

# 11 Future Focus

## Introduction

This final chapter reflects on how the information presented in this report can be used. This includes assessing the relevance of the information for disability research and policy development, as well as to the objectives of the New Zealand Disability Strategy (Minister for Disability Issues 2001). The chapter also considers recent international developments in the field of measuring disability and their implications for the design of future New Zealand disability surveys.<sup>1</sup>

## Scope of the disability surveys and this report

Key strengths of the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities were their size and breadth of coverage of disability-related topics, including important issues such as unmet need and barriers to accessing services. A particular strength of the Household Disability Survey was that its results could be linked to Census data, so adding considerably to the information about New Zealanders with disability. The ability to compare results with the 1996 and 1997 surveys and the improved reliability of Māori and Pacific data (because of the larger Māori and Pacific samples) were other important features of the 2001 surveys.

This report has described the findings from the 2001 surveys. In so doing, it has addressed all the main themes and issues covered in the survey questions, thus expanding on the results presented in *Disability Counts 2001* (Statistics New Zealand 2002a). It has also compared a selection of key results for 2001 with those of the 1996 Household Disability Survey and the 1997 Disability Survey of Residential Facilities.<sup>2</sup>

<sup>1</sup> This chapter does not summarise the survey findings or suggest how policy or services could be developed in response to the results. Topic-specific summary information is provided at the start of chapters 2–10 for readers wishing to access the main survey findings quickly. Identifying the policy implications of all the survey data presented here is a separate task and outside the scope of this report.

<sup>2</sup> In addition to the text and charts presented in this report, more detailed survey data are available in a comprehensive set of Appendix Tables. These can be downloaded from the Ministry of Health's website (<http://www.moh.govt.nz>).

## Relevance to the New Zealand Disability Strategy

The report contributes to the fulfilment of Objective 10 of the New Zealand Disability Strategy (Minister for Disability Issues 2001), which is to collect and use relevant information about the situation of people with disability and disability issues. As well, the information provided in the report has relevance to many of the other objectives of the New Zealand Disability Strategy (Table 11.1).

**Table 11.1:** Relevance of the report to the objectives of the New Zealand Disability Strategy

Objective of the New Zealand Disability Strategy	Chapters in the report providing relevant information
Objective 3: Provide the best education for disabled people	Chapter 4: Education
Objective 4: Provide opportunities in employment and economic development for disabled people	Chapter 5: Employment and Income; chapter 4: Education
Objective 7: Create long-term support systems centred on the individual	Chapter 3: Support, Equipment and Services; chapter 10: Adults with Disability in Residential Facilities
Objective 8: Support quality living in the community for disabled people	Chapter 6: House and Home; chapter 7: Travel and Transport
Objective 10: Collect and use relevant information about disabled people and disability issues	All chapters
Objective 11: Promote participation of disabled Māori	All chapters, especially chapter 8: Māori and Disability
Objective 12: Promote participation of disabled Pacific peoples	All chapters, especially chapter 9: Pacific Peoples and Disability
Objective 13: Enable disabled children and youth to lead full and active lives	Chapters 2–9
Objective 14: Promote participation of disabled women to improve their quality of life	All chapters
Objective 15: Value families, whānau and people providing ongoing support	Chapter 3: Support, Equipment and Services

## Future policy and services

Much of the information in this report will be useful for policy development and planning services for, and with, people with disability. Topics covered in the report likely to be of particular relevance include the:

- prevalence of disability in New Zealand in the whole population and different groups
- different types and causes of disability
- proportion of people with disability using certain kinds of support services, equipment and technology

- levels of, and barriers to, participation by people with disability in areas of society such as the workforce or post-secondary school education
- extent of the socioeconomic disadvantage and inequity experienced by people with disability, including indicators of the extent to which people with disability are more disadvantaged than people without disability (for example, levels of educational achievement and income)
- proportion of people with disability who report they have unmet needs relating to support services, equipment, technology, transport, work opportunities or housing.

