

Fetal Alcohol Syndrome and Women's Health

Setting a Women-Centred Research Agenda

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FINAL REPORT

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Dear Reader:

This report summarizes the discussions and recommendations arising from a three-day workshop hosted by the British Columbia Centre of Excellence for Women's Health in Vancouver, British Columbia, Canada on May 5, 6, and 7, 2002.

The object of the workshop was to examine the issues related to Fetal Alcohol Syndrome (FAS) using a women's health framework. Specifically, an evolving model of "women-centred care" was used to develop a research agenda that would encompass women's health issues and contribute to a preventative approach to FAS. This approach is rooted in previous research at the British Columbia Centre of Excellence for Women's Health that focuses on improving the health of the mother-child unit.

Twenty-eight individuals from Canada (and one guest from the United States) representing diverse disciplinary backgrounds and sectors participated in the workshop. We thank all of these participants for their commitment and energy and their collective contribution to the recommendations in this report.

The workshop was made possible through the generous support of the Institute of Gender and Health, Canadian Institutes of Health Research and in partnership with the Atlantic Centre of Excellence for Women's Health, the Prairie Women's Health Centre of Excellence, the National Network on Environments and Women's Health, the Canadian Association of Community Living, and the Canadian Women's Health Network.

We also wish to acknowledge support from the Women's Addiction Foundation and The Aurora Centre at British Columbia Women's Hospital for Dr. Norma Finkelstein's public lecture entitled **Guiding Recovery: A women-centred, trauma-informed model of care for substance-using women and their families.**

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Fetal Alcohol Syndrome and Women's Health: Setting a Women-Centred Research Agenda FINAL REPORT

BACKGROUND

While Fetal Alcohol Syndrome was first identified in the American literature in 1973, in Canada discussion and action on Canadian research began fifteen years later with a conference held in Vancouver in 1988, sponsored by the BC FAS Resource Society, Sunny Hill Health Centre for Children and the University of British Columbia. FAS has not been widely accepted and acted on internationally, the UK for example bases policy and intervention on a wider conceptualization of maternal risks. Within Canada, there exist differences in uptake on FAS-related issues, with more attention and action brought to FAS in the western provinces. Aboriginal communities have been the subject of considerable scrutiny on this topic. Over the past nine years in Canada, interest and action on Fetal Alcohol Syndrome has mounted significantly. At the time of this workshop on Fetal Alcohol Syndrome and Women's Health in 2002, the following key funding and policy initiatives have been put in place:

- The four western provinces and three territories have organized into a consortium called the Prairie Northern FAS Partnership designed to support coordinated strategic action on FAS issues
- Health Canada has put into place an 18 member National Advisory Committee on Fetal Alcohol Syndrome/Fetal Alcohol Effects as well as a National First Nations and Inuit CPNP/FAS/E Steering Committee
- In January 2000, Health Canada began a three-year, \$11 million *Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) Initiative*. This funding has been allocated to enhance FAS/FAE activities related to: a) public awareness and education, b) training and capacity development, c) early identification and diagnosis, d) coordination, e) surveillance, and f) a strategic project fund designed as a first step towards supporting existing FAS/FAE activities across the country as well as creating new ones where no previous activity or capacity exists.
- The 2001 federal budget included \$25 million dollars in new funding for FAS prevention efforts on reserves.
- The 4th edition of FAS/FAE Information and Support Services has been published by the Canadian Centre on Substance Abuse with support from Health Canada, the Brewers Association and the Distillers Association, listing 355 national, provincial and local groups working on FAS.

This significant level of policy, programming, and funding action has been put in place in the absence of a clear foundational evidence base. Critical foundational questions remain unanswered such as:

- What level of alcohol intake is necessary for fetal alcohol syndrome and other alcohol related birth defects and developmental disabilities to occur?
- Is alcohol use during pregnancy in and of itself the cause of Fetal Alcohol Syndrome and other alcohol-related birth defects and developmental disabilities, or must one or more other conditions also exist such as poor nutrition, poor general health, high stress levels such as those associated with mental health problems, experience of violence by pregnant women?

- How are diagnoses of FAS, partial FAS, alcohol related birth defects, and other alcohol related developmental disabilities best made?

The historical interest in Fetal Alcohol Syndrome reflects the overall interest in child health and “child centred” policy in general in Canada. Indeed all of the initiatives announced by governments have been contextualized as part of an agenda related to early childhood development. For the FAS field overall, a tension exists between the interest in the identification, diagnosis, intervention, and support of infants and children affected by FASD and the interest in the complexity of problems facing substance-using women that contribute to health problems in their children.

It is in this context that the British Columbia Centre of Excellence for Women’s Health (BCCEWH) (with its mission to improve the health of women by fostering collaboration on innovative, multi-disciplinary research endeavours and action-oriented approaches to women’s health initiatives, women-centred programs and health policy), assumed a leadership role in building a broader research agenda. In its research and policy work to date, the BCCEWH has paid particular attention to policy that will improve the health status of women who are marginalised and who face multiple disadvantages in health due to socio-economic status, ethnicity, culture, age, sexual orientation, geography, disability, and/or addiction.

