



Hidden Costs

Invisible
Contributions

“I wish that I could just have a break”: Consequences of supporting adults with disabilities.”

In the fall of 2007, we completed a national telephone survey of adults age 19 to 64 with chronic illness or disabilities, and of the family members who support them. The results of this survey are remarkable. Family members who support these adults with disabilities are at substantially higher risk of poor financial, social and health outcomes than any other group of caregivers we have examined in more than 20 years of research on families and care. The high levels of need are evident in the data and the voices of these families.

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“I wish that I could just have a break”:
Consequences of supporting adults with disabilities

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***“I wish that I could just have a break”:
Consequences of supporting adults with disabilities***

Executive Summary

This report describes the experiences of families supporting adults with disabilities. Information in this report comes from a national telephone survey conducted as part of the Hidden Costs/Invisible Contributions (HCIC) research program based in the Department of Human Ecology at the University of Alberta, in partnership with government and community partner organizations.

The study focused on adults between 19 and 65 years of age with disabilities, and their main supporters. Participants were recruited from among members or clientele of eight partner agencies. In all 4,979 letters of invitation were mailed to members of participating organizations. Additional invitations were circulated via e-mail. Between December 2006 and October 2007, 349 telephone interviews were completed with adults with disabilities and 320 interviews with their main supporters. Adults with disabilities were asked about their health and functional status, the types of tasks with which they required assistance, their unmet needs, and basic demographic information. Supporters were asked about their own health, functional status, and demographic characteristics as well as the type, amount and duration of support they provided to the person with disabilities, and the impact of providing that support on themselves and their family.

Respondents with disabilities experienced a wide range of types and severity of disabilities. Some have had complex physical and cognitive disabilities since infancy. Others acquired equally complex physical and psychological disabilities as adults. Still others have only physical or only psychological disabilities. Factors such as severity, nature, and age of onset of disability may have very different implications for support needs and, therefore, very different implications for supporters. To examine these differences we have described groups with different types of disabilities separately in this report.

Living with disabilities

The adults with disabilities who were interviewed for this study fell into one of four groups:

- ♦ Veterans with high levels of service-related disabilities
- ♦ Adults with spinal cord injury
- ♦ Adults with cerebral palsy
- ♦ Adults with schizophrenia

All respondents with disabilities were adults under age 65. About 70% of Veterans Affairs Canada (VAC) clients and Canadian Paraplegic Association (CPA) members were age 45 to 64. Members of the Cerebral Palsy Association (CPal) and Schizophrenia Society (SS) were the youngest participants with 48% and 20% respectively under the age of 35.

Supporting individuals with disabilities

Supporting an individual with disabilities is often a long term process. Respondents with cerebral palsy and schizophrenia have been living with their disabilities since childhood or adolescence. The majority of VAC clients and members of the CPA acquired their disabilities as adults, though a substantial minority of members of the CPA also acquired their disabilities as children or adolescents. The majority of respondents in all groups had multiple disabilities, though Veterans and respondents with cerebral palsy live with particularly complex challenges. The vast majority of supporters had been involved long term. Particularly high proportions (87%) of those supporting a family member or friend with schizophrenia had been supporting that person for a decade or more. Supporting an adult with cerebral palsy is somewhat more time consuming than supporting adults with other types of disability, with more than ¼ providing almost 24/7 assistance. Those supporting Veterans with high levels of complex disabilities are a close second: 55% provide five hours or more of help *each day*.

There is a good deal of variability in support trajectories both within and across groups. High proportions of those supporting Veterans and persons with cerebral palsy reported that the time they spend providing assistance had escalated over time, and almost as many of those supporting Veterans and persons with schizophrenia reported that support needs had been variable.

Economic consequences: "The financial cost alone is tremendous"

Like the disabilities, support needs are chronic. Lives are changed as a result of providing such high levels of support over many years. Families experienced high levels of economic and non-economic consequences as a result of providing assistance without adequate support for their roles or compensation for the consequences they experienced. Supporters' employment often was affected by providing high levels of support over the long-term. Employment impacts are important because they affect the short and long term economic situation of the family: families' income and benefits may be reduced, as may retirement pensions and benefits; and ability to save for retirement is compromised.

In addition to long term employment-related losses, many supporters reported that they also incurred extra expenses for the person with disability—mainly for medications, travel or transportation. This was most common among those supporting persons with spinal cord injury and schizophrenia (80%) followed by those supporting persons with cerebral palsy and Veterans with high levels of disability (68% and 63% respectively). For many, these out-of-pocket expenditures were modest, but for about 1/3 of supporters of persons with cerebral palsy, spinal cord injury or schizophrenia, they exceeded \$5,000 in the past year. These findings foreshadow the potential for lifelong economic costs related to the care work of families of an individual with disabilities.

The cumulative effect of lost wages and benefits and extra expenses is profound. Supporters of family members with cerebral palsy were more likely than any of the other groups of supporters to report direct financial consequences—reduced earnings (61%) and benefits (29%)—and perceived financial hardship (52%) as a result. For high proportions of supporters in all groups (41-45%), the financial impact of providing support impacted negatively their overall quality of life.

Health and social consequences: "The non-financial cost, you can't count it"

Health and social consequences resulting from supporting the individual with disabilities were equally common and worrisome. While less tangible than economic costs, they have a powerful impact on supporters and their families. The majority were exhausted, sleep deprived, and lacked time for personal activities. Not surprisingly, most also said that their health was affected.

The whole family suffers as a result of such stressors. Family relationships were especially strained for those supporting a family member or friend with schizophrenia. Supporters of family members or friends with cerebral palsy were at greatest risk of experiencing most of the social consequences examined. Collectively these findings suggest a high potential for isolation of these families.

Services: "It doesn't reveal struggles for support"

Services from the public or non-profit sector can help off-set the stress of supporting someone with serious disabilities and extend their capacity to provide support. We found that almost half (48%) of all supporters needed help that they did not have. Even more (72%) said they lacked the supports they needed to continue assisting the person with disabilities in the future, an indication of the fragility of such families. Respondents supporting a family member or friend with cerebral palsy were most likely to report currently needing supports they didn't have (58%), but those supporting someone with schizophrenia were the most likely to indicate that supports needed to continue providing assistance in the future were absent (92%).

Chief among the reasons for lacking needed supports is cost. Almost 60% of all supporters said that supports are too expensive and 67% reported that supports are not covered by insurance. Those assisting someone with spinal cord injury were most likely to report cost as the issue (64%), while lack of insurance coverage was cited by a full 80% of those supporting someone with schizophrenia. Overall, resources of these families were being stretched with insufficient other assistance available.

Support for the person with disabilities: "They don't include the family"

This study did not include questions about impact on families, nor about help with managing changes in their lives. Yet comments volunteered by respondents indicate that some supporters felt as though they and their families were invisible.

Next steps: Responding to the needs of families and individuals with disabilities

Findings from this study tell us that supporters to adults with severe, long-standing, and complex disabilities are far more likely than the general population of supporters to have reported almost every one of the major categories of economic and non-economic consequences of providing support. High proportions of supporters reported financial insecurity, stressful lives, and low levels of life satisfaction. They worry about their ability to sustain support for the adult with disabilities. They worry about their families whose lives had been changed profoundly.

The strongest message in these findings is that families have suffered as a result of assisting a family member or friend with disabilities without adequate support for that role. The missions of organizations providing services to persons with disabilities and their families have never been more important.

“I wish that I could just have a break”: Consequences of supporting adults with disabilities

The Backdrop

Across Canada, associations are organized with the purpose of focusing on the wellbeing of individuals with disabilities. These diverse organizations work hard to learn about and address the needs of their members and of the family members and friends who support them. Many such organizations exist, and we were fortunate to be able to partner with some of them in carrying out this project to study the hidden costs of supporting an adult family member or friend with disabilities.

Although the mission statements of our partner organizations focus on the individual with disabilities (see below), the needs of family members and friends who support these individuals are critically important. They play a crucial role in supporting the person with disabilities so they can remain as independent as possible and can thrive despite their disabilities. Research shows that the general population of those who support family members and friends with chronic conditions experiences a wide range of both positive and negative consequences of providing support. Often the negative consequences outweigh the positive ones, overwhelming the supporter. In this study we focus on the negative consequences, addressing the following questions:

1. Who are the family members and friends who assist non-senior adults with chronic illness or disabilities?
2. With what tasks do they assist persons with chronic illness or disabilities?
3. What are the economic and non-economic consequences of taking on responsibility for assisting persons with chronic illness or disabilities?
4. What factors are associated with the intensity of these consequences?

This document describes the experiences of family members and friends who are assisting persons with disability with a range of daily tasks.

Mission Statements

- ◆ **Canadian Association for Community Living (CACL):**
“To build communities in which people who have an intellectual disability have equality, opportunity, membership and the right to participate.”
- ◆ **Canadian Paraplegic Association of Alberta (CPAA):**
“To assist persons with spinal cord injuries and other physical disabilities to achieve independence, self reliance and full community participation.”
- ◆ **Cerebral Palsy Association of Alberta (CPAA, 2008):**
“Supporting and enhancing the lives of people affected by Cerebral Palsy.”
- ◆ **Schizophrenia Society of Nova Scotia (SSNS, 2008):**
“To improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy, and research.”
- ◆ **Veterans Affairs Canada (VAC, 2008):**
“To provide exemplary, client-centered services and benefits that respond to the needs of veterans, our other clients and their families, in recognition of their services to Canada; and to keep the memory of their achievements and sacrifices alive for all Canadians.”

The Survey and Sampling Strategy

Information in this report comes from a national telephone survey conducted to evaluate the experiences of family members and friends who support individuals between the ages of 19 and 65 who have a disability. The survey was conducted as part of the Hidden Costs/Invisible Contributions (HCIC) research program based in the Department of Human Ecology at the University of Alberta.

Survey development. In developing the survey instruments we relied heavily on previous Statistics Canada surveys on similar and related subjects (eg. the Participation and Activity Limitation Survey (PALS) and the General Social Survey (GSS) on aging and social support), and our experience with them, to identify both the domains of questions we would need to ask, and question structure and wording. From the person with chronic illness or disabilities, we needed information on their health status and functional abilities, the types of tasks with which they required assistance, their unmet needs, and relevant personal characteristics. Key domains for the main supporter questionnaire included personal characteristics, type of assistance provided, and the consequences of providing this assistance. Consequences included employment consequences, other economic consequences (e.g. out-of-pocket expenses and perceived economic security), social consequences, and health consequences. Questionnaires were further refined in consultation with community partners (e.g. Alberta's Office of Disability Issues (ODI), the Canadian Association on Community Living (CACL), and Veterans Affairs Canada (VAC)). Finally, we piloted questions about the types of consequences supporters experience with delegates at a CACL conference held during the questionnaire development period. In order to survey respondents residing in Quebec, and others whose first language was French, both care receiver and supporter questionnaires were translated into French.

