

FASD ONTARIO NEWS



THE NEWSLETTER

OF FASD

STAKEHOLDERS

FOR ONTARIO

EDITION 1, SEPTEMBER 2006

Role of this Newsletter

This newsletter was developed by FASD Stakeholders for Ontario to provide information that will help people in Ontario work together to address FASD. The newsletter reports on the activities of FASD Stakeholders for Ontario, and shares other news of relevance to individuals, caregivers and service providers in Ontario who are working in the area of FASD. The newsletter includes information about upcoming training events, new resources, community activities etc.

FASD Stakeholders for Ontario

FASD Stakeholders for Ontario is a provincial group that was brought together to address the recognized need for coordination and collaboration across Ontario regarding FASD. Members include Ontario parents, caregivers and service providers who are concerned with FASD. FASD Stakeholders for Ontario currently has five working groups including Urban Aboriginal, Prevention, Intervention & Support, Diagnosis & Disability, and Justice. The Public Health Agency of Canada has provided support and funding around the priorities of these working groups. As FASD Stakeholders for Ontario

grows, additional working groups may be added.

While this new provincial FASD group has worked together for less than two years, they have already accomplished many significant projects, including teleconference training on diagnosis, a conference about addiction and pregnancy, a camp for families affected by FASD, teleconference meetings between diagnostic sites, and a CD of information about FASD and the justice system. Pages 2-6 of this newsletter provide additional information about the activities of the working groups, as well as contact names for additional information.

FASD Intergovernmental Action Network of Ontario

The FASD Intergovernmental Action Network of Ontario (FIANO) is made up of Ontario representatives from different governmental Departments and Ministries, such as Education, Children and Youth Services, Community Safety and Correctional Services, Attorney General and Justice, as well as representatives from the Public Health Agency of Canada, Ontario Region. This network has been working

together for almost a year. Network members want to establish a provincial FASD strategy for Ontario, and to develop collaboration at Ministry/Federal levels, while supporting the initiatives of the FASD Stakeholders for Ontario where appropriate. Donna De Filippis, FASD lead for Ontario, Public Health Agency of Canada, is the current chair for FIANO. For more information about FIANO, call 1-416-954-6256.

FETAL ALCOHOL SPECTRUM DISORDER (FASD)

FASD is the term used to describe the range of health, developmental, intellectual and social concerns that may result from prenatal exposure to alcohol.

DURING PREGNANCY:

There is no safe amount of alcohol.

There is no safe type of alcohol.

There is no safe time to drink alcohol.

INSIDE THIS ISSUE:

Urban Aboriginal Working Group	2
Prevention Working Group	3
Intervention & Support Working Group	4
Diagnosis & Disability Working Group	5
Justice Committee	6
New Resources, Workshops & Conferences, FASD Awareness Day, Photo Gallery	7/8

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URBAN ABORIGINAL WORKING GROUP

The Urban Aboriginal Working Group formed to address unmet FASD needs in Ontario's urban Aboriginal populations. This Working Group has identified many urban Aboriginal FASD priorities for Ontario including asset mapping, diagnostic capacity and services, training and resources.

The Urban Aboriginal Working Group talked about the need to develop a resource that would help people initiate and manage an FASD Diagnostic Clinic. The Ontario Federation of Indian Friendship Centres developed a manual that contains everything that is needed to run a clinic, from personnel needs to diagnostic forms. The manual will be mailed to urban Aboriginal communities and will be available on request to other groups. It is hoped that the manual will give Aboriginal communities the tools to start much needed FASD diagnostic clinics.

This Working Group also wanted to identify FASD services in the rural/urban/off-reserve locations across Ontario, and to analyze their services. An asset mapping project helped to clarify the need for additional services in Ontario for urban Aboriginal people with FASD. The final report:

