

# **TO HAVE AN 'ORDINARY' LIFE KIA WHAI ORANGA 'NOA'**

**Community membership for adults with an intellectual disability  
Ko te noho-ā-iwi mō te hunga hinengaro hauā kua pakeke nei**

**A report to the Minister of Health and the Minister for Disability Issues  
from the National Advisory Committee on Health and Disability**

September 2003

The National Advisory Committee on Health and Disability is an independent committee appointed by, and reporting directly to, the New Zealand Minister of Health.

This committee, also known as the National Health Committee or the NHC, was established to provide an independent assessment of the quality and mix of services that should, in the committee's opinion, be publicly funded. It also advises the Minister on measures that would deliver the greatest benefit to the health of the population and groups of the population, with particular regard to groups at risk or disadvantage.

#### **Members of the National Health Committee**

Robert Logan (*Chair*)

Geoff Fougere

Kevin Hague

Linda Holloway

Cindy Kiro (*until August 2003*)

Andrew Moore

Teuila Percival (*until March 2003*)

Althea Page-Carruth

Neil Pearce

Lorna Sullivan

Lynette Stewart

Api Talemaitoga (*from June 2003*)

Gwen Tepania-Palmer

ISBN (Document): 0478-25239-X

ISBN (Web): 0478-25332-X

HP: 3686

National Advisory Committee on Health and Disability  
Wellington  
New Zealand  
2003

This report is available on the committee's website <http://www.nhc.govt.nz>  
Copies are available by phoning (04) 496-2277 or e-mailing [moh@wickcliffe.co.nz](mailto:moh@wickcliffe.co.nz)  
This report can be freely quoted, copied and circulated with appropriate acknowledgement.

**He aha te mea nui?  
He aha te mea nui o te ao?  
Maku e ki atu.  
He tangata. He tangata. He tangata.**

**What is the most important thing?  
What is the most important thing in the world?  
I will say to you.  
It is people. It is people. It is people.**

## ACKNOWLEDGEMENTS

A great many people have contributed their time, knowledge, skill and experience to this project. The National Advisory Committee on Health and Disability would like to express its thanks for the goodwill, openness and honesty it experienced from people across New Zealand. In particular it would like to thank adults with an intellectual disability, their families and whānau who so willingly repeated their stories and shared their lives. The committee hopes that as a result of their participation, action will occur that will lead to significant improvements in their lives.

A list of people who contributed to the project is provided at the end of the report.

## OTHER PUBLICATIONS

The other publications developed as part of this project are available on the NHC's website <http://www.nhc.govt.nz>, by phoning (04) 496-2277 or e-mailing: [moh@wickcliffe.co.nz](mailto:moh@wickcliffe.co.nz) (and quoting the HP number below):

- *To have an 'ordinary' life: background papers to inform the National Advisory Committee on Health and Disability* (The companion document to this report which provides more detailed information about the lives of adults with an intellectual disability). HP:3688
- *To have an 'ordinary' life* (a plain language summary of the committee's findings and recommendations). HP:3687

Literature reviews prepared by the Donald Beasley Institute<sup>1</sup>

- *Definitions of intellectual disability* HP:3662
- *Demographics and characteristics of people with an intellectual disability* HP:3663
- *Relationships and adults with an intellectual disability* HP:3664
- *Support for daily living for adults with an intellectual disability* HP:3665
- *Effective communication for adults with an intellectual disability* HP:3666
- *Community participation for adults with an intellectual disability* HP:3667
- *Education for adults with an intellectual disability (including transition to adulthood)* HP:3668
- *Work for adults with an intellectual disability* HP:3669
- *Income for adults with an intellectual disability* HP:3670

<sup>1</sup> These are also available from the Donald Beasley Institute, PO Box 6189, Dunedin.

## WHAT IS 'ORDINARY' ?

The word 'ordinary' is used in the title and throughout this report. This reflects the aspirations of adults with an intellectual disability to access the everyday things that others take for granted. Despite significant changes in society, the lives of adults with an intellectual disability are still very different from other New Zealanders.

In using the word 'ordinary' throughout the report, the National Health Committee recognises that all people, whatever their level of impairment, have the same fundamental human needs and expectations. These include having their lives taken seriously, being able to give and receive love, having enduring personal relationships, having their cultural values respected, being given opportunities to grow, learn and develop throughout life, and being valued by others for what they have to offer. It is also expected that all people will be accorded the 'ordinary' opportunities of access to goods and services, including housing, income, health services, education and community life.

