

A small decorative graphic consisting of a solid olive-green horizontal bar with a white bullseye symbol in the center.

## 2011 Disability Survey: Discussion paper on proposed content

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## Introduction

The first comprehensive survey on disability in New Zealand was conducted in 1996. The Disability Survey: 1996 measured the nature, extent and causes of disability in New Zealand, and provided information on the socio-demographic characteristics of disabled people. It also provided information on disability-related expenses incurred by individuals and families, and unmet needs for services and support.

The survey was repeated in 2001 and 2006 using the same methodology and with only minimal changes to the survey content. This resulted in output that was broadly comparable between the three surveys, enabling changes to be tracked over time. Because the survey content has not been modified in response to real world changes, its relevance has reduced over time.

The next disability survey is scheduled to take place in 2011. In view of developments relating to disability internationally and in New Zealand over the past decade, it is timely to review the content of the disability survey to ensure that statistics generated are relevant to current and emerging needs and conform with international best practice.

Significant amongst the developments that have occurred are:

- the introduction of the International Classification of Functioning, Disability and Health by the World Health Organisation (WHO), which replaces the International Classification of Impairments, Disability and Handicaps (ICIDH)
- the development of *The New Zealand Disability Strategy* (Office for Disability Issues, Ministry of Social Development, 2001)
- the development of *The New Zealand Carers' Strategy and Five-year Action Plan 2008* (Ministry of Social Development, 2008a)
- the ratification by the New Zealand Government of the United Nations Convention on the Rights of Persons with Disabilities.

These developments have seen the formerly medical model of disability, which describes people with disabilities as suffering from illness or disease, to be largely superseded by the social model. In contrast to the medical model, the social model emphasises that attitudinal, behavioural and physical barriers created by society hinder the independence and participation in society of people with disabilities. The social model is associated with recognition that people with disabilities have the same human rights as their non-disabled peers.

An evidence base is needed to fulfil the reporting requirements of The NZ Disability Strategy and the UN Convention of the Rights of Persons with Disabilities. Official statistics form part of this evidence base. They are needed to provide an objective picture of changes in the outcomes and experiences of disabled people across a range of domains.

*The New Zealand Carers' Strategy and Five-year Action Plan 2008* was released in August 2008 and aims to improve the choices of informal carers so they can better balance their paid work, caring responsibilities and other aspects of their lives. Monitoring progress of implementation of the strategy and whether it is achieving its vision will require information on the families and carers of people with disabilities.

## Key uses of disability data

Disability data is needed for a variety of purposes including:

- to report against domestic and international conventions and strategies
- to support policy analysis, programme development and service delivery
- to advocate for the rights of people with disabilities.

The following table identifies the main types of use of disability data and the information required to meet this use.

Information need	Type of data needed	Data use
Monitoring outcomes of disabled people	<ul style="list-style-type: none"> <li>• Measures of key social and economic outcomes for:               <ul style="list-style-type: none"> <li>◦ disabled and non-disabled population</li> <li>◦ sub-groups of the disabled population defined by age, sex and disability type</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• To monitor The NZ Disability Strategy and meet the reporting requirements of the UN Convention on the Rights of Persons with Disabilities</li> <li>• To advocate for the rights of people with disabilities (required by the Disability Sector)</li> </ul>
Health expectancy (as a Tier 1 statistic)	<ul style="list-style-type: none"> <li>• Disability prevalence by:               <ul style="list-style-type: none"> <li>◦ age-group (10 years)</li> <li>◦ sex</li> <li>◦ level of support required to perform activities of daily living</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• To monitor the wellbeing of New Zealanders – health expectancy is a key health outcome measure in <i>The Social Report 2008</i> (MSD, 2008b)</li> </ul>
Policy development and service delivery	<ul style="list-style-type: none"> <li>• Disability prevalence by:               <ul style="list-style-type: none"> <li>◦ age-group</li> <li>◦ sex</li> <li>◦ type of impairment</li> <li>◦ geographic location</li> </ul> </li> <li>• Environmental barriers to undertaking everyday activities and to participating in different areas of society, such as education, work, civic society</li> <li>• Unmet needs for support</li> </ul>	<ul style="list-style-type: none"> <li>• To help target support to disabled people to enable them to participate in society</li> </ul>
Carer information	<ul style="list-style-type: none"> <li>• Data is needed on informal carers, including their characteristics and the difficulties they face because of their caring responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>• To monitor implementation of <i>The New Zealand Carers' Strategy and Five-year Action Plan 2008</i></li> </ul>

