DAWN-RAFH Canada

DisAbled Women's Network Canada

Réseau d'action des femmes handicapées du Canada

Relief at What Cost?

Substance Use/Misuse: Tobacco, Alcohol and other Drugs

LESSONS FROM THE RESEARCH
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DAWN Canada: DisAbled Women's Network Canada Prepared by: Monika Chappell

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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 over 17,000 entries in the library 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.

Med-line, Social Work Abstracts, Canadian and American National Substance Abuse Clearinghouses and Addiction Foundation databases were searched, no useful entries were found. A search of other computer disability online networks also turned up no references that linked disabled women and the use of substances. Disability and Addiction Resource Centres in the United States 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)

Almost nothing is known about the extent of substance use by women with disabilities and/or whether it causes problems. In Canada, awareness has recently begun to expand. Women with disabilities were mentioned in recent Canadian Women and Tobacco Initiative of the Tobacco Demand Reduction Strategy and Alcohol, Drugs and Dependency Issues documents as an unknown population needing research. As of early 1994, people with disabilities were not specifically noted as a population at particular risk of harm in a

comprehensive research-based publication examining Canada s Drug Strategy s second phase. Populations on that at-risk list were: women, Métis, Inuit, off-reserve Aboriginal Peoples, out-of-mainstream youth, seniors and impaired drivers. However, a later 1994 Health Canada document, *WORKING TOGETHER*, clearly noted the need to undertake addiction research on the specific needs of women with physical disabilities.

At a conservative estimate there are over a half a million women with disabilities in Canada who are addicted to substances. There are clear indications that the rate of addiction among persons with disabilities is at least twice that of non-disabled persons. We have just reached the starting block when it comes to providing services for women with disabilities.This ground-breaking work, generously funded by Health Canada, attempts to address this major gap in knowledge.In this work we have attempted to search out why women with disabilities started, continued and cut back\stopped using substances, including tobacco. We probed for important issues that surround the use of tobacco, alcohol and other drugs. We examined why the use of substances is different from non-disabled women. We also sought to find which substances caused the most problems.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 a disability was examined. We defined substance misuse.

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

Participants thought that tobacco was the substance most commonly used. However, they felt that 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.

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 had no women-only services. Over two thirds of current treatment services are self-identified as completely inaccessible.

Of the 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 the services were unable to meet their needs.

Many types of substance misuse problems noted were similar to those of non-disabled women. Different problems were increased consequences resulting from poor self care and overall level of ill health, bladder problems and problems related to prescription over-medication and the unwanted side effects of certain medications. Similar to non-disabled women, the reasons women with disabilities start and continue to use tobacco and alcohol were primarily social. However, for other drugs, women start because their

physicians prescribe drugs to them and continue because drugs relieve stress and numb feelings.The primary reasons why women have not tried to quit are a lack of accessible help, substances are too hard to quit and women do not consider them to be a problem.

Other big fears are that all medications will be taken away if women try to deal with their addiction to certain medications and that they may lose services due to breaks in their anonymity.The primary reason women reduce or stop their use of substances is current health problems. Reaching a major crisis, media cessation campaigns, support groups and life skill courses are other important factors that make women consider stopping substance misuse.

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:

1. not taking a substance as it is intended
2. when the use of substances seriously impairs their ability to function
3. when the use causes definite related legal and health problems.

The key internal barrier that needs to be addressed is lack of self esteem and self worth. If women do not value themselves they will not even begin the process of recovery. Other issues that need to be addressed are internalized societal stigma, shame, isolation and anger.Inaccessibility of services, lack of sensitivity and lack of training of service providers were crucial external handicaps. Another major handicap was the lack of accessible transportation as well as the lack of availability of alternate format material (e.g. Braille, captioned videotapes, plain language etc.)

Inaccessible in the broadest sense includes but is not restricted to: facilities that do not have proper ramps or wheelchair 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 knowledgeable or sensitive to women s disabilities. It often includes financial inaccessibility.

Complete specifications of access can be found in the DAWN Canada document *Meeting Our Needs*.

Poverty, discrimination and abuse were major factors that effected women s substance use.

Other important components of successful cessation/reduction programming are self esteem building, support groups being peer led, and service providers needing to have welcoming non-judgemental attitudes.

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

1.0 INTRODUCTION

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 DAWN Canada attended. 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 substances by women with disabilities.
Further discussions took place 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.

2.0 BACKGROUND

2.1 Who is DAWN Canada?

DAWN Canada: DisAbled Women s Network Canada is a national, 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 Definitions

2.21 Definition of Disability

The World Health Organization has clarified definitions of impairment, disability and handicap. These are:

- Impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.
- Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- Handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Practically, this means that:

- An Impairment is what is physiologically or psychologically not working to full capacity in your body (any type of loss or abnormality);
- A Disability is a particular inability to do something resulting from what is not working in your body (any loss of function resulting from an impairment);
- Handicaps are the outside barriers placed by society that impede your ability to function (external barriers that create disadvantages and limit the fulfilment of roles considered normal for particular human beings given certain factors.)
- Disabilities include mobility, and mental health disabilities, blindness and low vision, deafness and being hard of hearing, cognitive disabilities such as being labeled mentally handicapped, brain injured, or having learning disabilities, HIV + and AIDS, and hidden disabilities such as epilepsy, arthritis, diabetes and heart conditions. Many women have multiple disabilities and/or have disabilities combined with substance dependency/addiction.

2.22 Defining Substance Misuse

The Tobacco and Substance Misuse and Women with Disabilities literature review initially reviewed as a definition for substance abuse, a medical model from the Diagnostic and Statistical Manual of Mental Disorders (DSM). This definition states that substance abuse is a maladaptive pattern of substance use manifested by recurrent and significant adverse consequences related to repeated use of the substance. The substance abuse often results in repeated failure to fulfill major role obligations, repeated use in situations in which it is physically hazardous, multiple legal problems, and recurrent social and interpersonal problems. These problems must reoccur during the same twelve months.

The DSM makes a clear distinction between substance abuse and substance dependency (substance abuse being limited to harmful consequences of repeated use while substance dependency is characterized by tolerance to substances and the need to increase dosages in order to achieve the same effect).

The review points out that the DSM states alcohol dependency and abuse to be among the most prevalent mental disorders in the general population. The DSM goes on to note that mood disorder, anxiety disorder and schizophrenia may also be associated with alcohol dependence. Antisocial behaviour and antisocial personality disorder are associated with alcohol related disorders but are even more common with the use of illegal substances.

By using a medical definition of substance abuse the person is seen to be somehow faulty (maladaptive) and the diagnosis of substance abuse is often linked with an additional mental health disorder. This definition does not take into account the fact that many women with disabilities need to take medications in order to alleviate the effects of their disabilities.

Further in the same section a more suitable definition for people with disabilities is noted and is the one used by the Addiction Research Foundation. John de Miranda, a well known researcher 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." This definition was used as the base to stimulate discussion during the focus groups.

2.3 Gender Differences

The use of tobacco, alcohol and other drugs by women in general is recognized as a major health problem in Canada and over the past twenty years research data has been collected on this population.

The proportion of women 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.

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.

CADS surveyed five types of prescription medications and reported that women use more prescription drugs than men (23.9% - 17.7%). It should be noted that the above report did not include non-prescription medications.

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%).

The difference between women and men was less marked for the use of pain relievers, with women being only slightly more than men (14.1% - 12.0%), and is the only rate to have changed markedly from the General Social Survey reported on 1993. The figures increased from 9% - 7% in 1993 to 14.1% - 12.0% (respectively) in 1994. No explanation was suggested for the increase.

Although women used 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 women did for most other "illegal" drugs surveyed 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%).

As noted in the literature review, medical evidence has shown clear links between smoking and increased risk of lung cancer, heart disease, stroke, cardiovascular disease and other respiratory diseases.

Tobacco related health concerns specific to women are risks during pregnancy and to the development of the fetus, breast cancer, cervical cancer and other reproductive cancers, menstrual disorders, early menopause and osteoporosis.

As well, women who take birth control pills are 5 - 10 times more likely to have strokes or develop heart disease. Approximately 15,000 women die each year in Canada from smoking related diseases. This means that every 35 minutes a woman in Canada dies from a preventable cause.

The Addiction Research Foundation s Information Package, which focuses on women, reports that for women who use and misuse alcohol and other drugs there are clear consequences which are gender related. These risks include breast cancer, infertility, increased risk of reproductive disorders and the high risk of causing damage to the fetus.

This package, which summarizes current literature, goes on to note some physiological differences between men and women. These differences include gender differences in weight, body composition (muscle/fat/ water ratios), and hormonal differences. How men and women metabolise alcohol is related to these differences. Women tend to have higher blood alcohol levels than men after equivalent doses because of their higher body fat and lower body water than men.

Mortality rates from alcohol related health problems are up to twice as high for women alcoholics when compared to male alcoholics and death rates are three to seven times as high when compared to non-alcoholic women.

A number of similar social factors that have gender related differences have been identified in several recent Canadian documents that report on women and addiction. *Treating Addicted Women: The Henwood Experience, Skirting the Issue, The Many Faces of Women and Substance Abuse*, and *Women and Substance Abuse: the Invisible Problem* are just a few of the well written documents that identify women s issues in Canada.

These documents reported that women who are substance dependent have very low self esteem, high rates of depression and anxiety and are more likely to have attempted suicide. They are more likely to experience social stigma and have increased levels of guilt and shame, particularly internalized shame because it is less acceptable for women within our society to drink.

Women have high levels of role related stress. Because of societal expectations and the way women are socialized, women tend to be caregivers and nurturers and see themselves as having responsibility for family relationships. They are often passive and dependent and blame themselves even though they are unable to change their situation.

Addiction in women is less likely to be identified by professionals. In part due to lack of information and in part due to the fact that increased substance use is often linked to some other life crisis, like separation, abortion

and children leaving home. High levels of denial and the fact that many women drink alone are also factors.

Finally these researchers note that lack of women-only services, lack of child care, fear of their children being taken by Social Services, lack of money and insensitive services are barriers to getting help. All of the above factors play a part in why women are underrepresented in helping programs.

Violence against women is now known to be far more widespread than was once acknowledged. Although statistics vary, incidences of sexual abuse and of physical and psychological violence are very high for women. DAWN Canada's most recent research showed that 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.

The recent Statistics Canada document, *The Violence Against Women Survey*, using a legal definition of violence, showed that 51% of all women have experienced violence. Most likely this survey actually underreports the level of violence against women with disabilities because it was restricted to women who had phones, lived in households and who could communicate in of one of our two official languages.

Statistics Canada reports there are 2.2 million women with disabilities living in Canada.

By extrapolation, using either DAWN Canada's latest percentages or Statistics Canada's percentages, over one million women with disabilities in Canada have experienced physical violence. When we extrapolate the DAWN Canada figure for sexual abuse, we come up with an incredible figure of almost 1.5 million women with disabilities that have experienced sexual abuse.

One Canadian document reported that over 74% of alcoholic women had experienced sexual abuse at least once. Other documents report at least 70% of women in treatment for alcohol and drug problems are survivors of childhood sexual abuse and figures may go as high as 90% of women in treatment that have had a history of sexual abuse. The link between the misuse of substances and having a history of sexual abuse is slowly becoming established. Although these figures are not specifically reported for women with disabilities, it is likely the link is similar. This has implications for what would need to be covered in substance reduction cessation programming.

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

2.4 The Extent of the Problem

Almost nothing is known about the extent of the use of substances by women with disabilities and/or whether

it causes problems or not. In Canada, awareness of this issue has recently begun to expand. Women with disabilities were mentioned in recent Canadian Women and Tobacco documents as an unknown population needing research. People with disabilities were not specifically noted as a population at particular risk of harm in *Horizons 1994*, a recent comprehensive research-based publication examining Canada s Drug Strategy s second phase. Populations on the at-risk list are: women, Métis, Inuit, off-reserve Aboriginal Peoples, out-of-mainstream youth, seniors and impaired drivers.

However, another recent Health Canada document did mention in a stream (titled Immigrant Women and Women of Colour), the need to undertake research on the specific needs of women with physical disabilities. As well, one expectation identified at the onset was the need to explore the needs of different sub-groups of women including: lesbians, immigrants, women with disabilities and Aboriginals. During the workshop many sub-groups were explored, although women with disabilities and lesbians as separate sub-groups were not specifically explored.

This research project, funded by Health Canada, attempts to fill in this gap.

In the United States, people with disabilities have been identified as high risk groups since 1979. De Miranda reports that the California Alcohol, Drug and Disability Study (CALADDA) recommended in 1989:

> That the State declare persons with disabilities a special population at risk for alcohol and other drug-related problems requiring a variey of remedial measures to assure access to treatment, recovery, and prevention services.

In the same document de Miranda goes on to list some findings of a later (1990) National Task Force on Disabilities convened by the Federal Office of Substance Abuse Prevention. Two of the major findings were:

1. people with disabilities are the most underserved population in treatment and prevention,
2. there are no state-of-the-art preventions programs serving this population.

Reports of the actual incidence of substance misuse in the disabled population vary. Statistics provided by the National Clearinghouse on Alcoholism and Alcohol Abuse show that one in ten (10%) nondisabled persons will become chemically dependent. While relatively little research has been done on the prevalence of substance misuse among various disability communties, professionals have published studies that estimate the rate of substance abuse and addiction is up to three times more common than that of nondisabled persons (15 to 30%).

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 have the highest rates of incidence of substance abuse. Rates may range as high as 83% of persons with some types of mental health disorders also abusing substances.

California Attorney General s Commission on Disability stated in 1989 that: "There are reliable estimates on the incidence of alcohol and drug abuse among people with disabilities; indications are that it is at least double that of non-disabled people."

Even though there are no separate figures for women with disabilities, it is fairly safe to assume similar figures for them. Although there are greater social risk factors for women that may increase their rate of addiction and they use more prescription drugs, men as a general rule drink more and use more illicit drugs. These factors may tend to balance out each other.

There are 2.2 million women with disabilities living in Canada (16.2% of the total female population). 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 Canadian society.

Although this overwhelming figure is created purely by extrapolation, it is likely a conservative estimate. Studies report that people with certain types of disabilities have much higher rates of addiction. The reported ten percent figure does not include the percentage of persons who have substance misuse problems which do not qualify them as being addicted.

The problem of substance misuse in women with disabilities communities is much more extensive than what might at first appear. Although in Canada we are only beginning to look at the problem of substance misuse among women with disabilities, in the United States they have been addressing the issue of substance misuse among people with disabilites for many years. One of de Miranda s most recent papers on substance misuse among people with disabilities ended on a hopeful note.

He said:

> As few as five years ago, many in the AOD problems field were simpy unaware that yet another enormous special population existed and was in dire need of prevention and recovery services. In a few short years the old thinking -that is, thinking characterized by denial of the existence and needs of people with disabilities- has given way to a new perception. The new perception acknowledges that people with disabilities are a vital force in our communities. While the old thinking accepted segregation and exclusion, the new thinking aims for inclusion in the universally accessible community and extends beyond treatment and recovery to prevention of alcohol and other drugs problems among people with disabilites.

His comments about the state of affairs in the United States sound a note of hope for those of us in Canada, women with disabilities and service providers alike, who are at the beginning stages of addressing these issues. Things do change, provided the willingness and resources to implement the changes are available.

3.0 RESEARCH METHODOLOGY

3.1 Staff

The project required one full-time Project Researcher and one part-time Project Coordinator. All project staff were women with disabilities who were thoroughly familiar with disabled women's communities and disabled women's issues. An initial education bulletin was produced, followed by a focus group format. A literature review was initiated prior to the field work. A final education bulletin, a mini-report summarizing the research, was sent out to women with disabilities across the country.

3.2 Advisory Committee

The input of women with disabilities and from women who are familiar with the issues of tobacco and substance use/misuse played a major part in this project. Women were chosen for their experience, knowledge and expertise on substance misuse and women with disabilities.