Research on addiction-related issues undertaken by the BCCEWH has resulted in the identification of the benefits of a women-centred approach that focuses on the mother-child unit, and takes a holistic, comprehensive, multi-sectoral (i.e., merges social, cultural aspects, clinical practices, and biomedical perspectives), and harm reduction approach (Greaves, L., Varcoe, C., Poole, N., Morrow, M. H., Johnson, J., Pederson, A., & Irwin, L. 2002. *A Motherhood Issue: Discourses on Mothering Under Duress*. Ottawa: Status of Women Canada). It is possible that utilizing a women-centred framework in addictions intervention could result in a reduction of FAS. Described below is the format of the workshop followed by a series of recommendations for how the Institute of Gender and Health and its partners should pursue a woman-centred approach to the reduction of the occurrence of FAS and other alcohol and drug-related birth defects and developmental disabilities.

THE WORKSHOP

A three-day workshop was hosted by the British Columbia Centre of Excellence for Women’s Health on May 5, 6, and 7, 2002 in Vancouver, British Columbia. The workshop brought together experts to develop a plan to effectively respond to substance-using women of childbearing years (including pregnant women) with the goal of reducing the incidence of Fetal Alcohol Syndrome in Canada. Specifically the participants sought to expand the approach to addressing the issue of Fetal Alcohol Syndrome by developing a complementary, innovative, woman-centred perspective.

The aim of the workshop was to reflect on the current knowledge base and develop a research agenda to be used by the Institute of Gender and Health and other CIHR Institutes (e.g., the Institute of Neurosciences, Mental Health, and Addictions, the Institute of Health Services and Policy Research, the Institute of Human Development, and Child and Youth Health) for research programming activities in the area of FAS and women’s health. Specifically, these activities will be aimed at developing

effective knowledge generation in prevention and intervention strategies for substance-using women of childbearing years and their families.

Twenty-eight individuals from Canada (and one guest from the United States) representing diverse disciplinary backgrounds (e.g., sociology, psychology, nursing, anthropology, medicine) and sectors (e.g., community researchers, academics, policy makers, representatives from not-for-profit organizations, aboriginal people and government), participated in the workshop.

The format of the workshop involved opening presentations on *The Uterine Tradition* by Dr. Lorraine Greaves of the British Columbia Centre of Excellence for Women's Health and *The US Experience in Addressing Substance Use in Pregnancy* by Dr. Norma Finkelstein of the Institute for Health and Recovery in Boston. These opening presentations were then followed by individual presentations/discussions in each of the following areas:

- *Bringing a women-centred approach to broad publicly focussed FAS prevention strategies*
- *Bringing women-centred approach to FAS prevention strategies focussed on women of child-bearing years and their support systems*
- *Bringing a women-centred approach to FAS prevention focussed on pregnant substance-using women and their support systems*
- *Bringing a women-centred and culturally competent approach to FAS prevention focussed on pregnant, substance-using Aboriginal women*
- *Additional issues re: mothering and substance use*

Individual presentations were then followed by group responses to the issue under debate. The content of the presentations and responses included an overview of current knowledge in each of these areas, gaps in knowledge in each area, and critical research questions, to be considered when designing and conducting research on these issues.

Linked to this 2-day session was a public lecture on Monday, May 6, 2002 presented by Dr. Norma Finkelstein from the Institute for Health and Recovery in Boston entitled *Guiding Recovery: A women-centred, trauma-informed model of care for substance-using women and their families*. This lecture was funded through the Institute of Gender and Health's New Perspective on Gender and Health Program, the British Columbia Centre of Excellence for Women's Health, The Women's Addiction Foundation and The Aurora Centre. The lecture was attended by approximately seventy people working in women's health, substance use, and related health and social justice fields.

A notable effort to bring attention to the need for a stronger evidence base to the FAS field and to point to promising practice in both prevention and intervention on FAS was a Health Canada-funded project undertaken by the Canadian Centre on Substance Abuse in 1999/2000. This project resulted in the publication of the report entitled *Best Practices Fetal Alcohol/Syndrome/Fetal Alcohol Effects and the Effect of Other Substance Use During Pregnancy*. This document was used as a conceptual base for this workshop.

The *Best Practices* document includes a review of the literature in the area of pregnancy, mothering, and substance use. A bibliography of articles published in the past two years since the publication of this document is appended to this report.

RESEARCH AGENDA FOR A WOMEN-CENTRED APPROACH TO FAS PREVENTION

UNDERSTANDING THE NATURE AND SCOPE OF WOMEN'S SUBSTANCE USE DURING PREGNANCY

Participants voiced their concern about the lack of Canadian data on girls' and women's use and misuse of substances in general, including substance use when pregnant/mothering. Also voiced by participants as a limitation of the current research literature was the limited substantive information concerning assessment of risk in relation to dose-effects or threshold level where alcohol and other substances become harmful during pregnancy. More research is required in order to determine how to measure the prevalence and incidence rates of substance use during pregnancy and the spectrum of birth defects and disabilities associated with prenatal exposure to alcohol in Canada. The following questions, generated by the group reflect these concerns.

