

# ***Fetal Alcohol Spectrum Disorder [FASD]***

**Stakeholder Forum:** *Towards a Coordinated Approach to FASD in Nova Scotia*

**Workshop Held** March 26, 2008, Halifax, Nova Scotia

APRIL 22, 2008 FINAL



# ***Fetal Alcohol Spectrum Disorder*** ***[FASD]***

**Stakeholder Forum:** *Towards a Coordinated Approach to FASD in Nova Scotia*

**Workshop Held** March 26, 2008, Halifax, Nova Scotia

APRIL 22, 2008 FINAL



Developed by:





## Executive Summary

In 2007, the Department of Health Promotion and Protection (NSHPP) launched a provincial Alcohol Strategy to lead a major cultural shift so that Nova Scotians who choose to drink will do so without harm to themselves, their families or their communities. The Strategy reported on harmful drinking patterns and contexts including alcohol consumption during pregnancy. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a full range of physiological and neurological disabilities that may occur as a result of prenatal alcohol exposure.

Following the release of the strategy a small working group representing several government departments (Community Services, Health Promotion and Protection and Education) met to discuss opportunities to move FASD forward in Nova Scotia. The working group expanded to include the IWK Health Centre, Addiction Services Capital District Health Authority, Addiction Services South Shore Health Authority, Nova Scotia Reproductive Care Program and South Shore Family Resource Centre and planning for the 2008 FASD Forum began.

The purpose of the Forum was to bring together key stakeholders from across the province to share experiences and resources and to explore a process for a more coordinated approach along the continuum of programs and services from prevention to supporting individuals and families affected by FASD.

Following opening remarks by Deputy Minister Duff Montgomerie, presentations were given to provide the context for the day. These presentations included the provincial and federal context related to FASD, the results of a pre-forum questionnaire, and highlights of findings from a document review and synthesis of information on FASD in Atlantic Canada.

Following the presentations, themes that capture the continuum of programs and services to address FASD were presented (prevention, screening and diagnosis, intervention and supports, and training and education). The themes provided the framework for small group work where participants reflected on activities, challenges/opportunities, and opportunities related to addressing FASD.

The final session of the Forum involved a discussion related to building a coordinated approach for FASD. Following are the key actions identified by meeting participants to ensure a coordinated approach to address FASD:

- Create structures (e.g., Steering Committee and Working Groups linked to the themes) to coordinate and bring the diverse stakeholders together (e.g., the Child/Youth Strategy Group, Community Services, Education, Health, Health Promotion and Protection, parents, advocates, employers, etc.), and ensure stakeholders represent geographic areas, cultural groups, areas of expertise (e.g., prevention, screening, diagnosis, etc.), and various sectors and disciplines.
- Identify the roles and responsibilities of the various stakeholders.
- Identify a champion (individual(s) and organization) to lead ("drive the bus"), coordinate, and be accountable to move the issue forward (e.g., fund a FASD Provincial Coordinator within Addiction Services or Nova Scotia Health Promotion and Protection).
- Implement a Clearinghouse to coordinate information, resources, expertise, etc., and to disseminate information and share resources.
- Allocate funds to support the coordinator position, structures and clearinghouse.
- Use existing strategies and leadership structures such as the Child and Youth Strategy, the Alcohol Strategy, and Social Policy Working Group to integrate FASD and build a coordinated approach.
- Compile the findings and outcomes from the Forum and report from Gary Roberts and share with senior leaders and decision makers such as Deputy Ministers and Ministers (from various sectors) and structures (e.g.,

Social Policy Working Group) to continue to move the issue forward and build political will.

- Build infrastructure and support interdisciplinary teams and networking at the community and grassroots level.
- Provide resources to local community organizations to support ongoing work to address FASD.
- Build federal and provincial relationships to keep the issue on the agenda and move forward collaboratively.
- Explore the development of a formalized diagnostic screening program across the province.

# Table of Contents

<b>Executive Summary .....</b>	<b>I</b>
<b>Introduction.....</b>	<b>1</b>
Background.....	1
Purpose of the Forum.....	1
<b>Overview of the Workshop.....</b>	<b>3</b>
Welcome and Context.....	3
Presentations.....	5
Meeting Process .....	9
Closing Remarks.....	9
Next Steps.....	9
<b>Working Session 1: What is Happening, Challenges &amp; Opportunities .....</b>	<b>10</b>
Themes.....	10
Activities, Challenges/Gaps and Opportunities Related to the Themes .....	11
Moving Forward – Potential Areas for Action .....	23
<b>Working Session 2: A Coordinated Approach .....</b>	<b>25</b>
<b>Participant Feedback .....</b>	<b>26</b>
<b>Appendices .....</b>	<b>28</b>
Appendix 1: Participant List.....	28
Appendix 2: Presentation Slides .....	29
Appendix 3: Participant Feedback.....	34



# Introduction

## Background

In 2007 the Department of Health Promotion and Protection (NSHPP) launched a provincial Alcohol Strategy to lead a major cultural shift so that Nova Scotians who choose to drink will do so without harm to themselves, their families or their communities. Addiction Services within NSHPP led the development of the Strategy which addresses alcohol-related harm in the context of best practices. This includes population health approaches (e.g., prevention programs, social marketing, public policy) and harm reduction interventions that target the most harmful patterns and contexts of alcohol consumption (e.g., drinking to the point of intoxication, drinking while pregnant, and drinking and driving).

The development of the Strategy was undertaken by an Alcohol Task Group, a partnership of the Department of Health Promotion and Protection and District Health Authorities' Addiction Services. The Alcohol Task Group developed the original framework (principles and values, vision, goals and key directions), which was endorsed by 60 stakeholders at a Provincial Alcohol Roundtable in September 2006.

The Strategy reported on harmful drinking patterns and contexts including alcohol consumption during pregnancy. Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a full range of physiological and neurological disabilities that may occur as a result of prenatal alcohol exposure. The Strategy notes that FASD has only recently been recognized as a cultural issue. Traditionally FASD has been considered to be a "women's" or "aboriginal" issue. The Strategy notes that a cultural shift is required so that FASD is viewed as a community responsibility.

As a result of the Provincial Alcohol Strategy Roundtable in September 2006, a small working group representing several government departments (Community Services, Health Promotion and Protection and Education) met to discuss opportunities to move FASD forward in Nova Scotia. The working group expanded to include the IWK Health Centre, Addiction Services Capital District Health Authority, Addiction Services South Shore Health Authority, Nova Scotia Reproductive Care Program and South Shore Family Resource Centre and planning for the 2008 FASD Forum began.

## Purpose of the Forum

The purpose of the Forum was to bring together key stakeholders from across the province to share experiences and resources and to explore a process for a more coordinated approach along the continuum of programs and services from prevention to supporting individuals and families affected by FASD. The objectives of the Forum were:

- To present and review opportunities to link FASD with government initiatives and community based programs (e.g., the Alcohol Strategy, Child and Youth Strategy, Healthy Beginnings, Aboriginal Head Start, CAPC and CPNP programs, etc.).
- To present and discuss the Environmental Scan related to FASD (A Document Review and Synthesis of Information on Fetal Alcohol Spectrum Disorder [FASD]) in Atlantic Canada.
- To showcase current initiatives addressing FASD from across the province, and discuss successes, challenges/gaps and opportunities for addressing FASD.
- To explore opportunities to develop a coordinated approach to addressing FASD (from prevention to supporting individuals and families affected by FASD) and identify next steps in moving forward.

The Forum is considered to be the first step in developing a process and plan for a coordinated approach to FASD by gathering stakeholders from across the continuum of care together to facilitate networking and sharing and the identification of opportunities for action.

This report provides an overview of the workshop proceedings, results from the small group working sessions and participant feedback survey. A list of meeting participants is provided in Appendix 1.

# Overview of the Workshop

## Welcome and Context

### Purpose and Objectives

The workshop began with a welcome and introduction by Ms. Barbara Miles, Coordinator, Prevention and Community Education, Nova Scotia Health Promotion and Protection, and Ms. Kathy Inkpen, Coordinator, Family Health, Nova Scotia Health Promotion and Protection. Ms. Miles thanked participants for their attendance and indicated that the planning committee was overwhelmed by the interest in the Forum, and number of attendees (over 60 participants). Ms. Inkpen provided an overview of the purpose and objectives of the session, noting the importance of obtaining the input of a broad base of stakeholders in developing a coordinated approach to addressing FASD. The planning committee for the Forum was introduced and acknowledged for their ongoing work in addressing FASD, and their efforts in planning the current meeting process and agenda.

#### PLANNING COMMITTEE MEMBERS

---

- Glenda Carson, *IWK Health Centre*
  - Daniel Demers, *Department of Education*
  - Kathryn Inkpen, *Nova Scotia Health Promotion and Protection*
  - Kim MacLean, *Addiction Services, Capital Health*
  - Donna Malone, *Public Health Agency of Canada*
  - Barbara Miles, *Nova Scotia Health Promotion and Protection*
  - Nancy Ross, *Addiction Services, South Shore Health*
  - Annette Ryan, *Reproductive Care Program*
  - Debbie Smith, *South Shore Family Resource*
  - Denise Stone, *Department of Community Services*
  - Nancy Taylor, *Department of Education*
- 

### Opening Remarks

Ms. Miles welcomed Deputy Minister Duff Montgomerie who provided opening remarks. Deputy Minister Montgomerie thanked participants for their interest and support in addressing FASD and taking the time to provide their input, share with colleagues, and explore how to develop a coordinated approach to addressing FASD. The participation of Mr. Robert Wright, Executive Director of the Child and Youth Strategy, was acknowledged and his commitment to child and youth health and support for addressing FASD highlighted. Deputy Minister Montgomerie noted the importance of partnerships and collaboration across government departments and levels of government, with community organizations and individuals and families in effectively addressing FASD.

Deputy Minister Montgomerie noted that the release of the provincial Alcohol Strategy in the fall of 2007 with the aim of preventing and reducing the burden of alcohol-related harm in Nova Scotia helped to raise the profile of FASD. The Alcohol Strategy called for FASD to be addressed through a community lens versus being addressed as an individual woman's issue. The importance of comprehensive and multiple strategies in addressing FASD such as programs and services, policy, social marketing and communication, and research was highlighted. The Deputy

Minister concluded by acknowledging meeting participants for their commitment to the issue and the importance of their contribution in identifying gaps/challenges, potential opportunities, and beginning to develop a coordinated plan to address FASD and support individuals and families impacted by FASD.

