TO HAVE AN ‘ORDINARY’ LIFE
Kia whai oranga ‘noa’

Background papers to inform the National Advisory Committee on Health and Disability

Information about the lives of adults with an intellectual disability in New Zealand

January 2004
The National Advisory Committee on Health and Disability is an independent committee appointed by, and reporting directly to, the New Zealand Minister of Health.

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

Members of the National Health Committee
Robert Logan (Chair)
Geoff Fougere
Kevin Hague
Linda Holloway
Cindy Kiro (until August 2003)
Andrew Moore
Teuila Percival (until March 2003)
Althea Page-Carruth
Neil Pearce
Lorna Sullivan
Lynette Stewart
Api Talemaidoga (from June 2003)
Gwen Tepania-Palmer

HP: 3688

National Advisory Committee on Health and Disability
Wellington
New Zealand
2003

This report is available on the committee’s website http://www.nhc.govt.nz
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WHAT IS ‘ORDINARY’?

The word ‘ordinary’ is used in the title of this document and in other publications from this project. 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’, 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.
OTHER PUBLICATIONS

The other publications developed as part of this project are available on the website www.nhc.govt.nz, by phoning (04) 496-2277 or e-mailing moh@wickliffe.co.nz (and quoting the relevant HP number below):

- To have an ‘ordinary’ life: Community membership for adults with an intellectual disability - a report to the Minister of Health and the Minister for Disability Issues (this document summarises the Committee’s findings and lists recommendations to Ministers) HP:3686

- 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 for 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.
1. PROJECT OVERVIEW

In early 2001, the National Advisory Committee on Health and Disability (National Health Committee, NHC) began 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 the 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.

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. This project arose from concern by the National Health Committee about the way services were being provided in relation to non-institutional or community-based care for adults with an intellectual disability.

What is intellectual disability?

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

In developing the project the committee needed a definition that clearly identified this population. Definitions are often used as the basis for significant decisions about people’s lives, and the committee considered definitions currently used around the world. The definition the NHC chose to use was published by the British Government in 2001, 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 estimated 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

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2 Department of Health 2001.
Project overview

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:
- amongst older adults, there are 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.

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.

Definitions of intellectual disability and demographic information are discussed in more detail in Chapter 2: Definitions and demographics.

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, not children, with an intellectual disability, for a number of reasons no specific lower age limit was set.

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.³

³ This is recorded in the Chapter 3: History of service provision.
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
Project overview

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.

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.4

• 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 people live, their friends, work, and money. Where Māori were part of a focus group, Māori facilitation was available.

• Three focus groups were held, each with 10–20 family/whānau members, as well as a number of individual interviews with families/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.

4 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 6.
Project overview

- Specific work was undertaken with Māori, including looking at kaupapa Māori services.\(^5\)
- Work was also undertaken with Pacific peoples to gather their views and experiences of services for Pacific people with an intellectual disability.\(^6\)

About the background papers

The background papers in this publication 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. These papers were developed during the project to brief the members of the National Health Committee. They draw on the information that was gathered in the course of the project, in particular the Donald Beasley Institute’s literature reviews and the focus groups involving adults with an intellectual disability. The background papers give a picture of the lives of adults with an intellectual disability, but do not cover all issues affecting their lives.

Throughout the papers are quotes from the focus groups as well as from published literature. The quotes give an idea of how adults with an intellectual disability see their own lives.

About the report to Ministers

The findings from the National Health Committee’s project were summarised and presented to the Minister of Health and the Minister for Disability Issues as a publicly available report. This report "To have an ‘ordinary’ life: community membership for adults with an intellectual disability" contains the committee’s thinking about how services affect the lives of adults with an intellectual disability and detail its recommendations about what changes are needed in government policy and service purchase.\(^7\)

About the plain language summary

A plain language summary accompanies the report to Ministers. It summaries the key findings from the project and presents the National Health Committee’s recommendations in an easy-to-read way.\(^8\)

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\(^5\) This process is detailed in Chapter 14: Whakaritenga mahi mö te hunga pakeke Māori kua hauā-ā-hinengaro.

\(^6\) This process is detailed in Chapter 15: Pacific adults with an intellectual disability.

\(^7\) Copies of the report to Ministers are available on the NHC’s website [http://www.nhc.govt.nz](http://www.nhc.govt.nz), by phoning (04) 496-2277 or e-mailing: moh@wickcliffe.co.nz (and quoting the number HP 3686).

\(^8\) Copies of the plain language summary are available in the NHC’s website [http://www.nhc.govt.nz](http://www.nhc.govt.nz), by phoning (04) 496-2277 or e-mailing: moh@wickcliffe.co.nz (and quoting the number HP 3687).
2. DEFINITIONS AND DEMOGRAPHICS

“I am not a disabled person because I have Down Syndrome. I am just like everyone else. You should look at the person first and their disability second. You should not judge them by their disability but as a person.”

This chapter:
• discusses what is meant by the term ‘intellectual disability’
• details what is known about adults with an intellectual disability living in New Zealand
• identifies the gaps in information about people with an intellectual disability.

What is known about adults with an intellectual disability in New Zealand?

It is very difficult to get a clear picture of how many adults with an intellectual disability live in New Zealand, or to find any demographic data about them. This is a cause for concern, because good information about people who may need support is vital to inform service development.

One difficulty in gathering good information is the variety of definitions of intellectual disability. Many different terms have been used, which change over time, particularly when their connotations become unacceptable in common usage.

During the course of its project, the National Health Committee considered the definitions currently used around the world. Some of these definitions include reference to scores in intelligence (IQ) tests. As a result of discussion within the committee and advice from advocacy groups and service providers, the NHC decided not to include reference to intelligence test scores in the definition used for its project. IQ measures are often used as rationing tools to determine eligibility to access services, and there is much debate about their validity or usefulness, in comparison to looking at functional ability across a range of settings.

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10 The term ‘intellectual disability’ is not common in other countries, but has gradually become the preferred term in New Zealand in recent years, at least within policy and service provision arenas and among people to whom the term is applied. See Bray 2003a.
The National Health Committee chose to use the definition in the 2001 British White Paper ‘Valuing People’. This definition is functional in its approach, defining 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.11

This is very similar to the American Association of Mental Retardation definition, but excludes an IQ measure.

The term preferred by People First, the self-advocacy movement for people with an intellectual disability, is ‘people who use services’. This term reflects their desire to be seen as no different from the rest of the population. It emphasises that they are the same as the rest of the population, other than that they use services to support them, and highlights their desire to be treated in the same way as everybody else.

Intellectual disability is a socially defined phenomenon. It is a description of a society’s current judgement on an individual’s functioning. Intellectual disability is not a condition or disorder, although some conditions, or damage to the central nervous system, can result in an intellectual disability.12 The current understanding of intellectual disability recognises that intellectual and adaptive functioning can change in an individual over time. For instance, a child may meet the criteria for having an intellectual disability during his or her school years but not in adulthood. Intellectual disability is not necessarily a permanent, biological condition, but represents a social evaluation of an individual’s current behaviour compared to others of the same age and culture.13

People with a more severe intellectual disability are usually recognised as ‘disabled’ in any time or culture, and need lifelong support with daily life to varying degrees.14 It is on this group that the National Health Committee project is particularly focused.

There is also a substantial group of people who are seen by society as ‘less different’ and depending on the definition used, may or may not be identified as having an intellectual disability. Generally these people do not use disability support services and would reject the label of intellectual disability.15 While the National Health Committee acknowledges that people with a ‘mild’ intellectual disability may need specific support at times of change or during challenging stages of life, such as parenting, its project has specifically focused on the group of people who need regular and ongoing support.16

The literature review on definitions that was prepared by the Donald Beasley Institute as part of the NHC project discusses definitions in more detail.17

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12 Bray 2003a.
13 Bray 2003b.
14 Bray 2003a.
15 Bray 2003a.
16 Bray 2003a.
17 See page 6 for a list of the literature reviews and details of how to obtain copies.
Definitions and demographics

How many people in New Zealand have an intellectual disability?

The two main ways of determining the number of people with a particular characteristic are “incidence” and “prevalence”. Incidence refers to the number of new “instances” of intellectual disability within a specified time, whereas prevalence refers to the actual number of people with an intellectual disability in a given population at a given point in time. Estimating incidence is complex because many factors can contribute to its calculation, including the range of definitions that are used and the variation in the age at which intellectual disability is identified. Prevalence is easier to determine and is accepted internationally as the more reliable measure.

Internationally, prevalence studies suggest that between 7.0 and 12.6 people per 1000 have an intellectual disability. The prevalence rate for ‘severe’ intellectual disability is estimated to be between 3.0 and 4.4 people per 1000. There is a considerable range in the estimated prevalence rate for ‘mild’ intellectual disability of between 3.7 and 9.2 per 1000, with the rate varying between age groups.

New Zealand surveys of intellectual disability

A report prepared for the Midland Regional Health Authority in 1993, for use in service planning, provided estimates of the number of people with a ‘severe’ intellectual disability. The researchers estimated that the average prevalence rate for adults aged 20 years and over was 2.9 per 1,000. Based on their research they calculated that there were 2,078 adults with a severe intellectual disability living in the Midland region, which equated to a national estimate of 10,400 people. The study pointed out that the prevalence of people with “severe intellectual disabilities” had declined since the 1970s and suggested that contributing factors included neonatal screening, improvements in perinatal care and environmental factors.

In 1996, Statistics New Zealand carried out the first population-based study of disability in New Zealand. Separate surveys were undertaken of people with disabilities living in households and those in residential care. The 1996 surveys identified that there are approximately 21,000 adults with an intellectual disability living in New Zealand. Statistics New Zealand undertook disability surveys again in 2001. The results from these surveys estimated that 32,400 adults had an intellectual disability. This equates to approximately five percent of the adults with a disability or one percent of the total adult population of New Zealand.

\[18\] Bray 2003b.
\[19\] Bray 2003b.
\[20\] Mitchell and Whitehead 1993.
\[22\] Statistics New Zealand 1997a; Statistics New Zealand 1997b.
\[23\] "Adults” was defined as people aged 15 or over.
\[24\] Statistics New Zealand 2002.
These results were based on question 25a that asked:

Do you need support or help from other people or organisations because of an intellectual disability or an intellectual handicap?

(Notes to interviewer)
In the past, people with intellectual disabilities have also been labelled: mentally handicapped, mentally retarded and developmentally delayed.

Tick “yes” if R receives any support from an individual or an organisation or group like IHC or People First because she or he has an intellectual disability.

The estimate of 32,400 people with an intellectual disability in the 2001 survey was much higher than the figure of 21,000 calculated in the 1996 survey. Interestingly, only 16 percent of those who responded “Yes” to question 25a went on to identify intellectual disability as their main disability. The data gathered by Statistics New Zealand can only be regarded as indicative for people with an intellectual disability, due to significant problems in definition and ascertainment.

The Disability Survey is a sample survey, rather than a census, therefore all its results have some degree of sampling error. The information accompanying the survey findings indicates that there is a high rate of sampling error in the data for people with an intellectual disability living in households. For most figures relating to people with an intellectual disability the sampling error is between 30 and 100 percent, and for some it is over 100 percent.

Non-sampling errors (things like the way respondents may perceive a question may differ from the purpose of the question) can also occur in such surveys. The questions around intellectual disability could have been interpreted in a number of different ways and it is likely that they include responses from other people with disabilities, such as older people with dementia or people with cognitive difficulties arising from acquired conditions such as head injury or stroke.

To provide background information for its project, the National Health Committee contracted the Donald Beasley Institute in Dunedin to prepare literature reviews on specific topics. Two of the literature reviews were on definitions of intellectual disability and on demographics of people with an intellectual disability. In the demographics literature review it is estimated that the prevalence rate for intellectual disability in New Zealand is 7–13 people per 1,000. This gives an estimated adult population of between 19,850 and 36,860 people. The Donald Beasley Institute estimates that about 3–4 people per 1,000 have a more severe disability and need ongoing support. This equates to between 8,510 and 11,340 people, which is generally consistent with the data from other sources.

During the project, the National Health Committee was not able to locate any data on non-demographic factors, such as how many people with an intellectual disability can read and write or need assistance with mobility or communication. The Statistics New Zealand disability surveys do have some information about characteristics and needs of disabled

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25 See page 6 for a list of the literature reviews and details about how to obtain copies.
26 Bray 2003b.
27 The 2001 Census identified a usually resident population of 2,835,309 people over the age of 15.
28 Bray 2003b.
Definitions and demographics

people, but the high sampling errors and potential non-sampling errors for the data on people with an intellectual disability made this information difficult to interpret.

Other sources of data
Data from service providers and government agencies offers potential sources of information about the number of adults with an intellectual disability. This tends to be accounting information of service use and its focus tends to be on the cost of the service and the management of that cost, rather than about the needs of the group of people using the service. However it does give some ability to formulate demographic information in the absence of anything better.

IHC estimate
In the early 1990s, IHC, the largest provider of services for people with an intellectual disability, estimated that there were 10,500 adults who required ongoing support because of an intellectual disability.\(^{29}\)

Ministry of Health
The Ministry of Health has data on purchased residential beds, but not on the number of people with an intellectual disability who use other disability support services. The Ministry advised that as at August 2002 it was paying for 5,335 community residential beds for adults with an intellectual disability.\(^{30}\) In addition, as at August 2002 there were 369 people living at Kimberley Centre in Levin and 75 people with an intellectual disability in Braemar Hospital in Nelson. The Ministry of Health estimates that around 400 people with an intellectual disability are living in aged residential care, either in a rest home or a private hospital. This gives a total of approximately 6,180 adults with an intellectual disability who live in some form of residential care, funded through Vote Health.\(^{31}\)

Table 1: Adults with an intellectual disability who live in residential care, funded through Vote Health

<table>
<thead>
<tr>
<th>Ministry of Health</th>
<th>5,335</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kimberley</td>
<td>369</td>
</tr>
<tr>
<td>Braemar</td>
<td>75</td>
</tr>
<tr>
<td>Aged residential care</td>
<td>400</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>6,179</strong></td>
</tr>
</tbody>
</table>

Ministry of Social Development (Work and Income)
Data is also available about people receiving a Sickness or an Invalids Benefit, whose principal disabling condition is an intellectual disability. Work and Income, part of the Ministry of Social Development (MSD), identified that as at 31 May 2002 there were 11,102 people in this category. In this group will be people with an intellectual disability, aged between 16 and 65, living in a variety of accommodation.\(^{32}\) The benefit data provided by MSD will be an underestimate of the number of adults with an intellectual disability under the age of 65 who require support with daily tasks, as it does not include people who receive income from other sources, such as paid employment or another type of benefit. The number

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\(^{29}\) Bray 2003b.

\(^{30}\) Information provided by the Ministry Of Health, Disability Support Directorate.

\(^{31}\) The NHC’s understanding from discussions with the Ministry of Health with regard to these figures is that they do not include respite beds, nor do they include people who are supported to live in their own home or private accommodation under an independent supported living contract.

\(^{32}\) 47 recipients were recorded as being aged 65 or over.
Definitions and demographics

of people with an intellectual disability in these situations is estimated to be very small. The data gathered by MSD includes information about gender, ethnicity and location.

Table 2: Summary of recent estimates of the number of adults with an intellectual disability in New Zealand

<table>
<thead>
<tr>
<th>Total adults with an intellectual disability population</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2001 New Zealand Disability Survey. Estimated prevalence of 11 per 1,000. Data from people aged 15 years and over</td>
<td>32,400</td>
</tr>
<tr>
<td>New Zealand Household Disability Survey and Disability Survey of Residential Facilities (1996/97). Estimated a prevalence rate of 8.0 per 1,000. Data from people aged 15 years and over</td>
<td>21,000</td>
</tr>
<tr>
<td>Donald Beasley Institute (Bray 2003b). Based on estimated prevalence of 7–13 people per 1,000 (aged 15 years and over)</td>
<td>19,850–36,860</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adults with an intellectual disability who need regular support with daily activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extrapolation from Midland RHA data of people aged 20 years and over. Estimated prevalence rate of 2.9 per 1,000 (Mitchell and Whitehead 1993)</td>
</tr>
<tr>
<td>IHC estimate</td>
</tr>
<tr>
<td>Adults aged 16–65 with an intellectual disability receiving a Sickness or Invalids Benefit (Ministry of Social Development, May 2002)</td>
</tr>
<tr>
<td>Donald Beasley Institute (Bray 2003b). Based on estimated prevalence of 3–4 people per 1,000 (aged 15 years and over)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adults with an intellectual disability living in residential care (including community residential homes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001 New Zealand Disability Survey (Statistics New Zealand)</td>
</tr>
<tr>
<td>1997 Disability Survey of Residential Facilities (Statistics New Zealand)</td>
</tr>
<tr>
<td>Ministry of Health data (2001/02)</td>
</tr>
</tbody>
</table>

In summary, it is estimated that there are between 20,000 and 37,000 adults with an intellectual disability in New Zealand. Of these, around 12,000 people need regular support with daily activities, including over 6,000 adults who are in government-funded residential care.

Demographic information

Age

International prevalence studies show marked variations between age groups. The highest rate of intellectual disability is generally found in children and young people, and the lowest in the older age groups. This is an international phenomenon, and is in part explained by the higher visibility which school-aged students have to educational and health professionals. Furthermore, people with an intellectual disability have had a lower than average level of life expectancy, and so have been less likely to live into old age. (See Chapter 5: Health for more information on life expectancy.)

Figure 1 shows the age distribution of adults with an intellectual disability who receive a Sickness or Invalids benefit. There is quite a marked difference between the shape of this curve and the one in Figure 2, which shows the age distribution of the total New Zealand population. In Figure 1, the steep decline around age 65 relates to people moving from Invalids and Sickness Benefits to New Zealand Superannuation.

33 In the 2001 survey, the definition of a residential facility excluded supported housing and group homes, in which many people with a ‘severe’ intellectual disability live.

34 This is a composite figure of the 11,100 adults under age 65 who receive a Sickness or Invalids Benefit, and an estimate of the number of adults with an intellectual disability over the age of 65.
Definitions and demographics

Figure 1: People receiving a Sickness or an Invalids Benefit, whose principal disabling condition is intellectual disability (at 31 May 2002)\textsuperscript{35}

Figure 2: Usually resident New Zealand population between the ages of 15 and 65 years\textsuperscript{36}

\textsuperscript{35} Data provided by the Ministry of Social Development.
\textsuperscript{36} Statistics New Zealand 2001 Census information.
Definitions and demographics

Children
For children with an intellectual disability the 1996/97 Household Disability Survey found a prevalence rate of 7 per 1,000 for children with an intellectual disability under five years, and a rate of 17 per 1,000 for those aged 5–14 years.  The prevalence rates have remained constant, the only change being a decrease from 17 to 16 per 1,000 for those aged 5–14 years.  A brief description of the demographic characteristics of children with an intellectual disability is outlined in the section on future adults with an intellectual disability on page 23.

Adults (15–64 years)
The 1996/97 New Zealand Disability Surveys found a prevalence rate of 7 per 1,000 for adults aged 15–65 years. These surveys estimated that the total population of people with an intellectual disability in this age group was 17,881. The population estimates for intellectual disability in the 2001 disability surveys were higher than in the 1996/97 surveys. The 2001 surveys estimated that there were 19,100 people aged 15–44 and 6,000 people aged 45–64 with an intellectual disability. This is a total of 25,100 adults aged 15–64 years living in households who had an intellectual disability in 2001 and a prevalence rate of 10 per 1,000 for adults aged 15–64 years.

Figure 3: Age distribution of Sickness and Invalids Benefit recipients with an intellectual disability in six District Health Board areas

Ministry of Social Development data on Sickness and Invalid Benefit recipients at 31 May 2002 shows quite marked differences between DHBs in the age distribution of people with an intellectual disability. This is illustrated in Figure 3, which shows six very different age distributions. Wairarapa and Hutt DHBs have a high proportion of youth and young adults, Midcentral DHB has a predominance of middle-aged people, West Coast DHB has a

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38 Statistics New Zealand 2002.
39 Bray 2003b.
41 Statistics New Zealand 2002.
42 Data provided by the Ministry of Social Development.
Definitions and demographics

A significant number of people aged 45–54, while South Canterbury and Auckland DHBs have a considerable number of people in the older age groups.

Older people
The 2001 disability surveys estimated that 3,800 people aged 65 and over had an intellectual disability and were residing in households.\(^{43}\) This is a prevalence rate of 9 per 1,000. Due to the broad definition used for intellectual disability in the 2001 survey it is not clear how many of these people have an intellectual disability and how many have acquired an intellectual impairment in their adult life (for instance through a head injury or Alzheimer’s disease).

The estimates of the number of older people with an intellectual disability in the 1996/97 disability surveys were slightly lower. From the two surveys it was concluded that there were approximately 2,225 people who were aged 65 and older, and 490 of these people were living in residential settings.\(^{44}\) As noted earlier, the Ministry of Health estimates that about 400 people with an intellectual disability are in aged residential care. IHC has advised that 165 of its residents are aged 65 or over.\(^{45}\) These figures suggest that there are between 490 and 550 older adults with an intellectual disability living in some form of residential care. There is no clear data on how many in this age group are living in the community.

There has been one New Zealand study of people aged 50 years and over who have an intellectual disability, which was undertaken in 1989–91 by Jennifer Hand. This study identified 1,063 people, and calculated a prevalence rate of 1.45 per 1,000 people.\(^{46}\) If the prevalence rate calculated by Hand is relevant to today’s population, then there would be approximately 1,500 people over the age of 50 with an intellectual disability.\(^{47}\) However, increases in life expectancy mean that the figures are likely to be slightly higher.

Forty percent of the group identified by Hand were said to have a borderline or mild intellectual disability. This suggests that around half of older adults with an intellectual disability could require regular support services as a result of intellectual disability.

People with an intellectual disability are living longer than in the past.\(^{48}\) In her study, Hand identified 118 people aged 70 years or older. The study in 1993 for the Midland RHA calculated the prevalence rate for people aged over 74 years and found there to be less than 1.0 in 1,000 people in that age bracket.\(^{49}\) This would equate to less than 204 people with an intellectual disability currently aged 75 and over.\(^{50}\)

Table 3 summarises the estimates of prevalence of intellectual disability in New Zealand for different age groups.

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\(^{43}\) Statistics New Zealand 2002.
\(^{44}\) Statistics New Zealand 1997. Note the figures for intellectual disability in the New Zealand Household Survey, which are included in this calculation have a sample error of between 30 and 100 percent.
\(^{45}\) Personal communication with IHC 2001.
\(^{46}\) Hand 1993.
\(^{47}\) In the 2001 Census there were 1,023,426 people in New Zealand aged 50 or over.
\(^{48}\) Changes in life expectancy are discussed in more detail in Chapter 5: Health.
\(^{49}\) Mitchell and Whitehead 1993.
\(^{50}\) In the 2001 Census there were 204,255 people in New Zealand aged 75 or over.
Definitions and demographics

Table 3: Summary of estimated variation in prevalence rates of intellectual disability across age groups

<table>
<thead>
<tr>
<th>Age group</th>
<th>Prevalence rate per 1,000 population</th>
<th>Source</th>
<th>Equivalent population size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 5 years</td>
<td>7.0</td>
<td>1996 Household Disability Survey (cited in Bray 2003b)</td>
<td>1,900</td>
</tr>
<tr>
<td>Under 5 years</td>
<td>7.0</td>
<td>2001 Household Disability Survey</td>
<td>1,700</td>
</tr>
<tr>
<td>5–14 years</td>
<td>17.0</td>
<td>1996 Household Disability Survey (cited in Bray 2003b)</td>
<td>9,800</td>
</tr>
<tr>
<td>5–14 years</td>
<td>16.0</td>
<td>2001 Household Disability Survey</td>
<td>9,500</td>
</tr>
<tr>
<td>15–64 years</td>
<td>7.0</td>
<td>1996 Household Disability Survey (cited in Bray 2003b)</td>
<td>17,881</td>
</tr>
<tr>
<td>15–64 years</td>
<td>10.0</td>
<td>2001 Household Disability Survey</td>
<td>25,100</td>
</tr>
<tr>
<td>50+ years</td>
<td>1.45</td>
<td>Hand 1993</td>
<td>1,500</td>
</tr>
<tr>
<td>65+ years</td>
<td>Not estimated</td>
<td>1996/97 Disability Surveys</td>
<td>2,225</td>
</tr>
<tr>
<td>65+ years</td>
<td>9.0</td>
<td>2001 Household Disability Survey</td>
<td>3,800</td>
</tr>
<tr>
<td>75 years +</td>
<td>Less than 1.0</td>
<td>Mitchell and Whitehead 1993</td>
<td>Less than 204</td>
</tr>
</tbody>
</table>

Gender

Most prevalence studies show a higher rate of intellectual disability among males than females, particularly in teenage years. This probably represents the higher male rate of some genetically-based conditions which result in intellectual disability, and the greater biological vulnerability of boys to negative development outcomes. There may also be social factors involved in terms of different expectations for males and females, and more perceived “behaviour problems” in boys, leading to higher referral rates.51

The 1996/97 New Zealand Household Disability Study showed a noticeable gender difference for adults in New Zealand. This gender difference was most noticeable among people living in households. The results suggested that 41 percent of adults with an intellectual disability living in households were women, and 59 percent were men.52 However, the gender balance was very different in residential settings, where there was almost an equal balance between men and women.53

However the 2001 New Zealand Disability Study shows a somewhat different picture with almost equal numbers of men and women living in households, while men represented 40 percent of those living in residential settings and 60 percent were women.54

Gender differences are also evident in the Sickness and Invalids Benefit figures at 1 May 2002, which show that 56 percent of recipients with an intellectual disability were men. These recipients will include people living in residential and household settings.55

The higher proportion of men appears to reduce or reverse in older age, which is consistent with the trends in the general population where women outnumber men in all older age

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51 Bray 2003b.
52 Statistics New Zealand 1997b.
54 Statistics New Zealand 2002.
55 Data provided by the Ministry of Social Development.
Definitions and demographics

In her study of people aged 50 and over, Hand found equal proportions of men and women. Overseas studies also indicate that the gender ratio tends to reverse in older age.\(^5^6\)\(^5^7\)\(^5^8\)

Location
Adults with an intellectual disability live in every area of New Zealand. Comparison of data from MSD and the 2001 Census shows that people with an intellectual disability who receive a Sickness or Invalids Benefit are not evenly distributed across the country.\(^5^9\) The percentage of recipients varies from 0.045 percent of the population in Canterbury DHB, to 5.86 percent of the West Coast DHB’s population. The DHB regions with the highest proportion of recipients are West Coast, South Canterbury and Wanganui. At the other end of the spectrum, in addition to Canterbury DHB, Otago (0.075 percent) and Capital and Coast (0.0966 percent) DHBs have the lowest percentages of recipients with an intellectual disability.

Ethnicity
The ethnicity data that is available on adults with an intellectual disability is not reliable. Of those who responded to the ethnicity question in the 2001 New Zealand Household Disability Survey, 74 percent identified as European/Pakeha, 20 percent as Māori and 0.05 percent as Pacific.\(^6^0\)

As at 1 October 2001 only 55 percent of Sickness and Invalids Benefit recipients who had an intellectual disability, had identified their ethnicity. However, by May 2002 this had risen to 82 percent, which shows that over this time period the Ministry of Social Development was very proactive in recording ethnicity data.\(^6^1\) Of this 82 percent, 58.4 percent identified as New Zealand European, 13.8 percent as Māori and 3.3 percent as Pacific.\(^6^2\)

2001 Census information shows 70.5 percent of the total population between the ages of 15 and 64 identified their ethnicity as New Zealand European only, Māori represented 12.8 percent of the total population, while 5.1 percent identified as Pacific.\(^6^3\)

When the Sickness and Invalids Benefit ethnicity data is broken down by DHB it gives a very clear picture of the ethnic distribution of people with an intellectual disability who are likely to require ongoing services. The data from May 2002 showed Māori recipients in each of the 21 District Health Board areas, but the highest proportions were in Tairawhiti and Lakes DHBs, with significant numbers in Northland, Bay of Plenty and Counties-Manukau regions.\(^6^4\) These proportions are very similar when compared to the total population between the ages of 15 and 64. Just over 42 percent of the population in the Tairawhiti DHB region is Māori, followed by 29.4 percent in Lakes DHB, with Northland and Bay of Plenty also over 20 percent.\(^6^5\)

\(^{56}\) Statistics New Zealand 2001 Census information.  
\(^{57}\) Hand’s findings may have been due to the small size of her sample or may reflect gender-biased classifications made about people in earlier years of their lives.  
\(^{58}\) Hand 1994.  
\(^{59}\) Statistics New Zealand 2001 information.  
\(^{60}\) Statistics New Zealand 2002.  
\(^{61}\) The Ministry of Social Development advised in September 2003 that 98 percent of people receiving a Sickness and Invalids Benefit had their ethnicity identified.  
\(^{62}\) Data provided by the Ministry of Social Development.  
\(^{63}\) Statistics New Zealand 2001 Census information.  
\(^{64}\) Data provided by the Ministry of Social Development.  
\(^{65}\) Statistics New Zealand 2001 Census information.
Most Pacific recipients are located in the three Auckland DHBs.\textsuperscript{66} Figure 4 shows the distribution by DHBs of Sickness and Invalid Benefit recipients who have an intellectual disability, for whom ethnicity was coded. The table does not include those coded as European/Pakeha.

\textbf{Figure 4: Location of Sickness and Invalids Benefit recipients by ethnicity (excluding European/Pakeha)}\textsuperscript{67}

Future adults with an intellectual disability

In considering the characteristics of the population of adults with an intellectual disability, it is also helpful to review the demographics of children, who are likely to be future adults with an intellectual disability. Indications are that this group may have different characteristics from the current population of adults with an intellectual disability.

The 1996 Household Disability Survey estimated that there were approximately 11,300 children with an intellectual disability who are under the age of 15 and residing in households.\textsuperscript{68} By 2001 this figure had risen to 13,000.\textsuperscript{69} Data from the Ministry of Social Development shows that as at 1 May 2002, there were just over 2,900 children with an intellectual disability for whom a Child Disability Allowance was paid.\textsuperscript{70}

\textsuperscript{66} Data provided by the Ministry of Social Development.
\textsuperscript{67} Data provided by the Ministry of Social Development.
\textsuperscript{68} Statistics New Zealand 1998.
\textsuperscript{69} Statistics New Zealand 2002.
\textsuperscript{70} A Child Disability Allowance is paid to the parent or guardian of a seriously disabled child who lives at home and requires constant care and attention.
Definitions and demographics

Age
As has been noted, prevalence rates of intellectual disability among children are greater than for adults. Among children high levels of ‘mild’ intellectual disability are identified.

Prevalence rates are lower in preschool than school age groups reflecting the differing ages at which a child’s intellectual disability is identified. Some conditions, such as Down syndrome are picked up at birth. For others, it is only when a child does not reach his or her milestones that the possibility of an intellectual disability is considered.\footnote{Bray 2003b.}

Prevalence rates peak in the teen years. It is suggested that children who are identified at school as having an intellectual disability may not continue to be labelled in this way in their adult years. This may be because behavioural or learning problems identified at school are the result of factors other than an intellectual disability. Furthermore, a number of children who may have difficulty learning in a school setting are able to function without additional support in their adult years.\footnote{Bray 2003b.}

Gender
The New Zealand Household Disability Survey shows that the gender imbalance is greater among children than adults. Sixty-eight percent (over two-thirds) of children aged 0–14 years with an intellectual disability are boys.\footnote{Statistics New Zealand 2002.} Child Disability Allowance figures as at 1 May 2002 show a similar pattern, with 64 percent of children for whom gender was identified being boys.\footnote{Data provided by the Ministry of Social Development.}

Ethnicity
The ethnicity data on children with an intellectual disability is extremely limited. The results of the Household Disability Survey suggest that approximately one-quarter of these children identify as Māori, and approximately 63 percent are European or Pakeha.\footnote{Statistics New Zealand 2002.}

Location
Figures from the Ministry of Social Development show that children with an intellectual disability are more evenly spread across the country than adults whose distribution is influenced to some extent by the location of past and present institutions. This difference has implications in planning future services for adults with an intellectual disability.

Key issues

- There is a lack of adequate demographic information about adults and children with an intellectual disability.
- It is estimated that there are between 20,000 and 37,000 adults with an intellectual disability in New Zealand. Of these, at least 11,500 need regular support with daily activities.
- Ethnicity data on adults with an intellectual disability is very poor.
- There is little or no information on factors such as how many people with an intellectual disability can read and write or need assistance with mobility or communication.

\footnote{Bray 2003b.}
\footnote{Bray 2003b.}
\footnote{Statistics New Zealand 2002.}
\footnote{Data provided by the Ministry of Social Development.}
\footnote{Statistics New Zealand 2002.}
There is considerable regional difference in the distribution of adults with an intellectual disability, partly as a result of historic factors such as the location of past (and present) residential institutions. But children with an intellectual disability are more evenly spread across the country and this will have implications for service delivery in the future.
3. HISTORY OF SERVICE PROVISION

"None of us can hold our heads up high when we look back over history at how Māori and non-Māori with an intellectual disability have been treated historically."  

This chapter:
• provides a history of the provision of social and support services in New Zealand
• outlines changes in thinking about support for people with disabilities
• details the development of services for people with an intellectual disability
• identifies some of the changes that are needed to achieve community membership for adults with an intellectual disability.

Changing approaches to service provision

While much of the specific detail of service provision in New Zealand is unique, the changes in approach to service provision that have occurred in this country are consistent with international trends. These approaches can be divided into three stages.

1. Era of institutional services
   In the era of institutionalisation, dependence and segregation were the main approaches. The services that were provided were custodial and medical and their main objective was to segregate from society people who were seen as sick and vulnerable. The end of this era occurred with the shift to a developmental model, the concept of ‘normalisation’ and growing dissatisfaction with institutional care.

2. Era of deinstitutionalisation
   With the move to deinstitutionalisation people were no longer placed in institutions, but were supported at home or moved into group homes and worked in sheltered workshops. These homes and workshops were physically integrated into the community but continued to provide services in socially segregated settings.

3. Era of community membership
   The third and emerging stage is that of community membership. This approach emphasises developing functional supports to enhance inclusion and quality of life, encompassing both physical and social forms of integration.

The differences between these three approaches are summarised in Table 4.

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76 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
The historical overview provided in this chapter focuses particularly on the first two stages. In doing so, it provides a context for the findings from the NHC project. Two key themes emerge from this historical overview. Firstly, understandings of ‘disability’ and what it means have changed over time. There is now a greater expectation than in the past that people with disabilities will live ‘ordinary’ lives and a range of social changes have affected the concept of disability. These include changes in levels of education and wealth, and developments in medical science.

Secondly, both the public and voluntary (not-for-profit) sectors have played crucial roles in the provision of services for people with disabilities. The relationships that have developed over time between these sectors have been complex and in recent years have undergone significant changes.

The following sections provide a chronological history of the social provisions for people with an intellectual disability in New Zealand.

### Charitable aid (1840–1910)

In the early 1800s social services were provided by charitable organisations, rather than government agencies. These services focused on helping the poor, the sick and children. It

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77 Adapted from Bradley et al 1994.
History of service provision

was not until the 1840s that the New Zealand Government began to accept that it had a role in the provision of some social services, such as health\textsuperscript{78} and employment.

During the second half of the nineteenth century, the public sector became a major provider of welfare services – both directly and indirectly – through providing support to charitable organisations. In 1846 four government-funded hospitals were proposed and the Destitute Persons Act was passed. These two initiatives effectively established the respective roles of the government and voluntary organisations for the next 150 years. The voluntary sector decided on the services it would provide and government assisted with grants to support specific services. The 1875 Official Handbook of New Zealand noted that some hospitals and orphanages received a mix of provincial government subsidies and per capita grants. This was the origin of government grants to support voluntary sector activities.

In 1877 the Education Act introduced free education for children aged 7–13 years, but children with temporary or permanent infirmity were specifically excluded. The next significant piece of legislation was the Hospitals and Charitable Institutions Act 1885 which established Hospital and Charitable Aid Boards throughout New Zealand. These boards took on the role of dispensing charitable aid and were the forerunners of such government agencies as the Departments of Health and Social Welfare. The boards provided income support as well as hospital and asylum care, and were the agencies with which disabled people had the most contact, although most disabled people were cared for at home. In the late nineteenth century hospitals became more treatment-oriented and there were calls for ‘homes for incurables’ run by the public sector.

This period began to establish the central role of the state in funding and providing services for people with disabilities. At the same time lip service was also paid to the principle of voluntary charity. Voluntary aid was perceived as more ‘worthy’ than assistance provided directly by the government, which meant it was harder to obtain accountability from voluntary organisations.\textsuperscript{79}

Although disability services were used predominantly by Pakeha, there are some records of Māori using these services. For example, between 1870 and 1910, three to four percent of patients at the Auckland Lunatic Asylum were Māori.\textsuperscript{80} Other voluntary providers tended to misinterpret low use by Māori parents as reluctance to seek help for their children. Providers emphasised the need for Māori to better understand them, rather than understanding why Māori were reluctant to use their services.\textsuperscript{81}

Social security and institutional development (early 1900s to 1970)

During the first part of the twentieth century a range of legislation was introduced which related to services for people with disabilities and also established definitions about intellectual disability. The first such legislation was the 1907 Education Amendment Act, which introduced compulsory education for ‘defective or epileptic’ children aged 6–21 years.

\textsuperscript{78} The original purpose of hospital-based medical services was that they would be funded by voluntary subscriptions rather than the government having a role in providing these services.\textsuperscript{79} Tennant and Moore 1997.\textsuperscript{80} Tennant and Moore 1997.\textsuperscript{81} Tennant and Moore 1997.
In 1908 a special government school for ‘mentally retarded’ boys opened in Otago, with an equivalent school opening in Nelson in 1916.

In 1911 the Mental Defectives Act was passed, which defined ‘mentally defective children’ as “dullards, the feeble minded, imbeciles and idiots”. These definitions were to remain in place for over 50 years. In 1914 the new Education Act consolidated the previous provisions, established special classes for backward children, and instituted compulsory notification of all mentally defective children. Eligibility for special classes was determined largely by IQ tests.

The 1925 Committee of Inquiry on Mental Defectives and Sexual Offenders\(^82\) recommended the exclusion of children with a severe disability from special schools. Instead, a policy on Special Education was established with four grades of handicapped children: low-grade subnormal; high-grade subnormal; problem children and imbeciles. The prominence of eugenics in the early part of the twentieth century led to intellectual disability often being framed as evidence of ‘degeneracy’ and a threat to national efficiency. In keeping with this, a major theme in the 1925 Inquiry’s recommendations was the need to prevent the procreation of those seen as unfit.

Establishment of institutions
During this period, adults with an intellectual disability had the choice of living at home with no government support, or in one of the publicly funded psychiatric institutions. These were Seaview in Hokitika, Seacliffe near Dunedin, Tokaanui near Hamilton, and Kingseat in Auckland. Children with disabilities began to have more options in 1929 when the government opened Templeton Farm and School for people with disabilities, the country’s first psychopaedic hospital. This facility provided both residential care and a school. The Kimberley Centre in Levin, which took the same approach as Templeton, was opened several years later.

The depression of the late 1920s and the 1930s led to increased demand for Hospital Board charitable aid, put pressure on local income maintenance schemes, and provided the impetus for the development of the modern New Zealand welfare state. The first form of direct publicly funded income support to people with disabilities was a pension for blindness which was introduced in 1924. In 1936 the Invalid’s Pension was introduced, acknowledging government’s responsibility to support people unable to work due to illness or disability. This was followed by the 1938 Social Security Act, which included the provision of services for the maintenance and medical needs of people with disabilities.

By this time many people with an intellectual disability were housed in public psychiatric or psychopaedic institutions. These large institutions cared for more than 3,000 people nationwide.\(^83\) Most were built in the country, away from other residential or commercial activity, and operated as self-sufficiently as possible. Once a person with a disability entered an institution it became their ‘world’, with all activities taking place inside its boundaries. For instance, one dormitory at Templeton housed 106 people, who shared clothes and were required to work on the farm or around the institution regardless of their age.

\(^82\) Note the linking of intellectual disability and sexual offending in this legislation.  
\(^83\) Numbers at Templeton peaked at 1200 residents in the late 1970s.
History of service provision

Significant numbers of people in these institutions were admitted as young children, who subsequently lost all contact with their families. Throughout the 1950s and 60s, parents were encouraged to place children with disabilities in psychopaedic institutions, and to leave them there. Many anecdotal reports describe parents being told that it disturbed children when their parents came and went, and they must accept that their children were in the best possible location and getting the best possible care. This enforced isolation has created a legacy of lost histories for many older adults with an intellectual disability. The impact of lost histories and isolation from whānau, hapū and iwi is discussed in more detail in Chapter 14: Whakaritenga mahi mö te hunga pakeke Māori kua hauā-ā-hinengaro.

Development of independent providers

Despite this considerable social pressure to place people with an intellectual disability in institutions and lack of assistance for families who chose to keep their children with an intellectual disability at home, a number of parents chose this second option. In 1949 the Intellectually Handicapped Children’s Parents Association (IHCPA) which later became IHC was begun by a group of Wellington parents wanting an educational facility for children with disabilities who were not receiving any support from publicly provided services. By 1957 the IHCPA had seven centres nationally catering for 244 pupils, and by the end of the 1960s this had grown to 15 Children’s Day Care Centres and 11 Occupation Groups.84 In the mid 1950s IHC also began to provide residential homes – initially to enable rural children to go to town for schooling and provide respite care for families.

In 1956 Hopeha Homes was formed with the purpose of establishing home schools for the curative education and social therapy of children, young persons and adults with an intellectual disability. The residential services established by the trust were based on the principles of Rudolf Steiner. Both of these independent providers are still operating today.

Changing approaches to work

During the 1950s and 60s ‘special’ work settings for adults with an intellectual disability proliferated. Sheltered workshops became the most common ‘work’ in which adults with an intellectual disability were involved. The provisions in the Disabled Persons Employment Promotion (DPEP) Act 1960 excluded these workshops from having to meet labour legislation covering pay and other conditions.

Disability services for Māori

Prior to World War II, use of disability services by Māori remained minimal, and at times Māori were actively discouraged from using such services.85 Another barrier was the fact that using disability services meant separation from whānau and other supports. In addition, the increasing medicalisation of disability support services meant that physical dimensions of ill health were emphasised – a position at odds with traditional Māori concepts of wellbeing.

It is thought that until urbanisation in the latter half of the twentieth century brought Māori into closer contact with specialised disability agencies, the majority of Māori with disabilities lived with their own whānau. Several voluntary health initiatives emerged from within Māori

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84 It is of interest to note that it was not until 1992 that IHC had completely passed over to the State the responsibility for meeting the pre-school and school needs of children 0–19 years of age.

85 For instance, before hospital benefits were brought in under the Social Security Act 1938, hospital boards often claimed that Māori did not pay the fees, and should therefore not be eligible for treatment.
communities during the twentieth century, many of them initiated by women. While these services were not specifically concerned with assisting people with a disability, they had important implications for both the incidence of disability amongst Māori, and Māori access to health services.

The shift towards community-based services (1970s and 80s)

By the late 1960s changing ideas about people with disabilities had led to the development of ‘normalisation’ as a guiding principle for the provision of services to people with an intellectual disability. This approach changed opinions about placing children in institutions and in turn led to more people with disabilities living in the community, either at home with their families or in smaller residential facilities, rather than in the large institutions of earlier decades.

The focus on ‘normalisation’ coincided with major changes to social services in New Zealand. In December 1969 the Government established the first Royal Commission of Inquiry into Social Security, and the Commission’s report led to significant changes to social security benefits and the establishment of the Department of Social Welfare (DSW) in 1971. A Royal Commission into Psychopaedic Hospitals was also held in 1972. As a result, some public funding was diverted from expanding long-stay psychopaedic hospitals to providing community beds for people with an intellectual disability who were either in institutions or on their waiting lists.

The major changes during the 1970s and 80s included:

- the surfacing of a parent ‘voice’ through provider organisations
- the expansion and increased complexity of the not-for-profit service provision sector
- a large increase in public sector funding of voluntary organisations
- a growing significance of private sector provision
- acceptance of the need for Māori perspectives within disability organisations, as well as multicultural perspectives.

New legislative provisions

The Industrial Relations Act 1973 established the Under-Rate Workers Permit. This enabled a person with a disability to work in the open labour market and receive a wage commensurate with their productivity (where their productivity was assessed as below what would be expected for the market rate for the job). This was a significant move in that it blurred the line between ‘sheltered’ work and the open labour market for people with disabilities. ‘Sheltered work’ and other forms of employment assistance are discussed in Chapter 8: Work (paid and unpaid).

Legislation concerning people with disabilities was further reformed in 1974, with the passage of the Accident Compensation Act. This separated the funding and provision of services for people disabled as the result of an accident from those for people whose disabilities had other origins.

