

F.A.S.D. NEWS

FETAL • ALCOHOL • SPECTRUM • DISORDER

Spring 2006

A Publication of the Coalition on Alcohol and Pregnancy

Defining the Future of CAP

What does the future hold for Coalition on Alcohol and Pregnancy (CAP)? A new working group will be addressing that question over the next several months.

After many years as the unflagging Chair of CAP, Dale Kendel stepped down from the role in November 2005. Jill Isbister of Healthy Child Manitoba and Zenon Lisakowski of Addictions Foundation of Manitoba were nominated and agreed to act as co-chairs until September 2006.

Many thanks to Dale

On behalf of the Coalition, the new co-chairs wish to publicly express their gratitude to Dale and acknowledge his commitment and hard work both for and on behalf of CAP.

A CAP working group of approximately 30 individuals will be evaluating the purpose of the Coalition, its function and operating structure, and how CAP can operate within a provincial scope.

The working group was formed from individuals who have either attended

one of the last three CAP meetings or expressed an interest in participating. The working group meetings are scheduled for the third Monday of each month at the Healthy Child Manitoba office. Anyone who is interested in becoming part of the working group is welcome to contact either of the Co-chairs. Teleconferencing is available for those outside of Winnipeg.

First steps for the working group will be determining the Terms of Reference for CAP as a group. This will be followed by an evaluation of the operating structure. For example, will there be a steering committee, chair, rotating co-chairs, etc. Once the Terms of Reference and operating structure are determined, the working group will look at the priorities of the Coalition.

In the immediate future, a subcommittee has initiated a CAP information series (see story on right).

To renew your CAP membership or to join the working group, contact Jill Isbister at 945-8641 or Zenon Lisakowski at 944-6358.

CAP Information Sessions: Series on New FASD Services

Join us over the lunch hour for a new information series from the Coalition on Alcohol and Pregnancy. Bring your own lunch - coffee is on us! For more information, contact Jill Isbister at (204) 945-2266.

Free! Fridays, 11:45 - 12:45 sharp

April 7

Creating a Better Future for Youth with FASD in the Justice System: Presentation on the FASD Youth Justice Project

Dan Neault and Teresa Brown, Manitoba Youth Centre, Conference Room, 170 Doncaster St. RSVP to Jocelyn at (204) 475-2019

May 12

Bridging the Gap between Diagnosis and School

This session will present a strength-based learning profile developed after a diagnosis of FASD is made at the Clinic for Alcohol and Drug Exposed Children. Jo and his dad Chris will share their journey through the diagnostic process to planning and implementing this profile for Jo at school and home. Room 1188 "Gimli Room" at Cancer Care Manitoba, 675 McDermot Ave.

For this session there will be telehealth links available in Brandon, Thompson and Norway House. Contact Mary Cox-Millar at (204) 787-1822 for more information.

June 16

Supporting Adults and Late Adolescents

Brenda Bennett, FASD Life's Journey Inc., 110 - 114 Garry St.

Interdepartmental Committee FASD Strategy Pending

As reported in the Winter 2005 issue of *Manitoba F.A.S.D. News*, the provincial FASD Interdepartmental Committee was created to develop a strategic plan that will inform and advise on options for action, and make recommendations to government and community. A draft strategy has been presented by the Manitoba FASD Interdepartmental Committee to Healthy Child Committee of Cabinet and a response is pending.

(continued on page 5)

New Beginnings: Better Endings

Adapting Practice and Programs and Promoting Collaboration to Improve Outcomes for Adolescents with FASD

Full-day Workshop with Dan Dubovsky & Jan Lutke

The Coalition on Alcohol and Pregnancy is pleased to present a full-day workshop with Dan Dubovsky and Jan Lutke. This event is open to both families and professionals at no charge.

Dan Dubovsky is an FASD Specialist with the SAMHSA FASD Center for Excellence in Rockville, Maryland. Dan has worked for over 30 years in the fields of mental health and developmental disabilities, presenting around the world on FASD for the past 8-10 years. Dan's son Bill was his mentor and best teacher. **Jan Lutke** is the co-chair of the National Advisory Committee on FASD to Health Canada, chair of the sub-committee on Quality of Life issues, founder and former director of the FAS Support Network of BC, and the Senior Consultant for FASD Connections (fasdconnections.ca), a website dedicated to issues for adolescents and adults with FASD.

Friday, June 2, 2006
9:00 a.m. to 4:00 p.m.

(Coffee will be served at 8:30 a.m. Participants are responsible for lunch on their own from 11:30 a.m. to 1:00 p.m.)

Free - No Charge!

Winnipeg location TBA. Advance registration required. To register or for more details, call the: **Fetal Alcohol Family Association of Manitoba** at (204) 786-1847 or toll free 1-866-890-1402. Email: fafam@mts.net.

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Study Results on Children with FASD in Care

(The following information was drawn directly from the Executive Summary of the final report released October 2005 and a fact sheet summarizing results specific to FASD-related disabilities. Available at: www.cecw-cepb.ca/Research/Research-PCW.shtml)

The study "Children with Disabilities: Receiving Services from Child Welfare Agencies in Manitoba" was conducted by the Faculty of Social Work, University of Manitoba, and the Child Protection Branch of the Manitoba Department of Family Services and Housing under the auspices of the Prairie Child Welfare Consortium. Funding was provided by Health Canada with the support of the Centre of Excellence for Child Welfare.

The report's authors included Don Fuchs, University of Manitoba, Linda Burnside, Child Protection Branch, and Shelagh Marchenski and Andria Mudry, from the University of Manitoba.

For purposes of the study, children with disabilities were defined as those children whose ability to participate in age-appropriate activities of daily living was compromised by limitations in one or more areas of functioning. The researchers investigated the characteristics of 1,869 children with disabilities who were receiving child welfare services in Manitoba on September 1, 2004.

It was noted that children with disabilities are at greater risk of maltreatment and/or neglect than children without disabilities.

They have been known to suffer maltreatment at three times the rate of children without disabilities (Sullivan & Knutson, 2000). Those with behavioural disorders face the greatest risk at seven times the rate of children without disabilities.



Looking specifically at children with fetal alcohol related disabilities, FASD was diagnosed in one-third (34.2%) of all children with disabilities in care or 11% of all children in care. Of this group, 75% had an intellectual disability and 56% were diagnosed with, or suspected to have, a mental health related disability. FASD and ADHD were coincident in 39.1% of the children with an FASD diagnosis.

