FASD I ontario news

The Newsletter of FASD Ontario Network of Expertise

JAMES GIDEON RECEIVES TWO AWARDS



Lezah Flynn, Sharron Richards and James Gideon

James Gideon is the 2013 recipient of the Kim Meawasige Award for Excellence and the FASD ONE Individual Award of Excellence. James is an adult affected by FASD who is currently employed by the John Howard Society of Sudbury, who nominated him for the awards for these reasons: [James has] "an insight and understanding of living and working with FASD that few, if any, people could accomplish. He continually strives to exceed the requirements of his responsibilities at the John Howard [despite] the FASD that he lives with. These strategies have become teaching tools for the staff of our organization and more importantly life skills for the youth clients that Mr. Gideon works with. He has been able to achieve unheard of success with our youth clients because he works with them respecting their individual challenges as he understands his own unique challenges.

Among Mr. Gideon's accomplishments, there are two which are most notable. The first is the development and implementation of a program unique in Northern Ontario in which youth learn daily living skills through a multi-faceted approach using horses on a local ranch. The second is his ability, through his Aboriginal culture, to awaken in the Aboriginal youth we serve their cultural roots.

The Horses and Youth program has received provincial accolades through the United Way organization because of its innovative approach to teach youth and give these youth the tools they need to make needed changes in their lives to avoid further criminal behavior. The John Howard Society has received innumerable requests from organizations across Ontario to instruct other youth service providers on the mechanics of delivering a horse program for their clientele. It is without question that this would not have occurred without the expertise and guidance of Mr. Gideon at the helm of this work.

Through his work with Aboriginal youth, Mr. Gideon has become a role model and more importantly, a mentor for the youth. It is well documented and understood that many Aboriginal youth have the daily challenge of living with FASD. As Mr. Gideon shares his own challenges of FASD with the youth, they become inspired to change. They see in Mr. Gideon the fact that they too can become successful and positive adults like Mr. Gideon even though they may be living with FASD."

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 submission requirements and 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





FASD ONE UPDATE

On March 24 & 25, 2013, FASD ONE hosted three events in which caregivers, service providers and policy makers shared strategies on how to work collaboratively towards more effectively serving those affected by FASD. The three events were:

CAREGIVER WORKSHOP, March 24, 2013

Over 50 caregivers attended an afternoon workshop facilitated by Helen Hoy and Shiona Watson, both caregivers themselves, as well as academics and FASD educators. The workshop provided an opportunity for caregivers to: discover unexpected commonalities; share hopes and frustrations; focus on the on-going losses and grief that come with caring for someone affected by FASD; network and share information about FASD support groups; and take away specific new strategies for caring for children, youth and adults affected by FASD. Participants enjoyed talking with other caregivers, discovering they are not alone in their struggles and learning new strategies to care for a family member affected by FASD.

When asked about their priority issues, they responded with the following: more awareness about FASD as a disability; strategies and protocols to deal with the education system, including the transition to secondary schools; have FASD classified as an exceptionality within the education system; funding for respite, employment support services and supportive housing; enhancing caregiver skills to advocate on behalf of their family member(s); the need for advocacy at the provincial level; addressing the needs of non-affected siblings within the family; strategies for navigating the service system in order to access needed services and resources; support, self-care and resources for caregivers; caring for adults affected by FASD; the need for a provincial framework to address FASD; funding for youth transitioning to the adult service system; the development of a parent advocacy group; supporting a family member who does not have a formal diagnosis; dealing with children/youth who have been involved in the care of the child welfare system.

KIM MEAWASIGE MEMORIAL LECTURE/WEBINAR, March 24, 2013

Kim Meawasige was a mother, grandmother, mentor, inspiration, friend, innovative trainer and consultant on FASD intervention, prevention, and programming, and creator and promoter of FASD resources for urban Aboriginal people in Ontario. She was passionate about her culture as an Aboriginal woman and all her children walked with her on her life's journey on Turtle Island. She was well known in Toronto for her significant work and dedication to all who were living and working in the FASD world. All who knew her enjoyed her funny and quick wit and appreciated her unrelenting advocacy on behalf of those affected by FASD, especially Aboriginal peoples living with the disability.

In May, 2011, Kim's journey on Turtle Island came to an end. As one way to honour Kim, FASD ONE established the Kim Meawasige Memorial Lecture/Webinar as a fitting way to celebrate her life and honour all she contributed to addressing FASD in the many roles she performed throughout her life. Prior to her death, Kim worked at the Ontario Federation of Indian Friendship Centres (OFIFC) as a FASD trainer, educator and advocate and so it was remarkable and appropriate that FASD ONE was able to partner with the OFIFC in organizing and presenting the webinar. The webinar site was the OFIFC head office in Toronto.

