RELIEF...
AT WHAT COST?

WOMEN WITH DISABILITIES
AND
SUBSTANCE USE/MISUSE:
TOBACCO, ALCOHOL AND OTHER DRUGS

SUMMARY OF THEMES

March 1996

DAWN Canada: DisAbled Women's Network Canada

Prepared by: Monika Chappell

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The opinions expressed in this report are those of the author and do not necessarily reflect those of Health Canada

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Project Supervisor
Eileen O'Brien

Project Researcher
Monika Chappell

Project Coordinator
Shirley Masuda

EXECUTIVE SUMMARY

Women with disabilities, as a separate research population, are almost completely missing from current literature. While conducting the literature search for this project a number of databases were searched for the key words: women, disabilities and substance use; zero entries were found, even after the key word combinations were expanded to cover all possible permutations of those words. Disability and addiction resource centres had information about people with disabilities and about people with specific types of disabilities but none about women and disabilities. Through much effort a couple of articles and chapters in books were discovered. (Finkelstein et al, '90; Toews, '87)

Perhaps it is not surprising then that almost nothing is known about the extent of substance use by this population and/or whether it causes problems. In Canada, awareness on this subject has recently begun to expand. Women with disabilities were mentioned in recent Women and Tobacco Initiative Sections of the Tobacco Demand Reduction Strategy and the Alcohol, Drug s and Dependency Issues documents as an unknown population needing research.

At a conservative estimate there are over a half a million women with disabilities in Canada who are addicted to substances. Despite the fact that there are clear indications that the rate of addiction among persons with disabilities is at least twice that of non-disabled persons, in Canada we have just reached the starting block when it comes to providing services that meet the needs of women with disabilities..

This ground-breaking work, generously funded by Health Canada, attempts to address this major gap in knowledge.

In this work, we sought to find which substances caused the most problems and we defined substance misuse. We sought out common themes leading to substance use/misuse and why women with disabilities use substances, including tobacco. We probed for the important issues that surround the use of tobacco, alcohol and other drugs, including how the use of substances is different from non-disabled women.

The use of substances within the whole context of a woman's life - the social, political, economic and intimate realities of her day-to-day existence as a woman with disabilities was examined.

Most of all, we looked at progams and whether they were successful, and if women were currently using them, and why or why not. We looked for barriers to existing programs and what are the important characteristics of services.

Participants thought tobacco was the substance most commonly used. However, most felt the use of alcohol and prescription medications caused the most problems for them. Little information was known about the use of "illegal" drugs and over-the-counter medications and less than half the participants felt their use caused problems for women.

Substance misuse problems are hard for women to detect because most have to use substances in order to manage their disabilities. Key factors that define substance misuse were:

a) not taking a substance as it is intended,
b) when the use of substances seriously impairs their ability to function
c) when the use causes related legal and health problems.

The key internal barrier that stops disabled women from addressing their substance misuse is lack of self esteem and self worth. If women do not value or believe in themselves, they will not even begin the process of recovery from addiction. Other internal barriers that need to be addressed are internalized societal stigma, shame, isolation, confidentiality concerns and anger.

Inaccessibility of services and lack of sensitivity/training of service providers were crucial external barriers to help. Another major handicap was the lack of accessible transportation as well as the lack of availability of alternate format material (eg. Braille, captioned videotapes, plain language literature, etc.)

Women felt it was important to be able to go to women-only services. They also wanted a choice between going to mainstream services with other non-disabled women and going to services tailored to women with disabilities.

Yet, no services tailored to women with disabilities were found during the research and a number of provinces did not have any women-only services. Over two thirds of current treatment services are completely inaccessible.

Inaccessible in the broadest sense includes but is not restricted to: facilities that do not have proper ramps or wheechair access or washrooms with bars and doors wide enough for wheelchair access; places that do not have light strips at stairs and doors; no TTD/TTY; no provision for personal care attendants or interpreters; and program staff who are not knowledgable or sensitive to women's disablitites. It often includes financial inaccessibility. Complete specifications can be found in the DAWN Canada document *Meeting Our Needs.*

Of approximately 350 accessible services, most could not serve women with cognitive disabilities, women who had spinal cord injuries or who required a high level of personal care, women who were completely visually or hearing impaired as well as those who had more than moderately severe mental health disabilities. Stories were told of women who were turned away from help because those services were unable to meet their needs.

A note of some concern was the high incidence of Fetal Alcohol Syndrome and Fetal Alcohol Effect (FAS/FAE), particulary in tiny rural and northern communities and the lack of services for pregnant FAS mothers.

Information about substance misuse and the availability and accessibility of programs does not get out to women in disability communities. Women in the deaf community who have been deaf from birth may have very low levels of general reading and comprehension; many have the understanding that addiction is an "infectious" moral disease.

Another important component of successful substance misuse programming is self esteem-building; support groups need to be peer led, services need to be completely accessible; and service providers need to have welcoming non-judgemental attitudes.

The primary reason why women reduce or stop their use of substances is current health problems. Many women also consider stopping or reducing their use of substances because of pressure from their peers, families or work situations.

Overall women wanted help, but did not want that choice forced upon them. They wanted to be able to make the choice to seek it out. Services need to be there when women with disabilities make the choice to access them.

