



Fetal Alcohol Spectrum Disorder

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FASD is Preventable!

There is neither a safe time to drink alcohol during pregnancy nor a safe amount to drink.

It is best to stop drinking before trying to get pregnant, when trying to conceive and as soon as you know you're pregnant.

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INTRODUCTION

What This Booklet Is

This booklet is an introduction to basic strategies for managing the challenges associated with Fetal Alcohol Spectrum Disorder (FASD). It is intended for parents and care providers (whether biological, foster, kinship or adoptive), as well as service providers and educators. It is not meant to be a comprehensive guide covering all topics. However, it introduces the reader to basic themes, ideas, and strategies as well as resources and organizations that can be accessed for more information and support.

Who Produced This Booklet

This booklet is a project of the Toronto FASD Coordinating Network. We are committed to enhancing and expanding the capacity of service providers, care providers and educators throughout Toronto to better serve children, youth, adults, parents, care providers and pregnant women affected by FASD. It is hoped that sharing the information in this booklet will help to reduce the incidences of FASD among women of childbearing years.

FASD in a Nutshell

Fetal Alcohol Spectrum Disorder is an umbrella term used to describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioural and/or learning disabilities. The term FASD is not meant as a clinical diagnosis. The adverse effects of gestational alcohol exposure exist along a continuum. While FASD is a lifelong disability for which there is no cure, early diagnosis and intervention as well as lifelong supports can help mitigate and/or prevent its effects.

PREVENTION OF FASD

Since the impact of FASD cannot be reversed, it is important to focus efforts on prevention and early intervention. Prevention of FASD involves strategies to reach, inform and care for women who use, or may use, alcohol during pregnancy. Prevention of FASD requires a variety of inter-related strategies that build upon each other. Prevention activities vary from those that focus on the total population to efforts aimed at an individual considered to be at high risk. Prevention is divided into three levels:

- ***Universal prevention*** activities are targeted at the general public, and include public awareness campaigns, television advertisements, pamphlets, posters, labelling of alcoholic beverages, and signage informing individuals of the risk of alcohol use in pregnancy.
- ***Selective prevention*** interventions are directed at pregnant women or women in the reproductive age range who drink alcohol. Selective prevention activities include screening for alcohol use, the provision of brief interventions, and referrals.

- ***Indicated prevention*** activities are directed at the care of pregnant women who have significant alcohol problems or addictions as well as high risk women, i.e. those who have children with FASD. They may require more than information, advice or brief interventions in order to change their alcohol use during pregnancy. Indicated prevention activities acknowledge and address the complex range of social and economic circumstances that bring women to alcohol use, and that make it difficult for them to stop or decrease their use during pregnancy.

EARLY IDENTIFICATION/ DIAGNOSIS

Importance of Early Identification and Diagnosis.

The primary disabilities caused by prenatal exposure to alcohol include:

- Distinct facial characteristics
- Growth retardation
- Damage to the brain and central nervous system and
- Various birth defects

Drinking alcohol during any phase of pregnancy can cause developmental harm and disabilities that have lifelong mental, behavioural and social consequences. These disabilities may include attention and learning deficits, increased activity, delayed speech, and severe behavioural problems.

FASD is the leading, preventable non-genetic cause of intellectual disability in North America. There is no known safe level of alcohol consumption in pregnancy.

Identification and diagnosis pave the way for interventions and supports, which may help to prevent secondary disabilities. These include mental health problems, disruptive school experience, trouble with the law, dependent living, and inappro-

priate sexual behaviour. The earlier a child is identified and diagnosed, the better. A diagnosis can only be achieved using a multi-disciplinary team.

FASD is an umbrella term for five distinct diagnostic categories. They are listed below, along with contact information on obtaining a diagnosis, and on how to get the FASNET screening tools, which can help with initial identification of FASD.