Of the 1,403 children in care with an intellectual disability, 46% had diagnosed FASD. The proportion of boys to girls (61% boys and 39% girls) was

very close to the 60:40 ratio found in the general disability population of children in care in Manitoba. The average age of the children with FASD in care was 10.08 years.

The number of children in care with FASD, in both genders, reaches a peak at an earlier age than those with non-FASD disabilities. The overwhelming majority of children with FASD (89%) were in the permanent care of a child welfare agency. In comparison, 61% of the general population of children with disabilities in care in Manitoba were in permanent care. Only 3% of the FASD group coming into care had Voluntary Placement Agreements compared to 18% of the general group of children with disabilities in care.



The reasons for children with FASD coming into care were predominately related to a difficult parental situation (62% of children came into care because of the conduct of the parents or the incapacity of the parents to fulfill their parental role). Only 6% of the children with FASD came into care because of reasons related to the child's condition or the child's conduct. By comparison, in the non-FASD population, 54% of children were in care for reasons related to parental care and 18% for reasons related to child's conduct or conditions.

The study demonstrated that children with disabilities represent a significant proportion of the children in care in this province. The child welfare system is not currently structured in a manner to serve children with disabilities and their families.

The authors found that the data indicates that there are many children with disabilities and their families who are not receiving the services necessary to meet their needs from within the child welfare system or from other service sectors. (Please see a summary of the report recommendations on the right.)

Children in Care Recommendations

Recommendations from the report on "Children with Disabilities: Receiving Services from Child Welfare Agencies in Manitoba" for the child welfare, education, disability and health sectors included:

- 1) Develop policy to ensure intersectoral collaboration occurs between service sectors in the provision of services.
- 2) Develop and implement collaborative models with intersectoral teams of service providers to provide the necessary services to children with disabilities and their families.
- 3) Develop training programs on disabilities, including information on how intellectual and biological limitations affect functioning and how to deal with problem behaviour. This training should be available for all child welfare workers, foster parents and other direct care providers.
- 4) Develop and implement culturally appropriate prevention and service delivery programs. This would include: strengthening programs on prevention of FASD; providing services to families with children with FASD; understanding the issues relating to disabilities; supporting families in dealing with the additional stress of caring for children with a disability; and linking available resources to families.
- 5) Continue the development of the information database on the needs of children with disabilities, specifically those involved with the child welfare system, and the development of a mechanism to ensure the information is integrated into the annual planning of agencies, their Authorities and government departments.



Download the entire final report from the Centre of Excellence for Child Welfare website at:

www.cecw-cepb.ca/Research/ResearchPCW.shtml

Welcome to new Stop FAS staff

Healthy Child Manitoba is pleased to welcome three new Stop FAS coordinators to the program: Tammy, Laurie and Vanessa.

Stop FAS is a voluntary three year home visiting/mentoring program designed to work with pregnant women who have used alcohol or drugs heavily throughout their pregnancy to avoid the birth of other children affected by alcohol and drug use. Program sites are located in Winnipeg, Thompson and The Pas.

All four Stop FAS sites currently have space available for new participants. To be eligible, women must be pregnant or have had a baby within the past two months, have used drugs or alcohol heavily during this pregnancy, and have few positive connections to community services.

To make a referral, please contact one of the Stop FAS site coordinators:

Tammy Frederiksen
Nor'West Mentor Program (Winnipeg)
(204) 940-6646

Vanessa Collins
Aboriginal Health and Wellness Centre (Winnipeg)
FASD Prevention Program
(204) 925-3750

Laurie Vallance
Grassroots Mentoring (Thompson)
FASD Prevention Program
(204) 677-5356

Joanne Wyman
The Pas Mentor Program
(204) 623-9649

For more information on the Stop FAS program, contact Jill Isbister with Healthy Child Manitoba at (204) 945-8641.

COALITION ON ALCOHOL AND PREGNANCY (CAP)

CAP represents over 160 organizations interested in FASD issues in Manitoba. Six focus areas include: Family Support, Education (including early years), Service Co-ordination/Development, Justice, Research, and Communication and Information Dissemination. Special task forces are formed around specific issues. CAP's members represent a diverse cross-section of individuals, groups and communities throughout Manitoba. We bring together the needs of parents (including birth, adoptive and foster) and professionals.

Manitoba F.A.S.D. News is published by the CAP.

Newsletter Editor: Beth McKechnie

CAP Co-Chairs: Jill Isbister, Healthy Child Manitoba, (204) 945-8641
Zenon Lisakowski, Addictions Foundation of Manitoba, (204) 944-6358

CAP receives funding support from Healthy Child Manitoba.

Understanding the Dynamics of Attachment and FASD

(The following article was written by Julia Wellwood and Karen Johnston of the FASD Outreach Team, Children's Special Services. They explain the specific dynamics of attachment theory and practice as it applies to children with FASD and their parents.)

What comes to mind when you think about attachment? Maybe you picture how your child likes to cuddle up with you or how they look over their shoulder for you as they venture away from your side to explore at the playground, how they run to you with a scraped knee and how your kiss seems to make it all better. Or maybe you think of how they cling to you when you need to go out or how you can't go to the bathroom without a little shadow!

We know from research on attachment that out of all the roles that a parent plays, such as playmate, teacher and nurturer, it is the role of attachment figure that is critically important and lays the foundation for all else. This means that how we respond when our child is emotionally upset, such as feeling scared, sad or mad, or when they are physically hurt or ill determines whether our child will feel safe and secure or insecure, anxious or even confused (disorganized).

When a child is in this kind of distress, we say that their attachment system is activated. This means that we can observe, through their behaviour at this time, how they have learned to cope based on repeated past experiences with distress. Infants are "hard-wired" to seek the attention of their primary caregiver to have their needs addressed.

This typically includes behaviours such as crying, lifting up their arms to be held or running to the parent. Research shows that the strategies that a child uses are reflective of their experience of care-giving and they will develop either a secure attachment style or perhaps an anxious or avoidant style.

This means that if these hard-wired behaviours elicit an effective response from their parent that settles them and helps them to cope, the child will feel safe and secure and will use these strategies again. If a parent finds it difficult to tolerate distress in a child, they may respond by directing the child away from themselves and by offering toys or a soother for comfort. The child learns to minimize their expression of emotional distress and to calm themselves with objects. If a parent responds to a child in an inconsistent and variable way, the child will learn to heighten their signals of distress. They will cry harder and longer, and may be generally fussy and clingy to ensure contact with their parent.

Keeping in mind that attachment is best understood in the context of relationship, it is therefore important to recognize what is happening for the parent as well as for the child.