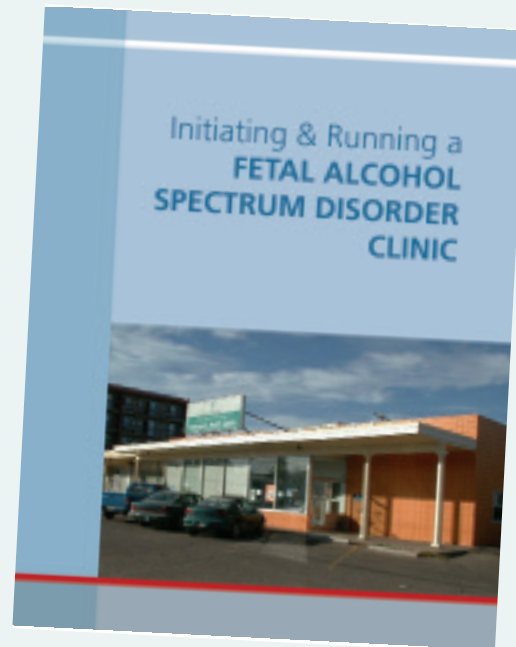
- Provides statistics on FASD diagnosis of Aboriginal and non-Aboriginal individuals in Ontario
- Lists the locations of FASD diagnostic clinics
- Describes the availability of FASD support services
- Discusses the need for Aboriginal specific FASD programming in Ontario

The Working Group also planned four tele-education training events for Ontario service providers who work with Aboriginal people who may have FASD. These tele-education training sessions included:

FASD Screening and Diagnosis, April 26, 2006.

Presented by Dr. Gideon Koren and Dr. Ellen Fantus. Included 9 tele-education sites.

Co-Morbidity in FASD: Bipolar Disorder, Impulsivity, Aggression, Seizures and Disabilities Associated with FASD, May 25, 2006. Presented by Dr. Irena Nulman and Dr. Ellen Fantus. Included 6 tele-education sites.



Diagnosing Youth and Adults with FASD, June 22, 2006. Presented by Dr. William Watson and Dr. Brenda Stade. Included 22 tele-education sites.

Diagnosing Youth and Adults with FASD, June 27, 2006. Presented by Dr. William Watson and Dr. Brenda Stade. Included 22 tele-education sites.

These training events were very successful. In fact the registration for the last 2 sessions was at capacity, and no additional sites could be added.

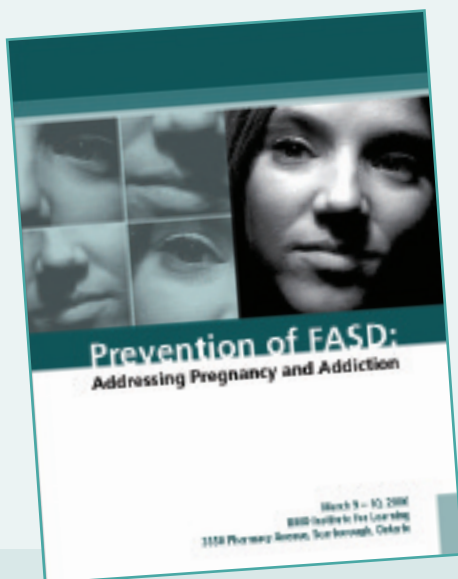
The Urban Aboriginal Working Group also re-printed the successful resource *FASD Tool Kit for Aboriginal Families* and mailed copies to Ontario Early Years Centres, public health units, CAPC and CPNP sites and Healthy Babies Healthy Children Programs across Ontario. To view this resource, go to www.ofifc.org.

The Urban Aboriginal Working Group is currently considering priority projects for 2006/07. For more information about the Urban Aboriginal Working Group, contact Kimberly Meawasige at the Ontario Federation of Indian Friendship Centres, kmeawasige@ofifc.org.

PREVENTION WORKING GROUP

The Prevention Working Group of FASD Stakeholders for Ontario chose to focus on preventing and reducing prenatal alcohol use in high-risk groups, addressing areas such as addiction, mental health and other underlying factors for alcohol use during pregnancy. This focus may change over time, depending on provincial needs, interests and opportunities in the area of FASD prevention. Current representation on the Prevention Working Group includes Motherisk, Mothercraft/Breaking the Cycle, FASEout, Best Start Resource Centre, CAPC/CPNP Ottawa, Porcupine Health Unit and the Union of Ontario Indians.

The Prevention Working Group realized its first major initiative, a two-day conference titled *Prevention of FASD: Addressing Pregnancy and Addiction*, in Scarborough, Ontario on March 9-10, 2006. The objective of the conference was to examine the root causes of women's alcohol use during pregnancy, including addiction and mental health problems, and ways to support women with significant alcohol problems or addictions in pregnancy. The two-day event included an evening policy forum, followed by a day of concurrent sessions, keynote speakers and displays. This conference was accomplished through funding from the Public Health Agency of Canada, the support of the Working Group, and significant contributions of staff time from Motherisk, Mothercraft/Breaking the Cycle and the Best Start Resource Centre.



