



Inquiry into the quality of care and service provision for people with disabilities

Report of the Social Services Committee

Forty-eighth Parliament
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Inquiry into the quality of care and service provision for people with disabilities

Key recommendations

The Social Services Committee recommends to the Government that it

- appoint an appropriately funded lead agency with responsibility for disability issues, accountability for the disability sector, and a role monitoring the sector (page 15)
- make the new lead agency responsible for ensuring that the New Zealand Disability Strategy is put into action effectively, and establish a national plan of action to ensure that the strategy is implemented without delay by the appropriate agencies (page 17)
- establish an independent disability commission if this arrangement has not achieved significant change within six years (page 15)
- investigate the appointment of an independent disability commissioner, possibly within the office of the Health and Disability Commissioner. Any required legislation should also expand the areas the commissioner may examine to include, for example, access to services and individual funding issues. The commissioner should be responsible for considering disability issues in relation to health, education, social development, and housing, and promote the recognition that disability is a fact of life and not primarily a health matter (page 36)
- establish a new entry point in the community for people seeking disability information, in the form of an agency with the additional role of building community capacity and support, along the lines of the local area coordination system established in Western Australia. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 24)
- change the role of existing Needs Assessment and Service Coordination agencies to ensure there is no duplication with local area coordination, and that they focus on meeting the needs of individuals, rather than those of service providers. All Needs Assessment and Service Coordination agencies should have a clear separation from service providers. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 23)
- direct the relevant ministries to ensure that funding is provided in a way that allows people with disabilities more choice about their day-to-day living arrangements. They should have better access to supported independent living and individualised funding. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 26)

- ensure that evaluations and audits of disability services focus on the quality of life and the opportunities for people with disabilities. Evaluations and audits should be focused on development and satisfactory outcomes for people with disabilities rather than on compliance with minimum standards for audit purposes. Teams must have the freedom and the responsibility to talk with all stakeholders involved in services. We consider this should be in place within 12 months (page 34)
 - introduce legislative change to strengthen and expand the scope of Government-funded advocacy and complaints services for people with disabilities. This should enable the independent disability commissioner to oversee access to disability services (page 36)
 - establish a strategy for improving training, pay rates, and working conditions for the caring and support workforce in the disability sector, including those funded through Vote Health. Such a strategy should include a structured career path, a skills-based pay system, values-based training for all staff, and consistent and appropriate conditions of work, including health and safety, safeguards, and paid training. The funding should take into account the requirements and costs of training. The relevance and appropriateness of all current training programmes should be reviewed immediately in the light of our recommendations. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 40)
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Other recommendations

The Social Services Committee also recommends to the Government that it

- introduce effective systems for information sharing and collaboration between the main Government agencies responsible for disability support (page 15)
- extend pilot programmes for students with disabilities in transition from school into employment, training, or further education, and ensure that the effectiveness of these programmes is monitored closely. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 29)
- ensure that age-appropriate services that provide a good quality of life in ordinary surroundings are made available for younger people with high needs, who are now placed in rest homes inappropriately. We consider this should be achieved within two years (page 26)
- allocate sufficient funding and resources to make high-quality respite care available nationwide (page 30)
- ensure that better support is provided for unpaid caregivers, and that the New Zealand Carers Strategy is implemented urgently. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 28)
- provide more flexible, streamlined funding for equipment and modifications by allowing providers to authorise expenditure on lower-cost supports up to set limits. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 31)

- develop disability standards for community services, with appropriate outcomes-focused evaluation processes, and require the lead disability agency to ensure that duplication is avoided and that best practice is followed. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months (page 34)
 - give people with disabilities and their families a key role in the monitoring process, to ensure that quality of life is measured and valued. We consider this should be done within 12 months (page 34)
 - make the evaluation reports of services readily available to the public, taking care to preserve the privacy of individual residents or service users, and their families. We consider this should be done within six months (page 34)
 - make it possible for complaints about disability support to be lodged verbally, to improve access for people with disabilities (page 37)
 - establish an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health (page 37)
 - require the disability commissioner to establish a process for checking that his or her recommendations have been acted upon (page 37)
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1 Introduction

Background to the inquiry

In 2005 and 2006 concerns about support services for people with disabilities were raised by the media and discussed in Parliament. In particular, two major service providers were accused of inappropriate treatment of people with disabilities in their care, and one was found to have received funding to which it was not entitled. Publicity about abuse and irregular financial dealings appeared to be indicative of wider issues in the disability sector, and organisations representing the disabled community publicly expressed dissatisfaction with current service provision.

Concerns about the quality, training, and availability of staff looking after people with disabilities with complex needs were raised, deaths in care facilities were examined in the media, and the Government's management and funding of the disability sector was questioned. A series of investigations and audits produced evidence of strengths in the system, but there was also evidence of unacceptable conditions and abuse, making an inquiry necessary.

In May 2006, we announced this inquiry into the quality of care and services for people with disabilities. During the inquiry we heard from many people and organisations that deliver excellent and innovative support to people with disabilities. However, we found that the provision of disability services lacks direction and leadership, services are variable throughout the country, and significant systemic problems have developed unchecked. In particular, the New Zealand Disability Strategy, introduced in 2001 to widespread support from the disabled community, has not been effectively implemented. In this report, we survey the quality of the support provided for people with disabilities and make recommendations to the Government for much-needed change. We also assess the adequacy of current services to enable people with disabilities to lead independent lives as free as possible from disability-related constraints.

This inquiry addressed the following high-level terms of reference (see Appendix B for a more detailed list):

- a Current service provision arrangements for people with a disability and future directions (including home-based, residential, vocational and community)
- b The way National Standards of Care are determined, implemented and monitored, and any lessons learned from historical complaints and systemic failure
- c The advocacy and/or complaints process for clients, and their families, residents and the public
- d The level of accountability, funding, information sharing, transparency, and collaboration between relevant Ministries, community agencies, and providers

- e The quality of training, career structure, and workplace conditions of the disability workforce
- f An assessment of the extent to which the New Zealand Disability Strategy is central to the wellbeing, rights, and care of disabled people.

We received approximately 150 submissions from Crown entities, organisations, and individuals, and received advice from Government advisers (the Ministry of Health, the Office for Disability Issues, and the Ministry of Social Development) and from an independent adviser.¹ This report draws heavily upon this material. Most submitters focused on the services offered by the Ministry of Health, rather than the many other Government agencies that provide or fund disability services around the country.

Disability support in New Zealand

Service provision for people with disabilities has changed significantly in the past 50 years. The formerly prevalent “medical model” of disability, which describes people with disabilities as suffering from illness and disease, often requiring medical treatments, has been largely superseded by the “social model.” The medical model was associated with institutionalisation, with people with disabilities being placed in facilities away from their families and local communities. There was an assumption that some people with disabilities, such as war veterans disabled when serving in the armed forces, were more inherently deserving of help than others.

In contrast to the medical model, the social model emphasises that attitudinal and environmental barriers created by society hinder the independence and participation of people with disabilities; it is often associated with a recognition that people with disabilities have the same human rights as their non-disabled peers. This shift in thinking about disability, which was expressed in the 1975 United Nations General Assembly’s Declaration of Rights for Disabled Persons, was one of the reasons for the closure of large residential institutions that provided services for people with disabilities away from the community. People with disabilities now generally reside in the community, with a focus on mainstreaming and normalising their lives. In 2006, the last large institutional facility, the Kimberley Centre in Levin, was closed.

Independent living within the community was one of the objectives of these changes. De-institutionalised people received services intended to meet their needs in a community setting. People with disabilities can now obtain disability support funding and services to help them to become more independent and to engage with their communities and with society. These changes were supported by the Human Rights Act 1993, which prohibited discrimination on the grounds of disability and was amended in 2001 to refer to discrimination in Government services. Such changes in New Zealand mirror those in countries such as the United Kingdom. New Zealand was among 81 member states that signed the United Nations Convention on the Rights of Persons with Disabilities in 2007.

¹ Angus Capie, the independent adviser, has several decades of experience working with people with disabilities and their families in New Zealand and overseas and holds academic qualifications in education and psychology. Among other appointments, Mr Capie held the position of Chief Executive for the Standards and Monitoring Service in Wellington from 1991 to May 2006.

This convention, which seeks to promote and protect the rights of people with disabilities, is awaiting ratification by the New Zealand Government.

In keeping with these changes, since 2001 the New Zealand Disability Strategy was to have served as a guide to the Government's provision of disability support. The strategy says that New Zealand society should be inclusive, enabling people with impairments to be valued and to participate as they wish in community life. In recent years the Ministry of Health, one of the main Government agencies funding disability services, has premised its strategy on "living in their home and taking part in their community in the same way that other New Zealanders do." We consider these changes to be positive, but in this report we note that in many instances the strategy has not been well implemented. We consider there is a need for adequate funding for implementation, and a timeframe with target dates.

We note that no one agency is held accountable for the disability sector and the overall provision of disability services. We consider there is a need for a single agency able to have oversight of the sector, taking responsibility for the implementation of the disability strategy, managing and coordinating the provision of disability services, and acting as an advocate on disability issues. Without the establishment of a single, overarching entity with responsibility and accountability for the disability sector, we are concerned that the required changes may not be achieved.

We specify a number of other areas of concern in this report. People with disabilities often feel they have little control over the services they receive, and funding is relatively inflexible. We were interested to learn about the local area coordination system in Western Australia, a model with a single entry point for access to disability-related services which we believe is worth adopting in New Zealand. We also believe that the Needs Assessment and Service Coordination (NASC) model, where particular organisations assess, plan and coordinate tailored packages of support funded through Vote Health, fulfils an important role. However, there should be a clear separation between NASC agencies and service providers, so that the NASC agencies are specifically focused on the needs of people with disabilities rather than the entities providing disability services.

The large institutions that dominated the disability sector have been abolished in recent years, and we were concerned by claims that this has in effect led to the establishment of hundreds of miniature institutions where people with disabilities still have little say over their daily lives. While supported living arrangements may offer more flexible support and more independence to people who choose to live in their own homes, some people claim that the support provided is not always adequate to meet their needs. The Ministry of Health is working towards individualised funding, and we welcome this development.

