

**A METHODOLOGY FOR SURVEYING DISABLED PERSONS USING A
SUPPLEMENT TO THE CANADIAN LABOUR FORCE SURVEY**

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A. Introduction & Background

On May 23, 1980 the Canadian government created the Special Parliamentary Committee on the Disabled and the Handicapped. The committee was made up of seven members of parliament chaired by David Smith. The objective of the committee was "to evaluate the scope and effectiveness of existing government programs for the disabled and the handicapped, as well as the degree to which they interlock with voluntary programs and services, with the objective of suggesting measures to improve the quality of services provided to such persons".

In February 1981 (the International Year of the Disabled), the Special Parliamentary Committee on the Disabled and Handicapped published its report, entitled "Obstacles"[4]. This report made 130 recommendations to various areas of the federal government. Recommendation 113 of the "Obstacles" report reads in part:

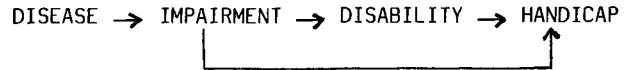
"That the Federal Government directs Statistics Canada to give a high priority to the development and implementation of a longterm strategy which will generate comprehensive data on disabled persons in Canada, using population-based surveys and program data."

The government, wishing to respond positively to the recommendations contained in the report, thus requested that Statistics Canada undertake a survey of disabled persons.

An ad-hoc interdepartmental committee, called the Data Development Group, was established with representation from the Department of National Health and Welfare, the Canada Employment and Immigration Commission, Central Mortgage and Housing Corporation and Statistics Canada. Working through this group, Statistics Canada has undertaken substantive direct consultation with organizations, identified as potential users of disability statistics, and solicited descriptions of their data requirements. Those approached included federal and provincial government departments, agencies and crown corporations, and a broad range of associations representing the interests and needs of the disabled community. In total, over 170 responses were received, describing requirements for data on the disabled.

B. Definitions

Definitions developed by the World Health Organization (W.H.O.), given in [8], were employed by the Special Parliamentary Committee. These definitions arise out of a model which focuses on the consequence of disease, and addresses the following illness-related phenomena.



As given in [7], the definitions of these terms are as follows.

Impairment: In the context of the health experience, it is any loss or abnormality of psychological, physiological or anatomical structure or function. It is characterized by losses or abnormalities that may be temporary or permanent, and that include the existence of an anomaly, defect, or a loss in a limb, organ, tissue, or other structure of the body, including the systems of mental function. Impairment represents the exteriorization of a pathological state, and in principle reflects disturbances at the level of the organ.

Disability: It is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or in the range considered normal for a human being.

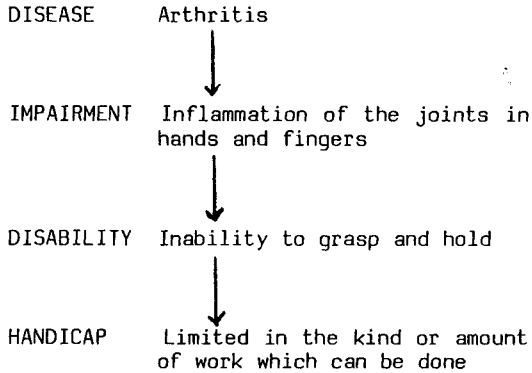
It is characterized by excesses or deficiencies of customarily expected activity, and may be temporary or permanent, reversible or irreversible, and progressive or regressive. Disabilities may arise as a direct consequence of impairment or as a response by the individual, particularly psychologically, to a physical, sensory, or other impairment. Disability represents the objectification of an impairment, and as such, it reflects disturbances at the level of the person.

Handicap: It is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Handicap is concerned with the value attached to an individual's situation or experience when it departs from the norm. It is characterized by a discordance between the individual's performance or status and the expectations of the individual himself or the particular group of which he is a member. Handicap thus represents the socialization of the impairment or disability, and as such reflects the consequences for

for the individual (cultural, social, economic and environmental) that stem from the presence of impairment and disability.

