Persons with Disabilities

Persons with disabilities were identified as a population of interest because they face unique challenges that affect health and well-being more so than persons without disabilities. Although there is limited information about persons with disabilities in the Winnipeg Health Region, this chapter may be used as a starting point for further development in this area. As in the other special populations, health issues and determinants of health for persons with disabilities will be discussed. The first section uses national reports as sources of information for this discussion, and the second section contains WHR-specific information.

Health Issues and Health Determinants

Disability can be defined in several ways: a legal perspective, a biomedical perspective, a functional perspective, or a social or environmental perspective. The most commonly referred to definition is that developed by the World Health Organization (WHO), which states that disability is a limitation of daily activities resulting from impairment associated with physical or mental conditions or health problems.[1] This definition was revised in 2001 by the WHO, with the introduction of the International Classification of Functioning, Disability and Health (ICF), to take into account environmental factors and disability. The ICF framework "views disability as the interrelationship between body functions, activities, and social participation, while recognizing that the environment provides either barriers or facilitators."[2]

The overall rate of disability in Canada is 12.4%.[2] This varies by age group, with seniors being the most affected by disability. The Participation and Activity Limitation Survey (PALS) reports that the rate of disability in Canada ranges from 1.6% among preschool age children to 53.3% among seniors, 75 years of age and older.[2] Different types of disability affect people at different ages and stages of life. For example, in school-age children, chronic conditions, learning and speech are the most commonly reported disabilities, while for most adults, pain, mobility and agility were the most common. The rates of disability in Manitoba, by age group were similar to those of Canada for those 0-14 years and 15-64 years. For senior citizens (65 years and older), there was a slightly higher rate of disability in Manitoba compared to Canada (see Table 1).

Table 1: Rates of Disability by Age group Manitoba and Canada, 2001

	0-14 years	15-64 years	65 + years
Canada	3%	10%	41%
Manitoba	4%	11%	45%

Source: Disability in Canada, 2003[1]

There is strong evidence to suggest that persons with disabilities have much poorer health status than those without disabilities, even after the disability has been taken into account.[3] Persons with disabilities experience more chronic diseases and decreased life expectancy.[3] It has been suggested that the combination of illness and disability has a multiplicative effect on the health of those with disabilities. McColl et. al. found in an analysis of National Population Health Survey 1998-99 data that disability accounted for a two- to-three-fold increase in health services utilization and that despite using more health services than the general population, people with disabilities still had unmet health needs.[3]

The determinants of health that affect the overall health and well-being of persons with disabilities include social support, social attitudes, the physical (built) environment, and economic factors, including employment.[4] The central theme in the Disability in Canada report stated that there are barriers to full participation in Canadian society for persons with disabilities. Information generated by PALS shows that those with disabilities are less likely to be employed, have lower income levels, and have lower education levels. Another key issue was access to supports. A large proportion (about 35%) of those surveyed said that they did not have all of the

[1] World Health Organization 1980, as cited in: Disability in Canada A 2001 Profile, Human Resources Development Canada.2003.
[2] Canada. Human Resources Development Canada. Disability in Canada A 2001 Profile. Ottawa: Government of Canada, 2003.
[3] McColl MA et al. (2003) Health Status and Health Care in the Disability Community in Canada: Final Report to Canadian Population Health Initiative. Queen's University.
[4] Taylor, RJ et al. (eds) Health and illness in the Community. London:Oxford University Press, 2003. p.161.

support that they felt that they needed, and this proportion is even larger for families of children with disability (about 68%). Support could include assistance from another person with everyday activities, devices that assist the individual and specialized transportation.

Disability in the Winnipeg Health Region

Information about disability in the WHR is derived from the Canadian Community Health Survey (CCHS, Cycle 2.1, 2003) and is also reported in the **WHR Overview**. This has been grouped into the domains of quality of life: i.e. physical and emotional functioning. Both domains were identified as health issues in the WHR population as a whole. Respondents in the WHR were slightly more likely than Canadian respondents to report having chronic pain or discomfort, which prevents or limits activities on a continuing basis. In contrast, WHR respondents were nearly 15% less likely to report severe chronic pain than Canadians were.