The forum on March 9 brought together a panel of six experts. Panelists were asked to consider how systems of care, programs and services to high-risk women and children, and related policies might be integrated to improve women's health and prevent FASD. Nancy Poole, Research Consultant on Women's Substance Use Issues, BC Women's Hospital in Vancouver and the BC Centre on Excellence for Women's Health, was the discussion moderator. A report was developed including a summary of panel presentations, group discussion, delegate evaluations, recommendations and related resources. This report is available at www.motherisk.org/JFAS.

The keynotes and concurrent sessions on March 10th focused on prevention strategies that are directed to the care of pregnant women who have significant alcohol problems or addictions, and who require more than information, advice or brief interventions in order to change their alcohol use in pregnancy.

The conference was a great success. Despite the short planning cycle, over 200 people attended. The evaluations were strongly supportive of the event. Many participants expressed interest in an annual conference on alcohol, addiction and pregnancy.

The Prevention Working Group is focusing on next steps. This Working Group would like to enhance training about preventing and reducing alcohol use in pregnancy in high-risk groups by building on existing training tools and developing additional training resources. The Working Group is also considering a follow-up conference on alcohol, addiction and pregnancy in 2007/08. For more information about the Prevention Working Group, contact Wendy Burgoyne at the Best Start Resource Centre, wendyb@beststart.org or Susan Santiago at Motherisk, susan.santiago@sickkids.ca.

"Two of our staff went. They were SO knocked out by it, so impressed, so 'stretched'. They were raving about it and bubbling over with enthusiasm. Sounds like it was right on the mark and very intellectually stimulating."

Comment re: Prevention of FASD Conference

INTERVENTION & SUPPORT WORKING GROUP



A camp for Ontario children affected by FASD and their families was held at Geneva Park in Orillia from March 17-19, 2006. It was planned and implemented by members of the Intervention and Support Working Group. Timiskaming Brighter Futures, a program of Timiskaming Child and Family Services, under the leadership of Pat Spadetto and staff, managed the project

and funding from the Public Health Agency of Canada. Six members of the Intervention and Support Working Group and one FIANO member planned and implemented this project from across Ontario.

The purpose of the Intervention and Support Working Group focuses on encouraging, initiating and training those who provide care and support services to individuals with FASD. Group priorities are to increase **knowledge** about FASD, **expertise** in professionals and caregivers and enhance community **supports**. The camp was planned and implemented to focus on these priorities.

Things children with FASD liked about camp:

- *“was invited to eat with another family for the first time.”*
- *“seeing families with the same problems as ours.”*
- *“making new friends just like me.”*
- *“meeting Joe and thinking I can be like him.”*

A total of 186 enthusiastic campers participated in the three-day event. This included 65 caregivers and 121 children (75 of the children had FASD and 46 were siblings). The Intervention and Support Working Group distributed applications across Ontario and using geographic criteria, served families from most areas.

The camp was a huge and unprecedented success. Geneva Park staff, the Intervention and Support Working Group, volunteers and family members were fulfilled, buoyant and motivated albeit exhausted at the end. Feelings of despair were replaced with new enthusiasm for the future of interventions with children with FASD. Some comments helped us to learn new ideas for future planning. We smiled when one child reported that there was “nuffin” about camp they disliked and celebrated with comments from families, such as, *“this has changed our lives forever”*.

The camp forever changed the staff and volunteers who left Geneva feeling wonderfully depleted of energy that had been expended on one of the most important events in their lives. One group member, a seasoned veteran in child protection, reported that although she had been interested in children with FASD before, now she was really hooked on FASD prevention, intervention and support. A member, working in the field for many years, reported this was the first time she had seen families benefit so greatly, in front of her eyes, showing gratitude and appreciation for their learning and experience. Wow!

