Inclusive Communities

Guidelines about Disability for Councils and District Health Boards

September 2004

we can!

www·dpa·org·nz

Nothing About Us Without Us

- Disabled people are not sick.
- Disabled people are of equal value to other people.
- Disabled people have the right to be involved in decision-making.
- Disabled people have the right to live in the community.
- Disabled people have the right to good homes.
- Disabled people have the right to access transport (buses, trains, planes).
- Disabled people have the right to income that is adequate and exceeds the poverty line.
- Disabled people have the same rights as all New Zealand citizens.

This document is a partnership initiative between DPA and CCS.

DPA (New Zealand)

Level 4,

173-175 Victoria Street, PO Box 27-524,

Wellington 6035, New Zealand

Ph/TTY: 04-801 9100, Fax: 04-801 9565

gen@dpa.org.nz

New Zealand CCS

Level 1

86-90 Vivian Street, PO Box 6349

Wellington, New Zealand

Ph: 04-384 5677, Fax: 04-382 9353

info@no.ccs.org.nz

Contents of This Document

Introduction

Why This Document?

Disabled people are a part of our community who are not well understood or recognised. The official 2001 Census found that one in five New Zealanders are disabled. Because disability also affects a disabled person's family and whanau, the real figure is even higher.

In the affairs of Councils and District Health Boards, disabled people and their families/whanau have many different roles: as users of services, staff, committee members, voters and candidates in elections. Many decisions that affect the lives of disabled people and their families/whanau are made by the elected members and staff of Local Councils, District Councils and Regional Councils ("Councils") and District Health Boards ("DHBs").

As citizens, disabled people and their families/whanau can have their say about which people are elected to each Council or DHB.

This document:

- Describes general principles, key concerns and specific actions for Councils and DHBs to work on in partnership with disabled people and their families/whanau.
- Provides valuable insights and reminders, whether you are an elected member of a Board or Council, a staff member, a community advocate or part of the community.
- Draws on the collective wisdom of many individuals and organisations.
- Provides a basis for local disability organisations to include issues from their own area.

How To Use This Document

This document is a tool for producing more effective regional relationships between disabled people and their families/whanau and Councils and DHBs. It describes the collective views and aspirations of disabled people and their families/whanau throughout New Zealand. In particular, this document draws on the experience and ideas of DPA members over more than two decades. It will continue to evolve along with our relationships and understanding.

The vision of organisations like DPA and CCS (see page 6) and the vision of guiding documents like the *New Zealand Disability Strategy* and the *To Have An Ordinary Life* report can only be achieved and made real by national and local government and DHBs working in true partnership with disabled people and their families/whanau at national and local levels. There is much to be done if disabled people are to be fully included in our communities.

Before Elections

This document should be used before the elections by:

- DPA regional assemblies and members, CCS Local Advisory Committees (LACs) and members, and other disability organisations to influence candidates standing for election, including through forums.
- Candidates, to inform their disability policies and commitment to disabled constituents, and to seek endorsement.

Between Elections

After the elections this document should be used by:

- DPA, CCS and other disability organisations to remind Councillors and Board members of their commitments.
- Members of DHB disability services advisory committees (DSACs) and Council advisory groups to take to and use at meetings.
- Councillors, Board members and staff to implement policies for a fully inclusive and non-disabling region.

Any Time

This document can be used at any time to increase understanding of the concerns and aspirations of disabled people and their families/whanau.

All may benefit from reading the description of some specialised terms used in this document (see page 25).

Who This Document is By

This document was created by the Disabled Persons Assembly of New Zealand (DPA) as a partnership initiative with New Zealand CCS.

DPA New Zealand is a national umbrella organisation that is the recognised voice of disability. DPA represents the interests of all disabled people, their families/whanau, advocacy organisations and those who work with disabled people. DPA's vision is a fully-inclusive society without barriers which provides both equity and maximum opportunity to participate for all.

DPA New Zealand is represented throughout the country by DPA regional assemblies. Regional Assemblies have local knowledge and advocate on local issues consistent with nationally agreed policies.

DPA also represents New Zealand on international disability organisations, and is part of the New Zealand delegation to the United Nations to negotiate an international Convention on the Rights of Disabled People.