The photos used in this report are a selection of those taken by members of People First for a photo display 'A window on my Life' to accompany the findings of this project. The photos show how members of People First see their lives and the things that are important to them.

# FOREWORD

New Zealand citizens enjoy a wide range of human rights that are accorded through government support for international human rights conventions and treaties and our own laws, such as the Bill of Rights Act and the Human Rights Act. In addition, there are specific rights that are acknowledged in the Treaty of Waitangi.

Two years ago the Government released the New Zealand Disability Strategy (NZDS) – a rights-based framework that aims to achieve a society that highly values the lives of disabled people and enhances their full participation. This is the framework within which the National Advisory Committee on Health and Disability (also known as the National Health Committee or NHC) has undertaken this project to look at the lives of adults with an intellectual disability who need regular support for living.

In considering the rights of citizenship of adults with an intellectual disability, the NHC has looked at whether this group of people are accorded, and can access, the same rights and responsibilities as other New Zealanders and to what degree they are supported to lead the ‘ordinary’ lives that others take for granted.

The NHC has found that adults with an intellectual disability have difficulty accessing rights of citizenship. Their lives are very different from other New Zealanders and not consistent with the vision of the NZDS. Adults with an intellectual disability are seldom integrated into community life on their own terms, individual choices in the most fundamental of life decisions are not available to them, and their aspirations and goals are not supported.

The committee believes this is the first piece of work in its 10 years’ existence that deals with a group of the population whose rights of citizenship are not being taken seriously. Accordingly this report details the actions the NHC believes are necessary to align the lives of adults with an intellectual disability with the Government’s stated goals for disabled people.

The NHC is strongly of the view that if action is not taken to facilitate access for people with an intellectual disability to the personal freedoms and entitlements of citizenship, the increasingly complex cognitive environment in which we live will be even more inaccessible to them.

When it released the NZDS, the Government signalled that progress by its ministries and departments would be reviewed after five years. The NHC believes that the advice in this report – coming two years after the establishment of the NZDS – presents government with an opportunity to translate the vision of that strategy into actions that will have a positive impact on the everyday lives of this group of people.

In undertaking this project the NHC found a strong desire among people with an intellectual disability, their families, whānau and service providers to see meaningful changes occur. The committee believes that the findings and recommendations within this report have significant implications for future disability service provision, not only for adults with an intellectual disability but for all adults across the range of disability types. Action can be taken now that will result in community membership for adults with an intellectual disability.



**Robert Logan**

*Chair, National Advisory Committee on Health and Disability*

# CONTENTS

ACKNOWLEDGEMENTS	4
OTHER PUBLICATIONS	4
What is 'ordinary'?	5
FOREWORD	6
EXECUTIVE SUMMARY	8
PROJECT OVERVIEW	10
What is intellectual disability?	10
The project scope and methodology	11
<i>The information-gathering model</i>	12
<i>Applying the New Zealand Disability Strategy</i>	14
FINDINGS AND RECOMMENDATIONS	17
Priorities for action	17
Rights of citizenship	18
<i>Community membership</i>	18
<i>Achieving 'ordinary' lives</i>	19
<i>Removing barriers through social interpretation</i>	20
A whole-of-government approach to promoting community membership	21
The delivery of support for people with an intellectual disability	22
<i>Accommodation</i>	22
<i>Health</i>	25
Assortment of photographs	27
<i>Communicating</i>	31
<i>Paying for things</i>	32
<i>Work (paid and unpaid)</i>	33
<i>Being part of the community</i>	35
<i>Learning new things</i>	37
<i>Relationships</i>	38
<i>Having fun</i>	39
<i>Moving around</i>	40
<i>Māori adults with an intellectual disability</i>	41
<i>Pacific adults with an intellectual disability</i>	43
Government capacity and service development	45
<i>Creating an aware and responsive public service</i>	45
<i>Improving Needs Assessment and Service Coordination (NASC)</i>	48
<i>Supporting family and whānau</i>	50
<i>Promoting workforce development</i>	52
REFERENCES	54
THANKS TO	55

# EXECUTIVE SUMMARY

Over the past two and a half years, the National Advisory Committee on Health and Disability has been collecting information to build a detailed picture of the lives of adults with an intellectual disability who are supported by government-funded services in New Zealand.