Comments about camp from parents and caregivers:

- *“My life has been changed forever for the good.”*
- *“It was wonderful to get away and not worry about my child’s behaviour.”*
- *“Meeting Joe, a wonderful young man with FASD and his girlfriend, seeing them play and work with our children, helped us, for the first time to see their potential.”*
- *“Thank you for the best weekend our family has ever had.”*

A report was prepared about the camp, including background information, planning and implementation process, budget, camper feedback and lessons learned. Some paperwork used by the Intervention and Support Working Group is included in the report. The Working Group hopes to run a camp in the future and will share this model, with lessons learned, across Ontario. Anyone wishing to read the report may get an electronic copy from cunninghammary@rogers.com

DIAGNOSIS & DISABILITY WORKING GROUP

The Diagnosis & Disability Working Group of FASD Stakeholders for Ontario focuses on issues around diagnosis of FASD. Early diagnosis and access to appropriate services have been shown to be effective in decreasing the risk of secondary disabilities of FASD. The emotional costs, social implications and costs to society are decreased if FASD is diagnosed early. A diagnosis is important in understanding an individual with FASD and in developing an appropriate care plan.

FASD Diagnostic Clinics in Ontario:

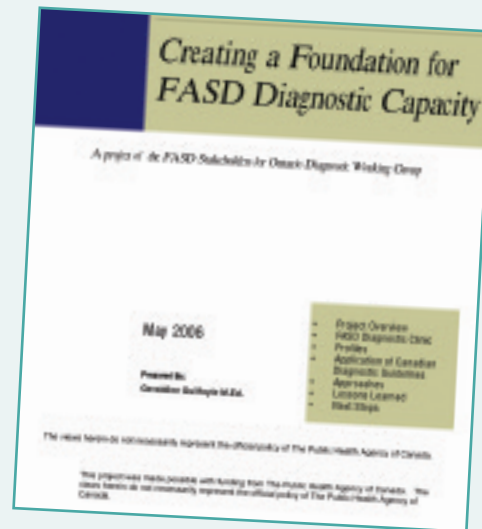
- Healthy Generations, Northwestern Ontario FASD Clinic, Sioux Lookout
- St. Michael's Hospital, FASD Diagnostic Clinic, Toronto
- The Hospital for Sick Children, Motherisk Program, Toronto
- Native Child and Family Services of Toronto-St. Michael's Hospital, FASD Diagnostic Clinic, Toronto
- Anishnawbe Health Toronto – St. Joseph's Health Centre, Toronto
- Grandview Children's Centre, Oshawa
- FASD Team: Resources for Exceptional Children, Ajax
- Breaking the Cycle FASD Diagnostic Clinic, Toronto

Activities of this working group:

- Gathered information about existing clinics in Ontario and developed a report
- Held 2 videoconference meetings with all existing and emerging FASD clinics to share information re: approaches, application of diagnostic guidelines, needs of clients and team members, lessons learned and next steps for best practices
- Established communication among existing FASD diagnostic teams and emerging FASD diagnostic teams
- Established next steps for long term network system

This working group recently completed a project entitled, *Creating a Foundation for FASD Diagnostic Capacity*.

The goal of this project was to identify the strengths and challenges faced by FASD diagnostic teams in Ontario and to create a foundation of diagnostic capacity development in Ontario. The project was funded by the Public Health Agency of Canada.



The report, *Creating a Foundation for FASD Diagnostic Capacity* includes:

- FASD Diagnostic Clinic Profiles
- Application of Canadian Diagnostic Guidelines
- Approaches
- Lessons Learned
- Next Steps

Please feel free to access a pdf version of the report at: www.slnhacl.on.ca/fasd/word/Foundation-FASD-Diagnostic-Capacity.pdf

The FASD Stakeholders of Ontario Diagnostic and Disability Working Group will continue to work collaboratively to nurture diagnostic capacity and welcomes continued networking towards this end. For more information contact Sheila Burns at sburns@rfecdurham.com or Brenda Stade, stadeb@smh.toronto.on.ca

“Prevention, early diagnosis and early treatment are worth the investment.”

Dr. Brenda Stade, St. Michael's FASD Diagnostic Clinic

Justice Committee



The Justice Committee, formed in the fall of 2005, is the newest addition to FASD Stakeholders of Ontario. Members of this working group include Jonathan Rudin, Joyce Atcheson, Nancy Dinnigan, Carol Lee Smith, Judy Mungovan, Sue Khowessah, Linda Johnston, and Elaine Cousineau. The members' combined expertise includes legal, FASD content knowledge and experience, communications, corrections, First Peoples culture, and community education.

