



Statistics Canada
Housing, Family and
Social Statistics Division
Catalogue no. 89-578-XIE



A New Approach to Disability Data:

Changes between the 1991 Health and Activity Limitation Survey (HALS) and the 2001 Participation and Activity Limitation Survey (PALS)

December 2002



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A New Approach to Disability Data:

Changes between the 1991 Health and Activity Limitation Survey (HALS) and the 2001 Participation and Activity Limitation Survey (PALS)

Published by authority of the Minister responsible for Statistics Canada

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December 2002

Catalogue no. 89-578-XIE

Frequency: Occasional

ISBN 0-662-33230-X

Ottawa

Cette publication est disponible en français (n° 89-578-XIF au catalogue)

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Symbols

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- . not available for any reference period
- .. not available for a specific reference period
- ... not applicable
- ^p preliminary
- ^r revised
- x suppressed to meet the confidentiality requirements of the Statistics Act
- E use with caution
- F too unreliable to be published

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EXECUTIVE SUMMARY

Statistics Canada has been involved in conducting surveys on persons with disabilities since the 1980s. In 1986, Statistics Canada conducted its first post-censal disability survey — the *Health and Activity Limitation Survey (HALS)* — after the 1986 Census. HALS is a post-censal survey because it uses the census as a sampling frame to identify its target population. The 1986 Census questionnaire included two general questions on activity limitations and long-term disabilities (*referred to as “census disability filter questions”*). The 1986 HALS respondents were selected through the use of the census information on age, geography and the responses to the disability filter questions.

The HALS survey was repeated in the fall of 1991 immediately after the 1991 Census. The 1991 HALS again used the census filter questions to pre-identify its target population. This population consisted of respondents with the potential of reporting activity limitations to the post-censal survey. A decade later, the 2001 post-censal disability survey, renamed the *Participation and Activity Limitation Survey (PALS)*, was carried out in the fall of 2001, about four months after the 2001 Census.

Both HALS and PALS provide detailed information about the demographic and socio-economic situation of persons with disabilities as well as the type and severity of their disabilities. However, the data from the two surveys cannot be compared because of significant differences in the 1991 and 2001 Census filter questions, the sampling plans that were used in HALS and PALS and the content of the questionnaires. The following summarizes the major differences between the 1991 HALS and 2001 PALS:

- 1) **New census disability filter questions:** The 2001 PALS uses new census disability filter questions to identify its population. The new filter questions are more inclusive than the ones used in 1991.
- 2) **New sampling plan:** The HALS sample included both respondents who answered YES to the disability filter questions on the census form and those who answered NO. But the 2001 PALS survey sampled only those individuals with positive answers to the 2001 Census filter questions. Respondents who answered NO to the census disability filter questions were excluded from the PALS.

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- 3) New questionnaire content:** The PALS questionnaire content, including new screening questions, is significantly different from that used in the 1991 HALS questionnaire, in particular the content related to the identification of the types and severity of activity limitations. For example, for the 2001 PALS survey new questions were designed to better identify non-physical disabilities including learning disabilities, developmental disabilities and psychological conditions. In the 1991 HALS, persons with learning disabilities, mental illness and developmental disabilities were grouped together under the category of “Other”.

Compared to the 1991 HALS, the 2001 PALS used a different approach in the identification of the severity of the activity limitations. For example, the HALS severity scale gave more weight to physical disabilities than to non-physical disabilities, but the 2001 PALS severity scale assigned an equal weight to all types of disabilities. In addition, the severity scale in the 1991 HALS was divided into three groups (mild, moderate and severe), while the PALS severity scale was divided into four groups (mild, moderate, severe and very severe).

1. INTRODUCTION

Statistics Canada has been involved in conducting surveys on persons with disabilities since the early 1980s when a special parliamentary committee was formed to study issues surrounding this population. Among its 130 recommendations to the Parliament in 1981 was a directive that Statistics Canada “give high priority to the development and implementation of a long-term strategy which will generate comprehensive data on disabled persons in Canada.”¹

In 1986, Statistics Canada conducted its first post-censal disability survey — the *Health and Activity Limitation Survey (HALS)* — after the 1986 Census. HALS is a post-censal survey because it uses the census as a sampling frame to identify its target population. The census questionnaire included two general questions on activity limitations and long-term disabilities. The 1986 HALS respondents were selected through the use of the census information on age, geography and the responses to these two general questions.

