



## Comparing consequences of supporting older & younger adults with disabilities

### Summary

To date, consequences experienced by those who support younger and older adults with disabilities have not been compared across different interest groups that vary by age of onset and type of disability. These comparisons are useful to policy makers who wish to determine effective responses to the complex needs of persons with disabilities and their supporters. Using Statistics Canada's 2002 General Social Survey (GSS) on aging and social support and a telephone survey we conducted with supporters of younger adults with disabilities, we compared the characteristics of and consequences experienced by supporters of younger and older adults with long-term health problems. We found that:

- Who supports an adult with a disability depends on the adult's age and time of the onset. The main supporters of older adults are most commonly their adult children or friends, whereas younger adults with disabilities are usually supported by their spouse or parent.
- Providing assistance affected the physical, social and/or emotional well-being of all supporters, but it took an especially high toll on those assisting younger adults with disabilities. Overall, over 2/3 of these people experienced stress, were deprived of sleep and did not have enough personal time.
- Supporters of younger adults with disabilities also reported economic consequences more often than those providing eldercare, incurring extra out of pocket expenses or reducing income.
- Half of the persons assisting younger adults with disabilities experienced financial hardship and one third felt their future economic security was compromised.
- Employment consequences are high for those assisting younger adults with disabilities. Compared to 12% of those providing eldercare, 20-40% or more of those supporting younger adults with disability changed work patterns or reduced hours of work.
- Future income was also compromised for those supporting younger adults with disability: up to one third declined a job promotion and up to one half quit work altogether.
- One-third of those supporting a younger adult with a disability felt the need to postpone retirement to cope with the financial costs of providing care.
- Nearly 75% of supporters of younger adults with disabilities lacked the supports needed to continue providing support, particularly those supporting someone with Schizophrenia.
- The principal barriers to access to services among those assisting younger adults with disabilities were that services were too expensive, not covered by insurance or not available locally.
- Social and employment policies need to take into account the complexity and the high degree of need of persons with disabilities and their supporters. Supporters need to be shielded from financial hardship by a broad range of health, income security and employment programs.

People may experience chronic health problems or disabilities at different times across the life course and for different reasons. The age of onset of the disability and the type of disability may affect who provides support, and the kinds of consequences they experience.

While assumptions are made that the consequences of supporting persons with disabilities varies across disease group, most recent survey research has not compared the consequences of providing support across different interest groups that vary by age of onset and type of disability.

### Research Objectives

- To compare the impact of providing support on family members/friends who assist seniors and younger adults with disabilities.

### Data source

The data came from two sources:

*For consequences of eldercare*, we analyzed Statistics Canada's 2002 General Social Survey (GSS) on aging and social support. From the total sample of 24,870 respondents aged 45 and older, we drew a sub-sample of 4,428 people. This sub-sample consisted of people who had provided assistance in the last year to an adult aged 65 or older

who had long-term health problems.

*For consequences for supporters of younger adults with disabilities*, we conducted telephone interviews with 320 main supporters of adults aged 19 to 64 recruited from eight partner agencies: Veterans Affairs Canada, Canadian Paraplegic Associations of Alberta, Manitoba and Saskatchewan, Cerebral Palsy Association of Alberta, and Schizophrenia Societies of Saskatchewan and Nova Scotia. Questions asked paralleled those asked in the GSS; we also asked detailed questions about employment consequences that were not asked in the GSS. Survey data were augmented by quotes obtained in response to open-ended questions. Quotes used here are noted in italics.

Tasks with which all supporters provided assistance included: housekeeping, meal preparation, outdoor maintenance, shopping, transportation, banking/bills and personal care.

### Analysis

Data were sorted into five groups:

- older adults with long-term health problems
- Veterans with high levels of service-related disability
- persons with Spinal Cord Injury (SCI)

- persons with Cerebral Palsy
- persons with Schizophrenia.