Sampling and recruitment of respondents. Because there is no directory of adults with disabilities, obtaining an adequate sample was not an easy matter. Sample recruitment therefore relied heavily on the co-operation of the following partner organizations: Canadian Paraplegic Associations of Alberta, Saskatchewan and Manitoba; Schizophrenia Societies of Saskatchewan and Nova Scotia; Cerebral Palsy Association of Alberta; Canadian Association for Community Living (including their 13 provincial/territorial associations); and Veterans Affairs Canada. Collectively these organizations represent individuals with a wide range of physical, mental and cognitive disabilities, both acquired and lifelong.

Most potential participants were recruited via a letter of invitation, which included information about the purpose of the survey, a request for permission to contact them if they consented to participate, a request to refer us to the person providing them with the most support, and a letter of support from the relevant partner organization. Letters were sent to the persons with disabilities. If they agreed to participate, they then referred us to the person they considered to be their main supporter. Both the person with disabilities and the supporter completed and mailed the consent forms to the research team at the University of Alberta.

Exceptions to this procedure included the Canadian Association for Community Living, Canadian Paraplegic Association of Saskatchewan, and Veterans Affairs Canada. Individuals affiliated with the CACL were informed of the survey solely by electronic mail. The CPA of Saskatchewan selected members between the ages of 19 and 64 and only these members were mailed letters of invitation. VAC selected clients between the ages of 19 and 64 who had been discharged from active service with a high level of disability (78% or more full body impairment according to VAC's assessment of the Veteran's physical, mental and social impairment). The sample frame for VAC clients included in this study thus includes the most disabled 4% of the 28,500 Veterans aged 19 to 64 who are receiving VAC benefits.

In all cases, only willing participants who completed and returned consent forms were contacted for interviews.

Data collection. Between December 2006 and October 2007, the Population Research Laboratory at the University of Alberta conducted telephone interviews with 349 persons with disabilities (PWD) and 320 of their main supporters. At the end of the interviews participants were asked if they had questions or comments about the survey. Their responses provide additional qualitative data that set the survey findings in poignant, "life as lived" context.

Stakeholder consultation. Once descriptive analyses were completed, a draft of this report was prepared and circulated to representatives of stakeholder groups (see Appendix A for a list of participant organizations). The consultation had the following primary objectives: to triangulate findings (i.e. to help us evaluate how representative the sub-samples of survey participants we had obtained were of the relevant populations, and how representative their experiences were relative to those of the relevant populations); to help interpret findings and develop policy and practice implications; to assess whether and how findings might be useful to stakeholders in their work; and to solicit suggestions for dissemination of findings.

The Resulting Sample

The distribution of respondents to the main surveys by organizational affiliation is outlined in Table 1. Responses were received from ten persons with other types of disabilities, however there were too few of each to accurately report on them here.

Table 1: Organization Affiliation of Persons with Disabilities (PWD) and Their Supporters

Organization	PWD		Supporters	
	#	%	#	%
Veterans' Affairs Canada	142	40.7	115	35.9
Canadian Paraplegic Associations of Alberta, Manitoba & Saskatchewan	161	46.2	133	41.5
Cerebral Palsy Association of Alberta	21	6.0	31	9.7
Schizophrenia Societies of Saskatchewan and Nova Scotia	15	4.3	30	9.4
Total	349	100.0	320	100.0

As will be apparent from the difference in the total number of respondent PWD and supporters, not all persons with disability have a matching main supporter. Although we planned to interview only matched pairs of persons with chronic illness or disabilities and their main supporters who both returned consent forms, some persons with chronic illness or disabilities were unable to participate in a telephone interview, requesting that their supporter complete the interview on their behalf. Some persons with chronic illness or disabilities were willing to participate, while their supporters were not, and vice versa. Some persons with chronic illness or disabilities did not have a main supporter. In order to maximize the overall sample size, we accepted proxy interviews where persons with chronic illness or disabilities requested it and collected data from unmatched respondents.

It also is apparent that response rates were low across the board, but recruitment was more successful with some groups than others. We were able to directly assess the question of representativeness only for the sample recruited through Veterans Affairs Canada. For this group, the sampling frame comprised the full population of 1059 Veterans between the ages of 19 and 65 years with high levels of disabilities and we had sufficient information about the Veterans in the sampling frame to compare them with respondents on several relevant personal characteristics. This comparison showed that the sample closely represents the population of Veterans with high levels of disabilities, especially in terms of geographic (provincial) distribution, gender and number and type of health condition, though it included a somewhat higher proportion of married, and slightly older, respondents.

Information allowing similar comparisons between the other sub-samples and their relevant populations is not available so we cannot know how representative the samples are. ***Nonetheless, based on our consultation with stakeholder groups, there was strong agreement that the findings regarding the experiences of main supporters reported herein are representative of the clients of all the participating organizations.***

Adults Living With Disabilities

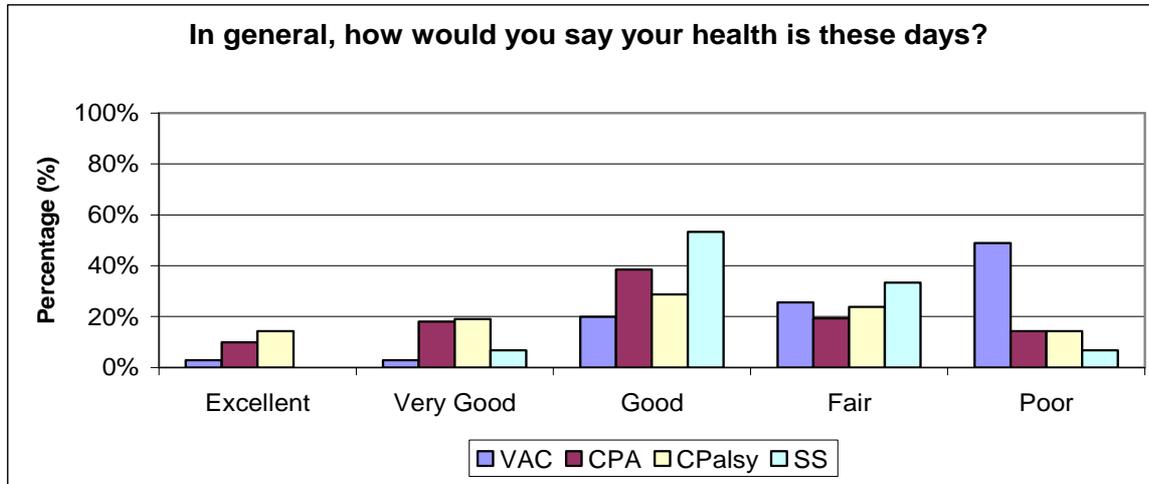
The adults with disabilities who were interviewed for this study had a wide range of types and severity of disabilities. Those included in this report fall into four groups:

- Veterans discharged from active service with high levels of physical, cognitive and/or psychological disabilities (78% or more full body impairment according to VAC's assessment).
- Persons with spinal cord injury. Spinal cord injury involves "paralysis of the lower extremities and part or all of the trunk muscles. Usually there is a loss of sensation in paralyzed limbs and other effects such as muscle spasms, pain and loss of bowel and bladder control. Spinal cord injury occurs when there is impairment at or below the T1 Thoracic level" (Canadian Paraplegic Association, 2008, Overview of SCI and its consequences, para. 4).
- Persons with cerebral palsy. Cerebral palsy is a group of non-progressive disorders affecting body movement, posture and/or muscle co-ordination, arising from an insult to or anomaly of the developing brain early in childhood. This damage interferes with messages between the brain and the body and may result in muscle tightness or spasms, involuntary movement, difficulty with gross motor skills, such as walking or running, difficulty with fine motor skills, such as writing or doing up buttons, and/or difficulty in perception and sensation. The same damage that caused cerebral palsy may also lead to seizures, learning disabilities or developmental delay. It is not a progressive condition, though the effects of the condition may change over time, and people with cerebral palsy have a normal life-span (Ontario Federation for Cerebral Palsy, n.d.).
- Persons with schizophrenia. Schizophrenia is a serious, treatable, biological brain disorder which affects a person's ability to think, feel and perceive, to know what is real and what is not. Symptoms, believed to be caused by disturbances of the flow of information in the brain, include delusions, hallucinations, disturbances in thinking and communication, and withdrawal from social activity. (Canadian Psychiatric Association & Schizophrenia Society of Canada, 2007).

All respondents with disabilities were under age 65. Veterans Affairs Canada (VAC) clients and Canadian Paraplegic Association (CPA) members were similar in age distribution. About 70% of respondents in each of these groups were age 45 to 64. Members of Cerebral Palsy Association and Schizophrenia Society (SS) were the youngest participants with 48% and 20% respectively under the age of 35.

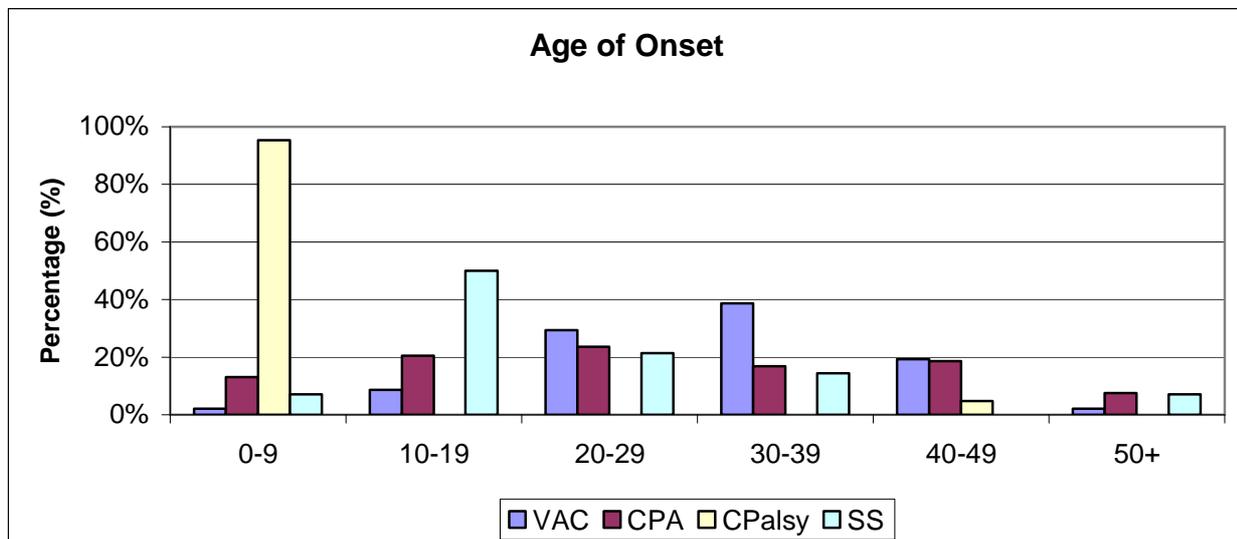
The general health of respondents with disabilities is poorer than that of the Canadian population. While between 1/3 (CPA members) and 3/4 (VAC clients) of respondents with disabilities said their health was fair or poor (Figure 1), only 13% of all Canadians between the ages of 45 and 64, and 5.5% of those aged 20-34 years reported that their health is fair or poor (Statistics Canada, 2005).