### **Provincial Context**

Ms. Miles introduced Ms. Carolyn Davison, Director, Addiction Services, Nova Scotia Health Promotion and Protection who provided an overview of the history of work related to FASD in Nova Scotia and nationally. Ms. Davison indicated that while there are many activities happening to address FASD, a coordinated approach is lacking and Nova Scotia is lagging behind other jurisdictions such as British Columbia and Manitoba.

In 2001 the provincial government invested 1.8 million dollars (equivalent to 2.4 million dollars today) into addiction prevention, health promotion, early intervention/early identification, outreach, connection into the continuum of care (treatment) for rural women and youth. Then in 2002 a provincial coordinator was hired to address alcohol and lead the development of the provincial strategy. As previously noted by the Deputy Minister, the Alcohol Strategy provides the foundation and impetus to begin the development of a coordinated approach to addressing FASD. Given the complexity of the issue and the need to involve an array of intersectoral partners from across the continuum of care, a coordinated approach is critical and fundamental to moving forward. Ms. Davison noted the importance of advocacy and policy in addressing FASD, as well as the importance of addressing broader determinants of health within a population health framework. Ms. Davison concluded by encouraging front line service providers to continue to become involved in advocacy and policy development and implementation, which help to create supportive environments for addressing FASD (e.g., advocating for reliable birth control for all women, which can have a significant impact on addressing FASD).

### **Federal Context**

Ms. Donna Malone, Program Consultant with the Public Health Agency of Canada (PHAC) provided an overview of recent federal work related to addressing FASD. In February 2000, the Population and Public Health Branch (now PHAC) and the First Nations and Inuit Health Branch of Health Canada, Atlantic Region co-hosted a Fetal Alcohol Syndrome Forum in the Atlantic Region. Following this Forum a small group from Health Canada and each provincial government in the Atlantic Region met to reflect on FASD activities and identify next steps, with the outcome being the establishment of an Intergovernmental Committee, to maintain an exchange of information between the Atlantic Provinces on the issue of FASD.

This committee, now called the Atlantic Intergovernmental FASD Partnership, continues to provide a forum for federal and provincial governments to collaborate to better address FASD. The group fosters knowledge development, information sharing on best practices and opportunities to identify challenges and priorities that are unique to the Atlantic Region. Provincial and federal members have backgrounds in health promotion, corrections, public health, women's health, addictions, education, early childhood development and share a passion for understanding why FASD exists and what governments can do to support affected families in our region.

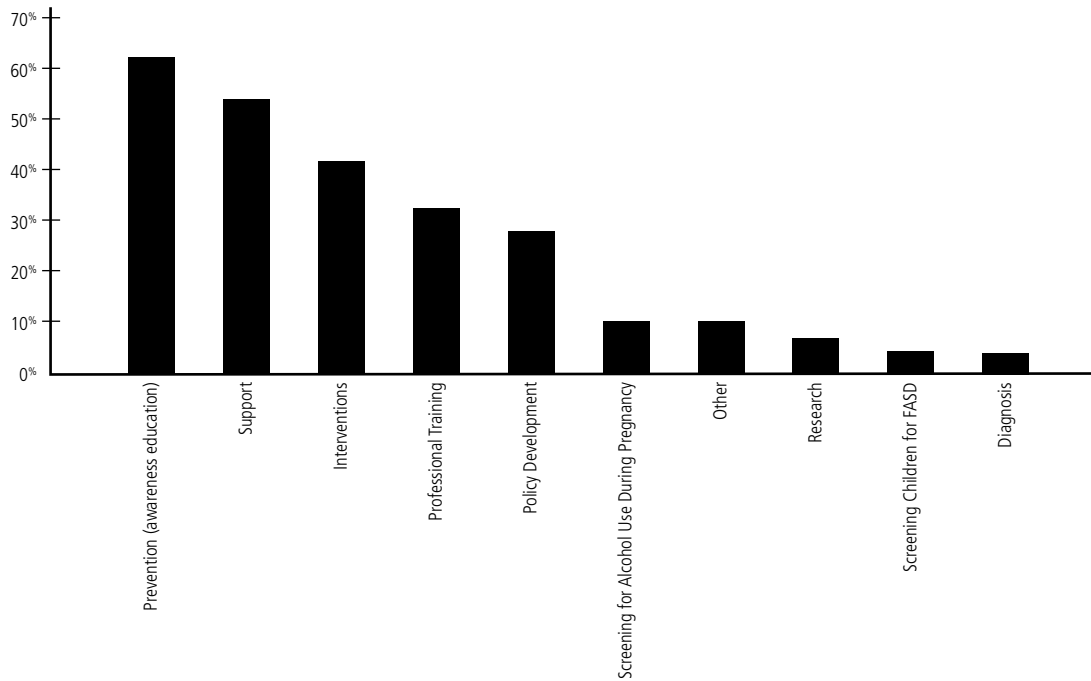
To support the work of this committee and provincial governments a FASD Environmental Scan project was initiated in 2006 to document: available information about the nature and scope of FASD in the Atlantic provinces; the economic impact; factors associated with FASD in the region (e.g. women's experience with the social determinants of health); and the current research and policy response in the region. Gary Roberts and Associates carried out the study with the findings compiled in a report. A second phase of the project was conducted to consult with stakeholders from around the region on gaps and opportunities for FASD programming, research and policy. Together, findings from these projects will form a substantial, published, Atlantic specific and current look at FASD in the region, as well as recommendations for future directions. The work that is done today at this Forum compliments and builds on the Environmental Scan.

## Presentations

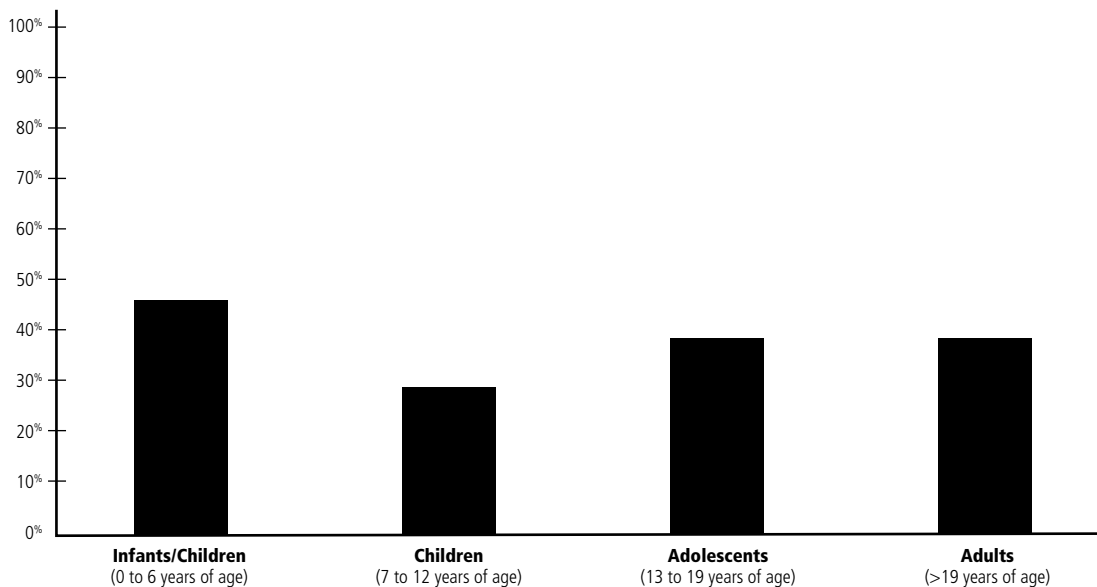
### Results from the Pre-Forum Questionnaire

The meeting facilitator, Ms. Stephanie Heath, provided a brief presentation on the results of a pre-forum questionnaire that was sent to registrants prior to the meeting to help inform the development of the meeting process and agenda. Following is a compilation and synthesis of the responses, provided by each question on the survey.

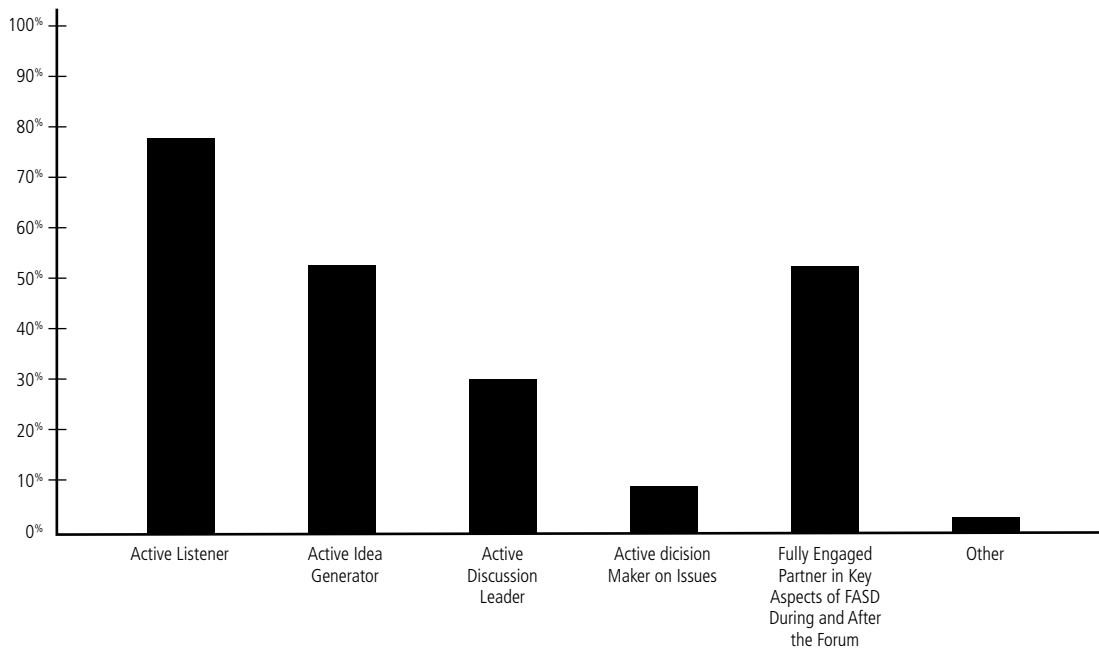
THE FOCUS OF PARTICIPANTS' WORK/INVOLVEMENT WITH FASD



POPULATION OF FOCUS IN PARTICIPANTS' WORK



THE ROLE PARTICIPANTS SAW FOR THEMSELVES DURING THE FORUM



**A COORDINATED APPROACH MEANS....**

- Working collaboratively together across sectors and across the continuum
- A common goal and unified approach
- A comprehensive approach (e.g., prevention, policy, social marketing, etc.)
- Sharing of information and understanding what is happening across the province
- Sharing of resources, maximizing resources, reducing overlap
- Identifying a lead agency to coordinate and facilitate networking
- A central service to direct inquiries
- Ongoing training and education

