

## Article

*Living with disability series*

# Help with activities of daily living for people with a disability

*by Patric Fournier-Savard, Chantal Mongeon and Susan Crompton*

October 19, 2010



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- . not available for any reference period
- .. not available for a specific reference period
- ... not applicable
- 0 true zero or a value rounded to zero
- 0<sup>s</sup> value rounded to 0 (zero) where there is a meaningful distinction between true zero and the value that was rounded
- <sup>p</sup> preliminary
- <sup>r</sup> revised
- x suppressed to meet the confidentiality requirements of the *Statistics Act*
- E use with caution
- F too unreliable to be published

## *Living with disability series*

# Help with activities of daily living for people with a disability

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### Introduction

Canada has a large and growing population of people with disabilities.<sup>1</sup> How many of them need help with the day-to-day tasks of daily life, such as running errands, doing everyday housework, or personal care? Where do they get the help they need? And how do the people who provide that help share the responsibility as a person's disability becomes more severe?

Although the issue of the care obtained by older people has been extensively studied, researchers have less often examined the care received by people with a disability. This presents a gap in knowledge about caregiving since findings about eldercare cannot be generalized to the disabled population, because, among other things, almost 60% of people with disabilities are under 65.

Studies that focus on the disabled population confirm the importance of the family as the primary caregiver; they particularly underline that this role fluctuates according to the tasks with which an individual requires assistance. They also corroborate that the help provided by the family grows as the severity of the disability increases.<sup>2,3</sup>

However, little is known about the extent to which family members may share the caregiver role, and how the necessary tasks are distributed among different caregivers.

This article uses the 2006 Participation and Activity Limitation Survey to shed light on these issues. It examines how many people with disabilities receive help with activities of daily living, the type of daily activities with which they get help, and their relationship to the person or persons who provide help with specific tasks. Then, it explores how these relationships change as the severity of the disability increases.

It is important to note that the activities of daily living (ADLs) discussed here include tasks that exceed basic care or simple physical needs. ADLs encompass all those activities which facilitate active engagement in everyday life for a person with disabilities. At first glance, these tasks may seem inconsequential, but being able to accomplish them contributes greatly to a person's quality of life (see "What you should know about this study").

### Getting enough help to meet the demands of daily life

Making sure that people with disabilities receive the help they need can be an important determinant of their social and economic participation. Of course, some do not need any help, and others require a minimal amount of assistance.

In 2006, one-third of people with disabilities reported that they did not need any help to perform the activities of daily living (ADL). More than one-third said they received all the help they needed; one-quarter would have liked to have had more help than they were getting; and 5% reported that even though they needed help, they did not receive any at all (Chart 1).

As the severity of a person's disability increased, their demand for help increased as well: 95% of people with very severe limitations needed at least some care, compared to 40% of those with mild disabilities. At the same time, it also became more difficult to get as much help as they needed; the large majority of people with a mild disability who needed help said they had enough care, but less than half of those with a very severe limitation reported that they received sufficient help (Chart 1).

## What you should know about this study

This article draws on data from the 2006 Participation and Activity Limitation Survey (PALS). Respondents were classified as having a disability if they reported that they had difficulties with daily living activities, or that a physical or mental condition or health problem reduced the kind or amount of activities they could do. The answers to the disability questions are self-reported and therefore represent the respondent's perception of his or her situation.<sup>1</sup>

The main study population consists of about 13,100 respondents—representing about 2.4 million Canadians aged 15 and over with a disability—who received care with at least one activity of daily living (ADL). PALS asked each respondent to identify their relationship to their caregivers as well as the ADL with which they received help from each caregiver. Data were collected on a maximum of three caregivers, although some people may have had additional caregivers.

### Definition of terms

**Care receiver:** A person aged 15 and over with a disability who received help with at least one activity of daily living (ADL).

**Severity of disability:** PALS constructed a scale measuring the overall severity of disability according to the intensity and frequency of the activity limitations reported by respondents. The disability severity scale is divided into four levels: mild, moderate, severe and very severe.

**Activity of daily living (ADL):** Respondents were asked the following nine questions:

Because of your condition do you usually receive help with:

- preparing meals?
- everyday housework, such as dusting and tidying up?
- heavy household chores, such as spring cleaning or yard work?
- getting to appointments and running errands, such as shopping for groceries or other essential items?
- looking after your personal finances, such as making bank transactions or paying bills?
- childcare?
- personal care, such as washing, dressing or taking medication?
- specialized nursing care or medical treatment at home such as injections, therapy, blood or urine testing or catheter care?
- moving about inside your residence?