We used descriptive statistics to examine the consequences reported by supporters of older adults and younger adults living with a physical and/or mental disability.

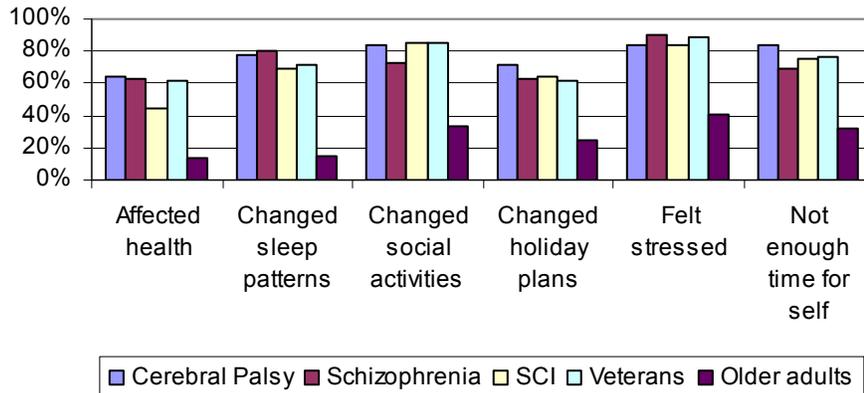
### Who supports younger and older adults with disabilities?

Who becomes the main supporter of an adult with a disability depends on their age and when the onset of disability occurred. *Adult children (-in-law)* were principal supporters of persons aged 65 and over (60%). *Spouses* typically provided support to Veterans who acquired a disability through a service-related injury (93.9%) and persons with SCI who also acquired a disability in adulthood (67.9%).

For those whose disabilities typically have their onset in early childhood or adolescence, *parents* were the main supporters of persons with Cerebral Palsy (61.3%) and Schizophrenia (63.3%). *Siblings* also were the main supporters of persons with Schizophrenia (16.7%).

*Friends and other relatives* also assisted older adults (36%), persons with Cerebral Palsy (29%), Schizophrenia (20%), and SCI (12%).

Figure 1. Physical, social, emotional impacts on supporters



**“The non-financial cost, you can’t count it”**

Family members who supported younger adults with disabilities were at much higher risk of poor physical, social and emotional consequences than caregivers to older adults (Figure 1).

In comparison to less than 1/3 of eldercare providers, more than half the supporters of younger adults with disability reported changes to their sleep patterns, social activities and holiday plans because of their caregiving. In addition, over 40% of supporters of younger adults and over 70% of those supporting persons with Schizophrenia reported that providing support strained the quality of their family relationships.

Providing support also affected emotional well-being, with twice

as many supporters of younger adults than older adults feeling stressed and not having enough personal time.

**“The financial cost is tremendous”**

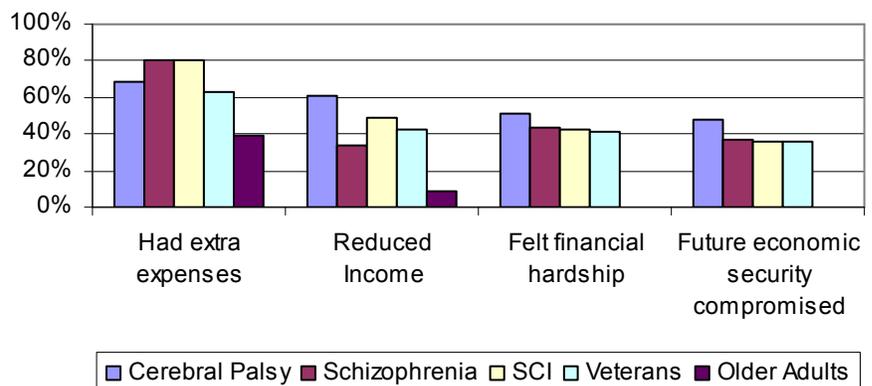
In comparison to those providing eldercare, supporters of younger adults with disabilities also reported more severe economic consequences

More than 1/3 of eldercare providers incurred extra out-of-pocket expenses, but over twice as many supporters of younger adults with disabilities had extra expenses, particularly those supporting persons with SCI and Schizophrenia.

