

**CASE STUDY 1:****THE DESIGN OF THE 1996 NEW ZEALAND HOUSEHOLD SURVEY OF DISABILITY**

(Originally provided by Denise Brown, Statistics New Zealand, for an earlier version of this manual.

*Revised to remove first person (from SNZ) perspective. )*

*Reconsider the structure of this appendix and give an outline and clearer sub-headings.*

**1. INTRODUCTION**

This case study examines the development and design of the 1996 NZ Household Disability Survey and the 1997 Disability Survey of Residential Facilities. It illustrates many of the issues discussed in the main part of this manual. Firstly, it covers the history of the two surveys and why Statistics New Zealand started collecting information on people with disabilities. Then the strategy for the development of the collection is outlined, with information about methods for deciding on the definition of disability to be used as well as how the definition was turned into survey questions and how the resulting statistics met users needs.

**History**

It became very clear during the public consultation on the content of the 1996 New Zealand Population Census that there was a very strong need for better statistical information about people with disabilities in New Zealand. It came through very strongly in the public forums that were held in each of the five main centres and was reinforced in the written census submissions. The single largest number of submissions was on the need for a question on disability to be included in the census.

Clearly this was a message that Statistics New Zealand (SNZ) couldn't ignore, but it raised an interesting dilemma. While SNZ accepted the arguments put forward on the need for statistics on disability, they knew from the experience of other countries and from their own testing program in previous censuses, that it is exceedingly difficult, if not impossible, to collect accurate information on disability through the census. Disability is a complex concept and one that cannot be easily communicated through a census-type format in which only a minimum amount of questioning is possible and which is reliant on self-completion. Many other countries that had considered including questions on disability in their Population Census had dropped them.

Where disability questions for censuses have been evaluated, the general experience is that they provide at best a very crude measure of disability. There are both false positive and false negative answers to questions. The net effect is to understate the level of disability, particularly amongst children and older people, and amongst people with mild disabilities. Statistics Canada's experience in 1991 that about 20 percent of people who answered on their census forms that they had a disability in

fact did not, and that 5 percent of those who said they did not have a disability, in fact a had one. [The false positive and negative rates reported in testing in Australia in the development for the 2000 Census round were even worse.](#)

Knowing this, SNZ were very reluctant to ask any questions about disability in the census. They knew that the questions would not only produce information that was inaccurate but that the information would have a systematic bias. They feared that the effective use of the data for public policy would be limited by debate about its quality, with inevitable criticism for knowingly collecting and publishing inaccurate statistics. They therefore looked to other ways of meeting the demand for statistics on disability. The two most promising models that emerged from their research were either to attach a special disability module to New Zealand's next Household Health Survey, or to conduct a post-census survey on disability.

The disability community quickly rejected the former approach on the grounds that it would result in disability being treated as a health issue only. Therefore, running a post-census survey on disability was determined the preferred option.

### **What is a post-census survey?**

The post-census survey methodology was developed by Statistics Canada. It involves a number of steps:

- Disability questions are asked in the census to identify people to participate in a follow-up survey. (One of the biggest difficulties in carrying out a statistical survey of people with disabilities is that there is no available register or frame of this population. Two questions on disability were included in the census to overcome this problem).
- A sample of people who respond positively to the census questions is selected, as well as a sample of those who respond 'no' to the questions.
- Each selected respondent is asked a more detailed set of screening questions to determine whether s/he has a disability.
- Each respondent who answers positively to one or more of the survey screening questions is asked additional questions on the impact of the disability on his/her daily life.
- Data for each surveyed respondent is merged with his/her census data.

One of the major advantages of the post-census survey methodology is the improved efficiency of sample selection and reduction in survey costs. By sub-selecting census respondents for the Household Disability Survey, information collected from them in the disability survey can be linked with their census data on marital status, living arrangements, income, housing etc. This process of adding census data to the disability survey data for each respondent minimises respondent burden and results in considerable cost reduction through not having to collect basic background and contextual information in the disability survey. Another advantage is that it enhances the analytical capacity of the survey database, by providing a wide range of

demographic and socio-economic variables for both the populations with and without disabilities.