3.3 Research Methods

This community-based research used qualitative methods rather than quanitative. This was partly due to DAWN Canada s feminist focus of directly asking women themselves, as well as the difficulty in surveying a large enough sample to be statistically valid. We initially developed an educative bulletin for women with disabilities. This was followed by the development of a focus group format as the primary needs assessment tool.

3.4 Education

The education of women with disabilities began immediately at the commencement of the project. A major objective was to educate disabled women about the use of tobacco, alcohol and other drugs. The education bulletin was sent to women with disabilities across Canada. It was translated into French.

In the education bulletin women were informed about the project and many of the issues surrounding the use of tobacco, alcohol, and other drugs. They were invited to participate in the project by sending in comments about their communities via mail, phone or fax. Responding to the education bulletin, thirty women sent in comments which were included among aggregate comments from the focus groups. The relatively small number of individual responses could be due to the lateness in sending out the education bulletin and/or the very short time deadline.

A final educational tool of this research project was the mini-report, which summarized the research and was

sent to women at the end of Phase 1.

3.5 The Needs Assessment Tool

The final needs assessment tool was a focus group format designed like a questionnaire meant to be used with small groups of DAWN Canada key informants. This tool was designed to get a general look at the issues surrounding substance use by women with disabilities with a particular focus on programming needs. It probed many facets of a disabled woman s life and tried to determine those factors that may lead to tobacco and substance misuse.

The tool was designed to get an overall view of the lives of women with disabilities. Women were specifically cautioned to generalize their comments and to speak for their communities. While personal questions were not asked, some women did take a chance and spoke personally, both in and out of the groups. Some of those comments are used in the body of this report.

The tool sought out whether particular substances caused problems for women with disabilities, why women started and continued to use substances. It looked at what prevents women with disabilities from stopping and what makes women consider stopping or cutting back on the use of harmful substances. It asked how their use of substances is different from non-disabled women and what are the important issues for women with disabilities regarding these substances. The tool asked women to define substance misuse.

It also probed for alternatives to substances, what programs are currently being used and what program barriers limit them. The focus group format also sought out the successful/necessary components for designing programs in Phase II.

Although the questions were meant to be asked in a group, a number of focus group formats were distributed to women who could not attend the focus groups. A total of forty women sent in comments. Ten women sent back actual copies of the focus group format. In the introduction of the focus group format they were instructed to comment on their knowledge of their communities, not for themselves personally. Since they were instructed to answer for their communities, it was assumed they did so and their comments were included among the focus groups in the research. As noted earlier, the other thirty women sent in comments, either in phone calls or by faxes. Again, these comments were focused on communities, not on personal use, and were included among the aggregate comments.

Some of the women who mailed in their answers to the focus group formats noted, "I don t know" to a number of questions. One woman, who sent back her format blank, wrote in the first section, "I don t really understand many of these questions. I felt there was something missing; something I didn t quite understand. Perhaps it would have been better with a video and a discussion group." These replies indicate the value of groups when addressing these issues.

3.6 The Needs Assessment Process

The needs assessment was accomplished with the help of the DAWN Canada Affiliates which provided key informants for the focus groups across Canada. These key informants were women with disabilities chosen for their expertise in this field. There were from two to ten key informants in each focus group. There were twelve focus groups (and one pilot group) across Canada.

Focus group locations were:

- Newfoundland,
- New Brunswick,
- Quebec (one English and one French),
- Ontario,
- Manitoba,
- Alberta,
- The North West Territories (four)
- British Columbia (not including pilot group).

In an extended field trip, the Project Researcher met with women across Canada in focus groups. Information about current programming and what needs must be addressed in order to make programs for prevention and cessation effective in these communities was of particular interest.

3.7 Who participated?

Total number of participants was 110, of which 64% (70) were focus group participants and 36% (40) were respondents outside of focus groups, including the 10 women who mailed in focus group formats. The focus groups were arranged in both small and large communities, with the weight being in larger cities, populations ranging from 15,000 persons to 2,000,000 persons. There were several groups held in very small Native communities and one 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 of participants idenitfied as other (Irish, Jewish, American). The smallest group were first generation Canadians (4%).

Definite gaps in the research were that no one identified as landed immigrants, and few women of colour participated. Also, based on visual estimation of the Project Researcher, there were much fewer young women than adults and seniors.

Most women (86%) identified their first language as English, however a number (6%) identified French as their first language. Other first languages noted were Gaelic, Slavey, Italian, Chippewan and German.

There was almost a full range of disabilities among the women present, although several categories were under-represented. The range of disability types in descending order of frequency was mobility, hidden, drug/alcohol dependency, mental health, learning and visual disabilities. The disabilities which were identified the least frequently were brain injury, hearing impairment and being labelled mentally handicapped.

An important gap was that no one identified as having HIV/AIDS. This might have been due to the possible stigma and fear of consequences of disclosing their status in a group or it may have been due to the reluctance of women who have HIV/AIDS identifying as having a disability. Scheduling conflicts with previously scheduled AIDS events was a factor in one case, and it may be simply that none were present.

Another identified gap was that no groups were held in an inner-city core. This resulted in a lack of representation from extremely poverty stricken inner city women with disabilities who find it difficult to leave their neighbourhood to attend groups/events.

One group refused to describe their disabilities because they felt so uncomfortable disclosing themselves in such a public fashion. They did agree to state the number of disability categories each woman had. Numbers of disability categories ranged from one to four, with the majority having three types of disabilities.

4.0 WHAT THE WOMEN SAID: Results from the research

4.1 Tobacco

4.11 Does the use of tobacco cause problems for women with disabilities?

The majority of group participants (73%) said yes, tobacco causes problems for women in the communities with which they were most familiar. Two groups were split between yes and no, and another was completely divided between yes, no, not sure and not more so than non-disabled women. One group was unsure and another group said it was a problem only for mental health communities.

4.12 What kinds of problems are caused through using tobacco?

Comments were made like, "For those women with disabilities who have mobility problems it causes further mobility problems such as numbing of the extremities. As well, it causes shortness of breath, smokers hack, incontinence, allergies, bronchitis, cancer, migraines, heart ischemia, miscarriages, poverty, isolation and discrimination."

Financial problems related to tobacco purchasing were noted by a number of women.

One group stated strongly that it is necessary to ensure wheelchair accessible designated smoking areas, especially in restaurants.

Several women spoke of the problem of women with disabilities who are forced to live with second hand smoke if their caregivers smoke. Given a choice between losing services and/or having a partner leave, a woman with disabilities may remain in second hand smoke rather than force a confrontation.

Several Native women mentioned that Tobacco is a Sacred Gift from the Creator and is used in Sacred Ceremonies. When It is used to excess and abused, It loses Its power. One woman said, "We need to get back to respecting Tobacco and the place It traditionally had in our culture."

Several women also spoke of problems in more remote northern communities caused by women using snuff (smokeless tobacco). It damages babies in the womb and nursing infants and causes mouth cancer. The fact that the spitting of tobacco juice is a factor in the spread of tuberculosis and some types of hepatitis was noted as a source of concern.

Several problems specific to women with mental health disabilities were mentioned. One problem was that women take chances with sex in order to get money for cigarettes. Another was the risk of selling or trading medications in order to get money for tobacco. This could cause an increased risk of mental health problems in the person selling, as well as contributing to unknown drug interactions for the purchaser. Several women mentioned an overall pattern on psychiatric wards and in group homes. They found that all they did was smoke, drink coffee and shuffle around. Another woman spoke of the problem of cigarettes being used for self mutilation on psychiatric wards.

One cannot assume that women with disabilities are even moderately well informed about addiction. Women with disabilities may be ill-informed and poverty stricken. They may be suspicious, resistant to information or may have little access to information produced in ways they can understand.

According to one woman, a member of the deaf community, women who have been deaf from birth may have general reading and comprehension skill levels in the grade four to five ranges and their information about addiction is at least 50 years behind the times. A recent article stated that many still believe addiction is a sign of a moral weakness and a disease which can be caught.

Another responded, "I don t believe all those things you hear about. My mother smoked till the day she died (of a stroke) and she never had cancer or emphysema. I think they re all lying to us. Besides I like smoking."

4.13 How does the use of tobacco affect disabilities?

Many of the answers for how the use of tobacco affected disabilities centred around how it created or

worsened disabilities. One participant said, "The use of tobacco makes us sick. It compounds and creates disabilities. It reduces immune levels and affects fatigue levels and makes you feel exhausted most of the time." Another told us, "It alters blood sugar levels. Smoking is the number one killer of women with diabetes. It worsens any disabilities which have restricted breathing and definitely affects allergies."

Others mentioned that if women are dependent on a caregiver to smoke, it increases their level of dependency on that caregiver. There is a chance of setting clothes on fire for those women with very poor physical coordination or who are spastic. One respondent wrote, "Smoking does nerve damage which can affect muscle control."

Women from the mental health communities provided mixed information. Some said the toxins in cigarettes can contribute to mental health disabilities and may even react with some psychiatric medication. Others said that tobacco lets women take a break, calm down and think things through. Some noted that cigarettes were also being used as a reward to control behaviour in psychiatric wards (and in jails).

Some women pointed out that low self esteem was a factor in the smoking of women with disabilities. Others mentioned that smoking seems to relieve stress and anger. 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 commented, "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! My son just suggested I start smoking again. He asked if I knew what I was putting him through! I just wanted to strangle him!"

4.14 Why start using tobacco?

Many answers for why women with disabilities started to smoke were similar to why any young women start to smoke. The two most frequently cited reasons for starting to smoke were their friends smoked (73%) and to be part of the crowd (63%).

Several participants noted the link between low self esteem and self image problems common to women with disabilities and smoking. One focus group member said, "We lose our own self image (through internalizing shame about our disabilities) and want to try to create a new self image. We see magazine images advertising women smoking and want to be more like them."

Some women focused on the role anger plays in why they started smoking. For example, "It is a way of acting out our anger and frustration at our disabilities, at the lack of access, at society s attitudes, at everything."

Still others linked pain reduction with the perceived effect of relaxation from smoking. A few women linked personal and social factors, like bulimia, and mid-life crises with starting smoking.

One woman in a wheelchair mentioned being bored in rehab centres and peer pressure as factors in

starting smoking. She also noted the stress just before or just after diagnosis as factors. Some other comments mentioned were it was something to do and smoking helps to control weight.

4.25 Why do women with disabilities continue to smoke?

The most frequently cited reasons why women continue to smoke were smoking is an addiction (74%), smoking is enjoyable (75%), it relieves stress (51%) and it helps women relax (46%).

The following points were also noted as reasons why women with disabilities continue to smoke:

- it is an avenue for acceptance
- women think they are invulnerable
- it hurts too much to stop
- it numbs feelings of despair
- smoking is mood altering

A number mentioned the factors of isolation and its opposite, socializing, as playing a role in smoking. One said, "You sit at home, always isolated, so why not smoke?" Another participant noted, "You can t get out, so you smoke as a pastime." Still another one voiced, "It s a social thing, to be part of the gang."

One woman noted the connection of smoking to drinking coffee, especially for those in the mental health communities. One focus group noting that smoking gives women time to think said, "Smoking gives us time to think, which is especially important for those disabilities which affect our minds." (eg. brain injuries, learning, developmental and psychiatric disabilities)

One woman stated eloquently, "What other choices do we have? There s no job, nothing to do and no hope for the future. Why should I quit?" Another 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."

Finally, somberly, one woman said, "It s a socially acceptable way to die."

4.16 Why not stop or cut down on the use of tobacco?

Almost all (98%) of the resondents noted that the reason why women with disabilities have not tried to stop or cut down on tobacco was they do not consider it to be a problem. Interestingly, a similar number, 99% of participants, felt that smoking was too hard to quit.

Additional reasons for not stopping or cutting down were:

- women liked smoking
- lack of accessible help
- addiction
- stress
- psychological pressure
- pressure from their daily lives

Another significant point, mentioned particularly in the eastern region, Quebec and in the North, involved the pervasiveness of smoking in these regions. During focus groups, comments were heard such as, "It s not all that terrible and mostly all the women I know smoke." Others said, "It s part of our culture." and "Everybody all around me smokes."

A number of comments were heard about the financial inaccessibility of stop smoking aids that played a factor in why some women with disabilities had never considered stopping. Women knew they needed help since smoking was so addictive but aids like the patch, hypnosis, laser therapy and acupuncture were not covered by Pharmacare, and most stop smoking programs involved at least a bus ride. It may not seem like much, but to women in the lowest income bracket in Canada this can be a significant factor.

Several women also commented about the lack of control in their lives and how smoking gives them control over something, even if it was just the way they died. This was a recurring theme throughout the research. As one woman said, "At least we can control the way we die."

One poignant statement illustrated two recurring themes, the general lack of knowledge of available help , as well as the lack of self esteem among women with disabilities. Addressing both factors is necessary in order for women to even begin the process of cutting down or stopping their use of tobacco. This woman remarked, "If you don t even think about going for help, you won t know about the possibility of trying to stop smoking."

Only one woman felt that smoking really helped disabilities. Lack of child care was not cited as a factor in tobacco cessation\reduction programs.

4.17 What makes them consider stopping?

Almost all (98%) respondents indicated that current health problems were why they considered cutting down or stopping their use of tobacco. The next most frequently cited reason was that smoking was too expensive (38%).

Peer, work or family pressures was also a factor that made women consider stopping their use of tobacco. This answer appeared to be split along cultural and economic lines. Most French and First Nations women noted their family as the main pressure while the remaining respondents noted peer or work pressure as the main factor in why they consider stopping.

Interestingly, the least frequently noted reasons were that women were worried about future health problems, because smoking was an addiction, and that women used smoking cessation programs. Possibly, future health problems seem far off when compared to today s current ones. It is also possible that women only found smoking cessation programs after a current health crisis.

It is also interesting that many women with disabilities cited addiction as the reason they continued to smoke, and noted that it is a factor in why some have never tried to stop or cut down Yet very few women noted it as a reason why they considered stopping. It is obvious that current health problems are more important than addiction and stop smoking programs when considering stopping or cutting back on tobacco.

A number of women with disabilities mentioned stepped up media campaigns as a factor in why some women consider stopping their tobacco use. However, they also said such campaigns would be more effective if they portrayed women with disabilities smoking and attempting to stop.

Solutions proposed by Native women involved the use of life skills groups, and the need to view themselves from a holistic perspective. These women spoke with dignity, clarity and passion of the need for community-based solutions using tradition and culture as a starting point. They stated that finding self worth and self respect is the key to stopping non-cultural tobacco use.

As one First Nations woman put it, "You just have to make a commitment to a healing path. Once you do that, then you can really experience how powerful a circle is. What you give in you get back. You have to look at how you want to change your life. If women see other women doing it, it opens their eyes. This lets them know they can do it too. There s always hope. You have to make that time to start appreciating yourself."

Additional factors that helped women stop smoking were:

- positive affirmations
- the length of time left with children
- saving money
- meditation and prayer
- having a new focus for living
- having a family history of cancer

Finally, one said, "I just wanted to stop hurting myself by my smoking."

4.18 How is their use of tobacco different from non-disabled women?

One respondent touched on a key difference between disabled and non-disabled smokers. It concerned the inability of caregivers to communicate clearly with disabled women and their resulting fear and discomfort. "Women with disabilities like to smoke. We are sometimes given too much leeway and allowed to smoke

in inappropriate places, or given smokes because the caregiver is not able to communicate with us. It s easier to enable our smoking than to breach intimacy barriers and work past their discomfort. This just reinforces our isolation."

Several comments pointed again to the lack of control in their lives. One group member stated, "Many women with disabilities are in denial about their disabilities. They want to believe they have the ability to control their lives. They can t really, but if they blame the smoking, something they can control, they can then maintain their denial about their disability."