**WHAT ROLE CAN YOU OR YOUR ORGANIZATION PLAY...**

- Direct service delivery for those affected by FASD (particularly children and families)
- Training and education
- Program planning and development
- Supporting collaboration and coordinating
- Research
- Advocacy and policy

**WHAT DO YOU HOPE TO GAIN FROM PARTICIPATING IN THE FORUM...**

- Learning about what is going on related to FASD (e.g., programs and services, resources, coordinated work, best practice)
- Networking (meet, share, learn other’s perspectives, build awareness)
- Personal learning (knowledge and skills)
- Identify gaps/challenges

- Identify opportunities
- A plan or a sense that a plan is underway
- Begin to set up collaborative relationships
- How to maximize resources
- To advocate

#### THE FORUM WILL BE A SUCCESS IF...

- There is learning and sharing
- There is a further work plan (or the beginnings of one), provincial direction
- There is greater commitment for a coordinated approach
- There are improved programs and services for those affected by FASD
- Structure and processes for collaboration are established (local)
- There is increased priority for FASD as a public health issue
- Opportunities are identified.

### **A Document Review and Synthesis of Information of Fetal Alcohol Spectrum Disorders (FASD) in Atlantic Canada**

Ms. Malone introduced Mr. Gary Roberts, from Gary Roberts and Associates who led the Environmental Scan project. Ms. Malone noted that Mr. Roberts' consulting business supports clients in social development and health promotion and he is also a senior advisor for the Canadian Association for School Health. Following are the highlights of the presentation provided by Mr. Roberts on phase one and two of the Environmental Scan project (slides from the presentation are provided in Appendix 2).

Mr. Roberts acknowledged the work of colleagues who participated in phase one (Document Review, 2007, <http://www.phac-aspc.gc.ca/canada/regions/atlantic/documents/index.html>) and phase two (Stakeholder Input Into Gaps and Opportunities, 2008) of the Environmental Scan. The document review consists of: a review of incidence, prevalence and economic costs from 37 studies; a review of knowledge, attitudes, and behaviours, related to FASD from 23 studies; Atlantic FASD-related policy (five federal and six provincial); and Atlantic specific research.

Prevalence data from the four provinces in the region was reviewed and Mr. Roberts noted the limitations with this data given the lack of diagnostic capacity related to FASD. Cost estimates were reviewed (with limitations in the estimates highlighted) and it was noted that estimated total direct costs for FASD to age 21 years is 65 million dollars in Nova Scotia.

Findings related to public and professional knowledge and attitudes associated with FASD were reviewed and it was noted that there is good general knowledge but that the specific knowledge (e.g., the life-long nature and severity of the disorder, effects of moderate amounts of alcohol) is weaker among the public. Providers have weaker knowledge related to diagnoses and understanding of the lifelong nature of FASD, and training is required, particularly in the Atlantic region. Among the public, stigma towards affected persons is an issue.

Knowledge related to alcohol consumption by women of children bearing age was also reviewed and it was noted that among the public, while there is good general knowledge of the role of alcohol, there is confusion around small amounts of alcohol and there is stigma and discrimination towards women who drink during pregnancy. Findings related to professionals were reviewed and revealed that professionals are generally comfortable with providing advice re: alcohol and pregnancy but are least comfortable in supporting alcohol-dependent women, and in the Atlantic region, were less likely to routinely use a standard screening tool. In addition, a small percentage of professionals are providing potentially harmful messages (i.e., that it is fine to drink small amounts during pregnancy).

Public attitudes for support for policy measures indicate support for increased efforts to prevent intoxicated persons from being served (75%) with less support for increasing taxes (25%) and raising the drinking age (35%).

Alcohol consumption patterns of child bearing women (15 to 44 years) in Atlantic Canada and alcohol consumption by pregnant women were reviewed. Highlights of the findings include the fact that a quarter of child bearing women binge drink and 14% of Canadian women report using alcohol during pregnancy. The profile of alcohol use and FAS, as well as a profile of persons with FASD was presented.

Federal and provincial FASD policy activities were reviewed, and it was noted that there was little activity in this area – there are broad level frameworks and strategies that may eventually provide direction to address FASD. Atlantic FASD specific research was reviewed and it was noted that although there is limited research underway, there are some national and internationally respected researchers (re: women and alcohol) within Atlantic Canada.

Issues arising from the review include:

- Knowledge of life-long nature of FASD is low
- Knowledge of societal costs are undoubtedly low
- High rates of hazardous drinking by young women
- Need for physician training on several topics
- Lack of FASD-specific policies in the region
- Little FASD-related research in the region

Phase two of the project was reviewed with key recommendations presented, which include:

1. That the Atlantic Partnership consider a vision of a regional and provincial coordination infrastructure that addresses six priorities:
  - i. Promoting the well-being of all women of child-bearing age through policy and programming that reflects a determinants of health and gender-sensitive lens;
  - ii. Promoting policy and program development for prevention (through provincial alcohol strategies where they exist);
  - iii. Fostering the formation of multidisciplinary diagnostic teams covering ages 1 to 18 years through policy and program development in the health sector;
  - iv. Promoting policy and program development in the education sector to provide support and learning plan development in the elementary and secondary school system, and post-secondary planning;
  - v. Advocating policy and program development in the community sector to support individuals of all ages with FASD (including adults) as well as their parents and families; and
  - vi. Establishing or serving as focal points for information exchange and multidisciplinary training across the region.
2. That the Partnership continue the community building that has begun with the first two projects, and nurture a network or community of practice, that would help address several needs identified through this process.
  - Reduce professional isolation,
  - Support increased coordination of effort,
  - Promote continued learning.

## Meeting Process

After the presentations, the meeting process consisted of small group working sessions and large group discussion. The outcomes of these sessions are presented in the third and fourth sections of the report, which provide a summation of the two main working sessions. During the first session participants worked in small groups to reflect on four theme areas that captured the continuum of programs and services to address FASD (prevention, screening and diagnosis, intervention and supports, and training and education) and discussed activities, challenges/gaps and opportunities related to each theme.

Following the small group work, a synthesis of the opportunities related to each theme was presented to the large group, and participants were asked to prioritize the opportunities using a dotmocracy process. During the final session of the Forum, participants worked in small groups to discuss a coordinated approach to addressing FASD, and each group presented the highlights of their discussion back to the larger group.

## Closing Remarks

The Forum was closed by Mr. Robert Wright, Executive Director, Child and Youth Strategy. Mr. Wright thanked the planning committee for the invitation to participate in the meeting and thanked all participants for their contributions throughout the day. Mr. Wright noted that through his work with children and families in education and social services he has seen the impact of FASD and the life time support it requires, as well as how the system struggles to respond to the needs of individuals and families affected by FASD. Mr. Wright discussed the importance of the four themes as they reflect the support that is required across the continuum of care, as well as a comprehensive approach. The importance of a collaborative approach in addressing the complex issue of FASD was acknowledged and it was noted that building teams of diverse intersectoral partners is critical.

Mr. Wright emphasized the importance of the need for a comprehensive approach to FASD within a population health framework. FASD is not just a health and social issue but also an economic issue, woven into every fabric of our society. Although there are diverse partners represented at the Forum, Mr. Wright urged participants to think about the importance of engaging other partners such as Finance, Public Works, Labour, etc., as this is a broader issue than social welfare and health, and we “need to draw more people onto the bus”.

Mr. Wright discussed the importance of addressing alcohol use through multiple “lenses” given that it is a comprehensive cultural issue. The Alcohol Strategy envisions a culture that places alcohol consumption in a different place, where the social, economic and health problems caused by its misuse are prevented and reduced. Mr. Wright noted that we must revision the role of alcohol in our society and culture. This means redefining the role of alcohol where it does not destabilize our culture and is not a tool of subjugation – it is about cultural transformation.

## Next Steps

Ms. Kathy Inkpen thanked Mr. Wright for his inspiring closing remarks, which challenged participants to think about FASD in the broad social, cultural and economic context, and emphasized the need for a comprehensive approach across the continuum of care based on population health principles. Ms. Inkpen also thanked Gary Roberts for his opening presentation which provided important context for the work throughout the day. Participants were advised that a report summarizing the feedback received during the workshop would be prepared and circulated. Ms. Inkpen concluded the meeting by thanking participants for their valuable input and feedback throughout the day, and noted that the Forum was a first step to develop a more coordinated approach along the continuum of programs and services from prevention to supporting individuals and families affected by FASD.

## WORKING SESSION 1:

# What is Happening, Challenges & Opportunities

Following the opening remarks and presentation by Gary Roberts an exercise was held where participants worked in small groups to reflect on four theme areas that captured the continuum of programs and services to address FASD. A description of each theme is provided below.

## Themes

### Prevention

**Universal Prevention:** Focused on an entire population with the intent to provide information, education and policy measures aimed at the entire population to inform society about the dangers of alcohol consumption during pregnancy and to assist individuals to make informed decisions (e.g., public awareness and education campaigns, increased taxes on alcohol, reducing density of alcohol outlets, explanatory warning labels on alcohol bottles or Responsible Bar Server programs).

**Targeted Prevention:** Programs, services and policies designed to engage and support those at high risk of alcohol use when planning or after becoming pregnant. For example, routine screening for alcohol use in women of child bearing ages, brief interventions with health care providers to identify risk.

**Prenatal Care and Assessment:** Comprehensive prenatal assessment includes a determination (usually through the use of a screening tool) of whether alcohol use has occurred at any point in the pregnancy.

