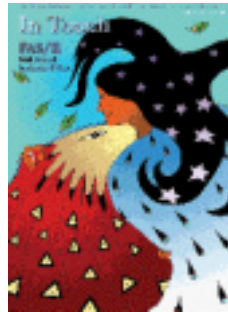


INTOUCH

FAS/FAE -FETAL ALCOHOL SYNDROME / EFFECTS



INTRODUCTION

by Lylee Williams

When the research on *Fetal Alcohol Syndrome-Fetal Alcohol Effects (FAS/E)* was being carried out for this issue of *In Touch* magazine, so many directions could have been taken that it was difficult to choose which 'road' to take. FAS/E is so multi-faceted and complex, examining it is like putting together a large puzzle with many interlocking pieces where each one plays an equally important part in creating a complete picture.

The magazine's intent is to introduce readers to some of these interlocking puzzle pieces and begins with the article *What is FAS/FAE?* and gives the current definition of FAS/E. With all of its primary and secondary characteristics, readers are advised to note that there are varying degrees of disabilities in both FAS and FAE. Therefore, when reading the lengthy list of characteristics found in affected individuals, perhaps only a few apply. Research consistently gives the following message: Each person with alcohol-related birth defects is different from the next person who is affected.

The articles "*Diagnosis*" and "*Where To Go For Diagnosis*" are here mainly because it is such an elusive area—such an air of mystery attached to it does not serve parents or caregivers very well if they suspect that their child may have FAS/E and are seeking an accurate and professional diagnosis. Therefore, the purpose of the information and inclusion of a list of diagnostic centres is to help demystify this area for parents and caregivers.

The article "*Some Thoughts on Preconceptual Health*" emanated from a dialogue that took place between the writer/researcher and Wanda Gabriel, a Mohawk woman and Social Worker from Kanehsatake, Quebec who is a regional representative (Ontario) for the Aboriginal Healing Foundation. In the article, Wanda creates a link between past Native societies and today, pondering such questions as 'Why are our societies the way they are? Why do we have such high rates of alcoholism and high rates of children with learning disabilities?' She also speaks about how, historically, communal responsibilities towards a new growing life did not allow a woman to abuse her body without intervention of family and community.

Teenagers, at-risk young adults, and pregnant women were focused on through articles such as *Baby, You Really Ought To Think It Over!*, *One Step Closer* (to independence), *Is There Such a Thing as a Safe Amount of Alcohol?* (to drink when pregnant), and *Sheway – An Oasis for Pregnant Women in Vancouver’s Downtown Eastside*. Finally, there are listings of *FAS Resources* for those who are searching for contact information on organizations that disseminate information and offer support, videos on FAS/E, current books and helpful Web addresses that can be contacted through the Internet.

Hopefully, this reading journey will shed light on Fetal Alcohol Syndrome and its equally devastating counterpart, Fetal Alcohol Effects.

Lylee Williams,
Researcher/Writer

WHAT IS FETAL ALCOHOL SYNDROME?

by Lylee Williams



Fetal Alcohol Syndrome (FAS) is the name given to a group of physical and mental defects caused by fetal exposure to alcohol in the womb. This condition is caused by alcohol use during pregnancy—when a pregnant woman drinks alcohol, it passes through the placenta* and is absorbed by the unborn baby. The alcohol can harm the embryo** and fetus even if the mother feels no effects.¹

*The placenta is a disk-shaped organ formed at the onset of pregnancy. It is attached to the wall of the uterus and is connected to the fetus by the umbilical cord where nourishment passes to the baby. However, toxins and other substances such as alcohol can pass through the membrane to become ingested by the developing baby as well.

**The embryo is the developing organism from the moment of conception to the end of the second month of pregnancy.

The Guidelines of Care for Children with Special Health Care Needs, Minnesota Department of Health (at website <http://www.mofas.org/guidelines/whatFAS.htm>) describes FAS as a condition affecting a mother’s offspring in the following ways:

Physical, mental and behavioral abnormalities
Most children with FAS will have different facial features

Most will have problems with growth
Permanent brain injury frequently occurs

FAS affects each child differently as the Minnesota Department of Health Guidelines further **describe the characteristics as follows:**

“Not all children with FAS are alike. The effects of alcohol use during pregnancy will vary. Some children are more severely affected than others. Some show more of the reasoning and behavioral problems than the physical features. Some have a normal IQ while others do not. Many will have learning disabilities. Each child will have his or her special needs, problems and potential.”²

Fetal Alcohol Effects:

Some children affected by alcohol in the womb are diagnosed with Fetal Alcohol Effects (FAE) because they do not have all the features of FAS. For example, they may have the following characteristics:

- Normal growth and a more normal appearance

- More likely to have a normal IQ than a child with FAS

- Similar to an FAS-affected child, can have mild to severe problems with reasoning, behavior and learning

Although it has been known for centuries that exposing a fetus to alcohol can adversely affect its physical and mental development, the term FAS was officially introduced to the world in 1973 by a group of doctors in Seattle, Washington. These doctors noted a pattern of malformations in newly born offspring of mothers known to have consumed alcohol during pregnancy. The major difference between FAS and other syndromes, such as Down's Syndrome, is that it is 100 per cent preventable – if a fetus is not exposed to alcohol in the womb, there is no risk of acquiring this condition.

FAS is the most common cause of defective cerebral (pertaining to the brain) development in industrialized nations. Research suggests that psychosocial factors such as stress, anxiety, social interactions, and maternal attitude towards pregnancy may also affect reproductive outcomes.³ According to Health Canada, the estimated rate of FAS in industrialized countries is 3 out of every 1,000 live births. On the other hand, studies in Native communities are limited and show alarmingly high rates of incidence.⁴ A study published by the Canadian Medical Journal states that one Aboriginal community reported an FAS rate of 1 out of every 10 births!⁵ Note that this figure does not necessarily present a picture of the incidence of FAS in all Native communities in Canada. It is believed that each community is unique and that there are pockets of high incidence within the Aboriginal population in Canada.

Characteristics:

Dr. Nora Setton, a specialist in Pediatrics and Neonatology (care for the newborn), explains the signs and symptoms related to this exposure:

“In newborns and children, we note anomalies (abnormalities) that affect pre-and post-natal growth (in and out of the womb), such as the development of characteristic facial features and long-term neurological (entire system of nerve tissue in the body that includes the brain, brainstem, spinal cord, and nerves) development.”

Dr. Setton further explains that such babies are born with growth retardation in the womb, often weighing less than 2.5 kg (approximately 5 lbs.) and this growth retardation carries on into childhood and adult life. The following describes the general characteristics of FAS/E, keeping in mind that these appear in different degrees in affected individuals. It appears that the amount of alcohol consumed, patterns of drinking (e.g. moderate to heavy; binge drinking), and the point at which alcohol was consumed during fetal growth all become factors in the degree that a person is affected.

General Characteristics:

Facial abnormalities are slight but clearly associated with alcohol consumption. These include narrower slits between the eyelids, drooping eyelids, poorly developed eyelashes, small upturned nose, absence of vermilion (red pigment) lip border, as well as a very thin upper lip. In addition, other physical abnormalities may include cardiac, ear, and/or eye malformations.

Neurological abnormalities are related to the nervous system and may include an abnormally small head in newborns, minor cerebral (portion of the brain where thought and higher function reside) deformities, and weak muscle tone. They have difficulties with coordination and concentration and may suffer from hyperactivity. FAS is one of the most frequent causes of mental retardation (after Down's Syndrome).

Cognitive disorders, which are disturbances in the mental processes related to thinking, reasoning and judgment, affect many intellectual activities. These include difficulty with cause and effect, comprehension, and not having a concept of time and space.





Characteristics by Age Group:

There are a great variety of characteristics found in children affected by FAS/E. It must be stressed that the developmental problems associated with this condition can be helped by early and supportive intervention.

The following lists are characteristics of FAS and other alcohol-related effects in different age groups. These lists have been obtained from the Ministry of Children and Family Development, Government of British Columbia at the Web address: http://www.mcf.gov.bc.ca/child_protection/fas/fas2c.htm). Take note that this inventory is not exhaustive, but there are many places for parents to go to for more information. For example, The FAS Support Network of British Columbia has pre-

pared booklets (called the FASNET Assessment Tools) that contain detailed listings of the range of problems that may affect those with FAS.