Figure 1



It is evident that respondents' disabilities have resulted in longstanding and complex problems. As is typical for the conditions from which their disabilities arise, respondents with cerebral palsy and schizophrenia have been living with their disabilities since childhood or adolescence. The majority of VAC clients and members of the CPA acquired their disabilities as adults, though a substantial minority of members of the CPA also acquired their disabilities as children or adolescents (Figure 2).

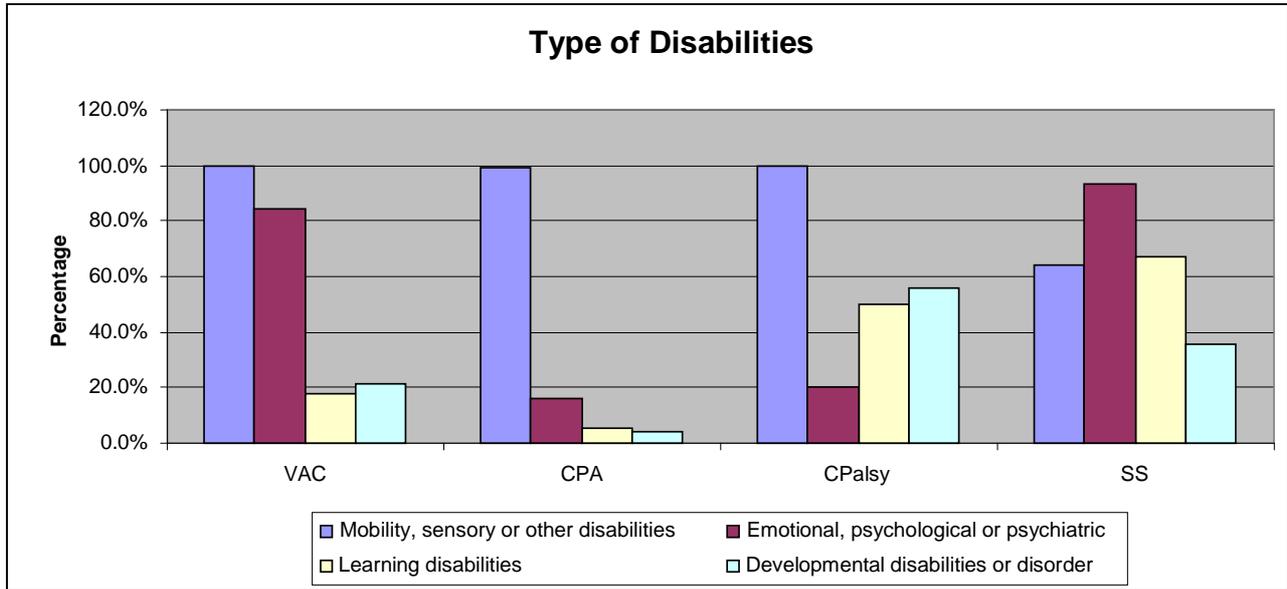
Figure 2



The majority of respondents in all groups had multiple disabilities, though Veterans and respondents with cerebral palsy live with particularly complex challenges. More than 90% of Veterans and 86% of respondents with cerebral palsy reported three or more conditions that limited their daily function.

The vast majority of all respondents, except those with schizophrenia, have frequent difficulty with their motor, sensory or cognitive function. Not surprisingly, the main challenge for those with schizophrenia relate to emotional, psychological or psychiatric conditions. Perhaps more surprising is that almost as many Veterans reported such problems. Half of respondents with cerebral palsy also reported learning and developmental disabilities, and more than 1/3 of those with schizophrenia also had been diagnosed with developmental disabilities. (Figure 3)

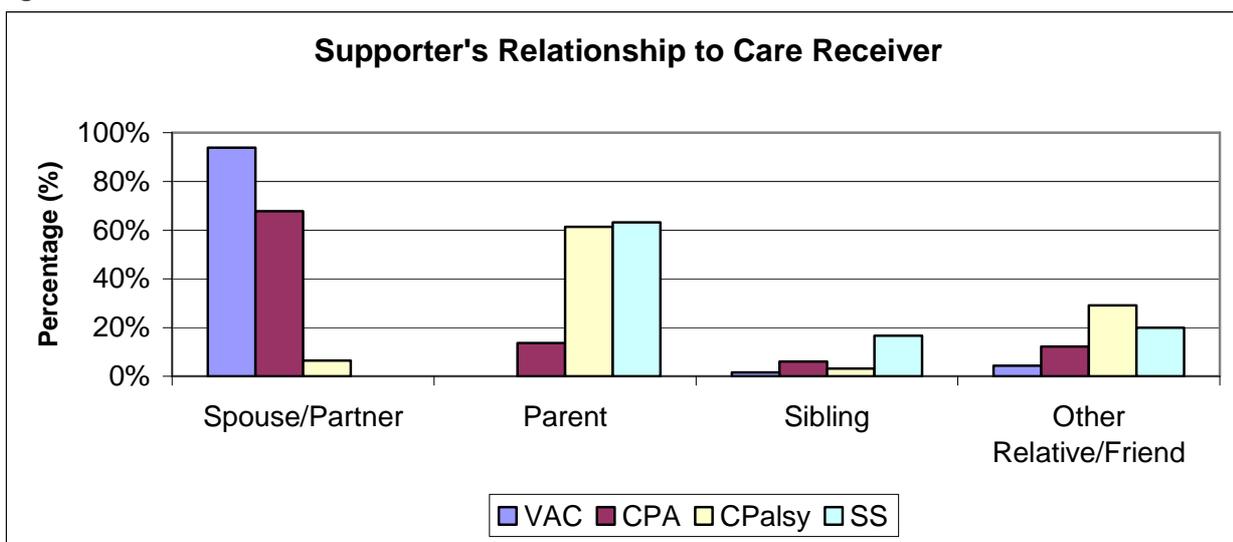
Figure 3



Supporters of Adults With Disabilities

As Figure 4 illustrates, most Veterans (94%) identified their spouse as their main supporter. More than 2/3 of CPA members also reported that their spouse was their main supporter. For 2/3 of those with cerebral palsy or schizophrenia, most of whom had acquired their disability as children or adolescents, parents played that role. Unique to respondents with schizophrenia, 1/3 of the main supporters were siblings or other relatives. We did not speak directly to other family members or friends who might also have been helping, but our previous research suggests that there may be more than one person in support networks. As a result we do not know about the roles in or consequences of supporting the person with disability for anyone other than the main supporter. However, we do get glimpses of the impact on these other family members from supporters' comments.

Figure 4



The majority of main supporters for all groups were women, though almost 1/3 of the main supporters of CPA members were men.

Respondents supporting family members or friends with schizophrenia were substantially older than other supporters: 87% were age 55 or over. The other three groups were fairly similar in age distribution with the majority (65% or more) being aged 45 to 64.

Almost all of the Veterans and their supporters live in the same household as their main supporters (95%), but so does a large majority of those supporting persons with spinal cord injury and cerebral palsy (80% and 71% respectively). Most respondents with schizophrenia, on the other hand, live independently from, though within easy reach of, their main supporter.

The majority of all main supporters are married, although almost 1/3 of those supporting a family member or friend with schizophrenia are widowed. This is not unexpected given that this also is the oldest group of supporters.

Between 80% and 90% of the main supporters of Veterans, persons with spinal cord injury and schizophrenia are supporting only the person who referred them to us. However, 1/3 of those supporting a family member or friend with cerebral palsy are supporting as many as four others.

Supporting a person with disabilities is an intense and long term process. As Figure 5 shows, more than 60% of Veterans' supporters had been providing support for 10 years or more. Even higher proportions of those supporting other adults with disabilities had been supporting the person long-term, with particularly high proportions (87%) of those supporting a family member or friend with schizophrenia having been supporting that person for 10 years or more.

Supporting an adult with cerebral palsy is somewhat more time consuming than supporting adults with other types of disabilities, with more than a quarter of these supporters (26%) providing almost around the clock assistance (Figure 6). Those supporting Veterans with high levels of complex disabilities are also providing many hours of care: 55% provide five hours or more of assistance each day. Clearly many of the adults with disabilities in this study had very high needs. The impact on their supporters also is severe, even when compared to those providing end-of-life care, another group of high-impact supporters. In our previous research, we found that the latter group provides an average of 10 hours per week of care (Fast, et al., 2002a, 2002b).