Other comments illustrated the high level of tobacco use in the mental health communities. (Another recurring theme) One woman felt that it was even possible that psychiatric drugs increased cravings for nicotine; even if they did not these women certainly smoked more. Another woman said "There are some really big positives about smoking. When stimulation gets too high, I get a break. I also get to meet new people and it forces me to pause."

A few participants mentioned that some women with disabilities would rather smoke than eat or take prescribed medications.

Many participants voiced reasons why women with disabilities may need tobacco. For example, "Disabled women sometimes consider tobacco calming and distracting from pain, so they need to have it." and "We live in a society that is inaccessible. We live in poverty, are abused and are put down almost at a whim. Tobacco is the one thing we can afford that gives us pleasure." Another respondent said, "Disabled women are way more isolated; there are no other distractions. We always have to face our pain and want some comfort."

One woman, noting it was more difficult for women with disabilities to smoke at work, due to patronizing feelings of public censure, heard statements like, "Why are you smoking? Things are bad enough for you. Why are you making them worse? Don t you know smoking is not good for you? "

4.19 What are the important issues regarding tobacco?

Only four out of the twelve groups had something additional to say in response to this question. Two of the four groups commented on the media campaign against tobacco. One group pointed out that stop smoking advertising is geared towards youths and does not really relate to women with disabilities.

Several women commented that government ads in the media tell them about the effects of smoking, yet they do not give out funds to help women with disabilities stop. For example, the patch is not covered nor are there any detoxes for smokers, much less accessible ones. This dilemma creates a great deal of guilt, anger and stress in women, they feel guilty about smoking yet are not able to quit because of the lack of accessible help.

Another point was that current media ads seem to only attack tobacco, and not others like alcohol. Comments

were heard like, "Alcohol is just as dangerous." and "Why not attack air pollution?"

Other important issues for women with regarding smoking are tobacco:

- causes health problems
- causes stress (and also seems to control stress)
- is connected to low self esteem and isolation

A couple of comments addressed the need to look at how information is presented. One group felt that showing videos in health clinics, having smoking workshops that use theatre, and using cartoons and humour was very important. Another felt that information needed to be given in accessible formats, plain language, audio and video tapes with very simple concepts, and perhaps Braille pamphlets or American Sign Language (ASL)/captioned videotapes. The same group also felt that general accessibilty was also a big issue; programs needed to be available, affordable and held in fully accessible buildings.

4.2 Alcohol

4.21 Does the use of alcohol cause problems for women with disabilities?

Almost exclusively, (99%) women with disabilities said yes, alcohol causes problems for their communities. Almost all of the groups, and all but one of the individuals who participated, said alcohol does cause problems for women with disabilities (One group had one member who was unsure).

4.22 What kinds of problems are caused through using alcohol?

There were a wide variety of answers given for this question. A number of women mentioned that the use of alcohol increases shame and isolation and is connected to either the abuse they suffered as children growing up, or the abuse in their lives today.

Types of problems caused by drinking alcohol included:

- low self esteem resulting from losing control
- financial difficulties resulting from using money needed for other purposes like food and rent
- family problems including abuse and relationship breakup
- health problems
- women taking more physical and emotional risks
- legal difficulties including jail
- hopelessness and death

It was also noted that drinking is connected to suicidal feelings. It either causes or masks depression, or

women drink in an effort to self medicate. Women can also stay disoriented and can hide from major feelings like grief and anger.

One woman voiced a note of concern when she described the problem of women going off needed medications in order to drink. This can be a major issue as relatively few women are aware that it often takes more time for the level of medications to decline in their systems. They drink, falsely thinking they are safe from poly-drug interactions.

A number of women spoke about the problems of mixing medications with alcohol. All of them stressed the danger.

4.23 How does drinking affect their disabilities?

Women said that drinking affects their disabilities in a wide variety of ways, some positively and some negatively.

Some of the positive ways mentioned were:

- hearing is better as a result of alcohol induced calm
- small amounts help women with Freidrichs Ataxia walk better
- small amounts reduce spasms for those women who have various spastic muscle diseases and lessen the possibility of falling
- alcohol reduces isolation- drinking helps women with disabilities feel a part of the world
- alcohol helps women with agoraphobia leave their homes
- drinking helps women cope with anxiety, post traumatic stress disorder and abuse related disorders

Negative effects of drinking were alcohol:

- decreases inhibition
- makes women prone to injury
- causes pain and depression
- makes women non-productive
- affects thinking
- women say things which are not meant
- makes women easily lost and confused in crowds
- decreases mobility, self-respect and self-care

Women also noted that alcohol leaves women s bodies slower so it takes less to get drunk; since the liver is forced to deal with alcohol first (a major poison which takes precedence in the body) the effects of normal medications are greater and prolonged.

Quite a few participants mentioned problems with bladder control and that coordination was worsened.

Several mentioned stories of embarrassing accidents. Others noted that poorer self care was certainly connected to drinking. Proper self care is important for all women, but it is vital for women with disabilities, whose health and well being depend on it.

At least one woman with a hearing disability felt that when drinking she needed to concentrate more in order to hear, as opposed to the woman mentioned above who heard better. Several group members remarked that when women drink they experience problems in using ASL due to poor coordination. Women with visual disabilities said their mobility was affected due to their loss of the sense of orientation to space.

One respondent felt drinking could lead to a relapse in mental illness since it changes chemicals in the brain. Another also noted the problems it causes with sugar diabetes (headaches, weight loss etc.).

One group member who had multiple disabilities said, "It makes me very physically vulnerable, so I almost never drink outside of my house. I m afraid I won t make it back.

4.24 Why start drinking?

The reasons most frequently given for starting to drink were it helps women socialize (71%), it helps women be part of the crowd (66%) and their friends drink (55%).

Similar to non-disabled women, participants also said:

- drinking helps women have fun
- drinking seems cool
- advertising promotes alcohol beverages.

Different from non-disabled women, women with disabilities start to drink because drinking:

- passes time for those house-bound
- reduces boredom in rehab
- kills pain
- helps women cope with diagnosis and their disabilities

Several Native participants responded that the physical, mental, sexual and spiritual abuse that occurred during forced attendance at churches and residential schools started many of them drinking.

Two women offered pain-filled statements, "We start to drink to forget we have disabilities." and "We also started to drink to escape the pain in our lives."

4.25 Why do women with disabilities continue to drink?

Similar to tobacco, the most frequent reasons given for continuing to drink were drinking helps them socialize (66%), it is enjoyable (55%) and drinking is an addiction (49%).

Other points mentioned for why women continue to drink alcohol were:

- hopelessness
- drinking relieves stress
- women feel less self critical
- self medication
- gives women something to do
- it relieves isolation and loneliness
- it gives "liquid courage"

One group, in the drinking discussion, echoed a point brought up previously in the tobacco section. These women linked the relative lack of media on the negative effects of alcohol, with women continuing to drink.

Women also said drinking is the only thing they do for themselves. A frequently voiced reason that women continue to drink is to feel like adults. This is an important issue for many women with disabilities, most of whom say they are treated like children. Their need to be treated as adult women will need to be addresed in future programs.

If we compare why women start and continue to drink, their reasons progressed from: starting to drink to be cool and to have fun; to continuing because of addiction, and the relief from hopelessness, stress, isolation and self-criticism obtained. It is evident that many reasons why women continue to drink have serious consequences.

4.26 Why not stop or cut down on drinking?

The most frequently stated reasons for why women do not stop or cut down drinking were lack of accessible help (79%) and language and cultural barriers (53%). Similar to tobacco, women also felt that drinking was not a problem (56%); less thought drinking was too hard to quit (23%).

Comments were heard almost everywhere about the lack of accessible transit.. (Several women stated that BC in general, and Vancouver in particular, were the most accessible place in Canada.) This lack of accessible transportation is linked to confidentiality concerns. The fear word may get out that they have a drinking problem because no other accessible transportation is available except through the disability organization they, their friends or caregivers work for. Others may find out and they may lose services or employment.

Other comments point to the role low self esteem plays in why some women with disabilities have never tried to

cut down or stop drinking. For example, "A source of attention is a source of attention, whether it is a bartender or caregiver." and "In order to stop or cut down you have to meet strangers, I don t think I could do that. Also, it s too scary." Another women said, "Not having somebody to go to support groups with is just too hard with low self esteem."

One woman with a brain injury vehemently commented, "I m angry and I am not able or willing to let go!" She went identified problems of access and lack of information about disability in society as major factors in her anger.

Other points mentioned were that women have not yet hit rock bottom and that support is almost nonexistent when there was a need for high levels of support in order for women with disabilities to stop drinking.

Many participants stated that not only do women start to drink to forget they have disabilities, they also continue to drink, and are reluctant to stop for the same reason. One said, "We drink like crazy to forget we can t walk."

Common elements for why women start and continue drinking and also have difficulty stopping were that drinking:

- helps women socialize
- relieves the effects of disabilities
- relieves boredom
- helps women celebrate\have fun
- relieves isolation
- is socially acceptable
- gives women something to do
- helps women be accepted

4.27 What makes them consider stopping or cutting back on drinking?

As with tobacco, the most frequently cited reason why women consider stopping or cutting back on drinking was current health problems (95%). Unlike tobacco (and other drugs), sixty percent of women responded that being worried about their children being taken away was also a major factor. Not far behind was the suggestion that peer, work, or family pressures made women consider stopping their use of alcohol (55%).

Again, the same as tobacco, reasons of little importance for why women consider stopping were because drinking was an addiction, stop drinking programs and that women were worried about future health problems. Like tobacco, current health problems are more important than future ones.

Many group members noted that a major life threatening crisis is what causes women with disabilities to consider stopping. One woman also noted that an inability to properly use electric wheelchairs when drinking may cause some women to consider stopping their use of alcohol. Another participant voiced that ultimatums and pressure from a partner may be a factor in causing women to consider stopping.

Finally, as one woman noted, knowledge is the key. She said, "Information is power. It is the key that gives women with disabilities more ability to stop."

4.28 What is different about their drinking from non-disabled women?

There were a wide variety of responses that described how the drinking of women with disabilities is different including:

- drinking is even more hidden
- women are are extremely isolated
- drinking complicates disabilities
- health is already poor
- drinking increases health risks
- skin breaks down due to poor self care when women drink excessively
- have problems getting out because of access barriers (barriers include physical, financial, cultural, informational, and attitudinal factors)
- mental capabilities are already affected and even small amounts of alcohol have great effects

Women also noted that they drink because they want relief from the effects of disabilities(especially pain), and that for women with mental health disabilities, drinking can bring on a blackout or psychotic break.

Several women noted the links between greater abuse toward women with disabilities who drink as well as the increased risk of suicide and depression. In a personal moment, one young woman with multiple disabilities shared how, as a child, she had been forced to drink and take drugs before she was sexually abused by her stepfather. This led to a life of drinking and drug use and abusive relationships. Today she is trying to put her life back together, without using alcohol or drugs to deal with the physical, emotional, psychological and spiritual pain. Another woman said, "My mother always hated me because I was not perfect. She let me be abused. I couldn t stand that so I drank to forget."

A point was voiced by a woman in a wheelchair. She noted that if a woman can t use her hands she has to depend on her caregiver, who might tell her it is right or wrong to drink. They may force her to drink or they may drink themselves. Few women will speak out as they are afraid they will lose services or be abused.

One focus group noted that non-disabled women have more avenues available for socialization that don t have to do with drinking, for example, fitness centres, hiking and outdoor recreation clubs, and other sports. They also have more money to go out to theatres, movies, etc. Most women with disabilities don t have those options.

One woman said, "Women in general suffer from discrimination. However, discrimination is much higher for women with disabilities and even higher if you also belong to other marginalized groups. This causes so much pain and anger that we isolate and abuse alcohol."

Passionately, one woman exclaimed, "Our use 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. I m particularly angry because most places aren t accessible for women who are brain and/or spinal cord injured, especially residential treatment and after-care programs."

4.29 What are the important issues regarding alcohol?

Two women voiced what (or them) are the obviously key issues of self esteem and anger. As one woman put it, "We drink to forget. We have little self respect and self esteem and lots of anger over how society treats us." Another continues, "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."

Other important issues mentioned were:

- health risks of alcohol unclear
- easily available and accessible transportation and services
- the need to socialize and end feelings of isolation- protecting and enhancing women s health
- work, family and peer relationships
- the stigma attached to alcoholism and the fear of being seen as not dependable
- the potential loss of jobs, children and needed services is directly related to seeking help
- doctors and family members enable women to drink.

Drinking by pregnant women with disabilities was an issue of concern, as well as the level of mothering skills of drinkers. Several First Nations women voiced their concern about women with Fetal Alcohol Syndrome or Fetal Alcohol Effect (FAS/FAE) drinking and getting pregnant. Their experience had been that it was very difficult to convey to these women that drinking may be a problem. One woman shook her head as she described an encounter she had while trying to convince a young woman with FAS to stop drinking. The young woman explained that her mother drank, that there was nothing wrong with her, so why should she stop drinking.

The help of somebody who has been there and knowing that we are not alone with these issues, were also voiced as being important. One woman with disabilities said, "It s important that women with disabilities know they are not alone with their problems. That they learn from their peers that the behaviour of excessive drinking is not OK but the person is OK!"

4.3 Other Drugs

4.31 Does the use of medications cause problems?

Similar to alcohol, almost all participants (96%) felt the use of prescription drugs causes problems for women

with disabilities. Unlike other substances, just over half (54%) felt the use of over-the-counter medications causes problems.

4.32 The use/misuse of medications prescribed for others

The majority said medications are sometimes shared. Many said that medications were shared regularly.

The four medications most frequently shared were pain medications, sleeping medications, cough medicines and anxiety medications. Others mentioned were anti-psychotics, antibiotics, muscle relaxants and ulcer medications.

Reasons cited for sharing medications were:

- financial reasons (drugs are too costly)
- convenience (it s available and hassle-free)
- friendship (the other person thinks they are being friendly or helpful when the asker s medication has run out)
- bartering prescriptions for tobacco, attendant care, companionship
- lack of awareness (women may not be aware of how to manage medications
- addiction (having someone to get high with)
- physician control of medication (physicians may be uninformed and insensitive about disabilities, so women have difficulty in obtaining needed medication and therefore share)

A point of concern noted by some participants was that they do not go or are not able to get to physicians. 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, there is little information about the effects of drugs so women assume the drugs are safe and nonaddictive."

In the Eastern and Northern regions and in Quebec, women sharing in general is part of their culture. Sharing was also related to the availability of doctors and medications in small communities. Women told us that sometimes they shared medications because the doctor does not make it in or comes infrequently, and it is just too far to travel elsewhere.

A number of women commented on the different levels of available health care, particularly prescription drug coverage. The 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 attendance at treatment programs, costs of which are often tied to a certain level of health care. Disabled women working at low paying jobs may not have coverage to attend.

4.34 Why start taking prescription medications?

Most women answered that the onset and/or worsening of disabilities was why medications were prescribed for them. A number of women noted coping with stress and various life problems as reasons they started taking prescribed drugs. Several mentioned that women became aware of the mood altering affects of some drugs by associating with women who used their medications to get "high."

A couple of women noted that their parents first gave them prescription drugs. One respondent said, "Women start taking prescription drugs because they are easy to get and besides they are free." Others mentioned that doctors encouraged them to take prescription drugs. It seemed to make the doctor feel better to actually be doing something for these patients.

4.35 Is addiction to medications a problem?

All participants agreed that addiction to physician prescribed drugs is a problem in their communities. Women had differing opinions on the magnitude of the problem, but the majority felt it was a major concern.

Over-the-counter medications were seen to be less of a problem than tobacco, alcohol, and prescription drugs. One woman commented, "On Pharmacare, why do over-the-counter drugs?" However, regarding over-the-counter medications, just over fifty percent felt that women are addicted.

4.36 What problems are caused through using prescription drugs?

Addiction and overmedication were most frequently mentioned. On the subject of overmedication, one woman said, "I have to take so many medications I feel like a zombie. I bounce off walls and I risk being addicted."

