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# *Renée Langlois:*
# *The Development of aGlobal Disability Indicator*

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## Recent Developments at Statistics Canada

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# The Development of a Global Disability Indicator

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## 1. INTRODUCTION

This paper presents the results of a research project undertaken at Statistics Canada between 1997 and 2001 to develop global questions to identify persons with disabilities in population-based surveys and censuses. The project began with qualitative research, including linguistic analysis of question wording, and continued with a quantitative evaluation phase, ending with a recommendation to adopt a new strategy to identify persons with disabilities. The paper is meant to be a brief overview of the project, not a detailed technical report. Technical references are provided at the end of the paper, and a detailed project report will be available at a later date.

## 2. BACKGROUND

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."[1] 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.

The following steps mark the important activities to date of this research program on disabilities:

1. The *Canadian Health and Disability Survey (CHDS)*, October 1983 and June 1984
2. The inclusion of a question on activity limitations and long-term disabilities on the 1986 Census of Population questionnaire long form
3. The *1986 Health and Activity Limitation Survey (HALS)*, September 1986 to March 1987
4. The inclusion of a question on activity limitations and long-term disabilities on the 1991Census of Population questionnaire long form

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[1] Obstacles, Report of the Special Parliamentary Committee on the Disabled and the Handicapped, Ottawa, February 1981, page 131

5. The *1991 Health and Activity Limitation Survey (HALS),* September 1991 to March 1992
6. Qualitative testing of new disability filter questions to be included in the 2001 Census of Population, January to May 1998
7. Testing of new disability filter questions following the National Census Test, April-May 1999
8. Inclusion of new disability filter questions on the 2001 Census of Population long form
9. The *2001 Participation and Activity Limitation Survey (PALS),* to be conducted from September to December 2001

## 3. THE 1986 AND 1991 EXPERIENCE

Research in the early 1980's revealed that the population with disabilities is a relatively small and dispersed sub-population in Canada. Following early trials at finding a definition, Statistics Canada chose to adopt the World Health Organization's 1980 model, which defines disability as a limitation in activity resulting from an impairment. This definition was operationalized through the use of a number of Activities of Daily Living questions (ADL's) developed by the OECD. However, the number of questions required for defining the population in this manner created the additional challenge of finding a survey frame

Given that the national database's objectives were to provide information on persons with disabilities according to selected age groups (including children under the age of fifteen) for each province and territory and selected census metropolitan areas, as well as for the various types and severity levels of disability, a detailed population frame was required. Statistics Canada determined that the Census could provide such a frame, and began the development of its first post-censal survey in the mid-eighties. A post-censal survey uses Census microdata to identify its target population, and is an effective method of identifying a small and dispersed population in order to gather detailed information.

This first post-censal survey on disability was the *1986 Health and Activity Limitation Survey (HALS).* The survey operationalizes the WHO's 1980 definition of disability with a detailed series of screening questions on activities of daily living to determine the presence of a disability, its nature and severity. Following sections dealt with the impact of the disability on the respondent's life, including education, employment, home life, recreation and income. However, the initial screening section required the use of many questions in order to cover all possible types of disabilities: physical, sensory, intellectual, cognitive, learning and emotional. The 1986 HALS used 25 questions in its disability screening section. The impossibility of including all 25 questions on the Census questionnaire, or on any other social survey instrument for that matter, 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.

The disability filter questions used on the 1986 and 1991 Census of Population long forms were the following:

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?
   No, not limited
   Yes, limited

   (b) At school or at work?
   No, not limited
   Yes, limited
   Not applicable

   (c) In other activities, e.g., transportation to or from work, leisure time activities?
   No, not limited
   Yes limited