## 2. DEVELOPMENT STRATEGY

Having decided to carry out a post census survey of disability, SNZ set out to find the answers to four critical questions:

- **Who** should be included in the survey? That is, who are people talking about when they say that they need information on persons with disabilities?
- **What** information is needed from these individuals?
- **Where** do these people live
  - in private households?
  - in homes for the elderly?
  - in hospitals? And finally,
- **When** should this information be collected and how often?

In answer to who, the first response they received was people with all types of disabilities - physical, sensory, intellectual, as a result of a psychiatric or mental illness or health condition, that is, all types. When they asked representatives from organisations of and for persons with disabilities, they reported that they wanted to know about people with all types of disabilities, but also wanted to know about the cause of the disability and the underlying health problem. Many of these organisations represented people a particular health problem or condition, such as the New Zealand Arthritis Association, the NZ Head Injury Association, the Alzheimer's Association. Most of these organisations wanted to know about people with their particular condition.

The users also said that they were interested in people of all ages because the issues facing children with disabilities were different from adults with disabilities and were different to those of old people with disabilities. For example, children might have learning issues, adults issues in seeking employment, and older people, issues about trying to stay in their homes but who now needed some support for daily activities.

The other main group that users said they wanted information about was Maori people indigenous population of New Zealand.

After the consultation they knew that the population should include all ages and all types of disabilities, and the underlying health problems of people with disabilities was also an important piece of information to collect.

The next thing they needed to find out from the users was what they wanted to know about people with disabilities. There was general agreement that they wanted to know about their demographic and social characteristics. Organisations of and for people with disabilities also wanted to know about the barriers that people with disabilities face in their everyday lives and their unmet need for special aids and support services.

Having found out this much from the users about their information needs, they were in a position to develop some broad objectives for the survey.

## **Survey Objectives**

The key objectives of the 1996 Household Disability Survey were:

- To measure the prevalence of disability amongst:
  - a. the total non-institutionalised population of children, adults and older persons at the national and regional levels (i.e. the four Regional Health Authorities which are the areas used by the New Zealand Government for the planning and delivery of services for people with disabilities) and
  - b. the total non-institutionalised population of Maori persons at the national level
- To provide information on all types of disability and the underlying health problem or condition
- To provide data on the socio-demographic characteristics of people with disabilities, including their age, sex, ethnicity, marital status, educational qualifications, labour force status, income and family and household circumstances.

The secondary objectives were:

- To provide information on the types of disability-related expenses which are incurred by individuals with disabilities and their families;
- To identify the current use of and unmet needs for technical aids and caring/support services (formal and informal) and the reason for the need remaining unmet amongst the non- institutionalised population with disabilities.

## **Definition of Disability**

The next step was to decide on how they were going to operationalise the definition of disability so that they could ensure that they would meet users needs. Fortunately, the World Health Organisation had already spent some time looking at a way to measure the consequence that disease or traumatic injuries had on an individual. From this work the WHO developed the first International Classification of the Consequence of Disease - the International Classification of Impairments, Disabilities and Handicaps (ICIDH). SNZ found that the ICIDH contained a definition of disability which was acceptable to the New Zealanders with disabilities with whom they were consulting.

While the users liked defining disability through a functional approach, they didn't accept the entire classification. They didn't like the impairment classification because it was too much like the medical model and they didn't like the handicap

classification because it classified the individual's deficiencies rather than the problems with the way in which society had been organised. SNZ convinced the users that they would only use the disability definition and those questions that had been developed to operationalise that definition.

So they used a functional concept, where disability was defined as:

*'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.'*

The definition was operationalised in the survey through a series of questions which asked respondents whether they experience any difficulty performing certain activities because of a long-term condition or health problem. The work that had been done in the international community had focused mainly on the development of questions to identify adults with physical and sensory disabilities. SNZ could not find suitable questions that had been developed that would allow people with an intellectual disability or a learning disability or a disability resulting from a psychiatric condition or a cognitive disability to identify themselves. They worked with representatives from organisations of and for people with disabilities, as well as with health care professionals, and developed a set of questions for use in the survey. The final set of questions that SNZ used in the collection are listed in Box x.

