

# **Global Measures of Disability**

**Statistics Canada's experience so far...**

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#### INTRODUCTION

Statistics Canada has been involved in surveying persons with disabilities since the early 1980's when a special parliamentary committee was formed to study issues surrounding this population. The Committee published its findings in a report entitled *Obstacles* in early 1981. Among its 130 recommendations to the Parliament of Canada was a directive that Statistics Canada "give a high priority to the development and implementation of a long-term strategy which will generate comprehensive data on disabled persons in Canada."<sup>1</sup> In response, Statistics Canada initiated a research program to build a national database on disability, which would include all types of disabilities and provide data for all geographic areas in the country.

Following early trials at finding a definition of disability, Statistics Canada chose to adopt the World Health Organization's 1980 model. This definition was operationalized through the use of twenty-five questions on Activities of Daily Living (ADL's) developed by the OECD, used to screen respondents with disabilities. The difficulties involved in including all 25 screening questions on most social survey questionnaires led to efforts to develop a disability *filter* question, otherwise known as a global disability indicator. The purpose of the filter questions was to identify the target population (the population reporting an activity limitation to any of the 25 screening questions of the survey) through a set of reduced questions. Accordingly, a two-question set was developed and included in the 1986, and eventually 1991, census of population questionnaires.

The primary objective of these filter questions was to cast a net in which a pool of potential respondents could be identified to participate in a follow-up survey on disability. The filter questions used in 1986 and 1991 are shown in Appendix A.

Results in 1986 and 1991 showed that the filter questions in use at the time excluded a significant portion of the target population. To correct this situation, the post-censal survey's methodology included the use of a sample of persons who did not identify a disability through the filter questions (a false-negative sample). If, after more detailed questioning, these respondents indicated an activity limitation, they were kept in the survey population. If not, they were excluded from the rest of the survey. While this methodology worked well for the post-censal disability survey, it had two major drawbacks: the cost (increasing the sample size with "potential" respondents who for the most part don't remain in the survey increases the collection costs tremendously) and the

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<sup>1</sup> *Obstacles*, Report of the Special Parliamentary Committee on the Disabled and the Handicapped, Ottawa, February 1981, page 131

comparability with estimates coming from other sources that didn't have the benefit of using a false-negative sample.

In the intervening years between 1991, when the last post-censal disability survey was conducted (*1991 Health and Activity Limitation Survey*) and 2001 when the current post-censal survey (*2001 Participation and Activity Limitation Survey*) was fielded, Statistics Canada redesigned its disability statistics strategy along two components:

- the development and use of new filter questions to improve the identification of persons with disabilities during the census with a view to select a sample for a post-censal survey;
- the use of common survey items to identify persons with disabilities in a range of social surveys, in order to broaden the scope of disability statistics.

Thus began the development of a set of questions to serve as a "global measure of disability", or "global disability indicator".

## **OBJECTIVES OF A GLOBAL DISABILITY INDICATOR**

A global disability indicator is a short set of questions used to identify respondents in a general population survey or census who perceive themselves to have some level of activity limitation/participation restriction related to long-term health conditions. Many of the global indicators currently in use have from one to four questions. The number of questions in use depends on the questionnaire type (whether a census or survey), the amount of space or interview time available, the amount of detail required and the data collection method used.

Generally, global disability indicators have one of the following objectives:

- they may serve a *descriptive* purpose: a useful tool to provide broad information on the functional status of a given population. This is of most interest to health service providers, disability and social policy analysts, demographers, the disability community, researchers, etc. The brevity of the question set can ensure that disability is included as a topic in social surveys that may otherwise ignore it, and the availability of a common indicator across all surveys expands the information available on the impact of disability in many different domains. In these cases, the indicator should be very clear about the definition of disability it is using, and must be as precise as possible in identifying the population of interest.
- they may serve as a *screening* mechanism: some surveys use a short set of questions to identify a "pool" of respondents who are highly likely to have the characteristics of interest for follow-up surveys. In these cases, it is important for the indicator to be as comprehensive as possible not to exclude persons in the target population. In fact, it can be overly broad, since the second phase of data collection should take care of eliminating those respondents who don't present the characteristics of interest.

Statistics Canada's primary objective was to develop a global disability indicator that would act as a screening mechanism for a post-censal disability survey. The primary focus of the post-censal survey is persons with "significant" disabilities, i.e., persons reporting that their daily lives are affected by activity limitations or social participation restrictions associated with a health-related condition. Although persons with milder levels of disability are also part of the target population (they have their own policy implications), the target population is not seen as including persons with very mild disability levels. Since the principal source of disability statistics is the post-censal survey, it was important to develop a screening mechanism that would identify the target population well, without excluding a significant portion of it.

The use of the global indicator as a descriptive item was a secondary, although not negligible, objective. An important component of the new disability statistics strategy was to expand the availability of information on disabled persons by using common concepts and survey items to define disability in other social surveys in Statistics Canada, such as surveys on employment and income, health, children and youth and Aboriginal peoples. Accordingly, the new indicator being developed would serve two purposes: as a screening mechanism for the post-censal survey, and as a global measure of disability in other surveys.

