

## Article

*Living with disability series*

# Defining disability in the Participation and Activity Limitation Survey



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## *Living with disability series*

# Defining disability in the Participation and Activity Limitation Survey

by Andrew MacKenzie, Matt Hurst and Susan Crompton

**D**efining disability is a difficult task. A multitude of perceptions surrounds the question of what constitutes a disability, and a disability to one person can be a typical part of life to the next. To confuse the issue further, perceptions of disability are fluid and ever-changing as society evolves and the sources of information about disability continue to change.

Over the course of the next few months, *Canadian Social Trends* is planning to release several articles that use the national Participation and Activity Limitation Survey (PALS) to examine a variety of issues related to disability. In this first article of the “Living with disability series,” we briefly explore the evolution of theories about disability and outline contemporary thinking about how to define disability. We then compare PALS data from 2001 and 2006 to see how the incidence of disability is growing in Canada, and the proportion of growth that is due to changing public perceptions of disability.

### **The ever-changing concept of disability**

Disability is a fluid concept and societal conceptions of disability have shifted dramatically over time. Before the 20<sup>th</sup> century, many

early conceptions of disability involved religious and supernatural explanations. These interpretations ranged from karma,<sup>1</sup> God’s will or a test from God,<sup>2,3</sup> reincarnation,<sup>4</sup> and divine protection,<sup>5</sup> to name just a few.

Many western cultures subsequently moved away from religious and supernatural explanations toward more scientific conceptions of disability. However, the rise of the scientific method of analysis also gave rise to a major obstacle for people with disabilities, namely the “medical model of disability.”<sup>6</sup>

The medical model of disability is oriented towards clinical diagnosis, treatment, cure and prevention. It focuses on the individual in terms of their deficiencies, ailments or inabilities. The model is interested in medical facts whereby disability is caused by a physiological disease or injury resulting in a “damaged” body or mind that does not function in a manner considered normal for a human being. As such, it ignores the fact that society organizes itself based on certain assumptions, one of which is that everyone is able-bodied. Having to navigate through a world designed to meet the needs and convenience of the able-bodied can marginalize people who are not able-bodied, affecting their physical,

social, political and financial well-being.

In 1965, this “medical model” of disability began to change. That year marked the publication of a seminal article that proposed a whole new approach to thinking about disability. Author Saad Nagi argued that every day, people with disabilities encounter barriers to their daily activities that are not caused by their impairments, but by an environment that does not take account of their impairment. In other words, it is this inattention that creates disability; for example, the building that does not include wheelchair ramps; the conference that doesn’t provide sign language interpretation for attendees with hearing limitations; or the doctor who doesn’t clearly explain how to take a new medication to someone with cognitive difficulties. In other words, Nagi proposed, disability is effectively a social disadvantage that an unsupportive environment imposes on top of an individual’s impairment.<sup>7</sup>

The 1965 article was the major breakthrough for Nagi’s concept of disability. The idea flourished in the 1980s and 1990s, and developed into the “social model of disability.” The basic concept—that disability is related to the way an able-bodied society organizes its physical,

political, economic, and social relationships—has had a profound impact on thinking about disability in western cultures. Some researchers have come to view disability as “a loss of civil rights rather than simply a physical impairment.”<sup>8</sup> And while it is true that this new model has been the topic of much debate during its relatively short life, it now underlies most discussions of disability.

### Putting the social model into practice

The social model’s greatest success is arguably its adoption by the World Health Organization (WHO), which has used it to develop its most recent (2001) classification system of disability. The system is designed to provide a universal framework for measuring, thinking and communicating about disability, and is intended to be used for both clinical and statistical studies.

The first WHO disability classification system was introduced in 1980. Although the ICIDH (International Classification of Impairment, Disability and Handicap) acknowledged the functional difficulties stemming from a health condition, it retained many features of the “medical model.” It modelled disability as a sequence of events, beginning with an illness or injury that caused a change or impairment to a person’s ordinary level of functioning. This impairment produced a disability if a person had difficulty performing an activity in a “normal manner”; and the disability produced a handicap if a person was limited in fulfilling a “normal role” in society.<sup>9</sup>

Almost from its inception, there was dissatisfaction with the ICIDH, and development of a classification system that reflected the social model of disability continued throughout the 1980s and 1990s. In 2001, the ICF (International Classification of Functioning, Disability and Health) was approved by all WHO member states. Unlike the uni-directional “straight line” approach of the ICIDH, the ICF describes disability