As parents, we are all doing the best we know how. A big part of how we parent is based on our own experiences of being parented as children. Sometimes we have had experiences that leave us vulnerable to aspects of our child's behaviour, which can lead us to misread their cues. The experiences that influence our parenting have been coined "ghosts in the

nursery." Sometimes we have big worries about food, shelter or safety that can understandably lead us to miss cues altogether. At other times, we might be sending contradictory signals to our child without being aware of it. All of this, along with what the child brings to the relationship, becomes part of the attachment experience for both parent and child.

Children with FASD

While these comments apply to all children and parents, at the FASD Outreach Program we are specifically interested in the dynamics of attachment theory and practice as it applies to the child with FASD and their parents. Children with FASD seem to be more vulnerable and therefore more at risk for developing insecure attachment patterns. This vulnerability is related to neurological factors as well as to environmental factors and quite often is a combination of both.

Neurological issues such as symptoms of withdrawal after birth, immature nervous systems, sensory processing difficulties, and in the older child, impulsive and hyperactive tendencies and cognitive differences place great demands on a parent. Per-

"disorganized." It is an extremely problematic classification given its high correlation with later mental health issues and significant behaviour problems. Based on the findings of the Secondary Disabilities Study by Anne Streissguth, notably the high rate of mental health issues in the population with FASD and the protective qualities associated with stability and longevity of placement, this is an important issue for these children.

Most of us have heard at one time or another that "children with FASD don't attach." Our work with families is showing us that attachment theory seems to be equally applicable to children with FASD and that, in fact, it provides a critically important framework for understanding their needs and a context for guiding intervention.

Exciting research

There is exciting work happening in the field of attachment, both in research and intervention. Modified Interaction Guidance (MIG) is an example of an intervention that has particular relevance here in Manitoba. The FASD Outreach Team has had

the good fortune of participating in training in this intervention this past year, along with a group of people from the community and from the Child Development Clinic.

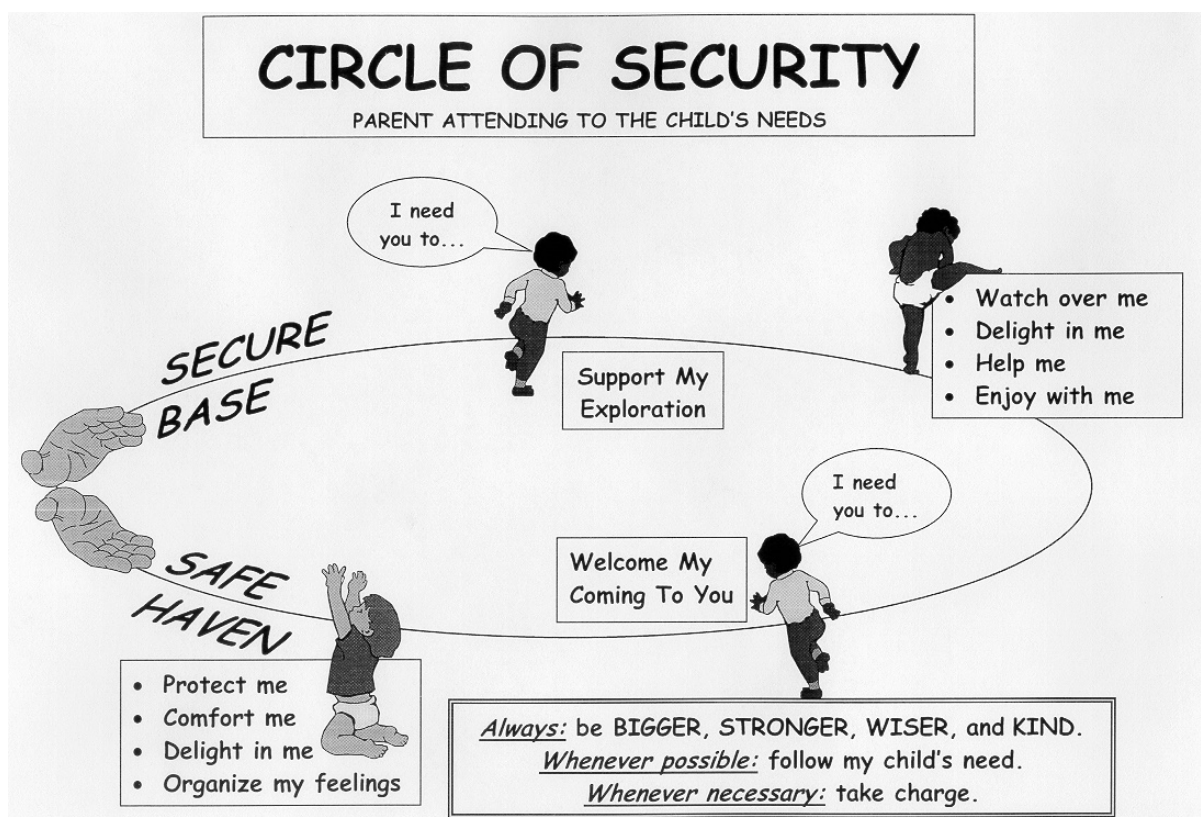
Dr. Diane Benoit, an Infant Psychiatrist with the Toronto Sick Children's Hospital, developed Modified Interaction Guidance as a short-term, play-based therapy for parents who want to improve the way they and their children interact together. They learn to watch more closely for their child's signals and to respond in more accurate and targeted ways. In addition, they can learn to recognize in themselves signals that

they might be unintentionally sending to their child and that they may wish to change.

Modified Interaction Guidance sessions include goal-setting by the parent, specific information provided to the family that is tailored to their needs, weekly review of progress and the weekly video-taping of a 10-minute playtime for feedback by the parent and by the therapist. Videotaping allows the parent to observe their interactions and to evaluate their progress. Weekly homework is based on the feedback session. During feedback, the parent learns to recognize which of their responses worked really well and which new responses they can try. These are then practiced at home. Success is measured by how the child responds when in distress and by the reduction of problematic behaviours.

The research on this and other interventions is showing that it provides a very important process for change. Those of us with the FASD Outreach Team feel that we finally have an intervention that helps to address the attachment issues that have concerned us for many years. Above all, we want to say how appreciative we are of the work that families do and what a privilege it is to be part of that!

For more information, please contact a member of the FASD Outreach Team, Children's Special Services, at (204) 945-8311.



haps you've experienced the helplessness of trying to comfort an infant who is inconsolable or holding a child who arches away from you or avoids your eye contact. Maybe you are weary from the constant supervision of your child's activity level and constant repeating, or maybe you worry because it seems like your child would go with anyone. The stress of daily care, in addition to possible grief issues, beliefs about the disability, and the individual strengths and vulnerabilities of the parent discussed earlier all influence the parent-child relationship.

