Deaf
AOTEAROA
New Zealand
TĀNGATA TURI

Deaf Way

Deaf Way

A New Service Delivery Model

Undertaken By

Fitzgerald & Associates

February 2010

There is nothing more essential, and more coveted, than human communication.

(Grant 2008)

Acknowledgements

Fitzgerald & Associates is grateful for the guidance of the Deaf Aotearoa Advisory Group in developing this report.

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Executive Summary

The Problem

There are around 4,000 people in New Zealand who prefer to communicate visually. Most are prelingually Deaf and are likely to be Deaf community members.

While the numbers of Deaf people are gradually decreasing because of medical advances and interventions, it is clear that there will always be people who prefer to communicate visually. Deafness is a normal part of life.

Delays in developing language and the resulting social isolation of Deaf children in families are thought to have huge impacts on their mental health and understanding. Despite having a normal range of intellect, roughly 40% of Deaf people receiving service have high social needs, with low literacy and both minor and complex social problems, and require social support, counselling and habilitation as a result. This is both unnecessary and tragic.

This research has confirmed that there is huge unmet need not only for specific Deaf groups (e.g. immigrants, elderly, children, deafblind) but for the whole Deaf population in terms of communication and social support. Deaf people feel misunderstood by or invisible to the New Zealand public and New Zealand public services. Whole communities as well as individuals need support and development.

New Zealand is not alone. The issues facing Deaf people in New Zealand are also experienced internationally. Deaf services in some developed countries however have a much broader range of services available, such as social work or intensive service coordination, peer support, training in Sign Language as well as services for Deaf people with physical or intellectual disabilities or mental illness. Roughly a third of all people born with hearing loss also have another disability, providing additional challenges to the strong need for communication.

Some international models provide advocacy rather than direct service provision. Nearly all focus on the needs of deaf disabled and have strong strategic alliances within the deaf and disability sectors.

Deaf Aotearoa New Zealand (Deaf Aotearoa) services have traditionally struggled to provide a large range of services with a small amount of resource and have been of variable quality. Services for deaf and hearing impaired are separate but are not working together closely enough to ensure consistent and collaborative approaches. Many key relationships within the Deaf and related sectors have been tense for a long time now and need improvement.

The Need

The needs of Deaf people are clear:

► The highest needs are for communication access to government services, with health, emergency services, Work and Income, and Police considered the four most important overall. Personal safety is the top priority. Communication in the family home, work and public transport are also considered vital. Both the Deaf participants in this project and international literature report how variable and generally poor communication access is for this population.

► It is not surprising then that interpreters are the most-wanted type of communication support. Booking interpreters without long waiting times, particularly in areas outside the major cities, is necessary. Deaf relay and trilingual interpreters and note takers are also needed by particular groups.

► Fortunately technology has and will continue to provide new communication solutions. The mobile phone capable of text messaging has provided a small revolution and the local development of video interpreting is eagerly awaited.

► Equipment provision is considered inadequate, fragmented and complex. Many Deaf people also note that equipment is expensive and therefore often inaccessible.

► Better access to public broadcasting and information, provided in captions or Sign Language, is called for strongly.

► Several parents called for free access to high-quality NZSL training, so they can communicate with their child from the earliest opportunity. They also need early information on the importance of early language development.

► The need for high-quality NZSL training for parents, schools and the wider community is key to all other development in Deaf services.

► Māori and Pacific Deaf people need services that are familiar with and respectfully acknowledge as well as challenge their own cultures. Despite best efforts, this does not appear to be the case. Internationally, there is evidence that ethnicity can be a primary indicator of poor employment outcomes. Being on the fringe or outside the mainstream Deaf community makes communication access even more challenging.

► Residential and intensive social support for Deaf people with additional needs is noticeably lacking in NZ.

► Mental health and counselling services are inadequate to meet need and require significant improvement.

► Accessible training needs to be available. Deaf people particularly called for training in Deaf Awareness, life skills and advocacy. Understanding who you are, getting fundamental skills to live in the world and getting what you need is clearly most important to many Deaf. More-educated Deaf called strongly for professional development as well as tertiary, leadership, advocacy and literacy training.

It is clear that there is not much extra money available to provide all the needed services in New Zealand. The current Government wants to look at how these services can be provided innovatively with the least impact on the public purse. While this is especially true in a recession, it is unlikely that all services required will ever be fully funded by Government.

The Solutions

Some people advocate that Deaf Aotearoa should be a "one-stop shop" so Deaf people can conveniently get all they need from one provider. While this is an understandable approach, this paper argues that it is impossible for Deaf Aotearoa to meet all Deaf people's needs. Their needs span every aspect of life and every possible organisation as Deaf people wish to live ordinary lives in New Zealand communities. Deaf Aotearoa needs to target its efforts and resources carefully.

This is a difficult challenge as the Deaf have experienced mainstream services as failing to acknowledge their language, culture and needs. It can be less painful to provide barely adequate services yourself, rather than observe the failure of others.

Nevertheless, this report concludes that Deaf people will need a very nimble and professional service providing innovative and value-for-money services, in close collaboration with a range of other agencies.

Deaf Aotearoa also needs to enable effective communication within its own sector. Crucial progress will only be made with a unified group acknowledging, valuing and working with differences, rather than having organisational focus distracted by conflict. Sponsors will require only positive associations with their brand. Deaf communities can be directly involved with plan and projects to improve relationships.

Services other agencies should provide well include counselling and mental health, residential care, captioning, equipment, training and employment. Close links with Deaf Aotearoa are needed in all these cases.

The use of existing systems and funding streams, including developing strategic alliances, and ways of making money commercially, are all needed to expand the scope and improve the quality of services.

Existing systems and funding that could enable better access at relatively little extra cost to Deaf Aotearoa include the Disability Allowance; Child Disability Allowance, Needs Assessment and Service Coordination (NASC), volunteers, peer support systems, Housing NZ and residential services for older and disabled people, engaging existing training and equipment providers.

Deaf Aotearoa should provide the following key core services:

► Expertise in working with Deaf people (NZSL training, Deaf Awareness, support, and advice to Government in providing access and information).

► Social support services, including intensive service coordination and peer support and community development.

► Communication support (interpreting, remote video interpreting, trilingual interpreters, deaf relay, note takers, oral interpreters, deafblind interpreters).

► A communication bridge between the hearing and Deaf worlds, including through media, research and persuasive policy advice to Government and close links to and networks with mainstream and other providers of Deaf services. Services need to consider Deaf from both a cultural and disability perspective.

Legislation and policy are supportive of Deaf people being able to access communications support but there are no other incentives to ensure government agencies provide this, and there is little legal support available to advocate access when it is not provided.

There is a growing trend for not-for-profits to develop into "social enterprises" or organisations that exist to meet social goals but also aim to make money and reinvest the surpluses into those social purposes. In this way organisations become more self-sustaining. There is evidence of a growing number of Deaf services internationally that are establishing business units to augment income.

Possible commercial ventures include:

► Interpreting

► NZSL training

► Deaf Awareness training

► Video production for cost-effective information transfer into Sign Language for government and commercial agencies

► Books and resources

► Targeted marketing for businesses.

This is a radical shift in strategy and organisational culture. It needs to be undertaken in a considered, planned and systematic manner. It will take time, focus and probably some errors on the way to establish profitable businesses that contribute to Deaf services.

Business experience will be needed at the board and senior management levels to develop a commercial approach combined with a culture of excellence and customer focus.

1 ▶ Recommendations

1 Call key interested parties (Government, Deaf sector, disability sector) together to develop a comprehensive approach to service change.

2 Consider the organisation's readiness and competitive advantages for commercial activity. Confirm key roles and strategic alliances among agencies.

3 Plan and cost the desired service.

4 Find additional financial resources through additional government grants, commercial activity and/or sponsorship. Expand use of existing funding and services to provide services to Deaf, and develop new areas of wealth generation. Develop one new area at a time to "learn as you go" and stay focused.

5 Make sure everybody is committed. Effective funding and service delivery depends on the whole system working together well. If a rise in service levels is to be achieved, the whole sector has to become involved and committed at the same time. Redevelop and confirm sector relationships with local Deaf communities, Māori, NZSL tutors, interpreters and families.

6 Broaden scope of work to include essential non-funded services: intensive service coordination, peer support and other volunteer programmes, NZSL training, support for Government changes, and legal support need to be provided. The effective use of volunteers and peer supports could be used in some personal support areas.

7 Increase the amount of service available in interpreting, training for hearing people (NZSL, Deaf Awareness), public communication and social support available through counselling, residential care and access to equipment.

8 Upgrade quality of services by committing to the principles of excellence and customer responsiveness at all levels of the service, including governance. A substantial leap in quality of services is required in a number of areas, including the welcoming and investigating of complaints in all services, as well as the development of clear performance measures.

9 Embed business experience in senior management and board levels so that a highly professional and customer-responsive service can be developed.

2 ► Project Objectives

Concern by the Deaf community has been expressed for many years that existing services do not support them enough to truly participate in their local communities.

Civic exclusion and disempowerment are still common experiences for many Deaf people and services from many agencies are often perceived as not being provided in a Deaf-friendly way.

Deaf Aotearoa has collected the thoughts of members of the existing Deaf community through regular community meetings over the years, so there is some information already available on the types of services needed and how they should be provided.

While Deaf Aotearoa believes it is clear as to what is needed, some independent analysis is required for the funder. The Ministry of Health agreed to fund some research that explores the development of a new service delivery model that best meets the needs of the Deaf community.

The Deaf community is commonly seen as one in which members identify as a social and cultural group. This project seeks further clarity since some people who are not active members of Deaf Clubs and groups nonetheless require services, e.g. children, people with cochlear implants, or people who have additional impairments over and above hearing loss.

This project aims to:

► Identify the range of members who belong to the Deaf community

► Describe existing services and methods of provision to the Deaf community as well as gaps in current services

► Describe essential services with levels of prioritisation

► Explore a range of service models for Deaf services internationally

► Explore a range of service models for disability services nationally

► Describe the most effective way to engage Deaf people in service delivery: the Deaf Way

► Provide recommendations on a preferred service model for future development of Deaf services

► Explore the implications of this model for Deaf Aotearoa and provide recommendations for the future development of the organisation.

3 ► Methodology

The first step was to establish an Advisory Group to advise on the scope and process of the research. This group recommended the project look at:

Deaf (or deaf) people and their families whose preference for communication is visual.

An extensive analysis of documents from meetings with Deaf communities was undertaken, including feedback from the Deaf community and other related Deaf Aotearoa documents. A comprehensive literature review identified core issues for Deaf people, as well as the key to effectively engaging Deaf people.

An analysis of a small cross-section of local disability providers allowed for some service comparison.

Literature on current approaches for not-for-profit services and other relevant issues was studied and taken into account. A recent environmental scan on government attitudes to disability service provision was also included in this review.

One hundred and fifty deaf people and their families participated in a series of focus groups and e-mail and phone conversations.

► Meetings with Deaf communities:

Hamilton (Māori)

Blenheim

Tauranga

Auckland ADS senior citizens

Spectrum Care (intellectual disability and autism)

Mt Tabor (disadvantaged Deaf)

Mental health clients

Mental health staff

Deaf Aotearoa staff

Deaf professionals – Auckland

Transition students at KDEC

Auckland parents of Deaf children with cochlear implants (two sessions)

South Auckland (Pacific) (two attempts)

► Electronic surveys were also sent to:

Hearing impaired (through Hearing Association, NZFDC and CCS Disability Action)

Wellington youth

CODAs

► Contacts were made with a number of services including CCS Disability Action, Laura Fergusson, Focus 2000 and two rest homes (that care for younger people with disabilities) but almost no people who are Deaf with physical impairments were found. One person was interviewed electronically.

► In addition, three sessions with Deaf Aotearoa staff and management and one with the Board were held to discuss early conclusions.

► The Communication Tips were sent to six mainstream agencies to ask their view of the information.

The information from the literature review and responses from review participants were so well aligned that key themes emerging from both sources are combined in this report. Common or key participant comments are italicised for easy reading.

While there seems to be some older people and younger deaf people who do not sign but still prefer to communicate visually through lip reading or gesture, the vast majority of people who identified as preferring to communicate visually are members of the Deaf community. This report has, as a result, focused on their needs but also makes some references where possible to the larger number of hearing-impaired people. Hearing-impaired people who have acquired significant hearing loss later in life share some service requirements with Deaf people but also have many differences. Where relevant and possible, these needs are noted.

This research does have limitations. While every effort was made to ensure a balance in participant selection across ethnicity, age, gender, communication mode and service need, some groups were disproportionately represented. A large group of older Deaf people were consulted but the numbers of hearing-impaired people who identified as visual communicators and deaf people with physical disabilities were very small in number. This research therefore does not claim statistical significance in its findings but instead draws on stated preferences and comments as qualitative indicators of need.

4 ▶ Visual Communicators in NZ: The Numbers

People with a hearing loss who rely primarily on visual rather than auditory input are less than 1% of the general population. (National Health Interview Survey, 1994 cited in Munro-Ludders et al 2004). Generally, these are people who become severely or profoundly deaf early in life. Children with an early and sustained profound or severe hearing loss are most likely to be lifelong users of Sign Language (Johnston 2006).