If respondents replied "Yes" to any one of these questions, they were classified as receiving care with activities of daily living.

Although persons receiving help with childcare constitute part of the study population of care receivers, this study does not discuss childcare as a separate topic because the relevant population is too small (2% of all care receivers) to provide reliable detailed estimates.

**Caregiver:** A person who usually helped the respondent with activities of daily living. Respondents identified a maximum of three caregivers and the ADL(s) with which they assisted the respondent.

**Sources of care:** Care receivers obtained help from four types of sources, depending on their relationship to the person or persons providing the care:

**Immediate family only/family only:** spouse or partner (including same-sex partner), daughter, son, mother, father, sister, brother. Whether the care receiver had one, two or three main caregivers, they were all members of the immediate family.

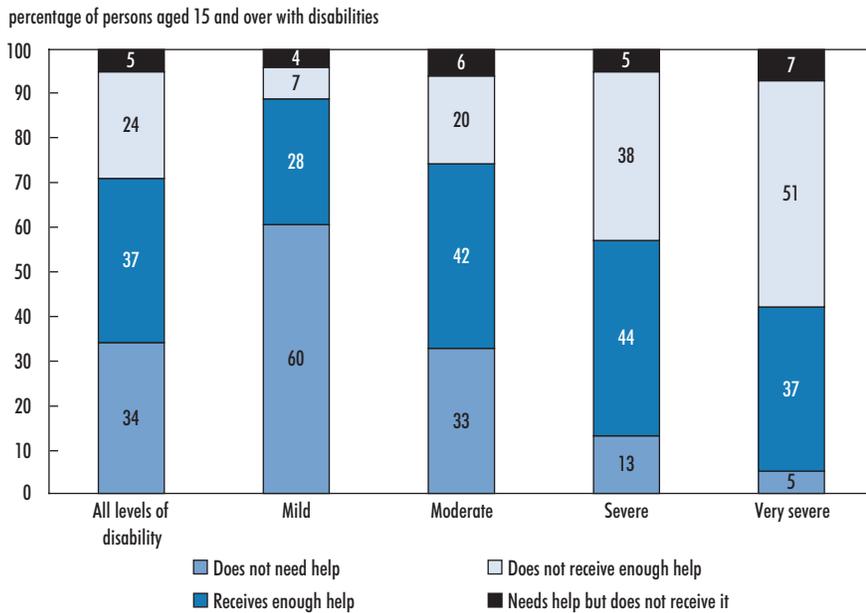
**Friends and extended family only/friends only:** Close friend, neighbour, work colleague, grandchild, grandparent, daughter-/son-in-law, mother-/father-in-law, sister-/brother-in-law, niece, nephew, aunt, uncle, cousin, former spouse or partner, other persons not associated with an organization. Whether the care receiver had one, two or three main caregivers, they were all friends or extended family.

**Paid help only:** Non-governmental organization, governmental (all levels), and paid employee of the care receiver. Whether the care receiver had one, two or three main caregivers, they were all paid helpers.

**Immediate family and others:** Care is received from two or three different sources. For example, a person getting help with meals from his daughter and from Meals-on-Wheels would be receiving care from immediate family and others, as would a person receiving personal care from her mother, a neighbour and a paid homecare worker. About 90% of the care obtained from this source includes some involvement from the immediate family.

1. For more detailed information about the concepts and definitions used by PALS, see MacKenzie, Hurst and Crompton, "Defining disability in the Participation and Activity Limitation Survey," *Canadian Social Trends* No. 88 (Winter 2009).

