Health Canada Santé Canada

It Takes a Community

Framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative

A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects

Canada

Framework for the First Nations and Inuit Fetal Alcohol Syndrome/ Fetal Alcohol Effects Initiative

Prepared by the FAS/FAE Technical Working Group
(accountable to the CPNP/FAS/E (FNIC)
National Steering Committee, representing the
Assembly of First Nations, the Inuit Tapirisat of Canada,
and the First Nations and Inuit Health Branch)

Prepared with the assistance of Clay McLeod, LL.B., B.Ed.,
Continuum: Advocacy and Educational Fieldwork

Our mission is to help the people of Canada
maintain and improve their health.

Health Canada

Published by authority of the Minister of Health

For additional copies, please contact:
First Nations and Inuit Health Branch
Health Canada
Postal Locator 1920A
Ottawa, Ontario
K1A 0L3

Tel: (613) 954-8641
Fax: (613) 954-8107

Également disponible en français sous le titre
Ça prend une communauté

This publication can be made available in/on computer diskette/
large print/audio-cassette/braille upon request.

© Minister of Public Works and Government Services, 1997
Cat. H34-84/1997E
ISBN: 0-662-25944-0

Reprint 1997, 2001

Table of Contents

1 PREFACE 1

2 INTRODUCTION 3
FAS/FAE 3
First Nations and Inuit Historical Background 3
Cultural Context 4
The First Nations and Inuit FAS/FAE Initiative 4
Community Feedback 5

3 PURPOSE OF THIS FRAMEWORK 7

4 GUIDING PRINCIPLES OF THE INITIATIVE 8
Strengthening and Supporting Families and Communities Wholistically 8
Family-Centred Prevention 8
Community-Based and Culturally Appropriate 8
A Coordinated Approach through Collaborative Partnerships 9
Contributing to Capacity Building 9
Universal and Equitable Access 9
Accountability 9

5 VISION, GOALS AND OBJECTIVES OF THE INITIATIVE 11
Vision 11
Goals 11
Objectives 11
Objective #1 — Raising Awareness 11
Objective #2 — Reaching Those At Risk 12
Objective #3 — Working with Those Affected 12
Objective #4 — Creating Linkages 13
Global Initiative Evaluation 13

6 INITIATIVE COMPONENTS . . . 17
Target Groups . . . 17
Operational Definitions of Initiative Components . . . 17
Health Promotion and Awareness . . . 17
Education and Training . . . 17
Identification of Diagnostic Tools and Intervention Supports . . . 18
Initiative Management Factors . . . 18
Linkages . . . 18
Coordination . . . 19
Research . . . 19
Initiative Management . . . 19
Initiative Evaluation . . . 20

7 INITIATIVE ELIGIBILITY AND FUNDING . . . 21
Eligible Project Sponsors . . . 21
First Nations and Inuit FAS/FAE Initiative Budget . . . 22
National Coordination and Support . . . 22
Special Projects Fund (National Steering Committee) . . . 22
Community-Based Projects . . . 22
Initiative Funding . . . 22

8 INITIATIVE IMPLEMENTATION . . . 24
Community Level . . . 24
Regional Level . . . 24
National Level . . . 25
Communications . . . 26

9 APPENDIX A: WHAT ARE FAS/FAE? . . . 27

10 APPENDIX B: REFERENCES . . . 30

11 APPENDIX C: GLOSSARY OF TERMS . . . 32

12 APPENDIX D: TERMS OF REFERENCE OF THE FAS/E TECHNICAL WORKING GROUP . . . 34

13 APPENDIX E: EXECUTIVE SUMMARY OF INITIATIVE FRAMEWORK . . . 36

Preface

CHAPTER 1

FAS/FAE is a nation-wide health concern, and it does not discriminate on the basis of race, socio-economic status, or sex. Because of lack of recognition and diagnosis, it is difficult to be certain of how many individuals have FAS/FAE. About one baby out of 500 to 3000 annual live births will have FAS; this is called the *incidence* of FAS (how often a problem occurs annually).

The incidence of FAS is greater than the incidence of either Down's Syndrome or Spina Bifida. The incidence of FAE is 5 to 10 times higher than the incidence of FAS (BC FAS Resource Society, 1998, p. 14 & Alberta Medical Association, 1999, citing A.P. Streissguth & D.M. Burgess, "FAS and FAE: Principles for Educators" *Phi Delta Kappa* 1992; 17: 437–443).

This means that, each year in Canada, somewhere between 123–740 FAS babies are born, and around 1000 FAE babies are born (based on 370,000 births per year). *Prevalence* means the number of people in a population that have a problem at a specific point in time. The prevalence of FAS/FAE in high-risk populations, including First Nations and Inuit communities, may be as high as 1 in 5 (BC FAS Resource Society, 1998, p. 14).

As a result of their organic brain differences, individuals with FAS/FAE, their families, and their communities experience a number of challenges and difficulties. Also, as a result of widespread myths about FAS/FAE, many people lack understanding of these difficulties. The extra lifetime costs to society associated with an FAS/FAE individual have been estimated at US$1.4 million (Streissguth, 1991).

Although this figure is dated and taken from the American context, it is the only such estimate that has been made. It is beyond question that FAS/FAE affected individuals require extraordinary health care, social services, corrections, and educational services that represent significant monetary costs to society (BC FAS Resources Society, 1998, p. 14). The economic and social costs associated with FAS/FAE are significant, impacting Canadian society as a whole.

The rates of FAS/FAE in some First Nations and Inuit communities are much higher than the national average. Moreover, FAS/FAE exists in the context of the history of colonization and devaluation endured by First Nations and Inuit, which has resulted in a loss of culture. Therefore, the issue of FAS/FAE is a serious concern to First Nations and Inuit communities.

In the past, because of a lack of awareness of FAS/FAE, people have tended to focus on the negative aspects of FAS/FAE. Individuals affected by FAS/FAE have been isolated from their families and communities, and the communities' men, pregnant women, and mothers have been impacted by shame, guilt, and grief.

Strategies are emerging, and awareness of ways to address FAS/FAE issues through prevention, identification, and intervention efforts. With support and intervention, FAS/FAE affected individuals can lead productive lives. Most importantly, people are beginning to realize that FAS/FAE are community issues that need to be addressed on an individual, family, and community level, utilizing partnerships at the regional and national level.

Introduction

CHAPTER

FAS/FAE

Regional differences exist in the classification, description, and diagnosis of conditions arising from prenatal exposure to alcohol. These conditions include Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), partial Fetal Alcohol Syndrome (partial FAS), Alcohol-Related Neurodevelopmental Disorder (ARND), and Alcohol-Related Birth Defects (ARBD). “There is not yet an agreed upon global term that encompasses FAS, partial FAS, ARND, and ARBD” (BC FAS Resource Society, 1998, p. 11). Throughout this framework, for simplicity and consistency, the traditional (although somewhat dated) and familiar terminology “FAS/FAE” will be used to encompass all of these conditions.

FAS/FAE are “medical conditions that must be diagnosed by a physician” (Special Programs Branch, 1996). Amongst other things, FAS/FAE individuals experience neurodevelopmental disorders as a result of prenatal alcohol exposure.

In other words, FAS/FAE are birth defects, resulting from a pregnant mother’s consumption of alcohol during her pregnancy. Through education, awareness, support, and healing, FAS/FAE can be prevented. Children living with FAS (1) have a low birth weight and a slow growth rate, (2) have abnormal facial features and ears, and (3) often experience learning and behaviour problems, such as hyperactivity, poor judgment, and anti-social behaviour. Children living with FAE have some, but not all of the characteristics described above. FAE children do not have a “milder” case of FAS, and they can suffer debilitating learning and behaviour problems as severe as those experienced by FAS children. FAS/FAE are leading causes of developmental delays in children.

Individuals affected by FAS/FAE often experience secondary disabilities such as mental health problems, disrupted school experience, involvement with crime, substance abuse, dependant living, and employment difficulties. Appendix A describes the diagnostic criteria for FAS/FAE and some of the difficulties experienced by FAS/FAE individuals.

First Nations and Inuit Historical Background

First Nations and Inuit in Canada find themselves living in “Fourth World” conditions. This means that many of them experience Third World socioeconomic conditions within the boundaries of a wealthy, industrialized, First World nation (Royal Commission on Aboriginal Peoples, 1996, vol. 3, pp. 1 & 107–108).

The colonial history of contact between European settlers and Aboriginal peoples has led to the devaluation and silencing of First Nations and Inuit cultures (Royal Commission on Aboriginal Peoples, 1996, vol. 1 & Berger, 1991). Policies ranging from the forced removal of First Nations and Inuit children from their homes to be raised in residential schools to the creation of reserves and the forced relocation of Inuit communities, and laws ranging from the prohibition of the potlatch to blatantly discriminatory voting laws, illustrate the dehumanization and objectification of First Nations and Inuit.

Having been stripped of political agency on the nation level because of colonial attitudes of dominance and paternalism, First Nations and Inuit, families, and communities find themselves with decreased levels of self-sufficiency (Mussell et al., 1991, p. 13–16). For instance, as a result of their upbringing in residential schools, generations of First Nations and Inuit have been unable to develop traditional knowledge and skills, including basic parenting skills.

In the face of enduring these hardships and cultural disruption, addictions, and substance abuse have become prevalent in Aboriginal communities (Royal Commission on Aboriginal Peoples, 1996, vol. 3, pp. 157–165). Furthermore, an intergenerational cycle of physical, psychological, sexual abuse, and loss of spiritual practices has sprung from this history of devaluation and control, providing fertile soil for addictions, alcoholism, and substance abuse.

As one woman appearing before the Royal Commission on Aboriginal Peoples put it, the "absence of self-government created a climate in which alcoholism and violence were allowed to flourish." (Royal Commission on Aboriginal Peoples, 1992, p. 19).

Cultural Context

The Western European concept of "health" tends to focus on disease and illness. In contrast to this focus, First Nations and Inuit conceptions of health focus on wellness (Mussell et al., 1991, p. 73). Furthermore, wellness is understood in a *wholistic* fashion, taking all of the *determinants of health* into account. "In First Nations cultures, from traditional times to present times, *health* [has meant] balance and harmony within and among each of the four aspects of human nature: physical, mental, emotional, and spiritual." (Mussell et al., 1991, p. 19).

In contrast to the Western European focus on individualism, First Nations and Inuit cultures also stress the importance of collective approaches to issues, approaches that integrate the individual with his or her community and family (Mussell et al., 1991, p. 88). Furthermore, a key notion in First Nations and Inuit conceptions of wholistic health is that of *healing*. Consistent with the First Nations and Inuit focus on wellness, healing is an integrative and dynamic concept that promotes the attainment of balance and harmony (Stevenson, 1997, pp. 6–7). To remain true to these traditions, First Nations and Inuit communities impacted by FAS/FAE need to address FAS/FAE issues as individuals, families, and entire communities, striving for wholistic health and healing for all members of the community.

The First Nations and Inuit FAS/FAE Initiative

The 1999 Federal Budget included an allocation of funds aimed at expanding the existing Canada Prenatal Nutrition Program (CPNP). Additional funding was earmarked for initiatives specifically addressing FAS/FAE issues. The First Nations and Inuit FAS/FAE Initiative will be delivered through the

First Nations and Inuit Health Branch (FNIHB) and the Population and Public Health Branch (PPHB). The funding breakdown is as follows:

	FNIHB		PPHB
1999/2000	$ 750,000		$1,250,000
2000/2001	$1,350,000		$2,650,000
Annually (Ongoing)	$1,700,000		$3,300,000
Total	**$3,800,000**	+	**$7,200,000 = $11 Million**

FNIHB is responsible for delivering First Nations and Inuit Component (FNIC) programs to First Nations (on-reserve) and Inuit communities in Canada. This means that $3.8 million will be available over the initial three years, and starting in 2001/2002, $1.7 million in funding will be available every year to support a new initiative addressing FAS/FAE issues impacting on-reserve First Nations and Inuit across Canada. Throughout this framework, the First Nations and Inuit FAS/FAE Initiative will be referred to as the "Initiative."

Community Feedback

Between January 20, 2000 – February 23, 2000, regional information-sharing and feedback discussion sessions were held in First Nations and Inuit communities across Canada. These sessions were designed to collect feedback and input from First Nations and Inuit communities about FAS/FAE issues, ranging from a description of the impact that FAS/FAE have in communities to an identification of the needs of communities in relation to FAS/FAE.

Feedback indicated that FAS/FAE have a significant impact on First Nations and Inuit communities; for instance, in the Northwest Territories, FAS/FAE were described as a "northern epidemic." Session participants described many of the secondary disabilities associated with FAS/FAE, ranging from school absenteeism to involvement with the corrections system, and many participants shared painful personal experiences and stories. Session participants also stressed the need to view FAS/FAE issues in historical context, as part of the legacy of colonialism and devaluation experienced by First Nations and Inuit in Canada.

Session participants also stressed the need to address FAS/FAE issues wholistically, taking all of the determinants of health into account and working towards solutions as whole families and communities. Session participants identified particular related issues that cannot be ignored when addressing FAS/FAE issues; examples of related issues described by participants include discrimination, poverty, domestic violence, solvent and drug abuse, and residential school syndrome.

Session participants attempted to identify the needs of their communities as they strive to address FAS/FAE issues. In many sessions, this task proved difficult because of a lack of awareness in relation to FAS/FAE generally, as well as a lack of information about existing programs and resources. Session participants also expressed frustration at the magnitude of the problem and the scarcity of funding. Participants stressed that solutions to FAS/FAE issues cannot be based on "band aid" approaches and need to be adequately funded to allow for grassroots work to proceed at the community level.

Particular needs identified by session participants include raised general awareness about FAS/FAE (including education in schools), support for FAS/FAE affected individuals, families, and communities, training for persons working with FAS/FAE affected individuals, training for social and health services professionals and community workers, information about existing resources, early identification and diagnosis of FAS/FAE affected children, substance-abuse treatment programs, and opportunities for networking and community healing. Most of these needs were echoed and reiterated in several regions, and some (e.g., raising awareness) were universally acknowledged as priorities for community action.

Purpose of this Framework

CHAPTER

The purpose of this framework is to guide the development, implementation, and evaluation of the Initiative, which will provide a structure and identify Initiative components relative to the needs of First Nations and Inuit communities. This framework is based on the values, principles, objectives, and needs identified by First Nations and Inuit communities across Canada during the information-sharing and feedback discussion process described on page 5.

Guiding Principles of the Initiative

CHAPTER

Strengthening and Supporting Families and Communities Wholistically

Parents are primarily responsible for taking care of and guiding the development of their children. Since "it takes a community to raise a child," (Van Bibber, 1997) the extended family and community as a whole shares responsibility with and supports the parents in carrying out their responsibilities.

Examples of community support of parents in carrying out their responsibilities include helping parents deal with behavioural challenges, teaching parents coping skills, providing respite care, and facilitating parents' access to helpful information. This approach is consistent with First Nations and Inuit concepts of approaching issues wholistically, as families and communities.

Family-Centred Prevention

Mothers, fathers, children, and the extended family will be the primary consideration in planning, developing, carrying out, and evaluating projects, services, and activities undertaken as part of the Initiative.

Community-Based and Culturally Appropriate

Decision making and action must be related to the needs and in accordance with the goals and aspirations of each individual community and at a pace determined by that community. Initiative participants must have and need to take an active role in planning, designing, carrying out, operating, and evaluating individual projects, services, and activities undertaken as part of the Initiative. Expectations and requirements for projects, services, and activities undertaken as part of the Initiative should be flexible, allowing individual communities to fashion and tailor local Initiative components to their diverse needs and circumstances.

Furthermore, Initiative components must meet the social, cultural, and language needs of the target groups in the communities in which they are to be carried out. This means that tools and resource materials must be culturally sensitive, user-friendly, easily understood, and translated into First Nations and Inuit languages when appropriate.

A Coordinated Approach through Collaborative Partnerships

Communities and organizations operating and carrying out projects, services, and activities undertaken as part of the Initiative should coordinate their efforts with those of governments (where appropriate) and other organizations operating and carrying out similar projects. This will help to avoid overlap and duplication and to encourage the sharing of expertise, information, and resources (mutual aid). The creation and maintenance of partnerships and liaisons should also be encouraged, because such linkages will facilitate networking and communication vital to the effective and efficient implementation of projects and activities and delivery of services.

This type of collaboration (working together) may also enable communities and organizations to stretch their funding and maximize outcomes by integrating programs, initiatives, or activities (e.g., joint conferences) when possible. Communities and organizations need active financial and technological support if such collaboration efforts are to succeed.

Contributing to Capacity Building

"Capacity building" means increasing the personal and collective knowledge, strength, skill, and ability of First Nations and Inuit to plan, develop, implement, carry out, manage, and evaluate programs and services needed in their communities. As administration and governance of community programs and services devolves to First Nations and Inuit communities, First Nations and Inuit require access to training which can facilitate their development of the self-sufficiency to be able to manage and sustain those programs independently.

By their nature, Initiative projects, services, and activities should contribute to and encourage First Nations and Inuit self-determination and capacity building, including innovation and creativity in the design of projects and activities and the delivery of services.

Universal and Equitable Access to Quality Programs

Initiative participants are entitled to the same level and same quality of service compared to other Canadians living in similar locations.

Accountability

Projects, services, and activities undertaken as part of the Initiative should be carried out and delivered efficiently and effectively, with an emphasis on achieving goals and objectives in a fiscally responsible manner.

Projects, services, and activities undertaken as a part of the Initiative should be accountable to the people that they serve. This accountability can be enhanced through community involvement in the planning, carrying out, provision, implementation, and evaluation of such projects, services, and activities. To ensure accountability to individuals, children, families, and communities served, communities need to be represented in management structures (e.g., steering committees with community member representation); they also need to be informed about and meaningfully involved in making funding decisions.

Financial reporting structures shall be consistent with accepted accounting standards, practices, and methods. Reporting structures shall be established and will include and inform individuals, families, communities and governments.

Furthermore, eligible recipients undertaking projects, services, and activities as part of the Initiative shall evaluate the benefits of such projects, services, and activities to the individuals, children, families, and communities that they serve, as well as the fit between projects, services, and activities and the vision, goals and objectives of the Initiative (described in Chapter 5).

Vision, Goals and Objectives of the Initiative

CHAPTER

Vision

The vision and ultimate purpose of the Initiative is to *create conditions in which maternal and infant health will flourish.* This vision can be addressed by striving to achieve definable goals and objectives.

5.2 Goals

Goals

The goals of the Initiative are to (1) prevent FAS/FAE births, and (2) increase the knowledge, skills, and quality of life of FAS/FAE affected children, mothers, fathers, and families. These goals can be addressed by striving to achieve measurable objectives.

Objectives

Objective #1 — *Raising Awareness*

The aim of this objective is to avert health problems relating to FAS/FAE before they occur by increasing the awareness of the general population, particularly young people, about FAS/FAE and the dangers of drinking during pregnancy (this is called “primary prevention” or “health enhancement”).

Examples of Related Initiative Activities:

Increase community awareness about FAS/FAE

- Distribute culturally-relevant basic information (e.g., pamphlets, brochures, videos, and websites)
- Utilize diverse methods of and settings for communication (e.g., conferences, workshops, focus groups, various media, and press releases)

Establish educational initiatives relating to FAS/FAE

- Create and deliver school awareness curricula
- Create and deliver awareness curricula for various segments of the community (e.g., parents, youth, and community workers)

Objective #2 — *Reaching Those At Risk*

The aim of this objective is to identify and work with persons at risk, such as pregnant women or women in their child-bearing years who consume alcohol ("women at risk") and their partners, in order to reduce the risk of FAS/FAE (this is called "secondary prevention" or "risk reduction").

Examples of Related Initiative Activities:

Train community workers and health care professionals to deal effectively with persons at risk

- Deliver training
- Create referral networks
- Facilitate access to prenatal support programs

Promote healthy community development

- Change community attitudes, values, and beliefs
- Shift focus from blame to acceptance

Create linkages and provide referrals to other programs designed to assist persons at risk, such as:

- Programs that provide mental health services to persons at risk
- Programs that provide detoxification services for pregnant women at risk, their partners, and their families
- Programs that develop specialized detoxification methods for pregnant women
- Programs that address the determinants of why women use substances while pregnant, including:
  — Domestic violence
  — Isolation
  — Poverty
  — Residential school experience

Objective #3 — *Working With Those Affected*

The primary aim of this objective is to identify and work with FAS/FAE affected individuals in order to lessen the educational, social, and behavioural impact (complications, impairments, and disabilities) of FAS/FAE by supporting them. Another aim of this goal is to reduce the risk that these individuals will have FAS/FAE children themselves (this is called "tertiary prevention" or "minimizing complications and chances of recurrence").

Examples of Related Initiative Activities:

Create linkages and provide referrals to other programs designed to support individuals with FAS/FAE, such as:

- Programs that increase early identification and diagnosis of FAS/FAE affected infants and children
- Programs that establish diagnostic infrastructures

Train health care professionals

Incorporate FAS/FAE issues in relevant post-secondary curricula

Train First Nations and Inuit, as well as their service providers, to use strategies, methods, and approaches for supporting and teaching FAS/FAE individuals

- Families, social workers, community workers, educators, and justice workers

Objective #4 — *Creating Linkages*

The aim of this objective is to create connections between related programs and initiatives to ensure that (1) projects, services, and activities designed to address interconnected problems and issues are not fragmented and (2) people and organizations with similar or shared goals have the opportunity to share information and expertise in an atmosphere of cooperation, collaboration, and coordination.

