in focus

backgrounder

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Leading knowledge exchange on home and community care

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Diversity: Disability Issues in Home and Community Care

Diversity has many dimensions. A broad and comprehensive understanding includes religious beliefs, cultural traditions, mental and physical ability, sexual orientation, class as well as differences in race, language and ethnicity. This In Focus, the third of our *Diversity Series*, looks at the challenges which people with disabilities and their providers face in home and community care.

What do we mean by disabilities?

We adopt the definition of disability used by The Participation and Activity Limitation Survey (PALS) which is a national survey designed by Statistics Canada to collect information on adults and children who have a disability. Disability is defined as a limitation of everyday activities because of a condition or health problem. The definition includes disabilities that are both visible (e.g., problems with mobility), and invisible (e.g., psychological, hearing, learning or developmental issues (Statistics Canada, 2007)

Why focus on disabilities issues in home and community care?

Equity and human rights. Disability is a prohibited ground of discrimination in Canada under the Canadian Charter of Rights and Freedoms and under provincial and territorial human rights legislation. This means that people with disabilities have the right to (among other things) accessible health and social care services.

As well, Article 19 of the *UN Convention on the Rights of Persons with Disability* (http://www.un.org/esa/socdev/enable/rights/convtexte.htm) states that countries such as Canada, which is a signatory to the Convention, must recognize the equal right of all persons with disabilities to live in the community, choose their place of residence and living arrangement, have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and, be able to access similar community services and facilities that are available to the general population.

Poorer health and unmet care needs
People with disabilities are less likely than the general population to report good health and be able to obtain needed health care and social supports (Canadian Council on Social Development, 2003). While people with disabilities tend to be older and have poorer health, the health differences remain after taking age into account.

Increasing numbers of people with disabilities

- Between 2001 and 2006 the number of Canadians (excluding persons living in institutions and on First Nations reserves) who reported having a disability increased by roughly three-quarters of a million people. This increase is attributed in part to an aging population (Statistics Canada, 2007). However, aging does not explain the entire gain. When the impact of population aging is controlled for, disability rates increased for nearly all age groups. The data suggest a combination of changing disability profiles and higher

rates of self-reporting due to reduced stigma attached to having a disability (Statistics Canada, 2007).

- 1 in 7 or 4.4 million Canadians who do not live in institutions or on First Nations reserves reported having a disability in 2006 (Statistics Canada, 2007).
- The disability rate is higher among women aged 25 and over than among men in the same age group.
- Excluding the territories, First Nations reserves, and institutions, an estimated 3.7% or 202,350 of children aged 14 and under, live with some type of disability. This proportion is up from 3.3% in 2001(Statistics Canada, 2007).

Shift from institutions and hospitals to communities. For over forty years in Canada, trends in care provision have shifted responsibility from large institutions toward community-based responses. Increasingly people with complex and ongoing care needs that are often associated with many disabilities are being supported by home and health care workers and families in the community although some people with high level needs remain in hospitals. In Ontario, the last of three large institutions for the developmentally disabled - Huronia Regional Centre in Orillia, Rideau Regional Centre in Smith Falls, and Southwestern Regional Centre in Blenheim have been closed since March, 2009.

Deinstitutionalizing care has in large part been driven by cost and legal considerations, as well as societal pressures. Care in the community is believed to be more cost effective than care in hospitals and institutions. Furthermore, hospitals and institutions wished to avoid possible legal challenges over "involuntary" hospitalization or institutionalization after laws were changed to protect the rights of people with disabilities by narrowing the conditions under which involuntary hospitalization and treatment were legally permissible (Hartford et. al., 2003).

Finally, deinstitutionalization also reflected changing values. People with disabilities, their families and the agencies that provide supportive services to people with disabilities have long advocated for more options around their services, including supports to enable them to remain independent. Unfortunately, support for people with disabilities has shifted out of institutions and hospitals without appropriate or sufficient resources for health and social services in the community. As a result, the burden has increased for families, informal carers and other sectors of our health and social system.