86 Tennant and Moore 1997.
87 Tennant and Moore 1997.
88 The new department began its operations in 1972.
89 Tennant and Moore 1997.
History of service provision

In 1975, the Disabled Persons’ Community Welfare (DPCW) Act provided people with disabilities (who were not ACC claimants) with legislative entitlement to funding for a number of specific services. These included respite and attendant care, travel and equipment costs, and grants for home alterations. Funding for these services was demand-driven and eligibility for a service was set out in legislation. This meant that if a person met the entitlement criteria then they received the service, but if they did not they received no assistance. Despite this limitation, entitlement to specific services was regarded as a significant breakthrough in government assistance to families and people with disabilities living outside institutions. These provisions remained in place for the next 20 years.

Growth in community-based services

Within this context of significant social and legislative change, there were also changes in the funding and provision of community-based services for people with disabilities. Throughout the 1970s there had been significant government emphasis on increasing the provision of community services for people with disabilities and their caregivers. This was reflected in further public funds being granted in the mid 1970s, under the Community Care Scheme, to build residential facilities. These were commonly ‘mini’ institutions or clusters of units on a single site, and marked the beginning of what would later become a major expansion of community-based residential disability services. It also had a significant impact on the numbers of people with disabilities accessing community-based services in the 1980s.

During this period, however, disability services were still seen as primarily a public sector responsibility, with minor supplementary assistance by voluntary and private organisations. Although this era saw significant growth in the numbers of service providers, the Government’s stated goal of developing services remained focused on a few main providers.

At this time IHC was the major provider, in both actual size and the amount of government funding it received, and experienced further rapid funding growth throughout the 1980s. During the 10-year period from 1977 to 1988, IHC grew from 33 branches, spending $6m on 4,000 clients annually, to five regions covering 50 branches, spending $66m on 7,000 clients. An increasing focus on residential provision and additional services such as sheltered workshops accounted for much of the increase in funding levels.

This increased funding could not, however, match rapid growth in service provision, and by the early 1990s IHC’s financial position had become so dire that the Government agreed to act as guarantor and pay the interest on a $10m bank loan to the organisation. The Government’s willingness to do so highlights both IHC’s importance as a provider of services and IHC’s reliance on public subsidies.

The symbiotic relationship between central government and IHC is in many ways a classic example of the mode of interaction between government and voluntary agencies that had existed since the beginning of the twentieth century. Under this arrangement, voluntary sector organisations decided on the services they would provide, and government assisted

90 Tennant and Moore 1997.
91 It has also been observed that the increased subsidisation by government occurred in an ad hoc way, with large organisations benefiting the most (Tennant and Moore 1997).
92 Salary subsidy figures show the number of residential staff doubled between 1986 and 1988, and vocational staff increased by 50 percent.
History of service provision

them with grants. By deciding on the types and levels of service they would provide, providers tended to drive government policy on disability services. For example, decisions about the services provided by IHC were driven by the philosophy of its membership, which at that time was mainly parents of people with an intellectual disability, as well as by the needs of the people who used its services. Over time these services moved from residential services for children to attend special schools, to sheltered workshop services for those children when they became adults. However this ‘provider-driven’ policy development was about to change.

A decade of change (late 1980s and 1990s)

The late 1980s and early 1990s in New Zealand were a time of significant and widespread public sector reform and reorganisation.

Under the Public Finance Act 1989 and the State Sector Act 1988, chief executives of government departments were contracted for specific outputs as part of their performance agreements. This focus on outputs was mirrored in a dramatic shift in the Government’s approach to funding social services. A contract-based funding model was used to create a split between the providers and funders of social services, with the aim of promoting improved accountability, more competition among service providers, and more choice of services for clients. This, it was argued, would result in more efficient organisations providing more effective services.

The Department of Social Welfare was restructured into separate business units, including the Income Support Service: the Children, Young Persons and their Families Service; the Community Funding Agency; and the Social Policy Agency. These new units came into existence on 1 July 1992.

In the health sector, from 1 July 1993, the Department of Health and Area Health Boards were reconfigured into a central Ministry of Health managing purchase agreements with four Regional Health Authorities (RHAs). The RHAs in turn purchased services from a range of providers.

Contracting for clearly defined outputs was a major and controversial change from the previous policy of providing 75 percent salary subsidies to service providers in the voluntary sector. It represented a fundamental ideological move from the partnership model between government and voluntary agencies that had existed virtually unchanged since the beginning of the twentieth century. Approval standards were introduced for all organisations contracting with government, not just those that provided residential care. Once an organisation had proved that it met the standards, a contract was negotiated and signed for the provision of specified types and amounts of service, and measures were put in place for contractors to report against.

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93 This agency was later called Work and Income New Zealand. It is now known as Work and Income and is part of the Ministry of Social Development.

94 The Regional Health Authorities, established in 1993, have subsequently been restructured a number of times, becoming one Health Funding Authority and now devolving back into District Health Boards.
History of service provision

Many providers and others involved in supporting people with disabilities were strongly opposed to these changes. In addition to the stresses involved in shifting to a new philosophy and funding model, many argued that the new approach was not an effective method of funding social services. Firstly, the accountability requirement to collect and pass significant amounts of information to the contracting agency resulted in providers incurring significant administration costs. Secondly, contracts with the Community Funding Agency only provided a percentage of the cost of providing the service, even though organisations were required to provide, and be evaluated on, the total service. This situation, combined with the need for not-for-profit organisations to have a range of contracts with different agencies in order to continue to provide their previous range of services, created many difficulties for providers. These included significant time spent on securing contracts and lack of certainty about future funding.

In addition, the restructuring of the public sector had a number of important implications for people trying to access disability services. Even within DSW, people no longer received services from one agency. Individual payments and reimbursements were the responsibility of the Income Support Service, while the Community Funding Agency purchased service provision from the not-for-profit sector. Policy relating to services and service provision was developed in the Social Policy Agency.

This approach to social services has been subject to significant criticism – particularly the lack of an overall funding philosophy during this period, and an apparent reliance on ad hoc and uncoordinated decision-making.\(^{95}\) The main focus of accountability was financial, and broader evaluation of the value and performance of providers and programmes was given little, if any, priority.

**Legislative change**

Against this backdrop of significant change in how government agencies were structured, funded and their performance measured, several pieces of legislation with significance for people with disabilities were passed during the late 1980s and early 1990s. These were based around the ‘normalisation’ principle and furthered existing moves for people with disabilities to live in the community. In 1987 an amendment to the Education Act was passed mainstreaming children with disabilities into the ‘normal’ school environment. This enabled parents to choose whether children with disabilities would be educated in ‘special’ schools, or with their peers in mainstream schools. 1987 also saw concessional interest rates announced for housing loans for people with special needs, and in 1988 the Protection of Personal Property Act provided a legal framework for the protection and assistance of people with disabilities. The other piece of relevant legislation was the Children, Young Persons and their Families Act 1989. This Act includes provisions for children and young people who are severely disabled to be placed in approved care or residential care.\(^{96}\)

A review of the Disabled Persons Employment Promotion Act 1960\(^ {97}\) also began in the late 1980s. This review was driven by concern about the working conditions for people in sheltered employment, including the lack of industrial relations protection and poor health and safety standards in some workshops. Concern was also mounting over the perceived

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\(^{95}\) Tennant and Moore 1997.

\(^{96}\) See sections 141 and 142.

\(^{97}\) See Chapter 8: Work (paid and unpaid) for more information about the Disabled Persons Employment Promotion Act 1960.
narrow focus of sheltered employment, with pressure building for the development of a range of employment options including assisted and open employment.

Health/welfare interface – “A New Deal”
In 1992, the Government announced “Support for Independence for People with Disabilities – A New Deal”. Building on the concept of a health/welfare interface, this policy proposed that responsibility for all public services for people with disabilities should be amalgamated into a single agency. The underlying rationale for this transfer was that people with disabilities frequently had to access more than one agency. This created a number of problems, the greatest of which was the potential for people to ‘fall between the gaps’ between publicly provided services.

Following public consultation, it was announced that services for people with disabilities, or Disability Support Services (DSS), would be the responsibility of the four RHAs. With the exception of vocational services, all welfare programmes that funded disability support services (including all residential care funding and funding provided under the DPCW Act) were transferred from the Department of Social Welfare to the health sector between 1993 and 1995. A decision on the possible transfer of vocational services for people with disabilities was intended to be the subject of further reviews.

The previous legislative entitlement to specific services (for instance under the DPCW Act) was replaced by general requirements in the Health and Disability Services Act 1993 for health agencies to promote the independence of people with disabilities and to provide disability services. This was seen as adopting a more holistic view of the needs of people with disabilities. In line with this new approach, a person’s need for services was to be determined by a ‘needs assessment’, followed by a service coordination process that would assist the person in accessing the range of services they required to meet their assessed needs. It was intended that this process would enable integrated planning of services for each individual, to meet their particular needs.

Closing institutions
In 1988 a contract was signed between IHC and the Auckland Hospital Board to move 61 people out of Kingseat Hospital into the community. This action was initiated by IHC and supported the policy of reassessing the position of people with an intellectual disability in psychiatric hospitals. It is considered to be the first formal deinstitutionalisation project in New Zealand.

Deinstitutionalisation continued under the management of the RHAs, with more than 10,000 people moving out of institutions into the community over the period 1990–1999. In 1996 the progressive closure of the Templeton and Porirua facilities was announced, and by 1997 Mangere, Kingseat and Cherry Farm were closed, and very few people were left in Porirua Hospital. By this point, people had also moved out of Tokaanui into the community. By 1998 only 1,500 people were still in institutions, and in 1999 all Templeton residents, other than 80 remaining in long-term care, moved into the community. In 2002, planning began for moving residents out of Kimberley, the last remaining psychopaedic institution in New Zealand.

History of service provision

Many of the people who moved out of psychopaedic institutions had high-level needs. At much the same time, there were many young people with disabilities who have never been institutionalised leaving mainstream schools and looking for services to meet their adult needs. This situation placed significant strain on service providers. Some providers entered into agreements with the RHAs and developed services to meet the needs of people moving out of institutions. New providers emerged to support particular groups of people or offer the services that government agencies wished to purchase. In some cases, the RHAs and other government agencies actively recruited new providers to create competition and consumer choice in line with the philosophy underpinning the structural reforms. However, there was very little money available to develop new services.

Increased visibility and debate
This period also saw disability providers become increasingly active in voicing and debating issues relevant to people with disabilities and lobbying for change. At the same time people with an intellectual disability were becoming increasingly vocal about the types of services they needed and wanted.

This increased visibility and activity among service providers stemmed not only from philosophical differences about the types of service to be provided, but also from frustration at differences in approach between the four RHAs, constant government reviews of services for people with a disability, and increasingly stretched and pressurised conditions facing service providers.

Māori service provision
A key element of the 1992 “A New Deal” was the desire for disability support services to be sensitive to the needs and preferences of Māori. Throughout the 1980s there was increasing recognition that Māori should have greater input into, and control over, services affecting their own wellbeing. The 1995 He Anga Whakamana report, prepared for the NHC, concluded that mainstream services alone would not adequately meet Māori needs. This conclusion was paralleled by the emergence during the 1990s of social and health services run ‘by Māori, for Māori’. Reductions in the role of the state in providing services, and the move to a greater range of contracted services, offered new opportunities and greater independence of action for Māori service providers during this period. Services designed specifically for Māori faced a complex array of accountability demands, with accountability to whānau and iwi sometimes coming into conflict with accountability to government bureaucracies.

Effects of changes
The late 1980s and 1990s witnessed a fundamental change to almost every aspect of disability policy, funding methods and service provision. This, in turn, resulted in a significant amount of stress being placed on both government agencies and providers.

Changes to government departments led to what the disability sector described as ‘silo’ policy development, with the Ministries of Health, Education, and Social Policy and the

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99 For example, Gracelands and the Waikato Community Living Trust were set up to provide services for people moving out of Tokaanui Hospital.
100 Ratima et al 1995.
101 Tennant and Moore 1997.
102 Tennant and Moore 1997.
Department of Labour all having responsibility for aspects of disability policy. The absence of an overall strategic framework for disability policy and services was seen by many as contributing to the lack of coherence and leadership in disability policy and the reason why focus was not given to the emerging social model of disability.

The fundamental shifts in the funding, provision, and policy surrounding disability services created an equal amount of change for disability service providers. The move to contracting for specific services and outcomes forced voluntary agencies to define and examine their services and cost structures. In response to this, most of the major disability organisations underwent significant restructuring of their own. Collective concern on the part of providers regarding the fragmentation of policy and lack of an overall strategic framework for the provision of disability services resulted in increased collaboration, leading to the formation of umbrella groups for different types of service providers and a more cohesive approach to lobbying.103

The New Zealand Disability Strategy (2000–03)

Until 1999, there was no Minister or government agency in New Zealand with overarching responsibility for disability issues. The ‘silo’ approach to policy development and service provision led to disabled people and their families experiencing gaps between services, duplication of assessment procedures and confusion about who was responsible for what support or service.

In December 1999, the portfolio of Minister for Disability Issues was established with overarching responsibility for disability issues. Shortly after this, the New Zealand Public Health and Disability Act 2000 came into effect. This legislation included the requirement for a New Zealand disability strategy to “provide the framework for the Government’s overall direction of the disability sector in improving disability support services”.104 The first strategy was developed during 2000 and 2001 and consulted on widely in the disability sector.105 More than 700 submissions were received and 68 meetings were held around the country. Many people with an intellectual disability, their families and service providers made submissions. The New Zealand Disability Strategy (NZDS) was released in April 2001.

The NZDS is a rights-based framework based on the social model of disability. It states that while people may have physical, sensory, neurological, psychiatric, intellectual or other impairments, they are only ‘disabled’ by the fact that society is not designed with their needs in mind. In other words, society is built in a way that assumes that everyone can see signs, read directions, understand instructions and have stable moods, when the reality is that many people with impairments may not be able to do some of these things. This creates barriers for people with impairments, which can exclude them.

103 The chief executives of the major disability organisations now meet on a regular basis to discuss common concerns and develop pragmatic solutions.
104 This requirement is outlined in Part 2, section 8 of the Act.
105 The Minister is required (under the New Zealand Public Health and Disability Act) to consult before determining or amending the strategy, to make copies of it publicly available and present it to Parliament, and to report each year on progress in implementing the strategy.
History of service provision

In the past, intellectual disability was seen as an unvarying state determined by deficits in intellectual and adaptive behaviour, usually measured by comparison with accepted norms of society. Under the social model of disability, it is seen as a function of the interaction between an individual and his or her environment. This approach emphasises the individual character of the person and the potential to reduce some of the challenges they face, by providing support or making environmental adaptations.

The NZDS presents a long-term plan for changing New Zealand from a disabling into an inclusive society that highly values the lives of disabled people and enhances their full participation. It sets out the values that must underpin all government actions. It also identifies 15 objectives, each with a detailed list of actions. Each government department is required to have an annual implementation plan which sets out what it is doing to implement these objectives and actions, and to report to the Government annually on its progress.106

Office for Disability Issues

In July 2002, the Office for Disability Issues was established within the Ministry of Social Development to:

• provide disability policy advice, by leading strategic whole-of-government disability policy development and by contributing a disability perspective to policy developed in other areas of government
• lead the NZDS, through promotion and monitoring its implementation
• support the Minister for Disability Issues in her advocacy role, by providing ministerial administration services and by strong relationships with disabled people and their communities.

Looking towards the future

Before the reforms of the 1990s, the public and voluntary sectors worked within a model of partnership. The introduction of a new state sector relationship with government, an increase in accountability and the use of contracting for service provision, altered this relationship and generated tensions between purchasers, providers and consumers of disability support services. The increased specificity of service provision also highlighted many gaps in services and support for disabled people.

With the advent of the NZDS framework and a strong push towards developing a cohesive whole-of-government approach, it is hoped that the journey from the era of institutionalisation through deinstitutionalisation will now move to the era of community membership for all disabled people, including all people with an intellectual disability.

It has become increasingly accepted that people with disabilities are a diverse group, with differing perspectives. In particular, recognition of cultural identities is beginning to be reflected through more responsive service provision, for example, the growing number of Māori service providers. The NZDS clearly states that services must support people to have valued and participative lives, with long-term support centred around each individual, and that disabled people themselves should play a much greater role in service provision and policy development.

106 For more about the New Zealand Disability Strategy and to view recent implementation plans, see www.odi.govt.nz.
To achieve community membership (see Table 4), new thinking is needed about how to provide assistance to people with an intellectual disability. Support services need to be based on the concepts of individual planning, personal preference, choice, and building appropriate support networks. This approach places the preferences of disabled people at the centre of decisions about where they live, work, or seek recreation, and for this reason it is vital to actively seek and understand their perspectives. This requires a profound change in the relationships between the people who use services and those who provide those services. It entails a shift away from a system that provides services toward a system of supports that incorporate the concept of ‘being of service’.

"Today bringing about reform is ... complicated by the emergence of new interests and the depth of change being contemplated. The new interests include people with disabilities themselves who are organising as self-advocates. They also include local citizens, schools, generic social services and civic organisations whose participation will be needed to ensure that people with disabilities become supported and welcomed members of their communities. Furthermore, the change from a system based on services to one based on supports requires a profound shift from a professional provider dominated system to one that is driven by the choices and preferences of people with disabilities. The complexity of the task at hand is apparent."  

4. ACCOMMODATION

“At their house they are the boss and when they come to our house they still think they are the boss, but I said ‘this is our house and you guys should be doing what we want to do’.”108

This chapter:
• describes where adults with an intellectual disability live and who they live with
• explores the impact that accommodation arrangements have on the lives of adults with an intellectual disability
• identifies housing issues that need to be addressed to achieve community membership for adults with an intellectual disability.

Role of housing in community membership

Housing is fundamental to wellbeing. Suitable housing provides a stable base from which good health, positive relationships, successful education, sustained employment and appropriate community participation can develop. This is true for all people, including adults with an intellectual disability. To achieve the goal of promoting the independence and improving the quality of life of adults with an intellectual disability, the development of a range of housing options is of critical importance.

Where adults with an intellectual disability lived in the past

In the past, many adults with an intellectual disability lived a segregated life, apart from mainstream society. This history and the subsequent changes are detailed in Chapter 3: History of service provision. IHC established the first community-based services, and over time developed community-located residential services. As the children who had lived at home or in these more community-oriented residential services grew up, the demand for non-institutional forms of housing increased.

Pressure for deinstitutionalisation developed slowly throughout the 1970s and 1980s. In 1988, after considerable lobbying by families and IHC, a contract was signed to move people out of Kingsseat Hospital. This marked the formal beginning of an active deinsitutionalisation process.

108 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Where adults with an intellectual disability live today

Data from Work and Income, part of the Ministry of Social Development (MSD), indicate that of the approximately 11,100 people between the ages of 16–65 years who receive an Invalids or Sickness Benefit because of an intellectual disability, around 37 percent have their accommodation purchased as part of their care package. There is considerable regional variation in the percentage of adults with an intellectual disability living in ‘purchased accommodation’. Most of this accommodation provides segregated group living with other people who have an intellectual disability. Table 5 shows the percentage of adults in each DHB region who have their accommodation purchased as part of their care package.

### Table 5: Percentage of adults with an intellectual disability in each DHB region who have their accommodation purchased as part of their care package

<table>
<thead>
<tr>
<th>DHB region</th>
<th>Percentage of adults with an intellectual disability in ‘purchased accommodation’</th>
</tr>
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<tbody>
<tr>
<td>Auckland</td>
<td>39.51</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>33.69</td>
</tr>
<tr>
<td>Canterbury</td>
<td>46.41</td>
</tr>
<tr>
<td>Capital and Coast</td>
<td>36.09</td>
</tr>
<tr>
<td>Counties-Manukau</td>
<td>42.60</td>
</tr>
<tr>
<td>Hawkes Bay</td>
<td>40.72</td>
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<tr>
<td>Hutt</td>
<td>35.78</td>
</tr>
<tr>
<td>Lakes</td>
<td>31.14</td>
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<tr>
<td>Mid Central</td>
<td>18.46</td>
</tr>
<tr>
<td>Nelson-Marlborough</td>
<td>24.55</td>
</tr>
<tr>
<td>Northland</td>
<td>36.95</td>
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<tr>
<td>Otago</td>
<td>32.27</td>
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<td>South Canterbury</td>
<td>34.54</td>
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<tr>
<td>Southland</td>
<td>35.84</td>
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<td>40.00</td>
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<td>Wairarapa</td>
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<tr>
<td>Waitakere</td>
<td>45.29</td>
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<tr>
<td>West Coast</td>
<td>26.74</td>
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<tr>
<td>Wanganui</td>
<td>34.75</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>36.81</strong></td>
</tr>
</tbody>
</table>

The majority of those living in private households (91%) and residential facilities (75%) are aged under 65 years. This partly reflects the shorter life expectancy for people with some types of intellectual disability, although life expectancy is increasing. Currently about 400 people with an intellectual disability, aged over 65, live in long-stay residential care for older adults.

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109 Data as at 31 May 2002. Provided by Ministry of Social Development.
111 Changes in life expectancy are discussed in Chapter 5: Health.
Accommodation

people. The proportion of older adults with an intellectual disability in aged care is lower than for the general population.

The type of accommodation in which adults with an intellectual disability live has a greater impact on their lives than it does for other adults. This is because adults with an intellectual disability tend to be dependent on others for their housing, and also their access to support services usually depends on where they live. Dependence on others for housing means that adults with an intellectual disability have less choice about how they live and what they do than other adults.

‘Purchased accommodation’

There are a variety of types of accommodation purchased by government as part of the care package for adults with an intellectual disability. These are:

- institutions or wards in hospitals
- smaller specialist residential facilities (where more than 10 people live together with staff)
- cluster housing (where a number of smaller houses are grouped together to form a community)
- group homes (where between five and ten people with an intellectual disability live in a house with assistance from a contracted service provider).

It is usual for people living in these types of accommodation to have their Invalids or Sickness Benefit paid direct to the provider to pay for their accommodation and living costs. As well the provider receives government funding to provide support services. In some cases, the resident pays the service provider for accommodation and living expenses, which better reflects the housing arrangements of other New Zealanders.

Throughout this document the terms ‘residential care’ and ‘purchased accommodation’ are used to collectively refer to accommodation that is purchased by government as part of a person’s support package.

Institutions

As a result of deinstitutionalisation the number of adults with an intellectual disability living in institutions in New Zealand has declined in recent years. In August 2002 there were still 369 people living in Kimberley and 75 in a ward in Braemar Hospital in Nelson. Kimberley and Braemar are in the process of being closed. Adults with an intellectual disability living in larger institutions or hospitals have tended to have all their services provided on-site, and often have not had access to community-based services, such as vocational services.

Residential facilities

At present there are 24 residential facilities with more than 10 beds that provide housing and support services for adults with an intellectual disability. Of these 12 provide

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112 Data provided by the Ministry of Health 2002.
113 In the total population of people aged 65 and over, approximately four percent live in residential care (source: Ministry of Health). For adults with an intellectual disability aged 65 and over, the figure is two percent (calculated from data from Ministry of Health and Statistics New Zealand).
114 Data provided by the Ministry of Health 2002.
accommodation and services to people who have other types of disability as well as those with an intellectual disability. 115

Cluster housing
Cluster housing is a new development to house adults with an intellectual disability within the community and provide access to support services, through locating several houses within the same area. Rescare was the first cluster housing initiative to be set up in New Zealand following the closure of Mangere Hospital. In Christchurch Brackenridge was built to provide for the needs of adults with an intellectual disability who were moved out of Templeton Hospital.

Group Homes

| “I live in a house with four residents or clients which are not quite my age. I hope to get out of there and live with people my own age.” |
| “I really like where I am and really enjoy it. I like people coming in and helping us out cooking and doing all sorts of things. We do our own rooms – clean it, dust it, vacuum it. In the morning we have our breakfast at about 7am.” |
| “I can’t move because she (the co-ordinator) wants us to stay in the same house. She’s the boss of our house. I can’t stay by myself because I’m not allowed. Some of the things staff say are sad.” |

Group homes were developed in the 1980s as an alternative to segregated large institutions. They offer accommodation and support services. The number of adults accommodated on one site is smaller than in residential facilities and the house is usually located in a community setting. People living in these homes may have all their support services provided on-site or go out to community services. Currently there are 246 group homes with between six and 10 beds and 316 homes with five beds.

Private housing
There is little information about the physical nature of the housing of adults with an intellectual disability who live in households. It is assumed that they live in the same range of housing as the rest of the New Zealand population.

The majority of adults with an intellectual disability, who live in private housing, live there with family/whanau members. In many cases they have remained in the family home with their parents, while their siblings have grown up and moved out to live independently. In discussions with parents, many raised concerns that their adult children were unable to leave home and move into appropriate accommodation, as they had been advised that alternative accommodation was only available if things at home reached a crisis point.

It takes strong advocacy from family to develop other housing options, such as renting or owning a home. Most adults with an intellectual disability do not have the financial resources to purchase a home. The upfront costs of taking on a tenancy (bond, rent in advance) can be a financial barrier to renting accommodation. In addition, if adults with disabilities and their families pursue independent housing, they also have to find a way to put together a package of support. The Housing New Zealand Corporation does have some rental

115 Data provided by the Ministry of Health - figures taken from database of Residential Care facilities as at July 2001.
116 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Accommodation

houses designed for people with disabilities. These tend to be for people with physical or sensory disabilities or rented to organisations running a group home. In addition, demand for these properties outstrips supply.

Some families have got together and established private trusts to buy and staff houses for their adult family member with an intellectual disability to live in. Families who have managed to successfully establish such homes appreciate the opportunity to have control over where the houses are, and the standard and level of support provided. During the National Health Committee project, a few parents talked about how they had moved out of the family home into alternative accommodation, so that their adult offspring with an intellectual disability could continue to live in the family home with purchased support. There is no data available to indicate how many adults with an intellectual disability are housed through family initiatives, however, the significant cost associated with these options suggests that the number will be very small.

Contract board

‘Des’ was living in an IHC flat. After the flat was burgled he did not want to stay there. A former IHC employee who had known Des for many years offered him board which Des says is “great”.

Contract board is a housing option provided by IHC. Families in the community are contracted to provide ‘bed and board’ and a degree of companionship and support for an adult with an intellectual disability. The payment provided to the family covers board costs and some recognition of the informal support and care given by the family. Before a contract board arrangement is set up, IHC checks the appropriateness of the home. It also provides access to support services, such as vocational services, and assists the family with any issues relating to having an adult with an intellectual disability in their home. This form of housing operated informally for many years before IHC adopted it as a formal service.

In the past, contract board occurred because a staff member or other contact of an adult with an intellectual disability befriended a person and offered them board. It has been particularly successful in assisting adults with an intellectual disability who have become unhappy in their residential care or group home to find suitable alternative housing. Currently around 150 adults with an intellectual disability live in a contract board situation.

Supported living

“A person comes to help with the cooking. I lux my own flat and that sort of thing. My support worker takes me out shopping.”

“We have a lady that comes round and helps with cooking and budgeting – all sorts of things – helping buy clothes, going on holiday. If we have a problem she will sort it out.”

Supported living describes a range of accommodation options where adults with an intellectual disability are supported to live in the environment they choose. Adults with an intellectual disability are assisted to locate suitable housing, and then provided with support to help them to live there. This could involve living with other adults (who may or may not

117 Weaver 1999.
118 Scenario developed from information provided by IHC.
119 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Accommodation

have an intellectual disability), on their own or with family/whānau members. In supported living arrangements the adult with an intellectual disability receives support tailored to their needs and living situation. This may include a mix of paid support, such as government-funded services, and voluntary or community assistance. For instance, a flatmate might pay reduced rent in exchange for assisting with housework and cooking. Where possible, supported living encourages adults with an intellectual disability to be a lease-holding tenant or homeowner, rather than an organisation having these functions.

The philosophy of supported living is that living arrangements are flexible enough to respond to the changing needs and preferences of the adult with an intellectual disability. Another key component is actively supporting relationships and natural networks with family, friends and the community. In setting up supported living arrangements safeguards are put in place to ensure that the adult with an intellectual disability is not placed at risk. There is growing interest within New Zealand about supported living options, but no data is available on how many adults are living in these types of arrangements.

Who adults with an intellectual disability live with

Adults with an intellectual disability are most likely to live with their family/whānau (often continuing to live at home with their parents), or with other adults with an intellectual disability in ‘purchased accommodation’. A small number of adults with an intellectual disability live with non-relatives (for instance contract board), flatmates, or a partner and/or children.

Living with other adults with an intellectual disability and support staff

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

“Having someone who you get along with is more important than doing the job. It’s important to have someone who understands me and talks to me like any other person.”

“It’s awful. They don’t talk and they are just watching the clock all the time…. I feel they don’t like me because they don’t answer me when I talk to them.”

“Always short-staffed. I don’t get my days how I want it, because the organisation needs her for something else. It’s not fair on me.”

In ‘purchased accommodation’ people live with other adults with an intellectual disability and paid support staff are often present 24 hours a day. In the majority of ‘purchased accommodation’ settings, adults with an intellectual disability have little or no choice over who they live with, as the service provider decides who lives in the facility. It was very clear during the National Health Committee focus groups that it is not uncommon for people to be moved between facilities, such as group homes, with no consultation and little notice, because of economic and other constraints facing service providers.

Adults in residential facilities live within a routine established by the provider of the accommodation. This routine includes the normal range of daily activities (domestic tasks,

120 MacArthur 2003.
121 MacArthur 2003.
122 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Accommodation

social outings, employment, education), however the range of activities and the degree of choice is significantly determined by the facility.

Historically, residents of large institutions were not treated as individuals but as a group. This sometimes extended to not having their own personal items, for instance clothing being a communal rather than individual item. Over time, large institutions have moved to provide a more individually oriented service and allow more personal freedom within the daily routine of the facility. Large institutions, however, by their very nature, find it difficult to provide a significant level of choice as they are meeting the daily needs of a large number of people and tend to have a more regimented system of care.

Group homes aim to provide a more home-like environment and consequently a greater degree of flexibility and choice for those who live there. Residents of group homes have their own bedrooms and personal belongings. The extent to which individual preference and lifestyle can be catered for depends on the size of the home, the philosophy and practice of the service provider and the attitude of staff. Larger homes tend to be more institutional in structure. Some providers, often for financial reasons, have to operate their homes in a fairly regimented way. In these situations, residents may have little choice over daily activities and may only be able to access services or activities provided by that facility.

Staff attitudes have been shown to play a critical part in determining the lifestyle of adults with an intellectual disability in residential facilities or group homes. Where staff are well trained, well supported and have an understanding of the individual needs and rights of the adults they work with, the adults can have a positive lifestyle. Due to low pay rates and the often challenging nature of the work, turnover of staff in residential facilities and group homes can be high. This adds to the underlying feeling that a facility is an ‘institution’ rather than a ‘home’ and that the adult with an intellectual disability is a ‘job’ or a ‘patient’.

Living with family/whānau

“I live with my parents. Mum does all my cooking for me but I help out. We share the housework.”

Living with family/whānau can be a positive experience, but providing ongoing support can place significant stress on the household, especially as the family caregivers grow older. Furthermore, continuing to live at home with their family can limit an adult’s independence and participation in community activities, particularly if their parents continue to treat them as a child rather than an adult.

While adults with an intellectual disability living with family/whānau may have some say in their daily lifestyle, they are more likely than siblings who are living independently to have to fit in with family routines and lifestyle, irrespective of their own life stage needs or personal aspirations.

Living with family/whānau does not necessarily mean that adults with an intellectual disability participate in all household and family activities. Factors such as their level of impairment; the needs and socioeconomic situation of their family; and attitudes about what is appropriate for them to do will affect whether they are included in family events such as

123 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Accommodation

holidays, family celebrations, and social outings. The degree to which adults with an intellectual disability access employment or vocational services, cultural and recreational activities, community events, and their own network of friends, also varies between families. Furthermore, some families are better resourced and more able to provide, or advocate for, support services than others.

Relationships with family/whānau, services providers and other adults with an intellectual disability are discussed in more detail in Chapter 11: Relationships.

How housing affects the lives of adults with an intellectual disability

There is only a small amount of New Zealand-based research into the lives of adults with an intellectual disability. Developments in services and support for adults with an intellectual disability have followed similar patterns to those in Australia, the United Kingdom and the United States. We can therefore assume that many of the findings of overseas research have some validity for this country.

Studies have shown that the move from large-scale institutions or hospitals as the main form of non-family housing for adults with an intellectual disability has brought positive changes. People living in smaller group homes have shown greater levels of satisfaction with their living situation than those in larger hospital settings. Group homes were never meant to be the only non-family housing option for adults with an intellectual disability. They were initially seen as part of a continuum of support moving from institutions to independent living. In reality, however, group homes have generally been an ‘end point’ for adults with an intellectual disability. Currently there are few other forms of housing available. This has significant implications for the lives of adults with an intellectual disability.

A house or home?

“We made a deal in our house not to eat or drink in the lounge, but one of the staff did.”¹²⁴

A house in itself is not a home. A home has many dimensions from the physical through to the emotional. Studies have shown that most adults want a home to provide a sense of belonging (“this is my space”), a sense on control (“I decide what happens here”) and a sense of security (“this is mine”).¹²⁵

Group homes generally succeed in providing the basics, such as an adequate physical environment, but they are not always able to provide a home.¹²⁶ Provision of housing for adults with an intellectual disability has largely focused on providing ‘home-like’ housing. Group homes have therefore had a tendency to become ‘mini-institutions’. Although the physical nature of the house may be more appropriate and enjoyable than large institutions, the daily routine may be very similar.

¹²⁴ Quote from an adult with an intellectual disability, NHC focus groups 2002.
¹²⁵ MacArthur 2003.
¹²⁶ MacArthur 2003.
Accommodation

Choice and autonomy

“You are not allowed to go to the supermarket and choose your own food. Staff decide the menu.”
“We don’t have our own keys to our own house. The house key is with the van.”

Options for independent living, such as supported living are only beginning to be developed in New Zealand. For most people, the only alternative to living with family is to move into an established residential service, such as a group home.

When the house is owned by their family or a service provider this puts the adult with an intellectual disability in a situation of dependence. Overseas research with residents of group homes suggests that issues to do with dependence and lack of day-to-day autonomy are a primary cause of dissatisfaction. When adults with an intellectual disability are able to live in their own home (rented or owned) with suitable support systems, there is greater satisfaction and less desire to move or change living situation.

As mentioned previously, in many group homes residents have little choice over whom they live with, what they eat, what activities are provided and which staff provide support. In some homes, residents are not able to stay home during the day and are not free to use the telephone or eat food when they want to. Some homes place restrictions on the number of visitors and when they can visit. Most adults without a disability would find this situation difficult to deal with, yet adults with an intellectual disability (and often physical and sensory impairments as well) are expected to ‘get on’ and ‘behave appropriately’ in such environments.

Choice and autonomy are two key attributes that define adulthood. Many adults with an intellectual disability are denied the opportunity to develop and exercise these attributes.

Privacy

“We have privacy in our room, toilet and shower.”
“We should know about the people before they come into the house.”

During the National Health Committee focus groups and other discussions with adults with an intellectual disability, lack of privacy was frequently raised as concern. Although group homes generally provide a separate bedroom for all residents, this is usually their only private space. This means that all the activities of daily living, including talking on the phone and having friends or family to visit, must either take place in the bedroom or in view of other residents. This is not a normal situation for adults in our society. While the majority of adults in New Zealand live with other people, they are able to choose who these people are, and establish patterns of intimacy and privacy that suit their household.

127 Quotes from adults with an intellectual disability, NHC focus groups 2002.
128 These sentiments are expressed by residents in terms of frustration at lack of choice, lack of control over their money, no say in daily routine and similar complaints. MacArthur 2003.
130 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Accommodation

Staff attitudes also determine levels of privacy. Where staff have an awareness of the importance of privacy and respect the house as the ‘home’ of the residents, privacy can be maximised. Where staff do not observe basic courtesies (such as knocking before entering a bedroom or bathroom) and view the house as a workplace, privacy is very limited.

Community participation

Adults with an intellectual disability are often isolated from their community. Studies have shown that adults with an intellectual disability are unlikely to have significant relationships outside their immediate family. They generally live and work with other people with an intellectual disability, have few non-disabled friends and experience only brief, superficial contact with others. Group homes may have physically moved adults with an intellectual disability into the community, but they do not necessarily create real connections within the community. Contact with neighbours is often non-existent, and loneliness is a real problem. Incompatibility between residents can also add to the sense of isolation and loneliness. These issues are discussed in more detail in Chapter 9: Being part of the community.

Linking of housing and support services

A major reason why housing for adults with an intellectual disability tends to have an ‘institutional’ approach is that housing and support services are usually seen as part of the same support package. In many cases, adults with an intellectual disability have few options about where they live because this is determined by the type and level of support they require. This linking of ‘bed and board’ with support means that adults with disabilities have to fit in with established arrangements, rather than being supported to live in a place of their choosing. As well, housing for adults with an intellectual disability has tended to become focused on programmes or therapy, rather than encouraging social relationships, emotional security and community participation.

The linking of support with ‘bed and board’ has also led to inequalities between the provision of support to adults with an intellectual disability who live with family/whānau and those living in ‘purchased care’. Historically, there was little assistance available to families who chose not to place their children with an intellectual disability in institutions. In recent years service provision has improved, especially in the area of day care and vocational services. However, families who have continued to provide care for their member with an intellectual disability receive limited support, in comparison to the support available to people living in purchased care. This lack of support for families is becoming a significant issue as many of the parents who have provided lifelong care reach older age and find it hard to continue to provide care.

Young adults with an intellectual disability

During the NHC project, many families of young adults with an intellectual disability expressed frustration at the lack of options available to enable the young adult to move out of the family home. It was reported that this is especially difficult if the young adult required certain levels or types of support. When a young adult with an intellectual disability leaves school, funding for their support moves from the Ministry of Education to the Ministries of Health and Social Development. This abrupt transition in funding can make planning for the young adult’s future difficult. The focus of services for adults with an intellectual disability who have left school is on vocational training or community participation. Families

131 MacArthur 2003.
Accommodation

commented that housing is largely ignored until a crisis or other event necessitates moving out of the family home.

Creating community membership

If New Zealand is to make the transition from deinstitutionalisation to community membership, changes in philosophy and practice are required. It requires a new way of thinking that moves from a focus on service provision to ‘being of service’ and responding to an individual’s needs and aspirations as citizens. This is congruent with the rights-based approach of the New Zealand Disability Strategy, which views adults with an intellectual disability as citizens with the right to live and take part in the community and receive services based on the individual’s ideas of what is a good life. This philosophy takes the focus off care and treatment and emphasises empowerment and self-determination. Instead of building specially designed housing and services to which adults with an intellectual disability must adapt, it is more appropriate to adapt the housing and supports to the individual.

Overseas, this kind of philosophy is gaining momentum and changing the way in which service providers approach housing. Supported living is one result of this new approach. As supported living is a new concept it has not yet been comprehensively evaluated. Initial research suggests that compared to group homes and other forms of residential facility, supported living has the following advantages:

- independence – adults with an intellectual disability who have supported living services are more likely to own or lease their own home
- choice – supported living allows adults with disabilities to decide whether or not to have flatmates and who they will be, and allows them to be the decision-makers about their daily affairs
- community participation – supported living provides a greater level of participation in normal community activities
- cost-effectiveness – to date organisations do not report the need for increased funding to provide supported living (although some organisations require one-off funding to make the initial shift from facility-based care).

There are some disadvantages to this more independent and flexible form of housing. There is a danger that without adequate support services and suitable housing, adults with an intellectual disability will be effectively dumped in poor housing. Also research has found that supported living does not necessarily make it easier for adults with an intellectual disability to build social relationships. On the administration side, providers of supported living have often had to chase funds from multiple sources in order to put together an appropriate housing and support package.

In New Zealand, the successful implementation of supported living and other independent living options requires:

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133 See Chapter 3: History of service provision for more information about changes in approach to service provision.
134 The New Zealand Disability Strategy is described in Chapter 3: History of service provision.
137 MacArthur 2003.
Accommodation

- **A greater variety of housing to suit a wide range of needs**
  New Zealand housing stock was generally built on the assumption that people are young, in good health, mobile, live in a four-person household and can drive a car or use public transport with ease. People who fall outside of this ‘norm’ (such as older people, single people, people with disabilities, and extended families) can find it difficult to locate appropriate housing. This is particularly true for people on low incomes.

  There is some funding available for home modifications from ACC or the Ministry of Health, but this generally applies to alterations relating to physical or sensory impairments, rather than support to locate housing and assistance with associated costs.

- **Separation of the funding for support services from the purchase of ‘bed and board’**
  The historical linking of support services and housing makes it difficult to develop independent living options. Existing arrangements lock both providers and the people they support into particular properties and styles of service provision. Independent living requires flexibility so that services can be based where the person is located and can adapt and change as the person’s needs and goals change.

- **Flexible funding frameworks**
  Current contracting systems make it difficult to provide individually based services. Funding is generally attached to a particular service or programme irrespective of whether that service meets the needs of a particular individual. Services cannot therefore respond to changing needs and accountability requirements mean providers cannot shift funds if needs change. Adults with disabilities tend only to have a choice of provider, rather than a choice of service.

  For independent living options to be developed, funding needs to be more flexible and individually focused. Also, accountability mechanisms will need to focus on the outcome for individual people and be responsive to changing needs.

- **Greater flexibility among service providers**
  The ability of service providers to respond to the varied and changing needs of the adults they support is essential in enabling adults with an intellectual disability to have more choice over, and say about, their lives. Service providers will face challenges in refocusing their services away from specific residential services to mobile, individually oriented support services. This will require changes in thinking about how to provide services and effective staff training will be essential.

- **Increasing community awareness, understanding and acceptance of people with an intellectual disability**
  If adults with an intellectual disability are to live successfully in New Zealand communities, they will require acceptance and support from all they meet. The history of institutional housing for adults with an intellectual disability means that many New Zealanders have had little contact with them and do not have a good understanding of intellectual disability. Public education will be required if people are to overcome fear, and ignorance.
Accommodation

Key issues

- The type of accommodation in which adults with an intellectual disability live has a great impact on their lives.
- Choice, autonomy and privacy are important aspects of ‘ordinary’ living environments.
- The majority of adults with an intellectual disability who live in private housing, live with family/whānau members.
- Over one-third of adults with an intellectual disability live in accommodation that is purchased as part of their care package.
- Linking the funding of support services with the purchase of accommodation locks providers and the people they support into particular styles of service provision.
- Group homes were developed as an alternative to large institutions, but never intended to be the main non-family housing option for adults with an intellectual disability.
- Supported living options have been developed overseas and are in the early stages of being established in New Zealand.
- To achieve community membership for adults with an intellectual disability, changes are needed to the way that services are funded and provided.
5. HEALTH

“Although evidence has existed for decades in the literature that people with an intellectual disability have poor health, there has never been a loud call for this injustice to be redressed; not even from the organisations which exist to improve their welfare.” 138

This chapter:
• describes the health status and needs of people with an intellectual disability
• identifies barriers to accessing health care
• outlines initiatives to improve the health status of adults with an intellectual disability and their access to health services.

Summary of national and international evidence

“People with an intellectual disability experience inequalities in health outcomes, and inequity of health care access. Compared to the general population, this group experiences lower life expectancy and greater prevalence of health problems. However not infrequently these health conditions are either under recognised or inadequately managed. It has also been established that people with an intellectual disability do not access preventive health care and health promotion programmes to the same extent as others in the community.” 139

Adults with an intellectual disability are a highly diverse group of people. There is wide variation in the extent and nature of their intellectual impairments, their functional disabilities, the presence of sensory and physical disabilities, and their social and family backgrounds. Despite this diversity, there are some very common patterns of health needs, and it is clear that people with an intellectual disability have a greater degree of ill health than the general population.