Regarding addiction, one woman spoke up saying, "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 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!"

In addition, women noted drugs often were not effective. As one woman put it, "Pain relief is not well looked at. The drugs are very addictive and don t really do the job. They just wear you out and are filled with chemicals. It ends up that you are no longer just taking drugs for pain but now for addiction."

Several women also mentioned dependency as a problem caused by the use of prescription drugs. For example, "Women with disabilities are forced to remain dependent on a system which sees women as weak and helpless and not to be taken seriously!" and "The whole medical community is based on dependency! Medicine is a business, focused on pharmaceutical companies not on individuals."

Another woman told an alarming story of being slipped a sleeping pill so her caregiver could use drugs while she was sleeping. She was dependent on her caregiver for help and was unable to resist.

A number of women mentioned the power physicians have in their lives as a problem. Several told stories of being forced to take prescription drugs for their own good. One woman told us, "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!"

Another matter of concern expressed in the North was some First Nations women (and men) feel they have a right to take prescription drugs to hide the pain caused by abuse they suffered at residential schools and through the church, as well as today s racism and oppression. Men are now getting women in their lives to go to health clinics and get prescriptions for them, sometimes by force.

Other problems cited related to using medications were:

- physical, mental, familial, financial and work related problems
- brain damage and other health related problems
- difficulty coping with feelings
- depression and loss of motivation
- drowsiness or hyperactivity
- unwanted, painful, unusual or irreversible side effects, like Tardive Dyskinesia which is caused by long term use of major tranquilizers
- overdosing and suicides
- possible drug interactions with other prescribed medications
- the risk of physical danger caused by stupor-inducing medications
- medications may hide changing or worsening effects of disability or other health problems

Speaking about self-prescribing and over-the-counter medications one woman explained, "Women with disabilities are then self-prescribing often without full information of the effects of these over-the-counter drugs and how they combine with others." Another quipped, "If they re over-the-counter, how strong can they really be? There s a little doctor in all of us!"

Finally, one woman succinctly noted, "Overprescribing (or overusage) of medications decreases the quality of life, making us unable to live up to our full potential."

4.37 What problems do multiple prescriptions cause?

The most frequently cited problems caused by multiple medications were deliberate and non-deliberate

over-medicating. The risk of drug interactions, including overdosing, confusion, inabilty to concentrate or make decisions and inability to function were mentioned by many participants.

Loneliness, shame and isolation were noted by some. Regarding forgetfulness, one woman said, "Forgetfulness and memory loss are big problems. Because women forget what they ve taken, this causes serious problems in the management of their prescription medications."

Also mentioned were financial problems related to increased health costs as well as legal problems if women are caught "doctor hopping." Still another noted, "overmedication cocktails" cause women to be more dependent on service providers. Several women told us that, in general, physicians lacked a global view and followed up inadequately.

One participant addressed the problem of senior women. She said she had heard that the majority of geriatric psychiatric admissions to hospitals were the result of overmedicating. She went on to relate that she had discussed this with a health care professional responsible for overseeing a large care facility. She had told her that more than 90% of admissions to that care facility were the result of substance abuse due to mismanagement and mixing of medications.

4.38 Does the use of other substances like pot, glue, gasoline, heroin, cocaine etc. cause problems for women with disabilities?

Compared to previous mentioned substances, responses to whether other substances like pot, gasoline, heroin etc. causes problems were completely mixed. The women named pot, cocaine, heroin (and in some places, solvents) as the problem drugs.

As could be expected, most participants in the largest centres were confident other substance useage causes big problems. Interestingly, the respondents in one of the smallest communities also felt these other substances cause big problems. Others were unsure (23%) or felt these substances probably cause problems (31%). A few (2%) felt the use of these other substances did not cause problems.

There is neither a clear cultural nor geographic pattern for the five focus groups which were split. The Quebec groups were the most split (possibly cultural). This is not necessarily true for the other three groups, Newfoundland, Manitoba, and Alberta. Each group had at least one participant who also happened to be a service provider in the addiction field. Work experience let them know these other substances were a big problem, others did not agree.

The women in the smaller communities tended to say their use probably caused problems. They indicated that the use of these other drugs probably was happening but was extremely hidden. One anomaly was the previously mentioned group in a small remote northern community, the participants said pot was a big problem.

One unsure participant noted, "People don t need to take these other substances because we already take so many drugs. And Medicare covers our pills, we would have to buy solvents or other drugs, so why would we buy them."

Several French women expressed strongly, "This is such a huge taboo. It is not even talked about."

One woman related a story of a newspaper article that described women in wheelchairs selling their bodies to pay for drugs. Another stated that the use of these other drugs was a much larger problem than anyone realizes. She said the majority of addicts she knows used drugs as a result of trying to self medicate psychological and physical problems, like depression and migraines. This was echoed by another woman, who told us the only time she had felt normal was on speed.

4.39 What problems are caused through using these other substances?

The range of problems is similar to problems mentioned for alcohol and prescription medications. Major differences seemed to be the increased level of isolation, shame and rejection and the greater physical and legal risks due to the hidden and "illegal" nature of these substances.

Women also noted that other substance useage caused health problems and increased mental health problems including hallucinations and depression.

The women in one focus group put it starkly, "Many of these drugs are illegal and result in criminal records and/or jail terms. Because these drugs are not prescribed, they are more expensive. They are difficult to get and women with disabilities must use dangerous methods to get them. There are big risks and dangers. Women are more vulnerable to violence, stay in relationships and put up with violence because they are getting the drugs they need."

4.310 How does using other substances affect disabilities?

Comments were split along positive and negative lines. Negative statements included their use complicates or makes disabilities worse. Other comments centred around the mental health effects caused through using drugs. Women told us that these drugs are mind altering and may cause women to be violent and paranoid. They also said using drugs negatively affects behaviour; women are not sensible and are more apt to be short tempered. They noted their use affects mental health stability. At first women are hyperactive and temperamental, then they crash, similar to manic depression.

One woman explained a problem relevant to dually diagnosed women. "With dual diagnosis (having both mental health and substance misuse diagnosis), ostracization from both the disability and recovery communities compounds the issues. Nobody wants you and you just can t get help. It s a deadly combination."

Some of the more positive comments regarding the use of other drugs included that their use eases the pain of glaucoma, reduces spasms, helps women sleep, takes away the pain of migraines and can level depression. The use of these other substances helps to relieve stress and anger and reduces the nausea from cancer and AIDS medications.

The use of other substances, like heroin, is more effective for very intense pain and enables women to move in the mornings. These drugs also help women with disabilities take a much needed break from the world.

One woman put it simply, "Sometimes it seems that these substances work better than prescription drugs so, at least for some period of time, life seems improved - BUT - the detoxification is awful. Eventually they just stop working."

The final significant comment was, "Pot in particular helps with anger and stress, but you feel less motivated to do anything. You just feel mellow. I think that s why it s condoned by society. They (the government/patriarchy) want to keep us mellow rather than actively fighting for change. Angry thinking women sure have a better chance to create change, than drugged out mellow ones. That goes for prescription drugs too!"

4.311 Why did women start using drugs?

Unlike tobacco and alcohol, the most frequently cited reason why women start to use all other drugs was their doctor prescribed them (71%). Similar to tobacco and alcohol, the next two most frequently cited reasons were their friends/spouse used drugs (60%) and to be part of the crowd (60%).

Women also told us that they could not see any other option so they started using drugs. They also noted that the relief of physical and emotional pain, dealing with social isolation and anger are major factors. Others said drugs are used as a coping mechanism and women want to find something that really helps their disabilities. Several mentioned marital problems.

4.312 Why do women with disabilities continue to use drugs?

The most frequently voiced reason why women with disabilities continue to use drugs was drugs relieve stress (65%). Unlike either tobacco or alcohol, the next most frequently cited reason was drugs help numb feelings (64%). Also unlike alcohol and tobacco, the next most frequent cited reasons were drugs relieve spasms, pain and depression (50%). Similar to alcohol and slightly less than tobacco, fifty percent of respondents felt addiction causes women to continue using these other substances.

As well, women with disabilities told us they continued to use drugs because these other drugs work, they relieved anger and because their use is controlled by the women.

4.313 Why not try to stop or cut down?

Similar to alcohol, the most frequently noted reason why women with disabilities have never tried to stop or cut back using drugs was the lack of accessible help (76%). Unlike alcohol or tobacco, this was followed fairly closely by these other substances really help their disabilities (64%). Much less than tobacco, relatively few participants noted that drugs are too hard to quit (39%) and that women do not consider their drug use to be a problem (36%).

A number of participants spoke about the difficulty of getting help. They said that most recovery and treatment programs are inaccessible and the disability services they use do not know anything about addiction. It s a catch-22! One woman expressed with cynical bitterness, "Why bother!" Of importance women mentioned they are afraid that needed drugs will be taken away.

Another recurring issue throughout the document was that substances helped women cope with or numb feelings, especially regarding abuse.

Relatively few women felt lack of access to child care was an issue in their considering stopping their use of tobacco, alcohol or other drugs. Possibly this may be the result of lack of awareness or that few women with disabilties with children 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.

4.417 What makes women consider cessation or reduction?

Like tobacco and alcohol, the most frequently cited reason why women consider stopping or cutting back was current health problems (76%). The two second most frequently noted points were peer, work or family presures (53%) and drug related legal problems (41%). Paralleling answers given for tobacco and alcohol, the least frequently noted answers were programs to stop using drugs, worrying about future health problems and because drugs are an addiction.

Additional points for what makes women consider stopping or cutting back were reaching a crisis and self esteem and life skills courses. Participants said that the use of more innovative media techniques like accessible pamphlets in doctor s offices, cartoons and theatre might be effective.

Women also told us that support groups and counselling for other issues, deciding to do things for them, wanting more out of life, and the guidance of a spiritual teacher or someone they respect were major reasons why they consider trying to stop. First Nations women suggested having education programs on substance misuse at school for kids, who go home and talk about it to their moms, and videos being shown in waiting rooms of health clinics.

4.315 How is their drug use different from non-disabled women?

Women need to take medications to deal with their disabilities BUT still get addicted. Women with disabilities, for the most part, have easy access to prescription drugs. Women already have major health issues; using drugs just complicates their disabilities and health.

Friends, family and professionals enable the use of prescription drugs and even some other drugs like marijuana. Others think women should not use any substances and try to shame them into stopping. When, and if, women want to find help it is extremely hard to find, or it is totally inaccessible.

Some women, noting that marijuana in particular helped their disability, said, "Pot is a significant anti-spasmodic. It is more effective than alcohol because it allows you to retain control more easily and you don t have to pee like you do on alcohol. For myalgic muscle pain a couple of puffs will work."

One group spoke about some of the different stress factors related to substance misuse for women with disabilities. They told us, "We have little money, we are among the poorest people in the country. Society is not accessible, we have high levels of stress and oppression AND we have to take drugs. We <u>are</u> worried about addiction. We want relief of pain yet are vulnerable to addiction. Because we are women, we are subject to the same oppressions as non-disabled women and also to the same lack of services. There are <u>a few</u> women s treatment centres but are there <u>any</u> women only detoxes? Most treatment and recovery programs are set up to help white able-bodied men. Let s face it, we don t fit on two counts, and some don t fit on all three counts. Makes it pretty hard to find help, don t you think?"

4.316 What are the important issues regarding drugs?

Women told us these issues were important to them:

- doctors lack full knowledge of medications and\or do not inform about their interactions, side effects and addiction potential
- there is a medical gender bias (doctors are much more willing to prescribe to women)
- prescription drugs are socially acceptable, especially in disability circles
- women want pain relief without addiction and risk
- addiction does concern them (even though using drugs helped women cope with the effects of their disabilities)
- that they have control over what drugs they take (this excludes prescription drugs which are under a physician s control)
- the lack of accessible programs and buildings.

A concern particularly related to residential addiction programs was they do not accommodate disabilities, especially if women need attendants, are in wheelchairs or have cognitive, visual or hearing impairments, or spinal cord injuries.

Finally, describing an important issue somewhat tongue-in-cheek, one woman quipped, "Whether your dealer

will deliver to the door!" She went on to note, "With regards to getting off drugs - it s just harder - more difficult - to get off drugs. You have to admit to a problem and we already have enough of them!"

4.317 What substitutes are used if the drugs wanted are unatainable?

Women s responses could be separated into two streams of thought, those describing more positive alternatives, and those describing negative. Some of the more positive were:

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

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

Some of the negative were:

- isolating
- eating disorders
- hurting our selves
- gambling
- bingo (excessive)
- stealing
- becoming depressed
- excessive sleeping
- becoming sex and relationship addicts - prostitution

One woman spoke of her belief that she creates a psychotic break when she gets too stressed, can t deal with her life, and is unwilling to rely on psychiatric medication. Another stated that she will purposely have a breakdown in order to be hospitalized and get some drugs.

It was noted that most positive alternatives cost money and negative ones were detrimental to health. As one participant put it, "We don t become participating members of society. We have to turn down opportunities because we can t guarantee to be responsible."

One woman said, "We use whatever we can get - not always what we prefer. It s easy to get alcohol delivered if we have money. Or we lie to doctors saying we dropped our prescription in the toilet or elsewhere to get more prescription drugs. Not really that much different from my friends without disabilities!" Others noted different kinds of drugs such as pills, alcohol, tobacco, pot, caffeine and prescription drugs. It seems evident that some women with disabilities lack knowledge as to what drugs are and that the use of the term "drugs" was unclear in this context.

4.318 What substance causes the most problems?

All participants in the focus groups initially said that tobacco was the substance used most frequently. Upon closer examination of what the question was really asking (which substances actually caused the most problems) opinions were divided. Since the groups were clearly not unanimous on this issue, each participant was asked to rank the top three (not all of the women complied, and the women who mailed in answers did not rank their choices because those instructions were only given verbally during focus groups). Accordingly, the substances were ranked solely by their top choice.

The substance which causes the most problems for women with disabilities is alcohol (44%). Prescription medications are next (30%), and then tobacco (13%), followed closely by illegal drugs (12%).

Three percent of participants ranked caffeine as their number one choice for the substance causing the most problems. This is somewhat surprising and caffeine addiction may be something to address in the

future. Those women who mentioned caffeine were either women in wheelchirs or women with a mental disability.

Household products were ranked by a few as their second or third choice. Solvent/inhalants were only noted by two women (from the N.W.T.) However, a Native woman with disabilities, (who was a service provider) shared some information about the use of solvents. She said that during some recent field research in Labrador for a tobacco project with which she was involved, the use of solvents was identified as a major problem in the First Nations communities visited.

4.4 Life Situation

4.41 Discrimination

Of the ten groups that discussed whether discrimination in the lives of women with disabilities affected their use of substances, participants in seven stated that discrimination did affect women s use of substances. The remaining three groups were unsure. Of the individual respondents, the majority noted that discrimination did affect the use of substances. Interestingly, one participant noted no for tobacco, yes for alcohol and not sure for other drugs. (Not all focus groups answered this section due to insufficient time available to complete the format)

Points raised linking the use of substances to discrimination were to cope with:

- painful feelings
- life problems
- increased feelings of stress and isolation
- societal pressure
- anger over treatment in society
- not fitting in
- feelings of being unwelcome, unwanted and in danger
- and to rebel

A participant expressing some very strong views said, "The patriarchy is misogynistic and one of its (hidden) goals is to perpetuate the oppression of women. They really want to maintain the status quo. Of course, status quo means true power is held in the hands of white, able-bodied men at the peak of their earning power. They don t want to have to share the power and wealth in order to change things. The farther you are from this "ideal", the more different you are and the more oppressed you are, the less able you are to affect real change. All of this creates incredible stress, anger and frustration. It s no wonder we want to escape."

One group that was unsure whether life discrimination affected their use of substances was clear, however, that discrimination due to being women with disabilities did affect their use of substances. They thought it unlikely though, that other forms of discrimination (due to sexual orientation, race, religion etc.) also affected the use of substances by women with disabilities.