To explain these definitions more clearly, consider an example:



C. Target Population

The next step for the project team was to take these definitions and translate them into a definition of the target population subject to practical constraints of collecting data through a sample survey. As explained in the next section, the data will be collected through the use of the supplementary capacity of the Canadian Labour Force Survey (LFS). The use of the LFS vehicle has imposed one significant limitation. The target population of the disability survey is not to include the "mentally handicapped". For example, the target population excludes illnesses such as alcoholism, amnesia, neuroses and phobias but includes impairment of intelligence such as mental retardation and dyslexia. It was felt that asking for this information could potentially be very sensitive in nature and negative reactions could possibly compromise the primary objectives of the LFS.

Two important dimensions of disability which need consideration are severity and duration. Severity can be regarded in terms of the person; i.e., how severely is a person disabled, or in terms of disability; i.e., how severe is the specific disability. In defining a target population, a measurement of severity must be included, if only implicitly. The duration of disability is the dimension which must be explicitly addressed. To capture all disabilities, including those arising out of acute illnesses of relatively limited duration, would identify a large percentage of people and run contrary to the spirit of the "Obstacles" recommendation. Nevertheless, to limit the population to the permanently disabled is avoiding the issue and ignoring the needs of the long-term but not chronically disabled.

To summarize the above discussion with regard to decisions made, the target population includes all persons having one or more physical (nonbehavioural) disabilities, or knowledge acquisition or other educational disabilities (arising from impairments in intelligence, attention, psychomotor functions and language), whose duration has been or is expected to be at least six months. It also includes individuals

suffering from diseases of a chronic and degenerative nature and which have a high probability of producing impairments which are physically disabling. In addition the normal constraints of the LFS are in effect which precludes individuals in institutions.

D. Data Collection

The difficulty is in translating the definitions into a set of questions which identify persons of interest from a set of persons in the general population. This leads to setting an objective to collect information on those who have a high probability of being disabled by any user's definition, and at the same time, keeping the number of people surveyed within reasonable limits.

For reasons of expediency and cost the decision was made to use the supplementary capacity of the LFS to collect the required data. The LFS is a monthly household survey conducted by Statistics Canada across the country. Approximately 56,000 households are in the sample each month. Each selected household remains in the sample for six consecutive months. Each month, one-sixth of the sample are new households and one-sixth of the sample rotates out. The data is collected by both personal and telephone interviews. A "knowledgeable" respondent reports non-proxy information for himself/herself and proxy information for the rest of the household members. The primary purpose of the survey is to collect data on labour force characteristics.

The data collection for the disability survey will be conducted in two stages. First, all persons in all households in the LFS sample, except the one-sixth of the sample which is in its first month of the survey, will undergo a "screening" process. Persons of potential interest will be identified by means of a "screening" questionnaire. The mode of data collection will be same as for the LFS interview. However, the interviewers will be asked to obtain non-proxy interviews as often as possible, even if it means calling back at a later time. This "screened in" population will then be asked another set of questions in a follow-up survey. All of these interviews will take place about a week after the screening interview. They will be entirely personal interviews and non-proxy responses only will be accepted. This second set of questions is designed to collect the data identified as being desirable by the consultation process with the users as described above.

The schedule for the survey is as follows. Three proposed screening questionnaires were tested in November 1982 and January 1983. More details on these surveys will be given later. Based on the results of these surveys, one screening questionnaire has been developed. Two "full" surveys with a screen and a more detailed questionnaire as described above will be conducted in October 1983 and in May 1984. As well, the 1986 Canadian Census of Population has committed itself to the inclusion of a done with respect to the LFS supplementary disability survey will be valuable input to the development of the census question.

E. Approaches to Screening -- Other Surveys

The first step in constructing a set of screening questions was to investigate experiences encountered by other groups that had previously conducted disability surveys.

