

Disability Support Services
Strategic Work Programme:

Building on the New Deal

Published in June 1998
by the Ministry of Health
PO Box 5013
Wellington

ISBN 0-478-22812-0
ISBN 0-478-22813-9 (Internet)

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

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Foreword

Over the last five years there has been significant change to the way disability support services are funded and delivered. Prior to the transfer of funding for these services from social welfare to health agencies in 1993, there was a wide-ranging debate on the merits of one agency over the other. The Government decided that funding for disability support services should be with one agency, and that was with health, through the regional health authorities.

Since 1993 there have been substantial improvements for people with disabilities and their families/whānau. Greater emphasis on community-based care and accessing care through a needs assessment and service co-ordination process has meant that more people are receiving services tailored to their actual needs.

There is a need for further progress in improving the way we deliver disability support services. We need to focus more on services to Māori and Pacific people, and to those people with multiple disabilities. We must plan and prioritise in a way that focuses on individual needs while at the same time recognising that there will always be finite resources.

I am aware that for some people with disabilities there are aspects of the current funding arrangements that actually disempower them from making their own decisions about the services they need and who provides them. It is my view that we should look at how we can bring some flexibility into funding arrangements so that people who want to, and are able, can have the independence they seek to assist themselves.

The *DSS Strategic Work Programme* has been jointly developed by the Ministry of Health and the Health Funding Authority to build on the progress already achieved in disability support services and to address areas of concern that still remain.

The work programme included in this document is designed to give service providers, consumers and their representatives a comprehensive overview of the direction that the Ministry of Health and the Health Funding Authority are taking over the next three to five years.

The recent announcement that health would not be exempt from the Human Rights Act 1993 is significant for providers of disability support services. The Government's announcement means no change to the current law as far as health and disability support services are concerned.

As Minister of Health, I am committed to three broad goals for services for people with disabilities:

- maximising independence

- effective habilitation and rehabilitation
- supporting opportunities to participate.

The work programme outlined in this document will go a long way towards meeting these goals.

Hon Bill English
Minister of Health

Introduction

This document sets out the disability support services (DSS) strategic work programme for the Ministry of Health and the Health Funding Authority (HFA) over the next three to five years. The Ministry of Health role focuses on strategic policy, monitoring the HFA, regulatory functions, and providing services for the Minister. The HFA focus is on operational policy and policy implementation in the purchasing of health and disability support services.

Progress to date

New structural arrangements for disability support services, growing out of the Health and Disability Services Act 1993, are now in place.

- Vote Health now has clear responsibility for funding most health and disability-related services for people who have disabilities.
- A Health and Disability Services Commissioner was appointed in December 1994.
- The Government created the national HFA, a single agency, which replaced the four regional health authorities on 1 January 1998.
- The consolidation of the funding agencies has resulted in a review of the respective roles of the HFA and the Ministry of Health (as above).

The new DSS structures have already led to significant improvements for people with disabilities. Clearly, not all issues have been resolved, but significant progress has been made in the following areas:

- Funding provision and matching of services are becoming based on assessed needs of individual people, rather than on generic assumptions based on the type of disability they have.
- There is a continued move towards community-based care. This includes new types of community residential care, deinstitutionalisation, and increased home-based support services to help people stay in their own homes.
- DSS providers are more aware of the need to specify clearly which services they will provide, and to plan for these services.
- There is a greater focus on providing information and on co-ordinating services.

Recommendations of the steering group to oversee health and disability support changes

The Steering Group was established in 1997 to provide advice to Ministers on the policy requirements and implementation issues of the health and disability sector changes contained in the Coalition Agreement on Health.

Their report identified three areas where there need to be changes if we want to make sure that service users' needs are better met and if we want to realise efficiency gains. These are increased flexibility, empowerment of service users, and better links between and among services.

