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VARIATION IN DISABILITY RATES IN STATISTICS CANADA NATIONAL SURVEYS: BUILDING POLICY ON A SLIPPERY FOUNDATION

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ABSTRACT

Much Canadian disability policy work depends on evidence obtained from Statistics Canada surveys. Statistics Canada surveys employ a set of standard filter questions to identify the population with disabilities with the intent of providing consistent and reliable estimates of the disabled population. However, examination of disability rates from major surveys reveals considerable variation across surveys. Our paper examines some of the potential methodological factors that may explain this variation. We go beyond this methodological exploration to question whether policy development truly requires a single “gold standard” estimate from survey research or whether, instead, estimates constructed for various purposes are more appropriate.

KEYWORDS: Disability; ICF; Policy; Survey Design

1. INTRODUCTION

Formulating and managing policies to address the needs of Canadians with disabilities requires information about this population. At a most basic level one must know how many people are or are potentially included in the population with disabilities. Beyond this, estimates according to age, family status, living arrangements, income and a host of other attributes may be important to specific policy initiatives.

This paper was prepared for a Statistics Canada conference addressing methods for surveying “difficult to reach” populations. However, unlike some groups where their “difficult to reach” status is rather obvious (e.g. people who are homeless or people engaging in crime) persons with disability are everywhere. Indeed this is one of the central claims often made in defence of increased funding for disability-related policy—that is, “disability affects us all.”

While disability is a very common experience, however, it is one that has proven somewhat slippery to capture in survey research. Indeed attempts to pin it down have sometimes produced very different results—frustrating the desire for a simple answer to what seems to be a simple question—“how many Canadians have disabilities?”

National and international reviews of survey results have also found that survey estimates of the rate of disabilities can vary widely (Mbgoni 2003; Bajekal et al 2004; Gregory 2003). Bajekal et al (2004) identify three major factors that contribute to different rates of disability found by national surveys: actual changes in the population, differences in the definition of disability and differences arising from research methods. In order to use survey results when conducting disability policy it is critical to be able to separate these three factors. Changes in the population are, of course, fundamental as these changes certainly drive the potential costs and impacts of policy. However, the determination of what counts as a disability (definition) is equally fundamental since specific policies are almost always designed to meet the needs of a subset of the population that might be considered disabled. Methodological factors can introduce “spurious” differences in survey-based estimates if they are not fully understood and taken into account.

The paper explores some of the factors underlying differences in disability rates reported by Canadian surveys, describes an example policy application and concludes with some suggestions for advancing Canada’s ability to analyse and apply disability-related survey results in disability policy work.

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1.1 Definition of disability

Understanding of what constitutes disability has varied historically and culturally. Further, this understanding is continuing to evolve today and there is a broad literature tracing these developments (See Bury, 1996 and Schalock, 2004 for two examples). Traditional cultural or religious beliefs about disability as a punishment from God for past wrongdoings or a curse from an evil spirit are not likely to be found in survey research. However, biomedical models developing throughout the 19th and 20th centuries have frequently provided the conceptual underpinnings for survey questions. In the biomedical view disability is generally understood as arising from defects or problems in the body and the corresponding survey questions might probe for the presence of such defects. Closely related to the biomedical model, rehabilitation sciences identify disability in terms of functional limitations and survey items focus on the ability to complete activities of daily living (Schalock 2004).

Biomedical approaches to understanding disability focus on the individual. However, beginning in the 1980s, disability studies scholars and activists with disabilities began to build on the foundations of the civil rights and other social movements to highlight the social causes of disability. From this vantage point, some advocates of a social model of disability argue that survey questions should focus on sources of social oppression rather than on personal impairments or functional limitations (Oliver 1990). The social model leads to an expectation that disability surveys should be sensitive to the various social environments in which respondents participate.

Yet another perspective on disability sees it as normal human variation. Members of the Deaf community present themselves as a minority culture with its own history, language and institutions distinct from those of a hearing world. Disability arts attempt to build a positive disabled identity through arts, performance and literature. The implications of these perspectives for survey research are still unclear.

Since 1981 the World Health Organization has provided a standardised conceptual framework intended to bring a bit of order to understanding and collecting information about disabilities. The first version of this schema was called the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This framework has guided many disability surveys including Statistics Canada's principal disability survey, the Health and Activity Limitations Survey (HALS) conducted in 1986 and 1991. The ICIDH was replaced in 2001 with the International Classification of Functioning, Disability and Health (ICF). The ICF defines disability as activity limitations or participation restrictions that result from a negative interaction between a person with bodily impairments and the environment in which that person functions. The ICF is a direct response to the challenges posed to ICIDH by a social model of disability.

1.2 Canada's disability survey strategy

In 1999, in anticipation of the 2001 Census, Statistics Canada adopted a disability survey strategy comprising two elements. First, a standard set of disability filter questions was devised that would be incorporated into all surveys including the Census itself where it was desired to identify the population with disabilities. Second, it was proposed to resume conducting a detailed post-censal disability survey following the 2001 Census and every census thereafter. The sample for this survey, now called the Participation and Activity Limitation Survey, would be drawn from those who had responded affirmatively to the disability filter questions in the Census.

It was expected that incorporating a standard set of filter questions on all surveys would eliminate or at least reduce the inconsistency of results. In effect, use of standard questions would eliminate both definitional confusion and question wording as sources of variation in the disability rates produced by all of Statistics Canada's surveys.

The two filter questions are reproduced in box 1. As can be seen, the first question focuses more or less on disability understood as "activity limitation" while the second one addresses disability as a "participation restriction". In order to calculate an overall prevalence rate, the possible answers are combined with an "or" condition so that any affirmative answer results in considering that person to have a disability.

Box 1: Statistics Canada Disability Filter Questions

Do you have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?

- *Answer categories:*
 - Yes, sometimes
 - Yes, often
 - No

Does a physical condition or mental condition or health problem reduce the amount or the kind of activity you can do:

- At home?
- At work or at school?
- In other activities, for example, transportation or leisure?
- *Answer categories:*
 - Yes, sometimes
 - Yes, often
 - No

Since 1999, the filter questions have been incorporated into a variety of major national surveys including the Survey of Labour and Income Dynamics (1999-2002), the Canadian Community Health Survey (2000-2001, 2002-2003) and the Aboriginal People's Survey (2001). The questions are to be included in the 2004 Survey of Household Spending as well as future years of the SLID and CCHS. The disability filter questions have also been used in public opinion research (Enviroics 2004).

2. VARIATIONS IN CANADIAN DISABILITY SURVEY RESULTS

Despite the standardisation of the disability filter questions, Canadian surveys continue to produce very different estimates of the disability rate. Of the surveys shown in figure 1, the Participation Activity Limitation Survey (PALS) produces the lowest rates, followed by the Census and the Survey of Labour and Income Dynamics (SLID) and finally the Canadian Community Health Survey (CCHS) is highest. The two rates shown for PALS are the rate based on responses to the filter questions only and the rate based on the combination of filter questions plus the additional detailed disability screening questions.

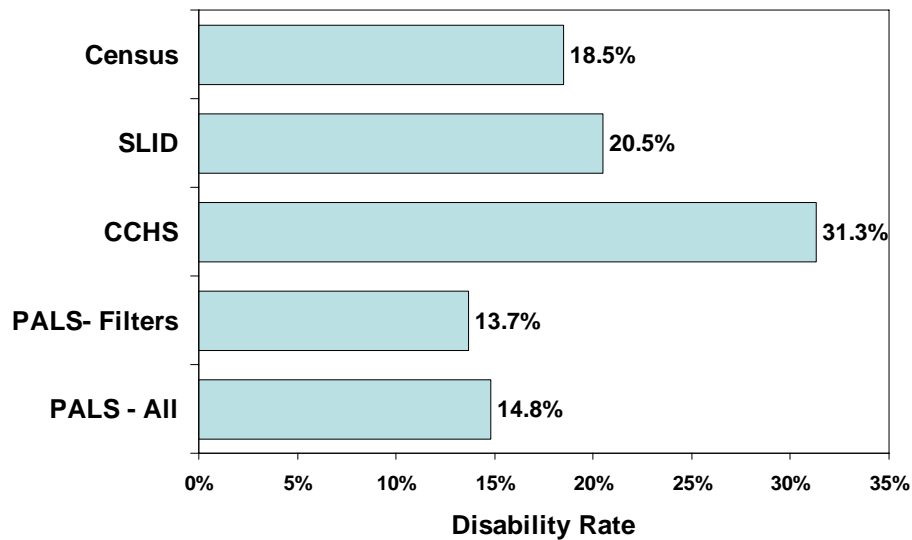
2.1 Possible Reasons for Variation in the Disability Rate from Canadian Surveys

There are many possible explanations for the fluctuations in the disability rate measured by Canadian surveys. This section explores sampling, subjective versus objective questions, survey context, proxy responses, placement of the disability filter questions, and language / cultural issues as possible explanations.

