

FASD | ontario news

The Newsletter of FASD Ontario Network of Expertise

“WOLF HOWLING AT MOON” WINS PEOPLE’S CHOICE AWARD



Linda Rosenbaum

“The catharsis thing has never really worked for me. I do relive things.” Linda Rosenbaum is talking about her spare, powerful piece for this year’s CBC Canada Writes creative nonfiction contest, featuring her 26-year-old adopted son, who lives with FASD. However, she adds, “I’m always interested in helping the public learn more about fetal alcohol syndrome. And of course, the more interesting and better written the piece is, the more likely you’re going to have a broader audience.” Hence, the success of her “Wolf Howling at Moon,” one of 2,500 contest entries, which last summer made the five-story shortlist and was winner of the People’s Choice award.

A video gallery her husband, Robin Christmas, is assembling is the device for sketching Michael’s early years, before the crushing diagnosis: “Robin has so many plans and dreams for his son. They will build a crystal radio set together and make volcanoes erupt from test tubes....Finally, someone to watch Formula One racing with.”

The story describes what came after that moment two decades ago when Linda and Robin gazed at an illustration of FASD facial features – you know the one – and saw Michael: “[W]e’ve tried our best. Tough love, soft love, plain love, always love....Time outs. Logical consequences. Reward systems. Changes to diet. Various therapies, special needs camps, treatment centres, tutors, social skills programs, therapists.”

What makes “Wolf Howling” more than a variation on every parent’s wrenching account of the day she learned of her child’s brain damage, and gives it its title, is the twist the piece takes. Linda describes how she and Robin kept trying to “help Michael find something of interest, build confidence, bring a little joy.” To learn what that was, visit <http://www.cbc.ca/books/canadawrites/2013/07/wolf-howling-at-moon-by-linda-rosenbaum.html> and see a photo of Michael on page 4 of this newsletter.

The piece forms the epilogue of a memoir Linda has completed, for which she is now seeking a publisher. As for the winning article, she sees it as a “message of hope.” “It may take time,” she says, “but many of these kids will find their place in the world. Everyone has some gift.”

Submitted by: Lynn Cunningham

Purpose:

This newsletter was developed to help people in Ontario work together to address FASD. It reports on activities of FASD Ontario Network of Expertise (FASD ONE) and shares news of relevance to individuals, caregivers and service providers who work on FASD across Ontario.

For previous editions visit:
<http://www.fasdontario.ca/cms/newsletter>

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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Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

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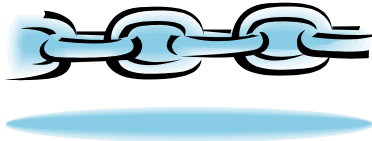
FASD ONE UPDATE

The Leads and Co-Leads of the seven FASD ONE Working Groups recently held a two-day meeting to review 2013 work plans and establish 2014 priorities. While the nature of being a provincial network necessitates most of our work being conducted by conference calls, the opportunity to meet face-to-face is always appreciated and highly productive.

Work plan reviews accompanied by establishing future priorities led to the following important decisions:

- The process of developing a provincial FASD framework continues and is in its final stages. A critical path has been developed to guide us towards its completion, distribution to our stakeholders and presentation to the provincial government.
- While it was important to have a stand-alone Aboriginal Working Group when the Network was first established, it's believed that FASD ONE has reached the stage when it is important to infuse a First Nations, Metis and Inuit (FNMI) perspective throughout all of the Working Groups. Therefore, it was decided to integrate the Aboriginal Work Group into all FASD ONE Working Groups: Prevention; Assessment and Diagnosis; Intervention & Support; Education; Justice; and Communications. This will allow the FNMI experience and perspective to inform and guide the work undertaken by the Working Groups, a step welcomed by Working Group members who know it will enhance and add value to the activities they undertake. If you are a member of the FNMI community and are interested in joining a Working Group, please contact us at info@fasdontario.ca and identify which Working Group interests you.
- Revising the FASD ONE website is a 2013-2014 priority for all Working Groups. Funding has been received from the Public Health Agency of Canada to revamp the website in order to enhance opportunities for knowledge exchange and community capacity building. The Communication Working Group will play a lead role, working in collaboration with the five other Working Groups, each tasked with developing its own page on the website. Considerable work will be undertaken by members of the Working Groups as we all look forward to a revamped and updated FASD ONE website.
- FASD ONE wants to acknowledge the many successful FASD Awareness Day events of September 9, 2013, organized by the over 30 local community FASD networks and other community groups across Ontario. They all, in their unique ways, brought public attention and awareness to the disorder. The range and diversity of events was nothing short of remarkable, knowing the limited resources available to produce such events. Congratulations to all.
- Recognizing that the revised website will be a primary communication source for FASD ONE and striving to maximize our limited resources, a decision was made to incorporate the information contained in the semi-annual newsletters into the website. This will be the last FASD ONE newsletter produced in this format. We would like to acknowledge Wendy McAllister, Best Start/Nexus Ontario; Yvette Nechvatal-Drew of Girls Incorporated of Durham; and Cheryl Neave, FASD ONE Vice-Chair and Lead of the Communication Working Group for their significant contributions over the years to producing the FASD ONE newsletter. Many thanks for the informative and awareness-raising newsletters you made possible.

