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Participation and Activity Limitation Survey, 2001

Children with disabilities and their families



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Statistics Canada
Housing, Family and Social Statistics Division

Participation and Activity Limitation Survey, 2001

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- ^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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Children with disabilities and their families

Introduction

This article is the third in a series of data releases from the 2001 Participation and Activity Limitation Survey (PALS). This survey provides the most up-to-date and detailed information on children with disabilities in Canada, including information on the impact of their condition or health problem on the family. The PALS sample consisted of 8,000 children residing in households in the 10 provinces.

This article describes the lives of children between five and 14 years old who have disabilities, and the impact of their disability on the everyday activities and employment situation of their families. Specific themes covered here are:

- Help with everyday activities received by children with disabilities;
- Parents' access to formal and informal help;
- Impacts of the child's disability on the family's employment situation;
- Children's access to specialized aids and services;
- Household income

For detailed statistical tables on these themes, including provincial breakdowns, see Statistics Canada catalogue no. 89-586-XIE. For information about PALS, consult the section titled "Survey background" at the end of this document.

Help for children

An estimated 155,000 children between five to 14 years old, living in households, had activity limitations in 2001, according to the data from the Participation and Activity Limitation Survey. This represents about 4% of all children of this age group.

Of these children, about 89,000, or more than one-half (57%), experienced mild to moderate disabilities. The remaining 66,000, or 43%, experienced severe to very severe disabilities.

Children with mild to moderate disabilities include those whose health condition causes some activity limitations, for example, children who experience some or a lot of difficulty walking or moving their hands.

Those with severe to very severe disabilities include children with multiple significant disabilities, or children with a total loss of function, for example, those who cannot walk or those with a total loss of sight.

The survey asked parents or guardians of children with disabilities whether their child received help with everyday activities including personal care, such as bathing, dressing or feeding, or

moving about within the home because of a condition or health problem. If their answer was affirmative, parents were then asked who provided most of the help to the child.

About one quarter of children with disabilities receive help with everyday activities because of their condition

Of the 155,000 children with disabilities in 2001, about 35,000, or 23%, received help with their daily activities because of their condition. Of the children who received help, about 15% had mild to moderate disabilities and the remaining 85% had severe to very severe disabilities.

Most of the help that children received with everyday activities was for personal care rather than for moving about within the home. For example, while 22% of children with disabilities received help with personal care because of their condition, only 4% received help with moving about within the home.

In 62% of cases where the child required help with personal care, it was the mother who provided most of the help, while in 30% of cases it was both mother and father. In only 3%^E of cases did the help come primarily from the father. A small proportion of children with disabilities received help mostly from other sources.

Help for parents

Among the 155,000 children with disabilities, parents or guardians of 31,000, or 20% of the total, reported that they received help with housework, that is, housecleaning and meal preparation, family responsibilities, and time off for personal activities because of their child's condition.

Parents rely primarily on family members and government organizations

Data from PALS underline the importance of the help received by parents of children with disabilities from informal sources, such as family, friends and neighbours.

For example, of the 31,000 children whose parents received help with housework, family responsibilities, and time off for personal activities, 44% received help from family members not living with them, 28% from family members who did live with them, and 27% from friends or neighbours. (Respondents could report more than one source of help.)

Help provided through formal sources, such as government organizations or agencies, also played an important role. Of the 31,000 children with disabilities whose parents received help, about 44% received help from government organizations or agencies.

Parents of children with severe to very severe disabilities were more likely to receive the help from government organizations or agencies, compared to parents of children with mild to moderate disabilities. For example, an estimated 23,000 children with severe to very severe disabilities had parents who received help. In just over one-half (51%) of these cases, the parents received the help from government organizations. This was more than twice the proportion of 22%^E among parents of children with mild to moderate disabilities.

Parents of children with severe to very severe disabilities more likely to need additional help

Using PALS data, it is possible to identify children whose parents received all the help they needed, those who received some help but needed more, and those who received no help but needed some. This information can be used in identifying whether there was a gap between the help that parents needed with housework, family responsibilities and time off for personal activities, and what they actually received.

