

FASD ONTARIO NEWS

THE NEWSLETTER

OF FASD

STAKEHOLDERS

FOR ONTARIO

EDITION 6, APRIL 2009



Message from the Chair

It is a great honour to be re-elected as the Chair of FASD Stakeholders for Ontario. I am pleased with the progress, scope and quality of the work of this group. Many volunteers commit their time and expertise to advancing the issues related to this disability in Ontario.

As the Stakeholders have found their direction, accomplished tasks and seen success, we have been able to increase the clarity of our message and define the challenges for government colleagues. We have found over the last number of months an increased readiness to hear about FASD and to consider the needs of this complex but manageable disability.

Sheila Burns, Chair, FASD Stakeholders for Ontario

News Worth Checking: Bill 77

The government of Ontario has approved legislation that redefines the definition of developmental disability for adults. The intelligence quota (IQ) required for developmental services previously excluded many individuals with FASD. Bill 77 was passed in October 2008 and should be an important access vehicle for improving the lives of adults with FASD.

The regulations (the parameters around the new legislation) are still being developed, but the bill is an important foundation. The legislation appears to increase access to many of the resources that would provide a smoother transition from youth to adult services. The bill also provides a menu of services that can be tailored to the specific strengths, challenges and needs of individuals. This also may help families work more effectively with local resources and services.

Go to the Ministry of Community and Social Services website www.mcscs.gov.on.ca/mcscs/english/pillars/developmental for the detailed legislation. Let your MPP know that these changes will meet the needs of vulnerable adults and should contribute to improved outcomes for individuals with FASD and their families.

Ontario Region

In November 2008, the Ontario regional office of the Public Health Agency of Canada (PHAC) hosted a workshop with Dan Dubovsky, a renowned FASD specialist. Dan's presentation, "Stopping the Revolving Door," focused on the life-cycle of FASD which includes prevention, diagnosis, treatment and coping with the disorder. This event brought together many sectors representing federal and provincial governments, Aboriginal organizations, non-for-profit organizations, health care providers, school boards, correctional services, and front-line workers. PHAC continues to support the work of the FASD Stakeholders for Ontario and FIANO, the FASD Intergovernmental Action Network. Currently Donna De Filippis is the PHAC Regional Lead for the FASD file in Ontario and can be reached at (416) 954-9754.

PURPOSE :

This newsletter was developed to help people in Ontario work together to address FASD. It reports on the activities of FASD Stakeholders for Ontario and shares news of relevance to individuals, caregivers and service providers who work on FASD across Ontario. For submission requirements and previous editions visit: www.beststart.org/projects/index.html

FETAL ALCOHOL SPECTRUM DISORDER (FASD)

"FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and learning disabilities with lifelong implications."

FASD: Canadian Guidelines for Diagnosis, 2005

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Editor for FASD Ontario News:
Wendy Burgoyne
Best Start Resource Centre
w.burgoyne@healthnexus.ca



DIAGNOSIS AND DISABILITY WORKING GROUP

FASD Diagnostic Working Group aims to increase the availability, accessibility, and consistency in FASD diagnostic services across the province.

Review of Progress – In 2008, this working group received funding from the Public Health Agency of Canada to train 28 professionals in Ontario on diagnosis of FASD. This group included 12 Family Physicians, 6 Paediatricians, 2 Nurse Practitioners, 6 Psychologists, 1 Speech-Language Pathologist, and 1 Project Coordinator. These professionals came from a wide variety of regions including Kingston-Belleville, Hamilton, Brant County, North Bay, Thunder Bay, and Dryden-Sioux-Lookout.

Future Goals – For the period of 2009 through 2010, this working group plans to develop expertise and consistency in diagnosis across Ontario through video conferencing training and information exchange sessions. Sessions will include topics such as interacting with Local Health Integration Networks (LHINs); review of the Canadian Guidelines for diagnosis; and FASD psychological assessment updates and procedures. Each session will be professionally facilitated and available to video conferencing sites across the province.

Lead: Valerie Temple, Surrey Place Centre, valerie.temple@surreyplace.on.ca

URBAN ABORIGINAL WORKING GROUP

This group is working to ensure that culturally-based, Aboriginal owned information is being disseminated within mainstream and urban Aboriginal communities regarding appropriate protocols and interventions to be used when delivering services to Aboriginal peoples.

A communications strategy is being developed to increase awareness and publicize the existence of FASD in Aboriginal communities. It will include the development

and distribution of culturally appropriate promotional materials such as mouse pads, post cards, posters and stadium cups. Local Aboriginal communities can use these promotional items in their efforts to share important information about alcohol use in pregnancy and about FASD.

