



Persons with Disabilities as Caregivers:

Understanding Support Requirements and the Path to Developing Effective Models for Caregiving Assistance

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Background

Caregiving is an essential element of Canada's social support system. It involves the direct and unpaid provision of care to other adults (including relatives, friends, neighbours, and acquaintances). Because it is neither paid nor provided through a volunteer agency, it is very difficult to measure the exact amount of caregiving that is provided. It depends on the strength of relationships among people who require some form of care and those who are able and willing to provide it. Without it, however, our system of social supports would crumble. It is estimated these unpaid caregivers contribute some \$5 billion worth of labour which amounts to more than 80% of the care required (Fast Niehaus Eales and Keating, 2002). While more and more research has provided profiles of these caregivers and the nature of the care they provide, one subgroup of caregivers has been absent from these profiles—caregivers with disabilities. The Canadian Association of the 50 Plus (CARP, 1999) has generally identified caregivers as “silent victims in a silent system”, caregivers with disabilities seem to be even more silent or invisible. *They are without a voice.*

While there is an emerging literature and body of research focusing on people with disabilities as recipients of caregiving, there is a somewhat stereotypic void in the literature when it comes to a focus on people with disabilities as the providers of informal care to other adult family mem-

bers, friends, neighbours, and acquaintances. Yet, anecdotal evidence derived from the disability community suggests that informal caregiving to other adults by people with disabilities is actually quite common in Canada and that there are many serious gaps in our support systems which create significant barriers. Our systems of support have developed out of a historical view of people with disabilities as solely recipients of caregiving. With the introduction and acceptance of the social model of disability, we can begin to recognize the need to step outside this stereotype and recognize that people with disabilities can assume and have been assuming a much wider range of roles within their families and communities, including that of caregiver. But as providers of support, people with disabilities have requirements for assistance to carry out these roles. There is, therefore, a need for our system of supports and services for people with disabilities to recognize these requirements.

Introduction

As a group, caregivers with disabilities are invisible in terms of research. They have been excluded from policy, program, and service development as well as from general caregiving strategies. There is a paucity of information concerning the profile of this population, the nature of the services they provide, and their unmet needs. In late 2007, Human Resources and Skills

Development Canada issued a request for proposals to conduct policy-related research investigating people with disabilities who provide or wish to provide informal caregiving to other adults. CCDS was awarded the contract. The study was conducted between March 2008 and November 2008. It included an extensive literature review and environmental scan as well as the gathering of qualitative data during which twenty-eight people were interviewed as key informants. Of these 28 participants, 21 were caregivers with disabilities from the provinces of British Columbia, Alberta, Manitoba, Ontario and Nova Scotia and the remaining seven participants were service providers, policy makers, or researchers from British Columbia, Manitoba and Nova Scotia.

Results

Demographics and the nature of the caregiving including living arrangements, supports received and gaps in the support system were captured. The study found that caregivers with disabilities provide a wide variety of services to care recipients which sometimes results in the recipients experiencing greater community participation and even employment. Often, the care is reciprocal between the dyad. Consistent with mainstream caregivers, family and friends perform a critical role in supplementing supports. Important findings regarding the complex caregiving process were inadequate home supports, inadequate community supports, and inflexible policies. Caregivers with disabilities identified a lack of recognition by family, friends and the system for the work they carry out. Policy makers, service providers and researchers acknowledged this lack of

recognition of the caregivers' work. In our study, we found that policies and proposed caregiving strategies do not address this critical area, and we made the case that this is an essential subject to study in light of our aging population which will lead to an increasing number of caregivers who will be disabled themselves while providing care to increasing numbers of people who are also aging or have aged into disabilities. Recommendations were provided for future policy development, service provision, and research. A major recommendation was to dismantle the aging and disability silos to ensure neither group is "lost" in service provision, policy, and programming.

This is the first Canadian study of caregivers with disabilities and the researchers were unsuccessful in locating international research. This study begins to address gaps as identified by the Disability Knowledge Strategy, by focusing upon adults with disabilities in Canada and the difficulties they face when contemplating or assuming the role of caregiver to other adults. It provides rich qualitative data and insights to guide future directions in policy and program development and new research directions.