## Monitoring change

Information presented in the report, the report's Appendix Tables, or available directly from the survey databases, is also likely to be useful for monitoring changes in the areas mentioned above. These changes may occur for many different reasons, including:

- demographic changes in the population, such as increases in the proportion of older people in the population
- changes in social attitudes towards people with disability
- policy changes in various sectors, such as changes in the accessibility of support services, the provision of income support, or the removal of social or physical environmental barriers
- new developments in the prevention or treatment of specific health conditions associated with disability or in the rehabilitation of people with certain kinds of disability.

## Future disability research

This report contains a large amount of descriptive information, but there is still potential to examine the data in more depth. Readers are encouraged to identify areas of interest from the data published in the report and its accompanying Appendix Tables. More detailed survey data on specific topics also can be obtained directly from Statistics New Zealand, and further analysis can be undertaken using appropriate research questions and analytical expertise.

The report's structure largely reflects the main themes and organisation of the disability survey questionnaires and the New Zealand Disability Strategy. Clearly, though, there are other ways the survey results could be organised and presented. For example, separate reports or chapters could be prepared focusing on people with disability in different age groups (for example, children, working-age adults or older adults) or people with certain types or causes of disability.

Further work includes developing estimates or projections of future levels of disability in New Zealand by applying reported prevalence rates to population projections.

The data could also be used for modelling the prevalence of disability at a smaller regional level, for example, for District Health Board service planning.<sup>3</sup>

<sup>3</sup> The survey sample allowed data to be analysed only at the level of four regions – Northern, Midland, Central and Southern.

Interested readers may also wish to obtain additional cross-tabulations of data from Statistics New Zealand, where survey numbers allow. These could be used, for example, to age-standardise results that have not already been age-standardised in this report.

Multivariate analyses may also be appropriate to explore aspects of the survey findings in more depth.<sup>4</sup>

Using age-standardisation and multivariate analyses, the survey results could be examined without the confounding effects of age or other demographic variables that may be affecting the mainly bivariate analyses presented in this report.<sup>5</sup>

Information in the report could also be compared with the results of other national or regional disability surveys from New Zealand and overseas. This would help put the New Zealand survey findings into a broader context.<sup>6</sup>

The data presented here also provide a basis for identifying important disability-related topics that could be further examined using qualitative research. This type of research provides the potential to investigate specific issues related to the experience of living with disability in considerable depth. In combination with quantitative survey research, qualitative research would help fill in key information gaps and contribute to answering the many ‘why?’ questions likely to emerge from the results presented in the current report.<sup>7</sup>

## Future disability surveys

Statistics New Zealand is planning a further Household Disability Survey and Disability Survey of Residential Facilities for 2006. These surveys will provide the third national, five-yearly picture of disability in New Zealand. It is timely, therefore, to consider ways that aspects of these future surveys might be enhanced. This would include considering:

- different or additional survey questions
- more appropriate and clearer terminology and definitions
- more efforts to seek the views of people with disability about the survey design (including children and young people).

<sup>4</sup> Multivariate analyses examine several interrelated variables together. The aim is to determine which variables are most important in influencing a particular outcome, such as whether people have a disability or not.

<sup>5</sup> Bivariate analyses examine the relationship between two variables. See also the discussion on disability and age in chapter 1.

<sup>6</sup> Where definitions, concepts and data collection methods are similar.

<sup>7</sup> Examples of these questions are: why is the prevalence of disability relatively high in the most socioeconomically deprived areas of New Zealand?; why is the severity of disability relatively high among younger Pacific adults? and why do so few Māori adults with disability live in residential care?

