# ONTARIO WOMEN'S HEALTH STATUS REPORT

### PREPARED FOR

THE ONTARIO WOMEN'S HEALTH COUNCIL

BY

THE UNIVERSITY HEALTH NETWORK WOMEN'S HEALTH PROGRAM

THE CENTRE FOR RESEARCH IN WOMEN'S HEALTH

THE INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES

### EDITED BY

Donna E. Stewart, Angela M. Cheung, Lorraine E. Ferris, Ilene Hyman, Marsha M. Cohen, and J. Ivan Williams

(FEBRUARY 2002)

ISBN 0-7794-3614-8



The Ontario Women's Health Council is fully funded by the Ministry of Health and Long-Term Care. This report does not necessarily reflect endorsement by the Ministry of Health and Long-Term Care.

# TABLE OF CONTENTS

OVERVIEW	v
PART ONE: DEMOGRAPHICS	
1. Sociodemographics, by Doug Manuel and	
SUSAN SCHULTZ	3
2. MORTALITY INDICATORS, BY DOUG MANUEL,  DAR MALAVIARACHCHI, LOUISE PICARD, AND VALERIE MANN	21
PART TWO: MORBIDITY INDICATORS	
3. HIV / AIDS, BY ROBERT S. REMIS	37
4. SEXUALLY TRANSMITTED DISEASES, BY HAJERA ROSTAM AND ENZA GUCCIARDI	47
5. MENTAL ILLNESS, BY ELIZABETH LIN, ANNE RHODES, AND PAULA GOERING	64
6. Eating Disorders, by Enza Gucciardi and Donna E. Stewart	75
7. SUICIDE AND SUICIDE BEHAVIOUR, BY PAUL S. LINKS	86
8. SEXUAL ASSAULT AND INTIMATE PARTNER VIOLENCE, BY MARSHA M. COHEN AND DONNA ANSARA	96
9. Bone Density Testing, by Susan Jaglal	113
10. HIP AND KNEE REPLACEMENT, BY JACK WILLIAMS, GILLIAN HAWKER, DON DEBOER, AND HANS KREDER	121
11. Work Injuries, by Jennifer Payne and Cam Mustard	138
12. DISABILITIES, BY DEBORAH STIENSTRA AND ENZA GUCCIARDI	146
PART THREE: REPRODUCTIVE HEALTH	
13. FERTILITY, BY KAREY IRON, SHERRI ENNIS, AND DOUG MANUEL	165
14. TEEN PREGNANCY, BY ENZA GUCCIARDI	175
15. INDUCED ABORTION, BY KAREY IRON AND LORRAINE FERRIS	178
16. Hospital Obstetric Care, by Geoffrey M. Anderson	191
17. Hysterectomy, by Antoni Basinski	200
PART FOUR: HEALTH BEHAVIOURS	
18. SELF-REPORTED HEALTH PRACTICES, BY SUSAN BONDY AND SUSAN SCHULTZ	217
19. CANCER SCREENING, BY VERNA MAI	
20. SMOKING, BY KIM BERCOVITZ, ROBERTA FERRENCE, AND BRONWEN WALLER	
21. Physical Activity and Weight, by Jill Slack and Enza Gucciardi	269
PART FIVE: SUBPOPULATIONS	
22. Adolescent Girls, by Marsha Cohen	287
23. Lone Mothers, by Enza Gucciardi	
24. Postmenopausal / Senior Women, by Angela Cheung and Ruhee Chaudhry	
25. IMMIGRANT / VISIBLE MINORITY WOMEN, BY ILENE HYMAN	338
26. ABORIGINAL WOMEN, BY SHERRY GRACE	359
27. RURAL / NORTHERN WOMEN, BY ENZA GUCCIARDI AND ANNA BIRNIE-LEFCOVITCH	
CONTRIBUTORS	
COLLINIDALAM	567

## CHAPTER 12 - DISABILITIES

### DEBORAH STIENSTRA AND ENZA GUCCIARDI

### **OVERVIEW**

Women with disabilities in Ontario face many of the same health concerns and issues as other women. Their health status and access to services may be complicated by their physical or mental conditions, but their health is affected even more by the social context within which their condition becomes a disability. Many health-care providers fail to recognize or accept the autonomy of women with disabilities to make informed decisions individually or with their chosen advocate. These health-care providers often reduce women to their disability and are unable to consider their other health concerns. In addition, women with disabilities face differing levels of access to health-care services depending on their disability, ethno-racial background, or language. Women with disabilities can expect poorer levels of health partly because they have more difficulty obtaining paid employment and often live in poverty. Much of the most recent research related to women with disabilities has been done by the women themselves, shedding a much-needed light on a diverse population. Governments and health professionals must increase their awareness of, and become more active in addressing, the special health-care issues that face women with disabilities.

### BACKGROUND

Disability is a term with many different meanings. Some assume it refers simply to a medical or psychological condition that limits functioning within society. According to the 2001 World Health Organization International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001), it is imperative to describe how people live with their health conditions and to consider the intersections between health, body functions, activities and participation from a body, and the individual and the societal level. This assertion suggests that disability encompasses not only the physical or mental conditions that affect the body/mind but the ways in which environments create obstacles or barriers to those individuals with these conditions. Thus, disability refers to the societal context that renders a person with a physical or mental condition as different from the norm and requiring different treatment.

The Canadian Charter of Rights and Freedoms and the Canadian Human Rights Act provide the framework for the treatment of all Canadians, including those with disabilities. Equality and full citizenship for all, including those with physical or mental disabilities, are considered rights (Valentine, 2001). These rights were confirmed by the Supreme Court of Canada. In 1997 the Court ruled, in the Eldridge case, that the failure of the British Columbia government to provide sign-language interpretation to deaf individuals when they received medical care was an infringement of their rights (The Canadian Hearing Society, 1997). Individuals with disabilities are also ensured equal access to appropriate care under the Canada Health Act (Department of Justice Canada, 1984). Despite this legislation, many Canadian women with disabilities continue to be more at risk for poverty and other factors that negatively determine health. Consequently, they feel that

their needs are not being met by the health-care system, particularly in the primary care sector (Branigan, Stewart, Tardif, & Veltman, 2001; DeJong, 1997; Masuda, 1999; Veltman, Stewart, Tardif, & Branigan, 2001).