DIAGNOSTIC CRITERIA

Category 1:

Fetal Alcohol Syndrome (FAS) with confirmed maternal alcohol exposure:

- Growth retardation
- Characteristic facial features and
- Central nervous system abnormalities

Category 2:

FAS without confirmed maternal alcohol exposure:

- If all three elements described above are present, then a diagnosis of FAS is possible. (This is often the case when children are in foster or adoptive care and accurate information about the pregnancy is not attainable.)

Category 3:

Partial FAS (pFAS) with confirmed maternal alcohol exposure:

- Evidence of some of the characteristic facial features and/or
- Pre and/or post-natal growth retardation
- Central nervous system abnormalities and
- Behavioural or cognitive abnormalities

Category 4:

Alcohol-Related Birth Defects (ARBD):

Congenital malformations such as:

- Cardiac defects
- Skeletal abnormalities
- Renal dysfunction
- Eye problems and
- Hearing problems which are associated with prenatal alcohol exposure.

Category 5:

Alcohol-Related Neurodevelopmental Disorder (ARND):

- The presence of complex patterns of behavioural and/or cognitive abnormalities

FASD Diagnostic Clinics

St. Michael's Hospital Paediatric Clinic 61 Queen Street, 2 nd Floor Toronto, ON M5C 2T2	Phone: 416-867-3655 Fax: 416-867-3736
Hospital for Sick Children Alcohol and Substance Use Helpline Motherisk Program 555 University Avenue Toronto, ON M5G 1X8	Toll Free: 1-877-327-4636 http://www.motherisk.org
Native Child and Family Services St. Michael's Hospital Fetal Alcohol Spectrum Disorder Diagnostic Clinic 464 Yonge Street, Suite 201 Toronto, ON M4Y 1W9	Phone: 416-867-3655 Fax: 416-867-3736

FASD Diagnostic Clinics

<p>Anishnawbe Health Manager WAASH-KESHUU-YAAN Unit (health unit) 225 Queen Street East Toronto, ON M5A 1S4</p>	<p>Phone: 416-360-0486 Fax: 416-365-1083 http://www.aht.ca</p>
<p>FASD Durham Resources for Exceptional Children & Youth Durham Region 865 Westney Road South Ajax, ON L1S 3M4</p>	<p>Phone: 905-427-8862 Fax: 905-427-3107 http://www.information.com/details.asp?RSN=9452 Additional information: http://www.fasat.ca</p>
<p>Mothercraft - Breaking the Cycle Margaret Leslie FASD Diagnostic Clinic 761 Queen Street West, Suite 107 Toronto, ON M6J 1G1</p>	<p>Phone: 416-364-7373 Fax: 416-364-8008 http://www.mothercraft.ca</p>
<p>Surrey Place Centre FASD Adult Diagnostic Clinic (18 yrs and older) 2 Surrey Place Toronto, ON M5S 2C2</p>	<p>Note: Surrey Place Centre serves adults with an Intellectual Disability</p>

RESOURCES FOR FASD ASSESSMENT

Canadian Guidelines:

A. E. Chudley et al. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. CMAJ. March 1, 2005; 172 (5_ suppl).

These guidelines can be found on-line at:

http://www.cmaj.ca/cgi/content/full/172/5_suppl/S1

Resource for information about alcohol use in pregnancy:

MOTHERISK ALCOHOL AND SUBSTANCE USE HELPLINE

Hospital for Sick Children

Phone:

1-877-FAS-INFO

1-877-327-4636

<http://www.motherisk.org>

STRATEGIES FOR HOME AND SCHOOL

Much of the following information is based on strategies first presented in *FASD: Strategies Not Solutions* and *The Golden Hoop of Life*. These resources are highly recommended, as is the Victoria Order of Nurses (VON) guide. Information about where to obtain copies can be found on pages 33 & 34 of this brochure.

Differences in Learning

At times, it may seem as though a child with FASD simply cannot learn a task or a pattern of acceptable behaviour. The child may respond favourably one day but not the next. However, the problem may not be the child's inability to perform required tasks, but that the method of teaching is simply incompatible with the effects of FASD.

