

MAKING A WORLD OF DIFFERENCE

WHAKANUI ORANGA

**THE NEW ZEALAND DISABILITY STRATEGY
DISCUSSION DOCUMENT**

Hon Ruth Dyson
Minister for Disability Issues

September 2000

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Judith Mercer
New Zealand Disability Strategy
Ministry of Health
P O Box 5013
WELLINGTON

Phone : (04) 496 2554
Fax : (04) 496 2340
E-mail : nzds@moh.govt.nz

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He Mihi

He hōnore, he kororia ki te Atua. He tangi aroha ki ō tātou tini mate e hingahinga mai nā i ngā marae maha puta noa i te motu, mai i tēna pito, ki tēra pito. E kore e taea ēnei āhuatanga te karo, nō te mea, ka pā ki tēnā, ki tēnā, ahakoa ko wai. Heoi te kōrero, e ngā mate haere, whakangaro atu ki tua o te ārai, haere atu ki ngā mātua tīpuna kei konā hei awhi i a koutou. Nā reira, haere, haere, haere!

Ka huri atu ki ngā iwi, ki ngā reo, ki ngā karangatanga maha o ngā hau e whā, tēnei te mihi atu ki a koutou kātoa. Tēnā koutou, tēnā koutou, ā, tēnā tātou katoa.

Tihei mauriora.

The honour and the glory to our Creator. To those who have passed on to the great beyond, farewell. And to all peoples, all voices, all the many relations from the four winds, we greet you all.

The New Zealand Disability Strategy Sector Reference Group,
September 2000

Incorporating the Treaty of Waitangi

The Treaty of Waitangi is the founding document of New Zealand and underpins the development of the New Zealand Disability Strategy. *Making a World of Difference: Whakanui Oranga* is consistent with the principles of the Treaty relevant to social policy, which are as follows:

- *Partnership*: Māori and the Crown will have a relationship of good faith, mutual respect and understanding, and shared decision-making.
- *Participation*: the Crown and Māori will work together to ensure Māori (including whānau, hapū, iwi and communities) participate in the disability sector at all levels of decision-making around disability issues. Participation includes the right to self-determination and self-management.
- *Protection*: the Crown actively contributes to improving the wellbeing of Māori, including support for independent living and the protection of Māori property and identity, in accordance with Māori values. Māori have the same rights and privileges as other citizens.

The New Zealand Disability Strategy Sector Reference Group has drawn on and learnt from these principles in developing its vision of a fully inclusive society.

Foreword from the Minister for Disability Issues

E ngā iwi, e ngā reo, e ngā karangatanga maha o ngā hau e whā, tēnei te mihi atu ki a koutou kātoa. Tēnā koutou, tēnā koutou, ā, tēnā koutou katoa.

Tihei mauriora.

To all people, all voices, all the many relations from the four winds, I greet you all.

One in five New Zealanders has a long-term disability. Many are unable to reach their potential or participate fully in the community because of the barriers they face in doing things that most New Zealanders take for granted. The barriers range from the purely physical, such as access to facilities, to the attitudinal, due to poor awareness of disability issues. The aim of the Government's New Zealand Disability Strategy is to eliminate these barriers wherever they exist. This discussion document is the first step towards that end.

Making a World of Difference: Whakanui Oranga opens the public debate on the development of the Strategy. It has been produced by the Ministry of Health with a 15-member reference group representing people with disabilities. It identifies some of the key issues to be addressed to achieve the vision of a fully inclusive society, and suggests desired outcomes and actions.

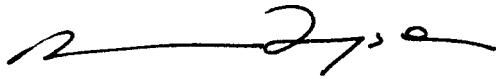
The Strategy will be finalised by the Government early in 2001 and will incorporate feedback on this document. It will guide future government action to promote a more inclusive society. This means the primary focus will be on what government agencies and other publicly-funded organisations need to do to remove the barriers faced by people with disabilities. The Government will take the lead — but we will also be doing all we can to influence attitudes and behaviour of society as a whole. For example, a requirement that all government departments identify and resolve disability issues when they develop policy, services and legislation could significantly improve the physical environment for people with disabilities, and create better access to services.

The Strategy will sit alongside other government programmes, such as the Positive Ageing Strategy (which will incorporate strategies for the health of older people), the Human Rights Review, the New Zealand Health Strategy, and the Closing the Gaps programme that is aimed at removing disparities between Māori and Pacific people, and other New Zealanders.

I would like to thank the individuals and groups in the disability sector whose work has contributed to *Making a World of Difference: Whakanui Oranga* and who have promoted the development of the New Zealand Disability Strategy.

I would also like to acknowledge those people with disabilities who generously shared their experiences and allowed us to use them in the 'stories' included in this document.

Making a World of Difference: Whakanui Oranga offers you a chance to have your say on what the strategy should include and how it could be implemented (see page 23 for further details). I encourage you to respond.

A handwritten signature in black ink, appearing to read 'Ruth Dyson', with a stylized flourish at the end.

Ruth Dyson
Minister for Disability Issues

Summary

Making a World of Difference: Whakanui Oranga is a discussion document which invites people who experience disability, along with other interested individuals and groups, to contribute to the Government's New Zealand Disability Strategy. The Strategy will be finalised in early 2001.

Along with other New Zealanders, people experiencing disability aspire to a good life. However, they also face huge barriers to achieving the life that so many take for granted. These barriers relate to attitudes, education, employment, access to services, socioeconomic status, and other factors which can help or hinder our goals and aspirations.

The proposed Strategy will be based on a social model of disability which recognises that people experiencing disability are disadvantaged by social and environmental barriers (such as those mentioned above) to participation in their communities. For example, although the Government provides a range of services, the experience of accessing these services can be very disabling because sometimes they are not flexible enough to meet individual needs. The Government wants to ease the way into community life for people experiencing disability — by removing barriers to their participation.