Figure 5

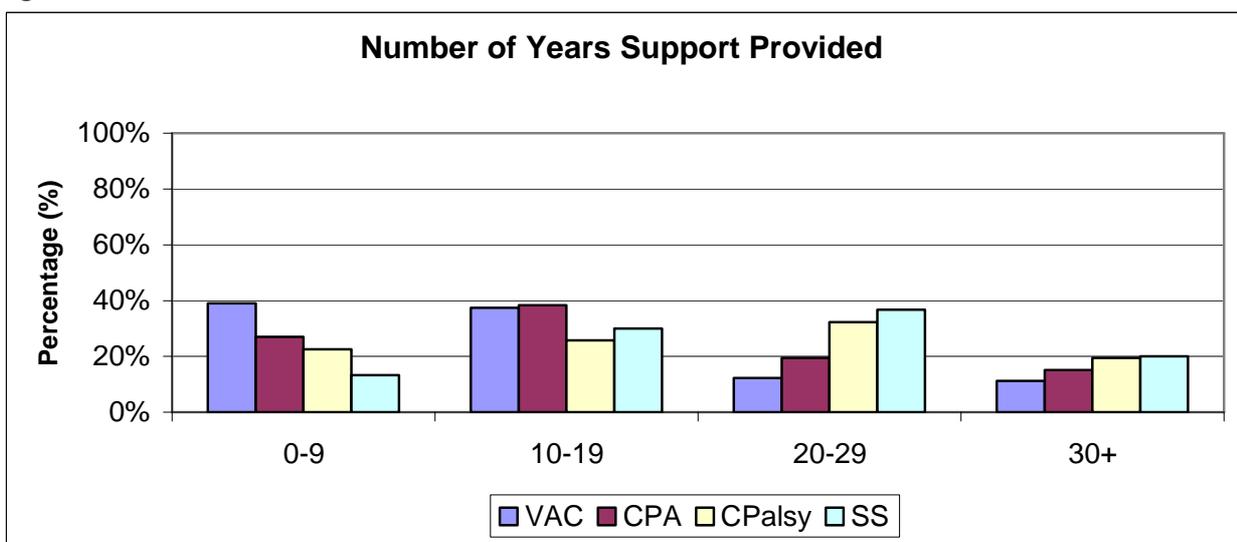
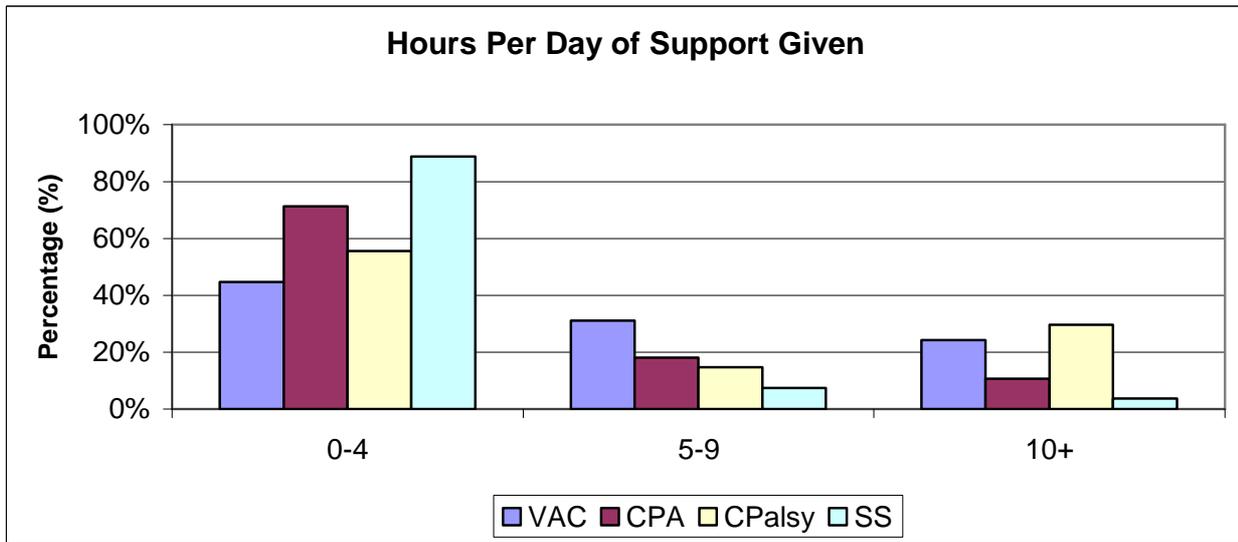
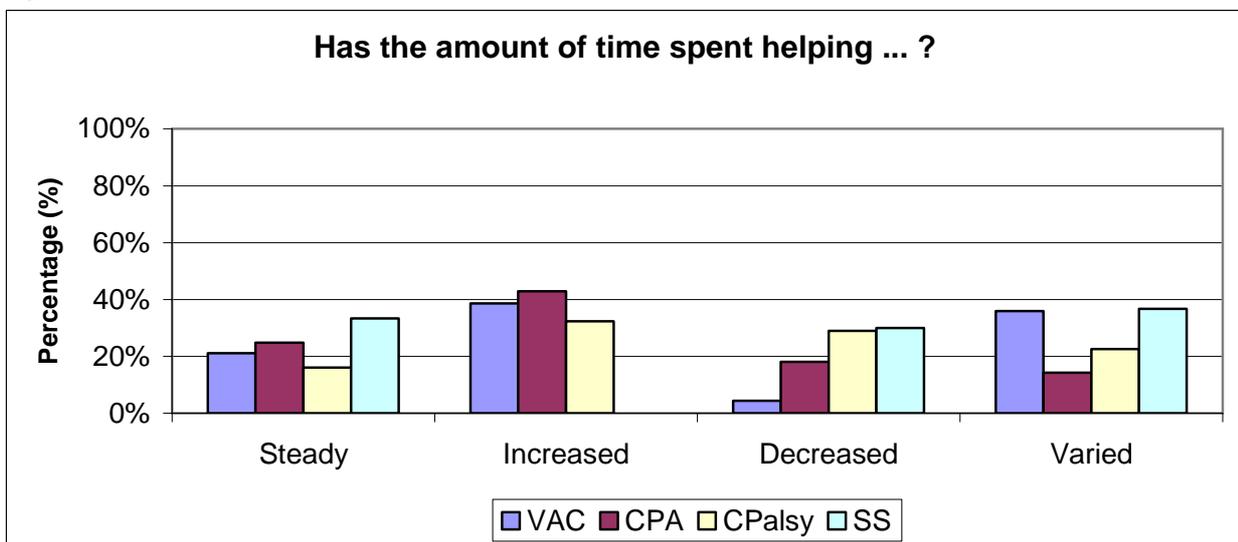


Figure 6



The support trajectories of the four groups of supporters examined here appear to be quite different. In fact there is a good deal of variability both within and across groups. High proportions of those supporting persons with physical disabilities, Veterans, and persons with cerebral palsy report that the time they spend providing assistance has increased over time, and almost as many of those supporting Veterans and persons with schizophrenia report that support needs have been variable (Figure 7). The unpredictability and volatility that comes with such patterns make it difficult to plan ahead and to maintain regular commitments to other activities, such as employment.

Figure 7



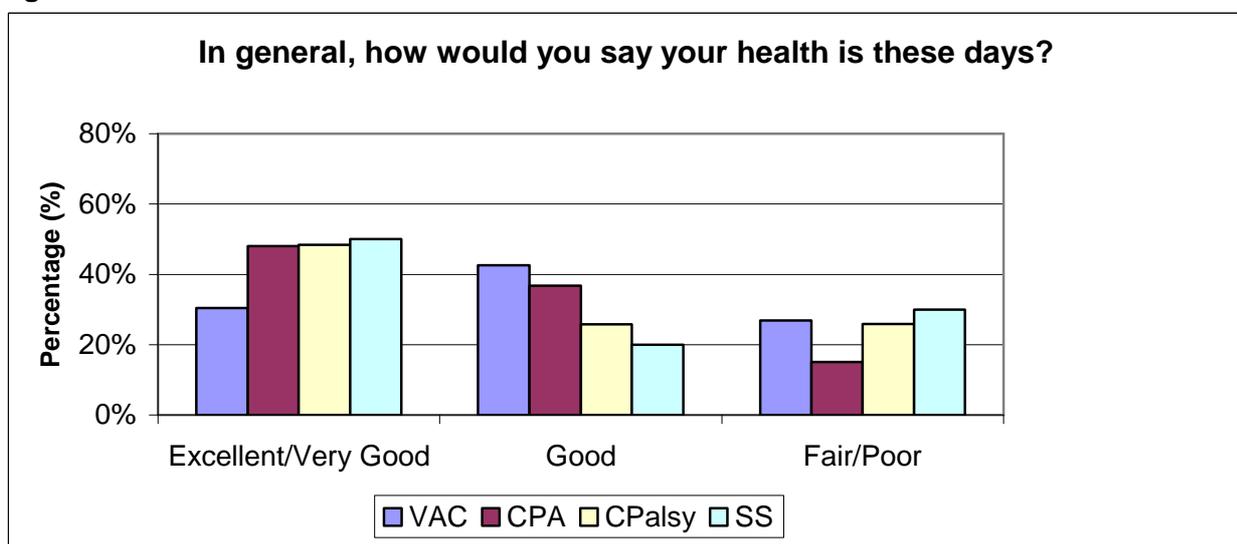
Patterns of supporters' involvement in specific types of support tasks are generally consistent with the types of disabilities of the person they're supporting. As Table 2 shows, adults with schizophrenia are less physically dependent (only 13% require personal care, 7% require medical care and none require assistance with mobility) but they require more active monitoring. Adults with other types of disabilities are more physically dependent with the vast majority requiring assistance with everyday life tasks such as meal preparation, housekeeping, personal and medical care. Those with cerebral palsy also need more help with care management, financial management and communication.

Table 2: Type of Support Provided, by Type of Disabilities

	VAC (%)	CPA (%)	CPalsy (%)	SS (%)
Meal preparation	90.4	78.9	93.5	53.3
Everyday housework	93.9	81.2	87.1	36.7
Heavy housework	82.6	88.0	83.9	43.3
Appointments/errands	91.3	87.1	87.1	66.7
Finances	68.7	45.8	77.4	56.7
Child care	29.5	10.7	9.7	6.7
Personal care	59.1	51.1	77.4	13.3
Medical care	17.4	27.1	51.6	6.7
Mobility at home	38.6	45.9	51.6	0.0
Emotional support	93.3	98.5	96.8	100.0
Checking up	65.7	41.4	71	83.3
Care management	64.9	45.9	83.9	56.7
Communicating	41.2	18.8	74.2	26.7

The burden of providing support is evident in the supporters' reports on their own health. Respondents supporting someone with spinal cord injury reported the best health. Only 14% of these supporters said that their health was fair to poor, while between 27% and 30% of the other supporters reported being in only fair to poor health (see Figure 8). However, it is important to note that all supporters' self-reported health is worse than that of the general Canadian population. Of the Canadian population aged 12 and older, 60% report very good or excellent self-rated health and 28.7% report good health; only 11.3% report fair/poor self-rated health (Statistics Canada, 2005).