The webinar, titled *FASD Effective Practices, An Aboriginal Perspective*, was moderated by Holly Johnston, NEAP FASD Project Coordinator, Northeastern Aboriginal Education Partnership Project, North Shore Tribal Council - Health Unit, Sudbury, Ontario and included a presentation by Joanne Jackson, FASD Awareness and Prevention Educator with the Southwest Ontario Aboriginal Health Access Center in London, Ontario followed by a panel of caregivers and those themselves affected by FASD.

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FASD ONE UPDATE (continued)

Special thanks to the FASD ONE Aboriginal Work Group and especially its Lead, Laura Spero, for organizing the webinar. A very special thank you as well to the staff of OFIFC for their hospitality and generosity in providing the perfect setting in which to hold the webinar.

The webinar can be accessed at http://www1.webcastcanada.ca/online/fasd.php

BLUEPRINT FOR ACTION: COLLABORATING TOWARDS EFFECTIVE PRACTICES SYMPOSIUM, March 25, 2013

Over 150 care providers, service providers and policy makers were invited to attend this FASD ONE-sponsored event in order to engage in discussions about developing and implementing a more effective response to Fetal Alcohol Spectrum Disorder in Ontario.

The symposium addressed the impact of cross-sector collaboration on outcomes for individuals living with FASD, and their caregivers. Research shows that individuals with FASD, and their families, are best served through coordinated services that accommodate this life-long disability and produce better outcomes for everyone involved, including service providers. While Ontario lags behind other provinces in its investment in FASD prevention and intervention services, a number of innovative and effective practice models are developing in the province, resulting in better outcomes for all those affected by FASD. The agenda included:

- An opening and closing prayer by Aboriginal Elder Pauline Shirt.
- Minister Deb Matthews, Deputy Premier and Minister of Health & Long Term Care brought greetings from the provincial government. Minister Matthews was introduced as a champion of FASD and as such she invited the participants to "think big" in advising the government about what is required to address FASD in Ontario and to be willing to work together with the government to do what is deemed needed to better serve and support those affected by FASD.
- Keynote speaker Sheila Burns presented how cross sector collaboration more effectively produces better outcomes for those affected by FASD. Sheila is a FASD trainer and consultant, the Law Foundation of Ontario 2011-12 Community Leadership in Justice Fellow, former chair of FASD ONE and current Lead of the FASD ONE Justice Working Group.
- Parent/Caregiver Panel who contributed their experiences to the exploration of opportunities for systemic change toward a
 more effective and efficient response to the disability. The panel consisted of a birth mother, a grandmother, an adoptive
 father and a parent affected by FASD.
- Promising Practice Panel that included examples of innovative, collaborative approaches taking place across Ontario that are designed to improve services provision and result in better outcomes for those affected by FASD and their families. The presenters spoke about exciting and innovative approaches to: prevention Breaking the Cycle, Toronto; diagnosis Norwest Community Health Centre in Thunder Bay; justice the Sault Ste. Marie Justice Initiative; education the Niagara District School Board; and in the Aboriginal community Joanne Jackson, FASD Awareness and Prevention Educator with the Southwest Ontario Aboriginal Health Access Center in London, Ontario. The panel was moderated by Nancy Hall of the Southern Network of Specialized Care, Lead of FASD ONE's Intervention & Support Working Group and author of FASD ONE's paper "Advancing Effective Service Provider Practices in FASD", 2010.
- Cross-sector and regional discussion tables to explore strategy development opportunities for more effective cross-sector
 collaboration leading to local, regional, and provincial change in how services are designed for and delivered to those
 affected by FASD.

Discussions among the participants generated a wealth of ideas about what is needed in Ontario to more effectively serve and support those affected by FASD. High on that list of priorities is the need for a provincial FASD framework which FASD ONE is in the process of developing. FASD ONE anticipates that, soon, a working draft will be ready to present to its current members for review, feedback and endorsement. Once finalized, the framework will then be distributed for possible endorsement from a broad spectrum of provincial child-, youth- and adult-serving organizations, local FASD networks, as well as key groups and individuals committed to addressing FASD. The final step in the development process is to present the framework to the provincial government in the fall, 2013, hoping the government will adopt the framework as its own.

FASD ONE thanks the Public Health Agency of Canada, as well as Georgian College for their generous financial support for these events.