Of the 155,000 children with disabilities, about 52,000 had parents who needed help with housework, family responsibilities, and time off for personal activities because of their child's condition. Overall, 18,000 or one in three of these children had parents who reported they received all the help they needed.

Of children with disabilities whose parents required help, nearly 26% had parents who received help, but needed more. About 40% had parents who received no help, but needed some. **(See Chart 1)**

The parents of about 13,000 children with mild to moderate disabilities required help. In less than half of these cases, about 45%, did the parents get all the help they needed. However, among the 39,000 children with severe to very severe disabilities, only 31% of the parents got all the help they needed. **(See Chart 1)**

Parents of children with severe to very severe disabilities were more likely to report unmet needs for help with housework, family responsibilities and time off for personal activities, compared to parents of children with mild to moderate disabilities.

For instance, of the 39,000 children with severe to very severe disabilities whose parents required help, 69% had parents indicating that they did not receive all the help they needed. This proportion fell to 55% among parents of the 13,000 children with mild to moderate disabilities.

Cost the main reason in lack of help for parents

The survey found that cost was a contributing factor in preventing parents from getting help. Among parents of the 34,000 children with disabilities who indicated unmet needs for help

with housework, family responsibilities and time off for personal activities, seven out of 10 (71%) reported cost as a reason for unmet needs. In addition, 62% said that help from family and friends was not available, 42% said services and special programs were not available at the local level, and 36% said they did not know where to look for help. (Respondents could report more than one reason.)

Impacts on the family's employment

For many parents, balancing between paid work and family responsibilities is often a struggle. During the survey, this challenge was expressed by many parents of children with disabilities.

Parents of 84,000 children, slightly over one-half (54%) of those with disabilities, reported that their child's condition had an impact on their family's employment situation. For example, family members had to work fewer hours or change their hours of work to a different time of day or night in order to take care of the child.

Impact on family's employment increases with severity of child's disability

Among children with mild to moderate disabilities, about 40% had family members who experienced an impact on their employment situation. However, among children with severe to very severe disabilities, this proportion almost doubled to 73%.

Of the 89,000 children with mild to moderate disabilities, the family members worked fewer hours in 24% of cases; 22% changed work hours to a different time of day or night; 17% did not take a job in order to take care of the child; 11% quit working at some point of their career; and 10% turned down a promotion or a better job. (Respondents could report more than one answer.) **(See Table 1)**

However, among the 66,000 children with severe to very severe disabilities, these proportions were higher. The family members worked fewer hours in 47% of cases; almost 44% changed work hours to a different time of day or night; 42% did not take a job in order to take care of the child; 30% quit working at some point of their career; and 26% turned down a promotion or a better job. **(See Table 1)**

Mothers most often face the tough career decisions

Among the 84,000 children whose family's employment situation was affected, mothers (71%) most often experienced such impacts on their employment because of their child's condition. In about 14% of cases, both mother and father experienced such impacts on their employment situations. In only 11% of cases did fathers alone experience an impact on their employment. A small percentage of children had family members other than their parents who experienced impacts on their employment situations, according to the PALS data.

Access to specialized aids

Parents or guardians of children with disabilities were asked whether their child used some form of specialized aids and services to help the child with daily functions, such as hearing, seeing, speaking, walking, learning, and so on. Such specialized aids and services include hearing aids, wheelchairs, leg or arm braces, voice amplifiers, Sign language interpreters, and tutors. Parents were also asked whether their child needed any aids that he/she did not have.

PALS data can be used in identifying children who had all the specialized aids they needed, those who had some aids but needed more, and those who had no aids but needed some. This information helps in identifying whether there was a gap between what specialized aids children with disabilities needed and what they actually had.