### Screening and Diagnosis

**Screening:** Children who exhibit suspicious behavioural patterns and/or who may be at risk for FASD for any number of reasons may be identified for screening. Screening may be conducted through the health system, education system, the mental health system, the judicial system or social services. The purpose of screening is to facilitate referral to a diagnostic clinic.

**Diagnosis:** The diagnostic process consists of screening and referral, the physical examination and differential diagnosis, the neurobehavioral assessment and treatment and follow-up. Because of the complexity and the range of expression of dysfunction related to prenatal alcohol exposure, a multidisciplinary team is essential for an accurate and comprehensive diagnosis and treatment recommendations. The assessment process begins with recognition of the need for diagnosis and ends with implementation of appropriate recommendations.

### Intervention and Supports

**Interventions:** Typically targeted at those individuals who are affected by prenatal alcohol exposure. This may occur at any time in the individuals' life and may be medical, social, educational, vocational or justice-related. A successful intervention may help to minimize secondary disabilities that may stem from inappropriate care. Examples may include: specialized psycho educational support for school age children, assistance with basic social and communication skills, tailored job training or vocational support for adolescents or adults or support for independent living.

**Support:** Multifaceted and takes into account support for the individual affected with FASD as well as their caregivers. Strong support for all involved will likely result in a stable living situation that will encourage and promote a positive atmosphere. Examples may include: advocating for and accessing appropriate medical, educational and psychosocial services, pre-adoption FASD information or financial support.

## Training and Education

**Training:** In-service and post certification professional development programs or training opportunities aimed at increasing professional or personal competencies in better understanding or intervening within individuals or families affected by FASD (e.g., professional development sessions).

**Education:** Any educational endeavor that increases professional (e.g., psychologists, health care professionals, social workers, educators, criminal justice or law enforcement) competence (e.g., initial schooling or pre-service training) and professional certification of individuals (e.g., Undergraduate or Graduate Accredited Programs in Schools of Education, Schools of Psychology, Schools of Nursing, or Schools of Social Work, etc.)

## Activities, Challenges/Gaps and Opportunities Related to the Themes

Participants worked in small groups to discuss the activities underway, challenges and/or gaps as well as opportunities related to each of the themes. The following tables provide a synthesis of the participant feedback organized by the themes.

**TABLE 1: ACTIVITIES, CHALLENGES/GAPS AND OPPORTUNITIES RELATED TO PREVENTION**

### Prevention

#### Current Activities

##### UNIVERSAL PREVENTION

- Health and PDR in schools related to educating children and youth about drinking; simulated babies in class with FASD (through Nova Scotia Community Colleges for grade eight students in Yarmouth)
- Education is happening through a range of partners such as church groups as well as schools (e.g., FASD Support Network of NS)
- Baby Think it Over is a program for grade nine students, however this is not specific to addressing alcohol
- Advocacy and education work through the Nova Scotia Liquor Commission (NSLC) about the dangers of drinking – information in school bags, teacher's kit with paper bag and artwork
- Addictions Awareness Week the third week of November
- Posters/Coaster campaign for FASD Day launched in bars (a woman and her partner are drinking water in bars)
- There are programs and systems that could be used to address FASD such as Youth Health Centres, Prenatal Clinics, the Alcohol Strategy, the Child and Youth Strategy

##### TARGETED PREVENTION

- General life skills course in Corrections Services
- FASD programs and services with Women Services and Coordinators in the Western Region (South Shore Health, South West Health and Annapolis Valley Health)
- PHA through the Community Action Program for Children has a Gender and FASD resource (it shares women's stories and experiences on a range of issues including alcohol)

##### PRENATAL CARE AND ASSESSMENT

- There are some partnerships with physicians related to screening for alcohol use that are happening in Nova Scotia
- A Prenatal Assessment form is available to physicians through the Reproductive Care Program (however not all physicians use it)
- Nurse Practitioners offer services

## Prevention Challenges and/or Gaps

### SOCIAL NORMS/CULTURE CHANGE AND COMPLEXITY OF THE ISSUE

- Alcohol consumption is normalized and making it a woman's issue is not effective; it needs to be a community issue and we need to work with leaders in the community and women's partners
- Alcohol consumption is normalized as part of the youth culture (e.g., University Frosh Weeks)
- The issue of stigma and guilt challenges addressing FASD - this needs to be handled carefully in social marketing and in supporting women; how to educate without "driving it underground"
- It is a complex issue that requires the support of many individuals and organizations within a community to change the culture
- There is a challenge in identifying who is at risk
- Although the NSLC is a critical partner, there is tension when they are the health messenger as they have a profit motive

### A COMPREHENSIVE APPROACH IS REQUIRED

- Education and awareness strategies are not effective as stand alones, a broader comprehensive approach that includes policy, addressing social norms, etc. is required
- There is a lack of policy and advocacy efforts

### LACK OF AWARENESS, PUBLIC EDUCATION AND CONSISTENT MESSAGING

- There is a lack of awareness about the risks of binge drinking
- Harm needs to be defined
- Lack of public education resources
- There is inconsistency in the messaging with various providers giving different information and messages (e.g., physicians, Public Health Nurses, etc.)
- There is a lack of effective communication and knowledge exchange about the effects of alcohol use during pregnancy
- In addressing the issues it is important not to drive it underground

### LACK OF COORDINATION

- There needs to be coordination and someone to "lead the charge"
- There is a lack of structure and accountability as well as resources to support a coordinated approach
- Political will is required
- There is a lack of coordination and continuity of programs and services and navigating through the system can be challenging

### THE NEED FOR COMMUNITY DEVELOPMENT AND PARTNERSHIPS

- There is a need to mobilize at the grassroots
- There is a need to more effectively engage partners, including those with a powerful voice such as Doctors Nova Scotia
- There is a need for more community support groups

### LACK OF PROGRAMS, SERVICES AND TOOLS (OR THEIR USE)

- There are gaps in prevention and services, particularly for some populations – where do young women go?
- There are some tools available such as the prenatal assessment form and a social screening tool (Diane Laking from the Institute of Human Services) but these tools are not always used
- There is a lack of available training, particularly related to screening and "how to ask"

## Prevention Opportunities

### INTEGRATION, LINKING AND PARTNERSHIPS

- Integrate education and services into existing programs such as prenatal clinics, Youth Health Centres, sexual health education, University programs, education and curriculum in schools, guidance counselors, Healthy Beginnings program, Positive Effective Behaviour Support (PEBS) in schools
- Use existing tools such as Telehealth, the internet, knowledge transfer, comprehensive guidance at schools, Addictions Awareness Week, etc.
- Develop and implement strategies to support better continuity and coordination of programs and services – e.g., help individuals navigate the system
- Support the development of intersectoral partnerships across the continuum of care including individuals, families and communities

### A COORDINATING STRUCTURE

- Identify a coordinating structure for FASD – one government department with overall responsibility for a coordinated approach and this should include dedicated funding; currently there is a lack of coordination of existing programs and services, a lack of connection and sharing among organizations and individuals, and a lack of accountability – as there is not one organization or individual responsible (many individuals are trying to address “off the side of their desk”)
- Coordinate public awareness materials and message development

### A CLEARINGHOUSE

- Create and support a clearinghouse for information, resources, support (for both professionals and the public)
- Provide a central point of access for the range of providers involved in addressing the issue including Justice, Education, Community Services, Health, etc.

### TRAINING IN BEST PRACTICES

- Develop and implement training for professionals on best practices for FASD prevention
- Share and learn from the work and activities in First Nations communities

### WOMEN CENTRE APPROACHES

- Support a women centred approach to addressing FASD and address in the context of women’s overall health and the communities in which women live

### SOCIAL MARKETING AND CONSISTENT MESSAGING

- Develop and implement social marketing to support and sustain consistent messaging
- Integrate/address warning labels in social marketing strategies
- Ensure campaigns address the cultural use and issue of alcohol in society

### INTERDISCIPLINARY TEAMS

- Develop and support interdisciplinary teams at the local level
- Provide opportunities for dialogue at the local level (wrap around method service model)

**TABLE 2: ACTIVITIES, CHALLENGES/GAPS AND OPPORTUNITIES RELATED TO SCREENING AND DIAGNOSIS**  
**Screening and Diagnosis**  
**Current Activities**

**SCREENING**

- Screening of all births is done by Public Health Services (PHS) and one indicator is substance use including alcohol
- Most children in Nova Scotia are immunized by primary care providers and Public Health staff – developmental screening is part of this visit in some areas
- Prenatal screening for alcohol use is happening, but is not consistent
- There are enhanced partnerships in local areas
- There are well child immunizations tools such as Nipissing – to assess ages and stages from 2 months to 18 months; this tool is used by Public Health Services, FRCs, etc.
- Healthy Beginnings – parents who are “screened in” can access supports
- Preschool wellness clinics by PHS can support screening for and identification of FASD
- There is an interdisciplinary wellness clinic for preschoolers in Annapolis Valley where several agencies come together (e.g., Addiction Services, Understanding the Early Years Research Study, Public Health Services, Speech and Hearing) to provide assessments

**DIAGNOSIS**

- Developmental clinics are in place in Halifax (the IWK Health Centre) and Yarmouth where a FASD diagnosis can be made
- Diagnosis is happening for adoptive children
- There are a variety of “intervention attempts” for children – we cannot wait for the diagnosis as this can take years and in some cases the diagnosis can be incorrect
- Diagnosis can happen as there is some expertise in Nova Scotia, however this is currently “sketchy”
- There is limited capacity to do diagnosis in Nova Scotia (some physicians have been trained and a physician in New Brunswick can provide diagnostic services)

## Screening and Diagnosis Challenges and/or Gaps

### STIGMA

- Stigma makes it difficult to seek help or to diagnose; it is not easy for women to disclose as there is a lot of judgment, stereotyping
- Other diagnoses may be made as they are more socially acceptable (e.g., autism, ADHA)
- A FASD diagnosis is not socially acceptable; there is a lot of denial and unwillingness to accept FASD as a societal issue
- There is a lack of emotional supports for birth mothers whose child does receive a FASD diagnosis
- There is racism – it is easier to label visible minorities as FASD
- There is a misconception that this is just a First Nations issue
- Vulnerable families are more truthful about alcohol use during pregnancy
- It can be difficult to ask the questions (i.e., providers may be uncomfortable asking and screening)