Across the world, persons with disabilities are among the most underserviced people, in terms of medical care and other services (Frye, 1993). However, disability issues are now receiving greater attention worldwide. The UN Standard Rules identify the availability of suitable medical and health care as an essential perquisite if people with disabilities are to enjoy equal opportunities in the societies where they live (United Nations, 1994).

Various countries have enacted legislation to ensure medical accessibility. For instance, the American with Disabilities Act of 1990 (ADA) (Mandelman, 1990), which prohibits discrimination on the basis of physical or mental disabilities, mandates reasonable accommodation by removing obstacles that hamper persons with disabilities (Martin, 1994). ADA is intended to provide not only equal treatment but also equal opportunity, and it imposes significant new responsibilities on physicians (Howard-Martin, 1993) so that medical services will be provided to all individuals with disability, using the same standards of care as those provided for any other individual. However, there has been criticism that this Act is not fully enforced and that many physicians do not abide by its rules (Mandelman, 1990; Nosek, 1992).

### SOURCES OF INFORMATION

The last Canada-wide survey related to disability was the 1991 Health and Activity Limitation Survey (HALS) (Statistics Canada, 1995). HALS considered seven disability types: hearing, seeing, speaking, agility, mobility, mental/learning, and physical disabilities not otherwise classified. In 1989 Environics undertook a substantial survey of disabled Ontarians for the Office of Disabled Persons (Environics, 1989). In 2001 the Participation and Activity Limitation Survey (PALS) was completed, but data will not be available until 2003. Both HALS and PALS are linked with the census and provide the most complete information available on the situation of people with disabilities. In addition, the National Population Health Survey (NPHS) provides some indication of several key aspects related to disability, including changes in activity limitation status, but its data are generally less reliable in addressing broad dimensions of disability. Unfortunately, it does not cover the entire population, nor does it use the same definition of disability or activity limitation found in HALS or PALS.

Using the HALS data, Fawcett detailed the economic profile of people with disabilities (Fawcett, 1996). More recently, using updated data from a variety of sources together with qualitative methods, Fawcett developed a labour market profile of women with disabilities in Ontario (Fawcett, 2000).

### **METHODS**

As there is limited Ontario data on health issues and concerns for women with both physical and intellectual disabilities, a literature review was conducted using primarily Canadian and American qualitative and quantitative studies.

### INTERPRETIVE CAUTIONS

Several factors limit the generalizability of the research cited. Many studies used a relatively small sample of participants, drawn from volunteers or organizational membership. Women from minority groups were not well represented. Not all studies examined both physical and intellectual disabilities, and many studies focused only on one or two particular conditions. With limited data available, these studies provide a snapshot of key issues and concerns around the health of women with disabilities. Much more research is required to provide a clear overview of the health of women with disabilities in Ontario.

### **FINDINGS AND DISCUSSION**

### **HEALTH STATUS**

Very little is known about the health status of people with disabilities in Canada, especially women with disabilities. In 1991 people with disabilities made up 15.5 percent of the Canadian population (Fawcett, 1996; Statistics Canada, 1995), and women with disabilities, 16.2 percent of the population. Aboriginal and First Nations people have a much higher incidence of disability — 31 percent, or approximately twice the national rate (Statistics Canada, 1993). Diabetes is especially problematic among Aboriginal peoples (Assembly of Manitoba Chiefs, 1997).

There are provincial differences in the rate of disability, and, in Ontario, people with disabilities constituted 16.2 percent of the population. There is some indication that, between 1991 and 1996, the rate of disability increased across Canada and in Ontario (Fawcett, 2000). Women in Ontario aged 35 to 44 experienced a 29 percent increase in their disability rate, while other age groups experienced less severe increases ranging from 18.3 percent for women 65 years and older to 23.9 percent for women 55 to 64 years (Fawcett, 2000).

There are wide variations in the type and severity of disabilities. Mobility and/or agility limitations are the most common, with approximately 59 percent of all people with disabilities reporting some mobility disability in 1991.

Rates of disability increase with age and vary among seniors. The HALS and NPHS data give different ratios between senior women and men, likely because of the more limited definition of disability used in NPHS. HALS suggests that, in 1991, 48 percent of women over 65 had disabilities, while only 43 percent of their male counterparts did. NPHS data suggest that, in 1996/97, only 24 percent of women over 65 experienced disability, while 25.8 percent of men did (Statistics Canada, 2000).

Over half a million adult women have a disability in Ontario. They are more likely to be poor and without paid employment than women without disabilities. The poverty rate among women with disabilities in Ontario was 36.2 percent in 1995 (Fawcett, 2000). Employment rates for women with disabilities in Ontario varied by location: 67.6 percent of women with disabilities in Sudbury, 58.8 percent in Ottawa, 61.8 percent in Toronto, and 57.5 percent in Thunder Bay did not have paid employment in 1995 (Fawcett, 2000).

Women with disabilities are more likely to live alone than are men or women without disabilities, almost one in ten are lone parents, and over 15 percent experienced food shortages at least once in 1996 (Fawcett, 2000). These factors, with other issues such as access to child care and barriers to employment, lead to an increased experience of stress. Women with disabilities who are lone parents have the highest level of stress for any adult group, according to NPHS data, and women with disabilities have higher levels of stress than any other group, regardless of living arrangements (Fawcett, 2000).

### **HEALTH NEEDS AND CONCERNS**

Women with disabilities in Canada identify a variety of different issues and concerns related to their health, including reproductive health (sexuality, birth control, child birth, forced sterilization, and autonomy of choices), violence and abuse, addictions, reproductive and genetic technologies, poverty, access to services, and privacy and autonomy (Chappell, 1996; Doe & Kimpson, 1999; Masuda, 1998; Masuda, 1999; Morrow, 2000). These issues are similar to ones raised by other women in Canada, but for women with disabilities they are shaped by the predominance of an individualized, often over-medicalized approach to their lives (Gill, Kirschner, & Reis, 1994). Too often health-care providers and health researchers reduce women with disabilities to their disability and overlook other health issues (Morrow, 2000; Welner, 1998).