#### Box 1

#### **Screening questions to identify people with a disability in the 1996 New Zealand Household Survey of Disability**

The following screening questions were used in the 1996 New Zealand Household Survey of Disability.

1. Can you hear what is said in a conversation with one other person: easily, with difficulty or not at all?
2. Can you hear what is said in a group conversation with three other people: easily, with difficulty or not at all?
3. Because of a long-term term condition or health problem, do you have any difficulty seeing or being understood?
4. Can you see ordinary newspaper print, with glasses or contact lenses if you usually wear them: easily, with difficulty or not at all?
5. Can you clearly see the face of someone across a room (that is from 4 metres or 12 feet away) with glasses or contact lenses if you usually wear them: easily, with difficulty or not at all?
6. Can you walk the distance around a rugby field, without resting, that is about 350 metres or 400 yards: easily, with difficulty or not at all?
7. Can you carry something as heavy as a 5 kilo bay of potatoes, while walking, for 10 metres or 30 feet. That is about the length of 3 cars parked alongside the footpath: easily, with difficulty or not at all?

8. Can you move from one room to another: easily, with difficulty or not at all?
9. When standing, can you bend down and pick something up off the floor, for example a shoe: easily, with difficulty or not at all?
10. Can you dress and undress yourself: easily, with difficulty or not at all?
11. Can you use your fingers to grasp or handle things like scissors or pliers: easily, with difficulty or not at all?
12. Can you reach in any direction, for example, above your head: easily, with difficulty or not at all?
13. Can you cut your own food, for example, meat or fruit: easily, with difficulty or not at all?
14. Can you get in and out of bed by yourself: easily, with difficulty or not at all? Is that because of a long-term condition or health problem?
15. Do you have a condition or health problem, which has lasted or is expected to last for 6 months or more, that makes it hard in general for you to learn?
16. Do you have a condition or health problem, which has lasted or is expected to last for 6 months or more, that causes you on-going difficulty with your ability to remember?
17. Do you need help from other people or organisations because of an intellectual disability or an intellectual handicap?
18. Did you go to a special school or receive special education because of an intellectual disability or an intellectual handicap?
19. Does a long-term emotional, psychological or psychiatric condition, cause you difficulty with, or stop you from doing everyday activities that people your age can usually do?
20. Does a long-term emotional, psychological or psychiatric condition cause you difficulty with or stop you from communicating, mixing with others or socialising?
21. Do you have any OTHER condition or health problem, that we have not talked about? Does this condition or health problem make it impossible for you to do everyday things that people your age can usually do? Does this condition or health problem make it difficult for you to do everyday things people your age can usually do? Have you had this difficulty doing everyday things for 6 months or more?

People who said that they were unable to or experienced difficulty performing any of the activities asked about, or who responded 'yes' to any of the other questions which

asked about intellectual, learning and psychiatric conditions (i.e. questions 15-21) were considered to have a disability.

However, they were not considered as having a disability if they used an assistive device which completely eliminated their limitation, e.g. a person who wore glasses or contact lenses and stated that they had no limitation when wearing them was not considered as having a disability. The concept of time was also included as an additional parameter. The limitation had to be for a minimum six-month duration, that is, had lasted or was expected to last for six months or more.

## **Children**

SNZ found it difficult to develop questions to identify children with disabilities. There did not appear to be any questions that had been developed except those that had been used in the Canadian Health and Activity Limitation Survey. They took those questions as a starting point and worked with professionals as well as parents of children with disabilities to adapt the questions so that they were appropriate to New Zealand children. They ended up with a 'grab bag' of questions that identified children with disabilities as well as those who would be likely have a disability as a result of the presence of a chronic health condition. They considered it not to be perfect, but the best that could be done in the time frame.

The questions SNZ developed covered the following:

- Seeing, hearing or speaking limitations
- Emotional, behavioural, psychological, nervous or mental health conditions
- Chronic conditions (e.g. diabetes, cancer, cerebral palsy, kidney condition) .
- Attendance at a special school or special classes, and
- The use of technical aids
- Intellectual disability
- Learning disability and
- Developmental delay

A positive response in any of these categories indicated that a disability existed.