- What is the prevalence, incidence, and epidemiology of girls' and women's use of alcohol, tobacco, and other substances in Canada?
- What are the rates of tobacco use in girls and women who drink alcohol during pregnancy?
- What are the rates of other substance use in girls and women who drink alcohol during pregnancy?
- How do we define (for research purposes) "use" versus "abuse" of substances? What are safe levels of consumption of various substances (e.g., cannabis, opiates, cocaine, benzodiazepines, alcohol, tobacco, etc.)?
- How do we incorporate tobacco & other substance use and abuse into FAS research?
- How do we determine the prevalence of FASD?
- A re-analysis of FAS/FAE data from selected cultural and social perspectives (e.g., Aboriginal, immigrant, and visible minority)

Another recurrent theme arising from workshop discussions was the need to fully understand pregnant and mothering women's qualitative experiences with substance use and misuse, including the influence of socio-environmental variables. These issues were raised in a number of presentations (including those by Norma Finkelstein, Lona Hegeman, and Wendy Reynolds). Additionally, different methodologies were suggested to comprehensively understand the issues faced by pregnant women, mothers, and women of child-bearing age.

- How do factors such as poverty, tobacco use, mental health problems, and experiences with violence, when present during pregnancy, interface with a woman's substance use, and with the biological processes which affect her overall health, including increased risk of giving birth to a child with FAS?
- How can a socio-economic cost analysis further our understanding of FASD?
- How can a longitudinal study be designed to investigate the experiences of women affected by FAS and other alcohol related birth defects and developmental disabilities?

- How can a life course analyses of diverse groups of women including their experiences with substances use throughout their life course further our understanding of how best to prevent FAS and other alcohol related birth defects and developmental disabilities?

ETHICAL CONSIDERATIONS

A number of ethical considerations were raised that need to be addressed in the context of any research on FAS and other alcohol related birth defects and developmental disabilities.

While the focus of this workshop was on prevention of FAS, rather than on diagnosis and interventions with those affected, issues related to diagnosis were raised by some of the presenters and workshop participants. A principle concern was over the lack of availability of diagnostic assessments and the informal labeling, including self-diagnosis, of individuals as having FAS. As reported by participants this is a growing concern and largely involves Aboriginal populations where awareness of FAS is high. In some communities Aboriginal women were reported to be increasingly labeling themselves and their children as having FAS, apart from a formal medical assessment. Others reported that in some cases a general consensus had been formed that rates of FAS in ‘high risk’ communities where alcohol abuse is perceived to be widespread are reaching epidemic proportions, apart from individuals being medically assessed and knowledge about actual prevalence rates. In her presentation, Caroline Tait suggested that this type of informal labeling, self or otherwise, of individuals must be better understood in relation to Aboriginal people, as the implications of labeling an individual or a population present a range of social, health and ethical concerns. Several question were raised by this discussion:

- How do we best address the question of non-medical labeling within a medical context where formal medical assessments are difficult to access?
- How can consideration of racism as an underlying factor in the high rates of non-medical labeling of individual or cohorts of Aboriginal people be incorporated into methodological approaches and theoretical analysis of this phenomena?
- What are the advantages/disadvantages of being medically diagnosed as having FAS? What are the advantages/disadvantages of being informally labeled, self or otherwise, as having FAS? And how do the two experiences of labeling compare to one another?
- What would be an effective public health strategy to outline the dangers associated with informal diagnosis, and the importance of seeking medical confirmation about an FAS diagnosis?

Discussion also took place on issues relating to the potential of surveillance initiatives, that do not preclude effective relational work with women at risk, in contributing to our understanding of FAS.

- What is the role of drug screening, hair analysis, and other bio-markers? How are the results being used?
- Does surveillance contribute to our knowledge and/or how does it become intrusive and discriminatory?
- How do we ensure that surveillance and screening practices do not re-traumatize women who are survivors of trauma and/or prevent women from accessing pre and/or postnatal care?

PRIMARY PREVENTION AND HEALTH PROMOTION

The *Best Practices Fetal Alcohol/Syndrome/Fetal Alcohol Effects and the Effect of Other Substance Use During Pregnancy Primary Prevention* document described primary prevention activities as those that are “undertaken with a healthy population to maintain or enhance its physical or emotional health. Primary prevention activities are typically directed to individuals, focusing on behaviour change, or to their environment, addressing factors that influence individual or population health”.

One criticism leveled against FAS prevention efforts in general is that they traditionally have a narrow focus of providing information on substance use in pregnancy or FAS, through pamphlets, posters and educational sessions, as well as warning signage in public washrooms. A more comprehensive, integrated approach of the *Healthier Babies – Brighter Futures Community FAS Prevention Program* in Burns Lake, BC, was described in a presentation by Anne Price.

Workshop participants identified the need for, and the challenges inherent in undertaking integrated, multi-level health promotion and prevention work, that would have the broader goals of enhancing women’s health and preventing violence against women, substance use problems in women, mental health problems, and unwanted pregnancies. Key research questions generated in the workshop focused both on making FAS-specific prevention efforts more effective, and understanding the broader efforts needed to change the conditions of women’s lives that more fundamentally prevents substance use and related health problems. They included the following:

- How do women and girls respond to public media messages and policy?
- How can we support understanding on the part of girls and women of childbearing age of the concept of risk as it relates to substance use?
- What needs to be involved in public health messages and policies to minimize barriers (e.g. guilt, fear of accessing needed service in the event that their children are apprehended) for women?
- What combination of strategies (e.g., individual messages, community awareness activities, supportive services, supportive policy and community health promotion activities) will be effective in preventing/reducing substance use problems in women and substance use in pregnancy specifically?
- What strategies would be most effective in shifting the negative perception of substance-using pregnant/mothering girls and women held by practitioners and the public?