Figure 8



Economic Consequences: “The financial cost alone is tremendous”

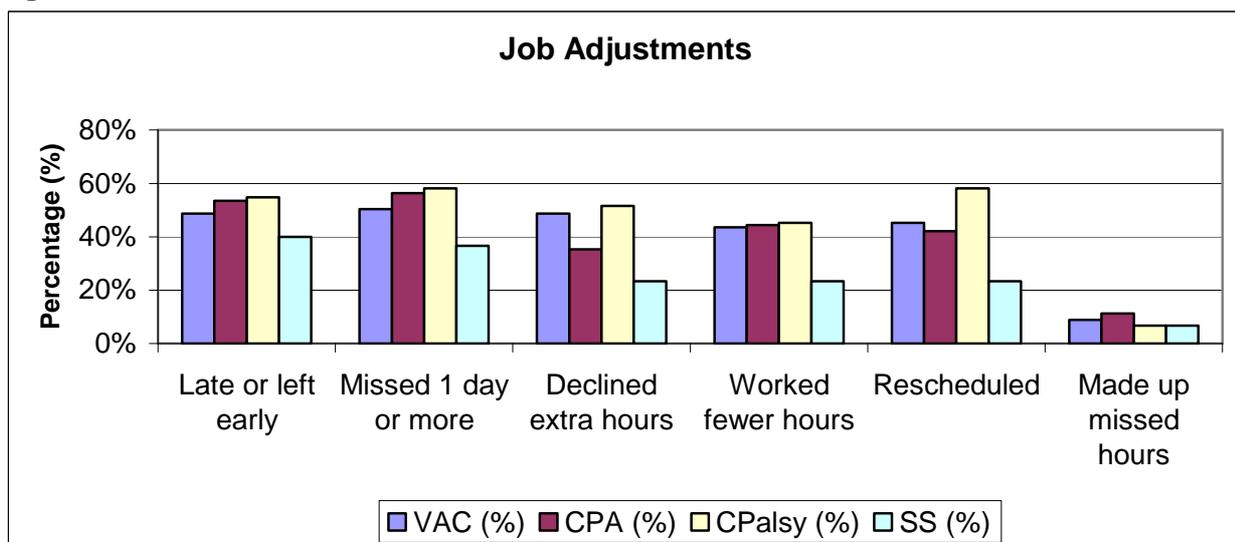
As is evident from the above, support needs are chronic. Providing high levels of assistance over many years, without adequate support, can have a profound impact on virtually every part of the supporter's life, though which domains are most severely impacted appears to depend in part on the type of disabilities they are dealing with. We begin with an examination of economic consequences arising from the way supporting a family member or friend with disabilities affects employment, or adds extraordinary expenditures associated with the disability.

More than half of those supporting persons with cerebral palsy and a quarter of Veterans' supporters had put off getting planned additional education. Education is strongly associated with labour market success, so it isn't surprising that we also see these supporters experiencing more employment consequences flowing from their responsibilities. However, substantial minorities of the other groups of supporters also postponed educational plans: 28% of Veterans' supporters; 21% of those supporting persons with spinal cord injury; and 17% of those supporting someone with schizophrenia.

Employment impacts are important because they affect the short and long term economic situation of families. In the short term, families' income and benefits may be reduced. In the long term, retirement pensions and benefits, as well as ability to save for retirement, are compromised.

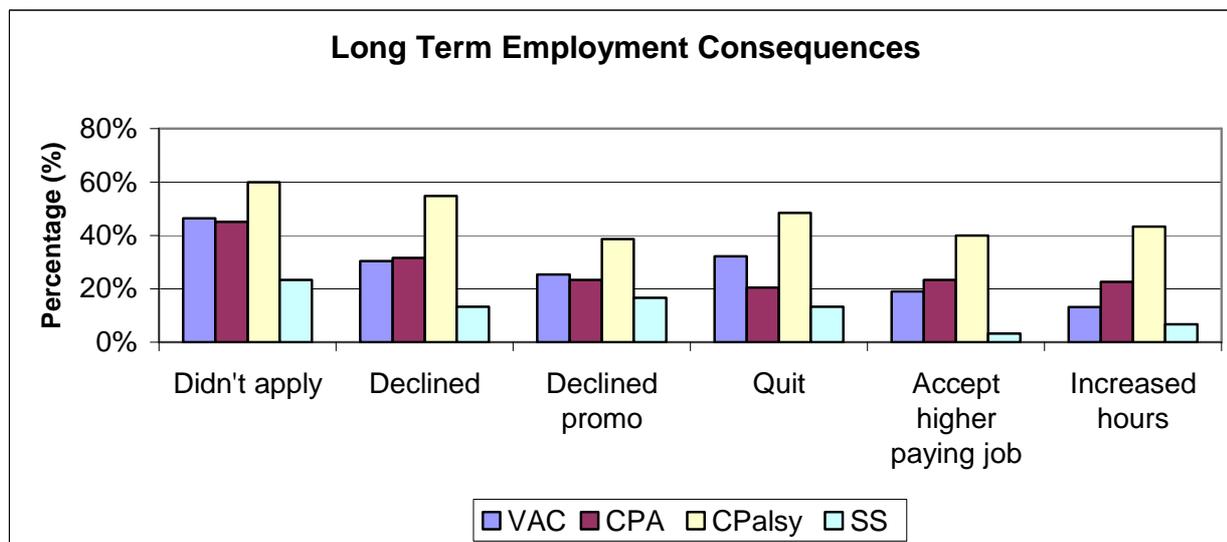
By far the respondents whose employment is most profoundly affected are those supporting persons with cerebral palsy. As is evident in Figure 9, more than half reported having missed whole or part days of work, turned down extra hours, and rescheduled their hours of work. That is not to say that other supporters' employment is unaffected by their care work. Only slightly lower proportions of supporters of veterans and persons with spinal cord injury report full or partial absenteeism, cutting back on regular or overtime work hours, and rescheduling hours of work.

Figure 9



Respondents supporting persons with cerebral palsy also were more likely to implement changes to their employment that have longer term implications (see Figure 10). More than half reported having not applied for jobs and turned down job offers. Almost half had quit working in order to provide support. Interestingly, they also were the most likely of all the groups of supporters studied here to increase their hours of work or take on a new job to generate more income for the family. Almost 1/3 of veterans' supporters quit a job as a result of support demands.

Figure 10



Some of these consequences also are much higher than among the general population of caregivers. In 1996 between 3% and 34% of those providing chronic care, and between 21% and 45% of those providing end-of-life care, reported similar types of longer term employment consequences (Fast, et al., 2002a, 2002b). In 2002, the rates reported by eldercare providers age 45 and over were between 3% and 22% (Walker, 2005). Some respondents, when given the opportunity to further comment or expand on their survey responses, volunteered examples of how their support to their relative or friend had impacted their employment.

"They won't pay someone to look after him, so I've lost at least \$25,000 a year by taking a half time job so I could look after him." [VAC Supporter]

"The hidden cost to me was the loss of my job." [VAC Supporter]

"I have to take off work because you can't leave him alone ... I work on contract, and if I'm not there I'm not paid." [CPA Supporter]

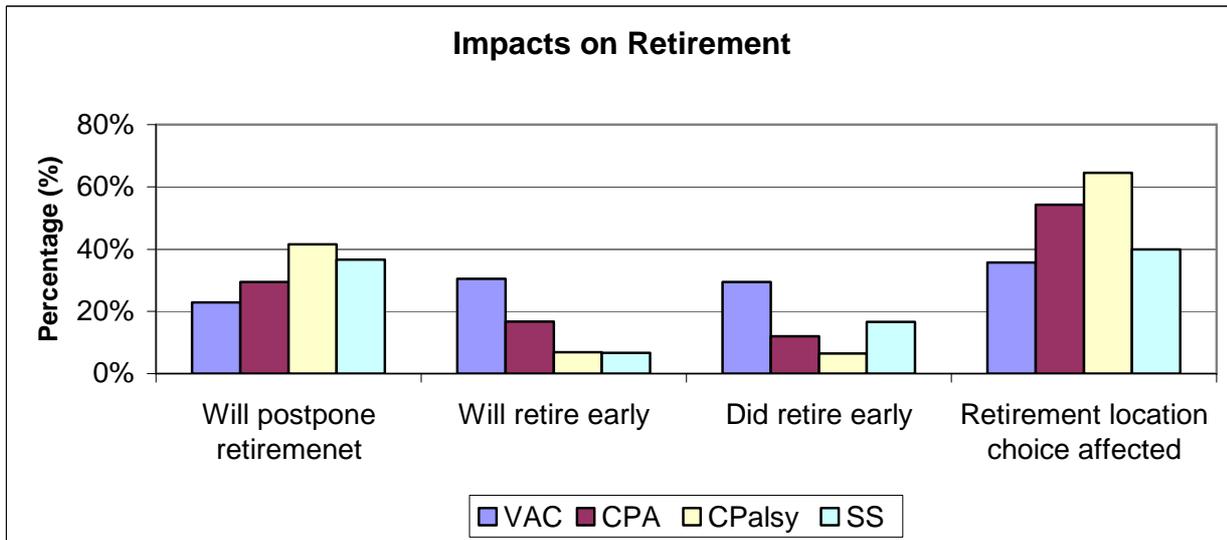
"My husband has a heart condition and I think the stress of (receiver's) condition contributed to it. He had to retire earlier than he probably would've wanted to because of the extra stress." [SS Supporter]

"... instead of working outside the home I work at home. Because of the downturn of her health (the care receiver) has become my full time job." [CPA Supporter]

"there is no compensation for caregivers who give up their careers to provide support." [CPalsy Supporter]

Many supporters also changed their retirement plans (Figure 11). Almost 60% of the Veterans' supporters expected to retire earlier than they had previously planned, or actually had retired early, in order to provide the needed support. In contrast, more than 40% of supporters of family/friends with cerebral palsy expected to stay longer in the labour force than anticipated to offset losses or extra expenses. Even the choice of retirement location had been impacted by supporters' situations, particularly for those supporting persons with spinal cord injury or cerebral palsy.