Health concerns and practices for women with disabilities are often complicated by their physical or mental conditions. Some individuals with disabilities may suffer from one or many conditions and may be more vulnerable than others without disabilities to common and chronic health conditions. This susceptibility can increase their health-care needs, as some conditions tend to surface earlier and have worse consequences than in the non-disabled population (Manton, 1989; Thomas, 1999)

Individuals with disabilities may present symptoms differently from non-disabled individuals or require alternative treatments that take into account their particular underlying impairments and functional limitations (Thomas, 1999). Among those with disabilities, therefore, certain conditions may not be promptly diagnosed and/or treated (Nosek & Howland, 1997). It has been noted that several components of a standard physical health examination may be omitted in women with disabilities, putting them at greater risk of having secondary conditions go undiagnosed (Nosek, Howland, & Young, 1997; Welner, 1998; Welner, Foley, Nosek, & Holmes, 1999).

### SEXUAL AND REPRODUCTIVE HEALTH

Women with disabilities are often assumed to be asexual by doctors, other health professionals, and their communities (Basson, 1998). Health professionals may talk to their attendants or family members and ignore the woman with disabilities (Carty, 1998). As a result, women with disabilities frequently receive insufficient or inappropriate health-care information and services related to their sexual and reproductive health. In an Ontario study, participants with disabilities reported low discussion rates of sexuality (28.4 percent), contraception (17.9 percent), STDs (14.4 percent), and reproductive choices (9.5 percent) (Branigan et al., 2001). Some women with disabilities may avoid regular gynecologic visits altogether (Becker, Stuifbergen, & Tinkle, 1997).

### Sexuality

For many women with disabilities, key issues related to sexuality include concern about lowering of sexual desire and physical limitations that may impair sexual enjoyment or changes in sexual response as a result of their condition or its treatment (Basson, 1998; Morrow, 2000). Once these problems have been acknowledged and discussed openly with her sexual partner and, if necessary, with health-care providers, a woman with disabilities may be able to find responses to assist her in engaging more enjoyably in sexual activities. Lesbians with disabilities face additional barriers to health care and information (Masuda, 1999).

### Contraception

Women with disabilities, in particular adolescents, may be uninformed or misinformed about sexual matters and safe sex practices. They may depend on health-care professionals for sex education (Berman et al., 1999). Many disabled women have difficulty in finding reliable contraceptive information. They may have problems finding a birth control method suitable to their particular disability (e.g., limitations in manual dexterity, contraindications of prescribed medications, or the ability to understand their proper use) (Nosek, Wuermser, & Walter, 1998). Failure to achieve reliable contraception will increase the risk of unwanted pregnancies and STDs (Basson, 1998; Becker, Stuifbergen, & Tinkle, 1997). Studies have found that women with severe disabilities are significantly more likely than the non-disabled to have hysterectomies or no contraception at all as a means of birth control (Nosek, Howland, & Young, 1998). Some women and girls with developmental disabilities in Canada were sterilized without their consent under the mistaken belief that it would prevent expressions of sexuality and the possibility of reproduction. In 1999 the Alberta government offered compensation and an apology for its actions in forced sterilization between 1928 and 1972. The British Columbia government was taken to court in 2000 for similar actions (Canadian Press, 2000).

### **STDs**

Sexually transmitted diseases can arise in women with disabilities from consensual intercourse or from sexual abuse (Welner, 1996). Sensory impairment may limit a woman's ability to detect common signs of pelvic infection, such as pelvic pain. Women with disabilities require testing for all STDs, especially if they are in a high-risk group and if they wish to be tested (Welner et al., 1999). Education about the signs and symptoms of STDs is crucial to achieve early treatment and to avoid transmission of, or the development of, late-stage STD complications (Walsh, Heller, Schupf, van Schrojenstein, & de Valk, 2001).

### Cancer screening

Women with disabilities have the same biological risks as other women for developing all cancers. Unfortunately, barriers to effective cancer screening for disabled women include lack of knowledge among these women, neglect on the part of health-care providers, and physical access barriers (Welner, 1998). Together, these factors may delay diagnosis and treatment of many common malignancies. Women with disabilities, in particular those who are older, are less likely to receive regular Pap tests and mammograms (Nosek & Howland, 1997). However, one Ontario study found that women with disabilities had Pap tests and mammograms at rates similar to those of the non-disabled population (Branigan et al., 2001). Although some of the barriers to cancer screening are structural, such as inaccessible examination

tables, stirrups, and lack of appropriate examining instruments for impaired women, studies show that physicians sometimes fail to recommend any screening for women with disabilities (Nosek, Young, & Rintala, 1995). Some disabled women describe health-care providers as insensitive to and unaware of disability issues and the way they affect reproductive health (Nosek, Young, & Rintala, 1995).

### Childbearing

Women with disabilities who are considering bearing children face a number of challenges. Since many physicians find it hard to perceive women with disabilities as mothers, they fail to provide appropriate information (Carty, 1998). Some disabled women still get negative reactions to pregnancy from family members and close friends, as well as from health-care providers (Burns, 2000; Traustadottir & Johnson, 2000). Access to physician's' offices and to hospital labour, delivery, and postpartum rooms is required. In addition, women with disabilities may require "attitudinal accessibility" — the recognition that they are not invisible and that they need appropriate supportive care (Carty, 1998). One Canadian study noted that First Nations women with fetal alcohol syndrome/fetal alcohol effect (FAS/FAE) (Masuda, 1999) may face unique challenges in pregnancy. "All of these women have trouble keeping their appointments and the doctors sometimes refuse to see them. The women are so intimidated they don't come back and they are afraid to see another doctor. They need special care during pregnancy.... They have a hard time looking after themselves. They regress after having a baby and become like children themselves, and they need to be watched carefully" (Masuda, 1999).

### Reproductive and genetic technologies

Despite recent federal legislation (introduced in 2001) to address reproductive and genetic technologies, there is almost no research on the implications of these technologies for women with disabilities in Canada. Two key areas are often identified by women with disabilities — the use of prenatal diagnosis and selective abortion; and the willingness of society to accommodate disability (Asch, 1999) and access to these technologies for women with disabilities (Drapkin & Anderson, 2001).