CCS is a national non-profit organisation that provides a range of services each year to several thousand disabled people, their families/whanau, and their communities. This document is part of CCS's commitment to community development.

Background to This Document

For some years the participation of disabled people in our communities has been steadily increasing. In 1999, DPA released a document *Our Vision* (updated 2002-2005) as a manifesto of what disabled people believe is achievable by Government. *Our Vision* has influenced the present Government's thinking on disability issues. Many of the recommendations in *Our Vision* were taken up, including the need for a New Zealand Disability Strategy.

After extensive consultation, in 2001 the Labour Alliance Government released *Whakanui Oranga: Making a World of Difference,* the New Zealand Disability Strategy (*NZDS*). In 2003, the National Health Committee produced a report called *To Have an Ordinary Life.*

Many of the recommendations of *Our Vision* and *To Have an Ordinary Life* are yet to be taken up by the Government, and many of the actions within the *NZDS* fall short of the realistic and realisable expectations of disabled people and their families/whanau. However, the vision and philosophy underpinning the *NZDS* are consistent with, and were developed from, DPA's vision and philosophy.

Given the influence of *Our Vision* on the Government, DPA in partnership with CCS is releasing this document, *Inclusive Communities*, to influence elected bodies and in particular Councils and DHBs. This document draws on DPA's *Our Vision* 2002-2005; CCS's Philosophy and Policy V1.6.2003; discussions at DPA National Executive Committee and Annual General Meetings since 2001 about issues like the devolution of age-related DSS funding to DHBs; and from the *NZDS* and its consultation process.

General Principles

What Disability Means

Disabled people are a significant group within the community but are not well understood or recognised. It's not as if we get taught about disability in school. Yet the official 2001 Census found that one in five New Zealanders are disabled.

Barriers and Assumptions

We no longer think of disability as something that individual people "have". People have impairments, such as deafness or arthritis or cerebral palsy. Disability is what happens when these impairments interact with an inadequate environment. The Government's guiding document about disability, the *New Zealand Disability Strategy* (*NZDS*), tells us:

> "Disability is the process that happens when one group of people create barriers by designing a world only for their way of living and taking no account of the impairments other people have.
> Our society is built in a way that assumes we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions."

Barriers are in:

- The built environment,
- Information and services, and
- Social attitudes and behaviours.

The barriers that disabled people encounter often affect their families and whanau as well. People's assumptions and expectations about disabled people often form the biggest barriers. Disabled people are mostly just like everyone else. High expectations are appropriate.

An Ordinary Life

Like most people, disabled people just want to live an ordinary life.

The *To Have An Ordinary Life* report (2003) says this includes:

> "Having your life taken seriously, being able to give and receive love, having long-lasting friendships, having your cultural values respected, being given opportunities to grow and learn, and being valued by others for what you have to offer."

It also includes the ordinary range of things that New Zealanders want for themselves and their families.

Removing Barriers Benefits Everyone

The *New Zealand Disability Strategy* notes that:

> "Along with other New Zealanders, disabled people aspire to a good life. However, they also face huge barriers to achieving the life that so many take for granted."

Initiatives like the *NZDS* aim to remove those barriers because it makes good sense both socially and economically. When we make New Zealand fully accessible for disabled people it's also right for everyone – like senior citizens reading bus timetables and young mums pushing prams.

Inclusion

Beyond accessibility, disabled people seek to be fully included in all aspects of our society and economy. Underpinning the *New Zealand Disability Strategy* is a vision of a fully inclusive society. New Zealand will be inclusive when people with impairments can say they live in:

> "A society that highly values our lives and continually enhances our full participation."

A Significant Community

Because one in five New Zealanders are disabled, they and their families/whanau are a significant community within the wider community.

- Councils are required under the Local Government Act 2002 to appropriately consult significant communities about decisions that affect them.
- For DHBs, the *NZDS* and *Health of Older People* strategies also make disabled people and their families/whanau a significant community to include in all decisions.

Disabled people and their families/whanau are also citizens, and are significant not just as users of services but in all areas including advocacy, employment and governance.