We were concerned by claims that much of the monitoring and auditing of disability service providers focuses on compliance with systems and processes, with little consideration of the quality of life offered to people with disabilities who receive the services. We were particularly surprised to learn that audits of the quality and effectiveness of residential services are often conducted without seeking feedback from staff, residents, or residents' families. We consider that it is essential that monitoring and auditing of providers take into account the quality of life afforded to recipients of the services, and includes them in the monitoring process.

We consider that advocacy services for people with disabilities need to be expanded. We consider that the single lead agency that we are recommending should have an advocacy role, but we believe that the advocacy role provided by the Health and Disability Commissioner should also continue. At the same time, we note that the commissioner has acknowledged that health issues often take priority over issues specifically affecting people with disabilities, and that his ability to advocate on non-health-related disability issues is limited. We therefore consider that there is a need for a new independent disability commissioner, possibly located within the office of the Health and Disability Commissioner, to provide additional dedicated advocacy for people with disabilities.

We are concerned about the working conditions in caring and support services in the disabilities sector, with low pay, high turnover, and a lack of training and career structure. We also heard about some unreliable and abusive staff, and we consider that background checks of new staff should be more thorough. At the same time, we recognise that many disability support workers genuinely wish to provide good service. We consider that a strategy should be developed to improve training, pay rates, and working conditions for the caring and support workforce.

We believe the improvements in the disabilities sector should be monitored by Parliament and for this reason have included with many of our recommendations a requirement that the Social Services Committee be provided with regular progress reports. We consider that although people with disabilities make up a significant proportion of the New Zealand population, their needs have frequently been marginalised and neglected. We hope that this report will effect some change for the better in this sector.

2 Accountability and collaboration

Overview of Government agencies

We heard evidence about a number of areas where current service provision is failing people with disabilities, and these are discussed later in this report. However, our overriding concern was the lack of accountability for disabilities services. Disability support is funded through 11 Votes, the Accident Compensation Corporation (ACC) account, the Land Transport Fund, and the Lottery Grants Scheme (as well as by people with disabilities themselves, their families, and communities). Each ministry or Crown agency is responsible for a different client group or type of disability support. District Health Boards (DHBs) fund services mainly for older people, and people with psychiatric disabilities. The Ministry of Health funds support for people aged under 65 years with physical, sensory, and intellectual disabilities. The Ministry of Social Development provides the largest amount of direct funding through the Disability Allowance, administered by Work and Income, and through Child, Youth and Family Services. The Ministry of Education provides disability support through Group Special Education for children at school and through the funding of tertiary institutions.

Many people receive support from several of these agencies, often through organisations contracted to provide disability support. A large number of these organisations are not-for-profit non-governmental organisations or their trading subsidiaries. In recent years an increasing number of for-profit providers have emerged, particularly in the aged-care sector. With such a wide range of providers, it is easy for duplicated or inconsistent services or gaps in service provision to occur.

Table 1: Public expenditure in 2005/06 on disability support for people with long-term impairments (excluding GST)²

Ministry or Crown Agency	\$ (millions)	%
Accident Compensation Corporation	256	9
District Health Boards	1,018	35
Ministry of Health	699	24
Ministry of Social Development	479	17
Ministry of Education	402	15
Other	22	1
<i>Total</i>	<i>2,876</i>	<i>100</i>

Collaboration between Government agencies

Submitters told us about difficulties people with disabilities encountered because of insufficient collaboration between the Government agencies that fund disability support

² These figures do not include national office overheads for all agencies because of differing accounting practices.

and poor coordination of services between agencies. Some agencies attempt to pass responsibility for services to others. We were told that the disability support system is difficult to understand and use. People with disabilities may have to seek support from multiple sources, as there is no one-stop-shop for accessing services.

Some submitters suggested that the Ministry of Health should not be funding services for people with disabilities, and proposed that responsibility for disability support should be transferred to another agency, such as the Ministry of Social Development, or a new agency to be created expressly for this purpose. We were advised that this could have some drawbacks: it would take five to ten years to see results from such a change, and in the meantime improvements to services could be deferred in favour of structural changes. Structural change could also disrupt current services, and be costly and difficult to implement. In the 1990s significant responsibility for disability support was transferred from the Ministry of Social Development to the Ministry of Health, but we were advised that complaints about service gaps continued despite the structural changes. The Office for Disability Issues' role was also questioned by submitters, some commenting that it had not shown leadership, while others suggested that it could take on a more substantial role.

Low priority of disability services

We were concerned to learn that the provision of disability services forms just a small part of the operation of many entities, so consideration of disability issues often gets crowded out. While in many departments someone in senior management has responsibility for disabilities, these people will have other responsibilities that frequently take precedence, so disability services often get neglected. We were concerned to note, for example, that the role of the Deputy Director-General of Health (Disability) had recently been widened significantly to include a number of responsibilities unrelated to disability.

We were particularly disappointed to hear the Health and Disability Commissioner acknowledge that his work on disability issues was not satisfactory and that health issues often take priority over those affecting people with disabilities, although we recognise that he is severely limited by legislation in addressing most complaints concerning disability. We consider it is essential that the delivery of disability services should not be marginalised or given low priority.

Work in progress

We were advised that accountability needs to be clarified in some areas. For example, the respective responsibilities of the Ministry of Social Development and the Ministry of Health for funding vocational support are uncertain. We understand that the two ministries are preparing advice to the responsible Ministers on this issue. Government advisers informed us that a review of the way agencies work together began in 2002, and has already led to a number of actions. Led by the Office for Disability Issues, the Review of Long-Term Disability Supports emerged out of discussions in 2000 about the New Zealand Disability Strategy. The review sought to improve outcomes for people with disabilities and their families, with services that are simpler to access, more flexible, better coordinated, and distributed more fairly and more consistently with the New Zealand Disability Strategy.

In February 2008 the Government decided on its response to the recommendations that emerged from the review. We were informed that Government agencies will be required to

consider alignment with other Government disability support policies and programmes when developing and reviewing disability support policies. Government funding agencies are to continue to simplify and standardise contracting arrangements, and efforts are also being made to improve the provision of information about services. It is probable, however, that in many cases more than one agency will always be involved with funding disability support. Schools, for example, will always play some part in supporting students with disabilities; but we were advised that extending NASCs' coordination role was one option for coordinating such support more effectively.

Establishing a lead agency

We consider it essential that a lead entity be established with responsibility for managing and coordinating the provision of disability services. Such an entity should have global oversight of the disability sector and a leadership role in the sector. It should also provide advocacy on disability issues in general, and for particular people with disabilities. The lead agency should be sufficiently funded to achieve its purpose, and should have responsibility for the effectiveness of disability services. We particularly believe that it should be responsible for ensuring the prompt and effective implementation of the New Zealand Disability Strategy, and for developing systems for sharing information among the various Government agencies with responsibility in the disabilities sector.

We consider that an independent disability commission, similar to the Mental Health Commission, would best serve the needs of the disabled community, but we feel that the time is not right for such a step, and that a single lead agency is needed instead. We recognise that such an entity could take a wide variety of forms, and we do not wish to recommend any form in particular. We expect the Government to give careful consideration to the form that the agency should take.

We do wish to raise a caution regarding particular connections between the lead entity and any other department, which might cause disabilities to take on the colour of the sector served by that department. We note, for example, that the issue has frequently been paired with health, causing disabilities to be perceived as a sickness or deficiency rather than in many cases as a whole-of-life issue.

We consider that the lack of any single overarching entity with funding, responsibility, and accountability for disability issues is the most important issue we have discovered in this inquiry. We are concerned that without such leadership, many of the other recommendations in this report may be disregarded or inadequately implemented. We therefore hope to see this need addressed as a matter of urgency.

We do not wish to see such a lead agency established only to create a new bureaucracy that fails to achieve meaningful results. For this reason, we consider that there should be a process for assessing the impact of this entity on quality of life for people with disabilities. We recognise that it will take time to achieve substantial results, but we consider that it should be clear within six years whether the agency has proved successful. After six years, should there be little demonstrable improvement in this area, we consider that the lead agency should be disestablished and replaced with an independent disability commission.

Recommendations

1. We recommend to the Government that it appoint an appropriately funded lead agency with responsibility for disability issues, accountability for the disability sector, and a role monitoring the sector.
 2. We recommend to the Government that it establish an independent disability commission if this arrangement has not achieved significant change within six years.
 3. We recommend to the Government that it introduce effective systems for information sharing and collaboration between the main Government agencies responsible for disability support.
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3 The place of the New Zealand Disability Strategy

Overview

In conducting our inquiry, we have given careful consideration to the New Zealand Disability Strategy. Introduced in 2001, this strategy was to have provided a guide for the Government's provision of disability support. The strategy is underpinned by the social model of disability. It ultimately aims to ensure that New Zealand society is inclusive, enabling people with impairments to be valued and participate in community life to the extent they wish. The strategy was written in consultation with the disability sector and people with disabilities, and provides a guide for the development of disability support by Government departments. However, no implementation dates have been fixed.

The Minister for Disability Issues is required to report on the implementation of the Disability Strategy in accordance with the New Zealand Public Health and Disability Act 2000, and Government departments are obliged to report annually the steps they are taking toward implementing the strategy. The Government has recently directed the Office for Disability Issues to develop, in 2008, a framework for longer-term planning and reporting against the disability strategy to make targets for achievement in priority areas, including disability supports. We note there is no Parliamentary scrutiny of the implementation of the strategy outside of an inquiry like this.

Submitters' concerns

Submitters reported strong support for the strategy amongst the disabled community, but noted that implementation was inadequate, and that people with disabilities are expecting more than Government departments consider is possible. We were informed that as no Government agency has sole responsibility for ensuring the strategy is implemented, any resulting change is limited and inconsistent. Central Government agencies are required to consider the strategy in their plans, but it does not cover local authorities, community organisations, Crown entities, or disability support providers (although providers' funding contracts may require them to plan and report under the strategy). Although submitters said that there is no national implementation plan and the strategy is not well monitored, we are aware that a review of the strategy is in progress. Government advisers informed us that the Office for Disability Issues proposes to develop a framework for longer-term planning and reporting against the New Zealand Disability Strategy in 2008. This is expected to make targets more transparent.