Lead: Kim Meawasige, Ontario Federation of Indian Friendship Centres, kmeawasige@ofifc.org

INTERVENTION AND SUPPORT WORKING GROUP

Funding from the Public Health Agency of Canada enabled this group to plan an ambitious year including:

- Surveying individuals, service providers and care providers on intervention and support needs
- Researching respite capacity and developing a public education strategy (includes an online survey of care & service providers in Ontario)
- Reviewing promising practices by existing service providers

- Disseminating information on research, resources, activities, conferences, support groups

With the support of the Public Health Agency of Canada, staff were hired to complete these projects. Parents, caregivers, service providers and teachers in Ontario were invited to participate in an online survey about education needs and services in Ontario. There was also an online survey for parents and caregivers about the need for FASD respite care services in Ontario.

Lead: Pat Spadetto, Timiskaming Brighter Futures, pat.spadetto@tcafs.org

PREVENTION WORKING GROUP

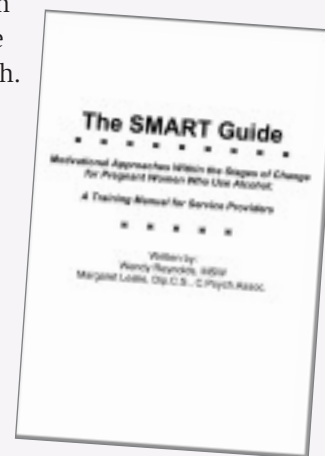
The Prevention Working Group achieved 3 main projects in 2008/09 through funding provided by the Public Health Agency of Canada, Ontario Region:

- **Awareness of FASD** – In February 2009 a provincial survey was conducted to determine levels of awareness, knowledge and intentions related to alcohol use in pregnancy and to FASD (see page 5). A report summarizing the results, trends and implications is available at www.beststart.org or www.fasdontario.ca.



- **Give and Take** – This booklet provides clear, easy-to-read, non-judgmental information for vulnerable women who are using alcohol and other drugs when they find out they are pregnant. The resource was originally developed by AWARE and was updated in 2009. It is available in French and English. To access copies of this resource, contact AWARE at aware@kos.net.

- **The SMART Guide** – This training guide describes how the Stages of Change Theory and Motivational Interviewing Strategies can be used to engage and support pregnant women who use alcohol. It was developed by Breaking the Cycle and AWARE. This guide was updated in 2009 and is available in French and English. To access copies of this resource, contact AWARE at aware@kos.net.



Lead: Susan Santiago, Motherisk, susan.santiago@sickkids.ca

JUSTICE COMMITTEE

In 2007, the Justice Committee created a website dedicated as a resource for judges and justices of the peace, lawyers, police, correctional personnel and others working in the justice system through funding provided by the Public Health Agency of Canada. The website contains a variety of information specific to the justice system, such as FASD and the Courts and Court Cases, as well as other useful information such as *Recognizing FASD*, *Understanding FASD*, and *Aboriginal Peoples and FASD*.

The Justice Working Group is currently enhancing the website to remain ever-fresh to users. A recent survey of the site has shown that it is relevant to users and is believed to be the only one of its kind in Canada. Thus far, it has received close to 350,000 hits – which validates the great need for the kind of information it provides. A large portion of website users are directly involved in the justice system yet the site is proving

useful to a broader range of other professionals. Users from around the world are accessing the site, taking advantage of its ability to translate into eight different languages. The Justice Working Group will increase its appeal to the justice sector and will

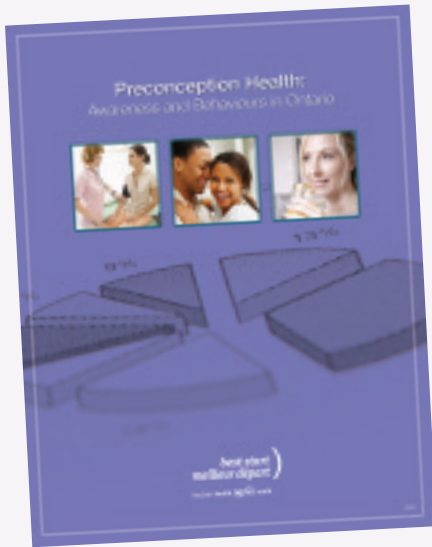


Promotional Mousepad

continue to update the case law section, provide more links to research and resources as well as enhance existing information. To provide feedback, please click 'feedback' on the website (www.fasjustice.on.ca). You can also use the 'feedback' option to request posters or postcards promoting the website.