Outcome indicators across a range of life domains are needed to fulfil the reporting requirements of the NZ Disability Survey and UN Convention on the Rights of Persons with Disabilities. Comparisons between people with and without disabilities, and between sub-groups of the disabled population are an important aspect of this reporting requirement.

Disability data is essential to shape policy, plan programmes and services for people with disabilities, and to predict the likely take-up rates of programmes based on different eligibility criteria. Of particular importance in this context is information on the prevalence of disability and the locations of disabled people. There is also a need to understand how accessible society and the built environment are to people with disabilities, and how this is changing over time.

The Disability Sector requires data to evaluate the impacts of government policies on people with disabilities so that they can advocate for the rights of people with disabilities. The sector has used statistical data in the preparation of submissions to improve the lives of people with disabilities.

Statistics New Zealand and the Ministry of Health have recently published a discussion paper proposing that health expectancy be considered a Tier 1 statistic. To derive the health expectancy measure, data on disability prevalence for adults and children and the level of support they require with day-to-day living activities is needed.

## Options for meeting information needs

Three main options for meeting the above information needs have been investigated:

- administrative data sources
- an add-on module to the General Social Survey
- a post-census Disability Survey.

### Administrative data sources

A range of administrative data on disabled people is available from government agencies. The main sources include:

- **Client Claims Processing System (CCPS)** (Ministry of Health) – contains information on disabled people assessed as requiring publicly-funded disability support services.
- **SWIFT Benefits Processing and Payments System** (Ministry of Social Development) – captures information on disabled people who receive disability-related financial support and on non-disabled people who receive assistance on behalf of a disabled person.
- **Special Education Needs** (Ministry of Education) – contains information on children and young persons with special education needs, including their type of disability and the type of equipment or teaching needed in order for them to continue learning.
- **RENTEEL database** (Housing New Zealand Corporation) – contains information on recipients of specialist services for disabled people.
- **NZ Birth Defects Monitoring Programme** – captures data on birth defects in New Zealand.

Data from administrative sources provide information on the numbers and basic characteristics of people receiving different types of disability-related services. The data can shed light on the effectiveness of particular interventions. An important disadvantage is that the data only provides information on disabled people receiving support or services that are publicly funded. As a result, they give an incomplete picture of people with disabilities, excluding those who are not accessing any services and those who are receiving services for which the carer is unpaid. This means that the data cannot be used to produce prevalence rates or measures of health expectancy. Administrative data sources provide very limited information on the socio-economic characteristics and outcomes of individuals, and so cannot be used to monitor changes in the wellbeing of people with disabilities. The exclusion of people with unmet needs for services limits the utility of the data for policy purposes and programme development.

## **Add-on module to the General Social Survey**

The General Social Survey was developed with the intention of running add-on modules in future iterations of the survey. The addition of a 10–15 minute module to the survey was investigated as a potential option for meeting information needs relating to disability. It was envisaged that the module would comprise a series of questions designed to determine the disability status of the GSS respondent. Outcomes of disabled people could then be compared to those of non-disabled people across the subject-matter domains covered in the GSS including: knowledge and skills, paid work, health, social connectedness, economic standard of living, leisure and recreation, housing, safety and security, human rights, culture and identity, and the physical environment.