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

   No
   Yes

The primary objective of these filter questions was to select a sample of respondents for the subsequent post-censal surveys. They were to cast a net in which a pool of potential respondents could be caught. According to preliminary research, it was known that the filter questions were less precise than the survey screening questions; as a result, some respondents with activity limitations could be missed by the filter questions. As well, some respondents could be included in the survey through their positive responses to the filter questions when in fact, they did not have activity limitations. In other words, all cells of the following matrix can be observed:

| | **Response to HALS** | |
|---|---|---|
| **Response to census filter questions** | *YES* | *NO* |
| *YES* | True positives | False positives |
| *NO* | False negatives | True negatives |

Ideally, all respondents to the post-censal survey would fall in the true positive quadrant, i.e., all respondents reporting a limitation to the HALS screening questions would also report a limitation to the filter questions on the Census form. Conversely, persons reporting no activity limitation to the census filter questions would also not report limitations when asked the detailed HALS screening questions.

In actual fact, the situation in 1986 and 1991 was quite different. The relationship between answers to the Census filter questions and the HALS screening questions is shown for adults in 1991 in the following table:

| | **Response to HALS** | | |
|---|---|---|---|
| **Response to census filter questions** | *YES* | *NO* | *TOTAL* |
| *YES* | 80% (=47%) | 20% (=3%) | **10%** |
| *NO* | 10% (=53%) | 90% (=97%) | 90% |
| *TOTAL* | **17%** | 83% | 100% |

The results of this table show that the disability rate from the Census filter questions was 10%, while the disability rate from the HALS was 17%. The difference between the two comes mainly from respondents who did not indicate a limitation to the two “global” filter questions, but who did reveal a limitation based on the more detailed screening questions in HALS. In fact, more than half of the population with disabilities as defined by HALS had originally been missed by the Census filter questions. These are the so-called “false negative” respondents. The vast majority of these respondents were found to have milder forms of disability than those respondents who had been identified through a positive response to the Census filter questions. However, since the post-censal survey’s objectives were to include all levels of disability, the false-negative respondents were considered to be part of the survey’s target population. A small portion of the difference can be also be attributed to respondents who reported a limitation to the global questions, but not to the detailed screening questions (“false positive” respondents).

In operational and sampling terms, this anticipated situation resulted in the need to sample respondents who answered positively to the Census filter questions, and also respondents who answered negatively to the Census filter questions. Selecting respondents from both YES and NO strata reduced the bias concerns. However, this is a very costly method to implement. For instance, the 1991 HALS survey sample size was approximately 129,000, consisting of 36,000 respondents from the YES stratum and 113,000 from the NO stratum.

## 4. PREPARING THE WAY FOR 2001

Despite the success of both post-censal disability surveys, and the enormous amount of information they provided on the situation of persons with disabilities, their high cost became a challenge. No post-censal disability survey was conducted after the 1996 census because of a lack of funds available to government departments. This gap in the disability database created an opportunity for a fresh look at Statistics Canada's disability statistics program, with a view to developing new approaches.

A major part of the cost of the disability surveys was the use of a sample of "NO" respondents. Since in 1991 only a fraction (about 10%) of these interviews yielded a respondent with a disability as defined by HALS, a significant additional cost was being added to the survey. In looking ahead to fielding a post-censal disability following the 2001 Census, Statistics Canada embarked on a research program to determine whether "better" filter questions could be developed and implemented to identify the survey's target population. It was hoped, as well, that better functioning filter questions could be used as a more general indicator of disability in other STC social surveys. In this way, the definition of disability could become standardized across surveys, and the development of a comprehensive database on persons with disabilities could continue. In other words, the search for a global disability indicator began in earnest.

The disability filter questions research program had two main phases: qualitative research on the attributes of the questions themselves, and a quantitative phase to measure their performance.

### 4.1 Qualitative Research on the 2001 Filter Questions

The first phase of the research program began in the fall of 1997. The objectives of this phase were to develop a set of filter questions that would identify the population with disabilities without the use of a NO sample. Given that the disability filter questions were to be used in population-based survey activities, a certain set of criteria was desired. For instance, the questions had to apply to the whole population - children, adults and the elderly – residing in households. As well, 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 should be broad enough to allow persons with all types and levels of disability to be included (remembering that a primary objective of the research project was to develop a survey methodology that could eliminate the use of a NO sample).