This aligns with Dugdale's (2000) and Johnston's (2006) conservative conclusion that there are around 400,000 potential members of the New Zealand Deaf community.

As a comparison, Statistics NZ in their 2006 snapshot of disability show that some 7,700 partially or completely deaf adults living in households use New Zealand Sign Language (NZSL) and/or Signed English, and 24,000 New Zealanders are able to use NZSL. Many of the deaf adults may not rely on NZSL primarily and so the Munro-Ludders, Dugdale and Johnston estimates of 4,000 are accepted in this report. Although the members of the deaf community share a common language and culture, their needs vary, depending on:

▶ age at onset of deafness

▶ degree of deafness experienced

▶ amount of parental support at time of diagnosis

▶ effectiveness of early intervention post diagnosis

▶ type of education received

▶ ethnic background

▶ their exposure, and degree of identification with, the Deaf community.

Lieu (2007) acknowledges the challenges that varying need presents to service providers intending to become culturally and linguistically competent practitioners.

This small group is also only a fraction of the over 200,000 people in New Zealand with a hearing impairment (Greville 2001, and Disability Survey 2001), who do not use a visual language and have acquired significant hearing losses later in life.

They still have much in common with Deaf people in terms of needing communication access in a variety of settings, share strong concerns about access to health services, and the need for note takers and lip readers.

However, these two groups have widely varying service requirements, with Deaf people commonly calling for alternative communication access and hearing-impaired people calling largely for augmented communication (Harris and Bamford 2001). Hearing amplification is wanted more than any other equipment, English is a well-developed language and higher education is considered the most important area for development by hearing-impaired people. These

groups do not share cultural, linguistic or political solidarity. Dugdale notes that Deaf and deaf people sometimes appear in conflict with very different world experiences, despite their common hearing loss.

The number of deaf or hearing-impaired people who do not use NZSL, and who are not comfortable in the Deaf or the hearing worlds, but are coming to Deaf Aotearoa for assistance from service coordinators, seems to be rising (according to staff). The numbers in the survey are small but there could be a substantial population whose social support and communication needs are not currently being met.

The number of Deaf people is now known to be gradually declining due to improved medical care, mainstreaming, rapidly increasing cochlear implants and genetic science. The signing Deaf community is also aging, and the size of the community is slowly shrinking at both older and younger ends. Nevertheless, it is clear that there will always be people who communicate visually and for whom Sign Language is their inevitable choice for interacting with the world. Demand for interpreters may fall but not for many more decades (Johnston 2006).

5 ▶ Local Disability Services

The Royal NZ Foundation of the Blind (RNZFB) is the sister organisation of Deaf Aotearoa in that it serves blind and vision impaired people, the other half of the sensory population. With nearly 12,000 members, it provides comprehensive services with only 26%[1] of costs covered by government service contracts:

▶ *Everyday life*, with daily living, counselling, social work, equipment, financial assistance, volunteer assistance.

▶ *Finding your way around*, with orientation and mobility and Guide Dogs.

▶ *Participating in the community* – employment assistance, peer support, recreation, volunteering.

▶ *Reading and writing in audio, braille and other formats* – library, Telephone Information Service, accessible formats, adaptive communications and technology.

▶ *Services for specific groups* including Māori, Pacific peoples, deafblind members, children and students.

RNZFB also provides financial assistance for specific aims to members through four key trusts. It develops major sponsorship arrangements and their fundraising ability is widely admired.

Ngāti Kāpo o Aotearoa is an organisation serving Māori blind people and provides Peer Support; Information and Advice; Advocacy and Policy advice; Training and Public awareness on behalf of its 500 members in five areas throughout New Zealand.

Vaka Tautua is a Pacific organisation that provides disability information, older people's information and day activities, mental health information and community support for its Auckland Pacific communities.

Connect Supporting Recovery is a small Auckland mental health provider that also provides information and advocacy on housing, community support for individuals to reach goals, family/whānau, residential, peer and employment support. It has one cultural specialist team for Asians.

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[1] RNZFB 2008/9 annual report

6 ▶ International Service Models

The following international models of Deaf Services were explored:

The Scottish Council on Deafness, Japanese Federation of the Deaf, the **Spanish National Confederation of Deaf People** and the American **National Association of the Deaf** are all national bodies with organisational and individual members. These umbrella organisations focus on advocating issues such as educating GPs on Deaf people's need for counselling, developing the interpreter systems, legal representation on cases taken for equal access or policy advice to organisations. They tend to focus on the needs of culturally Deaf people but link closely with other organisations for hearing-impaired and disabled people. The American National Association of the Deaf also advocates for hard-of-hearing people.

The Royal National Institute on Deafness (RNID) in the UK, **ASPA Services Ltd,** the **Service Foundation for the Deaf** in Sweden and **Deaf Services Queensland**, are service providers who serve Deaf, hearing-impaired and deafblind people as well as deaf people with disabilities.

The Finnish Association of the Deaf and the **Danish Deaf Association** tend to focus on the needs of Deaf people, including disabled Deaf people.

Most of these include advocacy or policy development as well, and all provide a range of services that include:

▶ Training in Sign Language and Deaf Awareness

▶ Communication support services – interpreters, lip speakers, note takers, speech to text reporters and deafblind interpreters.

▶ Several countries are in the process of developing video interpreting services, requiring an infrastructure of web cams and good broadband. Deaf relay interpreters are increasing in some areas but are still low in number

▶ Telephone relay

▶ Employment service, vocational habilitation and day activities

▶ Helpline for public information on Deafness or hearing loss

▶ Equipment service (or links to one)

▶ Information about community services and links to them

▶ Habilitation (sometimes also known as social work, community work, case management, intensive service coordination). Australia offers a walk-in service for "life's little problems", including reading letters or resolving disputes

▶ Counselling

▶ Peer support

▶ Training and courses or camps to targeted groups (e.g. youth, elderly, immigrants, leaders)

▶ Youth groups

▶ Care services for older people or people with additional needs or disabilities

▶ Supported housing (provision of staffed homes or support in the home with household tasks and personal help)

▶ Coordination of home help, transport and health appointments

▶ Individual support or learning programmes

▶ There is some community outreach for people in their own homes who need help with daily living skills, finding work, training, housing issues and social skills. Some services noted this was very difficult to provide for reasons of staff safety as well as the costs of travel and non attendance.

Close relationships with parent and hearing impaired services are seen as essential. All organisations cooperate with other disability organisations.

Most provide comprehensive services but examples of partnerships with mainstream agencies providing direct services (e.g. mental health, disability, employment) do exist.

Several services are increasingly running business ventures such as video production, marketing equipment to Deaf people, or selling books of basic signs to new parents. Major sponsorships are common. For example, IBM has worked with the Chinese Deaf Association to establish an online interpreting service in Taiwan, which also includes signed video clips on daily news, healthcare and legal services.

The Australian service in this review, for example, only gets 50% of its funds from Government and the rest has to be found from fundraising, sponsorship and commercial activity. Australia is also increasingly sharing some support services (e.g. IT, fundraising, finance and sometimes management) among state agencies.

Measuring performance against key indicators is an important means of accountability. Australia, for example, has developed client-focused key result areas (KRAs) and these are reported against regularly to the board and beyond. For example, KRAs for children, young people and adults are:

► experience increased self-esteem

► experience decreased isolation

► experience better educational outcomes

► have increased opportunities to participate in community life

► have knowledge and skills to achieve their own wellbeing

► have access to support services and learning opportunities.

7 ► Existing New Zealand Deaf Services

Deaf Aotearoa currently employs 12 Needs Assessors & Service Coordinators (NASC) and 13 Community Relations Officers to assess the needs of around 2,000 Deaf clients, and link them with existing services and communities. Two of these staff are qualified social workers and most NASC staff undertake some social work because of the volume of community need. Deaf Aotearoa also provides a small employment service for 200 clients a year with ten staff.

Some training for Deaf people is also provided as there are few other courses specifically designed for Deaf people. There are no formal peer support networks or programmes.

A small Deaf Awareness team of two staff operate out of Auckland and Wellington and current records in Auckland show 50 organisations using the training service in the last three years. Random calls to users of the service showed that people were favourably impressed with the information and presentation. Courses are generally between one and three days in duration.

Deaf Aotearoa does not employ FTE interpreters directly but offers a booking agency through its subsidiary iSign. There are around 70 qualified interpreters available but 50% of these are employed in academic situations (primary, secondary and tertiary). There is a strong sense of having an inadequate number of interpreters to meet need, although a recent interpreter review also concluded that many are in other part-time roles and could be better utilised. Most are self-employed, contracting directly with Deaf people or through Deaf Aotearoa and other smaller services: Advanced Interpreting Management Services (AIMS) and general interpreting services (Interpreting NZ and District Health Board interpreting services).

Funding levels and systems for interpreting are problematic. There is a small base fund for primarily health interpreting from the Ministry of Health. All interpreting undertaken on top of that has to be negotiated with each customer, which is resource intensive and therefore limiting access for many Deaf people.

There are no funded trilingual interpreters for Māori and Pacific other cultures, and no Deaf relay interpreters for people whose communication needs are especially complex.

No legal support is given to Deaf people denied access to any service, other than through the Human Rights and Health and Disability Commissions.

Deaf Aotearoa has close links with Deaf Youth Aotearoa providing camps, social contacts and learning opportunities for young Deaf people.

Deaf Aotearoa undertakes a public communication role about NZ Sign Language and the Deaf community. They maintain increasingly positive but not yet integrated linkages with the Deaf schools and NZ Federation of Parents of Deaf Children as well as growing relationships with a range of Government departments at national and local level.

In a piece of Wellington-based research (Dugdale, 2000), the most frequently used staff relating to the Deaf Association were interpreters (53%), service coordinators (24%), liaison officers, (16%), FYD training (13%), literacy training (8%), Māori group (6%) leadership training (4%).

A quarter thought Deaf Association services were very good, 55% thought they were variable and 20% didn't like the services. Participants expressed the greatest need for more interpreters. The biggest problems voiced about Deaf Association services were that staff did not do what was needed, and that language and cultural skills were lacking.

Staff commonly noted that they feel too stretched to provide a wide range of services, many of which are unfunded.

Conflict is common in the sector. Current major conflicts include a tense relationship between Deaf Aotearoa and interpreters, Māori Deaf and cochlear implant providers. Links with families could be much stronger at the point of diagnosis.

Mainstream Services

There are five Deaf mental health support workers currently employed by Richmond Fellowship in Auckland/ Northland, Hamilton and Wellington. The lack of specialist psychiatric professionals and support workers was frequently commented on by review participants.

There are also now three Deaf specialist Health and Disability Commission advocates.

There is little specialist residential care available with staff skilled in communicating visually, for older or physically and intellectually disabled Deaf. There is, however, a small but growing interest through Spectrum Care and another small residential service called Mt Tabor, which have employed and trained Deaf staff. No direct service or support is provided by Deaf Aotearoa, other than needs assessments on request, but guidance on service development would be very useful. There is some interaction with the Royal NZ Foundation of the Blind but Deaf Aotearoa does not specifically provide deafblind guides or communicators for deafblind people.

NZ Relay is providing telephone access and is currently trialling a video relay service.

A positive recent development has been the gathering of government agency heads to collectively look at the issues facing Deaf people.

One interview with a leading government agency suggested that links with Deaf Aotearoa should be stronger with more connection around issues such as launching the iSign service, and developing resources for agency staff. Patience and compromise is seen as needed in developing better services.

8 ▶ Key Themes from Literature Review and Consultations

The international and local literature review aligns well with participants' views. Many Deaf people perceive themselves as marginalised, discriminated against, and disadvantaged in the areas of health, education, employment and social opportunities as a result of communication barriers (Murray et al 2007, Dugdale 2000, Nealy 2007).

This section highlights the most important challenges as well as some solutions.

Much research acknowledges the need for increasing the number and skills of interpreters, promoting Deaf-centred training for employers, Government, service workers and other professionals, with a special emphasis on informing the hearing parents of deaf children (Murray et al 2007).

Participants in this research agreed with the original list of Deaf people's needs emerging from research, with some additions and clarifications. Most groups noted that all aspects of life need to be accessible, and it simply depends on your life stage and situation which ones are the most important to you at a particular time. Appendix 2 outlines further the responses from the various groups.

Challenges for the Deaf Community

Deaf people are born with the same range, level and potential of intellect as hearing people. There is ample evidence that Deaf children exposed to signed languages from birth acquire these languages at the same rate as hearing people acquire spoken languages. Internationally, Deaf people argue that visual language is easiest to learn, regardless of whether they learn to speak, lip-read or even hear at a later point (Krausneker 2008).

However, studies and review participants consistently reported low levels of signing to children by their families (Murray et al 2007). A recent UK study (Dye & Kyle, 2001) showed that only 16% of Deaf people were signed to as children. This has impact on the child's emotional wellbeing, socialisation, and intellectual growth.

There is ample evidence of the strong negative consequences if language acquisition is delayed. The need for bilingual language competency and functional literacy is essential for operating in the world, but there is low literacy among the Deaf. This is usually seen to be a result of not developing a strong first language early (Krausneker, Dugdale, Nealy). A 1984 New Zealand study showed that the mean reading age of 55 young adults who had been educated in both mainstream and deaf education was 9.8 years (Dugdale 2000).