The HALS survey was repeated in the fall of 1991 immediately after the 1991 Census, but was not conducted after the 1996 Census. The 2001 post-censal disability survey, renamed the Participation and Activity Limitation Survey (PALS), was carried out in the fall of 2001, about four months after the 2001 Census.

Both HALS and PALS provide detailed information about the demographic and socio-economic situation of persons with disabilities as well as the type and severity of their disabilities. However, there are significant differences between the two surveys as PALS has undergone major methodological and content changes compared to HALS. The efforts since 1991 to improve the criteria for identifying the disabled population resulted in changes in the census disability questions as well as changes in the methodology and the operational definition of the population used by the 2001 post-censal survey. This paper presents an overview of the changes that have taken place since the 1991 HALS and of the activities undertaken to improve the identification of disabled population.

¹ Canada. House of Commons. Special Committee on the Disabled and the Handicapped. 1981. *Obstacles - Report of the Special Parliamentary Committee on the Disabled and the Handicapped*. p.131.

2. BACKGROUND

2.1 Use of census as a survey frame

In the early 1980s, following early trials at finding a definition of disability, Statistics Canada chose to adopt the World Health Organization (WHO)'s 1980 model. It defined disability as a limitation in daily activities resulting from an impairment associated with physical or mental conditions or health problems. This definition was then operationalized through an adaptation of the Activities of Daily Living (ADL) questions developed by the Organization for Economic Cooperation and Development (OECD). The detailed ADL questions were useful to determine the presence of disability and also to identify the types and severity of disabilities.

Given that the objectives of the national database were to provide in-depth information on persons with disabilities according to selected age groups (including children under 15) for each province and territory as well as for the various types and severity of disability, a large sample of disabled persons was required. But early research revealed that Canada's population with disabilities was a relatively small and dispersed sub-population. These database objectives and the characteristics of the disabled population created a methodological challenge. Statistics Canada determined that the census could provide a survey frame that had the potential to meet this challenge and therefore began the development of its first post-censal survey.

2.2 Health and Activity Limitation Survey (HALS)

The 1986 HALS was the first post-censal survey on disability. However, prior to the 1986 HALS, Statistics Canada had to come up with strategies for selecting a sample of potential respondents for this survey. The chosen approach was to add two general questions on activity limitations and long-term disabilities (*referred to as "census disability filter questions"*) to the 1986 Census long-form questionnaire. The census disability filter questions were used as a "filtering" device to identify potentially disabled persons who could be asked more in-depth disability questions during the post-censal disability survey.

The second post-censal survey on disability was conducted in the fall of 1991 shortly after the 1991 Census. The 1991 HALS again used the census filter questions to pre-identify its target population. This population consisted of respondents with the potential of reporting activity limitations to the post-censal survey.

The census disability questions used on the 1991 Census questionnaire are below:

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

As for the 1986 HALS, the 1991 post-censal survey operationalized the WHO's definition of disability with a detailed series of questions on difficulty in performing daily activities in order to determine the presence of a disability, and the type and severity of disability. These detailed daily activity questions are referred to as "**disability screening questions**".

The 1991 HALS questionnaire for the population aged 15 and over used 32 questions in the disability screening section of the survey questionnaire. Any respondent having a positive answer to one of the screening questions was identified as disabled. In the 1991 HALS, the types of disabilities identified by these questions were hearing, seeing, speaking, mobility, agility and "other". This last category referred to individuals who were limited because of a learning disability, a mental health condition, an intellectual impairment or because of labeling by others.

3. THE CENSUS AND HALS

3.1 Overview of the relationship between the census and HALS

A post-censal survey uses census information to improve the efficiency of its sample design. That is, compared to a survey, which does not make use of any prior information, the post-censal survey approach will reduce the sample size required to reach a given number of individuals in the target population. There are many advantages to the post-censal approach. For example, because the census contains a large amount of information for each person, its information can be used in the sampling design of a survey on a relatively small and scattered sub-group of the population, such as the disabled population. Operationally, the post-censal approach also reduces the respondent burden by reducing the number of persons who will be asked in-depth disability questions during the survey.

