

FASD ONTARIO NEWS



THE NEWSLETTER

OF FASD

STAKEHOLDERS

FOR ONTARIO

EDITION 4, APRIL 2008

FASD Training for Justice Staff

The Ministry of Community Safety and Correctional Services received funding from the Ministry of Government Services' Ideas and Innovations Fund in September 2006 to develop and deliver FASD training to Correctional Services staff.

A five-day "train-the-trainer" session was held in January 2007 at the Ontario Correctional Services College for the Peer Trainers. The session provided them with basic facilitation skills, content knowledge and background information needed to deliver the FASD training. Between January 31 and March 27, 2007

the Peer Trainers delivered 46 sessions across the province to 459 staff. The feedback received suggests that the training was well received and provided new learning for many staff.

This training program is being incorporated into the basic correctional officer and probation and parole officer training. The FASD training initiative received a Level 2 Award at the 2007 Public Sector Quality Fair and has been nominated for a 2008 Ovation Award.

*Submitted by: Sawsan Khowessah,
Ministry of Community Safety &
Correctional Services*

Education Needs and FASD

School is often an ongoing challenge for families affected by FASD. Some parents find it helpful to change their child's exceptionality from "behavioural" to "physical" in their child's IEP (Individual Education Plan). The classification of "behavioural" means that teachers tend to classify the symptoms, instead of the disorder. A behaviour program with incentives, rewards and punishments does not work for children with FASD. Parents want teachers to understand that many of their child's behaviours are not a choice, but beyond their control,

and the result of a permanent physical brain injury. One family reports that this change in their child's IEP has made a big difference for their son. If he is 5 minutes late for class, forgets to bring materials to class or loses his assignment, he is given consideration instead of detentions. When he thinks he is going to "lose it", he can go home (if a parent is home) or go to Student Services and listen to music to calm down.

*Submitted by: Elspeth Ross, FASD Group
of Ottawa*

New Ontario FASD Support Groups

Fetal Alcohol Support Group of Niagara
Location: St. Catharines
Contact: IndigoMaman@aol.com

**Helping Hands for
FASD Youth Support Group**
Location: Barrie
Contact: 1-705-728-5137

New Aboriginal Child Nutrition/FASD Workers:

Community Support Workers:

Timmins Native Friendship Centre
1-705-268-6262

Red Lake Indian Friendship Centre
1-807-727-2847
Servicing: Red Lake, Sioux Lookout & Dryden

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. Previous editions of FASD Ontario News can be viewed at:
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

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 regarding FASD. For more information, contact the Chair, Sheila Burns at info@fasdontario.ca, or visit the website at FASDOntario.ca.

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PREVENTION WORKING GROUP

This year, funding generously provided by the Public Health Agency of Canada enabled the Prevention Working Group to develop new print and electronic



resources designed to increase awareness about alcohol and pregnancy. These resources were designed for women who consumed alcohol before they knew they were pregnant. The working group is making the new awareness resources available to organizations and interest groups across the province. Transit and mall ads will also be installed across Ontario. Expert review and focus groups were used to test and refine the resources. This new prevention campaign will help to bring a consistent message to women across Ontario regarding alcohol use in pregnancy. The resources can be accessed online and some are available in print (at cost) see www.beststart.org.

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

URBAN ABORIGINAL WORKING GROUP

This working group helped to send 10 people from across Ontario to the Leaders for Change Aboriginal Mental Health and Wellness conference in Toronto. These individuals included people diagnosed with FASD, as well as their caregivers or family members. There were several conference sessions related to FASD, including traditional approaches for people affected by FASD, and the benefits of the moss bag teachings for children with FASD. A CD was created about the conference sessions and participant feedback. The working group will send a copy of the CD to Health Access Centres, CAPC CPNP programs, Aboriginal Healthy Babies Healthy Children programs and Public Health Units across Ontario.