"Literacy is too low for some – employment agreements can be just inaccessible for example." (CODA)

"I hate it when they write things down."

"Hearing people need to know that some Deaf can't read and write."

"Some hearing get really frustrated that you want things simplified. Some Deaf are embarrassed about their English. It's less negative to say Deaf English than low language."

Schlesinger (2000) resubmits a convincing developmental model that explains the depressed achievement of deaf people that includes:

► difficulty in communication with parents;

► mothers' prolonged grief at having a deaf child;

► resentment at having to conform to the hearing world;

► delays in developing autonomy with protective parents (resulting in hostility in the child and failure to see current behaviour in terms of longer-term effects rather than immediate external control);

► lack of positive reinforcement for identity; and

► subsequent delays in development of self-esteem.

Emotional well-being is affected. Deaf people who are only oral at home often have lower self-esteem due to feelings of isolation and exclusion. Deaf children of Deaf parents consistently demonstrate the strongest deaf identity and highest self esteem (Nealy 2007).

Delays in language development can also cause some cognitive delays which, if not remedied, can result in high needs for social supports.

"She (middle-aged woman) was the second child of seven. Her family did not sign and she was not allowed to sign at (Deaf) school. She married a hearing person with a mild intellectual disability who used to put her down all the time. She ended up with a major anger problem. She didn't have a lot of contact with Deaf people but her NZSL has improved dramatically since she has had Deaf support staff and interpreters. She does not have an intellectual disability. She has been accessing counselling and is no longer angry all the time. Her parents still don't understand her and don't treat her like a woman with her own opinion (now in residential care)."

Need for Positive Awareness

Deaf people often feel treated as if they are second-class citizens or even as if they have an intellectual disability. They see that hearing people are uncomfortable or at worst afraid in their contact with them.

"I'm not dumb!"

"IHC was written on his (hospital) file but he had just been drunk. He was furious."

The need to educate hearing people is prevalent throughout the literature. In one study (Murray et al 2007) participants noted:

"We really have a hard time educating the community. We are trying to tell them that we are really the same... I don't know who is responsible for that. Is the Deaf community responsible to educate the hearing?"

Better public awareness and acceptance is seen as key to supporting the use of interpreters and communicating directly. There was widespread agreement that NZSL and Deaf Awareness training are vital to enhancing awareness.

"Communication between hearing and Deaf can be supported by Deaf relay interpreting, NZSL classes and Deaf Awareness. People need to learn how to rephrase, change register – it's good for migrants as well as Deaf people."

Deaf Awareness customers phoned for comments on the training have given very positive feedback on the training, although there was some mention of the need for shorter courses as well as longer ones. Only fifty customers were identified in the Auckland area over the past three years.

Some comments were made about the lack of NZSL courses available.

"Sign Language courses are so patchy, they really only teach Level 1 and their teaching skills are not great."

"We need NZSL classes here – there are none (rural area)."

The sale of Sign Language courses to businesses and interested members of the public boomed in the wake of the ADA legislation in the US (Sheffield 1996). Sign language recognition is also expected to "secure the social and legal space for its users to stop the tiresome work of constant self-defence and start creative, self-defined processes and developments" (Krausneker 2008 p 8).

Clash of Disability and Cultural Models

Before elaborating on service needs, the issue of whether deafness is a disability or a culture must be addressed because it impacts so strongly on service delivery.

Deaf people locally and internationally see themselves primarily as a linguistic minority with no disability as long as linguistic access is provided. The medical model of viewing deafness as a deficit is seen as focused at eliminating unwanted "otherness". Stone and Adam (2009) subscribe to this along with many others and define "Deafhood" as a process where people do not feel constrained by society because they cannot hear – they feel liberated because it explains to themselves and others their own existence in the world.

The current "social model" disability theory can align with the cultural model. It sees Deaf people as having a hearing impairment that creates a communication need. Disability only occurs if the communication need is not met.

Similarly, the European Union in 1997 concluded that both linguistic and disability perspectives can coexist. While Deaf people perceive themselves as a linguistic minority, they encounter barriers to access from society that are not experienced by other cultural groups and are therefore disabled. This understanding is critical for policy-makers because disability frameworks often have no tool or expertise to deal with a linguistic minority. The Integration of People with Disabilities Division of the Council of Europe in 2008 argued that equal and effective integration can occur for Deaf people with the recognition of language needs and cultural viewpoints, provision of early language development, equal and accessible education and technology (Krausneker 2008).

Harris and Bamford note that Deaf service users are in the "linguistic minority construction of Deafness" while hard-of-hearing service users commonly fall in the "disability construction of deafness".

Hearing parents without knowledge of the cultural or linguistic components of the Deaf world almost always have a medically orientated view of hearing loss. Dr Patricia Lang, a NZ anthropologist and parent of a Deaf adult, argues that parents who see themselves as (accidental) migrants into another culture means that they can understand their experiences more fully and positively (Deaf View 2004).

Disability services often do not see Deaf as a cultural group who prefer to be together for communication and cultural comfort. Most disability and mental health theory and practice aim to integrate people into their own communities with natural supports. There is often a low appreciation of Deaf cultural and communication needs within that model.

"They don't see us like a Māori service." (service provider)

Both disability and cultural models are clearly needed by both Deaf people and their service providers.

Services and Resources Required

The following are in order of priority (highest first), according to research participants.

Communication access is needed in:

1. Government departments
   a. Health – hospitals, GPs and specialists
   b. Emergency Services
   c. Work and Income
   d. Police
   e. Education
   f. ACC
   g. Mental Health
   h. Inland Revenue
   i. Courts
   j. Housing NZ
   k. Child, Youth and Family
   l. Prison
   m. Legal Aid
   n. Immigration
   o. Workbridge
   p. Civil Defence
   q. Drugs and Alcohol
2. Public transport
3. The home
4. Work
5. Training courses
6. Social work
7. Counselling
8. Businesses, including banks, insurance, real estate
9. Residential care
10. Media, especially television
11. Social places
12. Home help
13. Church
14. Legal situations
15. Sports clubs
16. Political meetings
17. Childcare

Types of communication access needed:

1. NZSL interpreters – including by video
2. Deaf relay interpreters
3. Note takers
4. Trilingual interpreters
5. Oral interpreters
6. Deafblind guides

Equipment preferences:

1. Mobile phone
2. Captioned DVDs, TV
3. Flashing vibrating doorbell, clocks, phones, etc
4. Fax
5. Computer – e-mail, chat, relay
6. Video phone
7. Online signed information
8. Hearing aids
9. Real-time captioning – in future
10. Video conferencing
11. TTY (few use these now)
12. Phone amplifier
13. Hearing loop
14. Cochlear implants

Preferred **courses**:

1. Deaf Awareness
2. Life skills
3. Advocacy
4. Polytechnic or university
5. Literacy
6. Professional development
7. Getting a job
8. Leadership
9. Handling stress
10. Parenting
11. Hearing Awareness
12. Youth
13. Computer training (added)
14. Volunteering (added)

General Communication Access

Deaf people consistently state they have difficulty in communicating or getting information in most life areas, including making restaurant reservations, changing a doctor's appointment, ordering theatre tickets or arranging to pick up a car at a shop (Gvozdas, 2004).

Responses from hearing people and organisations are variable and usually (but not always) poor. The small size of the Deaf population may be a significant component of this. There is interest though from some individuals. For example, some businesses provide staff with signing skills or at least access to texting (De Leon 2007).

The highest-priority areas for communication are government departments (health, emergency services, and Work and Income were the most important of these), followed by public transport (including taxis), home, work, training, social work and counselling.

Generally, communication is wanted through people who learn Sign Language properly (not just a six-week course) or interpreters.

While most people wanted NZSL access, Deaf and hearing-impaired people used other methods:

"Lip-reading is very important to me too. Too many meetings have the speaker with their back to window which puts their face in shade and makes it much harder to lip-read."

Broader access to intercom interfaces (e.g. McDonald's after-hours entry, automated car parks) is wanted.

With low expectations, Deaf people do not often make a concerted effort for change, and yet many argue that what is good for them also often meets the needs of people who speak English as a second language and all hearing-impaired people.

Public Service Access

The literature advocates consistently for the need for the public sector to better familiarise itself with Sign Language and deaf cultural awareness (Krausneker 2008, Kyle et al 2005).

Key recommendations for improving the situation are:

► Teach Sign Language to as many people as possible, especially to public service agency staff as well as school children

► Expand interpreting services and ensure obligations and methods of booking and using interpreters are understood

► Provide information in Sign Language

► Use remote systems such as videophones, as appropriate

► Provide distance and online training packages and develop a public access charter that sets out good practice

► Ensure text messaging is an allowable means of contact (Kyle et al 2005)

Deaf people internationally and locally report frustration in contact with hearing services, which contribute to their feelings of marginalisation.

Variability in communication access is the key theme in public services in New Zealand. Work and Income for example have a clear national policy as well as dedicated staff to ensure that interpreters are available for Deaf people when needed, but local provision is still seen as patchy depending on the interest and awareness of local staff.

Health

There is a strong sense among the Deaf of having to justify the need for interpreters or other access in most situations.

"We are never asked if we want an interpreter in hospitals. I don't always know what he (son) says and we sometimes need an interpreter." (mother)

"Why should we have to fight every time to get an interpreter?"

"Police are not using interpreters all the time. One Deaf man was cuffed so he couldn't communicate at all."

"WINZ can use Mum a lot."

Some agencies were also mentioned in some areas as being very supportive and communicative, including Workbridge, Work and Income, Housing NZ, Courts and community mental health centres. An individual police officer who signs was mentioned admiringly. Many of the groups mentioned churches that provided signed access to services.

"He (deaf child) went to a (pre-school) centre where all the staff learned some signs."

Doctors are the most-often-seen professional by Deaf people (Dugdale 2000) and yet contacts with health services are consistently considered the most stressful. Fear, mistrust, frustration and feelings of powerlessness are common experiences of deaf health service users. Communication difficulties are very common, information is inaccessible and interpreters are rarely available. Deaf people felt they were expected to adapt by lip-reading, speaking or writing, while hearing people are not seen to change to meet their needs. They are frustrated by the idea that the interpreter is widely considered only for them rather than for both parties (Kyle et al 2005, Rogel 2008, Steinberg et al 2005, Parise 1999, Mallinson, 2004).

A UK survey showed that 42% of people who had visited hospitals in a non-emergency capacity said they found it difficult to communicate with health staff. A third were unsure of their correct medication dosage and 70% said accident and emergency services did not provide an interpreter, making a stressful situation even worse (Dye et al 2001).

On one hand people are afraid of the consequences of miscommunication about their heath condition. On the other hand they are afraid of telling their clinicians about inadequate communication because they are unsure of their rights.

Research showed that doctors reported greater communication difficulties in understanding and maintaining free-flowing conversations with deaf people (Ralston et al 1996) and that patients had greater difficulties in understanding them, trusted them less, asked them to repeat statements more often, and were less likely to understand the diagnosis and recommended treatments. The doctors also reported feeling less comfortable with deaf patients and that deaf patients asked fewer questions than other patients. Deaf patients were not aware of their obligations under the Americans with Disability Act to provide interpreters.

One US study recommended that doctors lobby to be reimbursed for interpreter expenses or getting interpreters to bill to a third party (Kyle et al 2005).

Positive experiences were found where there were skilled interpreters and health practitioners with signing skills. Trans-cultural approaches are advocated (Lieu et al 2007) as for other ethnic minorities with various communication mechanisms used (e.g. text messaging, relay interpreters).

Emergency Services

The theme of personal safety continued with the second-most-important public service mentioned by focus group participants: Emergency Services. Civil Defence was also frequently mentioned. Immediate access is called for:

"You can't wait to fax (Emergency Services) if there's a fire – you have to get out of the house."

One participant went to the trouble of sending information to the authors about a South African alert system to Police, Fire and Ambulance services integrated in alarms.

This theme is also common internationally. Examples of software which communicates national warnings to TTY users as well as voice users, and text messaging in emergencies are cited. A trial is now being held in New Zealand, run by the Police.

Education

The Deaf community is predominantly a face-to-face culture, and therefore Deaf education and learning often needs to occur differently than for hearing people. Knowledge is seen as a valuable commodity that should be shared. Garrett describes Deaf learning preferences as collective, purposeful, present and practical (Garrett 2008).

Deaf people strongly advocate early intervention in language acquisition and learning. The UK Government's guidance for professionals "Developing early intervention/support services for deaf children and their families" to help local authorities provide effective post-diagnosis support is only one example of this.

Deaf people want high-quality education as well as cultural contact and recognition. Many deaf people criticise the

mainstreaming practice of education because of the isolation from other deaf and because of poor access:

"Mainstream schools don't generally cater to signing Deaf children well."

The curriculum is not taught from a visual perspective.

And they also criticise the often poor education and expectations provided by Deaf schools (Krausneker 2008, Murray et al 2008).

"We didn't learn much."

Locally, the five key gaps in the education system identified in 2006 by Deaf Education Aotearoa New Zealand (DEANZ) were:

► Early Intervention Services to ensure early linguistic development.

► Personnel and training at all levels of compulsory schooling who are skilled in working with Deaf and deaf children.

► Consistent accessibility to resources nationally.

► Service to Māori and Pacific Island families.

► Standardised assessment and monitoring.