To underpin the New Zealand Disability Strategy, a vision of a non-disabling society is proposed. In this vision, people who have experienced disability will be able to say they live in:

‘a fully inclusive society, where our capacity to contribute and participate in every aspect of life is continually being extended and enhanced’.

Achieving this vision will involve acknowledging the special relationship between tangata whenua and the Crown. People experiencing disability will have a meaningful partnership with Government, communities and support agencies, based on respect, equity and well-protected human rights. Their diversity of needs, goals and backgrounds will be recognised.

A key concern of the Strategy is to foster a society where people experiencing disability are integrated into community life on their own terms. Participation in communities will be at its optimum when people experiencing disability have the same opportunities and outcomes as other New Zealanders in all facets of life, including in education, employment, business, politics, income and housing.

To advance New Zealand towards a non-disabling society, critical actions are to:

1. encourage and educate for a non-disabling society
2. ensure rights for people experiencing disability
3. provide the best education
4. provide opportunities for employment and economic development

5. foster leading voices by people experiencing disability
6. foster an aware and responsive public service
7. improve services to people experiencing disability
8. improve access to quality information
9. promote participation of Māori experiencing disability
10. promote participation of Pacific people experiencing disability
11. enable children and youth experiencing disability to lead full and active lives
12. improve quality of life for women experiencing disability
13. value families, whānau and carers.

This discussion document proposes specific steps relating to each of these actions, and invites your input to develop them further.

Once the Strategy is established, appropriate monitoring is necessary to ensure that it is delivered as intended. Whatever approaches are chosen, people experiencing disability should have responsibility for that monitoring.

We seek your views on any or all of the issues raised in this discussion document, by **1 November 2000**. Please see page 23 for information on how you can contribute to the New Zealand Disability Strategy.

Disability today

The way New Zealanders think about disability today is very different from the views our society held only a few decades ago. Previously dominant was the 'medical model' of disability, which considered disability as a personal problem to be 'fixed'. Now the trend in thinking is towards a 'social model' of disability, where individuals with impairments are considered to be disadvantaged by the social and environmental barriers to participation that exist in a hostile environment. As a result of this disadvantage, people with impairments experience disability.

This changed view has developed alongside a growing international human rights movement which has promoted concepts such as rights, empowerment, self-advocacy, inclusion and mainstreaming. For its part, the movement has raised expectations among people who experience disability. New Zealand is part of this world-wide social change.

The New Zealand Disability Strategy Sector Reference Group has used the term 'people experiencing disability' throughout this document. It is aware that there are many different opinions as to which terms are appropriate among the range available to refer to the people at the heart of this Strategy; it is also aware that its chosen term will not sit comfortably with everyone. The Group asks that you focus on the content of this document rather than being distracted by its choice of term. If you think other language would be more appropriate in future, please include these suggestions in your response to the document.

Barriers — a disabling society

Disability is a common issue. One in five people in New Zealand experience disability. That's nearly a quarter of the population.

Disability is also a complex issue. Because everyone comes from different backgrounds, holds different beliefs and has different needs, there is a great diversity of people who experience disability.

The key common factor is that people experiencing disability today face many lifelong barriers to their full participation in New Zealand society.

- Attitudinal barriers in the general population operate at all levels of daily life. Attitudes make their presence felt as stigma, prejudice and discrimination. In the year to June 1999, disability discrimination was the largest category of complaints to the Human Rights Commission.
- People experiencing disability are much less likely to have educational qualifications than people who do not experience disability. Basic literacy is a problem for many. This problem extends to sign language literacy, even though

sign language is the first language of Deaf people. Similarly, Braille is the primary literacy medium for blind people, but a recent survey indicates that up to one in three persons registered with the Royal New Zealand Foundation for the Blind are unable to read what they themselves have written or to access any other form of written or printed material.

- People experiencing disability are less likely to be employed. Half of recent complaints to the Human Rights Commission in regard to disability related to employment.
- Among the working age population, 17 percent experience disability. In 1999, 10 percent of people employed in the public service identified as experiencing disability. This figure is only considered 'reasonably accurate', partly because there are many different ways of defining 'disability'. The uncertainty surrounding even these basic statistics illustrates the challenge of collecting information about people who experience disability.
- There are communication, transport and physical barriers for people who experience disability.
- Over 30 percent of people experiencing disability report that they have an unmet need for some kind of service or assistance. People experiencing disability do not have enough control over the services they are accessing.
- As a group, people experiencing disability are likely to have lower incomes and fewer financial and family resources than the general population. This economic disadvantage is compounded by the financial cost of disability. The earning potential of families with children experiencing disability can be curtailed by the need to live and work in areas where they can get support for their children.
- Women experiencing disability are more likely to have low incomes than all men are, and they are similarly disadvantaged compared with women who do not experience disability.
- People experiencing disability are almost three times as likely to get income from a government benefit than people who do not experience disability (excluding superannuation from this calculation).
- People in higher socioeconomic areas are more likely to access and receive support services than people in low socioeconomic areas. In effect, Māori as well as Pacific people are typically low users of support services.
- Older people experience difficulties when their problems are seen as an inevitable part of ageing. Faced with this attitude, they miss the opportunity to remain able and independent through rehabilitation, correction of health problems or provision of support services.
- For older people experiencing disability, one of the biggest problems is being denied the opportunity to remain in their familiar surroundings and 'age in place'. Even in their own homes, some can feel isolated and insecure if they have limited contact with families, friends and their community. The majority of disability support service funding is spent on older people, and this proportion is likely to increase as New Zealand's population ages.

- For children experiencing disability, it is hard to get the best start to their life ahead. Children's needs can put big demands, including financial pressure, on their families and whānau.