Conference Participants said:

- “Gave me tools and understanding of Aboriginal needs that I can use and share with my co-workers to improve the delivery of our care.”
- “The strength of the speakers empowered the participants; the conference was able to incorporate many of our traditions.”

In partnership with Dr. Brenda Stade, the working group arranged for testing of 40 Aboriginal children at risk of developmental delays from across Ontario. The children were assessed for issues such as FASD, ADHD,

behavioural issues and contributing factors. A report will be released, discussing the findings, trends and recommendations.

The working group also reprinted the Ontario Federation of Indian Friendship Centre resources “FASD Toolkit for Aboriginal Families” and “Aboriginal Approaches to FASD”.

These activities were made possible through funding provided by the Public Health Agency of Canada.

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



FASD Stakeholders for Ontario congratulates Sylvia Maracle for receiving a National Aboriginal Achievement Award for Public Service.

INTERVENTION AND SUPPORT WORKING GROUP

This Working Group recently developed a Strategic Plan. They wanted to address the most critical needs of people in Ontario who are dealing with FASD, make the best use of limited resources and to build partnerships and support. They did this by gathering information through an online survey tool and then the working group met for a two-day facilitated strategic planning session in February 2008.

The survey results were instrumental in informing the working group's priorities. About 70% of the respondents indicated that they were not receiving the supports that they needed. The interventions and supports that were identified as "most needed" focused on school issues, respite care, adult services, and

access to front-line service providers who are knowledgeable about FASD. Professional respondents also identified diagnosis as a critical need.

The strategic plan includes the following priorities:

- Sharing information on FASD activities and resources using the Stakeholders website.
- Evaluating Ontario-based promising practices in a number of service sector areas including adult housing and employment services, children's mental health, child welfare and education.
- Defining the types and opportunities for respite services in the province.

The Intervention and Support Working Group would like to thank the Public Health Agency of Canada for funding key aspects of the needs assessment and planning, and Toronto CAS for providing meeting space.

Interim Lead: Pat Spadetto, Timiskaming Child and Family Services, pat.spadetto@tcafs.org



DIAGNOSIS AND DISABILITY WORKING GROUP

The Diagnostic Working Group's intent is to increase both the availability of diagnostic services and access to resources for individuals with FASD and their families. The purpose is to increase the capacity of health care providers in Ontario to diagnose individuals who may have FASD through training, pilot testing, comparison methods and evaluating the outcomes.

The priority for 2007-2008 was to increase the capacity of health care provider's use of telemedicine and/or knowledge of current diagnostic process and techniques in North Bay, Thunder Bay and Hamilton. Funding from the Public Health Agency of Canada made this initiative possible. Both the North Bay and Thunder Bay teams were trained in the diagnostic process using the

Canadian Diagnostic Guidelines as well as piloting diagnostic clinics using Telemedicine with St. Michael's Hospital. Clinics were involved in the assessment and diagnosis of a minimum of nine clients. In Hamilton, several physicians were recruited to participate in a community initiative to increase diagnostic capacity in the region. The physicians completed online training in the Four Digit Code through the University of Washington. They also received a day of observational training and had a chance to review the Canadian Guidelines at St. Michael's Hospital in Toronto, compliments of Dr. Brenda Stade.

Lead: Dr. Brenda Stade, FASD Diagnostic Clinic, St. Michael's Hospital, stadeb@smh.toronto.on.ca

JUSTICE COMMITTEE

In 2006, the Justice Committee created a CD-ROM as a resource for criminal lawyers, judges, correctional personnel and others working in the justice system. In 2007 the Justice Committee transferred the contents of the CD-ROM to a dedicated website – www.fasdjustice.on.ca. The monthly statistics on website usage show a steady rise in both visitors and depth of viewing. In January, people from Canada, United States and fifteen other countries accessed the site. We know from word of mouth that Ontario lawyers and judges, the original target audience, are making use of it as well. Recently, the case law portion of the site was revised to reflect recent decisions.