Interestingly, many characteristics of FASD such as sleep issues, avoidance of physical contact or clinginess, picky eating, frenetic activity and indiscriminate friendliness can also describe attachment issues and reflect instead environmental factors in the child's life. All too often children with FASD have experienced relationship disruption due to multiple placements or other types of trauma, which makes attachment a very prevalent issue and a difficult one to sort out.

Of all the scenarios, it is the child who has no coherent strategy for coping with distress that is the most concerning. This is the child who, when upset, wants up and then down, approaches but then turns away, accepts a hug but then holds their body stiff, or who approaches but in a slow, apprehensive way. In the research literature, this child is classified as

Congratulations to Kaitlin Larabie on Yes I Can! International Award

Kaitlin Larabie was among five Manitobans honoured with an international Yes I Can! Award in 2006. Kaitlin is one of 24 children and youth from across North America receiving awards this year.

Featured in a *Winnipeg Free Press* article published March 27, 2006, Kaitlin explained that "When I was

in my mom's tummy, she drank, and I got a disability. Sometimes we can't remember and we forget."

Kaitlin, 11 years old, says that being affected by FASD is not going to deter her from becoming a teacher. She is currently a student in David Livingstone School's FAS program.

community service, employment, extracurricular activities, independent living skills, self-advocacy, and technology.

Kaitlin received her award in the area of self-advocacy for "helping other kids with their work and stuff, and explaining about my disability, what happened in my mom's tummy and what it did to me."

The self-advocacy award recognizes achievement in assuming practical responsibility for oneself, using knowledge of legal rights, advancing one's goals, and/or being effective in obtaining appropriate accommodations for oneself.

Each nominee for the Yes I Can! awards program receives a certificate of achievement personally inscribed with his or her name. At the awards ceremony, the name of each youth or child being honoured is announced along with a description of his or her accomplishment.

For more information on the Yes I Can! International Awards Program, including nomination forms, go to: <http://yesican.sped.org> or email yesican@ccc.sped.org. Contact the Foundation for Exceptional Children at 1-800-224-6830, ext. 450.



Photo by Ken Gigliotti, provided courtesy of the *Winnipeg Free Press*

Kaitlin had the opportunity to tell special education teachers what it is like to live with FASD at the Yes I Can! awards ceremony held April 7th. The ceremony was part of the Council for Exceptional Children's international conference in Salt Lake City, Utah.

The Yes I Can! International Awards Program was established by the Foundation for Exceptional Children in 1981 to recognize the accomplishments of children and youth with disabilities.

A maximum of three nominees are recognized in each of the following nine award categories: academics, arts, athletics,

Fetal Alcohol Family Association of Manitoba FASD Spring Workshops for Caregivers and Professionals

In partnership with FASD Life's Journey Inc. and Interagency FASD Program, the Fetal Alcohol Family Association of Manitoba (FAFAM) is offering a series of spring workshops for caregivers and those working with individuals living with FASD.

Workshops are offered free-of-charge for caregivers. Professionals and para-professionals working with individuals with FASD are required to pay a nominal fee of \$15 per session, which is reduced to \$10 per session for Associate Members of FAFAM. (An Associate Membership is \$5 annually.)

Pre-registration is required. To register and/or purchase an Associate Membership, please contact the FAFAM at (204) 786-1847 / toll free 1-866-890-1402 or by email: fafam@mts.net.

April 6, 2006, 6:00-8:00 p.m.

Location: Sir William Stephenson Library, 765 Keewatin (Keewatin and Burrows)

"Good Grief"

This session will focus on the grief issues caregivers raising children with FASD experience on an ongoing basis. The workshop will also be helpful for those working with families raising children with FASD.

Presented by: Brenda Bennett, FASD Life's Journey Inc.

May 4, 2006, 6:00-8:00 p.m.

Location: Millennium Library, 251 Donald (Donald and Graham)

"Becoming a Behaviour Detective"

This workshop will focus on exploring the elements of environment and discuss the process for determining the type of environmental adaptations to try when supporting individuals with FASD.

Presented by: Leilani Buschau, Fetal Alcohol Family Association of Manitoba

June 1, 2006, 6:00-8:00 p.m.

Location: St. John's Library, 500 Salter St. (Salter and Machray)

"Experiences with FASD"

The final workshop before summer break will discuss FASD through the experiences of families who are looking at issues related to adapting the environment, attachment and sexuality.

Presented by: Anita Posaluko, Interagency FASD Program



Fetal Alcohol Family Association's Annual General Meeting

Wednesday, May 31st, 2006

Canad Inn at Polo Park

5:30-6:00 p.m. Light snacks

6:00-7:00 p.m. AGM

7:00-9:00 p.m. Keynote speaker

Dan Dubovsky

For more info, call the Family Association at (204) 786-1847 or toll free 1-866-890-1402

Coming Event...

Diane Malbin

November 9, 2006

"A Hopeful Challenge for Children,
Families and Communities"



Diane Malbin, M.S.W., is a clinical social worker and consultant who provides support services, program development and technical assistance to individuals, families and agencies.

For details as they become available, call Community Living Manitoba at (204) 786-1607.

Check out the new website: www.fafam.ca
New FAFAM toll free number: 1-866-890-1402

Interdepartmental Committee FASD Strategy

(cont'd from page 1)

Based on community consultations held by the Interdepartmental Committee, the community expects the pending FASD Strategy to address the following 12 issues:

1. Fund individual supports for 100-150 adults across Manitoba who are living with FASD.
2. Build capacity of agencies to respond to the complex needs of supporting individuals and families affected by FASD.
3. Use functional needs as criteria for services and recognize that IQ is irrelevant.
4. Transfer the "Intensive Support and Supervision" (ISSP) model from Youth Justice to the adult system.
5. Increase capacity for diagnosis of youth and adults.
6. Provide respite services for families.
7. Increase capacity of Aboriginal organizations to respond to children and adults living with FASD.
8. Provide alternate sentencing and ensure there is some kind of support network/agency involved for individuals returning to the community from prison to reduce the possibility of recidivism.
9. Develop a training program for foster and adoptive families.
10. Secure ongoing funding for the Fetal Alcohol Family Association.
11. Continue prevention and awareness activities.
12. Address education issues regarding FASD and inclusive classrooms.

FASD cost to society: \$344 million per year

Researchers at The Hospital for Sick Children (Sick Kids) and St. Michael's Hospital in Toronto announced in a February 28, 2006, press release that the annual cost to Canadians of caring for children and youth with FASD is upwards of \$344 million a year.