While the use of the census filter questions to pre-identify disabled persons adds to the efficiency of the post-censal approach, it also causes some drawbacks. Since the number of disability questions on the census form is limited, the identification of disabled persons by the census is less precise compared to the post-censal survey which includes a large number of disability screening questions. Consequently, the responses to the census filter questions are not always consistent with the responses to the screening questions on the post-censal survey.

For example, respondents may answer YES to the census disability filter questions, but report no positive answer when responding to the post-censal disability screening questions (*these respondents are referred to as “false positive respondents”*). On the other hand, a respondent could answer NO to the census filter questions, but answer YES to the post-censal screening questions (*referred to as “false negative respondents”*). Ideally all respondents reporting a limitation to the census filter questions would also report a limitation to the post-censal survey (*referred to as “true positive respondents”*). As well, in an ideal situation, respondents reporting no activity limitations on the census form would also report no limitations in the post-censal survey (*referred to as “true negative respondents”*).

Table 1 summarizes the four scenarios that occurred in terms of the responses to the 1991 Census filter questions and 1991 HALS screening questions. As indicated in the table, in 1991, almost 80% of the adults classified as positive in the census were also classified as disabled in HALS (*true positives*). But 20% of the adults who answered YES to the census disability questions, later answered NO to the HALS screening questions (*false positives*). Furthermore, the results indicated that 10% of adults who answered NO to the census disability questions reported YES to the HALS disability screening questions (*false negatives*).

Table 1 – Relationship between the census filter questions and HALS disability screening questions (1991 HALS)

Response to 1991 Census filter questions	Response to 1991 HALS screening questions		
	YES	NO	TOTAL
YES	True positives (80%)	False positives (20%)	100%
NO	False negatives (10%)	True negatives (90%)	100%

A further analysis of the HALS data indicated that the false negative group represented almost 53% of the 1991 HALS adult population. In other words, more than half of the adults with disabilities as defined by HALS had originally been missed by the census filter questions. Consequently, sampling only from the group of individuals who reported YES on the census form would seriously bias the post-censal survey results, if the target population is defined by the HALS screening questions. In order to prevent such a bias, the HALS sampling strategy consisted of selecting a sample among individuals who answered YES to the census filter questions (*referred to as the **YES sample***) and a sample from those who answered NO to the filter questions (*referred to as the **NO sample***).

The 1991 HALS data showed that although the NO sample contributed more than half of the HALS disabled population, most of the individuals in that group were mildly disabled; that is, they reported fewer limitations and required fewer accommodations. This means that those who perceived themselves to be mildly limited were more likely to answer NO to the census and YES to the post-censal survey compared to those with severe limitations. The following table compares the level of severity among the disabled population identified in the YES sample and the NO sample.

Table 2 – Severity of disability among YES sample and NO sample (1991 HALS)

	YES Sample	NO Sample
Mild	29%	67%
Moderate	40%	27%
Severe	31%	6%

Although the sampling of the NO population was necessary to eliminate any bias, it was, however, very costly and time-consuming to implement, given the relative sample size required for the NO population compared to the YES population. This is because the probability of someone in the NO sample answering YES in HALS is about 8 times smaller than the probability of someone in the YES sample to answer YES in HALS. As a result, in the

1991 HALS, approximately 35,000 adults were selected from the YES sample compared to 113,000 from the NO sample.

An additional drawback of this sampling strategy was that it eliminated the possibility of developing comparable datasets on disability using other surveys. To achieve this goal it would be necessary to develop new census filter questions that correspond as closely as possible with the HALS definition of disability. If such filter questions could be developed, it would then be possible to use them as a substitute to the long series of HALS screening questions in other social surveys which are not focused on disability. This was not the case for the 1991 Census filter questions. These questions were too imprecise to be used without the follow-up post-censal survey.

3.2 Reasons for the existence of false positive and false negative respondents

A number of factors are responsible for the discrepancy between the proportion of the census disabled population and the HALS disabled population (discrepancy due to the existence of false positives and false negatives). Firstly, as mentioned earlier, the census disability filter questions consist of only two questions, while the post-censal survey includes an extensive number of questions to identify persons with disabilities. Therefore, compared to HALS, the census is less precise in identifying the disabled population, which results in a variation in the number of disabled persons provided by the census and the one available through the post-censal survey.

Secondly, the mode of data collection such as proxy versus non-proxy is likely to influence the difference between the census and post-censal results. A proxy method is one in which a member of the household other than the intended respondent answers on behalf of the respondent. During the census usually one household member completes the census form on behalf of all household members and therefore responds to the disability filter questions for everyone in the household.

However, during the post-censal survey, the information about disability is obtained as much as possible directly from the intended respondent (non-proxy). Proxy is allowed only in special circumstances. For example, the respondent's health condition could make it difficult for him/her to answer the questions. There could be a language barrier with the selected respondent or the respondent could be hospitalized or absent for the duration of the survey. Studies have found that surveys that allow proxy interviews are likely to result in lower disability rates since proxies tend to underestimate the degree of activity limitations experienced by household members.²

² Binder, D. A. and J. P. Morin. 1988. "Use of questions on activities of daily living to screen for disabled persons in a household survey." *The Canadian Journal of Statistics*. Volume 16, Supplement: 143-156.

Thirdly, the survey context within which the disability questions are put is likely to influence the variation in the proportion of disabled population.³ The emphasis of the census is on general characteristics of the household, while the HALS is a disability survey that targets individuals who may experience activity limitations. Responses to the disability questions depend to a great extent on the respondent's perception of the situation and are therefore subjective and influenced by the context in which the questions appear.

Fourthly, the time gap between a census and a post-censal survey might have an impact on the differences in responses. It is possible that persons with mild disabilities report limitations at the time of the census, but change their answers after four or five months during the post-censal survey because of the reduction in the degree of their activity limitations. Conversely, activity limitations may appear during the time elapsed between the census and the post-censal survey.

4. PREPARING THE WAY FOR THE 2001 PALS

4.1 Research project: Developing “new” filter questions (1997 – 2000)

In looking ahead to the 2001 post-censal disability survey, Statistics Canada embarked on a research project to determine whether more efficient census filter questions could be developed to improve the identification of the target population in the 2001 survey. The goal was to develop a short set of questions that would cover more of the potentially disabled population, especially those respondents with more severe disabilities. The objective was to find questions that would substantially reduce the false negatives to the point where the NO sample could be completely eliminated from the 2001 post-censal survey.

At the same time, it was hoped that more efficient and inclusive filter questions could also be used as a “global” indicator of disability. That is, the new filter questions could be incorporated in other social survey instruments and allow the definition of disability to become standardized across Statistics Canada's social surveys.

In summary, the two major objectives of the research project were:

- to streamline the collection process of post-censal disability surveys by reducing the required sample size (that is, to eliminate the use of a NO sample);
- to harmonize the definition of disability in Statistics Canada's social surveys including surveys on labour, health, education and Aboriginal people, in order to ensure the development of a comprehensive database on persons with disabilities.

This research project was undertaken between 1997 and 2000. It began with qualitative research, including linguistic analysis of question wording. This was followed by a quantitative evaluation phase in order to assess the efficiency of the new filter questions.

³ *ibid*

4.1.1 First phase of research: Developing the 2001 Census filter questions (1997)

The first phase of the research project began in the fall of 1997 with the purpose of developing new filter questions. Given that the disability filter questions were to be used at a broader level (that is, applicable to post-censal disability surveys as well as other social surveys), a certain set of criteria was desired.

First of all, the new filter questions had to be broad and inclusive in order to cover more of the potentially disabled population and to allow persons with all types and levels of disability to take part in the survey. Second, the questions had to be applicable to the whole population, that is, children, adults and the elderly. Third, the new filter questions had to be concise enough to be inserted in a number of survey instruments (whether social or general health surveys) and in the census long form. Fourth, the language used in the questions had to be understandable and clear enough to be used in self-administered surveys, without intervention from an interviewer, but also be applicable in telephone and face-to-face interviews.