In an effort to increase and expand use of the website, the Justice Committee recently developed tools to remind members of the legal profession/justice system about the website, and why they need it. With generous funding from the Public Health Agency of Canada and the Ontario Federation of Indian Friendship Centres posters, postcards and mouse pads will be developed. The Justice Committee is also exploring what resources are currently accessible for diagnosis and treatment of FASD in correctional facilities across Canada.

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



Promotional mousepad

FASD NEWS FROM THE PUBLIC HEALTH AGENCY OF CANADA

National Office

For the FASD Initiative (Public Health Agency of Canada), 2007-2008 has been a busy year, and includes tremendous participation, guidance, and partnerships with stakeholders. National strategic projects are underway, focusing on screening tools for alcohol use during pregnancy, tools to record the alcohol use, and tools to identify children who may need an FASD diagnosis. Core competencies for FASD trainers and guidelines for training programs are being developed, along with a web-based application. A course for training family physicians/allied professionals on awareness and prevention of FASD is available on-line (www.mdcme.ca). Train the trainer sessions on substance use and pregnancy (primarily for family physicians) took place, with more upcoming (www.addictionpregnancy.ca). A symposium to refine tools used for diagnosing the brain will take place shortly, and an RFP has been posted regarding a systematic literature review on alcohol use and women of child-bearing age. Also planned are case studies on community mobilization for FASD, and a survey of attitudes/knowledge of allied health professionals. Please go to www.publichealth.gc.ca/fasd for contact information, final project reports and new activities in 2008-2009!

Ontario Region

The Ontario regional office of the Public Health Agency of Canada (PHAC) has also been busy this year supporting a number of provincial initiatives of the FASD Stakeholders for Ontario. In October 2007, Regional PHAC staff brought together the leads of the five working groups that make up the FASD Stakeholders for Ontario – Urban Aboriginal; Prevention; Intervention and Support; Diagnosis and Disability; and, Justice – to meet with members of the FASD Intergovernmental Action Network of Ontario (FIANO). It was an opportunity to network, share updates, and plan collaboratively for future FASD activities. The Ontario Federation of Indian Friendship Centres graciously hosted the meeting. FIANO continues to meet regularly to network and help support FASD activities in the province. For further information regarding FIANO, please contact Donna De Filippis from the Public Health Agency of Canada, who is the Agency's lead for FASD in Ontario, at 416-954-9754.

“PICTURE” THIS: LIFE AS A PARENT OF CHILDREN WITH FASD



Multi-generational

My grandmother had FASD, my mother had FASD, and I most likely also have FASD. Since alcohol has existed, FASD has existed.

We come from all walks of life: all cultures and all ages. We have much potential and many great gifts.

Come walk with me a while, and “see” my “voice”.

A Photovoice Exhibit

Photovoice is a process that uses photography, group discussion and personal reflection to give a voice to the people who most often aren’t heard. When it comes to understanding community issues, the local people – not outside professionals – are the experts.

This Photovoice project brought together five courageous women from Sioux Lookout, Ontario, whose children are living with FASD. They are all members of the Healthy Generations Family Support Program, a vital yet largely unsung organization that has been providing services to Sioux Lookout for over a decade. The ongoing support from this program, over many years, was the key factor that empowered these women to come forth and share their stories.

“Being a birth mother and admitting that I did this to my son has been hard, but these ladies didn’t judge, just took me as I am, and have helped me deal with the guilt so that for the most part I can now talk about it a little better and I am not in tears or totally destroyed every time the subject comes up... and the subject comes up everyday in his behaviours. Everyday I am confronted by his FASD but it’s not as overwhelming as it used to be.”

Photovoice Participant

Each woman took photos that provide a window into her life as a foster mother, adoptive mother, or birth mother. Group discussions about the photos allowed the women to share their experiences and to support each other. Overall, the process allowed the mothers to recognize the challenges they face and to focus on their own strengths, as well as the strengths of their children. The group collectively realised that a lack of societal understanding about FASD makes the lives of their children more difficult.