Resources and Visibility

Disabled people and their families/whanau are historically under-resourced in income, assets, education, employment and commercial experience. They also face significant personal costs to overcome disabling barriers. As a result, they are not as visible as you might expect.

Nothing About Us Without Us

The most important principle when an organisation's work affects disabled people is to involve disabled people early in all aspects of that work, from strategic planning to implementation and review.

The expertise of disabled people makes decisions and services more effective and efficient.

In particular, young disabled people also have the right to participate in decisions made about them and to have control over their own lives.

Of Equal Value

Disabled people and their families/whanau believe that:

> The life of a disabled person has equal value to, and shall be accorded the same rights, dignity and respect as that of a non-disabled person . DPA acknowledges and supports the rights of disabled people to make informed choices without coercion.

Human Rights

Disabled people and their families/whanau believe that:

> Disabled people have equal rights to all other New Zealanders, including the right to participate in all aspects of economic, social and political life. These rights are protected by the Human Rights Act (1993) and must be enforced.

The Human Rights Act 1993 now includes the operations of government agencies that were initially excluded from its scope.

Treaty Partnership

Disabled people and their families/whanau believe that:

> The specific needs of disabled Maori, both individually and in the context of their whanau, hapu, iwi, must be considered whenever policy is being formulated which may affect them. Further, policy must be flexible enough to take into account that whanau, hapu, and iwi may also be disadvantaged by an individual's disability.

DPA will work with Government, Councils and DHBs on the basis of the principles that:

- Disabled Maori are consulted on Maori issues and disability issues.
- Services of, by and for disabled Maori are developed.
- Support networks are budgeted for when allocating resources for support services.
- Service provision is appropriate, flexible, adaptable, and applicable to the individual, whanau, hapu, and iwi rather than recipients having to fit the service.
- All disabled people have the choice of accessing services being offered by both Treaty of Waitangi partners.
- The debilitating effects of disability on whanau are acknowledged and provided for in rehabilitation support programmes.

Specific Action Areas

Organisational Processes and Leadership

Disabled people and their families/whanau believe that:

> Councils District Health Boards and other planning and decision-making bodies must have disabled people as board members so that the views and perspectives of disabled people and their families/whanau are incorporated in all matters related to community issues, disability support services, healthcare and health services. There must be active recognition of the "Nothing about us, without us" principle when formulating policy, developing services and reviewing practice.

Councils and DHBs need to ensure that:

- The Government is reminded of its obligations under the *NZDS*.
- There is a commitment to providing appropriate disability awareness training for all staff.
- An ongoing relationship exists with the local DPA regional assembly even when reference groups and advisory groups are in place.
- All disabled people and their families/whanau contributing to policymaking, practices and service development are on a fee-for-service basis, as for other people with recognised expertise.
- All information is made available at no extra cost in accessible formats (eg: Braille, audio, electronic) and all websites are fully accessible.
- All facilities comply with the Building Act, and Standard 4121:2001; Educating architects to exceed the minimum standard guideline.
- Public meetings are held in accessible venues, are advertised widely and through a variety of mediums, including accessibility information and plain language directions, with New Zealand Sign Language interpreters provided and funded.

- Disabled people are well represented within the Council and DHB workforces.
- They have the ability to respond immediately to a disabled individual's urgent needs, (eg: fixing potholes) as well as longer term strategic processes (eg: policy input).
- The following questions are answered before policies are signed off:
  - What are the implications for disabled people and their families/whanau?
  - Have we ensured that disabled people and their families/whanau can access these processes/services/facilities on the same basis as other people?

DHBs need to ensure that:

- Only disabled people or people who identify with disability, for example family members, are the non-board members of DHB Disability Services Advisory Committees (DSACs), and that disabled people make up the majority of the committees.

Councils need to ensure that:

- A permanent reference group of disabled people is established, or the local DPA regional assembly is contracted, to work in partnership with Councils in their region, providing feedback and input.
- Obligations under the Local Government Act are being met.
- Code requirements are properly met with no exemptions given.

Councils Adopting the NZDS

Disabled people and their families/whanau know that their lives are influenced by the decisions of Councils and believe they too should comply with the *New Zealand Disability Strategy*, which says:

> “The decisions that territorial authorities and non-departmental public bodies make also have a significant impact on the lives of disabled people. It is important that territorial authorities and other public bodies support and assist with implementing the *NZDS*, and ways of making this happen need to be considered in discussion with them.”

Councils need to:

- Work with DPA and Local Government New Zealand (LGNZ) to amend legislation including the Local Government Act, Resource Management Act and Building Act to ensure compliance of Councils with the *NZDS*.
- Work in partnership with LGNZ to ensure resources are available where necessary to comply with the *NZDS*.

LGNZ needs to:

- Establish and resource an advisory group of disabled people working in partnership, to give input and feedback on the successful implementation of disability issues policies in local communities, including standards for local reference groups.

Advocacy and Awareness

Disabled people and their families/whanau believe that:

> Self-Advocacy is the strongest and most effective form of advocacy and therefore DPA supports efforts by disabled people to promote assertiveness and self-confidence.

The first Objective of the *NZDS* is to "encourage and educate for a non-disabling society" and the first two Actions within that Objective are to "Develop national and locally-based anti-discrimination programmes" and to "Recognise that it is disabled people who are experts on their own experience".

Councils and DHBs need to ensure that:

- Locally-based inclusive community programmes led by disabled people are developed in partnership with other agencies, to inform the community about the rights, needs, potential and contribution to the community of disabled people.
- The training of disabled people in self-advocacy skills is funded in order to enhance self-responsibility and self-esteem.
- All disabled people have the right to an advocate of their choice to investigate their situations, to speak on their behalf and to assist in those situations where necessary, independent of a service provider.
- In identifying, advocating, and leading policy debates on disability concerns, the role of disabled people is recognised first, families and whanau and unpaid carers second, and finally disability professionals.

Access To the Built and Natural Environment

Disabled people and their families/whanau believe that:

> Everyone benefits from the human right of disabled people to participate with dignity in the normal activities and processes of life in the community.

Councils need to ensure that:

- All new and renovated buildings comply with the Building Act, Standard 4121: 2001 and that exemptions are granted only in truly exceptional circumstances.
- All new buildings including non-rental private dwellings on flat land are fully accessible by 2015. (For example, ban all steps at front doors, as in Britain)
- The access symbol is not used without authorisation.
- Lifts in public buildings have voice-activated technology installed.
- “Accessible journeys” are recognised and planned for, from all forms of transport, and including parking, appropriately gradiented kerb cuts and ramps, uncluttered pavements, tactile surfaces, audio and tactile traffic signals, and accessible toilets.
- All signage and other communication are accessible using alternative formats and new technologies.
- Most public parks, gardens, and walkways are made accessible, and all others are made as accessible as practicable.

Transport

Disabled people and their families/whanau believe that:

> Transport is the basic right of all people. All forms of transport and its infrastructure, in local communities and nationally, must be accessible to disabled people.

Councils need to ensure that:

- All transport policies and contracts take into account the needs of disabled people, ensuring access at no extra cost, and recognise demographic changes.
- Where public transport exists, all new purchases must be fully accessible, including signage and announcing, and all existing inaccessible public transport should be phased out by 2010.
- Airports, and ferry, train and bus terminals meet the needs of disabled people.
- Transport, including the provision of accessible parking, is seen as part of the entire “accessible journey”.

Total Mobility

As a complement to public transport, Regional or City Councils need to ensure a Total Mobility Scheme that:

- Provides at least a minimum of 50% subsidy to all fares.
- Meets with nationally consistent eligibility criteria.
- Recognises that some disabled people can take public transport sometimes and at other times cannot.
- Has an advisory committee in each region with a majority of disabled people.
- Provides recompense for external administrators.
- Provides incentives so that an adequate number of taxi mobility vans are available in all areas.

Accommodation

Disabled people and their families/whanau believe that:

> Accommodation support and housing policies must actively promote the right to human dignity and the right of the individual to choose their own lifestyle and accommodation options.

The *NZDS* reports:

> "Disabled people often have reduced housing options because of poverty or factors such as discrimination when neighbours object to supported houses being established in their area."

DHBs need to work with Councils to ensure that:

- Disabled people are supported to live in their communities free from the "not in my back yard" (NIMBY) syndrome through inclusive community campaigns and through ceasing to use the Resource Management Act inappropriately.
- A range of Supported Living options enabling disabled people to live independently within the community are developed and promoted.
- Accommodation options are developed to allow young disabled people to live in as they choose.
- Transitions of disabled people from institutions to the community are well resourced, appropriate, and smooth.
- Rural disabled people are supported to live in their chosen communities.
- Advocacy and support systems for disabled people living in residences is neutral, enabling and independently audited.

Councils need to ensure that:

- At least 50% of their existing public housing stock is accessible, and that all new public housing is accessible.
- At least 20% of all new private housing can be modified easily to be accessible to meet current need and future need based on demographic trends.

Arts and Recreation

Disabled people and their families/whanau believe that:

> All people have the right to seek and gain fulfilment in life through participation in arts, recreation, leisure or sporting activities in their community.

Councils need to ensure that:

- Disabled people have opportunities to create, perform and develop their own arts, and to access all arts activities as practitioners, participants and audiences.
- Arts, recreation and sports administrators and organisations work in partnership with disabled people and their families/whanau to learn how to create inclusive opportunities for participation.
- Arts, recreation and sports projects run by and for disabled people are developed and activities that celebrate and represent specific communities and cultures are promoted.
- Disabled people are included in community social activities.
- Community and tourism promotional campaigns include disabled people, and their needs as hosts, visitors and tourists are met.
- That all staff working in the areas of arts and recreation receive appropriate training in disability awareness delivered by disabled people.

Health Services

Disabled people and their families/whanau believe that:

> Disabled people have the right to receive a range of quality and appropriate health services. Health care must, with informed consent, provide a maximum of choice and personal input and take full account of the particular needs disabled people may have.

Disability is not a health issue. Disabled people may have health needs specific to their impairment – and the same health needs as non-disabled people, but needing to be addressed in an appropriate way.

DHBs need to ensure that:

- With the devolution of aged-related funding to DHBs, the funding agreement clearly distinguishes health and disability support services, and transparent processes are in place to ensure appropriate spending.
- Disability advisory committees are maintained to advise about disabled people's health issues even where DHBs do not fund DSS services.
- Disabled people receive appropriate personal and mental health care, including taking into consideration their cultural and ethnic origins and gender, with the maintenance of privacy.
- Impairment and disability should not prejudice the treatment of related or non-related conditions.
- Medical doctors, nurses and other health care professionals have ongoing training in all aspects of impairment and disability and an awareness of its implications for health care service providers.
- Medical research must include informed consent and ethical input from disabled people, particularly from those whose impairment is being researched.
- Accessible appropriate complaints procedures are in place and everyone receives information in the format appropriate to them.

- An understanding exists of the concepts of "managed care" and population-based funding around Public Health Organisations (PHOs) and other GP groupings in relation to the provision of health and disability support services.
- Mental health issues are seen where appropriate in an impairment and disability context.
- Mental health service users are the majority involved in developing / monitoring mental health policy issues.
- The Mental Health Commission's document *The Blueprint for Mental Health Services in New Zealand, How Things Need to Be* is implemented.

The Government needs to ensure that:

- It works with DPA and representatives of mental health consumers to decide what mental health services are to be funded nationally or locally.

The Government and DHBs need to work with DPA to ensure that:

- Complaints processes are extended to cover those situations where there are no health or disability support services or no funding for services.
- Service purchasing and delivery does not contravene the Human Rights Act or other international covenants and treaties to which New Zealand is a signatory.
- Sterilisation of young disabled women without their own informed consent ceases.
- Values advocates with an understanding of disability issues and values are available when critical decisions about a person's life are made.
- National guidelines are developed and implemented consistently for the provision of medical treatment including diagnosis, ensuring that decisions to withhold treatment are not made either solely or predominantly on the grounds of disability.
- Research decisions with ethical issues have input from disabled people, particularly those whose impairments are being researched.

Disability Support Services

Disabled people and their families/whanau believe that:

> Disabled people and their families/whanau must receive whatever services and other support or assistance, may be needed to reduce the disabling effects of impairment. Services should be designed to make possible for disabled people a full, meaningful and constructive life of their choosing.

DHBs are now required to manage Disability Support Services (DSS) for people 65 years old and over. Disabled people and disability organisations raised significant concern about this during the *NZDS* consultation process, and many are still concerned. Disability is not a health issue. It is imperative that DHBs have input from disabled people to ensure that services for people over the age of 65 years are appropriate to older people who may also have lived their life experiencing disability.

The Government needs to:

- Continue to work with DPA and other representatives of disabled people and their families/whanau to create a single national funder of DSS services.

DHBs need to ensure that:

- All DSS services are delivered consistent with the *NZDS*, with an understanding of impairment and disablement, and that medicalisation of DSS services does not occur.
- Contracts with DSS providers include mandatory ongoing training for staff in all aspects of impairment and disability.
- The disability sector is resourced to develop a set of principles and guidelines to describe what “good” DSS services are.
- Implementation of the DSS Framework, as originally envisaged, occurs allowing for coordinated service delivery.
- Census data is used as a basis of purchasing and planning decisions particularly in relation to unmet need.

- Needs assessment and service coordination (NASC) is based on clearly defined rights and principles rather than rigid criteria, and NASC providers are not linked to hospital sites or business units of the hospital health services.
- All needs are met and all services are fully funded and meet the quality standards that DPA has set in partnership with others.
- Equipment services are fully funded and equipment meets appropriate standards, meets the needs and aspirations of disabled people, comes with appropriate training and support, and equipment manufacture and maintenance capacities are maintained.
- Complete the processes of de-institutionalisation, ensuring disabled people are well resourced and supported to live in the community of their choosing.
- Contracts with DSS providers encourage a majority of disabled people on providers' governing boards, and that disabled people have proper input into all service decisions.
- Development occurs of service organisations and services of, by, and for:
  - disabled people;
  - disabled Maori; and,
  - disabled Pacific people and other ethnicities.
- Collaboration with other DHBs on national contracts with national DSS providers occurs.

Terms We Have Used

In this document, you will find some specialised words, phrases and abbreviations. These are the main ones and their meanings to us:

This Term …	**Means This …**
Disabled person	Person with an impairment – whether physical, intellectual, emotional or otherwise – who experiences disabling environments or attitudes as a result.
Disabled People and their Families/Whanau	Disabled people, together with their families/whanau, friends and unpaid carers. Disabling attitudes and environments often affect this whole group.
Service Provider	An organisation that provides commercial services to disabled people or their families/whanau.
Disability Sector	All organisations and people whose purpose focuses on disabled people or their families/whanau – including service providers, funders, policymakers and advocacy organisations.
Disability Professional	A person employed in the disability sector.
Government	The New Zealand Government.
NZDS	The *New Zealand Disability Strategy* – the New Zealand Government's guiding document for improving how publicly-funded organisations deal with the needs of disabled people and their families/whanau.
Councils	All territorial authorities including City Councils, District Councils and Regional Councils.
LGNZ	Local Government New Zealand.
Total Mobility Scheme	Regionally-managed system for subsidising taxi services for disabled people unable to access other forms of public transport.
DSS	Disability Support Services, which fund common supports for disabled people and their families/whanau.

This Term …	**Means This …**
DHB	District Health Board, which provides secondary health services for everyone and DSS services for people over 65 years old.
DSAC	Disability Services Advisory Committee to a District Health Board.
NASC	Needs Assessment and Service Co-ordination – the process that is the gateway to receiving most DSS services.
LAC	Local Advisory Committee within CCS.
HRC	Human Rights Commission.

This document is a partnership initiative between DPA and CCS.

DPA (New Zealand)

Level 4,
173-175 Victoria Street,

PO Box 27-524,
Wellington 6035, New Zealand

Ph/TTY: 04-801 9100,

Fax: 04-801 9565

gen@dpa.org.nz

New Zealand CCS

Level 1,
86-90 Vivian Street,

PO Box 6349,
Wellington, New Zealand

Ph: 04-384 5677,

Fax: 04-382 9353

info@no.ccs.org.nz