**Chart 1 Two-thirds of people with disabilities needed help with at least one activity of daily living**



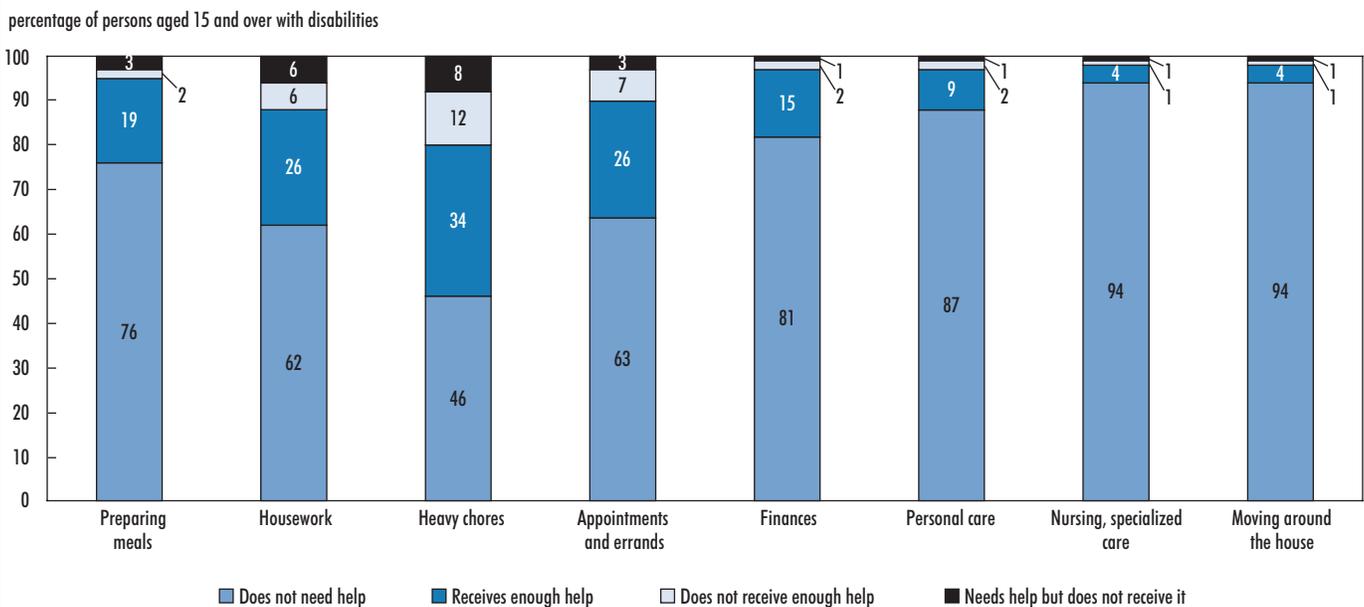
Note: Totals may not add to 100% due to rounding.  
 Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Different ADLs can make different demands of the caregiver in terms of the skills required to do the tasks and/or the frequency with which a task must be performed. As such, it is not surprising that people's assessment of the help they received varied considerably depending on the task. For example, 24% of persons with disabilities wanted help<sup>4</sup> preparing meals; of these, 8 in 10 felt that they got as much as they needed. In contrast, 6% of the disabled population wanted assistance to move around the house, but only two-thirds of these people reported that they received enough help (Chart 2).

**Accessing different sources of care**

Over 9 in 10 Canadians with disabilities who said they needed help with their daily tasks (more than 2.4 million people) regularly received assistance with at least one ADL. On average, these care receivers got help with about three activities of daily

**Chart 2 Most people with disabilities received the help they needed**



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

living, although the actual number of ADLs was strongly correlated to the severity of their disability. Over three-quarters of people with mild limitations received assistance with only one or two activities, while two-thirds of those with very severe disabilities had help with four or more (data not shown).

The principal source of help for people needing support with daily activities was their immediate family. Eighty percent of care receivers obtained at least some care from a spouse, child, parent or sibling (Table 1).

The sources of care expanded as the number of tasks multiplied. When the number of ADLs rose from one to four or more, the proportion of care receivers getting at least some help from friends and extended family<sup>5</sup> increased from 27% to 32%; and the

proportion sourcing at least some support from paid helpers<sup>6</sup> almost doubled, from about 17% to 30% (Table 1).

Yet even when the care receiver drew on a mix of sources for their care, the family maintained its primary role. The more ADLs that a person received help with, the more likely it was that they were getting at least some of that help from a spouse or other close family member.

### Sources of care for different activities of daily living

The source of care is likely to depend not only on the number of ADLs with which a care receiver needs help, but also the type of activity. The care receiver may need to have injections or to be monitored doing physiotherapy exercises; on the

other hand, they might need help only with routine daily tasks like meal preparation or housework. Clearly, a different set of competencies, skills or proximity to the care receiver is required to meet these distinct needs.

