

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.

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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@wickliffe.co.nz
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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 (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 Institute¹

- *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

¹ 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.

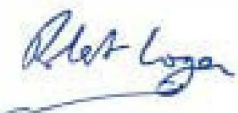
The NHC has found that adults with an intellectual disability have difficulty accessing rights of citizenship. Their lives are very different from other New Zealanders and not consistent with the vision of the NZDS. Adults with an intellectual disability are seldom integrated into community life on their 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

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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.²

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 2001³, 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.

² 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.

³ Department of Health (United Kingdom), 2001.

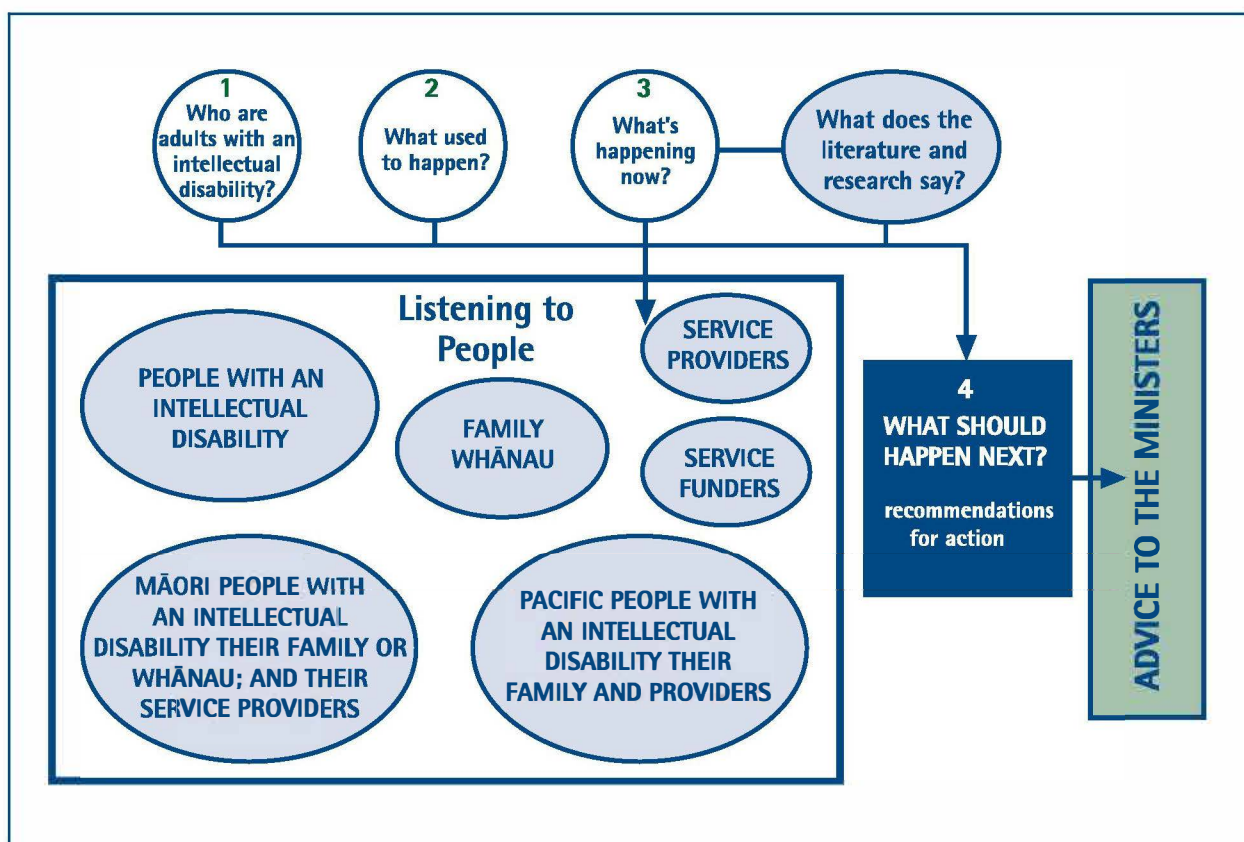
During the project, adults with an intellectual disability have been clear that regardless of the degree of their impairment, they can make their needs and feelings known, and that they must be an integral part of future service development and delivery.

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.⁴

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

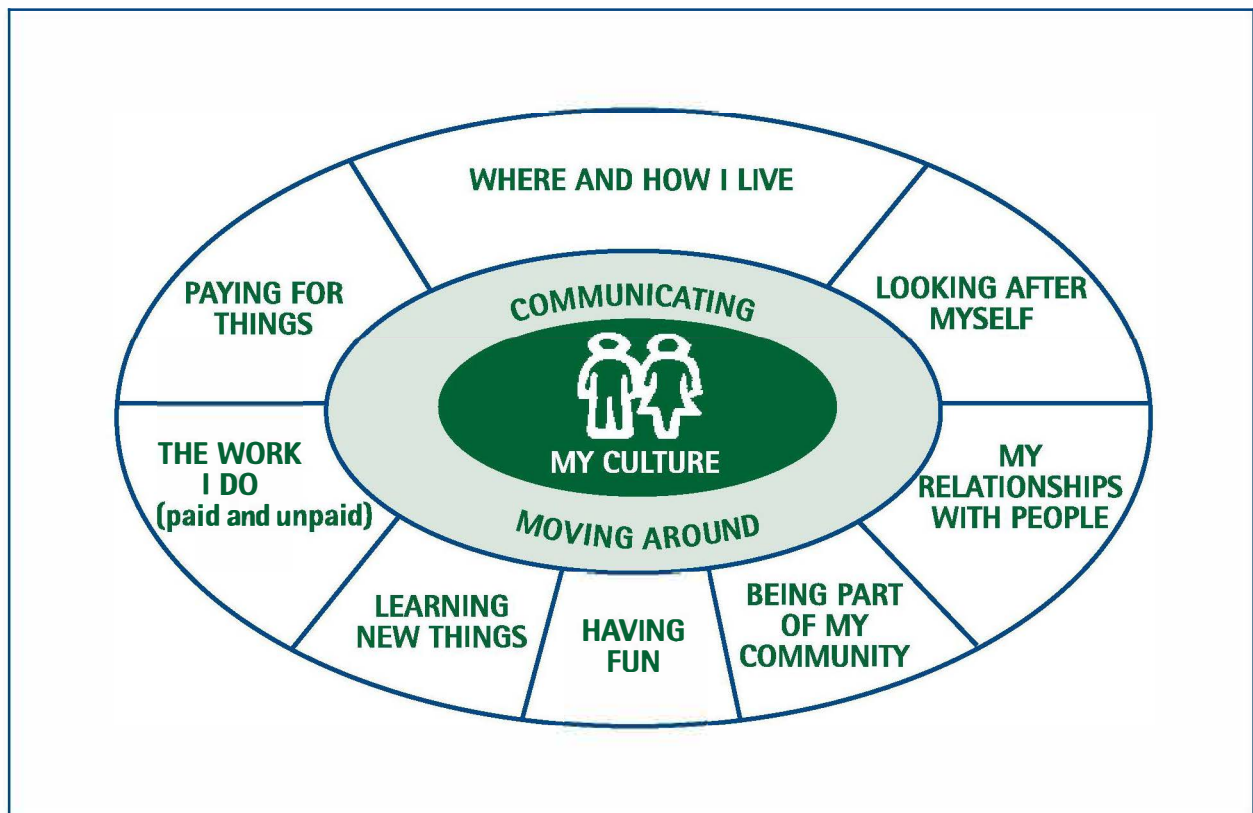
The work I do (paid and unpaid) – everyone wants to do interesting things with their life, and needs to be recognised as having social value

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.

⁴ 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.⁵
- 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.⁶

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

⁶ This process is detailed in the chapter *Māori adults with an intellectual disability* in the background papers to this project. (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.⁷

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.⁸ 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.⁹

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:

New Zealand will be a fully inclusive society when:

- disabled people have a meaningful partnership with government, communities and support agencies, based on respect and equality
- we move forward from exclusion, tolerance and accommodation of disabled people to a fully inclusive and mutually supportive society
- disabled people are integrated into community life on their own terms, which means that equal opportunities are assured but individual choices are available and respected
- the abilities of disabled people are valued not questioned
- interdependence is recognised and valued, especially the important relationships between disabled people and their families, friends, whānau and other people who provide support
- human rights are protected as a fundamental cornerstone of government policy and practice
- the diversity of disabled people, including their cultural backgrounds, is recognised, and there is flexibility to support their differing aspirations and goals
- disabled people are treated equitably, regardless of gender, age, cultural background, type of impairment or when and how the impairment was acquired
- community-based services ensure that disabled people are supported to live in their own communities, and institutionalisation is eliminated
- the idea that society imposes many of the disabling barriers faced by people with impairments is widely understood, and therefore legislation, policy and other activities enhance rather than disable the lives of people with impairments
- the principles of the Treaty of Waitangi are recognised.¹⁰

⁷ 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.)

⁸ *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.)

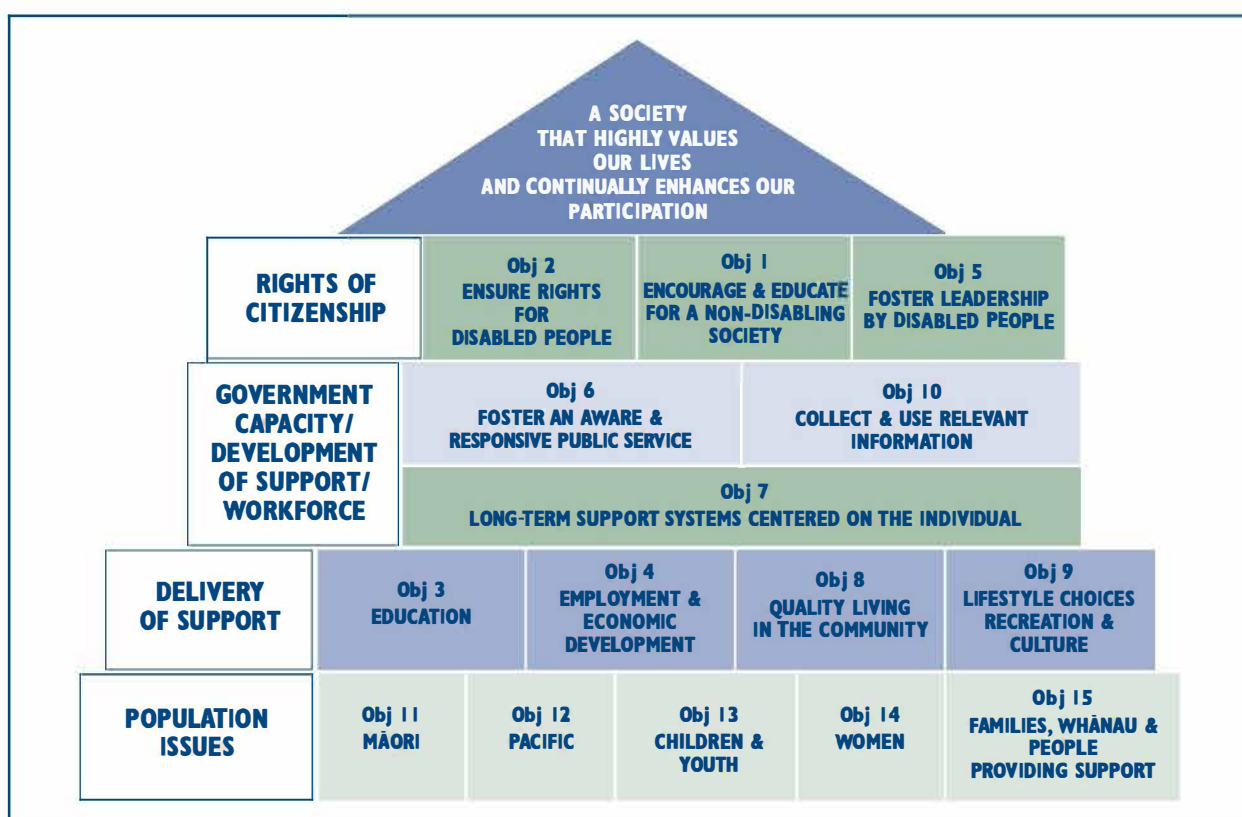
⁹ This document is available on the NHC website [//www.nhc.govt.nz](http://www.nhc.govt.nz) by phoning (04) 496-2277 or emailing moh@wickliffe.co.nz

¹⁰ 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.