In particular, the Steering Group pointed out¹ four major and specific problems in the current arrangements for delivery of services to people with disabilities:

- There is a tendency to treat disability support clients as though they were a single, homogeneous group. There are, however, significant differences not only between various client groups but also within single groups. As well, there are also different expectations for disability support services from particular populations – for example, from Māori.
- The move to third-party funding (via service providers) has decreased choice and autonomy for some DSS consumers. These are consumers who had been provided with individual cash entitlements, allowing them to arrange their own services, but who are now funded via a single, regionally based funder.
- Specifications of the interface between disability support and personal health have not been analysed. The lack of clarity can be compounded by people with a primarily medical background assessing and co-ordinating needs of individuals with a disability when the needs of those individuals are not in fact medical.
- Administrative costs have increased. This is particularly the case for costs associated with needs assessment and service co-ordination.

The Steering Group recommended the following developments for implementation of the Coalition Agreement on Health in the area of disability support services:

- Greater flexibility for individuals who have stable, well-identified needs to have more opportunity to organise their own support services.
- Lifting the existing requirement to separate needs assessment and co-ordination processes where there are clear benefits from integrating them.
- Strengthening the existing needs assessment process for greater consistency and quality.
- Flexibility for the funder to develop different approaches to implementing its contracting strategies, including being able to supply cash rather than in-kind assistance.

- Providing service users with better information about conditions of access to services or cash assistance.
- Improved links with government agencies offering services for people with disabilities.
- Further development of a culturally appropriate framework for disability support services for all New Zealanders, particularly Māori.

Clearly, many of the initiatives suggested cannot be undertaken immediately, and some will be achieved only in the medium to long term. Some are already under way, and planning for others will begin soon.

Consolidation phase begins

The completion of funding transfers from social welfare, the election of the new Government, and the introduction of new policies by the Government has provided an opportunity to take stock and plan for the future.

Much of the focus of the last few years has been on developing structure and mechanisms for policy, funding and service delivery. Now it is time to change the emphasis from structure to content.

This work programme provides a direction for the next phase. Using the work of the last five years as a foundation, it provides a direction for the next three to five years, the years of consolidation.

The Government is committed to providing security for, and avoiding unnecessary disruption to, people with disabilities and their families/whānau. Therefore, any changes proposed will be carefully planned and managed in consultation with DSS client groups and service providers. Changes will not be introduced until there has been a sufficient period of notice.

This *DSS Strategic Work Programme* is based on the Government's three key goals, which form the basis for any approach to assisting people with disabilities:

- maximising independence
- effective habilitation and rehabilitation
- supporting opportunities to participate.

(See Appendix 1 for details of these goals.)

These goals build on the framework and underlying principles contained in *A New Deal: Support for independence for people with disabilities*,² the Government's 1992 statement on support for independence.

This work programme is consistent with the Coalition Agreement on Health. It clearly establishes the Government's commitment to the disability sector, and it contributes to the Government's Strategic Result

Areas (SRAs) for health and disability services (SRA 7) and economic and social participation (SRA 5) (see Appendix 2).

The programme also takes note of the above mentioned recommendations of the Steering Group to Oversee Health and Disability Changes.

In identifying the further work that will be undertaken in DSS in the next three to five years, the *DSS Strategic Work Programme* focuses on what can be achieved within Vote Health. This work is organised under the following six broad aims:

1. increased recognition of DSS issues within the health sector
2. more flexible and transparent funding arrangements
3. increased quality and flexibility of service planning and delivery
4. consistent prioritisation and targeting of services
5. more effective intersectoral collaboration
6. appropriate services for groups with DSS needs, particularly for Māori.

In the interim, the budget for disability support services (DSS) remains ring-fenced to ensure it is not used on other services; it must be recognised, though, that funding for DSS (like all funding) is finite and will stay finite.

Priorities will therefore need to be set, to maximise support for people with disabilities in a way that makes the best use of available resources. It is also vital to make sure that funding allocations and decisions are transparent and made equitably. To this end, the HFA has asked the National Health Committee to provide specific advice on setting priorities and on decision strategies.

There will also be an ongoing process of regular consultation with people with disabilities, building on the National Health Committee's public dialogue programme, to make sure that all current issues are identified, options are fully discussed, DSS policy is comprehensive, and priorities are clearly identified.