1.0 INTRODUCTION

The Office of Alcohol, Drugs and Dependency Issues of Health Canada held a workshop in 1994 on women and substance use where the need was expressed for information about women with (physical) disabilities and their use of alcohol and other drugs. In the same year, Health Canada held a women and tobacco conference which was attended by DAWN Canada. Initial discussions took place between those two parties and a proposal was sought by Women and Tobacco Reduction Programs for a needs assessment related to tobacco use. DAWN Canada felt strongly that it was necessary to focus on the use of all addictive substances by women with disabilities.

Further discussions took place between DAWN Canada and Health Canada and a proposal was submitted early in 1995. It was decided that this project would be a needs assessment of issues surrounding the use of tobacco, alcohol and other drugs, based on community input, with particular emphasis placed on use of current programs and what would make programs work for these women. An literature review began the needs assessment process.

After distribution of an initial education bulletin, twelve focus groups took place across Canada (October, 1995) comprised of DAWN Canada key informants (women with disabilities chosen for their expertise in this field). The focus group locations were:

Newfoundland	New Brunswick
Ontario	Manitoba
Quebec (English and French)	North West Territories (4)
British Columbia (plus pilot group)	Alberta

Total number of participants was 110, of which 64% (70) were focus group participants and 36% (40) were respondents outside of focus groups, including 10 women who mailed in aswers to the focus group format's questions. Focus groups were arranged in both small and large communities, with the majority being in larger cities. Several groups were held in very small Native communities and one was held in a rural town.

The women who responded by phone or fax (27%) did not give any identifying characteristics and were not counted among the following statistics. The majority of women identified as Canadian/Québécois (56%), the next largest group was Non-status Aboriginals (19%). Not far behind were women who identified as Status Aboriginal (11%). Nine percent identified as Irish, Jewish or American. Only four percent identified as first generation Canadians.

Most disability categories were present among participants, although several were under-represented. The range of disabilities included mobility, hidden, drug/alcohol dependency, mental health, learning and visual disabilities, brain injury, hearing impairment and being labelled mentally handicapped.

An important gap was no one identified themselves as having HIV/AIDS. This might have been due to the possible stigma and fear of consequences of disclosing their HIV/AIDS status in a group or it may have been due to the reluctance of women who have HIV/AIDS identifying themselves as having a disability. It may have also beenthat there were no particpants who were infected.

Other definite population gaps in the research were: no one identified themselves as a landed immigrant; few women of colour participated; much fewer young women under 21 participated than other ages and/or seniors; and there was a lack of representation from inner city women with disabilities.

This document summarizes the main document, *Lessons From the Research*. The focus of this work was to link common themes that cut across each of the substances, identifying major differences among substances and with non-disabled women, and also seeking to find out how these themes might be used to design future cessation/reduction programs.

2.0 CONTEXT

2.1 Who is DAWN Canada?

DAWN Canada: DisAbled Women's Network Canada is a national, non-profit, cross disability organization of women with disabilities in Canada. We are affiliated with provincial DAWN groups and other disabled women's groups in Canada and internationally. DAWN Canada's focus for the last eight years has been in the area of research, defining needs and concerns of women with disabilities and designing programs to address those needs and concerns.

2.2 Extent of the problem

The proportion of women from the total population that are current smokers (28%) is approximately the same as men (31%). Total number of current smokers has steadily declined since statistics began to be collected in 1978. In contrast, current use of tobacco by teenaged women, which had seen a steep decline between 1979 -1990 (46% - 21%), rose to 29% in 1994.[1]

1. *Women in Canada A Statistical Report.* (1995) pp. 39, 51. Ottawa, Ontario: Statistics Canada..

Women are less likely than men to be current drinkers. Canada's Alcohol and Other Drugs Survey (CADS) showed, in 1994, of those who had consumed alcohol in the past year, 66.7% were women and 78.1% were men.[2]

CADS surveyed five types of prescription medications and reported that women use more prescription drugs than men (23.9% - 17.7%). Women used more than twice as many anti-depressants (4.2% - 1.7%) and almost one and a half times more sleeping pills (5.4% - 3.7%). They also used just over one and a half times more tranquilizers than men (5.3% - 3.4%). However, the difference in usage between women and men was much less marked for the use of pain relievers, with the percentage of women being slightly more than men (14.1% - 12.0%). [3]

Although women use more prescription and over-the-counter medications, men use more "illicit" drugs. CADS reported that over the last year, men used marijuana almost double the rate of women (10.0% - 4.9%). Men also used twice the amount that women used of most other "illegal" drugs suveyed including heroin, LSD and speed. Overall use of these drugs has more than doubled since 1989 (0.4% - 1.1%). Figures were not broken down by gender for the use of cocaine; the overall use of cocaine has dropped to almost half the rate of use in 1989 (1.4% - 0.7%).[4]

Reports of the actual incidence of substance misuse in the disabled population vary. Statistics provided by the United States National Clearinghouse on Alcoholism and Alcohol Abuse show that one in ten persons will become chemically dependant.

While relatively little research has been done on the prevalence of substance misuse among various disability communities, professionals have published studies that estimate the rate of substance abuse and addiction is as much as three times more common in this population thanfor nondisabled persons (15 to 30%).[567]

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2. *Canada's Alcohol and Other Drugs Survey* (1995) pp 2. Ottawa, Ontario: Health Canada.