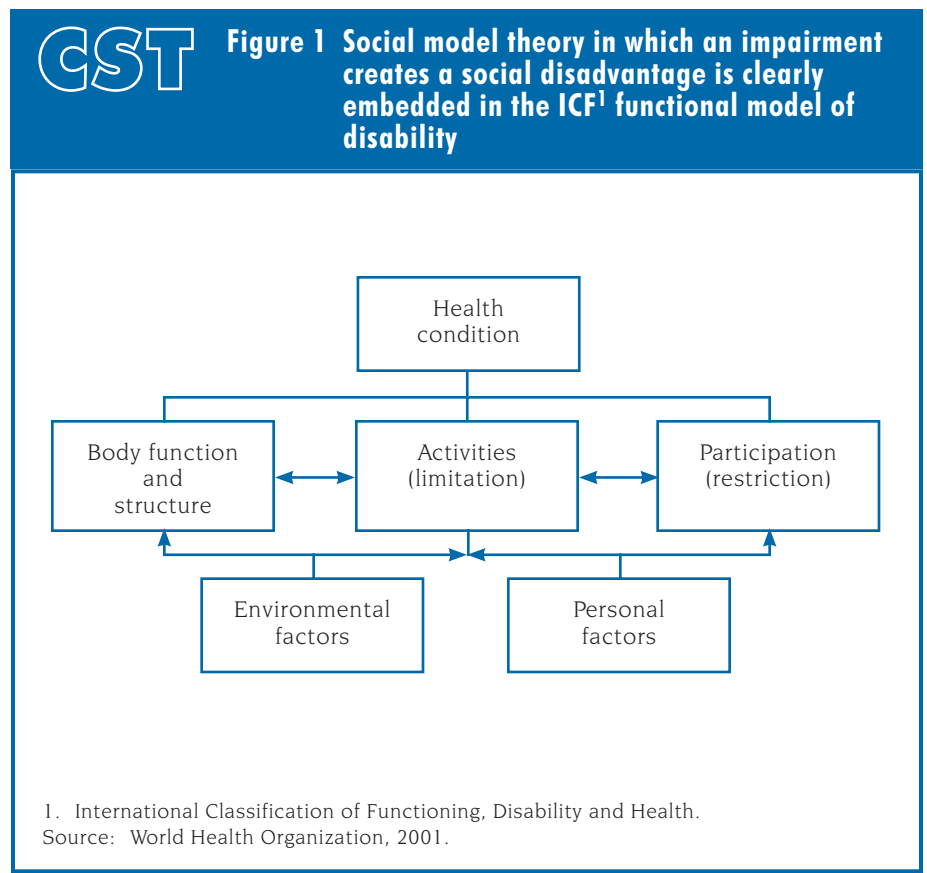
as a complex set of relationships in which various factors can operate on the individual’s impairment, both directly and indirectly; it also expands the number of factors affecting the individual to include the larger society. These factors include: the everyday activities the individual undertakes (activities); individual characteristics, such as education, income, family and friends, motivation, and so on (personal factors); their involvement in social and community relationships and events (participation); and their general environment, which includes the physical, social, financial and political elements that make it easier or harder to function day-to-day (environment) (Figure 1).

### How did Statistics Canada implement the WHO definitions?

To develop a survey on disability, one of the first steps is to decide upon a conceptual model that defines what is considered a disability. Statistics Canada’s Health and

Activity Limitation Survey (HALS), conducted in 1986 and again in 1991, adopted the 1980 ICIDH model of disability. HALS was Statistics Canada’s first post-censal disability survey<sup>10</sup> and it produced important information about the demographic and socioeconomic characteristics of people with disabilities, the type and severity of their disabilities, and their day-to-day living experiences.

When planning began in 1997 for the 2001 post-censal disability survey,<sup>11</sup> it was decided to adopt a draft version of the ICF as its underlying framework. The draft ICF contained a description of what was and what was not considered a disability or activity limitation, while simultaneously acknowledging the effects of the environment on impairment. Moreover, the definition of disability as occurring only when someone feels they are prevented from participating in desired or necessary activities lends itself very well to survey applications: when the



respondents themselves determine the extent to which they are limited by their condition, the survey does not need to judge whether a condition is or is not disabling. In other words, the survey only needs to ask the right questions and let the respondents decide.