Employment

Nealy notes that deaf students were less prepared than their hearing peers for tertiary study. They lacked motivation, relied too much on support services and did not get all the information they needed because of insufficient numbers of interpreters or note takers, and poor English skills. Studies showed that hard-of-hearing students also felt misunderstood and discriminated against and concluded that both groups need a critical mass of peers with whom they can identify and explore social options (Nealy 2007).

Access to tertiary study is however improving. Nearly three quarters of the 18–29 year olds in the UK progress to tertiary education while only 2% of the 60–75 year olds did so. Nevertheless, only 5% of Deaf people have a tertiary qualification compared to hearing people (22%) (Dye & Kyle 2000).

The trend towards low skills in reading and mathematics and need for adapted communication has a powerful influence on employment. Employment rates are believed to be around 45% in New Zealand (Dugdale 2000) compared to 68% for the New Zealand hearing population. Underemployment is also believed to be common.

"He would have run that company if he was hearing."

Still, many Deaf struggle with employment. Nealy (2007) notes a US study showing that deaf and hard-of-hearing people found social functions, departmental meetings and training the most difficult aspects of employment. It also found that many in this group needed ongoing support to keep a job as they did not have an adequate understanding of the working world. Most also had difficulty with basic independent living skills including cooking, shopping, budgeting, transportation, punctuality and absenteeism. Over half of the clients in this study lacked social and/or emotional skills in areas of problem-solving and decision-making, stress and behaviour management, and self-esteem.

Key risk factors for poor employment histories included:

► Personal attributes (ethnicity, substance abuse and secondary disabilities)

► Social conditions (lack of family support, lack of appropriate role models, low socio-economic status, lack of participation in family and cultural traditions, discrimination)

► Service delivery (lack of interpreters, access to services, inadequate funding and inappropriate diagnosis).

(Re)habilitation services commonly involve:

► The provision of an assessment of skills

► Work adjustment and specific skill development such as development of résumés or interviewing

► Career fairs

► Work experience

► Online resources for employers

► Provision of equipment

► Peer support and mentoring opportunities (Sheffield 1996, Michael 1999).

Mental Health

Boutin and Wilson (2009) identified from a review of 21 Deaf vocational services that job placement, rehabilitation technology and job search assistance, in addition to tertiary training, were key factors in the successful employment of service users with hearing impairments.

One study of Deaf entrepreneurs (Pressman 1999) showed that most needed help with marketing, advertising, writing business plans and identifying funding sources.

Deaf people have nevertheless an increasing variety of professions. One UK study (Dye & Kyle 2000) showed that those aged under 45 were more likely to be in non-manual professions now (50%) than in the 1970s (18%). One vocational rehabilitation service (Sheffield 1996) reports several engineers, people with masters degrees and others in medical professions on their books.

Dugdale's study in Wellington (2000) provides useful insights into local practice. People preferred to use family, NZ Employment Service, Workbridge, newspapers, and Deaf Association, in that order, to find work. Difficulties in understanding staff were the biggest barriers to using services. One Workbridge officer noted that an assessment for work often takes two to three times longer for a Deaf person to ensure that all concepts and work details were understood.

Signing Deaf people are commonly seen as exhibiting "bizarre behaviours", "physical agitation" and "violent gestures", and as a result are often misdiagnosed, not communicated with, not given informed care, have unnecessary admissions and unnecessarily long hospital stays. Common misdiagnoses include psychosis, hyperactivity, ADHD and mental deficiency (Swanson 2007).

Bridgman's research on Deaf mental health needs in 2000 still provides the most recent overview of mental health in New Zealand. It notes that the Deaf community has a high risk of mental illness, a high need for mental health services and a perception of current mental health services, including substance abuse services, as being inaccessible. Barriers to mental health access and receiving appropriate treatment are supported consistently by many researchers (Thomas et al 2006, Munro-Ludders et al 2004, Tuohy 2007, Alvarez et al 2006).

A random selection of Deaf Aotearoa clients were interviewed by Deaf people using a standardised mental health assessment. Bridgman found in New Zealand that:

► Nearly 10% of the Deaf population were positioned at the chronic and severe end of the mental illness spectrum (as

compared to 3% in the mainstream population).

► 20% were using a mental health service or professional. This was half of those who stated that they wanted some form of counselling and/or medication (44%) and also half the proportion using mental health professionals in the Netherlands where there are comprehensive mental health services.

► The prevalence of mental distress for Deaf children is believed to be 1.5 times higher than for hearing children. Tuohy also notes that rates of Deaf requiring mental health services are nearly double that of the hearing population.

► Social support, counselling and employment services are needed by around 40% of the population. Thirty social workers, 26 community mental health workers, 15 intensive mental health staff for residential support, four inpatient beds and 15 community residential beds were thought to be needed. Funding was recommended to be withdrawn from existing mental health services. Social work provision was recommended to be provided centrally by a specialist Deaf service.

► Mental health, employment, accommodation and Deaf community services were not seen

as effective, and psychiatrists and hospital/residential mental health services actually made things worse.

► Alternative health, Māori health, social workers and interpreters were considered most helpful by their clients.

► National coordination of Deaf mental health services were called for to ensure a broad range of mental health supports were made available.

Thomas et al (2006) note that while there are similarities between Deaf and other linguistic minority groups, deafness itself also makes an impact on mental health. Issues relating to attachment (90% are born to hearing parents), education and opportunities for employment all impact Deaf people's mental health.

Tuohy (2007) also notes the correlation between positive Deaf identity and positive mental health. Where there is impoverished communication, isolation, negative attitudes and medicalisation of deafness, Deaf people struggle to achieve a positive identity.

Because clinicians do not receive training in working with Deaf people, many are unaware of it or why their services are inaccessible (Swanson 2007). Key themes from Thomas's UK study (2006)

of service providers, however, show that community mental health team staff felt they had inadequate knowledge, skills and resources to provide care for Deaf people with severe mental illness. Generic services need at least basic training in Deaf awareness and Sign Language as a minimum requirement (although such minimal skill level is inadequate to deliver services effectively).

Deaf people tend to prefer specialist services for cultural and linguistic access (Funk 1997), but serving a minority population over a large geographical area is very challenging.

Thomas concludes that specialist and local services are both necessary and that "something between them is needed to ensure effective continuity of care" (p 309). Local services need to develop their knowledge of Deaf language and culture and provide easy access (e.g. text). Specialist services need to provide value-enhancing services such as telemedicine, although careful training of staff is needed to work this way (Austen & McGrath, 2006). Improved information-sharing and awareness of specialist services are needed. Specialist training is certainly needed for interpreters.

Burling notes the development of a regional mental health centre for deaf people in Washington, which

hires specialist staff and provides residential and day programmes, intensive case management and outpatient therapy. Another multi-agency approach in Leeds in the UK (Tuohy 2007) shows agencies from very different perspectives (medical and social models) committed to a partnership to improve services to deaf people.

An American standard for providing mental health, which established service accessibility standards (technical support, staff training, information availability, interpreter policies, monitoring system and a developing tele-psychiatry service) was found to increase the number of deaf and hearing-impaired users by 60% (Munro-Ludders et al 2004).

Justice

The high numbers of deaf and hard of hearing face huge challenges in the criminal justice system (Twersky Glasner 2003) when it comes to communication access. While required to provide interpreting and other communication accommodations (e.g. flashing lights, alarms), these are often not provided. The attitudes and awareness levels of employees in the justice system are considered significant barriers to, for example, ensuring grouping offenders with like needs, providing telephone access, ensuring handcuffing procedures are appropriate, and providing relevant equipment.

The availability and usefulness of mental health services and the effect of incarceration on deaf people's mental health are the two biggest challenges for the justice system.

Transport

Public transport was frequently commented on as needing improvement in access.

"You need to be able to text for a taxi."

"I use my (mobile) phone to tell the driver what I want – but some don't take the time."

Tong (2006) writes about the US lawsuit against an airport that did not provide teletype phones and enough visual information to allow equal access for the deaf. They subsequently agreed to provide two extra monitors to display messages and pages broadcast over the public address system, a video information kiosk, use of interpreters on request, and to increase the number of teletype pay phones.

Technology

Research (Power et al, 2006) and participants in this review acknowledged the enormous value provided by technology to help with communication, and Deaf participants seemed eager to embrace new technologies as they emerge (Keating & Mirus 2003).

The mobile phone with text capacity is now considered the most important communication tool. People who had difficulty with written English also used text to a great extent (Pilling & Barrett, 2008).

"Mobile phones have revolutionised Deaf."

There is often a distinction between those literate deaf people and those who do not like communicating in written form. For example, many people found the written text in the relay service difficult. More literate people tended to use e-mails and online chat to communicate with hearing people. Many participants did not use or even know about the NZ relay service.

Older people who became deaf later in life are less likely to use SMS or e-mail, so better ways of providing communication to this group are needed (Power et al 2006).

Captioning on television is widely available in the US (100%), Canada (90%), UK (80%) and Australia (65%), while New Zealand provides under 20% (Deaf View 2004). It is not surprising then, that increasing the level of captioning on TV and movies was also mentioned as both highly important and currently inadequate by most participants (particularly literate Deaf). More signing on news or podcasts is also wanted.

"Hardly attend movies as only one theatre in Ak shows captioned ones – prefer to get DVD and watch at home, unless it's a foreign film and has subtitles."

Video phones and video relay are also revolutionary and are thought to be particularly useful for communicating over time and space in sign, and the expansion of this technology is eagerly awaited. Research shows that it can be an effective way to communicate, but it is still an emerging form. Video relay pilots were closed last year in the UK but online interpreters are being trialled in a variety of countries and situations. One US PhD thesis (Brunson 2008) describes how access is created through work schedules and work stations and the professional work of interpreters can be organised in the call centre setting.

Videoconferencing technology has the potential to link the rural and urban areas in tele-interpreting, tele-vocational rehabilitation, tele-mentoring for interpreters, tele-counselling, tele-case management (Medical Devices 2005).

Video remote interpreting (VRI) or relay (VRS) will certainly be useful to many and reduce travel time and therefore costs, as shown by the high level of support for the current VRS trial by NZ Relay.

The limitations for video interpreting include challenges in matching client communication style and situation with a specific interpreter, and the need to have specialist knowledge in some areas (e.g. mental health, minimal language, education areas). Broadband capacity also needs to improve in NZ before this is widely used.

Nevertheless new web-based software such as Skype and Oovoo will enable many Deaf and hearing people to communicate through ordinary computers and webcams.

Computer-aided real-time translation (CART) technology, which provides instant translation of spoken words into text, has been particularly helpful in education, employment and training (Salvatore & Stanton

2007). For example the Canadian cities of Edmonton and Ottawa now offer this service automatically at all civic events within City Hall (Canada Newswire 2005), as a result of the rising number of older people with hearing loss. Few participants mentioned this but when raised as a possibility, many thought that real-time captioning would be useful.

Other innovative technologies are developing including sign-recognition software for small vocabularies (Von Agris et al 2008) and the provision of key signs for target audiences.

"GPs have SignTranslate (website and FAQs in Sign Language with online interpreter) in the UK."

Older technology such as doorbells, phone and faxes that alert Deaf people by pager are still seen as useful, although TTYs are rarely used now in New Zealand. New Zealand is exploring a simple list of words with GPs.

Equipment

A New Zealand Ministry of Health review conducted in 2005 (Scanlen) that is still relevant, showed that consumers, assessors and providers agreed that:

► Hearing loss was not seen as a significant disability

► Equipment funding for deaf people was inadequate, fragmented, complex and requires improvement

► Eligibility was not equitable with other disability groups and should extend past safety, work and education requirements

► Many people who were not funded for hearing aids could not fund themselves

► There is a need for a holistic and coordinated service.

There was strong agreement among focus group participants on all these points, and the group added that equipment can reduce isolation.

"Hearing aids not fully subsidised if over 65. $500 per aid but powerful ones (cost) $4000."

"Need to be in accident to get ACC!"

Hearing loops are important for those that use them.

"Note on loop systems – they are really good – when working! I have one at home to hear TV in kitchen. Ones in public buildings are very unreliable."

Cochlear Implants

Families' first preference for cochlear implants and improved hearing is usual and for most hearing people, understandable. In some parts of the world, cochlear implants are the "expected intervention" for profound deafness.

While cochlear implants are an effective tool, they cannot be viewed as a "cure" for deafness. Extensive clinical research indicates that, although most users find them useful, cochlear implants do not change deaf people into hearing people (Spencer and Marschark 2003). Some children do very well with their cochlear implants and other children do poorly (Pisoni et al 2000). Certainly, it is widely acknowledged that many implanted children still

need support from specialist deaf education and the cochlear team (Council of Europe 2008)

Teaching technologies are important to note because there is vigorous debate over the best way to introduce spoken language to children after an implant.

Advocates of auditory verbal therapy often argue that the environment should offer only intensive training in spoken language to acquire hearing and speech strategies. Visual stimuli is seen to interfere with learning audition and therefore should be kept to an absolute minimum. There is a belief that children will more naturally focus on Sign Language or visual cues if they are

available because they are more easily perceived, at the expense of developing hearing, which requires an undistracted environment.