It is important to note that respondents' answers to the disability questions represented their own perception of their situation and are therefore, subjective. Also, it is possible for respondents to report more than one type of disability.

## **Defining Age Groups**

SNZ needed to decide how to define the three age groups that users wanted covered in the survey. International work had defined adults as 15 years and over so they used that definition and defined children as aged 0 through to 14 and old people were defined as aged 65 years and over.

In terms of where these people might live, they were told that the priority was to obtain information about people with disabilities living in private households. This was the group about whom users had no information. A certain amount of

information was available from administrative sources about people with disabilities who lived in institutions.

Because of the limited funds available to conduct the survey, people living in institutions were excluded from the survey. Including them would have meant having to develop a separate set of procedures for gaining access to this population and a separate questionnaire, since the issues and barriers confronting people in institutions are different from those facing living in private households. This would have added to the cost of the survey and would have meant having to make savings in other areas, through for example reducing the sample size or cutting back on the content of the survey. The users were reluctant to make these trade-offs in order to get information about the institutionalised population of people with disabilities.

### **Survey Population**

The survey was confined to the total, non-institutionalised, civilian population of New Zealand of all ages, residing in private dwellings at 1996 census date. This meant that the following people were excluded:

- Residents of hospitals and psychiatric institutions
- Residents of rest homes
- People living in welfare, educational or religious institutions
- Residents in seasonal group quarters
- Members of the New Zealand permanent armed forces
- Crew or passengers on vessels
- Inmates of penal institutions and police lock-ups
- Residents of non-private dwellings such as hotels, motels, boarding houses, boarding schools: motor camps, work camps

### **Content of Survey**

Finding out what questions that would allow all persons with disabilities to identify themselves was only part of the content development. In addition, SNZ needed to ask users to identify those issues that should be addressed in the survey. They did this by getting them to complete a form which asked:

- What topics they wanted included in the survey
- A description of the specific information they required on each topic
- An explanation of why the requested information was needed and how it would be used (e.g. specific policies or programs the data is needed for, the uses of the data in policy-planning, monitoring and research applications, and any legislative or other authority which requires use of the data)
- What types of geographical area they required the information to be available for (e.g. rural and urban areas, Regional Health Authority Areas)
- Any specific population sub-groups they wanted the information to be available for (e.g. Maori, employed people, social welfare beneficiaries etc.)
- Other topics they wanted the information to be linked to (e.g. educational qualifications, hours worked, income etc.)
- A description of any concepts or terms relevant to the proposal.

From the information supplied on the forms, they were able to identify the issues to be addressed in the survey. From those issues, the survey team developed the questions that would address those issues. For the most part they tried to use questions that had already been used in other household surveys in New Zealand. In that way, they minimized the testing needed to be conducted. Of course there were some issues that were specific to people with disabilities and so they had to develop and test them.

The issues that were covered in the survey can be grouped into three main areas:

#### Uses and unmet needs

- Need for and use of technical aids
- Reasons why the aids that were needed were not available e.g. too costly, applied for equipment but wasn't eligible, didn't know the equipment existed etc.
- Use of and need for support in daily activities and who provides the support and the frequency
- Health care utilisation - types of persons seen - how often - and reasons for not utilising health services when needed

#### Barriers experienced

- The identification of barriers experienced in the areas of education, employment, transportation and accommodation.

#### Expenses related to disability

- Specific income questions relating to their disability and out-of-pocket expenses related to their disability.

A different questionnaire was developed for children since their issues and method of identification of disability were different.

Information on the respondents' socio-demographic characteristics was not collected in the survey but was obtained by linking the survey record of each respondent with their census record.

### **Questionnaires**

There were four questionnaires used for the survey – two for adults and two for children. The following is a summary of the format and content of the questionnaires

#### Adult's Screening Questionnaire

The questions in this questionnaire were designed to determine if respondents were limited in their day-to-day activities because of a condition or health problem which is expected to last for six months or longer. Other questions are asked about the cause of the disability, the duration of the disability, the main condition or health

problem that causes the disability, and the cause of the condition (e.g. disease or illness, accident, work environment, existed at birth, natural ageing process, psychological or physical abuse).