Evaluating the impact of broad based health promotion and prevention efforts presents numerous challenges, but in the investigation of prevention programming directed to youth, advances in research methods are being made, including long term analysis of changes in levels of use and changes in practices of community institutions by researchers associated with prevention programming funded by the Substance Use and Mental Health Services Administration in the US. Comparable studies of prevention work are much needed in the Canadian context.

SECONDARY PREVENTION

The *Best Practices Fetal Alcohol/Syndrome/Fetal Alcohol Effects and the Effect of Other Substance Use During Pregnancy Primary Prevention* document described the aim of secondary prevention as “to identify and address a problem as early as possible before it becomes severe or persistent. When applied to the issue of substance use during pregnancy, secondary prevention activities are directed at women of childbearing age who use substances and include outreach, screening, referral and brief intervention activities with the intent of promoting the health of the mother and preventing or minimizing harm to the fetus”. Susan Santiago described the secondary prevention work of the Alcohol Help Line offered through Motherisk. Callers to this toll-free help line are provided with information about FAS and referrals to appropriate services across Canada.

Dr Finkelstein provided information on early identification and brief intervention work being done in the USA that also meet secondary prevention objectives. She provided examples of self administered and professionally administered tools that support pregnant women and women of child bearing years in offering information about their use of alcohol and other risk factors (5P’s, MassASAP Screening Tool Checklist, Pregnancy Needs Assessment). She provided information on research demonstrating the effectiveness of these screening efforts and lessons learned in implementing such universal screening and brief intervention initiatives. She spoke knowledgeably on addressing provider barriers to screening and making treatment referrals, the advantages of using self administered tools to increase disclosure, and the usefulness of coordinating screening efforts with substance use treatment linkages.

Participants stressed their concerns with current practices related to screening and assessment, and the trend towards using technology-based versus relational approaches. The group agreed that research on the use of women-centred screening and assessment practices, that build on the American experience are important. Key research questions include:

- What comprises women-centred screening and assessment approaches and what is the impact of using them?
- What are the advantages and disadvantages to working with women’s support systems (i.e., partners, peers, and family)?

Concerns regarding the screening of women at risk (i.e., women of childbearing age, pregnant women, mothering women) were also raised:

- In the current context where universal screening is not implemented, who is being targeted for screening? Specifically in what ways are Aboriginal people over represented in those being screened for substance use in pregnancy and in those seen as affected by FAS and related disabilities. What is the impact of this on the health of Aboriginal women and their children?
- Who has a role in screening women at risk? What provider(s) are best positioned to screen for substance use in pregnancy?
- What does biomarking and other testing accomplish? What do we do with this information?
- Does web-based screening and advice help pregnant women who drink?
- How might provider attitudes to women who use alcohol and drugs and to the use of screening questionnaires in pregnancy be best influenced?

- How can providers support disclosure of substance use by different sub-groups of girls and women? How can we frame screening questions so that the health of the mother-child dyad is stressed and the threat of apprehension is minimized?

TERTIARY PREVENTION

The *Best Practices Fetal Alcohol/Syndrome/Fetal Alcohol Effects and the Effect of Other Substance Use During Pregnancy Primary Prevention* document described tertiary prevention activities as “those that target individuals in whom the condition has already developed. Applied to FAS and related effects, tertiary prevention may be viewed as intensive multi-component services, that include substance abuse treatment and birth control services directed to women and families at highest risk of delivering a child affected by substance exposure. Those considered at highest risk are heavy drinking women with few personal and social supports, along with women who have already given birth to an affected child”.

Understanding of the needs of the needs of women at highest risk of having a child affected by FAS is increasing. Dr Sterling Clarren of the University of Washington, a renowned leader in the FAS field has recently made a significant contribution to this understanding by studying the characteristics of the birth mothers of the children diagnosed as affected with the full Fetal Alcohol Syndrome. He found extremely high levels of mental health problems, universal experience of serious violence/abuse, controlling relationship that prevented women from stopping use and getting out of the home, as well as high levels of mortality.

Dr Finkelstein and other participants at the workshop identified the importance of preventing FAS and improving the health of women using integrated, multi focus treatment models that:

- are based on understanding of the multiple and complex links between experience of trauma and substance use problems,
- build on women’s strengths and competencies and avoid confrontational approaches
- stress development through making and maintaining connections with others,
- are culturally competent
- use harm reduction practices, transdisciplinary care, one-stop access and other methods to reduce barriers and access to care

Many research questions were generated in this topic area, including:

- How can we integrate interventions that take into consideration history of trauma, substance use, and mental health?
- How can we integrate the service needs of both substance-using pregnant/mothering women and the fetus/child?
- How do we reduce barriers to substance use treatment for women and girls and support them to stay in treatment once they get there?
- What are the best practices regarding harm reduction as a tool for addressing substance use by women of childbearing age, pregnant women, and mothering women?
- Can a community offer an outreach treatment program that includes after-treatment and addresses trauma?

- What are some effective strategies for involving partners in tertiary prevention efforts?
- How do we integrate understanding of tobacco as a problem drug and provide integrated intervention?