Lead: Jonathan Rudin, Aboriginal Legal Services, rudin@lao.on.ca

ONTARIO SURVEY HIGHLIGHTS: ALCOHOL USE PRIOR TO CONCEPTION



Health before conception is important – in fact by the time a woman knows she is pregnant, it is too late to prevent many birth defects. Best Start Resource Centre conducted a survey of men and women of childbearing age on the topic of health before pregnancy in August 2008. The results were released in a 2009 report titled *Preconception Health: Awareness and Behaviours in Ontario*. This article shares a few survey highlights that pertain to alcohol use and pregnancy. Look for the complete report at www.beststart.org.

About half (49%) of female respondents indicated that they drank alcohol. Respondents with higher incomes were more likely to report that they drank alcohol.

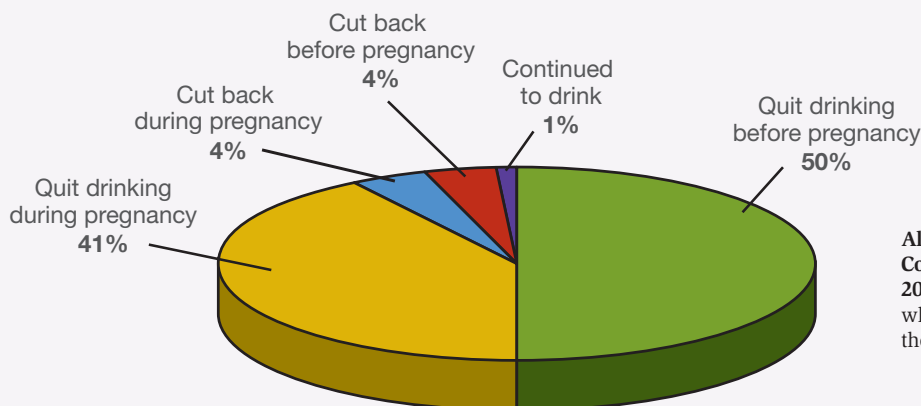
Most female respondents described their last pregnancy as planned (70%) with 30% indicating that their last pregnancy was unplanned. This was consistent with 2002 data. However, only 44% of women in 2008 made health changes prior to their last pregnancy.

When asked about health changes that women should make prior to conception, 38% of female respondents mentioned stopping drinking. This was an increase from 2002, where 29% of women mentioned stopping drinking.

Respondents were also asked about health changes they made prior to conception or during their last pregnancy. The most commonly reported health change for women was reducing/stopping alcohol consumption. This was consistent with 2002 data. Over half (53%) of women who drank alcohol, stopped or reduced their alcohol consumption *before* their last pregnancy, and an additional 45% stopped or reduced their alcohol consumption *during* their last pregnancy.

Of the women who drank alcohol before conception, 9% continued to drink alcohol throughout pregnancy (8% cut back and 1% did not change their drinking). Almost half of those who quit or cut back their alcohol use did not make this change until they were pregnant, i.e. 45% drank alcohol at previous levels in the early stages of pregnancy.

Health care providers were seen as the most important source of preconception information; however, only 8% of respondents recalled being advised to stop drinking prior to conception.



Alcohol Behaviours in relation to Conception for Ontario Women in 2008: Responses from female drinkers who were pregnant or had a child in the last 6 years

ONTARIO SURVEY HIGHLIGHTS: AWARENESS OF FASD

The Prevention Working Group developed a survey of Ontario men and women of childbearing age concerning their awareness of alcohol use in pregnancy and FASD. The survey took place in January 2009. The results were released in a report titled *Implications for Ontario: Awareness of FASD in 2009*. To view the report, go to www.beststart.org or www.fasdontario.ca.

The 2009 data was consistent with data from previous years in most areas, and overall indicated a high level of awareness concerning alcohol use in pregnancy and FASD. Ontarians understood the risks of alcohol use in pregnancy. They recognized that the more a pregnant woman drinks, the higher the risks (96%). The majority of respondents identified stopping or cutting back on alcohol as important for the health of the baby (98%). Most respondents felt that there was no safe time to drink in pregnancy (79%) and most knew the safest time to stop drinking is prior to conception (68%). Eighty one percent recognized that there is no safe type of alcohol in pregnancy. There was an increase in mentions of effects on the brain (41% in 2006 and 51% in 2009).