To conduct this study, 148 parents of children with FASD, aged 1 to 21 years, completed a survey related to the cost of caring for a child with FASD, such as direct costs like medical, education, social services, and out-of-pocket costs; and indirect costs, such as productivity losses to parents and caregivers.

The average annual costs per child with FASD was \$14,342. The largest single component was found to be education and medical costs. The study also found that 19% of total costs were paid by parents caring for their child with FASD.

Costs for children six to 15 years were higher than in all other groups, reflecting the costs of specialized education and the use of health specialists such as psychologists and occupational therapists.

It was acknowledged that while the cost of FASD is staggering, it does not reflect those aspects that cannot be measured in dollars, such as quality of life and suffering.

For more details, see the February 28, 2006, issue of *Journal of FAS International* at www.motherisk.org/JFAS.

Justice Training on FASD Screening Tool for Young Offenders

An FASD screening tool developed specifically for youth involved with the justice system is being considered for implementation in Manitoba. The Youth Justice FASD Project partners will be reviewing the feasibility of using the tool to help staff identify youth with cognitive issues.

Developed by Dr. Patricia Blakley, Associate Professor, Department of Paediatrics, University of Saskatchewan, Garry Prediger, Director, Saskatchewan Corrections & Public Safety, and Garry Perry, Supervisor, Young Offender Program, Child and Youth Services, Saskatoon Health Region, the screening tool was piloted in Saskatchewan. (For details, please see the Winter 2004 issue of *Manitoba F.A.S.D. News*.)

Staff from the Portage Correctional Institution for women, Manitoba Youth Centre, Agassiz Youth Centre, Headingley Correctional Centre's Mentally Disordered Offenders Unit and the Brandon Correctional Centre took part in a two-day training session on this screening tool in early March, thanks to funding support from Healthy Child Manitoba.

"With this tool, all youth coming into the system can be screened for cognitive and behavioural issues. It's not an assessment tool, but it will provide a better picture of the number of young offenders who may have a cognitive disability," notes Carol Robson, Divisional Coordinator for Special Needs/FASD with Manitoba Justice.

In addition, it will help Manitoba Youth Centre staff identify which youth should be referred for assessment by the Clinic for Alcohol and Drug Exposed

Children as part of the FASD Youth Justice Pilot Project. The goal of the pilot project is to ensure that youth affected by FASD in conflict with the law receive appropriate judicial dispositions, including a multi-disciplinary assessment, diagnosis and improved access to services. (For details, see the Fall 2005 issue of *Manitoba F.A.S.D. News*.)

Robson says the strength of this particular screening tool lies in the fact that it was designed for corrections and is proving to have a high reliability and validity.

"We're quite excited about the training, as we'd been looking for this type of screening tool. The researchers have been doing a lot of work to validate it and it's showing good results."

She hopes to ensure that Corrections staff are asking the right questions and looking for appropriate information to identify youth with cognitive issues.

"As a result of the FASD Youth Justice Pilot Project, we have found that we had youth within our system who were previously diagnosed with FASD and we were unaware. This has shown that diagnosis alone is not the answer," says Robson. "We need to be consistently looking to identify youth and adults that need extra support and then we must work toward developing a multi-system plan for providing it. If we do implement the screening tool, we could possibly assist in further validation with the FASD Youth Just Project."

For more information, contact Carol Robson at (204) 945-6482.

Using Graphics to Explain Brain Domains

How do you explain to a child or youth how FASD has affected his or her brain? How do you help them understand that they can have deficits in one brain domain but be strong in another? It's a challenge that regularly faces Dr. Sally Longstaffe of the Children for Alcohol and Drug Exposed Children (CADEC), particularly when she is diagnosing young people at the Manitoba Youth Centre.

Recognizing that individuals affected by FASD learn best visually, it occurred to her that children and adolescents love video games and computers. She began to ponder ways of using visual approaches instead of language, experimenting with diagrams and other graphic representation that could depict how the disability can be different for each person.

Ideally, the graphic representation would show each young person their specific areas of strength and other areas where they might need to let teachers and caregivers know they need help. In this way it could be used both to help the youth understand his or her own disability and to explain it to others.

Mary Cox-Millar, coordinator at CADEC, has taken the lead in exploring the possibility of creating such a visual tool. This process led to a partnership with instructor Eric Crone from the Graphic Design program at Red River College (RRC).

Crone and his students are now approaching it as a class project, and will attempt to develop workable ideas to graphically represent the different brain domains.

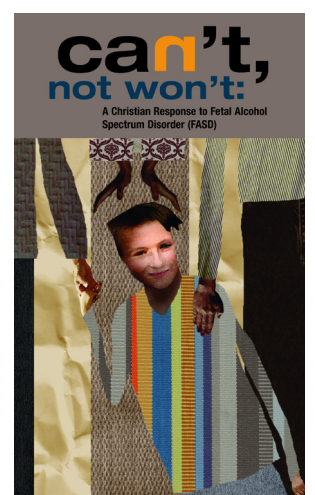
Young artists from the Graffiti Gallery in Winnipeg are collaborating with the RRC students. In addition to their design skills, they offer a real understanding and connection with the youth being diagnosed, often coming from a similar background.

"We're just in an exploratory phase," notes Cox-Millar. "We don't know if it will be successful, but the idea of using graphic representation has great potential and many possible applications."

Mennonite Central Committee Produces Video & Guide on FASD

Mennonite Central Committee Canada has produced a video called *Can't, Not Won't: A Christian Response to FASD* in which three young men who live with FASD and their parents share their stories and provide insight on how individuals and congregations can be more supportive and understanding of people affected by FASD and their families. The 45-minute video or DVD comes with a six session study guide. Session topics in the guide include: What is FASD?; FASD and secondary disabilities; Thinking through our faith as it pertains to FASD; What can our church do to make a difference?; FASD and the community; and Supporting parents who are grieving.

Copies cost \$28.50 including shipping and handling. To purchase, call toll free 1-888-622-6337 or order online at: www.mcc.org/fasd



Video Self-Modelling to Promote Positive Changes in Behaviour

Jeff Sandelli, a community support case manager with Opportunities for Independence, Inc., has initiated a project using video self-modelling as a means to promote positive behaviour change with one of his clients living with FASD. Opportunities for Independence is a non-profit organization that delivers programs specifically geared toward developmentally disabled adults who are in conflict with the criminal justice system or at risk to do so.