What has been unique in this project is that the NHC has collected much of this information through direct dialogue with the people themselves, giving a comprehensive insight into the lives of adults with an intellectual disability in New Zealand. The project sought to gather information across all areas of a person's life to enable the committee to fully understand the impact of services in general, not just of health-funded services.

Adults with an intellectual disability are a diverse group, with a wide range of skills and abilities. The common features of people with an intellectual disability are intellectual impairment and impaired social functioning from birth or early childhood. People with an intellectual disability have 'ordinary' goals and aspirations. In order to achieve these they need support to minimise the barriers created by their impairment. One way in which this is done is through family, whānau, friends and service providers acting as 'social interpreters'. This important role – making sense of the cognitively complex world we live in – is often unrecognised.

The NHC's findings indicate that although services in New Zealand have, with good intent, sought to move away from institutional-based services, much of this has focused on removing bricks and mortar rather than on ensuring support is provided in a way that is not institutional. Service purchase and provision have failed to keep up with international best practice.

The nature of the support provided at present tends to be custodial and constrictive, focusing on keeping things the same, rather than actively moving towards community membership of people with an intellectual disability. This is to a large extent a result of the limited range of services that are contracted, the disability support workforce being undervalued, lack of understanding and knowledge about the potential of adults with an intellectual disability, and the narrow focus of assessment and planning processes.

The NHC's findings fall into three major categories:

- **disturbing** – 'life-defining' services; systemic neglect of the development potential of this group of people and their families and whānau; inadequate and improper health care provision; low levels of understanding among people in authority of the impact of their actions and decisions on the lives of adults with an intellectual disability
- **worrying** – high poverty levels; low educational opportunities; lack of communication support; little opportunity to form sustaining personal relationships; lack of purposeful futures; lack of culturally appropriate services
- **encouraging** – individual examples (nationally and internationally) of positively supported lives; an emerging body of knowledge about what is possible; the self-advocacy movement.

The committee has identified three priorities for action where it believes the most significant changes are required.

- ***Refocusing needs assessment, service coordination and service purchasing.*** The needs assessment process requires considerable refocus and upskilling of staff. There should be an emphasis on strategic assessment or planning for life with the disabled person and their family and whānau. Correspondingly, the concept of service coordination needs to make a significant shift from allocating people to a limited range of services to a focus on service design to meet the individual's changing support and development needs over time.
- ***Moving away from the custodial ownership model of service delivery.*** In many instances, providers own the houses in which people live; provide the services within these houses; are ascribed residents' benefits; and control residents' personal income. The committee recommends that adults with an intellectual disability have full tenancy protection and access to full benefit and housing entitlements. This will require disentangling the cost of accommodation from the funding of service provision.
- ***Addressing the neglect of basic health needs.*** Many adults with an intellectual disability endure prolonged suffering from health conditions that are treatable, relievable and curable, yet receive inadequate medical management. The project also uncovered disturbing prescribing practices. The committee recommends that high priority be given to addressing the neglect of the health of adults with an intellectual disability.

The NHC has made 23 recommendations that detail how to make changes in these priority areas and other aspects of policy and service provision for adults with an intellectual disability. The most critical component in actioning these recommendations is to adopt a new way of thinking which focuses on individuals and their aspirations as citizens and how these can be better achieved.

The committee believes a cross-government response is necessary to achieve the concept of community membership for people with an intellectual disability as envisaged by the New Zealand Disability Strategy. The NHC's report provides the evidence for change and outlines practical steps to implement the New Zealand Disability Strategy for adults with an intellectual disability.

# PROJECT OVERVIEW

In the 10 years that the National Advisory Committee on Health and Disability has been providing independent advice to the New Zealand Government, it has produced a number of reports on services for people with disabilities. This is the first time the committee has looked specifically at the services supporting people with an intellectual disability. The following report is the culmination of a two-and-a-half year project to gather information about adults with an intellectual disability who need regular support for living, to look at the impact that support has on their lives, and to provide advice to Ministers about future service provision.<sup>2</sup>

This project arose from concern by the NHC about the service provision environment that was emerging in the wake of deinstitutionalisation of adults with an intellectual disability.