Deaf people advocate that natural use of visual language is good because language acquisition is a crucial goal in its own right. Archbold & O'Donoghue (2008) further argue that the outcomes in speech perception three years after implantation were similar between children who had started communicating with signed input and those who had used oral communication throughout. Generally the trend is undeniably to support the use of spoken language, but there is increasing use of visual communication to attain this (Archbold, Yoshinaga).

Types of Support Required

The expressed need for interpreters was highest, and there is some excitement at the idea of having access to interpreters by video directly or through relay. This is at least partly due to the fact that interpreters and funding can be so hard to access.

"Sometimes it's really important to have interpreters at family meetings. But you are seriously questioned if you ask for one."

Some tension was noted between Deaf people and interpreters, particularly by Deaf professionals, as roles and responsibilities and the power of professional/client relationships advance and develop:

"We need to have a range of interpreters and we can ask them to be changed."

"They need to have less power." (Deaf staff)

"Interpreters have a code of ethics and the information doesn't go anywhere." (interpreter)

Deaf relay interpreters are also advocated regularly especially by CODAs and particularly for people who preferred Deaf English.

"There is a real need for Deaf Relay Interpreters on a daily basis used for where a Deaf person is now or never will comprehend fully just an interpreted/translated message." (CODA)

Literate young and professional Deaf particularly called for more note takers, while Māori and Pacific called for more trilingual interpreters.

The demand for oral interpreters came from older Deaf and a small number of hearing impaired (primarily those who do not sign but still need to communicate visually).

Deafblind people have confirmed their need for communication support through communicator guides.

Interpreting Booking

There is still confusion over who is responsible for paying the interpreter.

"Who's supposed to book the interpreter? I went to WINZ four times without an interpreter – there was confusion about who was supposed to book or pay."

There is also frustration at the responsiveness of the service.

"Why do you have to book 2 weeks or more ahead?"

Social Work

The need for social workers was frequently mentioned by participants and in the literature, especially to help with problems, written communication and navigating complex systems, such as Courts or Child, Youth and Family services.

People who needed these services generally did not attend the focus groups and others spoke for them.

"I go to (several) mental health assessments but none of those people are here tonight (or are on Deaf Aotearoa client lists)." (communicator)

Social work was traditionally provided under a missionary framework because services were traditionally provided by churches (Harris and Bamford, 2001). Recent developments have tried to move away from any paternalistic and dependency-creating service models. Social workers may now be called intensive service coordinators or community workers, but they are usually qualified people who help people make decisions about their personal problems, link people with community resources such as benefits and accommodation and support people in crisis situations[2]:

Deaf Aotearoa moved away from calling their often unqualified staff "social workers" to "service coordinators" in the 1990s, but staff have still been filling these roles because the need for this service is so evident. There are now some qualified social workers on staff.

Qualified specialist social workers are employed in the UK to focus primarily on Deaf people with severe mental illness, Deafblind people and Deaf adults with children of concern, as well as others with intensive needs. Services include assessment, service coordination, case management, residential placements, equipment, transport, vocational and day services, interpreter services, benefit advocacy, home help, respite, holiday care, budgeting and so on (Deaf View 2004).

Counsellors

Access to counselling is seen as critical for many, but the lack of payment sources make this very difficult.

"We can't afford counselling – I have problems but can't pay for counselling."

"People often don't find out (they need a counsellor) until they are in a crisis."

"The school social worker brought someone from Auckland to try and help me and my daughter but she wouldn't use an interpreter. It didn't work."

"It's too late now – my kids have grown up (in tears)."

Some people have already accessed the Disability Allowance for this purpose.

[2] From the Association of Social Workers website

Training

The number of people identifying desired training courses is lower than the demand expressed in all other areas of need. Perhaps many people have learned to cope but are not confident around learning following their earlier education experiences.

The most popular courses cited by Deaf people are for Deaf Awareness, Life Skills and Advocacy. Hearing people (family members or professionals) are more likely to state the need for literacy than Deaf people.

Deaf people who are most skilled (professionals) are more likely to want training and see the need for training for others. Training is considered a way to improve and empower yourself. Māori Deaf also expressed a strong need for training.

Some problems with communicating in mainstream courses are expressed.

"Training Incentive Allowance should also pay for interpreters but sometimes it's a game between Workbridge and WINZ."

Other courses mentioned included computer use and volunteering, especially by older people.

"These courses should be available to deaf parents so they can help their deaf or hearing children with homework and understand their responsibilities as parents and caregivers."

Frequent mention of the preference to train with other Deaf was made.

"NZSL classes that are age specific and level of English. Need day classes." (Deaf staff)

Specific Groups

Family

There is wide agreement among Deaf people that if families sign at home, early language development and family communication become possible for Deaf children. Lack of communication at home can have huge impact on family relationships and other areas of life.

"My father was far more connected with the Deaf community than his own family." (CODA)

The importance of communication within the family was understood by most families participating in this review. Some noted they had been unclear about what supports might be needed.

"We need more frequent, local and better NZSL classes. It should be free for parents."

"My child was implanted at 3 (there were delays in getting one) and he started to access NZSL at 5. (The provider) then stopped their habilitation programme."

Family participants with visually communicating children are most concerned about understanding Deaf culture, parenting well, and providing life and language skills to their child, including literacy and adult education.

Youth

The need for young deaf people to meet, socialise and gain an understanding of being Deaf is widely considered by the literature and review participants crucial in their development of positive self-esteem as well as language.

Key Themes from Literature Review and Consultations

Māori

When adjustments are made for the reduced life expectancy of Māori, the rate of hearing loss for Māori is 12.1%, compared with 9.6% for non-Māori (Scanlen 2005). All Māori in the Wellington research attended Deaf schools and had higher unemployment than Pakeha (Dugdale 2001).

Māori Deaf want similar things to Pakeha Deaf (communication, awareness and supports) but also want better access to their own culture and have Māori culture recognised and respected. Deaf culture needs to recognise these additional cultures. The call to respectfully challenge Māori culture was also made.

What Deaf are looking for from hearing is exactly the same as Māori are looking for from Pakeha: Awareness.

"Māori also need to be challenged – I was refused at a te reo course because I couldn't speak Māori. I was refused a tattoo because I didn't reply, even though I know my whakapapa."

"Interpreters on marae are waking up the Māori community."

"(Māori) family members need to understand Deaf potential – they used to learn this at KDEC."

"We need to be working with Māori on their terms and in their ways. You can't go to a kapa haka and not leave a koha or dress appropriately. Relationships with local iwi are vital. We have to all work together."

"Courses are better by Māori for Māori."

Māori participants in the 2001 Dugdale research similarly made it clear that they want:

► Māori staff, especially Māori interpreters who are competent in Māori, English and NZSL (Dugdale 2001)

► Services that are culturally comfortable

► Access to marae and marae-based courses

► Accessible training in health and education

► Awareness programmes for hearing Māori

► Leadership training

Trilingual interpreters familiar with Māori as well as Deaf culture and language are also being called for.

Some Māori Deaf have a tense relationship with Deaf Aotearoa and a separate service organisation Manaturi has been established to meet the needs of Māori Deaf. It has a close relationship with Te Puni Kokiri and actively supports a "by Māori for Māori" policy.

Pacific

Discussions with Pacific Deaf revealed desires similar to Māori (to be part of their families and communities and also have access to communication). Most Pacific participants said their families did not sign at all or only a little. A brother or sister would often sign, but family communication would often be limited.

"I really wish Mum could sign."

"I don't understand what he says half the time." (mother)

Access to family and community meetings or knowledge is also very important, so trilingual interpreters would facilitate this. Many families speak the home language and this is very difficult for Deaf people to learn as well as English.

There is general agreement among participants that Pacific people did not see Deaf as a separate cultural group and often treated them like they are not intelligent, or showed no real interest in them.

"They don't want to know what he wants or how he communicates, he's just Deaf."

Families are seen to be loving, if protective.

"I told him that he will stay with me until I die and then his sister will look after him." (mother)

"I didn't learn NZSL until I came to NZ when I was 5 – it was a very hard struggle (learning a language and communicating with family)."

Churches and Pacific festivals are thought to be good ways to show-case interpreting and Deaf people.

"He goes to another Church because there's an interpreter there. It's frustrating for me." (mother)

The Deaf Club is seen to be a long way away from South Auckland and visited only for major events. It was seen as a place for older people. Pacific Deaf people found each other and socialised together at homes or on outings, like beaches, malls or parties, and often had little to do with the palagi Deaf community.

Immigrants

With the rise in immigration to New Zealand also comes a rise in the number of Deaf people with no English or NZ Sign Language. The opportunity to learn both is needed as well as the ability to use spoken language interpreters.

Older Deaf

The biggest issue for this group (according to Murray et al 2007) and according to participants, is the marked lack of residential support services with staff who can sign, and the continued need for social contact.

"The rest home was full of hearing people who complained about the subtitles. They moved her to her own room with a TV but that did nothing for her isolation."

"I have someone come into my home to help but I can't communicate with her."

"The family like them close (to them) but they need to be close to their Deaf friends – they get so lonely."

Deaf in Smaller Towns

Many people in the smaller towns and areas felt comfortable using family as interpreters if it saved time and is not unduly complicated or private. They talked of adapting without good services but called for access to Sign Language classes so that local people could learn to communicate with them.

Deaf Plus

Deaf Plus is the term often used locally for people who are "deaf with disabilities". Examples might include deaf people with an intellectual, visual, emotional or physical impairment. Estimates are that around 35% of all deaf and hard-of-hearing children have accompanying disabilities (Laurent Clerc 2009, Hoad 2002).

Their need for additional care is well documented and met in many countries. Many commented on the lack of support available in New Zealand.

Deaf people with a disability also need to communicate, and they and their advocates strongly supported having Deaf or signing staff.

"I live with hearing people but would rather live with Deaf."

"We need more Deaf home helpers and a community care house."

"The social worker in hospital didn't understand my needs. Counsellors, psychiatrists, doctors, other staff like my WINZ case manager, they don't understand."

"(I need) Communication, which then ensures access for me to information and rehabilitation access e.g. O&M, ADL, Guide Dogs, Technology, also socialisation support, all being equally vital for independence without isolation." (deafblind)

It is estimated that there are about 250 deafblind people in New Zealand who use or would use Sign Language. Like other disabled Deaf, their inclusion within the Deaf community is not straightforward.

They need to be out and involved in the community, but ADS gave a very negative response. Some Deaf people are just not interested – it just depends who's there.

One UK report noted that Deaf people reacted to deafblind people, much as hearing people react to Deaf, feeling uncomfortable and unsure of how to communicate. This was seen as something of a double standard, as they thought that society was responsible for ensuring communication with them but that it was the responsibility of others to ensure deafblind communication was provided (Fitzgerald 2008).

Integration of Deaf people with disabilities into the Deaf community clearly needs to be sensitively undertaken. Many Deaf people have rejected the disability label but are not confident to welcome those who are differently labelled.

Communication Tips

There is overwhelming support for the communication tips, although many did not actually mark their surveys to this effect. The low number of objections to the tips in the survey reflects the supportive discussions within the groups.

Service Providers

When asked whether it mattered who provided the services as long as they knew how to work with deaf people and could communicate effectively, focus group participants consistently answered it did not matter as long as the service is well known and accessible for Deaf, and they are effective.

"Trust is important between Deaf person and the social worker or counsellor. If other organisations provide services, trust has to be built."

9 ► Recommended Service Model

Service Model Objectives

It is clear that Deaf people want to live in their own New Zealand communities as equal peers, able to communicate as freely as possible. This means that communication support is needed or hearing people will need to learn to communicate visually.

To achieve this, three things are needed:

a. Positive public awareness

The public will ideally view visually communicating deaf people positively as a cultural group. This is a huge task for a very small population, although NZSL Week has already been a great start. It will require intensive and valued training and public communications around NZSL and Deaf Awareness in particular. Relationships with mainstream providers as well as within the Deaf sector need to be essentially positive.

b. Communication support and access

Interpreting needs to be much more widely available, particularly for key communications such as IRD, Work and Income, the bank, or even within the family. Communication equipment and captioning are also critical as is support for agencies to effectively work with Deaf people.

c. Social services

This report suggests that the high need for social supports required by Deaf people (social work, counselling, needs assessment and service coordination, employment, training, residential care and social opportunities) would be significantly reduced if communication is enabled at a very young age within families and at school.

The model of service recommended for Deaf Aotearoa must match the complexity and breadth of its clients' needs, as well as its current stage of development. It needs to focus on improving the core services that no other organisation can easily provide, as well as enabling other services to provide directly. **Core services include:**

1. Expertise in working with Deaf people for hearing people (NZSL training, Deaf Awareness, support and advice to Government in providing access and information).

2. Social support services, including intensive service coordination, key Deaf training (e.g. literacy, deafhood), peer support, legal support, and advice and community development.

3. Communication support (interpreting, remote video interpreting, trilingual interpreters, deaf relay, note takers, oral interpreters, deafblind interpreters).

4. A communication bridge between the hearing and Deaf worlds (especially media, information, and research) along with persuasive policy advice to Government, and close links to mainstream and other providers of Deaf services.

While some feel that Deaf Aotearoa should be a one-stop-shop to make it easy for Deaf access, this report argues that mainstream services need to embrace the challenge of serving this community well. No one service provider can meet all needs.

Other agencies should provide Deaf relay, counselling and mental health services, residential care, captioning, training and employment, and social opportunities. Close links with Deaf Aotearoa are still needed to ensure Deaf cultural and communication comfort.