Video self-modelling is an intervention technique for behaviour change in which a person observes positive self-images that focus on target behaviours. The person's target behaviour is videotaped under either natural or staged conditions. The film is then edited to show only desired behavioural sequences and skills. The subject repeatedly views the edited tape and post-behaviour changes are evaluated.

"The great thing about video self-modelling is that you can tailor it to any client to affect change," explains Sandelli. "And when it's staged, you can focus on something they're not yet capable of doing. For example if someone has trouble with their wake-up routine, you edit the film to show them going through their routine step by step — waking up, yawning, checking their watch, going through the steps to get ready and go to work, showing the clock, etc. It gives them the confidence that they can do it."

Sandelli modified the classic video self-modelling slightly to promote positive behaviours rather than trying to get the client to stop negative behaviours.

He and the client's support worker chose four areas on which to focus with this particular client who is affected by FASD and schizophrenia, and who has been involved with the justice system: 1) his membership to AA; 2) his relationship with his mother; 3) his spiritual practice, attending sweatlodge; and 4) his volunteering.

Over a couple of months, the frontline support worker used a digital videocamera to tape the client engaged in these four activities. Afterwards, Sandelli edited the digital videotape using software that comes with Windows XP. The trick, he notes, is editing the tape for length and not getting caught up in making it too artistic or perfect.

Sandelli split the tape into four sequences with each section introduced by a black slide with white text describing the segment to come, e.g. "Mom." This was coupled with a recording of the client saying the title before that segment of film played. Sandelli also incorporated still photos from each portion of the film to create a slide show, including images such as the subject hugging his mom or standing in front of the door to his AA meeting.

"The idea of including both moving film and still photos is based on the spiderweb notion and how people with FASD catch different things in different ways," says Sandelli.

He also integrated music, an idea that came from the client's love of music. After compiling some of the fellow's favourite songs, Sandelli sat down with him to gauge his reaction while listening to each. Sandelli included one of these songs during the introduction to the film, another during the slide show and a third one that plays at the end.

The initial viewing of the finished tape was treated as a celebration that included important people in the client's life, such as his mother, support worker and other people he has worked with in the past.

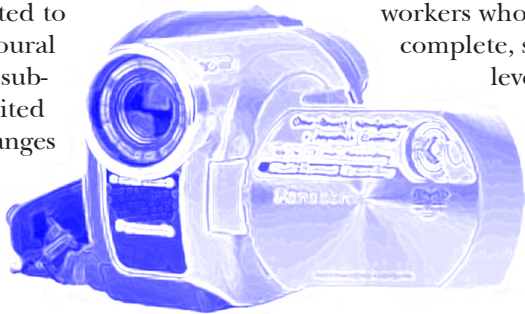
Subsequent viewings with the client only took place once a week for two months, then bi-weekly for another two months, and finally once per month for two more months. When this process is completed, Sandelli will evaluate whether there has been any change in behaviour in the four target areas.

Before starting the videotaping process, Sandelli and the support worker ran three evaluation measures: the Cooper-Smith self-esteem scale, Modified Beck Inventory and Self-report Depression Questionnaire. These measures will be repeated after the six-month viewing schedule is finished.

Sandelli also created a checklist for support workers who are with the client every day to complete, such as noting his mood, energy levels and prompts to take part in certain activities. The measures and notes will be used together to determine any positive changes toward the target behaviour.

While Sandelli has no immediate plans to repeat the process, he notes that its broad applicability of video self-modelling makes it useful in many situations.

For more information on the project, contact Jeff Sandelli at Opportunities for Independence, Inc. at (204) 784-5830.



U.S. Study finds 5% of Pregnant Women Use Meth

A large-scale study to estimate the prevalence of prenatal substance use in areas of the United States known to have methamphetamine problems found that 5% of women living in these regions used meth at least once during their pregnancy. One-fourth of the women in the study used tobacco and 23% used alcohol while pregnant. In addition, 11% used illicit drugs prenatally.

The study's authors noted that "the finding that approximately 5% of pregnant women in this study use methamphetamine at some point during their pregnancy highlights the need for educating primary care physicians and obstetric and gynecologic specialty practitioners to be aware of treatment options and community resources to enable access to treatment."

These findings are initial results of the Infant Development, Environment, and Lifestyle (IDEAL), an ongoing longitudinal multi-site study of prenatal meth exposure being conducted in Los Angeles, California; Des Moines, Iowa; Tulsa, Oklahoma; and Honolulu, Hawaii.

Reported in the Feb. 20, 2006, Vol. 15, Issue 7 weekly fax from the Centre for Substance Abuse Research (CESAR) at the University of Maryland, College Park. See: www.cesar.umd.edu.

Freezing Death To Be Reviewed by Coroner

(The following article by Robert Matas appeared in the Globe & Mail on December 15, 2005.)

The sudden death of developmentally disabled native Joseph Ignace earlier this month will be reviewed by the B.C. coroner's office and a medical consultant with a provincial agency responsible for community facilities, a government spokeswoman said yesterday.

Mr. Ignace, 34, froze to death in a wooded area east of Hope. He was found in snow, leaning against a tree, 2 ½ weeks after he walked away from a community facility in Abbotsford. Authorities have said he was schizophrenic and suffered from fetal alcohol syndrome.

He has been in the public eye since the RCMP charged him with attempted murder during a violent confrontation in 1995 between a group of natives and the RCMP at Gustafsen Lake in remote B.C. He was later acquitted by a jury after evidence at trial showed he was developmentally disabled and had confessed to crimes he could not have committed.

Coroner Tara Dickson said yesterday she anticipates her review will take a few months. She will decide during the investigation whether to hold an inquest. A public report will be issued after she completes her review, she said in an interview.

Valerie Richmond, a spokeswoman for Community Living British Columbia, said Mr. Ignace's death will also be looked at by a medical consultant in what is called a mortality review. Further details about the review were not available yesterday.

Community Living British Columbia is a provincial agency created last summer to run the government's community facilities.

Ms. Richmond said she did not anticipate that the results of the review would be made available to the public, in accordance with provincial privacy laws. However, she said the facility in which Mr.

Ignace had lived had a "very good" international reputation for working with extremely challenging individuals. The facility also was known for understanding native traditions and working with the native community.

Ms. Richmond said Mr. Ignace was discovered after "enormous co-ordination" of several groups in the Fraser Valley. "It was huge throughout the valley, with medical institutions, the Greyhound bus depot [and] many local people and organizations," she said. She was not aware of any other residents who had died under similar circumstances, she also said.

Mr. Ignace had been living for the past six years at a home run by a group called Healthy Opportunities for Meaningful Experiences Society.