## WHAT IS INTELLECTUAL DISABILITY?

The NHC was surprised to discover there is no generally accepted New Zealand definition of intellectual disability that is used in policy making across the state sector. Furthermore, intellectual disability is often confused with acquired impairment of intellectual function in late adolescence or adulthood, either through accident, such as head injury, or illness, such as Alzheimer's disease or stroke.

In developing the project the committee needed a definition that clearly identified this population. Definitions are often used as the basis for significant decisions about people's lives, and the committee considered definitions currently used around the world. The definition the NHC chose to use was published by the British Government in 2001<sup>3</sup>, and defines intellectual disability as:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood with a lasting effect on development.

In plain language, having an intellectual disability means it is hard to learn new things or to think about problems; you need support in your life; and it has been like this since childhood.

From a range of data, the committee estimates that between 11,500 and 15,000 adults nationally need ongoing support due to an intellectual disability.

Throughout the NHC's extensive consultation and information gathering process, the enormous range of skill and ability within this population became evident. People with an intellectual disability are an extremely heterogeneous group. Health, communication, mobility, literacy, and social interactions all show huge variation.

There are definite cohorts within the population:

- older adults, including those whose lives have been shaped by their time spent in large institutions, and those who have remained at home with their parents all of their lives
- younger adults who tend not to have lived in large institutions. Many have used the services of smaller providers, which have been established since the late 1980s
- adults who have recently left school, where they were mainstreamed and have different experiences and expectations from older adults.

<sup>2</sup> This report outlines the committee's advice and recommendations. A variety of other publications have been produced during the project. These are listed on page 4.

<sup>3</sup> Department of Health (United Kingdom), 2001.

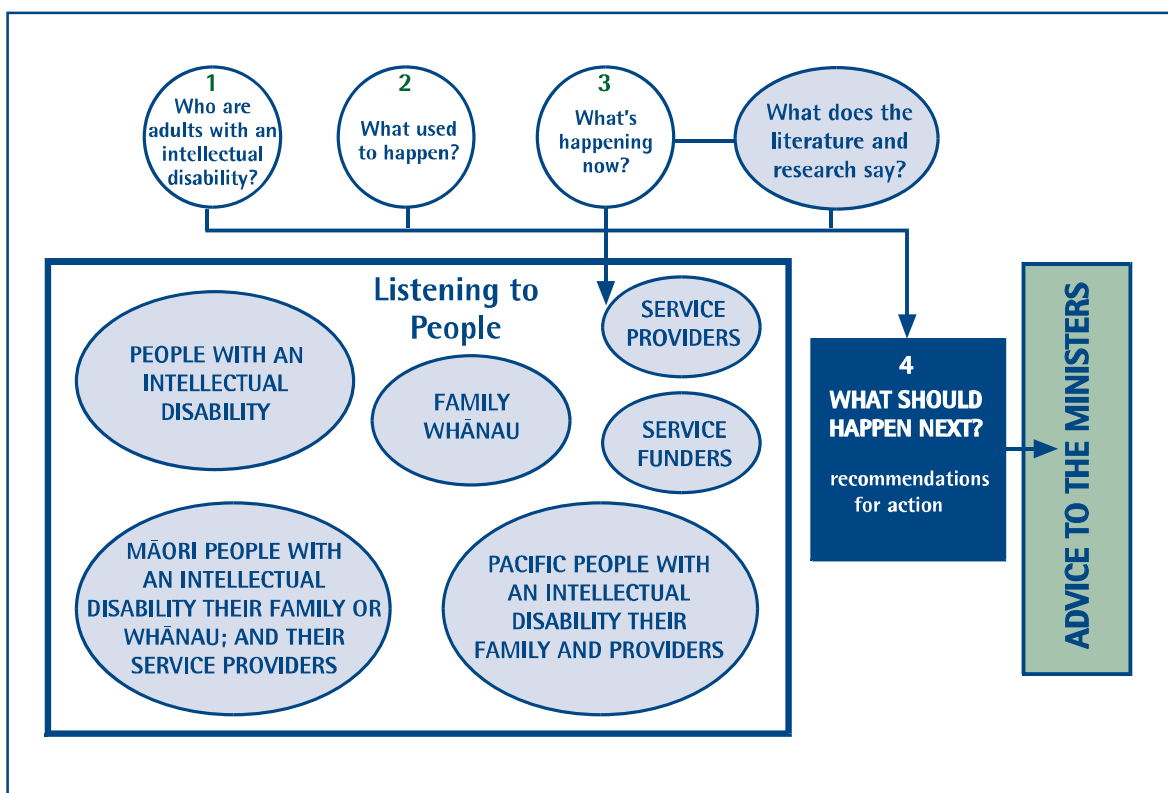
During the project, adults with an intellectual disability have been clear that regardless of the degree of their impairment, they can make their needs and feelings known, and that they must be an integral part of future service development and delivery.