The PALS data show that, regardless of the severity of the disability or the type of help required, most care receivers identified immediate family as their main source of care; in a large number of cases, the immediate family was the only source of care. The sole exception was help with nursing and specialized treatment, most of which was received from paid help. Friends and extended family were most often accessed to help with heavy chores, and with going to appointments or running errands, but even for these activities, they did not provide as much assistance as immediate family (Table A.1).

**Table 1 Source of care by number of activities of daily living for persons with disabilities aged 15 and over receiving care with at least one activity, 2006**

Source of care	Number of ADLs <sup>1</sup> with which a person received help				Total
	One †	Two	Three	Four to nine	
	percentage of care receivers				
<b>All care involving immediate family</b>	<b>72</b>	<b>75</b>	<b>85*</b>	<b>89*</b>	<b>80</b>
Immediate family only	57	49*	56	49*	53
Immediate family with friends and extended family	11	17*	19*	19*	16
Immediate family with paid help	3	8*	8*	14*	8
Immediate family with friends, extended family and paid help	F	2 <sup>E</sup>	2 <sup>E</sup>	8	3
<b>Friends and extended family only</b>	<b>14</b>	<b>9*</b>	<b>6*<sup>E</sup></b>	<b>3*</b>	<b>8</b>
<b>Friends and extended family with paid help</b>	<b>F</b>	<b>3<sup>E</sup></b>	<b>F</b>	<b>3<sup>E</sup></b>	<b>3</b>
<b>Paid help only</b>	<b>13</b>	<b>13</b>	<b>4*<sup>E</sup></b>	<b>5*</b>	<b>9</b>

† reference group

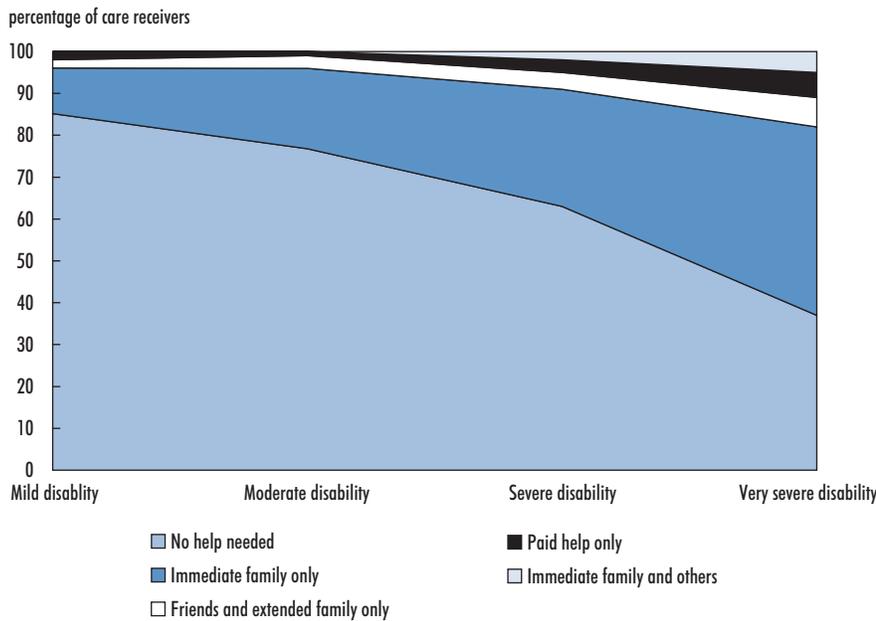
\* statistically significant difference from reference group (one ADL) at p < 0.05

1. Activities of daily living.

Note: Totals may not add to 100% due to rounding.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