An indicator of short-term disability, two-week disability days, were measured by asking the respondent how many days in the past two weeks were daily activities limited by illness or injury. In the WHR approximately 1 in 7 persons aged 12 and over reported one or more two-week disability days; and in Canada a similar value was reported (approximately 1 in 6 persons aged 12 and over reported one or more two-week disability days). This may also be linked to functional health status, which is based on nine dimensions of functioning (vision, hearing, speech, mobility, dexterity, feelings, cognition, memory and pain). In the WHR and Canada, approximately 1 in 5 persons aged 12 and older reported moderate or severe functional health problems based on the 9 categories of functioning. Also, approximately 1 in 5 persons in the WHR and Canada aged 12 and older reported having a disability or being limited in certain activities on a continuing basis because of a physical condition, mental condition or health problem.

In the area of emotional functioning, WHR residents were more likely to report a moderate level of life stress than Canadians, but were less likely to report a high level of life stress. The indicator for life stress is measured by level of psychological distress based upon a series of 17 questions in the CCHS. In both the WHR and Canada, approximately 1 in 10 persons aged 12 and over who showed signs of depression are at probable risk of suffering a “major depressive episode”. However, they were less likely to report low self-esteem and fair-to-poor self-rated health than Canadian respondents.

The rate of hospitalization for mental health disorders in the WHR was 5.95 per 1000 population in fiscal year 2002-2003, accounting for 3908 inpatient cases. This was nearly evenly split between males and females, with crude rates of 5.89 and 6.01 per 1000, respectively. It is important to remember that hospitalization data would most likely capture only the most severe cases of mental health disorders in a population. There is a wide range of diagnoses in the mental health disorders category, such as substance abuse, schizophrenia, depression, personality disorder, dementia, and anxiety disorders. These diagnoses accounted for nearly 65.5% of hospitalizations. Of these, substance abuse, schizophrenia, and depression comprise the majority of diagnoses (35%, 30%, and 22%, respectively).

In September 2002, the WRHA held a community consultation with some of the key disability organisations in the Winnipeg Health Region. The following summary from this event is presented.

Summary Notes: WRHA Disability Consultation Event of 27 September 2002

Background: In April 2002, the Vice President, Community Care, WRHA called together some of the key disability organisations in Winnipeg. The WRHA wants to ensure that there is feedback on current services and identify new initiatives to meeting the needs of people with disabilities in Winnipeg. As such, its goal was to identify opportunities for service improvement that could be submitted for consideration during the business planning cycle for the 2003-2004 fiscal year. To accomplish this, the WRHA felt that a broad-based community event would enable it to ascertain priority issues or gaps from a variety of perspectives, as such, several disability organisations became the Planning Committee for this event, which was held on 22 September 2002.

Event Keynote Speaker: The event's keynote speaker, Professor Michael Prince, provided four reform options for fundamental action on disability income and supports:

- Disability Supports Framework
- National Personal Supports Fund
- Supports for Canadians with Disability Agreement
- National Disability Benefit Strategy

Professor Prince concluded by indicating that it is time for the Federal Government (in collaboration with the provincial and territorial governments and the disability community) to create a modern system to deliver disability supports, but wondered whether it was up to the challenge.

Provincial Round Table Discussions on Disability: Jim Derksen outlined a series of recommendations that emerged from the Round Table Discussions, reinforcing the value of and need for the establishment of a Disability Office in government. Participants stressed a series of needs and recommendations that centred on:

- the need for the provincial government to implement more effectively its commitment to employment equity by employing people with disabilities
- the need to define and establish disability support to enable people with disabilities to participate fully in all aspects of life
- a recommendation for the WRHA that focussed on the need for the RHAs to develop a consistent province-wide policy on the usage of "Do Not Resuscitate Orders".