Future Research Needs

Given the paucity of research on caregivers with disabilities, it is clear that further research is required. It should also be noted that little research exists in the area of various cultural groups, especially the Aboriginal and First Nations communities. With the exception of one study (Gahagan et al, 2004), which specifically interviewed caregivers with disabilities and

focused on women as caregivers in Nova Scotia, this study is the first to address caregivers with disabilities in a broader context.

The reviewed literature suggested the need for further research in the general area of caregiving and caregivers including studies to determine efficiency and effectiveness of various models of care and models of funding to healthcare (Hollander et al., 2007), the impacts of an aging population on future health costs and the need to understand the caregiver trajectory (Grant, Nolan & Keady, 2003), life transitions (Kramer & Lambert, 1999), the cost of informal care and time spent (Langa et al., 2002), the determination of carer's assessment of carer demands (Wallhagen, 1992A), the development of sound practice models (Canadian Caregiver Coalition, 2003), and the examination of the types of economic support models that are most acceptable and beneficial to carers as well as cost effective to the government (Gerald, 1993). There is a call to support research on informal/formal caregiver needs and coping strategies in rural and remote communities to determine the necessary supports required to reduce caregiver burnout and empower clients and family (Canadian Home Care Association, 2006). These areas of study are equally applicable to caregivers with disability studies.

Due to the absence of recognition of this population in statistical collections, statistical and demographic data is needed to provide a comprehensive portrait of caregivers with a disability. National and provincial statistical surveys must take this

population into account in future survey development. This not only includes surveys administered through Statistics Canada but also data collection of "clients" through various government health, aging and disability departments.

Additional qualitative and quantitative research is needed and must address aspects such as the effects of disability on caregiving with a focus on the effects of various disabilities on the caregiving experiences, the impact of caregiver disability on caregiver stress and health, financial implications, relationships with care receivers, and specific supports to facilitate caregiving. Future research could focus on the perceptions of friends, family, professionals and the general public regarding caregivers with disabilities and whether they are valued as a result of providing care to others. Longitudinal and case studies will be valuable to understand how gaps in the system impact caregiving outcomes and cost-benefits.

It is important to gather the caregivers' with disabilities voices as has been started in this research project. More qualitative studies are needed to learn the complex interplay of social systems, policies, the disabilities of two people in the caregiving team, and their environments. At the same time, large scale surveys with the assistance of national and provincial caregiving organizations will shed light on this growing population and needed area of study.

Recommendations

Caregiving is a central part of Canadian society and everybody has a role in care-

giving. This area of study is critical because our growing aging population means that in the near future we will have more caregivers with disabilities providing care to older people with disabilities. A key principle is the provision of supports to balance work and caregiving commitments to ensure that caregivers are not faced with choosing between caring for family members or their future financial security (Canadian Caregiver Coalition, 2003). Health promotion, prevention, and healthy aging are also key principles to guide support practices for caregiving (Hollander, 2007). Many key concepts from the disability consumer movement (consumer control, citizenship rights, participation in participation in decision making, supports to independent living, full participation and contribution to society) must be a natural part of the caregiving process.

Although this study has provided a great deal of valuable information, it is only the beginning of research in this field of study. Caregivers with disabilities are helping to support an untold number of persons in their homes, in assistive housing and other situations. Through the extensive, yet under-recognized effort of caregivers with disabilities, many care recipients can avoid increases in their formal home support or can delay the need for long term care. Indeed many care recipients participate in their communities, and are sometimes employed due to the efforts of this “invisible” group. Often caregivers with disabilities provide insight and guidance with respect to coping with disabilities and how to navigate complex support systems due to their experience.

It is clear that caregivers with disabilities share many of the same barriers and facilitators as do non-disabled caregivers. However, they also face unique issues due to their own disabilities and their own need for supports and accessible environments. Many times support policies do not accommodate both the caregiver and the care-receiver. They also face, in some cases, different financial constraints due to their own past limitations with work or limitations in current policies. This area must rise to international, national and provincial agendas. Questions about caregivers with disabilities must be placed in all of the relevant Canadian and provincial surveys. This is not a “niche” target group issue; it is a growing area with the aging of our population.

For more information visit
CCDS’ website at:

www.disabilitystudies.ca

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