Home and community care promotes independence and well-being. Respecting that people with disabilities have varying levels and diversity of needs, they often require assistance with daily living activities. According to the Canadian Council on Social Development, the most common types of assistance required include:

- housework
- getting to appointments
- meal preparation

This is consistent with Statistics Canada data showing that mobility limitations were the most frequently reported form of disability for seniors (Statistics Canada, 2007).

Community-based agencies can often provide assistance with daily living activities and thereby enhance quality of life and enable people with disabilities to live relatively independently in the community at relatively low costs.

According to the Canadian Council on Social Development (2005) however, only about two-thirds of individuals needing such assistance get it, with women more likely to get assistance than men. Furthermore, the majority of help is provided informally by family and friends. While assistance from family and friends is much appreciated, this type of informal help does not promote independence, autonomy, self-management and control. People with disabilities may have to adjust to the schedules and time frame of

their helpers and may feel that they are a burden to them. In contrast, agencies providing home and community care do so in a scheduled and predictable way (Lum et al., 2005). People with disabilities tend not to feel that they are a "burden" to community agencies whose goals are to provide home and community supports.

As for children with disabilities, parents of one-third of these children required some type help with daily activities, including housecleaning, meal preparation, and time off for personal activities because of their child's condition. Most of the help was informal assistance from friends and family. Only 44% received formal assistance from government organizations or agencies (Behnia & Duclos, 2003).

Caring for a child with a disability presents special challenges for parents, which can affect their employment status (e.g., not taking a full-time job, working fewer hours, or having to arrange a modified work schedule):

- 54% of the parents of children with disabilities reported that caring for their child affected their employment in some way. This figure increases with the severity of the disability.

- The impact on employment status affects women more acutely than men. Among families of children with disabilities where the parents' employment status is affected, only the mother's employment status was affected in 71% of cases; the father's employment status was affected in 11% of cases; the employment status of both parents was affected for 14% and in the remaining 4%, family members other than the parents were affected as well.

Models of disability

Before identifying barriers to accessing home and community care, it is important to understand the social context within which barriers are, or are not, identified.

- The **medical model** of disability was prevalent historically. It regards disability as a medical problem to be "cured" by professionals. Those who cannot be "cured" are deemed functionally inferior to "normal" people, and are expected to see their impairment as their problem - something they will have to "make the best of." Society really has little role in facilitating independence and well-being.

- The **social model** makes a distinction between "impairment" and "disability." While impairment refers to a person's condition, disability is a social and political problem of society's barriers. Instead of trying to cure people with impairments, this model places responsibility on society to get rid of barriers so as to accommodate and include people with disabilities. Barriers, prejudice and exclusion (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society.

- The **affirmative model** challenges the view of impairment as an inherently abnormal and negative life condition. Instead of seeing a deficit, this model positions impairment as an ordinary aspect of the human experience. Unlike the social model which focuses solely on remedying barriers and limitations (e.g., hearing aids, ramps), this model affirms the normalcy of impairment and prefers to recognize impairment as an ordinary rather than an extraordinary characteristic of human experience. A good example is deaf culture (Self Directed Support Scotland, n.d.)

Barriers to accessing home and community care

Implicit in identifying barriers to accessing home and community care is the social model of disability described above. For people with disabilities and their families to have choice

and control over their care, services need to be accessible in all respects.

- Environmental or physical - ensuring that facilities or transportation is appropriate by, for example, replacing stairs with ramps, using automated doors, having doors wide enough for scooters; providing audio cues in elevators, announcements in public transportation and audio and visual cues for life safety systems such as fire alarms, emergency exits.

- Structural, institutional or systemic – ensuring that services are available and appropriate by, for example, giving people with disabilities more time during for appointments as opposed to inflexible time allotments; and re-examining overly narrow eligibility requirements for supports or services.

- Informational - by providing clear guidance about where and how to get assistance, particularly for assistance in activities of daily living. Information needs to be in an appropriate format or be linguistically or culturally appropriate, for diverse populations with disabilities.

- Attitudinal - by ensuring not to stigmatize service users. If people with disabilities fear negative experiences, they may avoid needed services until a crisis occurs.

- Geographical - by making sure appropriate supportive services are within reasonable distance of users including those living in suburban or rural areas.