3. Ibid. pp 4.

4. Op. Cit. [See note 2. pp 5.]

5. Guthmann, D. (1995) *An analysis of variables that impact treatment outcomes of chemically dependant deaf and hard of hearing individuals.* pp 3. Minneapolis, MN: Minnesota Chemical Dependance Program.

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

7. 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 & Social Services.

Estimates of substance abuse and addiction vary according to substance type, severity and type of disability. Persons with mental health and learning disabilites or who have spinal cord and head injuries seem to have the highest rates of incidence of substance abuse. Rates of substance abuse may reach as high as 83% of persons with some types of mental health disorders also abuse substances.[8][9][10]

There are 2.2 million women with disabilities living in Canada (16.2% of the total female population).[11] From the figures previously quoted there are upwards of thirty percent of women with disabilities who have addictions. Thus, even using a conservative estimate of 20%, **almost half a million Canadian women with disabilities have problems with addiction and need help.** Many of them are not receiving the help they need to be able to acheive their potential as full and equal members of society..

2.3 Substances causing the most problems

Participants thought tobacco was the substance most commonly used. However, most felt the use of alcohol and prescription medications caused the most problems for them. Little information was known about the use of "illegal" drugs and over-the-counter medications and less than half the participants felt their use caused problems for women. A small number thought the use of caffeine and household solvents caused problems for women with disabilities.

2.3 Defining substance misuse

The *Diagnostic and Statistical Manual of Mental Disorders* provides a medical definition of substance dependance and addiction that is currently accepted by professionals. A more suitable definition for people with disabilities proposed by de Miranda, a well known reseacher in the field of substance misuse by people with disabilities, states that **substance misuse is the use of "any substance for other than its intended purpose and which seriously damages either the person's health or his/her ability to function."**[12]

8. Heinman, A.W. (July 1991) "Substance abuse and spinal cord injury." in *Paraplegia News*. pp 16-17.

9. Karacostas, D.D.; Fisher, G.L. (1993) "Chemical dependancy in students with and without learning disabilities." in *Journal of Learning Disabilities 26(7) Aug-Sept. pp 491-5.* Los Vegas, Nevada: Clark County School District.

10. "Comorbidity rates of substance abuse, mental illness found to be surprisingly high." (December 21, 1990) in *Psychiatric News*.

11. Op. Cit. [See note 1. pp 163.]

12. de Miranda, John. (1990) The Common Ground: alcoholism, addiction and disability. *Addiction and Recovery*: Cited in- *Substance Abuse and Disabled Persons: An Information Package*. pp 1. Toronto, Ontario: Addiction Research Foundation..

The research participants proposed a similar definition. They also suggested that substance misuse problems are hard for women to detect because most have to use some medications in order to manage their disabilities. Key factors that define substance misuse were:

a) not taking a substance as it is intended,
b) when the use of substances seriously impairs their ability to function
c) when the use causes related legal and health problems.

3.0 FACTORS LEADING TO SUBSTANCE USE/MISUSE

3.1 Sexual, physical and psychological abuse

Most participants clearly and emphatically stated that histories of violence and abuse affect their use of substances. Primary reasons women use/misuse substances is to kill the pain, to escape and to numb themselves. Women said substances allow them to forget about their problems, to rebel against family, caretakers and society as a whole, and to maintain denial about their abuse. Although cautioned to speak generally about communities, several women disclosed stories of abuse and their need to escape, mentally and physically, through substances use/misuse.

DAWN Canada's most recent research showed exceptionally high rates of abuse. Of the almost 400 women with disabilities who participated in their recent survey, 50.8% had reported physical abuse, 51.1% reported emotional abuse, 43.1% were neglected and 66.3% had experienced sexual abuse.[13]

Of the 2.2 million women with disabilities in Canada, extrapolating DAWN Canada's latest statistics, **over one million women have experienced physical violence** and **almost 1.5 million have experienced sexual abuse**.

Some researchers have reported that high percentages of women in treatment for alcohol and drug problems are survivors of childhood sexual abuse.[14][15] The link between the use/misuse of substances and having a history of abuse is slowly being established. Although these figures are not specifically reported for women with disabilities, it is likely the link is similar. This has clear implications for what must be addressed in designing programs.

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13. Masuda, S. (1995) *Don't Tell Me To Take A Hot Bath: Resource Manual For Crisis Workers*. pp 93. Vancouver, British Columbia.: DAWN Canada: DisAbled Women's Network Canada

14. Covinton, S.S.; Kohen, J. (1984) Women, Alcohol And Sexuality. *Advances In Alcohol And Substance Abuse*, 4(1). pp. 41-46.

15. Doiron, Paula. (1993) *Needs Assessment Report for Women and Substance Abuse: The Invisible Problem*. pp 3. Moncton, New Brunswick: Support for Single Mothers Inc./Crossroads for Women/New Brunswick Advisory Council on the Status of Women.

This link between substance misuse and violence\abuse also supports the need for women-only programs. Since most sexual abuse is perpetrated by men and often there are male abusers in a co-ed facility, it seems only logical that women should have the choice of not having to face abusers while in the vulnerable state of trying to recover from substance addictions.

3.2 Discrimination, societal lack of acceptance, isolation and poverty

Many participants voiced concerns about discrimination and societal lack of acceptance and how they play a role in substance use. Feeling unwelcome and unwanted is a factor in women's low self esteem and increases feelings of stress and isolation. Continually women said they felt isolated from the world, citing reasons of not feeling they fit in, not feeling accepted and general inaccessibility of society. They then sit at home and use/misuse substances to cope with those feelings, a self-perpetuating cycle of lonliness and pain.