Figure 11



Some supporters commented on their disappointments in retirement:

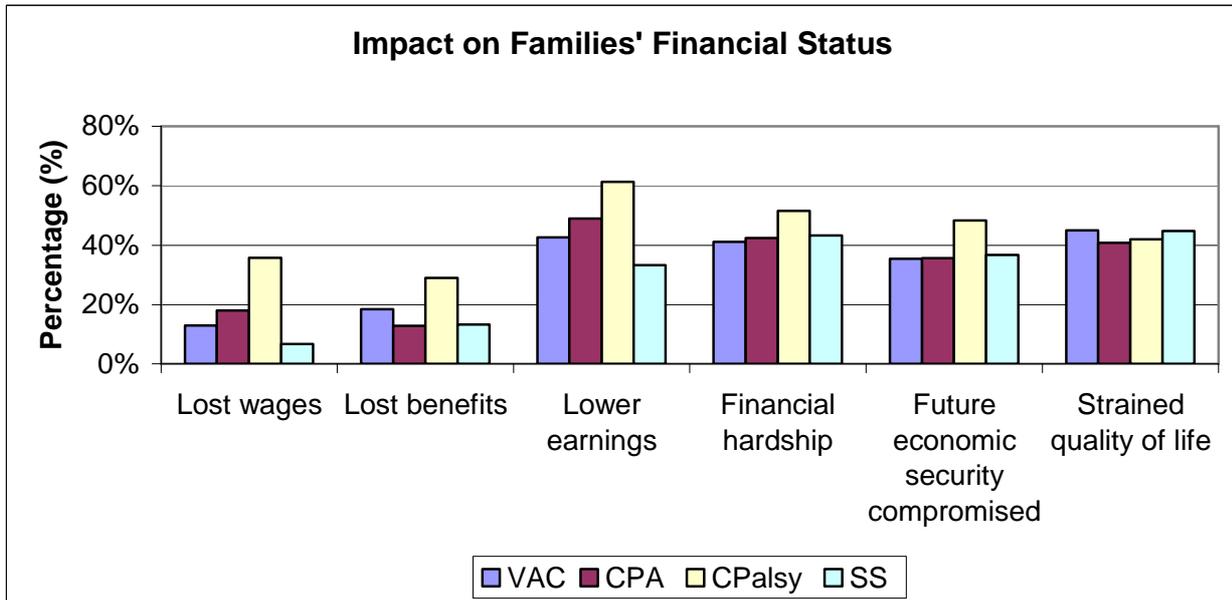
"What frustrates me is that in retirement I'd like to do things and travel and do what other people do, and we can't. It's frustrating that we're going to sit around and exist in our house." [VAC Supporter]

"Overall, supporting an adult child can be very difficult, but the future is a huge, stressful issue now that I'm retired." [SS Supporter]

In addition to long term financial losses because of employment, many supporters reported that they also incurred extra expenses for the person with disabilities—mainly for medications, and for travel or transportation. While this was true for the majority of all supporters, it was most common among those supporting persons with spinal cord injury and schizophrenia (80%) followed by those supporting persons with cerebral palsy and Veterans (68% and 63% respectively). For many, these out-of-pocket expenditures were modest, but for about 1/3 of supporters of persons with cerebral palsy, spinal cord injury or schizophrenia, they exceeded \$5,000 in the past year. These findings foreshadow the potential for lifelong economic costs related to the care work of families of an individual with disabilities.

For some, the cumulative effect of lost wages and benefits and extra expenses is profound. Not surprisingly, given the higher incidence of employment consequences, supporters of family members/friends with cerebral palsy also were more likely than any of the other groups of supporters interviewed in this study to report direct financial consequences—reduced earnings (61%) and benefits (29%)—and perceived financial hardship (52%) as a result (see Figure 12). High proportions of supporters in all groups reported that the financial impact of providing support impacted negatively their overall quality of life.

Figure 12



Supporters reported startling financial sacrifices:

"Our income is dramatically reduced: I would be making \$100,000 at the job lost due to it. His disability lump sum is no where near the salary he would have had, and he's lost the opportunity for another salary after military retirement." [VAC Supporter]

"The constant use of medical machines/equipment (C-pap) etc uses up a lot more electricity and drives up the utility bills." [CPA Supporter]

"My daughter is living in one of my other properties and doesn't pay rent. This loss of rental income is about \$875 per month. My daughter was living in another one of my properties which, while she was living there, was left in disrepair causing \$10,000 in damage." [Supporter]*

"If you'd given up your child years ago and he's now in the system, they're fully supported by the government. But, if you've kept your child at home to give them a better life, we're responsible for paying for them and many parents, including myself, have had to stop working to support our disabled children, no matter how old they may be. If we had given him up years ago, when he was 3 or 18, all his supports would've been paid for by the government." [CPA Supporter]

"In the last year, we've had to purchase a new house to accommodate [care receiver]. The house had to be built with wide doorways, specialized bathrooms, and various other features. The additional cost to build all of these custom features into our new house did cost about \$50,000." [CPA Supporter]

Supporters also may be torn between the need to work for pay and to support their families:

"The biggest problem is the... loyalties divided between caring for your family and bringing in a wage. Who suffers the most? The kids suffered." [VAC Supporter]

"When I worked there were more problems in the family unit." [VAC Supporter]

"I can't work full time, give him the care that he needs and be a mother to two children." [CPA Supporter]

"I stopped working last year ... to help him focus on his transition to college/university. I'm moving with him to help him take notes, get to class, and settle in. My husband will have to stay in (a different province) to continue working. It's a huge sacrifice for our child." [Supporter]*

Health and Social Consequences: "The non-financial cost, you can't count it"

The health and social consequences resulting from supporting adults with disabilities were equally common and as worrisome as the economic consequences. They often are less tangible than economic costs, but have a powerful impact on supporters and their families:

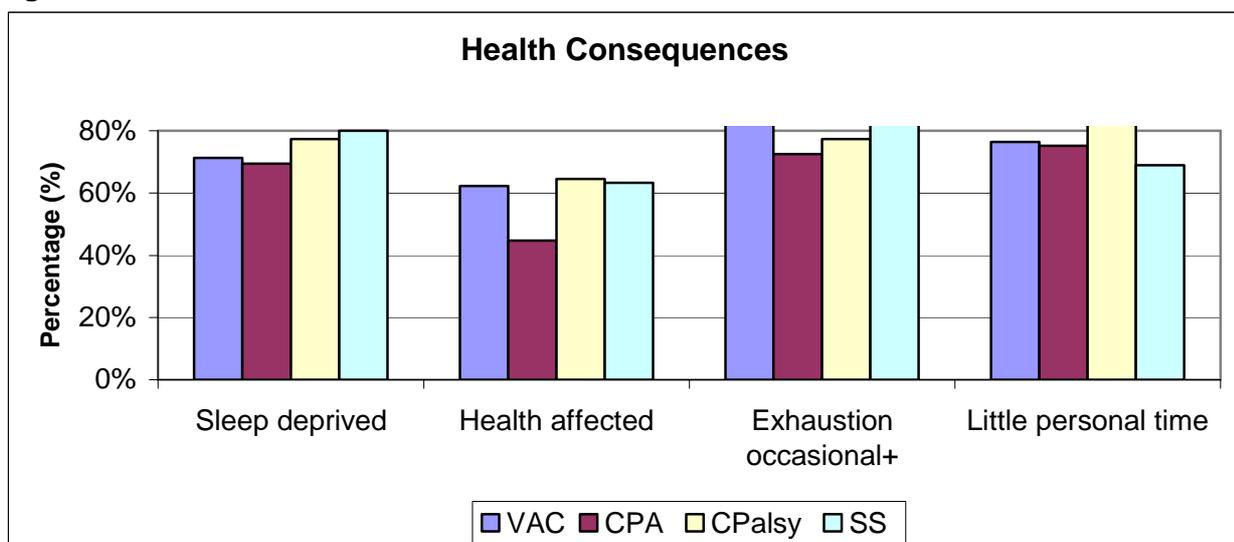
"Everything is affected because I have to do things for him that he can't do for himself, so everything that I would do otherwise is decreased. It is more draining on emotions than the physical. The financial cost alone is tremendous, the non-financial cost, you can't count it." [VAC Supporter]

"Sometimes he doesn't like to be out in the community so you don't go either. It does affect who you are friends with, (and you're) not as close as you used to be with old friends because you can't do the same things." [CPA Supporter]

"The basic needs for a person are not only physical; [it] can impact your spirituality, psychological, emotional, sexuality for the care receiver, [care] giver or the family." [SS Supporter]

As shown in Figure 13, the majority of all supporters were exhausted, sleep-deprived, and lacked time for personal activities. Not surprisingly, most also said that their health was affected.

Figure 13



"I'm sure that it's because of my situation that I'm clinically depressed." [VAC Supporter]

"For me, the biggest issue (is) the mental stress from looking after (the care receiver), not the monetary costs." [VAC Supporter]

"There have been times in the past where I have been gravely ill from the situation." [CPA Supporter]

"Physically I think I'm OK. It's the lack of sleep and mental drain of it all that affects me the most. But, because it's all fairly new to us I'm just sort of taking it all in." [CPA Supporter]

"The stress is the biggest problem. Stress is quite severe sometimes." [CPA Supporter]

Mental health problems are especially difficult for supporters to deal with.

"Because his illness is mental it is difficult for people to completely understand and you almost think things are ok, but there are lingering things. He's doing better, but the little things that are there forever finally eat away and it hits you all at once." [VAC Supporter]

"I would say in our case my husband suffers from PTSD [post traumatic stress disorder] which is a predominantly mental health issue and so we don't deal with the physical aspects but we deal with the psychological aspects ALL THE TIME." [VAC Supporter]

Families suffer as a result of such strain. Most made changes in their social activities, changed their holiday plans or took no vacation (Figure 14). Chronic disabilities often make vacations impossible. Interviewers recorded the following comments from supporters who had been providing support to the person with disabilities for many years.