While most results were encouraging, and showed consistently high levels of awareness, other results indicated areas of concern:

- There was an increase in the proportion of respondents who thought that the effects of FASD disappeared as the child grows older (4% in 2006, 9% in 2009).
- Fewer respondents mentioned cutting down/stopping alcohol use as one of the most important things that pregnant women can do to have a healthy baby (52% in 2006, 45% in 2009).
- There was continued confusion about the potential impact of small and moderate amounts of alcohol use in pregnancy. In 2009, 24% of respondents believed that moderate alcohol use in pregnancy can usually be considered safe.
- Some respondents (15%) felt there were safe times to drink in pregnancy.
- There was confusion about when to stop drinking (32% felt women should quit drinking in early pregnancy, as opposed to before conception).



- When asked how many drinks were considered safe in pregnancy, only 54% of respondents indicated that no alcohol was safe in pregnancy. Eight percent of respondents felt that 5 or more drinks a week were safe in pregnancy.
- Some respondents (17%) felt there were safe types of alcohol in pregnancy, with wine (10%) and beer (5%) most commonly mentioned as safe in pregnancy.
- There was a decrease in respondents who had heard of FAS/FASD (88% in 2006 and 83% in 2009).

In 2009, 80% of women who drank alcohol indicated that they would stop drinking alcohol if they became pregnant. This is a decrease from 2006, when 89% said they would stop drinking if pregnant.

The results showed strong support for a range of strategies to warn people about the risks of alcohol use in pregnancy. Two thirds of respondents had seen or heard information about alcohol use in pregnancy or FASD. Those that received information had higher levels of awareness. Overall, the survey results indicate an ongoing need to continue to share key information about alcohol and pregnancy.

Kingston Penitentiary Native Brotherhood participates in FASDay 2008!

On the ninth minute of the ninth hour, on the ninth day of the ninth month, the only sound that could be heard in communities across Ontario was the beat of Mother Earth – her heart beat.

The Anishinabek honoured International FASD Awareness Day, within the walls of Kingston Penitentiary (KP), on September 8th, 2008. Dan Ross, KP Elder and Tanya Michelin, Aboriginal Liaison Officer, assisted the Union of Ontario Indians by helping to organize an FASD 101 session with the Native Brotherhood. The Native Brotherhood is an inmate group that shares traditional teachings and organizes cultural events. Aboriginal Initiatives, at Regional Headquarters with Correctional Services Canada took tremendous strides to host the event as a follow-up to the FASD training on March 2008. Staff from various institutions across Ontario and the National Parole Board gathered at the Regional College, to learn more about FASD.

Members of the staff were presented with a pouch of tobacco that was placed inside a birch bark canoe, decorated with the FASD Knot made of buckskin. The gifts were assembled by the KP Native Brotherhood, as a sign of their appreciation to staff for increasing their knowledge with respect to FASD that will lead to helping their fellow brothers and sisters.

To learn more about Union of Ontario Indians programs and services, contact Laurie McLeod-Shabogiesic at 1-877-702-5200.



Teepee on sacred grounds at Kingston Penitentiary

NETWORKING FORUM

The Stakeholder's first FASD Networking Forum was held in Toronto on March 26, 2009, through funding generously provided by the Public Health Agency of Canada. The forum was attended by representatives from 17 Ontario FASD committees, coalitions and networks that collaborate at the regional or community level to address FASD. The Forum was designed to provide an opportunity to discuss FASD activities taking place in the province.

Each of the five Stakeholder working groups showcased their activities and plans. This was followed by a facilitated discussion of the challenges and opportunities, successes and struggles that exist in communities across Ontario. Priority issues and insights into emerging issues were identified and will be incorporated into the Stakeholder's strategic planning.

Donna De Filippis, regional FASD Lead from the Public Health Agency of Canada, provided an update on the FASD Intergovernmental Action Network of Ontario (FIANO) as well federally funded FASD initiatives. Christine Hughes, Ministry of Community and Social Services, gave an update on Bill 77, the new legislation redefining developmental disabilities and services for adults. Representatives from the Ministry of Education and the Ministry of Child and Youth Services also participated in the Forum.

All communities reported hosting prevention campaigns designed to reach a variety of groups including physicians, the public, students, and women in high risk groups. The value of respite services in stabilizing homes, supporting women who are recovering from addictions, and providing structure and support for women with FASD who are parenting was also discussed. Most communities are exploring or providing diagnosis either directly or through tele-diagnosis. The shortage of case management, post diagnostic resources, and psychologists were common challenges. There were a few local FASD justice



initiatives, but nothing systemic. In terms of supporting individuals with FASD, the following needs were identified: professional development for teachers, principals and other administrative staff; Ministry of Education standards on FASD addressed within exceptionalities; and access to psycho-educational assessments. Local FASD initiatives for urban Aboriginal populations were mainly provided through the child nutrition programs offered across the province.