The role of women as mothers is inextricably linked to the prevention of FAS and other alcohol related birth defects and developmental disabilities. Our focus in preventing FAS must support women in mothering, as well as support their changes in health and substance use at the point of pregnancy. A recent study undertaken by the BC Centre of Excellence for Women's Health researchers, soon to be published by Status of Women Canada found current media discourse and policy to be strikingly unsupportive and disapproving of mothers with substance use problems. Workshop presentations by Margaret Leslie of the Breaking the Cycle program and Dr Peter Selby of St Joseph's Hospital in Toronto, as well as Dr. Ron Abrahams of the Sheway Project and BC Women's Hospital in Vancouver spoke to the importance of directly addressing the very real barriers experienced by pregnant women and mothers to identifying their needs, and the strong need for collaboration with the child welfare system if these barriers are to be eliminated. Discussion took place on the needed changes to substance use, health and other social services to make them welcoming and supportive of the mothering role and research questions such as the following were generated:

- How do we meet the needs of women using substances in their roles as mothers?
- How do we balance/integrate our service response to substance-using mothers and their children?
- How can drug use be compatible (or not compatible) with adequate child care? Under what circumstances can a woman's substance use be compatible with adequate child care?
- What resources and/or supports in a woman's life will enable both substance use and adequate child care?

DEFINING AND MEASURING WOMEN-CENTRED CARE

A model of women-centred care, as it has evolved in discussion and practice in Vancouver over the past three years was introduced (See Appendix). Issues surrounding how to define, implement, measure, and evaluate "women-centred" care, programs, and services were raised. Further, participants felt it is important to demonstrate that a women-centred approach directly benefits women at risk.

- How is women-centred care defined and/or measured? What are the elements of "women-centred care"?
- How can we evaluate the extent to which a program or service is "women-centred"?
- How "women-centred" are existing FAS/FAE programs, services, and educational videos?
- What are culturally appropriate models of care for Aboriginal women and are they compatible with a women-centred approach?
- What is a women-centred approach to delivering a diagnosis of FAS and the spectrum of other birth defects and disabilities associated with prenatal exposure to alcohol?
- Do women-centred practices lead to better treatment outcomes for women compared to traditional practices?

Participants stressed the importance of involving women at risk (i.e., pregnant, substance-using pregnant/mothering women) in the planning, design, and implementation of research, programs, and services. Among the relevant questions raised include the following:

- How do pregnant women who drink alcohol estimate the risk to their fetus?
- What do women of child-bearing age think about alcohol consumption and FAS in pregnancy?
- How would women of child-bearing age like to be screened for substance use problems?
- How do we involve women in designing and delivering all levels of care?

Another theme emphasized by participants is the need for a coordinated response to developing and implementing women-centred programs and services. Several American studies have identified the benefits of perinatal service networks (Grason et al. at John Hopkins and Brindis et al. in California). A coordinated response would include the involvement of government (municipal, provincial, and federal), universities, non-government organizations (NGOs), health service providers, women accessing help, etc.

- How can the various sectors, service providers, funders, and so on, be brought together to coordinate services, research, data collection, and to have discussion that will lead to cohesiveness and mutual learning? (e.g., models for coordinating on system and service-delivery levels could be developed and tested)
- How do you train front line providers and organizations to do women-centred care?
- How do we facilitate/promote/nurture community service partnerships in support of women using substances? How do we evaluate the effectiveness of these networks of support?

POLICY ISSUES

Workshop participants felt it that it is crucial to identify, compare, and contrast policies relevant to the field of FAS initiated by the provincial government, the federal government, and the international community. Dr. Deborah Rutman presented the main findings of the Status of Women Canada policy document, *Substance use and pregnancy: Conceiving women in the policy making process* (Rutman, Callahan, Lundquist, Jackson, & Field, 2000). Additionally, ethical and practical complexities arising from policies targeted at substance-using pregnant women were raised in a number of presentations (e.g., Ron Abrahams and Caroline Tait) and in the general group discussion. Key research questions arising from these presentations and discussions included the following:

- What is the impact of the different approaches in each province? Are there any provinces where the ministries are working well together?
- What are some of the FAS policies in other countries (e.g., USA and UK) and can they be integrated into Canadian FAS policy?
- What other impacts do policies have on the behaviour of pregnant women (e.g., increasing use to cause a miscarriage)?
- How can FAS programming and policy be conceptualized as being both women- and child-centred rather than a dichotomy?

RECOMMENDED THEME AREAS TO PURSUE

The workshop provided the opportunity to critique current research and best practices in prevention and intervention strategies and health services aimed at providing support to substance using women and their families. It is difficult to put the areas discussed in order of priority.

- The *epidemiological* data is a critically needed foundational piece. This is an important priority for a national research agenda as provinces have not had the scope of perspective or resources to take this on independently.
- Another high priority area relates to the important *ethical* issues raised at the workshop, such as questions about the impacts of diagnosis, labeling, selective discrimination in screening and intervention, assumptions about causation, etc
- In order to see changes in practice, studies are needed that define and support pragmatic, effective, *women-centered interventions*, for each level of intervention and for achieving a balance of amongst primary, secondary and tertiary prevention efforts.
- Research that addresses issues of *mothering, maternity and substance use* is also of priority. Critical questions regarding the development and application of child welfare policy that integrates a supportive response to substance-using mothers and their children need to be answered if we are to effectively address the health needs of women and their children and particularly if we are to increase access to care.