## Addressing information gaps

While the 1996, 1997 and 2001 surveys clearly provide a large amount of information relevant to the objectives of the New Zealand Disability Strategy, significant information gaps remain.<sup>8</sup> Some of these gaps, particularly those related to the objectives not covered by the disability surveys, are highlighted in Table 11.2.<sup>9</sup>

**Table 11.2:** Objectives of the New Zealand Disability Strategy and related information gaps

Objectives of the New Zealand Disability Strategy	Actions of the objectives not covered by the disability surveys
Objective 1: Encourage and educate for a non-disabling society	Anti-discrimination programmes; achievements of people with disability; participation of people with disability in ethical debates; recognition that people with disability are experts on their own experience; wider public debate about disability issues.
Objective 2: Ensure rights for disabled people	Provision of information about the rights of people with disability (to general public, people with disability and support agencies); education of agencies about the rights and abilities of disabled parents; review of Human Rights legislation; United Nations convention on the rights of people with disability; access to independent advocacy; New Zealand's performance regarding rights of people with disability.
Objective 5: Foster leadership by disabled people	Participation of people with disability in governance, management, planning and evaluation of support services; self-help initiatives, service provision and advocacy by people with disability; modelling and mentoring of leadership roles for people with disability; register of people with disability for government appointments; provision of information to people with disability and advocacy groups.
Objective 6: Foster an aware and responsive public service	Consistency of government policy, legislation and services with New Zealand Disability Strategy; provision of information in appropriate formats; access to buildings of government agencies and public services; territorial authorities' support of New Zealand Disability Strategy.

<sup>8</sup> The New Zealand Disability Strategy was developed after these disability surveys were designed.

<sup>9</sup> See also Brown (2003) and Hughes (2003). Not all the actions associated with the other 10 objectives are covered by the disability surveys. For instance, while Objective 15 is partly covered because the surveys ask questions about the level of support for everyday activities that families and whānau give to people with disability, other actions under this objective are not covered. These include actions related to the involvement of families, whānau and support people in assessment processes and decision-making; the improvement of support and choices for people who support people with disability; and the provision of accurate, accessible and easily found information to people who support people with disability. Likewise, while Objective 4 is partly covered by the surveys in questions that cover current patterns of employment and workplace needs, actions relating to planning and training for entering employment (work-related training) are not particularly well covered. Other strategy actions not well covered by the survey include ensuring service providers are well-trained and understand the needs of people with disability, and ensuring certain services, for example, residential facilities, are accessible, acceptable and responsive to people with disability.

Objective 9: Support lifestyle choices, recreation and culture for disabled people	Choices of people with disability about their relationships, sexuality and reproductive potential; opportunities in arts, recreation and sports; education of arts, recreation and sports administrators about disability issues and inclusion; development of arts, recreational and sports projects run by and for people with disability.
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At least some of these information gaps could be addressed in future disability surveys. The levels of participation of people with disability in arts, recreation and sport, for example, or their access to, or needs for, information, are all readily amenable to measurement in these surveys.

Other information gaps may need to be filled using different methods, for example, audits of the practices of government agencies and other organisations, analyses of administrative data, social surveys of the general public (which may include questions to identify people with disability), surveys of the physical environment, evaluations of services, and qualitative research with people with disability (for example, investigating their perceptions of the accessibility and appropriateness of various services).

## Defining disability

When designing surveys, it will be important to think carefully about the criteria used to define whether people have certain types of disability.

Two years ago the World Health Organization published the International Classification of Functioning, Disability and Health (ICF) (World Health Organization 2002). This is a new, internationally recognised system for defining and measuring health and disability. In contrast to many previous approaches, it focuses on health, rather than disease or dysfunction. It also takes into account interactions between the following sets of factors or ‘domains’:

- body functions (for example, sensory functions, mental functions and voice and speech functions)
- body structures (for example, structure of the nervous system and cardiovascular system)
- activities and participation (for example, learning and applying knowledge, communication, mobility, self-care, relationships, community and social and civic life)
- environmental factors (for example, products and technology, natural and human-made physical environment, social attitudes, services, systems and policies).

The 1996, 1997 and 2001 New Zealand disability surveys used definitions of disability type that incorporated a mixture of ICF domains, including:

- body functions – seeing disability and hearing disability for both adults and children
- body structures – chronic condition/health problems for children
- activities and participation – mobility disability for adults and learning disability for adults and children
- environmental factors – use of technical aids and use of special education services for children.