The Work Programme

Aim 1: Increased recognition of DSS issues within the health sector

DSS information databasee 30 June 1999

The Disability Survey undertaken by Statistics New Zealand³ provides a useful snapshot of the characteristics of people with disabilities and their needs. However, there is a lack of ongoing robust information on the incidence of disability, the needs of people with disabilities, service availability and where funding is going. The HFA is leading a joint project with the Ministry of Health to develop a DSS database to improve the routine collection and analysis of information on people with disabilities, their needs, and the quantity and quality of services currently available.

Scoping has been completed and work will begin shortly to identify information needs. The development, testing and piloting of the database is planned for completion by the end of June 1999.

DSS outcomes

Concurrent with the development of the DSS database, the Ministry will undertake work to develop appropriate outcome measures and targets for people with disabilities.

In addition, health funding and strategy documents will include a section focused on DSS wherever this is appropriate.

Aim 2: More flexible and transparent funding arrangements

Contracting options

The Ministry and the HFA will assess various options for increasing the flexibility of funding provisions to more effectively meet the needs of disability support clients. This will include consideration of increased flexibility for the funder to develop different approaches to implementing its contracting strategies (such as budget holding, where an organisation is given the responsibility for ensuring that a defined population

receives a specified set of services, from within a certain budget). Work will also be undertaken to provide better definition and clarity for service users about conditions of access to services.

Options for individuals

The Ministry will explore mechanisms to provide greater flexibility for individuals who have stable, well-identified needs so that there is more opportunity for them to organise their own support services. Some service users are aware of their own needs and can organise services to meet their support requirements, while others require someone to act on their behalf. The Ministry is aware that if the agent role (the individual or organisation making a decision on behalf of someone with disabilities) is not interpreted flexibly enough to take account of these differences, the process can be disempowering for some clients.

Aim 3: Increased quality and flexibility of service planning and delivery

Review of DSS framework 30 June 1999

By 30 June 1999, the Ministry will have completed a review of the DSS Framework. This review will include examination of:

- the definition of DSS, to decide whether it is either feasible or desirable to widen the definition to include other groups, such as some people who have disabling conditions as a result of chronic illness
- the operation of needs assessment and service co-ordination processes to make sure that they are as effective as possible (a needs assessment process, independent of service providers, will continue to be a key element of the framework)
- the financial targeting framework to ensure that any flow-on effects or implications for prioritisation of access and eligibility for services, are addressed, as well as their appropriateness in light of the Coalition Agreement.

Expanding services

There will be further work in expanding the diversity and range of services provided to cater for the diverse needs and preferences of people with disabilities. There is, however, a need to balance consumer choice with costs and service provision implications. Whatever the mix of services, all providers will be expected to have a strong quality focus and be able to demonstrate how services are aligned with the goals and aims outlined in this *DSS Strategic Work Programme*.

Workforce development

Major skill, training and education gaps in DSS service provision will be identified by the Ministry and the HFA. A co-ordinated DSS workforce strategy will be developed, in consultation with the industry training organisations and educational institutions, to fill identified gaps.

Deinstitutionalisation 30 June 1999

In 1990, the Government endorsed the policy of deinstitutionalisation. The process of moving residents of psychiatric and psychopaedic hospitals from long-stay residential care to community-based living settings is continuing. The HFA is developing and implementing plans to complete the movement of people from institutional care to community settings, where appropriate. The Ministry is undertaking approval of the HFA plans as well as monitoring the effects and impacts of deinstitutionalisation. The deinstitutionalisation process is scheduled to be completed by 30 June 1999.

Compulsory care legislation 1 January 1999

By mid-1998, new legislation will be introduced to authorise the compulsory assessment and compulsory care of two specific groups of persons who have an intellectual disability. Firstly, those who are a serious danger to the health or safety of themselves or others. Secondly, those who have been charged with an imprisonable offence. The Compulsory Care Bill is expected to be passed and implemented by 1 January 1999, and is intended to be used only as a mechanism of last resort.