Although the Government provides a range of services, the experience of accessing these services can be very disabling because sometimes they are not flexible enough to meet individual needs. To get a benefit, a piece of equipment, or maybe some help at home you might have to tell your story to three or four different people — just to get what you need at that particular time. Next year those three or four people may have moved on, with a new lot of assessors in their place. These kind of arrangements and turnover of staff are disabling because the person, their families and whānau spend a lot of time fighting the system, in order to get access to the same opportunities other New Zealanders have.

The Government needs to help open the way into community life for people experiencing disability — by removing the barriers to their participation.

As a wheelchair user I'm restricted when it comes to meeting family and friends in their homes. I have access to public buildings, and friends can come to visit me but I can return very few visits. Why shouldn't I be able to drop in for a coffee when I want to?

I also feel for young people who use wheelchairs. They cannot leave home and go flatting when and where they like in the way that many of their friends are able to do. It's a big issue for older people too — they suddenly find that the family home they've lived in for years is no longer suitable and they have to move.

I would like to see all homes wheelchair accessible. There are things the Government could do — for a start, all future state houses could be built without doorsteps. But there are also things that architects, designers and builders could do if they thought about it. I'd like to see architectural and design awards for private buildings where accessibility is beautifully and stunningly presented as a feature, and as an essential part of what a home needs.

Lesley

There are no minimum standards for access to and within private dwellings for people experiencing disability. There is also a big shortage of accessible housing available for people with disabilities. Demand is twice what is available.

Question

1. What do you think are the main barriers faced by people experiencing disability?

Vision of a non-disabling society

Along with other New Zealanders, people experiencing disability aspire to a good life.

The vision that underpins this discussion document is for a non-disabling society where people who have experienced disability can say they live in:

‘a fully inclusive society, where our capacity to contribute and participate in every aspect of life is continually being extended and enhanced’.

This will happen in a country where:

- there is acknowledgement of the special relationship between the tangata whenua and the Crown under the Treaty of Waitangi
- people who experience disability have a meaningful partnership with Government, communities and support agencies, based on respect and equality
- the social model of disability (ie, the idea that it is society that imposes many of the disabling barriers faced by people with impairments) is widely understood and used in well-informed legislation, policy and activity involving and benefiting people who experience disability
- a mutually supportive society values the lives of people who experience disability and integrates people into community life on their own terms
- human rights are protected as a fundamental cornerstone of government policy and practice
- the diversity of people who experience disability, including their cultural backgrounds, is recognised, and there is flexibility to meet their differing aspirations and goals
- people experiencing disability have equity, regardless of gender, cultural background, type of disability and when the disability was acquired
- institutionalisation is reduced significantly, while community-based services increase to ensure people are supported to live in their own communities.

Questions

2. Do you think the vision is the direction in which New Zealand should be heading?
3. How would you change it?

Knowing when we have achieved the vision

New Zealand will have achieved the vision of a non-disabling society when individuals who have experienced disability reach and can sustain their optimum level of participation within their communities.

Participation in communities will be at its optimum when opportunities and outcomes for people who experience disability are the same as for other New Zealanders. Among these opportunities and outcomes are:

- equal educational opportunities and achievement
- equal employment opportunities and employment rates
- equal access to business opportunities
- the same levels of political participation (such as voting in elections)
- comparable income levels
- comparable housing, in terms of quality of the housing and living situations
- equal access to a range of lifestyle choices, family life, culture, recreation and social networks
- equal access to the built physical environment
- equal access to transport
- equal access to communication (including mainstream and assistive technology) and information
- equal access to effective medical care.

Progress towards these opportunities and outcomes should be able to be measured regularly through the post-Census disability survey, and other data sources.

Questions

4. What are other ways to tell when the vision has been achieved?
5. What information would help measure this?

Action plan

To make the New Zealand Disability Strategy work, the Government must be prepared to:

- live by the Strategy, and operate according to its philosophy
- provide the resources for its implementation. The Strategy may not necessarily cost more money, but it will require more dedication. It will require innovation and change in behaviour and procedures.

Outlined in this section are 13 actions that are critical to the achievement of the vision of a non-disabling society:

Action 1: Encourage and educate for a non-disabling society

Encourage the emergence of a non-disabling society that respects and values the lives of people experiencing disability and supports integration within communities.

Key steps:

1. Educate communities (including employers, educators, government agencies, media and service providers) on disability issues, focusing on development of local disability education networks, and destigmatisation programmes.
2. Educate communities about their inclusion of older people experiencing disability, and the issues they face.
3. Debate disability issues widely including: ethical and bioethical issues, the role of children in decision-making, parenting choices, abuse, the role of family and whānau in decision-making, use of language, Deaf culture, and Māori and Pacific concepts of disability.
4. Ensure that publicly funded curriculum development and workforce training incorporates discussion of disability issues and involves people experiencing disability.

When I was about one, a hearing specialist told my parents I was Deaf.

My Mum, Roimata, and my Dad, Chris, had always dreamed that their kids would grow up speaking te reo. The specialist told them that if they wanted me to speak te reo, my only chance would be an operation to restore some hearing. Then I could concentrate on spoken language and not have to learn sign.

At that time, my parents didn't know anyone who was Deaf. What they did know was that they needed to get more information. Eventually they made contact with members of the Deaf community, who told them about Deaf as a culture in itself, and the need for me to be exposed to that culture, and learn the language of that culture.

My parents had to go out and seek that information — and that's always going to be the case. But as a society, we don't know much at all about disability issues, and for some reason we don't seem to like to talk about them.

Matiu

Questions

6. How should communities and individuals be educated to be more aware of the ways that society disables people?
7. How can we increase debate on disability issues?

Action 2: Ensure rights for people experiencing disability

Uphold and promote the rights and responsibilities of people who experience disability.

Key steps:

1. Proactively implement and monitor the human rights framework in the government sector and throughout society.
2. Resource the Human Rights Commission to ensure greater focus on rapidly and fairly resolving complaints about disability discrimination.
3. Review current disability discrimination legislation to enhance and strengthen the rights of people experiencing disability, eliminate systemic discrimination, review exemptions, and revisit the concept of 'reasonable accommodation'.¹
4. Ensure that all legislation, regulations and policies are in line with the legislation against disability discrimination.
5. Investigate structures and processes that might deliver rights more fully to people experiencing disability and their families.