### Menopause and other midlife health issues

One Canadian study of women with disabilities highlighted some key midlife health issues for women with disabilities. Not only do many women with disabilities experience social and economic changes as a result of a worsening of their disability but they also face intensified or more complicated health concerns than women without disabilities. These problems include mental and emotional changes, physical changes (especially a decrease in energy), changes in sexual intimacy, and changes in their disabilities as a result of midlife changes (Morrow, 2000).

### VIOLENCE AND SEXUAL ASSAULT

Children and women with disabilities are one of the most highly victimized groups in Canada (Rivers-Moore et al., 1993). The Disabled Women's Network of Canada surveyed 400 women with disabilities, and 50.8 percent reported physical abuse, 51.1 percent reported emotional abuse, 43.1 percent were neglected, and 66.3 percent had experienced sexual abuse (Masuda, 1995). Children and women with intellectual disabilities are more likely to be physically and sexually abused than the population at large (Carlson, 1997; Mansell, Sobsey, & Moskal, 1998). While women with physical disabilities are at the same risk for physical and sexual abuse as other women, they experience abuse over longer periods of time (Young, Nosek, Howland,

Chanpong, & Rintala, 1997). It has been estimated that women with disabilities are 1.5 to ten times more likely to be abused than non-disabled women, depending on whether they live in the community or in an institution (Sobsey & Vamhagen, 1989). Disabled women who live in institutional settings and severely disabled women are at higher risk of abuse because they are more dependent on larger numbers of people and are less able to escape or to report the abuse (Rivers-Moore et al., 1993). Overall, only a small proportion of abuse among women with disabilities is ever reported to the police, community agencies, or other authorities (Beail & Warden, 1995; Rivers-Moore et al., 1993).

Women with disabilities face some unique risk factors that make them especially susceptible to physical, emotional, and/or sexual abuse. These risk factors include the inability to leave an abusive situation because of impaired mobility or communication skills; dependency on the abuser for affection, communication, housing, and financial, physical, and medical aid; and greater perceived vulnerability because of physical, mental, and emotional limitations (Carlson, 1997; Nosek, 1996; Rivers-Moore et al., 1993; Sobsey & Vamhagen, 1989). Furthermore, few rape/crisis centres, shelters, and treatment programs are available or appropriately set up for women with disabilities (Carlson, 1997; Mansell, Sobsey, & Moskal, 1992; Welner et al., 1999).

### Substance abuse and violence

The consequences of violence and sexual abuse in women with disabilities frequently include depression, anxiety, low self-esteem, post-traumatic stress disorder, and substance abuse (Martin, Morris, & Romans, 1998). There is considerable evidence for an association between a woman's substance abuse and her victimization through violence, which suggests either that there is a correlation between early victimization and the development of substance abuse later in life (Chappell, 1996; Miller & Downs, 1995; Miller, Downs, & Testa, 1993) or that abusing alcohol or illicit drugs increases a women's chance of becoming a victim of violence (Bennett, 1995; Kantor & Straus, 1989). The literature confirms that women with disabilities are more likely to be victims of substance abuse-related violence than their male counterparts (Li, Ford, & Moore, 2000).

### **Barriers**

Despite the high risk of abuse among girls and women with disabilities, primary health-care providers often fail to look for symptoms of abuse from medical histories and physical examinations (Nosek, Howland, & Young, 1997). When a woman with a disability reports abuse to a physician, the physician should directly and privately acknowledge her experience, ask whether or not she is in imminent danger, document on the woman's chart the sites and kinds of injuries, plan for follow-up care, and provide her with appropriate information and resources (Nosek, Howland, & Young, 1997; Welner et al., 1999; Young et al., 1997). Awareness of abuse issues, knowledge of reporting laws, and social services contacts enable the practitioner to make appropriate suggestions (Welner et al., 1999).

### **SUBSTANCE ABUSE**

The extent of substance abuse among women with disabilities in Canada is unknown, although one study estimates that approximately half a million women with disabilities in Canada have problems with addictions (Chappell, 1996). US studies suggest that rates of substance abuse and addiction among women with

disabilities are three times higher than among non-disabled persons (Buss & Cramer, 1989; Greer, 1986; Perez-Stable, Miranda, Munoz, & Ying, 1990).

According to a Canadian study, women with disabilities reported tobacco as the most commonly used substance but considered the use of alcohol and prescription medications to cause greater problems. Many women said they used substances because of isolation, discrimination, lack of acceptance, lack of control over their life, high levels of stress and anger, depression, poverty, low self-esteem, poor overall health, and dependence on medications related to their disabilities, all of which could exacerbate addiction problems (Chappell, 1996; DeJong, 1997). The consequences of substance abuse and addiction vary according to the substance used and the severity and type of disability (DeJong, 1997). Inaccessibility to medical services, lack of physician sensitivity, and the inability of service providers to give assistance and information about programs available for substance abuse problems were cited as key barriers to treatment (DeJong, 1997). Family physicians or other health-care professionals may not spot substance abuse addiction in women with disabilities partly because these care providers are unaware of the higher risks in the disabled population (DeJong, 1997).

### Tobacco and alcohol

Smoking among women with disabilities is estimated to be double the rate in non-disabled counterparts (DeJong, 1997; Nosek, 2000). Alcohol use is a similar concern among people with disabilities (Bombardier, 2000; Hogan, McLellan, & Bauman, 2000). Young people with both mental and intellectual disabilities are more likely to get drunk and to smoke cigarettes than those without disabilities (Blum, Kelly, & Ireland, 2001; Hogan, McLellan, & Bauman, 2000; Milberger et al., 1997). One Ontario study (Branigan et al., 2001) reports that smoking was discussed by health-care professionals with only 15.4 percent of participants with disabilities. Similarly, inquiry about alcohol consumption was as low as 13.4 percent (Branigan et al., 2001).

### Prescription drugs

According to qualitative data, disabled women in Canada claimed that physicians were always willing to prescribe additional drugs (DeJong, 1997) but did not always provide enough information about a drug's side effects, addictive characteristics, and interaction with other medications (DeJong, 1997; Masuda, 1999).

