Foundation, Arthritis Foundation, Alzheimers, Support Works

Lifelong Disabilities

- NZ Foundation for Blind
- Hearing Association
- Deaf Association
- Neighbourhood connections
- HBSS
- HBSS, NZ Care, Idea Services, People First, DPA

Disability inclusion/exclusion

- Excludes: Children & Mental Health
- Includes: Sensory
 - Physical
 - Intellectual Disability
 - Health of Older People

HOP and LLD

- Māori Health providers
- GP reps
- Hospital Allied Health
- Hospital Nurse Leaders

We need to get a picture of how health and hospital service is provided to and experienced by those people with a disability in NMD/IB.

Any questions/comments?

Question format.

We need to get a picture of how health and hospital service is provided to and experienced by those people with a disability in NMDHB.

1. How is primary care provided to and experienced by a person with a disability.

Prompts

Tell me about service from doctor (practice), dentist, podiatrist, audiologist, pharmacist, physiotherapist, occupational therapist, dietician, speech language therapist, ophthalmologist, nurse?

Teeth? Hearing aid? Medications? Foot care?

2. How is hospital services provided to and experienced by a person with a disability?

Prompts

Inpatients

Outpatients/specialists visits?

3. Do you have Knowledge/awareness of disability strategy? Do your staff?

4. Is there any disability specific awareness training available?

5. Who else should we speak to?

6. In terms of the overall health for a person with a disability – what would make the biggest impact on achieving better health?

Prompt

If the DHB could change three things right now what should they be?