For example, most children acquire mastery of a task through a series of sequential steps, starting with simple steps and gradually increasing the level of difficulty. However, a child with FASD may need to be taught a task repetitively until it becomes automatic.

All children/youth learn best when taught in a way that matches their strengths.

FASD

Children/youth with FASD are no different. Some learn with visuals, some learn by doing, some learn best through sound and music.

However, even with a successful teaching strategy, children with FASD are coping with attention and memory problems, difficulty dealing with abstract concepts (such as having a sense of time), and difficulty linking action and consequence. These symptoms must be kept in mind when a child/youth does not seem to learn from mistakes, is constantly late, cannot pay attention or is restless or fidgety. These actions are not caused by laziness, stubbornness, or stupidity, but instead are the result of the damage caused by FASD.

The Importance of Routine

A theme that is repeated again and again in FASD literature is the need for routine. Children with FASD do not deal well with change, so daily routines are a source of stability and comfort. Routines can also help affected children with attention, behaviour, social skills and time management. When children know what comes next, they know how to behave in the situation. When children have a solid routine or foundation, it is easier for them to cope with an unexpected situation.

Routines and practices should remain constant between environments. For ex-

ample, if possible, use the same plates and utensils used at school as those used at home. Also, use the same calming item in the car as is used at home.

Many parents and teachers have found that using visual signs helps children remember routines and tasks. For example, effective visual signs help children remember the order in which to put on clothes, brush teeth, and put away toys.

Behaviour and Discipline

It is important to keep the effects of FASD in mind when dealing with behaviour and discipline. Routine and consistency are vital. Changing or making exceptions to rules can be confusing and may lead to problems that are due to the disability instead of being the child's fault. Problems with memory and with making linkages between actions and consequences means strategies such as long time outs, contracts/deals, or reflecting on past mistakes may not be successful.

Children with FASD often interpret things very literally, and will not respond well to threats. Instant reinforcement works wonders, as does task repetition. Keeping a small set of simple house rules posted will likely be more effective than having a large number of more complex rules.

Adapting the Environment

Whether at home or at school, a child's environment has a significant impact. The effects of FASD magnify the importance of a safe, well-adapted environment.

Sensory integration may be problematic for persons with FASD. It is important to determine how a child is experiencing the sights, smells, sounds, tastes, and touches of the world around her. Parents and/or caregivers are urged to consult an occupational therapist to get an assessment if they think their child is having problems with sensory integration. A referral can usually be had through the family doctor or caseworker. Some strategies for dealing with sensory disorders are listed below:

Hypersensitivity (feeling too much)

- Use soft bedding and avoid new linen
- Remove labels from clothes and wash them several times before wearing
- Avoid wool sweaters, turtlenecks, jeans, or other clothing that is either fitted close to the body or has a distinct texture or feel
- Avoid crowds or other high traffic areas
- Wear sunglasses to cut down glare, even when inside

- Turn off strong overhead lights or use lamps for indirect lighting
- Keep your home clutter free, less is definitely more

Hyposensitivity (not feeling enough)

Supervise your child carefully. He may not feel heat, cold, or pain. Be sure that he is not underdressed in the winter or overdressed in the summer, whether inside or outside.

Oral stimulation may help, for example, crunchy food like pretzels, chewy food like gum, or ‘slurpy’ food like applesauce or jello taken through a straw.

The chance to run, jump, do some heavy lifting or yard work, such as shovelling snow, can help fulfil the body’s need for intense activity. Bear hugs can help fulfil the need for physical contact.

A ‘fiddle toy’ such as a stress ball or bean bag can help a child stay focused when needing to sit and pay attention for extended periods of time.

FINANCIAL SUPPORT AND RESOURCES

Persons under the age of 18

Assistance for Children with Severe Disabilities (ACSD) is designed to meet the unique needs of persons with disabilities who are in financial need.