People with disabilities told us that social attitudes toward them need improvement to remove barriers to their full participation in their communities and in society. Exclusion from opportunities such as access to employment is still a problem. Submitters said that people with disabilities were not engaged in meaningful consultation on matters with a bearing on their welfare, and were often consulted only after decisions were made. However, we also heard that central and local Government are increasing their consultation with the disabled community and taking steps to improve the employment of people with

disabilities. It was suggested, however, that people with disabilities should not just be consulted, but should be included in the decision-making process on matters that affect them.

Implementation of the New Zealand Disability Strategy

We wish to make it clear that we generally agree with the New Zealand Disability Strategy's vision for the future, and believe the document offers a good guide for the development of disability support. However, we are concerned about the poor implementation of the strategy. Seven years after it was released, no timelines for implementation have yet been set. We consider that if the strategy is to achieve significant change in the lives of people with disabilities, adequate funding must be provided for its implementation, and a timetable with target dates must be developed. We consider that the lead entity we are recommending be established would be able to lead the implementation of the strategy and the development of a national plan of action.

Recommendation

4. We recommend to the Government that it make the new lead agency responsible for ensuring that the New Zealand Disability Strategy is put into action effectively, and establish a national plan of action to ensure that the strategy is implemented without delay by the appropriate agencies.

4 Current service provision

Overview of disability support services

In the early 1990s the Government of the day began making significant structural changes to the provision of disability services. In 1993, four Regional Health Authorities (RHAs) were established and over the next few years began purchasing many disability services from provider organisations, reflecting a new separation of funding, purchasing, and service provision. The RHAs took over responsibility for purchasing most services from the Department of Health, Area Health Boards, and the Department of Social Welfare.³ Needs Assessment and Service Coordination (NASC) organisations also began allocating disability services and support to individual people with disabilities on the basis of assessed need.

Since the mid-1990s, a wider range of people have received disability support as eligibility criteria have been widened and more people have taken up services. After the 1996 election the RHAs were amalgamated into the Transitional Health Authority, which became the Health Funding Authority in the late 1990s. The authority's responsibilities were subsequently transferred to the Ministry of Health after the passage of the New Zealand Public Health and Disability Act 2000. Responsibility for disability services for those with mental illness and services for older people had been devolved to DHBs by 2003.

The Government now funds various disability services, which are accessed through several Government agencies, to allow people with disabilities to live at home in their communities and in residential facilities. The funding pays for “home and community support”, which includes help with housework and personal care, and for support to facilitate employment, education, and transport. The support provided includes, for example, the employment of personal support workers, New Zealand sign language interpreters, equipment, and modifications to homes and motor vehicles. People using home-based support have various levels of need—they may require anything from a handrail in the bathroom to 24-hour care. People with disabilities mostly live in their own homes, but community-based residential facilities house many of those with high needs. We were informed that family, friends, and community groups provide most of the support for people with disabilities.

Responsibility for disability support falls largely on the Ministry of Health's Health and Disability National Services Directorate, the Ministry of Social Development, the Accident Compensation Corporation, DHBs, and the Ministry of Education. The Ministry of Health provides support for people, mostly aged under 65, with physical, sensory, and intellectual disabilities expected to last six months or more. DHBs provide support mainly for those over 65, and for people with mental-health-related disabilities. DHBs also support people who are expected to be disabled for less than six months. The Ministry of Health is responsible for policy as to what disability support the DHBs fund.

³ The disability allowance and most vocational supports for people with disabilities, education and housing services, and supports for people injured in accidents were excluded.

The Ministry of Social Development provides people with disabilities with social assistance payments such as unemployment, sickness, or invalid's benefits, childcare assistance, and disability allowances. If a person with disabilities receiving a benefit is in residential care, most of any benefit they receive is applied toward the cost of care, with the Ministry of Health paying the balance. The Child, Youth and Family Service, part of the Ministry of Social Development, may also be involved with the care of some children with disabilities. The ministry funds most vocationally-related supports and services, and provides some individual support for people with disabilities with very high needs. The ministry has also funded transition programmes, and is responsible for Pathways to Inclusion, a programme which we were told has had a significant effect on the disabled community.⁴

The 2006 New Zealand Disability Survey estimated that 414,000 New Zealanders required disability support. About 105,500 of them required help with daily tasks such as food preparation, shopping, everyday housework, bathing, and dressing. The other approximately 308,600 people used assistive devices or had some home help for heavier or more difficult household tasks. In 2006/07 the Ministry of Health spent \$754.9 million (excluding GST) on disability support. Environmental supports (such as items of equipment or modifications to houses and vehicles) accounted for \$76.6 million of this expenditure and a further \$320 million (excluding GST) of this money was spent on residential facilities for people with disabilities. In addition, \$26.2 million was spent on carer support and \$15.1 million on respite care.

Table 2 below analyses Vote Health's expenditure on disability services since 1996/97, excluding expenditure on support for people with mental health conditions.⁵

Disparity between Ministry of Health and ACC support

ACC and the Ministry of Health both provide disability support, but obtain their funding differently and allocate it according to different obligations. Under the Injury Prevention, Rehabilitation and Compensation Act 2001, ACC provides a no-fault national accident compensation scheme, which funds support for people disabled as a result of personal injuries that are covered under the scheme. ACC funds social and vocational rehabilitation entitlements, including home and vehicle modifications, which can include the costs of purchasing and modifying vehicles, and the costs of aids and appliances in accordance with Schedule 1 of the Act. This support is intended to restore to the maximum practicable extent the recipient's health, independence, and participation.

We were advised that the Ministry of Health has to divide a capped pool of money to fund support for people with disabilities that are not accident-related. This includes such things as home and community support services, residential services, supported independent living, carer support, and equipment and modification services. In some cases, it does not pay for the full cost of support. For example, in many cases, it pays for home modifications and vehicle purchases only after conducting income and asset tests—tests which ACC does not require, as the scheme operates under an entitlement-based framework. People with

⁴ Pathways to Inclusion is a vocational programme that supports people with disabilities seeking employment or community participation. In line with the New Zealand Disability Strategy, this initiative fosters the ability of people with disabilities to live an ordinary life and participate fully in the community.

⁵ Disability support transfers to Vote Health from Vote Social Welfare were completed by 1996/97.

Table 2: Vote Health expenditure on disability support, 1996/97 to 2007/08⁶

Year	Disability support⁷	Estimated DHB expenditure⁸	Total expenditure on disability support from Vote Health	% of Vote Health's non-departmental expenditure
	\$ (million)	\$ (million)	\$ (million)	\$ (million)
1996/97	852		852	17.6
1997/98	945		945	18.3
1998/99	1,047		1,047	18.7
1999/2000	1,125		1,125	19.0
2000/01	1,168		1,168	18.8
2001/02	1,185		1,185	18.7
2002/03	1,277		1, 277	18.8
2003/04	807	610	1,416	18.9
2004/05	638	856	1,493	18.3
2005/06	699	1,018	1,717	19.3
2006/07	755	1,074	1,829	18.7
2007/08	839	1,162	2,000	18.4

disabilities who have cover under the ACC scheme and an assessed need can have entitlement to home modifications, to more than one residence if necessary, and they are not income tested. These modifications can be extensive (for seriously injured clients) if they are assessed as necessary. While ACC funds the full costs of hearing aids for occupational noise-induced hearing loss, in most cases the Ministry of Health subsidises hearing aids only partially. This means that funding from the ministry may not enable people to participate in activities in the wider community. ACC will also fund a number of specific aids that the ministry will not. For example, it funds sports wheelchairs to allow people to continue to participate in sports they undertook before being injured, but the ministry is unlikely to do so.

People with disabilities eligible for entitlements through ACC can in general obtain more support than those funded by other sources. Submitters considered this inequitable, as people with similar disabilities can be funded quite differently depending on the cause of their disability. Government advisers pointed out that the ACC scheme has a different legal basis from the provision of support by other agencies to people with disabilities. ACC is a social insurance scheme funded through levies and Vote ACC, to provide entitlements to allow people who are injured to be restored to the maximum extent practicable, while the ministry receives a finite sum of money from which to fund all of its services.

⁶ These figures do not include funding for mental health services.

⁷ Until 1 October 2003 these figures included those both under and over the age of 65. From that date these figures include those with physical, sensory, and intellectual disabilities, largely aged under 65.

⁸ From 1 October 2003, DHBs became responsible for funding disability support for those aged 65 and over. Hence these figures are split from 2003/04 onward.

We were advised that it would not be appropriate to provide support in accordance with the obligations that ACC met: ACC focuses on supporting people to help them regain a degree of independence, whereas some people supported by other agencies have generally never had the opportunity to be fully independent. Moreover, ACC is a no-fault entitlement-based scheme under which accident victims lost the right to sue for lost wages or treatment costs. This means that in some cases accident victims may receive far less from ACC than they might if they could sue, although others would receive less than their ACC entitlements if they did sue. We note that there is no political support for the restoration of the right to sue. We are aware, nevertheless, that when the ACC scheme was conceived equitable service provision for all was the long-term aim.

Needs Assessment and Service Coordination

Needs Assessment and Service Coordination (NASC) organisations allocate most of the Ministry of Health's funding for disability support. NASC contracts are held by various organisations. About half of these organisations are owned by DHBs, and the remainder are community-based trusts or privately owned organisations. NASCs assess, plan, and coordinate tailored packages of support. Each person's disability support needs must be reassessed at least every three years, and their support package is reviewed at least once each year. People with disabilities and their families can, however, ask for their situation to be reviewed or their needs reassessed at any time.

Originally, NASC services were to be "one-stop shops" where a disabled person's needs in various sectors (for example, health, education, welfare, or justice) could be determined by a single assessor. This would have saved people with disabilities considerable time, energy, and anxiety. However, NASC systems have become confined to providing only those services and resources funded through Vote Health, although they do refer people to community-based services and other agencies that may be able to assist them.