Examples of Related Initiative Activities:

Establish and maintain channels of communication

- Forge and maintain partnerships

Encourage and provide opportunities for networking

- At the community, regional, and national levels

Integrate related resources

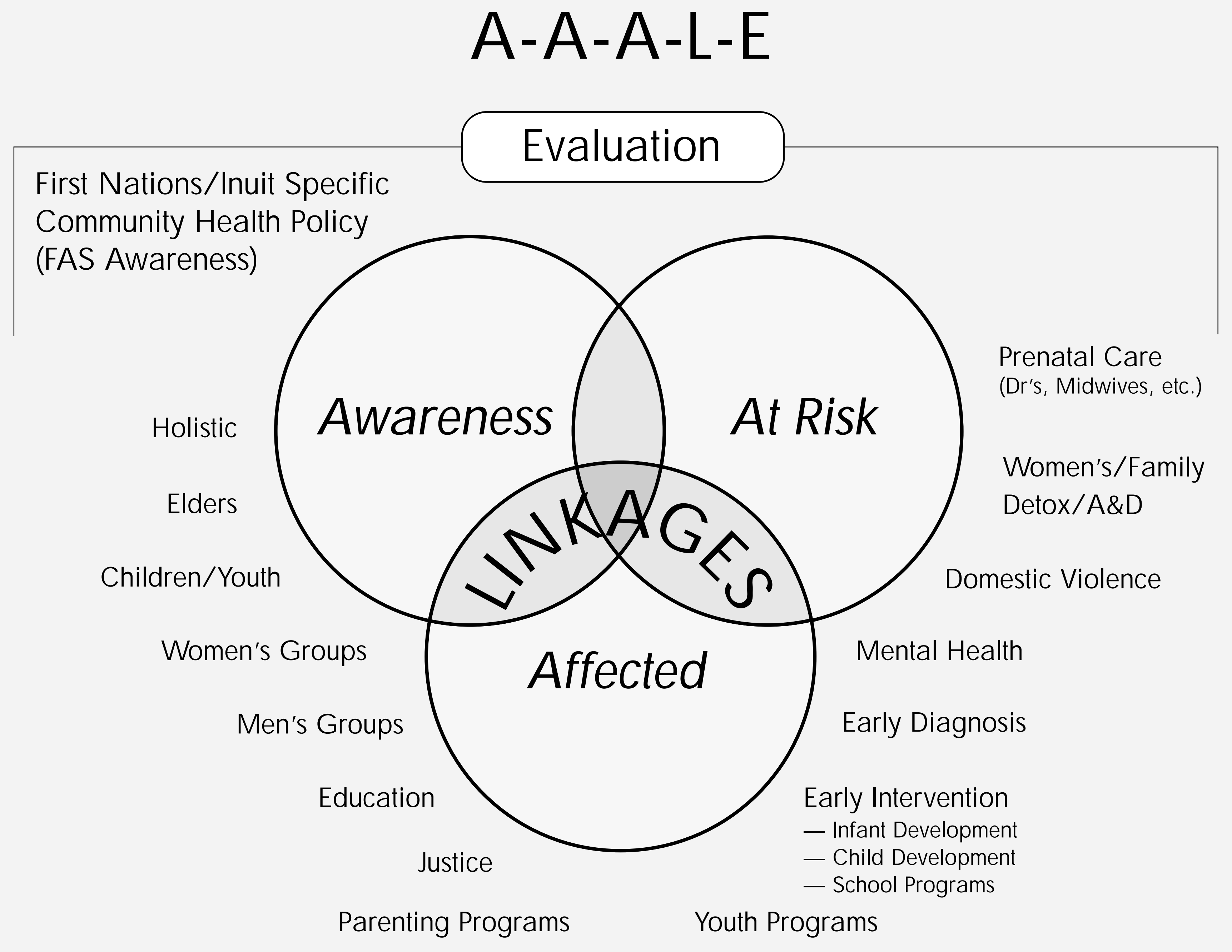
- Take a multidisciplinary approach to FAS/FAE issues

Encourage wholistic healing of communities

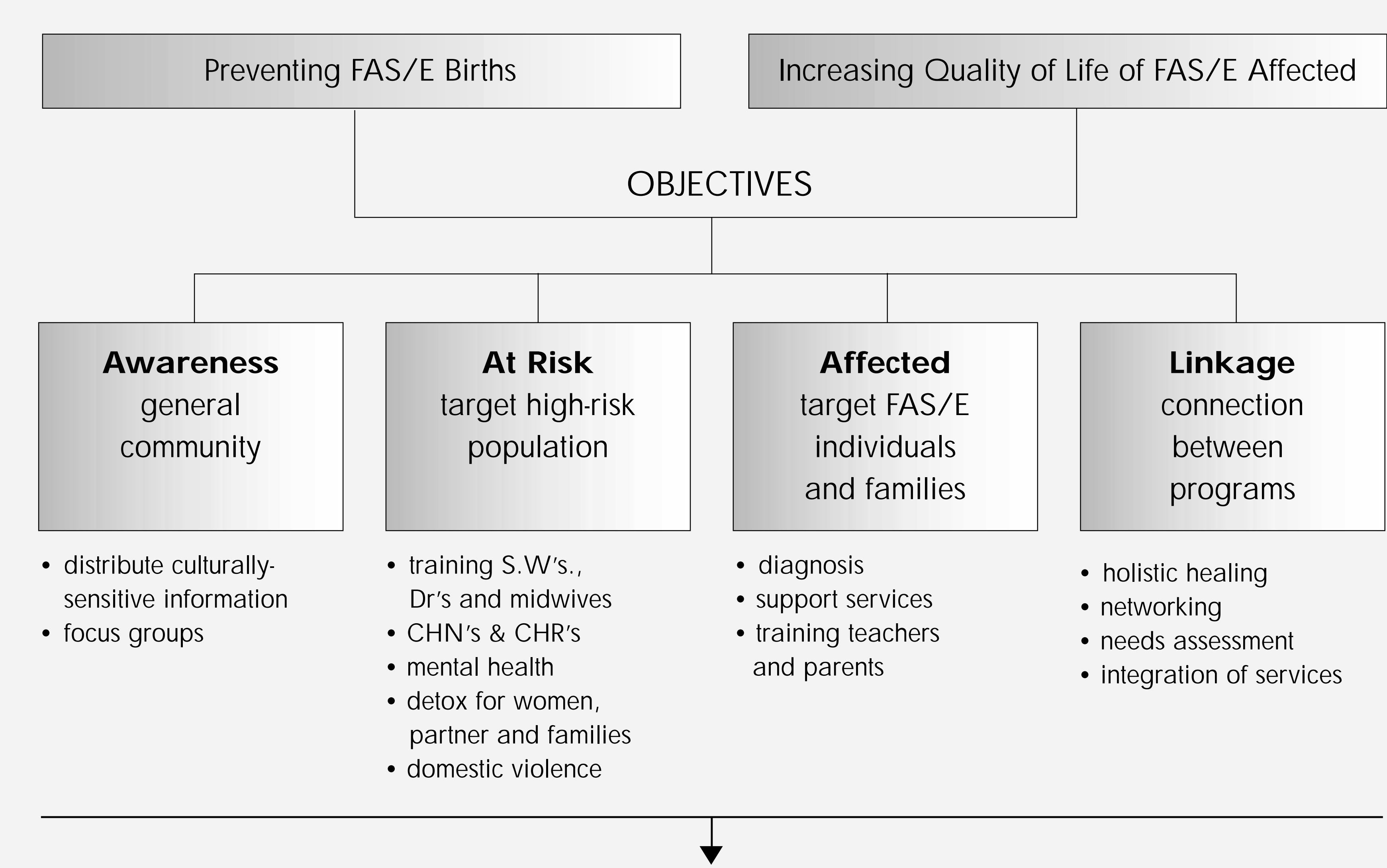
- Research prevalence and context of FAS/FAE
- Implement needs assessment
- Address underlying factors contributing to substance abuse

Global Initiative Evaluation

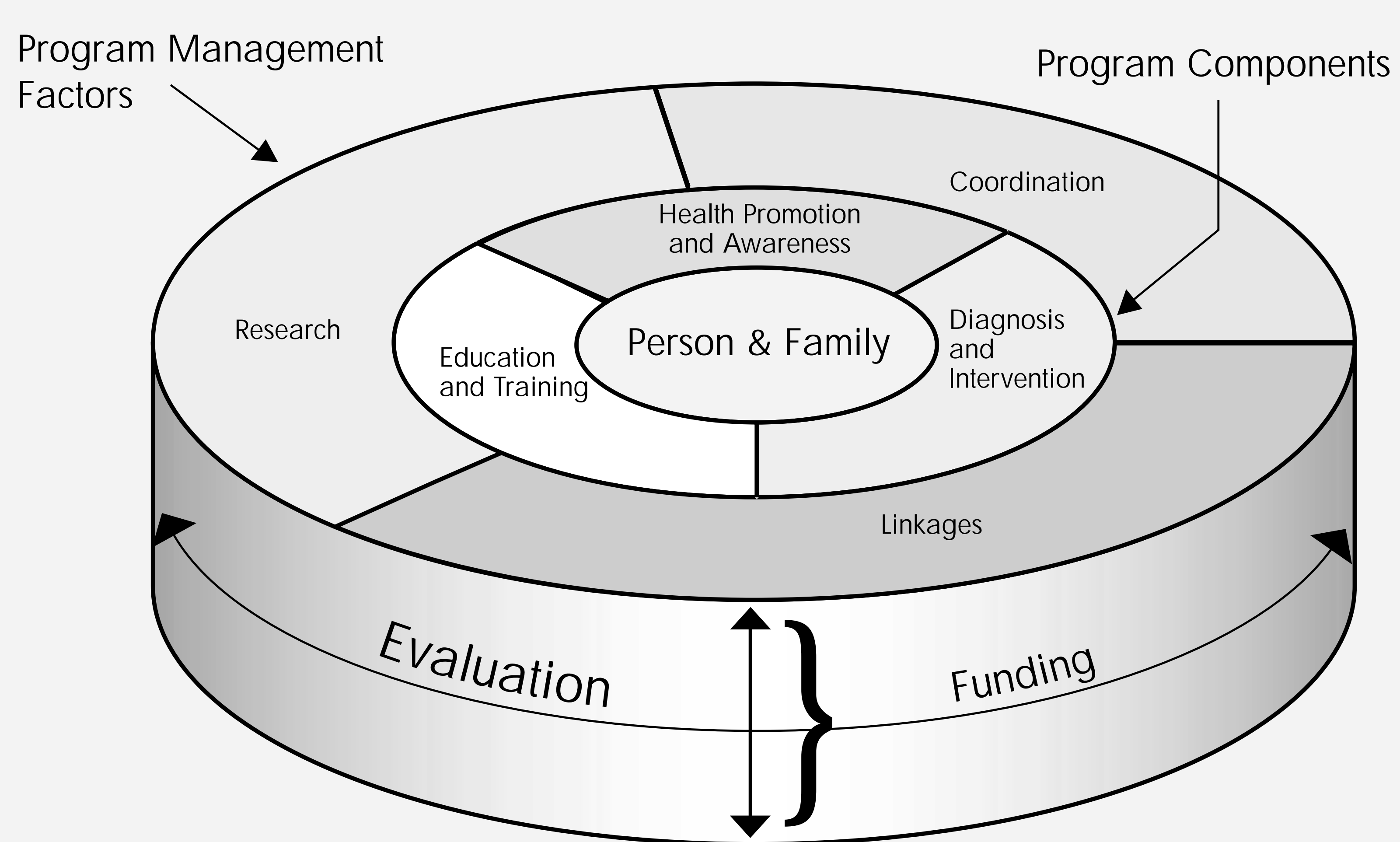
The global evaluation of the entire Initiative (as opposed to evaluation of specific projects, services, or activities undertaken as a part of the Initiative, which is discussed on page 20) will involve assessing whether the four objectives of the initiative have been accomplished.


A-A-A-L-E
Evaluation
First Nations/Inuit Specific
Community Health Policy
(FAS Awareness)
Holistic
Elders
Children/Youth
Women's Groups
Men's Groups
Education
Justice
Parenting Programs
Awareness
At Risk
Affected
LINKAGES
Prenatal Care
(Dr's, Midwives, etc.)
Women's/Family
Detox/A&D
Domestic Violence
Mental Health
Early Diagnosis
Early Intervention
— Infant Development
— Child Development
— School Programs
Youth Programs

Goals and Objectives



FAS/FAE Initiative Model



Initiative Components

CHAPTER 6

Target Groups

Target groups of the Initiative include FAS/FAE affected individuals, persons at risk, families, community members, health and social service providers, community leaders, teachers and other educators, and corrections and justice system workers.

Operational Definitions of Initiative Components

Projects, services, and activities that are undertaken, provided, or carried out as part of the Initiative will fall into one of these three categories:

Health Promotion and Awareness

This component includes projects, services, and activities that address Objective 1 (Primary Prevention) by facilitating the wide-scale dissemination of relevant, useful, accurate, and easy-to-understand information about FAS/FAE issues.

This component consists of all efforts at front-line, general awareness raising in relation to FAS/FAE issues and the dangers of drinking alcohol during pregnancy, including, but not limited to the following:

- workshops and forums aimed at community members in general,
- education efforts in schools,
- videos,
- brochures,
- pamphlets, and
- radio, television, and newspaper advertising.

This component will have the largest target group (essentially, the general public and all First Nations and Inuit community members, including children) and will be implemented in a wholistic fashion that addresses the determinants of health in First Nations and Inuit communities.

Education and Training

This component addresses the need for capacity building in order for First Nations and Inuit communities to undertake, provide, and carry out projects, services, and activities that address Objectives 1, 2, & 3 (Primary, Secondary, and Tertiary Prevention).

This component consists of all efforts to educate and train families, health and social service workers, teachers and educators, community workers, and corrections and justice system workers to provide services (1) in a way that is sensitive to the needs of individuals and families affected by FAS/FAE or (2) that specifically address FAS/FAE issues, including but not limited to the following:

- training teachers to use effective instructional techniques with FAS/FAE students,
- training Community Health Nurses to access referral resources for families at risk,
- educating health care professionals and workers about the First Nations and Inuit cultural contexts of FAS/FAE, and
- training parents, foster parents, and family members to use effective ways of dealing with FAS/FAE children.

Identification of Diagnostic Tools and Intervention Supports

This component includes projects, services, and activities that address Objective 3 (Tertiary Prevention and Minimizing Complications) by encouraging (1) the development of diagnostic infrastructures and (2) the implementation of support systems and strategies designed to increase the quality of life of individuals and families affected by FAS/FAE.

This component consists of all efforts to identify FAS/FAE individuals and subsequently support them and their families in an effort to (1) reduce the impact of FAS/FAE on their lives (i.e., reduce the chances of secondary disabilities, such as mental health problems) and (2) reduce the chance of those individuals having FAS/FAE children themselves, including but not limited to:

- efforts aimed at early identification and diagnosis,
- implementing appropriate teaching/learning strategies in classrooms,
- implementing appropriate teaching/learning strategies in families,
- interventions in the justice system designed to refer FAS/FAE affected individuals to rehabilitation resources, and
- multidisciplinary care for FAS/FAE affected individuals, including family support medical care, counselling, occupational therapy, speech therapy, and teaching assistance.

Initiative Management Factors

The existence and quality of the following three factors influence the Initiative's potential to achieve its goals and objectives through the implementation of the components described above:

Linkages

Since funding for this initiative is limited, the need to stretch funding as far as possible dictates that projects, services, and activities undertaken, provided, and carried out as part of the Initiative *will need to make connections with related programs and initiatives* that work to achieve similar objectives. This may take the form of cooperation with other programs to carry out joint projects through cost sharing and leveraging (e.g., piggybacking onto already planned community health forums and workshops) and referrals to appropriate existing service providers (e.g., National Native Alcohol and Drug Abuse Program).

Coordination

In order to ensure that

(1) projects, services, and activities designed to address interconnected problems and issues are not fragmented, and
(2) people and organizations with similar or shared goals have the opportunity to share information and expertise in an atmosphere of cooperation and collaboration, projects, services, and activities undertaken, provided, and carried out as part of the Initiative need to be coordinated. Such coordination can be accomplished through the development of active lines of communication and effective networking systems.

This will lead to the harmonious combination of programs and interaction between organizations and service providers. Furthermore, this will enable service providers to achieve common goals and objectives wholistically, addressing the determinants of health in a comprehensive fashion.

Research

Research is fundamental to the identification of areas of need and evaluating the success of existing projects, services, and activities. By identifying patterns of incidence and prevalence, needs and priorities can be confirmed, and contributing factors and underlying issues can be identified. The collection and analysis of data relating to incidence and prevalence can be used to monitor and measure the effect of prevention efforts and consequently evaluate the success of prevention efforts.

Initiative Management

The Initiative will operate in conjunction with the CPNP (FNIC); accordingly, it will have strong links with that program. It will also operate in partnership with the federal government, provincial/territorial governments, and First Nations/Inuit organizations, governments, and communities.

Under the Initiative, the Federal Government, the regions, and communities will have the following roles and responsibilities:

Federal Government will be responsible for:

- coordinating
  - funding allocation,
  - advocacy efforts aimed at securing further funding, and
  - framework liaison efforts;
- communication
  - information dissemination (e.g., national FAS/FAE website), and
  - facilitating awareness (e.g., national awareness campaign); and
- in partnership with First Nations and Inuit communities, and in recognition of the principle of First Nations and Inuit ownership, control, and access (OCA), research and global initiative evaluation, including the collection, analysis, and reporting of pertinent statistics.

The regions will be responsible for:

- coordinating
  — resource allocation, and
  — linkages and partnerships;
- training; and
- project support, including
  — capacity building,
  — facilitating regional awareness, and
  — facilitating community access to resources.

First Nations and Inuit communities will be responsible for:

- project delivery;
- service provision;
- activity implementation; and
- in partnership with the Federal Government, and in recognition of the principle of First Nations and Inuit ownership, control, and access (OCA), research and global initiative evaluation, including the collection, analysis, and reporting of pertinent statistics.

The NSC will develop reporting requirements for eligible recipients, as well as criteria for reporting success (performance/outcome indicators) for projects, services, and activities undertaken, provided, or carried out as part of the Initiative components. These reporting requirements and outcome indicators will be incorporated into the terms and conditions of contribution agreements between FNIHB and eligible Initiative recipients.

Initiative Evaluation

Projects undertaken, services provided, and activities carried out under the Initiative need to include outcome-based evaluation component. Outcome-based evaluation for Initiative projects, services, and activities can be accomplished by (1) creating pre-determined criteria (also known as "performance indicators") that describe the type of evidence that will show whether a specific objective has been met (what would it look like to meet that objective?) and then (2) measuring actual results or outcomes against the pre-determined criteria (did the actual outcomes look like the objectives were supposed to look like?).

A key part of outcome-based evaluation is careful and conscious planning that involves articulating (describing) specific objectives or intended outcomes for the project, service, or activity. Once clear and specific objectives have been identified and articulated, one creates criteria (performance indicators) by asking, "what will the results look like if the objectives are met?"

For example, one of the goals of the Initiative is to prevent FAS/FAE births. If we achieve the goal of preventing FAS/FAE births, this will result in evidence of decreased incidence of FAS/FAE (numbers of FAS/FAE births). Therefore, the evidence to measure achievement of the goal is the incidence of FAS/FAE, and the criteria for successfully achieving that goal will be decreased incidence of FAS/FAE. Accordingly, to evaluate success in this regard, the Initiative will have to include a component of data collection and record keeping in relation to the incidence of FAS/FAE in relevant populations before and after the implementation of relevant Initiative components.

Initiative Eligibility and Funding

CHAPTER

Eligible Project Sponsors

Because of the nature of the mandate of the Initiative (which corresponds to FNIHB's mandate), the Initiative is directed towards on-reserve First Nations, First Nations North of 60º, and Inuit communities.

The following groups are eligible to receive FNIC/FAS/FAE Initiatie funding and sponsor projects:

- First Nations Bands, First Nations and Inuit organizations
- Tribal Councils, provincial/regional First Nations and Inuit organizations
- Community-based organizations or agencies, where supported by First Nations or Inuit governments

To be eligible for funding, applicants must:

- demonstrate that their project, service, or activity has objectives which further the goals and objectives of the Initiative, without duplicating existing services;
- demonstrate that their project, service, or activity is well planned and has a realistic chance of achieving its objectives;
- demonstrate that their project, service, or activity will be implemented, delivered, or carried out in a manner that is consistent with the principles of the Initiative, including, but not limited to:
  - establishing a community need,
  - involving the community in planning and implementation,
  - integrating and coordinating project, service, or activity with existing programs, and
  - maintaining cultural sensitivity and accessibility; and
- incorporate an outcome-based evaluation component into their project, service, or activity.

Within this Framework, projects developed in the Governments of the Northern Territories need to be developed in partnership with Inuit.

First Nations and Inuit FAS/FAE Initiative Budget

Fiscal Year	National Coordination and Support	Special Projects Fund (NSC)	Community-Based Projects *	Total
2000/2001	$170,000	$910,000	$ 270,000	$1,350,000
2001/2002	$170,000	$480,000	$1,050,000	$1,700,000
2002/2003	$170,000	$250,000	$1,280,000	$1,700,000
Ongoing	$170,000	$250,000	$1,280,000	$1,700,000

* Community-Based Projects will be jointly managed by First Nations, Inuit, and FNIHB at the regional level.

National Coordination and Support

This category describes funds managed at the national level to fund the following: National Coordinator (salary, travel, and overhead), Corporate Services Tax, Communications Tax, National Forum (annual contribution), and National Steering Committee (travel, etc.).

Special Projects Fund (National Steering Committee)

This category describes funds managed at the national level to fund projects that provide leadership to the regions and have a national impact (e.g., national awareness campaign, environmental scan, needs assessment, curriculum template development, and global initiative evaluation). These funds will be managed by the National Steering Committee (NSC). Each year, the NSC will (1) develop criteria and guidelines that reflect and articulate strategic funding priorities for that year and (2) using those criteria and guidelines, determine which projects will receive funding.

Community-Based Projects

This category describes funds distributed to the regions to be used for projects with a regional and local community focus, including: regional coordination, regional awareness campaigns, local awareness efforts, the local adaptation of curricular models, and training. In 2000/2001, each region will receive $30,000, and the Northern Secretariat (Yukon, Northwest Territories, and Nunavut) will receive $60,000. During 2000/2001, the NSC will review potential regional distribution models and determine the most appropriate formula to use. Once distributed to the regions, these funds will be jointly managed by First Nations, Inuit, and FNIHB at the regional level, with each region having discretion in relation to the distribution of funds to communities.

Initiative Funding

Given the amount of money involved in the Initiative ($3.8 million across Canada over three years), there are insufficient funds to allocate a share of funds to each First Nations and Inuit community across Canada. If this amount were to be divided equally amongst 600 communities (a conservative estimate of

the number of First Nations and Inuit communities in Canada), it would amount to about $2000.00 per community annually for the next three years. To use the funds effectively, they need to be allocated strategically, distributing them where they can do the most good addressing priority goals.

Given that some of the objectives of the Initiative can be met on a national level and remain the responsibility of the Federal Government under the terms of this framework, the FNIHB (at the national level) and the NSC will manage funds at the national level to accomplish objectives associated with the Federal Government's responsibilities (defined on pages 19-20).

The remaining funds will be distributed to the regions. Regions will retain a portion of their allocated funds to cover the costs of meeting their responsibilities under this framework, such as coordination (once again, defined defined on pages 19-20).

The remainder of the funds will be distributed to eligible recipients, at each region's discretion, to undertake projects, deliver services, and carry out activities that address priority goals and objectives of the Initiative. Regional FNIHB offices will make funding decisions in collaboration with First Nations and Inuit partners, after consultation with communities. Once a proposed project, service, or activity has received funding, that funding cannot be transferred and must be used in a fashion that is consistent with the objectives and plans of that project, service, or activity.

As mentioned in the preface, the extra lifetime health care, education, corrections, and social services costs to society associated with an FAS/FAE individual have been estimated at US$1.4 million (Streissguth, 1991). This estimate was part of a 1989 report on FAS presented to the Alaska State Legislature (Canadian Perinatal Surveillance System, 1999). Since it is over 10 years old and applies to an American context, it is almost certainly an underestimate of the extra lifetime costs associated with caring for an FAS individual in Canada.

This estimate illustrates the potential costs that FAS/FAE represents. Take the extra lifetime costs per FAS affected individual (US$1.4 million) and multiply it by the incidence of FAS (potentially 740 FAS births a year in Canada). The total is over US$1 billion; this represents the total cost (in monetary terms alone) of FAS to Canadian society for one birth cohort alone (group of children born in one year). This cost needs to be balanced against the continuing annual funding allocated to the Initiative (CND$1.7 million) when making FAS/FAE funding decisions in the future.

Initiative Implementation

CHAPTER

Community Level

First Nations and Inuit communities chosen will complete a work plan outlining the program activities that will be offered to address community needs. The NSC will develop at the national level a standard format and an Initiative guidebook that will clarify the work planning process. Project work plans will be consistent with the Initiative's guiding principles, vision, goals, objectives, components, and management factors. At the First Nations and Inuit community level, Initiative activities will include raising awareness and training.

Raising awareness will consist of setting in motion and maintaining campaigns utilizing various tactics to raise awareness in the general public about FAS/FAE issues and the dangers of drinking during pregnancy. "Raising awareness" is broad enough to include a variety of media (e.g., radio, posters, and pamphlets) and activities (e.g., the education of community health workers, and workshops/forums attended by community members) geared towards raising awareness or education about FAS/FAE issues.

Individual regions and communities will decide what "raising awareness" means to them based on an assessment of their current levels of awareness and identification of awareness priorities. Community awareness about FAS/FAE issues is a necessary foundation for the Initiative.

Training is necessary to build capacity in First Nations and Inuit communities. Training will consist of instructing social services, health care, education, and other important professionals, community workers, and family members how to effectively address FAS/FAE issues at the local and grassroots level in their communities.

Regional Level

At the regional level, Initiative activities will address the need for regional leadership, coordination, communication, and integration. In partnership with First Nations and Inuit communities, FNIHB regions will establish a regional coordination and management mechanism and clarify the coordination process. At the regional level, Initiative activities will include coordination and curriculum development.

Coordination will consist of developing a coordination mechanism and identifying and developing opportunities for leveraging, integration, and partnerships. Coordination will help to make the Initiative cost effective.

Curriculum development will consist of identifying, developing, and creating training, teaching, and learning programmes and materials (curricula) designed to

(a) educate or raise awareness about FAS/FAE (in the general community or with high-risk or affected individuals),

(b) build capacity of First Nations and Inuit communities to address FAS/FAE issues (e.g., training community workers methods of supporting FAS/FAE affected individuals), and

(c) train professionals (e.g., doctors, nurses, teachers), community workers, community members, and family members to address FAS/FAE issues (e.g., raise awareness or support FAS/FAE affected children).

Curriculum development is necessary to provide the foundation for training efforts, and to make the Initiative cost effective, curriculum development needs to be carried out in an organized and systematic fashion at the regional level.

National Level

At the national level, the NSC, which is made up of First Nations, Inuit, and FNIHB representatives, will guide the development and implementation of the Initiative. At the national level, Initiative activities will include raising awareness, coordination, environmental scan, needs assessment, and evaluation.

At the national level, a National Coordinator will be directed by the NSC to undertake national-scale coordination activities.

At the national level, raising awareness will involve a wide-scale national public information campaign designed to raise awareness in First Nations and Inuit communities across Canada about FAS/FAE issues and the dangers of drinking alcohol during pregnancy.

An environmental (models and approaches) scan will consist of conducting an exhaustive inventory of existing models, approaches, programs, projects, services, and activities across Canada that are available in First Nations and Inuit communities and accessible by First Nations and Inuit clientele. An environmental scan is necessary to identify foundations that can be used as role models, built upon, and accessed in their present form.

A needs assessment will consist of assessing the needs of First Nations and Inuit communities by identifying the prevalence of FAS/FAE in individual communities and determining the nature and severity of secondary disabilities impacting FAS/FAE affected individuals, their families, and their communities. A needs assessment is necessary to specifically identify the nature and extent of community needs and to determine areas of focus (geographical and otherwise).

Evaluation will consist of the development and implementation of an evaluation framework that will allow for the incremental evaluation of the effectiveness of the entire Initiative in meeting its goals and objectives. To be meaningful, evaluation has to be incremental (step by step), so that each component of the Initiative can be evaluated after it has been implemented, not before. Meaningful evaluation is essential to identify the outcomes of the Initiative and to justify current levels of funding and make a case for further funding.

Communications

Communications regarding the Initiative will identify the focus on preventing FAS/FAE births and increasing the knowledge, skills, and quality of life of FAS/FAE affected children, mothers, fathers, and families through community-based prevention and support strategies.

Appendix A

What are FAS/FAE?

Introduction

Alcohol is known "teratogen," which means that it has a negative effect on the fetus (unborn child). It can cause birth defects by affecting the growth and proper formation of the fetus' body and brain (Canadian Paediatric Society, 1996, p.4). When a pregnant woman drinks alcohol, the alcohol enters her bloodstream and is carried by her blood into the fetus' developing body. The brain and nervous system of the fetus are especially sensitive to alcohol exposure (Canadian Paediatric Society, 1996, p.4).

Alcohol has a negative effect on the fetus, because it may interfere with cell migration, and ethanol and its metabolites are toxic (poisonous), particularly if alcohol is consumed regularly (as little as two drinks per day) or during binges (Alberta Medical Association, 1999). Other factors, such as stress, malnutrition, smoking, and the use of other drugs, increase the likelihood that alcohol will harm the fetus. We do not know how much alcohol a pregnant woman can safely drink, and there is no safe time period during pregnancy to consume alcohol (BC FAS Resource Society, 1998, p. 12).

Diagnostic Criteria for FAS/FAE

In the traditional diagnostic criteria for FAS, the first diagnostic criteria for FAS is prenatal exposure to alcohol. According to the traditional diagnostic criteria, FAS children also exhibit the following characteristics:

1. Delayed prenatal growth, postnatal growth, or both.
   - Such delay must result in height and/or weight below the tenth percentile.
2. Central nervous system involvement.
   - This can result in one or more of the following conditions, amongst others, being observed in the child:
     a. head circumference below the third percentile,
     b. developmental delay or intellectual disabilities, and/or
     c. learning disabilities or attention deficit/hyperactivity disorder.
3. Characteristic facial features.
   - These include short eye slits, elongated mid-face, long and flattened nose and upper lip, thin upper lip and flattened facial bone structure. These facial features are most noticeable during early childhood. They are sometimes not evident in infancy and may change during adolescence and become less evident in adulthood. Changes in the pattern of facial features in an FAS individual do not indicate that he or she is no longer FAS. Furthermore, a child exhibiting these facial features, but not the other diagnostic criteria, is not FAS.

According to the traditional diagnostic criteria, a child is FAE when there has been prenatal exposure to alcohol and some, but not all, of the above-noted diagnostic criteria. FAE is not a milder form of FAS; both are spectrum/continuum disorders, meaning that FAS/FAE individuals present varying degrees of intellectual and physical deficits (Special Programs Branch, 1996).

The Alberta Clinical Practice Guidelines diagnostic criteria for FAS distinguish between FAS with confirmed maternal alcohol exposure and FAS without confirmed maternal alcohol exposure (Alberta Medical Association, 1999). Its diagnostic criteria for FAS with confirmed prenatal alcohol exposure are as follows:

FAS with confirmed maternal alcohol exposure

A Confirmed maternal alcohol exposure

B Evidence of characteristic pattern of facial anomalies including: short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface)

C Evidence of growth retardation, in at least one of the following:
- low birth weight for gestational age
- decelerating weight over time not due to other identified causes
- disproportional low weight to height

D Evidence of CNS abnormalities in at least one of the following:
- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, cerebellar hypoplasia)
- neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor hand-eye coordination

The BC FAS Resource Society recommends using the terms partial FAS and Alcohol-Related Neurodevelopmental Disorder instead of FAE. The Alberta Medical Association also uses these terms. The current diagnostic criteria for FAS and other alcohol related effects list five conditions in two categories: (1) the FAS Diagnostic Criteria Table describes (a) FAS with confirmed maternal alcohol exposure, (b) FAS without confirmed maternal alcohol exposure, and (c) partial FAS, and (2) the Alcohol-Related Effects Diagnostic Criteria Table describes (a) Alcohol-Related Birth Defects and (b) Alcohol-Related Neurodevelopmental Disorder (Alberta Medical Association, 1999 & BC FAS Resource Society, 1998, pp. 36-37).

A child has partial FAS when he or she has (1) some of the facial abnormalities associated with FAS and (2) either delayed growth or central nervous system involvement, when there was a significant prenatal exposure to alcohol (BC FAS Resource Society, 1998, p. 10).

A child has Alcohol-Related Neurodevelopmental Disorder (ARND) when he or she suffers neurological abnormalities and/or FAS-like behavioural and learning problems, when there was a significant prenatal exposure to alcohol (BC FAS Resource Society, 1998, p. 10).

A child has Alcohol-Related Birth Defects (ARBD) when he or she has a congenital birth defect, such as skeletal abnormalities, heart defects, cleft palate and other craniofacial abnormalities, kidney and other internal organ problems, and vision and hearing problems, when there was a significant prenatal exposure to alcohol (BC FAS Resource Society, 1998, p. 11).

In this Framework, “FAE” has been used in a sense that encompasses ARND and partial FAS, and “FAS/FAE” has been used in a sense that encompasses all of these conditions, including ARBD.

Difficulties Experienced by FAS/FAE Affected Individuals

FAS/FAE individuals may experience all or some of the following intellectual, physical, social, and learning difficulties, amongst others:

- attentional difficulties (distractibility);
- inability to connect cause and effect (understanding consequences);
- a lack of understanding of social cues and relationships;
- poor comprehension of social rules and expectations;
- trouble making friends and easily influenced;
- a poor sense of personal boundaries;
- poor impulse control;
- even minor changes in routine can be overwhelming;
- poor and inconsistent memory function, leading to a need to be retaught the same concepts over and over again;
- trouble remembering where things are;
- learning and retrieval of information may be spotty or intermittent;
- difficulty remembering and understanding directions (especially if lengthy or complicated);
- trouble with spatial relations and orientation;
- trouble with abstract thinking (understanding ideas and relationships between things);
- can be lethargic or hyperactive;
- demanding of lots of one-to-one attention;
- trouble telling right from wrong;
- wanting lots of physical contact;
- giving an appearance of capability without actually having the abilities that they seem to have (illusion of competency);
- difficulty separating fact from fantasy;
- temper tantrums, lying, stealing, disobedience, and defiance of authority;
- lack of fear and tendency to take risks (high pain threshold);
- application of faulty logic;
- egocentrism and inability to comprehend and/or respond appropriately to the feelings, needs, and desires of others;
- low motivation;
- low self-esteem; and
- physical difficulties, including vision, hearing, heart, and growth problems and deficits.

Appendix B

References

Books and Stand-Alone Documents

Alberta Medical Association, *The Alberta Clinical Practice Guidelines* (Edmonton: Alberta Medical Association, 1999).

BC FAS Resource Society, *Community Action Guide: Working Together for the Prevention of Fetal Alcohol Syndrome* (Victoria: British Columbia Ministry for Children and Families, 1998).

Thomas R. Berger, *A Long and Terrible Shadow: White Values, Native Rights in the Americas* 1492–1992 (Vancouver: Douglas & McIntyre, 1991).

Canadian Paediatric Society et al., *Joint Statement: Prevention of Fetal Alcohol Syndrome* (FAS) Fetal Alcohol Effects (FAE) in Canada (Ottawa: Health Canada, 1996).

Canadian Perinatal Surveillance System, *Alcohol and Pregnancy* (Ottawa: Health Canada, 1998).

Canadian Perinatal Surveillance System, *Addendum to Alcohol and Pregnancy* (Ottawa: Health Canada, 1999).

Marilyn Friend, William Bursuck, & Nancy Hutchinson, *Including Exceptional Students: A Practical Guide for Classroom Teachers* (Scarborough: Allyn and Bacon Canada, 1998).

Diane Malbin, M.S.W., *Fetal Alcohol Syndrome and Fetal Alcohol Effects: Strategies for Professionals* (Minnesota: Hazelden Educational Materials, 1993).

Brenda McCreight, *Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects*: A Guidebook (Washington: CWLA Press, 1997).

William J. Mussell, ed., *Royal Commission on Aboriginal Peoples: Think Tank Reports and Proceedings* (Chilliwack: Sal'i'shan Institute Society, 1997).

William J. Mussell, William M. Nicholls, & M. Terry Adler, *Making Meaning of Mental Health Challenges in First Nations: A Freirian Perspective* (Chilliwack: Sal'i'shan Institute Society, 1991).

Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples, vol. 1 Looking Forward, Looking Back* (Ottawa: Minister of Supply and Services Canada, 1996).

Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples, vol. 3 Gathering Strength* (Ottawa: Minister of Supply and Services Canada, 1996).

Royal Commission on Aboriginal Peoples, *Overview of the First Round* (Michael Cassidy Ginger Group Consultants, 1992).

Ann Streissguth, *Fetal Alcohol Syndrome: A Guide for Families and Communities* (Baltimore: Paul H. Brookes Publishing Co., 1997).

Ann Streissguth & Jonathan Kanter, eds, *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (Seattle: University of Washington Press, 1997).

Marilyn Van Bibber, *It Takes a Community: A Resource Manual for Community-based Prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects* (Ottawa: Minister of Public Works and Government Services Canada, and the Aboriginal Nurses Association of Canada, 1997).

Articles

Judi Stevenson, "Notes for a Talk on the Final Report of the *Royal Commission on Aboriginal Peoples" in William J. Mussell, ed., Royal Commission on Aboriginal Peoples: Think Tank Reports and Proceedings* (Chilliwack: Sal'i'shan Institute Society, 1997) 1.

Ann Streissguth, "What Every Community Should Know About Drinking During Pregnancy and the Lifelong Consequences for Society" *Substance Abuse* 1991; 12(3): 114–127.

Internet Sites

http://www.mcf.gov.bc.ca/child_protection/fas/fae_index.htm (BC FAS Resource Society, *Community Action Guide: Working Together for the Prevention of Fetal Alcohol Syndrome* (Victoria: British Columbia Ministry for Children and Families, 1998)).

http://www.bced.gov.bc.ca/specialed/fas/contents.htm (The Special Programs Branch of the B.C. Ministry of Education, Skills and Training, *Teaching Students with Fetal Alcohol Syndrome/Effects* (1996)).

http://www.nofas.org/

http://mel.lib.mi.us/health-fas.html

http://www.irsc.org/fas.htm

http://www.taconic.net/seminars/fas02.htm

http://www.ccsa.ca/fasgen.htm

http://www.come-over-to/FAS/

http://thearc.org/misc/faslist.html

Appendix C

Glossary of Terms

Accountability — The quality of having to account for, defend, or justify the effectiveness, sensibility, and sustainability of something.

Capacity — The personal and collective knowledge, strength, skill, and ability of First Nations and Inuit to plan, develop, implement, carry out, manage, and evaluate programs and services needed in their communities.

Components — The parts, pieces, or elements of the Initiative, explained through operational definitions (descriptions that explain why a particular part is necessary and how it furthers the goals and objectives of the Initiative).

Criteria — (Also *Performance Indicators*) A clear and measurable description of what the specific outcomes or results of a project, service, or activity will be if it is successful in meeting its goals and objectives.

Determinants — (*of health*) Factors that determine health and well-being. The determinants of health go beyond medical care and include:

- wealth, poverty, and other economic conditions;
- social, emotional, psychological, and spiritual well-being;
- environmental conditions; and
- genetic inheritance (Royal Commission on Aboriginal Peoples, 1996, vol.3, pp. 215–220).

Fourth World — A term used to describe the reality of the lives of First Nations and Inuit, insofar as they experience Third World socioeconomic conditions and the imposition of a culturally-foreign, colonial political structure within the boundaries of a wealthy, industrialized, First World nation located within their traditional territories.

Goal — The purpose of one's efforts. The end-point that one intends to reach by expending energy. Goals are more specific than a vision, but broader than objectives.

Incidence — How often a problem occurs annually, based on vital statistics information on live births (BC FAS Resource Society, 1998, p. 14). These sources contain information about the incidence of FAS/FAE: Friend et al., 1998, p. 192; McCreight, 1997, p. 7; & BC FAS Resource Society, 1998, p. 14.

Linkage	A connection or bond between distinct programs, projects, services, or activities, allowing for services to be provided comprehensively and in a coordinated fashion.
Objective	Something worked towards or striven for. The specific target that one is aiming for. An objective is more specific than a goal, and one may need to accomplish several objectives in order to achieve a goal.
Prevalence	The number of people in a population that have a problem at a specific point in time. For information about the prevalence of FAS/FAE, see BC FAS Resource Society, 1998, p. 14.
Vision	The ultimate, global, primary purpose of one's efforts. Visions define an intentional image of the future that one aspires towards. In this way, a vision determines goals, which in turn, determine specific objectives.
Wholistic	(Also *Holistic*) A definition of health that looks at the whole picture and takes all determinants of health (physical, intellectual, emotional, and spiritual), including social determinants, into account. According to this *wholistic* conception of health, health issues, such as FAS/FAE, cannot be isolated from their larger socioeconomic and cultural contexts, and solutions must take other related issues into account. In other words, FAS/FAE is not just a "medical" issue; it is a health, social, economic, political, and justice issue. In his statement to the Royal Commission on Aboriginal Peoples, Dr. Chris Durocher asserted that "the overall [Third World equivalent] health status of Aboriginal people [is] an outcome of social, economic, political, educational, and environmental factors, and in particular, the relationship between poverty and ill health." (Royal Commission on Aboriginal Peoples, 1992, p. 33). Therefore, FAS/FAE issues need to be addressed in context.

Appendix D

Terms of Reference

FAS/FAE Technical Working Group
November 26, 1999

Background

The February 1999 federal budget allocated $3.8M over three years and, by fiscal year 2001/02, ongoing funding of $1.7M for the enhancement of current prevention efforts that address Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE). A National Steering Committee (NSC) has been established to give direction to the development, implementation and evaluation of this initiative, along with the CPNP-FNIC.

Mandate

To provide technical support in the areas of FAS/FAE to the National First Nations and Inuit CPNP/FAS/E Steering Committee (NSC) in carrying out its mandate.

Composition

The Working Group will be comprised of a maximum of eight members including the chair. Two members each to be nominated by First Nations, Inuit and First Nations and Inuit Health Branch (FNIHB) with technical expertise in the areas of FAS/FAE, community development or other relevant area; and to represent various geographic regions of the country and community, regional and national perspectives.

Additional members may be included who will bring an academic or other required perspective at the decision of the chair. The chair is to be appointed by the National First Nations and Inuit CPNP/FAS/E Steering Committee.

Term

The role and composition of the FAS/FAE Technical Working Group to be reviewed annually by the National First Nations and Inuit CPNP/FAS/E Steering Committee.

Decision Making

Decisions will be by consensus.

Role

During the development phase (November26–March 31, 2000) the Working Group will:

1. Direct and review the work of the consultant to the Working Group which will include:
   - development and collection of documents for inclusion in the Information Sharing and Feedback Kit
   - development of the question to guide the information sharing and feedback process
   - development of a brief overview of the information sharing and feedback process to inform regions and communities
   - dissemination of appropriate communications in a timely fashion to keep stakeholders informed about the process
   - design national program and evaluation framework based on regional discussion and feedback reports and other relevant reports and data
   - development of a draft implementation plan for the program and evaluation framework

2. Provide above documents to the NSC for review and approval as identified in the workplan and timelines.

Meetings

The FAS/FAE Technical Working Group will meet four times during the development phase (November 26 – March 31, 2000) to carry out their work as follows:

December 14-15, 1999	Ottawa	develop Information Sharing and Feedback Kit
January 6, 2000	Teleconference	finalize kit for approval by NSC
February 23-25, 2000	Vancouver	develop program and evaluation framework and implementation plan
March 2, 2000	Teleconference	finalize framework and implementation plan for approval by NSC

Secretriat

Secretariat support to be provided by First Nations and Inuit Health Branch, Community Health Programs Directorate.

Budget

Financial support will be provided by FNIHB to allow the working group to carry out its work. Those participating without reimbursement through their employment will be fairly reimbursed at an agreed upon daily rate.

Accountability

The FAS/FAE Technical Working Group is accountable to the National First Nations and Inuit CPNP/FAS/E Steering Committee.

Appendix E

Executive Summary

Introduction

FAS/FAE is a nation-wide health concern that does not discriminate on the basis of race, poverty, social class, or sex. More babies are born with FAS/FAE than with Down's Syndrome or Spina Bifida. An even greater number of FAS/FAE babies are born in high-risk populations, including First Nations and Inuit communities. The issue of FAS/FAE is a serious one for First Nations and Inuit communities.

The purpose of the Initiative Framework is to guide and describe how the First Nations and Inuit FAS/FAE Initiative will be carried out.

FAS/FAE

With awareness, support, and healing, FAS/FAE can be prevented. There is no known safe amount of alcohol that a pregnant mother can drink, so women who are pregnant or who could become pregnant should NOT drink any alcohol at any time during their pregnancies. FAS/FAE are life-long conditions.

FAS babies and children weigh less and grow slower than healthy babies and children, have abnormal facial features and ears, and they have learning and behaviour problems, such as hyperactivity. FAE babies and children have some, but not all of these things, however they can have just as much trouble as an FAS child learning and behaving properly (FAE is not a milder form of FAS).

Babies, children, and adults living with FAS/FAE can also have other spin-off problems and disabilities related to their FAS/FAE, such as mental health problems, dropping out of school, trouble with the law, substance abuse, dependant living, and employment difficulties.

First Nations and Inuit History and Culture

Many First Nations and Inuit in Canada experience poverty and health problems. This poverty and poor health exist in light of the history of First Nations and Inuit. First Nations and Inuit families, and communities find themselves with less self-sufficiency than they used to have.

Addictions, substance abuse, physical, psychological, and sexual abuse, have become part of life in First Nations and Inuit communities.

Some people think of "health" as a lack of disease and illness. First Nations and Inuit see "health" as wellness. Wellness is understood in a *wholistic* fashion, taking all important factors into account, like poverty, housing, friends, family, emotions, and spiritual well-being. First Nations and Inuit cultures realize the importance of doing things together, as families and communities. First Nations and Inuit also realize the importance of *healing*, which means trying to achieve balance and harmony.

The First Nations and Inuit FAS/FAE Initiative

The 1999 Federal Budget included funds earmarked for an initiative addressing FAS/FAE issues. The First Nations and Inuit FAS/FAE Initiative (the "Initiative") will use $3.8 million over the initial three years, and starting in 2001/2002, $1.7 million in funding will be available every year to support the Initiative.

Community Feedback

In early 2000, regional information-sharing and feedback discussion sessions were held in First Nations and Inuit communities across Canada. Feedback indicated that FAS/FAE have a significant impact on First Nations and Inuit communities. First Nations and Inuit community members said that they need raised general awareness about FAS/FAE (including education in schools), support for FAS/FAE affected individuals, families, and communities, training for persons working with FAS/FAE affected individuals, training for social and health services professionals and community workers, information about existing resources, early identification and diagnosis of FAS/FAE affected children, substance-abuse treatment programs, and opportunities for networking and community healing.

Guiding Principles of the Initiative

Strengthening and Supporting Families and Communities Wholistically
Family-Centred Prevention
Community-Based and Culturally Appropriate
A Coordinated Approach through Collaborative Partnerships
Contributing to Capacity Building
Equitable Access to Quality Programs
Accountability

Vision, Goals and Objectives of the Iniative

Vision

The vision and ultimate purpose of the Initiative is to *create conditions in which maternal and infant health will flourish*.

Goals

The goals of the Initiative are to (1) prevent FAS/FAE births, and (2) increase the knowledge, skills, and quality of life of FAS/FAE affected children, mothers, fathers, and families.

Objectives

1. Raising Awareness

This objective aims to prevent FAS/FAE health problems before they occur by increasing the awareness of the general population, particularly young people, about FAS/FAE and the dangers of drinking during pregnancy.

2. Reaching Those At Risk

This objective aims to identify and work with persons at risk, such as pregnant women or women in their child-bearing years who consume alcohol (“women at risk”) and their partners, in order to reduce the risk of FAS/FAE.

3. Working with Those Affected

This objective aims to identify and work with FAS/FAE affected individuals in order to reduce the impact that FAS/FAE will have on their lives (reducing the chances that they will have spin-off problems/disabilities related to FAS/FAE) by supporting them. This objective also aims to reduce the risk that FAS/FAE adults will have FAS/FAE children themselves.

4. Creating Linkages

This objective aims to create connections (links) between related programs to make sure that parts of the Initiative work together and that people share information and work together.

Global Initiative Evaluation

Evaluating the Initiative will involve measuring or seeing how successful it is at achieving its goals and objectives.

Initiative Components

Initiative Components/Parts

Health Promotion and Awareness

This part of the Initiative involves raising awareness by allowing for the distribution of relevant, useful, accurate, and easy-to-understand information about FAS/FAE. This part involves efforts at front-line, general awareness raising in relation to FAS/FAE and the dangers of drinking alcohol during pregnancy.

Education and Training

This part of the Initiative involves capacity building in First Nations and Inuit communities, by educating and training families, health and social service workers, teachers and community workers, as well as corrections and justice system workers about how they can work to prevent FAS/FAE and support people affected by FAS/FAE.

Identification of Diagnostic Tools and Intervention Supports

This part of the Initiative involves identifying FAS/FAE individuals and then supporting them and their families. This will help to lessen the impact of FAS/FAE on their lives and lessen the chance that those individuals will have FAS/FAE children themselves.

Initiative Management Factors

These three things will influence how well the parts of the Initiative work:

Linkages

Initiative funding needs to be stretched as far as possible. This means that communities and organizations carrying out parts of the Initiative need to connect and cooperate with other communities and organizations.

Coordination

By coordinating (cooperatively organizing) all the different parts of the Initiative, we can make sure that FAS/FAE programs interact and work together wholistically and people and organizations working on FAS/FAE issues have the chance to share information and expertise.

Research

Research about the rates of FAS/FAE in different areas will allow us to determine needs and priorities and identify underlying issues. Future research will also help us to see how successful prevention efforts are.

Initiative Management

The Initiative will involve cooperation between the federal government, provincial/territorial governments, and First Nations/Inuit organizations, governments, and communities, each of which will have their own roles and responsibilities under the Initiative.

Initiative Evaluation

The success of different parts of the Initiative will be measured using "outcome-based evaluation." This means that communities and organizations doing things as part of the Initiative will need to carefully plan their activities, with specific objectives in mind. Then, they will need to collect information to see whether they have met their objectives through their activities.

Initiative Eligibility and Funding

Eligible recipients may include First Nations bands, First Nations and Inuit organizations, tribal councils, and community-based organizations or agencies, where delegated authority by First Nations or Inuit governments. To be eligible for funding, applicants from these groups must show that they are working towards the goals and objectives of the Initiative, that they have a realistic plan, that they will carry out their plan in a way that is consistent with the guiding principles of the Initiative, and that they will include an outcome-based evaluation component in their plan.

Initiative funds will support national coordination, regional coordination, national projects like a national awareness campaign, an environmental scan, a needs assessment, curriculum template development, and global initiative evaluation in year three, projects with a regional and local community focus, like local awareness efforts, the local adaptation of curricular models, and training.

It Takes a Community

A Resource Manual for
Community-based Prevention of
Fetal Alcohol Syndrome and
Fetal Alcohol Effects

"It takes a community to raise a child"

Table of Contents

Acknowledgements . . . 45

Preface . . . 47

Using the Manual . . . 51

1 Guiding Principles for Effective Strategies . . . 53
2 Educating the Community . . . 57
3 Traditional Teaching . . . 59
4 Community Strategies that Address the Root Causes of FAS/E . . . 65
5 The Facts About FAS/E . . . 69
6 Developing Prevention Strategies . . . 77
7 Interventions for At-Risk Pregnant Women . . . 85
8 Living with FAS/E . . . 91
9 Referral and Assessment . . . 103
10 Tips for Teachers . . . 107
11 Advice for Caregivers . . . 111

Conclusion . . . 115

Bibliography . . . 117

Acknowledgments

Health Canada and the Aboriginal Nurses Association of Canada would like to acknowledge and express their appreciation to all the people who contributed to the development of this manual.

A special thank you to Marilyn Van Bibber the author and principal researcher for *It Takes a Community*. Throughout her career Marilyn has dedicated herself to increasing awareness of FAS and FAE in Aboriginal communities. She has strengthened Aboriginal communities through her efforts and enabled them to be better prepared to plan and undertake much needed prevention and intervention strategies. This document would not be possible without her tireless effort.

It Takes a Community was developed under the guidance of a national First Nations/Inuit Working Group. Drafts were also submitted to a community review in 10 locations across Canada.

It Takes a Community National Working Group	
Margaret Moyston Cumming	Chairperson, First Nations and Inuit Health Program, First Nations and Inuit Health Branch
Elsi Casaway	Assembly of First Nations
Janice Nicotine	Saskatoon Tribal Council
Dr. Fred Baker	Canadian Paediatric Society, Toronto Indian and Inuit Health Committee
Barb Heavyshield	Child Family Services, Standoff Alberta
Evelyn Voyager, R.N	Port Hardy, B.C.
Helen Cromarty	Nishnawbe-Aski Nation, Ontario
Janet McGrath	Pauktuutit, Inuit Women's Association
Linda Grieve	Southeast Resource Development Council, Manitoba
Betsy Jackson	Whitehorse, Yukon
Cindy Ginnish	Eel Ground First Nation, New Brunswick
Lise Bastien	First Nations Education Council, Wendake, Quebec

Dr. Christine Loock made significant contributions to the section entitled The Facts About FAS. The sections on Living With FAS/E, Referral and Assessments as well as Tips for Teachers were prepared with the cooperation and expertise of Julie Conry.

The FAS/E Support Network provided advice and access to their documents which are referenced throughout *It Takes a Community.*

The ANAC also wishes to acknowledge Gail Peekeekoot for her help in starting the manual and Margaret Moyston Cumming of the First Nations and Inuit Health Branch for her kindness and assistance throughout the project.

It Takes a Community Steering Committee

Thank you to members of the Steering Committee who facilitated community consultations in:

Ross River, Yukon

Inuvik and Fort McPherson, NWT

Port Alberni, B.C. and the surrounding Nuu Chah Nulth communities

Blood Reserve, Alberta

Saskatoon, Saskatchewan and the surrounding Saskatoon Tribal Council communities

Little Black River, Manitoba

Wapekeka, Ontario

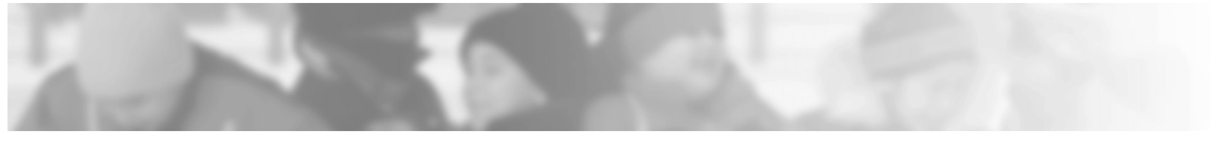
Kitigan Zibi, Quebec

Eel Ground, New Brunswick

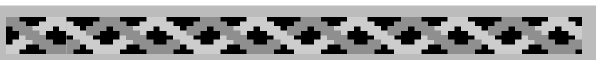
A special acknowledgement to the people who participated in the community consultations across Canada. The production of *It Takes a Community* was guided by the contributions of those who took time from busy schedules to willingly share their knowledge, experiences and ideas.

Funding for the research, writing and production of *It Takes a Community* was provided by the First Nations and Inuit Health Branch of Health Canada.

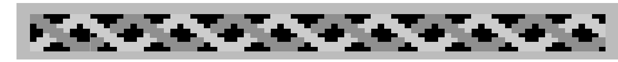
Preface



Children are a special gift of the creator. An individual child is not owned by the parents — but borrowed for a time to be in the physical world and live as an integral part of creation. A new child has been given many "gifts" by the creator. These are interpreted differently by Aboriginal nations — but they are generally known as humility, respect, compassion, courage, truth, wisdom and love. These gifts provide guidance and strength to the child. How these gifts affect a child's life will depend on the nurturing received in the child's home and community. A stable loving and caring home will bring out these special attributes in the child. In turn, the child will help to make the future for his or her community.



The family and community are challenged to help children with FAS/E find a place in the community and world at large.



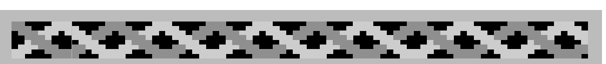
This life-view has a uniquely First Nations perspective. Yet, there are common values within this view that are shared by many — be they of First Nation, Metis or Inuit heritage. Parental love, care, responsibility and nurturing are qualities that every child needs. The absence of same often reflect a family's troubled history and, as all generations are connected, the problems of the parents are likely to be passed on to their children — until the pattern of neglect is broken.

When the history of a community or a family results in alcohol use by a mother during her pregnancy, the child is at risk of being born with a range of physical, mental and emotional disabilities. These are called, depending on the nature and extent of the condition, Fetal Alcohol Syndrome or Fetal Alcohol Effects (FAS/E). Children born with FAS/E will still have their own gifts and talents — but not the same as they might have otherwise had in a pregnancy free of alcohol. The family and community are challenged to help children with FAS/E find a place in the community and the world at large.

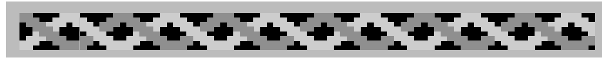
Our "connectedness" to each other and the world around us means that our behaviour usually affects someone else — this can be a helping or hindering influence. Like a stone tossed into a pond, our actions ripple out into the world touching others in our families and communities. Similarly, the birth of an FAS/E child has a ripple effect felt foremost by the parents and immediate family. Eventually the entire community will be affected by this birth because of the actions and needs of the affected child and family members. This child need not and cannot live in isolation — nor should the mom or dad. The strength they need

to find balance and harmony for their afflicted child must come from within — but it must be supported from outside the family. Aboriginal traditional family values are based on the belief that "it takes a community to raise a child". Ideally this principle of family and community relations should guide communities at all times — particularly so in the case of children with FAS/E.

Although FAS/E has been a concern of Aboriginal careproviders and laypeople for some time only recently have communities had access to resources which helped them develop comprehensive prevention approaches. Most of these successful initiatives tend to view FAS/E as a manifestation of a number of conditions in the community — because understanding root causes, such as the sociological and familial conditions which lead to FAS/E, helps program planners design balanced and comprehensive strategies that are ultimately more beneficial for affected individuals, families and communities.



Equally important as prevention activities are intervention strategies that help families and communities now living with the presence of FAS/E.



Understanding the far-reaching effects of alcohol is also significant. Alcohol use during pregnancy can lead to Alcohol Related Birth Disorders (ARBD) which include conditions such as FAS/E. Yet the use and abuse of alcohol remains a global problem. It exists in many industrial and developing countries around the world. It exists in large and small communities — urban and remote places — in the north and south. Alcohol misuse and abuse affects many people, directly and indirectly, in all walks of life, regardless of race, culture or socio-economic standing — it does not discriminate. But it is the most vulnerable communities, with the poorest economies and all the attendant social and health problem, where alcohol abuse can have the greatest impact. Not only in it's immediate threat to individual and familial wellbeing and social conditions — but also from the unsuspected, unseen and life-long congenital conditions like FAS/E. For such communities prevention is the key. Fetal Alcohol Syndrome and Fetal Alcohol Effects are entirely preventable conditions that are directly caused by alcohol use and abuse during pregnancy. This fact alone make prevention activities worth the effort. Because, while the extent of the problem is unknown, FAS has been identified as one of the leading known causes of birth defects and developmental delay in North American children. (Loock 1990)

Equally important are prevention strategies that help families and communities now living with the presence of FAS/E. Such support programs help affected individuals live to their fullest potential and achieve balance and harmony in their daily lives. This is not a simple task nor one that should be carried alone. Successful prevention requires hard work, caring, respect and commitment from affected families

and the community caregivers who serve them. But people with FAS/E cannot be continually sheltered within the comforts of home and family nor confined to the safety net provided by caregivers. Ideally they must be enabled to function freely in the community, achieve their full potential, accorded due respect and live in joy and safety and for that to happen it takes a community.

This publication is called *It Takes a Community*. It is intended to help people prevent FAS/E and guide those who want to make their community a caring and supportive place for individuals and families already living with this condition.

Using the Manual

It Takes a Community is intended to provide a broad base of FAS/E information that will stimulate discussion, facilitate networking and help First Nation and Inuit communities design, develop and deliver their own community-based prevention and intervention strategies. This manual will provide sufficient information to enable everyone to effectively participate in the planning process, when community members work together to develop their own prevention strategy. Particularly, it will help community people who do not have background knowledge of FAS/E.

It Takes a Community DEFINES PREVENTION AS:

- Promoting healthy lifestyles
- Intervening to minimize risk behaviour
- Assisting those living and learning with FAS/E disabilities
- Assisting persons with FAS/E in the prevention of risk behaviours

Each new community initiative increases awareness of FAS/E. More Aboriginal caregivers will care and contribute as community awareness increases and people acknowledge that FAS/E is a concern that requires a coordinated, multidisciplinary approach. *It Takes a Community* was written with a team and multidisciplinary approach in mind and is directed at community resource people in the fields of health, education, justice, social services, as well as Aboriginal political leadership at all levels. It can be used with other resource materials such as positive parenting programs, training for trainers programs, cultural teachings, or any community development process in the community.

It Takes a Community recognizes the complex causes, effects and potential community responses to FAS/E. Accordingly, the strategies outlined herein suggest that prevention activities and the care of individuals with FAS/E involve schools, health education and public awareness initiatives, alcohol abuse prevention and treatment programs, social and child welfare programs, the judiciary and a great deal of political will.

From this broad perspective *It Takes a Community* attempts to cover a wide range of information in a concise, clear and simple manner. For some readers with particular interest in a certain aspects of FAS/E the information presented may be too concise. So, for those interested in getting more information, there is a short reference list of further reading at the end of each chapter. The manual is laid out in sections for easy reference. Each section covers a specific aspect of FAS/E such as prevention strategies, living with FAS/E or advice for teachers. Also included are loose leaf “fact sheets” that careproviders can use when doing community information sessions with laypeople or other caregivers.

The term "Aboriginal" is used throughout the document and refers mainly to the First Nations and Inuit target group. However this does not necessarily exclude other Aboriginal groups that have concern about FAS/E and find this document useful. In fact the publishers encourage widespread use of *It Takes a Community* to any and all groups, Aboriginal or not, who strive to prevent FAS/E and undertake supporting interventions for persons already affected.

Communities will have their own unique perspectives on the contents of this document. In fact, information on programs and prevention initiatives from different regions of the country will have more relevance to readers once they apply their own template of community concerns and needs over the ideas presented in this document. These programs and initiatives are described in short summaries and where possible include addresses or phone numbers. Hopefully, users of this manual will network with other community workers, share information and ideas and be proactive in their approach to creating FAS prevention strategies.

Throughout this manual the terms Fetal Alcohol Syndrome and Fetal Alcohol Effects have been combined as the acronym "FAS/E". Although FAS and FAE are considered distinct, for the purposes of this document FAS/E is being used to identify both conditions, when generally referencing neuro-developmental disability due to prenatal alcohol use. When FAS is used alone, it is specific to Fetal Alcohol Syndrome. When FAE is used it refers to Fetal Alcohol Effects.

Guiding Principles for Effective Strategies

CHAPTER 1

FAS/E can bring forward a host of conflicting feelings and emotions. The following offers some guiding principles and positive perspectives on FAS/E that can help community members and caregivers objectively understand the nature and far-reaching effects of FAS/E on individuals and communities.

Respect

Respect is a fundamental teaching of indigenous peoples around the world. It can be summarized as respect for all creation — the land, animals, plants, people, and self. Respect comes from the belief that every living thing has a spirit. All creation fits into the circle of life and as such is deserving of kindness, caring, and honesty. Using respect as a guiding principle in FAS/E prevention will promote positive development in the community, among family members, individuals affected by FAS/E and community workers.

Respect can come from:

- Understanding the traditional First Nations and Inuit teachings.
- Understanding the history of your community — what changes has it gone through? What was it like before European contact?
- Understanding your family history — what has been the impact of colonization and economic development? How has alcohol affected the family?
- Understanding the mother's story — is she an adult child of alcoholics, at risk of FAS/E herself? Has she suffered abuse in her life? Does she currently live under stressful conditions?
- Understanding that the individual affected with FAS/E is, first of all, a spiritual being.
- Understanding that a person with FAS/E is a person with a disability.

Resource workers, coming to terms with the special needs of these community members, sometimes look upon persons with FAS/E as teachers who challenge communities to rethink existing perceptions and remember old values and teachings.

- Understanding that a person with FAS/E has talents and potential.
- Healing the resource worker — the community resource worker will likely have, directly or indirectly, experienced similar traumas as the at-risk group in the community. Personal growth and coming to terms with past traumas must be respected as a vital part of community prevention activities.

Caring

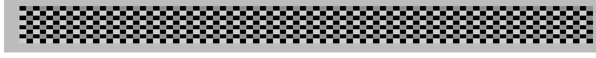
Newborn babies respond to and thrive from anyone who looks them in the eyes, caresses with a gentle touch and soothes with a kind and loving voice. All living creatures respond to the positive energy of kindness. Caring is also a fundamental element of Aboriginal traditional teachings which guide personal conduct.

Caring is something that can be done by all partners in the prevention of FAS/E. It costs nothing and takes no formal training — just practice. Caring and a positive demonstration of respect could be a kind word, a smile and taking time to understand the past and present life circumstances of people who are touched by FAS/E.

The will to care is often challenged by the circumstances of FAS/E in the community. For example:

- Some characteristic behaviours of persons with FAS/E can try the patience even of those who love them the most.
- Often extra effort is required to understand prospective parents that are abusing alcohol when the woman is pregnant.

All children are heavily influenced by the conditions in which they grow up. A child, whether normal or challenged with FAS/E, can have either a positive or negative upbringing.



- Sometimes it is a challenge to care and believe enough in ourselves to continually offer support and guidance to other affected community members in a respectful and caring way.

Hope

Earlier papers on FAS, whether scientific or popular, painted a bleak and hopeless picture of FAS. The early research was done primarily on individuals who were severely affected by prenatal exposure to alcohol (Kleinfeld, Wescott, *Fantastic Antoine Succeeds*). It is important to emphasize that there is a wide spectrum of effects of alcohol during pregnancy. FAS is part of that spectrum. Within the definition of FAS there is a range of intensity of those characteristics. FAE also has a range of effects. This means there is a range of disability. It also means there is a range of positive potential for each FAS/E child.

All children are heavily influenced by the conditions in which they grow up. A child, whether normal or challenged with FAS/E, can have either a positive or negative upbringing. There are children severely affected with FAS/E with multiple physical,

psychological, emotional, intellectual, and social problems. There are also children who have coped and managed to work around their disabilities to lead self-sufficient and productive lives. A hopeful attitude from all concerned — caregivers, family, educators and community members — about the positive potential of an FAS/E child will positively reinforce the child's image of himself and others.

HUMILITY

When caring people become aware of the long term and far-reaching effects of FAS/E, it is a common feeling to want to rush out and prevent further harm in their community. Some people may even try to immediately identify community members at risk or name those already thought to be affected.

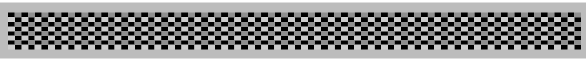
Although well intended, quick action does not guarantee good results. It is important for community workers and members to use caution and avoid hasty action. Understanding the complexity of FAS/E, the people it affects, its characteristics and root causes take time. Because there are other similar medical conditions, identifying whether someone has FAS/E is a medical diagnosis and should only be done by a skilled medical practitioner. It is not possible to become an FAS/E expert overnight by reading pertinent literature or attending conferences — but it certainly helps. Understanding and accepting what positive action can and cannot be taken in an FAS/E community situation is largely a learning process guided by respect, caring and being supportive.

COMPASSION

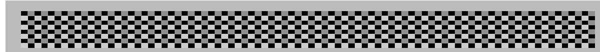
Medical journals often present a clinical, grim and narrow outlook on the condition called FAS/E. However, to caregivers they are real people — brothers, sisters, a neighbours child, cousins or grandchildren who have FAS/E. Perhaps they are people whom caregivers and other community members see everyday. As such each possess their own special, unique qualities and rightfully deserve a place in the community.

PATIENCE

Parenting or teaching approaches that work fine for children not affected by FAS do not necessarily work for alcohol affected children and adults. Sometimes conventional parenting or teaching methods simply do not work regardless of good intentions or amount of effort. The reason — alcohol affected children have trouble processing information and may be only able to understand part or none of any given instructions. This requires the parent or teacher to use other instructions to get the child to do the task. Sometimes approaches used successfully one day, may not work the next. Caregivers needs to be patient, flexible and creative.



It is important for community workers and members to use caution and avoid hasty action.



Cooperation

FAS/E is a complex health condition involving many mental, emotional, physiological and social factors. The causes of FAS/E are equally profound. One caring person can create awareness and initiate action. But it will take team work to be effective in the community over the long term — an organized team work with multiple approaches. Ideally, this means that when developing prevention strategies participation should come from all sectors of the community — parents, educators, caregivers, police and political leadership. The actions taken will depend on the needs and resources of each community. But whatever course of action is taken team building and team work are vital.

Educating the Community

CHAPTER 2

FAS/E is a very sensitive issue and there is no sure way to predict how people in the community might respond. When a resource worker is planning to present information about FAS/E at a community meeting there are a number of issues to consider before doing the presentation.

Disclosures

It is the responsibility of the person organizing the public education event to have a support network identified and ready to receive the referrals of anyone who might come forward. Presenting information in any community, especially high risk communities, could bring forward people who believe that someone they care for, or even themselves, might have FAS/E. What do they do? Where do they go? What issues are urgent? There could be a multitude of emotions attached to the possibility of having a child with FAS/E. If disclosures are made without an informed and caring support network, the new awareness could precipitate a personal or family crisis. Disclosures will require someone to follow-up in the community.

If disclosures are made without an informed and caring support network, the new awareness could precipitate a personal or family crisis.

Training

Presenting information about FAS/E requires someone with skills in communicating as well as an in-depth knowledge of FAS/E. Ideally, community workers should have workshop presentation or public speaking training or attended a train-the-trainers program before attempting public education activities.

Sensitivity Not Sensationalism

When organizing and presenting the public with information about FAS, present the information with respect and care, remembering that someone in the audience could be taking your words very personally. Participants should be left with a sense of hope.

Cultural Knowledge

Knowledge of traditional practices relating to conception, pregnancy and birth can be a good basis for developing community based prevention programs. FAS/E information presented in a larger socio-cultural context may facilitate easier understanding of FAS/E issues by setting a positive tone for public education.

The BC FAS Resource Society are developing a Community Planning Guide. Inquiries should be addressed to:
Alcohol and Drug Services
BC Ministry of Health
1520 Blanchard St.
Victoria BC V8W 3C8

SUGGESTED READING

Fantastic Antoine Succeeds, Kleinfeld/Wescott, University of Alaska Press, 1993.

Booklet on *HIV/AIDS and the Medicine Wheel,* by the Union of Ontario Indians.

Traditional Teaching

CHAPTER 3

Before contact with Europeans, First Nations and Inuit societies across Canada had their own customs and laws that guided people through life. While many changes have occurred since time of contact, the old way of doing things and guiding people are still an important foundation for personal and community development. Following are three examples of documented traditional teachings around parenting and childbirth.

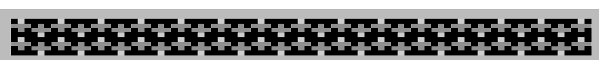
Traditional Health Practices and Childbirth in Inuit Society

Pauktuutit, the Inuit Women's Association, conducted extensive research into traditional childbirth practices with the goal of bringing back the practice of home births and use of traditional midwives. Part of the work has resulted in publication of their findings in newsletters and brochures. The following excerpts are taken from *Suvaguuq* Pauktuutit's Quarterly Newsletter Special Edition on Midwifery:

Traditionally, pregnant women and nursing mothers led a healthy lifestyle with lots of physical activity and a nutritious diet. Pregnant women throughout the north were advised to keep active, beginning with rising early each morning and going immediately outside to "smell the fresh air". Keeping active was seen as essential to promoting quick labours and ensuring that the placenta did not stick in the womb.

Women were encouraged to eat a variety of foods, especially caribou, char, muktuk, and seal, but they were advised not to eat too many berries and never to eat aged food while pregnant. Cold and frozen food helped to alleviate heartburn.

Traditionally, pregnant women and nursing mothers led a healthy lifestyle with lots of physical activity and a nutritious diet.



Nursing mothers were fed caribou broth, often made with blood, and sometimes fish soup to encourage milk production. One woman stated that in Labrador hunting camps, seal blood was given to the mother to drink immediately after the birth.

The interviews provide clear indications that the health and well-being of pregnant women in Inuit society is the responsibility of the woman and her family…. The advice and direction given by the family and elders was often overwhelming.

Few of the women recalled prohibitions on eating specific foods although one woman was instructed not to eat plants or seaweed during the latter stages of pregnancy. Clara Etok, from the village of Kangigsualujjuaq, lamented that she was denied Quiq, the outer part of the seal intestine and the "best part of the seal", during her pregnancy. A couple of the interviews suggest that prohibitions may have been more common in the old days. For example, Winnie Putumegatuk of Baker Lake said: "I was born when people started attending church services and my father, though I was aware of the taboos, told me I do not have to refrain from eating certain foods anymore because I was now a Christian."

Overall, the advice pregnant women received in relation to physical activity and the directives related to their behaviour indicate a concern for the health of the woman and her unborn child. This caring and concern was also expressed in reminders to eat regularly and nutritiously as well as in direct action… hunting for or preparing special foods. Apphia Awa remembered her father-in-law "had gone out rabbit or ptarmigan hunting to save for my meal after my delivery so I would produce milk." Similarly, soups and broths were prepared for lactating women and they were sometimes fed to the point of becoming sick of it… "After that I never want to eat broth again."

The interviews provide clear indications that the health and well-being of pregnant women in Inuit society is the responsibility of the woman and her family. In the past, young parents learned the responsibilities from their parents, in-laws, and elders. The advice and direction given by the family and elders was often overwhelming. Yet, they also felt the security of being surrounded by a circle of caring family members.

The elders interviewed in the study, said that many young women today, eat poorly and fail to keep active enough to ensure healthy pregnancies. While a traditional diet is high in protein and nutrients, many young pregnant women only have access to highly processed store-bought food.

The information on traditional Inuit lifestyle is being used to develop health promotion materials for Inuit communities.

For more information contact:
National Health Coordinator
Pauktuutit, Inuit Women's Association
131 Bank Street, 3rd Floor
Ottawa ON K1P 5N7
Telephone: (613) 238-3977
Fax: (613) 238-1787
E-mail: pauktuut@pauktuutit.on.ca
Website: www.pauktuutit.on.ca

Traditional Parenting

The Skookum Jim Friendship Centre in Whitehorse, Yukon has developed a traditional parenting program. The Traditional Parenting Program is a combination of two pilot projects dealing with Traditional Motherhood and Traditional Fatherhood. Project researchers, with the cooperation of knowledgeable local elders, have documented traditional laws and practices of child rearing for use in the parenting program. The program is designed to be delivered using circle discussions because it is an effective forum for communication and a traditional way of passing and receiving knowledge. Participants share their own knowledge and experience and are provided with the opportunity to learn about their heritage from traditional elders.

The target groups include:

- Aboriginal young women
- Women experiencing risk behaviour during pregnancy
- Women who do not access prenatal health care
- Aboriginal men experiencing risk behaviours
- Men in parenting roles
- Future fathers

The three primary goals of the program are:

- To encourage interest in and the practice of Yukon First Nation's traditional parenting practices values and principles; to preserve the First Nations' culture and improve the health of unborn children and infants, older children and families.
- To promote positive health behaviours by target group members, particularly those representing at risk pregnancies and to reduce the occurrence of FAS/E.
- To continually improve the usefulness of and access to the parenting programs, particularly to target group members in Whitehorse and other communities.

For more information contact:
Traditional Parenting Program
Skookum Jim Friendship Centre
3159 3rd Avenue
Whitehorse YK Y1A 1G1
Telephone: (867) 633-7680
Fax: (867) 668-4460

Researching Traditional Life Cycle

As community caregivers or laypeople start to develop their own FAS/E prevention activities, they may want to include information on local traditional birthing and child rearing practices. Researching traditional customs and practices can involve detailed studies or simple one-on-one interviews with a knowledgeable elder in the community. Decide what information you need. If possible identify the type of traditional knowledge that will facilitate understanding of FAS/E issues. This will determine your information requirements and research objectives. The cost, time frame, and ownership of information will be important considerations in this kind of research. Some of your study needs may already be recorded, so do a literature search to find out what research has been done on traditional life cycle in your area.

Research you want to conduct yourself could be done by interviewing key informants or by conducting a survey of community members who have knowledge of traditional lifestyle. Here are some suggestions for community-based research on traditional life cycle:

- Ask an elder
- Check to see if there have been any anthropological studies done on your community
- Conduct a survey among community people most knowledgable of traditional life cycle
- Convene a workshop to discuss traditional life cycle with a focus on pregnancy, childbirth and parenting

Prenatal Teaching

Rosella Kinoshameg, the Nurse-In-Charge at the Native Health Unit on Manitoulin Island in Ontario has developed a series of teaching models using Anishnabe teachings. In keeping with traditional teachings, Rosella has defined health as: "The power and energy to exist in balance of the body, mind and spirit and to function in harmony with the environment and the people."

Rosella teaches that each individual is born with sacred gifts of the creator and these are known as the seven sacred gifts. These gifts are: respect, humility, compassion, honesty, truth, wisdom and love. As well, the creator has given us the circle and medicine wheel so that we can view life in a holistic manner. The circle symbolizes completeness and interdependency that gives unity and strength. The medicine wheel divides the circle into four directions. The following framework allows for prenatal teaching using traditional symbols and teachings:
(See Illustration 1, page 63)

SUGGESTED READING

Barnsley, Jan and Ellis, Diana, *Research For Change, Participatory Action Research for Community Groups,* Women's Research Centre, 1992.

Illustration 1

MEDICINE WHEEL FOR BECOMING A MOTHER

The circle is a symbol of interdependence, wholeness, completeness that gives energy, vitality, healing, strength and unity. The circle represents the journey through life, "the circle of life" that begins at conception with the creation of new life.

Rosella M. Kinoshameg, 1995

This new life within the mother's womb is affected by the lifestyle and environment of the mother. So the mother must strive to be healthy in mind, body and spirit to provide a good beginning. To ensure that no harm comes to her baby she must give up smoking, alcohol, junk food and negative thoughts and feelings. She must accept that she is no longer a child but an adult with new responsibilities.

NORTH

WHITE | GIFT FROM CREATOR | SPIRITUAL

The mother easily begins the spiritual preparation. She accepts the baby as a gift from the Creator, a very special and precious gift to be guided and nurtured along life's spiritual pathway. She must prepare to teach the child how to live the seven sacred gifts: respect, humility, compassion, honesty, truth, wisdom and unconditional love. This child will become tomorrow, our blessing, our future, strong in the ways of our ancestors.

WEST

BLACK/BLUE | PROTECTION | SUPPORT

There must be involvement and support by family, relatives and the community. This circle of people plays a very important role in giving the child a sense of belonging and protecting the child with a circle of love. This includes giving support to the parents.

CENTRE

The mother is the centre and the foundation and the child's first teacher. She prepares the child for the "earth walk" by caring, giving, feeling and meeting every need. She demonstrates unconditional love, not only during infancy but throughout the whole life cycle.

EAST

YELLOW | BEGINNING OF NEW LIFE | STRENGTH

For the mother to be strong and also have a strong baby, she must eat good food and also she must balance exercise and rest. Exercises prepare and strengthen the muscles she must use during the delivery, allowing for a more comfortable pregnancy, minimizing loss of tone, decreasing fatigue and maintaining good physical form. Rest promotes physical and mental well-being, relieves tensions, reduces fatigue, builds up energy and at labour, reduces pains.

SOUTH

RED | DIRECTION AND DISCIPLINE | TEACHINGS

There is a colour, an animal or a bird, a sacred herb, an element and an aspect of the being in each direction. These are gifts from all the directions. Each gift comes with a teaching. The mother uses the teachings to help her with self-discipline as she sets new guidelines and goals so that her baby will be strong and healthy. The teachings give her direction as to how to follow the pathway of life, a whole way of life, "to do as we ought — to the best of our ability." From these teachings come knowledge and power.

For more information, contact Rosella Kinoshameg
United Chiefs and Councils of Manitoulin, Mnaamodzawin Health Services
Manitoulin Island, P.O. Box 104, RR#1, Shegviandah ON P0P 1W0
Telephone: (705) 368-2182   Fax: (705) 368-2229
E-mail: mnaanooj@kanservu.ca

Community Strategies that Address the Root Causes of FAS/E

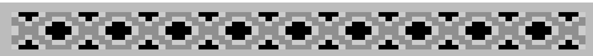
CHAPTER 4

Effective prevention strategies require an understanding of the characteristics of FAS/E and the events leading up to its emergence in Aboriginal communities.

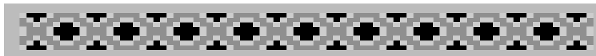
FAS/E in Aboriginal communities can find its roots in Canada's colonialist past. The deterioration of Aboriginal political and social institutions; the suppression of traditional spirituality, culture and language; the apprehension of Aboriginal children and loss of traditional lands and economies is the legacy of Aboriginal peoples after European contact in the new world. The current health and socio-economic conditions trace their beginning to these historic events.

But Aboriginal people have never ceased in their efforts to survive and flourish. Today Aboriginal nations work actively to counter the devastating impact of colonialism. They are regaining control over their lives through the development of Aboriginal community-based institutions in the areas of culture, education, health, economics and justice, and it is these efforts which provide a foundation and give direction to successful FAS/E strategies.

People designing community-based FAS/E strategies need to consider the root causes of alcohol abuse and the community responses. Recognizing the root causes will help community participants design an approach that truly reflects the communities history and its current needs. Because each community is at its own stage of development as it strives to become healthy and self-sufficient . The strengths of the community can be found in its efforts to regain control — and an important principle of community development is building new initiatives on the strengths of the community. Effective strategies recognize the issues that community members deem important. They also consider actions that the community has already taken and actions they plan to take to address these issues. Likely the important initiatives in the community involve efforts to counteract the debilitating impact of colonialism — the root causes of many social ills such as loss of lands,



Effective prevention and intervention strategies require an understanding of the characteristics of FAS/E and the events leading up to its emergence in Aboriginal communities.



language, culture and resources. If possible and appropriate, these factors should be integrated into the strategy. This means that an FAS/E strategy could have linkages to a number of ongoing community initiatives such as affordable housing, education, cultural programs or recreation. Following are several brief examples of proactive community initiatives that deal effectively with contemporary problems by addressing the root causes of loss of culture and community control.

Ross River

Ross River, a remote community in the Yukon decided that one way of addressing alcohol abuse was to bring back more cultural practices. They started having cultural exchanges with a neighbouring First Nation that still practice traditional songs and dances. The cultural exchange was a catalyst for community people to once again participate in traditional activities and reclaim ownership of the songs, dances and games that had been absence from the community for years. Cultural revitalization has instilled a stronger sense of identity and pride in community members. Today the community has its own drumming group of young men who travel to other communities, sharing the culture.

For more information contact:
NNADAP Worker
Ross River Dena Council
Margaret Thomson Centre, General Delivery
Ross River YT
Telephone: (867) 969-2430
Fax: (867) 969-2019

Blood First Nation

In 1988, the Blood Tribe took control of its educational system and established a Department of Special Student Services to research and develop resources and programs for Kainai students with special educational needs. Since tribal control became a reality, Special Student Services initiatives have included improvements in assessments, implementation of individualized program plans, and the development of special education language arts and living/vocational skills curricula.

The Special Student Services have initiated a longitudinal research project designed to lead to the development and implementation of culturally relevant programs appropriate for Kainai children with FAS/E. For the Blood, taking control of education is an effective means of ensuring quality education for all children in the community and also an important pillar supporting self-governance.

For more information contact:
Project Director
Special Student Services Department
Kainai Board of Education
Box 240, Stand Off AB T0L 1Y0
Telephone: (403) 737-3966
Fax: (403) 737-2361
E-mail: kainaied@telusplanet.net

Nuu Chah Nulth Tribal Council

The Nuu Chah Nulth Tribal Council have been leaders in resuming control over their health and social services and administration of programs previously provided through Indian and Northern Affairs Canada. As part of their health and human services, Nuu Chah Nulth have established their own Infant Development Program. It is a program aimed at working with parents/caregivers and other family members in a co-operative environment that fosters respect and sharing manner by:

- Supporting parents as the primary observers of their children's strengths and interests;
- Helping parents identify any developmental needs their children may have;
- Empowering parents by providing culturally sensitive information on child development;
- Fostering independent thinking; and
- Encouraging community growth towards awareness of child development and traditional child-rearing practices.

For further information contact:
Senior Infant Development Worker
Nuu Chah Nulth Tribal Council
P.O. Box 1280
Port Alberni BC V9Y 7M2

SUGGESTED READING

Aboriginal Peoples and Politics, Paul Tennant, University of British Columbia Press, 1991.

A Long and Terrible Shadow, White Values, Native Rights in the Americas, Thomas R. Berger, Douglas & McIntyre, Vancouver/Toronto, 1991.

Social Impact Assessment in Small Communities, Bowles, R.T., Butterworth, 1981.

Building Communities From the Inside Out: A Path Toward Finding and Mobilizing A Community's Assets, ACTA Publications, 4848 N. Clark St., Chicago, Ill., phone (312) 271-1030, Cost — $14.50 US.

The Facts About FAS/E

CHAPTER

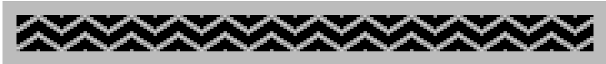
This section will provide general background information on Fetal Alcohol Syndrome and Fetal Alcohol Effects.

Historical Awareness

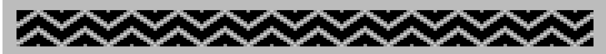
Concern about the harmful effects of alcohol on the unborn are not new. There is evidence of the possible dangers of alcohol for the unborn baby, going back to Biblical times. In the Bible, Sampson's mother is warned "Behold, thou shalt conceive, and bear a son; and now drink no wine or strong drink" *(Judges 13:7).* The ancient Greeks had laws prohibiting the drinking of alcohol on the wedding night for fear of begetting a damaged child.

During the *gin epidemic* in England in 1720 to 1750, cheap alcohol was causing a social crisis. The College of Physicians petitioned Parliament to control the gin trade as it was the "cause of weak, feeble and distempered children" (Rosett, Weiner, 1985). An artist of that period, William Hogarth created a series of etchings depicting drunken women and men. One etching portrays a child with facial features similar to those of a child with FAS.

Throughout the 19th and early 20th century, medicine and the temperance movement in the US were closely connected. Medical findings on the adverse effects of alcohol were used to justify Prohibition in the United States. After Prohibition in 1933, medical arguments about adverse effects of alcohol were ridiculed and discarded because they were considered unscientific. There was a belief that somehow the placenta provided a natural barrier protecting the unborn baby from alcohol. In fact alcohol was used for medical intervention of premature labour. A glass of beer or wine was considered to aid in milk production during breastfeeding.



Canadian and U.S. health authorities recommend abstaining from alcohol during pregnancy and breastfeeding.



In 1968, Lemoine published an article describing the characteristics of children born to alcoholic mothers in France. However, this work was published only in French and received little attention until 1973. That year, Smith and Jones of Seattle, Washington published in the medical journal, *Lancet,* an article describing a similar pattern of malformation and coined the term *Fetal Alcohol Syndrome* (Jones/Smith, 1973). Since 1973, there have been many articles written about FAS. Primarily in medical journals and papers.

Alcohol causes a wide range of effects on the fetus. This depends a lot on the level of blood alcohol in the mother and the stage of the pregnancy. The effects can range from miscarriage, premature delivery, Fetal Alcohol Syndrome, Fetal Alcohol Effects, isolated birth defects and learning and behavioural problems (Abel, 1991). The effect or damage could be influenced by a number of other maternal factors including general health, diet, smoking, other drugs, genetics factors and metabolism. The following describes terms associated with FAS:

Alcohol Related Birth Disorders (ARBD) is a broad term encompassing all birth defects resulting from prenatal alcohol exposure. Alcohol damages most organs and systems of the body. Damage ranges from single or multiple malformations of the heart, skeletal system, skin, kidney, bladder, genitals, facial features, spinal cord, and brain. The most critical damage is to the brain. FAS is a subcategory of ARBD.

Fetal Alcohol Syndrome (FAS) This is the most commonly used term relating to the adverse effects of alcohol on the fetus. It is a medical diagnosis describing a cluster of birth defects caused by heavy drinking during pregnancy. There is a spectrum of effects within the criteria for diagnosing FAS which indicates the importance of individual assessment and testing. A prenatal history of alcohol exposure and the following three criteria are needed for a full diagnosis:

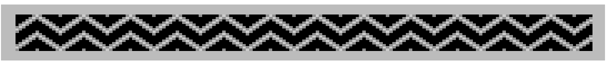
- Prenatal and/or postnatal growth delay
- Central nervous system (brain) involvement
- Characteristic facial features

Fetal Alcohol Effects (FAE) This term describes a history of prenatal alcohol exposure and the presence of one or two of the characteristics of FAS. It is often misused to describe any condition milder than FAS. Often these individuals may not have the obvious physical characteristics of FAS, but the damage could manifest in the brain. As a result, these individuals may have brain damage but look quite normal. It should be noted that FAE is not the less severe form of FAS; rather, a child with FAE does not have all the physical abnormalities of FAS. The cognitive and behavioural characteristics of FAS and FAE are similar (Streissguth/ Burgess, 1990).

Neonatal Abstinence Syndrome (NAS) refers to the presence of withdrawal symptoms in infants exposed to one or more drugs during pregnancy. These drugs include alcohol, narcotics, heroin, demerol, morphine, codeine and cocaine. Sedatives, anticonvulsants and stimulants are also harmful.

Blood alcohol level is a measure of alcohol in a person's blood. A woman's body generally contains less water and breaks down the alcohol more slowly than a man. As a result, the average woman gets drunk faster and on fewer drinks than a man.

Stages of Pregnancy are divided into three, three-month stages called the first, second and third trimesters. During the first three months, most of the cell development for the organs and systems of the



The more the mother drinks, the higher the risk of greater damage. Both heavy drinking on a daily basis and sporadic binge drinking are considered particularly dangerous.

body are formed. Throughout the remaining months of pregnancy, these cells grow. However, brain cells continue to form, develop and grow throughout the entire pregnancy with accelerated growth and development during the last three months and even on into the second year of life. Understanding the process of fetal development supports the premise that interventions to stop drinking at any time during pregnancy will increase the likelihood of a healthy pregnancy and baby.

Mechanism of Alcohol Effects

Following consumption, alcohol is absorbed into the blood, from the stomach and intestines and transferred to the liver. The alcohol is metabolized or broken down in the liver by two enzyme systems. The blood concentration falls at a rate of about one drink per hour, regardless of the initial level. With additional drinks the blood alcohol concentration rises. In the pregnant woman, alcohol easily crosses the placenta to the circulatory system of the fetus. Due to the baby's small and underdeveloped liver and enzyme system, it cannot rid itself of the alcohol at the same rate the mother can. One study showed that the rate of elimination of alcohol from the fluid surrounding the fetus was twice as long as the maternal blood (Seward, Barber, 1991). Alcoho also passes easily into breast milk.

Effects on the Fetus

While the alcohol is in the unborn baby's system, it causes damage:

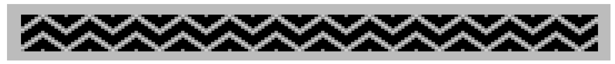
- By causing malformations to parts of the developing fetus during the first three months when the organs are forming. Brain development occurs throughout the pregnancy, hence drinking at any time during pregnancy may cause damage to brain tissue.
- As a toxic agent, the alcohol causes damage to the cells of the developing organs. As well the fetus is forced to divert its energy to metabolize the alcohol instead of using energy to grow new cells and tissues. The damage is especially dangerous to the brain.

The more the mother drinks, the higher the risk of greater damage. Both heavy drinking on a daily basis and sporadic binge drinking are considered particularly dangerous.

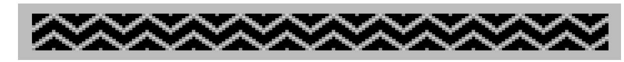
Canadian and U.S. health authorities recommend abstaining from alcohol during pregnancy and breastfeeding.

Paternal Drinking

The effects of paternal drinking on the fetus are not fully known. At the time of conception, alcohol can result in a lower sperm count and abnormal sperm, making the likelihood of pregnancy remote, and if pregnancy occurs, the likelihood of early spontaneous abortion is high (Abel, 1990). Children of alcoholic fathers have been shown to have defects in intellectual function such as learning and memory and to be more hyperactive than children of non-alcoholic biological parents. These data have raised the question of whether these effects are the result of genetic

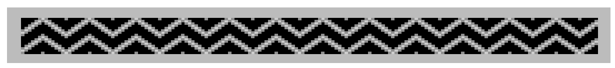


…interventions to stop drinking at any time during pregnancy will increase the likelihood of a healthy pregnancy and baby.



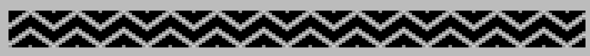
transmission or a direct effect of paternal alcohol consumption on the father's sperm prior to conception. There is no conclusive evidence that paternal drinking before conception causes direct adverse effects on the fetus.

The social effects of the father's drinking are enormous, as women most often drink with their partners. A father's drinking after the baby is born could also adversely affect the nurturing environment needed to raise a child.



"Preventing one child from being born with FAS, more than earns you your life's salary"

Dr. GC Robinson, founder of the BC FAS Resource Society.



The Effects of Other Drugs on the Fetus

During pregnancy, there are many other drugs that have a damaging effect on the fetus. The following summary has been added to the discussion which is focused on the effects of alcohol. Further information can be found in the reference section.

Tobacco: Risk of low birth weight, higher risk of death during the newborn period, higher risk of Sudden Infant Death Syndrome (SIDS — crib death). Second-hand smoke may also result in low birth weight.

Marijuana: Risk of low birth weight. May have some learning disabilities. Marijuana is often used with other drugs such as alcohol and tobacco so the baby is influenced by a combination of effects from multi-drug use.

Cocaine: Increased risk of premature labour, risk of low birth weight, risk of death during labour and delivery, risk of malformations such as limbs and kidney. Infants often are born addicted and suffer withdrawal symptoms. May have learning problems.

Opiates/Heroin, Methadone, and other opiates: Risk of low birth weight, increased risk of SIDS, can be born addicted and suffer severe withdrawal symptoms, long term developmental delays, risk of brain damage.

Talwin and Ritalin (T's and R's) and other illicit drugs: Some babies experience withdrawal and have learning problems. More research is needed.

Prescription drugs: Drugs carry side effects that may be damaging to the fetus, so the best advice is to check with your physician on whether a prescribed or over the counter drug is safe to take during pregnancy. There may be some health conditions where the medical need for the drug is weighed against the possible side effects to the baby.

The Characteristics of FAS

No two children are affected by FAS/E in exactly the same way. The child will have some of the common characteristics, but not necessarily all of them. Some of the characteristics may change as the child grows up.

Growth retardation: These babies may grow at a slower than normal rate during pregnancy and/or continue slower than normal after birth, failing to "catch up" to healthy children. Growth delay is defined as weight and/or length below the tenth percentile for the chronological age. These children are typically small and skinny, growing into short adults. Maternal smoking and poor prenatal nutrition may result in increased growth retardation.

Facial features: A clinical diagnosis of FAS requires an identification of at least two facial features. These include short palpebral fissures of the eyes (shortened eye slits), epicanthal folds of the eyelids, flattened mid-face, short turned up nose, flattened philtrum (midline ridge between nose and lip), and thin upper lip. There are other facial malformations involving the eyes, ears, mouth (palate and teeth). Not all clinicians agree on frequency of facial features, which become more difficult to diagnose as the child grows older. Distinct features may begin to fade due to normal facial changes into adulthood. Caregivers stress the need for a complete clinical diagnosis to determine the existence of FAS because basing such judgements solely on facial features may promote a stereotypical visual perception of an FAS affected child.

Central Nervous System involvement: The most critically important effect of alcohol on the fetus is the permanent damage to the central nervous system. Damage includes such conditions as microcephaly (small brain, head circumference below third percentile) or brain malformations, developmental delay, intellectual impairment, behavioural disorders, learning disabilities and attention deficit/hyperactivity. Alcohol can damage the brain at any point during the pregnancy, including the last part of the pregnancy when the brain is growing and developing rapidly. Researchers now recognize that prenatal alcohol exposure may affect the complex organization and communication within the brain, and hence may be responsible for the more subtle effects on judgement and reasoning in an individual with average intelligence.

Long-term Effects and Behavioural Effects of FAS/E

Damage to the brain is permanent for a person who has FAS/E. This does not mean there is no hope. As parents and workers learn more and more about how to respond to FAS/E, the prospects become more hopeful. Common behavioural problems found in a wide range of individuals with FAS/E show that they may function far below their chronological age. Poor judgement, learning difficulties, impulsive behaviour and poor social and communication skills are common characteristics. Good verbal skills, superficial friendly social manner and good intentions often mask their level of disability. These kinds of characteristics put persons with FAS/E at risk of exploitation or abuse by others. They may be at risk of becoming involved in criminal activity, alcohol and drug abuse. Once involved in high risk activities, it is difficult to break the cycle because of limited adaptive skills.

The special qualities of individuals with FAS/E often is overshadowed by learning and behavioural concerns. They are often loving, affectionate people with a willingness to please. Persons with FAS/E have done well in various pursuits of achievement. One young woman attributed her success in completing high school to encouragement and support of her potential rather than an imposition of limits. “Don’t tell me what I can’t do…show me what I can do” was an example of her philosophy. The expression of these qualities is very dependent on a nurturing and supportive upbringing.

In a follow-up study of 61 adolescents and adults with FAS, the average Intelligent Quotient (IQ) level was considered mildly retarded. The range was quite broad, from an IQ of 20 , indicative of severe retardation to 105, a normal range intelligence (Streissguth, 1986). This indicates that it is impossible to predict from the diagnosis alone, how disabled the individual with FAS is. Even with a normal IQ range, there can be damage to the organization of the brain leading to developmental and behavioural problems. Persons within the normal IQ range showed maladaptive behaviour such as failure to consider the consequences of their actions, a lack of appropriate

initiatives, unresponsiveness to social cues, and a lack of reciprocal friendship.

FAE is estimated to be at least three to five times as common as FAS. Intellectual impairment and behavioural characteristics are similar to FAS, but the child could look normal. This fact can place the child with FAE at greater risk of a poor outcome because his disability is hidden. Functionally, children with FAS and FAE were considered to be the same. However a recent study shows children with FAE may do worse, in certain environments (Streissguth, Spokane Conference, 1996). The child who looks normal but behaves in an inappropriate manner will likely be considered willful and bad. In the absence of intervention, secondary problems could develop over the long term. These include: substance abuse, mental illness, school problems, trouble with the law, homelessness and violent or threatening behaviour (Streissguth, 1995).

Publications such as *Fantastic Antoine Succeeds* stress that children with FAS/E are responsive to intervention strategies. Supportive and structured home and school environment can help children reach their fullest potential. Results come from "doing things differently rather than trying harder" is a message echoed by parents and educators alike.

Incidence of FAS

The incidence rate indicates the number of occurrences during a fixed time period, like the number of new FAS cases per year. In this case the incidence rate could be considered a *one year movie documentary* of new cases in one year.

The prevalence rate describes the actual number of children with a given disease or condition at one point in time for a given population. This could represent a *snapshot* of FAS in a community.

Few studies have been undertaken in Canada to determine incidence and prevalence rates of FAS. Most clinicians adopt the European and North American rates as being reflective of Canada. Studies of incidence among American Indians show that different tribes have varying rates of FAS. Studies in Canada are limited and show alarmingly high rates of prevalence. One explanation could be that there is not enough information to generalize high rates throughout the Aboriginal population in Canada, but it does indicate that there are *pockets* of high prevalence.

The incidence rate in North America of FAS can be compared to the incidence of other common birth disorders, Down's Syndrome, a birth defect caused by chromosomal abnormalities and Spina Bifida, a defect of the covering of the spinal cord. The following are approximate rates for North America that may vary regionally.

FAS: 1/500

DOWN'S SYNDROME: 1/600

SPINA BIFIDA: 1/700

Although the lack of research makes incidence and prevalence rate hard to quantify, experts do recognize that: FAS/E is the leading known cause of birth defects and mental handicap. Fully 50% of persons diagnosed with FAS/E are mentally challenged.

Also, research substantiates that FAE is at least three to five times more common than FAS.

Medical experts also caution that FAS is a medical diagnosis that can only be made by medical practitioner with knowledge in the field. Because there are other birth disorders that may be confused with FAS including Aarskog's Syndrome, Noonan's Syndrome and Shprintzen's Syndrome (Clarren, 1995). A psychological assessment is also recommended but not required for a diagnosis.

Costs of FAS

The greatest costs cannot be calculated in terms of dollars. The cost to the affected individual, his family and community is difficult, perhaps impossible to measure. The socio-cultural costs may be highest in small communities where alcohol abuse is high and intergenerational. FAS/E can be threat to cultural survival.

Researchers have attempted to figure out the financial cost of FAS. A study in Alaska found that the lifetime financial cost estimate per FAS birth is 1.4 million US dollars and the yearly cost for Alaskan babies born with FAS is $39.8 million per year. This accounts for continuing health care, special education, and social services. It does not consider the cost to the criminal justice system or the cost of lost productivity.

SUGGESTED READING

Fetal Alcohol Syndrome, National Institute on Alcohol Abuse and Alcoholism, Alcohol Alert, No. 13, US Dept of Health and Human Services, July 1991.

Alcohol-Related Birth Defects, Alcohol World and Health Research, Vol.18, No.1, National Institute on Alcohol Abuse and Alcoholism, 1994.

Alcohol and Child/Family Health: A Conference with Particular Reference to the Prevention of Alcohol-Related Birth Defects, BC FAS Resource Society, 1988.

Fetal Alcohol Syndrome, Earnest Abel, Medical Economics Co. Inc, Oradell, NJ. 1990.

Fetal Alcohol Prevention and Education, Family Album, Spokane Tribal Community Action Team, P.O. Box 453, Wellpinit, Washington. 99040.

A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects, The FAS Support Network, 14326 Currie Drive, Surrey, BC, V3R 8A4.

A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians, Streissguth, AP, LaDue, RA, Randells, SP, U of Washington, Seattle, Washington, USA.

Joint Statement: Prevention of Fetal Alcohol Syndrome (FAS) — Fetal Alcohol Effects (FAE) in Canada, Health Canada, October, 1996.

Developing Prevention Strategies

CHAPTER 6

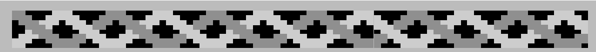
How do we prevent FAS/E? Some communities will decide to use traditional laws and practices to change behaviour in their community. Some will strive to improve economic conditions, develop special programs or design school curriculums. Each will choose a way that reflects the community's means and conditions.

This section describes examples of community-based approaches to preventing FAS/E and includes suggestions on strategies for different target groups within the community.

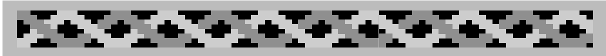
Understanding Your Community

In traditional societies, First Nation and Inuit people organized and lived under a collective authority. Communities followed laws and practices that protected the rights of the group and the individual. Mutual respect and sharing helped people live together in often harsh conditions. The importance of caring for one another was strongly reinforced by community beliefs, values and custom. So each person willingly accepted a responsibility for the collective wellbeing. As one elder stated "I was taught by my mother; never pass by someone in need." Another elder, tells of how her mother would cook all the best food for travellers coming into the village. Children were cared for by everyone. They could enter any home knowing they would be warmly received and safe. These same children were continually nurtured and guided in their conduct by the whole community. Everyone understood their role in keeping the community healthy and each person wanted to contribute to the wellbeing of the entire community.

This idealistic view of a healthy, functioning



Children need to know the actual facts of FAS/E and how to prevent it before they begin to be sexually active and before they begin to use alcohol and drugs.



Aboriginal society is intended to encourage readers to examine the qualities that make their communities work. Prevention strategies need to be built on a strong foundation that requires an understanding of the problems and potential of the community. What are the strengths of your community? What is needed to make it a healthy place to live? What is important to the people? These are but a few of the questions that must be answered before designing a prevention program.

Building a Team

The task of rebuilding a community might seem formidable. But it can be done even under the toughest conditions. It starts with one vision and one person working with another. In this manner the people of the Alkali Lake First Nation in British Columbia reversed generations of alcohol abuse over a ten year period. It started with one person, then two people, adding others until they grew to a small group, with the same vision of a sober community. Eventually through hard work, sharing and perseverance the vision and the strength of this small group allowed others to see what could be done and the community achieved near total sobriety. The community team grew one person at a time. Alakali Lake has been an inspirational model for others who seek community change — and there are other successful team building concepts that Aboriginal communities are using to make a positive difference.

At Eel Ground Reserve in New Brunswick, a group of community people formed a Community Resource Committee. They first came together because of a crisis in the community. The committee's main purpose was to make the community a good place to live. It is non-political and non-personal. They do not get involved in political debate nor deal with issues from a personal perspective. After the crisis was resolved the committee was asked to maintain its proactive approach to help deal with other issues in the community. It now functions as a volunteer team of concerned people that offers advice and complements the activities of Chief and Council and other committees. The group operates on consensus and committee members are seen as role models in the community.

For more information contact:
Cindy Ginnish
Eel Ground School
55 Church Road
Eel Ground, NB E1V 4E6
Telephone: (506) 622-2007
Fax: (506) 627-4624
E-mail: Macdonal@nbnet.nb.ca

Community Healing

Across the country Aboriginal people are working together to bring strength and dignity back into families and communities. Community healing is at the heart of this revitalization. Many communities acknowledge that before progress can be made on a number of social and health concerns, past trauma must be recognized and a healing process put in place. For the people of the Ktunaxa Kinbasket Nation understanding the causes and effects of FAS/E is a key part of community healing and community action.

Community Healing and Intervention Program (CHIP)

A survey commissioned in 1990-91 by the Ktunaxa/Kinbasket Independent School Society, revealed disproportionately high rates of mental retardation, severe learning disabilities and behaviour disorders within the school age population. Information from parents indicated cases of prenatal substance exposure and revealed that many parents were unable to provide stable and healthy environments for their children. Further research suggested that a large number of parents were also disadvantaged by prenatal substance exposure.

In response to this situation the community developed the Community Healing and Intervention Program. CHIP is a population-focused health promotion program for the Aboriginal people affected by FAS/E who reside in the traditional territory of the Ktunaxa Nation and Kinbasket People. CHIP helps create a community environment which increases people's health and well-being by enabling affected individuals to work productively and to participate

actively in the social life of their community. The capacity and skills of people are emphasized through the central theme of "hope and potential".

The program staff includes a coordinator, intervention planner and five community support workers — one for each of the Native communities in the region. Their educational backgrounds include nursing, education, social work, special education support, alcohol and drug counselling and community health representative training. Some are band members while others are non-Native. All required further education to understand FAS/E and how people experience living with FAS/E.

All CHIP activities, including activities such as public information, advocacy and support programs and career, education and life skills development, are based on the program principles of health development, community organization and empowerment.

Health Development

Health development activities are designed to create community conditions that enhance the health of fetal alcohol affected people and their families. This is done through program activities that start with the individual and family and move outward into the community to reach the general public, health and social service providers, educators, justice and law enforcement personnel and potential employers. For example, acting as an advocate for an FAS/E affected youth accused of being sexually intrusive has required the following:

- Preparing a treatment plan acceptable to social services, the RCMP investigator and the crown council and defending the rationale for this plan;
- Providing direct intervention in the form of socio-sexual education (sexuality and relationships) for both the offending youth and the victim. This includes preparing his and her family, friends and school to be part of a supportive structured environment;
- Finding a clinical counsellor that understands FAS/E and arranging funding for that service.

Beyond working directly with the youth, his family, friends and school, CHIP also:

- Provided resources on socio-sexual education for other parents through support groups;
- Educates social services, RCMP, crown council and forensic services clinical counsellors on FAS/E in the adolescent population;
- Responded to the provincial sexual assault policy review;
- Worked with school counsellors and PHNs on a proposal to add socio-sexual education to the curriculum for special needs students;
- Sponsored a conference titled *FAS/E: An Approach to Justice Issues.*

Community Organization

To create the greatest health benefit for the population, programs such as CHIP, must extend beyond the individual and family. Besides the involvement of individual band members, the Band's independent schools are structuring comprehensive approaches to early development, schooling, training and life skills. The goal of the treaty process — a meaningful future for everyone — supports the capacity building goals of the school's programs. Today, a personal development program, called Itaqnanam, developed by the Ktunaxa Independent School Society, helps students learn to coordinate home and work and to cope with the problems presented in these situations. Also, courses of study are being changed to meet the needs of learners with FAS/E.

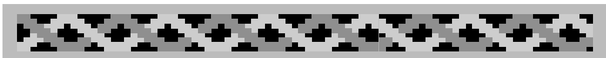
The region's five school districts, community college and local industry are working as development partners to meet the needs of the "career challenged". For example, the Native Women's Cooperative is undertaking a cooperative venture that manufactures and markets native crafts. Also planned are a Youth Truck Farm, a residential vegetable farm enterprise that youth will build and manage.

Empowerment

A key element of community healing is the understanding within the community that social and

cultural wellness and progress depends on taking immediate action to prevent further cases of FAS/E and support those already afflicted. This is often not easily accepted by community members. FAS/E is a complex issue. The rhythm and timing of such acceptance and subsequent action varies as with any process that manages grief, shame or sadness — regardless if the individual or family has been personally touched by FAS/E. CHIP attempts to reach community members in subtle interpersonal ways. Pregnant youth are encouraged by their peers not to take alcohol or drugs. There is a biweekly gathering of young mothers that prepare lunch and learn parenting skills from adult mentors.

Because of ongoing efforts like this most infants in the area are born alcohol and drug free. Concern about preventing future FAS/E births has become "something that is talked about at the kitchen table" and CHIP believes this is necessary for each community to fully realize its capacity. A "regional community" that understands FAS/E is being created. The Community Healing and Intervention Program uses a health promotion approach that empowers people to understand the health, cultural, social and economic complexities of FAS/E and to do so with respect and compassion for all concerned. This is the basis for lasting community healing.



A key element of community healing is the understanding within the community that social and cultural wellness and progress depends on taking immediate action…

For more information, contact:
CHIP Coordinator
Site 15, SS#3, Comp 122
Cranbrook BC V1C 6H3
Telephone: (604) 489-5762
Fax: (604) 489-2091
E-mail: kiss@cyberlink.bc.ca

Regional Strategies

Provincial and territorial governments and organizations are placing more attention on prevention of FAS/E. Some jurisdictions have developed strategies which include a multi-disciplined approach to prevention. The following describes the province wide approach Manitoba is taking:

Manitoba Provincial Committee on Alcohol and Pregnancy

This committee was commissioned by the Manitoba Medical Association and is made up of 30 people from various agencies and concerns including a representative from the Assembly of Manitoba Chiefs and the Cree Nation Health Clinic.

The committee arose out of the Community Consultation on Fetal Alcohol Syndrome/Fetal Alcohol Effects that was held in Winnipeg in June 1993. It's purpose was to carry out the recommendations of this consultation in two areas:

1. Develop a Manitoba FAS/E Network throughout the province; and
2. Promote initiatives to deal with the problem in Manitoba.

The committee has been active since September 1993 and meets on a monthly basis in order to

facilitate community based action. The committee has a number of working groups and sub-committees to carry out a wide range of activities. These include:

- Creating approaches to prevent FAS/E in the highest risk population;
- Developing broad based educational efforts in the province, including education of post-secondary educational facilities and elementary/high schools as well as efforts to reach high risk youth outside the school system;
- Developing guidelines for referral and diagnosis;
- Identifying risk populations and strategies to assess frequency of FAS/E;
- Improving social service responses to the needs of persons with FAS/E; and
- Developing effective ways to support parents of FAS/E children.

A data base has been established to identify all agencies, groups and individuals concerned about FAS/E in order to promote communication and networking. Another initiative underway is the creation of a Resource Centre which will provide comprehensive and accessible information and resources.

For more information contact:
Southeast Resource Development Council
366 Broadway
Winnipeg, MB R3C 0T6
Telephone: (204) 956-7500
Fax: (204) 956-7382

Ideas for Prevention Activities

Prevention can be an organized program or an informal community practice. It can be a simple touch or a few words from an Elder or another respected community person. Going fishing with someone might be as meaningful and helpful to a person as their involvement in structured programs. In essence, prevention is information, support, caring and coordination. Regardless of the approach, prevention strategies should include some means of evaluating effectiveness. It is important to know if preventive actions are benefiting people in the community.

This section will offer prevention ideas on public education and community strategies intended to strengthen the social fabric of the community. These ideas are aimed at different target groups — because everyone can play a role in FAS/E prevention. The author recognizes that not all of the following will have relevance in all communities. They are presented as a starting point for community members and hopefully will help community members develop ideas that are uniquely suited to the circumstances and needs of their respective communities.

Following the cycle of life, it is hard to know where to begin with education and prevention strategies. Does prevention of FAS/E begin in the womb or before, and who needs to be targeted? The ideas that follow start with strategies for women of childbearing age. But, prevention activities are equally important for all target groups.

Strategies for Women of Childbearing Age

Traditional teachings

- Researching the role of women
- Laws and practices surrounding conduct of women before and during pregnancy

Facts of FAS

- Written information on pamphlets, booklets, flyers and posters
- Audio-visual materials
- Workshop sessions on FAS with discussion groups
- Information on strategies for living with persons with FAS/E

Support networks for women

- Bringing women together for discussion or support
- Cultural activities such as beading or weaving
- Fitness and nutrition classes
- Child care for women's activities

Counselling and treatment

- Access to treatment for women
- Access to treatment that includes child care

Preschool Strategies:

- Traditional activities such as songs, stories and dancing
- Parenting classes (Nobody's Perfect Parenting Program)
- Head start program
- Intervention strategies for children with FAS/E

Primary/Elementary School Strategies

Traditional teaching

- Participating in ceremonies
- Going out on the land
- Cultural activities like drumming, stick gambling, or canoe pulling
- Visiting with elders
- Cultural camps
- Learning the medicine wheel or other traditional teachings

Nurturing the unique gifts and talents of each child

- Offering a variety of sports, art, music, and cultural activities
- Spending time on a one to one basis with each child

Teaching problem-solving and decision-making skills

- Getting kids to do things themselves such as hooking up a dog team or setting up their own sport or cultural activities

Teaching facts of FAS/E

Children need to know the actual facts of FAS/E and how to prevent it before they begin to be sexually active and before they begin to use alcohol and drugs. An emphasis needs to be placed on how important it is not to drink if a person is at any risk of becoming pregnant. Otherwise drinking could occur before they even know they are pregnant.

These children may also have some classmates, friends and relatives who are living with FAS/E. They need to know how to support these friends and relatives and help them find a productive life path. The more they know, the more they will be able to help. Facts about FAS:

- Can be taught on its own or part of sexuality education or family life education in school and /or;
- Can be part of a workshop on alcohol or self-esteem. Respect and other guiding principles should be part of the presentation.

Strategies for Young Adults

Good communication skills

- Listening, assertiveness, constructive criticism can be taught in classroom sessions as part of family life or in community workshops
- Youth directed training and activity gives more ownership and more commitment from the youth

Sexuality education

Facts about FAS

Dispute resolution skills

- Peer counselling courses should be available in the school and community
- Refusal skills training

Sports and recreation

- Build on the activities that are wanted by youth in the community

- Support fundraising and other developmental activities generated by the youth
- Support opportunities to travel to other communities to participate in competitions

Youth treatment

- Access to age appropriate alcohol and drug treatment

Traditional teaching

- Coming of age training and celebrations for achieving rights of passage such as killing a first moose.

Strategies for Men

Traditional teachings:

- About men's roles and responsibilities in the family and community
- Opening 'Grandfathers Trails' in traditional territories and learning the stories and laws of the land
- Role of men in ensuring a healthy pregnancy. The most effective way to do this is not to drink (Women usually drink with their partners)

Facts about FAS

- A broad based knowledge of FAS and its long term implications including the possible link between their own drinking and possible alcohol affects to the child
- Strategies for daily living with persons with FAS/E

Support and counselling

- For men who are drinking and whose partners are drinking during pregnancy.

Strategies for Persons with Learning Disabilities

Designing strategies for persons with learning disabilities is a critical area of FAS/E prevention. Many people who have FAS/E are at greater risk of misusing and abusing alcohol. They in turn could become parents of FAS/E children. Individuals diagnosed as having FAS/E must understand what happened to them so they are better positioned to prevent their children from having the same problems. When dealing with FAS/E persons who are learning disabled, emphasis should be on recognizing abilities and reinforcing self-esteem.

Facts about FAS

- Using mediated learning approaches
- One on one teaching

Traditional teaching

- Access to cultural activities and information
- Counselling with an elder
- Reinforcing traditional teaching in everyday activity

Support and guidance

- Self-esteem must be nurtured
- Reinforce life skills including assertiveness and refusal skills
- Having family or community members who can act as a guide and advocate for the person with FAS/E.

Strategies for Community Leaders

Strategies outlined in this section are directed at elected and natural leaders.

Model sober leadership

- Most Aboriginal communities that have made big advances in dealing with alcohol have done so under sober leadership
- Involving leadership in development of strategies on prevention and intervention

Political action

- Putting social development and FAS as a priority

- Bringing back traditional laws and practices
- Coordinating an information campaign
- Securing services and programs for persons with FAS
- Securing appropriate education resources
- Supporting alcohol free activities
- Putting warning labels on bottles of alcohol

Strategies for the Community

- Develop a community plan and coordinated community approach
- Hold community workshops on FAS/E
- Have a public education blitz with media, workshops, video, pamphlets and posters
- Organize cultural activities and events (camps, games, gatherings)

Agencies across Canada have been busy developing resource kits and guides and other source material useful in planning community based action on FAS. Several American agencies and organizations have developed resources related to FAS/E.

For further information call:
FAS/FAE Information Service
Canadian Centre on Substance Abuse (CCSA)
National Clearinghouse on Substance Abuse
Toll free: 1-800-559-4514
Website: www.ccsa.ca/fasgen.htm

SUGGESTED READING

Nobody's Perfect, Leader's Guide, chapter 2 'Working With Adults', Health Canada, available through the Health Promotion Branch of Health Canada and provincial health departments.

Nobody's Perfect, Handbook for Training, unit 2 & 3, Health Canada available through the Health Promotion Branch of Health Canada and provincial health departments.

Fetal Alcohol Syndrome, by AADAC Alberta Alcohol Drug Abuse Commission, Suite 200 Pacific Plaza, 10909 Jasper Ave, Edmonton, T5J 3M9, phone: (403) 427-7319.

FAS/E and NAS Community Prevention Guide, by Vancouver YWCA Crabtree Corner, 101 East Cordova St., Vancouver, BC, V6A 1K7, phone: (604) 689-2808, fax (604) 684-9171.

FAS/E and NAS Guide to Resources, by YWCA Crabtree Corner.

The Prevention Pipeline: Drug-Free Communities by the Year 2000, Center for Substance Abuse Prevention, Volume 8 No. 2, March/April 1995.

Bibliography on Alcohol and Pregnancy, Julien, C., Canadian Centre on Substance Abuse, National Clearinghouse, 300-75 Albert St., Ottawa, Ont., K1P 5E7, 1-800-559-4514 or fax (613) 235-8101 or email: cjulien@ccsa.ca.

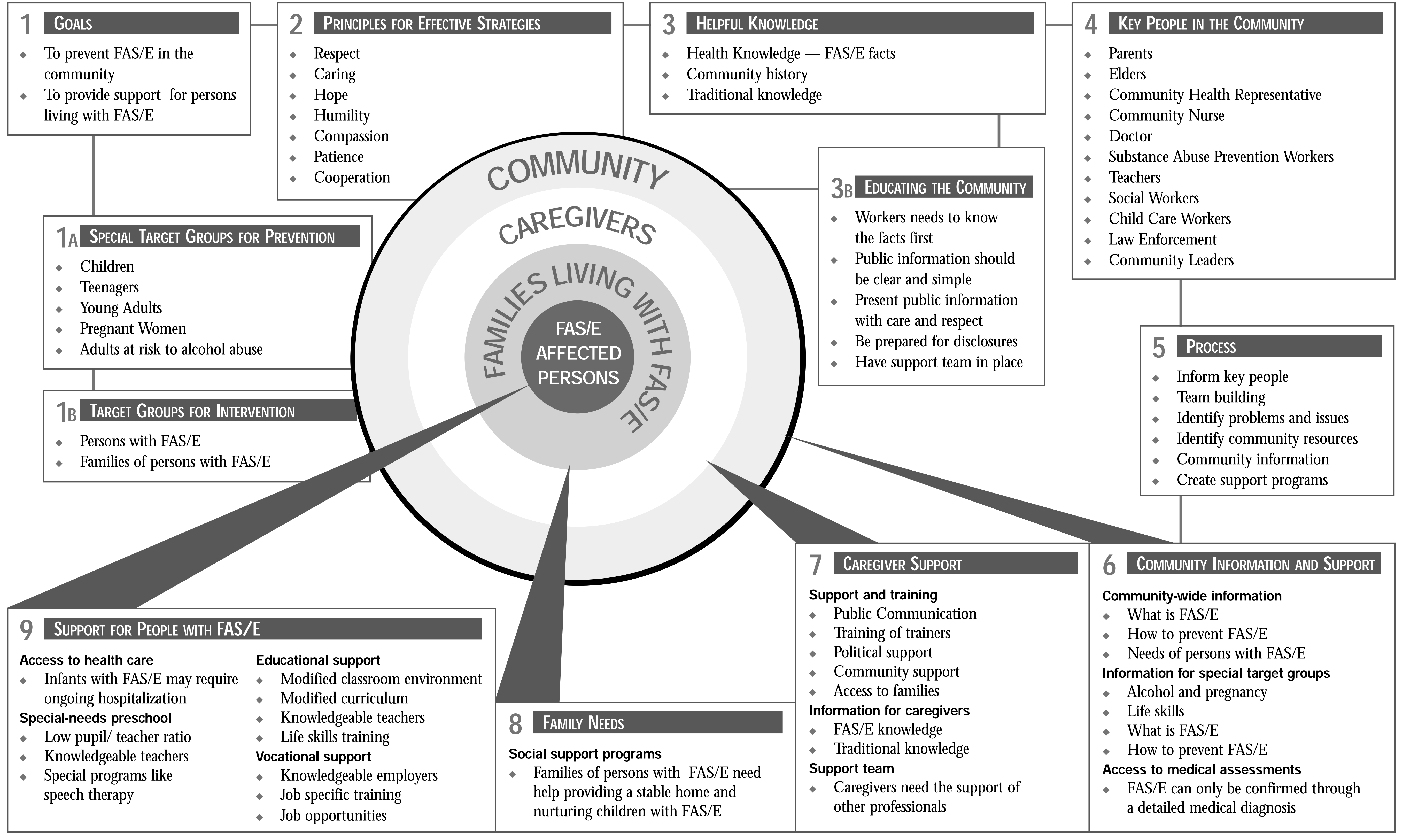
A Macro-level Fetal Alcohol Syndrome Prevention Program for Native Americans and Alaskan Natives — description, May, Philip A.; Hymbaugh, Karen J.; Journal of Studies on Alcohol, Volume 50, No 6, pg 508-518,1989.

Fetal Alcohol Syndrome: The Effects of Drinking Alcohol During Pregnancy, Pauktuutit Inuit Women's Association, National Inuit Working Group for FAS, Ottawa, 1996.

Training of Trainers (TOT) Manual: A Focus on Fetal Alcohol Syndrome Prevention, New Breast, Theda; Hill, Gerald; Wright, Carole, American Indian Family Healing Centre, Oakland, Ca.,1989.

Illustration 2 **It Takes a Community: A Prevention Strategy Outline**

The following illustration will guide readers through some of the key ideas in *It Takes a Community.*



Interventions for At-Risk Pregnant Women

CHAPTER 7

Traditionally in Aboriginal societies, women held a place of respect and honour for their role as keepers of the culture. Although their day to day responsibilities varied culturally across the country, the role as nurturer and teacher of the children was universal and very much respected and supported by local laws and practices. Today women carry the same responsibilities, but often the familial, social and community support are no longer there. In the absence of a strong support network women at risk, because of their personal and family histories or addiction, will be predisposed to consume alcohol during pregnancy.

FAS/E prevention is directly affected by whether or not a woman drinks during her pregnancy. But it is not the responsibility of only the mother to change the drinking practice. This is a difficult part of preventing FAS. In the past, most health and social services would have focused on the mother and worked to change the drinking mother's behaviour. Today, more people are recognizing that the mother and baby are part of a larger circle that involves partners, families and communities — and everyone has a responsibility in preventing drinking behaviour during pregnancy.

Intervention means interrupting a risk behaviour in an effort to minimize any negative effect of that behaviour. Intervening with pregnant women who are at risk of having a baby with FAS, is an extremely challenging venture:

- Pregnancy is very personal and not at all obvious to an outsider until much later in the pregnancy.
- Some women may not know that they are pregnant until their second or third month and occasionally later.

"Fundamental to any intervention action is the belief that nobody sets out to damage their child on purpose."

quote from the FAS Parent Support Group, Surrey, B.C.

- Not all women go to the doctor right away if at all, particularly women who are abusing alcohol and other drugs.
- Fear of child apprehension can keep women at risk out of the doctor's office and the social worker's office.

- Some of the women abusing alcohol and other drugs live under extremely difficult and often dangerous conditions.
- Persons with FAS/E are at risk of falling into alcohol abuse because of their impulsivity, lack of cause and effect reasoning and limited life skills.
- Some women are very addicted into the cycle of abusing alcohol and drugs.

Intervention is often left to the nurse, doctor, social worker or counsellor. Ideally interventions and support should come from professional caregivers, family, friends and community members. As we move further away from traditional teaching and our sense of community responsibilities, this type of broad intervention becomes more difficult. Such action from friends or concerned community members could be viewed as being 'nosey' or interfering. Still, help for women at risk can be offered in a respectful and non-interfering manner as indicated in Section One. In this manner community workers, family and friends can make a difference in supporting and helping a pregnant woman who is at risk. This section suggests a range of strategies that community groups may want to consider when planning an intervention for at-risk women.

Intervention Strategies for Women at Risk

Start with women of childbearing age, at puberty

- Emphasize effective use of birth control
- Emphasize respect for your body and traditional teachings

Education about the facts about FAS in a talking circle session or small group

- Utilize creative ways to educate women and their partners
- Train peer counselling skills

Deal with the drinking through support and treatment

- Access to treatment and child care
- Target teenage girls
- Target women who have other children with FAS/E
- Educate the community workers who have contact with women who are at risk
- Provide opportunities to learn about the special needs of children with FAS/E

Intervention Strategies for Women who are Pregnant

- Acknowledge the pregnancy as a special time, a gift of the creator. The community healing program (CHIP) in Ktunaxa/Kinbasket territory in southeast BC acknowledges a pregnant women with a bundle containing encouragement and information.
- Support — support — support.
- Early identification and assessment of risk for alcohol abuse. This can be done as part of the regular prenatal history when asking questions about diet and tobacco. A questionnaire called T-ACE, standing for Tolerance-Annoyance-Cut Down-Eye Opener, has been developed to determine risk during pregnancy. T-ACE has the following questions:
  1. How much alcohol do you drink before you feel it? (TOLERANCE)
  2. Has anyone ANNOYED you by saying you should cut down on your drinking?
  3. Have you ever thought you should CUT DOWN?
  4. Have you ever had a drink to get going in the morning? (EYE OPENER)

For T-ACE to be useful in a clinical setting, a simple scoring system is given. Ideally the physician should play an active role in educating the pregnant woman and creating awareness about alcohol issues and pregnancy. If the woman

answered Tolerance with two or more drinks, then a score of 2 points is given. A positive response for the other questions is a score of one point for each question. A T-ACE score of 2 or more indicates a risk drinking behaviour (*Alcohol and Child/Family Health conference proceedings*, BC, FAS Resource Society, 1988).

Target the friends and family

- Seek out the spouse, family and circle of friends closest to the woman at risk to make them allies for support of changing behaviour

Educating about FAS/E

- Educating about FAS/E for this target group should be done in a place and with a group where there is opportunity for group discussion, ie. a women's circle
- The educator or presenter should be prepared to deal with possible disclosures
- Critical to emphasize that stopping drinking at any time during pregnancy will improve the health of the baby — the earlier the better

Support and treatment

- Community-based multi-disciplined and cooperative approach to treatment and intervention using a community support team
- Access to treatment beds without having to wait
- Treatment that includes the whole family would be ideal
- Access to treatment for women only if required or treatment that includes the partner if required
- Access to therapeutic services within the community
- Detox services in a controlled setting such as a hospital
- Assistance and guidance when dealing with current crisis and stress factors in the pregnant woman's life
- Assess for safety — is the individual exposed to physical or emotional abuse?
- Develop alternative social activities, such as dry dances
- Develop parenting skills

Community action

- Zero tolerance of alcohol use during pregnancy should be encouraged as community norm
- Providing community support for the pregnant woman and her partner
- Community groups can lobby for treatment beds to be made available for pregnant women so they can enter a program at any time
- Develop community-based treatment services
- Traditional practices and events
- Work with bar and restaurant owners to develop prevention strategies

As women come to terms with drinking during pregnancy, they will likely experience strong emotional trauma, especially guilt. Again, caring support and counselling is needed to help the mother work through her suffering.

There are programs and services that attempt to address the needs of women at risk. The following are some examples.

Crabtree Corner

The YWCA Crabtree Corner began as an emergency drop-in daycare. It is located in the heart of the inner city in Vancouver, one of the poorest neighbourhoods in Canada. The original idea was to provide a safe place for young children in an otherwise dangerous environment. Crabtree Corner continues as a daycare and also offers a number of other programs to support families. It operates as a women's drop-in centre and offers services such as the FAS/NAS Prevention Program. This program provides information, referral and support services to pregnant women and their families. It has a resource library for families and community workers and has produced educational materials such as

written guides for community prevention workers and caregivers. Fetal Alcohol Syndrome and Neonatal Abstinence Syndrome (FAS/NAS) program workers conduct workshops and educational session throughout the province in an effort to increase FAS awareness among community workers, parents and health workers. Crabtree Corner has initiated a 60-member FAS/NAS Advisory Committee to plan and implement community-based prevention and educational activities.

For more information contact:
FAS Coordinator
Vancouver YWCA Crabtree Corner
101 East Cordova St.
Vancouver BC V6A 1K7
Telephone: (604) 689-2808
Fax: (604) 689-5463

PREGNANCY OUTREACH PROGRAM

The Pregnancy Outreach Program (POP) began as a BC Ministry of Health pilot project in 1988. POP was designed to provide information and support to at-risk pregnant mothers in the home and community. Each program is community based and responds to local needs. POPs focus on good nutrition, reducing alcohol, tobacco and other drug use, and promoting prenatal care. Education and support are given to women who do not otherwise access prenatal health care services. Funding is provided to existing community agencies, such as Native Friendship Centres. The results of these projects have been consistently positive.

For more information contact:
Provincial FAS/E Prevention Coordinator
c/o Sunny Hill Health Centre for Children
3644 Slocan St.
Vancouver BC V5M 3E8
Telephone: (604) 543-8300
Fax: (604) 543-8301
Website: www.cw.bc.ca

COMMUNITY SUPPORT WORKER

The social service agency in Inuvik, Northwest Territories is responding to some at-risk families with a new approach. An intervention worker is dispatched to the family's home to work on a one on one level. In this manner the agency is able to provide consistent and accessible support. The worker only deals with one family at a time and provides counselling, referral and advocacy services that will help the family change it's pattern of living.

For more information on the Inuvik approach, contact the
Regional Supervisor
Inuvik Health and Social Services
Government of NWT
Bag Service 9
Health Services Administration
107 MacKenzie Road, Suite 205
Inuvik NWT X0E 0T0
Telephone: (867) 777-7419
Fax: (867) 777-3197

HOMEBUILDERS

The Inuvik approach is similar to the *Homebuilders* program in the U.S., which is an intensive in-home family crisis counselling and life skills education program. It is designed to guide and support families in altering dangerous behavioural patterns. Homebuilders supports

change by helping families attend to their own basic needs and encouraging family members to create a safe and nurturing home environment. The primary goals of the program are to protect family members (especially children) maintain and strengthen family bonds and increase family skills. In Washington state the program has been effective tool in modifying family behaviours since it started in 1974. Today there are many intensive family preservation services modelled after the Homebuilder program operating in 30 states and several countries, including Canada, Denmark, Hungary, New Zealand and Australia.

For more information contact:
Behavioral Science Institute
181 South 333rd Street, Suite 200
Federal Way, WA 98003-6737
Telephone: (253) 874-3630
Fax: (253) 838-1670
Website: bsihomebuilders.org
E-mail: bsihomebuilders.org

SUGGESTED READING

A Guide to the Detoxification of Alcohol and Other Drug Dependent, Pregnant Women, Coalition on Addiction, Pregnancy and Parenting. 349 Broadway, Cambridge, MA (cost $16.60 US).

Alcohol World, Health and Research, Vol. 18, No. 3, 1994. National Institute on Alcohol Abuse and Alcoholism.

Keeping Families Together: The Homebuilder's Model, Kinney J., Haapala, D., Booth, C., 1991, 235 pages.

Reaching High Risk Families: Intensive Family Preservation in Human Services, Whittaker, J.K., Kinney, J., Tracey, E.M., 1990. 206 pages.

Living with FAS/E

CHAPTER 8

The level of disability in FAS/E depends on the degree of damage to the unborn baby and the environmental conditions in which they are raised. In addition to the loving caring environment needed by all children, alcohol affected children need lots of structure and different learning techniques. Over the years, parents, teachers, and other caregivers have found ways of meeting some of the common needs of children with FAS. The dedication of parents, families, educators and caregivers create a growing optimism for persons affected with FAS/E.

This section will describe common characteristics of persons with FAS/E from infancy to early adulthood. Understanding the characteristics of this disability will be helpful when community resource workers respond to the needs of alcohol effected individuals and their families. Also, understanding the human nature of FAS/E will enable community caregivers to develop strategies that truly consider the life situation of persons with FAS/E.

Information Processing

The normal brain operates in a certain way. For example, upon hearing a verbal order the information is brought into the brain, understood, stored, and then acted on in an appropriate manner. Information processing includes four steps: input is when the brain receives information from one of the senses (sound, sight, touch, taste, smell); memory represents the storage of information for later use; integration is the process of interpreting or understanding the information; output is the response to stimulation and requires appropriate use of language and motor skills or movement.

It appears that persons with FAS/E could have difficulty in all areas of information processing.

"FAS is a thing that you can't rub off or wear off. You can't sleep it off. It's something you have to carry with you for the rest of your life. It's hard"

Quote from Tim Manson, Nuu Chah Nulth citizen.

Like a computer that has missing keys on its keyboard, the sentence that is typed in, is not what appears on the screen. The organization of the brain and the internal communication may be affected. A child with FAS/E may have difficulty:

- Translating information into appropriate behaviours which include hearing into action, seeing into writing, reading into understanding and feeling into speaking
- Generalizing information such as transferring rules into new situations, recognizing patterns, forming associations and predicting outcomes
- Perceiving similarities and differences such as discriminating, discerning and comparing situations involving friends and strangers or safety and danger

Some parents describe the thinking of an FAS/E child as being 'black or white' with no middle ground.

Recognizing that the brain operates differently should bring about a shift in how you react to the child with FAS/E. No longer do you have a willful and naughty child, but one with certain disabilities. We now know that these children require parents and teachers to learn and do things differently. This different way of doing things will help teachers and parents work around the disability — and in doing so the focus is put on the abilities of the child rather than the disabilities.

Nurturing

Self-esteem is critically important. A warm and caring home, classroom and community are important aspects of nurturing the child with FAS/E. Although FAS is a recently recognized condition, it carries a negative stigma which is felt by FAS/E children. Low self-esteem, frustration and anger can isolate these children into an unhappy world. Like a delicate flower ina harsh climate, these children need a loving advocate who can help them make their way through life.

Characteristics of Infants

The children that parents, caregivers and educators deal with may have some or even most of the following characteristics. Each case of FAS/E is unique as the effected child, so there will be a range of disabilities depending on the extent of damage.

In the first months, infants who are severely affected with FAS/E may have significant medical problems that require a prolonged hospital stay after birth or repeated hospitalization in the early months:

- At birth, the infant may suffer withdrawal from alcohol and other drugs that the mother is using. This is referred to as Neonatal Abstinence Syndrome.
- There may be specific birth disorders affecting major organs: heart disorders, skeletal abnormalities, kidney problems, etc.
- Many affected infants are prone to infections. Some affected infants are hospitalized because of failure to thrive. A condition not always due to poor parenting or inadequate nutrition.
- Affected infants may have poor muscle tone; they are "floppy" babies. Or the other extreme of too much muscle tone, making them rigid.
- Some infants are tremulous and irritable.

In the early days and months, infants with FAS/E may develop more slowly than other infants. An immediate concern is some infants may have difficulty regulating basic functions such as sleeping and feeding.

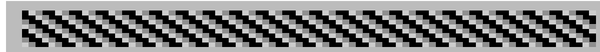
Infants with FAS/E may have difficulty falling asleep, sleep poorly, sleep a lot and/or be restless. Routine sleep patterns may take much longer to develop. This makes care giving difficult because poor and unpredictable sleep patterns have an impact on all family members.

Infants with FAS/E may have difficulty sucking and swallowing. Keeping food down and gaining weight may be problems. Some babies take a long time to feed well and may do better with many short meals over the course of a day.

The messages that the infant gives may be weak or confused. It may be difficult for caregivers to determine whether an infant is hungry or sleepy or in distress. Nurturing infants whose messages are difficult to read and/or whose behaviours are unpredictable may not initially be very rewarding for the caregiver.

Many infants with FAS/E quickly become over-stimulated when in contact with a caregivers. It is important to know the level of stimulation that the infant can tolerate, as well as the infant's ways of tuning out the environment — for example, by turning away or blinking.

In the early days and months, infants with FAS/E may develop more slowly than other infants. An immediate concern is some infants may have difficulty regulating basic functions such as sleeping and feeding.



Characteristics of Young Children

From infancy through preschool, young children with FAS/E may be slow to reach developmental milestones. As some of the children grow older, the label developmental delay is replaced by the diagnosis of mental handicap.

In addition to being delayed in development, children with FAS/E may not respond to their environment in ways that other children do. The activity levels of infants and young children, combined with other developmental problems, lead to socially inappropriate behaviour. This includes poor judgment, lack of impulse control, and over-reactions. Significant developmental delay is usually noted by the preschool years. It includes:

Speech

- Late talkers
- Poor articulation

Language

- Slow development of vocabulary
- Slow at forming sentences

Because of their small stature, children with FAS/E may appear younger than their age. For this reason, the extent of their developmental delay may not be obvious. Also mild developmental delays may be associated with significant learning disabilities later on when the child reaches school age. Parents may want to consider early referral to therapy and structured preschool experiences to counter any possible learning disability.

Other Behaviours Need to be Considered

- While some of these children are delayed in the development of motor skills and are described as "clumsy," "banging into things," "eating messily," others are adept at running, climbing, and bike riding at an early age.
- Because children with FAS/E are often impulsive and hyperactive, they do not anticipate danger and do not readily learn from their experiences. They are physically at risk for running into the street, falling from

high places, touching hot stoves or camp-fires or electrical outlets, and eating non-edible substances. They therefore require constant supervision.

- Over-stimulation, changes in daily routines, and having too many adult caregivers can lead to tantrums and destructive behaviour. This occurs at home and at preschool. Therefore children with FAS/E may require a gradual introduction to preschool.
- Children with FAS/E are frequently described as overly friendly. They do not have normal fear of strangers. They also tend to wander off. Therefore they are at risk in the community or on the land and require constant supervision.
- Children with FAS/E are slow to make the shift from learning through touching to learning through seeing and hearing. Their desire to touch people and objects becomes inappropriate as they grow older because of their overall developmental lags.
- Sometimes FAS children require special needs preschool, with low teacher/pupil ratio and access to speech/language and occupational therapies. Special needs preschools recognize the potential problems in interactions with other children and that the child may have difficulty adapting to class routines and transitions.
- As the child approaches school age, an assessment is needed to determine what special services need to be in place to ensure a successful transition.

Strategies for Persons with FAS/E

A Stable Home and Family Life

As much as possible, the first priority is to provide a stable home and family life for the child. Adequate and appropriate support is often needed for the birth parents in order to keep the family together. The parents may need help dealing with addictions, poverty, low self-esteem, limited work skills, limited parenting skills and a host of emotions such as guilt and anger. Foster care and multiple placements are far more likely for infants affected by prenatal drugs and alcohol than for any other group in our society today.

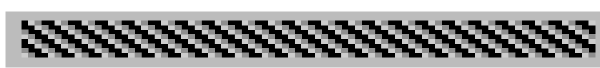
To increase the stable family life:

- Regular contact with biological parents by caregiver is needed
- Provide a secure and permanent homes for family

Support for Families

There are approaches to providing much needed support that respond to the disabilities and potential of FAS/E affected families.

- Caregivers should be respectful and non-judgmental.
- Recognize and acknowledge that parents of FAS/E affected children are performing a demanding job.
- Ensure that the community social safety net meets the basic needs of family members and provide early assistance to the child's family.
- Ensure that appropriate assessments, diagnoses, and interventions are provided and that families are empowered to contribute to all discussions about their child. Since infants prenatally exposed to alcohol are at high risk



As much as possible, the first priority is to provide a stable home and family life for the child.

for developmental problems consider early referrals to infant programs and preschools.

- Design family-centred interventions that provide parents with behaviour management skills, including knowledge of child development and behaviour which will help them recognize the unique pattern of each individual child.
- Provide knowledge of community resources and assistance to access those resources.
- Provide occasional access to respite care (care for the child as relief for the main caregiver), counselling, and emotional support that addresses early losses or abuse in the life of the parent, as well as guilt about the FAS/E diagnosis.
- Recognize that parents raised in communities with heavy alcohol use may themselves have FAS/E and require special assistance.
- Refer families to others who have coped with similar circumstances and who can offer support and guidance.
- Assist families to become effective advocates for their children.

Building Community Ties and Support

Parents need connections with the broader community of other parents and services. Raising any child is hard work, and parents need to feel part of a larger system. For this, families must be linked to resources and activities that:

- Acknowledge the challenge of parenting and are sensitive to family needs in general;
- Meet the unique needs of the particular family;
- Teach the child socially appropriate skills to self-manage behaviours such as temper, impulsivity, and hyperactivity; and
- Follow the child's lead and interests to become engaged in increasingly longer and more complex interactions with toys, objects, and people.

Self-Worth of Children and Their Families

The greatest gift we can give to children is helping them think of themselves as special and important — and treat them that way. This is no different for FAS/E children. Start at birth with positive messages given to the child — about the child and his or her family of origin. The following actions can contribute to an affected child's sense of self-worth.

- Caregivers provide positive reinforcement and learn to distinguish between the child and the behaviours.
- Provide simple explanations to the child, peers and others when differences in ability and development lead to an awareness of differences and frustration.
- Allow the child to experience regular community functions. On a day-to day basis provide routines and activities that are organized, structured, and predictable for the child. This allows the child to experience predictable choices and consequences for behaviour throughout each day. Adapting expectations of the child is important.
- Help the child's friends learn how best to play together.
- Important adults in the child's life can take time to positively interpret the behaviours of the child to the broader community.
- Fostering a good understanding for all family members and friends of what can and cannot be changed in terms of behaviour, learning style, and memory. But remember behaviour can be changed even if the child doesn't understand the reasoning.
- Family-centred and culturally sensitive care, with attention to the role that parents play in their child's development.
- Individualized interventions that recognize the uniqueness of each child, since no two children with FAS/E are alike, even if they have the same diagnosis and the same family experiences.

Characteristics of Elementary School-Age Children

Children diagnosed with FAS/E have been found to have measured Intelligent Quotients (IQ) that range from the mentally challenged to average. The diagnosis of FAS does not necessarily mean the child will have a mental handicap. Some children with FAS have a normal IQ. But on average the IQ is lower for FAS than FAE. Children with FAS/E will show some effect of the alcohol on brain development such as developmental delay, seizures, severe learning disabilities, or attention deficit/hyperactivity.

Children with other conditions, such as head injury or other syndromes and disorders like attention deficit disorder, may show similar patterns of learning and behaviour.

The commonly observed learning and behavioural difficulties of elementary school-age children with FAS/E can be divided into seven categories:

- Language development
- Memory
- Reasoning
- Learning disabilities
- Attention deficit and hyperactivity disorder
- Motor skills
- Adaptive and social behaviour

The following parts of this "Elementary School-Age" section provide some details about each kind of difficulty.

Language Development

Development of speech and language may be delayed:

- The child may have more speech problems than other children of the same age. For example, the child's speech may not be clear. It may be that only the immediate family will understand what the child is trying to say.
- The child may be slow to develop the speaking vocabulary and sentence structures for his or her age group.
- The child may have a more subtle language problem that become noticeable when she or he is expected to learn to read and write in school.
- The child may show evidence of a language processing disorder. This means that the child would have difficulty understanding the normal pace and complexity of the language of communication and instruction.
- It may take the child longer to organize thoughts in giving a response.
- Some children with FAS/E are always talking, but there is little substance or depth to their understanding. This is often called "cocktail chatter."

Memory

The memory problem for children with FAS/E may be both that information may not "register" and that information which has been learned cannot be "retrieved." This means that:

- The affected child may have difficulty remembering two or three instructions.
- Concepts that have been learned one day may be forgotten by the next.
- Learning the multiplication tables is frequently a problem.
- On the other hand, there may be good recall of events that happened long ago.
- Lying may be caused because the child can't remember the full information, so he fills in the blanks.

Reasoning

Cause and effect thinking or the basic ability to understand that consequences are results of an action is often impaired. Thus:

- The child seems not to learn easily from mistakes and instead repeats them over and over.
- There may be risk-taking and dangerous behaviours because the child acts impulsively and does not appreciate the possible outcomes. For example, the child doesn't understand that running out in front of a car is dangerous, because nothing happened at the time.
- Similarly, the ability to generalize from one situation to other situations is problematic.
- The abstract thinking and problem solving that are expected as the child gets older are slow to develop.

Learning Disabilities

Because of the inability to process and use information:

- The affected child will likely have difficulty mastering skills in reading, math, and spelling appropriate to the child's age and grade.
- Although a wide range of achievement in word reading is seen, reading comprehension, as in understanding a complete reading of a passage, often does not increase beyond the intermediate grades. This means that success in secondary school will require modified reading materials.
- Spelling ability is often at the same level as word reading when the student has been taught good reading decoding strategies and sound/symbol associations.
- Although some remembered computational skills can be mastered, math problem solving is a frustration. Life-skills math, particularly the understanding of time and money, as well as calculator use for necessary computations, is an important curriculum emphasis for the FAS/E student.