1. Activities of Daily Living / Physical Aids

The one approach that has been used in many surveys is the Activities of Daily Living (ADL) approach. The Activities of Daily Living are a set of activities which any person is required to perform during the course of their regular living pattern. There is no generally recognized "best" set of activities that should be used. However in 1978 the Organization for Economic and Co-operative Development (OECD) set up a working group with representatives from several countries including Canada. The objective of the group was to determine a set of ADL's applicable to most of the world's industrialized countries. That is, a set of activities that are performed regularly by most people in all these countries. The purpose of defining these activities was to use the responses to develop a disability status index. If a common set of activities was used, comparisons of disability status between countries could easily be done. The output from the OECD working group was the development of a list of sixteen activities [8]. The next stage, to weight the activities in order to construct an index, was never done. However the Statistics Canada project team felt that these activities could be used as a potentially good screening device. These OECD ADL's have been used in several countries including the United States[15], England, Austria, France[11], the Netherlands[13], Finland[10], Switzerland[12] and Japan. These sixteen activities are:

1. Running 100 metres,
2. Walking 400 metres without resting,
3. Walking up and down a flight of stairs,
4. Carrying an object of 5 kg. for 10 metres,
5. Moving from one room to another,
6. When standing, bending down and picking up an object from the floor, such as a shoe,
7. Dressing and undressing himself/herself,
8. Getting in and out of bed,
9. Cutting own toenails,
10. Cutting own food,
11. Biting and chewing food,
12. Reading ordinary newsprint (with glasses if normally worn),
13. Seeing clearly the face of someone from 4 metres (with glasses if normally worn),
14. Hearing what is said in a normal conversation with one other person,
15. Hearing what is said in a normal conversation with at least two other persons,
16. Speaking and being understood.

There are two ways in which these questions can be asked i.e., is the person able to perform the activity only when using a physical aid or is he able to perform it without the use of any physical aid? For example, in item 5, should a person in a wheelchair answer "Yes" or "NO" if he

can move quite easily from room to room when he is in his wheelchair but otherwise is unable. There are advantages to both approaches. If the government or an agency is considering supplying or subsidizing payments for physical aids, it would need to know to what extent each aid is being used. On the other hand, if a person feels that he is completely independent as long as he is in his wheelchair, then what additional services can be provided to him? Note that eyeglasses are a physical aid that is given special treatment (items 12, 13) because of the relatively high percentage of people in the general population requiring corrective lenses. In addition, a list of physical aids could be used as a screening device.

2. Major Activity Limitation

The United States Bureau of the Census (USBC) began development of a disability survey in 1978. Although funding was withheld to conduct the survey nationally, a pretest was conducted in Richmond Virginia in 1980. In addition to other questions, the ADL approach was used in the screening questionnaire. In this survey, one other approach used to screening was that of major activity limitation. If a person is limited in his/her major activity (i.e., work, school, home), that person is probably experiencing some type of disability. Other surveys using the major activity limitation approach were the Canada Health Survey (1978-79) sponsored by Statistics Canada and the annual Health Interview Survey sponsored by the National Centre for Health Statistics (NCHS). Neither of these two surveys were intended to be disability surveys however.

3. Chronic conditions

The target population as described above includes those persons with diseases of a chronic and degenerative nature, and which have a high probability of producing impairments which are physically disabling; such as multiple sclerosis. Note that persons with these conditions may presently be able to perform all their normal activities. This target population also includes persons with diseases that are periodically but not continuously disabling, such as epilepsy. Therefore a set of chronic conditions could be useful as a screening device for disability. The Canada Health Survey and Health Interview Survey include chronic condition lists. As well, in 1981, the Australian Bureau of Statistics used a list of conditions as its screening questionnaire.