There is considerable international evidence documenting the prevalence of health conditions among people with an intellectual disability. 140 There are, however, some difficulties with the documented evidence in such studies. Some international evidence comes from residential facilities, which may over-report health conditions due to the higher degree of disability of people and more regular health monitoring in such facilities. Other evidence used in studies comes primarily from small community registries and administrative data from outpatient clinics. These studies probably under-report health conditions as many individuals with an intellectual disability do not access health services on a regular basis. A third difficulty is communication barriers may lead to an under-reporting of conditions and

139 Durvasula and Beange 2001.
140 Horwitz et al (2000) considered 1100 articles and regarded 548 of those as sufficiently robust to be cited in their review ‘The Health Status and Needs of Individuals with Mental Retardation’.
Health

symptoms. Even given these variables and the possible under-diagnosis and misdiagnosis of conditions, it is clear that many people with an intellectual disability have higher, and different patterns of health needs, than the general population.\(^\text{141}\)

Life expectancy

There have been overall gains in the life expectancy of people with an intellectual disability over the last 30 years. In the 1930s people with Down syndrome had an average life expectancy of between 20 and 30 years, and now many are living into their seventies. Despite this, people with an intellectual disability still have a lower life expectancy than the general population. In New Zealand overall life expectancy is 76 years for men and 81 years for women,\(^\text{142}\) and in Western Europe and the USA the average life expectancy is between 74 and 76 years.\(^\text{143}\) A Californian study found people with a ‘mild’ to ‘moderate’ intellectual disability have an average life expectancy of 66 years, reducing to 55 years for people with Down syndrome, and 53 years for those with a ‘severe’ intellectual disability.\(^\text{144}\)

Studies from Sweden and England have shown that age and sex adjusted mortality rates of people with an intellectual disability are 2 to 18 times higher than the general population.\(^\text{145}\) A recent population-based analysis in Northern Sydney showed a mortality rate almost five times higher than that of the general population.\(^\text{146}\) It is estimated that people with a ‘mild’ intellectual disability have a mortality rate 1.7 times that of the general population, and those with a ‘severe’ intellectual disability 4.1 times the general rate.\(^\text{147}\)

Physical health

Many adults with an intellectual disability have physical and/or sensory impairments. In addition, epilepsy is associated with many forms of intellectual disability, occurring in 20 to 30 percent of people, as do musculoskeletal deformities and skin disorders. Cardiovascular abnormalities, obesity and endocrine disorders are among the modifiable health risk factors known to be associated with some forms of intellectual disability.

For people with an intellectual disability, levels of tolerance, for example to pain and discomfort, tend to be different from the general population and they often have a decreased ability to localise pain. Also many show a reduced ability to self-monitor, for instance to limit food intake. These factors combined with communication barriers can lead to masking of symptoms and diagnostic overshadowing, where abnormalities are attributed to the intellectual disability, and potential health conditions are ignored.

With a few exceptions, the prevalence of physical health problems, including cardiovascular disease, cancer, cerebrovascular disease, lung conditions and diabetes, is similar in individuals with an intellectual disability as in the general population. The most common

\(^{141}\) Dovey and Webb 2000.
\(^{142}\) Ministry of Health 1999.
\(^{143}\) Horwitz et al 2000.
\(^{144}\) Strauss and Eyman 1996.
\(^{146}\) Duvvasula and Beange 2001.
causes of death among individuals with an intellectual disability are cardiovascular diseases, respiratory illness and cancers.\textsuperscript{148}

There is an ever-expanding list of well-documented syndrome-specific conditions and risk factors. For instance, there is a 15 percent prevalence of hypothyroidism among people with Down syndrome, and a higher level of cardiac problems around those with Fragile X syndrome. In addition, there are specific disorders common to people with an intellectual disability who have lived in an institution, such as extremely high rates of helicobacter pylori.\textsuperscript{149}

The increased life expectancy, particularly of people with a ‘mild’ or ‘moderate’ intellectual disability, means an increased incidence of age-related conditions similar to the general population. This raises significant new challenges in the care and prevention of health problems.

**Physical activity**

A number of studies have shown that leisure activities of people with an intellectual disability are unlikely to include participation in physical activity.\textsuperscript{150} A 1997 British study found that 48 percent of people with an intellectual disability living in the community had done some physical activity over the past four weeks compared with 93 percent of the general population. Low levels of cardiovascular fitness are more prevalent than in the general population.\textsuperscript{151}

**Obesity**

Obesity is more common among individuals with an intellectual disability than in the general population, with overall prevalence estimates ranging from 29 to 50 percent.\textsuperscript{152} In a recent study of participants in the New Jersey Special Olympics, more than 66 percent were overweight, and a study of people with an intellectual disability living in the community found 56 percent of men and 73 percent of women were either overweight or obese.\textsuperscript{153}

Prevalence of obesity has been found to vary with living situation and the cause of the intellectual disability. Individuals living at home have the highest prevalence (55 percent compared to 40 percent for those living in group homes and 16 percent of people in institutions). Adults with Down syndrome are one and a half times more likely to be obese than people whose intellectual disability results from another cause.

**Diabetes**

In general people with an intellectual disability appear to have a similar prevalence of diabetes as individuals in the general population.\textsuperscript{154} Obesity is a major risk factor of diabetes, and individuals with diabetes are at higher risk of heart disease, stroke, high blood pressure, blindness, kidney disease, amputations and dental disease. In comparison with the general population, individuals with Down syndrome have an increased probability of being obese,

\textsuperscript{149} A bacteria that damages stomach and duodenal tissue.
\textsuperscript{151} Fernhall 1993.
\textsuperscript{153} Bell and Bhate 1992.
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and there is some evidence to suggest that they have a higher probability of having diabetes at a younger age.\textsuperscript{155}

Smoking

Studies suggest that while people with more severe disabilities are less likely to smoke, it appears that people with a ‘mild’ intellectual disability have smoking habits similar to the general population.\textsuperscript{156} An Australian study found that 36 percent of individuals with an intellectual disability smoked cigarettes compared with 26 percent in the general population.\textsuperscript{157} Another found that only three individuals were aware of the association between chronic bronchitis and smoking, and none had been encouraged to stop.\textsuperscript{158}

Cerebrovascular disease

Since the population of individuals with an intellectual disability is ageing, the risks of cerebrovascular disease, cardiovascular disease and cancer, are increasing.\textsuperscript{159} The prevalence of stroke among people with an intellectual disability has not been well researched. While it is unclear whether they are more likely to have a stroke compared to the general population, the ageing population of people with an intellectual disability do face a growing risk of cerebrovascular disease.\textsuperscript{160}

Cardiovascular disease

Cardiovascular disease is one of the most common causes of death among people with an intellectual disability, accounting for 10 to 50 percent of deaths depending on the population studied.\textsuperscript{161} In addition, individuals with Down syndrome are three to four times more likely to have cardiac conditions than other people.\textsuperscript{162} The presence of undetected cardiovascular problems is a common finding in the literature, with some researchers suggesting this may be linked to the high incidence of obesity among people with an intellectual disability. In one study, undetected hypothyroidism was found to be the cause of heart arrhythmias in six people with Down syndrome, none of whom had undergone thyroid function tests despite this being a known risk factor for this group.\textsuperscript{163}

Cancer

After adjusting for age, the prevalence of cancers among people with an intellectual disability living in the community is thought to be similar to the general population, with a couple of exceptions. Firstly, children with Down syndrome are more likely to have leukaemia than children in the general population. Also there is a very high proportion of gastrointestinal cancer among adults with an intellectual disability who have been in institutions. This is thought to be related to three interlinking factors, all of which occur with higher frequency among people with an intellectual disability than in the general population. These are the extremely high incidence of helicobacter pylori among individuals who have spent time in institutions; high levels of gastrointestinal reflux; and chronic constipation. Cancer accounts

\textsuperscript{157} Tracy and Hosken 1997.
\textsuperscript{158} Howells 1986.
\textsuperscript{159} Turner and Moss 1996, Evenhuis 1997, Cooper 1998.
\textsuperscript{160} Wells et al 1997.
\textsuperscript{163} Howells 1986.
for between 7 and 34 percent of deaths of people with an intellectual disability, depending on the population studied.\footnote{164 Carter and Jancar 1983, Dupont et al 1987.}

**Lung conditions**
Respiratory conditions, including Chronic Obstructive Pulmonary Disease (chronic bronchitis and emphysema) are common among people with an intellectual disability. Increased prevalence of respiratory conditions, particularly infections, has been shown to be associated with three factors. These are increased age, institutional residence (nearly half of all deaths in institutions result from pneumonia and influenza) and ‘severe’ intellectual and/or physical impairments (both of which are associated with limitations in physical activity and swallowing difficulties).\footnote{165 Day and Jancar 1994.}

**Epilepsy**
The prevalence of epilepsy in people with an intellectual disability is much higher than in the general population, affecting approximately 21 percent of those who do not have cerebral palsy, and approximately 50 percent of those who do. In contrast, the prevalence of epilepsy in the general population is around 0.5 to 1 percent.\footnote{166 Coulter 1993.} For adults with an intellectual disability seizures are often complex and difficult to control, and specialist input is required. Anti-epileptic drugs have side effects, and require regular review. In spite of this, there is little research that focuses directly on epilepsy among people with an intellectual disability or the support services they require.

A recent New Zealand paper suggests that ensuring regular specialist medical reviews, in order to achieve the best possible seizure control with the least possible anti-epileptic medication, is an overriding concern.\footnote{167 Webb et al in press.} This is particularly important as there is significant evidence to indicate that more than 50 seizures a year significantly increases the likelihood of death and injuries, and this risk increases even more if the individual with epilepsy also has cerebral palsy or other neurological disorders.\footnote{168 Forsgren et al 1996, Spitz 1992, Shackleton et al 1999.}

**Sensory impairment**
Vision and hearing impairments occur more frequently than in the general population, with about 33 percent of adults with an intellectual disability having poor eyesight and over 40 percent having a problem with hearing. However these sensory impairments often go undetected. In a study of 75 people with an intellectual disability, most failed either the vision or the hearing test, yet the majority had not had their hearing or vision checked in the previous five years. More disturbingly, most carers were unable to predict that the person for whom they were caring had a vision or hearing problem.\footnote{169 Wilson and Haire 1990.}

**Skin disorders**
Skin problems are associated with specific syndromes, such as the prevalence of acne among people with Down syndrome, and can also be linked to the use of anti-epilepsy medications. One study found 25 percent of participants had serious untreated skin conditions, such as

\footnote{164 Carter and Jancar 1983, Dupont et al 1987.}
\footnote{165 Day and Jancar 1994.}
\footnote{166 Coulter 1993.}
\footnote{167 Webb et al in press.}
\footnote{169 Wilson and Haire 1990.}
Health

psoriasis, which would be treated in the general population.\textsuperscript{170} Some skin disorders found by researchers suggest that they may be caused by ignorance of simple hygiene routines.

Sexual health

Families and caregivers often find it difficult to face the possibility that people with an intellectual disability can be sexually active. This attitude can preclude or delay sex education or render it ineffective. Also, people with an intellectual disability are at much greater risk of all forms of abuse, including sexual abuse.\textsuperscript{171} Most people with an intellectual disability need advice and information about their sexual development, about appropriate and acceptable behaviours, and how to keep themselves safe. Sexuality is discussed in more detail in Chapter 11: Relationships.

Women’s health

There are a number of health issues particularly relevant to women with an intellectual disability. For instance, they have been found to be at higher risk of developing osteoporosis than the age-matched general population.\textsuperscript{172} While there is little data on the prevalence of female cancers in the population of people with an intellectual disability, studies have found that mortality from breast cancer for women with cerebral palsy is three times that of the general population.\textsuperscript{173} As there is an overlap between the two populations, it is expected that women with an intellectual disability have a higher than average mortality rate from breast cancer.\textsuperscript{174} However, there is anecdotal evidence of problems in accessing breast screening services, and evidence to suggest that women with an intellectual disability are rarely offered cervical smears.\textsuperscript{175}

Menstrual management has been identified as a particular challenge to women with an intellectual disability. Hormonal and surgical interventions to suppress or eliminate menstruation and fertility have been common in the past without the women concerned being fully informed or involved in decision-making.\textsuperscript{176}

Dental health

Dental disease is twice as common in people with an intellectual disability as in the general population.\textsuperscript{177} Adults with an intellectual disability have more untreated caries (tooth decay) and prevalence of gum disease is 1.2 to 1.9 times that of the general population.\textsuperscript{178} It is thought that this may be the result of three factors. Firstly, lack of dental care, for instance problems with self-care and inadequate assistance with brushing. Secondly, the effects of

\begin{itemize}
\item Beange and Bauman 1990.
\item Sobsey 1994.
\item Center et al 1998.
\item Strauss et al 1999.
\item Durvasula and Beange 2001.
\item Stein and Allen 1999, Becker 2001.
\item McCarthy 1998.
\item Cumella et al 2000.
\end{itemize}
medication, for instance mouth dryness. And thirdly, care approaches like using juice rather than water for people who need lots of fluids when eating.

Studies have found that the proportion of missing teeth to filled teeth is higher among people with an intellectual disability, suggesting that extraction rather than restoration is the primary treatment of dental problems. Data on Special Olympic athletes showed untreated dental decay among United States athletes of 24.6 percent compared with 14.2 percent among the general US population. Another study showed over 25 percent did not maintain oral hygiene habits on a daily basis.

Unintentional injury

Adults with an intellectual disability are at least as, if not more, likely to die from an unintentional injury compared with the general population. No New Zealand disability-specific statistics are collected by the Accident Compensation Corporation (ACC) which would enable comparison with these international studies. However the Donald Beasley Institute is carrying out research in this area under contract to ACC. The first stage of this research found high levels of unintentional injury in residential and vocational services. A high proportion of these were from falls or caused by other residents. More information on this study is provided in Chapter 13: Moving around.

Mental health

For many years the assumption that mental health disorders did not occur among people with an intellectual disability, combined with the communication barriers to establishing diagnoses, led to a failure to recognise that people with an intellectual disability can and do have mental health disorders. While the relationship between intellectual disability and mental health disorders is a relatively recent area of study, there is adequate evidence that people with an intellectual disability experience high rates of mental disorders. The prevalence is nearly 50 percent in people with a ‘severe’ or ‘profound’ intellectual impairment, and about 20 to 25 percent in people with ‘mild’ intellectual impairments. About 10 percent of adults with an intellectual disability have behavioural issues. A recent survey in the UK identified that 48 percent of people with an intellectual disability had some sort of psychiatric condition (including behavioural problems) at the time of assessment.

Relationships between specific syndromes or patterns of behaviour and the development of psychiatric disorders are being recognised. For instance, the increased risk of Alzheimer’s disease among adults with Down syndrome; severe over-eating, temper tantrums and obsessional behaviours in people with Prader-Willi syndrome; and the characteristic

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179 Nowak 1984.
180 Special Olympics International 2000.
182 Bray 2002.
183 Holland 1999.
186 Personal communication, Professor Anna Cooper, Department of Psychological Medicine, University of Glasgow 2002.
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behaviour and neuropsychological profiles of people with autistic spectrum disorders. Overall rates of ‘behaviour disorders’ may be as high as 20 percent among people with an intellectual disability. The presence of such problems is the single most important cause of breakdown in community living, disruption of productive vocational involvement, and carer stress.\(^{187}\)

Risk factors that can make people with an intellectual disability vulnerable to mental health conditions can be broadly divided into four categories:\(^{188}\)

♦ Biological:
  • genetics and family history (as for the general population)
  • epilepsy
  • brain damage
  • physical ill health
  • medications and drug interactions

♦ Psychological:
  • adverse or traumatic events in early childhood that affect personality development, confidence, self-esteem, coping strategies and trust, including family dynamics, and/or lack of consistent parental figures
  • continued patterns of broken relationships in adulthood (eg, multiple care settings with no continuity)
  • events which reduce available psychological resources (neglect, abuse, exploitation)

♦ Social
  • multiple concurrent life events (eg, death of mother may also mean new living situation, loss of contact with existing networks etc)
  • limited social networks and support with a lack of continuity
  • social exclusion stigma attached to intellectual disability
  • lack of confiding relationships
  • limited choices
  • low income

♦ Developmental
  • lack of understanding
  • communication problems
  • differences between chronological and developmental age leading to inappropriate responses.

The full range of acquired mental health disorders can be found to affect people with an intellectual disability, yet many (particularly depression and withdrawal) are frequently not diagnosed or treated. The development of maladaptive behaviours, or changes in a person’s state of general wellbeing are often ignored, and the fact that this may be a marker of a physical or mental health problem may not be considered. It is very difficult for many people with mental health issues to recognise that they need help. This is especially so for people who, because of communication difficulties and intellectual impairments, depend on others to identify the significance of such changes.

In the general population, much of the assessment and ultimate diagnosis of mental or behaviour disorders depends on obtaining a description of their mental experiences. Good

\(^{187}\) Mental Health Special Interest Research Group 2001.

\(^{188}\) Cooper 2001.
longitudinal data from informants demonstrating there has been a change in an individual’s mental or behavioural status is an important diagnostic tool. Gathering this type of data can be difficult, particularly in ‘group home’ settings where there is a high staff turnover. During the NHC project, one parent reported that his adult son, who was developing increasingly challenging behaviours, had had 36 caregivers through his group home in a six-month period. Lack of continuity not only makes identification of behaviour change over time impossible, but also places at risk any attempt to manage behaviours consistently, thereby exacerbating the problems.

Pharmaceutical use

There is strong evidence of unnecessarily high levels of medication among adults with an intellectual disability and poor prescribing practice.

Studies reveal a tendency towards the use of co-pharmacy (the non-redundant combining of drugs) and polypharmacy (the simultaneous use of two or more similar drugs). For example, a pharmaceutical overview of IHC residential services in 10 areas showed 38 percent of residents were taking three or more medications. Over 12 percent of residents on medication were taking two or more anti-epileptics, creating a significant clinical risk and a likelihood of increasing behaviour problems.\(^{189}\)

New Zealand research found that approximately 40 percent of the service users surveyed take medication without having a diagnosed medical condition for which the medications would normally be prescribed. This is particularly evident in the use of neuroleptics for the treatment of behavioural conditions. Local and international research concludes that a substantial proportion of people with an intellectual disability are prescribed anti-psychotic medications for behavioural purposes, rather than for the treatment of a diagnosed psychotic illness, and that they can have their drugs substantially reduced or withdrawn, with improved mental and behavioural states.\(^{190}\) There appears to be national and international agreement that “drug therapy is often a measure of the lack of alternative approaches to unacceptable behaviour and programmatic shortcomings”.\(^{191}\) This is an international problem, not unique to New Zealand.

A further issue is that medications which should be prescribed, or at least approved by, medical specialists\(^ {192}\) are being prescribed by general practitioners alone. Furthermore, medications are often not reviewed by a specialist for some years. This means that people continue to take medications that have become outdated. For example the pharmaceutical overview of 10 IHC regions revealed that the anti-epileptic and anti-psychotic medications most commonly prescribed to adults with an intellectual disability are not considered first-line (up-to-date) therapy. Ten percent of users were regularly taking thioridiazine, which is now classed as third-line therapy, and this predisposes residents to potentially serious adverse effects.\(^ {193}\)

\(^{189}\) Kentra Group Limited 2002.
\(^{192}\) As in accordance with Medsafe Guidelines.
\(^{193}\) Kentra Group Limited 2002.
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There are also concerns about unsafe combinations and levels of drug use. The NHC received a number of reports of people on high and conflicting doses of medication that led to serious and potentially life-threatening situations. For example, three families in different regions of New Zealand described instances where hospitalisation was needed to reduce life-threatening drug ‘cocktails’. In all of these situations the person’s behaviour had shown significant changes over the period of at least a year, and their physical health had markedly deteriorated. All the families had been told by a number of health professionals that this was part of having an intellectual disability. It was only through persistence and finding an informed and interested physician that the cause was determined and remedial action taken. All three people made a good recovery and ‘became themselves again’.

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); 15 mg 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 respiridone, 20mls of paracetemol and 1 mg prn of haloperidol.

In addition to these prescribing trends (which again appears to be an international issue) other service provision factors compound the problem. For example, in a Canadian survey of 10 community-based settings, there was inadequate documentation of the drug regimes of 46 percent of the client population making it impossible to determine if, when and how often a drug had been administered.

Provision of health care

“People with mental handicap fit badly into a system of health care delivery in which no care is received unless it is asked for.”

As outlined in Chapter 4: Accommodation, the vast majority of people with an intellectual disability now live in the community, either with family, in their own home or in community-located ‘purchased care’. This population therefore relies principally on mainstream primary health and health promotion services.

As previously identified, people with an intellectual disability have an increased risk of complex and multiple health needs, and show significant inequalities in health status when compared to the general population. Prevention, early detection and timely management of illness are crucial. Individuals with an intellectual disability have the same needs as other people for preventive health care, episodic attention for acute illness and ongoing supervision for persistent medical conditions. Several studies have shown that people with an intellectual disability see their general practitioners just as frequently, if not more often, than others in the community. However, it is not uncommon for health conditions to be under-diagnosed, diagnosed late, or inadequately managed.

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196 Wilson and Haire 1990.
197 Minihan et al 1993.
198 Durvasala and Beange 2001.
The findings from six studies looking at the unmanaged health needs of people with an intellectual disability are summarised in Table 6. Each study defined a health need as “a chronic abnormality of structure or function that imposed a distinct and significant handicap on health and performance”\(^{199}\). This means that some conditions, such as skin and dental problems, were not included by all researchers. A condition was considered to be unmanaged if it was treatable, relievable or able to be cured, and was not receiving organised medical management.

Table 6: Percentage of unmanaged health problems found in six surveys of adults with an intellectual disability\(^{200}\)

<table>
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<tbody>
<tr>
<td>Obesity</td>
<td>20</td>
<td>46</td>
<td>23</td>
<td>29</td>
<td>22</td>
<td>57</td>
<td>32</td>
</tr>
<tr>
<td>Vision</td>
<td>25</td>
<td>44</td>
<td>31</td>
<td>64.5</td>
<td>38</td>
<td>68</td>
<td>45</td>
</tr>
<tr>
<td>Hearing</td>
<td>24.5</td>
<td>25</td>
<td>11</td>
<td>41.5</td>
<td>20</td>
<td>25</td>
<td>25</td>
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<tr>
<td>Dental</td>
<td>***</td>
<td>27</td>
<td>***</td>
<td>***</td>
<td>29</td>
<td>86</td>
<td>47</td>
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<tr>
<td>Central nervous system disorder (including epilepsy)</td>
<td>17.8</td>
<td>17.5</td>
<td>30</td>
<td>13.8</td>
<td>35</td>
<td>53</td>
<td>28</td>
</tr>
<tr>
<td>Cardiovascular</td>
<td>10.5</td>
<td>11</td>
<td>18</td>
<td>15.3</td>
<td>19</td>
<td>24</td>
<td>16</td>
</tr>
<tr>
<td>-</td>
<td>13.2</td>
<td>11.5</td>
<td>34</td>
<td>16.9</td>
<td>25</td>
<td>96</td>
<td>33</td>
</tr>
<tr>
<td>Behaviour</td>
<td>2.6</td>
<td>***</td>
<td>***</td>
<td>***</td>
<td>9.5</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>4.6</td>
<td>***</td>
<td>35</td>
<td>24</td>
<td>26</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>3.3</td>
<td>13</td>
<td>***</td>
<td>28</td>
<td>***</td>
<td>15</td>
<td></td>
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<tr>
<td>Psychiatric/Emotional (including psychosis)</td>
<td>***</td>
<td>7</td>
<td>***</td>
<td>***</td>
<td>5</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Sample size</td>
<td>n=151</td>
<td>n=165</td>
<td>n=104</td>
<td>n=65</td>
<td>n=251</td>
<td>n=202</td>
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As Table 6 shows, there are strong indications that even for those who are currently under the care of a physician, many chronic medical conditions and risk factors remain undetected. Other studies that have shown the high rate of undetected conditions include a study of 200 adults with an intellectual disability living in institutional and community care in Sydney. This study found an average of five medical disorders per person, half of which had not been previously detected.\(^{201}\) In New Zealand, when IHC used the Cardiff Health Check\(^{202}\) to screen over 1,300 people living in IHC residences, 73 percent of people screened required follow-up interventions. These ranged from health promotion (such as nutrition) to reviews of existing treatments (for instance, the replacement of longstanding medication regimes with more recent drugs) to lifesaving actions (such as inserting a pacemaker or surgery for previously undetected cancer).

\(^{199}\) Shephard 1997.  
\(^{200}\) Shephard 1997.  
\(^{201}\) Beange et al 1995.  
\(^{202}\) See page 65 for information about Cardiff Health Checks.
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Barriers to health care

A number of factors contribute to the high incidence of undetected conditions experienced by adults with an intellectual disability.

Lack of accessible health promotion material

There is very little health promotion material available in formats that can be understood by people with an intellectual disability. Many people – not only adults with an intellectual disability – would benefit from plain and simple information accompanied by pictures. Where there is information specifically developed for this population, it is often not widely distributed. There appear to be no national health promotion activities targeted at this group, despite its significant level of ill health.

Reliance on others to access health care

Many people with an intellectual disability report that they depend on their family or caregivers to initiate and facilitate access to health care. If access is not facilitated for them, then the person with an intellectual disability is unlikely to instigate it themselves. However, many studies have indicated that family members and carers may find it difficult to recognise health problems. Many people have a multiplicity of carers, so changes in health status may go unnoticed. With a few notable exceptions, there is little in the way of routine health checks, particularly once a person with an intellectual disability leaves school.

Lost histories

People who have lived in institutions may have few, if any, notes or historical medical information. During the National Health Committee project, mention was made of one man who, after 30 years in Templeton, had half a page of medical history to take to his new health provider.

Communication difficulties

Many people with an intellectual disability have limited communication ability, making it difficult for them to describe symptoms or even indicate that there is a problem. This can make it difficult for a health professional to obtain an accurate medical history or be clear about symptoms. Often the practitioner may be reliant on the family or a support worker for information, which may compromise its accuracy.

Lack of knowledge among health professionals

Surveys of general practitioners show that they feel they lack experience and confidence in dealing with people with an intellectual disability. Many lack knowledge of the relevant health issues for this population.

Attitudes about health care

Attitudes can place huge barriers in the way of adequate health care for this population. For instance, some caregivers feel that paying attention to health problems ‘medicalises’ disability. Some general practitioners have the view that undertaking health screening for this population should not be their job. Behavioural problems exhibited by some people with an intellectual disability can reinforce negative attitudes, and make health care provision difficult.

Misconceptions about adults with an intellectual disability can also create barriers to health promotion and health care. For instance, the view that people with an intellectual disability
are not sexually active. Another barrier is poor collaboration within the health sector (such as, between general practitioners and specialists) or between the health sector and support agencies.

Low incomes
Cost appears to be a major barrier to the provision of primary health care for people with an intellectual disability. This is particularly apparent for those people in residential care services such as group homes, whose only discretionary income is a small personal allowance. Low income levels restrict access to some types of health care such as dental services. During the National Health Committee focus groups, a number of participants commented on the high cost of medication and doctors’ visits.

Initiatives to improve the health of people with an intellectual disability

A number of initiatives and strategies to improve the health and personal care of people with an intellectual disability have been undertaken in New Zealand and internationally. One initiative in the United Kingdom is Community Teams for People With Learning Disabilities. These teams include a nursing service, along with social workers, psychologists and speech-language therapists and, in some places, a psychiatric consultant, registrar and senior house surgeon from the local hospital. The nursing service acts as a bridge between primary and secondary care providers and people with an intellectual disability.

Many authors have suggested regular comprehensive health reviews for people with an intellectual disability. International research indicates that the two most significant barriers to primary health care are communication difficulties with patients and problems obtaining patient histories, and that these barriers can be reduced if general practitioners carry out regular health checks using a set framework.

In New Zealand, the largest provider of services for people with an intellectual disability, IHC, has instituted health checks based on the Cardiff Health Check. This involves people living in IHC residential facilities completing a personal social/developmental history and a comprehensive health questionnaire/checklist with their support staff and/or family. This provides the general practitioner with the necessary comprehensive history, prior to the person attending their annual health check.

The health check package has three components. The first is the Cardiff Health checklist itself, which the general practitioner uses as a guide when examining the person and retains as part of their records. The remaining two are a set of Guidelines For The Use Of Neuropharmacological Medication; and an appropriate syndrome-specific checklist, both of which are for the general practitioner’s information. IHC also coordinates training sessions for the third year ‘Doctor in the Community’ module at the Otago School of Medicine and general practitioner registrar training sessions run through the Clinical Training Agency.

In acknowledgement of the considerable workforce issues involved in the delivery of medication, IHC has contracted a medication management system, where all medications arrive for individuals pre-packaged in date order. There have been concerns raised that this

203 Chapter 7: Paying for things explains the income support available to adults with an intellectual disability.
Health

approach treats adults as if they are in a hospital or institution and reduces linkages with the local pharmacy. IHC has also begun to employ nurse-educators to oversee training, particularly in personal care activities that can include invasive procedures, such as catheterisation.

A number of developments are underway to provide New Zealand general practitioners with further information. This includes Service Guidelines for People with Intellectual Disability and Epilepsy, which is currently under development, and The Clinical Assessment and Management of Children, Young People and Adults with Down Syndrome: Recommended Clinical Practice recently published by the Ministry of Health.

As part of the development of primary health care organisations, the Ministry of Health is piloting a Care Plus initiative to make primary care cheaper for people with chronic conditions. Criteria to qualify as a Care Plus patient, include having at least two chronic conditions. In recognition of the difficulties that people with an intellectual disability have accessing primary care, the criteria have been modified so that a person with an intellectual disability only needs to have one chronic condition to qualify as a Care Plus patient. The effect of this approach will be measured as part of the evaluation of the Care Plus pilots.

Key issues

• Many people with an intellectual disability have higher, and different patterns of health needs than the general population.
• Life expectancy for adults with an intellectual disability is increasing, but is still lower than the national average.
• As a result of increased life expectancy, the incidence of age-related diseases is increasing among adults with an intellectual disability.
• There is a high rate of epilepsy among adults with an intellectual disability.
• A growing number of syndrome-specific conditions are being identified.
• Many adults with an intellectual disability also have mental health conditions.
• There is a high rate of unrecognised health conditions among adults with an intellectual disability.
• Many adults with an intellectual disability are being prescribed out-dated medications or combinations of pharmaceuticals that are not in line with safe prescribing practices.
• Barriers to health care include communication difficulties, reliance on others to access health care, lack of knowledge among health professionals and low income.
• A number of initiatives are being developed both in New Zealand and overseas to improve health care for adults with an intellectual disability.
6. COMMUNICATING

“Speech is the most important thing we have. It makes us a person not a thing. No one should ever have to be a thing.”

This chapter:
• discusses what communication is and the barriers that people with an intellectual disability can face with communicating
• explains how adults with an intellectual disability can be assisted to communicate and the support available
• describes advocacy and self-advocacy.

What is communication?

“Communication is the process of using signs and symbols which elicit meanings in another person or persons… It has occurred when one person assigns meaning to a verbal or non-verbal act of another.”

“My favourite definition of communication is ‘transfer of meaning’. I like it because it says it all. But it does raise an interesting question. Who is responsible for seeing that the meaning is transferred? The sender of the message, or the receiver?”

“Wherever human beings live together, they develop a system of talking to each other… human society, relies heavily on the free and easy interchange of ideas among its members and for one reason or another, man has found speech to be his most convenient form of communication.”

Communication is a two-way process of giving and receiving information, and the importance of communication to ‘being human’ is so great that existence without it is inconceivable. It is a fundamental human right that gives us dignity. Being able to express needs and thoughts, and understand what others are saying is essential for control over care and life.

Communication enables interaction and exchanging of ideas and emotions with other people. It requires having thoughts, feelings or ideas, and to express those in some way that others can understand. Others receive and ‘decode’ the message, and respond by expressing their

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206 Sarbaugh 1979.
208 Denes et al 1993.
Communicating thoughts, feelings or ideas. It is a chain reaction, which requires both a sender and a receiver, and is predominantly a cognitive activity. The very nature of an intellectual disability means that all people with an intellectual disability experience some degree of communication difficulty. How significant a barrier it becomes is due to many factors, not the least of which is the behaviour of the other person or people in the communication chain.

Usually language implies a listener (using receptive language skills) and a speaker (using expressive language skills). Vocal sounds, manual signs or physical icons can all fulfil the functions of communication equally effectively. Having an interaction or dialogue with other people requires being able to understand their expressions in whatever form they are made. Effective communication is not only external. It has been long recognised that self-directed, private speech is of central importance in processes of human self-regulation.209

At a more sophisticated level, the capacity to communicate with others, for example by commenting, questioning and explaining, is central to human social functioning. Successful social functioning has been described as dependent on five ‘accomplishments’: - community presence; autonomy of action; respect from others; competence to perform valued activities; and participation in community life.210 Achieving these goals without effective communication skills would be virtually impossible. Such skills are essential to, and bound up in, virtually all human social processes. If people with an intellectual disability are to have any chance of achieving the vision set out in the New Zealand Disability Strategy,211 a strong focus on communication is vital.

The nature of an intellectual disability and its impact on communication

“There is no doubt that one of the key difficulties faced by people with intellectual disabilities is that of acquiring effective communication.”212

The nature of an intellectual disability means that thinking is difficult. It is more difficult to understand information; or to identify a problem, determine what is causing it, work out possible solutions and then put one of them into practice. People with an intellectual disability experience a wide range of communication difficulties. Some are intrinsic to the individual. For example, difficulties with understanding, memory and concentration skills; social interaction skills, as well as intelligibility of speech; fluency and rate of speech. Other difficulties are extrinsic to the individual. These include, the communication environment; the quality of personal relationships; the knowledge and experience of the communication partner; the accessibility of the language used and the method used to communicate.

Since an essential characteristic of intellectual disability is a difficulty in learning that began in childhood, language and communication development are inevitably affected to some degree. Some people have poorly developed speech musculature, which make articulation difficult and speech hard to understand. Hearing and visual impairments may exacerbate communication difficulties, or it may be difficult to understand and interpret people’s facial

211 The vision of the New Zealand Disability Strategy is described in Chapter 3: History of service provision.
212 Remington 1997.
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expressions and gestures. The way the message is sent may make it inaccessible – for example, complex writing or long sentences with lots of information.

An adult with an intellectual disability may find it difficult to express or understand complex ideas. This can lead to misinterpretation and communication breakdown. One parent described how her son uses “hot” when having a shower, not to mean that the shower is too hot, but that it is too cold, and he would like the temperature increased. A support worker described how a young man saying, “I want sex” was also meaning “I want some intimacy in my life”. Another parent talked about the need for her to teach her daughter that metaphors were not to be taken literally, and that she used a new metaphor in combination with its meaning until her daughter understood. For instance she would initially say, “Hang on a minute, just wait there”. Once the metaphor was understood, she would drop the explanatory phrase and just use, “Hang on a minute”.

During the National Health Committee project, many people with an intellectual disability expressed their frustration at people who did not help them to understand. One employer who had two people with an intellectual disability on his staff described how he quickly learned to supplement his verbal instructions with physical information. He said by giving verbal instructions in smaller chunks, and providing a visual backup, his staff with an intellectual disability were able to do the job at least as effectively as his non-impaired staff.

Opinions differ on the prevalence of communication difficulties for people with an intellectual disability. Surveys estimate that between 70 and 90 percent of people with an intellectual disability have communication difficulties. Findings include:

- approximately 80 percent of people with a ‘severe’ or ‘profound’ intellectual disability fail to acquire effective speech
- an estimated 66 percent of this population had some form of speech and language problem
- 78 percent of the adult population with an intellectual disability in West Berkshire, England had communication difficulties
- 29 percent of people with an intellectual disability in long-stay hospitals and day centres were only able to use non-verbal forms of communication
- 33 percent of adults with an intellectual disability have severe communication impairment
- 89 percent of the adult population with an intellectual disability in Avon, England, had communication difficulties that “required speech therapy”.

There is very little published New Zealand data on the prevalence of communication difficulties among adults who have an intellectual disability. A study related to the health needs of adults, including anecdotal evidence collected from service workers, is in progress at present. Evidence from this study suggests that at least 42 percent of adults with an intellectual disability, who are also older or medically fragile, have some difficulty in expressing themselves. The researchers believe that the prevalence of communication

214 McQueen et al 1987.
215 Parker and Liddle 1987.
217 RCSLT 1996.
218 Noble 1990.
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impairment in this study has been under-represented, possibly due to poor understanding of the factors that constitute communication impairment, and that the true figures will be much higher.220

No matter what their final level of communication ability, many people with an intellectual disability show significant distortions and delays in the normal pattern of language acquisition.221 The way in which word meanings are acquired (semantics), and the function of language as a form of social influence (pragmatics), develop as a result of interactions between a person and the social environment. Full symbolic communication is the product of a long developmental process in which environmental reinforcement plays a crucial part. It requires the maturation and development of other mechanisms that underlay perception, such as cognition and action.

While many people with an intellectual disability eventually achieve effective language skills, this is by no means true of all, and many more suffer delays in learning to speak or communicate. Difficulties with communicating over a lifetime often contribute to low self-esteem, social isolation and loneliness, learned habits of compliance, lack of trust, frustration, anger and disempowerment. Many studies have shown a significant reduction in behaviour management issues once communication systems and support are established.

"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."222

In addition to communication disorders significant barriers to successful communication for this population, include:

- lack of life experience and knowledge
- low functional literacy
- lack of continuity in support, resulting in lost notes or established communication patterns being lost
- inadequate knowledge and awareness of how to support people with communication issues.

Communication intervention for people with an intellectual disability

"Understanding communication as a two-way process, in which both partners have responsibility to make each communication exchange successful, is a crucial part of breaking the cycle of negativity which colours any communicative experiences for individuals with learning disabilities (an intellectual disability)."223

For many years there was little recognised intervention for the development of communication for people with an intellectual disability. However there are now a range of internationally recognised and powerful interventions that have emerged from ideas and methods based on behavioural psychology, cognitive development, and some branches of linguistics.

222 Quote from an adult with an intellectual disability, NHC focus groups 2002.
223 van der Gaag 1998.
Essentially, since the 1960s, there have been two types of intervention. The first emphasises language form, and the second emphasises language function.224 From reviewing the literature and consultation with people with an intellectual disability and their families and service providers, it appears that, in terms of outcome, functional approaches have been far more successful in developing and enhancing communication for people with an intellectual disability.

Functional communication intervention appears to have its basis in the development of the incidental teaching model,225 which found that teaching language within the social milieu of people with an intellectual disability removed the steps between formal teaching and functional use. Teaching was incorporated into the ongoing activities of the person being taught, with most daily activities providing opportunities for teaching and learning how to communicate.

A significant further development in functional communication intervention for people with an intellectual disability has been the emergence of ‘ecological analysis’.226 This essentially looks at the person and their environment and identifies two things: regularly occurring situations where it is necessary or useful for a person to communicate; and regularly required functions of communication that are relevant to those situations (such as asking, commenting and questioning). This information is then used to design a broad-based individually tailored intervention scheme. Using ‘ecological analysis’ makes it clear that a range of people in the lives of the adults with an intellectual disability are well-placed to act as teachers. In relation to functional communication, the role of the specialist language teacher (speech-language therapist) is less clinical, and more focused on developing and facilitating the interactions between the people with an intellectual disability and the important other people in their environment.

In the 1980s there were major research efforts looking at whether people with an intellectual disability could communicate using manual signs, similar to those employed by people with hearing problems, and/or use iconic physical symbols usually displayed on a communication board. The use of symbols and signs has been found to be attractive and in many situations to enhance the learning and teaching of communication for people with an intellectual disability, for example, by making a more concrete link between a word and the thing to which it refers. Signs and symbols are usually seen as functional communication tools rather than as an alternative to speech.

“The use of augmentative and alternative communication in parallel with ecological analysis has one final and very important implication. It affirms a principle of zero exclusion from intervention to develop communication skills.”227

For people with little or no spoken language, augmentative and alternative forms of communication can be used. These can range from a simple point-to-the-picture board to advanced technological equipment with voice synthesis, depending on the characteristics and language of the individual user. The information technology revolution has made important

227 Baumgart et al 1990.
Communicating

inroads into the field of communication intervention, and low technology solutions can also be powerful for many people.228

All of these interventions provide people with an intellectual disability with the opportunity to learn the fundamental lesson that the behaviour of other people can be controlled relatively effortlessly through communication. It is abundantly clear that while there are no miracles and quick fixes, developing effective communication for people with an intellectual disability is possible and must be given the highest priority.

The right to communicate

“ACC claimants are seen as having the right to a normal life – our children are not. Their communication impairment is not seen as an additional disabling condition, but as par for the course.”

“I have to speak for my son who is non-verbal, and that takes more time than bathing and feeding him, but that time is not recognised by needs assessment. He gets no speech-language therapy or any form of communication support other than me.”

“People with mobility issues have a menu of support to choose from, but there is no corresponding menu of communication support. It is immoral to wait 20 or 30 years for someone to help you communicate.”

“My daughter has had nothing to help her communicate, yet it is the major problem for her and for us. The lives of our children are determined by an economic and purchasing model, not on a philosophy of basic human rights, and that’s not OK”.229

It is internationally recognised that adults with an intellectual disability are likely to have some difficulty with communication, and that this in turn has a negative impact on interaction, socialisation, community participation, education, and a marked impact on their quality of life. It is equally well recognised that there are very effective communication interventions for adults with an intellectual disability that result in improved communication, reduced frustrations, and increased participation. Yet within New Zealand it is clear that adults with an intellectual disability have little or no access to communication support services. Not only do they have no access, there appears to be no policy reflecting their right to, and need for, communication support. Communication support does not seem to appear in needs assessment, or service provider contracts and funding.

229 Quotes from parents of adults with an intellectual disability, NHC focus groups 2002.
“The successful application and evaluation of these (powerful intervention procedures now available) depend on the continued co-operation between speech-language therapists, clinical psychologists, care staff, teachers, and managers. These are the people whose responsibility it is…to create the positive interactions on which successful communication intervention relies.”231

Very few speech-language therapists work with adults with an intellectual disability, and those who do are paid either by families or by organisations via fundraising, not by government-purchased service provision. In theory, adults with an intellectual disability could access state-funded assistance through hospital-based speech-language therapists, but caseload levels and prioritisation practices make this extremely unlikely. Families commented on the difference in level of assistance given to adults with an intellectual disability and that provided for rehabilitation, such as after a stroke. They felt this variation in available support indicates that communication impairment is seen as “par for the course” for people with an intellectual disability and therefore not given any focus or intervention. Even when assistance is given, it tends to be clinically-based individual treatment, rather than focused on developing and facilitating the interactions between the people with an intellectual disability and the important other people in their environment.

New Zealand has a population of between 12,000 and 15,000 adults with an intellectual disability who need regular support. Taking the lower estimate that 70 percent have difficulty with communication means that between 8,000 and 10,500 adults are likely to benefit from communication support. Even if speech-language therapists had a high caseload of 200 people, that would mean at least 40 speech-language therapists would need to be employed in New Zealand to work with adults with an intellectual disability. Extensive enquiry in the course of the National Health Committee project found three speech-language therapists actively working with adults with an intellectual disability, and for two of those this was only part of their work. There are other professionals with an interest and expertise in communication disorders and adults with an intellectual disability. However, the total number of professionals working in this area is fewer than ten.

In the area of augmentative and alternative communication, during the NHC project it was identified that two specialist assessment centres had provided interventions for adults with an intellectual disability and their families and support workers. However, this was only for a handful of people. The centres cited significant barriers to accessing funding for both assessment and equipment for this group, such as service definitions that require the person to be “unable” to communicate rather than needing support to communicate. They also mentioned regional variations in eligibility criteria and funding, both for equipment and specialist services. Staff working in the centres also confirmed comments made by parents about variable approaches to communication by needs assessment agencies. These ranged from assistance with purchasing individualised support to no acknowledgement of communication as a need at all.

Given the link between communication and challenging behaviour, and the fact that difficulties with communicating often contribute to many negative outcomes such as low self-esteem, social isolation, learned habits of compliance, frustration and disempowerment, the lack of communication intervention and support makes little sense.

Communicating

Self-advocacy and advocacy

“I think disabled people should be treated as equal as normal human beings because we are normal human beings. We should have normal human rights.”

“We have the right to make our own decisions and our own mistakes. We should have the chance to make our own choices. I’m telling them what I want but no one’s listening.”

“We talked about how to make people in the community hear what we think and want to achieve in life.”

“We want to find out information affecting us before it happens. Everyone should know what’s going on”.

Many people with an intellectual disability have limited opportunities to say what they would like or want. Their lives are controlled by other people, either unintentionally, for instance because there is no developmental focus to the support they receive, or intentionally through actions of support staff such as censoring what someone writes on their communication board or limiting the length of their phone calls. This is particularly so for older adults, whose whole life may have been determined by others, like staff or family, and who have never been enabled to make basic decisions in their own lives.

Advocacy and empowerment are about many things. They are about giving people voices and choices in their own lives. They are also about changing the policies and practices that have such a direct influence on the quality of life available to them. Advocacy is when someone else represents a person’s interests. Self-advocacy is when a person or group of people represent their own interests.

Self-advocacy

“Self-advocacy is all about speaking up for yourself, and making choices and decisions. We can all make choices and decisions for ourselves, even people who can’t speak. Self-advocacy is also about telling people things you do and don’t like and what you think about things.”

There are two types of self-advocacy:

- individuals who advocate for themselves
- a movement or collective of people with an intellectual disability that advocates for the collective, their families, and others with a disability.

People are likely to be much more confident about their own abilities and have greater control over their lives if they are enabled to speak for themselves. Self-advocacy helps people to know what they really want and be stronger in standing up for their rights. It helps people with an intellectual disability to be proud, and to challenge negative perceptions.