#### Adult's content questionnaire

The broad content of the adult questionnaire is provided in the table below.

<b>Topic</b>	<b>Description</b>
Services and Assistance	The purpose of this section is to obtain information on how the respondents' condition or health problems affect their ability to carry out everyday household activities such as preparing meals, shopping, doing light and heavy chores, managing personal finances etc. The responses to these questions provide information on how much support is needed by people with disabilities to live independently. Questions are also asked about the respondents' use of health services and professionals, as well as their use of prescription and non-prescription drugs.
Employment	The questions in this section are asked to provide insights into the barriers faced by people with disabilities in the labour market. People who are working, who are looking for work or who have stopped looking for work are all included in the survey.
Education	The intent of this section is to determine the impact of the respondents' disabilities on their educational experience
Transport	The questions in this section address the problems faced by people with disabilities in using the local transportation system and the difficulties experienced traveling longer distances by plane, bus, train or car.
Accommodation	This section asks questions about special features the respondent uses or needs for entering, leaving and moving about inside their home.
Special Equipment	The purpose of this section is to identify technical aids needed or used by respondents to help them get round and do things on their own.
Economic Characteristics	The purpose of this section is to obtain information on 'out-of-pocket expenses' incurred and the amount of disability-related allowances received.

#### Children's Screening Questionnaire

This section identifies diseases or illnesses, chronic conditions, the use of special aids, and limitations experienced by children with disabilities at home, school or play. Limitation questions are intended to determine if the child has difficulty doing an activity even when using special aids.

## Children's Content Questionnaire

<b>Topic</b>	<b>Description</b>
Services and assistance	The purpose of this section is to obtain information on any special services and medication required by children with disabilities to help them manage everyday activities.
Education	The purpose of this section is to help determine the impact of a child's disability on his/her education and the obstacles faced in obtaining education. The need for day care services is also investigated
Transport	The questions in this section address the problems faced by a child with a long-term condition or health problem in taking short local trips and in traveling longer distances by plane, bus, train or car.
Accommodation	This section asks questions about special features the child uses or needs for entering, leaving and moving about in the home.
Economic Characteristics	The purpose of this section is to obtain information on whether any government financial help was received because of the child's condition and whether a disability allowance was received.

### **Sample Design**

As noted earlier, one of the reasons that SNZ chose the post census methodology for the survey was because of the efficiency it provides in selecting the sample. The methodology involves two main steps. The first is the addition of one or two questions on disability to the census. Essentially, the aim of this step is to divide the respondents into two groups: those who answer 'yes' to at least one of the questions and those who answer 'no' to both questions. The objective is to identify, prior to the actual survey, a significant portion of the population with disabilities so that the survey resources can be concentrated on this target group. Prior surveys have shown that the group is not fully identified by the two questions. As a result, a sample of, no' respondents must also be drawn.

The second step is to select a sample of respondents to the census questions in each domain of estimation in order to meet estimate quality requirements. Selected respondents are then administered a detailed set of screening questions to verify that they do in fact have a disability. Those who are found to have a disability are then administered a further set of questions to obtain information about the impact of the disability on their day-to-day lives.

To develop the sample design for the survey they needed an estimate of the proportion of people who would answer 'yes' to the census disability questions as well as an estimate of the false positives and false negatives that would be produced by the disability survey screening questions. This information was critical to ensure that enough 'yes' and 'no' responses were selected from the census to achieve the required sample of children, adults and old people with disabilities for the survey and thereby avoid over-sampling or under-sampling and its associated costs.

A conversion test was undertaken to:

- Establish the proportion of people (by specified age group) who would respond “yes” to either of the census disability questions, by adding the two census disability questions to the October Household Labour Force Sample; and
- Establish the proportion of 'false positives' and 'false negatives' from the census questions by using the screening questions developed for the disability survey and administering these questions to the same individuals who responded to the October census disability questions.

Approximately 1,300 households were visited and responses obtained from 2,750 individuals. The information obtained enabled SNZ to determine how many 'yes' and 'no' census responses were needed for each of the groups that users had identified that they required information: children, adults, old people and Maori.