The above needs and recommendations broadened the context for the discussions that took place during the Planning Committee Sessions in which the Planning Committee identified <u>five</u> priority issues as potential topics. The five topics, organised into sessions, included housing and support services models; an independent living approach to training personal care attendants; services to assist individuals living with disability and their families with the transition to adulthood; how to find a family doctor - patients with disabilities and access to primary health care; and the role and value of technology in the enhancing the quality of life of persons living with disabilities. During each of the five sessions, panel presenters from a variety of organisations, were asked to provide at least <u>three</u> recommendations that the WRHA could consider for inclusion in the 2003-2004 business planning cycle.

Session One – Housing and Support Services Model: Panel presenters felt that the WRHA should:

1. Move the focus of spending from the acute care sector of create more of a balance whereby community options for accommodation and support services are enhanced.
2. Prioritise accessibility/universal design in all housing designs and focus on the value of integrating populations, which is expected to increase collaboration and partnerships in the community and with the WRHA.
3. Focus on bringing services to where the people are by not developing services that are unable to respond to where the people want services to be available, linking the provision and funding of services needs to the individual and not the program.

Session Two – An Independent Living Approach to Training Personal Care Attendants: Panel presenters felt that the WRHA should:

1. Make a commitment to the consumer controlled community-based training approach instead of a medical approach, both financially and philosophically, as a framework for staff training.
2. Commit to seek wage parity across organisations to place everyone on the same playing field when competing for personal care attendant staff in an effort to promote longevity and consistency for consumers.
3. Consider accreditation of the proposed Attendant Community Education (ACE) training program, which focuses on the needs of consumers in the community as directed by consumers, thus providing an alternative to the present Home Care Attendant training program.
4. Implement a partnership commitment with the ACE Committee confirming its support of this community-based program, and view the ACE as a pilot project to determine if this project is feasible and sustainable through the utilisation of appropriate evaluation components.

Session Three – Services to Assist Individuals Living with a Disability and Their Families with the Transition to Adulthood: Panel presenters felt that the WRHA should:

1. Declare that it functions out of a person-, recovery-, and independent-centred living approach as service providers, particularly regarding meeting the needs of people with disabilities and their families.
2. Provide all staff who will be working out of the six access centres in Winnipeg with education and training concerning a person-, recovery-, and independent-centred living approach to service development and provision for persons with disabilities and their families.
3. Review the relevancy of present WRHA policies that provide parameters for service provision that are arbitrary, such as, age limits for people with disabilities who are transitioning from children to adult service systems.
4. Address the difficulties that arise from the lack of continuity and consistency of staff who are assigned to work with individuals with disabilities and their families.

Session Four – How Can I Find a Family Doctor? – Patients with Disabilities and Access to Primary Health Care: Panel presenters felt that the WRHA should:

1. Work toward universal access to services for persons living with disabilities to ensure that barriers to receipt of care, such as physical access, language (interpreters and minority groups), and environment (scent free) are removed or minimised.
2. Initiate strategies that promote the continued education of doctors and nurses in the care and management of people with disabilities and their families; the education of new primary care physicians and nurses at the graduate level, incorporating community training within existing organisations and service; the ongoing education of staff in the Emergency Care Units, specifically in areas related to the assessment, care and management of clients with mental health issues.

3.1 Alert Manitoba Health and the medical community to the following systematic issues that have an impact on the care of those with a disability, namely: a) the shortage of primary care physicians and nurses b) the need for allowing physicians more billable time to allow for longer office visits to ensure appropriate care, management and consistency of practice c) the need to reduce waiting times in doctors' offices and transportation issues for persons with a disability d) a review of the policies on renewal of prescriptions for persons with a disability.

3.2 Consider funding a client/patient advocate or advocates to ensure both individual and systemic concerns/issues are raised, tracked and reported on across the region.

