SPECIAL SUPPLEMENT

MOVING SYSTEMS TO IMPROVE WOMEN'S HEALTH AND PREVENT FASD: A POLICY FORUM
Summary of Proceedings and Recommendations

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ABSTRACT

A conference entitled *Prevention of FASD: Addressing Pregnancy and Addiction* was organized by the Prevention Subcommittee of the FASD Stakeholders for Ontario. The conference took place at the BMO Institute for Learning in Scarborough, Ontario on March 9 – 10, 2006 and was funded by the Public Health Agency of Canada. The objective of the conference was to examine the root causes of women's alcohol use during pregnancy, including addiction and mental health problems, and ways to support women with significant alcohol problems or addictions in pregnancy.

A pre-conference Policy Forum on March 9th from 4:00 pm to 9:00 pm focused on systems of care and policies that impact the development and delivery of programs and services to high risk women and children. An expert panel was tasked to consider how these systems and related policies might be integrated to improve women's health and prevent Fetal Alcohol Spectrum Disorder (FASD).

Conference Day on March 10th focused on indicated prevention which is directed to the care of pregnant women who have significant alcohol problems or addictions, and who require more than information, advice or brief interventions in order to change their alcohol use in pregnancy. The goals of the conference were to increase understanding of service providers who have contact with pregnant women with significant alcohol use problems, of their role in the prevention of FASD; share information about evidence-based strategies for support of pregnant women with significant alcohol problems, including the elements of effective models of care; and promote the importance of an integrated and comprehensive response to women's health and FASD prevention.

This report summarizes the highlights of the March 9th pre-conference Policy Forum and each of the invited lectures presented by panellists. It also summarizes the points raised during an open discussion period. The report concludes with a summary of the recommendations made over the course of the conference.

Moving Systems to Improve Women's Health and Prevent FASD: A Policy Forum brought together a panel of six experts, each of whom was asked to speak to a specific "system of care" and its relationship to FASD prevention.

Dr. Peter Selby, Clinical Director of Addictions Program and Head of the Nicotine Dependence Clinic at the Centre for Addiction and Mental Health, spoke to the issues and challenges of addressing addiction and mental health concurrently. *Margaret Leslie,* Director, Early Intervention Programs, Mothercraft (Breaking the Cycle), spoke to issues related to outreach for high risk women. *Susan Jack, RN, PhD*, School of Nursing, McMaster University, addressed violence against women. *Sharron Richards,* Children's Aid Society of Toronto, discussed child welfare issues. *Colleen Ann Dell,* Assistant Professor, Carleton University and Senior Research Assoc., CCSA, spoke to key issues surrounding surveys and surveillance for research purposes. *Nancy Poole*, Research Consultant on Women's substance Use Issues, BC Women's Hospital in Vancouver and the BC Centre on Excellence for Women's Health, was the discussion moderator.

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SUMMARY OF PANEL PRESENTATIONS

Susan Santiago of the Motherisk Program opened the evening Policy Forum by welcoming the 100 delegates and panellists and briefly describing the Forum's objectives. In her remarks, Ms. Santiago referred to three tiers of FASD prevention. The first is *universal prevention* that is usually directed to the general public in the form of public awareness campaigns, alcohol control policies such as increased taxation, responsible service and beverage warning labels.

The second tier, *selective prevention* is usually directed to women of childbearing age who consume alcohol. Selective prevention measures involve screening tools (such as the T-ACE and TWEAK), referrals to counseling and brief interventions.

The third tier is *indicated prevention.* Aimed at pregnant women who have significant alcohol use problems, this third tier of prevention requires access to comprehensive and integrated services designed to prevent or reduce harms associated with alcohol or other substance use in pregnancy. Ideally, indicated prevention pays attention to the social and economic conditions that influence prenatal alcohol use, such as housing and food security, access to primary health, prenatal care, and addiction treatment, and supportive personal relationships free from violence. Indicated prevention (rather than universal or selective prevention) was therefore the central theme of the conference.

"The challenge," Ms. Santiago concluded, "is finding a way to access and integrate the systems of care represented by our panellists and many of you in the audience, in order to deliver the support and care that many women need." She also acknowledged that while it was unlikely that solutions to those challenges would result from a 4 or 5 hour discussion, the evening's proceedings would table important issues and help promote deepening consideration and discussion in Ontario and elsewhere.

Nancy Poole of the BC Centre of Excellence for Women's Health then took the podium as first presenter and Forum moderator and set the stage for the evening discussion. Ms. Poole described the increasing attention to prevention of FASD in Canada over the past decade, and the emerging understanding of FASD prevention as a women's health and social justice issue. Work to understand and influence women's substance use in pregnancy was discussed in relation to: media and policy discourse related to women's substance use; developments in our understanding of women's substance use, and experience of trauma, stress, and income/housing security; as well as the emergence of harm reduction approaches to addiction. These opening remarks also established the framework for the discussion by co-panellists who were asked to consider the following questions:

- Does the system that you work in or study address women's health in the context of alcohol use and/or FASD?
- What policies impact your system's response to women's health and/or FASD?
- Could bridging your system and services with others improve women's health and pregnancy outcomes?
- Are there policy concerns that might impact such integration?