A person applying for ACSD must:

- Provide current financial information
- Obtain a doctor's letter stating the child's diagnosis of (FASD), and how the individual fits into the range of what is considered a developmental disability or a physical disability
- Next, send the letter to ACSD to be reviewed and assessed by a board, after which a decision is made
- ACSD then sends a letter to the parent(s)/caregiver(s) informing them of the decision
- The ACSD rate is based on family size and income

Families can contact respite services at:

Tel 416-322-6317, Fax 416-481-1512 or

<http://www.respiteservices.com>

An access facilitator will assist them to complete funding application forms.

FOR MORE INFORMATION CONTACT:

<http://www.gov.on.ca>

General Inquiries: 416-325-0623

Persons 18 years and over

The Ontario Disability Support Program (ODSP) is designed to meet the unique needs of persons with disabilities who are in financial need.

ODSP may be provided to individuals who have been clinically diagnosed as having Fetal Alcohol Spectrum Disorder, if there is evidence that it causes a severe disability.

A person applying for ODSP must:

- Provide current financial information
- Obtain a Disability Determination Package (DDP)
- The DDP must be filled out by a doctor or a psychologist
- After completion of the DDP, the package must be returned to the Disability Adjudication Unit

FASD

- The Unit will assess the level of disability
- If there is evidence of a severe disability, funding may be provided

Contacts for ODSP

Ministry of Community and Social Services
Toronto Region
477 Mount Pleasant Road, 3rd floor
Toronto, ON M7A 1G1

Area Served

Toronto

Phone/Fax

Tel.: 416 -325-0500
Fax: 416 -325-0565

Office Directory

Toronto Regional Office
<http://www.mcass.gov.on.ca>

Special Services and Support Resources

Special Services At Home (SSAH) is designed to meet the needs of children, youth and adults who are eligible for ACSD or ODSP.

A worker is assigned to visit the family and provide support where needed.

Eligibility for SSAH is determined on the basis of a functional need rather than on a financial need. Families are advised to contact respiteservices.com where access facilitators can assist with filling out the SSAH application forms. It is important to complete the application forms correctly to get the best possible funding available.

FASD

Online Resources

FASD: Strategies Not Solutions

Published by the Region 6 FASD Child & Youth Sub-Committee in Edmonton

Available to download online: <http://www.region6fasd.ca>

Available in print. Order online: <http://www.child.gov.ab.ca>

Mountford, E. Allen, “The Golden Hoop of Life—A Community of Hope,” *A Handbook for Caregivers of children ages 3-6 with Fetal Alcohol Spectrum Disorder*, Ontario: Fetal Alcohol Spectrum Education Support.

Phone: 705-324-7801

E-mail: mountfrd@allstream.net

Public Health Agency of Canada (PHAC) website:

FASD Info.

http://www.phac-aspc.gc.ca/fasd-etcaf/about_e.html

FASD Booklet

http://www.phac-aspc.gc.ca/fasd-etcaf/pdf/faq_fasd_e.pdf

Victoria Order of Nurses (VON)

http://www.von.ca/FASD/fasdtool_fullproof_final.pdf. is an informative website for parents and care providers.

Visit the FAS Bookshelf Inc. online at <http://www.fasbookshelf.com> to view a large selection of FASD resources, including books, videos and training materials.

FAS Bookshelf Inc.

#438-6540 Hastings St.

Burnaby, B.C.