Having a mixture of concepts to define disability type has led to overlapping categories (for example, most children who used technical aids were also defined as having a chronic condition/health problem).

This, together with the fact that adults and children had different classifications of disability type, has led to some difficulties interpreting and reporting survey results.

Consideration should be given to using alternative ways to define disability in future surveys. One possible approach would be to develop definitions based on the ICF, with the definitions formulated and refined in consultation with the disability sector.

In 2001, the United Nations established the Washington Group on Disability Measurement to investigate and develop standard sets of population measures of disability that could be used in censuses and disability surveys throughout the world (National Center for Health Statistics 2004). These general measures, once finalised, will be based on the ICF and will enable disability data to be collected for several purposes, including international comparison.

At its last meeting in February 2004, the Washington Group decided the main purpose of the general disability measures it is developing should be to assess equalisation of opportunity, with the secondary purpose being to monitor the level of functioning in the population (National Center for Health Statistics 2004).<sup>10</sup>

Background papers prepared for the Washington Group have raised issues that are also relevant to the design of New Zealand Census questions and disability surveys (Hillerman 2002; Langlois 2002; Madans et al 2002; Madans et al 2004), for example:

- What questions about disability are suitable to use in general population censuses, as well as in more extended disability surveys?
- What measures of disability are appropriate for adults as well as children, and for people from different cultures?
- What measures of severity of disability are appropriate?
- Should people be defined as having a disability if they use equipment or technology that corrects or partially corrects any activity limitations they might have?

## Comparing sub-groups

Results from the disability surveys have been analysed in this report in relation to several demographic and disability-related variables (for example, age, sex, ethnicity, disability type, disability cause, severity of disability and levels of socioeconomic deprivation). This enables readers to compare how different groups in the population experience disability or use various kinds of disability-related services or equipment.

However, as explained in chapter 1, when analysing these results it was not possible to test the statistical significance of the differences between the groups (for example, to calculate p values).

<sup>10</sup> A third purpose – collecting data to assist with service provision – is not a priority for the group, because it was considered infeasible to develop a small set of questions that would be applicable to the different policy and service environments in different countries.

This was primarily because of the complex design of the survey sample. Should it be concluded that the ability to test for statistical significance is important for interpreting the results of future surveys, the design of the survey samples may need to be reconsidered.

That said, the advantages of simplifying the sample design, for instance by not oversampling certain population groups such as Māori and Pacific peoples, would have to be balanced against the considerable disadvantages of reducing the reliability of the data for these groups (see next section ‘Māori and Pacific perspective’).

The size of different sub-groups within the sample may also need to be reviewed to take account of changes in the New Zealand population. For instance, the increasing proportions of people in the oldest age groups (75 and over or 85 and over), and Asian peoples, may warrant special consideration when designing surveys.

It also could be useful to identify and describe the experiences of population groups such as migrants and refugees with disability.

## **Māori and Pacific perspectives**

This report indicates that Māori and Pacific peoples with disability are more disadvantaged in several areas than their non-Māori and non-Pacific counterparts. This is particularly in the areas of socioeconomic status, service use, access to amenities (such as private transport and non-rental homes) and knowledge of the resources available to them. Māori and Pacific peoples are also more likely to have relatively severe levels of disability, to need or receive more disability-related assistance, and to have more severe disability at younger ages.

Future disability surveys may expand on these survey findings, particularly if questions are designed to take into account the cultural attitudes, beliefs and values that Māori and Pacific peoples have towards health and disability, and their views of appropriate support services.

Future disability surveys should also allow comparisons of Māori and Pacific data to be made over time, for example, by continuing to oversample these populations and by considering the most appropriate way to define ethnicity.

## **Perspectives of people with disability**

The New Zealand Disability Strategy states that people with disability should be included in the development of the disability research agenda and enabled to put forward their own experiences in the context of the research. Consistent with this, people with disability should be involved in deciding what should be included in future disability surveys and how ‘disability’ is defined and measured. Survey participants should also be given, whenever possible, the opportunity to answer survey questions for themselves. This applies to adults with disability, as well as children and young people.