Self-advocacy among people with an intellectual disability is a fairly recent development. The first recorded occasion on which people with an intellectual disability spoke out

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232 Quotes from members of People First groups.
233 From a speech by Michael Alderidge to People First Marlborough in March 2002.
Communicating collectively was in Sweden in 1967. This was when the local Association for Retarded Citizens was addressed by a small group of people with an intellectual disability who asserted that they wanted to speak for themselves.\(^{235}\)

In 1974, the People First movement began in Oregon, USA. A small group who were planning a conference decided they needed a name. One of the group commented that they were “tired of being called retarded; we are people first”. From this the name People First emerged.\(^{236}\) Since then, People First groups have developed around the world.

In New Zealand, People First was started by IHC in 1978 and it was not until the early 1980s that independent self-advocacy groups started forming in New Zealand. IHC registered the name People First to protect it being used by other sectors. The organisation has actively promoted the development of People First groups and has provided a structure and staff support to groups around the country. However, having a provider organisation as the umbrella for the majority of self-advocacy groups does create some conflicts of interest. At the People First conference in 1993 there was a strong desire for People First to become independent, but this move was not supported by IHC, which felt that the movement was not ready for this to succeed. Now, 10 years later, People First has been set up as an independent organisation. The new organisation was formally launched in October 2003.

The other significant milestone for self-advocacy in New Zealand was the march on Parliament on 7 September 2001 to protest at the Government’s slowness in making a decision to close Kimberley (the last large institution in New Zealand for people with an intellectual disability). This march was the first sizeable civil action in New Zealand by people with an intellectual disability and their supporters.\(^{237}\)

The main barrier to improved communication is that, often, other people do not really want to listen. Greater awareness is needed within support services and in wider society about the importance of self-advocacy and the contribution it makes to good quality services. In New Zealand and internationally, the self-advocacy movement is making a real difference to the lives of people with an intellectual disability.

### Key issues

- Being able to express needs and thoughts, and understand what others are saying is essential for control over care and life.
- Surveys estimate that 70 to 90 percent of people with an intellectual disability have communication difficulties.
- People with an intellectual disability can make their needs and wants known if they are given the opportunity.
- Barriers to successful communication for this population, include lack of life experience and knowledge, low functional literacy, lack of continuity in support and inadequate knowledge and awareness of how to support people with communication issues.
- Functional approaches to the development of communication skills, have been shown to make significant differences in the lives of people with an intellectual disability.

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\(^{237}\) Taylor 2001.
Communicating

- Adults with an intellectual disability get virtually no assistance, such as speech-language therapy, and have very limited access to augmentative and alternative communication.
- Self-advocacy is an important component for adults with an intellectual disability having control over their own lives.
7. PAYING FOR THINGS

“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.”

This chapter:
• outlines international research about the income of adults with an intellectual disability
• provides details about the types and levels of income support that adults with an intellectual disability receive in New Zealand
• explains the differences in income support available to adults with an intellectual disability living in ‘purchased care’ and those who pay for their own accommodation
• discusses the support that adults with an intellectual disability can need to manage their money.

International research on income of adults with an intellectual disability

Much of the international literature in the area of income and disability considers disabled people in general. The average income for disabled people in the United States is as much as one-third lower than their non-disabled peers. Research in Britain and the United States found that 60 percent of people with disabilities live below the poverty line. Recent research by the Office of Population and Census Studies in Britain established that 75 percent of disabled people rely on state benefits as their main source of income, with fewer than one-third of those of working age in employment.

There is significant consensus around the world that people with an intellectual disability continue to be one of the most disadvantaged groups in the labour market. This is despite different political and economic contexts, as well as different social security systems and structures.

A significant number of people with an intellectual disability, particularly those who require regular assistance with living, rely on a combination of social security benefits and minimal earned income to meet their living and disability-related costs. Research estimates that fewer than 10 percent of people with an intellectual disability are in paid full-time employment and have sufficient earnings so that they have no requirement for benefit income. Research also

238 Quote from an adult with an intellectual disability, NHC focus groups 2002.
241 Mirfin-Veitch 2003a.
242 Mirfin-Veitch 2003a.
Paying for things

suggests that many people with a ‘severe’ intellectual disability realistically cannot enter the workforce and will depend exclusively on income support benefits throughout their lives.\textsuperscript{243}

People with an intellectual disability are increasingly voicing their dissatisfaction with their work situation and low income levels, particularly the frequent experience of low wages.

Effect of social security benefits

There is considerable research exploring the interface between social security benefits and the lives and incomes of people with an intellectual disability. Much of this research has been done in the United Kingdom. A study of the impact of the British Disability Living Allowance concluded that benefits can only reach their potential impact if they are accompanied by a social and environmental approach to enable more equal participation of disabled people.\textsuperscript{244} Another study suggests that any overhaul of disability benefits must be accompanied by policies to promote full access to the labour market.\textsuperscript{245}

In a further study, the British social security system for people with an intellectual disability is described as anomalous, complex, unreliable and lacking in coherence.\textsuperscript{246} It concluded that people with an intellectual disability are “vulnerable to either being classified as incapable of work (and treated as low priority for employment services assistance) or being judged as fit for work (and facing what may be inappropriate sanctions)”.\textsuperscript{247}

Similar concerns about the New Zealand social security system were echoed in the comments made during the National Health Committee focus groups and meetings with parents.

Poverty and intellectual disability

\begin{quote}
“As well as disablin policies and practice generating poverty among disabled people, notably through disabled people’s marginalisation and exclusion from the labour market, poverty generates ill health and impairment. This is true in both rich and poor societies.”\textsuperscript{248}
\end{quote}

One obvious outcome of part-time work, low-paid work, or reliance on benefits is that people with an intellectual disability are at risk of poverty. There are a number of definitions of poverty:

- **absolute poverty** relates to the notion of the lack of basic necessities of life
- **relative deprivation** is based on not being able to live in accordance with the customs and values of the society in which a person is a part
- **the rights-based approach** identifies the way in which civil, political and social rights are weakened by poverty, and sees poverty, like other consequences of institutionalised discrimination, as having the effect of restricting rights.

Research on the perspective of people who experience poverty indicates that they see it as more than the deprivation of material things, and perceive it to be about the denial of rights, emotional insecurity, and the inability to maintain responsibilities as individuals and citizens. Disabled people’s organisations have argued that poverty must be seen as one expression of the

\begin{footnotesize}
\textsuperscript{243} Mirfin-Veitch 2003a.  
\textsuperscript{244} Noble et al 1997 cited Mirfin-Veitch 2003a.  
\textsuperscript{245} Hyde 2000 cited in Mirfin-Veitch 2003a.  
\textsuperscript{246} Simons 1998.  
\textsuperscript{247} Simons 1998.  
\textsuperscript{248} Beresford 1996.
\end{footnotesize}
institutional discrimination that disabled people face. Prolonged economic hardship has been reported as impinging on routine activities of daily living, and decreasing access to quality services in the community.

Incomes of adults with an intellectual disability in New Zealand

“If you don’t have any spending money you have to do things that don’t cost money and that’s hardly anything.”

“Sixty dollars doesn’t go very far. After you have bought cat food and paid bills, I have about five dollars left.”

The 2001 Disability Surveys, found that people with disabilities were less likely to be employed than non-disabled people, with over 55 percent of adults with a disability reporting a gross personal income of less than $15,000 compared with 40 percent of non-disabled adults.

There are no national statistics on the number of people with an intellectual disability in paid employment, the hours they work or how much they earn. There is, however, strong anecdotal evidence to suggest that very few people with an intellectual disability earn sufficient income to completely remove the necessity for social security assistance.

Data from Work and Income, part of the Ministry of Social Development, shows that just over 11,110 adults under age 65, who receive a Sickness or Invalids Benefit, give their primary disabling condition as an intellectual disability. Around 37 percent of these people have their benefit directly paid to their residential care provider, with the remaining 63 percent living either with family members or in accommodation that is purchased separate from their support services. Table 5, in Chapter 4: Accommodation (page 41) shows the percentages of Sickness and Invalid Benefit recipients who live in ‘purchased accommodation’ in each District Health Board (DHB) region.

The distinction between adults in ‘purchased accommodation’ (often referred to as ‘residential care’) and those paying for their own accommodation is important. Benefit entitlement is altered in accordance with the way in which services are provided. In considering income levels, and their impact on the people receiving them, it is therefore necessary to look at the two groups separately.

249 Mirfin-Veitch 2003a.
250 Mirfin-Veitch 2003a.
251 Quotes from adults with an intellectual disability, NHC focus groups 2002.
252 Figures calculated from Statistics New Zealand 2002.
253 This data is from 31 May 2002.
254 This is just over 11 percent of the total population of Sickness or Invalids Benefit recipients.
Paying for things

Income support for people paying their own accommodation costs

People who pay for their own accommodation costs and have no or low income, may meet the eligibility criteria to receive income support. In New Zealand this consists of three tiers of assistance:

- a base benefit to cover basic living costs
- supplementary benefits for specific assistance with particular costs
- emergency assistance for unexpected or out-of-the-ordinary costs.

Each tier has different eligibility criteria, including different income and/or asset eligibility levels, and different rates at which they are abated (reduced) in accordance with earned income.

Table 7 shows that the majority of people with an intellectual disability (aged under 65 and not in 'purchased care') receive income support payments of between $150 and $300 per week. This is between $7,800 and $15,600 per annum. This income benefit distribution pattern is similar to that for the entire population of Sickness and Invalids Benefit recipients, with two exceptions highlighted in the table below:

- a small cluster of people with an intellectual disability are in the $20 to $39 range. These will be people in ‘hospital’ receiving what is known as the hospital rate of benefit. This was $28.82 per week at the time the data was collected
- a greater proportion of people among the total recipients receive higher levels of payment, which probably reflects family financial commitments.

Table 7: Comparison of level of income support received by all recipients and those with an intellectual disability aged under 65 and not in ‘residential care’

<table>
<thead>
<tr>
<th>Amount of income support received per week</th>
<th>Percentage of the total Sickness and Invalids benefits recipients</th>
<th>Percentage of recipients with an intellectual disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>$19 or less</td>
<td>0.05</td>
<td>0.01</td>
</tr>
<tr>
<td>$20–39</td>
<td>0.89</td>
<td>6.34</td>
</tr>
<tr>
<td>$40–59</td>
<td>0.26</td>
<td>0.51</td>
</tr>
<tr>
<td>$60–79</td>
<td>0.27</td>
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<td>$80–99</td>
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<td>3.02</td>
<td>1.04</td>
</tr>
<tr>
<td>$150–199</td>
<td>26.05</td>
<td>28.12</td>
</tr>
<tr>
<td>$200–249</td>
<td>33.74</td>
<td>41.76</td>
</tr>
<tr>
<td>$250–299</td>
<td>15.19</td>
<td>18.54</td>
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<td>9.42</td>
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<td>$450–499</td>
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<td>0.01</td>
</tr>
<tr>
<td>$500 and over</td>
<td></td>
<td>0</td>
</tr>
</tbody>
</table>

First tier – base benefit
There are a number of types of base benefits including the Unemployment Benefit, Domestic Purposes Benefit, Sickness Benefit and Invalids Benefit. Each has different eligibility criteria, relating to a person’s financial position and the reason(s) why they cannot earn income.

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255 Data provided by the Ministry of Social Development as at 31 May 2002.
Most people with an intellectual disability aged between 16 and 64 receive an Invalids Benefit. At 31 May 2002, there were 7,015 people with an intellectual disability (not in ‘purchased care’) receiving either an Invalids or a Sickness Benefit. Of these, only 161 were on a Sickness Benefit.

The criteria for eligibility for an Invalids Benefit is that the person has been declared by a medical practitioner to be unable to work as they are permanently or severely restricted due to sickness, injury or disability. “Permanent” means two years or more; and “severely restricted” means cannot regularly work 15 hours or more per week. A person on Invalids Benefit can earn up to $100 per week before the amount of benefit begins to be abated. The amount paid varies slightly according to a person’s age and marital status, and is adjusted each year in line with inflation. The current rate of Invalids Benefit for a single person aged 18 or over with no dependent children is $202.05 per week.256

All people over the age of 65 are eligible to receive New Zealand Superannuation if they meet certain residential criteria. There is no data available on how many New Zealand Superannuitants have an intellectual disability. Work and Income data identified that there were just under 50 adults with an intellectual disability who were aged 65 or over receiving an Invalids Benefit, rather than New Zealand Superannuation.

Second tier – supplementary assistance
There are two main forms of supplementary assistance:
• accommodation supplement
• disability allowance.

Accommodation supplement
The purpose of the Accommodation Supplement is to assist with board, rent or home ownership costs. The amount paid is dependent on the geographical region the person lives in and the level of accommodation costs they are paying. As at 31 May 2002, 3,620 (51%) of adults with an intellectual disability, aged under 65 and not living in ‘purchased care’, were receiving an Accommodation Supplement. As Table 8 below shows, the amount received varied considerably, just over half received less than $50 a week.

For a group of people who are mostly dependent on benefit income, 51 percent seems to be a low take-up of the Accommodation Supplement. This may be due to a number of reasons:
• families continuing to support adults with an intellectual disability who are living at home by not charging them board. In this situation, the adult with an intellectual disability would be considered to have no accommodation costs, even though these costs are being met by other family members
• poor understanding about the Accommodation Supplement by adults with an intellectual disability and their caregivers
• lack of advocacy and assistance to access supplementary assistance.

256 This was the rate at 1 April 2003. The rate is adjusted each year on 1 April.
Paying for things

Table 8: Percentage of adults with an intellectual disability paying their own accommodation costs who receive various rates of Accommodation Supplement

<table>
<thead>
<tr>
<th>Amount of accommodation supplement paid per week</th>
<th>Percentage receiving that rate of Accommodation Supplement</th>
</tr>
</thead>
<tbody>
<tr>
<td>$9 or less</td>
<td>6.63</td>
</tr>
<tr>
<td>$10–$19</td>
<td>14.36</td>
</tr>
<tr>
<td>$20–$29</td>
<td>9.31</td>
</tr>
<tr>
<td>$30–$39</td>
<td>11.27</td>
</tr>
<tr>
<td>$40–$49</td>
<td>9.39</td>
</tr>
<tr>
<td>$50–$59</td>
<td>7.24</td>
</tr>
<tr>
<td>$60–$69</td>
<td>6.33</td>
</tr>
<tr>
<td>$70–$79</td>
<td>5.28</td>
</tr>
<tr>
<td>$80–$89</td>
<td>4.67</td>
</tr>
<tr>
<td>$90–$99</td>
<td>3.70</td>
</tr>
<tr>
<td>$100–$109</td>
<td>3.07</td>
</tr>
<tr>
<td>$110–$119</td>
<td>2.13</td>
</tr>
<tr>
<td>$120–$129</td>
<td>2.46</td>
</tr>
<tr>
<td>$130–$139</td>
<td>2.15</td>
</tr>
<tr>
<td>$140 or higher</td>
<td>12.02</td>
</tr>
</tbody>
</table>

Disability Allowance
The Disability Allowance is paid to assist with the recognised additional costs incurred by people with a long-term illness or disability. Costs that can be claimed include costs associated with medical fees, special foods and pharmaceutical charges. The amount of Disability Allowance paid is dependent on the costs incurred (which must be verified by providing receipts or similar proof of these costs for the preceding year) up to a maximum of $47.44 per week.258

At 31 May 2002, 3,813 (54%) adults with an intellectual disability, aged under 65 and not in residential care, were receiving a Disability Allowance. Of this group 1,794 (47%) were paying all of this allowance as an attendance fee to their vocational service provider.

Fifty-four percent is a much lower than expected take-up of this allowance, given that people with an intellectual disability can have significant disability-related costs. For example, many people with an intellectual disability have high health needs and a high proportion are on medication, and therefore face pharmaceuticals costs. Once again, the lack of take-up of this allowance could be due to poor understanding of its availability. It could also be due to the fact that people with an intellectual disability need assistance to apply for benefits, and the process of collecting receipts and other proof of payment may be an additional barrier.

Table 9 shows the variation in take-up of Disability Allowance by DHB region for adults aged under 65 and not in ‘residential care’. It also shows the percentage in each region paying their allowance as a vocational service attendance fee.

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257 Data provided by the Ministry of Social Development as at 31 May 2002.
258 This was the rate at 1 April 2003. The rate is adjusted each year on 1 April.
Table 9: Take-up rate for Disability Allowance by DHB region for adults with an intellectual disability who meet their own accommodation costs259

<table>
<thead>
<tr>
<th>DHB region</th>
<th>Disability Allowance recipients</th>
<th>Percentage paying Disability Allowance as vocational services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Auckland</td>
<td>35</td>
<td>27</td>
</tr>
<tr>
<td>Bay of Plenty</td>
<td>38</td>
<td>70</td>
</tr>
<tr>
<td>Canterbury</td>
<td>34</td>
<td>51</td>
</tr>
<tr>
<td>Capital and Coast</td>
<td>33</td>
<td>48</td>
</tr>
<tr>
<td>Counties-Manukau</td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Hawkes Bay</td>
<td>34</td>
<td>51</td>
</tr>
<tr>
<td>Hutt</td>
<td>39</td>
<td>45</td>
</tr>
<tr>
<td>Lakes</td>
<td>35</td>
<td>47</td>
</tr>
<tr>
<td>Midcental</td>
<td>24</td>
<td>49</td>
</tr>
<tr>
<td>Nelson-Marlborough</td>
<td>38</td>
<td>48</td>
</tr>
<tr>
<td>Northland</td>
<td>30</td>
<td>30</td>
</tr>
<tr>
<td>Otago</td>
<td>49</td>
<td>58</td>
</tr>
<tr>
<td>South Canterbury</td>
<td>39</td>
<td>40</td>
</tr>
<tr>
<td>Southland</td>
<td>40</td>
<td>53</td>
</tr>
<tr>
<td>Tairawhiti</td>
<td>28</td>
<td>43</td>
</tr>
<tr>
<td>Taranaki</td>
<td>38</td>
<td>60</td>
</tr>
<tr>
<td>Waikato</td>
<td>36</td>
<td>61</td>
</tr>
<tr>
<td>Wairarapa</td>
<td>32</td>
<td>39</td>
</tr>
<tr>
<td>Waitemata</td>
<td>25</td>
<td>32</td>
</tr>
<tr>
<td>West Coast</td>
<td>47</td>
<td>27</td>
</tr>
<tr>
<td>Wanganui</td>
<td>37</td>
<td>46</td>
</tr>
</tbody>
</table>

There is a large geographical variation in take-up of Disability Allowance. It is of particular concern that many of the regions with low take-up tend to be in areas with the largest populations of Māori and Pacific adults with an intellectual disability. (Figure 4 in Chapter 2: Definitions and demographics provides ethnicity data on adults with an intellectual disability.) This variation may be indicative of regional differences in the administration of the allowance, differing attitudes on the part of Work and Income staff, low take-up rates of supplementary assistance among Māori and Pacific people, or lack of advocacy and assistance to access the allowance. The Downtown Community Ministry in Wellington has found ethnic differences in the receipt of Disability Allowance by children. It found that the take-up rates for Māori and Pacific children was half that of Pakeha children.260

Another area of concern is the fact that nearly half of the people with an intellectual disability receiving the Disability Allowance are paying all or part of it to the provider of their vocational service, as a fee for attending. This practice, which is an historical anomaly, began as an alternative source of funding for the provision of vocational services an area that has traditionally had variable levels of direct funding levels. In many cases, these services are now reliant on this funding for their survival. However, this practice penalises the adult with an intellectual disability, who is unable to utilise all or part of this allowance for their individual disability-related costs. This policy is currently under review.

Third tier – emergency assistance
As this level of assistance is for emergencies or exceptional circumstances, there are very tight eligibility criteria and income tests. There are several forms of assistance at this level,

259 Data provided by Work and Income and the Ministry of Social Development as at 31 May 2002.
Paying for things

from single payment grants to an advance on future benefit payments that must be paid back. Under certain conditions people with high costs and low income receive a Special Benefit. This is a discretionary benefit intended to provide assistance to people whose particular circumstances are causing them hardship. Although it is not time-limited, it is not intended as a long-term solution, and the person is expected to make an effort to adjust their outgoings and manage without the special assistance. As at 31 May 2002 just over one percent of people with an intellectual disability (aged under 65 and not in residential care) were receiving a Special Benefit.

Income of people living in ‘purchased care’

| "We had to sign these forms and they didn’t explain what they are for. We think it was to get control over our benefit.” |
| "A lot of us feel we should be getting our benefit and paying our bills ourselves.” |

When accommodation is purchased as a part of a person’s ‘residential care’ package, they are not eligible to receive second and third tier income support. This is because their accommodation and most of their living costs are deemed to be met by the payment that their provider receives for their care. The Social Security Act specifically excludes these people from receiving the Accommodation Supplement, Disability Allowance or Special Benefit.

A person living in ‘residential care’ receives a base benefit, usually an Invalids Benefit, but they are required to pay the majority of that benefit to their service provider as a contribution towards the cost of their care. In many cases, this benefit is paid directly to the care provider. A small portion of the benefit is retained as a personal allowance to pay for clothing and incidental personal costs. The current personal allowance rate is $44.26 per week.\textsuperscript{262} This means that people with an intellectual disability in ‘purchased care’ have very limited disposable income.

| “By the time we get the benefit, by the time they finish paying board, we are left with nothing.” |
| “I have my learners licence, but I can’t afford to sit the next bit.” |

Anecdotal evidence from both families and people living in residential facilities indicates that this limited income has a significant impact on their ability to participate in community activities. Often the cost of transport as well as the cost of the activity itself, whether it is going to the movies, having a drink with friends, or attending a sporting event, exceeds the amount they have available. During the National Health Committee focus groups it became clear that often this shortfall is met by parents and other family/whānau members.

Many ‘residential care’ providers have contracts that exclude them from meeting costs like doctors visits, pharmaceuticals, incontinence aids, and other treatment costs.\textsuperscript{264} This means that the individual is required to meet such costs themselves from their personal allowance.

\textsuperscript{261} Quotes from adults with an intellectual disability, NHC focus groups 2002.
\textsuperscript{262} This was the rate at 1 April 2003. The rate is adjusted each year on 1 April.
\textsuperscript{263} Quotes from adults with an intellectual disability, NHC focus groups 2002.
\textsuperscript{264} This is a situation that has developed over time since responsibility for disability support services moved from the Department of Social Welfare to the health sector.
Paying for things

unless there are alternative sources of assistance, such as through DHBs. As noted in Chapter 5: Health, many people with an intellectual disability have high health needs, and therefore have to use their discretionary income to pay for pharmaceuticals and other medical costs. During the National Health Committee focus groups a few people reported that, despite assistance such as a Community Service Card and High Use Health Card, their pharmaceutical costs alone exceeded their personal allowance. Meeting these costs means that there is little or nothing left to pay for other personal costs and involvement in recreation and community activities.

Money management

“I’d like to save for a CD player that you can walk around with.”
“I’m buying a small radio and a big speaker. I’d like to buy it so I can keep it in my room.”
“I’m saving up very well. I do go to Christchurch – just got to watch what I spend.”

Many of the adults with an intellectual disability who took part in the NHC focus groups were saving up for particular purchases or were very clear about what they would buy if they had enough money. Their aspirations tended to be modest and what others in their age group would take for granted – a CD player or visiting family. For many in the focus groups purchasing such items was a dream rather than a reality. Others had strategies for saving their limited income.

Many adults with an intellectual disability need assistance in managing their money. Some are unable to have any role in managing their money; others need assistance with banking or budgeting. Where other people have control of a person’s money, there are potential risks of fraud or misappropriation. During the focus groups several people raised concerns about what happened to their money and how little control they had over it. Many had little understanding of what money they had and where it came from. To protect the financial interests of adults with an intellectual disability, it is important both to increase their own understanding about their income and how to manage it and to ensure that they are not at risk of exploitation.

“Mum gets into my own bank and helps herself to the money there. I don’t touch it. I want to have it in an emergency.”

Plain language information about income support assistance would be of great value for adults with an intellectual disability. Research and education are also necessary in order for people with an intellectual disability to experience greater choice and control over their own money and the way it is managed.

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265 While incontinence supplies are provided through DHBs, the amounts and types supplied do not necessarily meet people’s requirements.
266 Quotes from adults with an intellectual disability, NHC focus groups 2002.
267 Quote from an adult with an intellectual disability, NHC focus groups 2002.
268 Bewley 1996.
Paying for things

Key issues

- Adults with an intellectual disability typically experience low levels of income and are at risk of poverty.
- Low income levels are the result of low employment, with those who do work often receiving low pay or working only part-time.
- The majority of adults with an intellectual disability are reliant on income support benefits as their main income source.
- For those adults under age the of 65 and paying their own accommodation, the take-up of supplementary income support is lower than would be expected given their financial situations.
- The take-up rate for Disability Allowance is particularly low in regions where there are the largest populations of Māori and Pacific adults with an intellectual disability.
- Nearly half of those receiving a Disability Allowance pay it to their vocational services provider as an attendance fee, which means they cannot access this assistance to pay for their personal disability-related costs.
- Adults with an intellectual disability living in ‘purchased care’ have access only to a weekly personal allowance which in many instances is insufficient to cover their personal living expenses, limiting their leisure and community participation.
- Many residential providers do not meet health costs which puts greater pressure on residents’ limited discretionary income.
- Most adults with an intellectual disability have little understanding about their income and need some degree of assistance with money management.
- There is potential for fraud and misappropriation by those helping with, or managing, the finances of adults with an intellectual disability.
8. WORK (PAID AND UNPAID)

"I have had a part-time job out of here working in a rest home. It was hard, but that’s alright. 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 of the kitchen. That’s why I got laid off. I now come here (vocational service) five days a week."  

This chapter:
- describes the expectations adults with an intellectual disability have about work and their experiences of work
- outlines recent changes in philosophy about employment opportunities for adults with an intellectual disability
- describes how the participation of adults with an intellectual disability in employment can be improved and barriers to work reduced
- examines transitions from school to work and from work to retirement for adults with an intellectual disability.

Employment policy and disability

"The world of work is changing, and everywhere the growing preoccupation of working age men and women, including people with disabilities, is how to get and keep a job … Productive work provides a person with livelihood, status and self-esteem, and is the most effective way to achieve economic and social integration." (Joint statement of the ILO, UNESCO, UNICEF and WHO.)

Many adults with an intellectual disability want to work in ‘real’ jobs that are paid. They have similar work aspirations and reasons for working as others of the same age and value the opportunity to work. Adults with an intellectual disability, who do have paid work in the community, report the benefits from this extend into other areas of their lives. Benefits include greater self-esteem, greater income and the difference that makes in their lives, improvement in their physical wellbeing, better social life and independence, and greater self-confidence. While there is no data available to indicate how many adults with an intellectual disability are in paid work, the 2001 Household Disability Survey shows only 40 percent of adults with disabilities were employed compared to 70 percent of the non-disabled population.

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269 Quote from an adult with an intellectual disability, NHC focus groups 2002.
270 Lunt 1997.
Work (paid and unpaid)

Current government policy reflects the desire of people with disabilities to get and keep a job. One of the 15 objectives in the New Zealand Disability Strategy\(^{274}\) is to “provide opportunities in employment and economic development for disabled people”. The importance of this emphasis has been reinforced by the comments and opinions expressed by people with an intellectual disability who took part in the National Health Committee focus groups. Almost without exception they discussed their goals and aspirations in regard to paid employment.

| “I want to be a hairdresser or else look after children from babies to four years old.” |
| “I’d like to help people in the supermarket – tell them where things are.” |
| “I would like to work in the second-hand clothes shop by the church.”\(^{275}\) |

Historically most adults with an intellectual disability were perceived as unable to work in paid employment, and it was the responsibility of the state to provide supervised daily activities or unpaid work within the institutional setting in which many people lived.\(^{276}\) During the 1950s and 60s ‘special’ work settings for adults with an intellectual disability proliferated. Sheltered workshops became the most common ‘work’ in which adults with an intellectual disability were involved. While many workshops provide a ‘work-like’ environment and real work tasks through contracted work, they were, and still are, excluded through the provisions in the Disabled Persons Employment Promotion (DPEP) Act 1960\(^{277}\) from having to meet labour legislation covering pay and other conditions.

In the 1970s concern began to be expressed about the segregated setting of sheltered workshops, the low expectations of the ‘workers’, the minimal if any ‘pay’ for the work done, and the frequent lack of qualifications and expertise in the staff. The fact that ‘sheltered work’ hardly ever led to ‘real work’ in paid open employment, even for the most competent workers, is a concern that remains both current and valid.

A recent US survey found that nearly 60 percent of adults with an intellectual disability were still in sheltered workshops rather than supported employment. The researchers concluded that although “originally conceptualised as a stepping stone to employment, sheltered employment has become, and continues to be, an end in itself for many”.\(^{278}\)

\(^{274}\) The New Zealand Disability Strategy is described in Chapter 3: History of service provision.

\(^{275}\) Quotes from adults with an intellectual disability, NHC focus groups 2002.

\(^{276}\) In New Zealand, for example, the Templeton hospital had a working farm that produced much of the food for the institution.

\(^{277}\) The New Zealand Government has indicated that this Act is to be repealed. (Department of Labour 2001).

\(^{278}\) Olney and Kennedy 2001.
The development of supported employment

“The concept of supported employment reflected a reversal in our thinking about mental retardation (intellectual disability) in two ways. First, supported employment held that the issue was not whether people with severe disabilities can perform work, but what support systems were needed to achieve that goal … Second, the concept proposed that the unsuccessful ‘place and pray’ orientation … should be replaced by the more pragmatic approach of finding a job for the person with disabilities then providing the training necessary for successful integration.”

Supported employment has six core principles:

• Placement first – careful career planning and job matching are important, but there is little time spent on ‘getting ready’ for work, with people placed directly in jobs with the training and support provided on site
• Ongoing support – providing support to enable the worker to succeed and stay in work, with the intention of reducing the amount of external or paid support, with more natural supports such as co-workers
• Financial remuneration – real pay for real jobs
• Universal eligibility - the level or type of disability is not used to deny access to supported employment services
• Integrated settings – work in ordinary work settings in the open labour market
• Career development and choices – support to advance or change jobs, with choice being a central value.

Current government-funded services

The historical background of the purchase of vocational services for people with disabilities in New Zealand is complex with funding streams that could best be described as murky. Throughout the 1990s there were a number of government reviews of ‘vocational services for people with disabilities’, as at that time these services were purchased by a variety of government agencies. Policies varied between agencies and there was no clear overarching government strategy or direction for vocational services for people with disabilities. In 1998 the delivery of funding and services were consolidated with one government agency, Work and Income New Zealand, which is now an operational division of the Ministry of Social Development. New Zealand government policy for vocational services for people with disabilities is now developed by the Department of Labour. These consolidated services have a current budget of just over $60 million.

279 Rusch 1990.
280 Parmenter 1993.
A review of the strategy and aims for this consolidated funding was carried out, and released in 2001 in a document entitled *Pathways to Inclusion: Improving Vocational Services for People with Disabilities.*282 This strategy sets out two clear aims for the use of this funding:

- to increase the participation of people with disabilities in employment
- to increase the participation of people with disabilities in their communities.

The primary focus of vocational services funding is on “providing genuine employment opportunities for people with disabilities”. A number of changes are required in order to achieve this goal. This includes the repeal of the DPEP Act, so that sheltered workshops that have an ‘employment relationship’ with their workers will be required to meet all current labour legislation including the Minimum Wage Act 1983. A five-year change period has been given. Work and Income has held a number of workshops with providers to discuss the operational implications of this strategy, and additional funding was provided in the 2002 budget to assist with the cost of making the changes.

*Pathways to Inclusion* also clarified what is not considered to be a vocational service. These are services that are focused on therapy or rehabilitation, or services that are primarily providing day care or carer relief. These types of services are currently purchased by the Ministry of Health’s Disability Services Directorate, which also has responsibility for the policy that underpins their purchase. During the five-year timeframe given for enacting *Pathways to Inclusion* there is a requirement that services purchased by the Ministry of Health and those purchased by Work and Income are further clarified by transferring between the agencies any contracted services that are not an appropriate ‘fit’. This is particularly aimed at exchanging vocational services currently purchased by the Ministry of Health as part of ‘deinstitutionalisation’ packages, with those services currently purchased by the Ministry of Social Development (Work and Income) focused on day care, carer relief and therapy.

During the National Health Committee project, it became clear that there was considerable confusion amongst providers over the *Pathways to Inclusion* strategy, with many people appearing to think that the strategy was intended to cover services purchased by the Ministry of Health as well as those purchased by the Ministry of Social Development. A number of people voiced concerns such as whether their day care services for people with higher levels of disability would fit with the focus on community participation, or whether their services fitted at all with the strategic direction set out in *Pathways to Inclusion*. A number of providers have contracts with both the Ministry of Health and the Ministry of Social Development for different aspects of their service. One provider was even unclear which aspects of its service were funded by which agency, although this confusion was not common.

A complicating factor is that services are funded differently between the Ministry of Health and the Ministry of Social Development (Work and Income). The Ministry of Health fully funds the services it purchases, while the Ministry of Social Development operates a partial or contributory funding model, where only a percentage of the cost of the service is funded and providers are required to find the rest from other sources. As noted in Chapter 7: *Paying for things*, some providers utilise participants’ Disability Allowances to help meet costs. The use of the Disability Allowance to pay for vocational services (estimated to total $15 million)
Work (paid and unpaid)

is being reviewed. This is adding to providers’ concerns regarding their future financial viability.

Over the past 15 years, other Western countries have also experienced and researched service change in vocational/employment services for adults with an intellectual disability. The major changes have involved moving from traditional day centres and sheltered workshops to supported employment services. Barriers to this change identified in research include regulatory, resource, organisational and attitudinal factors. Research indicates that service change is possible, but it is also complex, costly, often difficult to achieve, and can be lengthy. The established benefits to adults with an intellectual disability of quality transition and supported employment programmes provide the rationale for why services should change. 283

Increasing participation of people with disabilities in employment

“I worked on full wages. My arm got caught in a big stream roller. I was on ACC. I came back to the vocational service. I had no choice, because if I don’t come back my benefit would have got cut back.”

“I’m no longer doing the lawns. I put pads on headsets which go out to the airport for QANTAS and Air New Zealand. It’s reasonable wages.”

“The job I had is gone. I miss it. There is not much you can do. Just take what comes. Can’t fight the big boys – the corporate world. They put us on a proper contract, similar to the employment contract. It gave us a new experience. If we had to get the job out we sometimes worked overtime. Saturday we got time and a half.” 284

Issues related to people with an intellectual disability gaining paid work, include:

- learning about work
- finding appropriate work
- having support to get to work
- learning to do the job
- getting paid
- other things that impact on work.

Many of these issues were raised during discussions the National Health Committee had with providers and in the focus groups with people with an intellectual disability.

Learning about work

A number of the people with an intellectual disability who participated in the focus groups talked about the importance of learning about work – what it is and what it entails. This includes things like having to be ‘on time’ every day, being clean and tidy, wearing appropriate clothes, and understanding about things like tea breaks and time sheets. Providers spoke of the importance of these basic skills in both getting and keeping work. Oral hygiene was a commonly raised issue.

283 Bray 2003.

284 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Work (paid and unpaid)

Some people in the focus groups were learning about things that would assist them with work – such as money skills, using a bus, telling the time, and personal hygiene. Most of this activity was called ‘pre-work’ or ‘life skills training’, and was being taught as components of their day programme, along with community participation activities. Some adults said that they had not learned these things when they were at school, and they should have. This appears to be an international issue, with one British study finding that over 70 percent of the people who took part felt that school could have taught them more skills.285

Participants in focus group, most of whom were in part-time work, talked about work experience at school. They felt this had really helped them to know about what work was and the sort of work they liked or did not like doing. Providers stated that people with previous work experience were much easier to place into paid work, as they and their prospective employers had an indication of their work skills. One provider, who had received funding for a three-year pilot transition from school programme, told us how they had worked with a number of people from the age of 14 until they left school four years later. The majority of those people had moved straight into paid employment. Some got part-time work but four found full-time work. The provider attributed this success rate to the length of time that had been spent developing the skills needed for work, and the fact that this learning had been done on the job during a range of work experience placements. This reinforced the learning and gave it relevance, and the work experience highlighted areas of further learning that may not have been evident in a classroom setting.286 The issue of transition from school to work is discussed in more detail in Chapter 10: Learning new things.

Finding appropriate work

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

“I do commercial cleaning. I fill in for people who are sick anywhere. I’ve had heaps of work experience, but that always leads to nothing.”

“I used to work at the pet shop up the road, I think for about eight years. I was working up there half a day, once a week.”287

Feedback from focus groups and international and national research indicates that finding appropriate work can be a major barrier. There is significant prejudice and concern about people with an intellectual disability fitting into the workplace. Occupational Safety and Health (OSH) issues are frequently raised as a reason for not providing employment or work experience. Many providers also stated that with the major emphasis by government on getting people into work, there are now a growing number of agencies (including Work and Income and District Health Boards) seeking work opportunities. Employers, particularly in smaller provincial areas, were getting sick of being constantly approached, which was making it increasingly difficult to find work.

Balanced against this, people with an intellectual disability are usually stable and reliable workers, work with consistency, are loyal and are good at repetitive tasks. Some employers

286 Interestingly one US study (Hasazi et al 1985) showed that the most significant predictor of employment was involvement in paid part-time or summer jobs during high school. Work experience as part of the school programme was not found to be a predictor of employment.
287 Quotes from adults with an intellectual disability, NHC focus groups 2002.
commented on the benefits of having a ‘textured’ workforce – “he’s so punctual and reliable it gives my other workers a boot about their own punctuality.” Providers agreed that the challenge is to get an employer to focus on a person’s abilities not their deficits, and then the issue of ‘culture fit’ can be addressed. Many people spoke about how ‘getting in the door’ was often done by unpaid work experience, but people with an intellectual disability had many stories that indicated this did not always lead to paid work. Casual, part-time and seasonal work appeared very common, and this experience is supported in the literature.

Research indicates that employers’ perceptions of their employees with disabilities is clearly an important factor in their attitudes towards employing other people with disabilities. One study showed the three most significant factors relating to people retaining their jobs were attendance, punctuality and consistency in job performance, and that it was not related to workers’ severity of impairment. A study of 120 corporate executives found that the three key variables associated with positive attitudes towards employing people with an intellectual disability were:

- previous contact
- hiring experience
- large organisations.

**Learning to do the job**

On-the-job training and support can be provided in a number of ways, ranging from a job coach working beside the person with an intellectual disability, to utilising the usual training and support offered to new staff. Due to the nature of intellectual disability, learning new things takes longer than it does for people without a disability. It is important that instructions are given in short, easy to understand ways. Like all new staff, people with an intellectual disability need to be shown what to do and how to do it, with an awareness that this may simply take a little longer, or require the ‘try another way’ approach.

One role of a job coach or support worker can be to assist the employer to adapt the job to the person with an intellectual disability. An employer in a garden centre, reported that he quickly realised his usual watering instructions of “water plant bays a, b, c, d” were not easily understood or remembered. He therefore adapted the way he gave the instruction. He replaced his long verbal instruction with physically walking along the bays with the employee with an intellectual disability, pulling out one plant from each bay he wanted watered and placing it in front of the bay. His employee with an intellectual disability could then easily identify which bays to water, replacing the plant once he had completed that bay, ensuring the task was done well and in the same timeframe as a non-disabled employee. The same employer rapidly learned that the potting machine, which was usually run at 8 on the speed indicator, needed to be placed on 4 for his employee with an intellectual disability. Over time, as the employee became more skilled at the task, this speed was able to be increased to 6.

A regular comment from both people with an intellectual disability and service providers was that funding constraints meant that on-the-job support was less than optimal. For many people, support meant attempting to build on the natural supports in the workplace, perhaps by ‘buddying’ the person with an intellectual disability with another employee. While there were instances where this worked well, unkindness and intolerance in the workplace was often an issue, particularly in larger repetitive type workplaces where practical jokes and

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Work (paid and unpaid)

‘winding people up’ relieve the boredom of the work. A number of instances were cited where this type of workplace culture meant that it was unsafe for the person with an intellectual disability to work without support.

Another comment was that support needed to be available for as long as the person required it, and to be driven by the employee’s needs and not the funding or timeframe restrictions. One study of the actual activities performed by job coaches found that both coaches and employers identified the three activities importance as:

- regularly seeking feedback about the employee’s job performance
- impromptu check-ups
- providing additional supervision when needed.

Other valued activities included:

- assisting in clarifying work
- mediating interpersonal relationships with co-workers
- assisting with negotiating benefits and wages
- providing information about non-work issues that might affect the job
- solving health and safety concerns
- providing ‘spot’ training
- increasing speed and efficiency
- training to increase the breadth of duties
- assisting co-workers to provide support.  

Another quite different role is the provision of personal assistance to employees. This personal assistance role is about removing the barriers created by the employee’s impairment, helping them with personal things such as mobility, using the toilet, and some job function duties (such as making phone calls or reading documents). The personal assistance is determined by the nature of the person’s impairment and in New Zealand this support is available through a separately funded programme administered by Workbridge on behalf of Work and Income. Funding for this programme is capped and therefore access is limited.

Getting paid

“We all get paid, but some of us get a little bit more than others because of skills and ability.”

“I work two days a week at three dollars an hour.”

“I work at a rest home – no pay. Really hate it. I really need money. I can’t afford anything. I can’t afford cat food at the moment.”

Once the person with an intellectual disability is in a job, and has had some preliminary training and support, the issue of whether they are earning the market wage for that job needs to be considered. Currently in New Zealand if the answer is “no”, because the person is not producing at the same rate as a person without a disability, the question to ask is “why not?”

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290 Workbridge is a national vocational provider contracted to place people with disabilities in open employment.
291 Quotes from adults with an intellectual disability, NHC focus groups 2002.
If the answer is that they need more time to learn, with more training and support, there are a number of training options available. These include both mainstream options available to all people and options specifically for people with disabilities.

Many of these training options can be accessed through Work and Income (Ministry of Social Development), although comments made during the National Health Committee project indicated that this is not happening for a number of reasons. Firstly, not all people had sufficient support to recognise their training needs, or to access the help available. Also, many support workers appeared unaware of the range of government support available and others reported that there was some prejudice amongst Work and Income staff about people with an intellectual disability accessing mainstream assistance. In addition, there did not seem to be widespread use of the wage subsidy options available while on-the-job training was occurring.

There are at least two wage subsidy schemes that can be accessed through Work and Income. Job Plus is a mainstream option providing a wage subsidy up to the minimum wage for all people and available for six months. Job Plus Disability offers the same subsidy, but is available for 12 months. After the 6- or 12-month time period, or earlier if a person is operating at their full capacity, their productivity may still be below that expected for the market wage for that job. In this instance there is a process to determine a fair wage for the work they are doing, through an Under-Rate Workers Permit. This permit allows a rate to be set below the minimum wage. It is operated through a Labour Market Inspector and wage levels are determined on an individually assessed basis. The policies and procedures associated with this process are currently being reviewed.

In considering payment for work done, the issue arises of how to assess productivity, and who should assess it. How productivity can be measured in a way that is feasible and fair is currently being debated as part of the review of the Under-Rate Workers Permit. All people seem to agree that any such assessment must be done over a range of times and days to provide a fair measure.

The traditional model is that if productivity is lower than the norm, it is the individual who must make the accommodation, by getting paid less than others to do the job. In New Zealand, the severity of this is mitigated by the safety net of income support. While there is no limit to the number of jobs that can be created under this system, time and fiscal limits to wage subsidies mean that many people end up receiving a mix of wage and benefit. The current benefit system is complex, with a wide range of impacts and abatements of benefit linked to income earned, and this creates some serious disincentives to work. The benefit system is described in more detail in Chapter 7: Paying for things.

The social model of disability, which is the basis of the New Zealand Disability Strategy, is that the accommodation is made by the state or labour market, rather than the individual. For example, more support and training can be provided to the person. Alternatively, the state can provide a wage subsidy that ensures the person receives the market wage for that job. Another option is for the labour market to make the accommodation by ‘job carving’ or job creation. ‘Job carving’ is where the job description is altered to fit the person’s abilities by taking tasks they are able to do well from other people’s job descriptions. Job creation is where a similar process is used to create a completely new job. While some aspects of this

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292 The New Zealand Disability Strategy is described in Chapter 3: History of service provision.
social model are available in New Zealand they are restricted by the time and fiscal limits placed on job support and subsidies.

Other things that impact on work

“\text{I just about like doing anything, but I don’t like working at great big factories – I get lost too easily.}^{293}$

During the National Health Committee project, many vocational providers indicated that an important role they play is to assist and support adults with an intellectual disability with other life issues that impact on their ability to work. These include areas such as budgeting and financial management, managing travel, clothes and personal hygiene, personal relationships including sexual relationships, and accommodation and issues with flatmates. Some providers offered this type of assistance ‘in-house’ while others acted in an advocacy role and/or arranged for another agency, such as the Budget Advisory Service or Family Planning, to provide support or advice.