Need for a "woman-centered" shift in policies: Nancy Poole

In 1996 Winnipeg Child and Family Services requested assistance from the courts to involuntarily secure a young Aboriginal mother (subsequently known as Ms. G.) who continued to sniff solvents during her pregnancy and who child welfare workers felt unable or unequipped to help. In August 1996 a judge of the Manitoba court of Queen's Bench ordered that Ms. G. be detained in a health care facility because of concern about her mental competence. Ms. G. was pregnant and frequently sniffed solvents, a practice that was deemed potentially harmful to the foetus. The decision was set aside on appeal, and then that decision was appealed to the Supreme Court of Canada. The Supreme Court upheld the appeal court decision, which reconfirmed previous decisions – the foetus is not a person with rights in law. They referred the work of determining approaches to this serious social concern, however, to the legislature.

The Ms. G case served as a catalyst for policy discussion. It also sparked important debate that often became polarized around the rights of

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the woman versus the rights of the child, rather than addressing the needs and rights of the mother-child unit in an integrated way. The case highlighted the need for enhanced understanding and identification of risk factors surrounding pregnant women who are addicted to alcohol or other substances, and exposed the gaps in our systems of care. Barriers continue to exist in promoting a paradigm shift in policies related to alcohol use in pregnancy. These include the negative portrayal of women who use alcohol in pregnancy, especially the ascription of intent and choice to alcohol use in pregnancy by women who are addicted.

While awareness of issues that contribute to women's alcohol use during pregnancy has improved in recent years, there is much more work to do to increase public and professional understanding of these issues, and to decrease the stigma and judgment that is still directed at women using alcohol during pregnancy. More innovative approaches to the delivery of integrated care such as Breaking the Cycle in Toronto, Sheway in Vancouver, and home visitation programs are needed to improve outcomes for both mother and child.

There is also more work to be done to integrate our understanding of women's experiences of trauma as central to their mental health and substance use issues. The value of women-centered policy has to be explored in order to shift the prevention and treatment systems of care for substance-using women. The United Nations has identified certain priority objectives in overcoming barriers to success. The first is the need to attend to gender and national drug strategies that recognize diversity of race and ethnicity among women. The second is the need for political advocacy linkages and networking at various levels and within services to avoid another "Ms. G" case. The UN also underscored the need to continue to develop evidence based interventions and knowledge transfer.

Addiction and mental health: Dr. Peter Selby

How well are the addiction and mental health systems responding to alcohol and drug use, and related mental health problems among women who use during pregnancy?

Dr. Peter Selby is the Clinical Director of Addictions Program and Head of the Nicotine Dependence Clinic at the Centre for Addiction and Mental Health. Dr. Selby began by presenting a case that was reported in the American press.

The case: A young woman with a self-acknowledged alcohol use problem presented to the emergency department at her local hospital to give birth and reported her alcohol use. When born, both the young woman and her new baby boy were found to have high levels of alcohol in their system. The young woman was arrested and criminally charged for gestational alcohol use and her child was subsequently taken away, diagnosed with FASD by non-medically qualified personnel (the town Sheriff). The response to the situation was one of continuing anger by the media and the authorities at the young woman for her "callous act" of alcohol use during pregnancy.

This American case exemplified the lack of understanding that society affords the reasons and risk factors behind gestational alcohol use and highlighted the scarcity of prevention resources aimed at addressing the problems that predispose women to prenatal alcohol use.

A great deal of research on the consequences of alcohol use during pregnancy, as well as the risk factors predisposing women to gestational alcohol use, is currently available. However, despite the knowledge of the risk factors as well as the availability of validated screening tools to detect alcohol abuse during pregnancy, failure to implement these and other resources results in the relegation of society and the healthcare system to a reactive and reactionary role.

While Dr. Selby highlighted underlying psychiatric illnesses as strong risk factors for gestational alcohol use, the relationship between the two has only recently received attention. As a result, our mental health system is presently ill-equipped for the treatment of alcohol use during pregnancy. Moreover, when women with addiction and mental health concerns present to mental health centres, the contexts in which their concerns arise are largely ignored. The result is a lack of detection of alcohol abuse issues and lack of adequate management of these patients' respective illnesses. Similarly, while the presence of sexually transmitted diseases (STDs) and HIV have also been clearly identified as risk factors for

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prenatal alcohol use, patients presenting with them are rarely identified as "at risk" for gestational alcohol use and thus are almost never adequately managed.