### LACK OF SCREENING

- There is a lack of screening through the education system and there is a lack of screening tools in education for FASD
- There are a lack of “good” screening tools for FASD
- Middle class families are not screened - not asked about their drinking habits
- There is a challenge in obtaining maternal alcohol history
- No organization or provider has a mandate to deal with screening and diagnosis, and services do not connect and work together well

### LACK OF AND/OR MISDIAGNOSIS

- There is a need for better physician engagement in moving diagnostic work forward
- There is a lack of training to identify adults whose diagnosis has been missed earlier in life – what are the diagnostic criteria for adults?
- Clients are often misdiagnosed with ADHD, autism or conduct disorder without proper assessments – diagnosis is not readily available and there is lack of multidisciplinary teams with the expertise

### LACK OF PROGRAMS AND SERVICES

- There are a lack of development clinics in Nova Scotia – many people have to travel long distances to access these services
- There are a lack of advocates and supports for those diagnosed with FASD and there are a lack of resources/ services in French
- Families need support to go through the process and interventions and they are the key to success in addressing FASD – there have to be “wrap around” supports

### LACK OF AWARENESS

- There may still be a lack of awareness of the harmful effects of drinking

## Screening and Diagnosis Opportunities

### EXISTING PROVIDERS AND EXPERTISE

- Provide professional development for existing providers such as PHS and primary care – there is a need for trained sensitive physicians and other health care providers
- Use existing providers such as physicians and psychologists to train and mentor other providers
- Support local resource people who are working in this area and promote the work of organizations leading work on screening (e.g., Best Start – FASD Information and Consultation Services, Mother risk)
- Use Telehealth to provide training
- Explore Diagnostic Centres such as the one at Georges Dumont Hospital in Moncton – training needs to involve case studies to create understanding and empathy for families (role playing, etc.)
- Provide mentors and role models (i.e., those who do screening/diagnosis could mentor and model the behaviour for others)
- Build on the Gender and FASD Project (PHAC and FRC)
- Enhance well child systems and Early Years work

### LEARN FROM EXPERIENCE

- Learn from others' experience such as First Nations communities as they recognized the issue and addressed it "first", and they have accepted the issue and have a positive approach in some communities
- First Nations communities are encouraging both men and women to be substance free and recognize the role of men and the entire community
- Recognize the importance of early intervention but FASD is a life long issue and interventions may be required at any stage, and assessments are required at any stage

### INTERDISCIPLINARY TEAM MODELS

- Invest resources in building and supporting multidisciplinary teams (e.g., in Ontario investments have been made)
- Develop a "nuclear" team that takes on responsibility for training other teams
- Consider a team model as is used with Autism Spectrum Disorder
- Explore the role of the Department of Education and schools

### INTEGRATE, LINK AND SHARE

- Incorporate screening and diagnosis services in existing programs such as Developmental Clinics (e.g., the Developmental Clinic in Yarmouth is exploring piloting FASD national diagnostic guidelines), well child systems (e.g., tie into immunization and the electronic medical record), early intervention and primary to grade two, TAs and other supports in classrooms, well women clinics and visits

### WOMAN AND FAMILY CENTRED APPROACH

- Ensure messages have a women-centred approach
- Ensure that programs and services reach families as alcohol use is beyond only women – it involves partners and the community

### COMMUNITY DEVELOPMENT

- Support and expand local support groups that help with all aspects of FASD

**TABLE 3:** ACTIVITIES, CHALLENGES/GAPS AND OPPORTUNITIES RELATED TO INTERVENTIONS AND SUPPORT**Interventions and Support****Current Activities****EARLY INTERVENTIONS SERVICES (EIPS), HOWEVER THERE ARE SOME CHALLENGES WITH HAVING BEHAVIOURAL ISSUES FIT WITHIN THE EI MANDATE**

- Family Resource Centres provide support for parents and young children – many are funded through the Community Action Program for Children and/or Canadian Prenatal Nutrition Program
- Healthy Beginnings from PHS provide support for parenting and referral to other agencies
- Counselling for women affected by addiction
- CHOICES program through Addiction, Prevention and Treatment services recognizes the differences in behaviours with the diagnosis; they use their knowledge and expertise to ask about family history
- There are some providers available such as social workers in schools in HRSB, school psychologist, behavioural specialists
- Program in-services for teachers and professional development workshops for EIPS, child care, etc.
- FASD support services and programs on First Nations communities (e.g., Eskasoni Early Interventions, Youth Workers, Health Centres)
- Skills for Life available from grades 7 to 9 – an adolescent addiction counselor is available and other school health programs
- Pilot projects with mental health clinicians in schools (for parents, teachers and students)
- Positive Effective Behaviour Support (PEBS)
- VON National Program
- Nova Scotia FASD Network (Industrial Cape Breton)
- Kids First Referral centre (PHAC)
- Intake to Mental health (a policy or process to prioritize pregnant intake)
- Once special needs are identified an “IPP” can be developed for a child in the schools system

## **Interventions and Support Challenges and/or Gaps**

### **LACK OF PROGRAMS AND SERVICES**

- There is a lack of support programs, particularly in rural areas
- There is a need for more school health centres
- Just six of 13 First Nations communities have centres
- A lack of diagnosis and misdiagnosis challenges maximizing interventions, and interventions tend to be generic versus providing specific supports
- There needs to be recognition that this is a lifelong issue, and support and services are required across the lifespan
- Long wait lists are a problem even when programs and supports are available
- Lack of resources for youth and culturally sensitive materials
- Inconsistent criteria for access to services
- Lack of access to programs and services for those not in school

### **COMPREHENSIVE APPROACH**

- There is a lack of a comprehensive approach
- Supports need to be wide ranging (e.g., asking all women about alcohol use versus specific target groups)
- Lack of parental involvement
- Lack of planning frameworks and processes
- Inconsistent and lack of messaging

### **PROFESSIONAL DEVELOPMENT**

- There is a need for professional development and specialized training for diverse providers including those in health, community services, justice, education
- Medical and other front-line workers have little information
- Professionals have a lot on their plates and are spread thin

### **STIGMA**

- Issues related to stigma complicate addressing the issue but need to be recognized and addressed so it does not go "underground"
- FASD is sometimes seen as a woman's issue when it is a societal issue
- Some programs are located in locations that enforce the stigma (e.g., old buildings and rooms without windows, basements, etc.)
- Lack of a safe environment to access services

### **COORDINATION**

- There is a lack of coordination of services and a central point of access
- There is a lack of leadership, direction and accountability
- Communication, linking and sharing between programs is required

## **Interventions and Support Opportunities**

### **MULTIDISCIPLINARY TEAMS AND PARTNERSHIPS**

- Build and support multidisciplinary teams
- Provide opportunities for sharing among front line workers and for them to share their perspective
- Various stakeholders need to understand the issue and its impacts such as policy makers, lounge and bar owners

### **CENTRALIZED RESOURCE SYSTEM**

- Make resources available through a centralized library type system
- Provide centralized Nova Scotia centres without centralizing services and programs

### **STRATEGIES TO DE-STIGMATIZE**

- Develop strategies and communication to de-stigmatize disclosure
- Encourage parents to ask for help and provide options for parents – reach out to them
- Use safe environments for community access to resources/information

### **BUILD ON STRENGTHS AND LESSONS LEARNED**

- Use and further develop existing strategies and make use of current programs and services – build on our strengths and current activities to address FASD and coordinate
- Build on lessons learned from other initiatives (e.g., drinking and driving, smoking cessation)
- Make the New Brunswick Pre-service course available
- Utilize home support and respite care
- Learn from parents who are living with FASD and facilitate sharing
- Continue to strengthen the case conferencing process
- Build on the wrap around model as it increases accountability
- Use technologies such as Telehealth and teleconferences to disseminate information and for education and training

### **COORDINATION**

- Coordinate programs and services across the life span (children, youth, adults)
- Develop processes and systems to help with coordination so providers know where to send individuals and families for support and help
- Provide networking opportunities and mechanisms for gathering people and information together
- Build and support an Atlantic perspective and approach

**TABLE 4:** ACTIVITIES, CHALLENGES/GAPS AND OPPORTUNITIES RELATED TO TRAINING AND EDUCATION

## Training and Education

### Current Activities

- The 2001 conference in Moncton
- Lunch and learns with partners in the community
- September 9th is a provincial day to recognize FASD
- Internet, journals
- VON survey with families approximately two years ago to determine prevalence rates
- There is a FASD certificate course (Ellen Bubar) at the University of New Brunswick
- National train the trainer with First Nations communities (Head Start) by Della M – she also provides workshops for NS psychiatry lawyers
- Legal Aid provides briefings on how to advocate on certain issues
- Family Resource Centres across the Atlantic Region offer a range of programs and services that are gender focused, looking at biases
- CCSA initiative is pulling together best practices and guidelines with a list of facilitators who can provide these
- Nancy Ross and Debbie Smith will provide a “road show” on FASD in the South Shore (Lunenburg) for professionals
- There is a two day workshop in New Brunswick directed at families and professionals on FASD about children’s needs for education developmental issues – this is geared toward working with children and families
- “Just the Facts” programs for women on substance use
- Intervention strategies for Community College
- Gary Jonah provides training re: FASD and law enforcement that includes other sectors
- Functional assessment tools help identify defining behaviours – this aids in programming (training sessions with staff in schools)
- In Lunenburg and Queens there is a course for the school systems and others if they want it – currently the focus is on resource teachers and FASD behaviours
- There are various courses at Acadia University on a range of issues around substance use
- There is better knowledge among primary teachers and early intervention providers than before (as well as better support for families accessing services)
- Learn from other provinces who are more advanced (e.g., Ontario, Manitoba and British Columbia)
- There are online courses available for many disciplines and training has been incorporated into professional certification
- Mount St. Vincent University offers programs, workshops, and some conferences
- Behavioural specialists are developing in-services on sensitivity to FASD
- In-servicing provided for the school system
- There is a better understanding of the impact of FASD in the justice system
- PRIMA (Pregnancy Related Issues in the Management of Addictions) training in the spring of 2008 in Nova Scotia for physicians and other health care providers.