In considering the outcomes of its project examining services for adults with an intellectual disability, the NHC spent considerable time looking at, discussing and thinking about the NZDS and its application to people with an intellectual disability. As a result the NHC has grouped the 15 NZDS objectives into four categories:

- **rights of citizenship** for people with disabilities
- **government capacity and the development of support** for people with disabilities
- **delivery of support** for people with disabilities
- **issues faced by population groups** within the wider group of people with disabilities.

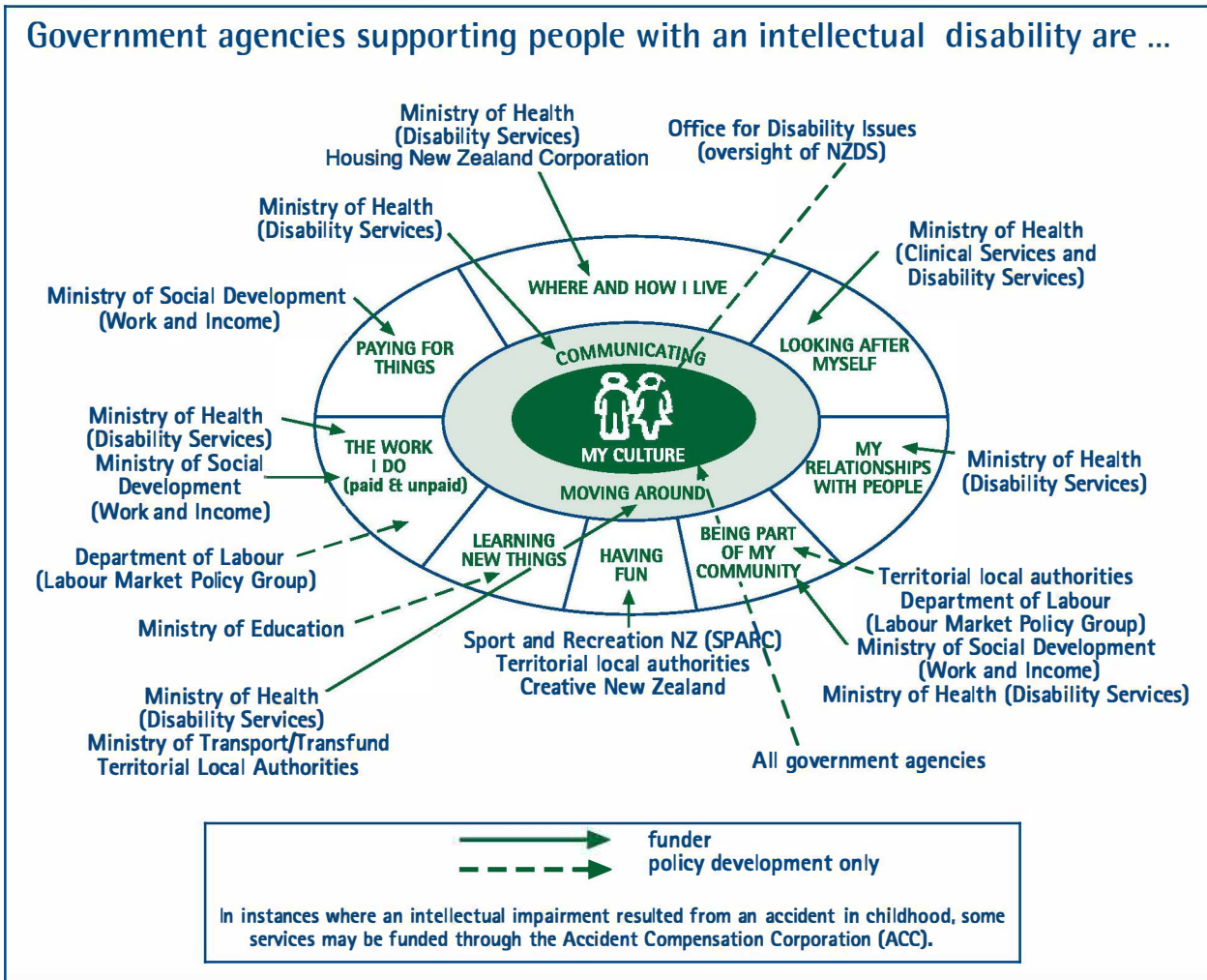
The NHC has visualised its thinking on the NZDS in the following diagram, setting out the 15 objectives in the four categories.



The diagram's pyramid structure reflects government processes for achieving societal goals. Legislation and strategies are the prime ways in which governments implement societal expectations about rights of citizenship. Where the government has a role in funding services, the public service develops policies for contracting and service delivery. These determine the type of support that is funded by government and specify reporting and monitoring requirements. Support is delivered by providers in line with the contracting arrangements and from within the levels of funding provided. The bottom line of the pyramid identifies that there are population groups of disabled people whose experiences differ because of factors such as ethnicity, age and gender. The NHC project looked in particular at the lives of Māori adults with an intellectual disability. It also looked at the lives of Pacific adults with an intellectual disability.

Responsibility for implementing the NZDS lies with the Office for Disability Issues, which is located in the Ministry of Social Development and reports to the Minister for Disability Issues. The role of the Office includes assisting government departments to identify work items to implement the NZDS. In doing this, and in providing policy advice to government agencies on disability issues, the Office works closely with many government agencies, in particular the Ministries of Health, Social Development, and Education.

The Ministry of Health is currently the agency that has the specified budget and responsibility for funding disability support services.¹¹ The other agency that has a significant impact on the lives of adults with an intellectual disability is the Ministry of Social Development, which through Work and Income provides income support assistance and funds vocational services. There are however a number of government agencies whose policies and funding decisions impact on the lives of adults with an intellectual disability. The following diagram identifies the relevant agencies. It does not cover service providers who are funded through a range of local and national contracts.



¹¹ Minister for Disability Issues, 2001

FINDINGS AND RECOMMENDATIONS

The project findings indicate that services for adults with an intellectual disability in New Zealand are stagnating in respect of international best practice.

There is no doubt that the manner in which services for adults with an intellectual disability have developed over the last 20 years in New Zealand has increased life opportunities for this group of people. We have moved a long way from services that less than 50 years ago routinely removed people with an intellectual disability from society and treated them in ways that would no longer be acceptable. This reflects the international move from institutionalisation to community membership.

However, from the evidence the NHC has collected, it is clear that many adults with an intellectual disability are still very disenfranchised and have a long way to go to achieve the same day-to-day rights of citizenship as the rest of the population. The project findings indicate that services for adults with an intellectual disability in New Zealand are stagnating in respect of international best practice and, with some notable exceptions, are not moving in the direction of the New Zealand Disability Strategy.

This project has been the first time in 10 years of providing advice that the NHC has focused on a group in the population whose basic human rights appear not to have been addressed and whose aspirations for an 'ordinary' life do not appear to be taken seriously.

PRIORITIES FOR ACTION

The most critical component in implementing 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.

In considering the rights of citizenship of people with an intellectual disability, and the support they need to access membership of the New Zealand community, the NHC has made 23 recommendations to the Minister of Health and the Minister for Disability Issues. Some of these are overarching or strategic, others are more specific and relate to particular areas of life for adults with an intellectual disability.

The most critical component in implementing 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. This change in thinking is needed across the disability sector, but because the NHC's role is to provide advice to the Minister of Health, the recommendations in this report relate specifically to actions that can be taken by the government sector. All of the recommendations aim to move away from the current policies and practices that create lump-sum services for the collective, and towards long-term support centred on the individual and their family or whānau.

Some of the NHC's recommendations relate to identified service gaps or areas of unmet need. Addressing these issues is likely to require new funding. These recommendations have been annotated with the symbol [F]. However, most of the recommendations are about taking a new approach to the use of existing funding.

In developing its recommendations, the NHC has identified three areas where it considers fundamental changes in thinking and policy are required if adults with an intellectual disability are to have their aspirations for ‘ordinary’ lives taken seriously and move towards achieving rights of citizenship. These are:

1. changing the focus of needs assessment, service coordination, and service purchase
2. ending the custodial ownership model of service delivery
3. improving poor health and prescribing practices.

Action in these three areas requires changes in how services to support adults with an intellectual disability are conceptualised, as well as changes in policy and service provision. Achieving these changes requires greater focus on the aspirations of individuals, their families and whānau; moving from providing a service to ‘being of service’; and a commitment to enabling adults with an intellectual disability to experience life and take an active part in New Zealand communities. Making changes in these three areas is critical to implementing the New Zealand Disability Strategy for adults with an intellectual disability. However, action is also needed in the other areas identified in this report.

In presenting its findings and recommendations, the NHC first considers what rights of citizenship means for adults with an intellectual disability, and then looks at the various aspects of their lives, using the components of the information-gathering model (see pages 12–13). The final section considers the factors relating to government capacity and service development that are critical to achieving community membership for adults with an intellectual disability. To make clear the links with the committee’s findings, recommendations are presented at the end of the relevant section, rather than in order of priority.

RIGHTS OF CITIZENSHIP

‘I want to be in my own home with a brown Labrador dog and a cat, and talk on the phone to my friends.’

Internationally, human rights are described in the Universal Declaration on Human Rights and other international conventions and treaties. In New Zealand, the Bill of Rights Act 1990 and the Human Rights Act 1993 detail our commitment to ensuring human rights for all New Zealanders. The Treaty of Waitangi also confers on Māori and non-Māori additional rights and obligations.

It is the committee’s view that the vision of disabled people as citizens, with the same rights and responsibilities as are accorded the rest of society, must be the foundation value against which all policy, service purchase and service provision are measured.

In considering the rights of citizenship of adults with an intellectual disability, the NHC has therefore 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.

Community membership

New Zealand, along with the international community, has in recent years, substantially altered the way we think about the rights of disabled people to participate in society. We now think in terms of community membership, which emphasises functional supports to enhance inclusion, with both physical and social integration. For Māori, this includes cultural values and kinship ties with whānau, hapū and iwi. The following table summarises the change in thinking from institutional services to community membership.