Photovoice was brought to Sioux Lookout by Krista Jane Lauer, a social development and health researcher, originally from Thunder Bay, Ontario. The exhibit that is now touring Canada provides honest, compelling insight into the reality of FASD. The Public Health Agency of Canada provided funding to allow the photo exhibit to be shown at several conferences.

Submitted by: Judy Kay, Healthy Generations Family Support Program, Sioux Lookout



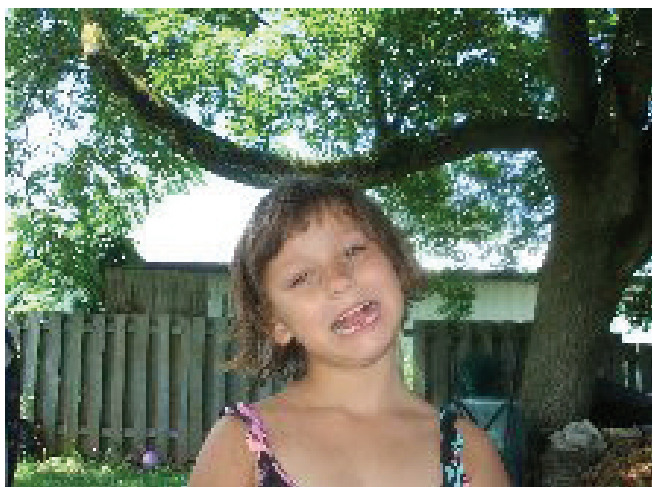
Overflow

The eaves were filled with muck, leaves and branches; rotting there, like the guilt that eats away at me and when it rained really hard the water couldn’t flow properly down the drain it overflowed in just the same way the guilt, anger and sadness have been overflowing out of me. Crying brings the release of emotions and the hope of healing and forgiving myself because it’s still hard to say out loud, admit I know that my son has FASD because I know it’s my fault. I am living with what I have done to my child; it confronts me everyday in his behaviours, his intense emotions and his frustrations with himself.

When people look at me will they see a mother who loves her child or a woman who did this to her child? Will my child forgive me?

I look at the water falling in this picture and it’s beautiful but there is a feeling of hope mixed with fear of the unknown too.

BRITNEY'S RAINBOWS



Britney, age 8, showing off her missing tooth

Our darling Britney came into our lives 8 years ago, while providing foster care to infants diagnosed with failure-to-thrive due to prenatal exposure to drugs and alcohol. I knew this was our daughter the day I held her in my arms at the hospital. Britney was legally adopted by us when she was 3 1/2 years old. I spent many late nights searching the Internet, trying to determine which of the prenatal drug exposures might be causing the behaviours we were experiencing each day. One day a drug website brought me to a Fetal Alcohol web site. As I read the story posted on the site, it was as if I was reading about Britney! I cried as I read the characteristics of FASD and knew that I had found the disability that was creating chaos in Britney's daily living. Once past the grief and loss, the anger and frustration, I decided to learn all I could about FASD, to make each day with Britney better than the day before.

There is a lot I can do that can make a difference. On a daily basis I create new ways to reach my daughter Britney, who is affected by ARND (Alcohol Related Neurological Disorder). Britney is my teacher. Each day we get to try again, as each day is new and exciting for Britney. Seeing the world through Britney's eyes creates a rainbow of optimism each day.

Once, while grocery shopping with Britney, she became over-stimulated. She started throwing her legs and

arms everywhere and I became concerned that she would accidentally hit or kick someone. I needed to redirect her behaviour, and quickly. Whispering to get her attention to come see me, I spoke to her softly to calm her emotions. I asked her to look around at others to see if anyone else was walking like her. She looked back and forth, then in astonishment said, "Gee no one is walking like me!!" I shared with her that this tells me that her style of walking is not acceptable behaviour and could hurt someone. I guided her to look around at others, being a detective, then to copy the way others were walking. She began to walk very slowly with her hands clasped in front of her like the seniors in the store! We spent the remainder of our shopping trip being behaviour detectives. She now carries a small magnifying glass while we are out to help her be a good detective.