Submitted by: Sharron Richards
Chair, FASD ONE



How Memory and Learning Are Linked for Students with FASD

Memory and learning are inseparable. When students have a hard time storing, recalling and holding information in working memory, frustration can result and academic success will often be compromised. Students with memory weaknesses also have difficulty keeping up with the pace in a classroom. Information is presented at a rate that is too fast for them to efficiently process. This further adds to their frustration. Frustration resulting from memory weaknesses is unfortunately the reality for many students with FASD.

In order to reduce student frustration and feelings of failure, recognition of the behaviours associated with memory weaknesses, both at home and at school, is crucial so that appropriate support can be provided. The following activities may present difficulties:

- completely understanding new or less familiar material the first time that it is presented or read (repetition and review will often be required);
- sounding out words – beginning sounds can be forgotten by the time they get to the final sounds;
- developing literacy skills, especially in the area of written expression;
- retrieving information from their knowledge base (e.g., “finding” the right word), which will make it difficult for them to participate in classroom discussions that are highly factual in nature as well as completing fill-in-the-blank tests (asking yes/no questions and providing a word bank can be helpful);
- following directions (provide visual support and break the instruction down into smaller steps);
- taking tests (their test results may not reflect their level of knowledge);
- learning a second language;
- transferring knowledge from formal learning to everyday application (e.g., they may be able to spell a word on their spelling test but not in their journal);
- organizing language in order to provide narratives;
- organizing the steps to complete a task such as cleaning their desks or their rooms;
- multitasking and monitoring their progress while working;
- acquiring skills in the area of mathematics (e.g., learning and remembering math facts and abstract visual symbols (e.g. -, +); remembering how to form the numbers; performing procedures that involve different operations and multiple steps (e.g., long division);
- holding events and/or information, including rules, in mind to guide actions (e.g., remembering to go to the principal’s office at recess, recalling the rules at home, remembering appointments) and as result, they may need external prompts to indicate appropriate behaviours;
- accurately recalling and reporting on what has happened – an area of concern for many students with FASD;
- independently reflecting on their actions and problem solving;
- finishing work within normal timelines including answering questions, completing seatwork and homework.

The first step in reducing student frustration resulting from weaknesses in memory is to recognize the associated behaviours. Once a student’s unique memory profile has been identified, supports can be put into place and we can help him to develop strategies to maximize his ability to deal with the memory demands that are a normal part of everyday living. Remember, adequate memory is not only crucial to academic achievement but to successfully coping in life.

Submitted by: Danielle Reynolds
Member of Education Working Group

Michael Christmas
and some of his
creations



The Government of Canada's Fetal Alcohol Spectrum Disorder (FASD) Initiative

The goal of the Government of Canada's Fetal Alcohol Spectrum Disorder (FASD) Initiative is to provide leadership and to collaborate with partners to prevent FASD and improve the outcomes for those already affected. The Public Health Agency of Canada is the federal lead on FASD in Canada, in partnership with Health Canada's First Nations and Inuit Health Branch, which has the federal lead with respect to First Nations and Inuit communities. Collaboration and intersectoral approach to program and service delivery can reduce the incidence of FASD and help improve outcomes for those affected and their families. The FASD Intergovernmental Action Network of Ontario (FIANO), which is made up of Ontario representatives from various federal departments and provincial ministries, continues to share updates to ensure our efforts are not duplicated. For further information regarding the federal FASD Initiative please visit the PHAC website at <http://www.publichealth.gc.ca/fasd>.

Submitted by: Donna De Filippis

Education Working Group Update

This past July, the Education Working Group came together for its annual face-to-face meeting. In two short days, the group updated the work plan, masterminded the forthcoming FASD ONE Education webpage and created a series of topics in education to be addressed initially in this newsletter and later on our webpage. The work plan reflects these already-mentioned priority activities as well as a new emphasis on training and educating preservice teachers and other allied professionals on FASD through various colleges across Ontario and at the Additional Qualification (AQ) level through the Ontario College of Teachers.