The range and type of information collected in the GSS on outcomes and participation closely matches the information needed to monitor The NZ Disability Strategy and UN Convention on the Rights of Persons with Disabilities. However, because the GSS sample of 8,000 people is likely to include only about 1,500 disabled people, the ability to produce estimates for sub-groups of the disabled population for outcomes of interest (eg educational qualification, personal income, housing tenure) would be severely constrained. This limitation is important, particularly because outcomes vary significantly between sub-groups of disabled people (eg by age-group and type of limitation). Monitoring at an aggregate level is likely to mask changes/differentials at a disaggregated level.

A further limitation of the GSS option is the restriction of the survey population to adults residing in private households. The exclusion of adults living in residential facilities and children from the survey population means that it would not be possible to produce disability prevalence estimates for the total population with disabilities. This would prevent the construction of health expectancy measures, which are dependent on the availability of data on disabled children and adults, including those living in residential facilities. The inability to produce accurate disability prevalence estimates for 10-year age groupings is another factor that would inhibit the construction of health expectancy measures from the GSS.

The limited time that would be available to collect information in an add-on module to the GSS (10–15 minutes) is a further drawback of this option. Based on the amount of time taken to administer the Disability Survey screening questions, it is likely that most of the available time would be used up in administering questions to identify the disability

status of the GSS respondent. Thus, the scope for collecting information on support needs, barriers to participation in society and carers would be very limited.

## Post-census Disability Survey

A post-census survey on disability is considered to be the option that has the greatest potential for meeting priority information needs on disability. However, the content of the previous post-census survey on disability will need to be redeveloped to align it to the new International Classification of Disability and Functioning (ICF). The content of the survey will also need to be updated to meet current information needs.

A household survey of around 5,000 disabled people should be able to produce reliable disability prevalence estimates for 10 year age groups by sex and by major impairment types. The production of health expectancy measures will depend on the availability of data on disabled people living in residential facilities in addition to those living in private households. This will require a separate survey of the population in residential care.

A number of outcome variables identified as being high priority for monitoring purposes by the Office of Disability Issues is collected in the census (eg educational attainment, employment characteristics, income, and housing tenure). Assuming that approval to transfer these census variables into the disability survey database is obtained, comparisons between the disabled and non-disabled populations for these variable will be possible. However, in order to provide comparative information for disabled and non-disabled people across the full range of outcome dimensions included in The NZ Disability Strategy and UN Convention on the Rights of Persons with Disabilities, the survey will need to collect an expanded range of information on social and economic outcomes.

A dedicated disability survey will provide scope for collecting information on the environmental barriers that prevent the full participation of disabled people in important life domains. A limited range of information on the characteristics of caregivers may also be able to be collected in the survey.