### POVERTY

Income is a determinant of health, and women with disabilities have substantially less access to employment income, lower income when employed, and more limited other sources of income (Fawcett, 1996). As a result, there is a higher rate of poverty among women with disabilities than among non-disabled women or men with or without disabilities (Fawcett, 1996; Roeher Institute, 2001; Statistics Canada, 1995). In addition, people with disabilities have additional non-reimbursed disability-related expenses that they incur, including prescription drugs, assistive devices, and medical services. In 1991 approximately 30 percent of people with disabilities of working age had these expenses. In Ontario it was almost 32 percent (Statistics Canada, 1995). As a result of limited income, many women with disabilities are unable to explore alternative forms of health care to address their disabilities (Masuda, 1999).

### **MENTAL HEALTH CONCERNS**

It has been suggested that women with disabilities may be at greater than average risk of having mental health problems such as depression and stress-related symptoms. This higher risk may result from pain and illness, low fitness levels, inability to carry out self-care activities and the need for personal assistance, low self-esteem (DeJong, 1997), and increased time, planning, and effort needed to do everyday tasks (Nosek, Young, & Rintala, 1995). Social isolation, lack of intimate relationships, and vulnerability to abuse may also make women with disabilities more prone to depression (Meins, 1993; Nosek, Young, & Rintala, 1995; Reiss & Benson, 1985; Rosen & Burchard, 1990; Sands & Kozleski, 1994; Traustadottir & Johnson, 2000). Poverty and limited access to the work and job market among women with disabilities may further increase their risk of mental health problems (Nosek, Young, & Rintala, 1995; Reiss, 1990; Traustadottir & Johnson, 2000; Walsh et al., 2001).

Many studies of primary care services find that physicians fail to detect depressive symptoms in more than half of their depressed patients (Katon, 1987; Nielsen & Williams, 1980; Perez-Stable et al., 1990). Similarly, among women with disabilities, mental health problems tend to go unrecognized and untreated (Lunsky & Benson, 2001).

Social withdrawal, a characteristic of the depressed states, may prevent depressed patients from discussing emotional problems with physicians, friends, or family (Vali & Walkup, 1998). Some individuals with intellectual disabilities have a limited capacity to express mental or emotional problems verbally, so their referral for mental health services depends largely on the ability of family members and program staff or physicians to recognize any behavioural and emotional disturbances (Borthwick-Duffy & Eyman, 1990; Branigan et al., 2001). Branigan found that only 41.8 percent of persons with disabilities were asked about emotions and only 41.3 percent were asked about sleep patterns (an indicator of possible depression) by their primary health-care providers (Branigan et al., 2001).

### PREVENTATIVE HEALTH

### Physical activity

Many individuals with disabilities are at above-average risk for chronic diseases such as heart disease, obesity, diabetes, and osteoporosis (LaPorte et al., 1983; Nosek, 2000; Pitetti & Tan, 1990; Rimmer, Braddock, & Fujiura, 1993; Rimmer, Braddock, & Pitetti, 1996; Walsh et al., 2001). Even moderate amounts of physical activity can prevent further loss of bodily function, reduce stress, help control blood pressure and body weight, and increase overall well-being (Compton, Eisenman, & Henderson, 1989; Janssen, van Oers, van der Woude, & Hollander, 1994; Santiago, Coyle, & Kinney, 1993; Thomas, 1999). Yet in an Ontario study, physicians asked only 38.3 percent and 35.3 percent of patients with physical disabilities about exercise and dietary practices, respectively (Branigan et al., 2001).

An American qualitative study reported that women with disabilities found sports and physical fitness rewarding because they help to enhance the sense of freedom, strength, and empowerment that may make people re-evaluate their physical capabilities and increase control over certain aspects of their lives. Furthermore, the ability to do something physical, to get out, and to be with people made them enjoy and look forward to participating in physical activities (Blinde & McCallister, 1999). A qualitative Canadian study confirmed these results (Masuda, 1999).

### Physical access

A recent Ontario study showed that people with physical disabilities experience difficulties in accessing adequate and appropriate primary health-care services (Veltman et al., 2001). They often lack the opportunity to engage in preventative health-care activities, which are usually administered by health-care professionals (Masuda, 1999). The ability of disabled people to receive services in a physician's office depends on their capacity to make appointments, arrange transportation, enter the buildings/offices, use the washroom, access appropriate medical equipment, and have sufficient time with the physician (Allen & Mor, 1997; Branigan et al., 2001; Jones & Tamari, 1997; Nosek, 2000; Veltman et al., 2001). Problems with any of these facilities may discourage women from tending to health issues at an early and perhaps more easily treatable stage (Greer, 1986). One Canadian study found that many women with disabilities were declined medical care because the services could not cater to their needs (DeJong, 1997).

Common issues of access for women with disabilities may include, but are not restricted to, lack of proper ramps or wheelchair access; washrooms without bars; doors too narrow for wheelchairs; places without light strips at stairs and doors; no telecommunication devices for the deaf; no teletypewriters; lack of alternative formatted material (e.g., Braille, captioned videotapes, plain language); no provision for personal care attendants or interpreters; staff who are not knowledgeable about, trained in, or sensitive to the needs of women with disabilities; and staff who do not know how to safely handle mobility-impaired patients (DeJong, 1997; Thomas, 1999). One Canadian study suggests guidelines for access to physicians' offices (Jones & Tamari, 1997).

### Privacy and autonomy

Women with disabilities are often not recognized by their health-care providers as "experts" on their own conditions or as knowledgeable partners in discussing health-care options. Women with disabilities want to play an active role in managing their condition and wish to make informed choices about their medical treatment, but they feel they are not given enough information by primary care providers to do so (Masuda, 1999). In addition, many women with disabilities have been subjected to what some have called "public stripping" — the humiliation of being forced to disrobe for educational displays in front of large groups (Gill, Kirschner, & Reis, 1994). Finally, forced sterilization, involuntary abortions, concealed contraception, and other procedures undertaken against their will deprive women with disabilities of their autonomy and their right to choose medical care (Gill, Kirschner, & Reis, 1994).