Women with disabilities are among the poorest of the poor. Many are unable to work and must rely on the social welfare system. Others experience discrimination while seeking employment. These employable women often are forced to sit at home, isolated and without meaningful work. Loneliness, lack of self esteem and high levels of poverty increase their stress and the desire for escape.

Discrimination also fuels anger. Many women voiced their anger over the discrimination that women with disabilities experience. One woman noted, "Smoking is a way of acting out our anger and frustration at our disabilities, at the lack of access, at society's attitudes, at everything." Another respondent said, "Women in general suffer from discrimination. However, discrimination is much greater for women with disabilities and even more so if you also belong to other marginalized groups. This causes so much pain and anger that we isolate and abuse alcohol." Programs will need to find ways to positively address the negative feelings caused by discrimination and its surrounding issues of isolation and poverty that women with disabilities experience.

3.3 High levels of stress

Participants noted that the high level of stress they experience can definitely lead to substance use. Although all women feel stress/pressure to conform to society's norms, this stress is greater for women with disabilities because disabilities make it more difficult to fit to society's norms.

Unlike non-disabled women, disabled women have stress related to society's inaccessibility, to the feelings surrounding newly diagnosed disabilities, the lack of control in their lives and the need to balance necessary medications with addiction. This may cause disabled women to move more towards substance misuse.

As noted previously, stress is also related to the abuse, discrimination, isolation and poverty that women experience. Effective programs will need to help women positively cope with on-going stress.

3.4 Physical and psychological pain and overall level of ill health

Most women have an overall level of poor health as a result of their disabilities. Perhaps the biggest difference to non-disabled women is most women with disabilities are in constant physical pain or discomfort. Others must contend with spasms, nausea, regular infections and illnesses, and very low levels of energy. Still others live with varying degrees of psychological distress. Living with constant pain and distress can certainly lead to substance use/misuse and may be difficult to address when designing programs.

3.5 Lack of control over life

Research participants often stated that women with disabilities lacked control over their lives. Relatively few women have employment and independent incomes. Their need to depend on the social welfare system for basic existence requirements results in feelings of powerlessness, shame, frustration, anger, a fear of 'rocking the boat', as well as high levels of stress. Some have to depend on caregivers while others rely on difficult and impractical accessible transportation systems. They can not just make a decision to go on an outing, rather they must book transportation days in advance. Most women are also dependent on a physician's care, one who may or may not be supportive of them. Women are unable to alter the fact they have (often progressive) disabilities, are subject to the disabilities' changing effects and often can not control whether or not they use prescription medications.

A number of women said that being able to control something, even if it was just their substance use, particularly of tobacco and some other drugs, definitely leads to the use/misuse of substances. One woman pointed out, "If you can't control your life, family or money, you can always get cigarettes, whether you beg them or buy them, That's something I control." Helping women feel they have some control over their lives is an important factor for programs to address.

3.6 Anger, despair, hopelessness, shame and lack of self esteem

Although many women experience varying degrees of low self esteem and feelings of anger, despair, hopelessness and shame, the degree to which women with disabilities experience these feelings is much greater.

Over and over women told us that having negative views of themselves, a complete lack of self-worth, anger over discrimination and societal lack of access, despair over their lives, hopelessness about the future and shame about being poor, unemployed and disabled leads women to use/misuse substances. One participant poignantly stated, "What other choices do we have? There's no job, nothing to do and no hope for the future. Why should I quit?" Touching on women's depths of despair, hopelessness and shame, one respondent noted, "(Smoking) is a socially acceptable way to die". Addressing lack of self esteem, shame and anger were named as being primary to effective programs.

3.7 Lack of knowledge regarding addiction and substance use/misuse

It was fairly evident throughout the research that many women lack knowledge regarding addiction and substance use/misuse. Many women had never talked openly about substance use/misuse, particularly of "other drug use". For many information regarding addiction is not provided in understandable and useable formats. Women from the deaf community said many of their members have very low levels of English comprehension and hold out-dated views on addiction. Participants noted that physicians often did not tell them about the addictive qualities of prescription medications or the dangers of multiple medications. They also noted that little information about alcohol reaches their communities. More information reaches communities about the effects of smoking however, a number of women were suspicious about this information. Lack of knowledge regarding addiction can certainly lead to substance use/misuse.

4.0 WHY WOMEN WITH DISABILITIES USE SUBSTANCES

4.1 Helps women cope with feelings including those regarding abuse

Most, if not all, women have some difficulty coping with feelings, especially those regarding abuse and many use substances to cope with these feelings. As noted earlier, women with disabilities experience high levels of abuse/violence and research is slowly establishing links between substance use/misuse and experiencing abuse/violence.

Women said that smoking helps them cope with feelings of despair. They told us that the use of alcohol and other drugs help them cope with or numb feelings connected to the abuse they had suffered.

A statement of concern expressed in the North was that First Nations women feel they have a right to take prescription drugs, to hide the pain caused by the abuse they suffered at residential schools and churches, as well as today's ongoing racism and oppression. In the previous section it was noted that women with disabilities experience almost a complete lack of self esteem and feelings of despair, hopelessness and shame, using substances help women cope with these overwhelming feelings.