4. Self-Perception

Most of the suggested screening approaches require a certain amount of self-perception. That is, something considered to be a disability by one person may not be considered a disability by another. For example, a computer programmer in an office building may be able to adapt much more easily to the loss of his legs and consider himself not to be disabled than a postal letter carrier, who would be required to change jobs if he lost the use of his legs. Therefore another method of screening for disability may be a single self-perception question such as "Do you

have any physical disabilities or handicaps?"

F. Test of Screening Mechanisms

The three Statistics Canada screening tests used combinations of these approaches. Also persons aged fifteen or over were administered a different questionnaire than those under fifteen years of age. No suitable set of ADL's has been compiled for children. In fact, most disability surveys that have been previously conducted have excluded children. The three tests were set up as follows:

- Test 1: Self-perception question.
- Test 2: (a) Age 15 List of physical aids ADL (with the use of aids)
- (b) Age 15 Limitation to daily activities
- Test 3: (a) Age 15 ADL (without the use of aids)
- Work limitation
- Chronic conditions
- Missing limbs
- (b) Age 15 List of physical aids
- Chronic Conditions
- Missing limbs
- Limitation to daily activities as a result of the chronic conditions

The results of these screening test are given in [6]. The Activities of Daily Living questions were identical in Tests 2 and 3 although slightly modified from the OECD list. One important note that should be made is that the proposed screening methods do not permit an assessment of whether or not the target population is being correctly identified, unless they are used on a control population. This has not been done for the Canadian survey.

Test 1 was asked as a supplementary question on the November 1982 LFS survey. Since it was only one question the cost was much lower than for a regular supplementary questionnaire.

Tests 2 and 3 were each asked to persons in one-third of the sampled households in January 1983. There was no overlap of respondents between Tests 2 and 3 but all sampled households for the screen test in January had been asked Test 1 in November. This permits comparison of responses between Test 1 and 2 and between Tests 1 and 3.

Test 3 considers all the proposed approaches. Each test takes a different approach to the ADL list. Test 2 permits the use of aids to perform the activities, while Test 3 does not. The two tests consist of different approaches to limitations imposed by disability. Test 2 looks at limitations to school, home and work activities rolled into a single question. Test 3 looks in great detail at job related limitations.

The project team felt that there would likely be differences in proxy and non-proxy responses related to any particular person. Therefore the interviewers were asked to solicit non-proxy interviews as often as possible.

A further reason to test two options (in

addition to the basic self-perception question) was the possibility that Test 3, which is more detailed, more complex and consequently requires more time to complete, would be incompatible with either the LFS interviewers, respondents or both. There was also the possibility of problems with some parts of either test; for example, the list of chronic conditions. If only one option was used and it failed to work, the screen to be used in the full October 1983 survey would be untested. Testing an alternative questionnaire with fewer questions, which is limited to a combination of two approaches (physical aids and ADL), would possibly help in the assessment of the success or failure of the longer more complex Test 3 document.

Each questionnaire, with the exception of the Test 3 adult questionnaire, fit onto one side of a single 8½ x 14" page. The Test 3 form required both sides.

G. Data Requirements

As a result of the solicitation of data requirements from users as described earlier, 173 responses were received which identified 588 issues of data needs. The following eleven areas were identified.

Issue	Number of users requesting data
1. Nature of impairment	123
2. Demographic characteristics	95
3. Employment	85
4. Assistance	77
5. Education	50
6. Accommodation	45
7. Economic characteristics	41
8. Transportation	29
9. Social activities	26
10. Health	9
11. Communication	8

The nature of impairment/disability/handicap is basic to the survey. Considerable detail is collected, including cause of disability. Most users of the data are interested in focusing on the impairment or disability groupings separately. Demographic characteristics are always important data as they allow the user to identify sectors of the population falling into different categories.

It can be easily understood that employment data about the disabled would be an important issue, as employment is a key component to the independent living of a disabled person. A great deal of employment data is already collected by the LFS. The follow-up survey will collect data related to employment limitations experienced as a result of the disability. In addition to the analysis of the data for the disabled population, this data will permit comparisons of the labour market characteristics of the disabled with those of the Canadian population as a whole.