Clearly the workshop provided the opportunity for rich discussion of an expanded FAS research agenda from a woman-centred perspective, that involves a focus on positive health outcomes for the mother-child pair, without prioritizing the needs of one over the other. We see a role for the Institute of Gender and Health in bringing this expanded FAS research agenda forth to add to the efforts undertaken by the Institute of Aboriginal Peoples' Health and the Institute for Human Development, Child and Youth Health in their workshop "Developing Strategies and Proposals for Fetal Alcohol Syndrome Research in Canada", held in March 2002 in Saskatoon. At this point, the potential is strong for easing the historical tensions between child- and women-centred approaches, for effectively integrating research that addresses all four CIHR pillars, and for coordinating national research efforts aimed at developing effective prevention and intervention strategies for substance-using women of childbearing years and their families.

Beyond setting and implementing a complex FAS research agenda, it will be important in the long term to translate this research into changes in practice and policy. It is recommended that the Canadian Centre on Substance Abuse, in collaboration with other national and provincial organizations with a stake in women's health, the prevention and treatment of substance use problems, the health of Aboriginal peoples, and pre/post natal health take on the essential role of ensuring that this research agenda is part of a larger strategy to deliberately influence programs and practice across the country.

VEHICLES FOR FUNDING

We propose models of funding that would be appropriate for the development of a women-centred approach to the prevention of Fetal Syndrome Syndrome: 1) Interdisciplinary Health Research Teams, 2) Network Funding; and 3) Funding for Community-Based Researchers.

INTERDISCIPLINARY HEALTH RESEARCH TEAMS

To have any level of success in creating an evidence base for the prevention of FAS there is a critical need for interdisciplinary research. Funding opportunities for Interdisciplinary Health Research Teams (IHRT) would allow researchers from different disciplines and sectors to pool their expertise, perspectives, and resources to address, for example:

- health promotion and nutrition among women of childbearing years
- prevention of substance use, violence, and mental health problems among women of childbearing years
- models of interdisciplinary and transdisciplinary intervention by health service providers that support women's access to care in the perinatal period

NETWORK FUNDING

Initiatives for general networking on the part of the broad spectrum of individuals, families, service providers, and others interested all aspects of FAS are taking place, largely through conferences and workshops. However there is need to develop and maintain mechanisms for linking researchers to develop research programs of interdisciplinary and collaborative research across key areas of relevance to the prevention of FAS (e.g., women's mental health, Aboriginal mental health, violence against women, women's substance use). For example, the momentum of this network interested in developing a women-centred approach to FAS (initially developed through the New Perspectives on Gender and Health Program) could be maintained through on-going funding by the Institute of Gender and Health to further develop resources and research programs. This funding could facilitate in-person and video-conferencing to continue to identify research priorities, develop research proposals, and build collaborative research teams in Canada around the complex issues of maternal substance use, mental health and experience of violence. Further, this funding would allow experts in women-centred health to work collaboratively with other researchers working on FAS in Canada through the Institute of Aboriginal Peoples' Health, the Institute for Human Development, Child, and Youth Health, and other CIHR Institutes.

FUNDING FOR COMMUNITY-BASED RESEARCHERS

Community-based researchers often do not have the resources (i.e., staff, funding, expertise, and so on) to develop research proposals for submission in CIHR grant competitions. Further, the criteria for evaluating the work of a community-based researcher frequently does not apply (e.g., number of peer-reviewed articles published, number of grants held, and so on). Despite these facts, the issue of involving community-level researchers and service providers in the research process as a means of bridging research, policy, and practice was frequently mentioned in this workshop and previous workshops organized and hosted by the BC Centre of Excellence for Women's Health. Funding for community-based researchers could take several forms: seed funding, community partnerships, funding programs, retraining awards, and so on. All of these funding programs could potentially allow for a community-based researcher to assume primary responsibility for a research project with the support and feedback of one or more academic or research institute-based researcher.

BRIDGING THE FOUR CIHR PILLARS

As described above, a mechanism for bridging the four CIHR pillars may be for the ICRH to commit funding for research programs that involve Interdisciplinary Health Research Teams. Interdisciplinary research and understanding is central to the achievement of national goals for prevention of fetal alcohol syndrome. An important dimension of research on maternal substance use and women's health is policy research foundational to policy that promotes the positive intersection of public policy on child welfare, mothering, women's and children's health and the health of Aboriginal peoples. Policy research can be considered as a fifth pillar for constructing IHRs.