Infants:

- Small size and slow development
- Sleeping difficulties
- Feeding difficulties
- Easily over-stimulated, sensitive to noise and light
- Birth defects such as heart problems, kidney problems, tumors and skeletal anomalies
- Susceptibility to infections

Pre-school Aged Children:

- Small physique
- Delays in development of speech, poor articulation, slow development of vocabulary and sentence patterns
- Poor judgment – difficulty in recognizing danger
- Difficulty following directions
- Destructive behavior and tantrums
- Distractibility, hyperactivity
- Over-friendliness – lack of fear of strangers
- Poor coordination, poor motor skills, clumsiness
- Lack of impulse control and emotional over-reaction
- Overly tactile (likes to touch persons and things)



Elementary School Aged Children:

- Small physique
- Intellectual impairment and learning disability (but many have normal intelligence)
- Delayed language and speech development
- School problems – particularly difficulties in reading, math, spelling, problem solving and comprehension
- Memory difficulties – both in registering and retrieving information
- Impaired reasoning from cause to effect
- Difficulty predicting and understanding consequences
- Difficulty separating fact from fantasy
- Temper tantrums, lying, stealing and defiance
- Poor motor coordination
- Attention deficit and hyperactivity
- Adaptive and social behavior difficulties – over-friendliness, need for physical contact, easily influenced, immaturity,
- Problems with changes in routines, difficulty with choices and life skills, appearing capable but not having the actual abilities

Adolescents and Young Adults:



Some catch up in growth
 Intellectual impairment and low level of academic achievement
 More pronounced difficulties with impulsiveness
 Poor ability to generalize (e.g. taking a situation and applying it to something else)
 Poor ability to anticipate and respond to consequences
 Difficulty in organizational skills and logic
 Poor motivation, passivity (does not respond assertively)
 Tendency to lie, cheat and steal
 Difficulty in setting and recognizing boundaries (e.g. that can lead to inappropriate sexual behavior)

Easily misled
 Difficulty in understanding and responding to others' feelings or needs
 Low self-esteem and depression
 Susceptibility to suicide, drug and alcohol misuse, unplanned parenthood, physical and sexual abuse, legal problems
 Difficulty in independent living and in getting and keeping a job

Secondary disabilities:

Secondary disabilities are those that a person with FAS or FAE is not born with and that could probably be improved through better understanding and practical help.¹ According to the State of Alaska FAS Website, "These disabilities arise when needs go unmet for children with alcohol-related birth defects."² In 1996, Dr. Anne Streissguth, a leading researcher and expert on FAS/E, studied such 'secondary disabilities' in 415 patients between the ages of 6 and 51 years old. She identified the following impacts that FAS/E had on these patients' lives:

Mental health problems
 Disrupted school experience (e.g. suspension, expulsion or drop-out for those 12 years and older)
 Trouble with the law (12 and older)
 Confinement (in-patient treatment or imprisonment by those 12 and older)
 Inappropriate sexual behavior (12 and older)
 Alcohol and drug use problems (12 and older)
 Needing dependent living situations (21 and older)
 Problems with employment (21 and older)



Universal Protective Factors:

Can anything be done to lessen these problems?

Dr. Streissguth's study reports that yes, these issues can be minimized if they are addressed early on and in a consistent manner. In fact, the study identified the following eight helpful actions, referring to them as 'universal protective factors':

Living in a stable, nurturing home for over 72 per cent of life
 Being diagnosed before the age of 6
 Never having experienced violence against oneself
 Staying in each living situation for an average of more than 2.8 years
 Experiencing a good quality home from age 6 to 12
 Having applied for and been found eligible for governmental disability services/benefits
 Having a diagnosis of FAS rather than FAE
 Having basic needs met for at least 13 per cent of life



Bibliography

- ¹ What is FAS/FAE? Guidelines, Minnesota Department of Health 1999: <http://www.mofas.org/guidelines/whatFAS.htm> (25 September 2001).
- ² What is FAS/FAE? Guidelines of Care for Children with Special Health Care Needs: <http://www.mofas.org/guidelines/whatFAS.htm> (24 September 2001).
- ³ Conference Proceedings: Interdisciplinary Approach to the Management of FAS and FAE. Red Deer, AB, November 1 & 2, 1994; <http://www.ccsa.ca/fasresrc.htm#F1> (13 September 2001).
- ⁴ It Takes a Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects, Health Canada, 1997.
- ⁵ CMAJ, Fetal Alcohol Syndrome Epidemic on Manitoba Reserve, July 1, 1997, <http://www.cma.ca/cmaj/vol-157/issue-1/0059.htm> (13 September 2001).
- ⁶ Streissguth, Ann, Helen Barr, Julia Kogan, and Fred Bookstein. Understanding the Occurrence of Secondary Disabilities in Clients with FAS and FAE. University of Washington School of Medicine, Dept. of Psychiatry and Behavioral Sciences.
- ⁷ State of Alaska: Dept of Health & Social Services FAS Website. <http://health.hss.state.ak/us/fas/disabil.html> (22 September 2001).

DIAGNOSIS

by Lylee Williams

When a doctor assesses an individual for FAS/E, all the results of tests carried out on that person are collected and analyzed in order to make an accurate diagnosis. For the purposes of this article, let us assume that the individual is a child. If that child has been diagnosed as having FAS/E, it is ideal that the diagnosis be accompanied by a listing of the following:

- * The child's specific deficits
- * The child's learning and/or behavior concerns
- * Appropriate recommendations to help the child with his or her special needs

Benefits of obtaining an accurate diagnosis:

Fetal Alcohol Syndrome is a medical diagnosis usually made by a physician specifically trained in the assessment of birth defects.¹ The benefits of obtaining an accurate diagnosis by a qualified physician and/or team of professionals have been identified by the State of Alaska Department of Health and Social Services as follows:

- It can improve the child's opportunity to receive appropriate interventions
- It can facilitate communication among clinicians, caregivers, and educators
- It provides better self-awareness and understanding by family members



Therefore, it must be stressed that an accurate diagnosis is an important part of the management of FAS/E. Once a child is diagnosed, specific deficits can be identified and interventions planned.² Diagnosis of FAS/E involves examinations and evaluations by doctors and other professionals who specialize in this area. When asked the question “How is FAS/FAE diagnosed?”, the Minnesota Organization for Fetal Alcohol Syndrome (MOFAS) offered the following **guidelines for diagnosis:**

“FAS/FAE is diagnosed after completion of a medical examination and psychological, occupational therapy and speech/language evaluations.”³

Roles of the various professionals:

MOFAS goes on to explain the role of the various examinations that are conducted:

The Medical examination includes:

- Evaluation of the prenatal and birth history and previous medical history
- General physical examination
- Evaluation of early and current growth patterns
- Measurement of facial features

The Psychological evaluation includes:

- Developmental tests to determine abilities and deficits

The Occupational Therapy evaluation determines:

- Motor functions and adaptive abilities

The Speech and Language evaluation determines:

- Abilities to understand and communicate

Preparing for a diagnosis:

To better assist health providers or professionals in obtaining a diagnosis, MOFAS advises parents to do the following:

- Think about their child’s medical history
- Write down what they know
- Try to collect photos of their child between the ages of two and ten

Once the diagnosis is made, specific deficits will be identified and recommendations for intervention and treatment will be suggested.

What determines an FAS diagnosis?

There are criteria that must be met in order to confirm an FAS diagnosis and there are two distinct categories: (1) FAS with confirmed maternal alcohol exposure and (2) FAS without confirmed maternal alcohol exposure. This second criteria applies when it cannot be confirmed that a mother drank alcohol during pregnancy such as in cases of adoption or foster parenthood. The primary diagnostic criteria are **described as follows:**

(1) FAS with confirmed maternal alcohol exposure:

- A.** Confirmed maternal alcohol exposure
- B.** Abnormal facial features (including short eye opening, short nose, flat midface, thin upper lip and small chin)
- C.** Pre-natal or post-natal growth retardation (as in at least one of the following: low birth weight for gestational age; failure to thrive that is unrelated to nutrition; disproportional low weight to height)
- D.** Neurodevelopmental impairments (as in at least one of the following: small brain size; impaired fine motor skills; “clumsy” and “accident-prone”; impaired hand-eye coordination; and memory deficits)

(2) FAS without confirmed maternal alcohol exposure:

- A, B, C, and D as above



Diagnosis of Fetal Alcohol Effects:

“Fetal Alcohol Effects” (FAE) is a term used to describe the abnormalities found in persons who do not meet all the criteria of FAS. On the one hand, a diagnosis of FAS is justified when the child meets all criteria as stated above: slow growth, identifying facial features, and central nervous system damage and these are seen in association with the mother’s consumption of alcohol during pregnancy.⁴

On the other hand, when a child has one or two of these signs and the mother has consumed alcohol during the pregnancy, then the child is said to have FAE or alcohol-related birth defects (ARBD).⁵

Dr. Nora Setton, Pediatrician and Neonatologist explains FAE as follows:

“In reality, FAE or fetal alcohol effects is a term used to describe the anomalies (abnormalities) found in patients who do not meet all the criteria of FAS.”