Submitters' concerns

Submitters raised a number of concerns about the NASC system. We heard that NASC organisations do not always allow people with disabilities control and choice, as the support they can offer lacks flexibility. It was suggested that NASC assessments do not consider what each person really needs, but work out how a disabled applicant's needs can be fitted into available services. NASCs are said to be bureaucratic, and to focus on deficits rather than building on people's strengths, which is sometimes termed a deficit-based model of disability support.

Submitters were also concerned that NASCs in different areas of the country offer different services to people with similar needs. Some raised concerns about the appropriateness of NASCs' allocating funding and managing budgets. They complained that NASC staff did not engage with people with disabilities or their families and welfare guardians sufficiently to understand what support might be most suitable in each instance.

NASC assessments were considered by some people to be too frequent, and often seemed to focus pointlessly on confirming that people with disabilities were still disabled, regardless of the nature of the disabilities in question. We are advised by the Ministry of Health that, where a person has a life-long disability, there is no need to continually reconsider whether a person is eligible for support. However, NASCs are required to

reassess people at least once every three years and to review the appropriateness of supports at least once a year, to ensure that the support a person receives continues to be appropriate in the light of changes in such things as a person's impairment, circumstances, or goals.

Work in progress

Government advisers informed us that a NASC development programme from 2005 to 2007, which sought to improve consistency between NASC organisations, has introduced changes that may deal with some of the issues raised by submitters. The Ministry of Health has provided each NASC with the materials for consistent induction training, and staff have received training on working with Māori and Pacific peoples. NASCs were also, for the first time, funded for their operational costs in the same way and received increased funding.

It was suggested that processes for managing the funding of low-cost items and discretionary funding could be reviewed. We were told that the Review of Long-term Disability Supports (led by the Office for Disability Issues) agreed with increasing the use of discretionary funding to tailor support to the individual needs of people with disabilities.⁹ Cabinet has also agreed to allowing more flexibility in choosing the providers to be contracted for services—the current system requires that only providers with existing contracts be used. The ministry acknowledged that the process for accessing some disability supports could be simplified.

The Ministry of Health has undertaken some initiatives to provide people with disabilities with more integrated needs assessment and coordinated services. This has involved collaboration between Government departments and various other agencies. For example, the ministry undertook three needs assessment and service coordination pilots with other agencies in order to improve inter-agency cooperation in this area. The ministry also contracted CCS Disability Action Bay of Plenty and Waikato to provide a Supported Lifestyle service, coordinating access to a wide variety of supports for children and young people with disabilities. This demonstrated the benefits of flexible services, and in 2007/08 the ministry contracted CCS Disability Action to extend this service to Auckland.

We were advised that the time might be right for considering other options and models. At present NASC organisations focus on services funded by the Ministry of Health or available in the local community, and do not carry out assessments, or allocate supports, on behalf of other Government agencies. They could be adapted to provide more cross-agency coordination, which would be consistent with their original purpose. We note that the local area coordination model used in Western Australia to coordinate the provision of personalised, flexible support to people with disabilities, might usefully be adapted for New Zealand. We discuss the local area coordination model in greater detail below.

⁹ In the review, the Office of Disability Issues and other Government departments worked to improve the provision of disability support, considering how people find out about and access support, whether Government-funded support is shared fairly, and how Government agencies can work together to improve things for people with disabilities and their families. The review considered information already gathered from people with disabilities and undertook new consultation. The review was approved by Cabinet in 2004 and has now been completed.

We consider that the NASC system plays an important role, and might still be retained if local area coordination is adopted. However, NASC agencies should be clearly separated from service providers, and be specifically focused on the needs of the individuals rather than the entities providing disability services.

Recommendation

5. We recommend to the Government that it change the role of existing Needs Assessment and Service Coordination agencies to ensure there is no duplication with local area coordination, and that they focus on meeting the needs of individuals, rather than those of service providers. All Needs Assessment and Service Coordination agencies should have a clear separation from service providers. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

Local area coordination

We have taken an interest in the local area coordination support strategy implemented by the Disability Services Commission in Western Australia. Local area coordination is not focused on determining the services needed by people with disabilities and ensuring they receive them. Rather, the model is focused on ensuring a person can lead a “good life”; ten principles help clarify and define this concept, including self-sufficiency, self-determination, and relationships with family, friends, and the community. Once an individual’s requirements for a good life are established, they are helped to access services to help them live a good life. Entry into the local area coordination system is voluntary, and people with disabilities may choose to seek support by other means.

Central to the model are the local area coordinators, each of whom has a caseload of between 45 and 65 people with disabilities, with a mix of lower and higher needs. The relatively small number of people assigned to each coordinator allows a close relationship to develop between coordinator and clients, so support can be easily, quickly, and accurately targeted to their particular circumstances and needs. While coordinators have access to small amounts of discretionary funding, they are not providers of disability services; rather, their role is to know what services are available, help people with disabilities to access the services that they require, and act as an advocate for them as necessary. The coordinator also works with the wider community to encourage it to welcome and support people with disabilities.

We were interested to learn that the model has relatively low infrastructure and operational costs. Nevertheless, it manages to achieve significant benefit for a large number of people. The system has also reduced costs in some areas by reducing demand for some costly services that are not always necessary. We were informed that the system has been assessed as offering more value for money than any other disability services delivery mechanism.

We were impressed by what we learned about the local area coordination system, which could form the model for an effective entry point for people seeking disability services in New Zealand. We consider that it warrants consideration as a potential model for adoption in this country.

Recommendation

6. We recommend to the Government that it establish a new entry point in the community for people seeking disability information, in the form of an agency with the additional role of building community capacity and support, along the lines of the local area coordination system established in Western Australia. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

Residential services

Services funded by the Ministry of Health to support the living arrangements of people with disabilities fall into two main categories: residential services, provided in establishments where people with disabilities live and are cared for; and home-based support, which is provided to people in their own homes.

Residential facilities

Residential facilities are run by providers who own or lease the homes and provide support services to residents with disabilities. Submitters told us that many people with disabilities living in these residential facilities have limited choice in and control over their lives; this was also reported in the National Health Committee's 2003 report, *To Have an 'Ordinary' Life*.¹⁰ Residents may, for example, have little choice over whom they live with, who provides them with care, what they eat, or when they get up and when they go to bed and what they do during the day; and they may often have little opportunity for involvement with the wider community outside the residence. Nor do those living in these homes have the protections offered by lease agreements or ownership rights.

Home-based support

People are also supported in living at home. Some are in supported living arrangements, through which supports are tailored to fit their specific needs. These arrangements can offer many people more flexibility and independence than residential services. Until recently, the Ministry of Health funded home-based support services, allowing people with disabilities to receive home-help and personal care. More recently, these services have been called "home and community support services", and offer people more flexibility in how the support is used. The ministry purchases these services through a service specification that was developed jointly with ACC.

Submitters' concerns

During this inquiry we learned that some people with disabilities who would prefer to live in their own homes have to live in residential facilities with others because they require a higher level of support than existing home-based services will provide or than can be funded. Others who choose to live at home do not receive adequate care for their degree of disability. Family sometimes therefore provide some or all of the necessary additional support, which can place considerable strain on them. Some submitters consider that institutional attitudes are pervasive even in community-based homes, arguing that deinstitutionalisation had led to the establishment of hundreds of miniature institutions,

¹⁰ The National Health Committee's report, *To Have an 'Ordinary' Life*, published in September 2006, is available online. See <http://www.nhc.health.govt.nz/moh.nsf/indexcm/nhc-ordinary-life#availability>.

where people with disabilities still have little say over their daily lives, and where they live with people not of their own choosing. While personal care is widely available to people with disabilities, funded support with tasks such as housework is restricted to those below a certain income, which usually means those with a Community Services Card.

Individualised funding

Individualised funding is based on the cost of home help and personal care for people with disabilities with high needs. It was introduced through the NASC organisations between 1998 and 2001 by the agencies that then funded disability support. However, soon after the Ministry of Health took over responsibility for disability support funding in 2001, it stopped the expansion of this service, as it was concerned about its inconsistent management and use in different parts of the country.

In 2003, a review of these services showed that approximately 250 individualised funding packages were being used across the country for people with long-term disabilities. It found that funding and eligibility criteria varied from place to place. In response the ministry developed principles and formal criteria for individualised funding, limiting it to people with high needs who would generally receive significant funding. It is currently based on the cost of home help and personal care for people with disabilities with high needs. The ministry also required assessment of the capability of the disabled persons or their appointed managers to manage the individual funding and meet the accountability and contracting requirements. Manawanui-In-Charge was contracted in 2005 to support people using individualised funding. This service provides advice about employment contracts, job descriptions, accounts, and other employment matters.

Submitters informed us that individualised funding is insufficiently used, as only a relatively small number of people in some parts of the country use this arrangement for a limited range of supports. As at July 2008, there were 129 people in Wanganui, Taranaki, Waikato, Auckland, and the South Island using the new programme, including some who transferred from the older arrangements and some newly referred.¹¹ There are also some arrangements that have been recently developed by other providers who are contracted to the ministry. We were told that the Ministry of Health is reviewing the programme with a view to continuing to roll out individualised funding around the country. It is also considering expanding the scheme and improving access to it.

We were advised that this method of funding requires people with disabilities and their families to be extensively involved in decision-making, care planning, and independent management of their care. While this is an attractive option for some people with disabilities, it is unlikely that it will suit everyone. The ministry noted that such funding would not resolve certain difficulties, such as that of finding good personal support workers. We understand, however, that measures can be taken to reduce the pressure on people with disabilities who use individual funding packages, and their families. The ministry and other Government agencies are looking into ways to provide individualised funding to more people with disabilities, in keeping with international trends.

¹¹ Those who were already receiving individualised funding packages and were not eligible to transfer to the new arrangements can continue to receive funding under their original agreements.