4.2 Relieves stress and anger

Although the relief of stress and anger were reasons why women used all types of substances, stress was most relevant in the use of tobacco and other drugs (marijuana, heroin, prescription medications etc.) and anger was most relevant in the use of alcohol and tobacco.

One young mother with a learning disability said, "I really want to quit smoking but I'm so stressed and smoking relaxes me. Well, I know it really doesn't but it just seems to. I guess I'll quit when things calm down." Another woman commented, "Pot in particular helps with anger and stress but you feel less motivated to do anything. You just feel mellow." An older mother stated with some force, "I just quit smoking and I"m so angry all the time. I just want to scream and I don't even know about what!" Another woman exclaimed, "Our use (of alcohol) is different because of our intense anger! We are angry because society is not accommodating, but we are really angry because they say 'Stop using alcohol.' But on the other hand they don't give us any help to stop."

4.3 Helps women cope with disability either by self medicating or through physician control

Women told us smoking seems to have a calming and relaxing effect which can help pain reduction and also reduce mental health distress.

Alcohol is often used to relieve psychological distress, particularly to help women cope with (forget) they have disabilities. One woman told us, "We drink like crazy to forget we can't walk." Drinking reduces anxiety, allows women with agoraphobia to leave their house and may cause or mask depression. Women with disabilities which affect muscle coordination said small amounts of alcohol can help muscle spasms and coordination.

Coping with the side-effects of disabilities, like nausea, pain, discomfort and mental health distress are primary reasons that women need prescription medications. The use of other substances like pot, heroin, solvents seems to be dependant on the particular effect of each substance.

While most of these other substances are used to relieve psychological pain, heroin is also used for effective physical pain control, marijuana is used to control spasms, nausea and to calm and relax women, while cocaine is used for energy. One participant told us that most addicts she knows used drugs as a result of trying to self-medicate psychological and physical problems like depression and migraines.

4.4 Provides pleasure, something to do and helps women socialize

Providing pleasure/fun, giving women something to do and socializing are reasons mostly relevant to using alcohol and tobacco. Women told us they drank and smoked to socialize, to be part of the gang, to have fun and to have something to do. One participant noted, "You can't get out, so you smoke as a pastime." Another said, "It's a social thing, to be part of the gang." Women explained that drinking helped them feel like adults, an important issue for women with disabilities, many of whom say they are treated as children.

Providing pleasure and socializing seemed irrelevant for most other substances (pot, heroin, solvents etc.), as women said their use tended to be very hidden and often caused extreme isolation.

4.5 Addiction and/or substances are too hard to quit

Almost all participants felt tobacco was too hard to quit and about three quarters felt that addiction to smoking played a major role in why women continue to smoke. (Interestingly, almost all participants also felt that women in their communities did not consider tobacco use a problem.) These two factors were relevant to all substances, but more so for tobacco than any other drugs/substances.

All research participants felt addiction to prescription medications was a major problem in their communities. Close to half felt addiction to other substances like alcohol, heroin and marijuana was a reason why women continued their use.

One woman spoke up, "Addiction is a really big problem seldom talked about out loud. There's something really shameful about it and women with disabilities don't want to admit that it is a problem in case all medications and/or services are taken away. Besides it's so hard to tell what's addiction and what's not. It's such a fine line for us. Since most of us have to take drugs of some kind or another, it's very hard to tell when it's a problem or not. Especially when the drugs you're taking make the difference between committing suicide and staying alive!"

5.0 BARRIERS TO SEEKING HELP

5.1 Lack of accessibility to help and accessible transportation

Most participants stated that women with disabilities are not using existing services, primarily because of inaccessibility. Risking a lot, one participant told us, "I did try to get help. With my abuse issues, I only wanted to go to a women's program. I went to the only place around here that I knew about, but they couldn't help me because I was in a wheelchair!"

The inaccessibility of helping services was noted primarily as an issue for alcohol and other drug use/misuse, although women noted the need to hold stop smoking programs in accessible buildings. Women told us that most recovery and treatment programs are inaccessible and the disability services they use lack knowledge about addiction, leaving them unsure about where to go for help. A number of women were particularly concerned that residential addiction programs do not accommodate disabilities, especially if women need attendants, are in wheelchairs, have cognitive, visual or hearing impairments or have spinal cord injuries. Many treatment programs do not accept self referrals.

Participants were unaware of any programs tailored to women with disabilities aimed at stopping or reducing their use of substances and many were unaware of any women-only programs. Women said they do not know where to go or who to phone for help. The accessibility of helping services is not well known and information about accessibility improvements of previously inaccessible services does not reach the women who need these services.

Out of approximately 1,100 treatment services in the Canadian Centre for Substance Abuse Treatment Database, about 350 services accept women and self report some level of accessibility. This number is however in doubt, as disabled women report that many services which say they are accessible are often times not truly accessible.

Key informants were also almost completely unaware of programs or resource manuals which offer help in alternate formats. Most current materials are unusable and are not understood by many women with disabilities. Lack of informational materials in alternate formats, such as large print, simplified concepts or captioned videotapes is another major barrier to seeking and obtaining help.

Another major barrier is the lack of accessible transportation and many comments were heard about the lack of accessible transportation.[16] Use of existing transportation is linked to confidentiality concerns. Women fear word may get out that they have a drinking problem because the only accessible transportation is available through the disability organization where they, their friends or caregivers work. They fear others may find out and they may lose employment or services.