After adopting the ICF concept of functional disability, the first hurdle for the new Participation and Activity Limitation Survey (PALS) was dealing with more than 1,400 different dimensions the ICF uses to describe possible forms of disability. But instead of using the body functions and structures components of the ICF, the PALS survey designers assumed that if a respondent had difficulties in day-to-day living associated with body functions and structures, then these would show themselves in other areas, such as the activity limitation, participation restriction, and environment elements that PALS had adopted from the ICF. Having made this decision, they then identified the most common types of disabilities (including chronic pain) based on existing data from HALS. By combining the most common types of disabilities with the material selected from the ICF, the PALS design team developed screening criteria for the survey questionnaire.

They chose the bulk of these screening questions by matching an ICF item for a given disability type with a question drawn from a bank of pre-tested questions about activities of daily living. These questions ask respondents to specify activities they have difficulty accomplishing because of a health problem or condition, for example, climbing stairs, hearing or learning. Using this cross-referencing approach, the PALS team was able to identify and select a large sample of the disabled population into the survey. Once the screening questions were chosen, they were finalized for the 2001 PALS survey and maintained for 2006 (see "How disability is determined using PALS" in Appendix I.)

Asking the same screening questions in 2001 and 2006 is meant to ensure that the universe of people with disabilities meet the same criteria for inclusion in the survey from one year to the next. However, the way that people respond to these identical sets of questions can never be controlled; thus, it is possible that changing popular perceptions of disability, or of what constitutes disability, are reflected in the PALS data. The analysis in the next section offers a preliminary exploration of the possibility that the public understanding of disability is shifting in Canada.<sup>12</sup>

### **Are perceptions of disability changing over time?**

To begin thinking about the way perceptions of disability can change, consider disability as part of a continuum or spectrum. At one end of this continuum, we locate the highest calibre non-disabled persons, perhaps Olympic athletes and Nobel Prize winners; at the opposite end are people with the most severe disabilities. In between these two extremes, we find graduated levels of ability/disability involving a mix of physical and mental abilities/disabilities.

Thus, the exact point on the continuum where a specific level of ability shifts to disability is not the same for every Canadian. So when a respondent decides to report a disability on a survey such as PALS, the answer is based on that individual's "threshold of disability" on the continuum rather than an exact "location". This also means that having a disability can be a transitory condition, since people can move into and out of a state of disability depending on their individual circumstances. For example, someone who has had a knee or hip replacement may face barriers to activities and participation during a lengthy period of recovery and rehabilitation, but upon regaining their mobility, they will no longer be considered functionally disabled.

If Canadian society has become more accepting of people with disabilities, and the stigma of reporting a disability is declining over time, we would expect the "threshold of disability" to shift toward the ability end of the continuum; that is, mild levels of disability would be reported more frequently in 2006 than in 2001. In contrast, minimal changes should occur among the more severe types of disability because perceptions of severe disability are more stable over time.

Indeed, this is what we find. Canadians were more likely in 2006 to say they were disabled than they were in 2001—16.5% versus 14.6%. Furthermore, this increase is statistically significant across gender, provinces and age groups. In 2006, 15.3% of men and 17.7% of women reported an activity limitation, disability rates that are about two percentage points higher than in 2001. As we would expect, the greatest increases occurred among those aged 65 and over, and in three of the four Atlantic Provinces where the population generally tends to be older than elsewhere in the country (Table 1).<sup>13</sup>

Furthermore, as expected, the change is most evident on the border of the ability/disability threshold. Between 2001 and 2006, the proportion of Canadians reporting a mild disability rose from 5.0% to 5.9%, or about 300,000 more people; in contrast, it remained roughly the same for those reporting a very severe disability. This suggests that people's "threshold of disability" is moving closer to the ability end of the continuum (Table 2).

However, we cannot ignore the fact that Canada's population grew older between 2001 and 2006, and that older people have a higher tendency to report activity limitations. To determine how much of the change in disability rates between 2001 and 2006 was due to population aging and how much to other factors that affect the likelihood of reporting an activity limitation, we conducted a linear decomposition analysis.<sup>14</sup>

The results show that over one-third (37%) of the increase in total disability rates was due to the age composition of the Canadian population; nevertheless, almost two-thirds (62%) was attributable to the "period effect." The period effect is the combination of societal and medical changes that occur over time and can affect the way disability is self-reported by respondents; these changes may include less stigmatization of persons with disabilities, higher expectations of personal functioning, better detection and treatment of disease or injury, better assistive technologies and devices, the way individuals interact with their environment, and so on. In other words, factors that are not related explicitly to an aging population were contributing substantively to higher rates of disability reporting in 2006 (Table 3).