### **CRITERIA OF A GLOBAL DISABILITY INDICATOR**

Given that the global disability indicator was to be used in many population-based surveys, a certain set of criteria was desired:

- the questions had to apply to the whole population - children, adults and the elderly – residing in households.
- the set of questions had to be succinct enough to be inserted in a number of survey instruments, whether social or general health surveys, and in the census long form.
- the language used in the questions had to be clear enough to be used in self-administered surveys, without intervention from an interviewer, but should also be applicable in telephone and face-to-face interviews.
- the questions had to "make sense" to respondents; the objective of the questions had to be easily grasped.
- the questions had to be broad enough to allow persons with all types and levels of disability to be included (remembering that a primary objective was to develop a survey methodology that would eliminate the use of a sample of respondents reporting no limitations to the filter questions).

### **DEVELOPING A GLOBAL INDICATOR**

The development of a global disability indicator began in the fall of 1997 with a two-phase research project: qualitative research on the attributes of the questions themselves, and a quantitative phase to measure their performance.

Briefly, the chosen methodology consisted in the following main steps.

- firstly, gathering data on the comprehension and interpretation of the terms in the filter questions used in 1986 and 1991 (for ease of comparison, these are labeled “old filter questions”); this was achieved through one on one interviews with persons with disabilities
- secondly, developing alternative sets and gathering data on comprehension and interpretation of these
- finally, testing the old set against the new in terms of correlation of their answers with the screening questions used in the 1991 disability survey.

The qualitative phase of the research project revealed many interesting findings about the perception of respondents regarding their activity limitations and the terms of the filter questions they were asked to review. The linguistic analysis of the questions revealed that a major cause of non-reporting of disability to the old filter questions was the use of negative sounding terminology. Terms such as “long-term”, “disabilities”, “handicaps” were viewed as extremely negative and suggesting a high level of severity. In particular, the terms “disabilities” and “handicaps” were seen as not applicable to many respondents. The term “disabilities” was viewed as difficult to define, and consequently, difficult to apply to oneself and the term “handicap” was viewed as antiquated and not politically correct. This led many respondents with milder activity limitations to exclude themselves from the answers.

Another highly problematic phrase was “is this person limited in...”. Many respondents disagreed that a health problem or condition was limiting *them*; rather, their activities were limited. “Being limited” was viewed as pejorative and indicative of quite severe disabilities. In other words, having an activity limitation is very different from being limited. This was true for all types of respondents, but especially so for parents of children with disabilities who resented the implicit labeling of the term “limited”.

The two-item answer categories to the questions were another source of non-reporting. The choice between a “yes” and a “no” was not always easy or clear for many respondents. Some reasons included:

- situations of mild or cyclical disabilities, which vary in frequency and intensity
- variable levels of restriction associated with some conditions
- the variety of environments (some facilitating, some neutral and some presenting barriers) in which persons find themselves

Drawing on these findings, a number of alternatives were tested during this phase of the project. A final question set was selected and quantitatively tested in a simulated post-censal survey setting. This phase began with the National Census Test in October 1998 and culminated with the 2001 post-censal survey pilot test. Information on the test results can be found in the documents listed as references.

The questions to be used as filter questions in the 2001 census and as global measures of disability in other surveys, read as follows:

1. Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
  - Yes, sometimes
  - Yes, often
  - No
  
2. Does a physical condition or mental condition or health problem reduce the amount of the kind of activity this person can do:
  - (a) At home?
    - Yes, sometimes
    - Yes, often
    - No
  
  - (b) At work or at school?
    - Yes, sometimes
    - Yes, often
    - No
    - Not applicable
  
  - (c) In other activities, for example, transportation or leisure?
    - Yes, sometimes
    - Yes, often
    - No

Compared to the previously used filter questions, this version has eliminated negative or severe sounding terms, and has shifted the limitation to the activity rather than to the person. In fact, the term “limit” has been replaced by “reduce”. The answer categories have been broadened and use a multiple-item response scale, to allow the possibility of reporting limitations that are not constant but variable depending on any number of factors. Finally, the questions on disabilities and handicaps have been replaced by a question on difficulties associated with certain activities of daily living (in fact, a shortened version of the ADL’s in the screening questions), something that was much more easily understood by respondents.

## **RELATIONSHIP TO THE ICF**

Looking at the language of these questions, it is clear that their focus is on activity limitations and participation restrictions related to health conditions. The aim of the questions is not to produce a prevalence rate of impairments or conditions, but rather to

provide an estimate of persons experiencing limitations in their daily activities or restrictions in their participation in various settings. The domains listed cover most of the domains of the ICF. The domains of personal care and interpersonal relationships were not mentioned specifically in the questions as they were viewed as sensitive issues and not appropriate to include in a census context. They can be handled quite well, however, in a disability or health survey. This situation illustrates some of the constraints of a global measure: it is difficult to cover all domains because of the necessary brevity of the question and some domains are simply not appropriate to include in some surveying contexts.