Explaining that some women are using services, one respondent put it this way, "Some women with disabilities are using existing programs, it depends on their disabilities and how severe they are. Women who have mild to moderate psychiatric disabilities, very mild developmental disabilities, partial sight and hearing loss or learning disabilities, can, and are being helped. It is the same for most women with HIV/AIDS and hidden disabilities. But the majority of women outside those categories are not using programs."

5.2 Lack of training\poor attitudes of service providers

Insensitive and judgmental attitudes of service providers is another primary reason why women do not get help. In the words of one woman, "How you get in is not really the problem, it's how you are treated when you get in that makes all the difference in the world!"

Participants told us service providers lack knowledge and staff are not trained in the needs of women with disabilities. Women said service providers often focus on the disability, not the addiction, and often enable substance use saying women have a right to use drugs because their lives are so difficult.

5.3 Lack of knowledgeable and sensitive care by medical personnel, over prescribing

Women felt that many physicians are uninformed and insensitive about their disabilities. Most physicians encourage women to take prescription medications. The women sometimes felt that it made the doctor feel better to actually be doing something for them.

16. Although many urban places have at least one accessible van through disability organizations or may have a handy bus system almost none have accessible taxi's or accessible regular buses. Vancouver has a fleet of about 50 accessible taxis and Toronto has a few. Most subways and Rapid Transit systems are inaccessible. The researcher used systems in Montreal, Toronto and Vancouver, only Vancouver's was accessible, except one stop.

One woman said, "It's so much easier for doctors to give us pills rather than deal with their difficulties around the fact that we can't be fixed. I went to a doctor who prescribed me medications. I didn't want to take them because I thought they were too high a dosage. When I protested he said I absolutely had to take these medications or find another doctor!"

A number of participants noted problems they had with physicians and the medical system. One woman explained, "I don't trust doctors. They are not careful and the medical profession is driven by large pharmaceutical companies." Another participant noted, "Doctors are sometimes not helpful and don't give us what we need because they are too cautious or because they don't really listen to us. In addition, little information is given to us about the effects of drugs so women assume the drugs are safe and nonaddictive." Another said, "Women with disabilities are forced to remain dependent on a system which sees women as weak and helpless and not to be taken seriously!"

Another problem is the different levels of available health care, particularly prescription drug coverage. Women who do not have prescription drug coverage are forced to use whatever means necessary to get the medications they need. This also applies to attending treatment programs, costs which are often covered by having a certain level of health care. Disabled women who are working at low paying jobs may not be covered.

Women also noted drugs often were not effective. Pain relief has not been addressed very well. Current drugs are very addictive and are not really effective. Women end up being addicted rather than combating pain.

Participants felt that many women were over prescribed medications and pointed out that this decreases their quality of life and they are unable to live up to their full potential. Other problems mentioned by many were the risk of drug interactions, including overdosing, confusion, inability to concentrate or make decisions and inability to function. Loneliness, shame, isolation, forgetfulness, memory loss and financial problems related to increased health costs were also mentioned. Women told us many physicians lack a global view and follow up inadequately.

One participant addressed the problem of senior women. Based on a conversation with a health care professional, she noted that the majority of geriatric psychiatric admissions to hospitals were the result of overmedicating and the mismanagement and mixing of medications.

5.4 Need for substances even though they cause some harm

A primary difference between non-disabled women and women with disabilities is that the latter need to take some medications to cope with their disabilities. The fact that medications are often necessary to cope with the effects of disabilities, yet still may cause addiction/life problems, is a major challenge to women and service providers alike. For each woman the solution may be different and both general and individualized solutions must be sought to find the proper balance between necessary use of substances and addiction/life problems.

5.5 Requirement to be substance-free to enter most treatment programs

Many treatment programs require clients to be substance-free to attend their program. Although some programs may make allowances for anti-depressants, this requirement still poses a barrier to many women who need to be on medications, including pain relievers and major tranquillizers.

5.6 Reliance on caregivers\need for personal care

Another key difference from non-disabled women is that women with certain disabilities need personal care and/or rely on caregivers. Some women who are seeking help for their addictions need interpreters, attendants, private rooms or several hours personal care time per day in order to attend these programs. Most treatment programs are not set up to accommodate their needs.

A number of women are dependant on caregivers who may or may not be supportive of their substance use/misuse and of their attempts to seek help. Women might wish to stop their substance use/misuse yet may be in the care of a caregiver that uses substances and forced to use substances against their wishes. Few women will speak out as they fear needed services will be taken away or they will be abused.

Other caregivers enable women's smoking (and drinking) because of the caregivers inability to work past their own discomfort to communicate with the women. It seems easier for them to not challenge the behaviour.

5.7 Need to fit group model treatment programs

Participants pointed out another major barrier to service. They said group leaders\intake workers often feel that support groups are inappropriate for some women with disabilities because they are unable to understand materials or because they do not fit in with the current group.

Group model treatment programs put the needs of the group first and if women do not fit or are potentially too upsetting to group routine they are told to seek help elsewhere. This particularly applies to women who have moderate to severe mental health or cognitive disabilities, as well as women who have visual or hearing impairments.

Unfortunately, most groups must have a certain number of participants. It may be difficult to find the required number of peers for a more compatible group. As has been noted previously there are relatively few services which are accessible and the vast majority of them are only accessible to women in wheelchairs who require limited personal care and can participate in groups. This leaves the large numbers of women with disabilities who require these services with very few options.