Vocational providers were very clear that this role was an extension of the support normally expected from an employer. While most employees expect and experience some personal support from their employer in times of crisis, the reported level of personal support required by many people with an intellectual disability is much greater. Similarly, while everyone has workmates, family/whānau or friends who provide ad hoc support when it is needed, the need for this support is often much greater for people with an intellectual disability. The nature of having an intellectual disability means that learning new things, awareness of interpersonal issues and knowing how to deal and think through issues can be difficult. Examples given ranged from issues in the workplace, such as using other people’s coffee mugs or sitting in the wrong chair at morning tea, to problems with out of work activities, like incurring serious debt through phoning 0900 numbers or being at risk because of unsafe sexual behaviour. While it is very clear that this is a role that needs to be filled, it is less clear how this should be provided or funded.

Other barriers to work

In addition to barriers already discussed, such as poor transition from school to work and the difficulty finding appropriate work in a supportive work environment, other issues identified during the National Health Committee project were:
- lack of clear processes for vocational service needs assessment
- that funding of training and support services is inadequate and the quality of services is variable
- that, like all employees, adults with an intellectual disability need ongoing career development
- that many adults with an intellectual disability need small levels of ongoing support in the workplace or support at times of change or crisis
- that to be eligible for an Invalids Benefit a person can work a maximum of 15 hours a week. It was clear during the focus groups that a significant proportion of adults with an intellectual disability are able to work more than 15 hours a week, but are not able to work sufficient hours to earn a viable wage

$^{293}$ Quote from an adult with an intellectual disability, NHC focus groups 2002.
Work (paid and unpaid)

- the benefit abatement process for people who receive an Invalids Benefit and have income over a specific limit is complex and difficult for adults with an intellectual disability to understand.

Alternatives to work – vocational and day services

“I should be paid for the work I do. Instead I have to pay them to come here.”

“I have been at two services and I have hated both of them. I didn’t really like none of the jobs, ‘cause they were just doing little kiddy things. None of these places pay me enough to come.”

“We do woolcraft. I enjoy it and do different things with my hands.”

“I work here four days a week and Fridays is my home day. I don’t think I should come to this service because I don’t get paid. I have to pay to come here and that stinks.”

During the National Health Committee project, many adults with an intellectual disability and their families/whānau expressed 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.

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/whānau were particularly vocal about the impact vocational and day services had on their lives.

As mentioned previously, people attending a vocational service are often required to pay an attendance fee, which comes from the individual’s Disability Allowance. This was seen as inappropriate by many of those taking part in the NHC focus groups.

Leaving the workforce

Older adults with an intellectual disability need appropriate transition support 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, for some people this transition may 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.

294 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Work (paid and unpaid)

Key issues

- Many adults with an intellectual disability have similar work aspirations as others of the same age. They want to work, in ‘real’ jobs that are paid.
- Historically most adults with an intellectual disability were perceived as unable to work in paid employment, and it was the responsibility of the state to provide supervised daily activities or unpaid work.
- Many vocational and day services do not have a developmental or future-focused approach and the activities undertaken are seen by adults with an intellectual disability as time-wasting.
- Sheltered employment options developed from growing dissatisfaction with segregated services and the principles of normalisation and integration.
- Work experience at school is effective in teaching young adults with an intellectual disability about work expectations.
- Attitudes about people with an intellectual disability and lack of knowledge about support and training available are barriers to finding appropriate work.
- On-the-job training and support is important, particularly when an adult with an intellectual disability begins a new job.
- A significant proportion of adults with an intellectual disability are able to work more than 15 hours a week, which would mean they would not be eligible for an Invalid’s Benefit, but are not able to work sufficient hours to earn a viable wage.
- Older adults with an intellectual disability need appropriate transition support to move out of work or vocational services, when appropriate.
9. BEING PART OF THE COMMUNITY

"... it is apparent that whilst people with intellectual disability may physically occupy a place within a residential house in a suburban neighbourhood, it does not automatically follow that this person is part of the local community."\(^{295}\)

This chapter:
• considers what is meant by ‘community’ and ‘participation’
• outlines the findings of research about the community participation among adults with an intellectual disability
• describes how community participation can be encouraged and supported.

**Living in the community**

> “Putting the residents into the van, driving to the shop, having them wait in the van while you hop out and buy the ice creams, taking them back to the van where residents stay and eat their ice creams, then driving everyone back home again, is NOT community participation.”\(^{296}\)

With the exception of the few people with an intellectual disability still living in special hospitals or hospital wards, the vast majority of adults with an intellectual disability in New Zealand live in homes in a suburb of a town or city, either with their families or with other people with an intellectual disability.

Simply living ‘in the community’ does not necessarily mean that a person will necessarily take part in that community. Much of the literature on community participation makes a clear distinction between being located in the community, and actively participating in that same community.

The vision the New Zealand Disability Strategy\(^{297}\) has for people with disabilities is of “a society that highly values our lives and continually enhances our full participation”\(^{298}\). This vision is based on the social model of disability, and identifies and challenges the community’s role in the construction of disability. This means that simply trying to ‘fit’ adults with an intellectual disability into existing structures and community activities, without addressing attitudes of discrimination, devaluation and rejection is bound to fail.\(^{299}\) To make participation work for everyone, the community may need to change too.

\(^{296}\) Comment from a service provider 2002.
\(^{297}\) The New Zealand Disability Strategy is described in Chapter 3: History of service provision.
\(^{298}\) Minister for Disability Issues 2001.
\(^{299}\) Bray and Gates 2003.
Being part of the community

The other New Zealand government strategy that relates to community participation is Pathways to Inclusion, one aim of which is “to increase the participation of people with disabilities in communities”.\(^{300}\) Pathways to Inclusion is discussed in more detail in Chapter 8: Work (paid and unpaid).

Community and participation

The concept of ‘community’ is often highly debated, and there is a considerable body of theoretical discussion.\(^{301}\) The general concept is that community is a geographical place that includes the ordinary and varied activities of its citizens, or as the DPA (New Zealand) puts it, “ordinary people doing ordinary things in ordinary places”\(^{302}\). It may also be seen as including sub-communities and communities of interest.

Some proponents of institutional care have argued that an institution, including ‘special communities’ and ‘sheltered villages’, is a community in its own right. However, the usual understanding of community and communities does not encompass segregated ‘communities’ as a total way of life except by personal choice, such as a religious community. Being limited to participation in one isolated ‘community’ is not what people with disabilities, nor the general public, conceive of as community participation. Disability literature regards ‘community’ as the opposite of segregation or isolation into special facilities, or of services that only include people with disabilities and the people paid to support them. People without a disability move between a number of different communities to reflect different aspects of their lives, enhancing their choices and experiences, and people with an intellectual disability want this too.

Community is not simply a location, as in ‘living in the community’. It is about people and place – a range and variety of people, in a range and variety of places. Another essential component of the experience of community is a personal feeling of belonging, including experiencing support and control over one’s life.

‘Participation’ means being involved in the social life of the community through a growing network of personal relationships.\(^{303}\) Community participation also requires a consideration of the many and varied roles that individual community members fill, for example, tenant, employee, volunteer and so on. Community participation includes citizenship, which can be described as “about a person’s capacity to fully participate in all dimensions of social, political and community life”.\(^{304}\) This means people participating in decisions that affect their lives and that community participation is an active process not a passive one.

\(^{300}\) Department of Labour 2001.
\(^{301}\) Bray and Gates 2003.
\(^{302}\) DPA (New Zealand) is an umbrella organisation representing people with disabilities, the organisation involved in advocacy on their behalf, and service providers.
\(^{304}\) Ryan 1997.
The reality of community participation

While community participation is widely espoused as a positive process and goal for adults with an intellectual disability, there is surprisingly little research that presents the views and experiences of people with an intellectual disability about ‘community’. Most of the research on community participation has focused on the number and types of activities and social relationships of adults with an intellectual disability. However, one study in 1999 provided an in-depth examination of the experiences of seven adults with an intellectual disability. It found that:

- they spent significant amounts of time in places designated for people with disabilities. These places included not only separate locations but also separate spaces within larger settings that included other people
- these separate places spanned most dimensions of daily life – educational, residential, work/day activity, and leisure time
- they also all participated in some community settings with other people without disabilities
- they spent very little time in the private social worlds of other people apart from their immediate family
- most of their time outside home or work was spent in public places, such as city streets and shopping malls
- most of the community places they visited focused around business transactions, which provided few opportunities for social interaction with other members of the community, unless they involved regular contact with the same people, for instance, a small local shop.

Research studies around the world show that many adults with an intellectual disability only participate in their communities to a very limited degree. These studies have also begun to identify what factors are necessary to create real community participation.

Participants in the NHC focus groups spoke about a variety of activities they did in the community. These included belonging to clubs, going to church, attending community classes, going to the pub and belonging to groups and organisations. Many commented that this required significant support from either staff or family members. Lack of transport, attitudes of other people and difficulties with communication were particularly identified as barriers to community participation. These issues are discussed in more detail in Chapter 13: Moving around, Chapter 11: Relationships and Chapter 6: Communicating. Chapter 12: Having fun discusses issues around recreation and leisure.

More than simply ‘living in the community’

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

> “I go to church on Saturday with Mum.”

> “I’ve got a neighbour who I like very much. I don’t go into their house and see them. I want to keep to myself.”

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305 Bray and Gates 2003.
307 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Being part of the community

A 1990 Welsh longitudinal study of the community activities and social networks of 318 people with an intellectual disability (the majority of whom lived with their families) found participants were involved in a range of community activities, with the most frequent being shopping, going to the pub, and swimming. However, further analysis of the activities showed that many of the more social activities involved groups of people with an intellectual disability, and only a small number of people took part in activities that had the potential for wider social contact. Family members and staff played a major role in arranging and providing these activities.308

Another study found patterns of very little social contact between adults with an intellectual disability and typical members of their local communities.309 While there was great variability across the 23 people directly observed, on average social contacts only occurred once every two days, and relationships seldom continued for more than 12 months, except for family or ‘best friends’. While there is no comparable information about the social contact patterns of people without disabilities, if one of the goals of community participation is a feeling of community belonging, the issue of social relationships and networks is of critical importance.

Social networks usually include two aspects – the people described as important to the individual, and the people with whom activities are undertaken. Many adults with an intellectual disability rely on paid staff or other adults with disabilities as sources of social support. This reliance reinforces the likelihood of limited opportunities for community participation and for the development of other sources of social support.310 Social networks are discussed in more detail in Chapter 11: Relationships.

As has already been indicated most of the community places visited by adults with an intellectual disability involve business transactions. An Australian study in 2001 of the rhythms and patterns of community life of 65 residents from 34 group homes in two urban and one rural area of New South Wales, found that all residents had some involvement in their communities. The number of community places used in the last three months ranged from two to 15, with an average of just over nine. The most commonly used were restaurants and the park, which were used by 92 percent of participants. Only 31 percent used the bus stop or train station, 29 percent went to watch live sport and 25 percent used a playing field/sport/exercise facility.311

When this study looked at the number of community places used without staff support, the average was less than one. In other words, without the support and assistance of paid staff, much of this interaction would not have occurred. A similar study a year earlier of more independent group home participants found that fewer than 25 percent used any community places without staff support.312 The individuals who did access community places independently (without staff support) tended to do so more frequently, presumably because they did not have to wait for staff help.

308 Bray and Gates 2003.
311 Bray and Gates 2003.
Being part of the community

A sense of belonging in the community can only be achieved through social relationships, networks and acceptance. Without repeated social contacts, an individual has little chance of gaining acceptance by members of a community.

More than increasing the number of community activities
The 1999 study that involved in-depth examination of the community participation of seven adults with an intellectual disability found that not all community experiences were the same. The seven adults who took part in the study:

- experienced the greatest sense of vulnerability in unfamiliar places, places they were sent against their will, and places where they witnessed frightening behaviour, felt rejected or experienced a lack of support
- did not want to go where they had had negative experiences, and positively identified with places associated with personal choice, interest and positive social interaction
- felt more isolated in large public places, even if they went there regularly, compared with small groupings of people where they went by choice on a regular basis and amongst whom they felt ‘known’
- were more likely to experience positive interactions in places where they chose to go, that included people of their own choosing, focused on social rather than business transactions, and where they felt supported
- found familiarity was a factor in community participation. This included knowing the routines or rituals associated with various places or contexts and knowing what to do
- were very aware of places where they could expect support or accommodation of their needs, but in some community places were never sure if support would be available.  

These findings show that simply increasing the frequency and variety of community activities will not necessarily increase positive experiences.

Supporting greater self-determination and community participation

"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."  

Staff and families have a critical role in supporting adults with an intellectual disability to participate in their communities. For instance, by being overprotective families can limit people’s entitlement to ordinary friends and community resources.

The questionnaire in the Australian study included an item about the ways in which residents contributed to their local community. Seven different types of community contributions were listed, such as volunteering or being an active member of a service club. Overall, 91 percent of people made no contribution to the local community. Of the nine contributions that were made, seven came from four participants who lived in two group homes. This supports the finding from other research that the most critical influence is what family members and support workers do to encourage greater self-determination and support community participation.

313 Walker 1999.
314 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Being part of the community

The following example from the study shows the impact that support staff can have on community participation. In this situation four women with severe intellectual and physical disabilities moved from an institution into a group home in the community.

“The group home manager, who is someone with many years’ experience in the disability field, took an active approach to introducing them to their new neighbourhood. In addition to inviting neighbours in for a ‘house warming’ barbeque, the house manager and other staff take it in turns to mow the lawn of an adjacent elderly neighbour who is no longer able to do this for himself. The women, whose disabilities preclude them from participating directly in this activity, are present when this act of neighbourliness occurs and have undoubtedly benefited from the ‘good will’ towards the household which has generated not just from the neighbour himself but from others in the street who have observed and discussed it. The manager also makes a point of the women being present in the front garden while staff garden etc at their own house, and inevitably passing neighbours stop to chat or just wave to say hello. The examples seem trivial but they make a huge difference…”

Research shows that deliberate strategies to train staff to assist people with an intellectual disability to have positive experiences of community participation bring good results. A 1993 study evaluated a ‘social guide model’ used to train residential staff to use a set of ‘community network strategies’. It found that staff training clearly resulted in an increase in both the size of residents’ social networks and experiences of social interactions, and these increases were maintained during the follow-up. A 1997 study looking to identify and reduce barriers to social participation for a group of people with severe disabilities, found that staff support can have a variety of unintended consequences, such as removing the need for simple instances of support from peers, and engaging an individual in a ‘social bubble’ that others find hard to penetrate. The study went on to introduce a number of strategies that were responsible for increasing the number of social companions, increasing the number of social activities, and making a positive change in the stability of some relationships.

The strategies included:
- a personal scheduling book and weekly scheduling of social activities, to reduce the barrier of difficulties in scheduling social activities
- a personal information sheet to reduce difficulties in making social introductions to new people
- a friendship form to enable staff to identify available social companions
- a photo address file and a photo activity file to enable the group with severe disabilities to express their preferences for people and activities
- weekly feedback to enable staff to get feedback and ‘keep track’ of the adults’ social lives.

A study that explored the views of people with an intellectual disability found that 48 percent of people living at home wanted to extend their community networks and friendships, but service providers were constrained by the often overprotective views of families. Huge amounts of staff time went into dealing with the family so that community participation and extending friendship could become possible. The study confirmed that more community participation was often a goal or a hope of the person with an intellectual disability, but other

316 Newton and Horner 1993.
key people in their lives may not share that vision, or may not have the time or resources to help them.318

**Choice, autonomy and self-advocacy**

“It seems that individuals are more likely to be involved in community activities when they have a voice in making decisions in the facility where they live.”319

A study in 1992 found that the majority of adults with an intellectual disability had no choice regarding when they went out with friends or how they could spend discretionary money.320 Another study found that the more a person was involved in policy making within the residence, the greater their community integration.321

Independent of whether they influence other outcomes or not, choice and autonomy are important basic rights. Having autonomy is also linked to the dignity and respect that adults are accorded. The importance of choice and autonomy is identified in the research and literature on ‘self-determination’. One approach to creating ‘self-determination’ involves:

- providing individuals with adequate opportunities to be the causal agent in their lives, make choices and learn self-determination skills
- enabling them to participate to the greatest extent in their lives and communities
- ensuring that supports and accommodations are in place.322

One example of supporting adults with an intellectual disability to improve their participation in community life is built on an existing forum for service users to influence service provision.323 The forum was redeveloped to foster greater sharing between adults with an intellectual disability of each other’s experiences, and to “foster a sense of shared identity and consciousness”. It was considered that opportunities for talking together and developing shared understandings about life experiences can provide the basis from which adults with an intellectual disability “begin to see themselves as members of a community, with the rights and obligations of citizens, rather than customers in the narrower field of service provision”. It can also help people to develop concerns about others, leading to possibilities of collective action. Since the 1990s there are numerous examples of the ‘self-advocacy’ movement providing valuable opportunities for the development of a positive identity and an active collective role in community action and participation.324

In New Zealand, as in many other countries, People First has developed as a self-advocacy group for people with an intellectual disability. Advocacy and self-advocacy is covered in more detail in Chapter 5: Communicating.

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323 Ryan 1997.
324 Bray and Gates 2003.
Being part of the community

Key findings

- Community participation for adults with an intellectual disability is an achievable goal with assistance and support.
- Location in the community does not necessarily increase community participation.
- Family and staff can be facilitators or inhibitors to effective community participation.
- A ‘sense of belonging’ in the community can only be achieved through social relationships, networks and acceptance.
- Without repeated social contacts an individual has little chance of gaining acceptance by members of a community.
- Training staff to assist people with an intellectual disability to have positive experiences of community participation can be effective.
- How adults are treated as citizens within the support services they use is important for community participation.
10. LEARNING NEW THINGS

“While the last 20 years have seen growing support for the inclusion of (disabled) children and young people in mainstream educational settings, it has only been recently that attention has been paid to adult education for people with an intellectual disability.”

This chapter:
- outlines the international literature on the transition from school to adulthood
- describes transition policies and practices in New Zealand
- looks at adult education and lifelong learning.

Transition to adulthood

“Although individuals and organisations go through many transitions during their lives, the transition of students with disabilities from school to life after school has emerged as a particularly crucial one, often affecting later participation rates in employment and further education and training, as well as quality of life.”

“Transition” is the word generally used to refer to the process by which students with disabilities (including those with an intellectual disability) move from the school environment to adult lives in the community.

In New Zealand, disabled students with high level needs can stay at school until they are 21 years of age. Under the Education Act 1989, all children from five years old are able to attend their local school until the end of the school year in which they turn 19. Students with a Section 9 Agreement or who are in the Ongoing and Reviewable Resourcing Schemes (ORRS) can stay at school until the age of 21. The Ministry of Education advises that over the past four years, 60 percent of ORRS students who left school did so at age 21. To

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325 Mirfin-Veitch 2003b.
326 Riches 1996.
327 Mirfin-Veitch 2003b.
328 A Section 9 Agreement is an agreement between a parent or caregiver and the Secretary of Education for a child or young person to enrol at a special education facility.
329 Ongoing and Reviewable Resourcing Schemes (ORRS) are part of the Government’s special education support package to provide funding for students with high and very high special education needs. ORRS provide funding for extra teaching, specialist programmes, therapy, consumerables, and education support. Students are verified for the ORRS by a panel appointed by the Ministry of Education as having very high, high or combined moderate needs that are likely to be ongoing throughout their schooling years.
Learning new things

remain at school until age 21, these students would have been attending either a special school or a special unit, which provided a programme designed to meet their needs.

For students with an intellectual disability to remain at secondary school until age 21 is a common policy in other countries as well. Internationally, a growing number of parents, researchers and practitioners have questioned whether this practice is age-appropriate. They have advocated for these students to receive instruction in similar settings to those experienced by their peers without disabilities.331 Research has confirmed the advantages of age-appropriate post-secondary educational opportunities for young adults with an intellectual disability.332 One factor contributing to the trend of remaining at school until age 21 is the lack of appropriate services outside the education sector, to meet the requirements of young disabled adults with high level needs.

Transition to adulthood as a complex process for all young people involving such milestones as gaining citizenship and taking self-responsibility. This transition is a particularly complex and complicated process for young disabled people.333 For young people with an intellectual disability, one of the most challenging aspects is fostering and aiding the transition to adult roles that are both stimulating and valued by society.334

There is a small, but growing, body of literature that provides some insight into how young people with an intellectual disability view transition in their own lives. A study in the UK of student expectations and experiences of transition found that young adults with an intellectual disability (much like their non-disabled peers) display a range of feelings at the prospect of leaving school. When asked about the future, participants in the study had clearly thought out aims and aspirations. In regard to moving out of the family home, some were very keen and positive while others felt ambivalent or were anxious at the thought of living away from their parents. Furthermore, respondents had made the link between employment, earning money and being able to achieve a more independent lifestyle.335

As Chapter 11: Relationships indicates families/whānau (in particular parents) have a significant influence over the decisions that young adults with an intellectual disability make, and their views about themselves. Families/whānau usually remain the primary ‘service coordinators’ for their sons and daughters, even after they have left school.336 Overseas research looking at parents’ views of transition indicates that parents do not simply see this as a move from school to work, but as a major family event that signifies a total life change for all concerned. Parents identified barriers to transition as waiting lists for adult services and the poor social networks that are common among children with an intellectual disability.337 Anecdotal information from supported employment providers in New Zealand suggests that often the parents of disabled students are focused on dealing with immediate challenges and therefore do not plan for the future or set post-school goals with their young adult offspring.

331 Mirfin-Veitch 2003b.
332 Mirkin-Veitch 2003b.
336 Mirfin-Veitch 2003b.
Transition planning

Transition planning is a process that is utilised in many countries to assist young adults with an intellectual disability to move from the school environment to adult roles. The focus of transition planning is the development of a formal, individualised transition plan. This plan may cover employment, recreation, post-secondary education, self-determination, and community living and participation.  

Transition planning is expected to take account of student views, preferences and interests, however, overseas research studies of young adults’ experiences, show considerable variation in the level of student involvement and input into transition planning. In the UK study, mentioned previously, many of the young people were less than enthusiastic about the yearly review meetings intended to chart the progress of individual transition plans. Others were more positive and saw the meetings as an opportunity to talk about their goals and how to achieve them. Another research study concluded that successful transition must include outcomes that match student preferences, interests and dreams for the future. Transition goals and outcomes are often based on other people’s perceptions of the likelihood that the goals will be achieved, rather than on the student’s choice. It has been suggested that self-determination is an important educational goal if youth with disabilities are to enjoy more positive adult lives.

Achieving student involvement in transition planning and decisions about their own futures, requires parents, families and schools to gradually allow students to assume increased levels of responsibility for themselves. This process involves parents relinquishing some control and supporting their young adult sons and daughters in this new ‘risk taking’ role.

One specific area of concern for many of the young adults interviewed in overseas research studies was the ways in which information was presented during transition planning. They expressed frustration at the use of long words and some suggested that it would be more helpful if pictures were used. In some instances video was used to try and make information accessible, but this was not necessarily positively received as it precluded the opportunity to ask questions of the presenters.

In addition, study participants highlighted that transition planning should not focus exclusively on employment or day activities, but should be about a whole range of issues that affect young people as they approach adulthood, including housing, income support and health. Other research studies have identified the importance of personal dimensions such as satisfaction, self-esteem and empowerment. The key factor in personal satisfaction has been found to be the existence of social networks, rather than employment.

Transition is a process rather than a set programme. The style or focus of transition planning will differ between students. Research has found differences in the importance of

338 Mirfin-Veitch 2003b.
341 Mirfin-Veitch 2002.
346 Riches 1996.
Learning new things

some activities for students with ‘mild’ disabilities compared with those considered to have ‘severe’ disabilities. For instance, interagency collaboration, transport and case management were perceived as more critical for students with a ‘severe’ intellectual disability.[^346] The research literature emphasises that particular attention needs to be paid to the requirements of young people with high support needs, as this group has been identified as failing to achieve positive adult outcomes.[^348]

A study which looked at the transition experiences of young people leaving special schools in the UK highlighted the difficult dichotomy between the aspirations young people (and in many cases their parents) hold regarding employment and the fact that real employment opportunities remain scarce for this group of young people.[^349] While students’ aspirations and goals may be realistic, other factors like competition for jobs in a specific employment area or negative attitudes by employers reduce the likelihood of a young adult with an intellectual disability getting the job they want.[^350] Furthermore, successful work placement is dependent on the approach and attitudes of both employer and employee. Education of potential employers can be an important part of the transition process. Overseas research also shows that students who have received work experience as part of their school vocational education programmes are more likely to maintain competitive jobs.[^351]

During the National Health Committee focus groups a number of young adults spoke about their experiences of work placement while they were at school.

> “School had a list and we could choose which ones we wanted to do. Some people got jobs from that full-time. That’s if there was a vacancy.”

> “When I did work the school had a list and we made a choice of the company and had to write a letter to see if they would take us on work experience.”

### Barriers to transition planning

A UK study noted that both parents and young people with an intellectual disability highlighted consistently the limited post-school options available. The study concluded that transition planning is meaningless if there are no options, services or support at the end of the process.[^352] From a student’s perspective, transition planning is not a positive experience if their deficits, rather than their achievements and skills, are emphasised.[^353]

Another barrier to successful transition planning can be attitudes of school staff and service providers about what young adults with an intellectual disability can achieve. Expectations by professionals about employment, community living and community participation may be more restrictive than those of the young adult. Furthermore, school personnel may not have adequate information about services available to assist adults with an intellectual disability in employment and daily life.[^354]

[^348]: Mirfin-Veitch 2003b.
[^351]: Knight and Aucion 1999 cited in Mirfin-Veitch 2003b.
Learning new things

Critical factors for transition planning
Factors identified in research as being critical to effective transition planning are:

- participation by the student in a way that is empowering and focuses on his or her aspirations and goals
- whole-of-life planning, which focuses on education and training, employment, financial security, housing, individual support needs for community living, community participation, recreation and leisure, friendships, satisfaction and choice
- effective coordination of services identified by the whole-of-life approach
- flexibility, with the process and content based around each student’s requirements
- opportunities for relevant work experience.

Transition planning in New Zealand

“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.”

The literature review on education prepared by the Donald Beasley Institute summarises the section on transition planning by listing the components needed to achieve the aim of supporting New Zealand young people with an intellectual disability to experience fulfilling adult roles within their communities. As well as the factors already identified, the literature review suggests there is an urgent need for intersectoral, strategic policy and operational planning in the area of transition services. Another key factor is ensuring that transition planning and the services into which the young adult moves are culturally appropriate for them.

The Ministry of Education encourages transition planning for students with special education needs. One of the principles of the Special Education Policy Guidelines is that “young children and students with special education needs will have access to a seamless education from the time that their needs are identified through to post-school options”. The guidelines note that to achieve this requirement, transition procedures need to “enable … students to move successfully from one education setting to another, or to a workplace”.

In its advice to teachers, support staff and parents/caregivers, the Ministry of Education suggests that transition planning begin around age 14. By the time the student is 16 years of age, the development of an Individual Transition Plan should have begun. It is expected that the planning process will involve the student, their parents or caregivers, relevant staff at the school and specialised staff from the Ministry of Education. The Ministry strongly advocates that ORRS resources be used to support transition, work experience and community participation. This can involve teacher aides becoming job coaches, and additional teachers (who are employed to work closely with disabled students) brokering work experience opportunities and developing partnerships with providers of services. It is noted in the Ministry’s advice that involving representatives from relevant services in the community for

355 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
356 Mirfin-Veitch 2003b.
357 Mirfin-Veitch 2003b.
Learning new things

12 to 18 months before the young person intends to leave school will encourage smooth transitions.

The Ministry of Education reports that in the year from 1 July 2000 to 30 June 2001, there were 316 planned transitions for students from school to post-compulsory settings. This represents seven percent of the population of students in compulsory education receiving ORRS funding.\(^\text{359}\) In collecting data on transition planning, the Ministry of Education noted that there is a lack of services available for young people with disabilities transitioning from school into post-compulsory settings, that these services are fragmented and there is considerable regional variation in availability of services. This lack of services for young adults is consistent with findings in international literature.

Very high needs school leavers
The Ministry of Social Development (Work and Income) funds tailored packages of post-school transition support for young people who have very severe disabilities and stay at school until age 21. This support is only available to young people who have been verified by the education system as having very high needs, and is provided to fewer than 100 people per year. These students are individually identified by the Ministry of Education. The funding is provided on an individual basis and Work and Income’s national office works directly with the parents or caregivers of the young adult to identify preferred options and providers. This may be to attend a vocational service, move into a community residential setting or, in areas where appropriate services are not available, to consider options like the family moving location or the young adult moving to a ‘residential’ service.

As this funding for very high needs school leavers is generally only available to students who stay at school until age 21, it provides an incentive for this group of young adults to remain in the school system until they are 21. Work and Income can also provide a small amount of funding to vocational services that take on school leavers who have moderate to high needs.

Policy interface issues
In the provision of work experience to students at school, there appears to be an interface issue between the education and employment sectors. Service providers have indicated that vocational agencies funded through Work and Income, such as Workbridge, are not permitted to work with students who are still at school, because this is perceived as double-dipping. Likewise, students receiving ORRS funding cannot access government-funded vocational services. One way of removing this impediment would be for Votes Education and Social Development to jointly fund transition planning.

In September 2001, Pathways to Inclusion: Improving Vocational Services for People with Disabilities, made recommendations about the vocational services that are funded by Work and Income.\(^\text{360}\) This review stated that, in general, only people with disabilities aged between 16 and 65 were eligible for vocational services funded by Work and Income. However, one of the actions identified in the review was that Work and Income is to “work with other agencies to ensure smooth transitions from school to work …”.\(^\text{361}\) Policy work to implement this action has begun.

\(^\text{359}\) During this period there were 4,482 primary and secondary school students receiving ORRS funding.

\(^\text{360}\) More detail about the review is covered Chapter 8: Work (paid and unpaid).

\(^\text{361}\) Department of Labour 2001.
A further component of successful transition, identified in the Donald Beasley literature review on education, is ensuring flexibility in the income support system to encourage young people with an intellectual disability into employment and to ensure that they are not disadvantaged financially when they seek work.\(^{362}\)

**Adult education**

> “I want to learn about cookery.”
>
> “I am learning to go on the phone and use the phone book (at a vocational service).”
>
> “I did a first aid exam. They read me questions and I figured out which was right and wrong.”\(^{363}\)

Research and policy regarding education for people with an intellectual disability has tended to focus on school and vocational education. Only recently has attention been paid to education for adults with an intellectual disability. Adults with disabilities continue to be under-represented in post-secondary education.\(^{364}\) Research also indicates that within education there is a hierarchy of disability, whereby people with an intellectual disability are least likely to be viewed as having a legitimate claim to tertiary education.\(^{365}\)

**Adult education initiatives**

The literature review on education compiled by the Donald Beasley Institute details a number of overseas programmes set up in mainstream educational institutions to cater for adults with an intellectual disability.\(^{366}\) Positive achievements included employment outcomes, improved self-esteem and increased friendships. These benefits, however, tended to be tempered by a number of barriers. These included prejudice and negative attitudes about the ability of students with an intellectual disability to learn, attitudes of non-disabled students, and organisational procedures. Older adults, who may not have received any formal education, tend to be disadvantaged in seeking placements in tertiary or other educational institutions.

Most of the overseas programmes, while including students within the post-secondary environment, have continued to provide education in segregated classes aimed at the developing life skills rather than the acquisition of academic credit. A constant theme in the literature review is the negative attitudes which are held regarding the ability of people with an intellectual disability to learn. There seems to be limited recognition by education providers and the wider community that adults with an intellectual disability require ongoing opportunities to learn new skills. For instance, opportunities to upskill in the work environment and take on a new role (as is expected of most employees); learning parenting or relationship skills; acquiring life skills, like money management or cooking; or taking on a new hobby or sport.

A number of educational agencies in New Zealand provide courses that are accessed by adults with an intellectual disability. The Correspondence School offers a range of distance education initiatives.

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\(^{362}\) Mirfin-Veitch 2003b.

\(^{363}\) Quotes from adults with an intellectual disability, NHC focus groups 2002.

\(^{364}\) Mirfin-Veitch 2003b.


\(^{366}\) Mirfin-Veitch 2003b.
Learning new things

courses, including life skills and communication courses which adults with an intellectual
disability can be supported to work through. There are also adult literacy programmes in
many parts of New Zealand.

Literacy

“The literacy programme – one hour a week – helps me do the stuff I never did when I was at
school.”

Many people with an intellectual disability have difficulty learning to read, write and do
maths. Improving literacy is a component of many of the overseas post-secondary
programmes. A learner-centred approach, whereby individuals identify their own goals and
needs, is particularly critical in literacy education for adults with an intellectual disability.368
Research indicates that achieving some level of literacy is possible for many adults with an
intellectual disability, with those in younger age cohorts who have been in mainstream
schooling likely to achieve more advanced reading and writing.369

A study undertaken by the Roeher Institute in 1990 identified a number of barriers that make
it difficult for people with an intellectual disability to access literacy programmes.370 The
attitude that adults with an intellectual disability are not able to learn these skills was
prevalent, even among adult literacy educators. The study also identified policy and
programme barriers, like costs, lack of support within programmes and eligibility criteria.
Other barriers included lack of appropriate training of tutors, modes of instruction and that
the programmes did not link with other aspects of the person’s life.371 The Institute has
published a practical guide about conducting literacy education with adults with an
intellectual disability.372

The Roeher Institute study concluded that lack of literacy is one of the obstacles to adults
with an intellectual disability participating and being independent within the community.
The researchers suggested that it contributed to entrenching poverty, unemployment and low
health status.373 Furthermore, literacy is critical to improving communication for people with
an intellectual disability.374

Research on adult education in New Zealand

A study of students in special studies courses in a New Zealand polytechnic concluded that
courses for adult students who require special tuition are valuable and lead to increased
participation in the community through extending personal independence and increasing the
chances of securing employment.375 Another New Zealand study looked at the experiences
of disabled students in three tertiary institutions. The study found that negative attitudes by

367 Quote from an adult with an intellectual disability, NHC focus groups 2002.
368 Mirfin-Veitch 2003b.
370 The Roeher Institute is a policy-research and development organisation in Canada focusing on
issues for people with intellectual and other disabilities. More information about the Institute and its
publications can be found on the website www.roeher.ca
372 Literacy in Motion: A Guide to Inclusive Literacy was published by The Roeher Institute’s
publication in 1994, and can be ordered through the Institute’s website.
373 The Roeher Institute 1990 cited in Mirfin-Veitch 2003b.
374 Mirfin-Veitch 2003b.
staff members made it difficult for students with disabilities to gain entry to certain vocationally oriented courses. It concluded that significant attitudinal change is necessary to ensure that students with disabilities do not encounter additional barriers to accessing tertiary education of their choice.\textsuperscript{376}

Reducing barriers
New Zealand and overseas literature identifies a number of areas that need to be addressed to reduce barriers and improve learning outcomes for adults with an intellectual disability. These include to:

- involve students with an intellectual disability in the planning and the running of courses
- change attitudes of institutions, tutors and non-disabled students about the abilities and requirements of people with an intellectual disability in regard to ongoing education
- give consideration to how “academic success” is determined. Students with an intellectual disability may require alternative models of certification or accreditation than their non-disabled peers
- incorporate sufficient flexibility within programmes and courses to meet the diverse requirements of adult students with an intellectual disability
- provide adequate support staff (in many of the programmes detailed in the literature, non-disabled student volunteers were used)
- establish learning opportunities within mainstream educational environments.\textsuperscript{377}

Key issues

- Transition from school to adulthood is as a key factor in determining the nature and quality of lives of adults with an intellectual disability.
- Transition planning needs to be based around the student and their aspirations, and take a whole of life planning approach.
- For transition to adulthood to be effective there needs to be adequate and appropriate services outside the school setting.
- Students with an intellectual disability who receive relevant work experience as part of their school-based transition planning are more likely to maintain competitive jobs.
- Greater coordination is needed between the education sector and funders of adult services to improve transition for young adults with an intellectual disability.
- Adults with an intellectual disability need access to ongoing opportunities to learn new skills.
- More positive attitudes are needed about the ongoing learning needs of adults with an intellectual disability.

\textsuperscript{376} McKay et al 1995 cited in Mirfin-Veitch 2003b.
\textsuperscript{377} Mirfin-Veitch 2003b.
11. RELATIONSHIPS

“If we do not regard the person as an adult then we will not think in terms of adult relationships and support networks. Subconsciously or not, we will only create options for support that are primarily paternalistic in nature and we will be satisfied that they constitute all that is required." 378

This chapter:
• looks at the relationships that adults with an intellectual disability have with their families/whānau, friends and service providers
• discusses forming and maintaining friendships and close relationships
• identifies the range of support that adults with an intellectual disability can require to make and keep relationships
• looks at attitudes to intimate and sexual relationships
• describes some of the issues facing parents with an intellectual disability.

Relationships with the wider community are dealt with in more detail in the Chapter 9: Being part of the community.

Society’s expectations

Society’s attitudes to, and stereotypes about, people with an intellectual disability have a significant impact on opportunities for forming relationships. While communication and social interaction are key components within relationships, it is too simplistic to assume that the difficulties some people with an intellectual disability have with these are the major reason for the social isolation of adults with an intellectual disability. 379 It has been proposed that many of the behaviours exhibited by people with more ‘severe’ impairments, which are labelled as attention-seeking or disruptive, are developmentally appropriate strategies for expressing the need for close relationships, such as friendships. 380 Further discussion about communication and people with an intellectual disability is contained in Chapter 5: Communicating.

Social networks

Research on friendships has found that people with an intellectual disability tend to have very small social and friendship networks. A recent UK study found the median size of respondents’ friendship networks, when staff were excluded, was two. One quarter of participants had one person or no one in their social networks. The size of participants’ networks was influenced by factors such as age, type and level of intellectual impairment and degree of challenging behaviour. Overall, staff and family members provided the main sources of information, practical and emotional support to participants, and people with an intellectual disability were rarely seen as providing support to others.381 There is very little, if any, data indicating the quality of these social networks, especially from the perspective of people with an intellectual disability.382

Research in the UK found that younger participants had larger social networks and that these networks were more likely to contain a relative, non-staff member, and a non-disabled person. It was concluded that older adults were at increased risk of social exclusion.383 These findings point out that the experiences of younger adults with an intellectual disability tend to be different from those in older cohorts. Many older adults with an intellectual disability spent the major proportion of their lives in institutions and, as a result, may have limited or no contact with their families/whānau and no community links. Furthermore, being moved between institutions tended to disrupt ongoing relationships with staff and family/whānau members. In the past, invisibility within the community of people with an intellectual disability meant that even people who lived with their families tended to have limited social contact throughout their lives.

Many relationships which people with an intellectual disability have are short-term and it appears from the research findings that few relationships are long-term. These findings are of concern as stability is a key component of relationships that are likely to provide social support and enhance a feeling of belonging.384

Relationships with family/whānau

“I can’t say anything about the family because I never see them. They are all over the place.”
“My step-mum and my two step-sisters – we are quite close and see each other a bit.”
“I go home at weekend to my family, without a staff member.”385

Having a family member with an intellectual disability usually means a lifelong caring or support role for parents, or for a member of the wider family/whānau, such as grandparents, or aunts and uncles. Siblings often take over this role when their parents die or are no longer able to provide care. However, for people with an intellectual disability who grew up in institutions, their relationship with family/whānau members can be quite different, particularly if they have lost contact for many years. A number of Māori adults who were

382 McVilly 1997.
385 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Relationships

taken into residential care when they were young were completely cut off from their whānau, iwi and hapū. These experiences have had a lasting effect on the people concerned.\(^{386}\)

Most of the research about families of adults with an intellectual disability has looked at the experiences of those who use services. This means that very little is known about families/whānau who do not use services. There is also a lack of information about ethnicity and cultural diversity, and about sole parent and reconstituted families.\(^{387}\)

Relationships and situations within families are not necessarily stable.\(^{388}\) Transitions occur for all family members. For parents this may include changes in employment, retirement and periods of ill health. For the family member with an intellectual disability, adolescence, leaving school or home, and changes in work environments can be major transitions. Their siblings may go through similar transitions at the same or different times. This can create expectations that the family member with an intellectual disability will achieve the same goals as their siblings.\(^{389}\)

It also cannot be assumed that household membership will stay the same over time. As well as young people leaving home, parents may split up or find new partners, and older family members may join the household or require additional support. When family caregivers grow older, role reversal often occurs where the adult with an intellectual disability provides care.\(^{390}\)

Research identifies that risk factors for family members include stress in parental relationships, increased depression and anxiety and social isolation. A contrary view emerging in the literature is that even under adversity, families can be highly resilient. It suggests that having a family member with a disability and the need to address the related demands can result in heightened resilience of families. This difference in findings may be due to earlier research focusing on stressful transition times, like when a family finds out that a child has an intellectual disability or when the child reaches adolescence.\(^{391}\)

Resilience in families may be a result of family members developing skills, coping strategies and experience. Resilience is also related to the family setting goals, like aiming to maintain the self-esteem of family members.\(^{392}\) Identifying factors that enable families to develop resilience will inform the development of strategies to assist families to cope under stress. However, families often require ongoing emotional as well as practical support, particularly during times of transition which can be particularly stressful for people with an intellectual disability and their families.

Relationships

Relationships with parents

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

“My mum and dad are dead, but I still love them.”

“My mother and father live in another town. Sometimes in the weekend I go to their house and have lunch with them. Father picks me up.”

Parents, or primary caregivers, play a pivotal role in the lives of offspring with an intellectual disability. As well as providing physical and emotional support, and assistance with coordinating services and activities, research indicates that they play a role in shaping the self-identity of adults with an intellectual disability.

Studies of the perceptions of adults with an intellectual disability about their relationship with their parents show a similar variation to that expected in the general population. Some appreciate the support they receive from their parents and others express dissatisfaction with the control their parents have over their lives.

In the literature on intellectual disability, there has been little attention given to parent-adolescent and family relationships during the developmental stage of early adulthood. One study identifies the stresses experienced by parents of young adults as uncertainty about the future; transition in services and lack of options; advocacy; physical maturity; and individual vulnerability. This is a time when all parents face dilemmas around creating opportunities for their young adult offspring, while ensuring that they are living a safe and satisfying life. The added dimension for parents of adolescents with an intellectual disability is the way in which attitudes in society work against people with an intellectual disability attaining the status of adulthood.

When an offspring with an intellectual disability reaches adolescence and early adulthood, relationships with parents can become complex because of the young adult’s desire to copy the behaviour of their peers and resist parental influence in their lives. Parents often find it difficult to see their offspring as an adult, as they are aware of their offspring’s support requirements and that they may make inappropriate decisions. Parents can be reluctant to take the risks involved in giving their adult offspring the degree of independence they may crave. A 1993 study found that where there was a mismatch of degree between parental risk-taking and their adult offspring’s need for greater autonomy, the relationships were characterised by mutual incomprehension and interpersonal conflict. In families where there was ‘shared risk-taking’, the adults with an intellectual disability tended to have increased social networks and enhanced opportunities. However, this meant that the adults were exposed to greater hazards and the family to greater anxiety.

Community-based accommodation means that it is now feasible for adults who require significant support to leave home. In many cases, the ongoing relationship between parents and their adult offspring continues to have a high support component. During the course of

393 Quotes from adults with an intellectual disability, NHC focus groups 2002.
394 Llewellyn 1997.
396 Llewellyn 1997.
397 Todd and Shearn 1997.
Relationships

the National Health Committee project, a number of parents expressed concern that moving from home to community-based accommodation appeared to occur only if arrangements at home were under significant stress. They felt that leaving home was part of the process of growing up and that community-based accommodation should be available as a developmentally appropriate option.

Several parents reported that they had moved out of the family home to alternative accommodation while their adult child continued to live in the family home with purchased support. This option, however, is only feasible where the family has adequate resources to finance this option.

Research has shown that most parents who care for their sons and daughters into mid-life want to care for them for as long as they are able. In these situations, arrangements for alternative support are often developed when parents get older and are no longer able to continue to provide care. This may be the first time that the adult with an intellectual disability has lived away from their parents and the family home. This major change, combined with the death or ill health of parents, can be a traumatic transition. Loss of a parent may leave a large gap in the person’s limited social networks. There may be no one who understands the care arrangements and communication signals that have developed over many years between the person with an intellectual disability and their parent.

It is not uncommon for the adult offspring to provide care or assistance to older parents. In this situation, the parents and their offspring may require external support services, and their needs may differ. Understanding of reciprocal caregiving roles is important in assessing needs and providing appropriate services.

Relationships with siblings

“I help look after my little nephew while my brother goes shopping with my mother.”

“One of my sisters brought me up when I was a baby because my mother was too sick.”

Relationships with siblings are also central to people with an intellectual disability, particularly in their early lives. Brothers and sisters may be protective of their sibling with an intellectual disability, involving them in their activities and protecting them from being bullied by other children. On the other hand, siblings are often frustrated or embarrassed by their behaviour.