If the conversion test had not been conducted, the survey design could have been flawed and resulted in data which would not meet the expectations of the user community. For example, it might not have drawn enough children to obtain reliable estimates of disability for this group.

Selection of the sample for the survey took place in several stages. Firstly, 80 census districts were selected from the 206 census districts in New Zealand. Then 3,883 meshblocks (these are the finest statistical collection unit in New Zealand) were selected from within these districts and finally people were selected within the meshblocks. The selection took account of factors such as the need to balance the sample across the country, to achieve Maori representation and a selection of ages.

Those who answered in the census that they had a disability were selected separately from those who answered they did not have a disability. Available evidence indicated that people who answer 'no' to census questions on disability when in fact they do have a disability tend to be people with less serious disabilities. Nevertheless, these people represent a significant segment of the population with disabilities and therefore need to be sampled to avoid significant biases in the estimates. By selecting a sample of those who answered 'yes' as well as a sample of those who answered 'no', SNZ could ensure that the sample would produce an accurate picture of people with disabilities. Children, adults and old people were selected separately.

Selection of the sample of respondents was an integral part of the census operations. In each of the census district offices a team was given the task of selecting the sample according to a set of instructions developed by our survey methodologists. Altogether 20,848 people were selected for the survey. This resulted in an achieved sample size of 4,100. The response rate was 86 percent. The majority of non-responses were attributable to non-contact because of people shifting address between the time of the 1996 census and the survey.

## **Collection Methodology**

The survey went into the field on 20 May 1996, just over two months after the Population Census. Over the following three months, the selected sample of over 20,000 respondents were interviewed. The survey was conducted using a combination of telephone and face-to-face interviews. The decision to use telephones was based mainly on cost considerations. Carrying out all interviews face-to-face would have increased the survey costs substantially, and since we had a set budget for the survey, would have meant having to cut costs in other areas such as in reducing the sample size or the survey content. Users were reluctant to compromise on sample size and content.

The decision to conduct interviews by telephone meant asking people to supply a contact number on their census forms. Where the respondent supplied a telephone number on their census form or where a telephone number could be found for them, the interview was carried out by telephone. Face-to-face interviews were used where the respondent could not be contacted by phone, for example a profoundly deaf person or where the respondent requested to be interviewed face-to-face. Overall, about 40 percent of interviews were face-to-face and 60 percent telephone.

If the person selected was a child aged less than 15 years, the adult responsible for the child (parent or guardian) was asked to give proxy information. Similarly, where an adult was not capable of responding for him or herself, a caregiver, friend or family member answered on their behalf or assisted them.

The interviewers were provided with full training, not only on the survey, but also on interviewing people with disabilities. This included a sensitisation session conducted by a person from the disability community to ensure that the interviewers were trained on the appropriate terminology to use when interviewing people with disabilities. The training also included exercises on how to present the survey to selected individuals and mock interviews.

## **Processing**

Once the fieldwork was complete a combination of clerical and computer-based systems was used to process the data. Clerical edits were initially applied by interviewers to ensure the completeness and consistency of the questionnaires. All questionnaires were again checked on receipt in the office to ensure interviewer workloads were fully accounted for and that all questionnaires for each respondent were completed.

Information on the questionnaires was converted to machine-readable format after the completion of the clerical checks and processed using Blaise. Blaise is a processing system which was developed in the Netherlands. An extensive range of edit checks was then applied to each record on the file to check that logical sequences had been followed in the questionnaires, that specific values lay within valid ranges and that relationships between items were within limits deemed acceptable for the purposes of the survey. The edits were designed to detect errors which may have occurred (e.g. during data transcription or original recording of the information by

the interviewer) and to identify cases which, although not necessarily errors, were sufficiently unusual to warrant examination. Listings of all records were produced and amendments made on the computer file as required.

There was no imputation of individual responses. Where a response to a question was omitted it was assigned to the 'not specified' category.

In a sample survey, such as the Household Disability Survey, each respondent in the sample represents a sub-set of people in the population being studied. Consequently, each data base record is assigned a weight corresponding to the number of people represented. In addition, the weight is further modified to offset non-response and discrepancies between the population studied and the target population. The results of the survey are then multiplied by a numerical weight to provide an estimate of what the response would be in the entire population. The survey records were weighted to represent the New Zealand population, excluding people not eligible for the survey, which were those living in non-private dwellings.