5.8 Lack of child care\poverty issues

Nearly all the participants felt poverty was a barrier to seeking help, particularly regarding transportation. One woman said, "Poverty is a barrier, for transportation and child care to attend programs. Your overall level of self esteem is lower when you are poor and you have less access to knowledge and help. You're less likely to know your rights and to know what to do to fight for them. All these things make it harder to get help."

Another woman noted, "Private counselling costs mega dollars, or if they are free they have long waiting lists. Transportation is a barrier, accessible private cabs are very expensive and there are very few around. Not too many women with disabilities have their own accessible vehicle and if there is an accessible van service, usually you have to book 48 hours in advance. When you are picked up, sometimes you have to ride the entire circuit, even if you don't need to, because they follow a pre-set route."

Less women felt lack of access to child care was an issue in not trying to stop or reduce their use of tobacco, alcohol and other drugs. Possibly this may be the result of lack of awareness or that few mothers with disabilities have tried to stop. It is also possible that few disabled mothers were included among participants, that there actually is adequate child care or that other issues seemed more important during this part of the discussion.

5.9 Language\cultural issues

First Nations women, women from Quebec and women from the deaf community felt that language and cultural issues posed barriers to service. Most First Nations women were very concerned about these issues and wanted treatment programs to have major cultural elements and where possible, to be able to speak or learn their own language. Some women from Quebec were concerned about the lack of services for women who did not speak French. Women from the deaf community felt that lack of interpreters, inadequate knowledge of American Sign Language (ASL) and lack of knowledge about deaf culture definitely posed barriers to seeking help.

5.10 Internal barriers

Women do not want to see themselves as being addicts and are afraid it will affect their services if they admit to addiction problems. As well, for the most part, they have difficulty even asking for help. Their denial, shame, lack of self worth and self esteem, fear of the effort needed to actually stop using substances, fear of being seen as having another dependancy and the fact that they live under close scrutiny in the disability community present major barriers to seeking help.

The main internal barriers of women with disabilities are:

- believing they have a problem
- working through their fears about what may happen if they take steps to reduce or stop their use of tobacco and substances
- getting past their fear of the stigma and possible loss of confidentiality
- raising their self esteem enough to face their addiction problem(s)
- finding the energy to overcome societal handicaps,
- believing they deserve help
- valuing themselves enough to take the steps to find it

6.0 IMPORTANT CHARACTERISTICS OF SERVICES

6.1 Need for women-only services

As noted previously, the link between substance use/misuse and abuse/violence is slowly being established. Similar to non-disabled women, many women with disabilities who misuse substances have experienced or are experiencing violence. Women wanted to go to women-only services because of their past abuse; they are afraid of being in treatment with males while they deal with abuse issues and also fear the real potential for abuse at co-ed facilities.

In addition, participants noted that they are **women** with substance misuse problems and they are subject to the same myths, biases and oppressions all women face; most would rather attend women-only services than co-ed services for all people with disabilities. Women need to be able to choose to attend women-only services.

6.2 Need for both integrated and tailored services

Almost all participants said that both integrated programs (programs for women with and without disabilities) and tailored programs (programs specifically for women with disabilities) were necessary in order for them to find help stopping or reducing their use of substances. One woman remarked, "It's best to mainstream (include women with disabilities in programs used for non-disabled women). But, either as a separate program or within these (mainstream) programs, it's also important to discuss issues with women with disabilities as their own group." Others noted that women should have a personal right to choose between either type of program.

6.3 Need to address low self esteem, stress, anger, shame and isolation

Throughout the research women told us that **the most important issue for programs to address is their lack of self esteem**. In addition, programs must address women's high level of stress and their feelings of anger and shame. Programs must teach women positive skills and methods to end their isolation and cope with their feelings and life situations.

One woman put it simply, "The basic issue is low self esteem. We are more susceptible to drinking and it is almost impossible for us to value ourselves enough to go and get help."

6.4 Need for help from peers who have been there

The help of a disabled woman who has had substance misuse problems and has overcome these problems is also extremely important. Women said they need to know they are not alone. Twelve-step programs and mainstream support groups can be helpful; however, they may be held in inaccessible facilities and are often not able to provide the unique support that another disabled woman would be able to provide. Borrowing a concept from twelve-step programs, women felt the value of having peer help is unquestionable.

One group member told us, "We need to encourage peer support with positive role models that talk about reducing our use of substances and these groups need to be led by women with disabilities who have been there. It is probably better to bring in professional outsiders to our own environment after a level of comfort and trust has already been built. The women in DAWN need to be sensitized to this issue and we need to work toward mainstreaming women into existing services.

6.4 Need for accessible programs including accessible transportation

Over and over women said programs need to be accessible. Not only do facilities need to have adequate space for women using wheelchairs and women with other mobility impairments including accessible washrooms, but they also need to be accessible to women with other types of disabilities. Service providers need to consider using light strips at doors and stairways, bells and raised numbers on elevators, shaking beds for alarms and flashing lights for phones. They also need to know how to access interpreters. Service providers should purchase and become proficient in the use of a touch-teletype device for the deaf (TTD/TTY). Service providers need to be aware of the need to have their space as smoke and scent-free as possible.