Research suggests that sibling relationships are mediated by parental expectations. For instance, siblings’ actions tend to mirror their parents’ views about the degree to which things should be done for the family member with an intellectual disability, or the degree to which self-reliance should be encouraged.

There is growing recognition that adults with an intellectual disability are increasingly likely to outlive their parents. When parents grow older, responsibility for the family member with an intellectual disability is often taken on by their siblings. In her research of people with an

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400 Quotes from adults with an intellectual disability, NHC focus groups 2002.
401 Llewellyn 1997.
intellectual disability in New Zealand who were cared for by family members, Jennifer Hand coined the phrase “hand-me-down people” to describe this transition. \(^{402}\)

The care provided by siblings may take many forms, including joint residence, regular contact and or administering the person’s personal and financial affairs. The transition between being cared for by parents and care by siblings is not necessarily smooth. Who provides care when the parent dies may not have been discussed between family members, and the offspring nominated to take on the caring role may not have been aware of this expectation.\(^{403}\) In other families, siblings have firm plans to take over the care when their parents are no longer able. A recent study found that sisters are more likely to provide care and support than brothers.\(^{404}\) The study concluded that women with an intellectual disability may be at risk of reduced care if their only sibling is a brother. Policy development must take the perspective of caregiving siblings into account.

Support for family/whānau

Many families/whānau who contributed to the National Health Committee project identified that they needed more support in providing care. Respite care, which enables caregivers to have a break from their responsibilities, is the main form of government-funded support available to families and whānau. During the NHC project, parents raised concerns about difficulties in accessing this service, particularly in times of crisis, as arrangements needed to be made well in advance.

A number of parents also pointed out that respite care does not meet the support needs of many families. Separating family members is not necessarily the best way to strengthen family relationships. One parent suggested that what would make the biggest difference in their lives was to have a commercial washing machine so that they could cope with the large amount of laundry resulting from their family member being incontinent. Another family, who had an adult son who regularly destroyed the décor in the house, suggested that financial assistance with wallpapering the lounge each year would be more helpful to them than respite care.

The Ministry of Health is currently funding three local initiatives to develop new approaches to supporting carers.

Relationships with support staff

“I have staff around me 24/7. That makes it difficult to spend time with people I want to.”\(^{405}\)

Support staff are a major component of social networks of people with an intellectual disability who live in group homes or who receive a high level of support at home. In many cases, staff are often the only people without an intellectual disability whom they meet regularly, spend time with, and share thoughts, feelings and aspirations. Often staff members continue to be part of a person’s social network, even when they are no longer paid to provide care. However, if the roles of ‘friend’ and ‘professional’ become blurred, then practical and

\(^{402}\) Hand 2000.  
\(^{403}\) Hand 2000.  
\(^{404}\) Orsmond and Seltzer 2000 cited in Mirfin-Veitch 2003c.  
\(^{405}\) Quote from an adult with an intellectual disability, NHC focus groups 2002.
Relationships

ethical problems can arise. For instance, when professional judgement is clouded by friendships, others may perceive favouritism, or a lack of clarity about responsibility when things go wrong. While it may be inappropriate for support workers to form close friendships with people for whom they are providing care, they do have a critical role in assisting people with an intellectual disability to form and maintain friendships.

Relationships between people with an intellectual disability and support staff have an inherent power imbalance, which needs to be thoroughly explored. While support workers often find themselves in situations in which they feel disempowered, the power balance does favour staff. The reasons for this include the fact that the person with an intellectual disability is dependent on staff for information and assistance with basic activities of daily living, which may be very intimate. Also, staff have more control over their daily lives than people living in ‘residential’ services and can leave their job. Few people with an intellectual disability are able to initiate changes to services or determine who are their support staff.

Friendships

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

It takes opportunity and time to get to know any person. For people with an intellectual disability, opportunities to get to know people without an intellectual disability, who are not part of their family/whānau or support staff, are limited. Often activities for people with an intellectual disability are organised as group events, arranged by support people, and to which they travel as a group in the service’s van. Participants in the National Health Committee focus groups often commented that it is very difficult to meet people outside the group during these types of activities. This was referred to as travelling around in ‘six-packs’.

Communication difficulties, appearing to be different, and responding in ways that differ from social ‘norms’, mean that it can take additional time for other people to get to know a person who has an intellectual disability. It is widely accepted that friendships are an integral part of health and wellbeing, and provide a buffer against psychological and physiological illness and promote longevity of life. Friendships enhance safety, social support, a sense of belonging and community integration, and also involve reciprocity. While, it is likely that the experiences and aspirations of friendship may be similar for people with an intellectual disability as for the general population, there are no coherent research findings, theory or framework around this issue.

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408 McVilly 1997.
409 The IHC Relationships and Sexuality Policy includes a section on intimate care and consent (IHC 2003).
411 Quote from an adult with an intellectual disability, NHC focus groups 2002.
In a project to determine the aspirations of people with disabilities in Victoria, Australia, just over one-quarter of those interviewed expressed the desire for a relationship. This covered a wide range of aspirations including greater or continued involvement with family, having their own family, friendships, and close meaningful sexual relationships. Eight in 10 saw potential barriers to relationships, two of the main ones were finding someone who would be accepting of a disability and lack of finances.\textsuperscript{414}

Support to form and maintain friendships
In line with changing paradigms about disability, there is an increasing focus on how people with an intellectual disability can be supported to establish and maintain meaningful relationships, particularly friendships.

For most people, making and maintaining friendships is not something that comes easily. It requires, among other things, time, opportunity, motivation, skills and the support of existing friends.\textsuperscript{415} For people with an intellectual disability, practical barriers to sustaining relationships include lack of access to a telephone, lack of autonomy and reliance on others for transport.\textsuperscript{416}

An Australian research project used focus groups to examine the friendship experiences of younger people with a ‘mild to moderate’ intellectual impairment. Participants identified the difficulties they face in maintaining friendships. These included being dependent on organised events to catch up, lack of opportunities to talk in private, and needing help to use the phone, with transport and to buy Christmas and birthday presents.\textsuperscript{417}

While research clearly indicates that people with an intellectual disability need support to initiate and maintain friendships, the actions of family members and staff can hinder friendships as well as encourage them. Families and support staff can play a vital role in facilitating relationships, including friendships. However, this must be based on listening to the aspirations of individuals and acting on their wishes. Supporting the maintenance of friendships can involve creating opportunities for people to see each other and where this is not possible, providing support for people to use the telephone, write letters, exchange audi-tapes or video tapes, or use technology such as e-mail and web cameras.\textsuperscript{418}

Disability Services Queensland (DSQ) has developed a Friendship Direction Statement, which “explores the opportunities for services to review the way in which friendship support is provided.”\textsuperscript{419} In New Zealand, the Ministry of Health funds some befriending and ‘buddying’ services from its disability support services budget. These mainly began in response to the needs of people with an intellectual disability who have moved out of institutions. Some of these initiatives have been widened to include other adults with an intellectual disability. However, contracts for these services are predominantly in the main centres and for most adults with an intellectual disability access to services to support friendships is inadequate.

\textsuperscript{414} DisAbility Services Victoria 2000.
\textsuperscript{415} McVilly 2001.
\textsuperscript{416} Bray and Gates 2003.
\textsuperscript{417} McVilly 2001.
\textsuperscript{418} McVilly 2001.
\textsuperscript{419} Disability Services Queensland 2002.
Relationships

Relationships between people with an intellectual disability

Social network research in the UK found that, once family and staff were excluded, the social networks of people with an intellectual disability were dominated by other people with an intellectual disability.\(^\text{420}\) This is a direct result of where many people with an intellectual disability live and the activities and work in which they are involved.

Research has more commonly focused on the relationships between an adult with an intellectual disability and a non-disabled person. This is in part due to the greater ease of accessing information from a non-disabled friend. This emphasis, however has the potential to devalue the relationships that adults with an intellectual disability have with each other. A perception that it is more valuable for people with disabilities to have relationships with non-disabled people may reduce opportunities for friendships and intimate relationships.

The UK research concluded that relationships between people with an intellectual disability are important, as they are often long-lasting and reciprocal.\(^\text{421}\) An earlier study by the same researchers found that those people who had a great number and proportion of people with an intellectual disability in their social networks had a higher level of satisfaction about friendships and relationships.\(^\text{422}\)

Qualitative research indicates that when offered appropriate support, adults with a ‘severe’ intellectual impairment and significant social skills difficulties can enjoy spending time together. However, developing and maintaining relationships is impossible for this group without an adequate level of support, both to provide opportunities to meet and to facilitate interactions.\(^\text{423}\)

Home and work make up a significant part of the social networks of people with an intellectual disability. However, organisational structure and attitudes have a big impact on opportunities for forming and maintaining relationships. For instance, there may be no opportunity to see work or vocational service colleagues in the evenings or weekends, or no place at home or work to meet and talk confidentially.

Forming intimate and sexual relationships

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“We are a couple and we have lots of difficulties and it’s really hard for us to work out our differences. And we really want to hang onto each other. I just hope other people don’t get into the same difficulties.”

“I asked my co-ordinator if I could live with my girlfriend but she said no.”

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

“I want to live with my boyfriend – marry him.”\(^\text{424}\)
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\(^{422}\) Bray and Gates 2003.


\(^{424}\) Quotes from adults with an intellectual disability, NHC focus groups 2002.
Many of the focus group participants expressed a desire to have intimate or sexual relationships. Having a partner, getting married and having children were common aspirations. There is no accurate data on how many people, who require support with daily living tasks as a result of an intellectual impairment, are married or live in a long-term relationship. The 1996 New Zealand Household Disability Survey found that of people with an intellectual disability who responded to the question about living in a long-term relationship, 29 percent had a partner or spouse.\footnote{Statistics New Zealand 1997b.} However there is a high rate of error in this data and no indication given as to how many of these people require regular support.

Research has shown that people with an intellectual disability are much more likely to desire close relationships, like having a boyfriend or getting married, than is perceived by those supporting them.\footnote{McVilly 1997.} This is a reflection of denial within society that people with an intellectual disability have the same right to intimate or sexual relationships as other people. There is a high degree of discomfort in the community about the sexuality of adults with an intellectual disability. Discussions of this topic tend to concentrate more on protection from sexual abuse, the need to provide sex education and the role of staff and services, rather than recognition of the need and right for all to have opportunities to form loving and intimate relationships.

Research involving women with a ‘mild’ and ‘moderate’ intellectual impairment found that they had a negative view of their sexual lives, in part because of the very high levels of sexual abuse which they experience.\footnote{McCarthy 1999 cited in Bray and Gates 2003.} Another study concluded that recognition of the right of adults with an intellectual disability to lead sexual lives has led to a focus on sexual abuse, in particular for women. Men with an intellectual disability have not had similar opportunities to reflect on their experiences of relationships.\footnote{Cambridge and Mellan 2000 cited in Bray and Gates 2003.}

The attitudes of family and support staff to the sexuality of adults with an intellectual disability have a big influence on the feelings adults have about their own sexuality and on their opportunities to form sexual relationships. Many parents are protective and therefore instil beliefs of the unacceptability of sex especially outside of marriage.\footnote{Heyman and Huckle 1996 cited in Bray and Gates 2003.} These beliefs can be reinforced within disability services where there is often a reluctance to address issues of sexuality. It has been suggested that these attitudes are a result of an underlying belief that sexual activity is ‘off-limits’ to adults with an intellectual disability and as a result there has been a failure to “…break through the barriers of prejudice and isolation and to create real opportunities for people with learning disabilities to live in different kinds of partnerships and family groups or to enjoy a wide range of sexual relationships, contacts and activities.”\footnote{Brown 1994 cited in Bray and Gates 2003.}

There are even greater barriers for adults who wish to pursue same-sex relationships. The growing social permission to form same-sex relationships has not yet reached adults with an intellectual disability. Men with an intellectual disability who have sex with other men are often not given education about safe sexual practices, even though their sexual preference is known.
Currently, in New Zealand, there is legislation that restricts intimate relationships for women with an intellectual disability. This is contained in Section 138 of the Crime Act (1961) and is currently being reviewed along with other outdated sections of the Crimes Act.

If adults with an intellectual disability are to be afforded the same rights as other adults, then the normalisation principle should also apply to the sexual options of people with an intellectual disability. In New Zealand, IHC recently released its relationships and sexuality policy. The philosophy of this policy is that “every individual has the right to be supported to develop loving and safe friendships and relationships”. The policy details IHC’s commitments and the responsibility of staff and caregivers in relation to aspects of personal interactions. These include intimate care and consent, friendships, sexual expression, contraception, reproduction and sexual health.

Parents with an intellectual disability

“I’d like to have a relationship, get married and have kids.”

“I am just happy my brother has had a couple of kids.”

“My mother thinks I barely know how to look after myself. She’s wrong. She thinks I won’t be able to look after kids.”

There is a perception that the number of adults with an intellectual disability who are parents is increasing. It appears that the majority of these parents have ‘mild’ intellectual impairments, do not usually use support services and do not want to be labelled as having an intellectual disability. It is not clear how many parents with an intellectual disability require ongoing support services. In the National Health Committee focus groups there were several women who had children, who were not living with them. One woman explained that she had become pregnant some years before as a result of sexual abuse.

The only New Zealand study of parents with an intellectual disability concluded that they are often extremely socially isolated and there is no structured system for support of families where one or both parents have an intellectual disability. The study attempted to identify the prevalence of parents with an intellectual disability. This group was defined as adults over 18 years of age with one or more child(ren) under 18 years, who may or may not live with the parent. The study identified 46 individual parents with an intellectual disability in Otago and Southland. These parents had a total of 96 children, 41 percent of whom were no longer being cared for by them.

There are conflicting findings from assessments of the quality of childcare provided by parents with an intellectual disability. However, there appears to be no clear association

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432 IHC 2003.
433 IHC 2003.
434 Quotes from adults with an intellectual disability, NHC focus groups 2002.
435 Bray 2003b.
437 Dowdney and Skuse 1993 cited in Mirfin-Veitch 2003c.
between parental competence and IQ, although mothers with an IQ below 50 may often have greater difficulties with parenting.\textsuperscript{438}

There is strong evidence to suggest that the difficulties facing parents with an intellectual disability are compounded by the effects of poverty. They are more likely than other parents to be unemployed, live in sub-standard housing, have no phone or transport and lack holidays or respite.\textsuperscript{439} One study found that children without an intellectual disability who had been raised by parents with an intellectual disability “experienced no problems of the type or magnitude sufficient to distinguish them from other people coming from the same socioeconomic background”.\textsuperscript{440}

Research about parents with an intellectual disability suggests that the nature of their relationships and the support they receive is affected by their household circumstances. An Australian study found that mothers who were living in a household with a parent or parent figure had more frequent contact with people providing support, but less contact with formal support services, than mothers living along or with partners. Much of this support came from household members and it is suggested that these mothers were less likely to be integrated into the community.\textsuperscript{441}

In comparison, mothers with an intellectual disability who were living alone were more reliant on professionals for support, used phone contact more frequently and generally turned to formal support services when in a crisis or needing a break. Mothers living with partners received some practical support from them, but also received a high level of support from professionals. In addition, mothers whose support networks were dominated by formal support arrangements tended to have fewer reciprocal relationships than mothers who had more informal support networks, for instance, those living with parents.\textsuperscript{442}

New Zealand research found that parents with an intellectual disability who were caring for children, but had previously had children removed from their care, received the lowest level of support. However, parents who had had all their children removed received the highest level of formal support. Much of this support came in the form of supervised access arrangements maintained by agencies such as child protection. This finding implies that the support needs of parents with an intellectual disability and their children “are approached in a reactive rather than a proactive manner”.\textsuperscript{443} The authors of this research point out that while the Strengthening Families initiative\textsuperscript{444} has the aim of improving the wellbeing of families, it fails to identify that parents with an intellectual disability represent a group with significant support needs.\textsuperscript{445}

Parents with an intellectual disability need access to services that are responsive to the particular barriers faced by them because of their intellectual impairments. The services need to be long-term with particular emphasis on parenting difficulties and/or periods of family crisis.

\textsuperscript{438} Mirfin-Veitch 2003c.  
\textsuperscript{439} Mirfin-Veitch 2003c.  
\textsuperscript{440} Booth and Booth 1997 cited in Mirfin-Veitch 2003c.  
\textsuperscript{441} Llewellyn 1997.  
\textsuperscript{442} Llewellyn 1997.  
\textsuperscript{443} Mirfin-Veitch et al 1999.  
\textsuperscript{444} Strengthening Families is an intersectoral initiative of the New Zealand Government which aims to improve services to children whose family and social circumstances place good life outcomes at risk.  
\textsuperscript{445} Mirfin-Veitch et al 1999.
Relationships

Key issues

• Adults with an intellectual disability tend to have very small social and friendship networks.
• Differences in life experience affect the size, complexity and stability of the social networks of adults with an intellectual disability.
• Families/whānau tend to play an important role in providing support throughout the lives of adults with an intellectual disability, and if providing ongoing care they need appropriate assistance with this.
• Many adults with an intellectual disability want to leave home as part of growing up.
• The approach of support staff and families can assist or hinder adults with an intellectual disability forming and maintaining friendships.
• Adults with an intellectual disability are much more likely to desire close relationships than is perceived by those providing them with support.
• There is a high degree of discomfort in the community about sexuality of adults with an intellectual disability.
• IHC has developed a comprehensive policy on relationships and sexuality, which details how to support the development of loving and safe friendships and relationships.
• Parents with an intellectual disability are often socially isolated and receive minimal support.
12. 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.”

This chapter:
• details the variety of recreational and leisure activities in which adults with an intellectual disability take part
• describes examples of sporting, cultural and leisure initiatives that have been set up in New Zealand and Australia
• outlines the barriers which prevent adults with an intellectual disability taking part in leisure activities
• identifies ways in which these barriers can be reduced.

What is leisure?

In New Zealand, ‘leisure’ generally refers to recreation or free time spent away from work or other obligations. As indicated in Chapter 8: Work (paid and unpaid) adults with an intellectual disability take part in a range of work or day activities. Given the nature of some of these activities, the line between work and leisure may not be clear-cut.

Leisure activities include passive or ‘spectator’ pastimes, like listening to music and watching television, as well as group activities, clubs and sport. For adults with an intellectual disability, involvement in leisure activities can be an important source of empowerment, self-expression and community participation.

Types of leisure activities

New Zealand studies show that adults with an intellectual disability spend their leisure time in a similar way to other New Zealanders, with a significant proportion of their time being spent on spectator activities. Among the adults with an intellectual disability who took part in the National Health Committee’s focus groups, the most frequently reported activities were watching television, listening to music, visiting friends and family, going out to the movies, craft activities (including needlework, knitting, artwork and jigsaw puzzles), going to the pub, and taking part in the Special Olympics.

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446 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Having fun

“I go out to lunch on Fridays. We all go in small groups to a café or restaurant.”
“I like to go to the pub sometimes.”
“I go to the pictures on Friday. A support worker takes us there and picks us up.”
“I like watching rugby on TV. Better than going to the game.”

As with all adults, the leisure pursuits that people with an intellectual disability undertake often originate from childhood activities organised by family/whānau or through school. Whether people continue to pursue these activities depends on the barriers they face and whether they receive adequate assistance and encouragement. Some focus group participants mentioned that they took part in leisure activities with family members. For instance one young man reported that he regularly plays pool with his father and a woman talked about how she had showed cats with her mother until this became too expensive.

Where a person lives and works also influences the leisure activities that are available to them. In addition, in the focus group discussions there were clear differences between the leisure pursuits of young adults and those in older age groups. This probably reflects the different life experiences of these age groups, with many of those in older age groups having lived in institutions and taken part in structured group outings and organised leisure activities. A number of younger adults with an intellectual disability mentioned computers, the internet, playstation, 0900 numbers and active pursuits like mountain biking.

“I am involved with People First making videos.”
“I like to play on DJ gear.”

For people with an intellectual disability, links with family/whānau and their culture are important components of self-identify. The kaupapa of Te Roopu Taurima o Manukau, a Māori service provider in Auckland, ensures that all services have a strong cultural dimension. This includes involvement of kaumātua in all aspects of the services, including maintaining links between residents and their families. As well as the range of leisure pursuits already mentioned, Māori adults with an intellectual disability identified specific cultural activities, such as kapa haka, gathering traditional Māori food and going to the marae.

For Pacific people with an intellectual disability, many providers ensure that Christian prayer and worship are an integral part of the activities and events in which they are involved.

The research literature and focus group discussions identified some gender differences in leisure activities for people with an intellectual disability, which tend to reflect social patterns. A study in the early 1990s found that cooking and needlework were pursuits almost exclusively undertaken by women, but that in all other activities participation rates between

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449 Quotes from adults with an intellectual disability, NHC focus groups 2002.
450 Quotes from adults with an intellectual disability, NHC focus groups 2002.
451 Philosophy or approach.
452 Experienced elders.
453 More information about the kaupapa of Te Roopu Taurima o Manukau is included in Chapter 14: Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro.
454 Māori song and dance.
men and women were similar. During National Health Committee focus groups, indications were that men are more likely than women to go out in the evening on their own, for instance to the pub.

**Integrated or segregated leisure?**

Many of the leisure activities that adults with an intellectual disability take part in are group activities organised by residential or vocational service providers, or arranged specifically for people with disabilities. There is a growing debate about whether it is appropriate that adults with an intellectual disability take part mostly in ‘segregated’ activities or whether the focus should be on integrating into wider activities in local communities.

Where adults live can determine the extent to which they are involved in ‘segregated’ leisure activities. A New Zealand study of a sample of people living in IHC facilities in the early 1990s found that while they were involved in a similar number of activities as adults with an intellectual disability living in other settings, a large proportion of their activities were initiated by the local branch of IHC. Running activities in residential settings or specifically for people with an intellectual disability limits opportunities for community participation, and perpetuates images of people with an intellectual disability as different from others.

On the other hand, it can be argued that focusing only on integrated activities gives the message that it is not appropriate for people with an intellectual disability to do things with others who have disabilities. This in turn suggests that people who have an intellectual disability are of lesser value as friends and leisure partners. There are times when, and activities in which, people with an intellectual disability may choose to be with others who have an intellectual disability. The key factor is that people have choices over the settings in which they do activities.

In recent years, a small number of mixed-ability initiatives have been developed. These initiatives involve people with disabilities and their non-disabled peers. The highest profile example in New Zealand is Touch Compass Dance. There appears to be no literature evaluating these initiatives to determine whether they meet the requirements of people with disabilities and how they influence other people’s attitudes about disability.

**Arts and creative activities**

Creativity among people with an intellectual disability is often overlooked. In New Zealand, art and creative activities for people with an intellectual disability are mostly in the form of vocational or day activity programmes. One of the issues identified during the National Health Committee focus groups was that day programmes funded by the Ministry of Health tend to have very limited budgets for buying materials. It was also apparent that the effectiveness of art and creative components is highly dependent on the skills and approach of staff.

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Having fun

Internationally a number of initiatives have been established to enable people with an intellectual disability to develop and share their creativity in dance, arts and music. Three very different examples are described: one from New Zealand and two from Australia.

**Touch Compass Dance Trust**

Touch Compass is a mixed-ability dance company, based in Auckland, which receives funding from Creative New Zealand and Arts Alive. Members of the company span in age from nine years to mid-thirties, and have a range of impairments and abilities. The dance troupe is managed by a non-profit trust that also runs classes and workshops for people of all ages and abilities. The trust was set up in 1999 and aims to promote mixed ability dance, eliminate fears and prejudices concerning people with disabilities and create role models for both disabled and non-disabled members of the community.

**Arts Project Australia**

Arts Project Australia is a charity organisation dedicated to the development of individual artistic expression of people with an intellectual disability and its recognition by the wider community. The project provides opportunities for people to develop artistic skills and awareness and to have their work appreciated in a serious way.

In 1974, when Arts Project Australia first began exhibiting art in major galleries, only the artists’ first names were used. This was because of fear of causing distress to the artists’ families, many of whom had been advised to place their children in an institution and “forget about them”. These early exhibitions emphasised the aesthetic and expressive qualities of the works, and in this way challenged attitudes towards people with disabilities.

The focus of Arts Project Australia is the work produced by the artists, rather than identifying that the artists have an intellectual disability. The achievements of the artists include receiving Australian art awards, having their work used in films and television, and contributing to exhibitions in art galleries. Currently, Arts Project Australia runs a supported employment programme that is accessed by 150 people a week.

**Holdfast Community Choir**

The Holdfast Community Choir was established in 1997 as part of the recreation programme at Minda, a large residential facility for people with an intellectual disability in South Australia. The impetus for setting up the choir came from a survey of residents which identified that singing and music were the most popular pastimes of people living at Minda. The choir is not restricted to residents at Minda, and involves many people from the local community. Currently of the 60 choir members, 30 are Minda residents. For residents, reported benefits of the choir have been establishing relationships outside Minda, providing a source of pride, and improved speech and general wellbeing. The choir’s repertoire includes original pieces written by members. It has held concerts around Australia and travelled to Canada to perform.

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458 Creative New Zealand is a crown entity funded through Vote Arts, Culture and Heritage and the New Zealand Lottery Grants Board. Arts Alive is the Auckland City’s funding programmes for the arts.

459 More information about Touch Compass Dance Trust is available at http://www.touchcompass.org.nz

460 More information about Arts Projects Australia is available at http://www.geocities.com/artsproject2000
Physical activity and sport

As noted in Chapter 5: Health, people with an intellectual disability tend to have a more sedentary lifestyle and a higher rate of obesity than the general population. Individuals who live at home have the highest rate of obesity.\(^{(461)}\) Sport and physical activity provide an opportunity for people with an intellectual disability to lead more active lifestyles.

New Zealand research suggests considerable individual variation in participation in physical activity. Some people with an intellectual disability had no involvement in physical activity, due to lack of time or motivation, or the individual’s personal circumstances.\(^{(462)}\) A research study in the early 1990s found that the only sport or physical activities people with an intellectual disability mentioned were walking, bowls, cycling and billiards.\(^{(463)}\) The most frequent sporting activities mentioned during the National Health Committee focus groups were involvement in Special Olympics, playing pool, tenpin bowling, biking, swimming and Riding for the Disabled (RDA).

A number of sporting and recreation initiatives have been set up to enable people with disabilities to play or compete against each other, including Special Olympics, Paraolympics and RDA. There is debate about the appropriateness of these initiatives. They do, however, highlight that the competitive nature of mainstream sport makes it inappropriate for many in society and raise the question of why standards for sporting success have to be set by non-disabled athletes only?\(^{(464)}\)

No Exceptions

No Exceptions is Sport and Recreation New Zealand’s (SPARC)\(^{(465)}\) policy targeted at people who have traditionally faced barriers that made it difficult for them to take part in the sport or leisure activity of their choice. People with an intellectual disability are one group identified in the policy statement, although there is no data on their level of involvement.\(^{(466)}\) The three objectives of No Exceptions are to:

- develop a culture that gives people with disabilities access to sport, fitness and leisure in their choice of segregated or integrated environments
- develop an environment where all national and community organisations support the involvement of people with disabilities
- create an environment where people with disabilities have the same opportunities as all New Zealanders to participate, enjoy and achieve in sport or leisure activities.\(^{(467)}\)

The No Exceptions policy is under review. This review is to determine if the policy meets the needs of all people with disabilities or if there are groups who are missing out.

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\(^{(462)}\) Neale 1995.
\(^{(463)}\) Henderson 1991.
\(^{(464)}\) Bray and Gates 2003.
\(^{(465)}\) Sport and Recreation New Zealand (SPARC) was formed in 2002 and incorporates the functions of the Hillary Commission, the New Zealand Sports Foundation and the sport policy arm of the Office of Tourism and Sport.
\(^{(466)}\) Hillary Commission 1998.
\(^{(467)}\) Hillary Commission 1998.
Having fun

Sports Opportunity Officers
To implement the No Exceptions policy, the Halberg Trust, with support from SPARC, employs 12 regional Sports Opportunity Officers. The role of Sport Opportunity Officers is to link people with disabilities into community-based sport. This is achieved through working with people on a one-to-one basis, liaising with schools, supporting coaches and developing support networks to assist the inclusion of people with disabilities into community-based sport.

He Oranga Poutama
He Oranga Poutama is an approach by SPARC to develop healthy lifestyles for Māori through sport and physical leisure. It focuses on a balance between the four cornerstones of Māori health – te taha tinana, te taha hinengaro, te taha wairua and te taha whānau. He Oranga Poutama is facilitated through 22 Kaiwhakahaere who work with local marae, iwi and communities to develop sport and leisure opportunities. He Oranga Poutama is closely integrated with other SPARC initiatives, including the No Exceptions policy. The review of the No Exceptions policy provides an opportunity to find out whether the needs of Māori with disabilities are being met.

Special Olympics

“...I go tenpin bowling with Special Olympics. It costs $10 for two games every Saturday.”

Special Olympics is a sports programme that provides people with an intellectual disability with opportunities to participate in individual and team sporting activities. It is an international approach that has been operating for about 30 years and now caters for over 400,000 people worldwide. The New Zealand Special Olympics Foundation was set up in 1985 and receives funding from Sport and Recreation New Zealand. The mission of Special Olympics is:

“... to provide year-round sports, training and athletic competition in a variety of Olympic-type sports, for persons eight years of age and older with an intellectual disability, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.”

Special Olympics is the focus of considerable criticism and controversy because of its ‘segregation’ approach. It has been suggested that Special Olympics perpetuates stereotypes about people with an intellectual disability. An overseas study of the perceptions of Special Olympics volunteers suggested that their involvement did not promote positive changes in volunteers’ views and those with greater levels of contact had more negative perceptions.

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468 The Halberg Trust was founded by Sir Murray Halberg in 1963 to honour sporting excellence. The aim of the trust is to link children and young people to sport and active leisure. More information is available on www.halberg.co.nz.
469 He Oranga Poutama is funded by Sport and Recreation New Zealand and the Reducing Inequalities Contingency Fund.
470 Coordinators.
471 Quote from an adult with an intellectual disability, NHC focus groups 2002.
472 Sport and Recreation New Zealand provides funding for Special Olympics as part of its No Exceptions policy.
474 nzine 1998.
The researcher proposed that situations where a person with an intellectual disability is dependent can reduce positive perceptions.475

Another study examined attitudes of parents and ‘experts’ in the field of intellectual disability towards Special Olympics. The majority of the experts (85%) considered that Special Olympics was a beneficial programme and cited positive outcomes like improved self-esteem, physical benefits and social opportunities. The rest criticised Special Olympics for its failure to become more integrated and felt it should be abolished. There was a view that the programme did not develop lifelong leisure skills or encourage community participation. Parents were generally positive and none said that they wished to withdraw their child. Parents identified social benefits related to self-esteem, happiness, a sense of comfort and belonging, and opportunity for friendship and making a contribution toward others. Ninety-five percent of parents reported that their son or daughter was involved in athletic activities other than the Special Olympics games, although over half of this was training for the Special Olympics.476

The study concluded that Special Olympics promotes a normalised lifestyle by giving people with an intellectual disability access to sports experiences generally available in society. On the other hand Special Olympics attempts to adapt its services to meet the needs of a special population. It was the view of the researchers that as specialisation is common in sports, this approach may be more normal than it generally realised. The study, however, did not canvass the views of people with an intellectual disability.477

Internationally, Special Olympics has attempted to address some of the criticisms by creating partnerships with other organisations and promoting the inclusion of people with an intellectual disability in community-based recreation facilities and programmes. The debate around the appropriateness of Special Olympics has had very little input from people with an intellectual disability.478

Special Olympics played a major role in the leisure activities of adults who attended the National Health Committee focus groups. For them it offered an accessible sport and leisure activity. However, there appears to be considerable regional variation in the activities offered.

Riding for the Disabled (RDA)

[Where would you like to be in 2-5 years?] “Teaching others with disabilities to do horse riding, to ride horses.”479

In 1962, the concept of Riding for the Disabled (RDA) was introduced to New Zealand from Great Britain. There are now over 50 RDA groups around the country providing therapeutic horse-riding to over 2,500 people. The age of riders varies between groups, with some focusing more on children and others also involving adults. RDA receives funding from Sport and Recreation New Zealand and the Lottery Welfare Distribution Committee. In

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479 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Having fun

addition, it is a component of some of the government-funded vocational and day activity services. RDA groups are run by volunteers, often with some involvement by riders, such as having a riders’ representative on the committee.

Barriers to leisure

Research in New Zealand in the early 1990s found that many community clubs and activities were unwelcoming to people with an intellectual disability. Removing this barrier is one of the objectives of Sport and Recreation New Zealand’s No Exceptions policy.

Lack of transport can be a significant barrier to taking part in leisure activities outside the home. This was confirmed in the National Health Committee focus groups, where very few participants had their own transport. The other major barrier identified in the consultation is insufficient income to meet the costs of transport and activities.

"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’d like to go and see my sister in Waikato, but I haven’t got enough money."

Other barriers identified in the literature are need for personal support, lack of energy and the extra time used up by ordinary tasks of daily living due to the effects of the person’s disability.

"Being scared of other people stops me doing things sometimes. I stay away from people. They give me a hard time."

"I go swimming and walking, but at the moment I can’t because there are not enough staff because they don’t pay enough. They don’t cover for staff who are sick."

Another potential barrier to involvement in leisure activities is the hierarchy that exists between types of disability. Community groups involving people with disabilities may be more ready to include people with physical or sensory disabilities than those who have an intellectual disability. Likewise, the approaches used in initiatives to break down barriers may be more appropriate to people with other impairments.

One local authority initiative to make leisure more accessible to people with disabilities is the Christchurch City Council’s Kiwiable Leisure Card, which is available free to people with disabilities who receive government income assistance. People who have a Kiwiable Leisure Card can access over 50 recreation and leisure facilities in the Canterbury region at a discounted price. If they require support from a caregiver, the caregiver gets free entry.

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482 Neale 1995.
483 Quotes from adults with an intellectual disability, NHC focus groups 2002.
484 Neale 1995.
485 Quotes from adults with an intellectual disability, NHC focus groups 2002.
486 This covers people on Invalids and Sickness Benefits or who are receiving ACC payments for more than 52 weeks.
Primoting leisure

The research literature indicates that, in whatever setting leisure takes place, it is important to focus on the individual’s abilities, not impairments, and on ensuring that barriers to inclusion are removed. “Abilities” includes a person’s strengths, capacities, interests and experiences.

During the NHC focus groups, participants were asked about their goals for the next two to five years. Some of these focused around leisure or creative activities, and travel.

| “What I want to try and do is do an apprenticeship horse-riding or martial arts instructor.” |
| “I want to be a DJ – the world’s best.” |
| “Go to Europe to find out about my heritage.” |
| “See the world – travel all around the countries.” |
| “If I had a chance I’d be a bone carver – I had a go at wood carving when I was at school.” |

Adults with an intellectual disability require support to participate in many leisure activities, particularly outside the home. This support could include help with transport, mobility, making arrangements, self-care or learning specific skills. The role of support staff in facilitating leisure activities is vital.

As with all people, choosing the type of activity to take part in enhances the participation and enjoyment of people with an intellectual disability. However, it is critical that difficulties with communication do not deny an individual the chance to enjoy leisure activities. Research shows that adults with ‘significant’ intellectual impairments can be taught to express their choice of settings for leisure activities.

In order for people with an intellectual disability to make choices or express preferences, they need to experience a range of activities. This is particularly true for people with a ‘severe’ intellectual disability whose opportunities to participate without support are limited. It is also important to remember that personal preference may change over time, which means that ongoing opportunities to experience new activities are needed.

Adults with a ‘significant’ intellectual impairments may need to learn particular skills to enable them to participate in leisure activities. These may be social interaction skills, specific tasks (like purchasing goods) or physical skills (such as catching a ball). While there is growing acceptance that people with an intellectual disability need support to learn skills associated with work, education and daily living, a lot less attention has been paid to the area of skills for leisure. Furthermore, the skills that are taught need to be age-appropriate.

488 Quotes from adults with an intellectual disability, NHC focus groups 2002.
489 Bray and Gates 2003.
491 Bray and Gates 2003.
Having fun

For people with a ‘mild’ intellectual disability, the main barriers to taking part in the leisure activities that interest them may be poor self-image and being discouraged from taking risks to do things for themselves. People can be assisted to overcome barriers like shyness, fear of rejection and not knowing what to say or do by imagining themselves differently. One approach used in Australia is developing stories of what they can do and who they can become. Live It Up is a leisure programme for people with a ‘mild’ intellectual disability in Sydney, Australia that provides group activities and individualised services that promote independence and community connections. This programme focuses on good planning and building self-confidence.493

Supportive policies, among government agencies, service providers and the community sector are necessary in order for people with an intellectual disability to take part in relevant and satisfying leisure pursuits. As has been noted, Sport and Recreation NZ takes a positive approach through its support and funding of No Exceptions initiatives.

Many of the day programmes funded by the Ministry of Health contain leisure and recreation components. The Ministry of Social Development (Work and Income) also funds some art and leisure activities as part of vocational services. This type of activity does not fit in with the Government’s direction for vocational services, the focus is of which is employment.494 The current changes in the way vocational services are funded provides an opportunity for Work and Income, the Ministry of Health and government agencies focusing on sport and cultural activities to consider how such initiatives will be funded and supported.

Key issues

- The leisure pursuits that adults with an intellectual disability take part in are similar to those of other people, with the majority of activities being sedentary.
- Most adults with an intellectual disability need support to access or take part in leisure activities.
- There is debate about the appropriateness of ‘segregated’ activities involving only people with an intellectual disability.
- It is important that a person with an intellectual disability has a choice about what activities they take part in and where they do this.
- In designing policy and services, consideration should be given to potential barriers to leisure, such as cost, transport and need for support.

493 Fullagar and Owler 1998.
494 Department of Labour 2001.
13. MOVING AROUND

"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."  

This chapter:

- covers both getting around the home and accessing the community
- identifies the diversity of mobility needs of adults with an intellectual disability
- details the support and equipment available to help with mobility and identifies areas of unmet need
- describes the modes of transport that adults with an intellectual disability use and some of the barriers they face in getting around their communities.

Diversity in mobility needs

Difficulties with mobility can limit all aspects of people’s lives. As noted in Chapter 5: Health, there is wide variation among people with an intellectual disability in the extent and nature of their intellectual impairments, the functional disabilities that they experience and the presence of sensory and physical impairments. It is estimated that at least one-third have poor eyesight and over 40 percent have difficulties with hearing. In addition, many people with an intellectual disability have physical impairments and there is a high incidence of over-medication and polypharmacy. All these factors can create barriers to mobility around the home or within the community.

Mobility is also affected when medical conditions or impairments are not identified or are inadequately managed. Studies looking at the health needs of adults with an intellectual disability suggest that between 30 and 70 percent have unmanaged visual impairments, and between 10 and 40 percent have hearing impairments that are unmanaged.

Getting around the home

In getting around the home, there are three groups of people with an intellectual disability who have difficulties with mobility, but whose requirements differ slightly.

- People with physical disabilities affecting mobility. Some people with an intellectual disability use equipment such as wheelchairs, crutches or walkers. It is important that the

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495 Quote from an adult with an intellectual disability, NHC focus groups 2002.
496 For more information and references see Chapter 5: Health.
497 For more information and references see Chapter 5: Health.
Moving around

environment in which they live and work is accessible including access to the building, bathrooms and communal areas. For families, this can be a considerable expense, although in some situations financial assistance is available. A small proportion of people with an intellectual disability have significant physical impairments and are unable to achieve personal mobility, even with the use of equipment. These people require assistance from others to move around their environment.

- **People with hidden mobility problems.** Mobility problems, like poor balance and lack of confidence in walking around, may be the result of factors such as undetected visual impairments or inappropriate medication. As these factors may not be obvious to others, these people can be at higher risk of falls and other injuries. These factors are more likely to be picked up if a person has regular health checks.

- **People who develop mobility problems as they get older that can result from medical conditions, such as a stroke or arthritis.** Regular health checks can pick up physical changes and identify risk factors such as poor balance. It is also important that the person receives appropriate medical care and the necessary equipment to maintain safe mobility.

Getting around the home safely

A recent research project by the Donald Beasley Institute looked at unintentional injuries among adults with an intellectual disability, who used residential and/or vocational services in Otago and Southland. This study found that 33 percent of the identified injuries were the result of a fall. While the research did not identify the factors contributing to the falls, researchers are of the view that many of the risk factors for older people are relevant to adults with an intellectual disability. It is suggested that the most important causative factors of falls for people with an intellectual disability are likely to be lower limb muscle weakness, poor balance, vision impairment and medication.

The high level of injuries identified in the research project suggests that injury prevention in services for people with an intellectual disability mostly focuses on factors such as fire safety and general environmental hazards. The next stage of the project includes developing a fall prevention programme and assisting service providers to improve systems and practices to document injuries.

Home modification

Data from 1996 New Zealand Disability Surveys indicated that up to 16 percent of adults with an intellectual disability who live in households (which includes group homes) used ‘special features’, such as grab rails, lowered benches and wet area showers, inside the home. Data for people living in residential facilities was not published.

The survey also asked about use of ‘special features’ such as handrails, ramps, or lift devices, to get in and out of or to move around the home. Results suggested that up to 15 percent of

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498 Bray 2002. The other high frequency incidents were assaults by other clients (22%). This survey is also discussed in Chapter 4: Accommodation.

499 Personal communication with Anne Bray, Donald Beasley Institute 2002.

500 Bray 2002.

501 Statistics New Zealand 1997b.

502 In the Disability Surveys, residential facilities include ‘intellectual disability units’ but exclude supported housing and group homes.
people with an intellectual disability living in households use this type of equipment. \footnote{Figures calculated using data from Statistics New Zealand 1997b.}

Neither question in the survey clarified whether there were people who needed this type of support, but were not receiving it. Information about unmet need was not available either from needs assessment and service coordination data.

The government funds, through Vote Health, home modifications such as ramps, widening of doors and handrails. This funding is only available to disabled people who live at home, for instance in a flat, with family members or as a boarder. It is not provided for modifying a home run by a service provider.

If a property is owned by the Community Housing section of Housing New Zealand Corporation (HNZC), access and safety modifications are usually undertaken by the Corporation. When houses are purchased as community residential homes, HNZC routinely modifies them to provide wheelchair access and wet area showers and to meet fire safety requirements. In modifying the home, the Corporation also takes into account the specific requirements of, and occupational therapy assessments on, the residents who are moving in. The National Health Committee was advised that if the requirements of residents change and further modifications are needed, this is usually undertaken and funded by HNZC, although the Corporation is not funded for this additional work. \footnote{Personal communication with HNZC staff 2002.}

Equipment

Data from 2001 Household Disability Survey indicated that nearly 30 percent of adults with an intellectual disability who live in households used ‘special equipment’, such as wheelchairs, walking frames and shower stools. Twelve percent identified that they had unmet needs for special equipment. \footnote{Figures calculated using data from Statistics New Zealand 2002.} Data for people living in residential facilities \footnote{In the Disability Surveys, residential facilities includes ‘intellectual disability units’ but excludes supported housing and group homes.} was not published according to disability type, but the 80 percent of the total sample of people with disabilities living in residential facilities used equipment to move about and 90 percent used one or more types of ‘special equipment’. \footnote{Figures calculated using data from Statistics New Zealand 2002.} 

While the government funds, through Vote Health, mobility equipment around the home, a person must either be in employment or formal education to get Health funding if they need mobility equipment outside the home. This is an inequity that has been highlighted for the last decade, but has remained despite there being no longer any legislative constraints preventing its removal. \footnote{Prior to the transfer of disability support services from welfare to health in 1994-95, criteria for mobility equipment were contained in the Disabled Persons Community Welfare Act. Once the services were transferred, the provisions of the Act no longer applied, although they were retained as policy guidelines.}

This policy limits the community mobility of some adults with an intellectual disability who are able to get around their home but when they are outside, where the distances are larger and the terrain more difficult, need a wheelchair or other equipment. People with an intellectual disability who are not in paid employment are very unlikely to have sufficient
Moving around

money to purchase mobility equipment. As few people with an intellectual disability are in paid employment, the current policy particularly disadvantages this group of disabled people. Also, adults with an intellectual disability are also unlikely to have the resources to buy additional mobility equipment, for instance, for sport and recreation.

The Lottery Grants Board has an ‘Individuals with Disabilities’ sub-committee that allocates grants for mobility and communication equipment “to help people with disabilities achieve independence and gain access to the community”. Mobility equipment funded by the sub-committee includes wheelchairs, mobility scooters and vehicle modifications. While most applicants meet the eligibility criteria, the high demand for the fund means that applications are prioritised with only about 40 to 45 percent of applicants receiving funding. Applications for wheelchairs for outdoor mobility are considered favourably, but are only a small proportion of the applications received. It is not clear how many people who need wheelchairs and other aids for community mobility are unable to obtain them.