## **Training and Education Challenges and/or Gaps**

### **PROVIDER AWARENESS, KNOWLEDGE AND SKILLS**

- A lack of education among providers means children do not get diagnosed early enough and it also means that there is limited follow-up in the system
- Education is required on various aspects of the issue (e.g., broaching the topic, assessment, how to be a resource to people upon disclosure, diagnosis, understanding underlying issues with function/behaviour, better understanding of early flags, health promotion strategies, how to refer, communication techniques, women-centred approach, nonjudgmental approach, that non-verbal and verbal communication contribute to stigma, social determinants of health, etc.)
- Lack of awareness among some professionals and providers about the issue of FASD and what training is available
- Providers give mixed messages and inconsistent information and education re: alcohol use in pregnancy
- Lack of providers with the required expertise to offer education and training, and there is a lack of awareness about who the experts are
- Lack of training and education on FASD for someone with “special needs” education
- The expertise and capacity of parents needs to be considered
- Lack of training, education and resources for francophones in Nova Scotia
- Lack of up to date education and resources
- Lack of research and evidence about alcohol consumption in pregnancy creates inconsistencies

### **COORDINATION**

- Lack of coordination of existing initiatives and there is no coordinated leadership on the issue
- Education efforts are disjointed
- Lack of awareness of resources for referral
- There is a need for consistent training

### **INCORPORATE WITHIN EXISTING PROGRAMS**

- Targeted education in medicine or nursing that is focused on addiction issues in general is required

### **STIGMA**

- Asking about alcohol use is not always done by providers as they may be uncomfortable due to the stigma
- Stigma is preventing professionals from using their knowledge, because of the implications, particularly in rural areas (stigma prevents effective use of education)
- A harm reduction approach is required
- There is a need for sensitivity training because when parents disclose and experience stigma this shuts down navigating the system

### **ENGAGING PHYSICIANS**

- It can be challenging recruiting physicians to sessions, there is a need to incorporate FASD training into CMEs and provide funding

### **INTERPROFESSIONAL EDUCATION**

- Inter-professional education is required
- Education is often discipline specific and polarized
- This is a complex issue and behaviour that requires specialization across disciplines

### **PUBLIC EDUCATION**

- Lack of education at the high school level
- Lack of coordinated education/training for families
- There is a need for education of many individuals (e.g., bus drivers, children in classrooms)

## **Training and Education Opportunities**

### **BUILD ON WHAT WORKS AND CURRENT EVIDENCE**

- Review current training and education initiatives and build on what works
- Support the implementation of standardized screening tools to facilitate a consistent approach
- Develop training and education based on needs and using existing capacities (e.g., existing expertise)
- Explore brief intervention models as these are key, particularly with primary care physicians who reach many women
- Use technology but also ensure a “hands on” social approach to learning
- Build on current evidence, research and best practices in developing training and education

### **CLEARINGHOUSE AND COORDINATION**

- Provide a central access point for education and training materials and resources (e.g., website, 1-800 #, web based, Telehealth, etc)
- Implement navigators, case managers and coordinators for education
- Provide a coordinated approach to care

### **NETWORKING AND SHARING**

- Build a network of trained individuals based on a train the trainer model
- Link with universities to identify and conduct research related to FASD
- Explore and expand current knowledge of consultants and specialists in the field (who, what, how to connect)
- Share experiences and resources through establishing networks, inter-professional education

### **INTEGRATE AND INCORPORATE INTO EXISTING PROGRAMS**

- Incorporate information and education on FASD into undergraduate and basic training programs – e.g., medical schools, nursing education, psychology, etc.
- Incorporate training for providers in existing programs such as Youth Health Centres

## Moving Forward – Potential Areas for Action

Following the small group work, the facilitator from each group provided a brief report back on the outcomes of the group discussions. Each facilitator synthesized the key opportunities identified, and forum participants were asked to prioritize the opportunities using a dotmocracy process (i.e., each participant was provided with two dots for each of the themes and asked to “vote” for the top two priorities within each theme). It was noted that none of the opportunities identified would be lost (presented in tables one through four) and that the point of the exercise was to begin to gauge interest and willingness in moving opportunities forward into action (versus an official priority setting exercise). In identifying priorities, participants were asked to reflect on:

- What is happening that we can build upon?
- Does it make sense to move on certain opportunities prior to other (e.g., chronology)?
- Are there opportunities to leverage resources?

The facilitators noted that there was often overlap between the themes in terms of opportunities (e.g., create and support multidisciplinary teams, coordination), which is not surprising given the inter-connectedness of the theme areas. Table five provides the list of opportunities (compiled and synthesized by the facilitators) and the number of “votes” each received.

**TABLE 5: RESULTS OF THE DOTMOCRACY**

OPPORTUNITIES	“VOTES”
<b>Prevention</b>	
Support a women-centred approach and women’s health	28
Develop and support interdisciplinary teams at the local level	20
Identify a coordinating “body” for FASD (who is “driving the bus”)	17
Create and support a clearinghouse for information, resources, support (for professionals and the public)	15
Develop and implement training for professionals on best practices for FASD prevention	12
Develop and implement social marketing to support and sustain consistent messaging	4
Use existing tools such as Telehealth and the internet in prevention, education, knowledge transfer, etc.	2
Integrate/address warning labels in social marketing strategies	2
<b>Screening and Diagnosis</b>	
Consider a team model as is considered with Autism Spectrum Disorder	24
Build on existing support through Early Intervention and Primary to Grade 2	20
Learn from experiences/successes of First Nations communities	16
Support and expand local support groups that help with all aspects of FASD (access, diagnosis and support)	12
Increase screening opportunities for young children through the well child system (immunization)	8
Use existing expertise from physicians, psychologist and other providers to train and mentor teams related to diagnosis	3
Increase access to TAs and other supports in classrooms for children with FASD	2
Learn from the current Yarmouth pilot to use national FASD Diagnostic Guideline	1

**TABLE 5:** RESULTS OF THE DOTMOCRACY continued...

OPPORTUNITIES	"VOTES"
<b>Intervention and Supports</b>	
Build and support multidisciplinary teams	34
Create and support a centralized resource system that is staffed	14
Build on our strengths and current activities to address FASD and coordinate	10
Develop strategies and communication to de-stigmatize disclosure	10
Use technology to disseminate information for education and training	5
Build on lessons learned from other initiatives (e.g., drinking and driving, smoking cessation)	0
<b>Training and Education</b>	
Build on current evidence, research and best practices in developing training and education	31
Explore and expand current communication strategies related to training and education (e.g., a clearinghouse for information, website, 1-800 #, Telehealth)	21
Review current training and education initiatives and build on what works	19
Explore and expand current knowledge of consultants and specialists in the field (who, what, how to connect)	6
Integrate FASD in undergraduate and basic training programs	6
Share experiences and resources through establishing networks, inter-professional education	3

## WORKING SESSION 2:

## A Coordinated Approach

During the final session of the forum, participants worked in small groups to discuss a coordinated approach to address FASD. Participants reflected on the following question: **What needs to be done or put in place to support a coordinated approach to move the opportunities forward** (i.e., the opportunities identified in the first small working group session). Following is a synthesis from the small group work:

- Create structures (e.g., Steering Committee and Working Groups linked to the themes) to coordinate and bring the diverse stakeholders together (e.g., the Child/Youth Strategy Group, Community Services, Education, Health, Health Promotion and Protection, parents, advocates, employers, etc.), and ensure stakeholders represent geographic areas, cultural groups, areas of expertise (e.g., prevention, screening, diagnosis, etc.), and various sectors and disciplines
- Identify the roles and responsibilities of the various stakeholders
- Identify a champion (individual(s) and organization) to lead (“drive the bus”), coordinate, and be accountable to move the issue forward (e.g., fund a FASD Provincial Coordinator within Addiction Services or Nova Scotia Health Promotion and Protection)
- Implement a Clearinghouse to coordinate information, resources, expertise, etc., and to disseminate information and share resources.
- Allocate funds to support the coordinator position, structures and clearinghouse.
- Use existing Strategies and Leadership structures such as the Child and Youth Strategy, the Alcohol Strategy, and Social Policy Working Group to integrate FASD and build a coordinated approach.
- Compile the findings and outcomes from the forum and report from Gary Roberts and share with senior leaders and decision makers such as Deputy Ministers and Ministers (from various sectors) and structures (e.g., Social Policy Working Group) to continue to move the issue forward and build political will.
- Build infrastructure and support interdisciplinary teams and networking at the community and grassroots level.
- Provide resources to local community organizations to support ongoing work to address FASD.
- Build federal and provincial relationships to keep the issue on the agenda and move forward collaboratively.
- Explore the development of a formalized diagnostic screening program across the province.

# Participant Feedback

At the end of the workshop, participants were asked to complete a feedback survey. Detailed findings from the survey are available in Appendix 3. A brief synthesis of the survey results is presented in the table below.

**TABLE 6: WORKSHOP FEEDBACK (N=30)**

QUESTION	SYNTHESIZED RESPONSE	PARTICIPANT QUOTES
<b>Overall, upon review of the meeting purpose, I would describe this meeting as...</b>	Great opportunity for networking, sharing information, learning and generating ideas	It was helpful to have people from various disciplines come together to share information  This meeting opened my eyes to some of the important issues surrounding FASD
	This provided the foundation for moving forward to address FASD	Definitely identified the priorities and came up with recommendations of where to go from here.  First of many steps
	Well organized and informative	Well organized, quite informative, great use of time, excellent conclusion  It was well organized and well attended... the planning committee did a great job.
	<b>If the meeting could happen again, what parts would you want to remain the same?</b>	The small group work
Networking and sharing		Wonderful opportunity for group work, networking and collective planning
Format and process of the workshop		I liked the carousel approach  Combination of presentation of research, small group work and large group work
Various stakeholders represented		The opportunity to hear many points of view (multidisciplinary)  Multiple agencies represented

continued on next page....