Half of children with disabilities who need specialized aids do not have all the aids they require

Of the 155,000 children with disabilities, about 94,000 or roughly six out of every 10 required some form of specialized aids, according to their parents. Of children with mild to moderate disabilities, slightly over one-half (51%) required specialized aids, while this proportion increased to 73% among those with severe to very severe disabilities.

Of the 94,000 children requiring specialized aids, about 37% had some aids, but needed more. Nearly 15% did not have any specialized aids, but needed some. In total, about one-half of children with disabilities requiring specialized aids did not have all the aids that they needed. **(See Chart 2)**

The proportion of children who had difficulties getting access to specialized aids increased with severity of the disability. For example, among children requiring such aids, only one-third of those with severe to very severe disabilities had their needs met. In contrast, two-thirds of those with mild to moderate disabilities had their needs met. **(See Chart 2)**

Cost was a contributing factor why children did not have all the specialized aids that they needed. Of the children with unmet needs, more than one-half (55%) did not have access to all the specialized aids that they needed because of the cost.

Other reasons were also cited. In about 44% of cases, parents did not have insurance coverage for the specialized aids needed by the child; 21% of parents did not know where to obtain them; and in 17% of cases, parents were not able to find the specialized aids needed by the child at the local level. (Multiple responses were allowed.)

Household income

In this section, the data from the 2001 Census are used to compare the before-tax total household income of households with disabled children between five to 14 years old with that of households with non-disabled children of this age group.

Households with disabled children had lower household income than households with non-disabled children

The results showed that the average household income of households with disabled children was \$63,366 in 2000, compared to \$72,069 for households with non-disabled children. In other words, on average, households with disabled children had 88% of the income of households with non-disabled children.

The data also showed that proportionally more households with disabled children had an income of \$29,999 or less. For example, 24% of these households had an income of \$29,999 or less compared to 18% of households with non-disabled children. At the other end of the scale, the proportion of households with disabled children making \$50,000 or more in 2000 was lower than the proportion of households with non-disabled children (53% and 61% respectively). **(See Chart 3)**

Households with children with mild to moderate disabilities had an average household income of \$63,976 in 2000, which represents 89% of the average household income of households with non-disabled children. Households with children with severe to very severe disabilities had an average income of \$62,548, or 87% of the average household income of households with non-disabled children.

Survey background

The Participation and Activity Limitation Survey was funded by Human Resources Development Canada (HRDC) and conducted by Statistics Canada between September 2001 and January 2002. The survey gathered information on adults with disabilities as well as children with disabilities whose everyday activities are limited because of a condition or health problem.

The survey used two separate questionnaires, one for adults with disabilities aged 15 and over and one for children with disabilities up to the age of 14. Information on children with disabilities was gathered through interviews with their parents or guardians.

The PALS sample consisted of persons residing in households in the 10 provinces. Persons living in institutions, on Indian reserves, and in the Yukon, Northwest Territories and Nunavut were excluded from the survey.

PALS provides information on the disability type and severity of adults with disabilities. It also provides data on the supports and specialized aids needed by adults with disabilities as well as difficulties experienced in securing needed supports. Furthermore, the survey contains data on the level of education of adults with disabilities, their employment profile, their income and their participation in social and community activities including recreation and leisure activities.

Regarding children with disabilities, PALS collected data on the type and severity of disabilities and the impact of their disabilities on the family. The survey also provides detailed information on the supports and specialized aids needed by children with disabilities at home, at school and at play or recreational activities. In addition, it provides data related to the schooling of children with disabilities and their participation in special education programs.

The first survey results were published in December 2002 and provided information on the number of adults and children with disabilities by age and sex in each province as well as information on the type and severity of disability. The data were made available in an analytical article co-authored by Statistics Canada and HRDC, titled *A Profile of Disability in Canada, 2001* (89-577-XIE). A set of national and provincial level tables was also published in December 2002 (see Statistics Canada Catalogue no.89-579-XIE). (The article and tables are available free of charge at www.statcan.ca. From "Our products and services", under "Browse our Internet publications", choose "Free", and then "Health".)