### SUBPOPULATIONS

### Immigrant women and women of visible minority groups

Immigrant and visible minority women with disabilities are largely underrepresented in the research literature (Ethno Racial People with Disabilities Coalition of Ontario, 1999). According to one American study, the combination of disability and minority status increases barriers to health care (Becker, Stuifbergen, & Tinkle, 1997). Minority women with disability may have increased difficulty in finding a physician, care attendant, or an interpreter who speaks the same language or is of the same cultural background to help them benefit fully from available services.

### Aboriginal and First Nations women

In a study of health service delivery in Manitoba, Fricke (1998) documents the complications many First Nations people with disabilities face in finding and using health services, especially those related to their disabilities. One Saskatchewan study (Durst, Bluechart, Morin, & Rezansoff, 2001) of urban Aboriginal people with disabilities identifies many of the same themes as those outlined above with regard to health status, sexual and reproductive health, and pregnancy. It adds to the level of isolation and loneliness that many Aboriginal women with disabilities face when they have to relocate from their home communities (Durst et al., 2001).

### Rural and northern women

While rural and northern Ontario residents generally experience more barriers to accessing primary health care than those living in urban centres (Buske, 2000), accessibility may be further hindered for anyone with disabilities (Lishner, Richardson, Levine, & Patrick, 1996). An American study (Omohundro, Schneider, Marr, & Grannemann, 1983) found that persons with disabilities in rural locations suffered from limited access to a range of services available in urban areas and that few sought or obtained professional help. The limited information on women with disabilities who live in rural, northern, and remote regions in Canada points to a consistent and serious neglect of the complex medical issues faced by this population.

### REFERENCES

Allen, S. M., & Mor, V. (1997). The prevalence and consequence of unmet need: Contrasts between older and younger adults with disabilities. *Medical Care*, 35, 1132–1148.

Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy. *American Journal of Public Health*, 89(11), 1649–1657.

Assembly of Manitoba Chiefs. (1997). First Nations with disabilities: Dismantling the roadblocks. Winnipeg, MB.

Basson, R. (1998). Sexual health of women with disabilities. *Canadian Medical Association Journal*, 159(4), 359–362.

Beail, N., & Warden, S. (1995). Sexual abuse of adults with learning disabilities. *Journal of Intellectual Disability Research*, 39(Pt. 5), 382–387.

Becker, H., Stuifbergen, A., & Tinkle, M. (1997). Reproductive health care experiences of women with physical disabilities: A qualitative study. *Archives of Physical Medicine & Rehabilitation*, 78(12) (Suppl. 5), S26–S33.

Bennett, L. W. (1995). Substance abuse and the domestic assault of women. *Social Work*, 40(6), 760–771.

Berman, H., Harris, D., Enright, R., Gilpin, M., Cathers, T., & Bukovy, G. (1999). Sexuality and the adolescent with a physical disability: Understandings and misunderstandings. *Issues in Comprehensive Pediatric Nursing*, 22(4), 183–196.

Blinde, E. M., & McCallister, S. G. (1999). Women, disability, and sport and physical fitness activity: The intersection of gender and disability dynamics. *Research Quarterly for Exercise & Sport*, 70(3), 303–312.

Blum, R. W., Kelly, A., & Ireland, M. (2001). Health-risk behaviors and protective factors among adolescents with mobility impairments and learning and emotional disabilities. *Journal of Adolescent Health*, 28(6), 481–490.

Bombardier, C. H. (2000). Alcohol and traumatic disability. In R. G. Frank, & T. R. Elliott. (Eds.), *Handbook of rehabilitation psychology* (pp. 399–416). Washington, DC: American Psychological Association.

Borthwick-Duffy, S. A., & Eyman, R. K. (1990). Who are the dually diagnosed? *American Journal of Mental Retardation*, 94(6), 586–595.

Branigan, M., Stewart, D. E., Tardif, G., & Veltman, A. (2001). Perceptions of primary healthcare services among persons with physical disabilities; Part 2: Quality issues. *Medscape General Medical*, April 06, 2001,

Burns, J. (2000). Gender identity and women with learning disabilities: The third sex. *Clinical Psychology Forum*, 137, 11–15.

Buske, L. (2000). Availability of services in rural areas. Canadian Medical Association Journal, 162(8), 1193.

Buss, A., & Cramer, C. (1989). *Incidence of alcohol use by people with disabilities:* A Wisconsin survey of persons with a disability. Madison, WI: Office of Persons with Disabilities, Department of Health and Social Services.

Canadian Press. (2000, December 3). Women sue BC government over forced sterilization decades ago. Toronto, ON.

Carlson, B. E. (1997). Mental retardation and domestic violence: An ecological approach to intervention. *Social Work*, 42(1), 79–89.

Carty, E. M. (1998). Disability and childbirth: Meeting the challenges. *Canadian Medical Association Journal*, 159(4), 363–369.

Chappell, M. (1996). Relief at what cost? Women with disabilities and substance use/misuse. Disabled Women's Network of Canada.

Compton, D. M., Eisenman, P. A., & Henderson, H. L. (1989). Exercise and fitness for persons with disabilities. *Sports Medicine*, 7(3), 150–162.

DeJong, G. (1997). Primary care for persons with disabilities: An overview of the problem. *American Journal of Physical Medicine and Rehabilitation*, 76(3) (Suppl.), S2–S8.

Department of Justice Canada. (1984). Canada Health Act. www.laws.justice.gc.ca/en/C-6.text.html.

Doe, T., & Kimpson, S. (1999). *CPP Disability benefits and women with disabilities*. Ottawa, ON: Status of Women Canada.

Drapkin, L. A., & Anderson, J. (2001). Human immunodeficiency virus and assisted reproduction: Reconsidering evidence, reframing ethics. *Fertility and Sterility*, 75(5), 859–860.

Durst, D., Bluechart, M., Morin, G., & Rezansoff, M. (2001). *Urban Aboriginal person with disabilities: Triple jeopardy!* Regina, SK: University of Regina.

Environics. (1989). The needs and attitudes of disabled Ontarians. Toronto, ON: Office for Disabled Persons.

Ethno Racial People with Disabilities Coalition of Ontario. (1999). Violence against women with disabilities. Toronto, ON.