Dr. Setton describes the characteristics of Partial FAS as follows:

- A. Confirmed alcohol consumption by mother
- B. Presence of some FAS facial features
- C. Growth retardation or neurological disorders

You may hear both professionals and non-professionals using either term ‘Fetal Alcohol Effects’ or ‘Partial FAS’. Keep in mind that these terms mean the same thing.

Diagnosis—the earlier the better:

Children may be identified as having FAS at birth, but most often require reassessment in early infancy to confirm the diagnosis. On the other hand, when these children grow older, their behavior is usually what drives caregivers to seek a diagnosis.

It is better for an individual to be diagnosed as early as possible in his or her life. According to prominent researcher and expert on FAS/E, Ann P. Streissguth, being diagnosed before the age of 6 has been deemed helpful and protective in terms of lessening secondary disabilities. Her research shows that the problems associated with FAS actually intensify as children move into adulthood. Therefore, it is important that intervention strategies be initiated right away because there is a better chance for a positive outcome.

Another good reason for obtaining an early diagnosis, in addition to referring an infant to appropriate services quickly, is to prevent future affected pregnancies.

Pre-screening Assessment Tool:

This is an assessment tool developed for parents and non-medical professionals with whom the mother and child have contact, and who possess an understanding of FAS and related effects, as well as knowledge of the diagnostic services that are available. These professionals may include childcare workers, social workers, addiction workers, speech and language pathologists, teachers and correctional workers. They have an important role to play in screening, referring for diagnosis, and supporting the diagnosis (Hess and Kenner, 1998; Niccols, 1994; Conry et al., 1997; Jenkins and Culbertson, 1996).

This assessment tool is not intended to make a diagnosis, but can alert the parent or non-medical professional making the assessment to the possibility of (1) an individual having FAS/E and (2) the need to obtain a thorough and comprehensive assessment where indicated. This tool looks at Infancy History, Physical Findings, Communication, Socialization, Behavior, Attention, Physical Skills, Memory, and Cognition (mental process of knowing, thinking, learning and judging)⁶. There are 260 questions and a score of more than 50 per cent points to the need for referral to a physician who can conduct a thorough and comprehensive assessment on the individual. There are five different versions of this tool, depending on the age of the individual. Information on how to obtain this assessment tool is located in the “Resources” section at the back of this magazine.

Seeking a diagnosis:

The following may lead a parent or caregiver to seek a diagnosis for FAS/E:

1. If a Pre-screening Assessment has been carried out with the child and the score indicates the need for a thorough diagnosis, and/or
2. The child displays characteristics such as those described in the article "What is FAS/E?" found at the beginning of this magazine.

In Canada, diagnosis is usually carried out by medical specialists, pediatricians, geneticists or dysmorphologists (people who specialize in genetics-related disorders). Locating the professionals or diagnostic centres to obtain an expert diagnosis of FAS/E is not an easy feat in Canada. Health Canada's publication, "Situational Analysis: FAS/FAE and the Effects of Other Substance Use During Pregnancy" (December 2000) provides a glimpse of how services are distributed in Canada:

Capacity (for diagnosis) is greater in western Canada

In some cities, those seeking a diagnosis go to genetics clinics

The shortage of diagnostic services is most felt in communities in northern Canada

It is difficult to find doctors who diagnose youth or adults

Where available, services to diagnose youth or adults are obtained privately and the family pays the costs

Where to go for diagnosis:

Finding the resources for diagnosis of FAS/E is not an easy task. Canada has few specialized centres with comprehensive diagnostic services. Where such services do exist, they are generally not available to children over 18 (in some cases, age 16) or adults.⁷ There is no national listing of resources for the diagnosis of FAS/E. However, the following Diagnosis List attempts to compensate for this lack of information by listing the names and locations of centres where diagnosis can be carried out, and descriptions of how they operate. Many of the following names were extracted from lists that were located at Internet Websites or gathered at FAS conferences where these doctors presented on the topic.

**Bibliography**

¹ Fetal Alcohol Syndrome: State of Alaska Department of Health and Social Services Website: <http://health.hss.state.ak.us/fas/diagnos/html> (25 September 2001).

² Diagnosis of FAS/FAE. <http://www.mofas.org/facts/diagnosis.htm>. (19 September 2001).

³ Ibid.

⁴ J. Kleinfeld and S. Wescott, "Fantastic Antone Succeeds: Experiences in Educating Children with Fetal Alcohol Syndrome" (Alaska: University of Alaska Press, 1993.)

⁵ H.L. Rosett, "A clinical perspective of the Fetal Alcohol Syndrome," *Alcoholism Clin Exp Res* 4 (1980): 119-122; R.J. Sokol and S.K. Clarren, "Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring," *Alcoholism Clin Exp Res* 13 (1989):

597-598.

⁶ On-Line Medical Dictionary: <http://www.graylab.ac.uk/omd/index.html> (19 September 2001).

⁷ Legge, Carol, Gary Roberts, Mollie Butler. *Situational Analysis: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy*. Ottawa, ON. Health Canada. December 2000.



DIAGNOSIS LIST

Alberta

The Campbell Clinic
Dr. L. Storoz, Pediatrician
430 Mayor Magrath Drive
Lethbridge, AB T1K 3E0
Phone: (403) 328-8101 Fax: (403) 328-8150

Services: Dr. Storoz provides diagnosis, some treatment, and referrals as necessary. She sees children from birth to 16. A referral from a family physician (letter with background information) is required for non-Social Services patients.

Children's Health Clinic
Dr. S.T. Govender, Developmental Pediatrician
#530 Marlborough Mall, Professional Building
433 Marlborough Way NE, Calgary, AB T2A 5H5
Phone: (403) 543-4090 Fax: (403) 543-4093

Services: Dr. Govender diagnoses and assesses FAS and makes recommendations and referrals as necessary for children from birth to age 18. A referral from a family physician is required.

Alberta Children's Hospital
Dr. Ross McLeod, Director
Clinical Genetics Unit
Calgary, AB T2T 5C7
Phone: (403) 229-7246 Fax: (403) 543-9100

Services: Through the clinical genetics service and outreach programs in Medicine Hat, Red Deer, and Lethbridge, the hospital can provide an FAS diagnosis to children.

Dr. Margaret Clarke
Calgary, AB
Phone: (403) 541-7515

Dr. Lindsay Crowshoe
Calgary, AB
Phone: (403) 850-2716
Email: crowshoe@ucalgary.ca



British Columbia

Asante Centre for FAS
Ms. Audrey Salahub, Coordinator
22326 (A) McIntosh Avenue
Maple Ridge, B.C. V2X 3C1
Phone: (604) 467-7107
1-866-327-7101 (Toll-free)

Service: Diagnostic, assessment and family support centre for individuals of all ages affected by FAS.

Sheway Project
Ms. Jane Trussler, Acting Coordinator
Vancouver Native Health Society
369 Hawks Avenue
Vancouver, B.C. V6A 4J2
Phone: (604) 658-1200

Services: An outreach program located in the downtown eastside of Vancouver that provides holistic services to pregnant women with substance abuse problems, support to mothers and their families until their children are 18 months of age. Access to diagnosis services available.

Sunny Hill Health Centre for Children
Ms. Norma Carey &
Dr. Christine Loock
Children's and Women's Health Centre of B.C.
3644 Slocan Street
Vancouver, B.C. V5M 3E8
Phone: (604) 453-8300

Services: Inpatient and outpatient services to children up to 19 years of age and their families. Consultation and initial linking to available community resources, diagnosis and developmental assessment, medical and social support to inpatient infants experiencing withdrawals.

Manitoba

Clinic for Alcohol & Drug Exposed Children
Ms. Mary Cox Millar, Coordinator
Children's Hospital
CK-275, 840 Sherbrooke Street
Winnipeg, MB R3A 1S1
Phone: (204) 787-1822

Services: The clinic provides multi-disciplinary assessment and diagnostic services. Referrals for up to age 18. Tele-video diagnostic services also available.

Tele-Medicine links – In northern and remote communities of Manitoba, FAS/E diagnosis is provided by using this system. There is a diagnostic team available in the northern community of Thompson. Using video technology, this team and their clients can consult with FAS/E experts at a clinic in Winnipeg. This clinic provides diagnosis, assessment and treatment recommendations in addition to support for families to help them deal with the diagnosis and to connect with community resources.

New Brunswick

FAS/FAE Community C.A.R.E. (Counselling Assessment Research Education)
Dr. Lori Vitale Cox, Coordinator, Pilot Project
Big Cove First Nations, School Psychological Services
Site 11, Box 6
Big Cove, N.B. E0A 2L0
Phone: (506) 523-8312

Services: Project provides assessment, screening and referral as needed. An annual diagnostic clinic is held in the community in collaboration with Dr. Michael Dickenson, Pediatrician from Miramichi, N.B.