Another noted, "It s like saying, I m black and crippled so I might as well drink! It s more likely that women will drink if they are doubly disadvantaged."

A First Nations woman said, "Of course discrimination and prejudice affect our use of substances! Why do you think so many of us drink and do drugs. To escape, to forget that we were once proud and mighty. We were respected, we had our own lands, our own languages and our own cultures. We took care of each other, supported ourselves and our communities. Now all that is gone. We ve been abused and taken advantage of and our broken spirits and broken bodies have been reduced to spirit dreams in a bottle. I give Thanks to the Creator that it is finally starting to change. We are gaining back our respect and our power and taking our rightful place as a part of Creation."

4.42 History of abuse/violence

Participants in nine out of ten focus groups emphatically said that their histories of abuse and violence do affect their use of substances. The remaining group was not sure, but felt that probably violence did affect them. Most of the individual respondents said that the use of substances was affected by abuse and violence.

Some reasons why abused women with disabilities use substances were to forget about their problems, to maintain denial and because it is a learned behaviour to cope with abuse. Women also told us they used drugs because of pressure from their abusers and because of rebellion. Many women said they wanted to kill the pain, escape or numb out. As one woman put it, "When I m loaded I don t really care (as much) when I am being hurt." Another stated, "It s the only way I can cope with the pain of my childhood."

4.43 Other factors contributing to substance use

Factors such as stress caused by relationships breaking up, stress and anger caused by the worsening of disability and pressures caused by societal expectations of women were noted. Women described the stress caused by families trying to define their roles and the distress and anguish caused by seeing their significant others abused as contributing factors.

Women also mentioned factors such as poverty, lack of employment, lack of interests, being homebound and lack of things to do. They spoke of cultural and language barriers, childhood issues, anger, anxiety, stress and negative peer role models as factors contributing to substance use.

One group member told us, "Self esteem is the big issue. If women with disabilities don t value themselves they won t even consider stopping much less attempt to stop."

The influence of partners was noted by one woman, "We often do what our partners do, as we are so afraid that we will lose them and we already have a couple of strikes against us."

One woman identified an issue unique to the North regarding smoking and the weather. She spoke about the extremely long bitter winters and the need to always keep doors and windows closed for months on end. Houses tend to be small, well insulated and filled with people, because it gets so cold, everything is done inside and people have to smoke indoors. This ensures enormously high levels of residual and second hand smoke affecting everyone who lives there, for long periods of time. During the winter, increasing levels of stress develop, there is nothing to do, frustration and anger rises, as does the use of substances, particularly alcohol. Violence toward women also skyrockets.

Women in BC also identified climate as a factor in the use of substances. One said, "Climate is definitely a factor here in Vancouver. When it s rainy, and there s grey skies all the time, my body doesn t want to work right so I need to take pain relievers. It s harder to get up and to get around. I also feel depressed and lacking in energy. I need to take more substances in the rainy season."

4.44 Poverty

Nearly all respondents agreed that poverty is a barrier to getting help in reducing or stopping the use of substances.

One woman exclaimed, "Absolutely! Poverty is a barrier, for transportation and in order to get 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 said, "Poverty is a barrier to getting help, but not to getting addicted. Women make sure to budget to be able to buy alcohol and just eat less. If there were affordable, free alternatives [for getting help] in place, poverty wouldn t be an issue!"

Still another said, "Private counselling costs mega dollars, or if they re 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 vans and if there is an accessible van service you sometimes 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 only follow a preset route."

One woman pointed out that detoxification centres and treatment programs need to either have an accessible van or be willing to fund the fare for an accessible cab. Another noted that Social Services is unwilling to look at any self help or non-medical alternatives which usually cost money to access\attend.

Finally, one member commented with weary bitteress, "When you ve been abused and hurt all your life, you re dirt poor, society s not accessible, and there is no hope for the future, why begrudge yourself the only pleasure left!"

4.5 Getting Help

4.51 Defining substance use/misuse for women with disabilities

There were a wide variety of behaviours that help define substance use/misuse for women with disabilities suggested during the research. Women noted answers such as:

- getting too physically or psychologically dependant on substances
- not taking medications as they are intended
- when using interferes with daily functioning
- not being able to control the amount of substances used
- using substances to the extent that they cause related legal and health problems
- panicking when you run out because you need to have that drug
- using only to escape the pain or for despair

Women also suggested that drinking alone, overdosing, having blackouts, having mood swings, constant using and being unable to stop as behaviours that identified substance misuse. One respondent suggested that substance misuse was continuing to take substances, even when you clearly know they re hurting you, without trying to find alternatives.

A number of participants noted how hard it is for women with disabilities to tell if there is a substance misuse problem. One said, "Substance misuse is when using drugs starts impacting on all of your life. For some women it may be hard to tell if they don t have a large outside life. It s particularly hard to tell with prescription drugs." Another spoke up saying, "Substance misuse is using substances beyond when they re needed. We can cross the misuse line so much faster than non-disabled women because we have to use so much medication." Still another noted, "It s so hard to tell when we are misusing substances. Most of us have to take drugs. It s such a fine line I don t really know."

Women had opposing views on whether it should be professionals or themselves who decide whether substance use is a problem. One mentioned, "We need to have professional consultation." Another voiced, "Substance misuse is when the doctor suggests you cut down and you don t want to. Sometimes though, the doctor may decide that it s too much, but they don t really know. Perhaps pharmacists know better?" Another group member quickly exclaimed, "Only we really know if it s a problem or not!"

Along the same lines, a respondent from a different group stated, "What is appropriate use and misuse will vary a lot, it s very individual and personal." Still another woman, expressed, "But what about the problem of denial. Usually addiction is characterized by denial. We re not able to really tell if we re in trouble or not. Somehow we need help from an outside source to really tell if we are in trouble or not."

An additional point of view was, "Addiction causes mood altering behaviours that are life damaging.

Substance misuse is compulsive using, when all you can think about is when you can have that next cigarette, or that next pill or drink. How can you get something that will take you out of your pain, your feelings, the hopelessness of your life. It lessens your overall quality of life."

The key factors that define substance misuse are:

1. not taking substances as they are intended,
2. when the use of substances seriously impairs women s ability to function
3. when the use causes definite related legal and health problems.

4.52 What programs are currently existing aimed at stopping or reducing women with disabilities use of substances?

No participants were aware of any specific programs for women with disabilities. Most women were also unaware of which programs overall are currently accessible. In addition, many were unaware of whether there were any programs specifically restricted to women and some were not aware of any stopping programs. It was very clear that this type of information is not well known in disability communities.

The women were almost completely unaware of any alternate print programs\resource manuals that offered help or were accessible for women who had visual or hearing disabilities. Only one woman was aware of any programs for women who were cognitively/developmentally disabled or who had spinal cord injuries. No one knew of any programs\resource manuals that were available for women who had moderate to severe brain injuries or who had severe psychiatric disabilities. No one talked about access for women who had HIV/AIDS.

Women were aware of Alcohol and Drug Programs, laser therapy, hypnosis, women s spirituality groups, healing circles, life skills, wilderness programs, Y.W.C.A., Women in Recovery, Women For Sobriety, Elizabeth Fry, stop smoking programs at the Seventh Day Adventist Church, Pentecostal Church and stop smoking programs, like Break Free, at provincial lung and cancer organizations. Some women mentioned AA/NA and other twelve-step groups. They explained that many meetings are held in inaccessible church basements and there are few women-only meetings. Several were aware that AA/NA had information in accessible media (large print, audiotapes, Braille).

Relatively few participants knew about treatment options although in each group at least one woman was aware of several possibilities. Participants were most aware of accessible co-ed treatment programs in hospitals. Alberta, British Columbia and Ontario also had accessible residential women s programs. Manitoba had a residential women s program, the access was unknown. However, in Quebec, the Eastern and Northern Regions there were no known treatment programs solely for women, although each Region had at least one accessible co-ed program.

Several women described unsuccessful attempts to access residential women s programs. Some women

were turned away due to their particular disabilities, others because the treatment program was totally inaccessible. Others said they would only attend women s programs due to their abuse issues and accessible women s programs were in short supply. Still others spoke about the problem mentioned earlier in this document of anonymous accessible transportation.

During the research, an information specialist at the Canadian Centre for Substance Abuse compiled a list of 352 services that accepted women and offered some type of services to persons with disabilities. This list was compiled from their full Treatment Services Database, which contains over 1,000 entries. It should be noted that the accessibility of these 352 services was self-reported and their actual accessibility may be in doubt since women with disabilities often report discrepancies between self-reported and actual accessibility.

4.53 Are we using currently existing programs? If not, why not?

The majority of women in the focus groups answered that women with disabilities are not using existing services. Many participants also answered that some women are using services.

The prime reason given for why existing services programs and places are not being used by women with disabilities is inaccessibility. Risking confidentiality, one participant told us, "I did try to get help. With my abuse issues, I only wanted to go to a women s treatment 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!"

Poor and unwelcoming attitudes of service providers were named as another primary contributing factor for 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!"

Women also told us that a major factor is not knowing where to go or who to phone for help. The level of access of helping services is also not well known. One participant told us, "Toronto traditionally has had the place of being overserviced. There are so many services that how would you know which services were accessible. Information like that is usually by word-of-mouth. You don t know until you ve been there, how accessible the service actually is."

Other reasons given were service providers lacked knowledge and staff were not trained in the needs of women with disabilities. Women said service providers often focused on the disability, not the addiction, and often enabled their using by saying women with disabilities have a right to use drugs because their lives are so bad. Women also told us information about the accessibility improvements of previously inaccessible services is not being transmitted to the disability community, and many places do not take self referrals.

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."

Most programs are not equipped to help them. Information about accessible programs does not always reach the women who require these services. Women do not want to see themselves as being addicts and are afraid it will affect their services if they admit to addiction problems.

4.54 What would make existing programs work?

The sensitization of services providers, addressing the very low self esteem of women with disabilities, full accessibility of programs, and easily available and accessible transportation, were the four most frequently cited improvements needed to make existing programs work.

Many women voiced their need for women-only services. Women wanted to go to women-only services because many have experienced past abuse. They were also afraid of being in the room with an abuser and of the real potential for abuse at co-ed facilities. One woman described a situation where a woman she knew had been put in the same treatment program as her abuser.

Speaking about the value of groups being led by women with disabilities who had been there, 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 and educated about this issue and we need to work towards mainstreaming women into existing services."

Others identified points from the perspective of services. Participants stated that workers need to first understand how women live and must recognize first they are WOMEN then they have disabilities. Service providers need to be encouraged to be supportive of self help/peer support programs, workers must be educated about our need to take certain medications and services also need to have access to qualified interpreters. Helping programs need to make allowances for attendants and personal care time for women when necessary.

One focus group member told us, "One problem is that disability organizations are scattered. Some are jealous and won t share clients. In making programs work for women with disabilities the key is to be aware of the choices you have. Service providers need to be aware of this. Things can get to a point when traditional services and self help are at odds. Traditionally, service providers have the power, yet are envious of the kind of perspective that self help/peer support bring. We need to somehow bridge this gap."

One woman identified the need for consistently offering informational programs, such as videos or plays, in order to effect lasting change, as well as the value of using culturally appropriate tools.

Another woman, who was also a service provider, spoke of the need to develop methods appropriate to the community. She stated, "In the north, mostly we talk one to one and have home visits. That way, what you say can be made to fit each person. You can talk very simply or speak very loudly and there is always someone around to help. It s also better when I can speak my own language [Slavey] and can be helped in my own culture. And if I can t help them I ask around, somebody will know who can help."

4.55 Are integrated programs needed or programs that are specifically for women with disabilities?

Almost all respondents said that both integrated programs (programs for women with and without disabilities) and tailored programs (programs specifically for women who have disabilities), were necessary in order for them to find help stopping or reducing their use of substances.

Most, but not all participants said that women-only programs were important. They also said that it was more important to attend women-only services rather than attending co-ed services for people with disabilities, although one northern group did not agree. One respondent noted, "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 programs, it s also important to discuss issues with women with disabilities as their own group."

The two Quebec groups said that it really depends on the person, personal rights are important, so both types of programs are needed. One voiced, "Drugs are a consequence, we need to get at the root!"

4.56 What works best when trying to quit?

The most frequently cited method for what works best in trying to quit was going cold turkey This was followed by getting the help of a peer and then going to a twelve step program or other support group. Close behind were going to a detoxification centre and getting help from your family.

Some other quitting suggestions were that women were helped by using services at university, by experiencing definite consequences from the use of substances and by the death of a close friend from using substances. Women also told us hypnosis, laser therapy, prayer, education and the recent media campaigns helped them quit, as well as others previously mentioned.

The most important suggestion was that women have to really want to quit and they have to value themselves enough to do it.

4.57 What major issues prevent them from getting help?

Most of the points have been noted elsewhere. The most frequently cited barrier to women receiving help for reducing or stopping their substance use was a lack of self esteem. A number of other points

mentioned included the:

- lack of accessible services
- lack of accessible transportation
- overwhelming effects of poverty
- lack of women-specific programs
- women s lack of education regarding addiction including the lack of knowledge about where help can be found
- inability of women to recognize that substance use is a problem
- stigma associated with being seen as an addict

Respondents also noted that women have difficulty asking for help, they lack support from significant others. They also fear their disability will get worse and they will then need increased medications which would be denied to them. Other internal factors that prevent women from getting help were lack of self acceptance, high level of depression and their denial. As well, a fear of the effort that is needed to actually stop using substances, a sense of powerlessness and hopelessness and a fear of rejection or failure are also significant barriers to receiving help.

Women told us that their lack of anonymity and the judgemental attitudes in the disability community are also major barriers.

Women said that group leaders\intake workers sometimes 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 group. Unfortunately, since 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.

Women want anonymity and are not convinced services (or other attendees) provide it. One women said, "They fear that someone will report them to Social Services or the doctor that they are going to AA and their services will be lost. This is what stops women from getting help."

One woman identified another problem of services being too close to home in small communities. "There s a real problem with going to services so close to home in a small community (a culturally appropriate wheelchair accessible treatment centre is on the same reserve but it does not have any women s only programming). It s better where people don t know me. I do try to setup an aftercare program but it often doesn t work here. It may be better to have out-of-towners." A point echoed by others throughout the North.

One participant said, "Self-help and Twelve-Step groups are often in inaccessible places. For most treatment programs you have to be completely chemically free and there are no private rooms or time for care." Another participant noted a big problem, "Disability groups often use food and alcohol/drugs in order to bond and socialize."

One respondent, describing a problem in the mental health community, voiced, "When women are poor they need to resort to being automatically seen as a psychiatric patient in order to be covered when getting help. Not all women are willing to do this. This is a very strong medical model, as opposed to what we believe is necessary, a more holistic model." At the other end of the scale, another respondent spoke up saying, "Women with disabilities are reluctant to identify as addicts. We are already seen as dependent and don t want to also admit to dependency on drugs. There s also a fear of needed medications being taken away."

One northern First Nations woman with a disability, who also is a service provider addressed the issue of fear and the need for women s only programs. She said "A lot of women need to go to treatment but are really afraid. If I want to refer them I have to really make sure they know what they are getting into and what to expect. Women would rather go into a women s only program because most of them have been abused. Before they could go to a women s-only program at Action North at High Level, Alberta, but the [N.W.T.] government passed a close to home policy. They won t let them go to Action North any more, and in the Territories there are no women s-only treatment programs"

Other problems, from a Northern rural perspective were:

- small, relatively unknown population
- general lack of services
- high numbers of First Nations
- overall lack of accessibility
- there are nine different official languages
- numerous tiny rural communities, enormous distances apart

There was great flexibility shown working around these issues and accommodating the effects of disabilities. One woman told it eloquently by saying, "Well, since everyone knows Agnes is in a wheelchair and can t get about too well, someone will come and get her every day. When she needs to go up the steps, someone will carry her and the wheelchair. We all know that Uncle Joe can t hear too well so one of his nieces will make sure he understands what people are saying to him. We all know that since Gramma Bee can t read and can t see too well we need to walk with her and read for her. I guess what I m trying to say is, there is more willingness to find community answers and to work around problems up here. We all try to help each other out. In the North you have to, you won t survive if you don t."