KNOWLEDGE TRANSFER AND TRANSLATION

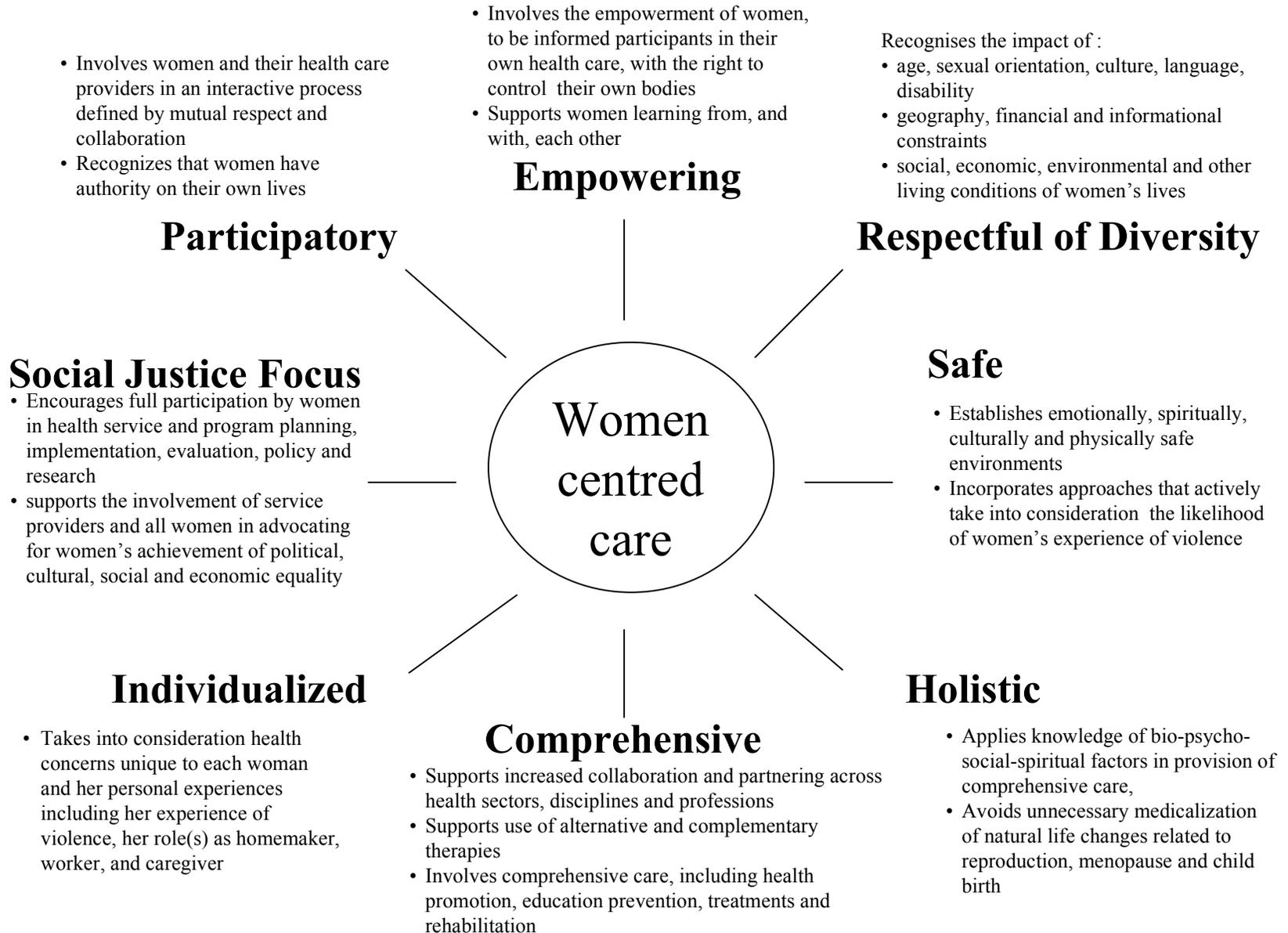
The importance of bridging research and practice was raised often during the workshop. Knowledge transfer and translation is an important component for the research programs suggested above. While academic publications are a key means for dissemination, it is as crucial to translate into practice, program development, clinical guidelines, policy, media strategies and lay publications. The Centres of Excellence for Women's Health Program (CEWHP) has developed a knowledge transfer strategy that targets individuals and organization in key sectors including academics, service providers, community researchers, policy/decision makers and government representatives at regional, provincial, and federal levels. Research findings are published in a series of reports appropriate to a variety of target audiences, (e.g., peer-reviewed journal articles, non-peer reviewed reports for academic audiences, short reports in lay language, full reports for policy makers, etc.). A range of other strategies for knowledge transfer expand on these publication efforts. Similarly, on the topic of FAS and its prevention, the Canadian Centre on Substance Abuse has developed mechanisms for knowledge transfer including notices of new reports posted on the website, opportunity to download resources from their website, online support for practitioners looking for information on best practice (FAS Tool Kit), as well as distribution of print reports.

All of these strategies can be utilized and built on to ensure successful knowledge transfer and translation. In addition, there is strong potential for information sharing and collaborating with service providers, community researchers, policy makers, parents and advocates as they gather in forums such as conferences and community FAS prevention agenda building processes. Again, established mechanisms such as initiatives taken by the Canadian Women's Health Network, the Canadian Centre on Substance Abuse, the Canadian Health Network, the National Native Alcohol and Drug Abuse Program (NNADAP), and the National Network for Aboriginal Mental Health Research (funded by the Institute of Aboriginal Peoples' Health) could be conduits for creating and transmitting such information.