The second PALS release occurred in March 2003. It focused on disability supports required by adults with disabilities. The data were made available in an analytical article co-authored by Statistics Canada and HRDC, titled *Disability Supports in Canada, 2001* (89-580-XIE). A series of national and provincial tables were also published in March 2003 (89-581-XIE). (The article and tables are available free of charge at www.statcan.ca. From "Our products and services", under "Browse our Internet publications", choose "Free", and then "Health".)

The final release of PALS data on children with disabilities is planned for December 2003, which will include information on:

- Education profile as well as leisure and recreation activities of children with disabilities
- Out-of-pocket costs for disability-related supports and services needed by children with disabilities
- Health conditions underlying disabilities

Table 1
Impacts of the child's condition on the family's employment situation, by severity of disability of children with disabilities aged 5 to 14, Canada, 2001¹

	Total ²		Severity of disability			
			Mild to Moderate		Severe to Very Severe	
			Number	%	Number	%
Total children with disabilities aged 5 to 14	154,720	100.0	88,690	100.0	66,030	100.0
Children whose family's employment situation was affected	83,720	54.1	35,800	40.4	47,920	72.6
Impacts on employment situation:³						
Worked fewer hours	51,940	33.6	21,130	23.8	30,800	46.6
Changed work hours	48,890	31.6	19,900	22.4	28,980	43.9
Not taken a job in order to take care of the child	42,980	27.8	15,180	17.1	27,800	42.1
Quit working	29,830	19.3	10,120	11.4	19,710	29.9
Turned down a promotion or a better job	26,380	17.1	9,190	10.4	17,180	26.0

¹ The population excludes persons living in institutions, on Indian reserves, and in the Yukon, Northwest Territories and Nunavut.

² The sum of the values for each category may differ from the total due to rounding.

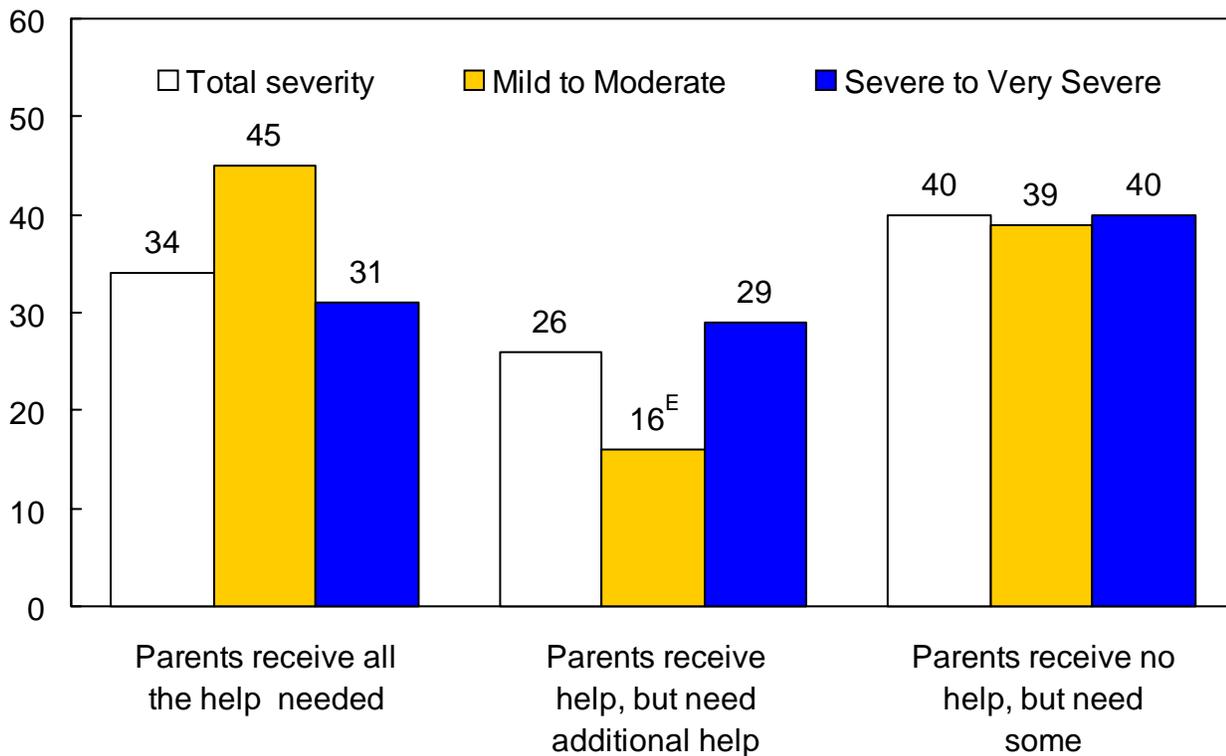
³ Respondents could report more than one impact.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2001.