### **Linking Disability Survey Data with Census Data**

The final stage in the post census survey methodology involves linking the survey records of the respondents with their census records. This means that data collected in the Disability Survey on the nature and extent of disability and the impact of the disability on the everyday lives of the respondents is merged with census data on the respondents' demographic and socio-economic characteristics. This process of adding census data to the Disability survey database has two main advantages. It minimises respondent burden and results in considerable cost reduction through not having to collect basic background and contextual data, such as age, sex and ethnicity in the Disability Survey. And it enhances the analytical capacity of the survey database by providing a wide range of demographic and socio-economic variables for both the populations with and without disabilities.

Available census data includes person-level variables as well as household and family variables for each person. Census person-level variables provide a wide range of information such as marital status, education, place of birth, citizenship, ethnic group, language spoken etc.

Household variables include size and type of household, as well as data pertaining to the dwelling in which the household lives (e.g. dwelling owned/rented by household member, number of rooms, rent costs etc.).

The actual matching of the census and survey records was done by computer for each selected person in the survey. This was done for both the "yes" and "no" samples. After the records had been matched, another series of edit checks were performed on the new data set to remove any inconsistencies between the survey data and the census data.

Finally, output checks of the data were carried out and attempts made to validate the survey data against data from other sources. However, as this was SNZ's first disability survey, they did not have other data to validate the results against. As a result they relied mainly on the findings from surveys run by other statistical agencies, in particular Statistics Canada and the Australian Bureau of Statistics.

Because SNZ had used a methodology very similar to Statistics Canada, their survey results provided the best source to check results.

### **Who funded the survey?**

A consortium of users sponsored the survey. The sponsoring agencies included the Ministry of Health, four Regional Health Authorities, Department of Social Welfare, Department of Labour, Accident Rehabilitation and Compensation Insurance Corporation, Ministry of Housing, SSC, Ministry of Education, Transit NZ, Statistics New Zealand and a coalition of organisations of and for people with disabilities.

### Development Process

A consultative committee, comprising representative of the sponsoring agencies and the disability community, was set up to assist in the development of the survey. The role of the committee was to advise on the survey objectives, the content of the survey and the survey outputs. It provided valuable input into decisions covering a range of issues, such as, the population groups to be covered by the survey, the categories of disability to be included in the survey and how these were to be defined, and the major topic areas for which information was required.

There was considerable discussion amongst members of the committee about what population groups should be included in the survey. In the end it was decided to confine the survey to the non-institutionalised population because this is the group of people with disabilities about whom least is known. A considerable amount of information is already collected about people living in institutions, particularly those living in health-related institutions.

The committee also discussed whether the survey should be confined to adults or include children as well. The question of whether all age groups of children should be included, or just those aged 5 years and over was also raised. Research and overseas experience had highlighted problems in obtaining reliable information about disabilities amongst children, particularly younger children. Mild and moderate disabilities, for example, are difficult to identify. In addition, certain types of disability are unlikely to be noticed until children attend school while others may be dismissed as slow development. In the end, it was decided to include children, as the Ministry of Education was particularly interested in obtaining information on this group.

In addition to the input from the consultative committee, SNZ consulted with a wide range of groups in the disability community, including the Deaf Association, the Blind Foundation, Head Injuries Society, ALADS, Epilepsy, Parkinson's Disease, MS, SPELD, Adults with Special Learning Disabilities and Workbridge. The relationships that were built up with these groups through seeking their input into the survey were also valuable when it came to testing the questionnaire. Through them they gained access to groups of people with different types of disability to test the screening questions on.

Another initiative taken during the development of the survey was to issue a newsletter providing information on progress with the development of the survey. It

was sent to a wide range of disability groups and was well received. Articles about the survey were published in the magazines and newsletters of different disability groups. These initiatives seem to have had the desired effect in obtaining support from the disability community for the survey. A lot of positive feedback were received on efforts to consult with disability groups and inform them about the survey.