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**Alcohol-Related Birth Effects and Aboriginal Peoples: Prevention, Identification and Intervention Services**

This presentation examines the challenges faced by Aboriginal peoples as they address the issue of substance abuse by pregnant women and alcohol-related birth effects in their communities. Particular attention will be paid to barriers and gaps in the continuum of medical and social service delivery for at-risk Aboriginal women and their children.

Good afternoon. I was asked to speak to you as a representative from Aboriginal communities and would like to say a few words about this before beginning my presentation. I am Métis from Saskatchewan and for the past twelve years I have lived in Montreal and been very involved in the urban Aboriginal community. While I come from two Aboriginal communities, one rural and one urban, my discussion today is an analysis of my research, rather than a presentation of an “Aboriginal perspective” of FAS prevention, although this inevitably threads its way through the presentation. Therefore, my presentation in no way is meant to represent how Aboriginal peoples collectively feel about the issue of FAS, nor that I am speaking on behalf of any Aboriginal community or Nation.

There are many ways in which to speak about Aboriginal peoples, alcohol abuse, and FAS. For my purposes here I will give a very pragmatic talk that highlights issues relevant to Aboriginal women and their children, particularly those women living off-reserve and in urban centers. A complimentary talk that could be given in relation to the one that I am about to present is one that focuses on traditional knowledge and Aboriginal teachings however, I am neither the person to give that talk nor do I want to assume that Aboriginal Elders would feel that this is an appropriate forum for this knowledge to be shared. However, it is important to acknowledge that as I speak about

alcohol abuse and FAS my intention is that local knowledge and teachings are the building blocks for appropriate prevention and intervention strategies.

The question that frames this panel is: “What can be done to improve and better coordinate prevention and intervention services that address the effects of alcohol and tobacco exposure on the fetus and on young children?” While focusing on Aboriginal women I would like to redefine our topic by asking three related questions: 1. If the problem of alcohol and tobacco exposure on the fetus and on young children is reframed as a women’s health issue that encompasses a holistic perspective-physical, psychological, emotional, spiritual, and socio-environmental what becomes visible that was previously hidden? 2. How can we re-think public health strategies as a result of this shift in focus; and, 3. By making FAS a “women’s health issue” do we lose sight of the health of the fetus or child? Because of the limited time I will touch on a number of points although ultimately this remains a superficial account.

My analysis is based on qualitative interviews with approximately 100 women, 83 of whom, are First Nations, Inuit or Métis and approximately 90 service providers including addiction specialists, outreach and pregnancy services, community centers, shelters, medical practitioners and social workers. At the time of the interviews most of the women were living off-reserve in urban or rural communities in Manitoba or Quebec, however some were currently living on-reserve, while other women regularly traveled back and forth from their home community to an urban center at different periods throughout the year. All reported having substance abuse problems, with alcohol being the substance of choice for most women. Tobacco use among this group was also high.

In general, the women in this study can be described as extremely poor, receiving social assistance, most experience high levels of mental distress, most have experienced sexual and/or physical abuse as children and/or adults, some have experienced multiple foster placements as children or were forced to attend residential schools, most have poor, and in many instances declining health, and have limited positive social networks and supports.

Service providers report that premature death in general is high among this client group, but especially true for Aboriginal women who continue to abuse substances into their thirties and forties. Premature death is usually the result of an alcohol-related illness, accident, violence, or is AIDS-related. Service providers report that these women generally do not have custody of any of their children when they die. Two questions that I would like you to think about and that I will come back to again in my discussion is, “Why when we are so outraged at babies being born with FAS are we seemingly indifferent to young women, many of whom are Aboriginal, dying from alcohol or drug-related causes?” and, “If we were to focus our outrage on this group of “high risk” women and improvements to their wellness and well-being, would our efforts at FAS prevention be more successful for the fetus, child, mother, and society?”

Returning to my first question, “what becomes visible that was previously hidden?”