Sampling: Sample design can have very powerful effects on the results of a survey. In the case of PALS, there is roughly a 25% drop in the disability rate between the Census and PALS. People who declare a disability at the time of the Census but do not indicate any condition for PALS are considered "false positives" because they were incorrectly identified as a person with a disability when selected to participate in PALS. Since there is a gap of 4-6 months between the Census and PALS, some of these "false positives" may be attributed to short-term conditions that no longer exist at the time of PALS. Less clear is the impact of proxy responses on the many Census forms that were completed by one individual in the household on behalf of all other members. Individuals identified in this way as having a disability may not have considered themselves to have a disability when they were asked to personally participate in PALS (see the discussion of proxy responses below).

Figure 1: Disability Rates for Major Surveys

**Figure 1: Disability Rates for Major Surveys,
Ages 16-102, 2001**



Subjective versus objective questions: The essence of survey research is to require respondents to decide how to answer the survey questions. In the case of Statistics Canada’s disability filter questions, there is a significant amount of judgement required on the part of the respondent to decide whether he or she “has any difficulty” or experiences “reduc[tions] in the amount or kind of activity [s/he] can do”. Issues of labelling, self-identity, fluctuating conditions, disability definition and other factors may create uncertainty or problems in making this judgement. In contrast to the filter questions, PALS also contains some 93 additional questions about very specific limitations. For example, respondents are asked whether they have difficulty reading a newspaper or hearing what is said in a conversation with three people. These additional screening questions are more objective in that (a) there is general agreement that they would constitute a disability and (b) they require less judgement in order to answer them in a particular case.

The impact of these objective questions is seen in the comparison of the two PALS rates shown in figure 1. The PALS disability rate based on the filter questions increases by about 1.1 percentage points following the screening questions. The increase indicates that the more detailed objective questions are finding conditions that people did not consider to be disabilities when they answered the more subjective filter questions.

To take advantage of this impact of objective questions in 1986 and 1991 HALS employed a different sampling design than PALS 2001. The HALS sample included a large “no sample” consisting of people who did not report a disability based on the filter questions on the Census. HALS found many “false negatives” within this “no sample” because many participants answered positively to one or more of the more detailed screening questions in HALS even though they had judged themselves not to have a disability when completing the broader Census filter questions.

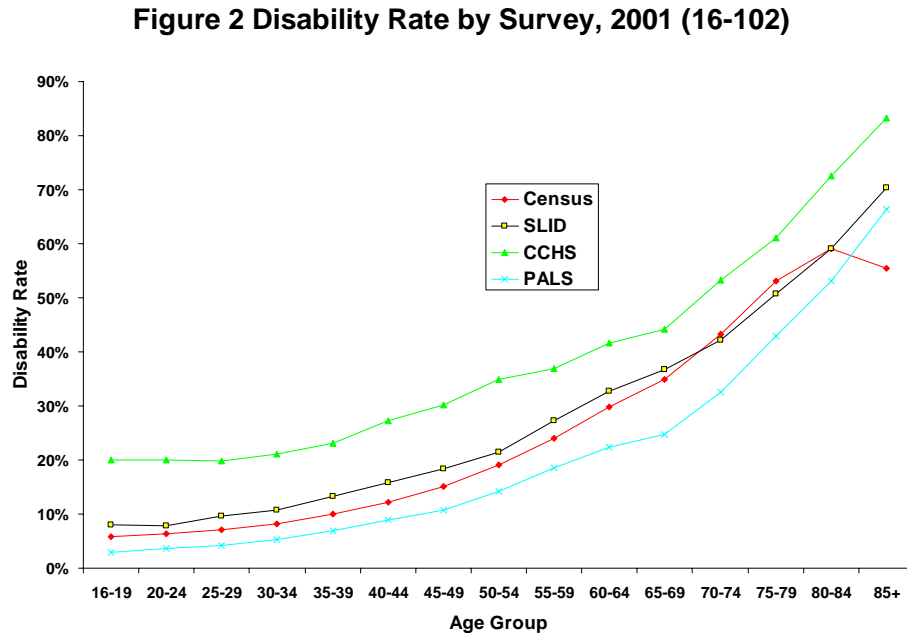
Survey Context: Health surveys have consistently found much higher rates of disability than any other type of survey. An example of this is seen in figure 1 where the overall CCHS rate of 31.3% may be compared to the lower rates of SLID (20.5%), Census (18.5%) and PALS (14.8%).