This flexibility does not address the issue of inappropriate dependence.

4.58 Overall, what needs are most important?

Few respondents answered this question. One suggested there needs to be an overall change in the system to eradicate systemic discrimination. Another suggestion was women need something with which to replace substances. They also need to know what the positive results would be for them if they stopped

smoking, drinking or using substances. Other suggestions included free treatment, advertising about the risks and the available help. The need for more adequate funding was voiced.

An important point was the suggestion that at least one treatment centre specifically for women with disabilities should be available in each province. Another related point was the need for accessible general programs that also look at disability-specific issues.

With some anger, one woman said, "The way society works, is that you re in care (after injury or onset of disability), then rehab, and then you re shoveled out. With caregivers, it is so much easier to do it for the disabled person than be patient and help to retrain the brain-injured. The medical system sucks. We need to take control in legitimate ways, especially with caregivers and attendants. We need to take back our own power and self respect."

4.59 Women with disabilities design programs

Many of the points for this question have already been mentioned. Two of the most important bear voicing again; the absolute value of having someone who has been there, someone that women can relate to and the need for programs to address self esteem, stress and anger issues.

Other suggestions cited were programs need to be woman-directed and peer led. Women should have a choice between integrated and stand alone programs. There should be a choice of women-only programs. Programming needs to be in tune with needs and must be flexible to suit different needs.

There must be clear objectives. Programs need to look at how to network and work with the scant resources that are already in place. They must be community focused and must accommodate different language, cultural and regional needs. Funding for child care, lunches and accessible transportation must be looked at in any woman-centred program.

Education, based on a feminist perspective, needs to be a big component. Materials need to be simplified and programs need to consider the personal care time, alternate formats, and attendant/interpreter needs of women.

Programs need to offer guidance, not insist women stop their use of substances. They need to be prepared to deal with survivor issues. In particular, programs need to address women s isolation, stigma and fear of judgement.

One respondent noted an important point, "There are different issues to consider regarding physical disabilities and mental health disabilities that will require different adaptations to programs."

Another respondent very simply told us, "It s important to know that others have gotten off tobacco, alcohol, and other drugs, that we re not alone. Education about what these substances do to our health, mind, body,

and spirit is also important. But what I need most is a place where I feel comfortable."

Several women talked about choice. "It s our choice!" said one woman. She went on to say, "For Twelve-Step Programs the issue is personal responsibility, while with social care, there is a need to care and enable. This doesn t work well with addiction and women with disabilities, since addiction is characterized by denial and a lack of personal responsibility. " She added, "I do have a concern with DAWN being feminist, since feminists often have a problem with 12 Step Programs." Another participant said, "Women with disabilities have a choice. We don t have to be dependent on current media campaigns which glamourize tobacco and alcohol. We must make a choice within for life."

Summing it up, one participant stated, "We don t want the Government and Health Canada to force programs on us. We want to be able to choose to get help. We can and will make that choice, if it is our own to make."

5.0 WHAT DOES IT ALL MEAN?

Almost all participants agreed that the use of alcohol and prescription medications causes problems for women with disabilities. Three quarters of respondents agreed that tobacco causes problems and slightly less than half agreed that the use of over-the-counter drugs causes problems for women.

Issues surrounding the use of heroin and cocaine, as well as household products were relatively unknown and this resulted in completely mixed opinions on whether the use of these drugs causes problems. Women did believe the use of these drugs was occurring, although it was extremely well hidden. Some women were familiar with the use of pot and spoke approvingly of its use, saying it had a positive effect on some disabilities. Women in larger cities were more familiar with the problems caused by the use of "illegal" drugs.

The kinds of substance use/misuse problems voiced by women were many and varied. There were several knowledgeable members in each group who were able to list a series of problems related to women with disabilities smoking, drinking or using other substances.

There were also many group members who appeared to lack knowledge about the negative effects of using substances, particularly tobacco and "illegal" drugs. For tobacco, there was denial and resistance to the idea that it causes problems. Some women, living in hopelessness, stated that they were not about to stop the only thing in life that gave them pleasure.

Some problems mentioned resulting from the use of substances were the overall level of ill health, less attention paid to self care and bladder problems. Disabilities were created or worsened. Women also mentioned the decrease in self esteem and increase in levels of shame, isolation, depression and hopelessness and that women took sexual and physical risks in order to get money for tobacco, alcohol or drugs. Legal problems, increased health costs and financial problems were noted. In addition, women expressed concerns about loss of motivation and increased suicidal feelings, as well as the problem of over medication, power

of physicians, unwanted side effects of prescription medications and increased dependency on family and caregivers.

Two major concerns of women who needed caregivers were the difficulties associated with caregivers who used substances themselves and/or caregivers who rigidly controlled the use of substances by women in their care.

The reasons cited why women started using substances were slightly different for each type of substance. Tobacco and alcohol were similar, it was primarily because their friends smoked or drank, it helped them socialize and they wanted to be part of the crowd. These latter two factors were also relavent for other drugs. However, with all other drugs, the primary reason cited was because their doctor prescribed them. These answers may reflect the time in their lives when they started the various substances. In other words, three separate reduction/cessation strategies may be required.

The reasons why women with disabilities continue to use substances were again different for each type of substance. For tobacco, the most frequent reasons cited for continuing to smoke were smoking is enjoyable and it is an addiction. For alcohol, the most frequent reasons cited were drinking helps women socialize and drinking is enjoyable. For other drugs, the primary reasons were drugs relieve stress and help numb feelings. Again, these answers will reflect slightly different reduction/cessation strategies.

Other reasons why women continue to use substances were anger, low self esteem, isolation and mid-life crises. Women mentioned smoking is a habit and allows needed timeouts. Drinking makes them feel like adults, feel less self critical, is socially acceptable and helps them forget about their disabilities.

The reasons cited why women have not tried to stop or reduce their use of tobacco were it is too hard to quit smoking and women do not consider smoking to be a problem. For alcohol, the prime reasons cited were a lack of accessible help and women do not consider drinking to be a problem. The two primary reasons cited why women have never tried to reduce or stop using other drugs were a lack of accessible help and drugs are just too hard to quit.

Lack of self esteem is the key reason cited why women with disabilities have not attempted to reduce or stop their use of all substances.

Stress in their lives is one of the primary reasons why women do not want to try to stop smoking. For alcohol, women told us that their intense level of anger, a desire to have fun, lack of accessible transit and their fear of loss of anonymity were reasons why they do not want to stop or reduce drinking.

For other drugs, women cited their fear that all drugs would be taken away if they tried to stop or reduce the use of those drugs which were being misused and that their pain and disability would still be there. They also feared their disabilities would get worse and needed medications would be denied to them. Participants also said women have not tried to stop because they have not yet reached rock bottom and also due to a perceived lack of support.

The most frequently cited reason why women with disabilities consider stopping or reducing their use of substances was current health problems. The next most frequently cited reason for other drugs and tobacco was peer, work or family pressures, while with alcohol, women were more worried about the effects on their family and whether their children would be taken away. The high price of substances and related legal problems were also important reasons why women consider stopping their use of substances.

Participants told us that recent media campaigns play a part in why some women consider stopping or reducing smoking. Also important were having a family history of cancer and thinking about how much time women have left with their children. Ultimatums from partners may make some women consider stopping their use of alcohol. Women mentioned that going to counselling or support groups for reasons other than addiction problems and the guidance of respected peers are factors in considering stopping the use of other drugs. Reaching a major crisis is what often makes women consider stopping their use of substances.

Throughout the research, women commented about holistic, community-based programs that involve self esteem and life skill courses, as well as the value of women finding self respect and self worth as reasons why they consider stopping or reducing their use of substances. Information at doctor s offices and health clinics, as well as school education programs for children of mothers who are substance users was also noted.

Of little importance to women considering stopping or reducing their use of substances were that using substances is an addiction, that substances may cause future health problems and attending programs to stop substance use.

There were many reasons cited why their use of substances is different from non-disabled women. Women with disabilities:

- are more isolated due to access barriers in society
- have very high levels of stress, anger and poverty
- have poor overall health
- experience greater health risks
- experience greater consequences resulting from poor self care
- have to take medications due to their disabilities yet still may use medications excessively and/or become addicted
- have easy access to prescription drugs
- friends, family and professionals enable their use of substances
- have difficulty finding help and more often than not it is inaccessible
- have few places to socialize and are largely unable to afford or access entertainment (unlike non-disabled women)

Another difference is that some women need to depend on caregivers, who may or may not agree with the disabled women s use of substances. These caregivers may also use substances and women may be forced to remain in their care and sometimes even to participate in substance use/misuse.

Smoking may actually help women with mental health disabilities and those with other cognitive disabilities to think during much needed time outs and cigarettes are sometimes used as a reward to encourage good behaviour.

A final difference is the high rate of violence against women with disabilities compared to non-disabled women, violence which has links to alcohol and drug use.

Mentioned throughout, was the need to address the very low self esteem, self image and self worth of women with disabilities. Women need to find positive ways to deal with their anger. Extreme isolation and that substance use helps women socialize were issues often cited. Another important issue cited was doctors and family members enable women to drink. Women said having control over what substances they take was very important.

Because work, family and peer relationships are valuable to women, participants said that the stigma connected to addiction is an extremely important factor. How women are socialized, whether they lose their jobs, children or needed services is directly related to whether they get help or not. Women also have difficulty admitting that they have addiction dependency problems when they are already seen as problem-prone and dependent.

Lack of accessible transit, and inaccessible programs/buildings were barrier issues echoed throughout the research. A concern particularly related to residential addiction programs was that these facilities would not be able to accommodate women with certain disabilities, especially those that need attendants, are in wheelchairs, are cognitively impaired or cannot hear or see.

Other concerns revolved around the power physicians have over women s lives. Women felt that doctors are more than willing to prescribe additional drugs and that doctors do not always tell them if drugs are addictive and lack full knowledge of drug interactions with other medications and side effects.

Women told us they wanted pain relief without addiction and risk, and that addiction did concern them, even though using drugs helped them cope with the effects of their disabilities.

How information is presented was an important issue. The need to use alternate formats to publish information, as well as non-traditional means of capturing women s attention, such as theatre and cartoons, were suggested as methods to consider. The help of somebody who has been there and just knowing that they are not alone with these issues also has great value.

Another issue concerned how media campaigns deal with the issue of substances, including that cessation\reduction advertising is geared toward youths, and that current media cessation campaigns are centred around smoking and do not target alcohol or other drugs.

Women described alternatives for times when they could not get the drugs they needed. The most frequent positive alternatives mentioned were various types of bodywork, herbs and meditation. First Nations

participants told us that traditional cultural remedies such as Sweats, Smudges, Circles and talking with Elders were the best alternatives for women.

Negative substitutes frequently mentioned were excessive gambling (including bingo), inappropriate sexual behaviours, eating disorders and isolating.

The participants in the focus groups told us the substance most commonly used is tobacco. However, when questioned specifically about which substance actually caused the most problems the women said alcohol causes the most problems. This was followed closely by prescription drugs. It is clear that both alcohol and prescription drugs cause problems for women with disabilities.

However, in some communities in the north and in mental health communities, tobacco remains the substance most commonly used and which causes the most problems. Alcohol is a close second in those communities.

A possible reason for the lesser rating of tobacco as the substance causing the most problems is the lack of knowledge about the effects of tobacco on women in disability communities. Even though there is agreement that tobacco is the substance most commonly used, women do not see it as causing the most problems. Another possibility is that the negative effects of alcohol and prescription drugs are more immediate and often public.

Most of the women felt that discrimination did affect their use of substances. The main effects of discrimination were to cause more isolation, anger and stress, and to decrease self esteem, self worth and self respect.

Almost all the participants told us clearly and emphatically that their histories of abuse and violence were linked to their use of substances. The main reasons cited were using substances helped women to forget and they helped numb the emotional and\or physical pain caused by various kinds of abuse. Women also said using substances was their way of being rebellious.

The climate was noted as a factor in substance use, especially during long, cold, northern winters and the wet, damp coastal rainy seasons. Other factors include the stress caused by relationship breakup, and the stress and anger caused by increased or additional disabilities. Women also said the pressures caused by societal expectations of women, the stress caused by families trying to define their roles and the distress caused by seeing significant others abused were also factors in their use of substances.

All the participants definitely felt that poverty was a barrier to getting help. They felt that poverty effected their ability to get accessible transportation and child care. Participants also stated that women living in poverty had lower overall levels of self esteem and had less access to knowledge. They therefore had less power and ability to affect change in their lives. Women also noted the high cost of private counselling and that Social Services is usually unwilling to look at non-medical alternatives to substances.

In defining substance misuse, women suggested that key indicators were when using substances interferes with women s daily functioning, when women do not take medications as they are intended, and when the use of these substances are clearly causing related legal and health problems.

Many participants expressed that it is extremely hard to tell when they cross that fine line into substance misuse, since most women have to take drugs. What is appropriate use and what is misuse could be different for each woman. Some said that perhaps women need professional help to decide if they are having a problem. Others said personal empowerment was the important issue and that only the women themselves could tell. However, one difficulty expressed was the fact that addiction is characterized by denial and an inability to control the amount of substances used. It could therefore be difficult for women in the grip of addiction to really tell if there was a problem.

The women who participated in the focus groups were unaware of any programs tailored for women with disabilities, aimed at stopping or cutting back on the use of substances. For the most part they were unaware of what addiction programs were accessible. Many were not aware of whether there were any programs tailored to women.

The participants were almost completely unaware of programs or resource manuals which offered help in alternate print. They also were unaware of programs which were accessible to women who had visual or hearing impairments, or who were cognitively/developmentally disabled or who had spinal cord injuries.

Some women were aware of various Alcohol and Drug Programs, healing circles, life skill programs, Women in Recovery groups, Women for Sobriety meetings and stop smoking programs given by provincial lung and cancer foundations. A number of women were familiar with several twelve step programs, however, they cautioned that these programs were often held in inaccessible places. Some women mentioned various co-ed hospital programs.

Although the Canadian Centre for Substance Abuse reports that, out of over 1,000 services, there are some 352 treatment services that accept women and offer some type of service to persons with disabilities, this number may be in doubt as these are self reported accessibility levels. Women with disabilities reported that services that say they are accessible can, in fact, be quite inaccessible. It is also unclear which of these services are women-only. It is obvious that this is an area needing more research.

The majority of participants told us women with disabilities are not using existing services.

Several factors were cited why existing services and programs are not being used by women with disabilities. Major reasons were the inaccessibility of programs and the poor and unwelcoming attitudes of service providers. Participants told us that their lack of knowledge about where to go or who to phone for help and their lack of knowledge of the accessibility of various programs were also reasons why they are not using

existing programs.

Women also told us that information about the accessibility improvements of previously inaccessible services does not reach the women who require the services and service providers had an inadequate level of knowledge as to the needs of disabled women.

Participants did say that some women are being helped. However, this help was largely restricted to women who have mild to moderate degrees of impairment and those who could participate in groups.

The sensitization of services providers, addressing the very low self esteem of women with disabilities, full accessibility of programs, and easily available and accessible transportation, were the four most important points expressed by participants, that would make existing programs work.

Most women wanted and needed women-only services and felt that addiction recovery groups needed to be led by women with disabilities who have been there. They wanted to go to women-only services because many of them had experienced past abuse.

It was suggested that bringing in professional outsiders would be better after a level of comfort and trust has already been established among support groups of women with disabilities.

Education of service providers was also an important factor. Service providers must recognize that we are WOMEN with disabilities and must be educated about the need to take certain medications, the need for personal care time and the necessity of personal attendants for some women. Services also need to know how to quickly access qualified interpreters

The value of using culturally appropriate tools, and the need to develop appropriate community-based solutions were also identified by participants.