A series of tests was conducted to compare the filter questions used in 1991 (*referred to as the “old filter questions”*) against the “**new filter questions**.” The testing results led to the replacement of the old filter questions with the new ones. The 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 or 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, the new ones eliminated negative or severe sounding terms, and shifted the limitation from the person to the activity. The term “limit” has been replaced by “reduce” in the new filter questions. The response categories of “sometimes” and “often” have been added to the new filter questions to allow the possibility of reporting limitations that are recurring, but not constant. Finally, the old filter question “Does this person have any long-term disabilities or handicaps?” has been replaced by a shortened version of the ADL questions. This new question, which is worded as “Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?”, is much more easily understood by respondents. In summary, the new filter questions are more similar to the post-censal disability screening questions.

4.1.2 Second phase of research: Evaluation of the new filter questions (1998 – 2000)

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 (NCT) which was the major field test for the 2001 Census. During the 1998 NCT, two versions of the long census form were tested. One version had the old filter questions and the other version had the new ones. Half of the respondents completed the old version, while the other half completed the new version.

The NCT results showed that the new filter questions with their changed wording did result in higher disability rates. In fact, the version with the old filter questions presented a disability rate of 12.2% among the adult population, while the version with the new filter questions indicated a disability rate of 18.8%. In other words, the new filter questions allowed a larger number of individuals to report a positive answer.

However, it was important to find out whether or not these individuals who answered YES to the filter questions during the NCT would correspond to the post-censal target population. A test (the 1999 HALS Test) was conducted with 12,500 respondents from the 1998 NCT to find out more about the impact of the new filter questions on the number of false positives and false negatives. Respondents who had answered YES or NO to the census questions were contacted by telephone in April 1999 and asked to respond to the 1991 HALS screening questions. Their answers to the screening questions were then correlated with their answers to the census filter questions. It was hoped that the new filter questions would capture more of the disabled population of all levels of severity, but particularly the mildly disabled individuals; a group that was previously coming mainly from the NO sample in 1991.

Table 3 shows the percentage of each severity level screened in by the census filter questions in the 1999 HALS Test. An analysis of the results indicated a stronger relationship between the new filter questions and the HALS screening questions compared to the old ones. That is, the new filter questions screened in more of the disabled population for all three levels of severity (mild, moderate and severe). This was particularly true for persons with milder activity limitations. For example, the old census filter questions screened in 12%

of persons with mild disabilities (88% of the mild disabled came from the NO sample), while the new filter questions screened in 23% of the mildly disabled persons. In other words, for each level of severity, the new filter questions screened in a higher proportion of the post-censal target population.

Table 3 – Severity of disability identified by OLD and NEW filter questions (1999 HALS Test)

	OLD filter questions	NEW filter questions
Mild	12%	23%
Moderate	45%	61%
Severe	76%	84%

The PALS Pilot Test was conducted between May and October 2000 to prepare for the 2001 post-censal survey, but also to gather further evidence on the performance of the new filter questions. This test was designed mainly to answer the question: *What population would be left out if the NO sample was excluded from the post-censal survey?* The results showed that the population that would be left out is the less severely disabled persons. For instance, only 2.4% of the pilot test's false negative respondents were severely disabled, compared to 20.6% of the true positive respondents (See Table 4).

Table 4 – Severity of disability among true positives and false negatives (PALS Pilot Test)

	True positives	False negatives
Mild	43.5%	84.6%
Moderate	35.9%	13.0%
Severe	20.6%	2.4%

Not only were there fewer severely disabled respondents among false negative respondents than in the true positives, but analysis of their characteristics indicated that the severely disabled false negative respondents reported fewer problems than the severely disabled true positive respondents. For example, a smaller proportion of severe false negative respondents reported being completely unable to work or receiving disability-related income compared to the severe true positive respondents. These results showed that the population that would not be included in the survey, if the NO sample were eliminated, was on average relatively mildly disabled.

4.1.3 Research project conclusions

The results of the testing projects conducted between 1997 and 2000 were consistent in showing that while the coverage of the new filter questions was not perfect, it was much improved compared to the situation in 1991. That is, the new filter questions covered a larger proportion of the target population than the 1991 filter questions, and most importantly, did not leave out a significant portion of the population with severe disabilities.

The new set of questions could also be used as a “global disability indicator” in other Statistics Canada’s surveys, thereby increasing the scope of available data on persons with disabilities. Although it was recognized that the resulting disability rates would vary depending on the survey context and methodology, this improved consistency in the measurement of disability would enhance the usefulness of data on persons with disabilities.