Question

8. What is the best way to ensure that the rights of people experiencing disability are met?

¹ For example, an employer is required to reasonably accommodate the needs of a person experiencing disability, unless this would cause unreasonable disruption, or pose a risk to health or safety.

Action 3: Provide the best education

Improve the educational opportunities and outcomes for people experiencing disability.

Key steps:

1. Improve the quality and choice of education provided to people experiencing disability.
2. Increase lifelong opportunities for learning for people experiencing disability.
3. Ensure that teachers and education institutions understand the learning needs of people experiencing disability, and incorporate that understanding into their everyday practice, so that teachers are able to effectively teach students with diverse needs.
4. Ensure that students, teachers and educational institutions can access the support needed to maximise educational opportunities.

Question

9. How can education outcomes for people experiencing disability be improved?

Action 4: Provide opportunities for employment and economic development

Enable people experiencing disability to work in the open labour market (in accordance with human rights principles) and maintain an adequate income.

Key steps:

1. Ensure that people experiencing disability can develop their individual capacity to go into jobs (through education, improved literacy and training), and create real job opportunities.
2. The Government and people experiencing disability will work together to define what work means to people experiencing disability.
3. Ensure that employment options are available, and that people experiencing disability have a smooth transition into employment where they have the same employment conditions, rights and entitlements that everyone else has and are covered by the same employment legislation.
4. People experiencing disability will lead the development of their own training and employment goals where appropriate and ideally make decisions about services and support options to achieve those goals.
5. Ensure that communication services, resources, and flexible workplace options are available to enable people who experience disability to be employed.
6. Government agencies and publicly funded services will operate with Equal Employment Opportunity (EEO) policies and will proactively employ and develop people experiencing disability at all levels of operation. People experiencing disability should be employed for their skills and knowledge, and should be overrepresented in areas which develop or operate disability policy or provide disability services. Annual EEO reports will be publicly released and distributed widely.
7. People who experience disability should have access to economic development initiatives, including business opportunities.

I was just a teenager when I started having mood swings and hearing voices that other people didn't understand. I lived in a small town, and the gossip spread like wildfire. After a while I didn't even want to go to the corner dairy because of the way people looked at me and I lost what little confidence I had left. I also ended up losing a lot of years out of my life.

What made a difference for me was being able to work. I moved out of the town where I grew up and got a part-time job. It wasn't really challenging but I couldn't seem to get the sort of job I wanted. I ended up going and getting some training and then I got the idea for the business I still run today. My parents helped me out with a loan to get started because the banks didn't want to know me.

I don't think its easy for anyone to get a business going. The failure rates are high. But if you've got a sound idea, what you really need is the opportunity.

Paul

Questions

10. What are other ways to increase employment and business opportunities, and to improve the economic situation of people experiencing disability?
11. How could the Government ensure adequate incomes for those people experiencing disability who cannot get a well-paid job?

Action 5: Foster leading voices by people experiencing disability

Build the capacity of people experiencing disability to take responsibility for governing, managing, advising and delivering disability-specific and mainstream services.

Key steps:

1. Require agencies and services that access government funding to work actively to ensure that people experiencing disability are in governance and decision-making roles, and involved in monitoring and evaluation processes.
2. Resource the development of service providers and advocacy organisations run by and for people experiencing disability.
3. Recruit and develop a workforce that includes people experiencing disability in all the services that impact on them.
4. Strengthen the voice of people experiencing disability at the national level so they can make a fuller contribution to the development of legislation and policy.
5. Ensure that people who experience disability can take the central role in discussion of issues that personally affect them.

Questions

12. What is the best way to ensure that the voices of people experiencing disability have a leading role in decisions that affect them?
13. How else might people experiencing disability have greater control over the services that impact on them?

Action 6: Foster an aware and responsive public service

Ensure that government agencies and publicly funded services are aware and responsive to people experiencing disability.

Key steps:

1. Government agencies and publicly funded services will have training and mechanisms in place to ensure that all legislation, policy, service development and service delivery are consistent with the New Zealand Disability Strategy.
2. Government agencies and publicly funded services will co-operate to ensure that the person experiencing disability is at the centre of service delivery with a single key contact point. Agencies will review current processes, with the aims of eliminating the replication of requirements and ensuring agency responsibilities are clear.

Each day I wake up I know I should be thrilled that I can share the breath with my four children and husband. At night I dream that this muddled brain will wake up refreshed, my body pain-free and energy restored.

I knew this life several years ago and dreamed of being amongst New Zealand's elite equestrians. Then four years ago I took a heavy fall show-jumping and knocked myself out. From that day onward I am a different person.

I have had a long and difficult process trying to get help. All I ever asked for was some help to cope with changes and challenges I faced coming to terms with the new me. I'm still waiting and wondering how you work with the system and get well.

If I could get a message to the system, I would say, 'Please give me your time, concentrate your efforts, just for a bit and complete the paper work, then put in place the recommendations and supports. Then I'll not have to keep writing, ringing and reminding.'

Marg

Question

14. Are there other things that government agencies and publicly funded services can do to remove barriers faced by people experiencing disability?

Action 7: Improve services to people experiencing disability

Improve access to and the quality of publicly funded goods and services.

Key steps:

1. Develop and implement clear, consistent and equitable eligibility criteria to clarify what people who experience disability can expect in terms of accessing goods and services.
2. Identify and aim to meet gaps in service and unmet need.
3. Develop and implement a consistent understanding and definition of disability across government departments, based on the social model of disability.
4. Improve the availability and range of services across the continuum of care, support and social services with an emphasis on community provision and integration.
5. Ensure people get services at the right time, instead of after inappropriately long delays.
6. Invest in realising people's potential through effective rehabilitation services, regardless of whether those in need of the service have an impairment that is acquired or lifelong.
7. Increase access to and choice of services for rural people.