When we examine the four different degrees of disability separately, though, we see a steady rise in the explanatory role of aging, and a concomitant decline in the importance of the period effect. The largest increase in disability rates was recorded for the mild category, and the decomposition analysis confirms that fully 77% of that increase is due to the period effect. In contrast, 77% of the growth in very severe disabilities is due to population aging. These results offer some support for the theory that we should see increases in the amount of self-reporting of milder disabilities (but little growth for more severe disabilities) as the stigma of disability diminishes (Chart 1).

### Conclusion

The concept of disability has been refocused over time. It has changed from being defined solely in medical

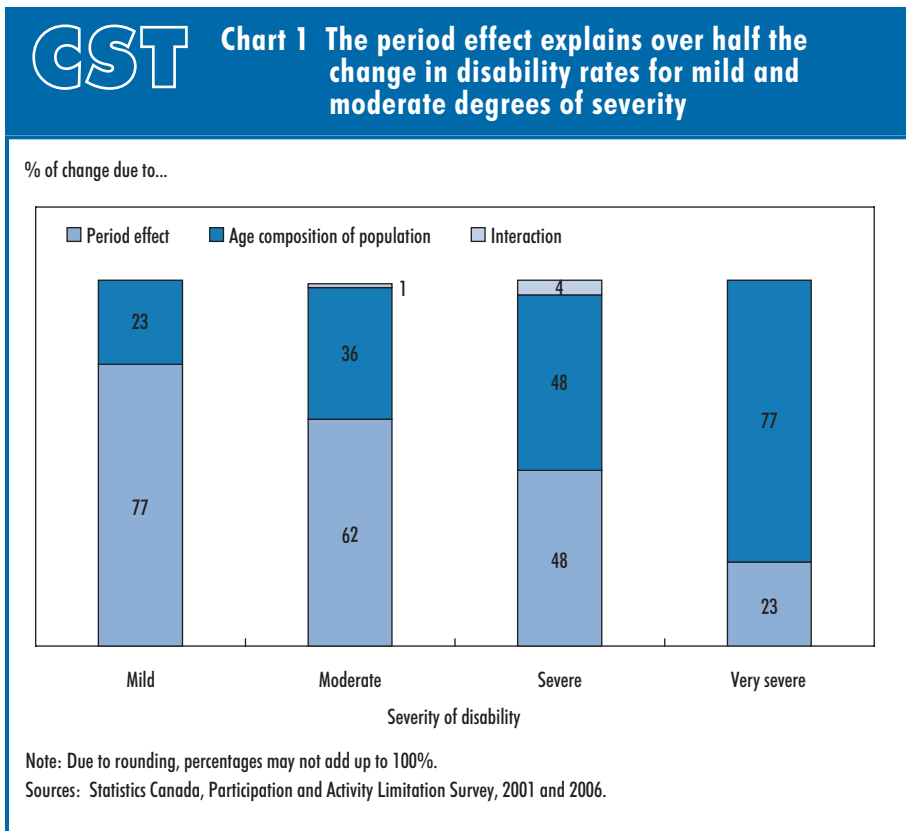
terms to being acknowledged as having a strong social dimension. Both concepts are now amalgamated in the classification system used in the ICF, as developed by the World Health Organization. Statistics Canada adopted this model for use in its 2001 and 2006 Participation and Activity Limitations Surveys.

One benefit of the definition of disability used in PALS is that researchers are able to learn whether attitudes to disability are changing in Canada over time. Certainly, a significantly higher proportion of Canadians reported being mildly disabled in 2006 than in 2001, though rates for very severe disabilities were about the same. A linear decomposition analysis of the factors contributing to this growth showed that, for milder disability rates, a smaller proportion of the change was due to population aging and a larger proportion was due to the period effect. This is consistent with the view that people may be more comfortable thinking of themselves as having a disability, and suggests there is a general lessening of the stigma associated with disability.