Fawcett, G. (1996). Living with a disability in Canada: An economic portrait. Ottawa, ON: Human Resources Development Canada.

Fawcett, G. (2000). Bringing down the barriers: The labour market and women with disabilities in Ontario. Ottawa, ON: Canadian Council on Social Development.

Fricke, N. W. (1998). First Nations people with disabilities: An analysis of service delivery in Manitoba. Winnipeg, MB: University of Manitoba, Department of Community Health Sciences.

Frye, B. A. (1993). Review of the World Health Organization's report on disability prevention and rehabilitation. *Rehabilitation Nursing*, 18(1), 43–44.

Gill, C. J., Kirschner, K. L., & Reis, J. P. (1994). Health services for women with disabilities: Barriers and portals. In A. J. Dan (Ed.), *Reframing women's health*. Thousand Oaks, CA: Sage Publications.

Greer, B. (1986). Substance abuse among people with disabilities: A problem of too much accessibility. *Journal of Rehabilitation* (January–March), 34–38.

Hogan, A., McLellan, L., & Bauman, A. (2000). Health promotion needs of young people with disabilities: A population study. *Disability & Rehabilitation*, 22(8), 352–357.

Howard-Martin, J. (1993). How the Americans with Disabilities Act will affect physicians' offices. *Healthspan*, 10(2), 15–20.

Janssen, T. W., van Oers, C. A., van der Woude, L. H., & Hollander, A. P. (1994). Physical strain in daily life of wheelchair users with spinal cord injuries. *Medicine & Science in Sports & Exercise*, 26(6), 661–670.

Jones, K. E., & Tamari, I. E. (1997). Making our offices universally accessible: Guidelines for physicians. *Canadian Medical Association Journal*, 156(5), 647–656.

Kantor, G. K., & Straus, M. A. (1989). Substance abuse as a precipitant of wife abuse victimizations. *American Journal of Drug & Alcohol Abuse*, 15(2), 173–189.

Katon, W. (1987). The epidemiology of depression in medical care. *International Journal of Psychiatry in Medicine*, 17(1), 93–112.

LaPorte, R. E., Brenes, G., Dearwater, S., Murphy, M. A., Cauley, J. A., Dietrick, R., & Robertson, R. (1983). HDL cholesterol across a spectrum of physical activity from quadriplegia to marathon running. *Lancet*, 1(8335), 1212–1213.

Li, L., Ford, J., & Moore, D. (2000). An exploratory study of violence, substance abuse, disability, and gender. *Social Behavior & Personality*, 28(1), 61–71.

Lishner, D. M., Richardson, M., Levine, P., & Patrick, D. (1996). Access to primary health care among persons with disabilities in rural areas: A summary of the literature. *Journal of Rural Health*, 12(1), 45–53.

Lunsky, Y., & Benson, B. A. (2001). Association between perceived social support and strain, and positive and negative outcome for adults with mid-intellectual disability. *Journal of Intellectual Disability Research*, 45, 106–114.

Mandelman, J. (1990). Disabilities Act could spell big changes for providers. *Provider*, 16(2), 24–25.

Mansell, S., Sobsey, D., & Moskal, R. (1992). Sexual abuse treatment for persons with and without developmental disabilities. *Professional Psychology: Research and Practice*, 23, 404–409.

Mansell, S., Sobsey, D., & Moskal, R. (1998). Clinical findings among sexually abused children with and without developmental disabilities. *Mental Retardation*, 36(1), 12–22.

Manton, K. G. (1989). Epidemiological, demographic, and social correlates of disability among the elderly. *Milbank Quarterly*, 67(Suppl. 2, Pt. 1), 13–58.

Martin, D.V. (1994). The Americans with Disabilities Act: Introductory comments. *Journal of Law and Health*, 8, 1–13.

Martin, J., Morris, E., & Romans, S. E. (1998). Violence against girls and women: Its relevance to mental health. In S. E. Romans (Ed.), *Folding back the shadows: A perspective on women's mental health* (pp. 147–162). Dunedin, New Zealand: University of Otago Press.

Masuda, S. (1995). Don't tell me to take a hot bath: Resource manual for crisis workers. Vancouver, BC: DAWN Canada.

Masuda, S. (1998). The impact of block funding on women with disabilities. Ottawa, ON: Status of Women Canada.

Masuda, S. (1999). Women with disabilities: We know what we need to be healthy! Vancouver, BC: British Columbia Centre of Excellence for Women's Health (Report no. 1481–7268).

Meins, W. (1993). Prevalence and risk factors for depressive disorders in adults with intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 147–156.

Milberger, S., Biederman, J., Faraone, S. V., Chen, L., & Jones, J. (1997). Further evidence of an association between attention-deficit/hyperactivity disorder and cigarette smoking: Findings from a high-risk sample of siblings. *American Journal on Addictions*, 6(3), 205–217.

Miller, B. A., & Downs, W. R. (1995). Violent victimization among women with alcohol problems. *Recent Developments in Alcoholism*, 12, 81–101.

Miller, B. A., Downs, W. R., & Testa, M. (1993). Interrelationships between victimization experiences and women's alcohol abuse. *Journal of Studies on Alcohol*, 11, 109–117.

Morrow, M. (2000). The challenges of change: The midlife health needs of women with disabilities. Vancouver, BC: British Columbia Centre of Excellence for Women's Health.

Nielsen, A., & Williams, T. (1980). Depression in ambulatory medical patients. *Archives of General Psychiatry*, 37, 999.

Nosek, M. A. (1992). The American with Disabilities Act of 1990: Will it work? *American Journal of Occupational Therapy*, 46(5), 466–467.

Nosek, M. A. (1996). Sexual abuse of women with physical disabilities. In D. M. Krotoski, M. A. Nosek, & M. A. Turk (Eds.), Women with physical disabilities: Achieving and maintaining health among women with physical disabilities (pp. 153–173). Baltimore, MD: Paul H. Brooks.

Nosek, M. A. (2000). The John Stanley Coulter lecture. Overcoming the odds: The health of women with physical disabilities in the United States. *Archives of Physical Medicine & Rehabilitation*, 81(2), 135–138.