Recommendation

7. We recommend to the Government that it direct the relevant ministries to ensure that funding is provided in a way that allows people with disabilities more choice about their day-to-day living arrangements. They should have better access to supported independent living and individualised funding. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

Young persons in aged-care facilities

We were concerned to learn from Government advisers that a number of people with disabilities aged under 65 are placed in aged-care facilities, which submitters described as unsuitable because they lack the social interaction and stimulation needed by younger people, though sometimes such younger residents are housed together, separately from older residents. We heard that those aged under 65 with disabilities requiring a high level of care are sometimes placed in these facilities, which the Ministry of Health considers to be an option of last resort. In April 2008 a total of 583 people under the age of 65 were living in such facilities.¹² We find this situation unsatisfactory and suggest that alternatives should be considered.

Work in progress

We were told that the Ministry of Health is looking at making support provision in clients' homes and in residential facilities more flexible. People with disabilities would then have more say in how the funding for their care should be used, rather than having providers or NASC organisations tell them what will happen. The boundary between household management funds and personal care funds could be made more flexible, which was one of the aims of a recent Home and Community Service Specification. A rehabilitation approach is planned to help people with disabilities become more independent. The ministry told us that it is evaluating ways of giving people with disabilities in residential facilities more choice about their support, living arrangements, food, activities, and personal support workers. The ministry wants such choices to be available for most people with disabilities.

While some people with disabilities may not desire changes to their services, for those who do it is best where possible to cater to their preferences. This would involve adjusting contracts with providers to make people with disabilities a key part of the decision-making process, and to make it clear that the quality of their everyday life is important. We were advised that not all providers will be readily able to introduce such changes, so it may take some time to achieve these goals.

Recommendation

8. We recommend to the Government that it ensure that age-appropriate services that provide a good quality of life in ordinary surroundings are made available for younger people with high needs, who are now placed in rest homes inappropriately. We consider this should be achieved within two years.

¹² Three of these people were aged between 23 and 29 years, 124 between the ages of 30 and 49, and 456 people between the ages of 50 and 65.

General service provision issues

Contracting limitations

Submitters complained that their choice of providers is constrained by the fact that Government agencies, particularly the Ministry of Health, issue contracts to a limited number of providers. People with disabilities using such Government services can access services only through the contracted providers, limiting their choice and sometimes causing delays where services are in high demand. We were also told that the lack of competition discourages providers from improving their services.

Government advisers told us that expanding the number of providers contracted to supply disability support services might provide some benefits, but could also have drawbacks. People with disabilities would have more choice, different cultures might be better catered for, and providers might be encouraged to improve their services. However, advisers informed us that bringing more providers on board could increase administration and service costs. New providers might initially have difficulty providing services as cost-effectively as existing providers. Opening up the system might not necessarily improve the choice of providers, particularly for those who have difficulty finding suitable providers for their particular needs; and a strong monitoring regime would be needed. Nevertheless, we also heard that while small providers might face challenges, they are often more innovative and flexible than larger organisations.

Impact on families

Submitters raised concerns about the disproportionate impact that significant impairments have on the families of people with disabilities. Heavy burdens fall on unpaid caregivers, who do not always have adequate support. We heard that unpaid caregivers would like more support, to help them cope with the strain of looking after family and friends with disabilities. The Ministry of Social Development has developed the Carers Strategy and Five-Year Action Plan for the Government, in consultation with the Carers Alliance, which was launched in April 2008. We were advised that the concerns raised in this inquiry about the lack of support for family caregivers were considered during the preparation of the Carers Strategy and Action Plan by the Government. The responsible agencies are now starting to implement the plan. We note that the action plan contains a number of detailed actions in five different areas, each action with a specified timeframe for delivery. We also understand that the governance and monitoring arrangements are being developed, and are expected to be in place by the end of October. We regard the impact on families caring for a person with disabilities as a matter requiring urgent attention, and we therefore welcome this strategy. We hope to see the various actions implemented promptly, consistent with the specified timeframes in the action plan.

Submitters also raised concerns about what will happen to children with lifelong disabilities when their parents can no longer provide support and advocacy for them. Government advisers suggested that this issue could be examined as part of the Ministry of Health's Disability Services Research Agenda.

We learned that the Review of Long-term Disability Supports reported problems with the support available to families with children with disabilities. We were told that methods of supporting families with children with disabilities early in the child's life are being

considered. The objective of this is to minimise stress on families, and to prevent crises from arising. We suggest options are developed to cover such families' needs.

We understand that the Ministry of Social Development plans a number of initiatives to improve access to support services. Some are intended to ensure that current services are provided effectively within existing constraints, and gather information about the circumstances of the families that access these services. Other initiatives seek ways to support informal carers more effectively, increase participation in early childhood education, and allow early recognition of children with special education needs to ensure that appropriate assistance is provided. We are informed that the Ministry of Social Development, the Ministry of Health, and the Ministry of Education are working together to provide equal access to mainstream services for children with disabilities.

Recommendation

9. We recommend to the Government that it ensure that better support is provided for unpaid caregivers, and that the New Zealand Carers Strategy is implemented urgently. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

Special education

The Ministry of Education is responsible for the provision of special education services for people with disabilities. While we heard some evidence about these services, it was not sufficient for us to make broad recommendations. We note that some submitters argued that the Ministry of Education is biased against "special schools" for children with disabilities and favours mainstreaming students with disabilities, which limits the choices parents can make regarding their children's schooling. We were also told that support for students with disabilities in some mainstream schools is inadequate, and some schools were biased against pupils with disabilities.

We learned that young people with disabilities may have difficulty making the transition from school to employment or other activities, and that support for some of them is lacking. The Ministry of Social Development has run successful pilot programmes to aid children in transition from school, allowing students with disabilities in their final year of schooling to experience various post-school options, including employment, training, or further education. Students are also assisted in creating a transition plan, setting their own goals, and making informed decisions on their options. These pilots, which involved 15 providers, have now been completed, and transition services are now being offered by 65 providers across the country for students who are funded for extra support under the Ministry of Education's Ongoing Reviewable Resourcing Scheme (ORRS). In some places, for the first time, students and their families now have a choice of provider. Individualised services have been made available for students of school-leaving age with very high needs, to purchase vocational services. Recently the criterion for this funding has been changed from requiring the students to be 21 years of age, to making funding available to students who are over the legal school leaving age. We recommend that these initiatives be further extended.

Recommendation

10. We recommend to the Government that it extend pilot programmes for students with disabilities in transition from school into employment, training, or further education, and ensure that the effectiveness of these programmes is monitored closely. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

Service gaps

Submitters expressed concern about the adequacy of funding for many kinds of disability support. We heard, for example, that the funds allotted by the Ministry of Health to pay for community-based residential services for people with intellectual disabilities are set to cater to people with disabilities living in residences with five or more other people, and do not cover the cost of providing what submitters consider to be adequate care.

There were also concerns about gaps in many areas of provision. We heard that very limited support was available through the Ministry of Social Development for people with disabilities who wished to work or participate in their community during the day, and that parents with disabilities are not well supported, nor are people needing rehabilitation.

Respite care, important for unpaid caregivers and family, is not readily available in some areas of the country, which can throw some families into crisis. Respite care is crucial in many cases to ensure that families can continue to manage the long-term care of family members with disabilities. We also understand that because of shortages in the caring and support workforce some respite care is inadequate, but still used by families desperate for support. We understand that the Ministry of Health is funding an additional 48 respite beds from 2008/09, at a cost of \$3.4 million per year. To date, the new services have been mainly in Auckland, but new residential respite services are also being sought in a number of other areas throughout the country. In addition, we are informed that respite services are being made more flexible to allow more choice about how to use these services. We consider that respite care should be available nationwide, with sufficient funding and resources to ensure an appropriate level of quality care. We therefore welcome this improvement, and hope to see further developments in this area.

Transport other than public transport is often unavailable; and in some areas, especially rural areas, access for people with disabilities to public transport is limited. We also heard that limited funding is provided for people with disabilities to participate in sport and recreation, and that children may have unacceptably long waits for disability-related surgery. For example, submitters informed us that the waiting time for spina bifida operations is too long, and many submitters felt that what they considered to be essential surgery for their children was given a low priority.

We heard concerns about the limited funding provided for those with autism spectrum disorders. Submitters informed us that autistic people cannot get funding for support unless they have a dual diagnosis, although we were advised that this is not the case in some areas of the country as there is some variation in operational practice; and autism is often treated as a mental-health condition rather than a disability. While the Ministry of Health funds a national disability information and advisory service for people with autism spectrum disorders and their families, it does not usually fund specific supports for people

with autism unless they also have an intellectual disability (as do 55 to 70 percent of people with autism spectrum disorders). DHBs may fund clinical support for those with autism spectrum disorders who also have mental health conditions. The ministry is aware that there is a gap in the service provided for some people with autism, particularly those with Asperger's Syndrome (also known as high-functioning autism), and we were advised that the ministry and other agencies are reviewing responsibility for funding for this group. The ministry hopes that new evidence-based guidelines for autism spectrum disorders will help develop better services.¹³

There were also concerns about gaps and mis-matches in the Ministry of Health's funding of equipment such as wheelchairs, or home and vehicle modifications. Submitters complained that the structure of the funding meant that only a restricted list of pre-approved supports could be provided, and suggested that more flexibility was needed to cater to individual circumstances. We were informed that the primary focus of the Ministry of Health's support provision is ensuring that a person is able to live safely in their own home; but people with disabilities want to live relatively normal daily lives, which includes being able to participate in their communities. Submitters argued that this should be the rationale for the provision of equipment and modifications.

The Ministry of Health is aware of the kind of limitations in its equipment and modification services that submitters described to us. In 2005, a review found funding gaps, which have been partly filled by making funding available for modifications to family vehicles (such as platform hoists) when a child is disabled, and additional funding for visual and vibrating alerts (such as specialised smoke detectors) for deaf and hearing-impaired people. We were told that the ministry considers that at least \$70 million per annum would be required to address the gaps in the equipment and modifications for which it is responsible. To begin to tackle them, in 2006/07 the Ministry of Health increased funding for equipment and modifications by \$9.65 million, an additional \$17.7 million in 2007/08, and a further \$4.5 million in 2008/09. Some of this additional funding, however, has been used to pay for the increased costs of, and demand for, existing services.