Figure 2 shows the higher rates of disability found by CCHS at all ages compared to the other surveys. Age is one of the most important factors associated with disability as disability rates increase with advancing age. The pattern

of higher rates of disability found by the CCHS is consistent across all ages, SLID and Census are always in the middle and PALS is the lowest.

One possible theory for why health surveys produce higher rates of disability suggests that the series of questions on health topics encourages people to indicate a disability, when in fact they are on the borderline of having a disability or have a very mild disability that they would not normally report to a survey. As people progress through the health survey and they are reminded of their current state of health, they may be more likely to indicate that they have a disability.

Figure 2. Disability Rate by Survey, 2001 (16-102)



Placement of the disability questions: The location of the disability questions in the questionnaire is closely related to the survey context. Answers to questions occurring late in a survey may be influenced by the topic of the survey. For example surveys on use of technology, care giving, or labour market participation (SLID) might bring about a somewhat different predilection on the part of the respondent compared to a health survey. Placing the disability filter questions near the beginning of the survey might reduce this effect. On the other hand, thinking of disability from a social model perspective suggests that it might be quite appropriate to allow the “environment” to influence respondents’ answers to disability questions.

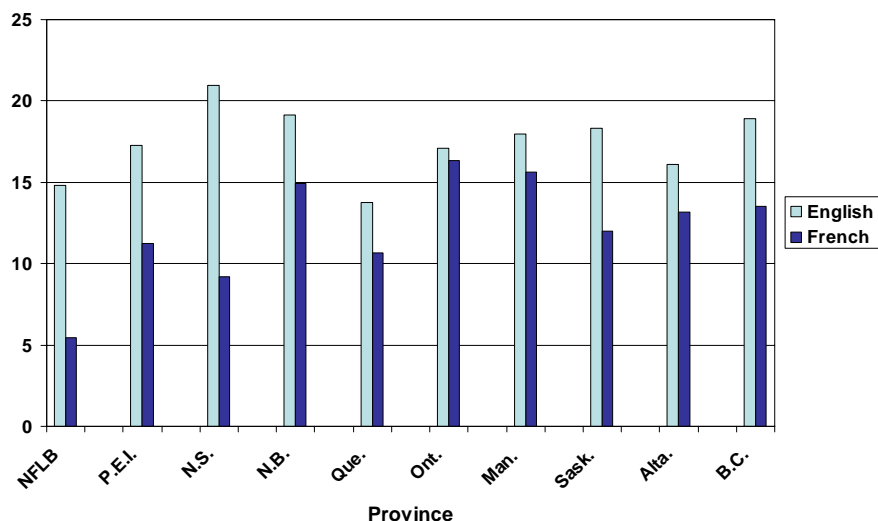
Proxy Respondents: Some surveys make greater use of proxy respondents—this is particularly true of the Census. The use of proxy respondents becomes particularly important when discussing people with disabilities. Some people are less able to communicate and must rely on others to assist them with their communication. Proxies may be more inclined to identify activity limitations in other people than the people themselves. For example, an ageing parent living with their middle-aged child may not think of himself or herself as having a disability, they just think they’re old. However, when the middle-aged child completes the Census form they may consider their ageing parent to have an activity limitation. If this ageing parent had been living alone and/or completed the Census form herself/himself, she/he would not indicate any type of activity limitation or participation restriction, and therefore would not be identified as a person with a disability.

Language and culture: The language and culture of respondents can have dramatic effects on the rates of disability found across the provinces for Canada’s two official languages. Of interest here is that Quebec typically displays

much lower disability rates for both languages, with French being the lowest. Figure 3 shows this pattern using the 2001 Census, but similar patterns have been found in other national surveys over the past several years. At first this may seem to be a language issue, but the Quebec rate is similarly low for English also. A recent public opinion poll sponsored by Social Development Canada found that a number of common conditions such as using a wheelchair were less likely to be considered a disability in Quebec than any other province (Enviroincs 2004). This finding suggests that people from Quebec may have a different belief system around what constitutes a disability. More work in this area is needed

Figure 3. Disability rate by questionnaire language and province

Figure 3. Disability Rate by Questionnaire Language and Province, 2001 Census



3. DISABILITY POLICY AND VARYING SURVEY RESULTS

These results point to some uncomfortable realities in the current fields of Canadian disability survey research and the disability policy work that draws on it.