The move from institutional thinking to community membership

FOCAL QUESTIONS	<i>Era of institutional services</i>	<i>Era of deinstitutionalisation</i>	<i>Era of community membership</i>
<i>Who is the person of concern?</i>	The patient	The client	The citizen
<i>What is the typical setting?</i>	An institution	A group home, special school, or special classroom	Ordinary places with ordinary people
<i>How are the services organised?</i>	In facilities	In a continuum of service delivery options	Through a unique array of supports tailored to the individual, that are focused on 'being of service'
<i>What is the model?</i>	Custodial/medical	Developmental/behavioural	Individual support
<i>What are the services?</i>	Care	Programmes	Supports
<i>How are the services planned?</i>	Through a care plan	Through an individualised habilitation plan	Through a personally meaningful future
<i>Who controls the decision-making?</i>	A professional, usually a doctor	A team usually interdisciplinary	The individual, with advocacy support
<i>What is the planning context?</i>	Standards of practice	Team consensus	A circle of support
<i>What has the highest priority?</i>	Basic needs	Skill development and behaviour management	Self-determination and relationships
<i>What is the objective?</i>	Control or cure	To change behaviour	To change the environment and attitudes
NB: Adapted by the National Advisory Committee on Health and Disability from Bradley, Ashbough and Blaney 1994.			

Achieving 'ordinary' lives

The National Health Committee believes that all current policies and practices affecting people with an intellectual disability must be fundamentally examined by asking 'Would this be acceptable for non-disabled people?' If the answer is 'no', then the further question is 'Then how do we justify this for people with an intellectual disability?'

Accordingly the committee adopted a two-stage process to formulate the recommendations in this report:

1. Look at what happens in the 'ordinary' lives of New Zealanders
2. Look at what support and safeguards are needed to achieve 'ordinary' arrangements for people with an intellectual disability.

In using the term 'ordinary', the NHC 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 nature of 'ordinary' lives achieved will vary between individuals. For example, between 70 and 90 percent of adults with an intellectual disability have communication impairments and many will require significant support to form and maintain relationships. How people with an intellectual disability are supported to access opportunities will, to some extent, be determined by the type and degree of impairment they have. The literature reviews prepared by Donald Beasley Institute found that the approach of support staff was more significant in promoting community membership than the type of impairment a person had. It is essential that the diversity of skills and abilities among adults with an intellectual disability are continually taken into account in developing and delivering services.

The NHC project found that services for adults with an intellectual disability are often prescriptive, life-defining, restrictive, and deny people the opportunity to achieve life goals that the rest of society would regard as 'ordinary'. There is still a long way to go to complete the move and change in thinking from the 'era of institutional services' to the 'era of community membership'. Instead of a focus on service provision, the committee believes that the focus should be on 'being of service' in a way that meets an individual's needs. Government policy, purchasing and service decisions play a major role in determining the nature of service provision.

The project findings also identified a lack of support in key areas, such as communication and advocacy, ongoing education and development, and making and maintaining friendships. Not surprisingly, this results in weak social inclusion and lives that are very different from those of the general population.

When asked about their future aspirations, most adults with an intellectual disability responded with comments that reflected their desire to live in a home with people of their own choosing, to have friends and be able to do meaningful things with their day. Such hopes are not extraordinary or unreasonable and are what other adults take for granted as part of their everyday lives.

Removing barriers through social interpretation

'Speaking for my son takes far more of my time than bathing him, but they weren't interested in that.'

We live in an increasingly complex cognitive environment. As the barriers faced by people with an intellectual disability relate to impaired intelligence and social functioning, they need support to think things through, to interpret social situations and to respond accordingly.

This parallels the support that other groups of disabled people require. For instance, a person with a hearing impairment needs support to interpret sound and a person with a visual impairment needs support to interpret the visual environment. As with hearing or visually impaired people, people with an intellectual disability need access to support for all of their lives. As many people with an intellectual disability also have sensory or physical impairments they may need other types of life-long support as well.

The NHC recognises the role of 'social interpreter' as a way to remove some of the barriers created by intellectual impairment. This is a role that is already performed by some organisations and by family and whānau members and the NHC believes that there should be greater awareness of its importance.

All New Zealanders use other people in their lives as social interpreters. They seek clarification and input from family, whānau, friends, work mates and service agencies. However, adults with an intellectual disability tend to have limited social networks, and so there are often fewer people available to take on the role of social interpreter. Also because of the nature of intellectual disability, this role can be time consuming and usually requires ongoing commitment.

In being ‘social interpreters’, family, whānau, friends or support workers assist the adult with an intellectual disability to understand what is happening in their environment, assist them to make the decisions they wish to take, and assist them to exercise their rights. In this way, a social interpreter helps a person with an intellectual disability to interpret the world, and correspondingly may assist others to understand the preferences, decisions or aspirations of a person who has an intellectual disability.

It is during times of change or when a person’s usual routine of life is disrupted that a social interpreter is most needed. This situation parallels other forms of support required by disabled people. For instance a person who uses a guide dog may not need the dog’s support to get around their home or work place, but does need the dog’s assistance to walk along the street or in unfamiliar surroundings.

When family or whānau members take on the role of ‘social interpreter’, it tends to be invisible, and its value is unrecognised. Within support services, it is often not part of the service specification and so is dependent on staff identifying the importance of this role. In both these settings it can be easy to take the quick option and ‘do things for’ the person with an intellectual disability, rather than working with them and/or assisting them to learn how to do things themselves. Depending on the nature of an individual’s intellectual disability, this may require constant modelling or prompting. Critical factors in providing social interpretation are continuity of involvement and the empowerment of the person with an intellectual disability.

As in other areas where support is provided in the lives of adults with an intellectual disability, it is important when considering social interpretation that the potential vulnerability of people with an intellectual disability is recognised and appropriate safeguards are put in place to ensure that the person is not exploited.

The NHC believes that there is also a society-wide responsibility to provide social interpretation. In order for community membership to become a reality, changes in attitudes about intellectual disability are needed throughout society. This includes an acceptance that all New Zealanders have a role in providing social interpretation when it is needed. For instance, companies, like banks could train staff in dealing with customers who have an intellectual disability, and advertise this using an appropriate logo. Such an initiative could be supported by the production of plain language information.

The committee believes that greater consideration needs to be given to the importance of social interpretation in the lives of adults with an intellectual disability, as it is an important part of achieving community membership.

A whole-of-government approach to promoting community membership

This report provides a clear indication of what is needed to implement the New Zealand Disability Strategy in the lives of adults with an intellectual disability. The recommendations outline steps that can be taken to turn the vision of the NZDS into reality for adults with an intellectual disability.

The NHC believes that a whole-of-government approach is necessary to promote community membership and realign policies, purchasing and provision of services for people with an intellectual disability with the NZDS. Therefore, while the advice in this report is provided to the Minister of Health and the Minister of Disability Issues, many of the recommendations require action(s) in other portfolio areas. In these instances, the committee has identified the relevant Minister(s) and areas in which it considers change is required.

The National Health Committee recommends that:

1. people with an intellectual disability are supported to exercise the same rights, opportunities and responsibilities as the rest of the New Zealand population, by the Minister of Health and the Minister for Disability Issues adopting the recommendations in this report as a focus for monitoring the implementation of the New Zealand Disability Strategy for adults with an intellectual disability.

THE DELIVERY OF SUPPORT FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

By using the information-gathering model, the NHC developed a picture of the lives of adults with an intellectual disability and the services that are provided in each aspect of their daily lives. It is very clear from this that this group has diverse support needs.

The same model was used to gather information about the lives of Māori adults with an intellectual disability and they raised many of the same issues as other adults with an intellectual disability. As Māori, on average, have lower incomes than non-Māori, have higher rates of unemployment and are less likely to access mainstream services, the difficulties facing Māori adults with an intellectual disability may be greater. Specific issues for Māori are covered on pages 41–43.

The following section provides a summary of the NHC's findings and recommendations for each area of the information-gathering model. It also includes a summary of the issues facing Pacific adults with an intellectual disability.



accommodation

*'I live in a house with four residents which are not quite my age.
I hope to get out of there and live with people my own age.'*

More than 6,000 adults with an intellectual disability (around half of those requiring regular support) live in 'residential care' where their housing is part of their disability support package. They have little choice about where they live, the people they live with, and what happens in their home. Their personal freedoms are often restricted. For instance, it is common to have no choice about what to eat, no privacy, no key to the door, and little, or no, say about being moved from one house to another. As these people are defined as being in 'residential' care they cannot receive supplementary income support, like the Accommodation Supplement or Special Benefit to meet living costs.¹¹

The historical practice of collective living, which in the past occurred in large institutions, has been transposed to what is now called community living. The NHC challenges the notion that group living with people not of your choosing is acceptable. This style of living should be a last resort, rather than the norm.

¹¹ This issue is discussed further in the section on *Paying for things*.

For many Māori adults with an intellectual disability, lack of choice about where they live is compounded by a desire to live in a way that is consistent with their cultural values, such as saying karakia¹² before kai¹³. This was particularly an issue for Māori living in mainstream group homes. A variety of kaupapa¹⁴ Māori services have been developed to provide support and care to Māori adults with an intellectual disability.¹⁵

Adults, who are not in ‘residential care’, live in a variety of settings. Many live with family. Some, particularly older people, live in rest homes. A very small number live independently in the community with a partner and/or children and some are in a variety of ‘supported living’ arrangements.¹⁶

Most New Zealanders grow up and move out of their parents’ home. The NHC believes adults with an intellectual disability should be able to leave the parental home – if they choose to. This is a usual life transition which, for this group of people, requires additional support. There is a lot of confusion about how best to do this under current service provision models. During the course of the project, many adults with an intellectual disability and their families/whānau expressed frustration at what they perceived to be lack of acknowledgement of the natural developmental stage of growing up and leaving home.

‘My brothers and sisters grew up and left home, and I want to leave home too, but they said I have to stay at home with Mum. Why can’t I get support to leave home?’

Being able to live an ‘ordinary’ life involves living in a house, usually with other people of your choice, and in a way that is consistent with your cultural values and practices. New Zealanders who need housing assistance generally seek this from housing agencies, like Housing New Zealand, and get financial assistance, if they need it, from Work and Income. The NHC believes that it is appropriate for adults with an intellectual disability to have their accommodation needs met in the same way.

To do this would mean separating accommodation costs from the funding of disability support. The person with an intellectual disability would pay their own accommodation costs in the same way as anyone else in the community, and receive disability support services to enable them to live safely in their accommodation. This arrangement already occurs for a small number of adults with an intellectual disability who are in ‘supported living’. Separating accommodation and support funding is in line with international best practice. Recent policy changes in Australian Capital Territory and Nova Scotia have introduced this split.^{17,18} The NHC believes that adoption of this approach needs to be accelerated in New Zealand.

The NHC recommends that high priority be given to moving to flexible supported living options that reflect the life goals of the adult with an intellectual disability. The committee is of the view that in many situations it is possible to do this without a significant increase in cost, particularly where people choose to live with others. In situations where there is currently significant unmet need, additional resources will be required, regardless of the person’s living situation.

¹² A literal translation of karakia is incantation. It refers to the ancient rites proper to every important aspect in the life of the Māori. A modern application is public worship/prayer.

¹³ Food.

¹⁴ A kaupapa Māori service is one that has a philosophy and services consistent with Māori philosophy and protocol. It may operate from within a mainstream service, or it may operate independently of mainstream services.

¹⁵ A description of types of Māori service providers is included in the chapter on *Māori adults with an intellectual disability* in the background papers to this project. (See page 4.)

¹⁶ The chapter on accommodation, in the background papers to this project provides detail of living arrangements. (See page 4.)

¹⁷ The Board of Inquiry appointed under Section 5 of the Inquiries Act 191 on 5 December 2000 to inquire into and report on the services for people with disability in residential care in the Australian Capital Territory (ACT).

¹⁸ Kendrick, 2001.

The committee has also made recommendations regarding the needs assessment and service co-ordination process (see pages 48–50). If these changes are made then it will be easier to identify appropriate accommodation options for individuals with an intellectual disability.

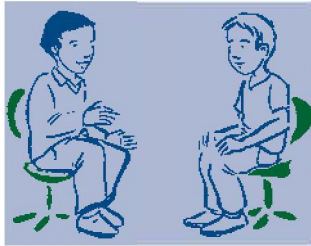
Many disability support services currently provide accommodation along with other forms of disability support. The NHC believes that when disability support providers are also landlords, unless the right safeguards are in place, this can create conflicts of interests and decisions can be made to suit the requirements of the service provider, rather than those living in the house. The committee suggests that the appropriate disability support role is to assist people with an intellectual disability to live within their home safely, and support them to live personally meaningful lives. Where a provider owns or rents the accommodation, the committee strongly recommends that the provider should establish tenancy agreements, offering tenancy rights like those available to other New Zealanders who are renting accommodation.

From the evidence it has collected, the NHC believes that the current model of ‘residential care’ does not promote community membership for adults with an intellectual disability and that a move to supported living arrangements is required. This would mean that adults with an intellectual disability would have access to the same housing and income support arrangements as other New Zealanders, and service providers would only be responsible for those supports that enable a person to secure appropriate accommodation and to live safely in their home. Ending the custodial ownership model of service delivery is one of the NHC’s three priorities for action.

The National Health Committee therefore recommends that:

2. to facilitate the move away from the current ‘residential care’ model to supported living arrangements, the Minister of Health and the Minister for Disability Issues initiate the separation of accommodation costs from the funding of disability support by:
 - a) determining with the Minister for Social Development and Employment and the Minister of Housing how adults with an intellectual disability can:
 - i) access housing in the same way as other New Zealanders, including through Housing New Zealand
 - ii) access supplementary income assistance to enable them to meet their accommodation costs [F]¹⁹
 - b) directing the Ministry of Health to:
 - i) separate contracts for the provision of support services from the funding of accommodation so that service providers are responsible only for those supports necessary to enable a person to secure appropriate accommodation and live safely in their home
 - ii) ensure all adults with an intellectual disability living in residential accommodation, irrespective of their landlord, have the same tenancy protection as any other New Zealand residents.

¹⁹ Indicates that implementing this recommendation is likely to require additional funding.



health

Many adults with an intellectual disability have conditions that are treatable, relievable or able to be cured but for which they are not receiving appropriate medical care or management.

The NHC found that the health needs of people with an intellectual disability are poorly met. This is an international, as well as a national problem.

Many adults with an intellectual disability have ongoing and complex health needs. These are often not recognised. It is often difficult for adults with an intellectual disability to access health care without support and they are often dependent on others to recognise their need for health services.

There is also much anecdotal evidence of discrimination in access to secondary and tertiary care. Furthermore, as Māori tend to access health services less readily than non-Māori with similar health needs, it is likely that Māori adults with an intellectual disability have less access to healthcare than their non-Māori peers.

Even when a person with an intellectual disability visits a health professional, diagnosis and treatment can be difficult because of poor communication on both sides. The outcome of this is that many adults with an intellectual disability have conditions that are treatable, relievable or able to be cured but which are not receiving appropriate medical care or management.

To improve health professionals' understanding of health issues for people with an intellectual disability and improve communication with patients, several health assessment profiles or tools have been developed, such as the Comprehensive Health Assessment Profile (developed by Queensland University) and the Cardiff Health Check in use by IHC in New Zealand. Guidelines for health professionals, such as the Ministry of Health guidelines on Downs Syndrome, are also extremely useful.²⁰

In addition to the significant barriers to receiving health care, the NHC is very concerned about prescribing practices for this group. Many people are over-medicated, use outdated medication and are unable to access specialist review. The committee was given access to an analysis of the pharmaceutical records of more than 2,500 adults with an intellectual disability.²¹ The records showed some very worrying prescribing practices. For instance, 40 percent of people being treated with psychotropic medicines had never been diagnosed as having a psychiatric condition. It appears that in many cases medications are being used to deal with behavioural problems, rather than the cause of behavioural issues being addressed.

A residential care provider reported that a resident had to be hospitalised to rationalise the dangerously high levels and numbers of benzodiazepines and hypnotics they were taking. The person, who weighed 40kg, was taking 150mg of oxazepam and 14mg of temazepam (which they had been doing for three months when Medsafe guidelines indicate that this combination should be taken for no more than four days to a week); 15mg of zopiclone (Medsafe guidelines state that no more than 7.5mg should be taken and no longer than for four weeks); plus 1 mg of resperidone, 20mls of paracetamol and 1 mg prn of haloperidol.

²⁰ Ministry of Health, 2001.

²¹ These are detailed in the chapter on *Health*, in the background papers to this project. (See page 4.)

There appears to be a high level of acceptance that poor health and high levels of medication are part of having an intellectual disability. Some families or whānau and service providers reported having to take extreme measures, including legal action, in order to have health needs addressed. Furthermore, despite high health needs there is little or no health promotion material for use by people with an intellectual disability.

As most people with an intellectual disability are on low incomes, lack of income is another barrier to timely and appropriate health care. Adults with an intellectual disability need access to income assistance to pay for health services in the same way as other New Zealanders. However, the committee found that many people with an intellectual disability were not getting all of the income support available, particularly the Disability Allowance which is specifically for disability-related costs.²²

This issue is further exacerbated for people in 'residential care' who are excluded through the Social Security Act from accessing supplementary income support to meet health care costs such as pharmaceutical charges. These items may cost more than the weekly personal allowance of \$44.26 that the adult with an intellectual disability retains from their income support benefit.

The NHC project has highlighted that, in line with the NZDS, the role of disability support services is to assist adults with an intellectual disability to access services, including health services. This may include ensuring regular health checks occur, assisting communication with health professionals, and enabling the person with an intellectual disability to apply for appropriate income assistance to meet the cost of health care. For Māori adults with an intellectual disability, this may include support to access traditional Māori healing services.

The NHC believes that to adhere to the principles of both the New Zealand Health Strategy and the New Zealand Disability Strategy, the provision of appropriate primary, secondary and tertiary health care for people with an intellectual disability is a health issue, not a disability support responsibility. Similarly, ensuring that adults with an intellectual disability have adequate income to pay for health care, is an income support issue which is the responsibility of the Ministry of Social Development. The committee asks that in developing solutions to resolve the significant health care issues for adults with an intellectual disability, each of these responsibilities be fully considered.

Improving poor health and prescribing practices is one of the NHC's three priorities for action. This needs to be addressed as a personal health, rather than a disability support, issue.

The National Health Committee therefore recommends that:

3. **the systemic neglect of the health of adults with an intellectual disability be urgently addressed**, by the Minister of Health and the Minister for Disability Issues
 - a) directing the Ministry of Health to ensure that:
 - i) primary health care providers are aware of the health needs of adults with an intellectual disability and have:
 - clearly developed policies for access to services
 - comprehensive health assessment tools for people with an intellectual disability
 - appropriate staff education programmes, including peer review processes
 - ii) health promotion material is produced that is directed towards and accessible by this population

(continued on page 31)

²² More detail on this is provided in the chapter on *Paying for things* in the background papers to this project. (See page 4.)



accommodation



communicating





work (paid and unpaid)



being part of the community





learning new things



relationships





having fun



moving around



- iii) prescribing practices for this population are consistent with current New Zealand best practice guidelines
- b) directing the Ministry of Health to ensure that service provider contracts include recognition, and adequate funding and that the disability support role includes assistance for people with an intellectual disability to regularly access health care [F]
- c) directing District Health Boards to examine access to their secondary and tertiary services for people with an intellectual disability, identify barriers and take active steps to minimise or remove them, and utilise their Disability Services Advisory Committees to provide ongoing monitoring of this.



communicating

'The bank is pretty good. They will fill out the form and we sign it. They explain it pretty well.'

It was very clear during the project that adults with an intellectual disability are a very diverse group. Some are extremely restricted in all aspects of their functioning. Others are able to perform complex tasks like driving a car. Some have had restricted life experiences, with limited goals and aspirations, while others have the same sorts of goals and aspirations as their non-disabled peers. One thing they all have in common is an ability to make their likes and dislikes known, either verbally or through their behaviour. However, a number of communication barriers were highlighted during the project.

As communication via language is predominantly a cognitive activity, the nature of an intellectual disability means that most experience some degree of communication difficulty. Many factors determine how significant a barrier this is, not the least of which is the behaviour of the other person or people in the communication chain. Many adults with an intellectual disability also have communication impairments, such as difficulties with speaking. International literature suggests this is the case for 70 to 90 percent of this population.²³

Despite this clear need for communication support, the NHC project found that adults with an intellectual disability are in most cases unable to access services that develop communication. For instance, there is little or no assistance at an individual level with assessment and intervention for the development of language(s), speech, or augmentative and alternative communication methods. There is also no government-funded support for caregivers to learn how to develop language and communication skills in their everyday interactions as they support adults with an intellectual disability. More generally, there is little acknowledgement at a societal level of the need for plain language communication. The project found that Māori adults with an intellectual disability and Māori service providers had greater difficulty accessing communication support. Also, Māori who contributed to the project expressed interest in learning and using te reo Māori.

The ability to communicate is key to each of us being able to exercise our rights of citizenship, participate in society, and have control over our life. Communication is a fundamental right, and this must be recognised in all policies, procedures, purchasing frameworks and eligibility criteria. Many people raised with the committee the right

'My friend in the institution could use 400 signs, but when she moved to another part of the country, her notes got lost so no-one knew and no-one listened to her signing.'

²³ For references and more discussion of this issue, see the chapter on *Communicating* in the background papers to this project. (See page 4.)

to communicate, expressing surprise and concern that the New Zealand Disability Strategy did not give communication higher priority and acknowledge it as an objective in its own right.

The NHC believes that communication for adults with an intellectual disability also includes the right to have a representative voice to promote the best interests of the group. People First, the self-advocacy group of adults with an intellectual disability, is gaining greater prominence and will shortly be established as an independent organisation.²⁴

Lack of support for self-advocacy and communication is a very significant gap and one that the NHC believes must be addressed as quickly as possible.

The National Health Committee therefore recommends that:

4. adults with an intellectual disability have a personal voice around the control of their own lives and a representative voice to promote the best interests of the group, through the Minister of Health and the Minister for Disability Issues:

- a) identifying and securing the funding necessary to enable adults with an intellectual disability to access and benefit from technical, professional and support services that maximise their ability to communicate with others in their daily lives in a way that takes cognisance of an individual's cultural values [F]
- b) providing financial assistance to support independent self-advocacy for people with an intellectual disability. [F]



paying for things

'If you don't have any spending money, you have to do things that don't cost money and that's hardly anything.'

Being part of the community includes being able to purchase goods and services in the same way as the rest of the population. Most adults with an intellectual disability are dependent to some degree on income support.²⁵ They face the same income issues as the rest of the benefit-dependent population.

This situation is further exacerbated by the fact that around half of adults with an intellectual disability live in 'residential care', and therefore only have access to a personal allowance of \$44.26 per week for discretionary spending. This allowance often does not cover personal needs, let alone the costs associated with getting out and about in the community.

The committee found that of those people receiving benefits, but not living in 'residential care' the take-up of supplementary assistance was poor. For example, only 52 percent of adults were accessing the

'I reckon I'm not getting enough. I just think the government is not giving me enough because I have to pay for lots of things like bus tickets, rent, food and telephone – and it's really hard.'

²⁴ People First was initially set up under the auspices of IHC. It will be launched as an independent organisation in October 2003.

²⁵ More information about income of adults with an intellectual disability is provided in the chapter on *Paying for things* in the background papers to this project. (See page 4.)

Accommodation Supplement and only 54 percent accessing the Disability Allowance. These rates of take-up were even lower in areas where a high proportion of the population were Māori or Pacific people. Half of the 54 percent receiving Disability Allowance were paying this directly to their vocational service providers, as a fee to attend the service. This means that one quarter of adults with an intellectual disability (not living in 'residential care') were unable to access the Disability Allowance to meet disability-related living costs.

It was clear during the focus groups and when talking with family, whānau and service providers that there is a lack of easily understood information about income support provisions.

Nearly all the adults with an intellectual disability who contributed to the project required assistance with financial affairs. As with all areas of support, it is important that adequate safeguards are in place to protect the interests of the adult with an intellectual disability.

'A lot of us feel we should be getting our benefit and paying our bills ourselves.'

Recommendations relating to 'paying for things' are on pages 32.



work (paid and unpaid)

'I should be paid for the work I do, instead I have to pay them to come here.'

It is 'ordinary' to want to do something meaningful with your day. Work (paid or unpaid) provides people with a sense of satisfaction and self-worth, adds to their life experiences, and usually involves interaction with a range of other people.

Through the Ministry of Social Development, the government currently buys vocational services for people with disabilities. These services are focused either on activities that lead to employment or on community participation. The Ministry of Health also purchases some vocational services for people who were moved out of institutions, and day activities in certain situations.

A range of government-funded assistance is available to support disabled people in paid employment. In situations where a person's productivity is below what is expected for the market wage, it is possible for employers to apply for an Under-Rate Workers Permit, which allows the person to be paid less than the minimum wage. This policy and its procedures are currently being reviewed.

Very few adults with an intellectual disability are in paid work. Those who are may need some ongoing support in the workplace or in seeking a new job. Many adults work in sheltered workshops or segregated work teams, where they are generally paid a minimal amount.²⁶

It is the NHC's view, that with some notable exceptions, many vocational and day services do not have a developmental or

'For about eight and a half years I had a kitchen hand job. I got half wages and half benefit. I got laid off. When I was working there they brought in an outside company to run all the kitchen. That's why I got laid off. I now come here (vocational service) five days a week.'

²⁶ More information about the employment and vocational services is provided in the chapter on *Work (paid and unpaid)* in the background papers to this project. (See page 4.)

future-focused approach. Within these services, support for education, recreation and leisure tends to focus on repetitive activities designed for a group, rather than focusing on individual's goals and development. During the project, many adults with an intellectual disability and their families or whānau expressed their dissatisfaction about the vocational services they were receiving, and their frustration at what they described as 'life-wasting' activities. They expressed a desire to learn new things, to be part of their communities and to work, preferably for money. They did not want to continue to be part of services that were segregated, custodial and meaningless. Many reported that they had very few options for the future and no opportunities to set a goal, and get support to achieve it.

'I'd like to help people in the supermarket – tell them where things are.'

The poor fit of these services was particularly evident for younger adults with an intellectual disability. Many of these adults had been through mainstream schooling but found when they left school that there were very few options available to them. They and their families or whānau were particularly vocal about the impact vocational and day services had on their lives. Transition to adulthood is a complex process for all young people. Transition planning can be used to assist the move from the school environment to adult roles, but the project found that there was considerable variation in how this process is undertaken and what is achieved.²⁷ As transition planning takes time, especially if the young adult is to move into socially valued and meaningful adult roles, the Ministry of Education suggests that transition planning begin around age 14. Best practice suggests that transition planning should involve the student in a way that is empowering, focus on the student's goals and aspirations, take a whole-of-life approach, provide work experience in a range of settings and work closely with parents, whānau and support agencies.

'I want to be a hairdresser or else look after children from babies to four years old.'

The NHC project also identified the importance of having appropriate transition support to enable older adults with an intellectual disability to move out of work or vocational services, when appropriate. As people with an intellectual disability have a lower than average life expectancy and may experience early onset of age-related conditions, such as Alzheimer's disease, this transition may for some people occur earlier than the usual retirement age. Also, to have meaningful activities during the day, it may be appropriate for an older adult to move to, or remain in, community participation programmes or to keep working past age 65. Individual circumstances will determine the appropriate time for such changes.

'I've got a cool job at the Salvation Army. I got that through school and I get paid for it.'

*Pathways to Inclusion*²⁸ is the New Zealand Government's strategy for vocational services funded by Work and Income. The National Health Committee endorses the direction of this strategy, with two exceptions. From the evidence it has gathered the committee believes that:

- transition from school to work must be broadened to become transition from school to adulthood and begin at 14 years
- community participation services contracted by Work and Income need to be fully funded.

'I would like to work in the second-hand clothes shop by the church.'

Recommendations relating to 'work' are on pages 35–36.

²⁷ Transition to adulthood and transition planning are described in more detail in the chapter on *Learning new things* in the background papers to this project. (See page 4.)

²⁸ Department of Labour, 2002.



being part of the community

'I talk on the radio, ask people questions and talk to them. I get to meet different people. A lot of other people should get a chance to do it like me.'

Community is not simply a location – it is about groups of people and their lives, and includes a sense of belonging or being accepted. Non-disabled people move between a number of different communities, which reflect different aspects of their lives. For Māori, community participation includes taking part in whānau activities like weddings, 21st birthday parties, cultural activities and going to the marae. People with an intellectual disability want to be able to do this too. Participation in the community is an essential component of living a socially valued life, and achieving the vision of the New Zealand Disability Strategy.

'I play pool and snooker with my father at the local club. I am a member.'

Participation means being involved in the social life of the community through a network of personal relationships. Both the literature and the personal experiences shared during the project highlight the fact that most adults with an intellectual disability spend very little private time with people other than their immediate family. Most of their time is spent in segregated living and work settings, or in public places such as shops. Adults with an intellectual disability frequently expressed to the committee the view that while they live in the community they do not feel part of it.²⁹ Many had ideas about what they would like to be involved in, such as helping on the marae or joining a group. It was equally clear during the project that the level of impairment is not the main limiting factor in community participation. What is far more critical is the skill of family and support workers in facilitating social participation and building networks in the community.

'Putting residents into the van, driving to the shop, having them wait in the van while you hop out and buy ice creams, eating the ice creams in the van, driving home again is NOT community participation.'

If adults with an intellectual disability are to hold socially valued roles and pursue personally meaningful lives, a number of changes are needed in the areas of income, work and community participation. They must be able to access existing income support, employment assistance and training opportunities. As well, it is not consistent with the approach of supported living for vocational services to be funded through individuals' Disability Allowances or for non-vocational community participation to be only partially funded. It is also essential that support is provided to assist young people in the transition from school to work and older adults to plan the transition from work to purposeful retirement.

²⁹ More information about the experiences of community participation is provided in the chapter on *Being part of the community* in the background papers to this project. (See page 4.)

The National Health Committee therefore recommends that adults with an intellectual disability:

5. **have access to the full income support, employment assistance and training to which they are eligible**, by the Minister of Health and the Minister for Disability Issues determining with the Minister for Social Development and Employment how Work and Income can:
 - a) simplify access procedures to income support assistance
 - b) provide plain language information
 - c) up-skill staff to better assist people with an intellectual disability
 - d) monitor the take-up of support by people with an intellectual disability.

6. **are able to pursue personally meaningful lives, in which vocational services and non-vocational community participation are available as part of the range of supported living options**, by the Minister of Health and the Minister for Disability Issues determining with the Minister for Social Development and Employment how to:
 - a) discontinue the policy of using the Disability Allowance as a means of funding vocational and day services [F]
 - b) give priority to fully funding community participation services contracted by Work and Income. [F]

7. **hold socially valued roles throughout their lives and are well supported during transitions from school and into retirement**, by the Minister of Health and the Minister for Disability Issues determining with the Minister for Social Development and Employment and the Minister of Education how best to:
 - a) develop jointly funded transition from school to adulthood for young adults with an intellectual disability, in line with best practice guidelines
 - b) ensure that transition from work to purposeful retirement is part of any long-term planning, assessment or services for older adults with an intellectual disability.



learning new things

'I didn't put all this work into my daughter for her to have nothing ahead of her. Forget the cradle to the grave society. This society can't even look after people in the prime of their lives!'

Within New Zealand society it is encouraged and accepted that learning new things is a life-long process. People of all ages participate in learning activities, both formal and informal.

These same expectations do not exist for people with an intellectual disability, many of whom stay at school until the end of their 21st year, mainly due to the lack of meaningful alternatives. Once they leave school, it appears that there is little or no expectation of continued learning on a daily basis.³⁰

Some providers acknowledge the need for learning throughout life, and facilitate access to correspondence school or adult literacy. Many vocational services do teach new skills, although these are often linked to the nature of the work or activities offered within that service, rather than being linked to the life goals or aspirations of the person with an intellectual disability.

The NHC acknowledges that it takes more time to teach someone to do something than it does to do it for them. For example, teaching someone to wash themselves is more time consuming than washing them. However, over time teaching new skills reduces a person's dependency.

'I did a first aid exam. They read me questions and I figured out which was right and wrong.'

'The literacy programme – one hour a week – helps me do the stuff I never did at school.'

The NHC believes that all disability support services for people with an intellectual disability must encourage the life-long process of individual development through learning new things.

The National Health Committee therefore recommends that:

8. the potential for adults with an intellectual disability to grow and develop throughout their lives be recognised, by the Minister of Health and the Minister for Disability Issues determining with the Minister for Social Development and Employment and the Minister of Education how best to purchase services designed to promote and measure:
- life-long learning
 - access to ongoing educational and cultural opportunities.

³⁰ The experience of adults with an intellectual disability with transition from school and adults education is detailed in the chapter on Learning new things in the background papers to this project. (See page 4.)



relationships

‘I asked my coordinator if I could live with my girlfriend, but she said “no”.’

It is usual to have a range of reciprocal relationships with family, friends and work mates, and to have intimate relationships. The NHC found that adults with an intellectual disability tend to have few longstanding relationships. Some older adults with an intellectual disability lost contact with their families or whānau when they were institutionalised. Reconnecting with whānau and hapū is a key component to the services of some Māori providers.³¹

People with an intellectual disability often need support to make and maintain friendships. This support can vary from practical help, such as assistance in making a phone call, buying a card, or having a friend to visit; through to learning and understanding about relationships and the things you need to do to make them work.³² There is a lack of clear expectations that this support will be provided. Development and maintenance of relationships is often dependent on the skill and goodwill of individual support workers. Furthermore government purchasing and service provision models, particularly lack of choice over where people live and who they live with, increase barriers to developing and maintaining relationships.

‘Friends who work in normal jobs and accept me for who I am and what I am – they are important to me.’

Some residential providers have policies in place regarding intimate relationships. The NHC is impressed with IHC’s newly established policy on relationships and sexuality, and would recommend other providers follow IHC’s example in this area.³³ The committee notes that there is legislation that restricts intimate relationships for women with an intellectual disability³⁴, which is currently under review.

‘I want to have a girlfriend – the right person. She has to like sports and going out to pubs.’

Having and maintaining a variety of reciprocal adult relationships is a key component of community membership.

The National Health Committee therefore recommends that:

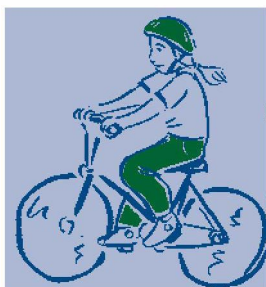
9. recognition be given to the importance of adult relationships in the lives of adults with an intellectual disability, by the Minister of Health and the Minister for Disability Issues directing the Ministry of Health to include active support to make and maintain reciprocal adult relationships as an essential component of all needs assessments, service specifications and purchasing arrangements.

³¹ For more information, see the chapter on *Māori adults with an intellectual disability* in the background papers to this project. (See page 4.)

³² Further information about friendships and relationships is provided in the chapter on *Relationships* in the background papers to this project. (See page 4.)

³³ IHC, 2003.

³⁴ Section 138 of the Crimes Act (1961).



having fun

‘My friend has a car and we put our bikes in the back and go out into the middle of nowhere and cycle around for a couple of hours.’

Getting out and about in the community and enjoying a range of recreational and leisure pursuits is a big part of New Zealand life. Many adults with an intellectual disability and their family or whānau told the committee of their frustration at the lack of access to recreation and leisure activities.

Barriers include having little or no discretionary income and limited access to public transport and community information.³⁵ For those living in ‘residential care’, the constraints of group living, such as the requirement to do the same recreation or leisure activity as the rest of the people in the house, exacerbate these barriers.

The committee was impressed with the Christchurch City Council’s Kiwiable Leisure Card which provides disabled people with access to a wide range of recreational and leisure activities at significantly reduced cost, by working with businesses in the community.³⁶

‘Money stops me doing things – I have to rely on staff coming to pick me up for things at night or I bike. Staff don’t always come at the right time.’

‘I go out to lunch on Fridays. We all go in small groups to a café or restaurant.’

For adults with an intellectual disability to enjoy the health and life benefits of recreation and leisure activities, a cooperative approach is required to reduce or remove the current barriers of income, transport, lack of awareness and lack of support.

The National Health Committee therefore recommends that:

10. **recreational, sporting and leisure opportunities for adults with an intellectual disability be promoted**, by the Minister of Health and the Minister for Disability Issues:
 - a) determining with the Minister for Local Government and Local Government New Zealand how local authorities can increase access to recreation and leisure activities for people with an intellectual disability
 - b) determining with the Minister for Sport and Recreation how current initiatives for disabled people can better cater for adults with an intellectual disability.

³⁵ Information about the leisure activities in which adults with an intellectual disability are involved and barriers to taking part in leisure are detailed in the chapter on *Having fun* in the background papers to this project. (See page 4.)

³⁶ See <http://www.ccc.govt.nz>



moving around

'I can't go out 'cause the van's being used for 10 pin bowling or the groceries, so I can't.'

In order to live an 'ordinary' life adults with an intellectual disability need to be able to get around their home and community easily. The variety of intellectual, sensory and functional impairments that can be experienced by adults with an intellectual disability means that barriers to mobility vary greatly between individuals.³⁷

At home, it is important for appropriate equipment to be provided, and that living environments are safe and accessible. The NHC found that difficulties with mobility may be compounded by unidentified sensory impairments or side-effects of over-medication. The Ministry of Health's policy that mobility equipment outside the home is only funded for those in paid employment or formal education particularly disadvantages people with an intellectual disability.

'I want to learn to walk to the bus and catch the bus by myself and do the money by myself with no-one telling me.'

The nature of an intellectual impairment can make it difficult to access the community independently. Learning to drive and using public transport both require complex cognitive skills. Some adults with an intellectual disability are able to learn these skills with the assistance of training, support and plain language information, others are not. The committee was told that the cost of transport and inflexibility in use of provider-owned vans were significant barriers in being able to access and be part of the community, and take part in leisure activities. For those people who are unable to use transport independently there are few options currently available.

For adults with an intellectual disability being able to access their home and community as easily as possible is an important component of community membership. To achieve this, the criteria for accessing mobility equipment outside the home need to be widened to include community involvement, and recognition must be given to the need for public transport to be accessible and safe to use by people with an intellectual disability.

The National Health Committee therefore recommends that:

11. **adults with an intellectual disability are enabled to access the 'ordinary' places of life and community, as easily as possible,** by the Minister of Health and the Minister for Disability Issues:
 - a) requiring the Ministry of Health to:
 - i) ensure that needs assessment processes identify individual requirements for assistance with transport, and training or support, to use transport
 - ii) change the eligibility criteria for provision of mobility equipment outside the home to enable people who are not in paid employment to access appropriate equipment [F]

³⁷ How adults with an intellectual disability get around their homes and communities and barriers to mobility are detailed in chapter on Moving around in the background papers to this project. (See page 4.)

- b) determining with the Minister of Transport how to make transport more accessible and safer for people with an intellectual disability, including:
 - i) taking this into account in the current review of Total Mobility
 - ii) encouraging public transport providers to develop information in plain language formats.



Māori adults with an intellectual disability

‘Down Syndrome is what he had, not who he was. His whānau and his whakapapa connect him to us’

The relationship between the Crown and tangata whenua³⁸ is based on the premise that Māori should be able to continue to live in Aotearoa as Māori. This means that Māori should be able to define and provide for their own priorities for participation and be encouraged to develop the capacity for delivery of services to their communities. This needs to be balanced by the Crown’s duty to govern on behalf of the total population.³⁹

‘My aunty taught me about the marae. My father had been teaching me before he died.’

Information about the New Zealand population as a whole indicates that there are disparities between Māori and non-Māori, particularly in health and income. It might be assumed these disparities also exist within the population of people with an intellectual disability. However, the committee was unable to verify this due to a lack of accurate ethnicity and other data on adults with an intellectual disability.

In the course of this project the NHC met with and spoke to Māori adults with an intellectual disability, their whānau and providers. It became apparent that the life issues were the same as for other adults with an intellectual disability, with some additional factors.

One of the general findings of the project is that services are provided according to a set approach, and are often not able to meet individual needs. Consistent with this, many Māori expressed the view that services were unable to meet their cultural needs. Kaupapa Māori services, which have a strong cultural component are strongly supported by Māori service users. Some mainstream providers, particularly those with a number of Māori staff, are attempting to adapt components of their service to be more culturally appropriate. All service providers have a responsibility to be culturally appropriate.

A number of Māori who had been institutionalised had lost their history and had no sense of Māori identity – even to the extent of hospital staff giving them English names for convenience. Some services were assisting these people to re-establish connections with their whānau, hapū and iwi. The committee believes that all Māori with an intellectual disability need to be able to access high quality services that are consistent with their values and meet their cultural

‘You gotta feed him, you gotta change him. He can’t walk, he can’t talk and he can’t see. He is like a bird with no feathers. His food goes on (to the stove) at 10.30 am and we take the bones out and mash. It took us two years and a half to learn to eat with a spoon, but we got there.’

³⁸ meaning ‘people of the land’ or indigenous people.

³⁹ Minister for Disability Issues, 2001.

needs. There are costs associated with meeting cultural needs, such as staff time, mileage, maintaining vehicles, koha,⁴⁰ and equipment for cultural activities. It has been estimated that in kaupapa Māori services at least 45 percent of these costs are currently not funded.⁴¹

Many Māori adults with an intellectual disability live with their whānau, and a common frustration was difficulty in accessing services, particularly lack of information about, and access to, culturally appropriate services. This was of particular significance in rural areas, where access to any service was often difficult. It is the committee's opinion that the compilation and distribution, on a regular basis, of contact details for Māori service provision would greatly assist both whānau and providers. There is also a need to strengthen leadership among Māori with an intellectual disability, to increase their voice and create positive role models.

'The staff teach you how to cook Māori food. Sharing and caring. Even if a Pakehā came into the house they still have to respect the Māori kaupapa, as it's set up as Māori.'

In recognition of the need to develop Māori service provision throughout New Zealand, a number of new Māori providers have been established to meet the needs of a particular iwi or hapū. Small providers in general are vulnerable due to their lack of infrastructure and fragile capital base and small Māori providers are no exception. They also face high demands and expectations from their Māori communities. Māori service providers face the same workforce problems as the rest of the disability service sector, including lack of training, poor career paths and low levels of remuneration. These factors tend to create high staff turnover and affect service quality. The NHC met with one Māori provider that had addressed these workforce issues with outstanding results. It is the committee's view that strengthening networks between Māori service providers will enable them to share successes and best practice approaches.

As discussed on page 48, the current approach to needs assessment and service coordination does not meet the needs of Māori adults with an intellectual disability. The NHC is strongly of the view that there is a need both to increase the number of Māori needs assessors and improve the cultural competency of other needs assessors.

Furthermore, if Māori adults with an intellectual disability are to achieve community membership, they also need to be able to access initiatives and opportunities, such as housing support, that are available to other Māori adults.

In addition to the recommendations in other sections of the report, the National Health Committee recommends that:

12. to facilitate community membership and 'ordinary lives' for Māori adults with an intellectual disability, the Minister of Health and the Minister for Disability Issues determine with the Minister for Māori Affairs and other Government Ministers ways of ensuring that Māori adults with an intellectual disability can access the same initiatives and opportunities as the rest of the Māori population, including access to Māori housing initiatives.
13. needs assessment, service coordination and service provision be relevant to the lives of Māori adults with an intellectual disability, by the Minister of Health and the Minister for Disability Issues determining the best ways to:
 - a) increase Māori needs assessment and service coordination
 - b) ensure that disability support staff are trained to collect nationally consistent and accurate ethnicity data

⁴⁰ Donation or gift.

⁴¹ See the chapter on Māori adults with an intellectual disability in the background papers to this project. (See page 4.)

- c) ensure the support needs of Māori adults with an intellectual disability and their whānau living in rural areas are adequately met
- d) actively build the Māori disability workforce, giving priority to:
 - i) increasing the number of skilled Māori needs assessors
 - ii) establishing career pathways for the Māori disability support workforce
- e) incorporate the concept of whānau ora⁴² in all areas of disability policy, contracting and purchasing
- f) develop indicators that assess responsiveness of mainstream services to Māori adults with an intellectual disability and their whānau, use these indicators for quality improvement, and monitor progress.

14. Māori adults with an intellectual disability have the option of referral to adequately resourced Māori service providers, through the Minister of Health and the Minister for Disability Issues directing the Ministry of Health to:

- a) develop Māori service provision in geographical or service areas where there is unmet need
- b) publish a regularly updated, publicly available list of Māori service providers, a description of their services and their contact details
- c) coordinate regular hui of Māori service providers and establish other means of networking
- d) identify business support and infrastructure needs of Māori providers and assist them to meet these
- e) investigate the feasibility of enabling successful Māori providers to mentor other service providers.



Pacific adults with an intellectual disability

‘It’s looking after one another, and caring and sharing with the extended family that is important.’

The Pacific population is very young and growing rapidly. Most live in the greater Auckland area. Given the rapid population growth, the number of Pacific adults with an intellectual disability will increase at a faster rate than for the total New Zealand population, over the coming years. In general, Pacific people with an intellectual disability appear to be restricted in their access to service and lifestyle options, and to have low status or value in their communities. Within Pacific communities there is a stigma attached to disability, which inhibits service access and limits outcomes for people with an intellectual disability.

It is important that disability support services and workforce development reflect the growth and distribution of the Pacific

‘... the person is seen as needing to be sheltered or nursed as opposed to contributing to their own and family welfare. As a result the Western idea of educating and enabling a person with a disability to go to school and enter the workplace is sometimes not supported.’

Makasiale and Williams, 1977.

⁴² The principle of *whānau ora*: supporting families to achieve their maximum health and wellbeing, is the overall aim of *He Korowai Oranga* (the Māori Health Strategy).

population. There is also a need for ongoing education in the Pacific population about disability and the support available, particularly how to access publicly funded disability support services. Information about services needs to be accessible to Pacific people. This is most effectively done verbally in the appropriate language. Positive role models of disabled Pacific people as highly visible participants in Pacific society are needed.

The NHC was concerned about the lack of information on Pacific people with an intellectual disability and their needs, the lack of cultural understanding among needs assessors, health professionals and support staff and the lack of Pacific service providers. Unless appropriate services are developed, growth in the Pacific population will create a significant and increasing service gap. One proposal that received considerable support from Pacific people was to have Pacific disability educators within primary health organisations (PHO) in areas with a significant Pacific population. Their role would include both educating health professionals about the needs of Pacific disabled people and working with Pacific disabled people and their families to increase their knowledge and their access to services.

In addition to recommendations in other sections of the report, the National Health Committee recommends that:

15. **to increase understanding within Pacific communities about intellectual disabilities**, the Minister of Health and the Minister for Disability Issues determine with the Minister of Pacific Island Affairs:
 - a) a sponsor or champion to increase understanding within Pacific communities about the lives of adults with an intellectual disability
 - b) strategies for promoting and supporting Pacific people with disabilities to be role models within their communities
 - c) how to actively build Pacific leadership within the disability support sector.
16. **needs assessment, service coordination and service provision be relevant to the lives of Pacific adults with an intellectual disability**, by the Minister of Health and the Minister for Disability Issues determining the best ways to:
 - a) increase Pacific needs assessment and service coordination
 - b) ensure that disability support staff are trained to collect nationally consistent and accurate ethnicity data
 - c) actively build the Pacific disability workforce, giving priority to:
 - i) increasing the number of skilled Pacific needs assessors
 - ii) establishing careers pathways for the Pacific disability support workforce
 - d) develop indicators that assess responsiveness of mainstream services to Pacific people with an intellectual disability and their communities, use these indicators for quality improvement, and monitor progress.
17. **Pacific adults with an intellectual disability have the option of referral to adequately resourced Pacific service providers**, through the Minister of Health and the Minister for Disability Issues determining how the Ministry of Health can best:
 - a) immediately develop Pacific service providers in regions of high need
 - b) develop and deliver services for the rapidly growing disabled Pacific population
 - c) publish a regularly updated, publicly available list of Pacific disability providers, a description of their services and their contact details
 - d) identify business support and infrastructure needs of Pacific providers and assist them to meet these
 - e) provide innovation funding for a pilot project to establish two disability educator positions. [F]



government capacity and service development

'They are only interested in the services they already have. They don't want to hear about other possibilities that would cost less.'

The Ministry of Health and the Ministry of Social Development are the main government agencies funding services for adults with an intellectual disability. However, as shown in the diagram on page 16, many government agencies have an impact on the lives of this group of people. Therefore achieving community membership requires action across government.

There are a few adults with intellectual disabilities who receive services funded through the Accident Compensation Corporation (ACC). These are people who developed intellectual impairments as a result of an accident in the early years of their lives. Several family members commented during the project about inequities in access between services funded by ACC and those funded by other government agencies. These result from the different ways that these funding streams have been set up and the philosophies behind them.

Disability support services, funded through the Ministry of Health, have a capped budget. Services are allocated on the basis of greatest need, within a set budget. In comparison, the ACC system is akin to social insurance. Each person is a contributor to the scheme and if they have an accident can access the support they need within broad guidelines. It appears that there is speedier and greater access to disability services funded through ACC than those funded by the Ministry of Health, and there is greater potential within the ACC approach for services to meet the needs of the individual and their families. Furthermore, there are legislative entitlements under the ACC system that mean that if the required services are not provided, then this can be reviewed.

The NHC is aware that these issues have been raised with the Government in other contexts.

Creating an aware and responsive public service

The movement of adults with an intellectual disability out of large institutions has changed many people's lives for the better. However, institutional practices and thinking still remain in policies and purchasing. For example, the personal allowance was developed in the days of institutions when the only costs faced by the disabled person were items of personal choice, such as cigarettes and confectionery. Despite the shift to living in the community, with the expectation of participation and increased autonomy, there have been no significant changes in the level of personal allowance.

Recently, service development has tended to be based on historical practice. This has meant that despite significant shifts in government thinking over the last 10 years, and the removal of legislative and accounting barriers, there appears to have been little change in the lives of adults with an intellectual disability. For instance, the eligibility criteria that were contained in repealed sections of the Disabled Persons Community Welfare Act 1975 continue to be used, despite their inappropriateness being one of the reasons for their repeal.

The degree of recent restructuring in the state sector has created high staff turnover and loss of institutional memory, leading to a poor knowledge base of the history and interrelationships between disability policies and issues. This, combined with the previous lack of a clear philosophy

and direction, and limited use of evidence-based information, has resulted in confusion. The Government's current work looking at the equity and coherence of disability policy is highlighting this. It also shows that past policies have tended to be issue-driven rather than developed using good information on current and future need, or on the lives of people with disabilities.

The NHC believes that if services are to support adults with an intellectual disability to have better lives in line with the vision set out in the New Zealand Disability Strategy, government departments need to be focused on achieving community membership and look to the future rather than focusing on historical practices.

Government departments focus on doing the best possible job in their designated area of service. However, there is no formal network or liaison between public servants working on disability-related policies, and no systems to determine the impact of new or changed policies on the lives of people with disabilities. This allows inconsistencies to develop in policies and practices, both within and between departments. These inconsistencies create gaps in support that have a significant impact on the person with a disability, but are often not apparent to the departments concerned.

Collecting good information

An aware and responsive public service, and the development of appropriate policy and purchasing frameworks for supporting people with an intellectual disability are not possible without good information. However much of the information that is currently collected regarding services that support adults with an intellectual disability is accounting, not management information.

'It seems to me that they know the cost of everything and the value of nothing.'

In the course of this project the NHC expected to be able to access robust information about the population of adults with intellectual disability who require regular support for living. This group of people have been assessed for, and have used, a wide range of government services since birth or childhood. Many of them are extremely high users of support services. Yet, it was very difficult to get basic demographic data.⁴³ Ethnicity data are very poor.

The committee was extremely concerned at the lack of information systems and processes for informed decision-making. At present, policy decisions appear to be made based on historical accounting information regarding the use and cost of current services, rather than developed with good information about current and future need, or the experiences of people with disabilities. Lack of information makes it impossible to adequately forecast future support needs and increases the likelihood that support services will lag behind the expectations and aspirations of the people they are supposed to be supporting.

The NHC is aware that the Ministry of Health stated in 1998⁴⁴ that the development of a disability support services management information database would be given top priority. However, it appears little if any progress has been made on this.

The collection of good demographic information, including accurate ethnicity data, to inform the development of policy and support services must be given the highest priority, if government is to implement the vision in the New Zealand Disability Strategy. The committee has been advised that the Office for Disability Issues is giving priority to the collection and use of disability-relevant information, both in its own work and in its discussions with other departments across the state sector.

⁴³ See the chapter *Definitions and demographics* in the background papers to this project. (See page 4.)

⁴⁴ Ministry of Health, 1998.

The committee is also aware of the recommendations of the WAVE report⁴⁵ and wishes to reinforce its recommendations, particularly those regarding:

- integration of health information systems
- collection of reliable ethnicity data.

The literature reviews prepared by the Donald Beasley Institute identified the paucity of New Zealand data and research about adults with an intellectual disability. There are many areas where more information is needed about the lives of this population. The committee has identified three groups about which there is very limited information:

- parents who have an intellectual disability
- families and whānau who support an adult with an intellectual disability
- adults who only need support some of the time.

Utilising national and international best practice

In addition to good information about the people who need support, national and international information is needed about the most effective ways to provide support. The regular coordination of this type of information, and some form of national network for its distribution, would ensure continued access to information to improve current practice and stimulate new ideas.

The Office for Disability Issues could facilitate this by hosting an annual meeting of self-advocates, families and whānau to talk about what is working well in service provision and where there are opportunities to make changes to create better futures for adults with an intellectual disability. This would enable the discussions that have taken place during the NHC project to continue. The Office could also promote workshops among service providers and policy makers to share information about best practice approaches. The information gathered through such forums could then be disseminated through the Office's networks within the government sector, among providers and with disabled people and their families/whānau.

Supporting innovation and creativity

The NHC feels strongly that it is important to encourage and reward innovation and creativity in the provision of supports that enable disabled people to achieve their goals. It is important that all departments think laterally about how they support disabled people in general and, in the context of this report, people with an intellectual disability in particular.

The National Health Committee recommends that:

18. **the collection and coordination of demographic information about people with an intellectual disability be improved** by the Minister of Health and the Minister for Disability Issues working with their Ministerial colleagues to ensure that all relevant government departments:
 - a) gather coordinated demographic information about people with an intellectual disability who use their services, including consistent and accurate ethnicity data
 - b) present this information annually in a useable format to the Office for Disability Issues, as part of their implementation of the New Zealand Disability Strategy.

⁴⁵ WAVE Advisory Board to the Director-General of Health, 2001.

19. **high quality research about the lives of adults with an intellectual disability is undertaken**, through the Minister of Health and the Minister for Disability Issues, in conjunction with their Ministerial colleagues, ensuring that adequate funding is available. [F]
20. **to improve current practice and stimulate new ideas about the most effective ways to provide support**, the Minister of Health and the Minister for Disability Issues establish a process to facilitate sharing of information about best practice, new directions and innovative approaches in service development, among self-advocates, whānau, families, services providers (including Māori services) and government agencies.



improving needs assessment & service coordination (NASC)

‘When government makes policy, they need to think about the fact that that policy comes into my living room.’