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 of the 1991 HALS.

Participants to this study were chosen from 1996 Census records.[2] In order to approximate different levels of severity, a sample of respondents who had provided answers to the filter questions was chosen on the following basis:

- only one YES answer to the two filter questions
- more than one YES answer to the two filter questions

The sample included English and French speaking respondents, children, adults and seniors. Participants who agreed to take part in the study were visited in their homes by an interviewer and an observer. Approximately 190 interviews took place, in three waves, in the Ottawa-Hull and Montreal areas.

The research protocol involved asking the participants to fill in a survey form that had been designed to resemble the Census form. One half of the forms included the old filter questions while the other half included the new filter questions. The participants provided the information in writing (to simulate the self-enumeration that takes place during the Census) for all members of the household. Following this first step, the interviewer administered a shortened version of the 1991 HALS questionnaire, which consisted in the screening questions and the sub-questions on the degree of difficulty associated with each activity. These data were gathered for each member of the household.

The next step in the interview consisted in a discussion of the participants' understanding and interpretation of, and their reactions to, the questions' concepts and terms. A structured interview had been prepared ahead of time, to be followed by all interviewers.

After the first wave of interviews, all responses were coded and correlations between answers to the filter and screening questions were established to divide participants into true positives and false negatives (false positives and true negatives were of lesser concern). Interview responses were analyzed as well and the results were used to design "better" versions of the filter questions. Three waves of interviewing were done in total before a satisfactory version of the questions was achieved.

This 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", "*chronique*" (in the French version), "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

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[2] Although HALS was not fielded in 1996 due to budgetary constraints, the filter questions were nevertheless included on the census form as a means of calculating an approximate disability rate.

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 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. Situations of mild or cyclical disabilities, or variable levels of restriction associated with some activity limitations, led many respondents to not report a limitation, feeling that their situation was not significant or constant enough.

Drawing on these findings, a number of alternatives were tested during this phase of the project. The resulting "new" filter questions, to be used in the 2001 Census, 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 old 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 to allow the possibility of reporting limitations that are not constant but recurring. Finally, the questions on disabilities and handicaps has 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.

### 4.2 Quantitative Evaluation

The next step in the research project was to evaluate the performance of the new filter questions in a simulated post-censal survey setting. This phase began in October 1998 with the National Census Test and continued until the pilot test of the 2001 post-censal disability survey.

The National Census Test (NCT) is a dress rehearsal for the actual Census. The NCT for the 2001 Census took place in October 1998. For the first time in the Canadian Census history, two versions of the long Census form were tested at the same time. This provided the HALS team with the opportunity to print the old filter questions on one version (2B.1), and the new filter questions on the other version (2B.2). Following the NCT, approximately 10,000 respondents were chosen to participate in the 1991 HALS filter questions test. Approximately half of the respondents had filled in the old version of the filter questions on the NCT questionnaire, while the other half had filled in the new version. These respondents were contacted by telephone, and were asked to respond to the 25 HALS screening questions. Their answers to these screening questions were coded to determine the presence of an activity limitation, and this was correlated to the answer to the filter questions. It was expected that the new filter questions would produce a lower rate of false negative respondents and a higher rate of false positive respondents (the filter questions were intentionally more inclusive in order to reduce the false negative rate).

Results showed a stronger relationship between the new filter questions and the HALS screening questions than with the old filter questions. The new filter questions screened in more respondents with disabilities of all levels of severity. This advantage becomes more pronounced as the severity decreases. Results showed that the new filter questions were superior to the old ones in selecting a larger portion of the target population and in missing a portion of the target population which is less critical (those with very mild limitations). These results led to the decision to adopt the new filter questions for use in the 2001 Census and as a frame for the 2001 post-censal survey on activity limitations.