Three aspects of assistance are considered: technical aids and skills, employment related assistance, and education related assistance. In all three areas, need for aids or assistance was deemed more important than was use. Under

technical aids and special skills, interest is greatest for those aids and skills which are most prevalent, or for which special services or facilities must be provided. The aids would be grouped under hearing, speaking, seeing and mobility. Employment related assistance refers to the impact of aids on the ability of the disabled to work.

The LFS already determines the highest level of education achieved by each respondent. In addition, the follow-up survey will collect data on current education activity and the impact of disability on current and past education.

The LFS collects information on the dwellings of the respondents.

Additional accommodation data will be collected on special architectural/structural features, both inside and outside the home and other buildings.

Economic characteristics will be considered in the following areas: personal income including financial assistance received due to disability, sources of financial assistance, and special expenses incurred as a result of the disability.

Transportation data will be collected on three types of travel: travel to work or school, other local travel and long distance travel. Details on each area will identify the modes of transportation used, frequency of use and problems encountered due to the disability.

Although some interest was expressed by users in data on social/leisure activities, health and communication, no data will be collected for these issues by the present survey. For the first and third of these issues it was felt that reliable and useful data could not be collected in this survey, especially given the already substantial response burden imposed by issues of higher priority. Questions related to health are also not included because of response burden.

H. Reliability of Estimates From the Disability Survey

When determining the content of a questionnaire, consideration must be given to the reliability of estimates produced for the various data items. It is useless to collect data which will not be reliable enough to publish, even if the data requirement has a high priority. The reliability of an estimate is tied directly to the sample size. For this survey, the number of persons receiving a screening questionnaire is fixed. Therefore the reliability of the estimates produced will depend on the number of disabled falling into the sample and the prevalence rates of each characteristic of interest. Based on population projections from the 1981 Census of Population and certain assumptions it is possible to estimate minimum prevalence rates required to produce an estimate which is "reliable enough" to publish. An estimate whose coefficient of variation is less

than or equal to 16.5% is considered releasable without qualification by LFS. The following table displays the minimum releasable estimates for the disability survey. The estimates of this size or higher will have coefficients of variation of less than 16.5%, subject to the validity of the following assumptions.

- (1) All LFS sampled households are administered the screening questionnaire except the one-sixth of the sample which is in its first month of the survey,
- (2) 2.95 persons per household on average,
- (3) 5% LFS non-response rate,
- (4) 5% disability survey non-response rate,
- (5) Design effect of 2.5 (this accounts for the fact that a simple random sample design was not used),
- (6) 19% of total adult population and 8% of total child population (aged less than 15) are disabled.

Province/Region	Min P (%)	Min X	Min D (%)	
			Adults	Children
Atlantic	0.4	7,500	2.3	16.2
NFLD	1.4	8,000	10.1	59.1
PEI	2.9	3,500	20.0	100
NS	1.1	8,500	6.9	54.5
NB	1.0	7,000	6.7	49.5
Quebec	0.5	30,500	3.3	28.2
Ontario	0.4	32,500	2.6	22.0
Prairies	0.3	10,000	1.7	12.4
MAN	0.9	9,000	7.0	47.6
SASK	0.8	7,000	5.0	38.0
ALTA	0.6	13,000	4.1	29.9
British Columbia .	0.7	17,500	4.4	38.2
CANADA	0.1	18,000	0.6	4.2

Where MIN P = minimum estimable percentage of the total population,

MIN X = minimum estimable total,

MIN D = minimum estimable percentage of disabled adults or children.