In terms of the immediate future, the Education Working Group is committed to creating the FASD ONE Education webpage. The Education Working Group will be working with the web designer over the fall months in hopes of having the webpage up and running by the spring of 2014. Similarly, the FASD education-related series of topics will begin with this newsletter and continue on our webpage. Working Group member Danielle Reynolds, a speech language pathologist with the District School Board of Niagara, has authored a brief article outlining some of the behaviours that are often associated with weakness in memory, one of the hallmark characteristics of FASD. See "How Memory and Learning Are Linked for Students with FASD" (page 3). Lastly, it is with great pleasure that the Education Working Group recognizes fellow Working Group member Allan Mountford, for his outstanding work on the latest video by NeuroDevNet, accessible on the NeuroDevNet website, www.neurodevnet.ca/resources/FASD. *FASD Is a Disability* focuses the discussion on FASD as an invisible disability with behavioural symptoms.

Submitted by: Stephanie Jones and Mary Cunningham

FASD ONE Intervention & Support Working Group Update

The Intervention and Support Working Group continues to work on several longer-term goals. One is to develop sustainable camp services in Ontario for families with children impacted by FASD. To date, the group has been exploring various community camp models that are currently in use and have been found to be effective for this population. In addition, the group has been engaging the Ontario Camping Association in activities that will increase members' knowledge and understanding of FASD.

The second main goal is to develop an across the life span resource for caregivers and service providers. This resource will provide important information to families regarding supports and issues based on the chronological age of the child.

Other goals include planning and supporting a provincial conference for caregivers and exploring options to advance knowledge of general effective practices in the successful support of children with FASD, with service providers across the province.

Submitted by: Nancy Hall

FASD ONE Justice Working Group Update



The FASD Justice Survey results are still being tabulated, but the responses to date provide us with a path for action. A few FASD justice-related research, innovation, programming or other initiatives were identified in the 100+ survey responses; however, many more respondents identified gaps and opportunities for improvement in the system. There was significant interest in FASD training, need for assessment and diagnostic resources, and development of effective intervention strategies. Victims, suspects and offenders with/suspected of being affected by FASD were seen as vulnerable in the community and institutions, and the cycle of court appearances and incarceration was unhelpful.

The Justice Consensus conference was held in Edmonton September 18-20. A jury of legal experts was presented with information regarding the interface of FASD within the justice and corrections systems. They heard about the complex challenges associated with screening, assessment and support. The jury's recommendations validated the findings of our justice survey: more training, improved access to assessment and diagnosis, and a more nuanced response to victims and offenders with FASD.

The summary report on the Ontario FASD Justice Survey and the Edmonton Justice Consensus Statement will be posted on the FASD ONE website in the coming months. In early 2014, the Southern Network of Specialized Care will host a Justice Working Group webinar to discuss the implications of these two documents for Ontario.

Submitted by: Sheila Burns
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The Neurobehavioural Model “Into Action”

Specialized Training of Trainers for Increased Capacity to Serve Persons with FASD



Nancy Hall and Diane Malbin

The core concept of “Into Action” is that brain function is the source of behaviours and that a neurobehavioural approach applies to Fetal Alcohol Spectrum Disorder/Neurobehavioural (FA/NB) brain-based conditions regardless of specific cause – pre- and/or postnatal exposure or injury. It is an alternative foundation for reframing the meaning of behaviours, a neurobehavioural paradigm. The goal of “Into Action” is to contribute to establishing informed networks of care and application of this understanding in all settings. The long-term goal is to contribute to prevention.

“Into Action” answers the questions, “What is FA/NB?” and “What do we do?” by linking brain function with behaviours and providing an approach for implementing a neurobehavioural approach. This approach considers the person and fit within environments, providing a structure for systematically developing appropriate strategies and managing the complexity associated with the spectrum of symptoms. It provides a common language for parents and professionals that enhances communication across all systems, contributing to the ripple effect and to *change*.

Diane Malbin, MSW, from FASCETS in Portland, Oregon, developed this model and a train-the-trainer curriculum to provide individual professionals working in the field with an opportunity to become facilitators and deliver this model to local communities. In March of 2013, an extended four-day, in-person training was held in Oregon and will continue with one year of mentorship, for all participants, from Diane Malbin.

Twenty-two individuals participated representing the United States (California, Kansas, Alaska, Arizona, North Carolina, Missouri, Oregon, Virginia and Texas), Canada (British Columbia and Ontario) as well as Tanzania. This group included the lead of the FASD ONE Intervention and Support Working Group, Nancy Hall, who works with the Southern Network of Specialized Care. She will be available to provide this specialized training across Ontario beginning in January of 2014! For more information, contact Nancy at fascets.ontario1@gmail.com.

Submitted by: Nancy Hall

Waterloo Region FASD Action Group – What Is New and Creative?