Government advisers told us that the Ministry of Health manages its funding in order to keep within its appropriated budget as required under the Public Finance Act 1989. They also suggested, however, that some improvements could be achieved by allowing people with disabilities to have more choice and control over what funds are spent on, thus targeting expenditure better. We consider there is a need for more flexibility when providing equipment and modifications. In particular, we consider that a mechanism might be considered where providers can easily authorise expenditure on lower-cost equipment up to a set limit. This would allow a person with disabilities to promptly access some required equipment without unnecessary hassle.

Recommendations

11. We recommend to the Government that it allocate sufficient funding and resources to make high-quality respite care available nationwide.

¹³ These guidelines are available online: <http://www.moh.govt.nz/moh.nsf/indexmh/nz-asd-guideline-apr08>.

12. We recommend to the Government that it provide more flexible, streamlined funding for equipment and modifications by allowing providers to authorise expenditure on lower-cost supports up to set limits. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

Waste in service provision

If effective, efficient disability services are to be provided, it is essential that the limited resources reach the intended recipients in a form that is of genuine worth. We were concerned when we heard about various examples of wastage of resources that could have been used to benefit people with disabilities. Some submitters reported having services allocated to them that they neither requested nor required. We heard that some people with disabilities were required to undergo regular NASC reassessments to determine eligibility for various services, even where there has been no change in their condition.

We are concerned that, where respite care services are unavailable in a region or where these services were not desired, funding cannot be carried over from one year to another, or cannot be used flexibly for other services.

We also heard a number of complaints that the costs associated with auditing disability services were excessive, and suggestions that the money spent on covering audit costs could be better used to fund additional services. (We discuss the audit process in more detail on pages 32 to 34.)

It is vital that the limited funding made available for disability services be targeted to achieve the greatest possible benefit for people with disabilities. For this reason, we expect departments funding disability services to ensure that the money is not being spent wastefully, and to respond promptly to situations where waste is found.

5 National standards

Overview

Providers are expected to meet standards, which vary depending on the kind of services they offer. Contracts with various Government departments can specify, for example, that providers comply with Health and Disability Sector Standards, and in some instances provide for monitoring arrangements. The monitoring and audit process is regulated by a number of Acts. The Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights, the Human Rights Act 1993, and the Health and Disability Services (Safety) Act 2001 may require disability support providers to meet certain requirements. For example, under the Health and Disability Services (Safety) Act residential disability support facilities with five or more beds are required to be certified, and must pay to be audited by designated audit agencies. Certification generally lasts from one to three years, with an additional surveillance audit in the middle of the certification. General safety legislation such as the Health and Safety in Employment Act 1992 and the Building Act 2004 may also apply to disability support providers.

As of June 2007, the Ministry of Health contracted for residential facilities covering 6,600 beds (not necessarily all in use). These beds were spread across 1,650 residential facilities, most of which (about 900) catered to fewer than five residents. However, the approximately 750 facilities catering to five or more people with disabilities provided the majority of beds (4,300). Facilities with five or more beds must be certified under the Health and Disability Services (Safety) Act. Those with fewer than five beds undergo a different kind of checking process, in which they are audited to ensure that they meet the obligations specified in their contracts (providers who are certified may also be subject to contract-based audits).

We were told that the Ministry of Health, in conjunction with the ACC, is moving toward outcomes-focused contracts with providers of home-based support services. Those funded through the Ministry of Health are required to conduct client satisfaction surveys, have processes for managing complaints, analyse complaints regularly for trends, and operate performance appraisal systems for staff.

Submitters' concerns

Submitters complained that audit checks monitored compliance with systems and processes, and did not focus on the quality of life offered to the people with disabilities in the facilities. While contracts may also contain requirements that services observe principles such as ensuring people with disabilities enjoy a high quality of life, submitters told us that providers and staff tend to focus on ensuring paperwork is up-to-date and all standards for equipment and processes met. Submitters suggested that it was more important to ensure that the environment created for residents allowed them a satisfactory quality of everyday life, with opportunities for them to develop their abilities.

It was suggested that audits are too frequent, especially when providers are subject to separate audits by multiple Government agencies. Some submitters were not aware of the standards; and some were not given ready access to information about whether the providers they used met certification standards. We were also told that the certification process is expensive, especially for small providers, and it is questionable whether it has improved safety or the services offered by residential facilities.

Providers are notified when an audit will take place, which some submitters feared allows them to ensure that services meet standards just for the period of the audit; so audits may not measure the normal running of a residence. However, we were advised that unannounced audits could be intrusive and disturbing to residents, although they might be appropriate and are used when there are risks of serious harm occurring. Submitters were also concerned that residential facilities with four or fewer residents are not required to meet mandated standards, in contrast to larger facilities, which are subject to detailed audits and compliance processes.

Work in progress

We were informed that the Ministry of Health is working on changes to the monitoring and audit system. For example, it is working with DHBs to reduce the duplication of monitoring processes when these two institutions are auditing the same providers and services. While we were advised that duplication with large providers, such as IDEA services (the service provider arm of IHC) has not caused significant issues, we learned from other sources that these providers are concerned about the number of audits to which they are subject.

We were advised that Disability Services in the Ministry of Health has recently changed the way it conducts contract-based audits of community-based residential services. These changes largely affect residential facilities with fewer than five beds, although such audits may also be used for larger facilities. The revised audit process (called “developmental evaluations”) gives people with disabilities and their families a greater role in the monitoring process. Developmental evaluations shift the focus away from systems and processes, to consider whether a service allows people to achieve their goals, have input into their living arrangements, influence the choice of facility in which they reside, and have some say as to who they live with. It will also look at access to programmes that foster independence and self-determination, and whether privacy and confidentiality are respected. The Ministry of Social Development uses a similar process of developmental evaluations.

We have been told the developmental evaluation approach is preferable to Ministry of Health auditing under the Health and Disability Services (Safety) Act because it addresses quality of life issues. We consider Disability Services’ recent introduction of developmental evaluations to be a step in the right direction, but wish to see this change extended to other monitoring and audit processes. We support the emphasis on measures of quality of life, and emphasise that they also should be used for monitoring under the Health and Disability Services (Safety) Act for all facilities.

We were surprised to learn that the ministry considers that effective audits of rest homes can be conducted without talking to residents, staff, or residents’ families. We consider that

feedback from the people involved in providing and receiving services is essential to adequately assessing the quality and effectiveness of the services.

The Ministry of Health accepts that establishing separate standards for monitoring the disability sector under the Health and Disability Services (Safety) Act could be desirable. We were advised that it might be useful to provide ready public access to audit and evaluation reports prepared by designated audit agencies. At present these are available only when requested under the Official Information Act 1982. This change would allow people with disabilities to access more information about the quality of the services that they receive from particular providers.

We were advised that the Ministry of Health is undertaking consultation on whether all residential facilities should have to meet the same standards and be certified under the Health and Disability Services (Safety) Act. It is also considering re-examining the process for designating audit agencies. The ministry has advised us that it is shifting the focus of contract-based monitoring on to outcomes for people with disabilities, away from processes and systems.

Recommendations

13. We recommend to the Government that it ensure that evaluations and audits of disability services focus on the quality of life and the opportunities for people with disabilities. Evaluations and audits should be focused on development and satisfactory outcomes for people with disabilities rather than on compliance with minimum standards for audit purposes. Teams must have the freedom and the responsibility to talk with all stakeholders involved in services. We consider this should be in place within 12 months.

14. We recommend to the Government that it develop disability standards for community services, with appropriate outcomes-focused evaluation processes, and require the lead disability agency to ensure that duplication is avoided and that best practice is followed. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

15. We recommend to the Government that it give people with disabilities and their families a key role in the monitoring process, to ensure that quality of life is measured and valued. We consider this should be done within 12 months.

16. We recommend to the Government that it make the evaluation reports of services readily available to the public, taking care to preserve the privacy of individual residents or service users, and their families. We consider this should be done within six months.

6 Advocacy and complaints processes

Overview

The Health and Disability Commissioner provides Government-funded advocacy for people with disabilities and their families. The commissioner's Nationwide Advocacy Service was established under the Health and Disability Commissioner Act 1994. The service employs 36 full-time-equivalent people to act as advocates on complaints regarding the health and disability sectors, and this is expected to rise to 41 people by 2010. The Code of Health and Disability Services Consumers' Rights obliges the commissioner to promote and protect the rights of people using health and disability services, and under the Act the commissioner is charged with making public comment on these matters. The commissioner acknowledged that his work on disability issues was not satisfactory and that health issues often take priority over issues affecting people with disabilities. The appointment of a disability commissioner might resolve some of these issues, but would require legislative change.

We were told that advocacy for people with disabilities is also provided by friends, family, and non-governmental organisations, with a number of groups advocating systemic change. The Ministry of Health also requires the residential facilities it funds to provide residents with access to independent advocacy services. The ministry's disability services group does not directly fund advocacy, but does fund independent advice for people with disabilities and their families through its Disability Information and Advisory Services. Organisations contracted under this service specification provide information on Government and non-government services, including information on support and advocacy groups.

Submitters' concerns

Submitters raised a number of concerns about current advocacy and complaints services. We heard claims that in New Zealand advocacy and complaints have become confused, with advocacy actions generally occurring only as a result of complaints. Advocacy and complaints should be distinct processes, we were told, and should be clearly separated, though it was recognised they are complementary. Many submitters told us that raising complaints about service and support provided is difficult as people with disabilities and their families fear repercussions. While a complaint is under investigation a person with disabilities is likely to continue receiving care and support from the service provider or person about whom they are complaining. Such complaints may be lodged by various means, through the service provider, the NASC, the Health and Disability Commissioner, the Ombudsmen, the Human Rights Commission, political representatives, or, in some cases, the police. Submitters also told us that complaints processes are often difficult to understand, adversarial, and require people with disabilities to undertake tasks such as writing, which may be difficult for them.