Chart 1

Children with severe to very severe disabilities are likely to have parents with unmet needs for help with housework, family responsibilities, and time off for personal activities

% of children whose parents require help

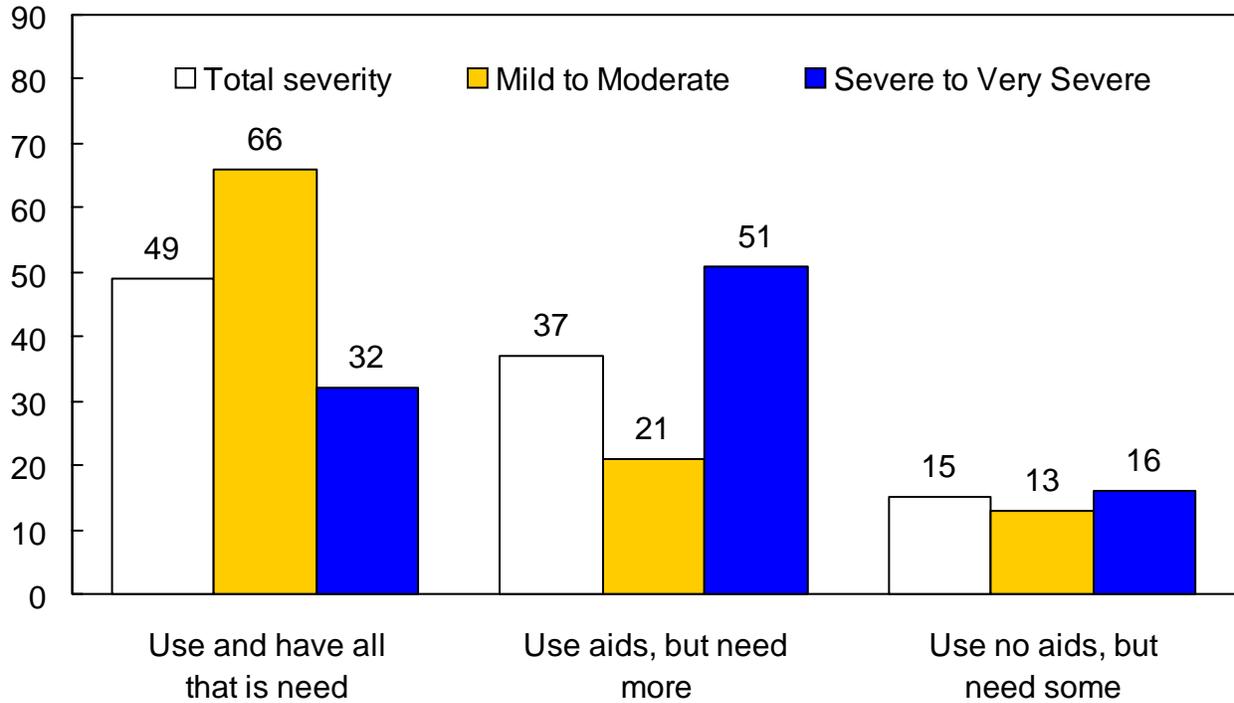


^E Use with caution

Source: Statistics Canada, Participation and Activity Limitation Survey, 2001.