Newfoundland

Medical Genetics Program
Dr. Ted Rosales, Pediatrician/Geneticist
Memorial University of Newfoundland
St. John's, NF A1A 1R8
Phone: (709) 778-4345

Services: Dr. Rosales provides FAS/E assessment and diagnostic services for children and adults. He works in conjunction with schools, social and community services.

Ontario

Children's Hospital of Eastern Ontario
Dr. Judith Allanson, Clinical Geneticist
401 Smyth Road
Ottawa, ON K1H 8L1
Phone: (613) 737-2275

Services: Assessment of children and adults to determine the likelihood of an FAS/FAE diagnosis.

Ontario FAS Clinic
Dr. Irene Nulman, Physician
Motherisk, The Hospital for Sick Children
Division of Clinical Pharmacology
555 University Avenue
Toronto, ON M5G 1X8
(416) 813-7887

Services: The clinic undertakes psychological and physical testing of infants and children.

Medical Genetics Program of Southwestern Ontario
Dr. Jack Jung, Director
Children's Hospital of Western Ontario
800 Commissioners Road East, Room 2250
London, ON N6C 2V5
Phone: (519) 685-8140

Services: The program provides medical consultations for possible FAS/E diagnosis, usually by referral.

Quebec

Montreal Children's Hospital
2300 Tupper Street
Montreal, QC H3H 1P3
(514) 412-4400

Ste. Justine's Hospital
3175 Cote Ste. Catherine
Montreal, QC H3T 1C5
(514) 345-4931

Saskatchewan

The Saskatchewan Institute on Prevention of Handicaps has provided the following list at their website: <http://www.preventioninstitute.sk.ca/fasreferrals.html>:

“Referral Resource for the Diagnosis and Treatment of Fetal Alcohol Syndrome”:

Alvin Buckwold Child Development Program, Kinsmen Children's Centre
1319 Colony Street
Saskatoon, SK S7N 2Z1
Phone: (306) 655-1070

Service: This centre operates an FAS/E clinic based on a multidisciplinary approach. The FAS/E team consists of a pediatrician, psychologist, physiotherapist, speech therapist and social worker. The team travels to remote communities to assist with diagnosis.

Wascana Rehabilitation Centre
2180 – 23rd Avenue
Regina, SK S4S 0A5
Phone: (306) 359-5559

Service: Assessment and rehabilitation services for children with physical and developmental disabilities. From infancy to age 16. Children from southern Saskatchewan. Doctor's referral required to Director of Children's Program.

Outpatient Pediatric Clinic
Department of Pediatrics
Royal University Hospital
Saskatoon, SK S7N 0W8
Phone: (306) 966-8108

Service: Assessment and treatment of physical disabilities and developmental disorders. Infancy to age 18. Doctor's referral required.

Division of Medical Genetics
Royal University Hospital
Saskatoon, SK S7N 0W8
Phone: (306) 655-1692

Service: Assessment and diagnosis of physical and developmental disorders. Provide genetic counseling. All ages. Doctor's referral required.

Clinical Teratology Program
Dr. Patricia Blakley
Kinsmen Children's Centre
1319 Colony Street
Saskatoon, SK S7N 2Z1
Phone: (306) 655-1096

Service: Diagnosis and assessment of children prenatally exposed to drugs and other toxins. Infancy to age 18. Doctor's referral required.

Traveling Clinics – In Saskatchewan, traveling clinics that are made up of a team of specialists visit remote communities to assist with diagnosis and development of local resources. This team is made up of a pediatrician, psychologist, social worker, physiotherapist, occupational therapist, and speech therapist. Local professionals, such as nurses and dieticians, participate as much as possible.

12 COMMON MYTHS ABOUT FETAL ALCOHOL SYNDROME

by Lylee Williams

(adapted from Community Action Guide: Working Together for the Prevention of Fetal Alcohol Syndrome as adapted from Ann Streissguth, Ph.D., University of Washington at website

http://www.mcf.gov.bc.ca/child_protection/fas/fas2c.htm)

MYTH #1: FAS means mental retardation.

FACT: Some people with FAS are mentally retarded and some are not. People with FAS can have normal and above-average intelligence. While there is injury to the brain, each affected person will have specific areas of strengths and weaknesses.

MYTH #2: Behavior problems linked to FAS and partial FAS are all the result of poor parenting.

FACT: Definitely NOT! Brain injury can lead to behavioral problems because people with brain injuries do not process information in the same way that other people do. Children with brain injuries are challenging to raise, and their parents need help and support—not criticism and judgment.

MYTH #3: Children affected by FAS will grow out of it when they grow up.

FACT: Unfortunately, they do not 'grow out of it'. FAS lasts a lifetime, even though the symptoms and types of problems can change with age.

MYTH #4: Admitting that a child has brain injury is to give up on him/her.

FACT: We need NEVER give up on any child with any problem. Instead, we need to understand the needs of those affected by FAS and explore ways to help them.



MYTH #5: Diagnosing children affected by FAS will “brand” them for life.

FACT: A diagnosis tells you what the problem is, helps you figure out how to treat the problem, and relieves the person of having to meet unrealistic expectations.

MYTH #6: Those affected by FAS can be effectively helped by a single agency or discipline.

FACT: The needs of those affected by FAS are such that many interventions and cooperation among numerous community services are required.

MYTH #7: Those affected by FAS lack motivation when they do not act in a way that we consider responsible.

FACT: It is more likely that the explanation lies in memory problems, the inability to solve problems effectively, or simply a state of being overwhelmed.

MYTH #8: The problem of FAS can be solved with existing research knowledge.

FACT: Research is needed on ALL aspects of FAS—epidemiology (study of the incidence of disease), prevention, early intervention, and treatment.

MYTH #9: The problem of FAS in society will go away.

FACT: FAS is preventable, but alcohol is so much a part of our society that practical and realistic activities that address the problem of alcohol abuse must continue.

MYTH #10: Women who are birth parents of FAS-affected babies chose to drink during their pregnancy and did not care if they damaged their children.

FACT: A drinking problem is never easy to overcome. Pregnancy is an excellent time for women with drinking problems to stop or reduce their use of alcohol. They do need respect, understanding, caring and support to accomplish this.

MYTH #11: The incidence of FAS is higher in First Nations communities.

FACT: FAS is related to the use of alcohol during pregnancy, not to race or ethnicity. Levels and cultural values related to drinking alcohol vary across First Nations communities and thus the prevalence of FAS varies as well.

MYTH #12: Forcing pregnant women who misuse alcohol and drugs into prisons or treatment centres will prevent their continued use.

FACT: Alcohol and drugs are available everywhere in our society, even in supposedly ‘protected’ environments. Rather than imposing solutions on a woman, it is important to support her as she works towards a chosen and sustaining change for herself and her children.





IS THERE SUCH A THING AS A SAFE AMOUNT?

by Lylee Williams



There is no such thing as a 'safe amount' of alcohol that can be consumed during pregnancy. In fact, alcohol can do more damage to the developing embryo and fetus than illegal or legal drugs.¹

The message is clear: No alcoholic beverage is safe during pregnancy. Alcohol can have an effect as early as 21 days into the pregnancy! The Minnesota Department of Health gives the following information about the effect of alcohol throughout a women's pregnancy: (See website address: <http://www.mofas.org/guidelines/danger/htm>)

Alcohol use in the first trimester may:

- Cause the greatest brain damage
- Impair cell development
- Affect major organs such as the heart, liver and kidneys
- Cause facial malformations
- Cause miscarriage

Alcohol use in the second trimester may:

- Impair brain development
- Cause miscarriage which may be life threatening for the mother
- Damage muscles, skin, teeth, glands, and bones

Alcohol use in the third trimester may:

- Impair brain and lung development
- Prevent adequate weight gain for the fetus
- Cause early labor and delivery

¹ Minnesota Department of Health 1999: Pregnancy Dangers: Guidelines. <http://www.mofas.org/guidelines/danger.htm> (3 October 2001).



SOME THOUGHTS ON PRE-CONCEPTUAL HEALTH

The following contains excerpts from a dialogue on the topic of Pre-conceptual health in Native society that took place between the interviewer, Lylee Williams and Wanda Gabriel, a Mohawk woman from Kanehsatake, Quebec. Wanda is the Community Support Coordinator, Ontario Region, for the Aboriginal Healing Foundation and possesses a Master's degree in Social Work from McGill University, Montreal.

Linking the past to the present:

"I ask myself, 'Why are our societies the way they are?' There are high rates of alcoholism, high rates of children with learning disabilities. A lot of our children are being diagnosed with Attention Deficit Disorder and being put on Ritalin. Sometimes this is a 'quick fix' without looking in depth as to what is really happening. Why do we jump to quick fixes? It requires a lifelong treatment. There are several things that are going to fix it and I look at it as the 'Three R's'; in other words, Roles, Rights and Responsibilities. We cannot have rights without responsibilities. The rights of women, the rights of men, but we forget what our responsibility is. Responsibility is to uphold our rights and to maintain a balanced lifestyle within ourself, physically for our own health and the health of our families and communities."