Almost all participants said that both integrated programs and stand alone programs, were necessary in order for all women with disabilities to find help stopping or reducing their use of substances. (Integrated meaning programs for both women with and without disabilities) Both the value of main streaming (including women with disabilities in general programs) and the values of separate programs for women with disabilities were mentioned.

When women told us what worked best in trying to quit, they said that going cold turkey was the most important thing. They also noted that getting the help of a peer and/or going to a twelve-step program or other support group helped them quit. The value of going to detox and/or getting help from their families also played a part in their attempt(s) at recovery.

Women said the most important issue in quitting was that women have to really want to quit and they have to

value themselves enough to do it.

The participants expressed that the most important issue that prevents women with disabilities from getting help is their extreme lack of self esteem. The lack of anonymity and the fact that they live under a magnifying glass in the disability community are also factors that prevent women from getting help.

Women have difficulty asking for help, they often lack support from their significant others and they fear their disability will get worse; these factors stop them from seeking help for their addiction(s). Other internal factors that prevent women from getting help were an inability to live life for today, a lack of self acceptance and a high level of depression and denial.

Women expressed their fears about the amount of effort needed to actually stop using substances, their sense of powerlessness and hopelessness, as well as their fear of rejection or failure, as significant issues that prevent them from getting help.

When women told us what was necessary, they said that an overall change in the system to eradicate systemic discrimination was necessary. Adequate funding is needed, including at least one treatment program specifically for women with disabilities in each province and/or accessible programs that look at disability-specific issues.

Another overall need is education. Women need something to replace substance use. They need to know what the positive results would be for them if they stopped smoking, drinking or using substances. The need for women with disabilities to take back their own power and self respect was expressed.

When women were asked what were the most important pieces of a program which could help them reduce or stop their use of substances, they stated that having someone who has been there who they could relate to and addressing lack of self esteem, stress and anger issues were essential components.

Women noted that programs need to be woman-directed and peer led, and that community-focused flexible programming was important. Education must be a big component. Current program materials need to be simplified and programs need to consider the personal care time, alternate formats, and the attendant/ interpreter needs of women. Women s abilities to make choices, to be guided, not forced, and to be in a place where they felt comfortable were deemed essential to any reduction or cessation program.

Programs must have clear objectives. They need workable options for child care. Lunches and accessible transportation must be looked at. Programs need to be prepared to deal with survivor issues. They will also need to address the isolation, stigma, and fear of judgement that surround addicted women with disabilities.

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 effected 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 even know where to begin looking for help. Help may not exist.

You may be unable to understand the 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 since 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. A few of the obstacles in society that these women have to face are:

- the absolute lack of services tailored to women with disabilities
- the relative lack of women-only services
- the lack of knowledge of the availability and accessibility of services
- the lack of knowledge of service providers about disabled women s issues

- service providers lack of sensitivity
- the inaccessibility of programs and buildings
- the financial inaccessibility of program
- the lack of accessible transportation.

The major internal changes required of women with disabilities just to try to find help 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 anonymity
- 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

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7.0 APPENDICES

APPENDIX A: EXTENDED SELECTED BIBLIOGRAPHY

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RESOURCES/ORGANIZATIONS

Canadian

will be uploaded soon

RESOURCES/ORGANIZATIONS

American

will be uploaded soon

APPENDIX B: Focus group format

Substance USE/MISUSE And Women With Disabilities

INTRODUCTION

The purpose of this focus group is to assess, in general terms, substance use and misuse for our communities. It is focused on the issues surrounding the use and misuse of tobacco, alcohol and other substances. The use and misuse of food was beyond the scope of this project.

We need to define for ourselves substance use, misuse and abuse for our communities since what is misuse for non-disabled women may be completely necessary for women with disabilities or it may be mis/use.

We are not going to ask personal questions, instead we want to get a general feel for how things are in your community. We need to look at our issues regarding substance use. We need to know what kinds of programs are currently available and if there are any programs that could be adapted specifically for women with disabilities. We need to know what is needed, what might work, and what are the gaps and barriers. Most importantly, we need you to tell us from your own vast pool of wisdom and experience how can those gaps be bridged in creative realistic ways.

The goal of this project is to try to design programs for women with disabilities aimed at cutting back or stopping the use of substances that harm us. Health Canada is planning a second phase that would implement the recommendations from the report. In order for that to happen, we need you to tell us what you need in your community to make these programs work for you.

From what you tell us we also may be able to see what the links are for us between how society works, discrimination and abuse with substance use/misuse.

Please answer the questions in a general way. If you do not feel comfortable answering a question follow your own internal guidance. Some of the following questions might be difficult for you to answer. Although we are not asking for personal information, they still may bring up painful feelings or you may be unsure of the answers. Please be respectful of your own safety. If you need support after we will try to help.

We will keep your identities COMPLETELY CONFIDENTIAL. Any comments which could be used to identify you will only be used as grouped anonymous comments.

If you have any questions, comments or concerns, please don t hesitate to contact the project researcher at any time.

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Substance Use/Misuse And Women With Disabilities

SECTION 1 GENERAL INFORMATION

The following questions will help us put your experience in the context of this community

1. What province/territory?______________________

2. This is a? (Check)

______city or ________ town or ______ Aboriginal community on reserve

3. Number of women with disabilities present in focus group? _____

4. How would you identify yourself? (Mark group # s)

_____ Canadian/Québécois

_____ Status Aboriginal

_____ Non-status Aboriginal

_____ landed immigrant

_____ 1st generation Canadian (acquired citizenship)

_____ other (please state)

5. What is your first language? (Mark group # s)

_____ English _____ American Sign Language

_____ French _____ other (please state)____________

6. Range of disabilities among those present in focus group? (Mark # s)

______ hearing

______ labeled mentally handicapped

______ learning

______ mental health

______ mobility

______ visual

______ hidden

______ brain injury

______ HIV/AIDS

______ drug/alcohol dependency

______ other (please state)________________

SECTION 2 PATTERNS OF USE, MISUSE, and AB/USE

In order to design substance use/misuse programs for women with disabilities we need to know information about what are the general patterns of use/misuse and what problems, if any, they cause. The following three sections ask questions about the use of body, mind and mood altering substances often collectively called drugs. To make things easier, we have grouped these drugs into three sections: tobacco, alcohol, and other substances, which include prescription drugs, over-the- counter drugs, household products, and "illicit" drugs.

SECTION 2(A) TOBACCO

The section on tobacco includes all forms of tobacco including: cigars cigarettes, snuff, chewing tobacco, patches, gum and pipes.

1. In this community do you think that smoking causes problems for women with disabilities? yes ___no___not sure___

2. What problems, if any, does the use of tobacco cause in the lives of women with disabilities in this community?

____

3. How does the use of tobacco affect our disabilities?

____

4. Why do you think women with disabilities start to use tobacco in any form? (Check)

parents smoked____

made them feel independent____

it seemed cool____

it helped them socialize____

advertising____

friends smoked____

to be part of the crowd ____

other (please explain) ___________________________

In addition to the many reasons able-bodied women continue to smoke women with disabilities may have reasons specific to their disability. Please consider this when answering this question.

5. Why do you think women with disabilities continue to smoke? (Check)

it s the only thing they do for them____

it gives them something to do____

hopelessness____

it helps them relax____

it relieves stress____

addiction____

it helps them socialize____

it relieves nausea____

it relieves spasms____

it helps numb feelings____

it relieves pain____

smoking is enjoyable____

it relieves depression____

it relieves loneliness____

other (please explain)____________________________________

SECTION 2(A) CONTINUED

6. Why do you think that some women with disabilities have never tried to cut down or stop smoking? (Check)

lack of accessible help____

really helps their disability____

no child care____

language/cultural barriers____

it s too hard to quit____

not ready yet____

they like smoking____

don t consider it to be a problem____

other (please explain) ____

7. Why do you think women with disabilities consider and/or try to cut down or stop smoking? (Check)

legal smoking restrictions____

too expensive____

peer, work or family pressures____

because it s an addiction____

worried about future health problems____

current health problems____

stop smoking programs____

worried about effects on family and other members of household____

other (please explain)____

8. What is different about the use of tobacco by women with disabilities from non-disabled women?

____

9. What issues are important to women with disabilities regarding tobacco?

____

SECTION 2(B) ALCOHOL

This section on alcohol should be read as including all forms of alcohol including: beer, wine, hard liquor, cider, moonshine as well as alcohol substitutes such as vanilla, hair spray, rubbing alcohol, perfume etc. Please answer the questions with this in mind.

1. In this community do you think drinking causes problems for women with disabilities?

yes _____

no_____

not sure_____

2. What problems, if any, does drinking cause in the lives of women with disabilities in this community?

____

3. How does drinking affect our disabilities?

____

4. Why do you think women with disabilities start to drink alcohol? (Check)

parents drank_____

made them feel independent_____

it seemed cool_____

it helped them socialize_____

advertising_____

friends drank_____

to be part of the crowd_____

other (please explain) __________________________

SECTION 2(B) CONTINUED

In addition to the many reasons able-bodied women continue to drink women with disabilities may

have reasons specific to their disability. Please consider this when answering these questions.

5. Why do you think women with disabilities continue to drink? (Check)

it s the only thing they do for them____

it gives them something to do____

hopelessness ____

it helps them relax____

it relieves stress____

addiction____

it helps them socialize____

it relieves nausea____

it relieves spasms____

it helps numb feelings____

it relieves pain____

drinking is enjoyable____

it relieves depression____

it relieves loneliness____

other (please explain)____________________________________

6. Why do you think that some women with disabilities have never tried to cut down or stop drinking? (Check)

lack of accessible help____

really helps their disability____

no child care____

language/cultural barriers____

it s too hard to quit____

not ready yet____

they like drinking____

don t consider it to be a problem____

other (please explain) ____

7. Why do you think women with disabilities consider and/or try to cut down or stop drinking? (Check)

drinking related legal problems____

too expensive____

peer, work or family pressures____

because it s an addiction____

worried about future health problems____

current health problems____

stop drinking programs____

worried about effects on family and other members of household____

worried about kids being taken away____

other (please explain)_______________________________________

8. What is different about the drinking of women with disabilities from non-disabled women?

---

9. What issues are important to women with disabilities regarding alcohol?

SECTION 2(C) OTHER SUBSTANCES

This section ask questions about your use of all substances outside of tobacco and alcohol. It is loosely grouped into prescription drugs, over-the-counter drugs and illegal drugs, and also includes solvents and inhalants. Please think about all the different kinds of drugs we are asking about and answer with these in mind. Where possible we have given some suggestions of drug types to help you but this list does not cover all drug types.

1. In this community does using prescription drugs cause problems for women with disabilities? (Eg sleeping medication anti-depressants, pain medication, anxiety medication, HIV/AIDS related medication, anti-spasmodic medication etc.)

yes____

no____

not sure____

2. Do you think women with disabilities use prescription drugs that have been prescribed for someone else s use?

yes rarely____

yes sometimes____

yes regularly____

no never____

(Check which ones are shared)

sleeping medication____

anti-depressants____

pain medication____

anxiety medication____

HIV/AIDS related medication____

anti-spasmodic medication____

diet pills____

cough medicine____

other (please explain)________________________________

3. Why do you think this sharing of medication
occurs? ____

4. When / why do you think women with disabilities start using prescription drugs? (Eg onset of disability
etc) ____

5. Do you think that addiction to physician prescribed drugs is a problem for women with disabilities in
this community?

yes a little____

yes it s a big problem____

yes probably____

no ____

not sure____

6. What problems, if any, does the use of prescription drugs cause in the lives of women with disabilities in
this community?

____

7. Many women with disabililties, particular senior women, use a number of prescription drugs, often from more
that one doctor. What problems, if any, does this cause in the lives of women with disabilities in this community?

____

8. Is the use of over-the-counter drugs a problem for women with disabilities in this community? (Eg. Gravol, cough syrup, wake ups, cold medication, nasal spray, sleep easing medication etc.)

yes____

no____

not sure____

9. Do think that women with disabilities are addicted to over-the-counter medications?

yes a few____

yes some____

yes most____

no____

not sure____

10. What problems, if any, does the use/misuse of over-the-counter drugs cause in the lives of women with disabilities in this community?

11. Do you think that the use/misuse of other substances causes a problem for women with disabilities in this community? (For example pot, glue, gasoline, heroin, cocaine, mushrooms, peyote, acid, speed etc)

yes____

a little____

yes it s a big problem____

yes probably____

no____

not sure____

12. What problems, if any, does the use of these other substances cause in the lives of women with disabilities in this community?

____

13. How does using the above substances (pot, glue etc.) affect our disabilities?

____

14. Why do you think women with disabilities start to use drugs? (Check)

parents used drugs____

made them feel independent ____

it seemed cool ____

it helped them socialize ____

advertising ____

friends used drugs____

to be part of the crowd____

doctor prescribed them ____

other (please explain) ___________________________

In addition to the many reasons able-bodied women continue to use women with disabilities may have reasons specific to their disability. Please consider this when answering this question.

15. Why do you think women with disabilities continue to use drugs? (Check)

it s the only thing they do for themselves ____

it gives them something to do ____

hopelessness ____

it helps them relax ____

it relieves stress____

addiction ____

it helps them socialize____

it relieves nausea ____

it relieves spasms ____

it helps numb feelings ____

it relieves pain ____

using drugs is enjoyable ____

it relieves depression ____

it relieves loneliness ____

other (please explain)____________________________________

16. Why do you think that some women with disabilities have never tried to cut down or stop using drugs? (Check)

lack of accessible help ____

really helps their disability ____

no child care ____

language/cultural barriers ____

it s too hard to quit ____

not ready yet ____

they like using drugs _____

don t consider it to be a problem _____

other (please explain) ____

17. Why do you think women with disabilities consider and/or try to cut down or stop using drugs? (Check)

drug related legal problems _____

too expensive _____

peer, work or family pressures _____

because it s an addiction _____

worried about future health problems _____

current health problems _____

programs to stop using drugs _____

worried about effects on family and other members of household _____

worried about kids being taken away _____

other (please explain)_______________________________________

18. What is different about the using of all drugs (prescription, over-the-counter, "illicit", and household products) of women with disabilities from non-disabled women?

____

19. What issues are important to women with disabilities with regard to drugs?

____

20. What substitutes/alternatives do you think women with disabilities use if they can t get the drugs they need

or want?

____

21. In general for this community, which substances cause the most problems for women with disabilities?

tobacco ____

prescription drugs ____

alcohol ____

over-the-counter drugs ____

house hold products ____

solvents/inhalants ____

"illegal" drugs ____

caffeine ____

SECTION 3 LIFE SITUATION

1. Does discrimination in the lives of women with disabilities affect their use of: (For example being poor, lesbian, senior or youth, race, culture, location, religion etc.)

tobacco: ____yes _____no _____not sure

alcohol: ____yes _____no _____not sure

other drugs: ____yes _____no _____not sure

(How)

____

2. Does the history of abuse/violence in the lives of women with disabilities affect their use of: (check)

tobacco: ____yes _____no _____not sure

alcohol: ____yes _____no _____not sure

other drugs: ____yes _____no _____not sure

(How)

____

3. What other things in our lives contribute to our use of tobacco, alcohol, and other substances? (Consider relationships, climate etc)

____

4. Is poverty a barrier in your community for women with disabilities to get help reducing or stopping the use/ misuse of substances?

yes ____ no ____ (please explain)

____

SECTION 4 GETTING HELP

This section asks questions about whether you are getting help now or even want help. **We are especially asking for your ideas on what barriers are in place now and what help might look like from the perspective of women with disabilities.** We would like to encourage you to be as creative as possible in your answers.

1. How would you define substance use/misuse for women with disabilities? ____

2. What programs aimed at stopping or cutting down on the use of tobacco, alcohol or other substances currently exist in your area for women with disabilities? (Consider medical, holistic, twelve step, prevention education, also consider programs which could be adapted to include a substance abuse section etc.)