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1. Ghai, A. (2002). "Disability in the Indian context: Post-colonial perspectives." In *Disability/Postmodernity: Embodying disability theory*. London, Continuum: 88-100.
2. Hussain, Y. (2005). South Asian disabled women: negotiating identities. *The Sociological Review* 53(3), 522-538.
3. Hassiotis, A. (1996). Clinical examples of cross-cultural work in a community learning disability service. *International Journal of Social Psychiatry* 42(4), 318-327.
4. Landsman, G. (2003). Emplotting children's lives: developmental delay vs. disability. *Social Science and Medicine* 56(9), 1947-1960.



5. Rao, S. (2006). Parameters of normality and cultural constructions of 'mental retardation': perspectives of Bengali families. *Disability & Society* 21(2), 159-178.
6. The term "medical model of disability" is somewhat misleading because it does not actually represent an ongoing school of thought supported by researchers or academics. Instead, this term is used to describe the historical approach and paradigm that has existed for people with disabilities throughout the 20<sup>th</sup> century.
7. Nagi was also among the first theorists to suggest that although impairment and disability are related, they should be considered separately. He pointed out that an impairment does not necessarily create a disability, nor do similar disabilities necessarily trace their origin to the same impairments.
8. Abercrombie, N., Hill, S., and Turner, B.S. (2006). *The Penguin Dictionary of Sociology, 5<sup>th</sup> Edition*. London, Penguin Books, p. 110.
9. Blakemore, C. and Jennett, S. (2001). Disability. *The Oxford Companion to the Body*. New York, Oxford University Press.
10. HALS was a postcensal survey because it used census "filter" questions on activity limitations and long-term disabilities to identify the target population that would be asked more detailed questions in HALS. The Participation and Activity Limitation Survey (PALS) is also a postcensal survey.
11. HALS was not conducted in 1996.
12. Many more years of PALS data using identical sets of questions are needed to provide a clear answer. It would have been preferable to start tracking changing attitudes with the 1986 HALS. However, HALS and PALS data cannot be compared because their definitions, concepts and methodologies differ significantly. Most importantly, the types and severity of activity limitations were expanded for PALS; new questions were designed to better identify non-physical disabilities including learning disabilities, developmental disabilities and psychological conditions. In contrast, the 1991 HALS grouped persons with these types of disabilities together into the category "Other". Also, the PALS severity scale assigns equal weight to all types of disabilities, whereas HALS gave more weight to physical than non-physical disabilities.
13. For detailed comparisons of 2001 and 2006 PALS data, go to <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007003-eng.htm>
14. Firebaugh, G. (1997). *Analyzing Repeated Surveys*. Series: Quantitative Applications in the Social Sciences. Sage Publications Inc., (115), 27.



**Table 1 Disability rates increased between 2001 and 2006, regardless of age, sex and province**

	2001	2006	Difference
	percentage		percentage point
<b>Total (age 15 and over)</b>	14.6	16.5*	1.9
<b>Age group</b>			
15 to 29	4.1	5.2*	1.1
30 to 44	7.7	8.6*	0.8 <sup>E</sup>
45 to 64	16.7	18.3*	1.6 <sup>E</sup>
65 and over	40.5	43.2*	2.7 <sup>E</sup>
<b>Sex</b>			
Men	13.4	15.3*	1.9
Women	15.7	17.7*	2.0
<b>Province</b>			
Newfoundland	14.1	16.9*	2.8
Prince Edward Island	17.0	18.8*	1.8
Nova Scotia	20.1	22.9*	2.8
New Brunswick	16.9	19.8*	2.9
Quebec	9.8	11.8*	1.9
Ontario	16.0	18.0*	2.1
Manitoba	16.9	18.4*	1.5 <sup>E</sup>
Saskatchewan	17.3	18.7*	1.4 <sup>E</sup>
Alberta	14.8	15.9*	1.1 <sup>E</sup>
British Columbia	16.3	18.3*	2.1

\* significantly different from 2001 at  $p < 0.05$

Note: The population in 2006 excludes three groups so that results can be compared to 2001 figures. The groups are: Aboriginal communities; persons in non-institutional collective dwellings (e.g. seniors residences); and persons living in Yukon Territory, Northwest Territories and Nunavut.

Sources: Statistics Canada, Participation and Activity Limitation Survey, 2001 and 2006.