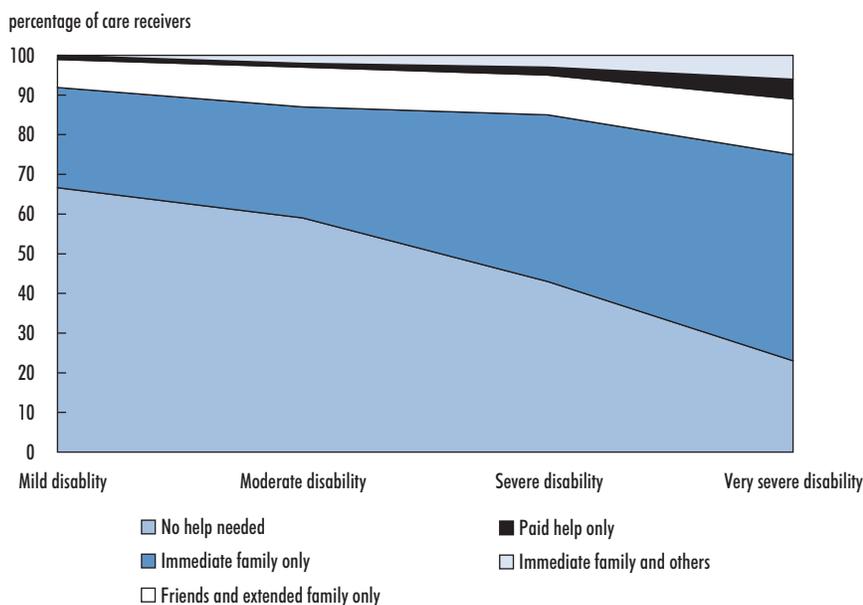
### Chart 3 Almost all help received with preparing meals comes from immediate family



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Just over one-third of all care receivers got help preparing meals, and most had help every day (Table 2). Demand for assistance rose as the severity of disability increased (Chart 3), but the most important source of care remained the immediate family.

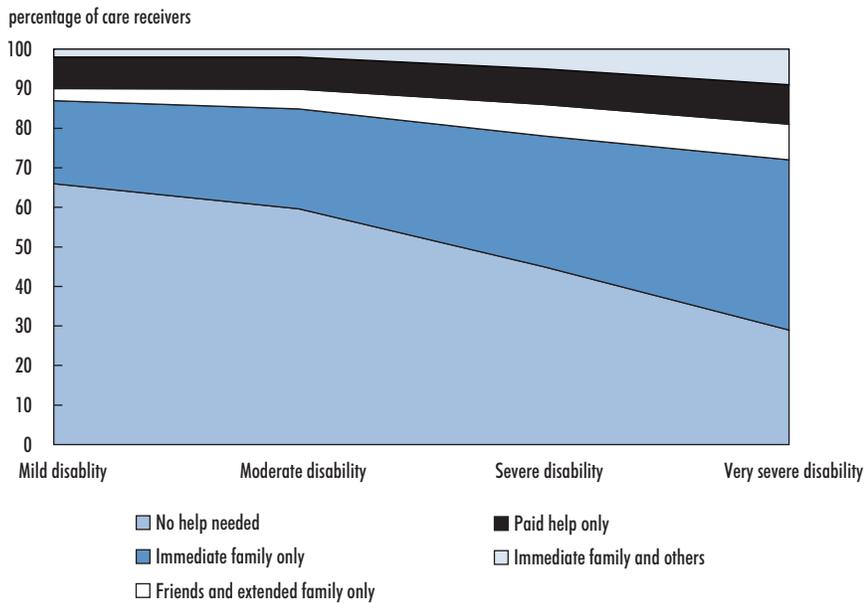
### Chart 4 Help going to appointments or running errands is received from friends as well as close family



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

About half of all care receivers had someone's help to get to appointments or do errands, although help received increased as the severity of the disability intensified (Chart 4). Irrespective of the severity of the disability, one in five care receivers got help with this task from friends and extended family (Table A.1).