Another challenge associated with alcoholism during pregnancy is the lack of understanding among health professionals of the concept of addiction as a disease. The result is the vilification of women who use alcohol during pregnancy and the labelling of these women as problem-patients by their physicians. The problem is made worse by policies that require health care professionals to report at-risk women to local authorities. Ultimately, the enforcement of such policies and stigma attached to a group of already burdened patients results in a decrease in self-reporting of alcohol use, which in the current health care environment, is critical to the early detection of alcohol exposed pregnancies.

Dr. Selby proposed that strong connections between mental health and addiction treatment be established to facilitate more effective management of patients in whom these illnesses are co-morbid. A bridge between systems, such as Toronto's Breaking the Cycle or Vancouver's Sheway were cited as examples. Dr. Selby envisions a system in which a woman presenting with mental illness or a history of personal trauma (e.g. rape) immediately receives a women-centred intervention that includes appropriate screening, counselling and treatment for alcohol use (given the risk of pregnancy). He believes that such a proactive approach would help to prevent the downward progression to addiction. Dr. Selby further recommended revisions of the policies surrounding the reporting of gestational alcohol use.

Current challenges to the implementation of the above recommendations were also discussed. In particular, regionalization of funding for specific areas and groups was cited. Dr. Selby expressed concern for the lack of motivation to treat patients requiring more time and effort (versus healthy patients) that may exist under such a model. He also highlighted an uncertainty regarding the quality of care that at-risk women would receive if elements of the Canadian healthcare system are privatized.

Dr. Selby concluded that the focus should shift from developing and funding each of the individual components of the mental health and addiction response systems, to a strategic integration of the two. Only through strong partnerships between mental health and addictions services can an adequate response to at-risk women-in-need be mounted.

Outreach for high risk women: Margaret Leslie

Ms. Leslie is the director of Early Intervention Programs at Mothercraft /Breaking the Cycle, a comprehensive, community-based program in Toronto involving seven partner organizations who collaborate to serve the needs of pregnant women with addiction problems and their young children. Breaking the Cycle (BTC) is delivered through a single-access model, with pregnancy outreach and home visitation components. Ms. Leslie's clinical experience over the past 20 years in the areas of prevention and early intervention has helped her and her staff develop a deeper understanding of the characteristics and life circumstances of women using alcohol in pregnancy and their inability to stop within the context of their lives.

Ms. Leslie presented the findings of a survey of the most common characteristics of women with substance use problems served at BTC:

- Family history of prenatal substance use
- Severe histories of trauma
- Low level of education
- Poverty and homelessness
- Mental health problems
- Domestic violence
- Drugs of choice: alcohol and cocaine

She stressed that isolation and social exclusion, as well as marginalization and alienation from people and relationships, both personal and professional, are most profound in this population. Positive intervention recognizes the need to:

- Engage women using substances in pregnancy and decrease isolation
- Help them access support such as food, transportation and company
- Increase their knowledge and awareness of available community resources

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- Promote use of services such as primary health care, prenatal care, safe housing and medically-supervised withdrawal management programs
- Increase the woman's involvement in future plans for herself and her expected infant
- Enhance efforts to build integrated and responsive community referral networks.

Ms. Leslie described strategies involving the care and treatment of women using alcohol in pregnancy that are helping to prevent FASD. The first step is outreach. Although pregnancy is a time for many women to consider change in their alcohol or substance use, pregnant women who use substances do not typically seek or access addiction treatment.

Barriers to effective care for pregnant substance-using women include: stigmatizing, judgmental and blaming attitudes towards pregnant substance users; women's fear of criminal prosecution, mandatory treatment, and loss of custody of their children; lack of gender-specific programs designed to address both the complexity of needs and experiences of pregnant substance using women as well as the needs and experiences of their child(ren) together. The goal of most pregnancy outreach programs should be to facilitate engagement with women earlier in pregnancy in order to promote maternal, fetal and child health outcomes. Ms. Leslie stressed how important it is to recognize that the circumstances that bring women to the use of substances during pregnancy also make it difficult for them to stop using or access the appropriate resources.

Engaging a woman on issues of substance use, pregnancy and her subsequent role as a parent is the first step and can be extremely effective. This can be further facilitated by:

- using a respectful, non-judgmental and women-centered approach
- using motivational interviewing strategies, in a nurturing context
- accepting harm reduction goals.

Evaluation of the BTC pregnancy outreach program found that engaging women earlier in pregnancy resulted in positive outcomes including reduced substance use, improved prenatal and neonatal health outcomes, and decreased mother-infant separation at birth. These results were primarily due to outreach efforts linking women to a web of resources such as the T-CUP program[1] and providing access to medical care, safe housing, medically-supervised withdrawal management programs and voluntary contact with workers from child welfare regarding their progress in pregnancy.

Ms. Leslie concluded that the challenge at hand in practice and in integrating policies is to find a way to keep the woman, the foetus, and the child in mind simultaneously and with equal respect and value.