## THE PROJECT SCOPE AND METHODOLOGY

The NHC was clear that in doing this project it wished to look at all aspects of life for adults with an intellectual disability. This meant looking beyond services funded by Vote Health, and considering all publicly funded services that support adults with an intellectual disability. The committee was also clear that the focus was to be on the impact of services on the lives of adults with an intellectual disability and their families and whānau. In order to do this, information needed to be gathered from the point of view of the adults with an intellectual disability.

The project aimed to provide answers to four questions:

- *who are adults with an intellectual disability?*
- *what used to happen in their lives?*
- *what is happening now?*
- *what should happen next?*



In seeking to answer these four questions, the NHC began by gathering demographic information about adults with an intellectual disability. This included trying to identify how many adults with an intellectual disability there are in New Zealand, where they live, what their skills and abilities are and what sort of support they need. While the project focused on adults, it included consideration of some of the issues around transition into adulthood and for this reason no specific lower age limit was imposed.

To better understand what is happening now and to look ahead to what might be, it is important to know what happened in the past. Therefore, the history of service provision in New Zealand and the national and international movements that affected it, was the next piece of the project.<sup>4</sup>

The NHC then sought information about all aspects of the lives of adults with an intellectual disability – what services are available to them, where they see gaps in services, what they think about the quality and effectiveness of the support they receive, and what they think is essential support, now and in the future.

## The information-gathering model

After some initial consultation and discussion, the NHC developed an information-gathering model, which looked at broad components of an individual's life. This model was slightly amended as the project progressed, and proved to be a very useful tool. Feedback during consultations confirmed that the model covered what matters most to people. The NHC recommends its use to others wishing to examine the impact of services on people's lives.

The model puts the person in the centre, and covers:

**My culture** – we all have ways of doing things that are right for us and our families and whānau

**Communicating** – expressing needs and thoughts, and understanding what others are saying is necessary for people to have control over their daily lives

**Moving around** – getting around our home and neighbourhood is an important part of belonging to a community

**Where and how I live** – having a home is an important and fundamental right. This component of the model included where home is, who else lives there, and how things like cooking, cleaning, and household maintenance are managed

**Looking after myself** – health impacts on every aspect of our ability to engage in living

**Paying for things** – money gives or limits our choices and our ability to actively participate in living

**My relationships with people** – we all need to have other people in our lives and to know that we are loved and capable of giving love

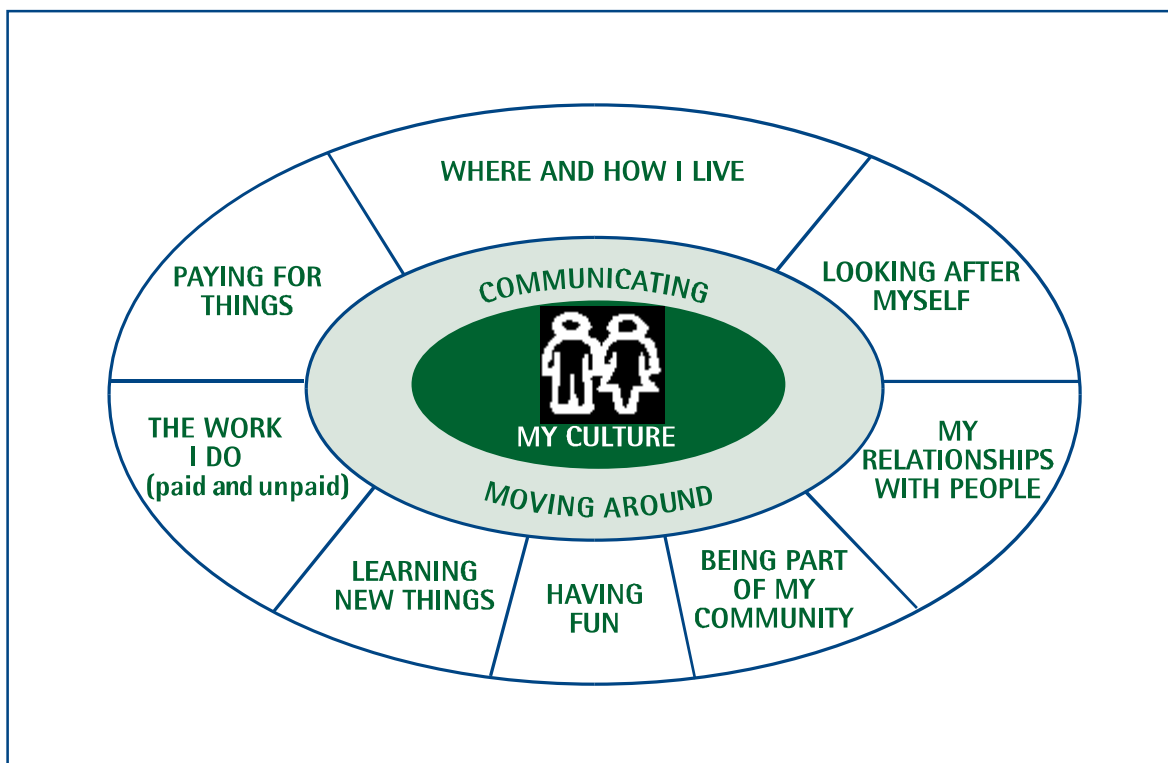
**The work I do (paid and unpaid)** – everyone wants to do interesting things with their life, and needs to be recognised as having social value