**TABLE 6:** WORKSHOP FEEDBACK (N=30) continued...

QUESTION	SYNTHESIZED RESPONSE	PARTICIPANT QUOTES
<p><b>What parts would you want to see improved? How would you improve them?</b></p>	<p>Broader representation</p>	<p>Need broader community [involved] – not just professionals</p> <p>More decision makers involved across various government departments</p>
	<p>Distribute information prior to the meeting</p>	<p>Fewer speakers. Information can be distributed in advance and points clarified at opening</p>
<p><b>From your perspective, what is the most important action that can be taken to support the successful development and implementation of a coordinated approach to addressing FASD?</b></p>	<p>Leadership, Political Will and a Champion</p>	<p>Need a champion and leadership</p> <p>Find an organization to take a leadership role for FASD (Health Promotion and Protection)</p>
	<p>A Coordinator Position and Resources</p>	<p>A coordinator to develop a clearinghouse of resources and community supports</p> <p>Dedicated funding to have someone at local levels to help integrate the work needed for FASD into current and existing programs and services</p>
	<p>A committed group/ structure and plan</p>	<p>A committed group to keep the ball rolling</p> <p>A provincial plan</p>
	<p>Sharing and Networking</p>	<p>Sharing information with coworkers and those with less knowledge of the subject</p> <p>These fantastic ideas need to be brought forward to those in government (not just to one department); would like us to report back in a few months to see how we have moved forward</p>

# Appendices

## Appendix 1: Participant List

Anderson, Kristen Youth Worker Nova Scotia Youth Facility	Demers, Daniel Special Education Consultant Department of Education – Student Services	Maguire, Della FASD Consultant	Roberts, Jennifer Public Information Officer NSHPP – Addiction Services
Archer, Wallace Supervisor, Dept of Justice Waterville Correction	Fancy, Clare Coordinator for students with Health Needs South Shore Regional School Board	Malone, Donna Program Consultant Public Health Agency of Canada	Rodgerson-Fuller, Wanda Educational Assessor Tri County Regional School Board
Atcheson, Joyce Maternal Child Health Program Coordinator Confederacy of Mainland Mi'kmaq	Giffen-Johnson, Cindy Student Services Coordinator Department of Education Annapolis Valley Regional School Board	McDonald, Wanda Manager, Prevention and Treatment Services NS Health Promotion and Protection	Ryan, Annette Perinatal Nurse Consultant Reproductive Care Program of Nova Scotia
Bowden, Michelle Program Consultant Public Health Agency of Canada	Graham, Allister Probation Officer Correctional Services	McDonnell, Esther Community Outreach Worker Addiction Services	Flanders-Scholfield, Jennifer NS Youth Facility
Bower, Lorri Principal Education Programs Correctional Services	Gray, Jennifer Manager, Corporate Responsibility NSLC	Melanson, Sophie Program Administration Officer, Alcohol Strategy Addiction Services, DHAs 4, 5, & 6	Samson-Sullivan, Jacinta Program and Student Services Consultant Conseil Scolaire acadien provincial (CSAP)
Campbell, Valarie CDHA Healthy Beginnings Coordinator PHS	Hudson, Amanda Program Administration Officer Addiction Prevention and Treatment Services	Melville, Cornelia Psychologist South West Nova District Health	Smith, Gail Consultant Chignecto Central Regional School Board
Carson, Glenda Perinatal Clinical Nurse Specialist Prenatal & Reproductive Health Care Team Women's and Newborn Health Program IWK Health Centre	Inkpen, Kathy Coordinator Family Health NS Health Promotion & Protection	Miles, Barbara Prevention and Community Education Coordinator Addictions Services, Nova Scotia Health Promotion and Protection	Smith, Michelle Clinical Therapist (women) Addiction Services
Chabassol, Joanne Coordinator of Prevention and Community Education Addiction Services	Jantzi, Sandi Prevention and Community Education Officer Addiction Services	Morse, Patricia Executive Director Progress Centre for Early Intervention	Southern, Sharon Coordinator Student Services Conseil Scolaire Acadien Provincial
Cochrane, Fabian Regional Behaviour Specialist Halifax Regional School Board	Jonah, Gary Special education/vocational instructor for special needs inmates at Dorchester Penitentiary Dorchester Penitentiary	Morrison, Jean Women's Services Coordinator Mental Health & Addiction Services	Stone, Denise Supported Child Care Coordinator Department of Community Services
Coffey, Theresa Past Director FASD Support Network	Laking, Diane Instructor at the Institute for Early Childhood Education Institute for Human Services Education	Mosher, Terri Social Responsibility Specialist NSLC	Swan, Karen Senior Program Officer National Crime Prevention Centre, Public Safety Canada
Coffey, Tom Past President FASD Support Network of Nova Scotia	Landry, Mary Community Outreach Worker CHOICES Adolescent Treatment Program IWK Mental Health and Addictions	Murray, Patricia Director, Children's Services Department of Health	Tobin, Jeanette Program Administration Officer Addiction Prevention & Treatment Services, Capital Health
Cukier, Samantha Social Marketing Coordinator, Alcohol Strategy South Shore, South West & Annapolis Valley Health	Landry, Tracy Probation Officer Correctional Services	Peters, Brenda Community Home Visitor Coordinator Public Health Services (SSDHA)	Tree, Rachel Clinical Therapist Addiction Services
Davison, Carolyn Director of Addiction Services Nova Scotia Health Promotion and Protection	Mackenzie, Janet Public Health Nurse Public Health Services	Pickles, Michelle Manager Public Health Services	Walsh, Katie Nurse Coordinator for FASD & Injury Prevention Health Canada
	MacLean, Kimberley Community Outreach Worker, Alcohol CDHA, Addiction Prevention and Treatment Services	Power-Grimm, Jane Student Service Consultant Tri-County Regional School Board	Ward, Michelle Executive Director Kid's First Association
		Rafferty, James Medical Doctor North Queens Health Centre	Watson, Sadie Prevention and Health Promotion Coordinator Addiction Services
		Richard, Charline Student Services Coordinator Department of Education	Wright, Robert Executive Director Child & Youth Strategy, Department of Community Services

## Appendix 2: Presentation Slides

### Fetal Alcohol Spectrum Disorders (FASD) in Atlantic Canada

A two-phased initiative led by the Public Health Agency of Canada

1. Document review (2007)
2. Stakeholder input into gaps, opportunities (2008)




### Acknowledgements

Phase 1  
Literature & stakeholder search: Heather O'Brien  
Prevalence and cost estimations: Linda Graham

Phase 2  
Online survey: Heather O'Brien  
Focus groups: Mona Wynn

On behalf of the team our thanks to:

- Working group members
- Stakeholders

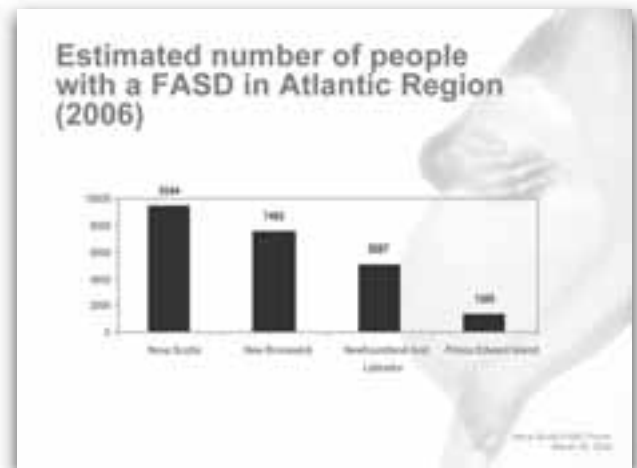


### Reviewed items

1. Incidence/prevalence & economic costs: 37 reviewed
2. Knowledge, attitudes, behaviours: 23 reviewed
3. Atlantic FASD-related policy: 5 fed items; 6 provincial
4. Atlantic research: 14 with broad relevance, 7 FASD-specific



### Prevalence estimates





### Cost estimates



### Canadian estimate

The lone Canadian study (Stade et al, 2006) puts the total adjusted cost for a child with FASD at \$14,342 a year with the annual cost to Canada for care for all FASD children aged 1-21 years at \$344,208,000.



### Estimated cost of FAS in Atlantic Canada (2006)

<b>To age 21</b>	
• Health care:	\$23M
• Education:	\$25M
• Respite, foster care, legal aid:	\$10M
• Miscellaneous:	\$6M
• Total direct cost:	\$74M
• Loss of productivity:	\$6M
• Total direct + indirect costs:	\$80M
<b>Age 22-65</b>	
Total:	\$80M
Grand total:	\$160M
Average lifetime costs:	\$535,024.77 (per individual)



### Knowledge and attitudes

*Public / professional*

*FASD / Alcohol consumption*



### Public knowledge & attitudes associated with FASD (2006)

**Knowledge**

- Good general knowledge
- Weaker specific knowledge
  - Life-long nature and severity of disorder
  - Effects of moderate amts of alcohol

**Attitudes**

- Stigma towards affected persons



### Professional knowledge & attitudes associated with FASD (2005)

- Good general knowledge
- Weak diagnostic understanding
- Weak understanding of lifelong nature
- Training greatest need to facilitate engagement, particularly the case in Atlantic



### Public knowledge & attitudes re alcohol consumption by women of child-bearing age (2006)

- Good general knowledge of role of alcohol
- Confusion around small amts of alcohol
- Stigma, discrimination towards women who drink during pregnancy

### Professional knowledge re alcohol consumption by women of child-bearing age (2005)

- Comfortable with advice re alcohol / pregnancy
- Not comfortable in supporting alcohol-dependent women
- In Atlantic, were less likely to routinely use a standard screening tool
- Small percentage providing potentially harmful message

### Public attitudes Alcohol policy measures (2005)

Support for...