Violence against women: Dr. Susan Jack

Susan Jack, RN, PhD from the School of Nursing at McMaster University focused on violence against women as a significant and emerging public health concern in Canada. Of particular concern is the rising prevalence of Intimate Partner Violence (IPV), defined as physical, sexual and/or psychological harm by a current or former partner or spouse. Recent research has found a correlation between IPV and pregnancy. While debated in the literature, there is minimal evidence to support that the act of becoming pregnant is a factor that will initiate intimate partner violence, and in fact pregnancy may be a protective factor for some women. Still, the prevalence of IPV during pregnancy is estimated to be approximately 6-7%. Dr. Jack also reported that women reporting violence during pregnancy are significantly more likely to have been victimized prior to pregnancy. Also, those whose partners were substance abusers were more likely to experience IPV. Not surprisingly, recent research has shown IPV experiencing women to be qualitatively similar to those engaging in substance abuse.

A number of deleterious health outcomes have been linked to IPV during pregnancy, the most concerning of which is increased maternal, fetal, or infant mortality. At present, however, there is a lack of data regarding long term negative outcomes such as FASD, in victims of IPV during pregnancy and/or their children.

Dr. Jack highlighted a current controversy facing the health care system, with respect to its

[1] Toronto Centre for Substance Use in Pregnancy, St. Joseph's Health Centre, Toronto ON

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response to IPV. At present, there appears to be uncertainty with respect to the efficacy and appropriateness of IPV screening in all women by health care providers during any health care encounter. From the perspective of many clinicians and professional associations, the importance of screening and identifying women at risk for IPV is clear, given the tremendous physical, mental and financial burdens incurred by both IPV-affected women and society at large (including the health care system). However, there is currently a lack of good evidence to support universal screening initiatives.

Currently, a large multi-centre randomized control trial is being conducted by researchers at McMaster to answer the question, "Does universal screening for violence against women do more good than harm?" The trial is designed to test the effectiveness of screening versus no screening in reducing violence and improving life quality. Some past studies have recommended caution against universal screening programs, given the obvious personal and family risks that may be incurred by IPV-exposed women when revealing the details of an abusive relationship. Specifically, focus groups conducted by the Violence Against Women Research Team at McMaster University, examining violence against women reveal that battered women are concerned about the actions of child protection agencies, reprisal violence from abusive partners and additional financial and emotional stress following revealed IPV experiences. Moreover, evidence regarding recommended follow-up actions for women rescued from violent relationships is also lacking. Overall, a clear benefit of IPV screening programs has yet to be demonstrated.

Current evidence recommends structured, post-rescue advocacy programs in which women are invited to stay in shelters, where counsellors are available to assist them in rebuilding their lives and ensuring adequate care for their children.

If the benefits of IPV screening are established, then future directions will likely center upon the education of primary health care providers with respect to IPV detection and management. Data from a recent survey showed that only 12% of physicians are likely to screen for IPV. Increased awareness of the role of various programs, such as child welfare agencies will also be important so as to facilitate their use by women requiring their support. Overall, a bridging of research and treatment efforts between epidemiologists and clinicians is necessary to ensure that quality answers are provided to the difficult questions regarding the screening and management of IPV that surely lie ahead.

Child welfare: Sharon Richards – CAST

Sharron Richards is the Manager of Community Development and Prevention Services at the Children's Aid Society of Toronto (CAST). Ms. Richards confirmed that no legislative mandate currently exists for child welfare to provide services for pregnant women. Furthermore, the current legal status of the foetus poses a limitation for child welfare in issues surrounding FASD prevention as the child has rights to protection only once it is born. Once born, legislation in Ontario has mandated that the paramount purpose of child protection agencies is to promote the best interests, protection and well-being of children.

However, Ms. Richards identified a number of policies within her agency that reflected a growing recognition of the importance of support for families and expectant mothers in high risk populations, such as substance abusers. For example, she discussed her agency's goal of improving the practice of educating the adolescent population regarding family planning and its implementation. She also spoke of her agency's commitment to developing new policies to guide future practice and interventions involving substance abusing women and their children.

Ms. Richards also summarized several modifications to practice within the child welfare system. The first is training about the causes and effects of fetal exposure to alcohol. Staff and foster parents are receiving introductory training about FASD, and advanced training related to case management strategies and screening for birth histories. Proper screening techniques and accurate history-taking methods at intake and throughout on-going services are gradually improving as their critical role in long-term outcome of the child is being recognized. A provincial risk assessment model has been put in place to help determine each mother's individual level of risk to help her gain access to pregnancy

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and aftercare programs most appropriate to her needs. Finally, Ms. Richards' agency is implementing new approaches to outreach and engagement of high risk pregnant women, and exploring the use of unconventional methods to meet the needs of each individual situation.

Currently, CAS of Toronto is conducting a pilot project in collaboration with the Motherisk Program of the Hospital for Sick Children to conduct as early as possible, assessments of children in long-term care with suspected FASD. Early assessment will allow CAS to access appropriate intervention programs that may help prevent secondary disabilities.