It takes a community to raise a child:

"We hear the expression 'it takes a whole community to raise a child', but we're really paying lip service to it today because we don't apply those things. In a school course I took on Child Welfare, I looked at the case in Canada where the authorities wanted to enforce treatment on a pregnant woman, an Aboriginal woman who was abusing alcohol and drugs. I talked to several men and women from different Native nations and asked them what their perspective was on the rights of a fetus because the law in Canada is such that the fetus does not have rights. So, I asked these men and women, 'What are the rights? How would we deal with a situation like this in our community?' What I was told by the Mohawk persons is that in the language, there isn't a word to separate the mother from the child. There is one word to represent the woman carrying a child. Her state of being while she's pregnant, there's no separation. They are one."

Responsibilities towards the new life:

"In terms of this case of the woman who was abusing her body while carrying a child, a lot of the men and women said that had we followed the norms of our ancestors, the woman would have never gotten to that state of abusing herself. The community and family members would have been involved as soon as they saw her going off balance, getting away from her roles and responsibilities as a woman carrying a baby. In regards to code of conduct, when a new life was coming into the world, it was a sacred time for the family and everybody assisted the couple to take care of and nurture that new life coming into the world from beginning to end. There were different teachings from both sides, male and female, preparing them for what was to come."



Communal attitude of caring:

"We see a lot of efforts happening to bring our ancestors' values to today. It's a struggle because we still have a high dependency rate on governmental assistance programs. In other words, the views and values are mainstream. We've bought into the view of individualism. You know, it happens in my house, in my yard, it's nobody's business. Whereas before, everybody naturally took care of each other. I think that attitude of caring is coming back, though. We see it happening more and more. In my work, I do a lot of travel to Native communities throughout Ontario. I'd see a group of children playing outside and if they are getting out of line, an adult will be passing by and will comment and say something to them to get their behaviors back in order. To me, that is the true meaning of 'It takes a community to raise a child.' Hopefully, we won't just pay lip service to it."

Teachings on health:

"It's really important that we get back to understanding our roles regarding pre-conceptual health. What is it that we need to be doing so that the child and the mother are nurtured to bring a healthy child into the world? They should be taken care of physically, emotionally, mentally and spiritually. Those are the four aspects that keep us balanced. Working those, we can bring children into the world who are healthy. There's teachings, ceremonies and foods that were given to a mother who was pregnant that were specific to nurture that new child coming into the world. There were specific foods she had to eat and specific foods she had to stay away from that could cause harm to her and the unborn baby. The support of other women, talking to her, mentoring her. There are teachings that happened with the men and the women from the community that helped prepare them for that moment when that sacred being came into the world."

Teaching youth today:

"In today's society, I think it's really important that we give our children as much information and teachings as possible so that they can make informed choices. If parents cannot do that, then there needs to be a formal mechanism in place that gets that information to the youth. If it's in the school, then it has to be in the school. We have a lot of taboos and when you look at it, you would think it is contrary to how we are living. We see so many things in the media, television, music and radio that are sexually explicit and objectify women. Then, society becomes freaked out about teaching our youth in the schools about healthy sexuality! It doesn't make sense. Teaching youth about caring for one's body is part of prevention, preventing people from going down that road to abusing their bodies."

Preventing FAS and FAE:

"If you look at FAS and FAE, it starts from age zero until they are adults and that affects all the systems, every single one of them. I heard a comment that still sticks with me that goes something like this: "If we don't really start dealing with the problems of alcohol abuse in our communities and the effects of FAS and FAE, the question in the future is not going to be Who is going to lead our people? Rather, the question will be, Who CAN lead our people? Who can lead our people because the mental and emotional capacities just won't be there. That's scary when you think about it."



BABY, YOU REALLY OUGHT TO THINK IT OVER!

BY LYLEE WILLIAMS

(BASED ON AN INTERVIEW WITH COLLEEN BUFFALO, CREE NATION)

Years ago, when Colleen Buffalo was enrolled in a Recreation Program in college, one of her assignments was to design a program that would benefit her community. Because of her love of working with young people and being tuned in to the unique needs and problems that accompany the teenage years, she created a program for them called the "Personal Development Camp".

At this camp, a group of 15 teens participate in workshops where they learn about family dynamics, personal hygiene, and explore issues such as peer pressure, self-esteem, suicide, and various abuses. Colleen offered the program and its success was astounding! Since then, she has facilitated 10 camps, each one held separately for boys and girls between the ages of 13 and 17. Over the five nights and six days they are together, each student is given parental responsibility for taking care of an infant!

Colleen explains this 'parenting' aspect as follows:

"On the first night that they arrive, each teen receives their very own 'baby' which is a computerized doll that resembles a human infant. It is programmed to imitate the needs of a real baby and taking care of it shows teens what parenting is really like.

These dolls imitate normal babies and every time it cries, whether it's 3 o'clock in the morning or 3 o'clock in the afternoon, the teen places a plastic key in the doll's monitor to quiet it. The teen holds the key in place for as long as it would take to feed, bathe, or diaper an infant. These young 'parents' also keep a journal of their experiences.

Now, towards the middle of the week, I switch four normal babies with four FAS babies. The FAS baby cries uncontrollably, shakes and has tremors. It simulates a real FAS baby born to a mother with a crack/cocaine addiction. Inserting the key does not calm it down as it does a normal baby."

This program has been so powerful that Colleen has been receiving numerous requests for Professional Development workshops from other communities, not only in Canada but in the United States as well. She is presently available to give the long and short versions, the shorter being where she works with facilitators so that they can continue the program after she leaves the community.

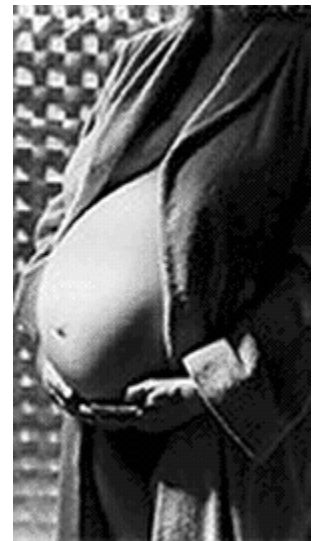
When asked about how the teens feel about becoming parents after the workshop is over, she laughs and is happy to report that by the end of the week, “the teens are ready to throw the dolls at me.”

(For more information about Colleen Buffalo’s Personal Development Workshop, you can contact her at the Howard Buffalo Memorial Center of the Samson Band, Alberta at (780) 585-3012. Additional information about the ‘Baby Think It Over’ dolls and program in the United States, you can visit their Website: http://www.education-world.com/a_curr/curr077.shtml)

SHEWAY: AN OASIS FOR WOMEN IN VANCOUVER’S DOWNTOWN EASTSIDE

A modern prefabricated building sits in a parking lot in one of Canada’s poorest neighborhoods, the modern parallel to finding a treasure chest in the middle of a jungle. The treasure is called Sheway and the recipients of its bounty are pregnant women with substance abuse problems who live in or frequent Vancouver’s downtown eastside.

The centre was created through a partnership between four organizations—Vancouver/Richmond Health Board, Vancouver Native Health Society, and the Ministry of Child and Family Development. Sheway is an appropriate name for this drop-in centre—it means “growth” in Coast Salish. It started in 1993 in response to the needs of pregnant and parental women living in or frequenting this impoverished area—women entrenched in the way of life of the eastside. Walking through its streets becomes a lesson in urban poverty: it is common to see drug dealers and addicts, drunken street brawlers, beggars, people passed out on the sidewalks in broad daylight, and men and women soliciting “customers” to support drug and alcohol addictions.



With an average of 100 female clients at any given time who are pregnant or have a child under the age of 18 months, Sheway works to promote a healthier pregnancy and positive parenting experience. Before the program was started, most of these women were not receiving prenatal care and babies were apprehended immediately because of their mother’s substance abuse. Sadly, their statistics show that 75 per cent of these women are Native. Some of the issues that women faced back then and now are: homelessness, food and nutritional deficiencies, lack of social support, violence from a partner, working on the street, unplanned pregnancy, involvement with the law, mental illness, and finally, their children being apprehended by child welfare because of an unstable home life.

To assist women in such dire life situations, there is a team of professionals at Sheway who offer a wide range of holistic services to women during pregnancy and to their babies up to the age of 18 months. Its staff is composed of the following: four Nurses, three Doctors, a Dietitian, an Outreach Worker, two Social Workers, an Infant Development Consultant, two Alcohol and Drug Counsellors, a First Nation Support Worker, Office Support staff and a Project Coordinator.