Questions

15. What are other ways to make sure people have fair and equitable access to goods and services?
16. What is the best way to determine access to services?
17. What is the best way to define disability?
18. How would existing ways of funding services have to change to promote rehabilitation and habilitation?

Action 8: Improve access to quality information

Improve the quality of information on people experiencing disability, disabling factors and needs, and improve access to this information.

Key steps:

1. Collect useful, valuing information of both a qualitative and a quantitative nature. Analyse and use this information to contribute to policy work, service development and monitoring of the New Zealand Disability Strategy implementation.
2. Increase research on disability issues and ensure people experiencing disability lead development of the research agenda.
3. Improve the quality of information available to people experiencing disability, their families, whānau and carers so that people know their rights; know what they can expect from mainstream and disability-specific services; and are able to make decisions on the basis of the best evidence available.
4. Government agencies and publicly funded services will make public information available in forms appropriate to the different communication needs of people experiencing disability.

Questions

19. What are other ways to improve the quality of information about people experiencing disability?
20. What are other ways to make this information more accessible?

Action 9: Promote participation of Māori experiencing disability

Promote opportunities for Māori experiencing disability to participate in their communities and access disability services.

Key step:

1. Build the capacity of Māori experiencing disability through the equitable allocation of resources within the context of Māori development frameworks such as the Whare Tapa Whā model and He Anga Whakamana.

After several years of heart problems, Dad was becoming really forgetful. He started to disappear off for walks without telling anyone, and he couldn't find his way back home again. We were really worried about him getting hurt.

Everyone in the whānau was either going to school or work so there was no one who could keep an eye on him. The doctor told us that Dad was going to get worse and that maybe we should put him into a rest home. We went to see some but when we got there Dad became upset. The people there were nice but it was nothing like home — it didn't have the same feel. There also didn't seem to be any other Māori living or working there.

My husband and I agreed that I should give up work. It's hard to make ends meet but we just couldn't do without him. He has given so much to this whānau.

Keri

A widely accepted way of thinking about wellbeing is the Whare Tapa Whā. This concept is based on the four walls of a house, where each wall is necessary for strength and balance, and they are all necessary for wellbeing.

- taha wairua — the spiritual side
- taha hinengaro — thoughts and feelings
- taha tinana — the physical side
- taha whānau — the family.

Questions

21. What prevents Māori experiencing disability from participating in their communities and accessing disability services?
22. How can the Government help remove these barriers?

Action 10: Promote participation of Pacific people experiencing disability

Promote opportunities for Pacific people experiencing disability to participate in their communities and access disability services.

Key step:

1. Build the capacity of Pacific communities, including their people who experience disability, through equitable and more appropriate distribution of resources.

A Pacific couple and their twin babies with physical impairments were living with their fanau. Their health care worker felt that their house was overcrowded, so encouraged and supported the couple to get their own place. Both parents then had to get jobs so that they could pay the rent. A social worker contacted a child care agency to arrange childcare, but this caused lots of ill feeling. Some of the fanau felt that they should be the ones looking after the babies.

They [professionals] seemed to know what they were doing and we just kind of got carried along with that. When I think back, I don't think any of them told us what other options we had. My aunties gave us heaps and said we should remember who we are more. Now we need to tell the social worker that we don't want the twins to go to the child care lady and we're not sure how to do it.

The best thing for all of us would be if someone would pay one of my aunties to look after the kids.

Sione

Questions

23. What prevents Pacific people who experience disability from participating in their communities and accessing disability services?
24. How can the Government help remove these barriers?

Action 11: Enable children and youth experiencing disability to lead full and active lives

Children and youth who experience disability should enjoy full and active lives, in conditions which ensure their dignity, promote self-reliance, and facilitate their active participation in the community.²

Key steps:

1. Ensure that government agencies, disability sector agencies, organisations of children, youth and families, and carers work in a collaborative and empowering way to support children and youth who experience disability and their families.
2. Ensure that children, youth and their families are able to access effective child or youth and family-focused support, education, health care services, rehabilitation services, recreation opportunities and training to help children and youth to achieve the greatest possible self-reliance and lead full and active lives in society.
3. Introduce ways of involving children and youth in decision-making and giving them greater control over their lives.

Question

25. How can the Government enable children and youth who experience disability to lead full and active lives?

² Based on Article 23 of the United Nations Convention on the Rights of the Child.

Action 12: Improve quality of life for women experiencing disability

Improve the quality of life, opportunities and choices for women experiencing disability.³

Key steps:

1. Provide more effective support for women experiencing disability, including: promoting their rights; increasing access to women's and other services; dealing with abuse, and supporting their choices.
2. Focus on issues and choices faced by women experiencing disability especially parenting and caring responsibilities, sexual health and sterilisation.

After having my baby and returning to the ward, people reacted to me really differently. Some people were very supportive. Others assumed that I was just a visitor from another ward or were amazed that I had actually been able to have my own baby. Some mothers I talked to even overheard comments like, 'I think it's disgusting, letting them have babies.'

Once I got home with my baby people would gaze into the pram and show surprise that my baby was 'normal'. I was inundated with the standard 'Oh, however do you manage?', I got used to it and replied, 'Just like any mother ... except I wheel instead of walk between chores.'

Personally I would recommend motherhood and I have no qualms about encouraging others to give it a go if it is what they want. Our disabilities are a fact of life and unless there's a health risk they must not be the deciding factor in our decision-making.

Sandie

Question

26. How can more support be given to women experiencing disability?

³ Many of these issues also affect men. However, women have been targeted because the impact of these issues is often more significant for them.

Action 13: Value families, whānau and carers

Acknowledge and support the roles, responsibilities and issues facing family, whānau and carers of people experiencing disability.