The need for repetitive learning can be draining on the person who must repeat the message. Each time we get into the van, Britney sits in her seat without putting on her seat belt, not remembering what to do next. Each time I would need to instruct her to put on her seat belt. After many years of doing this task I chose to allow a cassette tape to do the repeating for me. I just put the tape in and push play. The tape reminds her in a gentle manner to put on her seat belt. As she grew older, we started using a laminated chart with picture cues. She can be independent, checking off the list of what she needs to do, even though she cannot read yet. The board includes acceptable behaviour and things to do in the van. Promoting independent thought enhances her self-esteem and relieves me from the necessary repetitive guidance she requires.

What does a parent do when the child is challenged due to over stimulation or transitional difficulties? I find that redirection is the key to transitioning out of the rage. Creative thinking brings me to the kitchen where the flooring is in large squares. I jump into one of the squares, asking Britney to join me by standing on an EMOTIONAL SQUARE. At first she is reluctant. I tell Britney that I am standing on a HAPPY square, and my face and voice shows happiness. I ask Britney what emotion she is standing on. In an angry

voice she shouts out, ANGRY. With enthusiasm in my voice I ask what other square can she find? She jumps to another square, with a slight giggle and a goofy grin Britney states FRUSTRATED!! I eagerly jump to another square and with laughter I state FABULOUS FUN!! Britney jumps again, with her arms outstretched, she states she is in a RAINBOW SQUARE filled with lots of love. We keep the game going until she is no longer interested. I took the game to another level by making cards with words and pictures. We play the game just for fun, and it is also a good learning tool about emotions.

A day in the life of Britney brings many emotions to each of us. Each day she touches our hearts with unconditional love. Even though she may not fully comprehend, she wants to do good job and make others happy. When I asked her recently what was the hardest part about being affected by FASD she replied, "I can't remember what comes next to do a good job, or to be good to other people." This touched my heart, how hard this little girl tries everyday. I raise awareness about FASD as my gift back to Britney. We are so blessed to have her in our lives.

Submitted by: Dianne Labelle, E.C.E., Fetal Alcohol Support Group of Niagara

ONTARIO FASD COMMITTEES:

This is a list of Ontario FASD committees and coalitions. It does not include FASD support groups or individual FASD organizations or services. If you would like your FASD committee added to this list, please email w.burgoyne@healthnexus.ca.

Mamaweswen, North Shore Tribal Council-FASD Program
Cutler
mary@mamaweswen.ca

FASD Durham Committee
Durham Region
fasd@rfecydurham.com

Grey-Bruce FASD Community Mobilization Committee
Grey and Bruce Counties
bfowensound@bmts.com

The Hamilton Task Force on FASD
Hamilton-Wentworth Region
nhall@cfshw.com

FASD Coalition, Algonquin Child and Family Services
Huntsville
lexell@acfs.on.ca

FASD Action Network
Kingston
nszumanski@kflapublichealth.ca

London FASD Network
London
cha@soahac.on.ca

FASD North
North Bay/Nipissing District
AmandaD@metisnation.org

FASD Coalition of Ottawa
Ottawa
cfortier@ottawayoungparents.com

Peel FASD Steering Committee
Region of Peel
anne.fenwick@peelregion.ca

Peterborough FASD Committee
Peterborough
peterborough_fasd_committee@cogeco.net

Renfrew County and District FASD Committee
Renfrew
cforteach@rcdhu.com

FASD Committee
Sault Ste. Marie and Algoma
dcaputo@algomapublichealth.com

Simcoe County FASD Coalition
Simcoe County
1-877-721-7520 ext 7191

Six Nations of the Grand River Territory FASD Circle
Six Nations
degowadihsnye@sixnationsns.com