Ms. Richards stated that system bridging is essential, and enhanced collaborative partnerships in the following areas are necessary for the welfare of the child:

- Diagnostic capacity
- Family support and intervention
- Community education and awareness
- Research and evaluation of implemented changes in child welfare practice.

The challenges to policy integration include:

- Child welfare time frames
- Tensions between child welfare and substance abuse sector (welfare of mother versus welfare of child)
- Information sharing and confidentiality
- Child welfare mandate focuses on the protection of the child as the primary concern, paramount to all other issues
- Regional differences in service or program availability to serve families
- Differences in funding sources.

Research, surveillance, surveys: Dr. Colleen Ann Dell

Research in the field of FASD plays a pivotal role in answering key questions and motivating us to address new ones. FASD-related research:

- Improves results, treatments, policies
- Disseminates information and raises awareness
- Moves the FASD field forward by raising important questions and challenging existing assumptions.

There is insufficient research surrounding gender-specific addiction and women-centered treatment programs. To improve research on pregnant women and substance use, we need to focus on both the key elements of research and research approaches. Research practices should be modified to ensure that the research is of value to women. Knowledge dissemination is another crucial element of research practice, where application is necessary to have beneficial outcomes for society.

Dr. Dell confirmed the essential need to bridge systems and integrate services to improve women's health and pregnancy outcomes. She stressed the need for leadership, and challenged researchers and practitioners to think outside the box for success.

TALKING THROUGH THE ISSUES

With only five hours for presentations and group discussion, organizers decided to limit Forum attendance to 100 presenters and delegates. Participants included social workers, addiction counselors, child protection workers, public health nurses, physicians, community program coordinators, prevention and front-line outreach workers, FASD consultants, HR managers, prenatal educators, policy advisors, and researchers.

An experienced and committed group, Forum delegates contributed many thoughtful and thought-provoking observations during the open discussion session. While there were no easy solutions to the important issues raised during the panel presentations, there was consensus that present policies and practices needed to evolve towards a model that seeks to provide a continuum of care to the mother and child.

Waiting for evidence based research to inform practice

A public health nurse expressed concern about relying solely on prescribed practices, since even practices based on evidentiary research may not be appropriate in all situations. For example, although research suggests that screening for intimate partner violence (IPV) may do more harm than good, does that evidence then justify "a do nothing approach", effectively turning a blind

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eye toward pregnant women at risk? After all, not investigating these risks would constitute professional misconduct as there appears to be no obvious harm in incorporating routine questions about IPV during routine prenatal visits. Have studies on IPV calculated a harm reduction benefit-risk ratio?

Response: Dr. Jack acknowledged the importance of screening but also stressed the importance of identifying both the benefits and unintended harm that may arise from universal screening and that a balance between both should be reached. She stated the need to consider IPV and substance abuse "holistically" when considering how to help women.

Dr. Jack also reported that a new study grant being developed to address IPV would address substance abuse in the home as well as employment issues of partners. This proposed study will attempt to address all the issues associated with IPV holistically and on multiple levels.

Benefit of capacity building among aboriginal pregnant women

A home visitation worker based in an aboriginal community where there are high levels of alcohol and substance use spoke about the potential benefits of capacity building among aboriginal pregnant women. As part of her job, she facilitates the building of personal relationships with and among women in the hope that they will eventually become open and comfortable enough to disclose sensitive information in a non-professional context. Using this strategy, she has been able to obtain information that has been very useful in connecting women with appropriate services. The worker noted that many of her clients were keen to become more involved in helping other women.

Response: Nancy Poole agreed that capacity building is an excellent idea and that by offering support to the mother, the baby and all those around them, only positive outcomes are likely. In Ms. Poole's opinion, home visitation is undoubtedly an excellent outreach method of building community capacity. Mary Berube described a new program called 'Maternal-child health programming' created to support mother, baby and everyone around them. Capacity building in this project involves supervised visits from "lay home visitors" who are trained extensively in techniques to help support women experiencing IPV and engaged in substance abuse.

Concerns about taking the case history

While building FASD diagnostic capacity is obviously important, there is a growing concern regarding the process of taking a case history. One delegate raised the following questions:

- What is the next step after mom has acknowledged alcohol/substance use in pregnancy?
- What are the legal implications to the mother of her responses - can this information be subpoenaed?
- Can details provided by mom to help her child now be used against her given that there is no control over the context of the information?

Response: Sharron Richards of CAS Toronto acknowledged this predicament and suggested ways to address it. Welfare staff should be trained to ask questions in a nurturing manner where the welfare of baby is central. Workers should also be trained to understand the mother's history and level of risk, in order to be able to refer the mother to appropriate support services. Improved follow-up of the mother after she has given birth and integration of services could help meet the mother's needs and protect her interests. However, Ms. Richards also acknowledged that any child record can be subpoenaed and that there is no guaranteed protection for the mother.