Sheway takes a woman-centered, harm-reduction, culturally focused approach to providing services. ‘Harm reduction’ can be illustrated in this way: a pregnant woman who is taking heroin by using needles becomes immediately at risk for contracting HIV and Hepatitis C.

If she is willing to go on methadone, which will stabilize her, then she will not have to resort to illegal activities to get her drugs. Withdrawal symptoms are usually treated with substitute drugs. In this case, methadone is used because it is similar to heroin, is synthetic (man-made) and its use is legal in Canada. Street drugs such as heroin have a lot of impurities mixed into them. The risk of overdosing is greater as one does not know how much of the drug is cut with ingredients such as rat poison, baby powder, laxatives, etc. In addition, by using methadone instead of heroin, the pregnant woman minimizes the risk of miscarriage involved in stopping heroin use ‘cold turkey’. Her doctor monitors the dosage, which she picks up at the pharmacy on a daily basis.

The high-risk lifestyle of substance abusers puts babies at risk of being born with Fetal Alcohol Syndrome or Fetal Alcohol Effects. Sheway has the resources to have babies diagnosed and if FAS or FAE is present, there is access to a Pediatrician, Nurse Clinician, Occupational Therapist, Speech Therapist, and Physiotherapist, who all come to Sheway to work with the mother and child.

The clientele can always count on receiving the basic necessities that promote a healthy pregnancy: a free nutritious hot meal is served at lunch from Monday to Friday, there are food bank hampers containing dry goods such as pasta and canned tuna, as well as fresh fruits, vegetables and bread. They also give the women prenatal vitamins and prenatal food, milk and juice vouchers, and postnatal milk and juice vouchers. Mothers are given maternity and baby clothes that have been donated to the centre, when available. Once the baby is born, Sheway offers services to the mother and child until he/she is 18 months old. For example, there is a 'well baby clinic' that provides access to doctor care and immunizations. They also give mothers free formula, baby food and, when available, diapers.

Sheway is truly an oasis in Vancouver's downtown eastside!

SPOTLIGHT ON ABORIGINAL FAS/FAE PROGRAMS IN CANADA



Aboriginal Health & Wellness Centre of Winnipeg Fetal Alcohol Syndrome/ Fetal Alcohol Effects Prevention Program

Located in Winnipeg, Manitoba, this prevention program is offered by the *Aboriginal Health and Wellness Centre of Winnipeg*. It offers both modern and Native traditional approaches of support to Aboriginal women who are using alcohol during their current pregnancy or who have a history of using alcohol during past pregnancies.

The program supports Aboriginal women who are:

- Experiencing problems with alcohol and/or drug issues by getting them the help or treatment that they need.

- Requiring access to good prenatal and infant care. Addressing

concerns around child custody or child welfare issues. Addressing safety issues, housing problems, etc.

- Setting goals and reaching them

With regards to community outreach, the FAS/E Prevention Program reaches out into the community to promote healthy lifestyle choices in the form of workshops and education by:

- Contacting schools, community agencies, interest and support groups for networking and information exchange

- Sharing information on FAS/E topics such as: parenting, traditional teachings and Aboriginal culture

- Organizing FAS/E support groups and workshops

The Centre has included Seven Teachings on the inside of its information pamphlet. There can be many interpretations of its meaning, but in light of FAS and FAE, it can eloquently describe the traits and characteristics of parents, caregivers and those who have these disabilities.

‘ONE STEP CLOSER’ DAY PROGRAM FOR YOUNG ADULTS WITH CHALLENGING NEEDS

By Lylee Williams

(Based on an interview with Sirjirick Philipp Gibson, Director of *One Step Closer*)



One Step Closer is located in a large, comfortable home

Every person meets challenges when passing through the different stages of life, but many of those with FAS/E must also contend with disabilities of a physical, mental and social nature. In the stage of young adulthood, those with FAS/E are still trying to overcome intellectual impairment, difficulties with impulsiveness, poor ability to generalize and to anticipate and respond to consequences. Their motivation can easily be interpreted as poor and they appear passive. Some have a tendency to lie, cheat and steal, have difficulty in setting and recognizing boundaries and may find themselves in trouble because they do not understand appropriate sexual behavior. Also, a person who is gullible, as those with FAS/E are, becomes a prime target for exploitation by crafty criminals to do their front-line, risky work with the result that they are the ones who are more likely to get caught.

If they do not receive help at this life stage, possessing such characteristics can lead to their school experience being disrupted, followed by dropping out. Perhaps they are jobless and homeless, or may have borne children that are not planned and cannot be cared for without support. Some can get into trouble with the law and have mental health problems such as anxiety, low self-esteem, depression and panic attacks. Alcohol and drug problems can easily enter into their lives and ultimately and sadly, premature death.

Putting such severe problems into perspective and seeking a solution can be a daunting task, but the community of Kahnawake, Quebec has taken the challenge by starting a new program that is designed to meet the needs of young adults with developmental disabilities, including those with FAS/E. The program is called “One Step Closer” because it leads participants one step closer to independence and successful integration into the community. It was created primarily to help achieve the vision of the local Advocacy Group, that all members of the community:

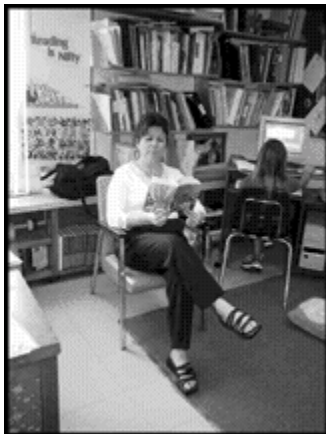
“Live in a state of dignity, share in all the elements of community life and have the opportunity to participate in a meaningful way. We believe that people with challenging needs and their families should be supported so that they can enjoy the same dreams, rights and privileges as any other community member and that their contributions to the community should be recognized and valued.”

This vision is becoming a reality via the program offered by One Step Closer, which is located in a large, comfortable home situated in the middle of the community. For every two clients, there is one staff member who acts as a support person and role model. Each day revolves around a structured routine that is fittingly called a “Typical Day”. It begins with a house meeting, which allows everyone a voice in deciding how they are going to become part of that day. For example, Mr. Harold, the lunch program facilitator, may announce that spaghetti is on the menu for that day and consequently ask for volunteer clientele who are good with their hands to cut up the vegetables. This is just one example of how the participants gain a sense of control over their lives by deciding which activities they want to be part of.

The curriculum is appropriately titled 'Community Integration Activities' because they lead participants towards successful integration into the community. For example, to help clients use community resources effectively, they are taught how to handle money in activities such as carrying money, making purchases, and opening up a bank account. They are constantly exposed to community services and resources, taught telephone usage, and stranger awareness. To learn self-advocacy, they participate in choice-making activities such as being exposed to opportunities in the community, identification of options, having the steps to achieving goals demonstrated, and taking responsibility for their actions. In the area of social skills, clients plan daily activities in a group setting made possible through the learning of effective communication skills. These skills extend outward to build meaningful relationships with friends, family and community members. They are encouraged to express their needs, wants and feelings, to problem solve, negotiate, resolve conflicts and are taught coping strategies to deal with the everyday stresses of life.

This is quite a list of curriculum objectives, but what will likely guarantee its success is the respectful collaboration between the staff, clientele and parents as well as the dedication of the Life Skills Educators and Support Staff who deliver activities that are developed around the strengths, interests, and needs of the clientele.

HOW ONE TEACHER ENTICED HER STUDENTS TO LEARN ABOUT FAS



Kaherawaks setting an example as a reader for her students

To provide an example to her grade 5 students during silent reading period, Kaherawaks Jacobs picked up the novel "The Broken Cord" by Michael Dorris and began reading to herself. She was so engrossed in the story about how an adoptive father struggled to understand his son's Fetal Alcohol Syndrome that it sparked the curiosity of her students. In answer to their questions about the book she was reading, she gave them a quick synopsis of what she had read so far.

The next day, the students wanted to know what else had happened in the book. Again, she gave them an update. These regular updates took place until the teacher and her students had read the entire book!

To her delight, Kaherawaks found out that the local high school had a copy of the ABC movie "The Broken Cord", which is based on the book. She immediately made arrangements to borrow it and obtained permission from the students' parents to allow them to view it. Of the two media, the students enjoyed the novel over the movie and gave clear and sophisticated answers when asked questions such as: Briefly describe what FAS is; Describe the story of "The Broken Cord"; and How can FAS be prevented in the future?

Feeling that the most important question asked concerned prevention of FAS, Kaherawaks **shares some of her students' responses:**

"They should be very careful if they are pregnant."

"Don't drink at all!"

"If someone is expecting a baby, tell them NOT to drink!"

"You can stop FAS by helping mothers to stop drinking, smoking and taking dope!"

"Think of your baby's life!"