Sudbury and Manitoulin FASD Network
Sudbury and Manitoulin
kandis.stoughton@ourchildren-ourfuture

FASD Program
Thunder Bay
mparkes@norwestchc.org

FACT Coalition (FASD awareness Cochrane (district) Timmins)
Timmins
normac@porcupinehu.on.ca

Toronto FASD Coordinating Network
Toronto
SRichards@TorontoCAS.ca

FASD Networking Committee of Waterloo-Wellington-Dufferin
Waterloo
mmary@region.waterloo.on.ca

FASD Coalition of York Region
York Region
1-877-464-9675 x2015

Photo Gallery – FASD Activities Across Ontario



Donna Debolt, well-known speaker and advocate, addresses a full house at the FASD Coalition of York Region's first training and information seminar, "Can't Not Won't". Participant feedback was very positive, and they were asking for more!



FASD Coalition of York Region

Feedback about FASD Ontario News:

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

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Also available in French

NEW FASD RESOURCES



Strategies Parents Find Helpful in Raising their Children Living with FASD
Developed by: Czaee Rajwani
St. Michael's FASD Diagnostic Clinic
<http://come-over.to/FAS/PDF/TorontoStrategiesParents.pdf>

PRIMA Provider's Resource on the Management of Addictions in Pregnancy, 3rd Ed.
The Prima Project
www.addictionpregnancy.ca

Fetal Alcohol Research (FAR) – The official journal of the FACE Research Network
On November 1, 2007, the Journal of FAS International – JFAS Int – was amalgamated with the Canadian Journal of Clinical Pharmacology, a peer-review journal. The section dedicated to FASD is called Fetal Alcohol Research (FAR). Research published in CJCP/FAR is indexed in PubMed – Medline. The amalgamated CJCP/FAR will continue to be web-based and freely available. For more info.: www.motherisk.org/FAR/index.jsp

9 Months, Zero Alcohol, Zero Tobacco Poster
City of Ottawa
Available online in English, French, Spanish, Vietnamese, Arabic, Chinese, Somali
http://ottawa.ca/residents/health/support/professionals/perinatal/zero_en.html



Exposure to Psychotropic Medications and Other Substances during Pregnancy and Lactation: A Handbook for Health Care Providers
Motherisk and the Centre for Addiction and Mental Health
http://www.camh.net/Publications/CAMH_Publications/psychmed_preg_lact.html

FASD TRAINING

TRAINING EVENTS IN ONTARIO:

FASD Video Info Series
April 7, 21 & May 5, 12, 2008
Degowadihsnye Program
Six Nations, Ontario 1-519-445-4922

FASD: A Community Issue Requiring a Community Solution
April 10th, 2008, Stoney Creek
The Hamilton Task Force on FASD
905-574-6876 x229 or x233

An evening with Allan Mountford
June 5, 2008, Kingston
Kingston and Area FASD Learning and Sharing Group
etate@kdacl.on.ca

Building Strategies and Strengths for Individuals with FASD Conference
June 11, 2008, Durham
FASD Durham Committee
info@fasddurham.com

Problematic Substance Use in Pregnancy
The PRIMA Project
Dates and Locations TBA
www.addictionpregnancy.ca

KEY TRAINING EVENTS OUTSIDE ONTARIO:

Third National Biennial Conference on Adolescents and Adults with FASD FASD and Mental Health: The Wisdom of Practice
April 10-12, 2008 / Vancouver, BC
www.interprofessional.ubc.ca/Adults.html

Canada Northwest FASD Partnership Conference / Building on our Strengths: Stone by Stone
May 21-24, 2008 / Banff, Alberta
www.cnfasdpartnership.ca/index.cfm

FACE Satellite, annual meeting of Research Society on Alcoholism
June 30, 2008 / Washington, DC
Deadline for abstracts May 1, 2008
susan.santiago@sickkids.ca

FACE Research Roundtable
September 9, 2008 / Montreal, Quebec
www.motherisk.org/FAR/econtent_conferences.jsp