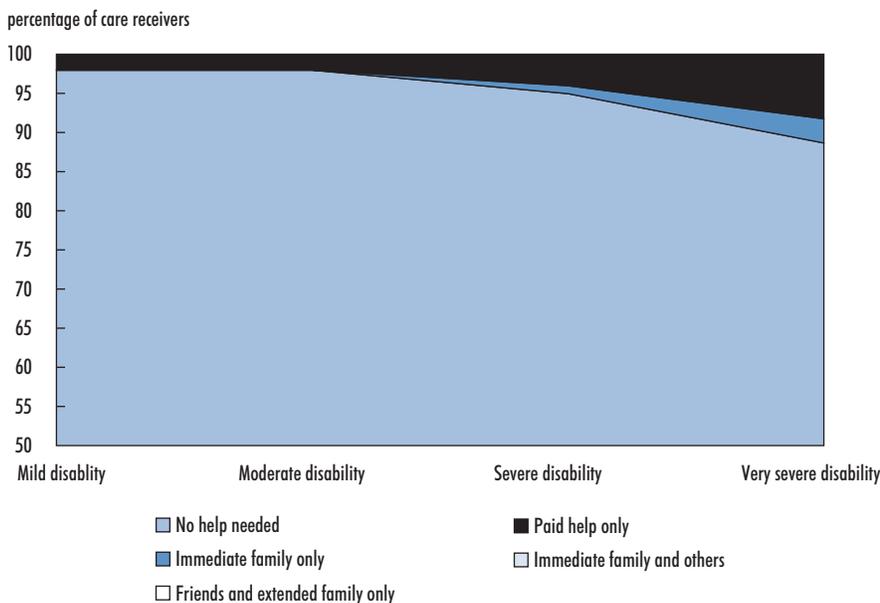
**Chart 5 Care receivers getting help with regular housework often looked to sources of care outside the family**



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Half of all care receivers obtained assistance to do their everyday housework (Table 2); people with very severe limitations were twice as likely to get help as those with mild disabilities (Chart 5). Paid help and friends and extended family were the sources of care for almost one-third of people who received help with this ADL.

**Chart 6 The majority of care receivers sourced nursing care or specialized treatment from paid caregivers**



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Only 6% of care receivers, most of them with severe or very severe disabilities, obtained nursing care or specialized treatments (Chart 6). About two-thirds of people getting help with this ADL received it only from paid helpers.

### Frequency of care received

The frequency with which care is provided is an important dimension of caregiving. Information about the frequency of care can help address issues related to the intensity or volume of the assistance needed by the care receiver as well as enriching understanding of the network of care upon which persons with disabilities rely.

For example, although the proportion of care receivers who cited friends as primary caregivers was much lower compared to immediate family, the frequency with which they gave help was similar to that of immediate family. This was the case for most ADLs except routine housework and heavy chores. For instance, only 4% of care receivers got help with meals from friends and extended family, compared to 25% from immediate family. However,

three-quarters of help from friends was received every day, the same frequency of care obtained from immediate family (Table 2).

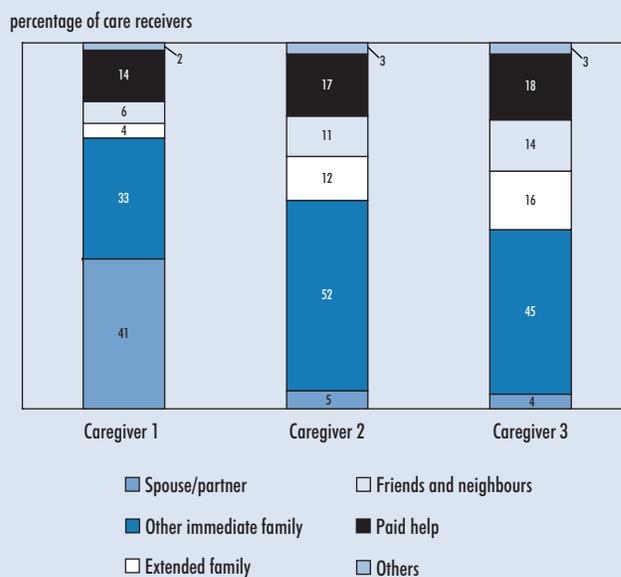
The frequency of caregiving was somewhat different when paid helpers were the source of care. For most ADLs, care receivers showed little reliance on paid helpers. Nursing care was most likely to be received from paid helpers, but they rarely provided it every day (Table 2).

## How many caregivers?

PALS collected data on the assistance received from the three caregivers who usually provided help with a given activity of daily living (ADL). Forty-three percent of care receivers reported that they had one main caregiver, 28% named two and 29% named three caregivers. Of course, the number of caregivers generally grew as the level of disability increased: care receivers with very severe limitations were over twice as likely to have three caregivers (42% versus 18% for those with mild disabilities).

As a care receiver acquired more caregivers, the nature of his or her relationship to the people providing help changed. As immediate family members were increasingly spoken for, friends, neighbours and extended family accepted more responsibility. For example, immediate family made up 75% of caregiver one, 57% of caregiver two, and 49% of caregiver three. In contrast, friends and extended family accounted for 10% of primary caregiver one, 23% of primary caregiver two and 30% of primary caregiver three.