FASD-affected individuals come into contact with the justice system as family, victims, witnesses, and offenders. However justice system personnel have lacked access to readily available, credible sources of information in an accessible format to assist these individuals. The Justice Committee chose, as its first priority, to address the difficulties experienced by FASD-affected individuals and justice system personnel by integrating resources in a single package for use by judges and lawyers.

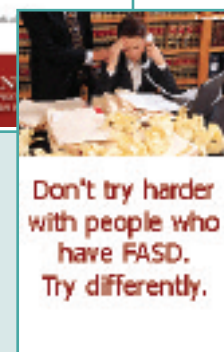
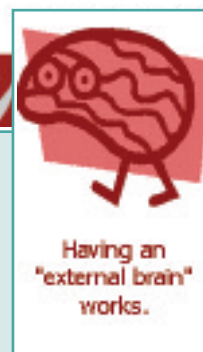
The CD-ROM *FASD and the Justice System* was released in April 2006. It includes information about:

- Recognising and understanding FASD
- FASD and the courts
- What judges and lawyers can do
- Aboriginal Peoples with FASD
- Case law
- Sources of additional information

Development and production of the CD-ROM was funded by the Public Health Agency of Canada through the administrative assistance of Ka: nen Our Children Our Future, active support of the members' employers, and commitment by committee members. This Justice Committee copyrighted resource was directed and finalized by the Justice Committee using peer-reviewed sources.

Currently the CD-ROM is being distributed within the Ontario justice system while demand for it increases. To date, all feedback has been positive about its potential to assist. A formal review is planned for the future to enable the Committee to revise and update the product. The Justice Committee hopes the format and practicality of the CD will aid in provision of compassionate, fair and effective strategies for dealing with FASD in the criminal justice system.

For more information about the Justice Committee and the *FASD and the Justice System* CD-ROM, contact the Justice Committee co-leads: Joyce Atcheson at Ka: nen Our Children Our Future, joycea@kanen.on.ca or Jonathan Rudin at Aboriginal Legal Services of Toronto rudinj@lao.on.ca.



NEW FASD RESOURCES

FASEout Website

PowerPoint presentations, reference articles, list of trainers etc.
www.faseout.ca

Pregnancy-Related Issues in the Management of Addictions: A Reference for Care Providers

The PRIMA Project
www.addictionpregnancy.ca
To order this resource, contact:
deana.midmer@utoronto.ca

Let's Talk FASD

Parent driven strategies in caring for children and adults affected by FASD
Developed by VON
www.von.ca/FASD/index.html

FASD National Link

A Canadian listserv about FASD hosted by VON. Post information about FASD or pose questions to the other members. To find out more, or to join the listserv: http://lists.von.ca/mailman/listinfo/fasd_national_link

Looking for More FASD Resources?

See the National Database of FASD and Substance Use During Pregnancy Resources at: www.ccsa.ca/fas

Helpful FASD Resources from the Public Health Agency of Canada:

- FASD Canadian Guidelines for Diagnosis (2005)
- FASD Booklet (2004)
- Results of a National Survey on Knowledge and Attitudes of Health Professionals about FASD (2004)
- FASD Framework for Action (2003)

Check back for new resources!

See www.phac-aspc.gc.ca/fasd-etcaf/index.html

FASD WORKSHOPS & CONFERENCES

ONTARIO:

FASD Introductory Training

Oct 12-13, 2006, Toronto
2 day workshop with Donna Debolt
Contact sterpstr@ccas.toronto.on.ca

Stronger Together: Moving Forward for FASD

October 18-19, 2006, Dryden Ontario
For more information:
www.fasdnorthwest.org

FASD Through the Lifecycle

October 26-27, 2006, Guelph, Ontario
For more information: www.fasat.ca
(check under News)

Introduction to Diagnosing FASD

Nov 2, 2006, Oshawa, Ontario
On-line course, University of Washington
Contact sburns@rfecdurham.com

Working with FASD

Nov 6-7, 2006, Renfrew, Ontario
For more information or to register call: 1-800-804-0772

Supporting Substance Involved Pregnant and Parenting Women

with Diane Malbin
November 7, 2006, Oshawa Ontario
Contact yndrew.durham@girls-inc.org or aendicott.durham@girls-inc.org