**Table 2 Increases in disability rates are highest for those with a mild disability**

	Severity of disability									
	All levels		Mild		Moderate		Severe		Very severe	
	2001	2006	2001	2006	2001	2006	2001	2006	2001	2006
	<b>percentage</b>									
<b>Total (age 15 and over)</b>	14.6	16.5*	5.0	5.9*	3.6	4.1*	3.9	4.4*	2.0	2.2
<b>Age group</b>										
15 to 29	4.1	5.2*	1.8	2.4*	1.0	1.3*	0.9	1.0	0.4	0.5*
30 to 44	7.7	8.6*	2.6	3.0*	2.0	2.3*	2.1	2.3	1.0	1.0
45 to 64	16.7	18.3*	5.1	6.0*	4.1	4.6	4.9	5.1	2.6	2.6
65 and over	40.5	43.2*	14.4	15.7	10.1	10.3	10.3	11.2	5.6	6.0

\* significantly different from 2001 at p < 0.05

Note: The population in 2006 excludes three groups so that results can be compared to 2001 figures. The groups are: Aboriginal communities; persons in non-institutional collective dwellings (e.g. seniors residences); and persons living in Yukon Territory, Northwest Territories and Nunavut.

Sources: Statistics Canada, Participation and Activity Limitation Survey, 2001 and 2006.

**Table 3 Change in disability rates is attributable to the period effect and the aging population from 2001 to 2006**

Severity of disability	Total change 2001 to 2006 (a)	=	Period effect (b)	+	Age composition of population (c)	+	Interaction (d)
	<b>percentage points</b>						
<b>Overall</b>	1.95*		1.21*		0.71*		0.02
% of total	100		62		37		1
<b>Severity of disability</b>							
Mild	0.89*		0.68*		0.20*		0.00
% of total	100		77		23		0
Moderate	0.45*		0.28*		0.16*		0.01
% of total	100		62		36		1
Severe	0.43*		0.21		0.21*		0.02
% of total	100		48		48		4
Very Severe	0.17		0.04		0.13*		0.00
% of total	100		23		77		0

\* significantly different from 0 at p < 0.05

Note: Due to rounding, percentages may not add up to 100%.

Sources: Statistics Canada, Participation and Activity Limitation Survey, 2001 and 2006.

## **GST** Appendix 1 How disability is determined using PALS

In order for PALS to reach its target population, all persons were included in the survey frame if they replied "Yes" to either of the two disability filter questions on the 2001 and 2006 Census of Population questionnaires.

The Census disability filter questions are as follows:

1. Do you 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 you can do
  - a) at home?  
Yes, sometimes  
Yes, often  
No
  - b) at work or at school?  
Yes, sometimes  
Yes, often  
No
  - c) in other activities, for example, transportation or leisure?  
Yes, sometimes  
Yes, often  
No

The disability filter questions were repeated during the PALS interview and followed by a series of PALS screening questions to determine the nature of their disability. If respondents did not report a limitation to either the disability filter questions OR the PALS screening questions, they were dropped from the sample. (They could report a disability to either the filters or the screeners and still stay in PALS.) It is not uncommon for respondents to report a limitation on Census day but not to PALS because of short-term conditions such as recovering from surgery, broken bones and so on.

Below is an example of the PALS disability filter questions. (This particular series is designed to identify respondents with learning disabilities.) The PALS filter questions are used to identify all 10 major disability categories; that is, hearing, seeing, communication, mobility, agility, pain, learning, memory, developmental and emotional disabilities.

- Q01 Do you think you have a condition that makes it difficult in general for you to learn? Such conditions include attention problems, hyperactivity, dyslexia and others.  
Yes  
No  
Don't know
- Q02 Has a teacher, doctor or other health professional ever said that you had a learning disability?  
Yes  
No  
Don't know
- Q03 Does this condition reduce the amount or the kind of activities you can do?  
Yes, sometimes  
Yes, often or always  
No  
Don't know

## **CST** Appendix 1 How disability is determined using PALS (continued)

Q04 How many activities does this condition usually prevent you from doing at home?

None

A few

Many

Most

Don't know

Q05 How many activities does this condition usually prevent you from doing at work?

None

A few

Many

Most

Don't know

Q06 How many activities does this condition usually prevent you from doing at school?

None

A few

Many

Most

Don't know

Q07 How many activities does this condition usually prevent you from doing in other areas, such as transportation or leisure?

None

A few

Many

Most

Don't know

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Source: Statistics Canada. (2008). *Participation and Activity Limitation Survey 2006: Research Data Center (RDC) User Guide*. Catalogue no. 89-628-X. Ottawa: Minister of Industry.