While less than 1 in 10 caregivers to older adults reported reduced income, at least 3 in 10 supporters of younger adults with disabilities did so, with the incidence of reduced income being the highest among those supporting persons with Cerebral Palsy (61.3%).

Not surprisingly, over 40% of supporters of younger adults with disabilities reported experiencing financial hardship, and over 1/3 felt their future economic security was compromised, especially those supporting persons with Cerebral Palsy (48.3%).

Figure 2. Economic consequences to supporters



**Employment consequences**

Providing support impacted paid employment for many supporters. Compared to more than 10% of those providing eldercare, more than 20% of those supporting persons with Schizophrenia and more than 40% of those supporting persons with Cerebral Palsy, SCI and Veterans reported changed work patterns or reduced hours of work as a result (Figure 3).

Up to 1/3 of those supporting younger adults with a disability declined a promotion, and up to 1/2 quit work to provide care. Nearly half of those supporting persons with Cerebral Palsy had quit their job because of competing care demands (48.4%), but they were also the most likely to increase their hours of work later on to generate more income for the family (43.3%). More than 30% of supporters of younger adults

with disabilities felt they needed to postpone retirement to cope with the financial costs of providing care, except for those supporting Veterans (22.9%).

**Access to services**

Nearly 75% of supporters of younger adults with disabilities lacked the supports needed to continue providing support, particularly those supporting someone with Schizophrenia (91.7%). The resources of these families were often stretched with insufficient assistance available from other sources. Chief among the reasons for lacking needed supports was cost. Supports are too expensive (58%) or not covered by insurance (67%). Over half of those supporting younger adults with disabilities reported that supports were not available in their area, particularly for those caring for someone with Cerebral Palsy (67%). Persons

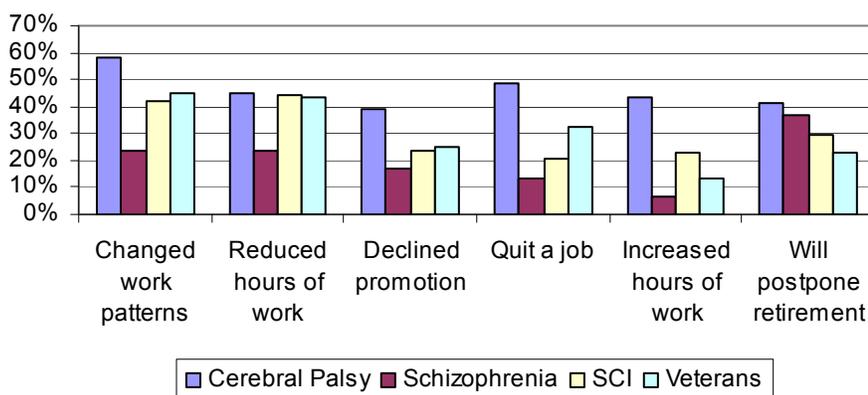
assisting someone with Cerebral Palsy were also the most likely to have their application for support turned down.

**Policy implications**

Supporters to adults with severe, long-standing and complex disabilities are far more likely than the general population of caregivers to have reported high levels of economic and non-economic consequences of care, despite very different disabilities and ages of onset. All groups compared have a strong need for services that will enable them to continue to provide support to family members without experiencing high negative health, economic and employment consequences.

Health, income security and employment policies need to recognize the hidden costs that these families are incurring and provide appropriate and timely services that will better support them. Employment supports, future pension considerations, home support and respite are among the suite of public programs required to support family/friend caregivers and protect their economic security.

**Figure 3. Employment consequences to supporters**



**This fact sheet was written by Julia Rozanova, HCIC doctoral student.**