

Enduring Questions in the

Disability Domain

An initial view from Statistics New Zealand based on the New Zealand Disability Survey

Statistics New Zealand

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1. Purpose

This document summarises knowledge currently held by Statistics New Zealand about information and evidence needs for disability data. It is based on an understanding of those needs gained through running the New Zealand Disability Survey (NZDS) and answering customer queries on that survey. The paper is designed to inform discussion and contribute to the process of establishing a comprehensive set of enduring questions in the disability domain.

1. Background

## Research Questions for the 2013 NZDS

The final research questions for the 2013 NZDS reflected discussions held in 2009 and 2010 between Statistics NZ and survey stakeholders during preparation for a disability survey in 2011. The research questions were retained unchanged for the survey in 2013 (delayed by the Christchurch earthquakes).

The five research questions in order of priority are:

1. 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?
2. 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?
3. 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?
4. What are the factors that facilitate or hinder the participation of disabled people in important life areas (e.g. learning opportunities, paid work, civic society)?
5. Who are the main carers of disabled people and what types of support do they provide?

## Structure of the Survey

In order to address the research questions above the questionnaire for the NZDS 2013 was structured as a series of modules. These modules show the broad topic areas that allowed us to capture the information required.

1. Disability screening: identifying who is disabled and the type and cause of impairment
2. Demographics: age, sex, ethnicity
3. Household help / general help: assistance required with what aspects of daily life and who provides that assistance, is there unmet need for assistance
4. Equipment: what equipment or assistive devices are used; unmet need for equipment and assistive devices
5. Health services: used and unmet need
6. Employment / labour market: employment status and issues faced in work participation
7. Education: levels achieved and issues faced in participation
8. Transport: access to public and private transport; difficulties in accessing and unmet need
9. Housing: status of housing; adjustments to housing and unmet need
10. Social Contact: levels of contact with family and friends; adequacy of contact
11. Leisure: participation in activities; reasons for not participating
12. Safety: feelings of safety at home and in neighbourhood; discrimination; crime victimisation
13. Carers (child only): some characteristics of the primary care-giver

The topics forming the module structure of the survey provide a guide to important areas of disability data need. Many have been in the survey since it was first run in 1996 and continue to be of interest to users thereby confirming their enduring nature.

New topics in 2013, such as social contact, leisure, and safety are currently of considerable policy interest and feature in long term monitoring commitments in which we are now engaged (e.g. Articles 11 and 30 of the UNCRPD).

## Population sub-groups

The survey is designed primarily to produce national estimates for all impairment types however the design does allow for robust estimates to be produced for some population sub-groups.

Data from the survey can be broken down by sex and by four broad age-groups. Estimates for Māori are reasonably robust while for Pacific and Asian ethnic groups only high level estimates are of good quality due to population size.

Estimates for larger regions are produced while smaller regions are combined. These geographic breakdowns can be based on regional council areas or district health board areas.

Estimates are produced, and have come to be expected, for a number of impairment types. Note however that impairment types are not mentioned in the research questions. The impairment types identifiable from the 2013 survey data are in the table below.

|  |  |
| --- | --- |
| Higher level | Lower level |
| Sensory | Vision |
| Sensory | Hearing |
| Physical | Agility |
| Physical | Mobility |
| Intellectual | Intellectual |
| Psychiatric/psychological | Psychiatric/psychological |
| Other | Learning |
| Other | Speaking |
| Other | Ageing (adults only) |
| Other | Development delay (children only) |

It is not necessarily the case that these are the impairment types needed by users. Sensory as a combined group is of little value to most disability data users while for other the difference between agility and mobility is not clear.

## Identified data needs

As a result of queries from people looking to find information on disabled people, Statistics NZ has identified some data needs that cannot be met by the 2013 NZDS. Examples are provided below. Data on small population domains is by far the most common unmet need for disability information.

Information has been sought on:

1. Geographical areas, such as small DHB’s, territorial authorities, suburban areas.
2. Age groups, such as 10 year or five year groups especially for children or people aged 65 and over.
3. Ethnic groups, such as Pacific people and Asian people.
4. Refugees.
5. Underlying medical conditions (e.g. aspergers, autism, macular degeneration).
6. The amount of unmet need for support services (not just the number indicating unmet need but also the extent of their need).
7. Disability and poverty
8. Use of wheelchairs.

At a higher level, data users have expressed concern about the consistency of disability data over time, the availability of a robust measure of the level of disability and the quality of identifiers of intellectual disability and mental health.

1. Consequences for Enduring Questions

A set core topics for enduring questions about disabled people can be proposed from the information above. For each topic key questions give detail of content. A total of 29 questions are included in 13 topics. These topics and questions assume that issues in the consistent identification of disabled people and of the level of their disability are addressed separately.

1. **Demographics of disabled people**
   1. What are the demographic characteristics of disabled people (age, sex, ethnic group)?
   2. Where do disabled people live?
2. **Impairment** 
   1. What impairments do disabled people live with?
   2. What are the causes of these impairments?
   3. How long have they lived with these impairments?
3. **Support** 
   1. What is the type and amount of support disabled people need and use?
   2. Who provides this support?
   3. What prevents disabled people from getting the support they need?
4. **Equipment** 
   1. What assistive devices or equipment do disabled people need and use?
   2. What prevents disabled people from getting the assistive devices and equipment they need?
5. **Health** 
   1. How does health status differ between disabled people and others?
   2. How does health service use and need differ between disabled people and others?
   3. What prevents people from getting the health services they need?
6. **Housing** 
   1. How does housing quality differ between disabled people and others?
   2. What ‘modifications’ do disabled people use or need in their home?
   3. What prevents disabled people from getting the modifications they need in their home?
7. **Transport** 
   1. Are disabled people able to travel in their local area when they need or want to do so?
   2. Are disabled people able to travel longer distances when they need or want to do so?
   3. What assistance, support or environment change do disabled people need in order to achieve the level of mobility they need or want both locally and further afield?
8. **Paid work**
   1. Do levels of labour force participation, employment and unemployment differ between disabled people and others?
   2. What assistance, support or environment changes do disabled people need in order to participate in paid work at the same level as others?
9. **Education and skills**
   1. Do levels of educational achievement and participation in education and training differ between disabled people and others?
   2. What assistance, support or environment changes do disabled people need in order to participate and achieve in education and training at the same level as others?
10. **Economic standard of living** 
    1. Do levels of income and material standard of living differ between disabled people and others?
11. **Community, social and civic life**
    1. Do levels of social contact and connectedness, leisure participation and civic engagement differ between disabled people others?
    2. What assistance, support or environment change do disabled people need in order to achieve levels comparable with others?
12. **Safety**
    1. Do levels of concern about personal safety or experience of discrimination or crime victimisation differ between disabled people and others?
    2. What assistance, support or environment change do disabled people need in order to eliminate these differences?
13. **Life satisfaction**
    1. Do levels of overall life satisfaction differ between disabled people and others?
14. Conclusion

As noted above this set of topics and questions has been drawn up with reference to the most recent NZ Disability Survey and knowledge held by Statistics New Zealand about data needs. We anticipate that it will be just one of many contributions to the process of developing a comprehensive set of enduring questions for the disability domain.