### Regardless of whether there is one, two or three caregivers, family always plays an important role



Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

**Table 2 Sources of care for individual activities of daily living, by frequency of assistance, 2006**

Activity of daily living	Persons with a disability who received help	Frequency of assistance		
		Daily	At least weekly par semaine	Less than weekly fois par semaine
percentage				
<b>Meal preparation</b>				
<b>All sources of care</b>	<b>34</b>	<b>78</b>	<b>20</b>	<b>3</b>
Immediate family †	25	78	19	3 <sup>E</sup>
Friends, extended family	4*	75	23	F
Paid help	3*	73	23 <sup>E</sup>	F
Immediate family and others	2*	84	15 <sup>E</sup>	F
<b>Housework</b>				
<b>All sources of care</b>	<b>50</b>	<b>52</b>	<b>35</b>	<b>14</b>
Immediate family †	30	64	31	5
Friends, extended family	7*	46*	37	16*
Paid help	9*	16*	43*	41*
Immediate family and others	5*	49*	39	13* <sup>E</sup>
<b>Appointments and errands</b>				
<b>All sources of care</b>	<b>52</b>	<b>16</b>	<b>41</b>	<b>43</b>
Immediate family †	37	16	41	43
Friends, extended family	10*	15	43	41
Paid help	2*	23 <sup>E</sup>	23*	54
Immediate family and others	3*	13 <sup>E</sup>	41	46
<b>Nursing and specialized care</b>				
<b>All sources of care</b>	<b>6</b>	<b>31</b>	<b>32</b>	<b>38</b>
Immediate family †	1 <sup>E</sup>	56	22 <sup>E</sup>	22 <sup>E</sup>
Friends, extended family	1 <sup>E</sup>	58 <sup>E</sup>	F	F
Paid help	4*	16* <sup>E</sup>	39	45*
Immediate family and others	1 <sup>E</sup>	50 <sup>E</sup>	F	F
<b>Personal care</b>				
<b>All sources of care</b>	<b>17</b>	<b>59</b>	<b>27</b>	<b>14</b>
Immediate family †	9	67	23	10
Friends, extended family	2*	58	22 <sup>E</sup>	20 <sup>E</sup>
Paid help	4*	39*	37*	24*
Immediate family and others	2*	58	32 <sup>E</sup>	F
<b>At least weekly      At least monthly      Less than monthly</b>				
<b>Personal finances</b>				
<b>All sources of care</b>	<b>26</b>	<b>52</b>	<b>40</b>	<b>8</b>
Immediate family †	22	54	39	7
Friends, extended family	2*	44	48	F
Paid help	1* <sup>E</sup>	36 <sup>E</sup>	33 <sup>E</sup>	F
Immediate family and others	1* <sup>E</sup>	40 <sup>E</sup>	55 <sup>E</sup>	F
<b>Heavy chores</b>				
<b>All sources of care</b>	<b>70</b>	<b>60</b>	<b>24</b>	<b>17</b>
Immediate family †	45	66	22	11
Friends, extended family	15*	51*	26	23*
Paid help	8*	34*	29	37*
Immediate family and others	4*	63	18	19*

† reference group

\* statistically significant difference from reference group (immediate family) at  $p < 0.05$

Note: Data were not collected on the frequency with which the receiver got help in moving around the house. Totals might not add to 100 due to rounding.

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

## Summary

People with disabilities who received help with activities of daily living (ADLs) most often identified an immediate family member as their primary caregiver. However, the majority of care receivers relied on more than one source of care to accomplish all the tasks with which they needed help, as the severity of their disability increased.

Help with certain ADLs was received almost exclusively from immediate family. This was particularly the case for personal finances, meal preparation, and moving around the home, where the family remained most closely involved.

But as people received more care for ADLs, the help they obtained increasingly came from outside the immediate family, as friends, neighbours, extended family and paid helpers took on a larger caregiving role.

In general, friends and extended family came forward when the care receiver needed help to go to appointments and run errands,

with general housework, and heavy household chores. Paid helpers tended to be a source of care when the care receiver required assistance with personal care and nursing or specialized treatment.

Frequency of care giving adds an important dimension to the understanding of care giving. The 2006 PALS data show that while friends and extended family were less likely to provide care than immediate family, the care they did provide was given just as frequently as family. Conversely, paid caregivers were least often called upon by care receivers, and provided care less frequently than any other source.