- Financial - by making support services affordable. High costs of assistive aids such as home adaptations and scooters, or high co-payment fees for community-based care can place financial burdens on people with disabilities and their families.

Challenges to providing home and community care to people with disabilities

One size does NOT fit all. People with disabilities may have varying ideas about what independence means and how best to achieve it.

- Following from the affirmative model described above, some may want to live as well as possible with their disability using minimal assistance from assistive aids and skilled professionals.

- Others may be less concerned with accomplishing daily tasks unassisted but want to control the direction of their lives by defining their needs, making decisions, managing and taking charge of nearly all of the administrative responsibilities associated with their own care (Bush, 2000; Helgøy et al., 2003). This is called the self-managed model of care, but even here, different variations exist. They include:

  - the “agency-sponsored, but user-directed” model, where a service provider organization is responsible for the hiring, training, supervision and payment of employees but the service-user and provider collaborate to arrange a personal support regime;

  - the “brokerage” model, where an intermediary acts as a liaison between the person with disabilities and the government to arrange a personal support plan (e.g., model used in Quebec);

  - the “Individualized Funding” model, which involves a transfer of funds directly from the government to persons with disabilities or their support group so they can purchase care at their own discretion. They are responsible for recruiting and supervising care providers and for how funds are spent (Bush, 2000). This is

the most common type of self-managed care program in Canada.

In some cases, institutional care may still be the best choice for some individuals with disabilities.

What is disability appropriate care?

Disability appropriate care is care that is sensitive to the varying needs of people with disabilities. It is important to understand that people with disabilities are diverse both in their disability and cultural background. Service providers must take these differences into account when delivering home and community care.

Kaiser Permanente (2007) has developed guidelines for culturally competent care for people with various disabilities. They include:

- Using "person first language" such as "people with disabilities" instead of "disabled people;"
- Considering the person with the disability to be the expert about his/her condition;
- Considering the nature of the disability;
- Identifying yourself and addressing the person with disability directly;
- Not making assumptions about the person with disability;
- Letting the person with disability ask for assistance when it is required;
- Allowing sufficient time for tasks and procedures

Selected "best practice" examples

There are many examples of best practices in home and community care for people with disabilities. Here, we highlight some that exemplify important principles specified by key organizations providing supports to people with disabilities.[1]

Age appropriate care
Some argue that age appropriate care is segregation by a different name. Others however claim that living in age appropriate settings is vital to quality of life. While some younger people with disabilities (like older people with disabilities) may prefer to live in mixed age settings, there should be choices available for those who prefer to live with neighbours closer to their age category (Pape, 2006). Here are some examples.

Castleview Wychwood Towers, Toronto is a long-term care home, mainly for seniors, but has a 20-bed younger adult unit. Many residents of this special unit have neurodegenerative diseases or MS or have experienced a stroke. http://www1.toronto.ca/wps/portal/contentonly?vgnextoid=78cd3293dc3ef310VgnVCM10000071d60f89RCRD

Privacy and respect
We all face crises from time to time and appreciate if these crises can be solved with minimal disruption and intrusion. Likewise, people with serious mental or physical illness would like services that can assist them in resolving dilemmas and crises using minimally intrusive options. Doing so preserves dignity and respects the extent of their ability to act independently.

Cheshire Southwestern Ontario provides attendant services for people with permanent physical disabilities in the London area. These services can be user-managed, and any restrictions on the activities of the service user

[1] These organizations include: The Canadian Coalition for Seniors' Mental Health, Canadian Network for Mood and Anxiety Treatments, CanChild Centre for Childhood Disability Research, Centre for Addiction and Mental Health, Connections for Information and Resources on Community Living, Health Charities Coalition of Canada, Individualized Funding Coalition for Ontario, Public Health Agency of Canada, Michigan Department of Community Health, National Children's Alliance for the First National Roundtable on Children with Disabilities and the Older Persons' Mental Health and Addictions Network of Ontario.

are implemented only after consultations and agreement with the individual.

Encouraging social engagement and participation in the broader community

LOFT (Leap of Faith, Together) Community Services provides supportive housing and integrated support services for people with disabilities that include serious mental illness challenges, addictions, physical health challenges, and homelessness. Staff members provide opportunities for joining clubs, social networks and religious/cultural groups while also encouraging individuals to participate in the mainstream of community life according to personal choice and preference. The setting allows for stability, social relationships and a variety of community activities. Volunteer opportunities and sometimes paid employment are available.