## 4.3 2001 Post-censal Survey Pilot Test

A pilot test of the 2001 post-censal survey on persons with disabilities was conducted in October 2000 to test the new questionnaire content and collection methods and to gather further evidence on the performance of the new filter questions. A frame for the survey was constructed by using a supplement to the monthly Labour Force Survey during the months of May and June 2000 (Phase 1 of the pilot test). The supplement contained the new filter questions in a form designed to resemble the Census form. Respondents of all ages, both those answering YES and those answering NO, were contacted in October 2000 to carry out the post-censal survey pilot test (Phase 2 of the pilot test). The proposed population definition being tested was the following:

- select respondents answering YES and respondents answering NO to the filter questions at Phase 1
- repeat filter questions at start of Phase 2 interview
- continue interview only with those respondents answering YES again to the filter questions at Phase 2.

The following table provides some summary results.

### **Disability Rates by Severity and Type of Respondent, Adult Population** (PALS 2001 pilot test)

| | DISABILITY RATE | | | |
|---|---|---|---|---|
| | Mild | Moderate | Severe | Total |
| **True positives** | 37.7 | 38.7 | 23.6 | 13.9 |
| **False negatives** | 70.9 | 24.4 | 4.7 | 11.0 |
| ***1991*** | *49.1* | *32.9* | *18.0* | *16.8* |

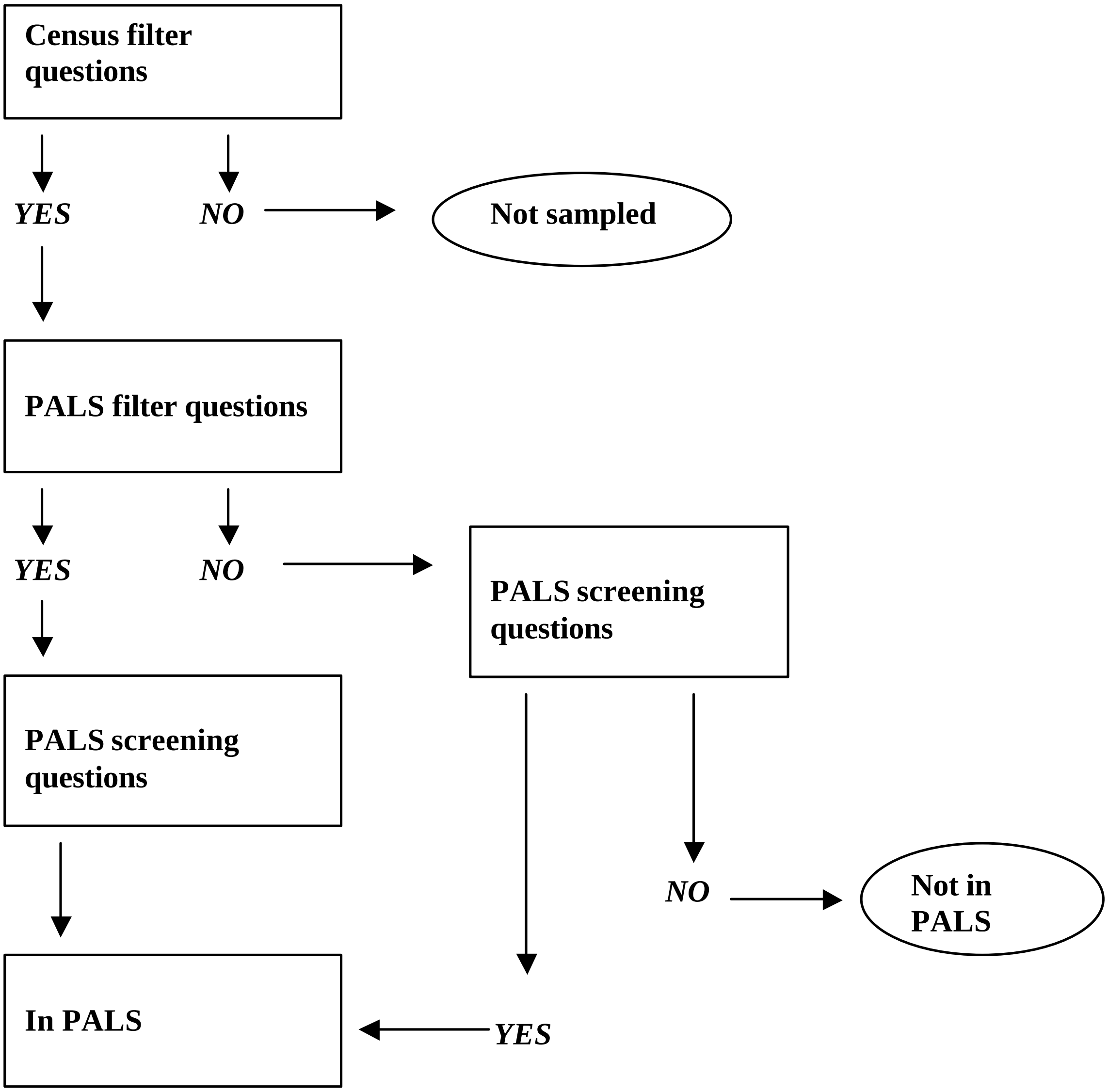
The results shown in this table indicate that the disability rate using the definition described above was 13.9%, compared to the 16.8% achieved in 1991. In addition, the severity profile of the population has shifted, from almost half of the population reporting mild disabilities in 1991, to about 38% in 2001 with the new approach. The severity distribution of the false negative respondents (those respondents who are left out of the disabled population using the new approach) shows that this is clearly a more mildly disabled population: only 5% report severe levels of disability, compared to 24% of the true positive population.