Key steps:

1. Ensure that, where appropriate, the family, whānau and carers of people who experience disability are given a legitimate voice in issues that affect them or their loved ones.
2. Work actively to ensure that the families, whānau and carers of people who experience disability can be involved in policy and service development and delivery, and in monitoring and evaluation processes where appropriate.
3. Encourage debate around responsibility for caring and how to further recognise and value the caring role.
4. Improve the support and choices provided to carers of people experiencing disability (particularly children) in order to minimise loss of employment and income, the impact on families and siblings, social isolation and pressures on women to remain at home in a caring role.
5. Address questions regarding rates of pay for professional carers and whether families should be paid for caring services.

One April morning, after eight months of assessment, observations and countless appointments we were told that our physically perfect, attractive four-year-old daughter was 'handicapped'; she was diagnosed as having autism and intellectual disability. The grief was almost all consuming and our lives changed forever.

Our daughter's inability to understand people and language caused her constant stress. She coped by organising her life into structured routines that only she knew. She is now nineteen and a valued member of our family. With a lot of energy from us and professional behaviour support, our daughter now has an acceptable communication method – we all write everything.

We still feel tremendous grief, but now it is for our daughter, not ourselves. Just coping is difficult for our family and for her. This has been compounded by the difficulties of the 'system' and an unaccepting community. With each milestone it feels as if we are the first ones to have got there. After years of trying to work with unaware, unco-operative teachers who failed to equip her with skills for adult life, we are faced with the task of supporting our daughter into adulthood. All we hope for is that our daughter be an accepted, valued member of our community who has the opportunity to contribute and participate.

Anne

Questions

27. What is the cost of disability experienced by families?
28. How can more effective support be given to families, whānau and carers?

Seeking any further feedback on the action areas

29. Are there any other key areas for action that have been left out?

The Government is also interested in feedback on the best ways to practically advance the action areas and steps outlined above. Your ideas might include advice on:

- how local government can contribute most effectively to implementation of the Strategy
- how public service structures or responsibilities might be changed to advance the Strategy's vision (for example, where responsibility for funding disability support services should sit)
- what debates, discussion and work are still needed
- what issues are most important and should be addressed first.

Delivering the Strategy

Once the New Zealand Disability Strategy is finalised, the Government will consider an implementation plan for government departments and other agencies. Within the implementation plan will be specific targets which agencies must build into their work programmes. It may also specify ongoing expectations to be reflected in performance agreements and contracts.

Progress on implementing the Strategy will need to be monitored. Those with responsibility for such monitoring should be people experiencing disability. The process should be well funded, with a formal cycle that uses data collected regularly, for example, through the Census. Moreover, the results of monitoring should have 'teeth' — in other words, the results should be used to improve the performance of government agencies.

There should be a staged approach to monitoring that reflects the timelines for implementation.

More specifically, some possible ways of monitoring the Strategy are as follows.

- Government agencies could undertake their own monitoring of their success in implementing the Strategy, including their performance on specific targets. However, it is important that agencies do more than just meet set targets; they must take a wider view of their responsibilities in creating a non-disabling society. With this self-monitoring approach, agencies will need to report on their findings.
- In addition to internal monitoring, there could be an external system where a single government agency, advised by a group of people experiencing disability, monitors other agencies or requires them to report to it. This agency could be an existing agency such as the Disability Issues Directorate at the Ministry of Health or the State Services Commission. The monitoring agency could have the ability to make recommendations to agencies or Government.
- Monitoring could be undertaken by a separate independent body, such as a Disability Commission.

The Strategy should be reviewed regularly and updated as necessary.

Questions

30. How can the Government and people who experience disability track progress on implementing the Strategy?
31. Who should monitor progress?

How you can respond to this discussion document

The Government is seeking your views on any or all of the issues raised in this discussion document. It needs to hear from you by **1 November 2000**.

Your comments will be used to help the Government create a New Zealand Disability Strategy that is highly relevant, workable and successful. The Strategy will be finalised in early 2001.

You may give your views in the following ways.

Make a submission

We invite you to make a written, audiotape or videotape submission on this document by **1 November 2000**.

The questions in this discussion document, and spaces to answer them, are included in the pull-out section at the back of this document. It will be easier to consider your views if you use the questions to respond to this discussion document, however you are welcome to comment on any other issues relevant to the Strategy.

You can also request an easy-to-read information pack with instructions on how to run your own discussion group about the Strategy. Get an information pack by phoning Judith Mercer on (04) 496 2554 or from the web sites below.

You can write to the project team at:

Judith Mercer
New Zealand Disability Strategy
Ministry of Health
PO Box 5013
WELLINGTON

Fax: (04) 496 2340

E-mail: nzds@moh.govt.nz

Web sites: www.nzds.govt.nz or www.dpa.org.nz

Attend a workshop, hui or fono

You may attend one or more of the 41 workshops scheduled to discuss the Strategy.

Some workshops are for people experiencing disability only so that people experiencing disability are assured of a strong voice in developing the Strategy. People experiencing disability may bring a support person to these workshops if they wish to, and non-verbal people may invite that person to interpret for them.

Other workshops are open to the public, including families, carers and service providers. People experiencing disability may also wish to attend and contribute to the public workshops.

You may also attend one or more of the four hui and four fono.