Assessment for, and provision of, mobility equipment require specialist knowledge, particularly when providing equipment to people with limited mobility. For instance, setting up a wheelchair and seating a person in it needs a high level of technical knowledge. The Accredited Assessor Scheme aims to improve the skills base of assessors in the New Zealand health workforce by setting standards and monitoring procedures for the assessment and provision of specialised equipment by professionals such as occupational therapists, physiotherapists and speech language therapists. To improve the skill-base, the Ministry of Health is in the process of letting contracts for specialist wheelchair and seating services that include training of staff involved in the provision of equipment.

Getting around the community

Access to transport is essential if people with an intellectual disability are to lead full and purposeful lives. However, this group currently faces many obstacles in using public or private transport. Participants in the NHC focus groups spoke of the difficulties faced in getting around their communities.

“Transport is terrible sometimes, you can’t get to places you want to get to.”

“If it’s raining, I don’t go.”

A survey of disabled people in Auckland found that people with an intellectual disability identified transport as their highest priority need. This finding correlates with a recent study of the views of disabled people in the UK in which nearly half identified transport as the main problem in the area where they lived.

Lack of appropriate transport creates a barrier to accessing community, jobs, friendships, education, recreation and leisure. The way in which transport services are delivered is important to disabled people, as well as the types of services that are provided. Increasing

509 Department of Health 2001.
510 Quotes from adults with an intellectual disability, NHC focus groups 2002.
512 DPTAC 2002.
513 DPTAC 2002.
Moving around

the understanding of transport providers about the different and varied needs of disabled people is likely to benefit people with an intellectual disability, particularly those who use public transport and taxis.  

The 1996 Household Disability Survey asked people living in households if they experienced difficulty travelling short and long distances.  

Around a quarter of people with an intellectual disability indicated that they had difficulty travelling short distances on buses, trams, trains or ferries, and the rest said they had no difficulty doing this.  

In comparison, nearly half stated that they had no difficulty travelling long distance by trains, planes and buses while 15 percent reported that they had difficulty with this.  

One-fifth of those surveyed indicated that they did not travel long distances.  

During the NHC’s focus groups, several participants talked about previous and planned trips overseas, while others had not travelled out of the city or town in which they lived.

The modes of transport used by people with an intellectual disability vary depending on where a person lives, their abilities and skills, and the range of transport options available in their local community.

Data from the UK suggests that the transport mode most frequently used by disabled people is a car driven by someone else.  However, over three-quarters of disabled people never drive themselves, compared to only a third of the general public.

There are no New Zealand figures indicating the proportion of people with an intellectual disability who use various modes of transport.  In a survey of disabled people in the UK, people with an intellectual disability reported that they had used the following forms of transport at least once in the last month:

<table>
<thead>
<tr>
<th>Mode of transport</th>
<th>Percentage of users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Car driven by self</td>
<td>7</td>
</tr>
<tr>
<td>Car driven by somebody else</td>
<td>66</td>
</tr>
<tr>
<td>Taxi/minicabs</td>
<td>45</td>
</tr>
<tr>
<td>Local buses</td>
<td>56</td>
</tr>
</tbody>
</table>

Respondents who used public transport and taxis/minicabs were also asked if they usually travelled alone or with someone else.  Nearly half of those with an intellectual disability usually travelled with someone else, which was slightly higher than the average for all disabled people.

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514 British Medical Association 1997.  
515 As with all data relating to people with an intellectual disability in the New Zealand Disability Survey, the figures reported need to be treated with caution because of the high sample error.  
516 Statistics New Zealand 1997b.  
517 Statistics New Zealand 1997b.  
518 DPTAC 2002.  
519 DPTAC 2002.
Moving around

Table 11: Whether disabled people travel alone or with someone else

<table>
<thead>
<tr>
<th></th>
<th>Usually travel alone</th>
<th>With someone else</th>
<th>It depends on the journey</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public transport</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with an intellectual disability</td>
<td>39%</td>
<td>46%</td>
<td>12%</td>
</tr>
<tr>
<td>All groups of disabled people</td>
<td>39%</td>
<td>40%</td>
<td>12%</td>
</tr>
<tr>
<td><strong>Taxis/minicabs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with an intellectual disability</td>
<td>38%</td>
<td>47%</td>
<td>7%</td>
</tr>
<tr>
<td>All groups of disabled people</td>
<td>36%</td>
<td>43%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Fifty-six percent of respondents with an intellectual disability reported that they had to plan their trips well in advance, and 46 percent of these respondents said that they got frustrated sometimes because they could not go out on the spur of the moment.521

Data from the New Zealand 1996 Household Disability Survey indicates that 70 percent of people with an intellectual disability living in households had access to a motor vehicle. In comparison, 88 percent of people aged 15 and over who do not have disabilities had access to a motor vehicle.522 This data does not indicate how many people with an intellectual disability have driver’s licences or can access transport when they need or want it.

Driving

“I am very close to getting my licence. I’m doing a course at polytechnic learning the road code. I might need help with reading.”

“I have my learner’s licence, but I can’t afford to sit the next bit. My mother doesn’t trust me on the roads.”

“I’m going for my driver’s licence. The police officer read out the questions.”523

A small proportion of adults with an intellectual disability hold a driving licence. It is stated in the guidelines, which assist medical practitioners to determine whether a patient is fit to drive, that adults with an intellectual disability can drive, if they are able to pass the requirements to hold a licence, such as theory and practical tests.524

To gain a driving licence, adults with an intellectual disability are likely to need support in learning to drive and sitting the driving licence test, for instance using a reader-writer for the written theory test.

Public transport

“I had support to learn to catch the bus – it took two weeks.”525

The difficulties of using public transport, particularly in Auckland, were constantly raised in the National Health Committee’s focus groups. This mirrors the findings of a survey of

520 DPTAC 2002.
521 DPTAC 2002.
522 Statistics New Zealand 1997b.
523 Quotes from adults with an intellectual disability, NHC focus groups 2002.
525 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Moving around

disabled people in Auckland, in which public transport in the region was seen as largely inaccessible, inconsistent and unaffordable. For people with physical or visual impairments, physical accessibility was the major issue. Cost was also identified as a key barrier.526

To use public transport independently, people with an intellectual disability may need support and training. Another barrier to using public transport is likely to be lack of understanding among transport staff and operators about the needs of people with an intellectual disability.527 In recent focus groups, as part of the review of Total Mobility, adults with an intellectual disability pointed out that some of them were able to use buses but only on familiar routes. They suggested that the provision of visual and verbal announcements of bus routes and stops would make it easier for them to use public transport.528

When asked how they usually get information about public transport, 30 percent of people with an intellectual disability in the UK survey reported that they use printed timetables. There were significant differences between disability groups in the preferred ways of obtaining information, which highlights the importance of having information about public transport available in a number of formats.529 Fifty-one percent of the people with an intellectual disability surveyed were of the view that improvements in public transport would have a positive impact on their social lives.530

Taxis

“Two people have to pay for a taxi themselves to go to the daily base (day service).”531

Private taxis and vans operated by service providers are important modes of transport for people with an intellectual disability in New Zealand. While providing much needed transport to people who, for a range of reasons are not able to drive or use public transport, there are significant barriers to their use. In the case of taxis, the major barriers are insufficient taxi services, particularly in rural areas, and the cost of a taxi ride, which to some degree is offset by the Total Mobility scheme.

The Total Mobility scheme is available to people who, because of disability, have difficulty using public transport. The scheme provides eligible applicants with vouchers for a half-price discount on taxi fares. Total Mobility is administered by regional councils, which meet 60 percent of the costs. The other 40 percent of funding is provided by Transfund NZ.

Total Mobility is not available in all parts of New Zealand and is not possible in areas where there is no taxi service. The eligibility criteria tend to vary between regions. Furthermore, many people with an intellectual disability do not have enough income to meet the cost of half a taxi fare. The survey of people with disabilities in Auckland found that many of those interviewed considered that Total Mobility was expensive and inaccessible.532

528 Transfund NZ 2003.
529 DPTAC 2002.
530 DPTAC 2002.
531 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Moving around

The Government is currently reviewing targeted transport assistance, including Total Mobility. Transfund NZ has been asked to coordinate this review and has undertaken a survey of Total Mobility users, administrators and transport operators. As part of this review IHC held regional focus groups for people with an intellectual disability, which identified some of the barriers they faced in using other forms of transport. Eighty-nine percent of all Total Mobility users involved in the review reported that they did not get any other government assistance with transport. The main forms of government assistance identified were Disability Allowance533 and free or discount bus passes (local government initiatives).

A number of service providers are now using the Total Mobility Scheme rather than running their own vans. In this situation, half the cost of a ride is met by the regional council and half by the service provider.

Vans and cars operated by service providers

“I want to go to church on Mondays and Tuesdays but a van is not available.”
“I can’t go out `cause the van’s being used for tenpin bowling or the groceries, so I can’t.”
“If staff take people out in the van we have to go whether we like it or not.”
“They don’t have any signs on the cars. They are just normal. That’s really important to me.”534

Where service providers have vans or cars, use of these tend to be determined by the timetable of the providers and the collective requirements of the people who use the service. This means that in many cases vans are not available if a person needs to travel individually, and often people spend a lot of time travelling and waiting for others to be picked up.

Focus group participants talked about how recreation and outings tended to be organised as group events, when everyone travels together in the service provider’s van to the same destination and stays together as a group. This was referred to as moving around “as a six pack”. Such outings were not seen as opportunities for real community participation. Another issue raised in the focus groups was the stigma associated in travelling in a van with the service provider’s name on it.

Biking

“My friend has a car. We put our bikes on the cycle rack, go out into the middle of nowhere and cycle around for a couple of hours.”

[What do you do for fun?] “Biking over hills, when I get a chance I go to the pub.”

“Going biking – sometimes go round to a mate’s place.”535

A number of participants in the NHC focus groups said that they bike either for transport or pleasure. This was more common in flat terrains like Nelson and Christchurch, and several young men mentioned biking among their recreational pursuits.

533 Chapter 7: Paying for things provides more information about the Disability Allowance.
534 Quotes from adults with an intellectual disability, NHC focus groups 2002.
535 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Moving around

Accessing the built environment

Requirements for accessibility of buildings are contained in the Building Act 1991 and subsequent amendments. While this legislation has led to improvements in access to some public buildings, many buildings and routes are still difficult or impossible to access for people who have physical impairments or who find signs difficult to read.

The survey of disabled people in Auckland also asked about services funded or provided by the Auckland City Council. As well as accessible transport, respondents identified the need for smoother roads and footpaths. Safety is also an important issue in the outdoor environment. The survey of visually impaired people in the UK found that nearly all respondents reported having had at least one accident when out walking, and over half had sustained injuries.

Cost of transport

The cost of transport was a major topic raised in the focus groups and discussed in the literature. Chapter 7: Paying for things highlights that most people with an intellectual disability have a limited income from which they have to meet their expenses. As has already been mentioned, paying half the cost of a taxi fare is beyond the income of many adults with an intellectual disability. So is the cost of car ownership or purchasing mobility equipment for sport or recreation. Some adults are unable to meet the costs of public transport. Insufficient money to afford transport is a barrier to community participation.

Key issues

- A significant number of adults with an intellectual disability have impairments or health conditions that affect their mobility.
- There appears to be a high rate of falls among adults with an intellectual disability who use residential or vocational services.
- Current criteria for mobility equipment outside the home prevents some adults with an intellectual disability from getting the equipment they need.
- Cost is a major barrier to mobility.
- Vans operated by service providers tend to reinforce collective living arrangements, rather than promoting community participation.
- Many adults with an intellectual disability need support to use, or learn to use, transport.
- There is a need for transport providers to learn more about adults with an intellectual disability and the provision of plain language information.

14. WHAKARITENGA MAHI MÖ TE HUNGA PAKEKE MÄORI KUA HAUÄ-Ä-HINENGARO
(Services for Mäori adults with an intellectual disability)

Whakataukī
E kore koe e ngaro te kakano i ruia mai i Rangiatea.

(Proverb
The seed that issued from Rangiatea will never be lost.)

Tënei Wähanga:
(This chapter:)
• outlines the issues facing Mäori adults with an intellectual disability and their whänau
• provides a historical context to service provision for Mäori adults with an intellectual disability and their whänau
• discusses indigenous and Mäori concepts of disability and health
• describes four services that provide support to Mäori adults with an intellectual disability and their whänau
• explores what is meant by a cultural approach to the provision of disability support services.

Te hunga pakeke Mäori kua hauä-ä-hinengaro me ö rätou whänau
(Mäori adults with an intellectual disability and their whänau)

Information-gathering about the experiences and specific issues faced by Mäori adults with an intellectual disability and their whänau occurred through Mäori participating in the National Health Committee project in several ways.

• Mäori adults with an intellectual disability and their whänau took part in the general focus groups that were held throughout New Zealand. A sample of four Mäori disability support service providers were visited.

• Mäori adults with an intellectual disability and whänau using the visited services contributed to the project through individual discussions.

• A Mäori focus group in Whakatane was attended by eight Mäori adults with an intellectual disability.

• Two Mäori families caring for adults with an intellectual disability at home, were visited in their homes in the Bay of Plenty region. A further Mäori family who cared for an adult with an intellectual disability was visited at a marae.

538 The term whänau is used in this document to recognise the wide diversity of families represented in Mäori communities. It is up to each whänau (family) and individual to define for themselves who their whänau is.

539 Significant gathering area of whänau, hapü or iwi, usually connected with an ancestor.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

- Māori staff working for Māori service providers were also spoken with for their views as support people. A separate discussion group was held with Māori staff of a large mainstream service supporting Māori people with an intellectual disability.

These avenues provided access to a large and diverse group of Māori adults with an intellectual disability.

All of the issues that have been raised in other chapters are pertinent to Māori adults with an intellectual disability.

Te neke haere (Moving around)

As with all people with an intellectual disability mobility issues were very real for Māori, particularly in relation to their ability to take part in community and cultural activities.

“Even doing sports. Going to sports. It comes down to someone to take me. It comes down to transport.”

During discussions with Māori adults with an intellectual disability in Whakatane a common theme was the difficulty in getting around. The question “If you could have one or two wishes, what would they be?” was asked. Several of the people present mentioned getting around their community.

“My wish would be to learn to drive. I have got a learner licence. I would like to learn to ride a bike. I’ve got one but I don’t know how to use it. Bad luck for me I can’t drive. I wish I could but I am not allowed to.”

“If I could drive.”

“My wish is to complete my road code. It’s my next step. That’s the step I’m on to now. I’ve got my learners licence.”

“The people that I stay with take me down to work. I could do that if we had a car. We used to have one just to do our training on. A red one. It got sold. The red car. Because we didn’t have any more support.”

More information on mobility issues is detailed in Chapter 13: Moving around.

Whakawhiti kōrero/Whakawhiti whakāro (Communicating)

Being able to communicate is a critical issue for all people with an intellectual disability. For Māori with an intellectual disability this issue was compounded by their desire to be able to use and understand te reo.

The nature of an intellectual disability means that thinking is difficult. It is more difficult to understand information or identify a problem, determine what is causing it, work out

540 Quote from an adult with an intellectual disability, NHC focus groups 2002.
541 Quotes from adults with an intellectual disability, NHC focus groups 2002.
542 Māori language.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

solutions and implement them. Communication enables us to interact and exchange ideas and emotions with others. Being able to express needs and thoughts, and understand what others are saying is essential for control over care and life. Being able to do so in Māori was an additional requirement for some Māori adults with an intellectual disability and their whānau.

A wide range of communication difficulties are experienced by Māori with an intellectual disability. Like other people with an intellectual disability, Māori adults and their families found it impossible to access services to assist communication.

“The times when you really need help is when you need to talk to her. I need help then. She could talk when she went to special education service. That was years ago. She doesn’t talk now. She hasn’t had a speech-language therapist for years. Do you think she can talk again?”

Accessing support with communication was a major difficulty for small Māori service providers in provincial areas. Accessing any specialist services was a challenge, and all were unable to access speech language therapy for adults who were resident in their service. While some general intellectual disability service providers in urban areas did have sporadic access to assistance, very few speech language therapists work with adults with an intellectual disability, and those who do are mainly paid either by families or by organisations through fundraising, not by government-funded service provision.

All of the eight Māori adults with an intellectual disability who participated in a Māori focus group in Whakatane said that they would like to learn to communicate in Māori.

“I would like to, for me, to learn a bit more (Māori).”

More information on communication issues is outlined in Chapter 6: Communicating.

Te wāhi me te āhua o taku noho
(Where and how I live)

Having a choice about where they live and who they live with was highly relevant for Māori people with an intellectual disability. They expressed the same level of frustration as non-Māori about lack of choice in where they live, who they live with, and how they live.

One woman with an intellectual disability told the story of how she misbehaved in most of the living situations she was placed in, until she was in a living situation that suited her.

“I was in Social Welfare. I was never at home. Then I went to boarding school. I lived with a Māori family. I learnt some Māori craft at boarding school. I didn’t like boarding school. I was naughty. I kept swearing at the staff and chucking things at them. I didn’t like them telling me what to do. My family got me back here. I came here to IHC in Whakatane. I didn’t like the staff telling me what to do. It was boring. I used to run away to my Aunty’s house and my dad would take me back. I was in an IHC flat for three years. They were doing some moving around. I am in the flat for independent living. We don’t have much staff. We don’t really need them. I had the choice of who I wanted to live with and I chose my friend. We get on really well.”

543 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
544 Quote from an adult with an intellectual disability, NHC focus groups 2002.
545 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Now that she is able to live with her friend, she no longer swears, runs away or throws things around at home. She is happy to finally be living with someone she herself has chosen.

A couple who both have an intellectual disability spoke of how they were able to live together, with support from their families and from disability support services.

“I don’t live in an IHC place. I have my own unit. I have my own money. I put down what I want and need. We look after our own money. My partner and I ask IHC to have our money for safekeeping. My partner and I have bought our unit and are looking at getting married next year.”

These issues were compounded by a desire to live in a way that was comfortable for them as Māori. Some people with an intellectual disability, who had the experience of a kaupapa Māori service being withdrawn in favour of a bicultural service, made the following comments.

“There isn’t Māori any more. They have got Pākehā in there now. That was a bad thing for myself it feels like they are taking away our Māoritanga. Taking our rights away. And we can’t say anything about it.”

“I will like another Māori place, if we had a choice.”

“They are moving. They are shifting. It won’t be kaupapa Māori. It’s disappointing for the Māori ones who still want their Māori and their Māori house and to learn Māori. He’s got Pākehā in there now, not Māori.”

Māori people with an intellectual disability who wanted to live in a way that was consistent with their cultural values and their cultural ways faced particular frustration. This was a major issue for people living in group homes. Simple day-to-day activities like karakia before kai, or eating particular food could cause problems. Māori people with an intellectual disability wanted to be able to have rotten corn, or mutton birds in their home, and this often was not allowed as the smell offended other residents. Collecting kai moana, cooking it together, and then sharing the meal is an important component of Māori culture, engendering a sense of self-worth and social contribution.

For more information on where and how adults with an intellectual disability live, see Chapter 4: Accommodation.

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546 Quote from an adult with an intellectual disability, NHC focus groups 2002.
547 A kaupapa Māori service is one that has a philosophy and service consistent with Māori philosophy and protocol. It may operate from within a mainstream service, or it may operate independently of mainstream services.
548 A person of predominantly European descent.
549 Māori culture.
550 Quotes from adults with an intellectual disability, NHC focus groups 2002.
551 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.
552 Food.
553 Seafood.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

Aku mahi (whaiutu, kore utu hoki)
(The work I do (paid and unpaid))
People with an intellectual disability have similar work aspirations and reasons for working as others of the same age, and value an opportunity to work. The evidence for the benefits of work include greater self-esteem, self-confidence, more money, improvement in physical wellbeing, better social life, and independence. These were reinforced by Māori we spoke to, many of whom want paid work.

“I work two days a week to raise money for my trip. They pay me by cheque. The money goes straight in to my own account. I got the job myself. Some of my friends knew the boss. It’s good to have friends.”

“I work. I do cleaning. They pay me. I work there every day, and sometimes weekends.”

“I work. I clean the workshop, smoko room and anything rubbish. I work for the Māori wardens. I go up to the wards and back down and make sure the visitors go. It’s a paid job.”

Even where paid work was not an option for the Māori adults with an intellectual disability, many had made opportunities to contribute to their Māori communities, and others were very clear that they wanted meaningful things to do during the day, including cultural activities such as kapa haka, learning Māori language, tukutuku and whakapapa.

More information on work issues is covered in Chapter 8: Work (paid and unpaid).

Te noho-ā-īwi
(Being part of my community)
Community is not simply a location, but is about people and place – a range and variety of people in a range and variety of places. An essential component of community experience is a feeling of belonging. Participation means being involved in the social life of the community through a growing network of personal relationships.

Community participation for Māori includes taking part in whānau activities in the community like weddings, 21st birthday parties, cultural activities and going to the marae.

“We went to the unveiling and we took a koha. We knew we were independent. No staff. All the staff did was take us there. M’s sister took us back into town.”

“If they need any more hands I help at the marae. To get to the marae I ring mum.”

“I just go (to the marae). I look in the newspaper to find out if a tangi is on. I ring them up to take me.”

“On other marae they are not allowed to karanga or whaikorero. We make allowances. It is the one place where intellectually disabled Māori have their say.”

554 Quotes from adults with an intellectual disability, NHC focus groups 2002.
555 Māori song and dance.
556 Ornamental panels which are often used to adorn marae or the home.
557 Genealogy.
558 Donation or gift.
559 Tangi refers to the traditional mourning practices of the Māori.
560 Traditional call of welcome to marae.
More information on community participation is contained in Chapter 9: Being a part of the community.

Te utu
(Paying for things)
Key themes identified by all people with an intellectual disability regarding income included:
- the significant impact of a low or benefit-dependent income
- inadequate income for people in residential care
- use of Disability Allowance for funding vocational services, denying people with disability the option of using this, as intended, for their disability-related costs.

These themes were all issues for Māori adults with an intellectual disability.

There are disparities between Māori and non-Māori household incomes. Māori households have lower average incomes and this relates to under-representation in higher paying occupations, higher rates of unemployment and lower levels of labour force participation. It is reasonable to assume that Māori families caring for adults with an intellectual disability and Māori adults with an intellectual disability will, on average, be poorer than their non-Māori counterparts.

““My favorite shop is the $2 shop.”

A common theme in discussions with families caring for adults with an intellectual disability was lack of knowledge about what they were entitled to.

““He needed heaps of Treasures (disposable incontinence pants). My friend helped me out and through the whare (Māori service provider) you can get them again. They have got heaps of stuffing, thick and padded and it doesn’t seep through. Much better. I didn’t know what I was entitled to.”

A manager from a Māori service provider received referrals for residential care of adults with an intellectual disability from a range of services other than the mainstream access needs assessment agencies, for example through the YMCA. These adults with an intellectual disability often arrived at a residential service with nothing – no toothbrush, change of clothes, or other personal belongings. It is important for people to access income assistance to purchase basic clothing and toiletries, and according to the manager, the service had had difficulty doing so for new people needing support.

For more information about income issues, see Chapter 7: Paying for things.

Te tiaki i a au ano
(Looking after myself)
Personal health care issues are a major concern for all people with an intellectual disability, many of whom face significant barriers to care, inappropriate pharmaceutical prescribing and

561 Speech making.
562 Quotes from adults with an intellectual disability, NHC focus groups 2002.
563 Quote from an adult with an intellectual disability, NHC focus groups 2002.
564 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
have high levels of unmet health needs. In general, Māori under-utilise primary health care services compared to non-Māori, and Māori have poorer access to secondary health care services. It is reasonable to assume that Māori adults with an intellectual disability will also have poorer access to primary health care and secondary health care than non-Māori adults with an intellectual disability.

There is a paucity of health promotion material for adults with an intellectual disability, and even more scarce are health promotion materials for Māori adults with an intellectual disability. Many Māori, not just those with an intellectual disability, would benefit from plain and simple information accompanied by pictures. This health promotion material needs to be widely disseminated. In addition, there is little activity in many Māori communities to increase awareness about Māori providers, cultural services and other services that are available in many Māori communities. This needs to be addressed.

Māori people with an intellectual disability or their families may wish to access traditional Māori healing services. Most of the Māori providers and Māori staff within mainstream services visited during the National Health Committee project assisted their clients to access these services.

More detailed information on personal health care is outlined in Chapter 5: Health.

**Whakawhanaungatanga**
(Relationships)
The lack of relationships in their lives, and the need for support to develop and maintain friendships are equally relevant for Māori with an intellectual disability as they are for non-Māori. To address the issues:

- service providers must be aware of the importance of supporting friendships and be able to assist rather than hinder
- appropriate services are required at times of transition – for example, school to work, parenthood, retirement, parental ill health – to ensure old relationships are maintained and new relationships developed
- funding and support are needed for forming and maintaining relationships
- services and support for parents with an intellectual disability are required.

If adults with an intellectual disability are going to have the same rights as everyone else in the community this must include the right to have intimate relationships. However, this may be against the moral stance of service providers. This was particularly evident with some of the Māori service providers, where kaumātua and older Board members often hold very strong views about intimate relationships between unmarried adults, disabled or not. Moral values can be in conflict with the wishes and desires of adults with an intellectual disability, and this was particularly evident when it came to going out to socialise or having an intimate relationship.

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565 Experienced elders.
“I can’t do what I want to do with my money. I can’t do what other people do. At night time going out to the movies or with friends. There’s boundaries. All these boundaries. They (the service) set the boundaries.”

“I want to have a relationship with guys. Mum says it’s OK as long as I know what a relationship entails. Apparently I heard that the service doesn’t allow it. …they (the service) say no or they say yes. There are other clients that feel like this. I can’t have relationships, I’m not allowed. They won’t change. They won’t allow it.”

“If IHC can (have intimate relationships) why can’t we?”

In other services, an intimate relationship is supported “as long as it is meaningful”. A Māori support worker who worked with a couple with a two-year-old child, who both had an intellectual disability, made the comment that she was happy to support them and said “they have a right to their own privacy and relationships”.

For more information see Chapter 11: Relationships.

Te ako i ngā mea hou
(Learning new things)
Opportunities to learn new things, is a neglected area for all people with an intellectual disability. Furthermore, the transition from school to adulthood is an important change for young adults with an intellectual disability and can impact on life options and employment opportunities.

Māori adults with an intellectual disability need to be given opportunities to continue to learn, and not be restricted by expectations that further learning is not possible. Some Māori families took a developmental approach in enabling the adult with an intellectual disability to have time to learn to do things for themselves. As one family commented “she can do more for herself, but she doesn’t always like it.” Some adult learning was focused in-house at service providers, or through community opportunities for learning.

“We are focusing on getting education now. Where I work. At the moment we are just starting. Like learning sign language, first aid, te reo.”

For more information on transition from school and on adult education, see Chapter 10: Learning new things.

Whakangahau
(Having fun)
Leisure pursuits for Māori adults with an intellectual disability are determined to a large extent by the activities and interests of people around them as well as access to transport and money.

“There are good things, it isn’t all bad. It is just frustrating not being able to do the things that you want to do (because of the limitations imposed by the service).”

566 Quotes from adults with an intellectual disability, NHC focus groups 2002.
567 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

“I like sitting on my chair at home. I am the only one who goes for walks.”

In addition to the range of leisure pursuits identified by non-Māori people with an intellectual disability there were specific cultural activities that the majority of Māori people we talked with enjoyed. This included kapa haka, gathering traditional Māori food, and going to the marae.

For more information about recreation and leisure, see Chapter 12: Having fun.

He tirohanga whakamua
(Historical perspective)

“None of us can hold our heads up high when we look back over history at how Māori and non-Māori people with an intellectual disability have been treated historically.”

Very few Māori used specific disability services prior to World War II. At times Māori were actively discouraged from using services. For instance, before hospital benefits were brought in under the Social Security Act 1938, hospital boards often claimed that Māori did not pay the fees, and should therefore not be eligible for treatment. Another barrier for Māori was the fact that using disability services would mean separation from whānau and other supports.

It is thought that until urbanisation brought Māori into closer contact with specialised disability agencies (in the latter half of the twentieth century), the majority of Māori with disabilities lived with their own whānau. There are instances of voluntary health initiatives emerging from within Māori communities during the twentieth century, many of them initiated by women. While these services were not specific to disability, they had implications for the incidence of disability among Māori, and Māori access to health services.

Many people with disabilities were taken into institutional care. This resulted in many Māori people with an intellectual disability being completely isolated from their culture and birthright. Some of these people did not speak English on admission, and there was no Māori language spoken in the institution. Most Māori people with a Māori name were given new English names.

Kia hoki ki te whānau, ki te hapū, ki te iwi
(Reconnection with whānau, hapū and iwi)

Experiences of institutionalisation and separation from whānau have had a lasting impact on the people concerned. Several Māori providers take a cultural approach to services, which recognises whānau and cultural identity as being of paramount importance. This means it is a priority to reweave each institutionalised person back into their whānau, hapū, and iwi. Staff training at Te Roopu Taurima o Manukau Trust (a Māori disability support service provider in South Auckland) stresses the importance of remembering that although these

568 Quotes from adults with an intellectual disability, NHC focus groups 2002.
569 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
570 Tennant and Moore 1997.
571 Tennant and Moore 1997.
572 Sub-tribe
573 Tribe
574 Te Roopū Taurima o Manukau is described on page 168.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

Māori people have an intellectual disability, and may have been isolated, they are a part of a whānau, hapū, and iwi.

For many Māori adults with an intellectual disability reconnection with whānau, hapū and iwi involves an extensive search using Māori networks by those experienced in Te Ao Māori. Where a connection is made, a time of healing is needed for both the person who has been institutionalised and their whānau.

The experience of Māori providers who have undertaken this work is that for some whānau it has been a complete shock to be contacted. In some cases surviving members of the whānau have had no memory of an older sibling or whānau member who was taken from the family at a young age. In some cases the hurt suffered from their removal has meant that after a person was institutionalised they were never spoken about again. For some whānau there has been an awareness that strands had been missing.

Te Roopu Taurima o Manukau Trust describes the backbone of its service as korowai aroha. Korowai aroha is a dedicated group of knowledgeable elders who have been overseeing the process of weaving institutionalised adults back into their whānau, hapū, and iwi. Korowai aroha has an ongoing commitment to ensuring wherever possible these mokopuna are a part of the bigger picture. This is an ongoing process of whānau healing which recognises both mokopuna and whānau interests. There is no historical support for claims that some whānau members were of lesser value than others.

During reweaving, acknowledgement of the difficulties of tracing families needs to be made and also the diverse realities of whānau. Not all whānau are functional. Patterns of whānau dysfunction include: whānau pōhara (marginalised families) who have poor access to resources and experience cultural poverty themselves; whānau wewete (laissez-faire families); whānau tū-mokemoke (isolated families) who are themselves isolated from society and Māori networks; and whānau tūkino (unsafe families) where there is abuse, violence and a disregard for others. There is real complexity in the tasks undertaken to trace families, initiate healing processes and reweave mokopuna into their whānau.

Kaumātua have been the appropriate people to guide the work of tracing families and have been integral to the process of reconnection and healing. This is a particularly delicate process that requires an intimate understanding of whakapapa and the complicated emotional and cultural issues that surround this. Supporting adults with an intellectual disability and their whānau require much more than medical knowledge of disabling conditions. It is also an ongoing process.

As part of the NHC project three whānau of adults with an intellectual disability who had been institutionalised took part in whānau interviews. The whānau who took part in the

575 The world of the Māori.
576 Personal communication. Tui Tenari, Chief Executive Officer of Te Roopu Taurima o Manukau Trust 2002.
577 The elders of Te Roopu Taurima o Manukau Trust.
578 A working definition of mokopuna used by Te Roopu Taurima o Manukau is “reflection of one’s tipuna” and this is the term used by Te Roopu Taurima to refer to adults with an intellectual disability.
580 Durie 1999.
 interviews had been aware of these whānau members when they were living in institutions. One man recalled why their whānau had been advised to place his sister into an institution.

“It was hard for the family to look after her. She was a roamer. You would hear all the logging trucks change gear as they came into the valley where we lived. She used to like walking the white line.”

His whānau maintained contact with his sister. On visits he noticed that there were no fences at the institution.

“The nurse was hardly saying anything (when they first went to visit). The second visit she (the nurse) started talking about my sister going astray. She (my sister) ended up on a farm and she was caught in the barbed wire and she was out overnight. I started laughing. They couldn’t find her. That’s what happens back home.”

His sister was in the institution for several years and, “They put a fence around her block when she was leaving”.

The three whānau of adults with an intellectual disability (who had left institutions and were now residing in Māori disability support services closer to their homes) were pleased to have their whānau members nearer to them. This meant that they were able to visit and to take them home more often.

A woman whose whānau member now lives in a Māori service near her home, after he had a long period of institutional care, commented on the change in her brother since he has been at the Māori service. She cannot cope with him at home alone, as he is too heavy for her. He has been in the Māori service for over 10 years. He spends some time at home as well when there is someone to assist. When asked about her experience with the institution she said:

“Please don’t talk about that. When we took him back (from the institution) he had a demanding voice. Night and day never meant anything to him. He would go under the table or under the curtain. He wasn’t a happy person. We would always give him a love and he would push us away. He’s progressed a lot since he’s been here. His attitude and his habits. At home he doesn’t sleep in the day. I notice a change in him. He’s very active. He does a lot more movements…. He was always getting a fright. You couldn’t put your hand near his head. He doesn’t seem to do that anymore. It took a long time. A lot of love …. I am quite happy with him now. I enjoy having him at Christmas. We always have a full house at Christmas.”

Adults with an intellectual disability are clearly defined as distinct from mental health consumers although adults with an intellectual disability can also experience mental illness. Some adults with an intellectual disability have been treated previously as mental health consumers and there was concern expressed by them, their whānau and disability support staff about the inability of mental health services to meet the needs of adults with an intellectual disability who are mentally unwell.

Te maimoatanga o mua i ngā whakaritenga mahi hauora hinengaro (Historical treatment in the mental health services)
Adults with an intellectual disability who were previously in the psychiatric system have experienced being placed in secure rooms, given psychotropic medication to control behaviour, and spending time in isolation. One Māori woman with an intellectual disability, now living in supported accommodation with minimal supervision, talked about her
experience of being placed in an institution 40 years ago following the death of her grandparents who had been caring for her. She was 11 years old, had lived in a remote rural area, and only spoke Māori. She was placed in an English speaking institution with no whānau support, and given an English name. Her records were subsequently lost, and she has not been able to trace her whānau. She shared some of her experiences:

“I had chains around my legs and arms for four hours. I said to them “You only chain dogs and I’m not a dog, so don’t chain me”. I couldn’t understand it (English). It was hard. I was given shock treatment after that.”

She also reported that all of her teeth had been removed during inpatient treatment in the psychiatric service because she had refused to take medication.

Adults with an intellectual disability can be vulnerable and spending time in a ‘secure unit’ within the psychiatric system has at times led to sexual assault from other patients.  

Vulnerability of adults with an intellectual disability has also resulted at times in imprisonment, and this was raised during visits to Māori service providers. One example previously reported was of a person with an intellectual disability setting fire to his workplace at night after being told to do so by co-workers, not understanding the subtleties of their teasing and doing as they suggested. For this individual it meant two years imprisonment on an arson charge. Police picked him up at the scene of the crime the next day when he returned to work unaware that a crime had been committed. Adults with an intellectual disability also have difficulty understanding the criminal justice processes and are further disadvantaged by this.

A small number of adults with an intellectual disability appear to access disability support through the justice system. For example, one of the Māori providers who contributed to the National Health Committee project had been contracted by the Ministry of Justice to respond on a crisis intervention level. This included assisting with legislation development that will give judges legal guidelines to place intellectually disabled people into disability support services rather than have them imprisoned under the Crimes Act. This highlights the issue of Māori providers feeling an obligation to take Māori clients even in the most challenging situations and regardless of whether resources accompanied them. Allocation of resources only occurs once a needs assessment has been completed and in the interim the provider’s generosity can be in danger of being exploited.

People with an intellectual disability who are not Māori, can be referred to the Māori disability support services. In these cases, the tikanga Māori process is translated into an appropriate process for each individual depending on their ethnic origin. There have been a small number of Pacific adults with an intellectual disability who have entered the services provided by Te Roopu Taurima o Manukau, and processes have been developed to meet their cultural needs.

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582 Durie 2001.
583 Custom.
584 Te Roopu Taurima o Manukau Chief Executive Officer 2001.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

Tatauranga taupori
(Demographics)

The collection of ethnicity data on adults using disability support services is limited. Disability support services staff and other organisations collecting information on people with disabilities need to be trained to collect ethnicity data, and ethnicity data needs to be collected in a useful standardised form nationally.

Data provided by the Ministry of Social Development (Work and Income) on adults receiving Sickness and Invalids Benefit as at May 2002, for whom intellectual disability was listed as their main disabling condition, identifies ethnicity in 82 percent of people, with 13.8 percent of that group identified as Māori. Very clear distribution patterns are evident for Māori, with the highest proportions residing in Tairawhiti and Lakes District Health Boards (DHB), with significant numbers in Northland, Bay of Plenty and Counties-Manukau regions.585

Data provided by Statistics New Zealand estimates that out of a total population of 32,400 adults aged 15 and over with an intellectual disability, 5,600 are Māori. This estimate is subject to both sampling and non-sampling error.

For more demographic information on Māori people with an intellectual disability, see Chapter 2: Definitions and demographics.

Tā te tangata whenua whakaaro mo te hauātanga
(Indigenous people’s concept of disability)

In an indigenous context issues like racism, poverty and social stigma associated with being indigenous may take precedence over identification as having a disability.586 There is evidence to suggest that although non-indigenous health professionals may classify indigenous peoples as having a disability, indigenous peoples may not identify as having a disability.587

An essential characteristic of indigenous peoples is the central role of the family, including a wider kinship network. The literature suggests that in cultures where sociability is a priority (this depends on family and kinship networks), sociability is not limited by a disability. In which case, a disability will not necessarily diminish personhood.588 A “person is more likely to be defined by their relationships rather than by their disability. Who they are related to, their clan and country are more important than their disability in defining their place and role in the community”.589

Only extremely visible conditions such as amputations, spinal cord injuries or severe mobility impairment tend to be regarded by Australian Aboriginal people as disabilities. In some indigenous contexts intellectual disability (as defined by non-indigenous health professionals) may not be considered as a disability or abnormal.590

585 Data provided by the Ministry of Social Development.
588 Armstrong and Fitzgerald 1996.
Given the diversity of the indigenous populations of the world, it is not possible to create a definitive concept of disability from the perspective of indigenous peoples. Moreover, even within one nation, for example, Navajo, a range of perspectives on disability will exist. A traditional philosophy will exist which approaches disability in a number of ways, however other Navajo may hold “different views depending on how much they are assimilated into the predominant American culture, how much western education they have, and how much they have been socially engineered not to live or to understand the holistic philosophy of Native life”.

One example of a traditional Navajo role of disability is as a “reminder or consequence when traditional Navajo law has been contravened; a disability’s root cause is in the past”. This breach of law has most often been committed by parents or grandparents, and in some cases by the individual themselves. This requires a Native practitioner “to make amends for the transgression” through Native Healing Arts. The person with the disability is “brought back into a state of balance and harmony with the universe”.

Tā te Māori whakaaro mō te hauātanga
(Māori concept of disability)
Generally, the Māori people with an intellectual disability participating in the National Health Committee project identified as Māori, rather than as disabled. They also identified with Māori culture rather than a disability culture. There were exceptions to this. Māori people with an intellectual disability who identified themselves primarily as a person with a disability, and who identified primarily with disability culture were adopted and raised by non-Māori families, or had been institutionalised from childhood.

“To him, Downs syndrome is what he had, not who he was. His whānau and his whakapapa connect him to us – there is no special Atua for him.”

Whakapapa is an integral part of a Māori worldview. Everyone and everything in the universe has its own whakapapa and all things are ultimately linked via the gods to Ranginui and Papatuanuku. There is no distinction in the whakapapa between the disabled and the non-disabled, both are part of a unified whole.

A Māori woman with an intellectual disability made specific reference to her whakapapa.

“I was in social welfare. I was never at home. Then I went to boarding school …. My family got me back here …. I want to learn my whakapapa in te reo. I only know it in English. I have got a family history book. Two of them. One on my Mum’s side and one on my Dad’s side.”

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594 God or supernatural being.
595 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
596 Sky Father.
597 Earth Mother.
599 Quote from an adult with an intellectual disability, NHC focus groups 2002.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

A Māori parent of an adult with an intellectual disability, discussing disability services, made an analogy using four strands of rope. These intertwined strands were physical, spiritual, emotional and family. All four strands are necessary to ensure strength, and each represents a different dimension of his son. He felt that disability service providers needed to “be aware which parts of the rope you are working with”. He emphasised the importance of working with the “whole rope” and “don’t leave pieces and strands hanging out the door”.

He āhua hauora Māori
(Māori models of health)

Māori models of health in the literature also describe this holistic concept of health.600 These holistic models provide a framework for further discussion of support services for Māori people with an intellectual disability, and have implications for disability service providers.

Te whare tapa whā
The whare tapa whā model compares health to the four walls of a house – taha wairua (the spiritual side), taha hinengaro (thoughts and feelings), taha tinana (the physical side), and taha whānau (family).601

Taha wairua

“Our whole world is based on our spiritual side. Taha wairua is the same (for a disabled person as a non-disabled person).”602

One person with an intellectual disability explained how important it was to them that there is a “Takahi whare”603 when someone dies” whether they were resident within a service or at their own home. Other family members of a non-verbal adult with an intellectual disability observed that when he was in the whare mate604 at a tangi: “he would never wander. He knew. He didn’t give any hassles.”

Taha hinengaro
Taha hinengaro, that is the thoughts and feelings of verbal people with an intellectual disability, are reflected throughout this document. The thoughts and feelings of whānau members of non-verbal adults with an intellectual disability are used to represent the non-verbal adults.

All participants at the Māori focus group thought that they could also be a voice for other Māori people with an intellectual disability who could not speak. They expressed a collective desire to “learn to speak for others”. They had Māori non-verbal friends with an intellectual disability and they spoke about the non-verbal communication between themselves and their non-verbal friends. This non-verbal communication meant that they could tell what their friends liked and did not like. Within disability services they had seen ‘good’ things and

601 Durie 1998.
602 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
603 Literally takahi is translated as tread and whare as house. Takahi whare refers to the protocol of walking through a house and spiritually cleansing the house of a recently deceased person.
604 Where the deceased person lies during a tangihanga (funeral) at the marae.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

‘bad’ things about the service their friends received. They wanted to have a stronger voice and “encourage those who really need the support”.

Taha tinana
Focus group participants and their whānau discussed taha tinana in terms of physical limitations experienced. All Māori workshop participants wished that they could get around more.

“Getting around: that’s the part I want to achieve because it is the only support I use the services for.”

Non-verbal adults had more physical limitations than others, and whānau commented on how this impacted on daily life.

“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.”

Despite physical limitations, whānau and focus group participants were very clear that the non-verbal adults with an intellectual disability do communicate with them.

“He communicates. He moans. You can hear it in his tone. He gives you a growling. He has his moan in the bath. He doesn’t like getting out of the bath. If he had his choice he’d stay in there all day.”

Taha whānau
Aspects of taha whānau were part of the discussions in the Māori focus group, and whānau views were recorded in the whānau interviews.

Some focus group participants spoke about the roles that particular whānau members had in teaching them about their culture.

“I learn them (things Māori) from my Dad. It’s good. I go home. Sometimes I go home in the weekends and help him (Dad) do the wash. He’s at home by himself since Mum died.”

“My aunty taught me about the marae. My father had been teaching me a lot before he died.”

“If they need any more hands I help at the marae. To get to the marae I ring Mum.”

Te wheke
Another holistic model which provides a framework for further consideration of support services to Māori with an intellectual disability is the octopus or ‘te wheke’ model. Each tentacle of the octopus symbolises a particular dimension of health, while the body and the head represent the whole family unit. The intertwining of the tentacles indicates the close relationship between each dimension. Like whare tapa whā, this model includes

605 Quote from an adult with an intellectual disability, NHC focus groups 2002.
606 Quote from a whānau member of an adult with an intellectual disability, NHC focus groups 2002.
607 Quote from a whānau member of an adult with an intellectual disability, NHC focus groups 2002.
608 Quotes from adults with an intellectual disability, NHC focus groups 2002.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

wairuatanga (spirituality), taha tinana (physical side), hinengaro (thoughts and feelings) and whānaungatanga (the extended whānau). The other dimensions are mana āke, the uniqueness of the individual; mauri, the life sustaining principle resident in people and objects, including language; hā a koro mā a kui mā – literally the life breath that comes from forbears and an acknowledgement that good health is closely linked to the positive awareness of ancestors and their role in shaping the whānau; whatumānawa, the open and healthy expression of emotion, necessary for healthy human development; and waiora, total wellbeing for the individual and the family, represented in the model by the eyes of the octopus.

The comments from one parent summarised this:

“It’s a simple thing really …. acknowledge the whole, not just for Māori, for everyone.”