To explain the table in more detail, consider, for example the province of Newfoundland. An estimate of 9,000 persons possessing a particular characteristic will have a coefficient of variation less than 16.5% and is publishable whereas an estimate of 7,000 will have a coefficient of variation greater than 16.5% and is not publishable. An estimate of 8,000 is approximately 1.4% of the population of Newfoundland. Given the assumptions about percentage disabled in the population, an estimate of 8,000 is approximately 10.1% of the adult disabled population and 59.1% of the child disabled population of Newfoundland.

REFERENCES

1. DATA CONTENT FOR THE STATISTICS CANADA SURVEY OF THE DISABLED, Disability Database Development Project, Health Division, Statistics Canada, April 1983.
2. Carter, R.G., Giles, P.D., Sheridan, M.J. DESCRIPTION AND RATIONALE FOR THE SCREEN TESTS FOR THE JANUARY 1983 DISABILITY SURVEY, Disability Database Development Project, Health Division, Statistics Canada, September 1982.
3. Grabowiecki, Frank DISCUSSION OF THE TARGET POPULATION FOR THE DISABILITY SURVEY, Disability Database Development Project, Health Division, Statistics Canada, July 1982.
4. OBSTACLES, Report of the Special Committee on the Disabled and Handicapped, House of Commons, Ottawa, Canada, 1981.
5. Morin, Jean-Pierre ENQUÊTE SUR LES HANDICAPÉS COMPTE RENDU DES REQUÊTES DES UTILISATEURS, Disability Database Development Project, Health Division, Statistics Canada, mars 1983.
6. Dolson, David, Giles, Philip, Morin, Jean-Pierre THE CANADIAN EXPERIENCE WITH SCREENING FOR DISABLED PERSONS IN A HOUSEHOLD SURVEY, Disability Database Development Project, Health Division, Statistics Canada, August 1983.
7. INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, DISABILITIES, AND HANDICAPS, World Health Organization, Geneva, Switzerland, 1980
8. McWhinnie, J.R. DISABILITY INDICATORS FOR MEASURING WELL-BEING, OECD Social Indicators Programme Technical Report Series, Paris, France, 1980.
9. McDowell, Ian, (1981), AN EXAMINATION OF THE OECD SURVEY QUESTIONS IN A CANADIAN STUDY, Rev. Epidém. et Santé Publ., 29, 421-429.
10. Klaukka, T., (1981), APPLICATION OF THE OECD DISABILITY QUESTIONS IN FINLAND, Rev. Epidém. et Santé Publ., 29, 431-439.
11. Mizrahi, Andree, Mizrahi, Arie, (1981), ÉVALUATION DE L'ÉTAT DE SANTÉ DE PERSONNES AGÉES EN FRANCE, À L'AIDE DE PLUSIEURS INDICATEURS, DONT LES QUESTIONS DE L'OCDE, Rev. Epidém. et Santé Publ., 29, 441-450.
12. Raymond, L., Christe, E., Clemence, A., (1981), VERS L'ÉTABLISSEMENT D'UN SCORE GLOBAL D'INCAPACITÉ FONCTIONNELLE SUR LA BASE DES QUESTIONS DE L'OCDE, D'APRÈS UNE ENQUÊTE EN SUISSE, Rev. Epidém. et Santé Publ., 29, 451-459.
13. Van Sonsbeek, J.L.A. (1981), APPLICATIONS AUX PAYS-BAS DES QUESTIONS DE L'OCDE RELATIVES À L'INCAPACITÉ, Rev. Epidém. et Santé Publ., 29, 461-468.
14. McWhinnie, J.R. (1981), DISABILITY ASSESSMENT IN POPULATION SURVEYS: RESULTS OF THE OECD COMMON DEVELOPMENT EFFORT, Rev. Epidém. et Santé Publ., 29, 413-419.
15. Wilson, R.W., McNeil, J.M. (1981), PRELIMINARY ANALYSIS OF OECD DISABILITY ON THE PRETEST OF THE POST CENSUS DISABILITY SURVEY, Rev. Epidém. et Santé Publ., 29, 469-475.