"The mother should get treatment if she drinks, so that the baby will be okay!"

"When you are pregnant, let people and friends help you!"

It is inspiring and hopeful to hear such wisdom and awareness coming out of the mouths of 10 and 11 year olds.

INTERNATIONAL FETAL ALCOHOL SYNDROME AWARENESS DAY

The following excerpt is taken from Health Canada's website on FAS/FAE)

A message from the Secretary of State for Children and Youth, the Honourable Ethel Blondin-Andrew:

"Since 1999, September 9, International FAS Day, has been a day for bringing messages of compassion, hope, solidarity and understanding about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) to countries around the world. September is the ninth month, symbolic of the duration of pregnancy. Once again this year, we ask that at 9:09 AM on September 9, people take a moment of silence to reflect upon the significance of a healthy pregnancy."

FAS/E INFORMATION, ORGANIZATIONS & SUPPORT

FAS/FAE Information Service

Canadian Centre on Substance Abuse
National Clearinghouse on Substance Abuse
75 Albert Street
Ottawa, ON K1P 5E7
Phone: 1-800-559-4514
(613) 235-4048
Website: <http://www.ccsa.ca>

FAS/E Support Network of BC

14326 Currie Drive
Surrey, B.C. V3R 8A4
Phone: (604) 507-6675
Website: <http://www.fetalalcohol.com>

The purpose of the FAS/E Support Network of British Columbia is to provide information, support and education for families, professionals and the broader community around prevention and intervention issues pertaining to alcohol-related birth defects, including Fetal Alcohol Syndrome and other disabilities caused by drug use during pregnancy

Vancouver YWCA Crabtree Corner

FAS Coordinator
FAS/NAS Prevention Project
101 East Cordova Street
Vancouver, B.C. V6A 1K7
Phone: (604) 689-2808

Description: Located in Vancouver's downtown eastside, this centre sits in one of the most impoverished neighborhoods in the country. It provides advocacy, counseling and peer support to women parenting children with FAS/E. Staff provide information, resources, training, and workshops to a wide range of groups including parents, addictions workers, teachers, corrections workers, women in correctional facilities, high school students, Aboriginal Community Health Workers, and daycare workers.

Sheway Program

101 East Cordova Street,
Vancouver, B.C. V6A 1K7
Call (604) 689-2808
Fax (604) 689-5463

Or email us at: enquire@ywcavan.org

Sheway provides services to pregnant women and those with infants under 18 months of age. Services include nutrition counseling, support to obtain medical care, housing and income assistance, prenatal and postnatal care from midwives, nurses and child development specialists, coupons for food and food bank hampers, parenting support, birth control and HIV counseling, alcohol and drug counseling, and referrals to other community resources.

Recommended Web Sites:

<http://www.fas-saf.com/>

Health Canada's FAS website

<http://www.fasstar.com/>

Fetal Alcohol Syndrome Support Training Advocacy and Resources (FASSTAR) is a website that offers training, information, and resources on FAS/ARND.

<http://www.ccsa.fasis/fasall>

The Canadian Centre on Substance Abuse provides a directory of FAS/FAE information and support services in Canada.

<http://www.fasworld.com>

FASworld was co-founded by volunteers in Toronto, and Tucson, Arizona, and is an international union of parents and professionals whose aim is to raise awareness of birth defects caused by alcohol consumed during pregnancy.

<http://www.fetalalcoholsyndrome.org>

FAS Family Resource Institute is a non-profit organization whose purpose is to identify, understand and care for individuals disabled by prenatal alcohol exposure and their families. Services: referrals and support in finding help, information packets for parents and professionals, and a quarterly newsletter.

<http://www.dcs.wisc.edu/pda/hhi/fen/resource.htm>

The Family Empowerment Network (FEN) is a national organization serving families affected by FAS/E, as well as professionals involved in their lives. This website contains reliable and useful information, written articles and suggested websites to help you understand FAS/E.

<http://www.come-over.to/fasstar>

FAS Stars displays photographs and stories of children and adults with FAS and FAE. This site offers a unique personal perspective. While these faces appear to be ordinary individuals, the personal reflections shared here reveal the painful devastation that alcohol has inflicted on these precious lives.

<http://www.geocities.com/Heartland/Prairie/4786>

Group of Moms who provide post-adoptive support to families who have adopted children who have been prenatally exposed to drugs/alcohol.

<http://TheArc.org/misc/faslist.html#research..radiology.uiowa.edu/Providers/Publications/MMWR/04.07.95>

The Arc's FAS Resource and Materials Guide. Comprehensive site of good information and dozens of links.

<http://www3.sk.sympatico.ca/dhunter/index.htm#home>

Therapeutic games for cognitively impaired adolescent and adult sexual offenders and children with inappropriate sexual behavior. Commercial site devoted to marketing a therapeutic game for adolescent sexual offenders who either have FAS/FAE or are cognitively impaired.

Resources and Publications

Books, Manuals & Reports

A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians

by A.P. Streissguth, R. Ladue & S. Randels

For information, contact:

Indian Health Service

Headquarters West, FAS Project

5300 Homestead Rd. NE

Albuquerque, NM 87110

Fetal Alcohol Syndrome: A Guide for Families and Communities

By Ann Streissguth, Ph.D.

Aimed at professionals, families and communities, this book is readable and easy to understand. It conveys urgent information about medical and social issues surrounding FAS. It gives an overview of FAS, explains how to identify the disorder, how to work with children and adults who have it, how to talk to parents about it and how to prevent its occurrence through sensitive education of prospective mothers and society.

The Broken Cord

By Michael Dorris (1945-1997)

Published by Harper Perennial, 1989.

"A deeply moving book about a single Native father who must deal with his adoptive son's Fetal Alcohol Syndrome. Throughout the book, we see Michael struggling to understand his son's illness, unaware that he has FAS." Michael Dorris, Sept. 24, 1996.

To read the author's entire article, visit the following website:

<http://rehab.educ.ucalgary.ca/courses/edps/425/forum/GoodBookCornerArticles/TheBrokenCord.html>

Reaching Out to Children with FAS/FAE

By Diane Davis. Paperback, 192 pages. ISBN: 0876288573. Published by the Center for Applied Research in Education, December 1995.

A handbook for teachers, counselors and parents who live and work with children affected by FAS/E. It contains an overview of the causes, how it is diagnosed, and the common characteristics seen in these children. There are suggestions and techniques for establishing guidelines at home and school to deal effectively with appropriate and inappropriate behaviors.

Flour Babies

By Anne Fine. Paperback novel, 192 pages. Reading Level: Grades 9-12. Published by the Center for Applied Research in Education, December 1995.

A fictitious novel about students in an English boys school who learn about parenting by carrying around and writing about a 'flour baby', a six-pound bag of flour, over a three-week period. They must keep it clean and dry, maintain its weight and never, never leave its side. The consensus of one grade 8 class who took part in this activity is, "If people were only aware of what a bother babies are, they would never have any."

The books listed below are available at: Parentbooks*

201 Harbord Street
Toronto, ON M5X 1H6
Open Monday to Saturday
(10:30 am to 6 pm EST)
Tel: (416) 537-8334
1-800-209-9182
Email: parentbk@netcom.ca
Website: <http://www.parentbookstore.com>

*Parentbooks stocks many books of interest to families and professionals on topics ranging from childbirth and infant care to education and health, parenting skills and psychology. Book lists are available on Parenting (various age levels), Attention Deficit/Hyperactivity Disorder, Learning Disabilities, and Early Childhood Education.

Fantastic Antone Succeeds:

Experiences in Educating Children with Fetal Alcohol Syndrome
Edited by Judith Kleinfeld and Siobhan Wescott. University of Alaska Press, 1993.

This book is full of true stories about the children and families who must cope with the problems of FAS/E. A must-read book to assist caregivers in understanding how to relate to children with FAS/E and help advocate for the special services that the child needs.

Fantastic Antone Grows Up:

Adolescents and Adults with Fetal Alcohol Syndrome
Edited by Judith Kleinfeld, with Barbara Morse & Siobhan Wescott. University of Alaska Press, 2000.

This is the sequel to *Fantastic Antone Succeeds*. Young people with FAS/E and their caregivers give accounts on their experiences coping with the problems of adolescence and young adulthood. This book contains hands-on, practical teaching methods, concrete communication, and visual-cuing strategies that work so well for individuals with these challenges.

Children with Prenatal Alcohol and/or Other Drug Exposure: Weighing the Risks of Adoption

By Susan Edelstein

This book is designed primarily for professionals working with prospective parents considering adopting an infant or child who has been pre-natally exposed to alcohol and/or other drugs.

Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living

2nd Edition revised and expanded by Sara Graefe

"This book will help parents, teachers, social workers, doctors and other professionals obtain what they need: information & education, support and understanding, referrals & services, realistic expectations and commitment." Elspeth Ross, Parent and Researcher

7th Generation Fetal Alcohol Syndrome Prevention Project

Information available at website:
<http://www.occe.ou.edu/all/7thgen.html>

A video and curriculum guide developed to raise awareness and knowledge about FAS/E. The American Indian Institute has developed a learning module for classroom presentation to grades 6-8 Native students. Students will be active participants in the learning process.

“It Takes a Community”

Author and principal researcher: Marilyn Van Bibber

A resource manual for Community-based prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects. Developed under the guidance of a national First Nations/Inuit Working Group within Canada, this manual includes the “Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative.”

For free copies, please contact:
First Nations and Inuit Health Branch
Ottawa, Ontario K1A 0L3
Tel: (613) 954-8641
Fax: (613) 954-8107

Resource Guide for Aboriginal Community Workers

A guide has been developed by the B.C. Aboriginal Network on Disability Society to assist Aboriginal Community Workers in their work around FAS/FAE. It includes introductory information about FAS/FAE and describes eight main categories of resources.

To order: BCANDS, 1179 Kosapsum Crescent, Victoria, BC V9A 7K7. Tel: (250) 381-7303;
Toll-free 1-888-815-5511; Fax: (250) 381-7312. E-mail: info@bcands.bc.ca.

Situational Analysis: FAS/FAE and the Effects of Other Substance Use During Pregnancy

This report provides an overview of FAS/FAE-related activities across Canada, based on the results of key informant interviews and a survey of programs by Health Canada.

To order: Health Canada Publications, Tunney's Pasture, Ottawa, ON K1A 0K9.
Tel: (613) 954-5995; Fax: (613) 941-5366.

Available online: <http://www.hc-sc.gc.ca/hppb/cds-sca/cds/pdf/>

Fetal Alcohol Syndrome and the Criminal Justice System

By Julianne Conry & Diane Fast
ISBN # 0-9693767-2-3

Information about people with FAS and FAE in the criminal justice system. Judges, lawyers, probation and parole officers, those working within the legal system, individuals and their families will find this tool an excellent resource.

To purchase a copy, contact:
BC FAS Resources Society
P.O. Box 525
Maple Ridge, BC V2X 3P2
(604) 467-5591 T
(604) 467-7102 F

Pamphlets & Posters

Pregnant? No Alcohol.

Available in English and French from Health Canada, there is both a pamphlet and poster advising women not to drink alcohol during pregnancy.

To order:

Health Canada Publications,
Tunney's Pasture, Ottawa, ON K1A 0K9.
Tel: (613) 954-5995; Fax: (613)941-5366

Information available online:

http://www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/pdf/FAS_brochure.pdf;

http://www.hc-sc.gc.ca/hppb/childhood-youth/cyfh/fas/pdf/FAS-poster_E.pdf.

In addition, the following poster can be obtained at the same address mentioned above:

Healthy Parents, Healthy Babies, Alcohol and Pregnancy Don't Mix

This poster is available in English and French and is being released in November 2001.

Video Resources

What is FAS?

24 min. Copyright 1989. No guide available.

Available from:

Luna Media

British Columbia

Telephone: (604) 943-4024

This educational video explores the effects of alcohol on the fetus, related birth defects, the characteristics of FAS children and adults, as well as the personal and social effects of this problem. It promotes prevention via public education, particularly of high-risk groups.

David with F.A.S.

"An unusual and striking film." Vancouver Sun

Directed by Cree filmmaker

Gil Cardinal

44 min. Catalogue #: C9196 039/EC009

Can be purchased by contacting:

National Film Board of Canada

1-800-267-7710

or On loan through local public libraries.

"Focusing on the human experience of fetal alcohol syndrome (FAS), this video centres around David Vandenbrink, a 21-year-old victim of FAS and his adoptive mother, Mary. Both are coping with the consequences of this difficult syndrome; David struggles internally, while Mary reaches out with teaching and advocacy." NFB Catalogue 2000

Frances and Irene

16 min. Northwest Community College

Two cases are presented whereby both women are referred to different agencies for help. Both agencies emphasize healthy lifestyle practices to help in recovery from substance abuse. One of these offers a six-week residential program incorporating some traditional Native beliefs.

Life Sentence Fetal Alcohol Syndrome

16 min. CBC International Sales

FAS can lead to learning disabilities, poor judgment and antisocial behavior. New research suggests that Canadian prisons are full of victims of FAS, many of them undiagnosed. A study shows that 20-25 per cent of prison inmates have some degree of FAS.

A Mother's Choice

27 min. Gryphon Productions

This video examines the root causes of FAS from the perspective of Native mothers. Focuses on FAS support group whose members provide strong messages about drinking while pregnant.

Preventing FAS

21 min. LENA Productions.

This video, for professionals in community development, education and health, looks at primary and secondary prevention of FAS. Primary prevention aims to reduce alcohol consumption generally and to raise public awareness of alcohol-related birth defects. Secondary prevention programs identify high-risk women, and help them to stop drinking.

Additional Video Resources:

Contact: FAS Bookshelf Inc.
#438-6540 E. Hastings Street,
Burnaby, B.C.
V5B 4Z5
Phone: (604) 942-2024
Fax: (604) 942-2041


INJURY-RELATED DEATHS IN ABORIGINAL PEOPLE IN CANADA

Submitted by Karin Johnson, NFNIIPWG

Injury is one of the leading causes of death in Aboriginal people. The number of injury-related deaths in the Aboriginal population is approximately three to six times higher than in the Canadian population. In both the Aboriginal and Canadian populations, deaths due to injuries are higher among males than among females. The age when these injuries occur is similar in both populations, with numbers being particularly high among those aged 15-24. The most frequent causes of fatal injury in Aboriginal people are motor vehicle accidents (MVA's) and suicides. Although injury-related deaths remains high, things have improved over time: injury deaths have decreased by 37 per cent between 1989-1993. Most of this decrease was in deaths due to MVA's and drowning; however the numbers of deaths due to suicide and homicide have stayed relatively the same.

Motor Vehicle Accidents

MVA's are one of the most common type of injury death, particularly among males, in the Aboriginal population. Risk factors for MVA's include: greater distances they have to travel for regular activities, their isolation from emergency facilities and their frequent use of riskier vehicles such as all terrain vehicles and snowmobiles, especially in the North.

Drownings

Aboriginal people experience a higher number of drowning-related deaths compared to the Canadian population. Drowning-related deaths are 15 times higher in toddlers compared to other age groups and are also higher among males. Approximately 8 out of every 10 drownings involve a male. In spite of the high number of deaths due to drowning, drowning-related deaths have decreased by 56 per cent between 1979 and 1993. Risk factors contributing to drownings include: proximity to water, especially in Northern climates where the water temperature is low and can produce death from hypothermia, the low use of floatation devices, and alcohol use.

Fire and Flames

Fire- and flame-related injuries are four to eight times higher than in the Canadian population. However, in the periods 1979-1981 and 1991-1993, deaths from fire and flames decreased by 44 per cent. Risk factors for fire and flame-related injuries include: wood frame construction, few smoke detectors and smoking habits.

Falls

Fall-related injuries are strongly associated with older age groups. In the Aboriginal population, fall-related injuries are approximately three times higher than in the Canadian population. Between 1979-1981 and 1991-1993, the deaths due to falls among people age 25 or older decreased.

Poisonings

Accidental poisoning seems to be more frequent in the Aboriginal population compared to the Canadian population. Accidental poisonings are four times higher than the average and are more common in children under the age of 4. However deaths due to accidental poisonings are increasing in older age groups.

Suicide and Homicide

Suicide is three to four times higher than in the Canadian population and accounts for roughly 25 per cent of all injury deaths in the Aboriginal population. The highest numbers of deaths due to suicides tend to be between the ages of 15 and 24 and the numbers of completed suicides are higher in males than in females. Deaths due to homicide in Aboriginal people are four to five times higher than average, with the majority of the victims being younger males.

Risk factors for suicide, violence, and assault include: community characteristics like high number of occupants per household, single-parent families, fewer elders, lower average income and education, and hunting lifestyle (access to firearms).

Aboriginal people face many risks of injuries. Although there have been some reductions in the number of deaths due to injury in the Aboriginal population, they are still high, especially compared to those of the general Canadian population. Injuries account for a large number of premature deaths in Aboriginal people. Motor vehicle accidents and drug poisoning cause many deaths, while suicide is widespread, and tends to occur at a young age. There is some hope, however, with many communities and organizations taking action to prevent injuries and reduce their accompanying burden in the Aboriginal population.

Source: Unintentional and Intentional Injury Profile for Aboriginal People in Canada, 1990-1999

Website: <http://hc-sc.gc.ca/fnihb-dgspni/fnihb/chp/ipc/publications>