The home is not an institution and Mr. Ignace was not prevented from leaving whenever he wished, Ms. Richmond said. "It is voluntary. He was not a criminal. [He] was not being held involuntarily." "Without talking in detail [about Mr. Ignace], these are extremely complex cases and extremely complex individuals we are dealing with," she said.

Cam Doré, the society's executive director, said earlier this week that Mr. Ignace received 24-hour care, with one staff member in the home overnight.

He walked out of the home in the middle of the night, after shutting off the alarm, Mr. Doré said. Mr. Ignace had been "instrumental" in changing how the group operated, he added.

Mr. Ignace was the first person from the native community that moved into their facility. The society subsequently became involved with elders and others in the province's native community, he said.

Mr. Ignace's father, Jones William Ignace, said in an interview he thought the community living agency did a good job in looking after his son.

"They took good care of him," he said. "They were also grieving."

UPCOMING CONFERENCES & WORKSHOPS

The Second National Biennial Conference Late Adolescents and Adults with FASD Conference

Navigating the Rapids: Doing What Works in Practice

May 4-6, 2006

The Coast Plaza Hotel and Suites at Stanley Park
Vancouver, British Columbia

This conference explores the transition from personal experience to best practices in supporting those with FASD

Prevalence studies indicate that over 315,000 people in Canada live with FASD. Very few have a diagnosis. In the absence of accurate identification *and* support, it is common for people with FASD to have damaging and limited school experiences, incomplete medical care, and inadequate legal representation. Isolation, depression, homelessness, unemployment and incarceration are among the results. Diagnosis and support makes a positive difference in the lives of individuals with FASD, their families, communities and the professionals who work in the field of FASD.

Who should attend?

This conference will be essential for those living or working with adults with FASD, across all professions and communities. It will also be of critical interest for those supporting late adolescents with FASD and planning for their futures. Educators will have the opportunity to learn and share ideas about supporting the transitions of students with FASD into adults roles. Legal education at this conference will have a blended focus: demystifying the law for those who need to understand it and educating lawyers about FASD.

Find the registration form and conference program online at:

www.interprofessional.ubc.ca/Brochure_AdultsFASD2006.pdf

Register online or call toll free: 1-877-328-7744

Presented by Interprofessional Continuing Education at The University of British Columbia in co-operation with Connections: Serving Adolescents and Adults with FASD and The Asante Centre for Fetal Alcohol Syndrome

Canada Northwest FASD Partnership Conference

Sharing our Stories, Strengthening Our Supports, Supporting Our Circle



May 17-19, 2006

Regina, Saskatchewan
Queensbury Convention Centre

Hosted by the Saskatchewan
Prevention Institute and the
Saskatchewan Government

Plan to attend this exciting conference!

The pre-conference day for the Canada Northwest Fetal Alcohol Spectrum Disorder Partnership Conference (CNFASDP) will be held on Wednesday, May 17. The two-day main conference takes place on Thursday, May 18 and Friday, May 19. Participants choose from a wide variety of half- and full-day workshops throughout the three days.

Plenary session speakers include: **Dr. Sterling Clarren** describing the Canada Northwest FASD Research Network and its activities, **Dr. Don Bartlette** talking about "macaroni at midnight," **Dr. Tim Feeney** (topic TBA), and **Dr. Lewis Mehl-Madrona** addressing the issue of empowering local knowledge and practice for community healing.

Further information and updates along with the program agenda and registration form can be found on these websites:

www.preventioninstitute.ca / www.cnfasdpartnership.ca

Contact the conference planners at:

Turner Coben Event Marketing Inc.

Tel: (306) 683-3663 / Email: tcem.lcoben@sasktel.net

7th Annual Fetal Alcohol Canadian Expertise (FACE) Research Roundtable

Plans are underway for the 2006 FACE Research Roundtable. The event will be held on International FAS Day in Moncton, NB.

FACE Research Roundtable
September 9, 2006
Moncton, New Brunswick

The day will focus on research in screening and diagnosis, the neonatal brain (a window of opportunity) and an update on community-based research. Speakers from across Canada will be presenting on:

- Evaluation of Spatial Working Memory Function in Children and Adults with FASD: A Functional Magnetic Resonance Imaging Study
- Diagnosis of FASD in the Presence of Co-morbidity
- Neonatal Screening for Prenatal Alcohol Exposure – Update
- Neonatal Brain Plasticity after Fetal Alcohol Insult – Critical Review of Animal Studies
- Brain Plasticity in Neonates – Experimental Paradigms for Intervention Studies
- NOGEMAG – Education of the Heart, Mind and Spirit – A Relational Model of FASD Intervention and Prevention
- FASD in a Correctional Population: Preliminary Results from an Incidence Study in a Federal Penitentiary
- Development of Pilot Programs in Native Communities

For ongoing updates and registration details, please see:

www.motherisk.org/JFAS

This year's FACE Research Roundtable is organized by the Motherisk Program in co-operation with the Aboriginal Women's Association of PEI, and sponsored by Health Canada and Brewers of Canada.

Diane Malbin Workshop for Educators

November 8, 2006

Victoria Inn, Winnipeg, Manitoba

Thirty years of research on FASD has confirmed that the most serious effects of prenatal exposure to alcohol/drugs are on the developing brain and central nervous system. FASD is, therefore, by definition, an invisible physical disability whose symptoms are primarily behavioural.

In this one-day session presented by Winnipeg School Division No. 1, Diane Malbin will introduce a neurocognitive model that links the idea of brain dysfunction with behaviours in order to rethink the meaning of behavioural symptoms of this disability and to develop appropriate and effective interventions.

Participants in this workshop will learn to:

1. Identify examples of positive outcomes for people with FASD and recognize elements of environments that support these outcomes
2. Know the diagnostic criteria for FASD, recognize paternal effects, discuss a working definition for FASD and become familiar with the definitions of primary and secondary learning and behavioural characteristics commonly associated with FASD
3. Understand a conceptual framework for rethinking behaviours commonly associated with FASD and begin to integrate this into professional and personal repertoires
4. Recognize common overlapping diagnoses, the limits of the DSM, and discuss the implications of the 'fit' between standard interventions and FASD
5. Begin to develop effective strategies and appropriate accommodations based on understanding FASD as a brain-based condition
6. Identify specific 'next steps' for integrating information about FASD into parenting, teaching and other work with this population

Contact Janet Thompson, Winnipeg School Division No. 1,
at (204) 774-4525 for more information or to register.