APPENDIX A

KEY ASPECTS OF WOMEN-CENTRED CARE

Key Aspects of Women-Centred Care



APPENDIX B

WORKSHOP AGENDA

FAS and Women's Health: Setting a Women-Centred Research Agenda
BC Centre of Excellence for Women's Health
May 5, 6 & 7, 2002
Vancouver, BC

Co-Sponsored by

Atlantic Centre of Excellence for Women's Health
Prairie Women's Health Centre of Excellence
Canadian Women's Health Network
Canadian Association for Community Living
Women's Health Bureau, Health Canada

Venues for Workshop-Related Events

Sunday, May 5th, 2002	7:00 pm to 8:30 pm	<i>Reception</i>
Room Granville B Plaza 500 Hotel 500 West 12 th Avenue Vancouver, BC		
Monday, May 6th, 2002	8:00 am to 4:30 pm	<i>Workshop</i>
Room D306 Children's & Women's Health Centre of BC 4500 Oak Street Vancouver, BC		
Monday, May 6th, 2002	7:00 pm to 9:00 pm	<i>Public Lecture, Normal Finkelstein</i>
Auditorium Chan Centre 4480 Oak Street (SE corner of West 28 th & Oak Street) Vancouver, BC		
Tuesday, May 7th, 2002	8:00 am to 12:30 pm	<i>Workshop</i>
Plaza 500 Hotel 500 West 12 th Avenue Vancouver, BC		

FAS and Women's Health: Setting a Women-Centred Research Agenda

Workshop Agenda: Day 1

Please note that there will be short breaks (5 to 10 minutes) between each session.

Monday May 6th	
8:00 - 8:30 am	<i>Breakfast (provided)</i>
8:30 - 9:30 am	Brief introductions by participants The Uterine Tradition – Approach to FAS prevention and the need to bring a women-centred approach to research and practice <i>Dr. Lorraine Greaves, BCCEWH</i>
9:30 - 11:00 am	The US experience in addressing substance use in pregnancy – examples of programming, coalition work, policy and research <i>Dr. Norma Finkelstein, Institute for Health and Recovery in Boston</i>
11:00 - 12:00 pm	Bringing a women-centred approach to broad publicly focussed FAS prevention strategies (public awareness, community development, policy development) Discussion starters: <i>Wendy Reynolds, AWARE, Anne Price, Healthier Babies Burns Lake</i>
12:00 – 1:00 pm	<i>Lunch (provided)</i>
1:00 – 1:45 pm	Continued discussion on broad publicly focussed FAS prevention strategies (public awareness, community development, policy development)
1:45 – 3:00 pm	Bringing a women-centred approach to FAS prevention strategies focussed on women of child bearing years and their support systems. Discussion starters: <i>Nancy Poole, BCCEWH, Susan Santiago, Motherrisk</i>
3:00 – 4:30 pm	Bringing a women-centred approach to FAS prevention focussed on pregnant substance using women and their support systems Discussion starters: <i>Margaret Leslie, Breaking the Cycle, Dr. Peter Selby, St Joseph's Hospital, Dr Ron Abrahams, Sheway and BC Women's Hospital</i>

FAS and Women's Health: Setting a Women-Centred Research Agenda

Workshop Agenda: Day 2

Tuesday May 7th	
8:00 - 8:30 am	<i>Breakfast (provided)</i>
8:30 - 9:00 am	Review of Previous Day and Adjustments to Agenda
9:00 - 10:00 am	Bringing a women-centred and culturally competent approach to FAS prevention focussed on pregnant, substance using Aboriginal women Discussion starter: <i>Caroline Tait, McGill</i>
10:00 – 11:30 am	Additional issues re mothering and substance use - supports for mothers with substance use problems, supports for mothers of children affected by FAS, bringing the voices of mothers into both policy and practice . . . Discussion starter: <i>Dr. Deborah Rutman, University of Victoria</i>
11:30 – 12:30 pm	Other considerations, moving this agenda forth, wrap up
12:30 pm -	<i>Light Lunch (provided)</i>

This workshop is being funded through the Institute of Gender and Health's (IGH; of the Canadian Institutes of Health Research) New Perspectives on Gender and Health Program. The objectives of the New Perspectives program are to synthesize information and build research capacity in key priority areas in gender and health. The Public Lecture by Norma Finkelstein is being co-sponsored by the Women's Addiction Foundation.

APPENDIX C

WORKSHOP PARTICIPANTS

Participants for the FAS Workshop
May 2002

First Name	Last Name	Organization	Email
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APPENDIX D

GUIDING RECOVERY PUBLIC LECTURE ADVERTISEMENT

Guiding Recovery

A women-centred,
trauma-informed model
of care for substance-using
women and their families

a presentation by

Norma Finkelstein, Ph.D.

Founder and Executive Director

Institute for Health and Recovery
Cambridge, Massachusetts, U.S.A.

For info on the IHR programs: www.healthrecovery.org

PRESENTED BY



British Columbia
Centre of Excellence
for Women's Health



The Women's
Addiction Foundation



BC WOMEN'S
part of Children's and Women's
Health Centre of British Columbia
The Aurora Centre



CIHR IRSC
Canadian Institutes of
Health Research
Instituts de recherche
en santé du Canada
Institute of
Gender and Health

DATE

MONDAY
May 6, 2002
7:30 pm

Reception
7:00 to 7:30 pm
refreshments served

LOCATION

**Chan Centre for
Family Health
Education**

4480 Oak St.
Vancouver
(SE Corner of W. 28th Ave.
and Oak St.)

REGISTRATION

**Admission is Free
Everyone Welcome**

INFORMATION

British Columbia Centre of
Excellence for Women's Health
604.875.2633
bccewh@cw.bc.ca

APPENDIX E

BIBLIOGRAPHY

Fetal Alcohol Syndrome and Women's Health

BIBLIOGRAPHY

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