Access to most disability support services is via an assessment of an individual’s needs, followed by a process to coordinate access to available services to meet the assessed needs. This service, which is contracted out by the Ministry of Health, is known as Needs Assessment and Service Coordination (NASC). The NASC agency also acts as a budget manager for the pre-purchased packages of service, allocating them according to preset eligibility criteria. Most NASC agencies are able to use a small amount of their allocated budget-holding to purchase discretionary services not covered by pre-purchased contracts.

While NASC was not the focus of this project, many people raised it in relation to accessing the support they required. There was much anecdotal reporting of significant variations in the approach and outcome of NASC across New Zealand, with many people expressing frustration on a wide range of issues. These included the lack of long-term planning for support, linked with the seeming inability of the NASC process to recognise or acknowledge developmental goals and work towards them. The lack of flexibility to fund non-standard options for support (such as a laundry service rather than home help), and no acknowledgement of needs in essential areas of life where services are not generally purchased (such as cultural services and communication), were other issues of frustration.

The committee believes that the NASC concept is a good one, and a crucial tool in the implementation of the New Zealand Disability Strategy. However the committee is clear that the current model is severely constrained by its focus on the allocation and rationing of pre-purchased existing services. Furthermore, it appears that the current needs assessment process is not meeting the needs of Māori and Pacific people. The current process does not match well with the Māori concept of holistic wellbeing as it fails to acknowledge that disability support services need to cater for the whole essence of the person, rather than just focusing on their disability.

All Māori providers talked about people accessing their service through a wide range of channels outside the NASC process, and that needs assessment frequently occurred once the person was already receiving services from the provider.

There are very few Māori needs assessors, so for most Māori, needs assessment is undertaken by non-Māori staff. The committee is strongly of the view that there is a need both to increase the number of Māori needs assessors and improve the cultural competency of other needs assessors. (Recommendations relating to this are on pages 42–43.)

For Pacific adults with an intellectual disability the issues relating to the cultural appropriateness of needs assessors are very similar. (Recommendations relating to needs assessment for Pacific adults are on page 44)

The NHC is aware that there is policy work underway to look at interdepartmental NASC, but based on the evidence from its project the committee believes that a more fundamental review of NASC is needed. It recommends that needs assessment should focus on strategic assessing and planning for life with disabled people and their whānau, using an approach that recognises and encourages the ‘ordinary’ process of development throughout life. The outcome of this strategic planning would be to design individual service responses, which utilise the services in the person’s community, have meaning to the disabled person and fit with their life aspirations.

This approach would require NASC to ask a new set of questions, to change the skill set for assessors, and focus on identifying the long-term support needs of an individual, including their cultural identity. It also fits with the approach of having an ‘ordinary’ life. In addition it would also enable thought to be given to a person’s fundamental needs and allow for consideration of solutions such as assistance with ‘social interpretation’.

Achieving this new approach would require greater flexibility in service coordination and purchase. The NHC recommends that the current flexible funding provisions be gradually increased to enable this to occur. It is concerned that the current policy work to determine the baseline cost of services (the Transparent Funding Model) appears to be basing its costings on group models of service delivery. This is counter to the strategic direction of the New Zealand Disability Strategy of ‘long-term support centred on the individual’.

The committee firmly believes that current resource limits will not inhibit taking on this new approach, as it has been demonstrated that it is possible to fund packages of support to meet individual need within existing resource allocations. On the other hand, providing services in areas of unmet need or filling service gaps will either require reallocation of resources or new money. The committee recommends that budget bids for these gaps should be given high priority.

It is the view of the NHC that there needs to be a fundamental redesign of the NASC process, which will require a significant change in thinking. This will include moving away from using a standardised assessment process based on short-term needs, to focusing on strategic and long-term planning to identify what support each adult requires to meet their particular needs. In regard to service coordination, a shift is needed away from matching people with pre-determined services toward a service design approach where the services and supports are developed to meet the specific needs of the people using them.

To achieve this change in NASC there is also the need to move away from bulk-purchasing a limited range of prescribed services to increased opportunities for individualisation of both funding and support arrangements. Furthermore, a change of approach is required in determining quality within disability support services. Rather than using a minimum standards approach, the NHC proposes that an outcome-based approach be adopted in determining quality within the provision of services. Changing the focus of needs assessment, service coordination and service purchase is one of the NHC’s three priorities for action.

The National Health Committee therefore recommends that:

21. to shift the focus of needs assessment and service coordination from allocating pre-purchased services to ensuring that each adult with an intellectual disability has support to meet their needs, the Minister of Health and the Minister for Disability Issues:
- a) direct the Ministry of Health to purchase needs assessment services which:
 - i) are designed to discern needs that will result in support for a personally meaning future
 - ii) focus on long-term life planning with the disabled person and their family or whānau, including cultural needs and perspectives
 - iii) create systems that enable an active cooperative partnership between the disabled person, their family or whānau and the needs assessment and service co-ordination agency
 - iv) monitor the outcome of the needs assessment and service coordination process for the individual disabled person
 - b) direct the Ministry of Health to facilitate the development of packages of support that are designed to meet individuals' needs by, in the first instance:
 - i) ensuring the direction of the policy work on the transparent pricing model, is aligned with the strategic direction of the New Zealand Disability Strategy
 - ii) incrementally increasing the level of flexible funding available to needs assessment and service coordination agencies
 - iii) developing and implementing flexible service provision/contracting frameworks which enable providers to offer more flexible packages of support
 - iv) ensuring needs assessment and service coordination agencies provide their staff with training on designing packages of support.



supporting family and whānau

'My family, especially my parents, are important to me. They are always there for me.'

The central role that family and whānau play, as a principal source of identity, support, security and strength in the wellbeing of people individually and collectively, was very apparent throughout this work. During the project adults spoke of their families and whānau as being central to their lives; others had little contact with their families or whānau. For some adults with an intellectual disability, their families or whānau were their total support network. Family and whānau members also provide much of the 'social interpretation' support needed by adults with an intellectual disability.

The principle of whānau ora: supporting families to achieve their maximum health and wellbeing, is the overall aim of *He Korowai Oranga*⁴⁶ (the Māori Health Strategy). A whānau focus is important in providing services to Māori adults with an intellectual disability, and is an underpinning philosophy in kaupapa Māori services.

⁴⁶ Ministry of Health, 2002.

During the project it was clear that support by family members and whānau is not a 'free' care option for government. Every parent spoken to had either stopped work, taken a lower paid position, or not taken promotion, in order to provide care for their family member. Most had stories of reaching a breaking point. Many family units had disintegrated. All of these consequences have a cost for government. Many of the issues identified in the NHC's discussion document on caring for the carers⁴⁷ remain pertinent.

The committee was concerned that many families and whānau described significant barriers to accessing service. All of them asked why things constantly had to reach a crisis point before support was given. Some of these barriers were relatively small things, yet caused significant concern and distress. One example frequently given was the inability to access respite care without pre-booking many weeks in advance. While respite care was much appreciated, many families and whānau pointed out that in all families it was during sudden and unexpected occurrences, such as family illness, an accident and other crises, when additional support was required, and families which include a disabled person were no exception. It was at times such as this that some flexibility was required, and that this flexibility needed to be built into the respite care system.

Currently, respite care is the main form of assistance available to support families and whānau. During its project, the NHC found that families often had significant unmet needs, which would not be met by respite care. For instance, the family of an adult who was incontinent suggested that a commercial washing machine would be more useful to them. Another family suggested that because their adult son regularly destroyed household décor, financial assistance with wallpapering the lounge would be more helpful than respite care.

Family and whānau play a critical role in the long-term support of adults with an intellectual disability. The NHC considers it important that this role be formally acknowledged and supported in policy and service development.

The National Health Committee therefore recommends that:

22. **to ensure that families and whānau are adequately supported**, the Minister of Health and the Minister for Disability Issues require the Ministry of Health to:
 - a) develop a range of flexible support options that enable families to:
 - i) stay together
 - ii) grow and develop
 - iii) plan positive futures
 - iv) have regular breaks
 - v) manage the day-to-day responsibilities of providing care and support
 - b) acknowledge in all policy, funding and contracts the importance of supporting and strengthening reciprocal relationships between adults with an intellectual disability and their family and whānau.

⁴⁷ National Health Committee, June 1998.



promoting workforce development

‘The staff should put themselves in our shoes and see what it is like to be us.’

Workforce is a critical component of effective disability support and service provision to disabled people. The NHC notes with concern the extremely high staff turnover among some services for adults with an intellectual disability, and its resulting impact on the quality of the support provided. It is clear that some of this turnover is due to pay and conditions, lack of training and a poor career structure. The committee found that a few providers had developed training and career structures that had significantly improved recruitment and retention. As mentioned previously, the committee is also worried about the lack of cultural competency among staff in mainstream disability services.

The Health Workforce Advisory Committee (HWAC) has identified three types of disability workforce. These are:

- the workforce that provides support with everyday things, such as home support workers, voluntary workers and advocacy workers
- the ‘assessment and linkage workforce’ which includes NASC staff, case managers and ‘key workers’
- the ‘specialised disability workforce’ which provides specialised assistance for specific impairments, and includes speech-language therapists.

Support workers play a pivotal role in the lives of many adults with an intellectual disability. Much of the international research makes it clear that it is not the level of impairment that is a deciding factor in the degree to which a person with an intellectual disability is able to live their life, but the skill and ability with which they are supported. Many people raised the issue that high staff turnover meant people with many years of experience, knowledge and understanding, are few and far between in the disability support workforce. This lack of wisdom and mentoring is of concern in a sector where, with one or two large exceptions, most of the service provider organisations are less than 12 years old.

A critical area for workforce development is needs assessment and service coordination. The training available is currently very limited. Unless those undertaking needs assessment and service coordination have a clear understanding of their role, disability issues and the skills they need, little progress will be made in developing community membership for adults with an intellectual disability. The committee suggests that improving the skill base of NASC staff is a good starting point to building up the professionalism and career structure of the disability support workforce.

The NHC wishes to reinforce the work of the Health Workforce Advisory Committee (HWAC), and endorses its three-pronged approach for health and disability workforce development:

- a person-centred approach to service planning and delivery
- a ‘systems’ approach to workforce development, engaging all stakeholders and addressing the interrelating domains of workforce development
- a planned and managed, evolutionary approach to workforce development.

The committee strongly supports HWAC's identification of the need to build Māori workforce capacity. (NHC recommendations relating to developing the Māori disability workforce are on pages 42-43.)

HWAC has also highlighted the importance of building Pacific workforce capacity, which the NHC endorses. (Recommendations relating to developing the Pacific disability workforce are on page 44.)

A catalyst for creating competent communities

For community membership to become a reality, communities need to be more confident and competent about including people with an intellectual disability. Staff working with disabled people can be a catalyst in building skills within families, whānau and wider communities and showing how people can be supported to define and solve their own problems. This will help to create communities that are inclusive and where there is greater acceptance of society's responsibilities, and create an environment that is conducive to community membership.

The National Health Committee recommends that:

23. **to strengthen the disability support workforce, the Minister of Health and the Minister for Disability Issues** direct the Ministry of Health to make an urgent investment in:
 - a) promoting, developing and complementing current leadership within the disability support workforce
 - b) workforce development across the disability support workforce
 - c) improving the confidence and competence of families, whānau and communities to create an environment that is conducive to community membership.

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