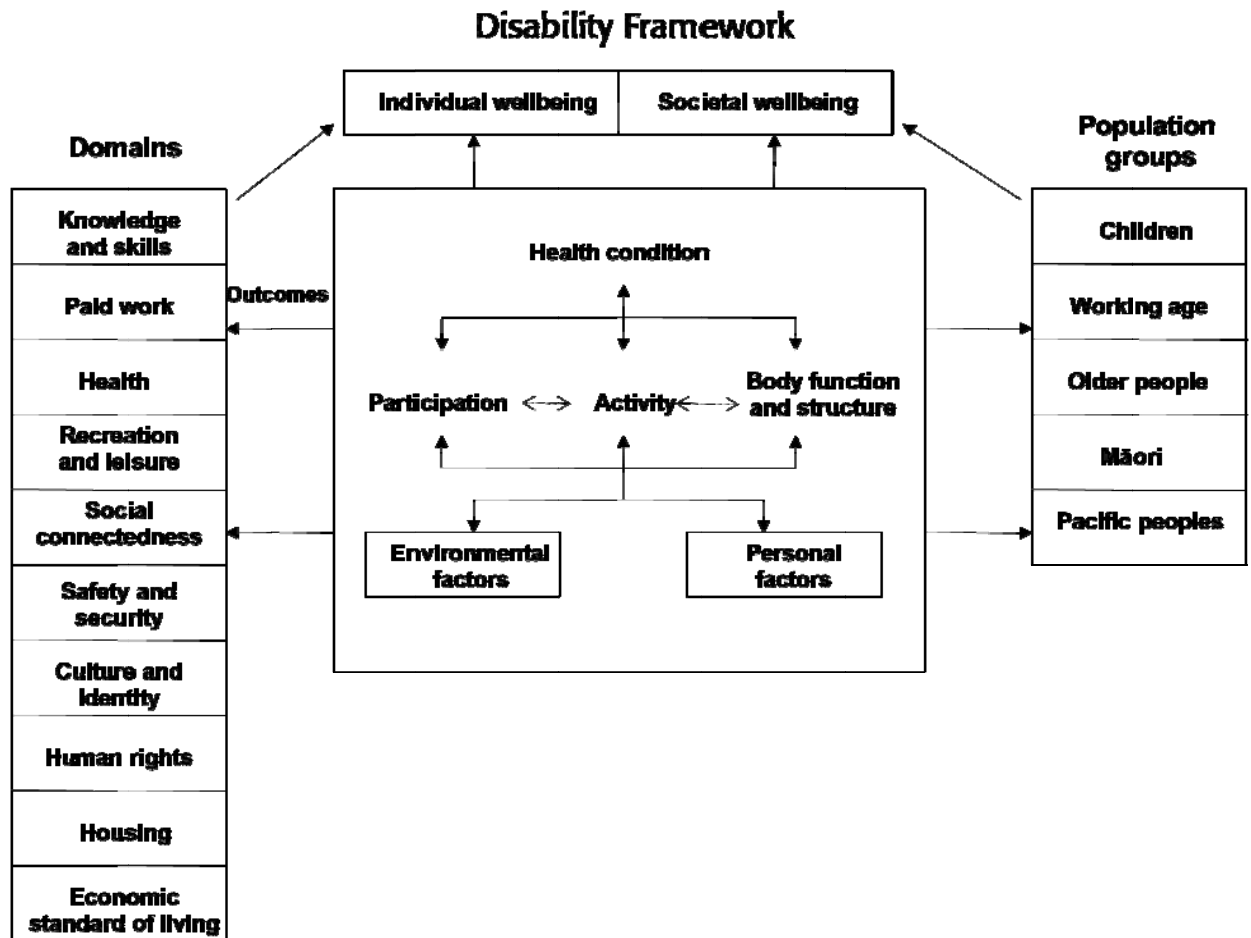
## Content development

### Conceptual framework

A framework provides a structured way of thinking about and organising information in a particular domain or area of interest. It helps define the scope of enquiry within a particular area, identifies key concepts and elements associated with the area and organises these into a logical structure.

The International Classification of Impairments, Disability and Handicaps (ICIDH) provided the conceptual basis for the previous three disability surveys. The ICIDH was founded on the medical approach to disability, which defines disability with reference to what is 'wrong' with the person, and how they are thought to differ from what is 'normal'. The focus is on caring for disabled people, with the implication that the way to overcome barriers to inclusion is to alter the individual to 'fit' better into society.

It is proposed that the 2011 Disability Survey is based on the new International Classification of Functioning, Disability and Health (ICF), which conceives disability as a dynamic interaction between health conditions, environment and personal factors. The following diagram shows key concepts and elements relating to disability and connections between them, drawing on the ICF.



## Definition of key concepts/elements

**Body functions** are the physiological functions of body systems (including psychological functions).

**Body structures** are anatomical parts of the body such as organs, limbs and their components.

**Impairments** are problems in body function and structures such as significant deviation or loss.

**Activity** is the execution of a task or action by an individual (eg reading the newspaper).

**Activity limitations** are difficulties an individual may have in executing activities.

**Participation** is involvement in a life situation (eg working in paid employment).

**Participation restrictions** are problems an individual may experience in involvement in life situations.

**Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives. These factors are either barriers to or facilitators of the person's functioning.