1. The first thing that becomes visible is that we have framed substance abuse by pregnant women and FAS prevention as more of a moral issue than an issue of addiction. In doing so we have tried to capitalize on the relationship that a pregnant woman has with her unborn child, and use societal notions of “proper mothering” to motivate pregnant

women to cut down or stop their use of dangerous substances. While this may work for women without substance addictions, it ultimately masks the real issue for women who are at “highest risk,” that being their addiction. For these women alcohol or tobacco use is not a simple matter of choice but is grounded in physiological, psychological, and environmental variables that collectively contribute to their abuse.

Secondly, by focusing on the mother and fetus/child “relationship” we miss the fact that most pregnant women when they abuse substances are responding to other relationships such as those that they have with social workers, service providers, partners, family members, and friends. Alcohol or drug abuse in this context is often a meaningful and very powerful act for women who generally feel completely powerless in their lives and relationships. For example, it is a way to express to partners or social workers feelings of pain, hurt, anger, and loss, a way to conform to peer pressure, and a way to “self-medicate” in order to cope with stress, traumatic experiences such as sexual or physical abuse, guilt, and shame.

2. In general pregnancy is a protective factor for Aboriginal women with substance abuse problems. Increasingly women who abuse substances are attempting, with greater or lesser success, to make healthier lifestyle choices when pregnant than when they are not pregnant. This suggests that the public health message has to some degree reached these women. Many women reported that they tried to improve their diet and about a quarter took prenatal vitamins during some or all of their pregnancy.

A small group of women in this study deserve special attention. These are women who are heavy substance abusers and because of their addiction either decided or

were coerced by others to have a tubule legation. While heeding the public health message, the steps taken by these women result in them simply falling off our radar map. Our focus on the fetus and child effectively means that we lose sight of these women because they never become pregnant again. In the continuum of care, addicted women who heed the public health message by deciding to have a tubule legation become invisible unless they end up in a hospital or in jail. This decision, in cases where the woman's children are all in permanent foster care, may actually end up placing her at greater risk of premature death.

3. For pregnant Aboriginal women living in some reserve and northern communities, and even for some women living in urban ghettos, access to healthy food, clean water, and proper sanitation is a daily struggle. While I believe that it is important that we focus on alcohol abuse, equally we need to acknowledge risk factors that interface with alcohol abuse to negatively impact on the health of the woman and fetus, such as Vitamin A deficiency, environmental contaminants such as lead, and the prohibitive cost, if they are even available, of fresh fruits, vegetables and meat in northern communities.

4. Limited incomes and the chaotic lifestyles of "high risk" pregnant women contribute to their being undernourished. Community meals at Friendship Centers and outreach centers are important sources of nutrition and support for Aboriginal women and provide a valuable social context in which outreach workers can work alongside women preparing

food, sharing a meal with them, and build relationships in a context that is not focused on the woman's "problems."

5. I cannot stress the importance of offering a safe place for women and their children where meals can be cooked together and shared, and where women can relax apart from the struggle of their everyday lives, including their substance addiction. We have become very program oriented and offer a range of programs for "high risk" women, however, we forget that just like us, relaxation without structured activities is necessary, especially for pregnant women.

Many "high risk" women do not have a place to go to where relaxation with other people is not automatically combined with alcohol or drug abuse. This is particularly true in the evenings and on weekends. A safe and supportive context where substance abuse is prohibited gives women a reason and opportunity not to abuse substances. It also allows service providers the opportunity to build trust over time and to reach out to "high risk" women who have little or no positive supports in their lives.

6. Building healthy social networks between women and between families to prevent FAS takes time. It was evident that women with substance abuse problems, past or present, understand each other and can support one another in ways that most service providers simply cannot. The best way to begin building support networks to help prevent FAS maybe by avoiding the "problem" of alcohol abuse. Some service providers said that they could be more successful with "high risk" women, particularly in smaller communities where issues of confidentiality deter women from accessing

services, if they could avoid attaching “problems” such as FAS, addiction, and alcohol abuse to their outreach services. They suggested that prevention begin by building upon the strengths and priorities of the community, for example by offering healing circles, community suppers, or a sewing group for women. One of the biggest barriers to this type of approach is that provincial and federal government generally fund programs for “problems” rather than program for community priorities.