He whakaritenga tautoko i te hunga Māori hauā: he huarahi tikanga (Disability support services to Māori: a cultural approach)

“You are experts in your field. With our boy, we are the experts in who he is and where he’s from. We need each other. We need to work together.”

A holistic concept of wellbeing has many implications for service provision to adults with an intellectual disability and their whānau. All service providers have a responsibility to be culturally competent.

Māori people with an intellectual disability had several comments to make about their experience with mainstream service providers who provided no kaupapa Māori services.

[Mainstream service providers with no kaupapa Māori services] “make you cross.”

There was consensus among the Māori people with an intellectual disability that this was because non-Māori service providers were not providing a culturally appropriate service. Non-Māori service providers planned activities which often did not incorporate traditional Māori activities, for example, one woman used to get annoyed because she wanted to go and get watercress, but had to go to the swimming pool instead. Some Māori people with an intellectual disability wanted Māori kai and were happy to gather it, but had to go where everyone else was going.

Access to all disability support services is through a needs assessment. A number of people who contributed to this project commented on the lack of Māori needs assessors, and the inadequate training of many needs assessors in meeting Māori needs. They expressed the view that a Māori provider should be the first choice for the facilitation of kaupapa Māori processes for a disabled Māori, enabling them and their whānau to make informed decisions about their future options and choices.

A kaupapa Māori service within mainstream was identifiably different from a non-Māori service to Māori adults with an intellectual disability using the services. Māori adults with an

609 Pere 1988.
610 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
intellectual disability were asked about their experience of this difference. Some comments from people who had experience of a kaupāpā Māori service operating within a mainstream service that was now no longer provided spoke about what they had lost.

“The staff teach you how to cook Māori food. They have Māori food. Sharing and caring. Even if a Pākehā came into the house they still have to respect the Māori kaupāpā (Māori way of doing things) as it is set up as Māori.”

“Take your shoes off at the door. Always greet you when you come in. Welcome you in powhiri. Bless the room. More karakia. They put all the mattresses in front of the TV on Saturday night and sleep there. We had karakia every time we have a meal and in the morning. Us as Māori we still respect the Pākehā. We still take our shoes off.”

“For myself, I still eat in the bedroom if I’m not feeling well, but generally we wouldn’t” (at a kaupāpā Māori service).

“We loved doing kapa haka. I wish we still did.”

The cultural determinants of health are acknowledged in the New Zealand literature. What is relatively new is funding the provision of cultural services. Recognition of the Treaty of Waitangi in relation to Māori people with disabilities is an acknowledgement that they have a culture before their disability. In acknowledging culture, disability support services must cater to the whole essence of a person rather than just their disability. Cultural services for Māori require Māori participation in developing, staffing and managing these services.

Central to a cultural approach is the recognition of whānau and spirituality in providing disability support services for Māori. Cultural services can meet the needs of Māori people with an intellectual disability in a holistic way. An example of the key components and activities of cultural services provided by Te Roopu Taurima o Manukau Trust are outlined in Table 1 below.

Table 12: Key components and activities of one Māori provider’s cultural service

<table>
<thead>
<tr>
<th>Whānaungatanga</th>
<th>Nga Mahi Māori A Rōpu</th>
<th>Tangi/ Hura Kohatu</th>
<th>Hui</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client</td>
<td>Kai gathering</td>
<td>Mokopuna</td>
<td>Whānau</td>
</tr>
<tr>
<td>Individual</td>
<td>Resource gathering</td>
<td>Whānau of mokopuna</td>
<td>Whare</td>
</tr>
<tr>
<td>Multiple</td>
<td>Art and craft</td>
<td>Staff</td>
<td>Awhi whānau</td>
</tr>
<tr>
<td>Meetings</td>
<td>Kapa Haka</td>
<td>Staff whānau</td>
<td></td>
</tr>
<tr>
<td>Sector Development</td>
<td>Rongoa Māori</td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Traditional Māori medicines</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Te Reo – Māori language clients/staff</td>
<td>Hura Kohatu</td>
<td></td>
</tr>
</tbody>
</table>

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611 Welcome ceremony.
613 Family-like relationship building.
614 Māori cultural group activities.
615 A gathering of where there is an unveiling of a headstone. Often occurs 12 months after a person has died. There may be a longer period of time before an unveiling depending on family circumstances.
616 Gathering.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

Cost associated with the cultural components of kaupapa Māori services include staff, mileage, maintaining vehicles, kōhā and other related costs (for example, equipment for kapa haka). These are real costs involved in meeting cultural needs. They are in addition to ‘standard’ activities required as part of any disability support service. A conservative estimate is that 45 percent of these costs are not funded. 617

In unequivocal terms the message is, “To meet Māori needs effectively, things need to be done differently, and that has resource implications which, as a matter of equity, the Crown must meet if it is to be taken seriously when it expresses its commitment under ‘the Treaty’ to ensuring Māori have the same opportunity to good health as non-Māori.” 618

One Māori provider described how they have had to align what they do to meet the cultural needs of the people they support with what the Crown agencies or other funders will contract for. They felt that flexibility is always on the side of the Māori provider, and that there was little if any recognition of the need for a cultural approach. The provider described it as a frustrating task, particularly because of the loss of institutional memory around contracting as a result of continual restructuring of the Ministry of Health. At times it has meant that Māori providers have had to go back to square one in relationship development with the Ministry of Health.

An example of this is that the funding that was once allocated for Māori provider service development is now allocated to all providers of disability services to deliver culturally appropriate services to Māori. This includes those providers who have no Māori clients, whilst existing Māori providers continue to try and strengthen their services under very difficult circumstances.

Approaches taken by government agencies in all areas related to disability support services, for example, funding, legislation, policy and strategy development have generally not been aligned with the service needs of adults with an intellectual disability. Partnership with Māori is needed in all areas relating to disability support services in order to incorporate Māori disability support service needs.

Ngā rōpū whakaritenga mahi Māori
(Māori service providers)

Māori service providers are defined as health service providers that have Māori governance, management and operational structures. 619 Māori providers can identify as ‘iwi’ or ‘pan-tribal’. Māori providers can sit outside mainstream organisations or be a part of mainstream organisations, although the distinction is not always clear-cut. 620 Characteristics of Māori service providers’ service models are tikanga Māori, the involvement of whānau, hapū and iwi, the use of traditional Māori healing practices (eg, kārakia), the provision of cultural assessment and practices, and whakawhanaungatanga (family-like relationship building). 621

617 Te Roopu Taurima o Manukau 2002.
618 Te Roopu Taurima o Manukau 2002.
619 Te Puni Kokiri 2000.
621 Keelan 1997.
Cultural integrity, medical pluralism and self-determination are three principles common to Māori providers.  

- Cultural integrity acknowledges traditional concepts of health and healing. Health is viewed as inextricably entwined with culture. Māori service models are distinctly different from Western service models.
- Medical pluralism incorporates choice in service delivery. It is an acknowledgement that health care is not the province of any single professional or group, and a single biomedical approach is not comprehensive. An example of the implementation of medical pluralism would be a terminal care service that enabled Māori to seek support from a tohunga and treatment from a medical practitioner simultaneously.
- Self-determination or rangatiratanga which incorporates te reo (language), tikanga Māori (Māori custom), marae, and kawa (protocols).

The emergence of Māori disability support service providers is providing a focus, and at times a voice, for Māori with disabilities. It also enables the further development and implementation of kaupapa Māori service models to assist in meeting the needs of Māori with disabilities in a holistic way. Māori service providers are increasing, and in some cases upskilling, the non-Māori disability support service workforce. It also encourages the development of a culturally effective information dissemination service for Māori with disabilities and their families.

Nga haerenga ki ngā rōpū whakaritenga Māori  
(Visits to Māori service providers)

A sample of Māori service providers were visited. Some of their experiences have already been told to provide an insight into some of the issues they have faced in meeting the cultural needs of Māori adults with an intellectual disability and their whānau.

Te Roopu Taurima o Manukau Trust is a large Māori disability support services provider based in Auckland, providing services from Northland to Hamilton. It is a pan-tribal service, with extremely well developed systems, excellent staff retention and highly developed staff training which is linked to an outside institution. Te Roopu Taurima o Manukau had been part of a mainstream service and split off. Its story highlights problems encountered by Māori working within mainstream services and provides a model of cultural service provision.

Te Whānau Tokotokorangi I Te Ora Trust in Rotorua started small in response to the needs of a few individuals, and has grown to be a reasonable sized service supporting 18 people in residential care and providing a number of other types of support to people with an intellectual disability in the community. In contrast to Te Roopu Taurima o Manukau, Te Whānau Tokotokorangi I Te Ora Trust operates in one provincial centre as opposed to a larger city or region.

Te Whare Manaaki in Te Teko, and Te Toi Huarewa in Ruatoki are both small marae-based providers although at very different stages of development. Te Toi Huarewa is a relatively

622 Durie 1996.
623 Traditional Māori healer.
new provider while Te Whare Manaaki is over 10 years old. There are different key learnings from each of these providers.

In addition, a meeting was held with Māori staff working in a mainstream service in Auckland, and a hui in Ruatoki was attended by Māori staff from around the central North Island who work in a variety of disability support services to get their views as support people of adults with an intellectual disability.

Te Roopu Taurima o Manukau
Te Roopu Taurima o Manukau Trust’s vision is, “To develop Māori services that will provide and manage services encompassing tikanga Māori and that will determine positive outcomes for Māori people with disabilities and their families demonstrating self-determination for all Māori people.”

Te whakatū i te Roopu Taurima o Manukau
(Establishment of Te Roopu Taurima o Manukau Trust) In the early 1990s, community-based residential care programmes were established under the auspices of SPID (Services for People with a Disability) and AHOT (Auckland Home Options Trust). In consultation with whānau, a Māori division was established within SPID to provide kaupapa Māori services to clients. The view of the organisation at the time was that this division would eventually become an independent organisation. In August 1992, after further consultation with whānau members, the Māori service division established an independent organisation Te Roopu Taurima o Manukau Trust. However, it did not begin providing services at this stage.

The development of an independent organisation was in response to the difficulties experienced in providing kaupapa Māori services within a mainstream organisation. Although the Māori services team within SPID and AHOT did their best to offer clients a service that was premised upon the principles of tikanga Māori, it was unable to do this effectively. Primarily, this was because the underlying philosophical foundation of SPID and AHOT was based on Western values. These values and principles permeated the service as a whole from governance to service delivery level. They did not constitute an appropriate basis for the delivery of culturally effective services to Māori as they neither reflected nor accommodated a Māori worldview. This same barrier was identified for the Hauora Waikato group in the provision of Māori mental health services within a mainstream service. In both cases, all final decisions made relating to the business of providing Māori services were the legal responsibility of non-Māori decision-makers.

Te Roopu Taurima o Manukau Trust was established with the aim of providing Māori clients and their whānau with a culturally safe and accessible service, which is responsive to their needs. Māori services remained a part of the mainstream service until a pathway to becoming an independent provider was achieved.

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624 Christensen 1994.
626 Ernst and Young Consultants 1998.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

In 1994 SPID and AHOT combined to become Spectrum Care Trust (Spectrum) and did not see the need at this time to separate Māori services to an independent organisation and the staff within the Māori services did not have the resources to pursue this themselves.629

An organisational review while Māori services was operating from within Spectrum found an inequitable distribution of resources received by Spectrum to Māori clients. Many Māori clients had never had a comprehensive needs assessment completed and consequently there was a misclassification that underestimated their dependency level. This placed extreme demands on staff who were under-resourced. This compromised staff professional development and the cultural services to Māori clients (ie, insufficient staff time and availability to enable attendance of clients at tangi and other whānau hui). Māori staff regularly volunteered their own time and resources to take clients to these events. Some Māori staff took clients home with them for special events, like Christmas, especially if travel and its associated costs were out of the question for a client’s family at that time of the year.630 In addition, Māori staff roles included meeting requests on behalf of Māori clients living in other community facilities (for example, IHC residential homes) to assist with cultural services.

In 1998 an opportunity arose for Te Roopu Taurima o Manukau Trust to apply for funding under the Māori Provider Development Scheme (MPDS). A Crown Objective that Māori have the opportunity to enjoy the same levels of health as non-Māori saw the implementation of a Māori provider development strategy631 throughout New Zealand.632 Te Roopu Taurima o Manukau Trust held a hui with mokopuna and whānau to ascertain their needs. Mokopuna and their whānau reiterated their desire to have an independent Māori service provider that recognised tikanga Māori.

Te māhi whakaritenga
(Service provision)

Te Roopu Taurima o Manukau Trust provides kaupapa Māori disability support services for people with an intellectual disability and their whānau by way of:

• Korowai Aroha Whānau which is made up of two kaumātua and four whāea633. These people provide support to all mokopuna and their whānau and all other staff. They are cultural experts and provide services in te reo, tikanga Māori and ahuatanga Māori634.635

• The Management Team.

• The Awhi Whānau team which delivers and/or coordinates the delivery of community support services to approximately 250 non-resident mokopuna and their whānau. This also includes day services for people who require daytime activities to expand their life experiences.

• The Residential Support Team provides 24-hour lifestyle services to resident mokopuna who have severe disability.636 Residential services include secure residential care, emergency short-term care and planned respite, in addition to supervised residential care.

630 Ernst and Young Consultants 1998.
631 The purpose of this strategy was to offer Maori clients a culturally safe choice of service providers, thereby increasing access levels to services and improving health status.
633 Experienced elder woman.
634 Other aspects pertaining to Māori culture.
As at July 2001, Te Roopu Taurima o Manukau employed 150 staff of which 98 percent were Māori. In 2001 Te Roopu Taurima o Manukau provided professional kaupapa Māori Health and Disability Services to:
- 90 residential clients and their whānau (99% Māori)
- 192 community-based clients and their whānau (100% Māori)
- 73 clients receive vocational services (100% Māori).

Te Whānau Tokotokorangi I Te Ora Trust
Te Whānau Tokotokorangi I Te Ora Trust is a Māori service provider in Rotorua. Its mission statement is “To offer a range of alternative services by Māori to families caring for family members with disabilities embracing our Māori perspective”.

Te Whānau Tokotokorangi Trust was set up by parents and support people and registered in 1992 as a charitable trust. The Trust opened its first home for five people with disabilities in 1996. It now manages four residential homes, a separate day service for people with disabilities, a family support service, and has developed and delivered all its training components relative to the services. Te Whānau Tokotokorangi Trust employs just under 50 staff.

Te mahi whakaritenga (Service provision)
- Residential Care – Te Whānau Tokotokorangi Trust’s core service is residential. Long-term residential care is provided 24 hours, seven days a week for people with multiple disabilities. There are currently 18 whāmari in long-term care.
- Crisis Respite Care – crisis respite care is offered to provide interim support to families, who have a member with a disability. This is currently based on individual need.
- Day Services/Recreational Programmes – Whare Whakatauira – House of Learning is a separate facility for day services available to families, which offers life skills programmes, self-development courses, cultural components, and recreational experiences.
- Family Support Service – Te Whānau Tokotokorangi Trust has established and developed a family support service offering a range of support and guidance. The service is family-focused offering updated information on all areas of health, welfare and education. The objective of this service is to create an awareness of disability issues, to advocate alongside families, and to provide them with choices and information.
- Training Development – Te Whānau Tokotokorangi Trust has developed its own training packages that are delivered to all interest groups, staff, as well as whāmari in their care. In-house training is provided every three months to all employed caregivers to teach holistic approaches, promote self-confidence, best work standards and practices, and to encourage kaupapa Māori within the service.
- Alternative Healing – traditional healing methods, such as mirimiri, are available on request, as an alternative to mainstream methods. These methods are only used in consultation with the family.

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636 Mokopuna have now had comprehensive needs assessment and have their level of dependency adequately assessed, and staff are provided to meet their needs.
638 At Te Whānau Tokotokorangi Trust whamari is the term used to describe people with disabilities.
639 Massage
Te Whare Manaaki
Te Whare Manaaki is a small Māori service provider in Te Teko. It has been operating a residential care service for people with an intellectual disability for over 10 years. Its residential service has capacity for six adults although, at the time of writing, there were only four residents. There is no method for Te Whare Manaaki to inform people with an intellectual disability and their families about its service. There may well be people with an intellectual disability in the main centres that would prefer to be in a small Māori provider residential service in Te Teko, particularly those with whakapapa ties to the area. Few residential services collect data on the iwi of residents and Te Whare Manaaki has not been able to identify a way to inform people about its service.

Te Whare Manaaki was established in response to an identified community need for 24-hour care for Māori people with an intellectual disability who had been institutionalised in Tokaanui Hospital. When vacancies for two clients occurred, the service ended reducing its staff by two as it was not able to identify any new clients.

Te Toi Huarewa
Te Toi Huarewa Trust is a Māori service provider in Ruatoki. It has four sections:
- Residential Care Services providing 24-hour care to five people with an intellectual disability
- Awhi Tangata Whaiora – a service provided by a Community Worker that includes a range of health promotion, advisory, liaison and coordination activities
- Tamariki Whaiora – a service provided by a Community Worker similar to the role of the Awhi Tangata Whaiora but for Māori clients aged 0–14 years
- Finance and administration.

Four of the five people with an intellectual disability in the residential service are Māori. There are set activities during the week and a monthly trip to Ferry Springs. There was some concern that the set activities may not be appropriate for all residents as their concentration span is short and it is difficult to find something that suits all residents.

Originally Te Toi Huarewa Trust aimed to locate its residential care in Whakatane, however it had problems getting consent. In discussions at Te Roopu Taurima o Manukau Trust about the location of its houses, staff commented that they got around potential negative responses from new neighbours by telling them that they are looking for a neighbourhood that was safe for people with an intellectual disability. This appealed to people’s sense of community and got a more positive response than saying that they wanted to set up a house for people with an intellectual disability. This is an example where the experience of one provider could assist another and highlights that a forum is needed to share information between Māori providers.

Te Toi Huarewa, as a fledgling Māori provider, would like to come under the umbrella of a well-established Māori provider. Poutiri Trust is a well established Māori provider that would have been agreeable to providing support to Te Toi Huarewa, but the Ministry of Health would not agree to contract for the service provided by Te Toi Huarewa via Poutiri Trust.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

Ngā Rōpū whakaritenga iti  
(Small Māori service providers)

Both smaller providers found that being based in a rural area has meant that there is a geographical barrier to accessing services. Particular problems occur in attempting to access speech language therapy, behavioural therapists, dental therapists and physiotherapy. Te Whare Manaaki found that some of its clients reacted negatively to providers of these services whom they recognised from Tokaanui Hospital and this meant that these treatment providers were not able to work with some clients.

Both smaller providers identified problems with staff training. There are small numbers of staff and enabling staff to leave service provision to attend training is a real issue. A further issue is that the provision of staff training occurs in the main centres and this is another barrier. Team building exercises are also difficult. Funding for staff training is also very limited.

Te Whare Manaaki and Te Toi Huarewa both identified a need to participate in a network of Māori disability support providers, in order to have sharing and learning experiences from others in the field.

Te whakapakari i te hunga kaimahi: Te aahua o Te Roopu Taurima o Manukau  
(Workforce development: Te Roopu Taurima o Manukau Trust model)

Workforce development is actively encouraged throughout Te Roopu Taurima o Manukau Trust. Throughout the National Health Committee project it was clear that staff play a critical role in determining the lifestyle of adults with an intellectual disability, particularly in residential care or group homes. Well trained and well supported staff who have an understanding of the individual needs and rights of the adults with an intellectual disability can create a positive residential care or group home lifestyle.

The selection and recruitment process used by Te Roopu Taurima o Manukau Trust is culturally appropriate for Māori and this is reflected in the Trusts workforce, which is 98 percent Māori. Staff turnover is relatively low and retention extremely high. This is likely to be multifactorial in origin but would include whakawhanaungatanga, professional development pathways, and a Māori team with a kaupapa Māori philosophy enabling a more natural application of self (for Māori employees) in the workplace.

Staff retention is a quality measure for the service. In some residential care services, as mentioned in other chapters, low rates of pay and the challenging nature of the work leads to high staff turnover. High staff turnover creates an institutional environment as opposed to a home, and may result in individuals feeling like they are a ‘job’ or a ‘patient’. High staff retention creates a feeling of security and may result in individuals feeling more supported.

Te Roopu Taurima o Manukau Trust utilises a whariki (woven mat) approach to view their organisation. This is a way of viewing their kaupapa Māori service model which is based on the needs of the clients. It is innovative integrated approach but is confidential to the organisation. It weaves together all of the strands of the organisation for the purpose of providing a service that meets the needs of the mokopuna.
Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

Wawati (2002) describes an awareness of this whariki in terms of what it is, what it does, how strong it is, where it is weak, how big it is, and how flexible and elastic it is and what size the holes are. Such a comprehensive analysis of the service model enables a rigorous kaupapa Māori approach to evaluation.

Te Roopu Taurima o Manukau has a strong relationship with the Auckland College of Education to facilitate training pathways to enable staff to complete tertiary level training. This begins with a Certificate in Educational Support (Disability Studies) and can lead on to a Diploma in Human Services and a Bachelor in Social Sciences.

Analysis of weakness is an important part of self-evaluation for Te Roopu Taurima o Manukau. Te Roopu Taurima o Manukau Trust has identified several weaknesses including that it is a very young organisation on a journey of significant change. There has been a history of a tendency towards “too much” ārohā. There is no long-term commitment from funding agencies. There are differing levels of understanding of practices of tikanga Māori among staff and this and the skill base of kāimāhi (support worker) in the care and development of mokopuna requires ongoing development. The information and communication systems of the organisation are in their infancy.

Aromatawai
(Quality including evaluation/audit)

Key issues that have been identified as the most important quality requirements for service delivery to Māori include:

- further development and support of Māori health providers
- improved access for Māori to high quality and responsive services
- introduction of components of service audits or clinical audits that are specific to Māori health.

As for any service provider, audit is an integral part of Te Roopu Taurima o Manukau Trust’s business. In addition to usual accounts auditing, Te Roopu Taurima o Manukau participated in an issues-based audit and a national audit programme for the Health Funding Authority on disability support services and home-based services.

The national audit programme reported that, “Māori providers offer a major contribution and presence to home-based services in New Zealand.” Furthermore it concluded that the “vision and kaupapa to establish and guide their service provision ensures their unique presence in the disability support service sector.” The issues-based audit reported that the organisation was “meeting its requirements and more in a very short space of time.” It was noted in this audit that Te Roopu Taurima o Manukau is “providing services for mokopuna that were only once a dream for many and are still a dream for many in terms of community integration both locally, nationally and internationally.”

640 Te Roopu Taurima o Manukau 2000.
641 Te Roopu Taurima o Manukau 2001.
642 Goodyer 1999.
643 Goodyer 1999.
644 Goodyer 1999.
645 Te Roopu Taurima o Manuakau 2001.

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Whakaritenga mahi mō te hunga pakeke Māori kua hauā-ā-hinengaro

He Korowai Oranga

There is government commitment to the relationship between iwi and the Crown under the Treaty of Waitangi. The principles of Partnership, Participation and Protection underpin this relationship, and underpin He Korowai Oranga (Māori Health Strategy).  

The overall aim of He Korowai Oranga is whānau ora: Māori families supported to achieve their maximum health and wellbeing. He Korowai Oranga acknowledges the central role that whānau play, as a principal source of identity, support, security and strength in the wellbeing of Māori both individually and collectively.

He Korowai Oranga “strongly supports Māori holistic models and wellness approaches to health and disability”. He Korowai Oranga also “seeks to support Māori-led initiatives to improve the health of whānau, hapū and iwi”.

Te Rautake Hauā o Aotearoa, me ngā whakaritenga mahi mō ngā pakeke Māori kua hauā-ā-hinengaro (The New Zealand Disability Strategy and services for Māori adults with an intellectual disability)

The New Zealand Disability Strategy (NZDS) acknowledges the relationship between Māori and the Crown under the Treaty of Waitangi. There is a common understanding that it is central to the Treaty relationship and the implementation of Treaty principles that Māori will have an important role in developing and implementing disability strategies for themselves.

All of the objectives of the NZDS except Objective 12 (promote participation of disabled Pacific peoples) are relevant to Māori people with an intellectual disability. Objective 11 of the strategy (promote participation of disabled Māori) recognises that additional and specific actions are necessary to ensure that Māori people with an intellectual disability are supported in a way that is culturally appropriate.

Ngā take matua (Key issues)

- Māori adults with an intellectual disability face specific issues in addition to those experienced by all adults with an intellectual disability.
- The collection of ethnicity data about adults with an intellectual disability is poor.
- Current needs assessment and service coordination processes are not appropriate for Māori adults with an intellectual disability and their whānau.
- As access to Māori services often occurs through a variety of routes other than needs assessment and service co-ordination services, it is important to ensure that Māori adults are able to easily access their entitlements to income support assistance and other support.

646 Ministry of Health 2002.
647 The New Zealand Disability Strategy is described in Chapter 3: History of service provision.
Kaupapa Māori services face a variety of challenges and constraints in providing culturally appropriate services for Māori adults with an intellectual disability and their whānau.

Information about kaupapa Māori services is not readily available for Māori adults with an intellectual disability and their whānau.

Active workforce development can have a positive impact on the quality of service provision and staff retention.

Recruitment and retention of the Māori disability support workforce is essential to the provision of culturally appropriate services.
15. PACIFIC ADULTS WITH AN INTELLECTUAL DISABILITY

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

This chapter:
• provides demographic information about Pacific people with an intellectual disability and their families
• describes Pacific people’s perceptions of intellectual disability
• details specific issues Pacific people face in accessing appropriate support
• describes three services that provide support to disabled Pacific people
• discusses issues relating to the funding and provision of culturally appropriate services for Pacific people with an intellectual disability, including workforce issues.

Pacific demographics

The number of people of Pacific ethnicity living in New Zealand is rapidly increasing. Approximately 56 percent of Pacific people in New Zealand were born in New Zealand. The other 44 percent entered as migrants from Pacific Island nations including the Cook Islands, Fiji, Nuie, Samoa, Tokelau and Tonga. Two-thirds of the Pacific population in New Zealand lives in Auckland.

The population profile for Pacific peoples is very different from that of the general New Zealand population. There are very few people over the age of 60 and most are under 30 years of age. Approximately 40 percent of Pacific people in New Zealand are less than 14 years old.

As noted in Chapter 2: Definitions and demographics, data on adults with an intellectual disability is poor, and ethnicity data even more so. During the National Health Committee project, many Pacific people expressed the opinion that the data that is available understates the number of Pacific adults with an intellectual disability. Anecdotal reports indicate that

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648 Quote from a parent of an adult with an intellectual disability, NHC focus groups 2002.
649 The Pacific population in South Auckland increased by 50 percent between the 1996 and 2001 census.
650 Personal communication with the Ministry of Pacific Island Affairs 2002.
651 Personal communication with the Ministry of Pacific Island Affairs 2002.
Pacific adults with an intellectual disability

there are significant numbers of Pacific adults not accessing services, other than income support.652

In the data from the Ministry of Social Development653 82 percent of adults with an intellectual disability receiving a Sickness or Invalids Benefit gave their ethnicity, and five percent of these people identified themselves as Pacific. Despite lack of data, very clear distribution patterns are evident, with the largest numbers of Pacific people with an intellectual disability living in areas covered by the three District Health Boards (DHBs) in the Auckland region. See Figure 4 in Chapter 2: Definitions and demographics.

Pacific cultures and disability

“All to understand peoples’ perceptions of disability we must develop a better understanding of their culture: and, once we begin to understand perceptions of disability, we better understand the cultures in which they develop. This is not a circular argument, it is an interactive one. It means we can, and should, investigate culture and perceptions at the same time.”654

Pacific peoples have many different views of disability, which at times may complement or contradict each other. During the project a variety of views were expressed, emphasising that the concept of disability not only varies between cultures but within cultures as well.655 As well as the range of views – which was influenced to some degree by the level of understanding people had of disability – there were also common themes.

“Values have a hierarchical base, being handed down through a well-defined ladder system from God through to Royalty, to nobility, to ministers (church, government) to elders, to grandparents, to parents and finally to children (eldest to youngest).”656

All Pacific people discussed the hierarchical structure of Pacific cultures in general, and identified that disabled people are placed at the bottom of that hierarchy. This hierarchical structure impacts in many ways. One example is the lack of questioning of comments made by high status professional people such as doctors, even if the family does not feel that the advice received fits with their views or wishes for the family member with a disability. Another example given was where a family member of greater authority, such as a grandparent, declares that schooling for a person with an intellectual disability is a waste of time, then the family may not send the person to school.

“… historically, the literature reveals that the terms ‘disability’ and ‘illness’ were often viewed as synonymous, and that, in itself, provides insight into the way disability has been socially constructed through language.”657

“Over there we don’t categorise anything … either you’re mad or you’re not … We don’t usually see a difference between the different disabilities…in the Islands we always try to

652  These access and service use issues are caused by a range of reasons discussed later in this paper.
653  See Chapter 2: Definitions and demographics for more information about this data.
656  Makasiale and Williams 1977.
657  Selway and Ashman 1998.
Pacific adults with an intellectual disability

look after them, try to treat them well … with those who have an intellectual disability, depending on that person they might be teased a bit, but usually there will be someone with them who will help protect them, we treat the two as basically the same…”658

It is common to view disability as an illness in Pacific cultures.659 The commonly used Samoan term to describe a person with a disability is ‘ma’i’ which translates as ‘sick’. Many people commented that there is little if any distinction in Pacific cultures between people with an intellectual disability and those with mental illness. This is reflected in the Samoan language in which the same term ‘ma’i ulu’, meaning sick in the head, is used for both. This lack of distinction in language appeared to be common across Pacific cultures.

“… the person is seen as needing to be sheltered or nursed as opposed to contributing to their own and the 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.”660

During the National Health Committee project several people mentioned that there is a lack of awareness in Pacific communities about causes and types of disability. They felt it impacted on the perception of what was possible for people with an intellectual disability and created a significant barrier for all disabled Pacific people. A common observation was that if a person’s disability is visually obvious, they tend to be regarded in Pacific cultures as needing help and unable to do things for themselves. Therefore, expectations are low and care that is provided can be almost ‘suffocating’.

Alternatively, if the disability is not visually obvious, then the expectations are often the same as if the person did not have a disability. While this has some positive outcomes, such as high levels of achievement with daily living tasks, the downside can be unrealistically high expectations and a lack of recognition that not all tasks may be easily achieved. This can lead to frustration and consequent behavioural issues. An example given was of a person being regarded as ‘naughty’ and strongly disciplined, rather than their behaviour being understood and help sought to appropriately manage it.

“A person with an intellectual disability can be viewed either as a valued member of the family who needs to be protected from the outside world, or as a punishment on the family for past sins. Often the person is perceived in one or more of the following ways: as being sick, mentally unwell, as an eternal child, as a source of amusement, or an object of fear.”661

“… nothing just happens for the sake of happening … so when we talk about disabilities…it is always interpreted as a sort of punishment or a curse.”662

“I think this shame is associated with themselves (the parents) not with the child. They see the child as a result of something that has gone wrong … the parents feel guilty because they feel they have done something bad and this has caused the child to have a disability.”663

Many people mentioned religious explanations about the causes of disability. This can focus on Old Testament teachings associated with religious wrongdoing, with the disability

658 Cited in Huakau and Bray 2000.
659 Huakau and Bray 2000.
660 Makasiale and Williams 1977.
661 Makasiale and Williams 1977.
662 Huakau and Bray 2000.
663 Huakau and Bray 2000.
Pacific adults with an intellectual disability

regarded as a form of punishment from God. This is not usually directed at the person with a disability, but more widely as a reflection of some wrongdoing within the family. It means that for some Pacific families there can be an element of shame associated with the disability, and a fear of how other people will interpret and talk about the person with a disability.

For Pacific people, being given a reason for the cause of a disability and why certain people are disabled, and others are not, is important. This is emphasised by the following comments from a participant in a recent New Zealand study:

“… in Samoa … we must have an answer for everything … even if it is not correct there must be a REASON … if we have some sort of reason then we can try to understand it … we don’t just accept things …like when doctors say they don’t know …”

Some people saw the tendency to give a religious explanation as still being a significant issue, while others felt it was an historical issue that was changing through education. One disabled Pacific person spoke of his anger at being told by a church minister that his disability was linked to wrongdoing. Others felt that many churches offered a strong and supportive network, which can have huge benefits for the family and the disabled person.

“… when it is beyond your understanding then you attribute it to a higher source … so the reality of the Pacific world … was to associate it to what they did know … we have seen other ways of living that is outside our way in the Islands … we learnt other reasons about disabilities …”

It was clear that there is still a stigma and a sense of low status attached to disability in Pacific cultures. A number of comments demonstrated how this lack of status impacts on the disabled person’s ability to fulfil the same roles and achieve the same social value in the Pacific community as a person without a disability. For example, since people with an intellectual disability are generally unable to provide for a family, they are not seen as a ‘real’ person. Discussions stressed that within Pacific cultures, and even within individual family groups, there can be widely different views about disability. Often these views are very different where younger members have been born and raised in New Zealand. In this situation more difficulties can arise as younger members tend to question the views of older family members. As with the wider New Zealand society, building an inclusive society for people with disabilities in Pacific cultures is a long journey.

Services for Pacific people with an intellectual disability

Awareness of services

Lack of information about services available to Pacific disabled people was a common concern raised during the National Health Committee project. It would appear many

665 Huakau and Bray 2000.
666 Huakau and Bray 2000.
667 Huakau and Bray 2000.
Pacific adults with an intellectual disability

professionals are not adequately explaining what services are available or not linking Pacific people with disability support services. Also, many Pacific people appear to have poor knowledge of both disability and the services available. Examples given suggest that there is a lack of coordination between health, education and social service professionals. For instance, disabled children and adults who had been seen at numerous hospital clinics, and been hospital inpatients, were discharged with no disability support and no information about how to access it, despite having an obvious need for equipment or support services. This included a school-age child who was unable to walk being sent home without a wheelchair.

A consistent message was that Pacific families and disabled people are shy about asking for help, and not assertive in finding out about their entitlements. For example, one person described how he had written a short article in a Tongan newspaper about services for Pacific people with disabilities. Within a week he had received 20 written responses asking basic questions like, “What is a needs assessment and service coordination agency?”, “Where can I get a wheelchair?” and “What help am I entitled to?”

Most people in Pacific communities knew about income support, and those who were eligible generally accessed the services offered by Work and Income (Ministry of Social Development). However, as identified in Chapter 7: Paying for things, data from the Ministry of Social Development would indicate that while people are accessing income support benefits, they are not necessarily receiving supplementary assistance such as Accommodation Supplement or Disability Allowance. For example, in the Counties-Manakau DHB region, which has one of the largest numbers of Pacific people receiving a Sickness or Invalids Benefit because of an intellectual disability, only 27 percent of those not in residential care receive a Disability Allowance. This rate is much lower than most other DHB regions.

Better education and information is needed about causes and types of disabilities, available services, and opportunities to influence service development. Language remains a significant barrier, particularly when information is only available in writing. The preferred Pacific approach is word of mouth rather than written material. Needs assessors and service providers gave many examples of new clients who had come forward as the result of personal verbal recommendations by other clients. Pacific radio stations are listened to widely, particularly by older Pacific people. Although currently there is very little coverage of disability issues, radio offers an opportunity to raise awareness of causes of disability, resources and where to go for help.

Pacific people need to receive information in appropriate formats, and simply translating information was not seen as sufficient. As one researcher put it, “for a Pacific family who has a disabled family member, problems can be exaggerated due to their own disability in being unable to communicate clearly and confidently.” Another factor that may play a role in creating barriers to service awareness is the shame stemming from some of the Pacific values around disability, with families often preferring to get support from people from other Pacific nations or those outside their family, and tending not to discuss issues openly.

Accessing services

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668 For instance Sickness or Invalids Benefit.
669 See Chapter 7: Paying for things for more information about income support.
670 Huakau and Bray 2000.
Many Pacific people stressed that the collective nature of the Pacific culture means that the extended family is often involved in caring for a person with a disability, and that the collective view is more important than the individual’s. Comments like, “we don’t come in ones or twos but always in groups,” were frequent.

In the Pacific nations disabled people are cared for by their family, with grandparents often providing care. This is based on the strong cultural belief that it is the family’s role to provide care. Having support services provided by someone outside the family is perceived by some Pacific people as going against a philosophy of ‘looking after your own’, that underpins Pacific cultures. However, for many reasons this can be difficult to do in New Zealand, and may not necessarily be in the best interests of the disabled person.

Anecdotal information indicates that many Pacific people are afraid or unwilling to access Palagi systems of support. Often families do not want others talking about their problems and are ashamed of having a disabled family member. Even when families do access needs assessment and service co-ordination, there are very few Pacific needs assessors, and even fewer Pacific support services. The National Health Committee heard a number of reports of families acting against their own beliefs and placing a person with an intellectual disability in residential care because they had been told this was the best thing to do, or because they were unable to afford to have a family member stay home to provide care.

In working with Pacific families it is important that needs assessors and service providers value the caregiving role played by families. Each Pacific group has its own way of operating, and providers need to be vigilant against generalising.

Financial constraints

The average per annum income of a Pacific person in New Zealand is approximately $14,000, and unemployment levels amongst Pacific people are currently twice the national average. As a result, in a Pacific household all those who are able to work, do so, to contribute to the family income. This often means that there is no one at home to provide care to a family member with an intellectual disability.

In addition, the income support that a person with an intellectual disability receives can be an important source of income for the family. There are anecdotal reports of people being removed from residential care because their income support was needed to meet the financial commitment of the family. While it is appropriate for the person with an intellectual disability to contribute to the household finances, like their non-disabled peers, it is of concern when this means that they are unable to access the support services they require.

671 Huakau and Bray 2000.
672 A Samoan term for Europeans.
673 Huakau and Bray 2000.
674 Data provided by the Ministry of Pacific Island Affairs.
Pacific adults with an intellectual disability

Behavioural issues
In some instances, the behaviour exhibited by an adult with an intellectual disability may make it difficult for the family or wider Pacific community to provide care. As discussed previously, care approaches in Pacific cultures have the potential to exacerbate behavioural issues for people with an intellectual disability. They may develop challenging behaviours as a result of frustration at the ‘suffocating’ style of care they are receiving. Or, at the other extreme, their behaviour may be difficult to handle because of not coping with the high expectations and demands placed on them. Often the family may not have the time needed to deal with specific behaviours or to support and encourage a family member with an intellectual disability to do everyday things.

Concern was expressed that some Pacific people with an intellectual disability were placed in residential care because of behavioural problems. One of the reasons suggested for this was that services for people with high and complex needs tend to focus on clinical issues, rather than acknowledging the social and cultural dimensions of behaviour. Examples were given of service staff developing a behavioural programme with families without ensuring that it is understood or culturally appropriate, and the family not understanding the plan and throwing it away. Another example was given of a person who was placed in respite care for behavioural problems, which did not surface while they were in respite care, so the behavioural programme was never instituted. Many people stressed it was how information is delivered that is important and that, in line with the Pacific way of doing things, the focus needs to be on working with the family as well as the individual.

Changing the attitudes of family members about what a person with an intellectual disability can achieve or how to manage a disruptive behaviour needs to be done in a way that is respectful and positive.

Funding
Lack of flexibility in funding of services was seen as a major barrier in ensuring the delivery of culturally appropriate services that met the needs of Pacific people with an intellectual disability, their families and communities. Contracting for set types or packages of services was seen as making it very difficult to develop alternative approaches in the community. However, the recent advances in needs assessment, particularly in South Auckland, was seen as enabling more flexibility.

Lack of information and leadership
There is a clear lack of data about the needs of disabled Pacific people, which makes it very difficult to develop and plan Pacific services. Concern was expressed at the lack of Pacific leadership and direction in this area. It was felt there was a real risk of creating ‘brown’ Palagi services rather than working out what ‘by Pacific for Pacific’ disability supports could look like. It was pointed out that making services more appropriate for Pacific people does not necessarily have to cost money. There are many changes that can be made in approach and protocol to better meet the needs of the Pacific community.

Many Pacific people were of the opinion that the people most at risk are those on the edge of their communities and who lack understanding of their disability. Many also expressed real concern at the lack of workforce development, and saw this as a major hindrance in the delivery of quality service, particularly in the areas of leadership, technical training, and needs assessment services.
The most pressing areas for action appear to be:

• undertaking a needs analysis to gather information on Pacific people with disabilities
• growing Pacific leadership in the sector
• ensuring workforce development, particularly focusing on the need for Pacific staff to be trained about disabilities and disability support (alongside the whole spectrum of health and support staff responding to the needs of Pacific people)
• planning how to deliver services in the future.

Pacific services

During the National Health Committee project, discussions were held with three agencies supporting Pacific people with an intellectual disability, all of which are not-for-profit organisations.

Spectrum Care
The largest agency was the Pacific service operating as part of a large mainstream provider organisation, Spectrum Care. Spectrum’s Pacific Service is staffed by Pacific people, and provides a range of services for Pacific people with an intellectual disability and their families. This consists of:

• a residential service of seven homes housing 33 people in South Auckland. Two homes are for women and five for men. All staff and most residents are Pacific people, and staffing levels “depend on the challenges that residents present”. It is a contractual requirement that the staff of a home includes at least one person from the same Pacific group as each of the residents. However, this has not been able to occur in practice, so cultural awareness exchanges are held between staff to increase their knowledge of the languages and cultures of residents
• a day programme for people living in the service’s residential homes who have been assessed as “not being able to take part in employment”. This service does not have a contract with either the Ministry of Health or the Ministry of Social Development. It is funded from a combination of Spectrum fundraising and the attendee’s Disability Allowance. In addition to people living in Spectrum houses, the programme caters for a small group of Pacific people who live in the wider community. All participants attend five days a week. The programme has a Pacific emphasis in the activities it offers, such as Pacific crafts, music and food, and is run by Pacific staff
• a holiday programme for school children, which is very well attended
• a community support team that supports Pacific families of people with an intellectual disability. The stigma associated with having a disabled person in a Pacific family means that many families do not seek support because they are embarrassed. Staff make contact with families, who they often hear about through word-of-mouth. They then visit the family and provide support and advice in areas such as schooling, mobility, incontinence aids, housing, liaising with doctors and income support. These community support staff work closely with the clinical team at Spectrum.

675 This is actually in contravention of the policy that Disability Allowance may only be used by people in residential care for vocational services, which are further defined as services contracted by the Ministry of Social Development.
Pacific adults with an intellectual disability

As part of staff development, Spectrum staff are enrolled in the Certificate In Working With People With Disabilities. However many of the Pacific staff find the style of the certificate course difficult and much of their learning occurs on the job through a ‘buddy’ system. A key factor in retaining staff is providing support and a sense of belonging. Quarterly staff functions are held, and one-to-one training is provided if needed.

Pacific Information Advice and Support Service (PIASS)
The Pacific Information Advice and Support Service (PIASS) has a contract with the Ministry of Health for “empowerment and advocacy for disabled people who are Pacific”. A priority for PIASS is education among Pacific people about disability and disability support. Pacific radio has been identified as a key approach to talking about disability issues with Pacific communities. PIASS also hopes to convene focus groups of Pacific people with different disabilities.

PIASS is also involved in the Community Reintegration Project which is working with the 400 people under the age of 65 living in rest homes in Auckland to identify more appropriate accommodation for them. While this project is mainstream rather than Pacific-specific, at least 36 percent of these 400 are Pacific people. As part of the project Pacific people are working with these people and their families to look at other residential and disability support options.

Women Heart of the Pacific (WHOP)
The third provider was a small community-based trust known as Women Heart of the Pacific or WHOP. This new service grew out a desire by three Pacific women to meet a need in their community. Using Pacific people they run a day service offering Friendship, Advocacy, Coordination and Education (FACE) for disabled Pacific people (friends) and their families. This ‘FACEfriends’ service embodies the concept of community integration by having activities taking place out and about in the community, doing ‘ordinary things with ordinary people’ rather than activities in specific premises. It currently provides a service to 40 people with an intellectual disability and has 20 part-time staff.

However because this service is innovative, it does not fit easily into the established pattern of service provision and it was difficult for the service to access any funding. Much of the work the staff do is unpaid, or they are only reimbursed for the cost of petrol to transport the disabled person. The service has only been able to access a small amount of the discretionary funding that the needs assessment and service coordination agencies can use to develop a person’s individual support package and utilise respite care funding.

Key issues

- The rapidly growing Pacific population, particularly in the Auckland region, presents a challenge to disability support services and the future training and development of the disability workforce.
- In general, Pacific people with an intellectual disability appear to be very restricted in their access to services and to have a low status or value in their communities.
- Ongoing education about disability (types, causes, and expectations) is needed in Pacific communities and this can most effectively be done verbally in the appropriate language.
- Pacific families are often not aware of what support is available, particularly publicly funded disability support services.
A small number of ‘by Pacific for Pacific’ support services, where staff speak the language and understand the culture of the disabled person, are beginning to be developed.
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