## 5. STRATEGY FOR 2001

The next post-censal survey on disability will occur in the fall of 2001. Given the major methodological and content changes the survey has undergone since 1991, it has been renamed the *Participation and Activity Limitation Survey (PALS).* The proposed strategy for PALS 2001 is slightly different than the one tested during the pilot test (described in Section 4.3). In 2001, the population will be 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. The PALS interview will begin 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 due to cognitive, learning, intellectual or emotional conditions. Respondents who answer YES to at least one of the filter questions at the beginning of PALS will be included in the population with disabilities and continue the interview to the end. Respondents who answer NO to all filter questions at the beginning of PALS will continue through the screening questions. If at least one YES answer is provided to the screening questions, the respondents will continue the interview to the end. If the answers to all screening questions are NO, the respondents will end the interview after the screening questions, and will not be included in the population with disabilities.

Figure 1 presents a graphical illustration of this definition (see page 12).

**Figure 1. PALS 2001: Operational Definition of Population with Disabilities**



The disability rate resulting from this approach, during the PALS 2001 pilot test, is shown in the following table:

**Disability Rates by Severity, Adult Population** (PALS 2001 pilot test)

| | DISABILITY RATE (in %) | | | |
|---|---|---|---|---|
| | Mild | Moderate | Severe | Total |
| **True positives to filters/ADL’s** | 43.5 | 35.9 | 20.6 | 15.7 |
| ***1991*** | *49.1* | *32.9* | *18.0* | *16.8* |

In comparing these results with those displayed in Section 4.3, it is obvious that this definition results in a somewhat higher disability rate (15.7, compared to 13.9), and in a slightly milder severity profile. This makes sense, since this definition provides a “second chance” to respondents to report a disability if they fall through the filters at Phase 2; typically, these respondents are persons with very mild limitations.

This population definition was chosen in consultation with the client of the post-censal disability survey. Human Resources Development Canada is the lead federal policy department responsible for the development of social policies related to persons with disabilities. While many of the policies the Department develops target mainly persons with significant disabilities, the Department chose this more inclusive definition in order to provide a broader scope to the population it serves. This definition also provides the advantage of allowing the derivation of a sub-set definition, as described in Section 4.3; it offers therefore a flexible approach to describing the population.

The second part of the 2001 strategy to define the population with disabilities involves 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%. Various data collection activities are planned over the next few years to include the common use of the disability filter questions, and a body of data will soon be available for analysis.

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