**Personal factors** are individual attributes such as their age, sex and ethnicity.

**Social outcomes** are states that contribute to the wellbeing or quality of life of an individual and which can be affected by the level of participation in a particular life domain.

**Disability** – in the context of each individual's health experience, the ICF defines disability as an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environment and personal factors).

## Key research questions

It is proposed that the 2011 Disability Survey be designed to address the following research questions, which are listed in priority order:

- What is the prevalence of disability in New Zealand, and how does it vary across key population sub-groups defined on the basis of age-group, sex, and ethnic group?
- To what extent do the social and economic outcomes of disabled people differ from those of non-disabled people, and how do outcomes vary between different groups within the disabled population?
- To what extent are the needs of disabled people currently being met? What level and type of support do they need to perform everyday activities?
- What are the factors that facilitate or hinder the participation of disabled people in important life areas (eg learning opportunities, paid work, civic society)?
- Who are the main carers of disabled people and what types of support do they provide?

The following sections discuss in more detail the information requirements associated with each of these questions.

### **What is the prevalence of disability in New Zealand, and how does it vary across key population sub-groups defined on the basis of age-group, sex and ethnic group?**

Information on disability prevalence is needed to monitor changes in the level of disability in the community and its variation between groups, such as different age groups and ethnic groups. Accurate estimates of disability prevalence are a key input into the construction of health expectancy measures.

For the purposes of the disability survey, it is proposed that a person be defined as having a disability if they have an impairment that has a long-term limiting affect on their ability to carry out everyday activities. This includes:

- loss of sight (not corrected by glasses or contact lenses)
- loss of hearing
- incomplete use of legs or feet
- incomplete use of hands or fingers
- difficulty gripping or holding things
- difficulty learning or understanding

- speech difficulties
- mental illness
- shortness of breath or breathing difficulties
- nervous or emotional condition
- long-term effects of head injury, stroke or brain damage
- chronic or recurrent pain.

The experience of disability and need for support varies significantly between people with different types of impairment. As a result, it is important to be able to identify the types of impairment that people have, including sensory, physical, psychiatric/psychological, intellectual, and other impairments. Because some people have multiple impairments, being able to identify their main impairment (self-reported) is also important. The underlying cause of the impairment (eg accident, illness etc) and its duration can also influence the type of support that people need and have access to, and therefore should be measured in the survey.

Key population sub-groups for which prevalence information is required are:

- age-group (10-year) and sex
- ethnic group (Māori, Pacific peoples, Asian, and 'Other')
- labour force status (employed, unemployed, not in the work-force)
- impairment type .

**To what extent do the social and economic outcomes of disabled people differ from those of non-disabled people, and how do outcomes vary between different groups within the disabled population?**

The reporting requirements of The NZ Disability Strategy and the UN Convention on the Rights of Persons with Disabilities call for robust information on the outcomes of disabled people. Information on outcomes is also needed for monitoring the wellbeing of disabled people in *The Social Report 2008*. Comparable data is needed for disabled and non-disabled people across the full range of outcome domains to determine the extent to which disabled people are disadvantaged relative to their non-disabled counterparts.

It is proposed that the 2011 Disability Survey produce measures for the following outcomes:

**Knowledge and skills**

- Highest level of educational attainment
- Satisfaction with knowledge and skills

**Paid work**

- Labour force status
- Hours worked
- Occupation
- Satisfaction with type and amount of work

### **Economic standard of living**

- Income
- Ability to manage with existing income (ie is income sufficient to support the independence of disabled people?)