A social enterprise model is recommended, developing some commercial areas, increasing efficiency and demonstrating accountability and transparency. This will take a significant amount of time and resource but is expected to provide new income streams.

10 ▶ Possible Funding Sources

Existing and Potential Funding Systems

To provide the required additional services, Deaf Aotearoa must cost the desired service and expand its amounts and sources of funding. There is little extra capacity within the organisation to provide additional service.

The Disability Allowance is available to meet the costs of disability and is available to people on low incomes. At $56 a week, it could possibly pay for counselling, interpreting or access to essential communication equipment as long as a doctor says that the disability is due to hearing loss. There are challenges, however, in applying for the Disability Allowance. It is usually paid to the person, rather than an organisation, so a specific agreement would need to be negotiated.

The Local Area Coordination model used in Western Australia may become a part of the New Zealand disability sector soon. It involves allocating funding on an "individual need" basis.

Interpreting may also possibly be funded by collective government grants, along with some self-funding.

The Child Disability Allowance could possibly be used to pay for NZSL classes for parents.

Existing Ministry of Health and District Health Board services are supposed to undertake needs assessment and service coordination (NASC) for all disabled people, including Deaf. They can also sometimes allocate resources for people with high and complex needs. Perhaps they can be better used to undertake or fund NASC for Deaf, leaving current Deaf Aotearoa staff to focus on intensive service coordination or social work.

Major business sponsors may be able to be attracted to an organisation committed to developing a sustainable business model that increases the self-sufficiency of an entire population.

Increased fundraising may be possible with a higher profile and positive direction.

Bank loans are another option.

Volunteers with at least basic Sign Language skill could be used in basic social support such as letter reading or writing, transport or organising appointments.

The Deaf community could be better supporting each other. Peer support is increasingly common in other countries and a formally trained peer support workforce could increase self-sufficiency within the community. Such initiatives within the Deaf community could be part of its own community development and empowerment.

Housing NZ and residential services for older and disabled people could be providing more accessible housing support options for people who need them.

Existing training providers (at least at the region level) could develop some speciality in providing training for Deaf in a number of key areas.

Equipment providers could possibly cooperate to ensure availability of the latest and most-effective technology.

Further discussion is needed on whether comprehensive employment and equipment services are able to be included in Deaf Aotearoa's stable of services. Both need Deaf specialist knowledge but this may be able to be delegated to other services, even in the meantime while other services are being improved or established.

Commercial Opportunities

Possible commercial (for money) services could include any of the following. A process is needed to select the easiest areas to develop first.

► Interpreting

► NZSL training

► Deaf Awareness training

► Video production for cost-effective information transfer into Sign Language for government and commercial agencies

► Books and resources

► Targeted marketing for businesses.

11 ▶ Options Analysis
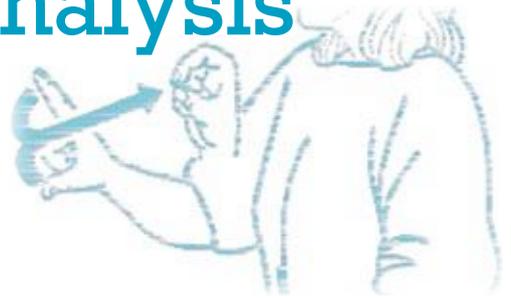
Deaf Aotearoa has a number of options:

Status quo

Provide no new services or links to services which would leave services at a similar level. This will not meet Deaf service requirements.

Steady improvement

Deaf Aotearoa could steadily improve services, as has been done over recent years. This is likely to take another 10–20 years to reach acceptable service levels.

The big leap forward

Deaf Aotearoa could look at making a massive change in services through additional service provision by itself and other agencies. This report advocates exploring the possibility of making radical change to upgrade services over a five-year period.

12 ▶ Critical Success Factors and Risks

Critical Success Factors:

▶ Deaf community support.

▶ Interest of the public.

▶ Interest of government departments, funders and providers.

▶ Constructive, respectful relationships between all parts of the sector.

▶ A commitment to excellence and the ability to provide business-like customer-focused services.

▶ Easily accessible information on services and issues, and responsive professional services.

Risk Analysis and Management

Risk	Hazard Level	Mitigation Strategy
Lack of support from a significant part of the community or sector	High	Commitment to conflict discussion until resolution
Public programmes are not high enough quality	High	'Train the trainer' programmes for hearing education – use Deaf skills in theatre Quality control with clear performance indicators Focused and responsive board
Investment funds not able to be found	High	Target known business contacts Explore all available funding streams
Funders/providers block inclusion of Deaf in existing programmes	High	Personal approaches to discuss need Legal challenges to the provision of communication access as necessary
Failure to manage Deaf or hearing expectations	High	Constant communication about developments within Deaf community and community discussions to move towards non-blaming approaches Skilled use of volunteers and peers to support Deaf
Failure to get consistency and equity in service delivery	High	Attention to sub-groups within the Deaf are needed: Māori and Pacific Deaf people want access to their own cultural environments and this requires interpreters who are culturally comfortable in those settings. There is no reason to suspect that other ethnic groups will not feel similarly Urban and rural service provision needs to be equalised further The most vulnerable Deaf people (deafblind, Deaf Plus, older people) have very few services to access for support

Objectives, Deaf Services Needed, Possible Providers and Funders

KEY

- Core purpose
- Core objectives
- Services
- Providers
- Funders

Core purpose: Living in NZ communities with communication support and access

Core objectives: Positive Public Awareness · Communication · Social Support

Communication

Interpreting (note-taking, Deaf relay)
- Providers: iSign, Other providers, NZ Relay
- Funders: MOH, MSD, Disability Allowance, Bulk govt funding MED

Equipment
- Providers: EnableNZ, AccessAble, Workbridge, MOE, ACC, Work & Income, Deaf Aotearoa or new agency
- Funders: MSD, MOH, ACC, MOE

Legal Support
- Providers: Deaf Aotearoa
- Funders: Human Rights Commission, Law firm?, Health & Disability Commission

Captioned & signed TV, movies
- Providers: TVNZ etc, Hoyts etc
- Funders: TVNZ etc, Hoyts etc

Social Opportunities Peer Support
- Providers: Deaf Clubs, Sports Groups, Deaf Aotearoa (CRO), Hearing Association, Schools
- Funders: ?

Positive Public Awareness

Communications – public – Deaf
- Providers: Deaf Aotearoa
- Funders: MOH sponsors

Building relationships
- Providers: Deaf Aotearoa
- Funders: MOH ODI

**Training hearing
- NZSL
- Deaf Awareness
- Agency staff
- Oral**
- Providers: Deaf Aotearoa
- Funders: Startup MOH → self-funded MOE

Social Support

Needs Assessment & Service Coordination
- Providers: NASCs
- Funders: MOH

Residential care – aged – Deaf Plus
- Providers: Deaf Aotearoa?, NGOs
- Funders: Housing NZ, MOH/DHBs

Counselling
- Providers: NGO and private Deaf & hearing counsellors, PHOs
- Funders: Disability Allowance

Social Work
- Providers: Deaf Aotearoa, Existing agencies
- Funders: Deaf Aotearoa (profit)

Peer Support
- Providers: Volunteers, Existing agencies (eg CYFS, hospitals, probation, corrections, NGOs, Mental Health, Alcohol & Drug, Refuge)
- Funders: Existing agencies

Education & Training for Deaf
- Providers: KDEC/VADEC, Deaf Aotearoa, Training agencies
- Funders: TEC, Community night classes, MOE

Employment Support
- Providers: Deaf Aotearoa, Employment agencies, KDEC/VADEC
- Funders: MSD, MOE, MOH, DHBs

Appendix 2

Survey Results: Communication Priority Areas[3]

Group	Overall Total	Senior Citizen	Total Tga	Total Blnm	Pacific	Total Māori	Total Profs	DANZ staff	Total Mental Health	Total Spectrum	Deaf Plus	Total Families	CODAs	Young Deaf	Phys. Disabled	Hearing impaired
Place		ADS	Tauranga	Blenheim	Papatoe-toe	Hamilton	Profession-als	Auckland	ADS	Auckland	Mt Tabor	Papakura & email	Email	Email + Transition	Email	Email
Number at-tending	150	47	5	9	4	6	21	6	7	8	6	9	6	12	1	3
Needs																
Government Departments	**53%**	**60%**	**40%**	**100%**	**50%**	**33%**	**62%**	**33%**	**57%**	**50%**	17%	**33%**	**83%**	**33%**	0%	**33%**
Transport	**42%**	**57%**	**60%**	**44%**	**50%**	0%	14%	17%	**43%**	25%	**100%**	**56%**	17%	**42%**	**100%**	0%
Home	**36%**	**36%**	20%	11%	0%	0%	14%	33%	**71%**	**38%**	**67%**	**67%**	**83%**	**42%**	0%	**67%**
Work	**35%**	2%	**40%**	**56%**	**50%**	**67%**	**71%**	**50%**	**43%**	**63%**	17%	22%	17%	58%	**100%**	**33%**
Training	**33%**	9%	20%	11%	25%	**67%**	**57%**	**83%**	**43%**	13%	0%	**67%**	**67%**	**33%**	**100%**	**67%**
Social work, counselling	29%	26%	20%	**33%**	25%	**67%**	**48%**	17%	0%	**38%**	**33%**	11%	**50%**	17%	0%	0%
Businesses, real estate etc	29%	21%	**80%**	**56%**	**50%**	**33%**	**33%**	0%	14%	13%	**33%**	0%	**33%**	**50%**	**100%**	0%
Social places	23%	9%	**40%**	0%	25%	0%	19%	17%	29%	**63%**	**100%**	22%	17%	**50%**	0%	0%
Media	21%	9%	20%	11%	25%	17%	**52%**	33%	29%	25%	17%	22%	0%	17%	0%	**33%**
Residential care	20%	**36%**	20%	22%	0%	0%	10%	**33%**	14%	25%	17%	0%	17%	8%	0%	0%
Church	19%	**36%**	0%	0%	25%	0%	5%	0%	29%	13%	17%	11%	0%	**33%**	0%	**33%**
Home helpers	18%	28%	**40%**	0%	0%	**33%**	5%	0%	**43%**	25%	17%	0%	0%	25%	0%	0%
Sports clubs	18%	15%	20%	0%	0%	0%	24%	0%	14%	25%	**33%**	**67%**	0%	25%	0%	0%
Lawyer	16%	23%	**40%**	**44%**	25%	17%	14%	0%	0%	13%	17%	0%	0%	0%	0%	0%
Political meet-ings	14%	11%	20%	0%	25%	**33%**	**38%**	**33%**	0%	0%	17%	0%	0%	0%	**100%**	0%
Childcare	11%	6%	20%	**44%**	25%	0%	5%	0%	0%	13%	0%	22%	0%	**33%**	0%	0%
Government Departments																
Health	**83%**	**91%**	**60%**	**100%**	25%	**83%**	**86%**	**50%**	**57%**	**75%**	**83%**	**100%**	**67%**	**100%**	**100%**	**67%**
Emergency	**63%**	**70%**	**40%**	**100%**	**50%**	**83%**	**48%**	**67%**	**43%**	**50%**	**100%**	**78%**	**50%**	**50%**	0%	**33%**
Work and Income	**49%**	**38%**	0%	**56%**	**100%**	**67%**	**48%**	**50%**	**57%**	**63%**	**100%**	11%	**50%**	**75%**	**100%**	**33%**
Education	**38%**	6%	**40%**	**33%**	25%	**67%**	**86%**	17%	**43%**	25%	0%	**100%**	**50%**	**50%**	**100%**	**33%**
Police	**37%**	**45%**	**40%**	**44%**	**75%**	**33%**	**33%**	17%	**43%**	**63%**	17%	0%	**33%**	25%	**100%**	**33%**
ACC	29%	**57%**	0%	22%	**50%**	0%	14%	0%	0%	13%	**67%**	0%	17%	25%	0%	0%
IRD	20%	26%	0%	11%	25%	0%	29%	17%	0%	0%	0%	11%	**33%**	**33%**	0%	
Mental Health	19%	9%	**40%**	22%	0%	50%	**24%**	17%	**43%**	**38%**	**33%**	22%	0%	17%	0%	0%
Courts	12%	6%	20%	0%	**50%**	17%	**29%**	0%	**43%**	25%	0%	0%	0%	0%	0%	0%
CYFS	10%	0%	20%	0%	0%	0%	**24%**	**33%**	0%	25%	0%	0%	17%	**33%**	0%	0%
Housing	10%	11%	20%	0%	25%	0%	10%	0%	14%	13%	0%	0%	17%	25%	0%	0%
Prison	6%	6%	0%	0%	0%	**33%**	5%	0%	**43%**	0%	0%	0%	0%	0%	0%	0%
No Answer	3%	4%	0%	0%	0%	0%	5%	0%	14%	0%	0%	0%	0%	0%	0%	0%
Drugs & Alcohol	2%	0%	0%	0%	0%	0%	10%	0%	0%	0%	0%	0%	0%	8%	0%	0%

[3] Preferences that were stated by 30% or more of each group are in bold.