Building Resilience in Children with FASD

December, 2006, Oshawa, Ontario
2-day workshop with Dr. Kathy Jones
Contact sburns@rfecdurham.com

NATIONAL:

FACE Research Roundtable

September 9, 2006, Moncton, New Brunswick
Registration deadline: August 29, 2006
Simultaneous translation in both official languages.
Program and registration form at: www.motherisk.org/JFAS/econtent_conferences.jsp

6th National Aboriginal FASD Conference: Promising Intervention Strategies for Parents, Teachers and Caregivers of Children and Adults with FASD

Oct 19-20, 2006, Winnipeg, Manitoba
For more information or to register, contact 1-888-683-7711 or wzarchikoff@msn.com

International Conference on Fetal Alcohol Spectrum Disorder: Research, Policy and Practice Around the World

March 7-10, 2007, Victoria, BC
UBC Interprofessional Continuing Education
For more information: www.interprofessional.ubc.ca/Adv-call_FASD_2007.pdf

The PRIMA (Pregnancy-Related Issues in the Management of Addictions) Project

Watch for upcoming train-the-trainer events: www.addictionpregnancy.ca
For more information, contact: deana.midmer@utoronto.ca

Looking for More Workshops and Conferences? See the FASD Calendar of Events at: www.ccsa.ca/CCSA/EN/TopNav/Home/Calendar/FASDEvent

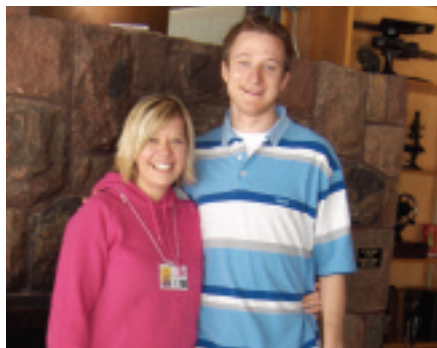
Photo Gallery – FASD Activities Across Ontario



In March 2006, 30 FASD Resource Persons received a four-day training delivered by Maureen Parkes, FASD Coordinator at the NorWest Community Health Centres, Thunder Bay. These new recruits are joining the network of more than 60 resource persons from within agencies that serve youth in conflict with the law in the Thunder Bay area.



FASD Coalition of Ottawa hosted a display with mocktail samples at the Ottawa Jazz Festival and reached over 750 people. June 25, 2006



Joe Margetson (who has FASD) and his fiancé Amanda Hurtibese work to give hope to families affected by FASD and to provide support, encouragement and fun to children with FASD.



The Waterloo-Wellington-Dufferin FASD Committee and Public Health staff launched an FASD awareness campaign September 12, 2005. The day included speeches, networking, the distribution of message bracelets and a celebratory cake.



Tom Wilkinson completed his 812 km walk across Ontario in May, 2006, raising awareness about Fetal Alcohol Spectrum Disorder (FASD). Tom was accompanied by his dog Shadow and his worker Mike Thompson.

Celebrate International FASD Awareness Day

When: Saturday, September 9, 2006
Location: FASD Awareness Day events take place worldwide and are organized by local communities to raise awareness about Fetal Alcohol Spectrum Disorder.

FASworld Canada Website:
www.fasworld.com

For more FASDay ideas, see:
www.fasday.com

Find out what is happening across Ontario:

The Motherisk Alcohol and Substance Use Helpline will include a listing of events to be held on FASDay, September 9, 2006, on a specially recorded voice message. Callers throughout Canada can access the event listing toll-free by dialing 1-877-327-4636.

Feedback about FASD Ontario News:

FASD Stakeholders for Ontario is considering possible future editions of this newsletter. If you have any comments about this newsletter, or suggestions for future editions, please contact: wendyb@beststart.org

Looking for FASD Information? Need Support or Services in Ontario?

See the Directory of FASD Information and Support Services in Canada at:
www.ccsa.ca/CCSA/EN/Topics/Populations/FASD.htm

Development of this newsletter was supported by the Public Health Agency of Canada. The opinions expressed in this publication are those of the authors and do not necessarily reflect the views of the Public Health Agency of Canada or the government of Ontario. Resources and events mentioned in this publication are not necessarily approved or endorsed by the Public Health Agency of Canada or by the Best Start Resource Centre.