Nosek, M.A., & Howland, C.A. (1997). Breast and cervical cancer screening among women with physical disabilities. *Archives of Physical Medicine & Rehabilitation*, 78(12) (Suppl. 5), S39–S44.

Nosek, M.A., Howland, C., & Young, M. E. (1997). Abuse of women with disabilities: Policy implications. *Journal of Disabilities and Policy Studies*, 8, 157–176.

Nosek, M. A., Wuermser, L. A., & Walter, L. J. (1998). Differences in contraceptive methods used by women with disabilities compared to women without disabilities. *Primary Care Update for Ob/Gyn*, 5(4), 172–173.

Nosek, M. A., Young, M. E., & Rintala, D. H. (1995). Barriers to reproductive health maintenance among women with physical disabilities. *Journal of Women's Health*, 4, 505–518.

Omohundro, J., Schneider, M. J., Marr, J. N., & Grannemann, B. D. (1983). A four-county needs assessment of rural disabled people. *Journal of Rehabilitation*, 49(4), 19–24.

Perez-Stable, E. J., Miranda, J., Munoz, R. F., & Ying, Y. W. (1990). Depression in medical outpatients: Underrecognition and misdiagnosis. *Archives of Internal Medicine*, 150(5), 1083–1088.

Pitetti, K. H., & Tan, D. M. (1990). Cardiorespiratory responses of mentally retarded adults to air-brake ergometry and treadmill exercise. *Archives of Physical Medicine & Rehabilitation*, 71(5), 318–321.

Reiss, S. (1990). Prevalence of dual diagnosis in community-based day programs in the Chicago metropolitan area. *American Journal of Mental Retardation*, 94(6), 578–585.

Reiss, S., & Benson, B. A. (1985). Psychosocial correlates of depression in mentally retarded adults: I. Minimal social support and stigmatization. *American Journal of Mental Deficiency*, 89(4), 331–337.

Rimmer, J. H., Braddock, D., & Fujiura, G. (1993). Prevalence of obesity in adults with mental retardation: Implications for health promotion and disease prevention. *Mental Retardation*, 31(2), 105–110.

Rimmer, J. H., Braddock, D., & Pitetti, K. H. (1996). Research on physical activity and disability: An emerging national priority. *Medicine & Science in Sports & Exercise*, 28(11), 1366–1372.

Rivers-Moore, B., Arenault, F., McPherson, C., Marcia Rioux, G., Roeher, A., Rueter, M., Ellerington, G., Graham, L., Masuda, S., Lagasse, V., & Phaneuf, G. (1993, February). *Family violence against women with disabilities* (Cat. H72-22/9-1993E). Ottawa, ON: Health Canada.

Roeher Institute. (2001). Disability-related support arrangements, policy options and implications for women's equality. Ottawa, ON: Status of Women Canada.

Rosen, J., & Burchard, S. (1990). Community activities and social support networks: A social comparison. *Education and Training in Mental Retardation*, 25, 193–204.

Sands, D. J., & Kozleski, E. B. (1994). Quality of life differences between adults with and without disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 29, 90–101.

Santiago, M. C., Coyle, C. P., & Kinney, W. B. (1993). Aerobic exercise effect on individuals with physical disabilities. *Archives of Physical Medicine & Rehabilitation*, 74(11), 1192–1198.

Sobsey, D., & Vamhagen, C. (1989). Sexual abuse and exploitation. In M. Csapo & L. Goguen (Eds.), *Special education across Canada: Issues and concerns for the '90s* (pp. 199–218). Vancouver, BC: Center for Human Development and Research.

Statistics Canada. (1993). 1991 Aboriginal peoples' survey: Language, tradition, health, lifestyle, and social issues (Cat. No. 89-533). Ottawa, ON.

Statistics Canada. (1995). A portrait of women with disabilities. Ottawa, ON: Ministry of Industry, Science and Technology.

Statistics Canada. (2000). Women in Canada 2000. Ottawa, ON: Ministry of Industry.

The Canadian Hearing Society. (1997). What is the Eldridge Case/Decision? (news release).

Thomas, D. C. (1999). Primary care for people with disabilities. *Mount Sinai Journal of Medicine*, 66(3), 188–191.

Traustadottir, R., & Johnson, K. (2000). Women with intellectual disabilities: Finding a place in the world. London, UK: Jessica Kingsley Publishers.

United Nations. (1994). Standard rules on the equalization of opportunities for people with disabilities. New York, NY.

Valentine, F. (2001, June 13). Enabling citizenship: Full inclusion of children with disabilities and their parents. Ottawa, ON: Canadian Policy Networks Inc.

Vali, F. M., & Walkup, J. (1998). Combined medical and psychological symptoms: Impact on disability and health care utilization of patients with arthritis. *Medical Care*, 36(7), 1073–1084.

Veltman, A., Stewart, D., Tardif, G., & Branigan, M. (2001). Perceptions of primary healthcare services among people with physical disabilities. *Medscape General Medical*, April 6, 2001.

Walsh, P. N., Heller, T., Schupf, N., van Schrojenstein, L., & de Valk, H. (2001). *Healthy aging adults with intellectual disabilities: Women's health and related issues.* Geneva, Switzerland: World Health Organization.

Welner, S. L. (1996). Contraception, sexually transmitted diseases, and menopause. In D. Krotoski & M. A. Nosek (Eds.), *Women with physical disabilities* (pp. 81–91). Baltimore, MD: Paul Brookes Publishing Co.

Welner, S. L. (1998). Screening issues in gynecologic malignancies for women with disabilities: Critical considerations. *Journal of Women's Health*, 7(3), 281–285.

Welner, S. L., Foley, C. C., Nosek, M. A., & Holmes, A. (1999). Practical considerations in the performance of physical examinations on women with disabilities. *Obstetrical & Gynecological Survey*, 54(7), 457–462.

World Health Organization. (2001). *International classification of functioning, disability, and health.* Geneva, Switzerland.

Young, M. E., Nosek, M. A., Howland, C., Chanpong, G., & Rintala, D. H. (1997). Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine & Rehabilitation*, 78(12) (Suppl. 5), S34–S38.