V5B 4Z5

Phone: 604-942-2024 or 604 942-2041

Support for Adoptive Parents and Birth Parents**Native Child and Family Services of Toronto**

Intake Department

295 College Street,

Toronto, ON M5T 1S2

Phone: 416-969-8510

- Provide Support Groups for parents <http://www.nativechild.org>

Native Child and Family Services of Toronto

Summer Camp/After-school Co-Coordinator Programming

494 Yonge Street, Suite# 201

Toronto, ON M4Y 1W9

Phone: 416-969-8510

- Provide Summer Day Camps and Overnight Camps for Children 7 to 24 years of age
- Throughout the year, there are many after-school programs
- Parent support groups are also available <http://www.nativechild.org>

FAS World Canada

FAS Community Resource Center

250 Scarborough Golf Club Road

Toronto, ON M1J 3G8

Voice Mail: 416-264-8000 Fax: 416-264-8222

- Provide Support Groups for parents
- Provide referrals for respite care

info@fasworld.com

<http://www.@fasworld.com>

Anishnawbe Health Toronto

Has an FASD diagnostic Clinic and resources.

- Diagnostic assessments/diagnosis includes integrated team assessment/diagnosis
- Psychometric assessments are included in the integrated model

The team and family progress together through the assessment, diagnosis and resource planning. Psychologists, Traditional Healers, Medicines people and medical team members work together with the families and clients being assessed and in the development of ongoing traditional and main stream supports and resources.

Contact: Manager WAASH-KESHUU-YAAN Unit (health unit)

225 Queen Street East, Toronto, ON M5A 1S4

Phone: 416-360-0486 Fax: 416-365-1083 <http://www.aht.ca>

Aboriginal-based Resources

- *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects*
- *What You Should Know About Alcohol & Pregnancy* – Colouring Book
- *What You Should Know About Alcohol & Pregnancy* – Activity Book
- *What You Should Know About Alcohol & Pregnancy* – Booklet
 - Ikajuqtigiinniq [Working together]: a resource for Fetal Alcohol Syndrome prevention and intervention work
 - Ontario Federation of Indian Friendship Centres

Toolkit For Families, a booklet, can be downloaded from the website <http://www.ofifc.org>.

RESOURCES FOR ADULTS LIVING WITH F.A.S.D.

- We Care: “Practical Skills for Front-line Workers Working with Adults Affected by Fetal Alcohol Spectrum Disorder: Specially designed for those working with people who are homeless or at risk of homelessness.”
 - Employability: “Living with Fetal Alcohol Spectrum Disorder” produced by the Lakeland Centre for FASD: <http://www.lakelandfas.com>. The Lakeland Centre also produced “Rainy & Red”, a book for adult with FASD
 - Employment: “Fetal Alcohol Spectrum Disorder and Employment: Supporting Adults on the Job” by Deborah Rutman, Corey La Berge and Donna Wheway. This resource can be ordered from: <http://www.fasbookshelf.com>

Resources for Teachers

Listed below are some resources to help teachers develop strategies for working with students affected by FASD. This list is not comprehensive or extensive, but provides a good starting point.

- What Early Childhood Educators and Caregivers Need to Know about Fetal

Alcohol Syndrome (FAS) on-line journal article can be purchased at <http://www.jstor.org>

- Challenges and Opportunities: A Handbook for Teachers of Students with Special Needs With a Focus on Fetal Alcohol Syndrome (FAS) and Partial Fetal Alcohol Syndrome (pFAS); Peggy Lasser, (1999) District Learning Services, Vancouver School Board <http://www.fasbookshelf.com/>
- Planning for Students with Fetal Alcohol Spectrum Disorder http://www.sasked.gov.sk.ca/branch/curr/special_ed/docs/mosc/fasd2004.pdf
- FAS/E and Education: The Art of Making a Difference. S.Berg et al, Vancouver, B.C.; Call to order: 604-589-1854
- Teaching Students with FASD, Alberta Education <http://www.learning.gov.ab.ca>

PROFESSIONAL DEVELOPMENT TRAINING

It is essential that care providers, service providers and educators at all levels receive specialized training that covers skills and strategies helpful in dealing with FASD. Knowledge about how to help those affected by FASD better manage the condition is equally essential for program planners and executive staff as it is for those on the front line.