Waterloo Region FASD Community of Practice

In September, eighty professionals in Waterloo Region from many sectors (child welfare, mental health, housing, public health, justice, education, etc.) began a series of training sessions to learn how to effectively support children, youth, adults and families living with FASD. The participants will engage in five days of intensive training covering topics such as screening, diagnosis, neurodevelopment, effective justice practices and how to effectively intervene and provide support. World renowned experts Dr. Gail Andrews, Diane Malbin, Sheila Burns and Dan Dubovsky will guide the sessions, and facilitator Paula Stanghetta will help participants integrate the learning into practice. Throughout the training series the group members will discuss how to share the information within their own organization and how to stay connected in order to develop a FASD Community of Practice in Waterloo Region. For more information go to: www.fasdwaterlooregion.ca.

REACH for It!

REACH for It! is an innovative and interactive program that involves the Waterloo Region FASD Action Group, Lutherwood, volunteers from the Waterloo Regional Police Service, and Conestoga College Recreation and Leisure students. It is a recreation-based program for children and youth with Fetal Alcohol Spectrum Disorder.

Early intervention and support of children diagnosed with FASD is important for their future. *REACH For It!* believes that children need to be engaged in their own lives and dream about their futures.

By supporting *REACH for It!* our community is saying:

- We value these children.
- We recognize their strengths.
- We look for solutions.
- We have reason for hope.
- We can help parents to see hope for the future.

Children living with FASD bring love and joy to their parents, family and community. They can be highly creative and need our help to find and appreciate their special talents. It is important to assist those affected by FASD and their support systems, as they often feel marginalized. Children affected by FASD, though challenged, are still able to contribute to society. The benefits of a positive, strength-based approach have significant economic and social impacts on our society. If the graduates of the *REACH for It!* program can continue to reach their personal goals, with necessary supports, it will have a positive long-term impact on the children, their families, their communities and our province.

An initial launch of the *Reach for It!* program in April brought over twenty families to the Waterloo Region Museum where the children enjoyed a "Day at the Circus." In September, *Reach for It!* took place at Steckle Farms and included crafts, games and information about farming life.

Five Health Departments Collaborate on Strategies to Prevent Alcohol Misuse in Women of Childbearing Age

In June, five health departments – City of Hamilton Public Health, Middlesex London Health Unit, Oxford County Public Health, Region of Waterloo Public Health, and Wellington-Dufferin-Guelph Public Health – met to discuss how they could combine efforts to reduce the incidence of alcohol misuse for women in their childbearing years.

A growing level of evidence suggests that talking about the dangers of drinking in pregnancy is too late. As the prevalence of women who consume alcohol at risky levels continues to increase (20% of women in their childbearing years consume five or more drinks at a sitting once a month or more – three times the rate from a decade ago – Canadian Community Health Survey, Statistics Canada 2012) and 40-50% of pregnancies are unplanned, it becomes critical to address alcohol use for all women in their childbearing years.

Many of the health departments found that talking about the effects of alcohol use on women in general, including the risks to a developing fetus, was positively received by women and may be more likely to create healthier changes in alcohol use. Evidence also suggests that combining alcohol screening and education with a discussion on effective options for birth control also produced either a change in consistent, reliable birth control or a decrease in alcohol use. Due to this emerging research, the five health departments will continue to meet to discuss and implement effective strategies aimed at decreasing alcohol use in all women of childbearing age. This will help to reduce the incidence of FASD and also the future incidence of chronic disease in women.

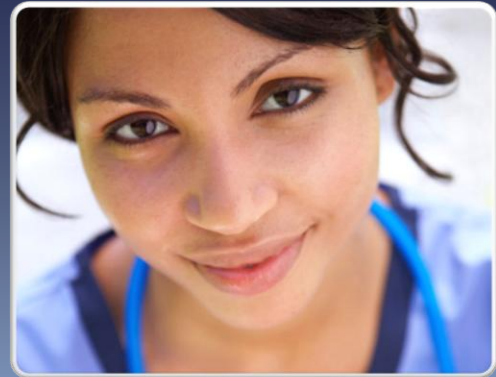
Website Submissions

As this is the final edition of the FASD ONE newsletter, submissions to the FASD ONE website are welcome. Examples include information about:

- Ontario FASD workshops or conferences
- National or international FASD conferences
- New FASD resources
- New FASD services in Ontario
- Photos of recent FASD activities in Ontario
- Short articles about recent Ontario FASD initiatives/news/events
- Success stories
- Submissions or inquiries can be sent to info@fasdontario.ca

Inclusion of submissions is at the discretion of FASD ONE. We reserve the right to edit submissions for length, grammar, consistency, etc. Please use “person first” terminology when referring to people affected by FASD. The opinions and accuracy of the information in submissions to the website are the responsibility of the original author.

For those submitting photos or identifying individuals in an article or at an event, please note that it is your responsibility to ensure you have the subject’s permission. Please be especially sensitive to the identification of children and other vulnerable individuals. A photo consent form is available on the FASD ONE website.



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Also available in French

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