Participants felt the Forum was an excellent opportunity to hear about activities – local and provincial – and to exchange ideas that will advance FASD strategies in communities across Ontario. The Stakeholders will strengthen communications among communities through the development of a dedicated provincial FASD listserv. We will continue discussions with different Ministries, and encourage and inform a cross-ministerial government strategy. We thank all who attended for sharing their successes and challenges and for the passion, energy and creativity demonstrated throughout the day. We would also like to thank Sandy Halloran for facilitating this event.

Participating Local FASD Committees:

FASD Durham Committee

Grey Bruce FASD Community Mobilization Committee

The Hamilton Taskforce on FASD

Kingston FASD Action Network

FASD Network Middlesex London

Norfolk County FASDAC

FASD Coalition of Ottawa

Peel FASD Steering Committee

FASD Peterborough

Algoma FASD Committee

Simcoe Muskoka Coalition

NorWest Thunder Bay FASD Committee

FACT Coalition Timmins

Toronto FASD Coordinating Network

FASD Coalition of York Region

Wellington-Waterloo FASD Committee

Niagara Region FASD

FASD Stakeholders for Ontario

FASD Stakeholders for Ontario addresses factors behind FASD and supports efforts to move to a coordinated, collaborative and complementary approach in Ontario. For justice related information, visit www.fasdjustice.on.ca and for more information about the Stakeholders, email info@fasdontario.ca or visit our website at www.FASDOntario.ca

New Ontario FASD Support Group

Windsor-Essex FASD Support Group
Essex, Ontario
susansmith844@hotmail.com

Feedback about FASD Ontario News:

If you have any comments about this newsletter, or suggestions for future editions, please contact: w.burgoynes@healthnexus.ca

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Also available in French

NEW FASD RESOURCES



FASD Prevention: Canadian Perspectives
Four-part framework for FASD prevention – Public Health Agency of Canada
www.phac-aspc.gc.ca/fasd-etcaf/pdf/cp-pc-eng.pdf

Fetal Alcohol Spectrum Disorder brochure

Toronto FASD Coordinating Network
www.torontocas.ca/wp-content/uploads/2008/09/FASD.pdf
To order: srichards@TorontoCAS.ca



Forgetful Frankie: The Worlds Greatest Rock Skipper
Children's book on FASD
www.wildberryproductions.ca

Canadian FASD Databases: FASD Organizations, FASD Resources FASD Trainers, FASD Training Programs
Canadian Centre on Substance Abuse
www.ccsa.ca/Eng/KnowledgeCentre/OurDatabases/FASD/Pages/default.aspx

FASD – Finding Hope
Online documentary film on how to support individuals with FASD
Force Four Entertainment of Vancouver
www.knowledge.ca/findinghope

FASD Fact Sheet
Ministry of Children and Family Development, BC
www.mcf.gov.bc.ca/fasd/pdf/Factsheet_FASD_Feb_2009.pdf

Early Intervention Program Guidelines
Ministry of Children and Family Development, BC
www.mcf.gov.bc.ca/spec_needs/pdf/ei_therapy_guidelines.pdf



The Fetal Alcohol Forum International Medical e-Network
Published in April and November
Send articles about fetal alcohol research and medical issues to: nofas-uk@midlantic.co.uk
To subscribe send email address to: fetal.alcohol.forum@midlantic.co.uk

FASD TRAINING

TRAINING EVENTS IN ONTARIO:

FASD: Moving Systems Forward For Effective Intervention: A Conference for Professionals
Dan Dubovsky
May 6, 2009, Hamilton
The Hamilton Task Force on FASD
Contact Monica or Angela at 1-905-574-6876

Motherisk Update: Preparing for Pregnancy – Selected Topics in Preconception Health
May 27, 2009, Toronto
www.motherisk.org

Brain Injury in Children
July 9-10, 2009, Toronto
Sick Kids Centre for Brain and Behaviour
www.sickkids.ca/Learning/Conferences/upcoming-conf/index.html

FACE Research Roundtable 10th Anniversary
September 9, 2009, Toronto
www.motherisk.org/FAR/econtent_conferences.jsp

Problematic Substance Use in Pregnancy
October 16/17, 2009, Thunder Bay
The PRIMA Project
www.addictionpregnancy.ca

KEY TRAINING EVENTS OUTSIDE ONTARIO:

National FASD Conference: Evidence-Based Strategies for Today, Tomorrow, and Beyond
April 30 – May 2, 2009, Madison, Wisconsin
www.dcs.wisc.edu/pda/fasd/conf_savdate_09.pdf

Consensus Development Conference on FASD: Across the Lifespan
October 7-9, 2009, Edmonton, Alberta
Institute of Health Economics
www.buksa.com