For more information on future training, contact:

The Toronto FASD Training, Consultation, and Mentoring Leadership Team
c/o The Child Welfare Institute

Phone: 416 924-4640, ext.2781

E-mail: dschatia@torontocas.ca or view the CCSA online Calendar at
<http://www.ccsa.ca>.

The SMART Guide: Motivational Approaches Within the Stages of Change for Pregnant Women Who Use Alcohol – A Training Manual for Service Providers
Publisher/agency: Co-produced by Action on Women’s Addictions – Research and Education (AWARE) and Breaking the Cycle

Description: Provides training within a stage model of change for working with pregnant women who are drinking alcohol.

Contact AWARE: aware@kos.net, <http://www.aware.on.ca>

Resource For Medical Doctors

“Fetal Alcohol Spectrum Disorder (FASD) Module 1: Preventing and Addressing Alcohol Use in Pregnancy”

Free on-line training for medical doctors that consists of a learning module worth three (3) MainPro M1 credits or three (3) Category 1 credits.

To register go to: <http://www.MDcme.ca>

Nurturing Change

Publisher/Agency: Mothercraft/Breaking the Cycle and Canadian Centre on Substance Abuse.

Description: Training manual for use either as a reading course or as a two-day training session. Develops skills to work with high-risk women and affected children to prevent and reduce the harms associated with FASD.

Available online: <http://www.mothercraft.ca>

Discussion Groups. Websites. Helplines

Motherisk

<http://www.motherisk.org>

The Motherisk Program at The Hospital for Sick Children in Toronto is a clinical, research and teaching program dedicated to antenatal drug, chemical, and disease risk counselling. It is affiliated with the University of Toronto. Created in 1985, Motherisk provides information and guidance about the safety of maternal exposure to drugs, chemicals, diseases, radiation and environmental agents.

Motherisk also provides various essential services to pregnant women and health/

social service professionals, including telephone counselling regarding alcohol and substance use in pregnancy and while the mother is breastfeeding. Motherisk Help Line numbers are previously listed.

The Motherisk Laboratory for Drug Exposure offers hair and meconium testing, which can detect prenatal exposure to alcohol and a variety of drugs. Call 416-813-8572 or the Alcohol and Substance Use Help Line for more information.

Alcohol and Substance Use Help Line 1-877-327-4636

Morning Sickness Help Line 1-800-436-8477

HIV & HIV Treatment in Pregnancy 1-888-246-5840

Motherisk Help Line –

416-813-6780 (for information on medications and other exposures in pregnancy)

Best Start - Research Articles

<http://www.beststart.org>

FASWorld

<http://www.fasworld.com>

FASLink

<http://www.faslink.org>

Founded in 1995, FASLink hosts a large and very active e-mail discussion group as well as an archive of over 100,000 FASD-related documents. The discussion group has an international membership, though most members are from North America. Membership consists of parents (birth, foster and adoptive), caregivers, adults with FASD, doctors, teachers, social workers, lawyers, students, law enforcement, psychologists, judiciary, corrections professionals and government policy makers.

Canadian Centre on Substance Abuse

<http://www.ccsa.ca>

The Canadian Centre on Substance Abuse (CCSA) maintains a database of FASD-related resources, including virtually all that are mentioned in this booklet. Resources can be searched by type (books, pamphlets, videos, etc.) and topic (i.e., early intervention, education, community mobilization, etc.). To access the database, visit <http://www.ccsa.ca/fas/>

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Margaret Walsh - Toronto Catholic District School Board

FASD is Preventable!

There is neither a safe time to drink **alcohol** during pregnancy nor a safe amount to drink.

It is best to **stop drinking** before trying to get pregnant, when trying to conceive and as soon as you know you're pregnant.



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To order copies of this brochure, contact: Sharron Richards, Children's Aid Society of Toronto, 416-924-4640 ext. 1-2981 OR email: srichards@TorontoCAS.ca

To download the latest version: www.TorontoCAS.ca/Publications