Workshops

North Island

| | |
|---|---|
| KAITAIA 17 October 2000 (Tuesday) Collards Tavern Whakatane Drive | 10.00 am-11.30 am (public workshop) (one meeting only) |
| WHANGAREI 16 October 2000 (Monday) Forum North Rust Avenue | 11.00 am-12.30 pm (people experiencing disability) 3.00 pm-4.30 pm (public workshop) |
| TAKAPUNA 25 September 2000 (Monday) Fairway Lodge Argus Place | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| CENTRAL AUCKLAND 26 September 2000 (Tuesday) Quality Hotel Logan Park 187 Campbell Road Greenlane | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| SOUTH AUCKLAND 27 September 2000 (Wednesday) Otarā Recreation & Leisure Centre Cnr Bairds Road & Newbury Street Otarā | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| HAMILTON 9 October 2000 (Monday) Quality Inn 100 Garnett Avenue | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| ROTORUA 25 October 2000 (Wednesday) Rydges Rotorua 272 Fenton Street | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |

| | | |
|---|--------------------------------------|---|
| GISBORNE 25 September 2000 (Monday) Gisborne Hotel Cnr Huxley & Tyndall Streets | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |
| NAPIER 26 September 2000 (Tuesday) Landmark Hotel Cnr Marine Parade & Emerson Streets | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |
| NEW PLYMOUTH 13 October 2000 (Friday) The Devon Hotel 390 Devon Street East | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |
| TAUMARUNUI 12 October 2000 (Thursday) Central Park Motor Inn Maata Street | 2.00 pm-3.30 pm | (public workshop) (one meeting only) |
| PALMERSTON NORTH 19 October 2000 (Thursday) Quality Inn 110 Fitzherbert Avenue | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |
| MASTERTON 4 October 2000 (Wednesday) Cophorne Resort Solway Park High Street South | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |
| PORIRUA 3 October 2000 (Tuesday) Aotea Lodge Whitbrown Avenue | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |
| WELLINGTON 2 October 2000 (Monday) The Terrace Conference Centre Level 3, Dalmuir House 114 The Terrace | 10.00 am-11.30 am 2.00 pm-3.30 pm | (people experiencing disability) (public workshop) |

South Island

| | |
|--|---|
| NELSON 9 October 2000 (Monday) Beachcomber Motor Inn 23 Beach Road | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| GREYMOUTH 18 October 2000 (Wednesday) Regent Theatre Trust Cnr Mackay & Herbert Streets | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| CHRISTCHURCH 10 October 2000 (Tuesday) Copthorne Central 776 Colombo Street | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| TIMARU 5 October 2000 (Thursday) Senior Citizens Hall 22 Church Street | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| ALEXANDRA 3 October 2000 (Tuesday) Centennial Court 96 Centennial Avenue | 10.00 am-11.30 am (public workshop) (one meeting only) |
| DUNEDIN 4 October 2000 (Wednesday) Southern Cross Cnr Princes & High Street | 10.00 am-11.30 am (people experiencing disability) 2.00 pm-3.30 pm (public workshop) |
| INVERCARGILL 2 October 2000 (Monday) Ascot Park Hotel Cnr Racecourse & Tay Streets | 11.30 am-1.00 pm (people experiencing disability) 3.00 pm-4.30 pm (public workshop) |

Hui

North Island

AUCKLAND 10.00 am-2.00 pm
29 September 2000 (Friday)
Manukau Institute of Technology Marae
Gate 12, Otara Road
Manukau City

ROTORUA 10.00 am-2.00 pm
26 October 2000 (Thursday)
Tunohopu Marae
Tunohopu Street
Ohinemutu

WELLINGTON 10.00 am-2.00 pm
19 October 2000 (Thursday)
Waiwhetu Marae
Puketapu Grove
Waiwhetu, Lower Hutt

South Island

CHRISTCHURCH 10.00 am-2.00 pm
11 October 2000 (Wednesday)
Rehua Marae
79 Springfield Road

Fono

North Island

AUCKLAND 10.00 am-2.00 pm
27 October 2000 (Friday)
Grey Lynn Community Centre
510 Richmond Road
Grey Lynn

SOUTH AUCKLAND 10.00 am-2.00 pm
27 September 2000 (Wednesday)
Cecilias Convention Centre
Tavern Lane
Papatoetoe

WELLINGTON 10.00 am-2.00 pm
16 October 2000 (Monday)
Hosanna World Outreach Centre
1115-1121 High Street
Taita
Lower Hutt

South Island

CHRISTCHURCH 10.00 am-2.00 pm
17 October 2000 (Tuesday)
Westpac Trust Canterbury Centre
116 Cashel Street Mall

A report on the consultation will be available on the Web site or by request.

Appendix 1: Membership of the New Zealand Disability Strategy Sector Reference Group

| | |
|---------------------|---|
| Ms Robyn Hunt | (Co-chair), Disability Consultant and Chair of the Workbridge Board of Management |
| Dr Jan Scown | (Co-chair), Chief Executive of the Community Living Trust |
| Ms Jennifer Brain | Chief Executive Officer of the Deaf Association of New Zealand |
| Mr Paul Gibson | President of DPA |
| Mr Les Gilsenan | Manager of the Whanganui Disability Resource Centre |
| Mr Mike Gourley | Producer and presenter of National Radio's 'Future Indicative' programme |
| Ms Judith Lunny | Co-ordinator and Facilitator for the Auckland Disability Providers Network |
| Dr Nigel Millar | Clinical Director, Older Persons Health, Healthlink South |
| Ms Missy Morton | Lecturer at the Education Department of Canterbury University |
| Ms Mary O'Hagan | Community and Mental Health Consultant |
| Mr Graham Stairmand | Health and Disability Spokesperson for Christchurch Grey Power |
| Ms Lorna Sullivan | National Service Development Manager for New Zealand CCS |
| Mr Patrick Thompson | Māori Deaf Development Manager for the Deaf Association of New Zealand |
| Mr Maaka Tibble | Māori Mental Health Manager for Waitemata Health |

Making a World of Difference: Whakanui Oranga

SUBMISSION BOOKLET FOR THE NEW ZEALAND DISABILITY STRATEGY

You might like to use these questions as a way of organising and presenting your feedback. Please feel free to make any additional comments or use a different format if you want. You do not have to answer questions or provide personal information if you do not want to.