Group	Overall Total	Senior Citizen	Total Tga	Total Blnm	Pacific	Total Māori	Total Profs	DANZ staff	Total Mental Health	Total Spectrum	Deaf Plus	Total Families	CODAs	Young Deaf	Phys. Disabled	Hearing impaired
Communication Support																
NZSL Interpreters	**75%**	**74%**	**60%**	**56%**	**75%**	**83%**	**86%**	**83%**	**71%**	**88%**	**100%**	**44%**	100%	**83%**	**100%**	0%
Video relay interpreters	**59%**	**53%**	**60%**	**44%**	**50%**	**83%**	**86%**	**83%**	**43%**	**100%**	**50%**	**33%**	**67%**	**50%**	0%	0%
Note takers	**46%**	**45%**	**60%**	**11%**	0%	**33%**	**71%**	**50%**	**29%**	25%	17%	**33%**	**67%**	**83%**	**100%**	33%
Deaf Relay	**45%**	**40%**	**60%**	**11%**	25%	**33%**	**62%**	**83%**	**71%**	**50%**	**67%**	**11%**	**67%**	**42%**	0%	0%
Trilingual interpreters	25%	28%	0%	0%	**50%**	**50%**	29%	17%	14%	38%	17%	11%	0%	**50%**	0%	0%
Oral Interpreters	23%	38%	**60%**	**11%**	0%	0%	10%	0%	14%	0%	0%	**33%**	**33%**	17%	**100%**	33%
Deafblind guides	14%	19%	0%	0%	25%	0%	24%	17%	14%	13%	17%	0%	0%	17%	0%	0%
Equipment																
Mobile Phone	**70%**	**70%**	**60%**	**67%**	**100%**	**100%**	**67%**	**50%**	**71%**	**63%**	**67%**	**78%**	33%	**92%**	**100%**	33%
Captioned movies etc	**65%**	**68%**	**60%**	**67%**	**75%**	**83%**	**67%**	**33%**	**43%**	**88%**	**83%**	**56%**	**83%**	**58%**	0%	33%
Flashing/ vibrating doorbells etc	**61%**	**74%**	**80%**	**56%**	**75%**	0%	**71%**	**67%**	**71%**	**88%**	**67%**	**11%**	**50%**	**33%**	**100%**	33%
Computer	**49%**	**38%**	**40%**	**67%**	25%	**67%**	**57%**	17%	29%	**38%**	**33%**	**100%**	**50%**	**67%**	**100%**	67%
Fax	**43%**	**74%**	**80%**	**89%**	**50%**	**33%**	10%	0%	29%	**38%**	**33%**	0%	**67%**	8%	0%	0%
Email	**40%**	23%	**40%**	**44%**	25%	**67%**	**57%**	33%	29%	13%	**50%**	**33%**	**67%**	**67%**	**100%**	67%
Video phone	**39%**	21%	**40%**	**44%**	75%	**100%**	**62%**	**50%**	29%	**75%**	**50%**	**22%**	**50%**	17%	0%	0%
Online signed	**31%**	13%	**40%**	**33%**	**100%**	**33%**	**71%**	**50%**	14%	**63%**	**50%**	**11%**	17%	0%	0%	0%
Hearing aid	29%	26%	**40%**	**56%**	0%	0%	19%	17%	**43%**	0%	17%	**67%**	17%	**33%**	**100%**	**100%**
Relay	24%	23%	**40%**	**22%**	0%	**33%**	**43%**	**50%**	14%	0%	17%	0%	**33%**	**25%**	0%	0%
Real time captioning	23%	23%	0%	**11%**	25%	17%	**52%**	17%	0%	13%	**50%**	0%	**50%**	8%	0%	**33%**
Video conferencing	18%	15%	20%	0%	25%	**67%**	33%	17%	14%	13%	**33%**	0%	17%	8%	0%	0%
Chat	16%	17%	**40%**	0%	0%	17%	19%	0%	0%	0%	0%	**44%**	0%	**42%**	0%	0%
TTY	10%	13%	**60%**	**11%**	0%	17%	10%	0%	29%	0%	0%	0%	0%	0%	0%	0%
Phone amplifier	8%	13%	0%	0%	0%	0%	0%	0%	29%	0%	0%	22%	0%	0%	0%	**67%**
Cochlear implants	6%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	**67%**	0%	25%	0%	0%
Hearing loop	6%	11%	0%	11%	0%	0%	0%	0%	0%	0%	0%	22%	0%	8%	0%	0%
Training																
Deaf Awareness	**44%**	**57%**	**40%**	**44%**	**50%**	17%	29%	17%	29%	**63%**	**33%**	**67%**	**50%**	**33%**	**100%**	0%
Life skills	**43%**	**43%**	**60%**	**33%**	25%	**50%**	**52%**	17%	29%	**50%**	**67%**	**33%**	**33%**	**58%**	0%	0%
Polytechnic/ University	**31%**	11%	**60%**	**67%**	25%	**50%**	**57%**	17%	14%	25%	0%	22%	**33%**	**42%**	**100%**	67%
Advocacy	27%	**30%**	**60%**	**11%**	25%	**33%**	**67%**	0%	14%	25%	17%	0%	17%	8%	0%	0%
Literacy	27%	23%	20%	22%	25%	0%	**38%**	17%	14%	13%	**33%**	**44%**	**50%**	**33%**	**100%**	0%
Professional development	25%	4%	**60%**	22%	25%	**33%**	**67%**	**33%**	29%	25%	0%	11%	**50%**	17%	**100%**	33%
Getting a job	24%	2%	**60%**	22%	**50%**	**50%**	**38%**	**33%**	29%	25%	17%	0%	17%	**75%**	0%	0%
Leadership	19%	6%	**60%**	11%	0%	17%	**76%**	17%	0%	13%	0%	0%	0%	17%	0%	**33%**
Handling Stress	19%	19%	**40%**	0%	0%	**33%**	**38%**	0%	14%	13%	**33%**	11%	0%	17%	0%	0%
Parenting	14%	2%	**40%**	22%	25%	17%	29%	17%	0%	0%	0%	**33%**	**50%**	8%	0%	0%
Youth	11%	2%	20%	0%	25%	0%	14%	0%	0%	25%	0%	**56%**	**33%**	17%	0%	0%
Hearing Awareness	11%	6%	20%	0%	25%	0%	29%	**33%**	14%	13%	0%	0%	0%	17%	0%	0%
Communication Tips																
Yes	78%	91%	80%	100%	100%	50%	71%	0%	86%	75%	50%	100%	100%	42%	100%	100%
No	3%	2%	0%	0%	0%	0%	0%	0%	0%	13%	17%	0%	0%	8%	0%	0%

Appendix 3
Communication Tips for Deaf People

Deaf people communicate in different ways. It depends on who they are and their level of deafness and education. How do you know the best way to communicate? Here are some practical solutions:

► **ASK** the deaf person what communication method will be most comfortable – what will work best for both you and them?

► **MAKE A NOTE** of this so other staff are aware and better prepared for future appointments.

► **CHECK** if the person has understood you – do not assume they have.

► **SHOW CLEARLY** when you have finished and **DOUBLE-CHECK** future plans.

► **SEEK ADVICE** from Deaf Aotearoa and other relevant organisations if you are not sure.

When someone says to you, "I'm Deaf", they are asking you to adjust your service so they can understand you. They will tell you their preferred communication method if asked. Here are some options for communicating.

Interpreter Booking

New Zealand Sign Language (NZSL) is one of three official languages of New Zealand. Government agencies are obliged to make their services and information accessible to Deaf people on an equal basis with others, in line with the New Zealand Sign Language Act 2006.

The Office for Disability Issues has an excellent guide to working with New Zealand Sign Language interpreters: Effective communication with deaf people and a contact list of interpreting agencies:

http://www.odi.govt.nz/resources/guides-and-toolkits/working-with-nzsl-interpreters/index.html

► Interpreters are usually the preferred choice of Deaf people, but not for everyone. Assume qualified and competent interpreters will always be needed for effective communication but check first and in advance with the deaf person. Contact the national NZSL agency: www.isign.co.nz

► You should know where, when and how to book one or two interpreter(s) depending on what is involved in the appointment and whether there are breaks.

► You need to arrange for the interpreter rather than rely on the deaf person to organise an interpreter or bring someone along. Inform the deaf person that the interpreter has been booked.

► Check who is paying for the interpreter. Keep in mind that the interpreter is not only for the deaf person – they will also help you communicate with your customer or client.

► Book a trilingual interpreter at least four weeks in advance if the meeting is conducted in Māori. If one is not available, consider booking both a spoken Māori-English interpreter and a NZSL interpreter.

► When meeting a deaf person with a foreign Sign Language, try to find a Sign Language interpreter who can interpret in that Sign Language. Bear in mind that sign languages all over the world are not universal. If this is not possible, seek advice from iSign, the national interpreting agency:

► Some Deaf people have not had access to Sign Language early in their life and as a result have minimal language (English as well as Sign Language). If you know this is the case, inform the interpreter or the booking agency as it may be appropriate to also book a relay interpreter who can further help with communication. Allow extra time for the appointment as the interpreter can ensure that the deaf person understands what is being discussed. At the meeting you should assist in filling in forms and book follow-up appointments as the person may not read your letters well.

► For deafblind clients, check with the person their preferences for communication – NZSL with visual modifications, tactile NZSL or deafblind finger spelling. Book an interpreter with relevant experience or check with the client if he/she has a preferred communicator/guide. Check lighting and seating arrangements. For further advice, contact iSign, Deafblind New Zealand or the Royal New Zealand Foundation of the Blind which provides deafblind co-ordinators.

► If using an interpreter, sit them right beside you or just behind your shoulder so you look directly at and talk normally to the deaf person. Make sure that the person can see both you and the interpreter at the same time. The person may look mainly at the interpreter to follow what is being said but will be able to also look at you.

► If all relevant meeting information can be given to interpreters in advance, this will ensure that the interpreter has advance knowledge of the context of the meeting and will enable better communication.

Deaf-friendly Environment

► Check the lighting. Ensure the light is on your face and avoid backlight.

► Have windows with blinds or curtains to control glare from the sun.

► Have plenty of space in rooms and corridors for physical signing. Offer the person a private room if possible and appropriate – somewhere quiet and calm, without distractions.

► No fragile objects or windows nearby that could be broken with vigorous signing.

► Use assistive technology devices in waiting rooms – subtitles on TV, mobile phones, text phones, pagers, loop system, with visual alerts and numerical displays so the deaf person knows when it is their turn to be seen.

► Allow time for the person to read any given papers as they cannot talk and read at the same time.

► If using an interpreter, prepare seating ideally in a horseshoe or circle for a clear line of sight.

Use Visual Communication

► This is especially useful for deaf people who do not have strong written English.

► Use clear gestures and visual aids to help communication.

► A chart of common Sign Language pictographs, finger alphabet and a list of Yes/No questions to refer to can be helpful.

► Provide information in Deaf-friendly format – leaflets in plain English, DVDs and websites with Sign Language translation. Deaf people need to express their opinions and complaints as well as access information.

► Use side-by-side computers to talk with text.

Communication Tips for Deaf People

Try pen and paper

► Some Deaf people have difficulty reading and writing English due to the historical ban on or late introduction of Sign Language. This meant that many deaf people's language development was delayed, and this makes a second language (English) even more challenging to learn. If the deaf person is happy to communicate by pen and paper:

► It's a good idea to have pen and paper ready on the desk when the person is making a brief request. They would ask for a pen and paper or they may bring in prepared notes.

► When they start writing, please be patient. Do not try to serve the next customer or divert your attention to something else.

► Make sure you write legibly and check if the person can read it.

► Use plain English: avoid jargon and use whole sentences, not just isolated words.

► Remember that written English is not a substitute for NZSL interpreters.

Use Clear Speech

► The best lip-readers can pick up only about a third of what is said by lip-reading. If the deaf person has started to speak to you first, you may ask them, "Can you lip-read me?" If they can't, offer to write down what you say.

► If you find you can't understand the person, you can offer them pen and paper. If the person can lip-read you, and you can also understand them:

► Speak normally and do not shout or raise your voice – exaggerated lip patterns make it hard to lip-read.

► Face each other, stand/sit as close as is polite.

► Keep your face well lit in order to make lip-reading easier.

► If you have to turn away, stop talking and resume only when you are facing the person again.

► Keep your face in clear sight at all times – do not block it with hands, instruments or masks.

► Let the deaf person know when you are changing the topic.

Pointing at Something

► Information placed up high and out of reach makes it difficult to communicate, e.g. takeaway menus up on the wall behind the counter:

► Have menus or lists of choices handy on the desk or counter for the deaf person to point at.

► Number your menu items or lists of services so people can easily show the numbers of their choices.

Appendix 4
Supportive Legislation

UN Convention on the Rights of Persons with Disabilities

This Convention requires States to ensure that deaf people have access to government information and services, to allow the use of New Zealand Sign Language, and to ensure the provision of Sign Language interpreters.

Article 21: Freedom of expression and opinion, and access to information.

Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

(a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

(c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;

(d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;

(e) Recognizing and promoting the use of sign languages.

NZSL Act

The New Zealand Sign Language Act 2006 recognises New Zealand Sign Language as an official language of New Zealand, alongside English and Māori.