FASD WEBSITES

FASD Connections: Serving Adolescents and Adults with FASD

www.fasdconnections.ca

Find information on the latest research, articles and events, upcoming conferences and workshops, and a birth mom's section on the FASD Connections website. This Canadian site is devoted to adolescents and adults with FASD.

Jan Lutke is the Senior Consultant for FASD Connections, along with Tina Antrobus, Bob Steeves, Brenda Knight, Janet Christie and Marsha Teichman.

Journal of FAS International

www.motherisk.org/JFAS

Launched in 2003 by Motherisk as the first ever scientific journal dedicated to Fetal Alcohol Syndrome, this online journal publishes peer reviewed original papers, as well as case reports, reviews and critical appraisals of papers published in other publications.

FASworld

www.fasworld.com

FASworld, a non-profit organization, is an international alliance of parents and professionals who are dedicated to the significant reduction of the incidence of FASD.



On this site, find information, articles, and subscribe to their electronic mailing list.

Bonnie Buxton and Brian Philcox of Toronto are co-founders of the FASworld Alliance, working in collaboration with Teresa Kellerman, coordinator of the FAS Community Resource Center in Tucson, AZ.

FAS Community Resource Centre

[www.come-over.to/
FASCRC/](http://www.come-over.to/FASCRC/)

The FAS Community Resource Centre is maintained by Teresa Kellerman and provides information, articles, resources and links to online support groups among many others.

FASlink

www.faslink.org

FASlink is a free Internet mail list and discussion forum for individuals, families and professionals who deal with FASD. The FASlink site carries an extensive archive of FASD information. Bruce Ritchie is the Moderator of the site and the discussion forum.

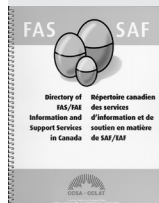
Canadian Centre for Substance Abuse

www.ccsa.ca

Look for upcoming conferences and workshops on the FASD Calendar of Events, see What's New (FASD), and locate information, readings and resources on FASD prevention and intervention.

CCSA FASD Resource Directory

www.ccsa.ca/fas



The Canadian Centre on Substance Abuse maintains provincial directories for FASD related service and supports.

Get your organization listed in the CCSA Directory

If you or your organization would like to be included in the June update of the directory, please contact **Karen Palmer** at the Canadian Centre on Substance Abuse (CCSA) at (613) 235-4048 or email: fas@ccsa.ca

FAS Bookshelf Inc.

www.fasbookshelf.com

Provides a list of FASD resources for purchase, including videos and books, plus links to informational sites. The site is operated out of Burnaby, B.C.



A comprehensive certificate program to prepare for positions working with children, youth and adults affected by FASD. Study part-time, evenings or weekends during the Fall, Winter or Spring terms. For a program outline, course information and schedule, go to: www.rrc.mb.ca and click on Continuing Education. Or call **697-1789 (toll free 1-866-242-7073)**.



For information on FAS call:
**Fetal Alcohol Syndrome
Information Manitoba
1-866-877-0050**



FASD RESOURCES

AFM Library

The Addictions Foundation of Manitoba's Library holds the largest collection of FASD resources in the province, focusing on FASD research, prevention and awareness, as well as parenting, caregiving and educational strategies. Membership is free and available to all residents of Manitoba 18+ years of age. For more information, visit the Library on the Main Floor at 1031 Portage Ave in Winnipeg, call (204) 944-6233 or email: library@afm.mb.ca.

Recent resources at AFM include:

Finding perspective... raising successful children affected by FASD: a parent's guide

Author: Liz Lawryk. (2005)

Call #: RG 629/.F45/L39/2005

Can't, not won't: a Christian response to FASD [video]

Produced by: Mennonite Central Committee. (2005)

Call #: VTR/RG 629/.F45/.C3/2005

Adult, 45 minutes. Close captioned.

Two families share their stories in the hope that they will help congregations in their effort to understand and include families living with FASD.

Fetal alcohol spectrum disorder - Dan Dubovsky [video]

Call #: VTR/RG 629/.F45/F483/2005

Dan Dubovsky presents issues regularly faced by service providers in an accessible, hands-on way, with insights provided from his professional and personal experience. The information has broad applicability for any frontline service provider working with adults living with FASD, and will provide staff with a better understanding of the links between mental health conditions, organic brain injury and challenging behaviours. The tape also delineates alternate approaches that address the underlying reasons for many challenging behaviours.

The tape includes the following issue-specific sections:

- 1) **Co-occurring Disorders & FASD**
Possible misdiagnoses and practical approaches.
- 2) **Socialization Coaching**
Methods to improve socialization, job coaching and supporting continued socialization.



Talking with Parents About Raising Children with FASD (2005)

This book for parents and professionals working with parents of children with FASD is published by Winnipeg's Child Guidance Clinic. It can be ordered for \$12.95 plus GST and a nominal shipping and handling fee. To purchase, call Cindy Zdrill at (204) 786-7841 or email: czdrill@wsd1.org.

Calming the storm: strategies for children with FASD (2005)

Booklet edited by Joanne Lussier-Ring and Ruth Trenholm Ring-Reynolds, and published by the Lakeland Centre for FASD in Cold Lake, AB. It provides practical strategies for caregivers of children with FASD to help them learn, develop and manage life skills. To obtain copies, call the Lakeland Centre for FASD toll free at 1-877-594-5454 or email: kmfascen@telus.net. Visit their website at: www.lakelandfas.com.

FASD: Tips for Parents & Caregivers (2005)

Series of pamphlets/booklets with examples and practical suggestions produced by the Saskatchewan Fetal Alcohol Support Network in Saskatoon (2005). To obtain a copy, call toll free 1-866-673-3276 or email: fasdnet-network@sasktel.net. Visit their website at: www.skfasnetwork.ca.

FASD Workshop Manual & Resource Guide: Justice System

Produced by the Newfoundland and Labrador FASD/Youth Corrections Project Steering Group in 2005, this manual provides practical suggestions and advice for working with youth affected by FASD within the criminal justice system. It includes case studies and examples on how to handle a variety of situations. To obtain copies, call Herb Maddick at (709) 729-2646 or email: hmaddick@gov.nl.ca.

FASD toolkit for Aboriginal Communities

Produced by the Ontario Federation of Indian Friendship Centres in 2005, this online resource is a practical guide for service providers. See: www.ofifc.org/ofifchome/page/Document/UP_FILE/2005091312710QTB.pdf

FACES of FASD

Putting a personal face on Fetal Alcohol Spectrum Disorder

Copies of FACES of FASD (2003) are \$5.00 each. Call Community Living-Manitoba at (204) 786-1607.