Submitters raised concerns about the Health and Disability Commissioner's office, which a number consider has not taken some complaints seriously. It was pointed out that even apparently minor complaints may have a significant impact on the quality of a disabled

person's life. Submitters complained that the Health and Disability Commissioner's advocates focused on complaints about the quality of services; people with concerns about the funding of services could not obtain assistance through the commissioner. We were told that the advocacy that is currently provided does not seek to establish solutions to problems, but rather to apportion blame for faults. The result is that resolving complaints takes priority over improving the quality of life and service for complainants. Some submitters conceded that improvements are being made to the Health and Disability Commissioner's Nationwide Advocacy Service, but they still considered it to be inadequate.

We consider that many of these concerns can be addressed by the establishment of an independent disability commissioner, although this could be formed as part of the Office of the Health and Disability Commissioner. We realise that the Health and Disability Commissioner is limited to providing advocacy for health-related issues affecting people with disabilities. However, as disability issues affect all areas of life for a person with disabilities, we believe a dedicated disability commissioner should have the ability to provide advocacy in all areas, including education, social development, and housing, as well as health. They should also have an increased ability to provide advocacy in areas such as funding decisions and access to services.

Submitters noted that funding decisions by the Ministry of Health and NASC organisations cannot be readily challenged, as there is no independent complaints service to monitor them and the Health and Disability Commissioner's advocacy service is not empowered to evaluate funding decisions. Most submitters argued that advocacy should be independent from providers and funders of services. However, two non-governmental organisations that provide disability services argued that they should continue to provide advocacy services.

Some submitters argued that systemic advocacy is important to address systemic problems, which are not dealt with effectively through individual complaints. Government advisers acknowledged the need for systemic advocacy and more transparent decision-making, but pointed out that it would not normally be appropriate for Government departments to fund systemic advocacy. This would lead to a conflict of interest, with organisations being funded by the Government to advocate against its own policies.

Recommendations

17. We recommend to the Government that it investigate the appointment of an independent disability commissioner, possibly within the office of the Health and Disability Commissioner. Any required legislation should also expand the areas the commissioner may examine to include, for example, access to services and individual funding issues. The commissioner should be responsible for considering disability issues in relation to health, education, social development, and housing, and promote the recognition that disability is a fact of life and not primarily a health matter.

18. We recommend to the Government that it introduce legislative change to strengthen and expand the scope of Government-funded advocacy and complaints services for people with disabilities. This should enable the independent disability commissioner to oversee access to disability services.

19. We recommend to the Government that it make it possible for complaints about disability support to be lodged verbally, to improve access for people with disabilities.
 20. We recommend to the Government that it establish an independent process for reviewing funding decisions made by Needs Assessment and Service Coordination organisations and the Ministry of Health.
 21. We recommend to the Government that it require the disability commissioner to establish a process for checking that his or her recommendations have been acted upon.
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7 Workforce conditions and training

Overview

People work in the area of disability support in many different capacities. The largest part of the workforce, about 40,000 paid members of the caring and support workforce, provide care for people with disabilities in their own homes, in residential and group homes, and in community participation day services. In recent decades there has been a significant increase in the provision of home help and personal care for people in their homes. Physiotherapists, psychologists, neurologists, occupational therapists, audiologists, optometrists, hearing therapists, speech language therapists, and social workers also provide support to people with disabilities. This workforce is expected to increase as life expectancy for people with disabilities improves and the population ages.

Submitters' concerns

Submitters informed us of serious concerns about the recruitment and retention of the caring and support workforce, and its high staff turnover. These problems affected all disability supports, including those funded by the Ministry of Health, DHBs, and ACC. We heard about many situations where irregular care, absent personal support workers, and untrained staff had caused distress. Serious staff shortages have arisen, and lack of training affects the quality of service provided.

The most significant problem lies with the personal support workers who provide daily support to people with disabilities. This is a low-status job, with low pay rates that do not reflect the difficulty or responsibility of the work. Low unemployment means that the caring and support workforce can find alternative work relatively easily, and there is a high turnover among workers. Working hours are irregular, and many support workers work long hours to the detriment of their wellbeing. People working as support workers are not often trained in disability care, and indeed few opportunities for vocationally appropriate training are available. We were also told that there is no career structure, which reduces incentives to stay in the industry, and workforce planning is also lacking. The ageing population will put further pressure on this workforce.

Caring and support workers can be unreliable, submitters informed us, and there is a significant problem with workers who do not show up on time or at all. This can cause significant hardship for people who, for example, need help getting out of bed in the morning. We were told that one person with disabilities was left in an upstairs bedroom and neglected for four days. We heard that people with disabilities often have little choice as to the personal support worker employed in their homes, some of whom fail to behave appropriately. Personal support workers sometimes cannot perform some of the tasks a person with disabilities thinks are necessary, because of inadequate training or limitations imposed by their contracts. In addition, we heard evidence that, in a period of low unemployment and high turnover among untrained workers, some employers do not vet employees as vigilantly as is desirable, adding to the potential for abuse. We heard that one

worker who lost their job after physically abusing a person with disabilities was quickly hired by a different provider.

Submitters believe the workforce situation could be improved in a number of ways. Some suggested background checks and mandatory training standards for those working with people with disabilities. They proposed that the training of disability support workers should include an understanding of the social model of disability, and the basic principles of rehabilitation. More specialists are needed; a shortage has caused difficulties for those caring for people with disabilities without expert input or backup. However, academic training opportunities in this area are limited, though we learned that a Bachelor of Human Services with a major in disability has recently been introduced.

We were told that there is a need for affordable foundation courses for disability support workers to teach them to respect and understand the needs of people with disabilities. This could take the form of values-based training programmes, to show staff how society has traditionally perceived people who are “different” to be of less value, teach them to value people equally, then give them the skills to ensure they can support people with disabilities appropriately. Skills-based training is also needed. Lengthy courses would be problematic in an industry with low pay and a high turnover. We understand the kind of short courses that would be appropriate for this industry are not widely offered and we suggest that steps be taken to establish them at appropriate tertiary institutions.

Work in progress

We understand that the Government has recently taken steps to ensure that people working in the disability sector will receive higher wages. The Home and Community Support contract (for care given to those who do not have a disability as a result of aging), signed by most providers, required a 2007/08 funding increase of 11 percent to largely flow through to wages. This additional funding is expected to help reduce staff turnover.

In response to concerns about training, a National Certificate in Community Support Services has been introduced. The Health Workforce Advisory Committee recommended that a career structure be formalised for the disability support workforce. A cross-health-sector care and support workforce initiative is working on initiatives to develop the disability support workforce. A career framework for the health sector was launched in October 2007 and, following additional consultation, the Disability Services Consumer Consortium endorsed the applicability of this framework to the disability support workforce in May 2008. DHBs, ACC, and the Ministry of Health have piloted and evaluated a training programme for providers employing home and community support workers.

We have been warned that the introduction of minimum standards for the disability workforce could restrict the pool of workers at a time of significant shortage. Requiring the workforce to pay for qualifications could also create difficulties in this low-paid area of work. We are concerned that in practice introducing workforce regulation may make it more difficult for providers to employ carers. Nevertheless, we consider that establishing minimum standards will ultimately improve the career opportunities of employees while providing better support for people with disabilities.

Recommendation

22. We recommend to the Government that it establish a strategy for improving training, pay rates, and working conditions for the caring and support workforce in the disability sector, including those funded through Vote Health. Such a strategy should include a structured career path, a skills-based pay system, values-based training for all staff, and consistent and appropriate conditions of work, including health and safety, safeguards, and paid training. The funding should take into account the requirements and costs of training. The relevance and appropriateness of all current training programmes should be reviewed immediately in the light of our recommendations. We also ask that progress reports on this matter be provided to the Social Services Committee every 12 months.

8 Conclusion

Accountability and collaboration

At present disability support services are fragmented, and often difficult to access. We consider that urgent improvement is needed to the coordination between the various Crown agencies involved, and a lack of leadership in the sector must be addressed. We recommend that a single agency should be established to manage and coordinate the provision of disability services, and take a leadership and advocacy role in the disability sector. This entity should be able to ensure the implementation of the New Zealand Disability Strategy, as well as the recommendations arising out of this report. Its dedicated focus on disability issues should ensure change in the disability sector.

The place of the New Zealand Disability Strategy

We wish to reiterate our endorsement of the New Zealand Disability Strategy, which has the potential to provide a clear guide for the development of disability supports. However, we consider that the implementation of the strategy has been unsatisfactory, and necessary funding has not been available. These issues need to be addressed urgently. We hope that our recommended single lead agency will provide the leadership to ensure that the strategy achieves its intended effect.

Current service provisions

A comprehensive review of funding for all disability support services, admittedly a huge task, would provide a sound information base for prioritising Government funding more effectively. In the meantime, we strongly urge the Ministry of Health to carry out its stated intention of making individualised funding available more widely, and its support services more flexible.

We would also like to see a high priority assigned to closing service gaps. Applying existing funding more flexibly should help to do this, but additional Government funding will also be needed to eliminate some of the gaps in provision.

We recommend an examination of the suitability of the local area coordination model used in Western Australia to provide personalised, flexible support to people with disabilities. We also recommend a clear separation between NASC agencies and service providers, and that the NASC model be focused on the needs of the individual person with disabilities.

We understand that the disabled community strongly supports individualised funding of disability support, and recommend that the Ministry of Health and the other agencies involved work to make it more generally available. We suggest exploring funding arrangements to allow more people with disabilities to choose and purchase their own equipment and modifications, along with auxiliary services to ensure that managing such funding does not put the families of people with disabilities under pressure.

The quality and continuity of service are crucial to the well-being of people with disabilities; the casualisation of this work is a trend that should be resisted, for the sake of both the workers and their clients. We recommend the promotion of good-practice employment agreements, and other measures to ensure that a stable, permanent workforce is maintained to support people with disabilities, and is appropriately valued.

National standards

We strongly urge the need for changes to streamline and reduce the cost of the audit and monitoring process for providers of care and support. These processes should focus on quality of life considerations and include evaluating the level of self-determination service providers make available to people with disabilities. Consideration should be given to requiring all providers to meet similar standards (we note our preference for developmental evaluations), and to ensuring people with disabilities and their families have a key role in the monitoring process.