- 25%: increase taxes
- 35%: raising drinking age
- 75%: increase efforts to prevent intoxicated persons from being served
- 44%: ban TV alcohol ads

### Alcohol consumption by women of child bearing age

### Alcohol consumption by women of child-bearing age (15-44 yrs) Atlantic Canada (2005)

- 81% drink alcohol
- 24% binged at least once/month
- 5% binged weekly

### Alcohol consumption by pregnant women (Canada)

- 14% report alcohol use during pregnancy
- Of them
  - 75% report using < once/month
  - 10% report once/month
  - 6% use 2-3 times a week
  - 6% weekly use
  - 1.3% daily use

### Profile: alcohol use & FAS

- Age 25 yrs +
- 3 or more children
- Alcohol dependent; multiple substance user
- Partner with substance use issues
- Early onset of use as adolescent
- Victim of violence, abuse + mental health issues
- May have been alcohol-exposed prenatally

### Profile: persons with FASD

- High needs in many areas of health and life functioning
- Secondary disabilities, due to:
  - Lack of diagnosis
  - Lack of stability in home life
  - Lack of appropriate services
  - All of which are common

### Federal FASD-related policy activity

- National alcohol and FASD strategies, including ENIHB Framework
- Best practices reports
- Status of women report
- CAPC/CPNP attention to the issue

### Provincial FASD-related policy activity

- Provincial alcohol, addictions/mental health strategies (NF, NS)
- Liquor Control Act signage requirement (NS)
- Addiction treatment priority for pregnant women (NS)
- Pregnancy/early parenting support standards (NL)

### Atlantic FASD-specific research

- Rosales and Smith (1998): estimation of prevalence
- Vernescu (awaiting publication): testing attentional model for FAS children
- Jardine and Furgal (2007): perceptions of health risks on Labrador coast
- Poulin et al (2001; 2005): adolescent drinking and sex
- Langile (2007): adolescent drinking and sex in rural NS
- MacPherson (ongoing): FASD in offender population

### Issues arising from the review

- Knowledge of life-long nature of FASD is low
- Knowledge of societal costs undoubtedly low
- High rates of hazardous drinking by young women
- Need for physician training on several topics
- Lack of FASD-specific policies in the region
- Little FASD-related research in the region

## Phase 2

- Great interest and passion shown by stakeholders
- Stakeholders identified the array of gaps in great detail
- But chose to frame the situation as one filled with opportunities
  - Coordination
  - Funding
  - Public awareness / multi-disciplinary training
  - Diagnostic resources
- Stakeholders favoured action on policy & programming, over research

## Recommendation #1 (draft)

- I. That the Atlantic Partnership consider a vision of a regional and provincial coordination infrastructure that addresses 8 priorities:
  1. promoting the well-being of all women of child-bearing age through policy and programming that reflects a determinants of health and gender-sensitive lens;
  2. promoting policy development for prevention (through provincial alcohol strategies where they exist);
  3. fostering the formation of multidisciplinary diagnostic teams covering ages 1-18 years through policy and program development in the health sector;

## Cont'd

4. promoting policy and program development in the education sector to provide support and learning plan development in the elementary and secondary school system, and post-secondary planning, and;
5. advocating policy and program development in the community sector to support individuals of all ages with FASD (including adults), as well as their parents and families;
6. establishing or serving as focal points for information exchange and multidisciplinary training across the region.

## Recommendation #2 (draft)

- II. That the Partnership continue the community building that has been begun with the first two projects, and nurture a network or community of practice, that would help address several needs identified through this process:
  - Reduce professional isolation
  - Support increased coordination of effort
  - Promote continued learning

Thank you!

[garyaroberts@sympatico.ca](mailto:garyaroberts@sympatico.ca)



### Appendix 3: Participant Feedback

1. OVERALL, UPON REVIEW OF THE MEETING PURPOSE, I WOULD DESCRIBE THIS MEETING AS: (CIRCLE ONE)  
(n=30)

1	2	3	4	5
		1	16	13

Average: 4.4

Please explain your response:

(n=26)

- Good process to gather information to move forward.
- It was helpful to have people from various disciplines come together to share information.
- Great participation; networking; accomplished a great deal
- Good broad range of interested people
- Thank you for proving an opportunity for many voices to be heard. More diversity of participants would have made a 5.
- A start
- First of many steps
- Networking with stakeholders. Priorities discussed and next steps suggested.
- Understand that everyone is in the same boat. Got to meet other professionals.
- Great opportunity to network; share and gather information
- Networking opportunity; Exposure to existing services
- Well organized, quite informative, great use of time; excellent conclusion.
- It was well organized and well attended. Current initiatives, challenges and opportunities were well discussed. The planning committee did a great job.
- Well organized and focused given the broad nature of the discussion.
- I think there was a lot of good discussion that happened today. I hope that it will make a point instead of just chat.
- Good collaboration and idea sharing
- Definitely identified the priorities and came up with recommendations of where to go from here.
- The first time I've been at a forum on FASD. Learned about what's happening more than I thought.
- Informative and an excellent opportunity to work with other stakeholders.
- It is a beginning
- This meeting opened my eyes to some of the important issues surrounding FASD
- Group work was a learning experience
- It was informative, beneficial and enlightening
- Well facilitated/ organized; modeled a collaborative approach
- Same ideas. Looking for good outcomes
- Very successful. All the stakeholders sharing and collaborating.

**2. IF THE MEETING COULD HAPPEN AGAIN, WHAT PARTS WOULD YOU WANT TO REMAIN THE SAME?****(n=26)**

- Process
- Process of sharing information
- Time to network; brainstorming
- All well done
- The opportunity to network
- Just excellent
- More stakeholders including those who have power to make changes – political will.
- Breakout groups
- Brainstorming carousel
- I enjoyed Robert Wright's talk; I liked the thematic approach.
- More information on the affects of FASD
- Input sessions; general invitation; need broader community (not just professionals)
- Organization, changing of groups, sharing time
- Small working group sessions
- Small group format
- A lot of discussion
- All the same people invited to keep consistent
- Wonderful opportunity for group work, networking and collective planning.
- Answering the questions in carousel.
- Like the carousel approach; like the dotmocracy.
- Information sharing
- Group work
- Small group work; multiply agencies represented; getting up to move – helped to keep us stimulated
- The morning small group work (carousel and sharing); bringing in the vast array of stakeholders to truly develop and make networks.
- Location/food; combination of presentation of research, small group and large group work; focus on opportunities/ action plan; opportunity to hear many points of view (multidisciplinary) /network
- Various stakeholders; lots of group work; organized activities – everyone got a change to share and be heard; Lord Nelson – nice meeting area.

### 3. WHAT PARTS WOULD YOU WANT TO SEE IMPROVED? HOW WOULD YOU IMPROVE THEM?

(n=17)

- Nothing
- A pre-conference preparation with 2 readings and agreement and involvement of the participants on determining the questions to be explored.
- Once the initial phase is complete then the logical step, once all suggestions are synthesized, would be to appoint an FASD coordinator and develop a prioritized strategy and coordinated partnership.
- When people sign up have them send in what they are doing or what resources are available in their communities. There may be people providing services in my community that I did not get a chance to meet today.
- More decision makers involved across various government departments
- For a one-day session – ok; larger room; more opportunity to join other groups.
- An area out of downtown Halifax (parking/traffic)
- More adult learning techniques put in place. A lot of sitting can damper creative thought.
- We need leaders in place; goals to meet before a next meeting
- Getting to meet more of the people in the room.
- A bit repetitive at times but very informative.
- Repetitive by the end of the day - finish after dotmocracy.
- Fewer speakers. Information can be distributed in advance and points clarified at opening
- Have similar meetings at local levels, this may help to plan at local level, build referral system, recognize and clarify roles; the themes are so inter-woven it was hard to separate the ideas/discussion for each (at times, I felt like I was repeating myself)
- I would like more to discuss working with/teaching and helping or empowering children/ youth/ adults living with FASD. What strategies, initiatives are there to deal with these?
- A little slow to get going between 9-10
- Not necessary to report back on initiatives to large group. Too late in the day (2pm). Most of the facilitators told us what the other groups had said.

4. FROM YOUR PERSPECTIVE, WHAT IS THE MOST IMPORTANT ACTION THAN CAN BE TAKEN TO SUPPORT THE SUCCESSFUL DEVELOPMENT AND IMPLEMENTATION OF A COORDINATED APPROACH TO ADDRESSING FASD? (N=28)

**Factor:**

- Being prioritized an important issue.
- Sharing information with coworkers and those with less knowledge of the subject
- Something to happen to get the important message of drinking in pregnancy – action is critical!!! Keep the momentum going.
- A committed group to keep the “ball rolling” and to organize contacts for everyone – online? Paper?
- De-stigmatization of women who are seeking help for alcohol and other substance use. This would require a broad, systemic approach.
- Need a champion – leader
- Political will; FASD coordinator; Time lined agenda
- Provincial plan and mandate related to FASD – political will must be there. Stakeholders must push issue of FASD at political level.
- Coordinator to develop a clearinghouse of resources and community supports. Maybe the job of the HEP coordinator until funding can be secured.
- Supporting existing services/service collaboration/coordination.
- Tie into political will \_\_\_social and economic impact data with a view to secure funding for continued grassroots work, provincial coordination, provincial resources, etc.
- Leadership – HPP with \$; hub/wrap around model at government and at community that involved community members not just professionals. Need strategies to enact what communities determine and it goes to government.
- Finding an organization to take a leadership role for FASD (Health Promotion and Prevention); Better communication – great things happening but too many key players are not aware of them; The need for French services, documentation, etc.
- Mobilize existing like minded to push the issue forward onto the political agenda. As well link with potential researchers within the larger community to support best practices.
- I think that because there are so many organizations and politics pushing each of the different stakeholders there needs to be a multidisciplinary team similar to the Autism team to ensure there is a presence and supports in the community.
- Leaders form HPP and Child Development and from the community.
- Government’s commitment to move this forward.
- Start developing the “structure”
- For each stakeholder to know their particular roles and responsibilities in relation to FASD.
- Information/resource database
- Someone to “drive the bus”
- Two distinct strategies for: 1) expectant mothers and 2) children with FASD
- Dedicated funding to have someone at local levels to help integrate the work need for FASD into current and existing programs/services.
- Keep current/share and network (open communication amongst stakeholders)
- These fantastic ideas need to be brought forward to those in government (not just to one department); would like us to report back in a few months to see how we have moved forward
- Time is now
- A coordinated plan – political will to move the agenda

## 5. FURTHER COMMENTS:

(N=12)

- Thanks for a great day! Looking forward to the great work ahead!
- Thanks for having me.
- FASD is a complicated issue. Thank you for this terrific forum! And great lunch!
- Well done and long overdue
- Thanks to the planning committee!!
- Thank you for an informative day! Please put recommendations into action!
- Thanks for forwarding this issue, hopefully the momentum won't be lost or derailed.
- Hope to see more action on this.
- Thanks
- Great day with lots of potential; once we move forward in some collaborative direction that we re-meet again with the same or similar group to recap and move even further along
- Really thrilled to be part of a multi-disciplinary forum; Robert's closing remarks – amazing, powerful and mind-expanding! Thank you!
- Would have liked to have the names and titles of the people who spoke in the morning in the participants package; Great lunch and breaks; great location. Very comfortable.