Submitted by: Sharron Richards Chair, FASD ONE

FASD ONE AWARDS of EXCELLENCE

Family Award of Excellence

This award was presented to Sheryl Over, a tireless advocate for the improvement of services for all individuals with FASD. As a parent she recognized the needs of her son were similar to other children. Rather than advocating solely on his behalf, Sheryl became a tireless advocate for all. Sheryl has led the Peterborough Caregiver Support Group that has recently expanded and, recognizing the gap for older children who would benefit from supported summer programming, is the driving force behind a summer camp for youth with FASD. As the chair of FASD Peterborough Committee, Sheryl led the collaboration of a dozen agencies to realize a vision for improved case management, securing funding for a two-year project to increase the understanding of FASD, advancing local diagnostic capacity and improving the response to children, youth, adults and their caregivers.

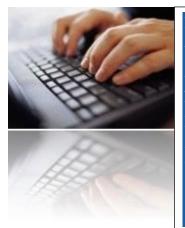
Organization, Agency, Program Award of Excellence

The 2013 recipient of this award is the Children's Aid Society of Toronto (CAST) who, for the past 10 years has played a lead role in addressing FASD, both within the organization and in the community. CAST has, and continues to have, a significant impact on bringing attention to FASD in Toronto. It has enhanced its' own organizational capacity to more effectively address FASD, has supported sister agencies to increase their capacity and has played a major role in building the City of Toronto's capacity to more effectively serve children, youth, adults and families affected by FASD. Some examples of its numerous accomplishments related to FASD are: the development of the Toronto FASD Coordinating Network; the creation of, and ongoing support for the Toronto FASD Training & Consultation Leadership Team which was replicated in several other communities across Ontario; the development of the first-in-Ontario FASD Certificate Program; and three in-agency pilot teams focused on addressing how to better serve children, youth and parents affected by FASD.

Community Award of Excellence

The Grey Bruce FASD Leadership Team received this 2013 award. Not only have they participated in an county-wide meconium research project in partnership with Motherrisk, but more recently they invited agencies in their area to attend a three-day training experience with Diane Malbin to learn about her community mobilization model. This led to the development of the FASD Leadership Team which is working collaboratively across service systems to better serve those affected by FASD and their families.

FASD ONE congratulates all the 2013 award winners for their outstanding work on behalf of those affected by FASD.



NEWSLETTER SUBMISSIONS:

We want to hear what is happening in your area. Are there some exciting developments or activities your FASD Committee is currently working on?

If you have a news submission for the next issue or feedback about FASD Ontario news, please email the editor, Cheryl Neave at info@fasdontario.ca

Fetal Alcohol Spectrum Disorder Ontario Network of Expertise

2013 Symposium Photos



Minister Matthews opens FASD ONE symposium



Participants listen to Effective Practices presentation



Effective Practices Panel



FASD ONE Chair, Sharron Richards introduces the next award recipient



Sheila Burns delivers keynote presentation



The Grey Bruce FASD Leadership Team accepts the FASD ONE Community Award of Excellence



Caregivers connect at FASD ONE Caregiver Workshop in Toronto

SHERYL OVER ACCEPTS FASD ONE FAMILY AWARD



I was so honoured to receive the FASD ONE Award of Excellence recognizing contributions made by a family in addressing FASD in Ontario. FASD came into our lives unexpectedly and has made a huge difference in who we thought we would be as a family, as parents and as members of our community. We were driven by love and to some degree (perhaps a big degree) by worry for our son. Thinking about what he would need at each stage of his life made us look proactively at what the community offered. In linking with the Peterborough FASD Committee we have developed programs and initiatives to improve services locally and to support other families.

I think this is why our name was put forward for this FASD ONE award. I hope we are a symbol of hope and a sign that things can change when families and agencies work together to bridge gaps in services to make our children's journeys more successful. One of the programs developed with the committee is the teen summer camp which focuses on life skills, social skills and recreation. I hope to see other communities replicate this valuable program. Thank you to my employer Five Counties Children's Centre for their support and educational experiences that allowed me to learn and grow, to the Peterborough FASD Committee and Tri-County Community Support Services for their foresight in taking on the challenges of this disability and to the Ontario Trillium Foundation for providing financial

I am humbled by this award and share it with my husband Jason, my children and all the other families in this community who are working to make this a welcoming, safe place for children, youth and adults with FASD.

support for community capacity training which will benefit many families in the community for years to come.

A CALL FROM ANDREW

The ring on my phone for calls from Andrew is called "Blues." So far today I've heard its tinkly tone twice, about average. The first time, he asked if I'd pony up for a music lesson this weekend; I said yes, although I periodically reflect that the monthly cost of his lessons could cover the lease for a Mercedes. The second had to do with a detail relating to his special needs status as a community college student. Oh, and he wouldn't be coming home this weekend.