### **Housing**

- Housing tenure
- Housing problems

### **Health**

- Self-perceived health status

### **Leisure and recreation**

- Amount of choice over leisure time activities
- Satisfaction with leisure time

### **Safety and security**

- Experience of crime victimisation
- Fear of crime

### **Social connectedness**

- Experience of loneliness/isolation
- Availability of help in times of crisis

### **Culture and identity**

- Ability to express culture
- Importance of disability to identity

### **Human rights**

- Experience of discrimination

### **Overall wellbeing**

- Overall satisfaction with life
- Level of choice to live life the way I like

Output on each outcome is needed for the following key population sub-groups:

- sex and age-group (15–24, 25–44, 45–64, 65 and over)
- type of impairment (sensory, physical, psychiatric/psychological, intellectual, and other)
- support level (low, medium, high)
- cause of impairment (existed at birth, disease/illness, injury, and other)
- duration of impairment.

**To what extent are the needs of disabled people currently met? What level and type of support do they need to perform everyday activities?**

The experience of disability can be influenced by environmental factors that can have the effect of hindering or improving an individual's bodily function and ability to perform activities. Environmental factors include, for example, personal assistance and equipment. Disadvantage associated with disability arises from environments that do not cater to the needs of people with disabilities, preventing them from undertaking activities and fulfilling roles appropriate to their age and sex, and social and cultural identity.

Information about the level of support that people with disabilities need to perform daily living activities is required for the construction of health expectancy measures. Disabled people who have high support needs require assistance with daily living activities every day. Those who have medium support needs use or have an unmet need for equipment or aids, or receive help, but not every day. Those who have low support needs do not require assistance with daily living activities.

It is proposed that the survey measure the frequency and adequacy of support received by people with disabilities in the performance of a range of daily living activities.

Examples of daily living activities include:

- personal care activities, eg showering, going to the toilet
- shopping
- meal preparation
- light housework
- heavy housework
- gardening
- financial management
- paperwork
- decision making/problem solving
- communicating.

For individuals identified as having an unmet need for support, information is required about the main types of support needed, such as specialised equipment, specialised features in the home, personal assistance, and medication etc.

**What are the factors that facilitate or hinder the participation of disabled people in important life areas (learning opportunities, paid work, civic society)?**

The extent that people with disabilities are able to participate in important areas of life such as learning opportunities, paid work and civic society can have a significant impact on social and economic outcomes and their overall wellbeing or quality of life.

Environmental factors, such as restricted access to or use of assistive equipment, or discriminatory attitudes and behaviours may be associated, for example, with delayed entry to the labour force or with reduced involvement in community activities.

It is proposed that the survey produce information on the ability (or level of difficulty) of people with disabilities to take part in learning opportunities, paid work and civic society,

and on the major factors that facilitate or impede their participation, such as lack of access to transport, inaccessible buildings, negative attitudes of others, or the need for modified duties or workspace.

In view of the importance of accessible transportation to the lives of people with disabilities, it is also proposed that the survey measure the mobility limitations of disabled people and environmental barriers to using public and private transport.

**Who are the main carers of disabled people and what types of support to they provide?**

Recent years have seen growing interest in informal carers and the extent to which their caring responsibilities adversely affect their wellbeing. This interest is reflected in the release of the New Zealand Carers' Strategy and Five-year Action Plan 2008. Some information on carers will be available from the next Time Use Survey (TUS). The TUS will provide data on people who spent time caring for a member of their own or another household aged 15 years and over with an illness or a disability, including their characteristics, the nature of the caring activity undertaken and the amount of time spent on the activity.

It is proposed that a limited range of information on carers be collected in the 2011 Disability Survey, if the interview time permits. Because the disabled person may not always be able to provide accurate information on the extent to which caring responsibilities affect the life of the carer, it is proposed that the survey collect information on:

- the relationship of the primary carer to the disabled person
- the characteristics of the carer, including their age, sex and labour force status
- the type and frequency of care provided to the disabled person
- whether the carer is paid or not, and if so, by whom.

## References

Ministry of Social Development (2008a). *The New Zealand Carers' Strategy and Five-year Action Plan 2008*. Wellington: Author.

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