Therefore, it was decided that the new filter questions would be used in the 2001 Census form. Table 5 presents the disability rates obtained from the census and post-censal surveys in 1991 and 2001.

Table 5 – Disability rates by age group in census and post-censal disability surveys, 1991 and 2001 (population in households)

Age Groups	1991		2001	
	Census	HALS	Census*	PALS
Total population	8.4	14.7	16.0	12.4
Under 15	2.6	7.0	5.0	3.3
15 and over	10.0	16.8	18.6	14.6

* Full results from the 2001 Census disability filter questions will be available from Statistics Canada in early 2003.

5. OPERATIONAL DEFINITION OF THE 2001 PALS POPULATION

Figure 1 presents a graphical illustration of the sampling strategy used by the 2001 PALS. As shown in the graph, the PALS interviews begin with the same filter questions that appear on the 2001 Census form followed by a series of detailed disability screening questions. The filter and screening questions are to be administered to all respondents. Respondents who answer YES to at least one of the filter or screening questions are included in the disabled population. These respondents continue the interview to the end. The interview for the other respondents (that is, those respondents who answer NO to filter questions as well as screening questions) stops after the screening questions. These respondents are not part of the post-censal disabled population.

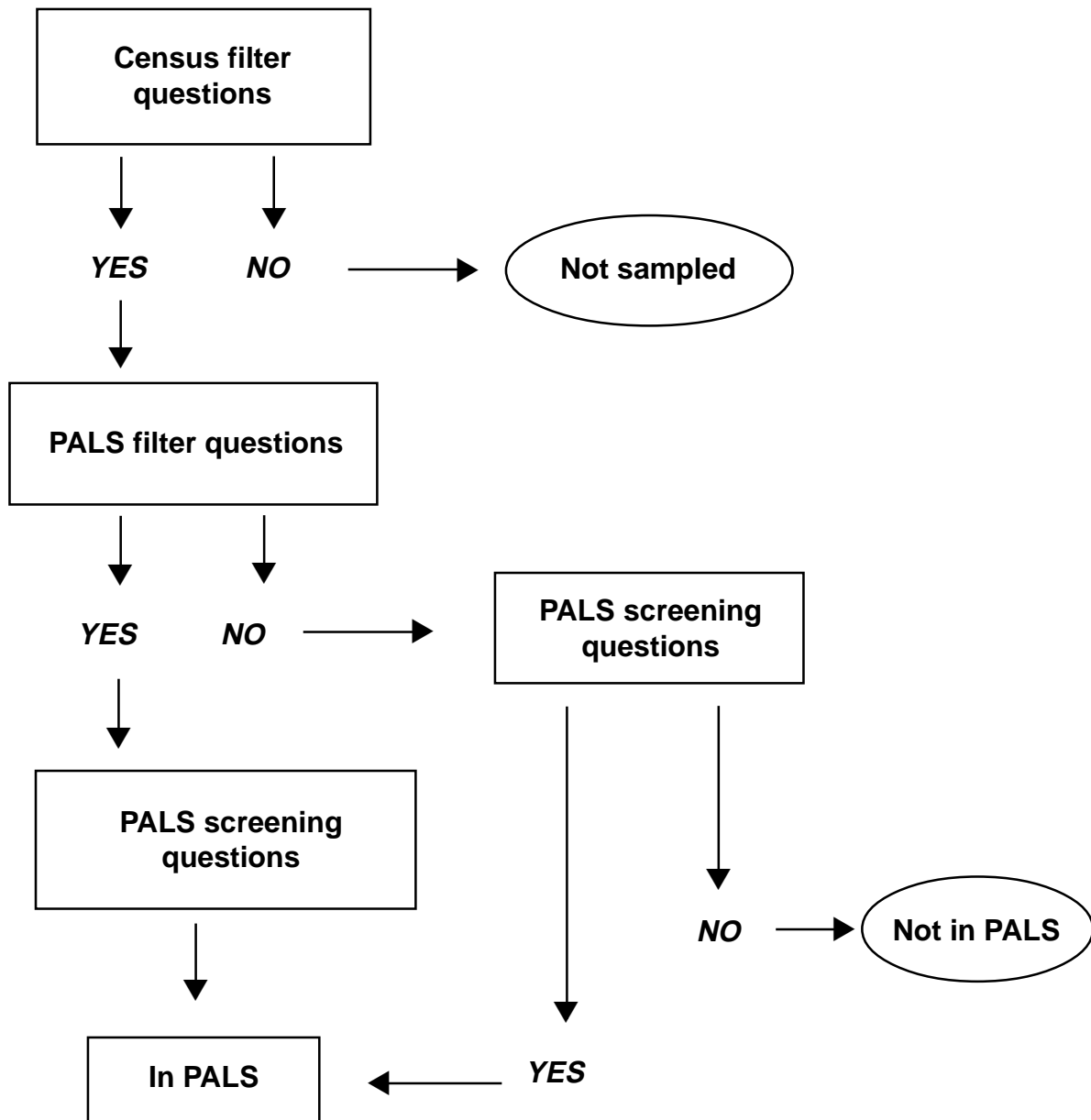
The target population of the 2001 PALS is therefore those respondents who indicate a limitation to the 2001 Census filter questions and who maintain some evidence of limitation in PALS through the PALS filter or screening questions. It therefore eliminates from its target population respondents who no longer report a limitation at the time of the PALS interview.