- the desire for a “gold standard” estimate of the number of Canadians with disabilities is frustrated by the tendency of each survey to provide a unique estimate due to a variety of definitional and methodological factors
- the failed expectation that implementing a single definition of disability (common filter questions) based on the ICF would largely eliminate differences in survey estimates of disability rates

The publication of the results of PALS 2001 provides a classic example of the dangers of seeking a gold standard estimate. HALS 1991 had found 4.2 million Canadians with disabilities—and most observers expected the number to be higher in 2001 due to population growth and aging. When PALS 2001 found 3.6 million, there was a need for some clear explanations! What was going on? The methodological explanations discussed above were forthcoming and policy makers and others who cared were told that they should not, indeed could not compare the results of PALS 2001 to HALS 1991.

The substantive result of the changes in methodology between HALS 1991 and PALS 2001 was to focus more precisely on a population of more severely disabled. This begs a new question, however. What exactly is the utility of this overall number? Is there any single issue that affects all 4.2 (or 3.6) million? Indeed, are there many included within this number not particularly needing any policy interventions at all? To the extent that governments must be concerned about affordability, headlining with 4.2 (or 3.6) million may simply conjure up images of mega-expensive and unaffordable policy options.

So, the “big number” may serve a useful purpose as a headline, but as we begin to examine specific issues it is generally not useful at all. This seems to beg the question of whether surveys should be designed to estimate the populations affected by particular disability issues or conforming to particular definitions. This could be done in addition to, or even rather than, simply aiming to produce generic population estimates. In a general sense, a social model of disability predicts that various environments will provide different opportunities and impose different participation obstacles and most policy initiatives are in turn focused on specific domains. From this perspective, survey estimates aligned with these domains could be of more value than those based on more abstract or general definitions.

3.1 Possible next steps

The Government of Canada in general and Social Development Canada in particular are committed to development and improvement of policies based on evidence. However, this brief paper has illustrated that we still face challenges when using survey-based disability estimates in Canadian disability policy work. In light of challenges such as these, it seems critical to continue to improve our ability to collect, analyse and apply survey data when doing disability policy.

A potential first step would be to acknowledge that there is no “gold standard” estimate of the number of Canadians with disabilities. Rather, the estimate must depend on the definition and, ultimately, the social purpose for which it is being constructed. It is reasonable to expect that the estimates of the number of people with physical or mental impairments, the number who believe that they are at risk of discrimination in employment due to a disability, and the number who require some type of assistive aids or services should differ. While this is already generally understood, there seems to be an undue emphasis on the “big number” in much ongoing policy work.

The Statistics Canada disability survey strategy built around the standard ICF-based filter questions is an elegant and efficient method of building up a large database of disability data. This is particularly so as the disability filter questions are also being adopted by some public opinion researchers as well. It is now clear, however, that adopting a single set of filter questions cannot be expected to result in nearly identical rates of disability from every survey. It will be important to determine more precisely the impacts of factors such as those identified above on rates including whether these effects differ for different demographic groups. At the same time, continuing to extend the range of surveys that incorporate the filter questions is recommended.²

Incorporating into selected surveys the definitions of disability corresponding to those embedded in key programs or legislation may be a useful strategy. This has already been done in the case of employment equity and the PALS. The disability tax credit and the CPP disability benefit are two other major federal government initiatives where this strategy might be employed. It would be important to determine which survey(s) would be most appropriate for this to be done and, if possible, to conduct some testing to explore whether methodological factors are affecting these estimates in the same way as they affect those arising from the ICF-based filter questions.

Members of the disability community have urged the Government to adopt a social model of disability in its legislative, policy and program initiatives. Recently, this call was also repeated by the technical committee on tax measures for persons with disabilities convened by the Ministers of Finance and Revenue (Torjman, Brown et al 2004) and the Government has acknowledged the importance of doing so (Canada 2002, 2004).

To support this direction, survey definitions of disability and survey methods must also be consistent with the social model. The ICF-based approach adopted by Statistics Canada permits this to occur and current survey development work on PALS 2006 is to be very explicitly guided by ICF and the social model of disability.

² Questions have been raised about the content of the filter questions themselves. Most significant is the absence of any type of qualifier that the conditions considered should be “long-term” in nature as recommended by the WHO guidelines for disability survey questions. Changes to the filter questions may be warranted, but should be introduced only after thorough testing to ensure that they have the desired effect.

In this paper, we have suggested that the social model points away from an expectation of a single gold standard estimate of the disability population and towards an expectation of multiple estimates. Canadian survey data do provide a variety of estimates that do seem to coincide with social model expectations. However, as we have attempted to show in a preliminary way, it is not always clear the extent to which differences in survey estimates are arising from actual differences in populations versus methodological factors. It is our hope that our efforts demonstrate the need for a modest research program to address this question. Success in this regard will substantially improve the evidential foundation required to develop sound disability policy.

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