7. A shortage of appropriate space for services to be housed is a key concern in small communities, as are issues of confidentiality. For example, services providers from an outreach program in a northern community in Manitoba said that women avoided their FAS prevention program for pregnant women because it was offered in the same building that housed child and family services. Women were afraid that their social worker would find out about their pregnant and alcohol abuse and then apprehend their children or their baby at birth.

8. Inuit, Métis and First Nation women come from very diverse cultural and social backgrounds and often this diversity is masked by the category “Aboriginal.” Services for Aboriginal women need to reflect this diversity.

9. Programs that in the opinion of service providers are well designed, may present unanticipated problems for women. For example, one young woman in this study had lost custody of her son and was required by the courts to attend a parenting program and an outpatient addiction treatment program in order to regain custody of him. She was

very happy about the parenting class, and wanted to use this opportunity to prepare for his return. Her social worker made arrangements for the class however, upon arriving at the class the young woman realized that all the other mothers attending the class had custody of their babies, and she was the only one in the class that did not have her child with her. She was very embarrassed and ashamed, and left the class and never went back. Later that week she was chastised by her social worker who suggested the woman must not love her child enough otherwise she would of stayed at the class despite being embarrassed. Completely distraught because of her “failure” she relapsed, never regained custody of her child, and was pregnant again a few months later.

10. The women who had family and community support networks, even when alcohol abuse was common, were doing much better than women who were isolated from supports altogether. Sometimes one person, a supportive mentor or an outreach worker can make all the difference in a woman’s pregnancy and in her life.

11. Aboriginal women for the most part are receptive to service providers approaching them about their substance abuse and the possibility of their attending an addiction treatment program *if* it is done in a respectful nonjudgmental way. The women in this study had attended a range of addiction programs and their experiences were very diverse. In accessing addiction treatment and other services there are numerous barriers and gaps. Those in need of particular attention include:

a. There are very few services, and in some communities no services, for pregnant woman who present for services while intoxicated. For example, if a pregnant woman is drinking and decides she wants help or wants to get off the street there are limited services that can accommodate her before she sobers up. If she is drunk and fleeing an abusive boyfriend, women shelters, for obvious reasons, cannot accommodate her and apart from asking for help from the police or getting arrested there are very few places she can turn to.

If a pregnant woman is living at a shelter or attending an outpatient or residential treatment program she maybe, again for obvious reasons, asked to leave the shelter or program because she is drinking. However, while a zero tolerance rule maybe necessary, there are inadequate concessions for when relapse occurs even though it is acknowledged that relapse is very common among chronic abusers.

b. While in some provinces pregnant women are prioritized for addiction treatment programs, this is not the case in all provinces. In general women can face waiting lists anywhere from a few weeks to a year to access addiction treatment program.

c. Compared to non-Aboriginal women, Aboriginal women are much more distrustful of service providers, especially social workers. This mistrust is generated from a long legacy in this country of colonialist oppression of Aboriginal peoples that is reinforced by the experience of individual women. We need to understand that for Aboriginal women, FAS, although this varies from community to community, is almost always framed as a child custody issue. For example, fear of child apprehension is a central reason why

Aboriginal women do not access addiction treatment programs, prenatal care, and other support services. Aboriginal women are, for good reason as history tells us, extremely fearful of losing custody of their children and/or losing custody at birth of their baby.

The difficulty here lies in the fact that child and family services are mandated to ensure the safety of the child. For many Aboriginal women this produces an adversarial relationship with the social workers of their children. Added to this is the heavy workload that most social worker carry. As one social worker explained, they are often doing case management rather than social work.