In summary, the following new strategies were implemented for the 2001 Census and 2001 post-censal survey:

- Use of the new filter questions on the census form and the 2001 post-censal disability survey as well as other Statistics Canada's social surveys;
- Exclude the NO sample (that is, those respondents who answered NO to the disability filter questions on the census form) from the 2001 post-censal sample;
- The 2001 PALS disabled population consists of those respondents who answer YES to the census filter questions and then during the PALS survey report a limitation through a positive answer to either filter questions or screening questions included in the PALS questionnaire.

Adopting the above new strategies allows the 2001 post-censal survey to efficiently identify a population with all levels of severity, including those persons with severe disabilities.

Figure 1 - PALS 2001: Operational definition of population with disabilities



6. THE 2001 PALS SURVEY

In the decade between 1991 and 2001, the World Health Organization revised its model and classification of disability. The *International Classification of Functioning, Disability and Health (ICF)* was officially launched in 2001. Statistics Canada's 2001 post-censal disability survey uses the ICF as its framework, and views disability as the interrelationship between body functions, activities and social participation, while recognizing the role of the environment as providing barriers or facilitators. The name change, from *Health and Activity Limitation Survey* to *Participation and Activity Limitation Survey*, serves to underscore this updated view of disability and the significant changes implemented in the survey.

The Participation and Activity Limitation Survey was conducted between September 2001 and January 2002. The survey population for both children (under 15) and adults (15 and over) was selected through the two new census disability filter questions on the 2001 Census questionnaire. After the 2001 Census, a sample of individuals who reported an activity limitation to the (new) census filter questions was selected. Respondents who answered NO to the census disability questions were not included in the PALS sample.

The population covered by the survey was persons residing in private and some collective households in the ten provinces. Persons living in institutions and persons living in the three territories as well as people living on the First Nations reserves were excluded from the survey. The interviews with respondents were conducted by phone with the interviewers completing a paper and pencil questionnaire. A small number of face-to-face interviews was conducted as well.

The PALS interview began with the census disability filter questions followed by a series of detailed screening questions on activity limitations. If respondents answered NO to all of the filter questions and screening questions, the interview ended. But if respondents answered YES to any of the filter questions or screening questions, the interview continued to collect information on the impact of disability on their everyday activities and other aspects of their life, such as education, employment, leisure, transportation and accommodation. The PALS sample size was 43,000 consisting of approximately 35,000 adults and 8,000 children. The response rate was 82.5%.

The PALS survey collected data on:

- difficulties with certain daily activities, such as moving around, hearing, seeing, communicating and learning;
- type and severity of the activity limitation;
- specialized equipment and aids that are used and/or needed;
- help required to complete everyday activities;
- impact on employment, education, leisure, accommodation and transportation;
- information on out-of-pocket expenses related to specialized aids and services, medications, transportation, etc.;
- economic characteristics, such as insurance coverage and sources of income.

There are major differences between the HALS and PALS with respect to the questionnaire content. For example, compared to the 1991 HALS, considerable changes have been made to the disability screening questions of the 2001 PALS. In 1991, 32 screening questions were used to identify six types of activity limitation among adults: hearing, seeing, speech, mobility, agility and other (a grouping of non-physical disabilities related to psychological conditions, learning, memory, etc.). The 2001 PALS collected data on ten types of limitation: hearing, seeing, speech, mobility, agility, learning, developmental disability or disorder, psychological, memory limitation and chronic pain. Major changes were implemented in the PALS disability screening section of the questionnaire compared to the 1991 HALS:

- Most of the 1991 HALS disability screening questions had only two response options of “YES, HAS DIFFICULTY” and “NO DIFFICULTY”. However, the choice between a YES and NO response was not always easy or clear for many respondents, in particular for those with mild or cyclical disabilities whose limitations were not significant or constant. Therefore, where applicable, the 2001 PALS screening questions offered respondents a new scaled-response category. For example, for questions on mobility and agility, respondents were provided with the option of selecting response categories of “YES, SOMETIMES”, “YES, OFTEN OR ALWAYS” or “NO”. In some questions, the frequency and intensity of the limitations were probed to provide more detail on the severity of the disability.
- In the PALS, some screening questions have been more precisely defined to avoid ambiguity and some have been expanded. For example, in the 2001 survey new questions were designed to better identify non-physical disabilities including learning disabilities, developmental disabilities and psychological conditions. In the 1991 HALS, persons with learning disabilities, mental illness and developmental disabilities were grouped together under the category of “Other”. This significant content development in the 2001 PALS shifts the focus from almost exclusively physical disabilities and provides a better balance between physical and non-physical disabilities.
- Another major difference between HALS and PALS is related to the approach used in the identification of the severity of the activity limitations. In 1991, a severity scale had been developed using the responses to the screening questions. Each respondent received a severity score by adding together the individual’s responses to all activity limitation questions. One point was scored for each partial loss of function and two points were scored for each total loss of function. The total score was then divided into three severity levels: mild, moderate and severe. Since some types of disabilities were identified through the use of many questions, they had more weight in the severity scale. As a result, the 1991 HALS severity scale gave more weight to certain disabilities (such as mobility and agility) than to others (such as the “other” category).

For the 2001 PALS severity scale, an index measuring the severity of the disability was constructed based on the answers to the survey questions. Points were given according to the intensity and the frequency of the activity limitations reported by the respondent. A single score was computed for each type of disability. Each score was then standardized in order to have a value between 0 and 1. The final score was the average of the scores for each type of disability. Since the survey questions differed depending on the age of the respondent, a different scale was constructed for adults (15 years and over), for children under 5 and for children aged 5 to 14. Each scale was then divided into different severity levels. The scale for adults and for children aged 5 to 14 was divided into four groups (that is, mild, moderate, severe and very severe), while the scale for children under 5 was divided into two groups (that is, mild to moderate and severe to very severe). The PALS severity scale is therefore equally weighted for all types of disabilities and this results in a different severity profile than in the 1991 HALS.

7. CONCLUSIONS

Both HALS and PALS represent post-censal surveys of persons with disabilities in Canada. They collect information on the type and severity of disabilities and the impact of disability on everyday activities as well as information on the barriers related to education, employment, transportation, accommodation and leisure activities. However, the data from the two surveys cannot be compared because of significant differences in the 1991 and 2001 Census filter questions, the sampling plans that were used in HALS and PALS, the operational definition of the post-censal survey population and the content of the questionnaires.

The following summarizes the major differences between the 1991 HALS and 2001 PALS:

- 1) **New filter questions:** The 2001 PALS uses new census disability filter questions to identify its population. The new filter questions are more inclusive than the ones used in 1991;
- 2) **New sampling plan:** The HALS sample included both respondents who answered YES to the disability filter questions on the census form and those who answered NO. But the 2001 PALS survey sampled only those individuals with positive answers to the 2001 Census filter questions. Respondents who answered NO to the census disability filter questions were excluded from the PALS.
- 3) **New questionnaire content:** The PALS questionnaire content, including new screening questions, is significantly different from that used in the 1991 HALS questionnaire, in particular the content related to the identification of the types and severity of activity limitations. This expanded content provides more detailed information regarding the type of disabilities. In addition, the new severity scale takes into account the whole range of disabilities.