Safety standards

The Government has announced changes to the legislation relating to the licensing of rest homes, hospitals and residential homes for people with disabilities. The Ministry is now required to ensure that national safety standards for these services are developed. The HFA has a wider interest in the development of national standards to support its moves to nationally consistent purchasing. Therefore, the two agencies have agreed to jointly develop and fund the 'infrastructure' for national standards setting. This initiative will provide for sector-wide involvement in setting national safety standards which, over time, will result in consistent, transparent and non-overlapping standards that are acceptable to key stakeholders.

Aim 4: Consistent prioritisation and targeting of services

Funding distribution

For historical reasons, there are inconsistencies in regional funding and between groups of people with different types of disability. These problems will be addressed, so that HFA funding distribution is based on priorities related to individual needs, rather than on generic definitions of conditions or on geographic location and also meets the requirements of the Human Rights Act 1993.

Needs assessment examination by end 1998

By the end of 1998, the HFA will have examined the purchase of Needs Assessment Services with a view to moving towards national consistency.

Analysis of funding allocations

Some aspects of DSS changes, and publicity associated with them, have created unrealised expectations about what can actually be done within a limited budget. The HFA is also faced with the impact of an ageing population, new technologies, early discharge from hospital and rising consumer expectations. All of these have resulted in increased demand for services and, in some cases, increased cost.

In this context, the HFA is undertaking a comprehensive analysis of the effectiveness of current funding allocation in achieving the Government's DSS goals. The analysis includes:

- identifying unmet needs (for example, from survey material or from the needs assessment process)
- assessing the extent to which highest priorities are met
- assessing how outcomes are monitored
- evaluating the effectiveness of the interfaces with personal health, mental health, and preventive health services.

Consistent access and contracting process

The HFA is currently also reviewing service access criteria and contracting procedures for national consistency. The intent is to reduce inconsistencies and transaction costs by means of:

- nationally consistent documentation, practices and reporting requirements for DSS contracting procedures
- a one-stop-shop approach, where appropriate
- development of a long-term contracting strategy.

Review of environmental support services 30 June 1999

The HFA is developing a national programme for the funding and provision of environmental support services, including equipment, housing, vehicles and vehicle modifications. These services are crucial in promoting habilitation and rehabilitation, maximising independence and supporting opportunities. Some aspects of the current funding and provision regime for these services are inconsistent and ad hoc. The HFA has developed a 12-month plan (due for completion by 30 June 1999) for reviewing environmental support services, to:

- develop an asset management system to maximise purchasing opportunities, reduce administration costs and address regional anomalies
- examine service delivery issues, with respect to possible development of Centres of Excellence
- work towards a co-ordinated approach to providing services across health and disability portfolios and with other organisations.

Aim 5: More effective intersectoral collaboration

Links with government agencies

The HFA and the Ministry are continuing to work to improve links with other relevant government departments, ministries and agencies on developing policy and/or operational interface protocols, including:

- Education and Children and Young Persons Service, for the needs of children with disabilities
- ACC and Education, on equipment issues
- Employment and Income Support services, on employment and income maintenance issues

- Education and Employment, on vocational training
- Housing
- Transport.

Lead agency roles

The Ministry will actively promote the establishment of 'lead agency' responsibility in relation to specific disability support issues. This will clarify who will be responsible for co-ordinating specific interagency disability issues, ensuring that the interface is effectively managed, and that the policies of one agency do not have unintended consequences for other agencies.

Provider collaboration

The HFA will work with service providers to develop a more collaborative approach to service provision (including joint ventures and pilot and/or demonstration schemes) so that better service packages can be offered. For groups or individuals frequently involved with both the personal health and the disability support sectors (such as some children or older people), greater co-operation, including joint ventures, will be actively promoted. Active collaboration between hospitals and non-governmental health service providers will also be promoted, including pilot or demonstration schemes. There will also be a closer interface with mental health services and preventive health services.

Aim 6: Appropriate services for groups with specific DSS needs, particularly for Mā ori

One of the key aims of the HFA is to ensure that the range and quality of services available to people with disabilities is more comprehensive than at present. There are insufficient appropriate services for some groups, either because services are not available, there are not enough services to meet needs, or access to services is difficult. Culturally appropriate services to Māori are one example of this; other examples are culturally appropriate services for other groups, particularly Pacific people, and comprehensive services for people with multiple disabilities and those with high support needs.

Planning for review of services 30 June 1999

Future work will include a review of service needs, service provision, and gaps in service availability for specific groups; this will be incorporated into the HFA planning process by 30 June 1999. Gaps in service delivery will be addressed within the context of prioritised needs, equitable provision for clients with similar needs, and the identification of core competencies for service provision.

Māori and Pacific service information 30 June 2000

The HFA will extend the gathering of national information on the adequacy and availability of disability support services for Māori and Pacific people, with a key aim of examining the needs of Māori and Pacific DSS consumers and providers. There will be a greater focus on providing DSS information and education for Māori and Pacific people, in particular the support available for whānau/aiga and other caregivers.

Services for Māori

In keeping with the need to meet the demand for culturally appropriate services for Māori, the Government will encourage and support the development of Māori providers of DSS. This is consistent with the Government's commitment to improving Māori health through increased resources and '... to enable the continuing growth and development of Māori health service provision by Māori' (see: Coalition Agreement on Health).

In addition, there will be more explicit requirements for existing providers to meet their obligations to provide culturally appropriate and therefore more acceptable and effective services.

Services for children

To meet the Government's goal of ensuring '... that children receive the care and protection they need for the best possible start in life', there will be improvement of services to children with disabilities and to their families/whānau. These services will be better integrated with other child health and family support strategies, such as Strengthening Families, the National Child Health Strategy, and Family Health Teams.

Services for older people

The needs of our increasing population of older people will be met, within resource priorities, by increased development and provision of a range of services. Many older people will require access to both disability support and personal health services. These need to be well co-ordinated, involving people and their family/whānau in the assessment process and aiming for seamless service delivery.

In Conclusion ...

This *DSS Strategic Work Programme* provides specific targets for the Ministry and the HFA in consolidating the changes in the delivery of support services for people with disabilities embarked upon in 1993.

The work projects described under the six broad aims of the programme directly address many of the concerns about services for people with disabilities and their families/whānau, which have continued from before the introduction of the DSS framework. This work also follows the recommendations for DSS in *Implementing the Coalition Agreement on Health*.

The Ministry and HFA have, through this *DSS Strategic Work Programme*, jointly committed the primary focus of their work over the next three to five years to successfully achieving these aims.

Appendix 1

DSS goals

Three goals form the basis of the Government's approach to assisting people with disabilities:

- *maximising independence*
- *effective habilitation and rehabilitation*
- *supporting opportunities to participate.*

These goals build on the framework and underlying principles outlined in *A New Deal: Support for independence for people with disabilities*, which were intended to reflect the Government's desire to improve the quality of life for people with disabilities through:

- access to appropriate services of an acceptable quality
- services that are responsive to the needs of people with disabilities
- incentives to promote rehabilitation
- a system that is responsive to the needs and preferences of Māori and other groups
- policies that reflect the needs and importance of caregivers, voluntary agencies and other service providers
- services provided give value for money
- cost that is acceptable to the Government as well as affordable and manageable in the long term
- changes being implemented in a way which minimises disruption to the lives of people with disabilities and their caregivers.

a) Maximising independence

The Government remains firmly committed to the concept of providing a range of services for people with disabilities designed to support their ability to live independently and interdependently within the community, as was outlined in 1992 in *A New Deal: Support for independence for people with disabilities*.

The basic prerequisites of living independently include access to information, equipment and environmental support services, income, appropriate housing and personal support services. The

Government remains committed to assisting with the provision of independent living settings in the community and in people's own homes, rather than institutions, wherever possible.

The users of DSS are made up of different groups with diverse needs, and the type of services required will vary according to the characteristics and needs of particular groups: for example, the working-age versus non-working-age populations.

b) Effective habilitation and rehabilitation

In terms of specific services, habilitation refers to services for people who have never had the experience of living independently and therefore focuses on developing skills to achieve independent living, whereas rehabilitation has more of a restorative focus, enabling a person to regain or learn skills and access resources to reassume their social role.

Rehabilitation can involve various forms of intervention as long as these are specific interventions with clear outcome goals over a specified timeframe. While debate about the definition of rehabilitation continues, this should not distract attention from the responsibilities to provide effective early intervention services and rehabilitation wherever possible. A greater focus on rehabilitation may require a closer link to personal medical services provided by specialists and hospitals.

In order for an habilitation/rehabilitation focus to be effective, it is essential to recognise the significant differences that exist between different disability groups and specific individuals with a disability. Government is committed to ensure there is access to habilitation and rehabilitation services for people with disabilities to assist in lessening the degree and extent of a disability, or to minimise the impact of the disability.

c) Supporting opportunities to participate

The two elements of habilitation/rehabilitation and support for independence form the basis for Government intervention, particularly in the context of the health and disability sector. These two elements could be viewed as summaries of the first set of UN Standard Rules⁴ which provide for medical care, rehabilitation and support services.

However, the wider public sector, including the health and disability sector, should be committed to a further aim of supporting opportunities for people with disabilities to participate as fully as possible in their families/whānau, community and society. This includes access to the full range of education facilities, meaningful work and activity, and recreational and social activities.

Improving opportunities for people with disabilities to participate will require a greater degree of intersectoral co-operation and collaboration than to date, particularly between the health and disability sector and the housing, transport, education, accident compensation and rehabilitation, income support and employment sectors. This approach is fully in line with government policy in other sectors, which is

seeking to enhance wellbeing and independence and to maximise employment and education opportunities. Collaboration and co-operation will also be needed between the various non-governmental disability organisations.

The Government affirms the principle of mainstreaming, that all agencies providing publicly funded services must take into account the needs of people with disabilities and seek to provide an appropriate range and quality of services as a matter of course. It is vital that the principles of 'normalisation' of people with disabilities and their inclusion in society are adopted and proactively supported by all key government agencies.

Appendix 2

Key principles of the Coalition Agreement on Health

Key principles relevant to providing disability support services are embodied in the Coalition Agreement on Health:

- providing a flexible, modern, properly funded, accessible health and disability support service that meets changing public needs and expectations
- publicly funded health and disability care that encourages co-operation and collaboration rather than competition between health and disability support services
- improving the health status of Māori and their access to disability support services
- a greater focus on health and disability support services for children.

Government's strategic result areas contributed to by the DSS strategy:

SRA 7: Health and disability services

Improve the overall health status of New Zealanders through health, disability support service and injury prevention regimes that:

- maximise health gains in a cost-effective way
- are accessible, responsive to changing public need and flexible enough to enable resources to go to areas of highest priority
- encourage co-operation and collaboration between service providers
- encourage individuals, businesses and communities to avoid and prevent behaviours that contribute to illness and injury

in particular by:

- developing sustainable funding arrangements that focus on maximising health outcomes, and which enable integration of service delivery and promote quality care

- providing comprehensive and integrated care and support services to maximise the potential of individuals with mental health and disability support needs, including implementation of the mental health strategy
- achieving improvements in the health status of Māori; by increased responsiveness to their needs and the development of appropriate professional, administrative and organisational expertise
- achieving improvements in health outcomes for priority groups, particularly for children significantly at risk of poor health; by developing and implementing innovative health promotion and service delivery strategies
- improving the regulatory and administrative frameworks for public and workplace health and safety, disability support and accident compensation so as to minimise the risks, incidence and impacts of illness and injury.

SRA 5: Economic and social participation

Enhancing the ability of individuals, families and communities to actively participate in New Zealand's economic, social and cultural development through co-ordinated policies and delivery approaches that:

- address causes of poor outcomes for individuals and families
- foster community participation
- are based on principles of respect, compassion and responsibility

in particular by:

- developing integrated long-term strategies to address the challenges of an ageing population, to enable older people to maintain their independence and participate in their communities.