"She wishes they could still go to Alaska, but the answer is no as it's not practical, no physically demanding activities are done. She goes swimming as [her husband] watches. She has at times felt resentful because of the changes to her life as she chooses to do things with [her husband]. She said she doesn't want to go on vacation alone." [VAC Supporter]

"There's the guilt--if I take respite, I'm leaving him behind." [CPA Supporter]

*"Sometimes I need respite or a break but there is limited support for such activities. Supporting (the care receiver) daily for 30 years takes its toll and sometimes I wish that I could just have a break." [Supporter**]*

"it would be really nice to get some respite or just have a break from all this." [SS Supporter]

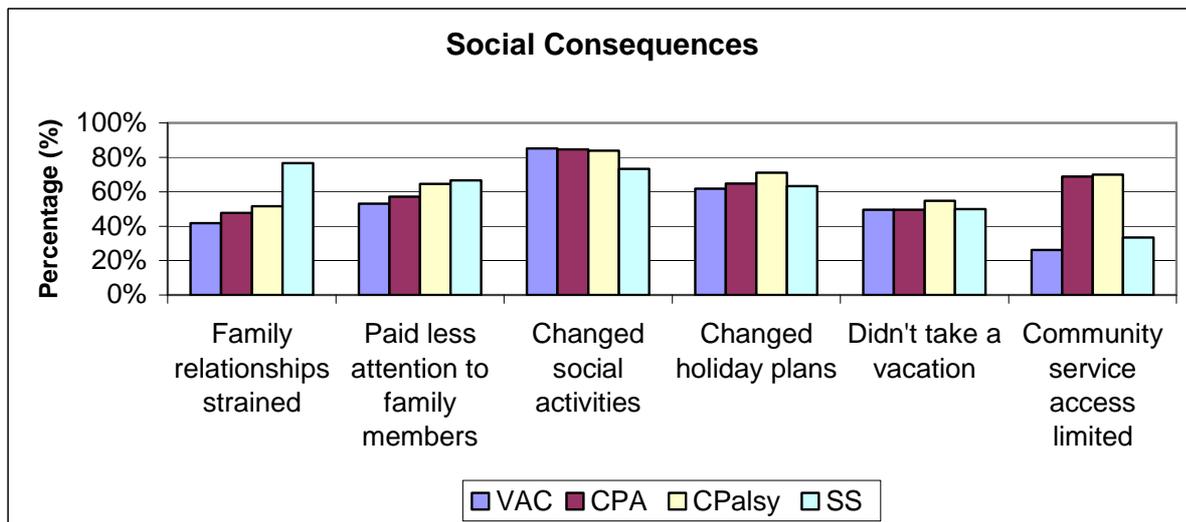
"The only issue I have had is finding somebody who can provide respite due to the shortage of labour; there is just nobody available." [CPA Supporter]

As Figure 14 also shows, family relationships were especially strained for those supporting a family member or friend with schizophrenia: 67% and 77% respectively reported that they were able to pay less attention to other family members and that their family relationships were strained as a result of providing support. In addition, about 70% of supporters of persons with spinal cord injury and cerebral palsy reported that they had difficulty accessing community services for themselves and the adult with

* Affiliation of supporter is unknown

disability they were supporting. Supporters of family members or friends with cerebral palsy were not only at greater risk of most of the economic consequences examined above; they also were at greater risk of experiencing most of the social consequences examined. Collectively these findings suggest a high potential for isolation of these families.

Figure 14



Comments from supporters underscore the enormity of the task that they have taken on:

"It makes you...it opens your eyes again. You don't dwell on it, you shut them and try to think of something good every day; you just try to keep going. A few years ago I had to write a letter to Veterans Affairs and I thought "Oh my God, this is my life." It was so depressing for a few days." [VAC Supporter]

"It's interesting how it affects the caregiver...I thought it was work, and wore blinders. Now I realize the effects. When I did go on stress leave and talked to close friends, they said 'I don't know how you dealt with it.'" [VAC Supporter]

The cumulative effect of all of the strains is immense. For these families, life is forever changed.

"In the beginning I felt I was dealing with it well quite well. As time went it has eaten away at me, this crept up quite quickly. Last year things that didn't bother me before were bothering me so much that I took nine weeks of stress leave. I was able to reconnect with him. If you don't take the time you reach rock bottom. Then you say I've been dealing with it for 10 years and have been able to cope. When you hit rock bottom you realize you do have a breaking point." [VAC Supporter]

"When (the disability) first happened it took a while to adjust. But one does." [CPA Supporter]

Given supporters' comments we might have expected to see them reporting even higher levels of stress and lower life satisfaction than Figures 15 and 16 show. Still, almost half of respondent supporters reported their lives were always or often stressful.

Figure 15

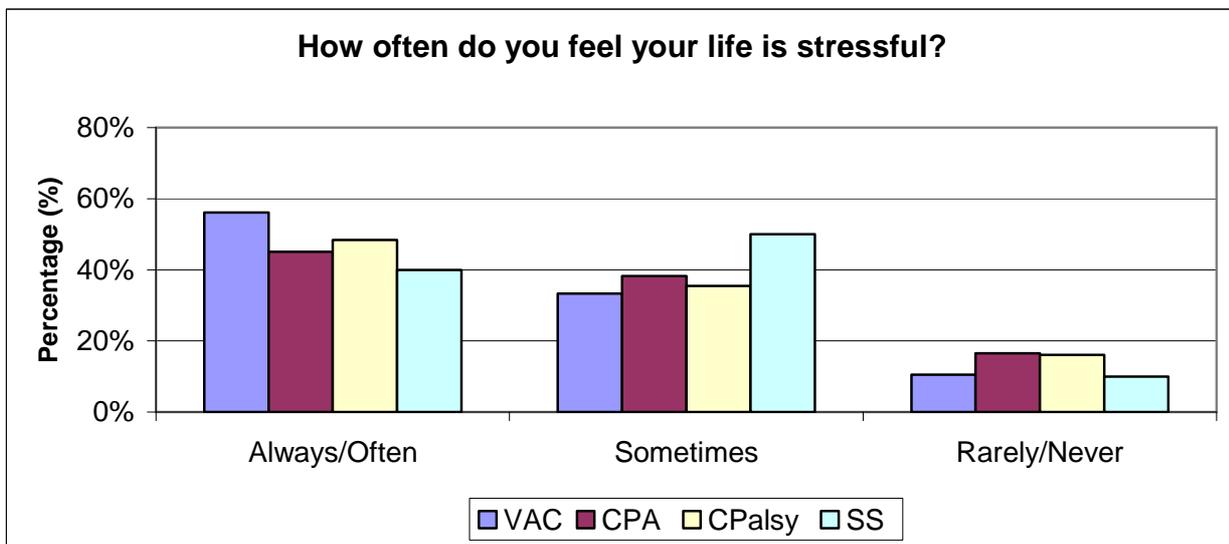
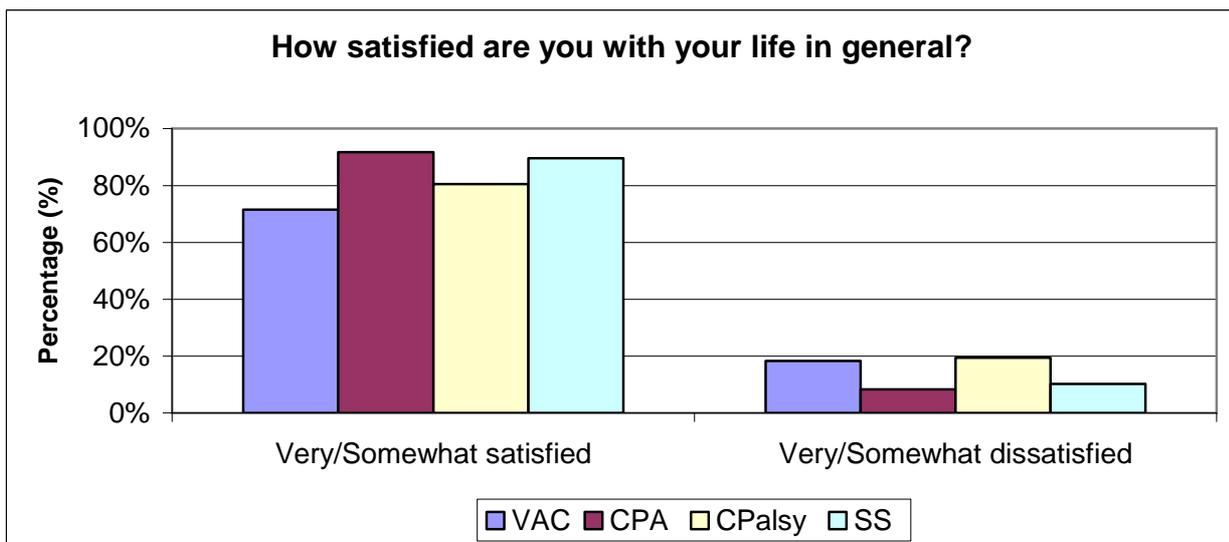


Figure 16



Services: “It doesn’t reveal struggles for support”

Services from the public or non-profit sector can help off-set the stresses of supporting someone with a serious disability. As Table 3 illustrates, we found that almost half (48%) of all supporters reported needing assistance that they did not have. Even more (72%) said they lacked the supports they needed to continue supporting the person with disability in the future, an indication of the fragility of such families. Respondents supporting a family member or friend with cerebral palsy were most likely to report currently needing supports they didn’t have (58%), but those assisting someone with schizophrenia were the most likely to indicate that lack of supports needed to continue assisting them in the future were absent (92%).

Table 3: Help for Supporters

	VAC	CPA	CP	SS	Total
Need supports you don't have	48.2%	34.9%	58.1%	41.4%	48.2%
Lack supports needed to continue supporting person with disabilities	66.7%	66.7%	88.2%	91.7%	71.9%

As a few supporters said:

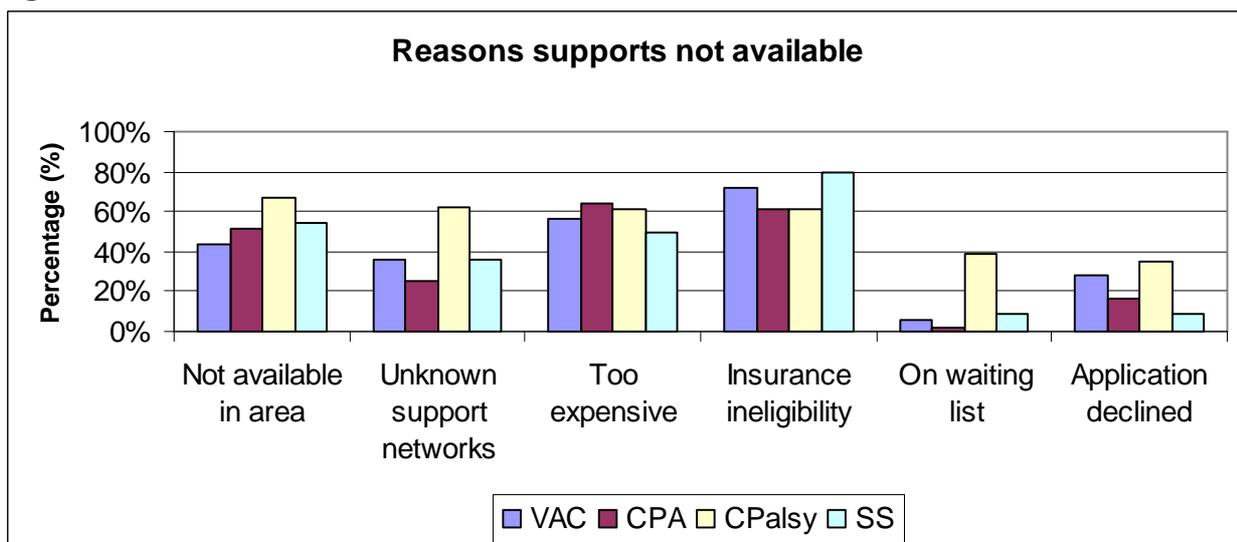
"It was a very bitter struggle for ten years with Veterans Affairs to get a pension...we're always under threat of losing it. Where's the compassion? All he has is medication, a bed, a walk once a day. He panics if I am not in the room." [VAC Supporter]

"I want to cry - in rehab I've seen couples separate, families destroyed due to this." [CPA Supporter]

"I wish there were more people to talk to about his illness because this type of support really helps me." [SS Supporter]

Chief among the reasons for lacking needed supports is cost. Almost 60% of all supporters said that supports are too expensive and 67% that supports are not covered by insurance (Figure 17). Those supporting someone with spinal cord injury were most likely to report cost as the issue (64%) while lack of insurance coverage was cited by a full 80% of those supporting someone with schizophrenia. Waiting lists were not of major concern to supporters, with the notable exception of those assisting someone with cerebral palsy, 39% of whom reported this as a reason they didn't have needed supports. Lack of local availability of supports and not knowing where to get them were most problematic for those assisting someone with cerebral palsy. Persons assisting someone with cerebral palsy also were most likely to have applied for supports but been turned down (35%). In all, resources of these families were being stretched with insufficient other assistance available.

Figure 17



The voices of supporters/family members show the strain of the ongoing challenge of getting support:

"There needs to be more clarity about where you can go to get help. If I hadn't had a doctor that was so concerned and involved, I would not have known where to go." [CPA Supporter]

"Every penny from Veteran Affairs you have to fight for, appeal - a councilor told us that. We've appealed six times now, reliving every detail, dwelling on it all... on the pain -- he won't anymore -- it's too much for him. It's such a strong emotional cost." [VAC Supporter]

"[It would help to have an] increase in financial aid without [the] distress of asking for it. They are making us feel like beggars who are bothering them. Not all of us are taking advantage of the system." [VAC Supporter]

"We have no family in (the same province). It's a very sensitive area -- are you going to call your friends to bathe your husband?" [CPA Supporter]

"I'm at a loss at what to do, and I don't know where to get help for him. I have no authority to do things for him and he is unwilling to accept my help a lot of the time. I find it hard to handle the situation but I'm learning how to respond to his complaints. He's often unwilling to see doctors and nobody can force him. I wish somebody could help him." [SS Supporter]

"Because of the labour situation, we have to treat our workers very well or else we will lose them. For this reason, we have to buy gifts for everyone who helps out." [CPA Supporter]

"I spend numerous hours studying and researching my sister's illness as well as dealing with doctors, police and psychologists." [Supporter]*

"there's nowhere to go that informs us as to what is available and what costs are covered." [CPA Supporter]

"It's very hard to access a lot of (the) programs. It took a lot of effort to get help, especially in provinces where money is lacking and especially for mental health." [SS Supporter]

"We shouldn't have to learn about the services through hear-say. Some people take advantage of the system while other's who really need the support don't know where to turn." [CPA Supporter]

Services need to be timely and appropriate to the particular needs of the person with disability and their supporter.

"It seems quite comprehensive. It is difficult to hit anyone right on, but in my case it seems to cover everything that concerns me." [VAC Supporter]

"It would be great to have an on-line support group, even to talk to. There is a group in [the city], but it is a three hour drive one way." [VAC Supporter]

* Affiliation of supporter is unknown.

"They have some very weird things going. We qualify for help cleaning the house, or yard, but they refused somebody to clean our blinds. The really difficult things, taking the blinds down and washing them, I can't get any help with. It is always the little things like that." [VAC Supporter]

"Because of long term notice we're not able to utilize the services because to send him somewhere for a week you need to give I think a month's notice. I don't know beforehand from week to week whether he'll be well enough. Income does come into it but the other supports are even more important." [VAC Supporter]

"Supports that he needed were turned down by the VA. He has a huge problem with hearing and it affects his everyday life. He needed a device to speak on the phone and he was turned down, so now he never picks up the phone. The hearing problem has also led to depression and affects everyday life and keeps him isolated." [VAC Supporter]

"She had said that some of the supports they wanted the VA are odd about them. They wanted to get an electronic bed and they said no but they gave him a hospital [bed] just for him. So they asked if the money that they spend on the hospital could be given to them and they could pay for the bed they want. The VA turned them down. Also they need more money for cleaning the snow because he cannot do it and she works, but again they said they cannot be given more money for that assistance." [VAC Supporter]

"The emotional support that I'm looking for is non-existent (because of) lack of funding they cut the program, they're closing the mental health part of the hospital." [SS Supporter]

Help for the Supporter: "They don't include the family"

This study did not include questions about impact on families nor about help to them to assist with managing changes in their lives. Yet comments volunteered at the end of the survey indicate that some supporters felt that they and their families were invisible:

"Health benefits offered through Veteran's Affairs sometimes include the family but in [his] case they don't include the family. He can't get health insurance because of his condition and Veteran's Affairs only covers his condition when he left the forces. I work part time so I don't have any health benefits so it's frustrating." [VAC Supporter]

"I have had zero support myself. Nor have I ever been contacted about supports outside this survey. It seems like the care supporter doesn't matter at all. I would like to see ways to get support made easier." [VAC Supporter]

"The professionals and doctors come and go but the family is always there. It's wrong for the family to be shut out. He's treated like an adult but he can't make all the decisions." [SS Supporter]

They worried not only about their ability to sustain support to the person with disability, but about the impact of long term disabilities on the rest of the family:

"What I want to know, and I have asked this before, is there ever going to be any help for the children? They have help for the spouses, the wives, but will there be help for

the children? Counseling for the children from someone who knows about PTSD."
[VAC Supporter]

"The psychological help that is needed is not provided or available for her adult sons. Her sons are 30 and they have a hard time dealing, and when the help is provided to the father or her but not them because they are not covered by the VA, that simply is not good since the whole family is hurt by his situation." [VAC Supporter]

Next Steps: Responding to the Needs of Families of Adults with Disabilities

Findings from this study tell us that supporters of adults with severe, long-standing and complex disabilities are far more likely than the general population of caregivers to experience almost every one of the major categories of economic and non-economic consequences of care. Despite nuances by type of disability, findings also are surprisingly consistent across the groups of respondents. Regardless of the type of disabilities they were dealing with, high proportions of supporters reported financial insecurity, stressful lives and low levels of life satisfaction. They worry about their ability to sustain support for the person with disabilities. They worry about their families whose lives had been changed profoundly. This suggests there is more common ground among disability groups than previously thought, at least with respect to the needs of their members' supporters.

Stakeholder groups consulted as part of this project universally agreed that the role of family members and friends in supporting adults with disabilities is crucial, but under-recognized and inadequately supported. Each also reported that their organizations are moving to develop programs and services for those who support their clients, and that the findings reported here will most certainly be used to guide those initiatives. Veterans Affairs Canada, which already provides more services and supports to veteran clients and their families than other persons with disabilities receive, is using the findings to support their efforts to make their programs more responsive to the of needs veterans' families.

Stakeholders highlighted the findings related to lack of access to needed services as of primary importance, noting that there is a tendency among public policy makers and service providers to focus on responding to crises rather than prevention. The finding that between 67% and 92% of the supporters we surveyed lacked the supports they needed to allow them to continue caring for their family member or friend should raise alarm about the sustainability of the family/friend care sector. It is even more alarming that family and friend carers are teetering on the brink at the same time that economic and labour market conditions are making it increasingly difficult to find paid caregivers to deliver home and long term care services. Poor pay and job quality in the formal care sector are reported to be particularly limiting (Gruss, McCann, Edelman, & Farran, 2004; Lavoie-Tremblay et al., 2005). Evidence from other studies makes it clear that even a small investment in supporting family/friend carers can help extend and sustain their capacity, especially if made early in the care trajectory (Masters, 2006; Parker, Mills, & Abbey, 2008). Such investments may, in turn, reduce the need for future public expenditures.

Stakeholders also echoed both quantitative and qualitative findings from the study that access to needed supports also is limited by lack of awareness of what services are available, lack of flexibility and diversity in services, poor service co-ordination and difficulty navigating the bureaucracy to identify and obtain services.

Even where services and supports are available, few are accessible to caregivers in their own right¹. At best, family and friend carers benefit indirectly. The evidence presented in this report echoes mounting scientific evidence from the research community, and anecdotal evidence from the disability community, that some carers experience significant hardships as a direct result of their care

¹ Two prominent exceptions in Canada include the Compassionate Care Benefit and the Caregiver Tax Credit.

responsibilities that need to be addressed directly. Moreover, their care work represents a significant social contribution that should create a public obligation to support and compensate for the consequences of their efforts.

Findings also reveal some ongoing knowledge gaps. For example, while changes in the situation and experiences of caregivers across the course of the disability are suggested by our data, additional retrospective and/or longitudinal data would allow a closer examination of patterns of the evolution of caregivers' needs over time. Our data also reveals remarkable out-of-pocket expenses for those supporting adults with high levels of long term, complex disabilities. Such data are rare, limiting the depth of our knowledge about this aspect of economic costs of care and associated risk factors. This study also contributes to our understanding of the under-studied phenomena of consequences of caring for someone with a mental health problem, and of caring for someone with a lifelong disability. Further study of these groups is indicated.

The strongest message in these findings is that families have suffered as a result of caring for a family member or friend with severe and complex disabilities without sufficient support for their role. The missions of organizations providing service to persons with disabilities *and their families* have never been more important.

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Appendix A: Stakeholder groups participating in consultation teleconference, May 2008

- ◆ Canadian Association for Community Living, Toronto ON
- ◆ Canadian Mental Health Association (Edmonton branch), Edmonton AB
- ◆ Canadian Paraplegic Association (Alberta), Edmonton AB
- ◆ Canadian Paraplegic Association (Saskatchewan), Saskatoon SK
- ◆ Cerebral Palsy Association of Alberta, Calgary AB
- ◆ Schizophrenia Society of Nova Scotia, Halifax NS
- ◆ Schizophrenia Society of Saskatchewan, Regina SK
- ◆ Veterans Affairs Canada, Charlottetown PEI