In response, a delegate with a legal background acknowledged that while the prospect of subpoenas can be extremely threatening, if records are subpoenaed, front-line workers are not automatically required to hand over all documents immediately. Rather, all workers have the right to question the relevance of the documents or records to the proceedings in court.

Ms. Leslie cautioned, however, that not asking women sensitive questions at the initial welfare worker's visit could be disastrous. "*Is it really ethical to miss an important, perhaps the*

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only window of opportunity for providing help to the woman with possible mental, health or violence problems for which [she] may desperately require help? If prenatal history is kept a secret then how do we help ensure the proper welfare of this child?"

A suggested solution was to provide the mother, prior to the commencement of the history taking process, with control over how much information she would divulge and with a list of the potential consequences of the information that she provides. Such an approach would allow the mother to make an informed decision regarding self-disclosure based on her understanding of the implications of providing certain information, and would eliminate concerns raised by intake workers documenting the information.

Limited resources in rural areas

The issue of limited resources in rural areas continues to be a problem. An outreach worker from a small community commented that while a mother's needs are great, they are often ignored due to a lack of available resources/services. Despite the fact that some mothers are prepared to seek help for their respective addictions, support workers are forced to refer them to urban centres for support. In this worker's opinion, the compartmentalization of funding for first nations combined with budget constraints are the main barriers to the successful treatment of maternal addictions.

Response: Dr. Selby suggested that front line workers might begin to overcome this issue by developing other resources. "*Why not train families to care for families in need who have alcohol or other substance abuse issues in their homes? Everyone benefits when a mother is brought into and surrounded by care."*

Legislative focus on the welfare of the child

A delegate who was an Ontario MPP and adoptive parent stated that his focus was first and foremost on the welfare of the child. He mentioned his personal view was perhaps biased as he himself had adopted a boy with FAS who eventually passed away. The delegate felt that he, his adoptive son and their family suffered greatly as a result of the poor choices that his son's birth mother had made. He pointed out that statistically, among the number of mothers who were provided help and services, the success rate (as defined by a decrease in substance abuse and a decrease in negative pregnancy outcomes) was discouraging. While he agreed that it was important to break the generational chain of FASD, as a provincial politician, his concern was that despite an increase in funding to the relevant support programs, high-risk mothers may not be capable of adequately caring for their children.

The delegate's comments prompted another participant to remark that mothers who are not helped are more likely to repeat risky behaviours (e.g. substance abuse) during subsequent pregnancies, leading to increased human and financial costs to society. In reply, the delegate acknowledged that there is a need for better understanding by the legislature of the potential long-term impact of not aiding vulnerable high-risk women.

Response: Dr. Dell brought the focus back to an added barrier to the resolution of this issue-society's prejudice toward or lack of understanding of the nature of the issue itself. "*Why should a hip replacement be more important or justifiable than a substance abusing woman's life?"*

Fast-tracking diagnosis of children in care

A question was raised as to the risks versus benefits of fast-tracking the diagnosis of children who are in the care of CAS. How would rapid diagnosis impact the birth mother? Would the guilt of a positive FASD diagnosis drive her into relapse?

Response: It is important to support the birth mother during this time and help her understand the assessment process. Nancy Poole suggested that a "mother-oriented" social worker rather than a "child-oriented" worker be a member of the diagnostic team and be prepared to address the mother's needs, thereby reducing concerns of relapse. Similarly, a domestic violence assessment team should be included as part of the welfare system to facilitate risk reduction in the home.

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Perception of women who use versus men who use
One delegate noted that a substance abusing father can still be considered a good parent while a mother in a similar situation is considered a bad parent. How we view substance use has to change.

Sharing successes
One final delegate comment noted that positive success stories are rarely publicized or shared. Reflecting on successes to-date while continuing to discuss barriers, can help those involved in seeking solutions retain hope of success.

CONCLUSION

Delegate response to the Policy Forum objectives and discussion was overwhelmingly positive. In their evaluations delegates noted that the Forum provided current, progressive information and approaches, as well as an excellent opportunity to interact with people from different disciplines. They also noted that the focus on policy promoted open discussion on the multiple risk factors associated with FASD prevention. Others appreciated the chance to network and the recognition that the experts, "don't have all the answers and that by discussing, we can find solutions together."

When asked to consider Forum weaknesses, delegates lamented the lack of time and restricted number of participants. Many would have appreciated more discussion of cultural diversity and substance abuse across socioeconomic groups, while others wanted more information on practical strategies for working with affected populations. Many observed that the panel would have been more complete if it had included representatives from Justice, Corrections, Education and provincial/federal legislatures.