Opportunities for caregiver training
More complex "high tech" care is now being delivered in homes and communities, but current training programs do not adequately prepare home care providers for the level of care they expected to provide. Informal caregivers are also being asked to perform complex procedures or monitor technologies with little or no training. Both formal and informal caregivers need appropriate training, and access to the right technologies

- To implement the principle of self-determination and autonomy for people with hearing impairment, *Bob Rumbell Home for the Deaf* emphasizes the right of seniors to understand and be understood in a communication mode of their choice-- not someone else's. The Rumbell Home therefore provides continuous staff training in various modes of communication and requires ongoing upgrading of skills.

- *Bellwoods Centres* provides support services and independent living education programs for people with physical disabilities and promotes formal staff educational upgrading through the Personal Support Worker (PSW) certification program.

  Bellwoods Centres also initiated a service plan to transition Cooperative Living Project clients and staff from a cooperative living model to an apartment living model, including education for clients.

Respite for family, friends and other informal care providers. Respite care is critical to help relieve the financial, emotional, and physical stress that informal carers experience. Strong parental or carer involvement in respite service development can ensure the relevance of such programs.

- *Huron Respite Network* provides emergency and planned respite care for children, youth, and adults with special needs in Huron County so as to support family life, relieve stress, and fulfill emergency needs/situations. It works with carers to identify respite options and develop a respite plan. It also provides a Screening Service in order to optimize the match between the needs of the person with disability, carers and/ or families and the respite provider. http://www.respiteservices.com/Huron/

- *Canadian Coalition for Seniors' Mental Health* has excellent educational materials giving informal caregivers across Canada access to information regarding the mental health problems and issues seniors may face, and solutions or resources that can be used for support. http://www.crncc.ca/download/CCSMHInformalCaregiverEducationalMaterials.pdf

How can I learn more? Link to the following sites:

- Bellwoods Centres for Community Living delivers supportive services, supportive housing and independent living services for adults with physical disabilities in the Greater Toronto Area, enabling them to live as independently as possible in the

community. Support services for daily activities are delivered under clients' direction in their home or workplace. Supportive Housing combines housing with 24/7 service access. The Independent Living Programs promote independence and quality of life by helping with life skills. http://www.bellwoodscentres.org/index.htm

- The Bob Rumball Home for the Deaf (Barrie, Ontario) aims to enhance the quality of life of deaf seniors by preventing social isolation through creating a sense of belonging and dignity. It emphasizes accessibility, communication and visual orientation. An integrated model of care allows residents to be assisted in all areas of daily life in a home-like environment. http://www.bobrumball.org/BRFD/longterm.html

- Canadian Coalition for Seniors' Mental Health (CCSMH) is a knowledge exchange and advocacy network for promoting seniors' mental health. CCSMH has created national guidelines for seniors' mental health, as well as numerous education and training modules for specific mental health issues facing seniors and their carers. www.ccsmh.ca

- Cheshire Southwestern Ontario supports adults with disabilities to help develop their independence and dignity. The organization aims to promote self-determination, choice and ability to participate in community life through outreach programs and supportive housing. Outreach programs are available in London and 5 surrounding counties, where consumers live in their own homes and attendant services are available on a prescheduled basis, 7 days a week. Supportive housing is available in London and 3 surrounding counties, each with a range of 6-17 residents who have access to 24 hour services, on a schedule or on-call basis. www.cheshirelondon.ca

- LOFT (Leap of Faith, Together) Community Services offers permanent housing, supportive housing and outreach programs. It provides programs for vulnerable and homeless youth, adults and seniors living with mental health, addiction and physical health challenges in over 60 sites in the Greater Toronto Area and York Region. It aims to help residents recover their health, dignity and self-esteem. http://www.loftcs.org/

- See also: In Focus: Seniors' Mental Health and Addictions http://www.crncc.ca/knowledge/factsheets/download/InFocus-SeniorsMentalHealthandAddicitions.pdf

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