The Act provides deaf people with the right to use New Zealand Sign Language in legal proceedings. The Act also states principles to guide government departments in the promotion and use of New Zealand Sign Language. In particular, the Act states in section 9 (1) (c) *that government services and information should be made accessible to the deaf community through the use of appropriate means (including the use of New Zealand Sign Language).*

Human Rights Act 1993

The Human Rights Act 1993 protects people in New Zealand from discrimination in a number of areas of life. Discrimination occurs when a person is treated unfairly or less favourably than another person in the same or similar circumstances.

The Human Rights Act lists the areas and grounds where discrimination is unlawful and also some exemptions or exclusions, particularly where it is not **reasonable** to expect the employer or service to provide those services or facilities.

New Zealand Bill of Rights Act 1990, section 24 g

States *that people shall have the right to have the free assistance of an interpreter if the person cannot understand or speak the language used in court.*

Children, Young Persons and their Families Act 1989, section 9

(a) that where the first or preferred language of the child or young person is Maori or any other language other than English; or the child or young person is unable, by reason of a physical disability, to understand English, the services of an interpreter are provided for the child or young person:

(b) that where the first or preferred language of any parent or guardian or other person having the care of the child or young person is Maori or any other language other than English; or that parent or guardian or that other person is unable, by reason of a physical disability, to understand English, the services of an interpreter are provided for that parent or guardian or that other person.

Health and Disability Commissioner Act 1994, section 20(d)

The duties of health care providers and disability services providers as they relate to the measures (including the provision of interpreters) necessary to enable health consumers and disability services consumers to communicate effectively with health care providers and disability services providers

Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights 1996, Right 5

The right *to be given information that you can understand in a way that helps you communicate with the person providing that service*

Mental Health (Compulsory Assessment and Treatment) Act 1992, section 6.

It shall be the duty of the court or tribunal, or that person, to ensure that the services of an interpreter are provided for the patient wherever practicable.

Appendix 5
Volunteering Trends

There is reason to be optimistic about the future of volunteering. Despite rapid change in organisations, volunteering, and the world at large, most experts conclude that we are in a "Golden Age" for volunteering. Certainly in New Zealand in 2004 there were over a million people who volunteered for one or more of 97,000 not-for-profit organisations. This represents nearly a third of the population over 12 years of age (Office for the Community and Voluntary Sector; 2007).

The face of volunteering is now changing across the world. There is remarkable consistency internationally and locally towards professionalising volunteer services.

The Ministry of Social Development simplifies the two essential models of volunteering that can conflict in transition:

► The traditional charity model attracts longer-term volunteers with a more family-like approach. It tends to often attract older women who are not in the workforce. It provides little role-specific training as long-term volunteers learn on the job, usually during normal working hours.

► The newer social enterprise model is more business-like and attracts younger, wealthier, employed, highly skilled and time-poor people as well as corporates. It focuses on matching the job to the person, training, outcomes for service users, and provides more project-type work that can be done when convenient to the person.

There is an inherent tension in moving from one model to another and a balanced considered approach is needed to ensure that volunteers do not become demotivated by the change.

Key Messages for Volunteer Recruiters

► Not all volunteers are the same

► Volunteering is a two-way relationship (despite historically being one-sided)

► Volunteerism has image problems (treated without respect)

► Volunteers want more structure (but not so formal that it intimidates)

► It is important to ask people to volunteer (using networks)

► Young people do volunteer (appeal to the fun of the position)

► Leadership is important (volunteers want well-run organisations, manageable workloads)

► Thank volunteers (with implicit and explicit rewards)

► Māori do volunteer (using whanaungatanga).

Appendix 6
Peer Support

Peer support is common in mental health contexts and is used to create social support and increase self-awareness and capability:

Intentional peer support is the support naturally exchanged by people with common needs. Such support helps people to make sense of their experiences and to focus on learning and growth. Fellow travelling and identification is something that professionals cannot give. (Jackson)

The main challenge here is one of governance. On the one hand, assurance is needed that the approach is well managed. On the other hand, the real strength of the approach is that it is a relationship, not an intervention. (Jackson)

Peer support translates well across cultures but requires adaptation to the cultural needs of each group (e.g. focus on kinship, customs, values) and is often best provided by people of the same or similar culture.

Common aspects of peer support: (Orwin)

► Clear philosophy and guiding principles to ensure differentiation from traditional support roles, ease of supervision and key performance indicators.

► Integrity – most effective when led by service users

► Effective recruitment processes are in place

► Training is provided to peer support workers

► Effective supervision structure is in place

Peer support has also been used successfully in the health sector to encourage self managing behaviours in diabetes, breast feeding, breast cancer, cardiac rehabilitation and other areas, mostly having a positive effect. (MacPherson et al).

Mentors can be trained to provide support. The **golden rules of mentoring** include: respect, listening, sharing your experience, not giving advice, encouraging people to get professional input as needed, setting limits, positivity, self care, avoiding undesirable behaviours like gossip or criticism, or co dependency

Recommendations from breastfeeding research:

► Peer support should be used as a multi faceted approach and not just as a stand alone intervention.

► Those who need help often don't ask for it. Health professionals and volunteers need to be proactive in making contacts.

► Evaluation of the programme is needed to monitor impact and cost effectiveness.

► A coordinated approach is needed to ensure good communication.

Appendix 7
Environmental Scan

Summary of Government and Funder Views of Future Disability Services

Funding is flat, although health received additional funding in the May 2009 budget, despite recessionary conditions. Funders, at Government's request, are driving to **increase throughput and efficiency.**

The current fiscal climate means that the immediate focus must be on using existing resources in more cost-effective ways rather than on major structural change or increased levels of funding. (Government Response 2008)

Client satisfaction with disability support services is generally low (MOH Disability Strategic Plan, 2008). Government wishes to review auditing and monitoring away from a "tick-box" approach towards more quality of life outcomes.

Outcome and evidence-based measures are preferred that show value for money. The Ministry of Health is using consumer feedback as a proxy. Anecdotally, some organisations are endeavouring to equate a level of resource to an outcome (e.g. $1,000 will buy you an average of two skills learnt).

"What difference are you making in people's lives?" (Personal interview)

The Government agrees that monitoring of disability services should focus on quality of life outcomes for disabled people, rather than a "tick-box" approach. (Government Response 2008, p 11)

The focus will be on what providers can deliver without compromising quality or quantity.

There is continued support for increasing choice and self-determination by disabled people and living in fully inclusive communities. Increasing individualisation of supports is required along with flexibility in meeting individual needs. Multi-disciplinary approaches are encouraged by a number of funders.

The Government is committed to an approach to accessing the disability support system that gives disabled people greater control over their lives and supports participation in the community. (Government Response 2008, p 4)

Innovation and creative consumer-focused responses are being called for. Partnerships with disabled people are advocated by the key strategies and health services.

Government's approach is to start with a clean slate and come up with ideas on how to serve disabled people. Don't tell them what they can have – ask them what they want. This Government does not want the "same old, same old" – we need innovation; consumer-led innovation. The money can be found if it's innovative and works for people. (Personal interviews)

There is a move towards increased integration and collaboration at all levels to minimise the impact of different funding silos and provide as seamless a service as possible.

(Government) will improve Ministerial-level collaboration on disability issues through establishing a Ministerial Committee on Disability Issues, chaired by the Minister for Disability Issues. (Government Response 2008, p 3)

The Government does not, however, favour establishing new agencies, such as establishing a Disability Commission. (Government Response 2008, p 4)

Greater access to information about services is being called for by consumers and funders.

Multi-year funding contracts are expected to be established eventually.

Reducing health inequalities, particularly for Māori and Pacific peoples, has been a major focus of health funders and service. It is unclear how this will continue in the future, but the current Government is closely aligned with the Māori Party which remains committed to this.

Funders are consolidating small providers and contracts where possible, to reduce risk and maximise efficiency.

Review of access method – The Ministry of Health will be reviewing the Western Australian Local Area Coordination (LAC) model[1] as a possible alternative to NASC.

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[1] The Disability Services Commission provides Local Area Coordination support throughout Western Australia. Local Area Coordinators (LACs) are based in local communities enabling disability support to be personalised, flexible and responsive. LACs aim to build and maintain effective working relationships with individuals and families in their local area.

There is an increasing number of very high need (VHN) clients, who may not have survived infancy earlier, in all services.

Higher unemployment is making it easier to recruit and retain higher-quality staff.

There is an increased focus on the aging population among funders. Over the next 20 years, the number of people over 85, for example, is expected to nearly treble in New Zealand (Statistics NZ, 2006), with a corresponding increase in the numbers of people with dementia (Fitzgerald 2007). Aging in place will remain the preferred option for care, where possible. Disability rates are expected to remain at similar levels largely because of healthier lifestyles (particularly among the most educated), and because of increased health prevention policies (Timmerman 2003).

Supporting carers of disabled people is a priority for Government and health services as a means to enable people to stay in their own home (Carer Strategy, 2008).

The Government agrees that better support for unpaid carers is important and is investigating the options for taking forward the Five-year Action Plan of the New Zealand Carers' Strategy. (Government Response 2008, p 9)

Workforce development is a priority especially for health services.

The Government agrees that a strategic approach is needed if the care and support workforce is to effectively support disabled people to be independent and participate in society. In accordance with this approach, the Ministry of Health has developed a Disability Services Workforce Strategy and Action Plan (for support that is funded by the Ministry of Health's Disability Services group). (Government Response 2008)

"User pays" is not featuring as an issue among funders but a new business model called "social enterprise" has emerged this century for not-for-profits (a model that combines market efficiency and social justice and advances the traditional not-for-profit approach into social entrepreneurship).

Appendix 8
Community Development

A Working Statement on Community Development (from the Standing Conference for Community Development – UK)

► Community Development is crucially concerned with the issues of powerlessness and disadvantage: it offers a practice that is part of a process of social change.

► Community Development is about the active involvement of people in the issues which affect their lives. It is a process based on the sharing of power, skills, knowledge and experience.

► Community Development takes place both in neighbourhoods and within communities of interest, as people identify what is relevant to them.

► The Community Development process is collective (local groups), but the experience of the process enhances the integrity, skills, knowledge and experience, as well as equality of power, for each individual who is involved.

► Community Development seeks to enable individuals and communities to grow and change according to their own needs, priorities and pace, provided this does not oppress other groups and communities, or damage the environment.

► Where Community Development takes place, there are certain principles central to it. The first priority of the Community Development process is the empowering and enabling of those who are traditionally deprived of power and control over their common affairs. It claims as important the ability of people to act together to influence the social, economic, political and environmental issues which affect them. Community Development aims to encourage sharing, and to create structures which give genuine participation and involvement.

► Community Development is about developing the power, skills, knowledge and experience of people, thus enabling them to undertake initiatives of their own to combat problems, and enabling them to fully participate in a truly democratic process.

► Community Development must take the a lead in confronting the attitudes of individuals and the practices of institutions and society as a whole which discriminates unfairly against black people, women, people with disabilities and different abilities, and other groups who are disadvantaged by society. It also must take a lead in countering the destruction of the natural environment on which we all depend.

► Community Development should seek to develop structures which enable the active involvement of people from disadvantaged groups, and in particular people from Black and Minority Ethnic groups.

Appendix 9
Social Enterprise Models

While many agree that not-for-profits have been doing good work with social missions, volunteer management and leadership for a long time, it has not guaranteed survival. Following a period in the early 1990's when governments were forced to look for more creative and sustainable funding options, a new business model called "social enterprise" started to emerge.

By the late 1990s and beginning of the 21st century the number of social enterprises began to increase (in response to the need for less dependency on government grants, and the need for increased self-sustainability in challenging financial times).

There are many different types of social enterprises and this may be why there is no clear accepted definition. However, one definition that captures its essence is "a business with primarily social objectives whose surpluses are principally reinvested for that purpose in the business or in the community, rather than being driven by the need to maximise profit for shareholders and owners" (Chell, 2007).

This model combines the market efficiency of commercial businesses and the social purpose of not-for-profits. It can be viewed either as "business with a social agenda" or as "charity run like a business". It calls for business disciplines and a focus of profit-making services into charities. If it came down to a choice, social enterprises would most likely choose to support their social outcome, but the organisation cannot survive without making a profit so the commercial business paradigm must remain equally strong in the minds of social enterprise staff.

Chell notes that research in the US shows that commercially successful not-for-profits tend to have a business-led board, tend to recruit key managers from business, and tend to have a strong business culture (Chell, 2007).

It can be argued that not-for-profits have become more business-like over many years. Social enterprise, however, is a radical development in the sector because of the clear imperative to hold the two paradigms of social purpose and wealth creation simultaneously and robustly. It is hoped that this dual focus will enable the key challenges of traditional not-for-profits to be surmounted.

The three principal characteristics common to both social and commercial entrepreneurship are proactivity, risk management, and innovativeness. Complex social problems need all these features to address their solutions.

Appendix 10
Glossary

ADA	Americans with Disabilities Act
ADL	Adaptive Daily Living
ADS	Auckland Deaf Society
CODA	Child of a Deaf Adult
Deaf Association	The previous name of Deaf Aotearoa
Deaf/deaf	The word deaf or hearing impaired refers to people with a hearing loss in general. The word Deaf refers to cultural membership of the Deaf community.
FTE	Full-time equivalent
NZFDC	New Zealand Federation for Deaf Children
NZSL	New Zealand Sign Language
O&M	Orientation and Mobility

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