Chart 2
Children with severe to very severe disabilities are likely not to have all the specialized aids that they need

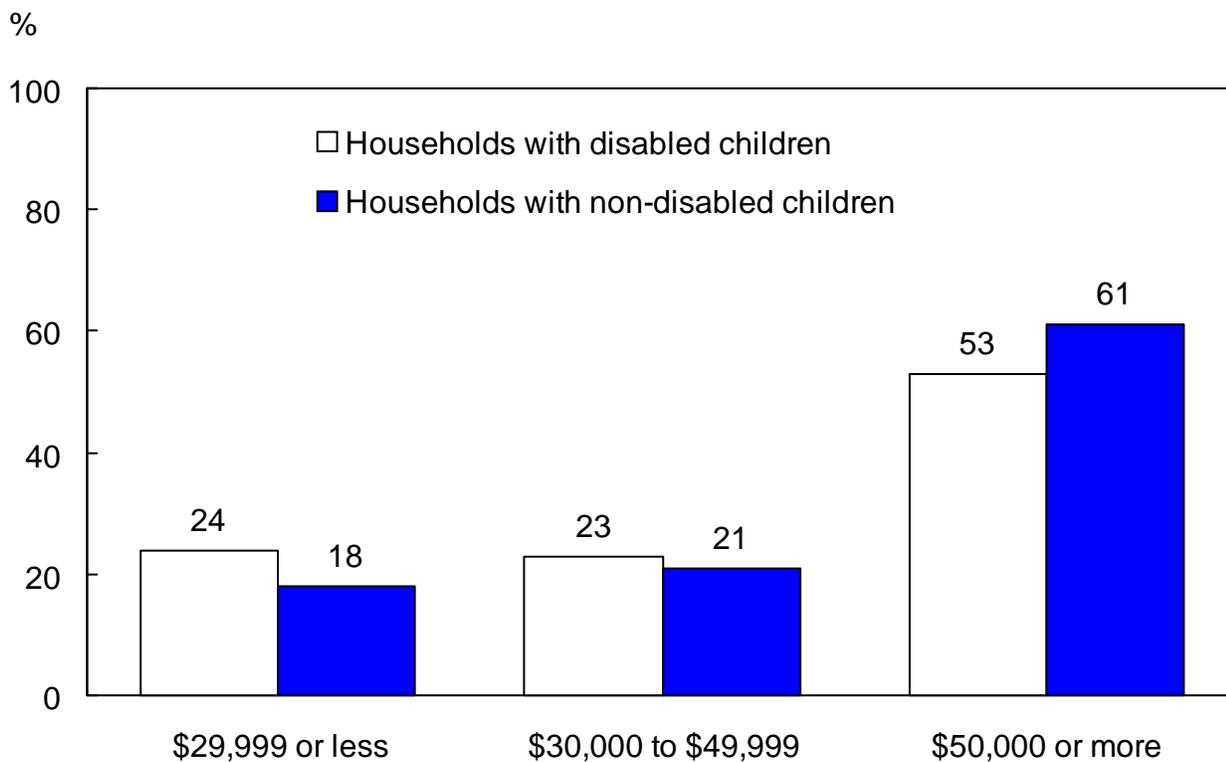
% of children requiring specialized aids



Source: Statistics Canada, Participation and Activity Limitation Survey, 2001.

Chart 3

Households with disabled children have lower household income than households with non-disabled children



Source: Statistics Canada, Participation and Activity Limitation Survey, 2001.

Definitions

Average household income

Average household income refers to the weighted mean total income of households in 2000. Average income is calculated from unrounded data by dividing the aggregate income of a specified group of households by the number of households in that group, whether or not they reported income.

Disability

The Participation and Activity Limitation Survey uses the World Health Organization's (WHO) framework of disability provided by the International Classification of Functioning (ICF). This framework defines disability as the relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors.