____

3. Are women with disabilities using existing programs? If not why not?

Tobacco: Yes ____ No ____

Alcohol: Yes ____ No ____

Other substances: Yes ____ No _____

____

4. What would make existing programs work for women with disabilities?

5. Are integrated programs needed or are programs specifically designed for women with disabilities needed in order for women with disabilities to stop or cut down on using substances?

Both ____ Neither ____

Integrated: Yes ____ No ____ Not sure ____

WWD specific: Yes ____ No ____ Not sure ____

Please explain

____

6. What works best in quitting and/or trying to quit? (Ask them to rank and check)

cold turkey ____

help of a peer ____

stop aids (Eg. gum/patches) ____

slowly cut back

programs to stop using drugs ____

going to detox ____

going to a treatment centre ____

changing towns ____

private counseling ____

getting help from family ____

going to twelve step program or other support group ____

avoiding people and places where substances are used ____

changing effects of disability (substances not needed or don t work) ____

other (please explain) ______________________________

7. What do you think are the major issues preventing women with disabilities from getting help? ____

8. Overall, what needs to be in place to help women with disabilities reduce harm caused by using tobacco, alcohol and other substances?

____

9. What would be important if you were designing a program, for yourself or for other women with disabilities?

For tobacco

____

For alcohol

____

For other drugs

____

Is there anything we haven t asked that you would like to add?

APPENDIX C: EDUCATION BULLETIN

Tobacco and Substance Use/Misuse Bulletin
Sept 1995

This project is funded by Populations and Health Issues Directorate at Health Canada.

Needs Assessment for Women With Disabilities Who Use/Misuse Tobacco, Alcohol and Other Substances

DAWN Canada has been given a contract by Health Canada to assess the needs of women with disabilities who use/misuse tobacco, alcohol and other substances. We are very much in need of your cooperation with this project.

Sometimes we feel like we are flooding our members with questionnaires and interviews. The truth is that **very little is known about women with disabilities** and the only way to find out is to ask. We are deeply grateful for your past and continuing cooperation in our research. Research which benefits us all. Once again we are asking you to participate in another research project. DAWN Canada will be contributing to the three year Tobacco Demand Reduction Strategy.

During October, the DAWN Canada project researcher will be travelling to the various regions of Canada. We will be holding focus groups in at least one community in each of the regions. **Special effort will be made to include First Nations women and women of colour in the focus group or in their own focus group.**

The purpose of the focus group is to assess, in general terms, substance use and misuse for our communities. It is focused on the issues surrounding the use and misuse of tobacco, alcohol and other substances. The use and misuse of food was beyond the scope of this project.

We need to define for ourselves substance use/misuse for our communities since, what is misuse for non-disabled women may be completely necessary for women with disabilities or it may be misuse.

We are not going to ask personal questions. Instead we want to get a general feel for how things are in your community. We need to look at our issues regarding substance use. We need to know what kinds of programs are currently available and if are there are any programs that could be adapted specifically for women with disabilities. We need to know what is needed, what might work, and what are the gaps and barriers. Most importantly, we need you to tell us from your own vast pool of wisdom and experience how can those gaps be bridged in creative realistic ways.

The goal of this project is to try to design programs for women with disabilities aimed at cutting back or stopping the use of substances that harm us, as well as making recommendations for adapting programs so that they

can include women with disabilities. Health Canada has informed us that a second phase is planned that would implement the recommendations from the report. We cannot guarantee that the programs will happen but we will have the information to share among ourselves and step two cannot happen, until we have done the first step. In order for that to happen, we need you to tell us what you need in your community to make these programs work for you.

We will also be looking to see, in general, if there are any links are for us between how society works, discrimination and abuse with substance use/misuse.

The current programs to help women overcome their dependence on tobacco, alcohol and other substances, for the most part, are not accessible to women with disabilities. The only way to make them accessible is to find out what we as women with disabilities need to help us stop using substances that are making us dependent on them while destroying our health.

It has always been a policy at DAWN Canada that we do not speak for women with disabilities unless we know what women want to say. Based on our previous research, we were able to produce manuals for transition house workers and for suicide crisis workers on how to become more accessible to women with disabilities.

We hope that you will continue to support our work and continue to answer our questions. This is how your voice is being heard and this is how we are going to make the changes happen.

Any research that DAWN Canada has done belongs to the women who participated in it, and you are entitled to have the results of those projects. We will continue to inform women of the results of this project and any other projects that we do. We will, over the next few months be sending copies of the final product of the suicide and abuse project, " Don't Tell Me To Take A Hot Bath: Resource Manual For Crisis Workers", to the women who requested it.

DAWN Canada has research guidelines that we follow to ensure that the women who help us with these projects benefit from them. They are as follows:

1.) The need for research is determined by the disabled women's community,

2.) Research must always benefit women with disabilities,

3.) Research must be done by members of the disabled women's community because members:

a. know the issues and priorities of the community,

b. understand the day-to-day reality of women who are disabled,

c. understand the social and political dynamics of the community,

d. can analyze data within the framework of these dynamics

4.) Action resulting from the research must be directed toward making positive changes for women with disabilities

5.) Research participants must be given the results of the research.

In writing project proposals and in negotiating project contracts we always work from this place because we not only represent women with disabilities but we are women with disabilities. This means that we feel we should never work in isolation. We must always come to you for help and anything we do is owned by you.

Why Is Tobacco Use Different For Women With Disabilities?

Tobacco is one of the substances we use in dealing with our every day lives and our disabilities. Women with mental health disabilities are in a system where we can be monitored. Therefore, we are the most visible users of tobacco. This is probably true of some other disabled women who need a lot of personal care. It is not possible to say how this might compare with women who can be more discrete about using substances.

Women who work in the mental health system estimate that about 80% of women who are consumers of these services use tobacco regularly. The use of tobacco and other substances seems cyclic depending upon money supply.

Young women who are on the streets or who are coming off the streets into half way houses are heavy smokers but can't afford alcohol. No matter how hard things get a woman can always find a cigarette. Smoking takes priority over food and health. Since it costs more just to be a woman every month, women make sanitary pads out of toilet paper so they can buy tobacco. We are reduced to panhandling or picking up butts when we have no money at all to buy cigarettes.

For women with disabilities who lead very dependant lives, smoking is often the only thing over which we have any control. (Mostly) **We decide** "If , when, and where" we smoke. It is one of the few "measures of freedom" we have left in our lives, and for this reason alone it has value. When this is combined with the addictive nature of nicotine and the other pleasurable effects smoking can bring, quitting becomes very difficult for us.

We must recognize that some substances, such as tobacco, are far more harmful than beneficial and energy must be put into discouraging their use. Many women are addicted to nicotine and many women are disabled by the use of tobacco which can cause many health problems from cancer to heart problems. Tobacco is a serious health issue for women with disabilities.

Women and Tobacco - The Bigger Picture

The steady decline in rates of smoking over the last ten years has been much slower for women than for men. More women than men are now smoking and more young women than young men are starting to smoke.

The papers on the use of tobacco and other substances published by Health Canada cite studies on smoking behaviour for women that see **smoking as a rational response to real pressures associated with gender and class inequities.** Not only do women have more stress due to inequality, we also have fewer options than men, for dealing with stress. Nicotine causes both relaxation and alertness depending upon the dosage. People self regulate through their smoking patterns to get the desired effect.

Smoking gives a woman a chance to feel that she is getting things under control. She has too much to do and too little time to do it. There is no time for herself. A smoke gives her that time - a break, a feeling of safety. The nicotine relieves the stress of being angry, abused, depressed, bracing for another encounter and/or being poor.

Smoking is a social event that gives her some independence, and a little fun. All of the advertisements tell her smoking is cool and it keeps her thin and sexy. It is easy to deny the long term risks when the positive effects are so immediate and quitting is so hard.

Lung cancer now exceeds breast cancer as the leading cause of death in women in Canada. In 1995 it is expected that 5,800 women will die of lung cancer. Smoking is also associated with cancer of the lips, mouth, pharynx, larynx, esophagus, pancreas, kidneys, bladder and cervix.

Smoking is also related to heart and circulatory disease, infertility, prenatal and postnatal problems as well as health problems for children and other family members from second hand smoke. **Fifteen percent of all women's deaths in Canada are a result of smoking and many of these women die prematurely, by an average of 22 years**.

Smoking is the leading preventable cause of death in Canada and other industrialized countries. More than 40 of the 4,000 constituents of tobacco smoke are known to be cancer causing agents and many others are proven or suspected of being toxic agents. Quitting is the single most important thing a woman who smokes can do to improve her health.

What makes quitting so hard? Smoking is more than a physical addiction. It is part of every facet of the smoker's life - a cup of coffee, talking on the phone, socializing, driving a car, after sex and so on. A woman who smokes is not trying to damage her health with every puff.

Many smokers want and have tried to quit. Some have used all sorts of aids from nicotine gum and patches to candy and licorice root tea. Some women have said they would rather go without food or alcohol than

without cigarettes. Many women have said that nothing will make them stop smoking.

All of the above issues are, of course, compounded for women with disabilities, who are among the poorest of the poor, have among the highest levels of pain, abuse and discrimination, (mostly) lead very dependant lives, have little access to true equality, and live in a society which is inaccessible.

If we are going to quit smoking we must find the reasons why women with disabilities smoke and make the quitting process more tolerable. The reasons why women with disabilities smoke may be different and more numerous than non-disabled women. **Programs must be designed to meet the needs of women with disabilities not add more stress to their lives. It is time to ask what they need and what kinds of programs will help them quit.**

Alcohol and Other Substances

Alcohol is readily available and relatively cheap. It is used far more frequently than illegal drugs. When money is short, shaving lotion, mouth wash, hair spray, lysol or anything that contains alcohol will substitute for alcohol. Cannabis is the most frequently used illegal drug, but cocaine, LSD, speed and heroin are readily available on the streets. A 1992 survey of street youth in Toronto showed that 83% of these youth have used cannabis, 64% of the youth have used cocaine and 12% of the young women use cannabis daily.

The Health Promotion Survey in 1990 showed 77% of Canadian women 15 years of age and over were current drinkers. The risks of excessive use of alcohol and other substances common for women are fatty liver, hypertension, reproductive disorders, infertility, cancer and damage to fetus. Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effect (FAE), and Narcotic Addicted Syndrome (NAS) cause totally preventable disabilities to infants through the use of alcohol and other substances while women are pregnant. Sexually transmitted diseases, HIV, and tuberculosis are also often associated with excessive alcohol use.

Physiological differences from men make alcohol and substance use more harmful to women's bodies - differences in weight and body composition, hormones and the metabolism of alcohol and other substances. Women have a higher blood alcohol level after drinking the same dose of alcohol, because women have more body fat and lower water content than men.

As women with disabilities we must use many medications to control the effects and the progression of our disabilities. This makes us vulnerable to improper use of these medications as well as trying medications that seem to work for others.

"Illicitly" obtained prescription drugs such as Fiornals, Valiums, long acting Morphine and Ativan are also available on the streets. Because there are such rigid controls on the prescribing of certain medication and the costs of others are beyond some women s reach, many women with disabilities are forced to share their medication in order to find relief that works for them. We are forced to find what we need on the street or in

our own "underground" network of shared medications.

The use of drugs is widespread. A recent drug survey administered to high school youth showed that 20% of the students had a problem with drugs and were at high risk of developing addiction problems. It also showed that most students had at least tried drugs.

Older women are at a greater risk of misusing medication and of self-medicating by mixing prescription drugs or with drugs mixed with alcohol. These problems are probably true of women with disabilities

Women with disabilities drink and take other substances for much the same reasons they smoke. Drinking and other substances provide an escape from a painful and unhappy life that has too many stresses and no opportunity for self renewal. Many women with disabilities drink and take drugs to ease physical pain. Clinical studies of women and men who come for treatment show women who are dependent on alcohol and/or drugs are depressed and anxious and have low self-esteem while men display antisocial behaviour.

It must be noted that these terms are based on society s views that commonly refer to women as being neurotic, anxious and depressed, with vague fears and worries ruling our lives. In the past, the responses given were simplistic, like "take a pill and see me in a week" to the voicing of our real concerns. Our pains and concerns were not seen as being serious and often the first diagnosis was a psychosomatic illness. It was "all in our heads"! Knowing this, it is less surprising that we have higher numbers of women who are labelled as neurotic, anxious or depressed.

Drugs that are used to relieve pain and anxiety have addictive qualities and craving for the drug may come to outweigh the pain factor. As the body quickly builds a tolerance the woman must take higher dosage or take the drugs more often for the same effect. She must continue to relieve not only the old pain but also the new pain of the chemical withdrawal as her tolerance to the drug increases. As she takes the drugs more and more frequently and in larger quantities she lives with only temporary ease and never experiences the feeling of euphoria that new users come back for.

The Part Society Plays in Our Issues Around Substance Use

Because women use tobacco, alcohol and other substances for different reasons than men, the programs for breaking addiction must be different for women. Programs must deal with the issues that brought women to this place. Women also have to overcome many barriers to treatment. Social stigma and inaccessibility of programs to women go together. Women who are "drunks or drug addicts" get far less respect than men who are drunks or drug addicts.

Of great concern is the relatively high "social acceptance" of using drugs, like pain medication, for those who have visible disabilities and "real pain," while there is low "social acceptance" for those who have non-visible disabilities and "psychological" pain. We use substances to deal with our pain. This is separated

into physical ("good") pain and social ("bad") pain. Women who use drugs for social pain are not validated and end up being abandoned. This societal splitting between them and us contributes to our isolation and keeps us from joining forces for change.

Women, in general, have to deal with child care, transportation, poverty, fear of losing their children and their feelings of not being worth the effort before they can even get to the treatment programs, as well as the sheer unavailability of helping programs. These difficulties are even greater for women with disabilities because of our need to rely on caregivers or social assistance programs. We already face a greater risk of having our kids taken away just because we are women with disabilities.

A further major barrier to us is the overwhelming inaccessibility of helping services. Accessibility which includes physical accessibility, but goes far beyond to include among other things, financial, language and cultural accessibility and attitudinal accessibility.

In this research we will probably have to redefine substance use/misuse for women with disabilities. We take prescription medications for our disabilities but often we find non-prescription or illegal drugs work better. As women with disabilities, we may have to take more medication than the average woman to get relief because without medication we may not be able to function at all. What appears to be abusive for one woman may not be so for a woman who must take large daily amounts just to be functional. Although we do not deny there may be a sense of well being that comes with these various substances, the fact remains that we could not function without them.

The isolation, poor self image, pain, abuse and poverty, which are so much a part of our daily lives, make us very susceptible to the sense of well being and escape produced by many prescription, over-the counter and "illegal" drugs, as well as tobacco and alcohol. Even when these substances are life threatening, the relief of the moment outweighs the long-term costs.

This is especially true of tobacco and alcohol which are so readily available and are so much a part of socializing for women who are lonely. Young women with disabilities who struggle to be like other young women, who want to be accepted and feel part of the group and have boy friends are particularly vulnerable to using substances just to feel like they belong.

For many women with disabilities, life is very difficult. We are lonely, bored, in pain and/or poor. There is no job to go to, there is no support from coworkers and no worker programs to help us overcome our dependence on substances that seem to offer some relief and/or escape from our daily woes. We need to tell each other our stories and we need to find ways that will work for us. We need to hear from you and at the end of this project we will be sharing our work with you.

Hopefully the needs assessment project that DAWN Canada is doing will help us understand the issues from the perspective of women with disabilities.

We would like to encourage you to submit any comments or suggestions. **Your identities will be kept COMPLETELY CONFIDENTIAL.** If you have any questions please don t hesitate to contact the project researcher at any time.

Please feel free to contact the Project Researcher if you have any questions or comments. Please mail or fax any input to the Researcher at the following address.

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