Other comments reflected the competing interests that make policy development in this field so challenging, and yet so necessary. For example, one delegate wrote: *I feel to some degree that CAS [Children's Aid Society] was once again dismissed and devalued with regard to the work that CAS tries to do with these mothers and children in some of the comments of the presenters i.e., ... references to "more mother focused, possible approval versus a negative child-focused approach (paraphrased). I don't think 'negative' + 'child-focused' belong in the same sentence."*

When asked to consider how their practice and services might change based on the Forum discussion, delegates wrote that they would think more broadly across programs and work towards an interactive, integrated approach that would incorporate collaborative services with other agencies.

Delegates were also asked to consider and describe their own, individual next steps. Among the replies were expressed intentions to:

Include more of a focus of advocating for more trauma work with women. To be more conscious of the need to assist women on expanding informal systems – enlarging their views of family. To mobilize external support which are effective/responsive to the needs of women and their potential unborn children.

Be more involved an all aspects of participants' lives not just what's relative to pregnancy. However, everything is related to pregnancy as I've now found out. More proactive in finding services and resources for women.

Try to be more proactive in reaching out to other community professionals in this field to come together in a collaborative manner for the best interests of the client. I would encourage expectant mothers with mental illness to maintain their medication (with doctor's support).

Prioritize this area and increase training for service providers.

Work to get pregnancy and substance use more on the national drug strategy agenda.

Explore establishing case conferencing with mental & addiction services to ensure a more holistic approach given different philosophies of treatment. Establish a more comprehensive screening process for mental health disorders for all women in program.

Integrate a more holistic model of health on all levels, not just focusing an addiction. Collaborating more with other agencies – case management and teams.

Begin to examine prevention at multiple stages in parent's life.

Tweak my research project. Move forward with programs, having received confirmation I am on the right track.

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Encourage our agency (child welfare) to discuss a balanced service approach for both the mother and child.

Pay closer attention to women's history and showing more empathy. Include more research studies for other professionals.

Look at ways of integrating services – one stop service. I will try to make more links with agencies in my community. Drive home message to our staff – woman does not want to use – many factors involved – trauma, abuse and even impact of housing.

Understand "where" mom is coming from. Always advise the risk of disclosure that way mom knows - or disclosure could be done in a sacred fire ceremony that way helping mom does not end up punishing mom. I understand that disclosure first of all is helping mom. However a lot more comes along.

Delegates were also clear on what they would like to see addressed in future Forums. Having identified integration as a key objective in service delivery, many are looking for success stories that include examples of: integrated practices involving "different mandated organizations" including helpful and collaborative relationships with CAS; the liaison between acute care and the transition to the community; and service interactions that include education, police, crown and judges.

There was also a recognized need for in-depth discussion of legal issues surrounding substance use in pregnancy and drinking with children in the home. A key concern is how the law affects women who disclose. Others stated the need to examine specific cultural proficiency of service systems and child welfare and courts.Still others wanted to discuss the progress of clinical research regarding FASD diagnosis and treatment, the use of biomarker to detect prenatal exposure to alcohol, and men's role in the prevention of FASD.

Finally, funding issues and the models of policy formulation were also included among a broad range of delegate suggestions for the next Forum.

RECOMMENDATIONS

There is a growing body of work by researchers and program directors that explores the characteristics and experiences of pregnant women who use alcohol and substances during pregnancy, the variables affecting their health and well-being and the well-being of their children, the barriers to successful intervention, and recommendations on how to meet their service needs. The Policy Forum was fortunate to have had several of those experts on its panel. Others who were unable to attend include Dr. Caroline Tait, who authored *A study of the service needs of pregnant addicted women in Manitoba, 2000*, and which includes no fewer than forty-nine pertinent recommendations. The Manitoba report is included among others in a list of related resources at the end of this report.

Recommendations emerging from the Policy Forum

While awareness of issues that contribute to women's alcohol use during pregnancy has improved in recent years, steps must be taken to increase public and professional understanding of these issues, and to decrease the stigma and judgment that is still directed at women using alcohol during pregnancy.

1. Treatment protocols should involve both mental health and addiction treatment to facilitate effective management of patients in whom addiction and mental health are co-morbid.
2. Government and professional groups should undertake careful consideration of potential revision of the practices and policies surrounding the reporting of gestational alcohol use by medical professionals and front-line workers.
3. Pregnancy outreach programs have been shown to be powerful support mechanisms that promote maternal, fetal and child health outcomes. Engaging women early in pregnancy results in reduced substance use, improved prenatal and neonatal health outcomes, and decreased mother-infant separation at birth. Outreach efforts should link women to a web of resources and provide access to medical care, safe housing, medically-supervised withdrawal management