Advocacy and complaints processes

Complaints processes need to be very clear, readily accessible to people with disabilities, and ideally independent. We consider that complaints processes and arrangements for advocacy on behalf of people with disabilities should be examined to determine how they can be brought into line with international best practice, if necessary by means of legislation. In particular there is a case for separating advocacy and funding roles; and people with disabilities and their families should be helped to advocate on their own behalf, to articulate goals, to make informed choices, and to apply for Government-funded support and services. Advocacy and complaints processes need to be expanded, and consideration should be given to establishing an independent disability commissioner to provide an advocacy role with responsibilities across all areas of life.

Workforce conditions and training

A high priority should be given to improving the disability workforce. Planning to improve training should consider the various needs of this workforce, their employers, and their clients. A range of educational and training opportunities are urgently required, and courses for the caring and support workforce should be affordable and include values-based training. We stress the need for mechanisms to safeguard work conditions (including health and safety measures and training) and standards of care. We favour the introduction of a structured career path and a skills-based pay system (applicable to all providers). We also expect to see further improvements to the increases the Government has made to the hourly rate paid to caring and support workers. Again, we consider that just one Government agency should have responsibility for effecting change.

Concluding comment

We are concerned by the issues raised by submitters. Future Governments should consider the recommendations of this report.

Petitions

We received three petitions on matters related to this inquiry, and the issues the petitions raise have been considered alongside those raised by submitters for the inquiry. The petitions are: petition 2005/47 of Kate Moulson on behalf of the Canterbury Branch of the Motor Neuron Disease Association of New Zealand and 124 others, petition 2005/49 of Averil Wooton, and petition 2005/56 of Sue Robinson and 533 others.

Appendix A

Committee procedure

We called for public submissions on the inquiry. The closing date for submissions was 25 August 2006. We received 152 submissions from the organisations and individuals listed in Appendix C and heard 76 submissions orally. We heard evidence in Wellington and Auckland. Submitters from other parts of New Zealand were heard via video conference and teleconference from Wellington.

The Ministry of Health, the Ministry of Social Development, and the Office for Disability Issues provided advice. Angus Capie was appointed as an independent adviser and provided comments on submissions and official reports. We thank the advisers for their assistance.

Committee members

Russell Fairbrother (Chairperson)
Sue Bradford
Hon Steve Chadwick (until 7 November 2007)
Bob Clarkson
Judith Collins (Deputy Chairperson)
Hon Harry Duynhoven (until 7 November 2007)
Hon George Hawkins (from 7 November 2007)
Dr Paul Hutchison
Hon Steve Maharey (from 7 November 2007)
Lynne Pillay
Heather Roy
Katrina Shanks
Judy Turner

Appendix B

Terms of reference

1. Current service provision arrangements for people with a disability and future directions (including home based, residential, vocational and community).
 - Historical changes in provision of care
 - Has New Zealand achieved appropriate models of care and choice, what changes are desirable including issues of continuum of care—what’s working successfully and why?
 - The right of those with a disability to live a life of independence and freedom (what are barriers and how can they be overcome?)
2. The way National Standards of care are determined, implemented and monitored, and any lessons learned from historical complaints and systemic failure.
 - That monitoring is carried out in the most effective way to ensure quality of care and support of individual disabled people and how best outcome is measured
 - Is the certification process a meaningful way of ensuring service quality?
 - That the current understanding of quality, as determined by the Standards, are appropriate to the function of supporting valued lives for disabled people. (Can the current auditing methods be improved?)
 - Contemporary issues relating to provider organisations that have caused public concern
3. The advocacy and/or complaints process for clients, and their families, residents and the public.
 - Is there a need for improved advocacy mechanisms—particularly for the most vulnerable?
 - Is there a need for improved complaints mechanisms?
4. The level of accountability, funding, information sharing, transparency and collaboration between relevant Ministries, community agencies and providers.
 - That there is clear accountability and understanding between the various Government agencies and providers of disability services
 - How responsive, effective and efficient are the current contracting arrangements, and how can they be improved?
 - Are the government departments working in tune with the practical application of the New Zealand Disability Strategy?
 - Office for Disability Issues

5. The quality of training, career structure and workplace conditions of the disability workforce

- Framework qualifications
- Workforce planning
- The level of availability of academic teaching, training, theory and learning in New Zealand

6. An assessment of the extent to which the New Zealand Disability Strategy is central to the wellbeing, rights, and care of people with disabilities.

Appendix C

List of submitters

1, 1A	David Heather
2W	Sean Parker
3W	Pip Cresswell
4W	Dr Brian Booth
5W	Joyce Calder
6W	Hazel Oldman
7W	Dick Bakker
8W	Ian Linn
9	Maree Kirk
10, 10A	People First New Zealand Inc.
11, 11A	Bronwyn Cooper
12	Raymond Alexander
13, 13A, 13B	Dixie Signal
14, 14A	D J Eivers
15, 15A	Auckland Disability Providers Network Inc.
16W	Calia Chevallier
17	Kathy Foote
18W, 18A	Phil and Maree Hobern
19W	Disabled Persons Assembly Eastern Bay of Plenty
20	Joan Power
21W	Golden Pond Home and Hospital
22W	Marion Eivers
23W	Helen Henderson
24	Ruth Gerzon
25W	Stuart Craig
26	Susan Mellsopp
27	Jessica Palmer Trust
28, 28A	Gracelands Group of Services
29W	Restcare Homes Trust
30, 30A	Action on Elder Abuse
31	Multiple Sclerosis Society
32W	Alzheimers Whakatane
33	Aaron and Sarah Pickering
34	Submission withdrawn
35	Justice Action Group
36	Royal New Zealand Foundation of the Blind
37	Chris Ruth Centre
38W	Taranaki APEPSI Trust
39W	Christine McKennan
40	Peoples' Advocacy Network
41, 41A	Community Support Services Industry Training Organisations
42, 42A	Gayle Cullwick

43	Anne Best
44W	Jan Glover
45W	Stroke Foundation, Central Region
46W	Disabled Persons Assembly Christchurch
47, 47A	Michael Keesing
48W	Lifestyle Trust
49W	Suzanne Win
50, 50A	Muscular Dystrophy Association of New Zealand
51	Hearing Association Inc.
52	Standards and Monitoring Service (SAMS)
53	Anne Chambers
54, 54A	Paul Deverall
55	Disability Equity and Lifestyle Support Incorporated (DEALS)
56, 56A	Dr Martin Sullivan
57W	Peter James et al.
58W	Heather Beaton
59	Christopher Brayshaw
60W	Hamilton Residential Trust
61W	Nationwide Health and Disability Advocacy Service
62	Disability Support Services Action Group
63	John Forman
64	Te Roopu Waioira Trust
65W	Parent to Parent New Zealand Inc.
66W	MidCentral District Health Board – AT and R ward
67	Central Potential Inc
68	New Zealand Federation of Voluntary Welfare Organisations
69, 69A	Disabled Persons Assembly New Zealand
70	Disabled Persons Assembly Auckland
71W	Standards Plus Ltd
72W	Disability Information and Equipment Centre
73	Social and Civil Policy Institute
74, 74A	Alan Jones
75W	Rebecca Short
76W	Dale Smith
77	Orau Ora, Maori Health Providers in Counties Manukau
78	Carole Gordon
79, 79A	Teresa Stuart
80	Christine Hayter
81W	Dunedin Community Care Trust
82W	Community Living Trust
83	Health and Disability Commissioner
84, 84A	CCS
85	Combined Trades Union
86W	Dianne Cowan
87	Michael Forde
88W	M and R Miller
89W	PACT Group

90W	Southland District Health Board Disability Support Advisory Committee
91	Darcey McDonald
92W	Disabilities Resource Centre Trust
93W	Eastern Bay of Plenty Ostomy Society
94	National Residential Intellectual Disability Providers (NRID)
95W	Judith M Hellyar
96W	Anne-Marie Farquhar
97	Graeme Farquhar
98	Autism New Zealand Inc, Wellington Branch
99	Valerie Newman, QSO
100W	Diana Josephine Lord
101W	GJ Barnard
102	MacLean Centre, Mt Roskill Grammar School
103W	Margaret McQuillan
104W	Elysse Jones
105	Interagency Group Palmerston North
106	Tiaho Trust
107	Autism New Zealand Inc
108W	Lifestyle Choices Ltd
109W	Mary McLaren
110W	Donna Butler
111W	Disabled Persons Assembly Taranaki Region
112W	Autism Spectrum Disorder Information Network
113	Jonathan Darby
114	Waikato Kirk Branch, Labour Party
115	The New Zealand Federation of Vocational and Support Services
116W	Te Hauora Pou Heretanga
117W	Ruth Wieblitz
118W	L Carter
119, 119A	Wendy McArthur
120W	MidCentral District Health Board
121W	Hutt Valley District Health Board
122W	Lakes District Health Board
123W	Post Polio Support Society
124, 124A	New Zealand Public Service Association (PSA)
125, 125A	Age Concern
126W	LIFE Unlimited
127W	Stroke Foundation
128W	Nelson-Marlborough District Health Board
129	Mind and Body Consultants
130	Auckland District Health Board Disability Advisory Committee
131W	Mental Health Commission
132	Human Rights Commission
133W	Waikato District Health Board
134	Spectrum Care Trust
135	Sigjaws
136W	Dr Cindy Kiro, Children's Commissioner

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137	Hearing Association Inc
138W	Janet McCracken
139W	Nelson Marlborough District Health Board
140W, 140A	IHC
141, 141A	Ripple Trust
142, 142A, 142B	Capital and Coast District Health Board
143W	Timata Hou
144, 144A, 144B	The Brain Injury Association
145	Margaret Priest
146W	R, M, and R Beale
147W	Helene Ritchie
148	Michael Grigg
149	New Zealand Riding for the Disabled Inc
150W	Anonymous
151W	Special Olympics New Zealand
152W	Philip Smith