SUBMISSIONS CLOSE ON 1 NOVEMBER 2000

Please return your submissions to:

Judith Mercer
New Zealand Disability Strategy
Ministry of Health
PO Box 5013
WELLINGTON
Fax: (04) 496 2340
E-mail: nzds@moh.govt.nz

An information pack on running your own discussion group is available by phoning Judith Mercer on (04) 496 2554.

All submissions will be acknowledged by the Ministry of Health. A report on the consultation will be available on the New Zealand Disability Strategy Web site (www.nzds.govt.nz or www.dpa.org.nz) or by request. You can also get a copy of this submission booklet from the web site.

PLEASE PULL OUT HERE

Completed by: _____ (name)

Address: _____

Organisation: (if applicable) _____

Position: (if applicable) _____

This submission includes the input of: _____ (number of additional people)

Are you responding as:

an individual? **(please go to (A) below)** or

a representative of an organisation? **(please go to (B) below)**

Section A – Individual response

Is your main interest in the New Zealand Disability Strategy because you are a: (choose ONE)

- Person who experiences disability?
- Parent of a child or youth who experiences disability?
- Unpaid carer of an adult who experiences disability?
- Other relative, guardian or whānau member of a person who experiences disability?
- Advocate for people who experience disability?
- Service provider to people who experience disability? (for example: a needs assessor, home help provider, teacher, general practitioner etc) (please specify)

- Interested member of the public?
- Other? (please specify) _____

Are you:

- NZ Māori
- NZ European
- Pacific Island
- Asian
- Other (please specify) _____

If you are a person who experiences disability are you:

- 0–14 years
- 15–24 years
- 25–44 years
- 45–64 years
- 65–74 years
- 75+ years

Section B – Organisation response

Is your main interest in the New Zealand Disability Strategy because your organisation:
(choose ONE)

- Represents and/or advocates for people who experience disability
- Represents and/or advocates for the interests of a professional group
- Represents and/or advocates for the interests of another population group (such as Māori, Pacific people, women, parents, rural people, people who have health problems) (please specify) _____
- Provides services to people who experience disability (for example school, hospital, vocational trainer) (please specify) _____
- Central government department or agency (including local offices or branches)
- Local government body
- Other (please specify) _____

If neither of these categories apply, please describe your interest in disability issues below

Your submission may be requested under the Official Information Act 1982. If this happens, the Ministry of Health will release your submission to the person who requested it. However, if you are an individual, as opposed to an organisation, the Ministry will remove your personal details from the submission if you check the following box:

- I **do not** give permission for my personal details to be released to persons requesting my submission under the Official Information Act 1982.

Question – barriers (refer to pages 1–4)

1. What do you think are the main barriers faced by people experiencing disability?

Questions – vision (refer to pages 4–5)

2. Do you think the vision is the direction in which New Zealand should be heading?

3. How would you change it?

Questions – knowing when we have achieved the vision (refer to page 5)

4. What are other ways to tell when the vision has been achieved?
5. What information would help measure this?

Questions – encourage and educate for a non-disabling society (refer to pages 6–7)

6. How should communities and individuals be educated to be more aware of the ways that society disables people?
7. How can we increase debate on disability issues?

Question – ensure rights (refer to page 8)

8. What is the best way to ensure that the rights of people experiencing disability are met?

Question – provide the best education (refer to page 9)

9. How can education outcomes for people experiencing disability be improved?

Questions – provide opportunities for employment and economic development (refer to pages 10–11)

10. What are other ways to increase employment and business opportunities, and to improve the economic situation of people experiencing disability?
11. How could the Government ensure adequate incomes for those people experiencing disability who cannot get a well-paid job?

Questions – foster leading voices (refer to page 12)

12. What is the best way to ensure that the voices of people experiencing disability have a leading role in decisions that affect them?
13. How else might people experiencing disability have greater control over the services that impact on them?

Question – foster an aware and responsive public service (refer to page 13)

14. Are there other things that government agencies and publicly funded services can do to remove barriers faced by people experiencing disability?

Questions – improve services (refer to page 14)

- 15. What are other ways to make sure people have fair and equitable access to goods and services?
- 16. What is the best way to determine access to services?
- 17. What is the best way to define disability?
- 18. How would existing ways of funding services have to change to promote rehabilitation and habilitation?

Questions – improve access to quality information (refer to page 15)

- 19. What are other ways to improve the quality of information about people experiencing disability?
- 20. What are other ways to make this information more accessible?

Questions – promote participation of Māori (refer to page 16)

- 21. What prevents Māori experiencing disability from participating in their communities and accessing disability services?
- 22. How can the Government help remove these barriers?

Questions – promote participation of Pacific people (refer to page 17)

23. What prevents Pacific people who experience disability from participating in their communities and accessing disability services?

24. How can the Government help remove these barriers?

Question – enable children and youth to lead full and active lives (refer to page 18)

25. How can the Government enable children and youth who experience disability to lead full and active lives?

Question – improve quality of life for women (refer to page 19)

26. How can more support be given to women experiencing disability?

Questions – value families, whānau and carers (refer to pages 20–21)

27. What is the cost of disability experienced by families?

28. How can more effective support be given to families, whānau and carers?

Seeking any further feedback on the action areas (refer to page 21)

29. Are there any other key areas for action that have been left out?

The Government is also interested in feedback on the best ways to practically advance the action areas and steps outlined above. Your ideas might include advice on:

- how local government can contribute most effectively to implementation of the Strategy
- how public service structures or responsibilities might be changed to advance the Strategy's vision (for example, where responsibility for funding disability support services should sit)
- what debates, discussion and work are still needed
- what issues are most important and should be addressed first.

Questions – delivering the Strategy (refer to page 22)

30. How can the Government and people who experience disability track progress on implementing the Strategy?

31. Who should monitor progress?

Question – future consultation

32. What are the most effective ways for you and your community or organisation to be involved in future consultation?

Anything else?

33. Would you like to comment on anything else related to the New Zealand Disability Strategy?