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4. programs and voluntary contact with workers from child welfare regarding their progress in pregnancy. Breaking the Cycle in Toronto and Sheway in Vancouver are successful program models.
5. Current evidence on intimate partner violence (IPV) recommends structured, post-rescue advocacy programs in which women are invited to stay in shelters, where counsellors are available to assist them in rebuilding their lives and ensuring adequate care for their children.
6. Future directions in IPV research should center upon the education of primary health care providers with respect to IPV detection and management. A bridging of research and treatment efforts between epidemiologists and clinicians is necessary to ensure that quality answers are provided to the difficult questions regarding the screening and management of IPV.
7. Child welfare agencies should take steps to forge collaborative partnerships that will enhance diagnostic capacity, family support and intervention, community education and awareness, and evaluation of implemented changes in child welfare practice.
8. Front-line workers should be trained to identify the key relationships in the lives of children of high-risk mothers, and what can be done to honour those relationships (be they with birth families or foster/adoptive families), and link mothers and their children to appropriate supports.
9. Research should ask how women and men are affected differently by mental illness, substance use and addiction.
10. Though it was acknowledged that progress would require collaboration, openness and innovative thinking, the Forum did not discuss one very critical issue -- who should provide leadership? The Manitoba study referenced above was commissioned by Manitoba Health and so many of the forty-nine recommendations were aimed at Manitoba Health as the primary agent for change.

A critical recommendation then, for future consideration should be the choice of effective leadership. Should it be Health Canada, the body most frequently charged with developing and promoting national priorities and strategies, or provincial governments that oversee implementation of clinical and social services? Or are there other ways to define and identify leadership in an endeavour that will require national, cross-sectoral, multidisciplinary collaboration and long-term, sustained support?

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RELATED RESOURCES

Apprehensions: Barriers to Treatment for Substance-Using Mothers. British Columbia Centre of Excellence for Women's Health, Vancouver, 2001

Best Practices in Action: Guidelines and Criteria for Women's Substance Abuse Treatment Services. Health Canada, 2006

Best Practices - Concurrent Mental Health and Substance Use Disorders. Health Canada, 2002

Best Practices: Treatment and Rehabilitation for Women with Substance Use Problems. Janet C. Currie, Canada's Drug Strategy Division, Health Canada 2001 Available at http://www.cds-sca.com

Drug Strategy Community Initiatives Fund - Funding Guidelines 2005 - 2006. Health Canada, 2006. Available at http://www.hc-sc.gc.ca/ahc-asc/pubs/drugs-drogues/fund_guide-fonds_lignes_direct/index_e.html

Enhancing FAS-Related Intervention at the Prenatal and Early Childhood Stages in Canada. Canadian Centre on Substance Abuse, 2001.

Let's Talk FASD: Parent Driven Best Practice Strategies in Caring for Children and Adults with FASD, Victorian Order of Nurses VON Canada; 2005. Available at http://www.von.ca/FASD/index.html

Linking Child Welfare and Substance Abuse Treatment: A Guide for Legislators. Available at http://www.ncsl.org/programs/pubs/xsmabuse.htm

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Markoff L, Finkelstein N, Kammerer N. et al. (2005). Relational Systems Change: Implementing a Model of Change in Integrating Services for Women with Substance Abuse & Mental Health Disorders & Histories of Trauma. *Journal of Behavioral Health Services Research*, 32(2), 227-240.

Morrissey JP, Ellis AR, Gatz M, Amaro H, Reed BG, Savage A, Finkelstein N, Mazelis R, Brown V, Jackson EW, Banks S. (2005). Outcomes for Women with Co-occurring Disorders and Trauma: Program and Personal-Level Effects. *Journal of Substance Abuse Treatment* 28, 121-133.

Mother and Child Reunion: Preventing FASD by Promoting Women's Health. British Columbia Centres of Excellence for Women's Health, 2003.

Motivating Pregnant Women to Address Substance Use Issues: A Conversation with Marlene Thio-Watts. Canadian Centre on Substance Abuse, 2001.

Nurturing Change: Working Effectively with High-Risk Women and Affected Children to Prevent and Reduce Harms Associated with FASD. Mothercraft/Breaking the Cycle and Canadian Centre on Substance Abuse, 2004.

Roberts LW, Dunn LB. (2003) Ethical Considerations in Caring for Women with Substance Use Disorders. *Obstet Gynecol Clin North Am*, Vol. 30(3), 559-582.

Research Bulletin: Mental Health and Addictions in Women. Spring 2006, Volume 5, Number 1. Centres of Excellence for Women's Health. Available at http://www.cewhcesf.ca/PDF/RB/bulletinvol5no1EN.pdf

Respect is key to helping pregnant women with substance use problems: a conversation with Pam Woodsworth. Canadian Centre on Substance Abuse, 2001

State of the Evidence: Fetal Alcohol Spectrum Disorder (FASD) Prevention: Final Report Alberta Centre for Child, Family & Community Research and University of Lethbridge, 2005

Tait C. (2000) A study of the service needs of pregnant addicted women in Manitoba. A policy research project funded by Manitoba Health and conducted in cooperation with the Prairie Women's Health Centres of Excellence. June 2000. Available at www.gov.mb.ca/health/documents/PWHCE_June2000.pdf

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