**Learning new things** – everyone needs and has the ability to learn and grow

**Being part of my community** – we all need to belong and be accepted

**Having fun** – we all need to have recreation and leisure time, to smile and laugh and have reciprocal relationships with others.

<sup>4</sup> This is recorded in the chapter on *The History of Service Provision* in the background papers to this project. (See page 4.)



This information-gathering model was used to collect information from a broad range of sources.

- The Donald Beasley Institute, a research organisation specialising in intellectual disability, was commissioned to carry out nine literature reviews on specific topics. These covered national and international literature, with a specific focus on research findings describing the experiences of people with an intellectual disability and best practice in the provision of support.<sup>5</sup>
- Ten facilitated focus groups were held in different parts of the country from Auckland to Dunedin. Each group had approximately 10 adults with an intellectual disability. In setting up the focus groups, the diversity of adults with an intellectual disability was recognised. As far as possible, participants were selected to ensure that views were canvassed from adults across the age span, who were receiving services from a variety of providers, with various types and levels of impairment, in varying locations and from a range of ethnic groups. The focus groups each met over two days, to discuss the issues that were the most important for them. This was done using plain language pictorial prompts covering a number of different areas of life, including talking about where they live, their friends, work, and money. Where Māori were part of a focus group, Māori facilitation was available. (A paper describing this consultation process in more detail is available from the NHC on request.)
- Three focus groups were held, each with 10–20 family and whānau members, as well as a number of individual interviews with families and whānau. In setting up the focus groups consideration was given to getting as wide a range of views as possible.
- Many individuals contacted the NHC directly with their own views and experiences.
- Meetings were held with policy makers, service funders and providers, and with consumer and carer organisations.
- Specific work was undertaken with Māori, including looking at kaupapa Māori services.<sup>6</sup>

<sup>5</sup> Copies of these reviews are available on the NHC website ([www.nhc.govt.nz](http://www.nhc.govt.nz)) or from the Donald Beasley Institute, PO Box 6189, Dunedin. For a list of the reviews see page 4.

<sup>6</sup> This process is detailed in the chapter *Māori adults with an intellectual disability* in the background papers to this projec. (See page 4.)

- Work was also undertaken with Pacific peoples to gather their views and experiences of services for Pacific people with an intellectual disability.<sup>7</sup>

The NHC appreciates the time and thought that organisations and individuals gave to the project. Many of those who assisted are listed at the end of this report.