Session Five – The Role and Value of Technology Enhancing the Quality of Life of Persons Living with Disabilities: The Technology and Abilities working group felt that the WRHA should:

1. Co-ordinate the development of a one-stop information clearing house on technology, products and services (virtual and physical).
2. Develop models to advance a direct funding initiative for individuals to purchase their preferred products.
3. Use its procurement power to require goods sold to the WRHA (e.g., sofa, desk, etc.) be accessible. Accessibility should become one of the key decision making criteria in purchasing goods.

Comments from the Honourable Minister of Family Services and Housing: Minister Tim Sale attended the reporting-back session on behalf of his colleagues. The Minister thanked the attendees and the community for supporting his government's initiatives on disability and offered to meet with the disabled community to discuss the advancement of technology in the lives of people with disabilities.

Summary Comments: Dr. Sharon Macdonald, Vice President, Community Care, Winnipeg Regional Health Authority: Dr. Macdonald thanked all the participants for attending and participating in the workshops. She also thanked them for the feedback on WRHA services upon which improvements can be based. She suggested that based on the recommendations some progress could be made in the upcoming year of business planning (2003-2004), which Dr. Macdonald indicated, would require leadership from the WRHA. It would also require the formation of a partnership between the WRHA and Family Services and Housing in regards to the development of housing and an advocacy role (on the part of event participants and other organisations) to support changes at the federal, provincial, and municipal levels of government to enhance independent living for persons living with disabilities.

Based on the various sessions, she also indicated that the WRHA is committed to working with the Department of Family Services and Housing and the disability community to improve the latter's housing options; improving the processes families and individuals living with disabilities undergo when individuals in the latter group make the transition to adulthood; ensuring improved access to primary care through the development of ACCESS centres in three community areas; developing primary care strategies in conjunction with Manitoba Health; and improving education in conjunction with the Faculty of Medicine and the Faculty of Nursing

Summary of the Key Issues and Themes

Although WHR residents are more likely to report short-term disability, they are less likely to report long-term disability. There was a higher proportion of WHR population that was identified as having low functional health status. While chronic pain affects activities of WHR residents, they are less likely to perceive it as severe pain. On an emotional level, a higher proportion of WHR residents was at probable risk of depression. However, they were less likely to report high levels of psychological distress (life stress), low self-esteem, and fair-to-poor self-rated health. So although it seems that there is some degree of physical and mental health challenges, the WHR population appears to have a good overall sense of well-being and is more likely to perceive good overall health.

Several recommendations arose from the community consultation event of September 2002. The key themes for these recommendations include:

- Co-ordinate housing and support services model.
- Ensure an independent living approach to the training of personal care attendants.
- Provide services to assist individuals living with a disability and their families transition into adulthood.
- Improve access to primary health care for persons with disabilities.
- Utilize technology for the enhancement of accessibility and quality of life of persons with disabilities.

Further Information

There are two reports that provide greater detail in understanding the health issues and health determinants for persons with disability in Canada. The first, *Disability in Canada A 2001 Profile*, is based upon PALS (Participation and Activity Limitation Survey). This national, post-censal survey of persons with disabilities was carried out in autumn 2001. The Canadian Census in 2001 was used to identify the target population and construct a large representative sample of both adults and children with disabilities (about 43000 persons were surveyed). Information was collected on demographic and socio-economic situation for persons with disabilities, prevalence, type and severity of various disabilities, the need for and access to disability supports, health, employment, education, out-of-pocket expenses related to disability, and a number of other socio-economic variables.

The second report of interest, *Health Status and Health Care in the Disability Community in Canada* was conducted by Queen's University Centre for Health Services and Policy Research. This study was sponsored by

the Canadian Population Health Initiative. Data from the National Population Health Survey 1998-99 were used to target those individuals 20 to 64 years of age with disabilities. The report summarizes utilization of health services by disabled people, factors affecting utilization, and factors affecting unmet needs. The reader is directed to these reports for further information about the disabled population in Canada.