Adequate time needs to be built in for breaks and personal care and private rooms for personal care need to be available. Group leaders need to be able to adjust their teaching speed and must be willing, if necessary, to use simple, repetitive concepts. More specific requirements are contained in the DAWN Canada document *Meeting Our Needs: An Access Manual For Transition Homes.* Programs also need to be available and affordable.

As detailed previously, women need accessible transportation to attend helping programs. If adequate accessible transportation is not available, then service providers need to consider purchasing, renting or contracting out accessible transportation for their mobility impaired clients. A small petty cash fund for accessible taxicabs is another possible option.

6.6 Need for accessible informational materials

Many women with disabilities have difficulty using current mainstream materials. Information needs to be available in accessible formats: large print, plain language, audio and video tapes with very simple concepts, picture ideas, Braille and American Sign Language (ASL)/captioned videotapes.

Creative solutions are most effective in reaching women who require help. Some ideas are videos in health clinics, workshops that use theatre, plays and large print, simple concept, picture idea, plain language and Braille pamphlets in doctor's offices. In particular, women said that using cartoons and humour has value in catching their attention.

If women can not understand the process of addiction nor understand the tools of recovery then it becomes almost impossible for them to even begin the process of treatment. As one woman noted, "Information is power. It is the key that gives women with disabilities the ability to stop."

6.7 Need to provide sensitivity training to service providers

As noted previously, judgmental, non-welcoming attitudes of service providers are even more of a barrier to women than lack of physical accessibility. The insensitivity of service providers and their own lack of self esteem were named as the two most important access barriers to women.

Services can be completely accessible but if women do not feel welcome they will not use that service. Service providers need to learn about the issues of women with disabilities including their need to use certain medications and other accessibility needs. They need to learn to find ways to work with the particular disabilities of women so that women can have full access to help.

6.8 Current health crisis important factor in stopping or reducing use

Women told us that a current health crisis is the most important reason that causes them to consider stopping or reducing their use of all substances. Participants felt that a current health crisis is a much more important consideration than thinking about future health problems, knowing they are addicted or attending cessation\reduction programs. Possibly education about addiction and its health related consequences may be effective in helping women stop their use of substances.

6.9 Peer, work, or family pressures important factors in stopping or reducing use

Many women also felt that the opinions of their peers, families and employers mattered. Women who misuse substances have high levels of shame, fear their confidentiality will not be maintained. They also fear the potential stigma that comes from admitting they are addicts. However, pressure to quit or control their use of substances from persons in their more immediate circle was important.

Education programs should consider using the value of these relationships to encourage women to actively take steps to reduce or stop their use of substances.

6.10 Alternatives to substance use

Women noted these positive alternatives to substance use :

- herbs
- acupuncture
- spiritual healers
- TENS machines
- good nutrition
- read books
- writing
- Tai Chi
- prayer and going to church
- therapy
- meditation
- primal therapy,
- herbal teas
- laser therapy
- listen to music
- art work
- yoga

Participants also mentioned a wide range of types of bodywork such as, massage therapy, physiotherapy, therapeutic massage, therapeutic touch, reflexology, kinesiology and naturopaths.

First Nations women suggested traditional cultural remedies such as:

- Sweats
- Healing Circles
- holding Eagle feathers
- talking with Elders & Medicine People
- Smudges
- Yuwippi's & Shaking Tents
- going out on the land.
- Fasting

IF YOU WERE a depressed mother, who is a wheelchair-user, with MS and developmental disabilities, living in poverty, strung out on prescribed sleeping pills, who smokes tobacco and uses marijuana for spasms, and you wanted to find help, probably you would be out of luck.

Even if you could get past your low self esteem and knew you had a problem, you would not know where to find the appropriate help you needed.

In most communities across Canada, you would not be able to access help because you were in a wheelchair, needed attendant care and particularly because you had a cognitive disability. You would find that most places are inaccessible. They are not set up to allow attendant care and will not allow persons with more than very mild cognitive disabilities to attend.

If you were unable to stop the use of anti-depressants, major tranquilizers or required pain relievers then treatment services may be unavailable to you. If you had difficulty participating in a group setting because of your personal care needs or mental health disabilities you would most likely be told you were inappropriate for this service. Another barrier may be if your MS had progressed to the point that it affected your sight, your ability to communicate or your ability to participate in usually strenuous treatment programs.

If you even believed your smoking was a problem and you wished to cut back or stop you would have difficulty. Because of your low self esteem, you may not believe you deserve any help. You may not know where help exists and you may not know where to begin looking for help. Help may not even exist.

You may be unable to understand needed educational materials or groups may be held in inaccessible places. You may be unable to participate in groups because you do not have access to appropriate transportation or you may be unable to pay for child care.

The group leader may feel that because you are unable to understand the material or that you do not fit in with the group, this type of help is inappropriate for you. Since most groups need to have a certain number of participants you may be unable to find the required number of peers for a more compatible group.

Stop aids like the "patch" may interfere with your medication or may be too expensive. If you are successful in stopping, staying stopped may prove impossible, while coping with your isolation and increased awareness of feelings of anger and low self esteem, without a support network

While this case scenario is quite specific, it is typical of the many problems women with disabilities face when trying to find help to stop their use of substances.

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DAWN Canada
Suite 408 - 3673 Cambie Street
Vancouver, British Columbia V5Z 2X3
Voice/Fax : (604) 873-1564

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