The term “difficulty” in the first question is broad in its applicability; although the term isn’t defined for respondents, cognitive testing has shown that it is interpreted as covering the components of quality, quantity, time required and assistance required to perform the tasks or actions mentioned. In our experience, the notion of difficulty is confusing in two cases especially. Firstly, persons with very mild limitations are sometimes unsure as to where to draw the line between a “real difficulty” and normal change associated with aging. However, as the severity of the difficulty increases, the uncertainty diminishes.

Secondly, qualifying the abilities (or limitations) of children in various domains is a difficult task for parents since children are in a constantly changing state of learning and acquiring skills. The huge amount of variation in the acquisition of skills during childhood renders it difficult to ascertain whether a difficulty is a “normal” or not situation. Generally, parents will wait to have a professional diagnosis of a health-related condition before feeling confident enough to report an activity limitation; this can take many months or even years to occur. This will result in under-reporting of “borderline” of developing disabilities. On the other hand, some parents do report difficulties in the specified domains because their child is only beginning to acquire the skills involved. This results in reporting situations that are not part of the target of the questions. In conclusion, then, it is difficult to capture disability in children with the same global measure used for adults. In the Canadian context, the census constraints mean that only one set of questions can be included on the census questionnaire; therefore the same global questions must be used for adults and children. Further analysis of results of the post-censal child disability survey will enable us to determine whether the approach is valid enough to pursue for this segment of the population.

The issue of assistance is somewhat problematic. Our cognitive testing has shown that most respondents phrase their answers to the global questions by taking into account the level of assistance (whether personal or technical) they require to perform certain tasks. However, the impact of the assistance goes both ways. For instance, persons wearing glasses generally report no difficulty in seeing because they assess their capacity in their usual state, that is with glasses (unless their impairment is not corrected by glasses and limitations still occur). The same holds for persons using hearing aids. On the other hand, persons requiring assistance, especially personal assistance, of a less common nature tend to report having difficulties or activity limitations *in spite* of having the assistance. This results mostly from two factors. Firstly, it seems that assistance rarely eliminates completely the activity limitation. Secondly, respondents realize that

assistance varies in different environments; it can be lost due to circumstances beyond the recipient's control (changes in governmental social policies, for example). Again, the brevity of global indicators makes it difficult to tease out these differences. This is an area that would benefit from further research.

Finally, the issue of the environment is not included specifically in the Statistics Canada global disability questions (as evidenced by the paragraph above on the impact of technical aids and assistance). However, the multiple item response categories are useful to respondents whose activity limitations or participation restrictions vary according to the level of accommodation in various environments. However, whereas this simplifies the task of respondents to indicate some level of limitation, it does not provide data users with any indication on the impact of environmental facilitators or barriers. This is another area where global measures would benefit from further research.

## **NEXT STEPS**

The current survey on disability, the *Participation and Activity Limitation Survey (PALS)*, was fielded in the fall of 2001. The population was defined by using the new filter questions on the census form and selecting only a sample of respondents indicating at least one YES to the filter questions. The PALS interview began with the same filter questions as appeared on the census form followed by a series of screening questions. These screening questions contain a series of ADL's, as well as questions on activity limitations and participation restrictions due to health-related conditions.

The 2001 strategy to define the population with disabilities will also involve using a consistent conceptual approach. In order to broaden the scope of the disability database at Statistics Canada, the new filter questions will be used in other Statistics Canada social surveys that require a global disability indicator, such as labour, health, education and Aboriginal peoples surveys. This strategy of using consistent definitions (i.e., common questions to identify the presence of a disability) will ensure the development of a comprehensive database on persons with disabilities. Although it is recognized that resulting disability rates will vary depending on collection methods, methodology and survey context, the consistent use of common disability filter questions, or of a global disability indicator, will enhance the analysis of the resulting data. Preliminary results from some surveys indeed show remarkable consistency in the rates being reported. For instance, where the disability rate for Phase 1 of the PALS pilot test was 19.4%, the same filter questions used by Cycles 13 and 14 of the General Social Survey show results of 20% and 21%. The results of the 2001 PALS will provide guidelines for the interpretation of the data coming out of the various surveys by developing algorithms to estimate severity, for example. Various data collection activities are planned over the next few years that will include the global disability indicator, and a body of data will soon be available for analysis.

## **APPENDIX A**

## 1986 and 1991 Disability Filter Questions

1. Is this person limited in the kind or amount of activity that he/she can do because of a long-term physical condition, mental condition or health problem:

(a) At home?

*Response categories:* No, not limited  
Yes, limited

(b) At school or at work?

*Response categories:* No, not limited  
Yes, limited  
Not applicable

(c) In other activities, e.g., transportation to or from work, leisure time activities?

*Response categories:* No, not limited  
Yes limited

2. Does this person have any long-term disabilities or handicaps?

*Response categories:* No  
Yes

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