This adversarial relationship can be a risk factor for increased substance abuse by pregnant women. For example, women reported dramatic increases in their abuse of substances when child welfare services apprehend their children. This indicates that apprehension of other children can be a serious risk factor for the fetus as well as the woman. However, because the mandate of the social worker is the child the social worker has limited resources to address the immediate needs of the woman resulting from the apprehension. While after the apprehension social workers may try to coerce the mother into treatment by threatening to apprehend her baby at birth if she is pregnant, or as a requirement to gain custody of her children, this does not happen immediately and adds to the animosity between the social worker and the mother.

d. Women who use inhalants are typically Aboriginal, and there are very limited outreach and addiction services to address their special needs.

12. Presently there are enormous gaps between addiction treatment and mental health services in many parts of Canada for both Aboriginal and non-Aboriginal peoples.

13. Not all pregnant women, especially younger women or women who have never been to a treatment program, are willing to travel away from their family when they are pregnant even though they may want to find ways to decrease their use. However, in many local contexts there are limited, or no addiction treatment options.

14. For women being sent from their reserve to urban centers to give birth, this waiting period of up to four or five weeks can be extremely stressful and lonely, and there are often inadequate supports for the women, factors that can contribute to alcohol abuse.

15. There is an extreme shortage of aftercare services for women who complete addiction treatment programs. Many women in this study did very well in the treatment programs however progress made in a four week program or even a residential one-year program can be undone very quickly if appropriate and adequate after care support is not available. Several pregnant women in this study said they relapsed after completing their treatment partially because there were no after care services for them.

16. Most of the pregnancies of the women in this study were unplanned and many women did not use contraception on a regular basis. However, while family planning is an important element, prevention of pregnancy should not be the central focus. The central focus must remain on alcohol abuse. The problem with overemphasizing pregnancy

prevention is that it fails to address alcohol abuse problems, and eventually these women will stop using their contraception and become pregnant.

17. Aboriginal women are over represented in this “high risk” group, this reflects the social and economic marginalization of Aboriginal women in Canada, and therefore a broader focus on issues of poverty, racism, and marginalization is warranted in FAS research and policy and program development.

19. There is a great deal that non-Aboriginal people can learn from the successes of Aboriginal designed FAS prevention and intervention services in both urban and rural/reserve contexts.

2. How can we rethink public health strategies as a result of this shift in focus?

1. We need to address FAS prevention first and foremost as an addiction and substance abuse issue.

2. Try to reinforce the protective factors that exist for women when they are pregnant to periods when they are not pregnant. For example, easy access to treatment programs, improvement in diet, and better community and social supports.

3. A community action plan that is coordinated among service providers for woman, particularly a pregnant woman, who want help for their substance abuse. A two or three

day waiting period while treatment services are being arranged can be a very long time in the life of a woman with an addiction and having immediate support services that reinforce her decision and provides transitional housing, if necessary, for her to stay until arrangements are made for her to enter a program is essential.

4. Coordination and communication between addiction programs, mental health services and front-line service providers to match the needs of women with appropriate treatment programs and after care services. Jurisdictional matters such as cost of transportation need to be better coordinated in some provinces.

5. Creation of more “safe places” for women and their children.

6. Services for pregnant women who present for services while intoxicated.

7. Funding of community priorities rather than community “problems,” including control by communities over service design, delivery, and evaluation.

8. Aftercare supports need to be integrated and coordinated with treatment programs, and involve the support network of the women, including service providers.

9. Recognition of the central role that child welfare services places in the lives of pregnant women, and the development of strategies that facilitate as much as possible the

breaking down of the adversarial relationship between mothers and the social workers of their children.

10. Empowerment of Aboriginal communities, especially women and Elders, to set the priorities for FAS prevention and intervention. This would include ways to facilitate sharing of information between Aboriginal communities, adequate human and financial resources, and support of Aboriginal self-determination.

Now for my last question,

3. By making FAS as a “women’s health issue” do we lose sight of the health of the fetus or child?

The simple answer is no, definitely not. However, that’s too simple, therefore I give the last word to one of the women in this study. I will finish by reading from a brief transcript of a conversation I had with her and that she agreed could later be published and used for purpose such as those today: