

**Talking About Special Education
Volume II ...**

Fetal Alcohol Syndrome/ Fetal Alcohol Effect

**An Information
Handbook
Prepared by**

**First Nations
Education Steering Committee
and the
First Nations
Schools Association**

October, 1998

Introduction

This handbook is the second in a series of informational handbooks prepared by the First Nations Education Steering Committee (FNESC) and the First Nations Schools Association (FNSA). This handbook follows from the general discussion of special needs included in *Talking About Special Education Volume I*, which includes issues such as parental involvement, special needs identification, individual education plans, and advocacy.

Several sources of information were used in the development of this publication. FNESC and the FNSA would like to gratefully acknowledge the following work:

Aboriginal Nurses Association of Canada (ANAC). 1997. *It Takes a Community. A Resource Manual for Community-Based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects.*

Contact the ANAC at 192 Bank Street, Ottawa, ON K2P 1W8, phone (613) 236 - 3373, e-mail Info@anac.on.ca

Proceedings of The First Nations Schools Association Conference on Special Needs Education. 1998. (copies available from the FNESC/FNSA office)

The articles used include the submissions from Debra Evensen and the Fetal Alcohol Support Network.

What is Fetal Alcohol Syndrome?

(Adapted from D. Evensen)



Fetal Alcohol Syndrome (FAS) is caused by alcohol intake during pregnancy. It is most easily diagnosed between the ages of 3 to 12 years of age. Physicians specifically trained in birth defects make the diagnosis which must include the following:

- 1 prenatal and/or postnatal growth retardation;
- 2 a characteristic pattern of facial features and other physical abnormalities; and
- 3 central nervous system dysfunction.

Fetal Alcohol Effect (FAE) includes some, but not all of the physical characteristics, but does include the organic brain damage. Although those with the effect may have disabilities like those with the full syndrome, they are less likely to receive the help they need because the handicap is “invisible.”

Educators and parents unfamiliar with the normal responses of children with FAS/E may wrongly assume that a child is misbehaving when, in fact, that child is trying desperately to do what is expected.

Only by addressing fetal alcohol [syndrome/effect] can we begin to stop it. ... Any community with the guts to talk about fetal alcohol can truly start to heal.
D. Evensen, 1998

Understanding People With FAS/E

(Adapted from Aboriginal Nurses Ass., 1997)

Infants

Infants may experience a range of characteristics. Severely affected infants may require hospitalization from disorders affecting major organs. Infants with FAS/E are also prone to infections, and they generally develop more slowly than other infants. They may have difficulty sleeping, sucking and swallowing, keeping food down, gaining weight, and may be irritable and unpredictable. Be patient, and keep their level of stimulation low.

Young Children

From toddler through preschool, children with FAS/E may be slow to develop, and if they are severely affected they may continue to have health problems due to organ damage. Delays in their speech and vocabulary may be noticeable in preschool years, and referral to therapy and special needs preschools may be considered. Children with FAS/E may be clumsy and accident prone due to late development of their motor skills, and their learning through experience, seeing and hearing may be delayed. They may rely more on touch to explore their surroundings. Over-stimulation or changes in daily routine can lead to tantrums and destructive behaviour, and interacting with other children may be a problem. An assessment may be needed to determine what special services are needed to ensure a successful transition to school.

School Age Children with FAS/E

There are physical, learning and behavioural difficulties common to most children with FAS/E. Their speech and language development may be delayed. They may have problems mentally “registering” information, and once information is learned it may take more time to be “retrieved.” Their ability to understand consequences may be impaired, and learning disabilities are common. The child may have a short attention span, under-developed motor skills, and reasoning and learning disabilities resulting in inappropriate behaviour.

Adolescents and Young Adults with FAS/E

Youth with FAS/E and their caregivers are dealing with normal teenage issues plus the concerns of FAS/E. Youth with FAS/E can be easily misled, and may need social skills interventions, a supervised environment and appropriate school programming. Affected youth may have problems making friends because of unacceptable or immature behaviour, and they may have difficulty in communicating and understanding instructions. Abstract thinking is slow to develop, and their literacy and numeracy skills may be below their age and grade level. Attention deficit and hyperactivity will affect learning and relationships with peers. Their excess energy should be directed. Some affected youth become skilled in individual sports like swimming or running, and sports can help to build self-esteem and social skills. The youth, however, may have difficulty with rules, daily living skills, managing money and time; therefore, life skills must be reinforced from an early age.

Basic Needs of Persons Living with FAS/E

(Adapted from Aboriginal Nurses Ass'n, 1997)



The person affected with FAS/E needs nurturing, understanding and support. A stable home, responsive school system, supporting friends and caring community are important aspects of nurturing the child.

The person with FAS/E needs to feel that he or she is a part of the community. Self-esteem and acceptance are critically important.

Parents of children with FAS/E need connections with the community, other parents, and services that provide family-centred and culturally sensitive support. Parents may need help dealing with addictions, poverty, low self-esteem, and limited work and parenting skills. Caregivers should be respectful and non-judgemental toward families living with FAS/E and acknowledge that the parents are performing a demanding job.

The community social safety net should meet the basic needs of family members and provide early assistance to the child's family. Families should have access to appropriate assessments and diagnoses and be empowered to contribute to all discussions about their children.



An Ideal Classroom for Students with FAS/E

(Adapted from D. Evensen)

The Ideal Classroom

- √ structured with flexibility
- √ spacious and space organized around themes

The Ideal Teacher Interaction

- √ warm and accepting
- √ consistent in behavioural expectations
- √ frequent positive feedback based on realistic expectations
- √ regular communications between parent and school

Teaching Methods in the Ideal Classroom

- √ emphasis on collaborative problem-solving
- √ more time allowed for completion of in-class assignments
- √ opportunities for building competence
- √ emphasis on practical application of the curriculum
- √ teaching of vocational and daily living skills
- √ focus on process, away from product





Common Misinterpretations of Responses in Students with FAS and FAE

BEHAVIOUR	MISINTERPRETATION	ACCURATE INTERPRETATION
noncompliance	willful misconduct, attention seeking, stubborn	difficulty translating verbal directions into action, doesn't understand
repeatedly making the same mistake	willful misconduct, manipulative	can't link cause to effect, can't see similarities, difficulty generalizing
often late	lazy, slow, poor parenting, willful misconduct	can't understand the abstract concept of time, needs assistance organizing
not sitting still	seeking attention, bothering others, willful misconduct	neurologically based need to move while learning, sensory overload
poor social judgement	seeking attention, bothering others, willful misconduct	not able to interpret social cues from peers, doesn't know what to do
overly physical	willful misconduct, deviancy	hyper or hypo-sensitive to touch, doesn't understand social clues regarding boundaries
doesn't work independently	willful misconduct, poor parenting	chronic memory problems, can't translate verbal directions into action

FAS/E in the Classroom

(Adapted from FAS/E Support Network)

When teaching students with FAS/FAE, try the following:

- provide order !!
- Keep a routine oriented classroom;
- Provide a highly structured environment;
- Build in transition periods;
- Make areas of the room clearly defined by activity -- wall decorations should reflect only what goes on in that area;
- Put as little as possible on the walls;
- Keep colour to a minimum;
- Put desks in rows -- groupings do not work;
- Put the child directly across from speaker for eye contact;
- Use uncluttered worksheets;
- Give immediate feedback on assignments;
- Keep a posted schedule for the day's activities;
- Ask visitors to the classroom to arrive on time;
- Flick the classroom lights to get attention;
- Test one on one for knowledge, not attention;
- Use redirects -- "this is your ... this is where it goes";
- Plan ahead for special events and keep them infrequent;
- Break up concentration activities with physical activities;
- Store books, materials, etc. by type, not size;
- Label shelves and cupboards with words and pictures/symbols;



- Remove charts, maps etc. after use;
- Break down work into small pieces;
- In group activities, pair a FAS/E child with a high tolerance child;
- Have the same teacher, teacher aide, assistant all year;
- Teach memory strategies;
- Control interruptions of the classroom;
- Do not allow any talking-out without hands up;
- Use homework books with parents, making the teacher and parents responsible for the books;
- Clean out the child's desk with them at least once weekly;
- Use wide spaced paper;
- Use pink highlighters, not yellow;
- Find a way to provide at least some lunch hour and recess supervision;
- Keep any time out very short;
- Supervise the child when going from one place to another;
- Use open book tests with the areas being tested highlighted;
- Limit homework to a reasonable amount;
- Allow the student more time to respond to questions;
- Try to have all people who interact with the child use the same language to mean the same thing;
- Give thought to developing a peer mentoring program;
- After elementary school, emphasize life skills and vocational training;
- Don't personalize behaviour; and
- Listen to parents! They often know what works best.



Sources of Information on FAS/E in BC

(Adapted from Materials from the Provincial FAS/E Prevention Coordinator)

Alcohol and Drug Information and Referral Service

#202 - 3102 Main Street, Vancouver, B.C., V5T 3G7

Toll-free: 1 - 800 - 663 - 1441

phone: (604) 660 - 9382

fax: (604) 660 - 9415

Information and referral to treatment services and agencies for those who are seeking assistance with alcohol and other drug misuse.

B.C. FAS Resource Society

Sunny Hill Health Centre for Children

3644 Slocan Street, Vancouver, B.C., V5M 3E8

Project Office

#302 - 11965 Fraser Street, Maple Ridge, B.C. V2X 8H7

phone: (604) 465 - 5211

fax: (604) 465 - 8204

Information about support and services to families, professionals and the broader community around prevention, intervention and treatment issues related to alcohol and other drug related developmental disabilities.



BC Aboriginal Network on Disabilities Society

1179 Kosapsum Cres., Victoria, B.C. V8X 7K7

Toll free: 1 - 888 - 815 - 5511

phone: (250) 381 - 7303

fax: (250) 381 - 7312

Resources are available to First Nations parents, groups and educators, including videos, manuals, displays and brochures dealing with FAS and the effects of alcohol on pregnancy.

Prevention Source BC

2750 Commercial Drive, Vancouver, B.C. V5N 5P4

Toll free: 1 - 888 - 663 - 1880

phone: (604) 874 - 8452

fax: (604) 874 - 9348

Information service to residents of BC seeking information about prevention, organizations, programs, materials and research in the area of substance abuse.

FAS/E Provincial Prevention Coordinator

Women's Health Centre

Rm 501, 4500 Oak Street, Vancouver, B.C. V6H 3N1

phone: (604) 875 - 3599

fax: (604) 875 - 2039

Information on how to access information, resources, expertise and services related to FAS/E. Helps with networking among relevant agencies, and setting up community based initiatives.



FAS/E Support Network

151 - 10090 152nd Ave., Suite 187, Surrey, B.C. V3R 8X8
phone: (604) 589 - 1854
fax: (604) 589 - 8438 e-mail: fasnet@istar.ca

Information on support, consultation and advocacy services for individuals, families, professionals and the broader community around prevention, intervention and treatment issues.

FAS/E Information Service

Canadian Centre on Substance Abuse
#300 - 75 Albert Street, Ottawa, Ontario, K1P 5E7
Toll-free: 1 - 800 - 559 - 4514
phone: (613) 235 - 4048
fax: (613) 235 - 8101

A national service that includes a listserver for discussion with other individuals interested in FAS/E. E-mail message to list@ccsa.ca and type “*join fastlink*” in the message.

FAS Early Intervention Consultant

Aurora Centre
4500 Oak Street, 5th floor, Vancouver, B.C. V6H 3N1
phone: (604) 875 - 2017
fax: (604) 875 - 3039

Works with health/social providers on early intervention approaches with women at risk. Develops policy regarding treatment and disseminates information on early intervention.

Society of Special Needs Adoptive Parents (SNAP)

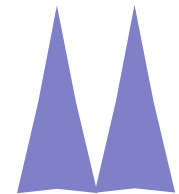
#1150 - 409 Granville Street, Vancouver, B.C. V6C 1T2
Toll-free: 1 - 800 - 663 - 7627
phone: (604) 687 - 3114
fax: (604) 687 - 3364

Assists special needs adoptive families through mutual support, information sharing and advocacy through support groups, one-on-one resource parents, and a lending library.

YWCA Crabtree Corner FAS/NAS Prevention Project

101 East Cordova Street, Vancouver, B.C. V6A 1K7
phone: (604) 689 - 2808
fax: (604) 689 - 5463

Offers educational workshops, a resource lending library, a peer support group for moms with children with FAS/NAS and information and crisis counselling. Posters and pamphlets are available, as well as guides to prevention, caring for children and a guide to resources.



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