In October 2009 I wrote about my step-grandson—my kid, Boop—in "Cause and Effect." He was 17; now he's 22, and an extraordinary success story for someone born with permanent brain damage from fetal alcohol syndrome. Unlike a tragically high proportion of young adults with FAS, he's not in jail, he's not an alcoholic or drug addict, he's not on the street. And now, having graduated from high school (an accomplishment in itself), he's not living at home, either.

Andrew's new digs are in the student ghetto close to York University in Toronto, which is also home to a satellite campus of Seneca College. There he's enrolled in a program called independent music production, the notion of which is to teach musicians how to turn their avocation into something approaching a living (presumably sans Mercedes). The business course is giving him trouble—he's flummoxed by an assignment that involves completing a grant application—but he seems to be soaring at songwriting. The kid who spent his entire school career in specialed classes turns out to have a gift for oddly spelled but sensitive lyrics set to sweet blues melodies.

I concluded "Cause and Effect" with the question "Who knows what dreams he's conjuring?" The answer, it seems, is styling himself "Drew" and trying to become a professional musician. There is no evidence that his imaginings encompass keeping the kitchen under control. When he's home on weekends, the place looks as if four or five episodes of *Top Chef Masters* were just shot there.

Part of my role in Andrew's new life is to serve as a wake-up service. Weekday mornings my alarm alerts me when it's 8 a.m.—time to get him up for class. He has two alarm clocks in his room, but can't work out how to set either one. The rest of the time, I'm the human Google at the end of the phone: "Nana, will the 106 bus stop at my street?" "Nana, how do you do an online course?"

His calls can make for amusing anecdotes, but there's a chilling bit of math behind them. Conventional wisdom in FAS circles is that those with the syndrome operate at two-thirds of their chronological age. By that reckoning, he won't be functioning like a 25-year-old until he's 38. That puts me close to 80, an age neither of my parents attained. Could the child of my heart continue to live his happy life and write his songs if I weren't here to backstop him, advise him, help him go in the right direction, sometimes literally?

Meanwhile, "Blues" sounds again: "Nana, I need some metaphors."

Submitted by: Lynn Cunningham

"Cause and Effect," which won two National Magazine Awards in 2010, can be found at thewalrus.ca/cause-and-effect.

FASD ONE Intervention & Support Working Group Update

The Intervention and Support working group is in the beginning stages of several important projects. One includes the development of a resource for caregivers that reviews the needs of individuals with FASD across the different ages of development, from birth to adulthood. This resource will act as a planning guide for both parents and service providers, ensuring support needs across ages of transition, are highlighted.

The second project includes developing a partnership with, and increasing knowledge within, the Ontario Camp Association (OCA) beginning with a series of educational articles in their provincial newsletter, over the next year, that focus on various aspects of FASD. Working group leads will be meeting with the OCA next year to talk about partnering to develop camp supports for this deserving population.

Lastly, the Intervention and Support working group has begun planning for a large provincial parent/caregiver conference for some time in early 2014 or 2015.

Submitted by: Nancy Hall

FASD ONE Justice Working Group Update

The March symposium was a wonderful opportunity for our group to hear about emerging justice-related activities and resources in the province. Many delegates shared information on initiatives that are advancing FASD within this important sector. The Justice Working Group postcards, designed by Georgian College, were the first step toward cataloguing program accommodations needed when victims or offenders have FASD.

We will continue to gather research, resources, links, and FASD justice-related news and will post promising practices on the FASD ONE website. Please submit your ideas to info@fasdontario.ca

Submitted by: Sheila Burns Justice Working Group Lead sheila.burns@rogers.com



CONFERENCE ANNOUNCEMENTS

Edmonton, Alberta



September 23 - 25, 2013



September 18 - 20, 2013

For more information visit www.fasdedmonton2013.ca

St. John's, Newfoundland and Labrador

2013 Fetal Alcohol Canadian Expertise (FACE) Meeting FASD Throughout the Lifespan: from prevention to lifelong support



A National FASD Conference hosted by fasdNL and the FACE Research Association

September 5 - 7, 2013

For more information visit www.med.mun.ca/pdcs/program_info.asp?programID=2600

Newsletter Submissions Criteria

Submissions and content suggestions 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
- Submissions or inquiries can be sent to info@fasdontario.ca

Inclusion of submissions is at the discretion of the newsletter task group. We reserve the right to edit submissions for length, grammar, consistency, etc. The opinions and accuracy of the information in submissions to the newsletter 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 for the posting. Please be especially sensitive to the identification of children and other vulnerable individuals.

It is the responsibility of the person submitting the photo/article to ensure he/she has permission to do so. A photo consent form is available on the



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Also available in French

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Driving progress on FASD