The information that the NHC collected is available as a collated set of background papers, which is the companion document to this report.<sup>8</sup> These papers provide detailed information about demographics and definitions, the history of service provision in New Zealand, and each of the components of the information-gathering model.<sup>9</sup>

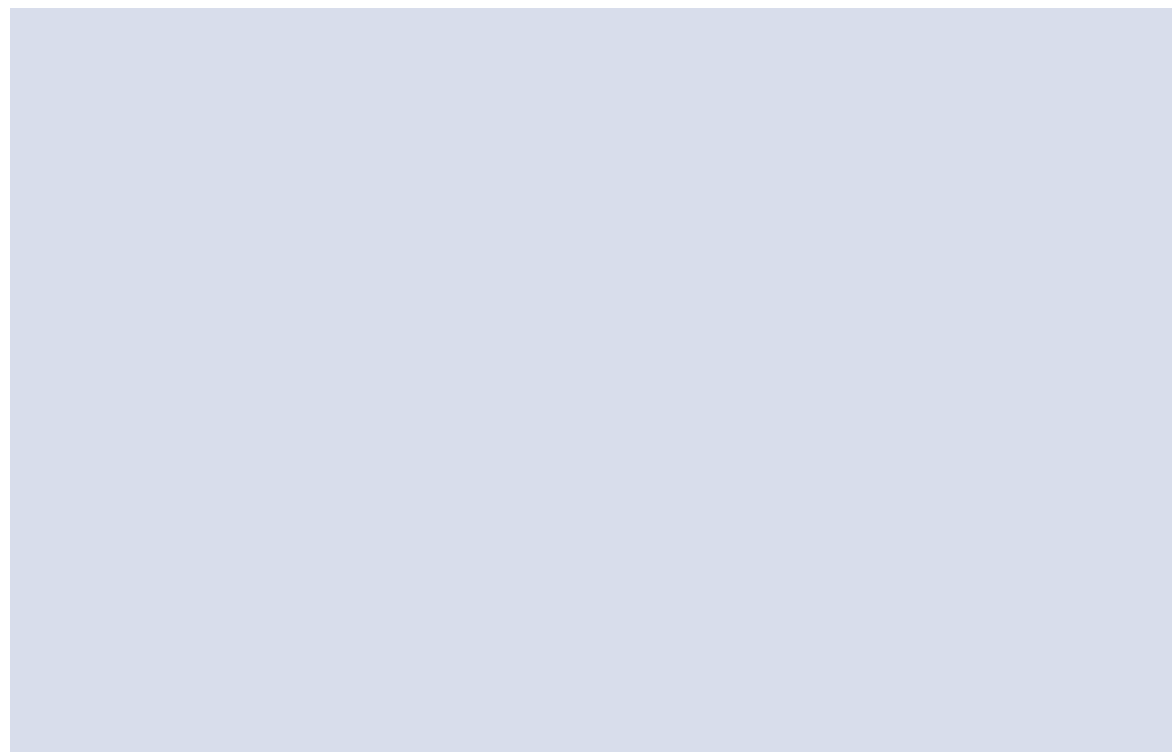
## Applying the New Zealand Disability Strategy

Part 2 section 8 of the New Zealand Public Health and Disability Act (2000), requires the preparation of, 'a New Zealand disability strategy', to provide the framework for the Government's overall direction for the disability sector and for improving disability services.

The first New Zealand Disability Strategy (NZDS) was prepared during 2000 – 2001 following wide consultation with the disability sector, and was released in April 2001. The NZDS is a rights-based framework with 15 objectives, each with a number of action points, aiming to achieve a society that highly values the lives of disabled people and enhances their full participation.

At the time the NZDS was adopted, the NHC was scoping its project examining services for adults with an intellectual disability. The committee therefore considered it appropriate that the NZDS should be the framework within which to report its findings.

The NZDS sets out a clear philosophical approach, based on the following values:



<sup>7</sup> Information from this work is detailed in the chapter *Pacific adults with an intellectual disability* in the background papers to this project. (See page 4.)

<sup>8</sup> *To have an 'ordinary' life: community membership for adults with an intellectual disability – background papers to inform the National Advisory Committee on Health and Disability*, September 2003. (See page 4.)

<sup>9</sup> This document is available on the NHC website [//www.nhc.govt.nz](http://www.nhc.govt.nz) by phoning (04) 496-2277 or emailing [moh@wickliffe.co.nz](mailto:moh@wickliffe.co.nz)

<sup>10</sup> Currently support services for older people and for people with disabilities are both funded through the Disability Services Directorate of the Ministry of Health. The Government recently made the decision to split the funding for disability support services and fund services for older people through District Health Boards. At the present time, no decision has been made about which agency or agencies will administer disability support funding for people under the age of 65.