### **Patric Fournier-Savard**

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**Susan Crompton** is a senior analyst with Social and Aboriginal Statistics Division at Statistics Canada.

1. In 2006, 4.4 million Canadians aged 15 and over identified themselves as having a disability, an increase of three-quarters of a million people since 2001.
2. Fawcett, G., C. Ciceri, S. Tsoukalas and A. Gibson-Kierstead. 2004. *Supports and Services for Adults and Children aged 5-14 with Disabilities in Canada: An analysis of data on needs and gaps*. Ottawa: Canadian Council on Social Development. [http://www.socialunion.gc.ca/pwd/\\_GAPS\\_Report\\_Eng\\_rev.pdf](http://www.socialunion.gc.ca/pwd/_GAPS_Report_Eng_rev.pdf) (accessed September 22, 2010)
3. Statistics Canada. 2003. *Disability supports in Canada, 2001*. Statistics Canada Catalogue no. 89-850-XIE. <http://www.statcan.gc.ca/bsolc/olc-cel/olc-cel?catno=89-580-X&lang=eng> (accessed September 22, 2010)
4. Wanted help includes categories: received enough help; did not receive enough help; and needs help but does not receive it.
5. Some help from friends and extended family includes the following categories: immediate family with friends and extended family; immediate family with friends, extended family and paid help; friends and extended family only; and friends and extended family with paid help.
6. Some support from paid helpers includes categories: immediate family with paid help; immediate family with friends, extended family and paid help; friends and extended family with paid help; and paid help only.

**Table A.1 Sources of care for individual activities of daily living, by severity of disability, 2006**

Activity of daily living	Persons with a disability who received help	Of these, proportion receiving care by level of disability			
		Mild †	Moderate	Severe	Very severe
percentage					
<b>Meal preparation</b>					
Immediate family	25	76	80	75	71
Friends, extended family	4	11 <sup>E</sup>	11 <sup>E</sup>	11	11
Paid help	3	11 <sup>E</sup>	7 <sup>E</sup>	7	10
Immediate family and others	2	F	F	6 <sup>E</sup>	7
<b>Housework</b>					
Immediate family	30	60	62	59	61
Friends, extended family	7	10	14	14	13
Paid help	9	23	19	17	14
Immediate family and others	5	6 <sup>E</sup>	6	10	13
<b>Appointments and errands</b>					
Immediate family	37	75	69	73	67
Friends, extended family	10	20 <sup>E</sup>	24	17	19
Paid help	2	3 <sup>E</sup>	3 <sup>E</sup>	4 <sup>E</sup>	6 <sup>E</sup>
Immediate family and others	3	F	4 <sup>E</sup>	5	8 <sup>E</sup>
<b>Nursing and specialized care</b>					
Immediate family	1	F	F	10 <sup>E</sup>	23 <sup>E</sup>
Friends, extended family	1	F	F	F	F
Paid help	4	75	52 <sup>E</sup>	62	60
Immediate family and others	1	F	F	F	F
<b>Personal care</b>					
Immediate family	9	64	62	57	51
Friends, extended family	2	F	F	10 <sup>E</sup>	13
Paid help	4	F	23 <sup>E</sup>	22	20
Immediate family and others	2	F	F	11 <sup>E</sup>	16
<b>Personal finances</b>					
Immediate family	22	89	81	83	83
Friends, extended family	2	F	13 <sup>E</sup>	7	9
Paid help	1	F	F	F	F
Immediate family and others	1	F	F	6 <sup>E</sup>	F
<b>Heavy chores</b>					
Immediate family	45	64	64	62	64
Friends, extended family	15	19	22	21	20
Paid help	8	13	10	12	8 <sup>E</sup>
Immediate family and others	4	4	4 <sup>E</sup>	5	7 <sup>E</sup>
<b>Moving around the house</b>					
Immediate family	6	80	78	68	61
Friends, extended family	1	F	F	17 <sup>E</sup>	14 <sup>E</sup>
Paid help	1	F	F	F	11 <sup>E</sup>
Immediate family and others	1	F	F	F	14 <sup>E</sup>

† reference group

 \* statistically significant difference from reference group (mild disability) at  $p < 0.05$ 

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.