For the purposes of PALS, persons with disabilities are those who reported difficulties with daily living activities, or who indicated that a physical, mental condition or health problem reduced the kind or amount of activities they could do.

The respondents' answers to the disability questions represent their perception of the situation and are therefore subjective.

Help with everyday activities received by children with disabilities

Refers to the help children with disabilities receive with personal care (e.g. bathing, dressing or feeding) and moving about within the home.

Household

Refers to a person or a group of persons (other than foreign residents), who occupy the same dwelling and do not have a usual place of residence elsewhere in Canada. It may consist of a family group (census family) with or without other non-family persons, of two or more families sharing a dwelling, of a group of unrelated persons, or of one person living alone. For census purposes, every person is a member of one and only one household.

Household income

The total income of a household is the sum of the total incomes of all members of that household before tax.

Median household income

The median income of a specified group of households is that amount which divides their income size distribution into two halves. That is, the incomes of the first half of households are below the median, while those of the second half are above the median. Median incomes of households are normally calculated for all units in the specified group, whether or not they reported income.

Severity

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 to 1. The final score is the average of the scores for each type of disability.

Since the survey questions differ 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).

Notes to Users

Chart 1: Derivation of variables on parents' access to help with housework, family responsibilities, and time off for personal activities

In PALS, parents or guardians of children with disabilities were asked a series of questions to identify whether or not because of their child's condition, they required help with housework, family responsibilities, and time off for personal activities.

In order to find out to what extent parents or guardians had access to the help they needed, the information about the USE of help and the NEED for help was combined by using the following steps:

Firstly, a new variable called "USEHELP_PARENT" was constructed by using the questions that identified whether or not parents received any help with housework, family responsibilities, and time off for personal activities (i.e. Questions C12a, C12b and C12c).

Secondly, the new variable of NEEDHELP_PARENT was constructed by using the questions that identified whether or not parents needed help with housework, family responsibilities, and time off for personal activities (i.e. Questions C17a, C17b and C17c).

Thirdly, the two new variables of USEHELP_PARENT and NEEDHELP_PARENT were combined to create four possible outcomes:

- (a) Parents receive help, but need additional help
- (b) Parents receive no help, but need some
- (c) Parents receive all the help needed
- (d) Parents don't receive help and don't need it *

** Note that the category of "parents don't receive help and don't need it" is not included in Chart 1.*

Chart 2: Derivation of variables on children's access to specialized aids and services

In PALS, parents or guardians were asked a series of questions to identify whether or not their child used specialized aids and services to assist him/her with daily functions, such as hearing, seeing, speaking, walking, learning, and so on. They were also asked questions about whether or not the child needed any aids that he/she did not have. In order to find out to what extent the child had access to the specialized aids that he/she required the information about the USE of aids and the NEED for aids was combined by using the following steps:

Firstly, a new variable called "USEAID" was constructed by using the questions that identified whether or not the child used any specialized aids (i.e. Questions B1, B6, B17, B27, B33, B39, B47 and B87).

Secondly, the new variable “NEEDAID” was created by using the questions that identified whether or not the child needed any aids that he/she did not have (i.e. Questions B8, B19, B29, B35, B41, B49 and B93).

Thirdly, the two new variables of USEAID and NEEDAID were combined to create four possible outcomes:

- (a) Use aids, but need more
- (b) Don't use aids, but need some
- (c) Use aids and have all that is needed
- (d) Don't use aids and don't need them*

** Note that the category of “don't use aids and don't need them” is not included in Chart 2.*

Chart 3: Household income

The household income data for households with disabled children included in this article come from the linked census data of the PALS respondents. As a post-censal survey, PALS selected its population from the answers to two general activity limitation questions on the 2001 Census of Population. In order to reduce the number of questions asked by the survey, the information provided to the census by the survey respondents, including information on household income, was linked to the PALS database during processing.

The household income data for households with non-disabled children provided in this article come from the 2001 Census data.