Attention Deficit and Hyperactivity Disorder

FAS can cause a child to have a short attention span which is quickly and easily side-tracked by other stimulations. Often added to that is the abundant and seemingly unending energy of the child. Attention deficit and hyperactivity can seriously impair the affected child's:

- Ability to benefit from classroom instruction
- Relationships with peers
- Adjustment within the family

The challenge of hyperactivity is not to stifle or control this abundant energy, but rather to channel it into acceptable activity (See Fantastic Antoine Succeeds). One example of channelling the energy was done through traditional dancing. A mother involved her daughter in round dancing. They made the dance regalia and the daughter was soon competing and winning competitions at pow-wows.

Hyperactivity often subsides at adolescence, but attention deficit and impulsivity may remain or even increase. The manifestations are different at different stages as are treatment approaches. Pharmaceutical treatment is an option used by some. But the use of drugs, such as Ritalin, to control behaviour in children should be considered after an exploration of alternative therapies — particularly for children who live in homes where addiction may be a problem.

At present there is little information available regarding the specific effectiveness of stimulant

medication to control hyperactivity in FAS/E. There is no specific information to indicate whether pharmaceutical treatment is any more or less effective for hyperactive children with FAS/E than it is for other hyperactive children.

It is possible to make some general statements about pharmaceutical treatment for hyperactivity and attention deficit disorder:

- Some children respond positively to medications, from the Doctor such as Ritalin, Dexedrine, Cylert, and Imipramine.
- Use of medications is most effective when combined with other behaviour-management therapies.
- If the decision is made to use medications, the dosage, response, and possible side-effects must be closely monitored by the physician, with dosage starting at a low level.
- School supervision is important in monitoring the effectiveness of the medication.
- The child with FAS/E cannot be expected to look after taking his or her own medication according to the prescribed schedule.
- Use Ritalin as a last resort rather than a first option, especially in communities where addiction is a problem.

Motor Skills

Affected children may have particular difficulty with motor skills involving the coordination of large muscle movements used for running or climbing and small muscle movements essential for handwriting.

- Occupational and physical therapy is frequently recommended to reduce these problems.
- While some affected children are clumsy, others become skilled in individual sports such as swimming, running, and skiing. These sports can afford an opportunity to build self-esteem and become a focus for life-long leisure activity.
- In team sports, difficulties with following the rules, waiting for turns, and interacting with teammates can provoke problems. Participating in team sports can provide an opportunity to promote social skills.
- Poor fine-motor coordination and tremor are frequently observed in activities requiring precise movements, such as handwriting. Affected children may have difficulty manipulating small objects like puzzle pieces or learning to use silverware. They are often described as disorganized and messy. However, some affected children are particularly artistic when allowed free expression.

Adaptive and Social Behaviour

The potential for disruptive, inappropriate or possibly self-harming behaviour is a constant concern with the FAS/E child. Understanding the nature and scope of such behaviours is essential when living or providing services to FAS/E affected persons.

- It may be first observed during the preschool years that the child with FAS/E is overly friendly with strangers. This behaviour can extend into adolescence and adulthood, when the affected individual may be predisposed to enter potentially harmful situations.
- The need to touch and have physical contact extends beyond the time when it is acceptable.
- Affected children have difficulty forming and maintaining friendships with peers because of unacceptable and immature behaviour. Rejection by peers further contributes to poor self-esteem.
- The children may not understand and therefore do not respond to societal prohibitions against lying, stealing, cheating, defying authority, etc.

- They often get stuck on an activity, resisting changes.
- Some of the children are described by their parents as anxious or upset in new situations. Others are described as excitement-seeking. Both characteristics pose problems in adaptation to life changes.
- Because of difficulty in connecting consequences to behaviour, affected children do not respond to being told what "might" happen and do not demonstrate age-appropriate "common sense." They therefore have difficulty making choices.
- They have difficulty with daily living skills that will lead to independent living in adulthood. These include personal care, household skills, handling of time and money, and participating in the community according to its cultural values and expectations. These skills need to be reinforced from an early age.

Adolescents and Young Adults

The challenges of dealing with teenagers with FAS/E is largely dependent on the degree of damage and the upbringing and social influences they might have experienced. In addition to the normal teenage trials and tribulations, these kids and their care providers are dealing with added obstacles and issues brought on by the affects of FAS/E. Some parents say the need for support and structure in the lives of their teenage children are as intense and often harder, than when they were toddlers.

Characteristics

Secondary school-age youth with FAS/E are, first of all, adolescents with adolescent characteristics. They face the usual problems of adolescence and in addition, they face special problems caused by FAS/E. They are in a position of double jeopardy.

Adolescence is a time of confusion and exploring possibilities. It is a time to search for an identity and become aware of the strengths and weaknesses in oneself and others. It is a period of awkwardness and a time for seeking independence, while needing dependence. During the teen years there are shattered illusions and growing concern about sexuality and relationships. There is the fear of being led in wrong directions and uncertainty over some basic life questions like — "Who am I?" — "Why am I here?" — "Where am I going?"

In adolescence, some characteristics of children with FAS/E, such as physical appearance and hyperactivity, tend to soften or diminish. However, unless proactive support is given in the teen years these characteristics may be replaced by psycho-social concerns such as low self-esteem in adulthood. The key to success is activities that build self-esteem while allowing a realistic acceptance of limitations. Also, it is important to recognize that other affectations do not lessen:

After about age 12, measured IQ scores for youth with FAS/E remain constant or decrease because their abstract thinking is slower to develop than their peers.

- After about age 12, measured IQ scores for FAS/E youth remain constant or decrease because their abstract thinking is slower to develop than their peers. Basic academic skills such as reading and math may level off.
- Characteristics such as impulsivity, attention deficit, poor ability to generalize, poor ability

to anticipate and respond to consequences, poor judgment, and generally inappropriate social behaviour (such as lying or stealing) may become more pronounced.

- Being unreflective, youth with FAS/E can be more easily misled than most youth by the mixed messages concerning socially acceptable behaviour given by popular media, especially TV. The social consequences for these characteristics can become increasingly serious with advancing years in light of existing community norms for socially acceptable behaviour. A combination of social skills interventions, a supervised environment and appropriate school programming can minimize these negative consequences.
- If FAS/E is indicated in children, make an early diagnosis. There are likely many undiagnosed cases of youth with FAS/E. Because of changing features and growth, the diagnosis is often more difficult to make in adolescence and adulthood. Also, some learning and behavioural difficulties associated with FAS/E may be found, to a lesser degree, in adolescents without FAS/E, adding to the uncertainty of a proper diagnosis during adolescence.

Support for Parents

With impending adulthood, families with FAS/E youth may come to a crisis point with the realization their child may not be able to live independently. The prospect of an adult son or daughter who will not be able to leave home and who will continue to require supervision can be an emotional and financial burden on the family. There is a continuing need for respite care and support for the parents.

- With the diagnosis of FAS/E, young adults may be eligible for certain disability benefits that allow for extended educational opportunities, needed supervision, and additional resources.

Community workers need to work cooperatively with families when providing support. A quote from FAS Support Network illustrates this point — “Families know their children best — respect their observations and opinions.”

Building and Maintaining Self-Esteem for FAS/E Adults

Youth and adults with FAS/E may be socially isolated because of immature behaviour or unacceptable interactions with peers. They appear to be at risk for affective disorders, such as depression. When such disorders are compounded by poor job prospects and lack of social support, a downward spiral can result. However, some youth with FAS/E have found satisfying relationships and acceptance through church groups, the Special Olympics, youth groups and other community organizations.

Building and maintaining self-esteem and confidence is an ongoing need. These qualities tend to be very fragile in many FAS/E affected adults. Fortunately, youth and adults with FAS/E usually come to the attention of doctors and psychologists because of the stresses and problems they are facing.

There are many success stories involving adults with FAS/E. However success would not be possible without supportive relationships, developed job skills and the ability to maintain confidence and self-esteem.

SUGGESTED READING

Fantastic Antoine Succeeds, Kleinfeld, J., Wescott, S., University of Alaska Press, 1993, for sale through The FAS/E Support Network, Surrey, BC, phone (604) 589-1854, fax (604) 589-8438.

A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects, The FAS/E Support Network, 14326 Currie Drive, Surrey, BC, V3R 8A4.

The Broken Cord, Micheal Dorris, Harper Row Publishers, New York, 1989.

Submission to the *Gove Inquiry,* 1995 by The FAS Support Network, 14326 Currie Drive, Surrey, BC, V3R 8A4.

Parenting Children Affected by FAS — A Guide for Daily Living, Shaskin, R., The Society for Special Needs Adoptive Parents, 1150-409 Granville St., Vancouver, BC, V6C 1T2, phone (604) 687-3114, fax (604) 687-3364.

C*ognitive Re-regulation Program Newsletter*, Vol. 4, no. 1, February 1994, Dept. of Educational Psychology, 6-102 Education Building North, University of Alberta, Edmonton, Alberta, T6G 2G5, phone (403) 492-3692.

Referral and Assessment

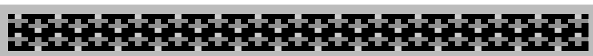
CHAPTER

Diagnosis and Assessment

In order to respond effectively to the needs of the FAS/E individual an accurate map of maternal alcohol use, growth, development and behavioural patterns must be created. This starts with a diagnosis by a skilled medical doctor and other specialists. There is no simple test that can be taken to determine whether the person has FAS or FAE. A complete diagnostic work-up includes the following elements:

- A history of maternal alcohol use, prenatal care, and previous pregnancies and children
- A determination of growth and development patterns of the child
- Defining characteristic facial features
- Vision and hearing assessment
- Language assessment
- Motor skills assessment
- Psychological assessment for older children

There are many barriers to getting a complete diagnosis. Doctors skilled in assessing FAS are often hard to come by in remote parts of Canada. In cities the waiting period might be months. Because there is still awareness needed of FAS/E, even among health professionals, local doctors and medical personnel might downplay parental concern. In Surrey, B.C., this unmet need was addressed by a group of concerned parents. They have formed a support and advocacy network called the FAS/E Support Network of BC (FSN). In response to many inquiries about assessment and diagnosis, these concerned parents put together an assessment tool for the various age groups from birth to adult. This tool is meant to be a guide for the parents and not a



Trying to parent a child with FAS/E without knowing the implications and how they play out developmentally, is like trying to find your way around Toronto with a road map of Vancouver. There are roads, they look similar, the street signs are also present, but nothing connects.

(paraphrased from: Fetal Alcohol Syndrome Fetal Alcohol Effects — Strategies for Professionals, Diane Malbin)

means of diagnosis. Its purpose is to determine whether or not the child should be seeing a specialist for the purposes of obtaining a complete diagnosis.

Activities such as the FSN help create a broad based awareness and knowledge of FAS/E among community members. With knowledge comes the realization that there are diagnostic procedures that can support and direct helpful intervention strategies. This is an important step to dispelling the negative stigma attached to FAS and the commonly held image of severely affected children with little hope for a future. In many communities, children who come from alcoholic homes and show signs of difficult behaviour and learning problems are 'pointed out' as having FAS or FAE. But, in the absence of a clinical diagnosis and assessment to determine if the child is FAS/E affected there will be no therapeutic action nor helpful interventions. A proper assessment should encourage families to reach for help instead of living in denial.

Do a Comprehensive Assessment

For appropriate interventions to take place, there need to be ongoing formal and informal assessments of the affected child's development. For appropriate planning, it is necessary to do a comprehensive assessment of the child in the context of the family, school, and community environments. It is important that a developmental assessment be part of the diagnosis of FAS/E. A Comprehensive assessment includes these five areas:

1. **A health assessment, which involves close monitoring.**
   - Some children with FAS/E have serious medical problems, such as congenital heart disorders and seizures.
   - They are at greater risk for illness, including respiratory and ear infections.
   - They often have dental problems such as crowded and/or crooked teeth, cross-bite or over-bite, needing attention for both health and cosmetic reasons.
   - Identifying pattern of maternal drinking.
2. **Vision and hearing assessment on school entrance and in the intermediate grades when children's eyes mature and visual acuity may change.**
   - A child prone to infections should have more frequent hearing checks.
3. **Psychoeducational assessment which should include assessment of intellectual potential, achievement, language, and memory.**
   - Adaptive behaviour measures and behavioural checklists are particularly relevant in the assessment of adolescence.
4. **Specialized speech/language and occupational therapy assessment are often needed.**
5. **Assessment of the child's strengths.**
   - Special interests and abilities — sports, music, art, etc. — should be noted and fostered.

Using the Assessment Results

The results of the assessment should be prepared as a written report and shared with parents, teachers, other care providers and child care workers as appropriate. The child also needs to receive an explanation that is appropriate to his or her level of development.

The results of the assessment may include recommendations for:

- Specific therapies relating to behaviour modification, language kills or occupational potential;
- An appropriate student/teacher match and with a modified curriculum; and
- School placement based on the child's specific strengths and weaknesses which should result in a better understanding of the child's potential and appropriate expectations by all concerned. Usually there is need for extra support and supervision in and outside the classroom.

Keeping Assessments Updated

Comprehensive assessments need to be updated at transition points in the child's life. For example, assessment should be done:

- When the child enters school
- When the child progresses to the intermediate grades
- When he or she is about to enter junior secondary or secondary school
- When plans are being made in preparation for school leaving and independent living

Each assessment will cover a range of issues. But as the child ages assessment information relating to abilities and disabilities become increasingly important.

The main purpose of any support or intervention plan is to enable the FAS/E affected person to live healthy and live to their full potential in school or in an independent or semi-independent living situation. In order to accomplish this intervention planning needs to consider questions such as:

- Will this person have the skills necessary for employment?
- Will this person be able to look after personal needs in day to day living?
- Will this person be at risk — to self and to others — in the community?
- Will the community support this individual to live as independently as possible?

What Happens After a Diagnosis of FAS/E?

Once FAS/E has been determined, thought must be given to the specific needs of the individual, which are based on his or her physiological, behavioural, emotional and mental characteristics. Planning effective interventions requires the use of all pertinent diagnostic information as a basis for an on-going systematic application of a range medical, social, behavioural and educational strategies including:

1. Development of an individualized education plan;
2. Appropriate intervention strategies for parenting and learning;
3. Advocacy by knowledgeable caregivers; and
4. A stable structured home life.

SUGGESTED READING

A Screening Guide for Fetal Alcohol Syndrome, Clarren, S.K., Astley, S., University of Washington, Seattle, USA, 2nd Edition, 1995.

Tips for Teachers

CHAPTER 10

FAS/E is often called the “hidden disability”. The affected child usually does not have a visible obvious handicap that would signal the need for special services or adaptations. Yet, due to the nature of the social skills deficit, the affected child routinely tests the patience of family, teachers and alienates peers through annoying behaviour and repetitive mistakes. Not understanding the nature and affects of FAS/E often leads to constant criticism, punishment, school failure and the downward spiral of isolation and low self-esteem.

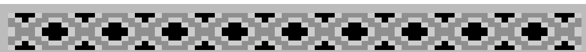
An Appropriate School Program

The most important aspect of the school is a good match between the individual child and a teacher who has a special commitment to meeting the needs and challenges that this student presents. Equally important is the cooperative approach between the school and the home. Although there is no cookbook for planning educational interventions, the following checklists may help.

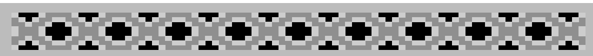
Classroom Environment

A suitable classroom environment includes these characteristics:

- Calm and quiet. Ensure that the room is not over-stimulating or cluttered.
- Consistent daily routines. Whenever possible, prepare the child for changes.
- Consistent rules. Combine a few simple rules with consistent enforcement and immediate consequences. Expectations must be realistic.
- Cultural knowledge and practices.
- Planned transitions. Provide warnings, and allow time for the child to get ready for the next activity.



Not understanding the nature and affects of FAS/E often leads to constant criticism, punishment, school failure and the downward spiral of isolation and low self-esteem.



Teaching Style

A suitable style for children with FAS/E includes these methods:

- Maintain eye contact to ensure that the child is attentive. Use the child’s name when giving instructions.

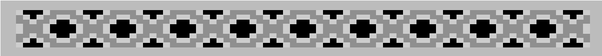
- Accommodate language disabilities. Provide information and instructions in short units, in a concrete form, and with more repetitions than for most students.
- Aim for "over-learning," because concepts learned on one day may be forgotten by the next.
- Use all modalities. For example, accompany oral information with visual aids.
- Be concrete wherever possible, because the child will find abstract concepts to be especially difficult.
- Help the child understand sequence by using written and pictorial lists.
- Make use of art and music, not only for their intrinsic value, but also to help teach concepts in other subject areas.
- Provide the child with the help of a learning assistant to simplify, explain, and reteach concepts. One to one teaching and support is important.

Managing Attention Deficit and Hyperactivity

Children with FAS/E often have attention deficit and hyperactivity. Sometimes they are hyperactive and other times are able to focus for lengthy periods when activities are of interest to them. This does not mean it is within their control to attentive at all times. Certain adaptations can therefore be helpful:

- Where feasible, include one-to-one instruction in a quiet setting such as a resource room. This will often minimize problems with attention deficit and hyperactivity.
- Seat the child where auditory and visual distractions are minimized. Often this is the front of the room.
- Help the child learn to recognize the times when the class environment is too distracting, and allow the child to then choose to work in another, more quiet, location.
- Ignore minor negative behaviour or moving about the room. But act consistently and decisively when behaviour is disruptive to others. It may be necessary to remove the child from the classroom and/or provide a teacher's aide to help the child focus and prevent disruption of others.
- Be aware when pharmaceutical intervention may be appropriate in combination with behaviour management techniques.

Parents, teachers, and other professionals involved with the FAS/E child need to form a strong alliance to maximize the effect of their efforts and minimize the effects of the condition.



Fostering Social/Emotional Development

- Because of immature and inappropriate social skills, use direct interventions such as role playing, video-taping, and confronting with "what else could you have done."
- Because of vulnerability, provide constant supervision during unstructured times before and after school, at recess, and during lunch period.
- Explain over and over how cause leads to effect in everyday living.
- Take every opportunity to enhance the child's self-esteem, as this is of critical importance.

Communication and Support

Parent – Teacher – Professional Communication

A consistent approach at home and school is extremely important. Parents, teachers, and other professionals involved with children affected by FAS/E need to form a strong alliance to maximize the effect of their efforts and minimize the effects of the condition. Intervention for specific deficits, such as language disability, combined with a structured, controlled environment is the Individual Education Plan (IEP) for success.

The Program of Schooling and Job Training

An Appropriate Program

Because many youth with FAS/E are verbally fluent, they are sometimes informally assessed as having more ability than they actually have. As a result they may struggle with the demands of a regular, academically oriented school program. Frequently, youth with FAS/E need to be steered into programs that stress a concrete style of learning — learning by doing — such as woodwork, metalwork, mechanics, construction, office skills, cooking or animal care.

It is important that sex education, geared to the abilities of the student, be reinforced throughout high school. The program should also stress basic life skills like:

- How to handle money
- How to be time-conscious
- How to apply for jobs
- How to interact with employers and fellow workers in a positive way
- How to approach social agencies
- How to feed and clothe oneself in a healthy way

Youth who are severely affected by FAS may be candidates for special schools and alternative programs.

Life Skills and Employment

Persons with FAS/E will be better prepared for life on their own and the workplace if they have had good vocational counselling and a supervised work experience where:

- Expectations are clear;
- Routines are consistent; and
- The employer is informed of the student's limitations in language, memory, and basic skills.

Although an appropriate school program helps, youth with FAS/E are still likely to have difficulties with life skills. For example:

- Because of poor ability to anticipate consequences, youth with FAS/E may not see the future events as things that are going to happen, e.g., that rent and car insurance will have to be paid.
- There is often an impulse for immediate gratification, e.g., the need to buy the car stereo now.
- They often fail to appreciate the importance of society's requirements, e.g., the requirement to wear a seat belt.

Obtaining and holding a job is often problematic due to such factors as:

- Interpersonal conflicts;
- Difficulty coping with the changing demands of the job;
- Inability to get to work on time; and
- Inability to work at the expected pace.

Where few paid jobs are available, youth with FAS/E may be able to obtain volunteer work with community groups. This provides personal satisfaction and fills the hours in the day.

Individuals with FAS/E often display low motivation and fail to take initiative in seeking jobs or even leisure opportunities. This can be discouraging to adults who attempt to facilitate activities for the FAS/E affected person.

SUGGESTED READING

Educating Children Prenatally Exposed to Alcohol and Other Drugs, D.M. Burgess, S.L. Lasswell, A.P. Streissguth, University of Washington.

Fetal Alcohol Syndrome Fetal Alcohol Effects. Strategies for Professionals, Diane Malbin, Hazendon Educational Materials, Center City, Minn. 1993.

FAS/FAE Curriculum for Native Americans, Northern Plains Native American Chemical Dependancy Association Inc., 1994.

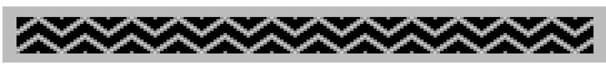
The Mind of a Child, Working With Children Affected by Poverty, Racism and War, documentary and teaching tapes (1995), Marcuse, Gary, Williams, Lorna, The Variety Learning Centre, 2600 East Broadway Avenue, Vancouver, BC, V4M 1Y5.

Advice for Caregivers

CHAPTER 11

The people caring for persons with FAS/E need skills, knowledge, good will and support to be most effective. The implications of FAS/E cross different segments of the community. In turn, it is the coordinated and team effort of the various disciplines, parents, extended families, community members and leaders working closely together that will bring success.

This section will discuss the issues facing caregivers. The caregivers are the people who spend the most time and have a professional or personal commitment for the person with FAS/E. They could be the natural parents, foster or adoptive parents. Other part-time caregivers would include family members, teachers, social workers, health care personnel, court workers, employment officers, police, lawyers and judges. They all are important in touching the lives of people with FAS/E.



The people caring for persons with FAS/E need skills, knowledge, good will and support to be most effective.

Ideas for Families and Caregivers

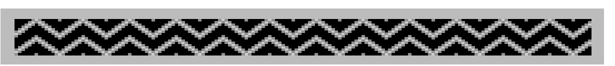
The importance of building self-esteem in these children cannot be overstated. Early diagnosis and intervention are critical in this process so that the parents and the child can understand that the behaviour is not willful misbehaviour but a result of neurological impairment. When the parents understand the reason for the difficulties and the child understands it is not his or her fault, they have taken an important first step in developing a life-plan that can accommodate and circumvent problem, build self-esteem and hopefully prevent another generation of FAS.

Without the recognition of FAS/E as a neurological disorder, parents or caregivers of children with FAS/E are often subjected to unwarranted criticism of their ability to parent the child. The extraordinary energy required to parent an affected child needs to be recognized through support groups and respite care. However this will happen only when caregivers and others who deal with the child are aware of the nature of any disabilities, and just as importantly, know of strategies that work with the child. Ideally the parent, as the main advocate for the child, should make the effort inform others — this way caregivers are better positioned to help the child and parents.

As parents come to terms with a diagnosis of FAS/E for their child, there will be need for added support as they adjust to the long term implications of this condition. Support and accurate information are needed to help parents through this transitional period. Biological parents have the added trauma of guilt, shame, depression and anger as they work through their grief. They may need counselling and greater support for an extended period of time.

Community caregivers are often at a loss as to how they might provide support. A broad based understanding of FAS/E is a good place to start in becoming supportive. Clearing away the myths and stereotypes will bring a shift in the attitude to a more positive perspective. There is a growing network across Canada of both parents and professionals. In British Columbia, a group of parents offer information, support and guidance to caregivers in need. They have set up a 'Warm-Line' that takes calls from all over Canada. The FAS/E NATION newsletter published a list of suggestions gathered by the FAS/E Support Network from other parents. Here are some of those tips for community caregivers aimed at supporting family caregivers:

- Listen, listen, listen! Really 'hear' what is being said and what is not being said.
- Find an advocate for the family until they can fill that role themselves.
- Understand that parents may view the system as adversarial. The system is seen to be all-powerful and needs to be more receptive.
- Track down resources and help families in using them. Make initial contacts, sort out red tape and learn the pitfalls.
- Don't wait for families and caregivers to call you. Check on them regularly, even when things are going well.
- Find respite care and/or a way to fund it.
- Adoptive and foster parents need specific and detailed information on what a child may have experienced if they are to deal with the aftermath.



The potential value of FAS/E knowledge that caregivers have to share cannot be underestimated — and sharing knowledge of strategies that work is one of the best ways that caregivers can help each other.

- Some children with FAS/E have also suffered from abuse and/or neglect. Understanding how this effects the underlying neurological disorder and behavioural problems is crucial. Both social worker and family caregiver need training in this area.
- Find a support group and/or buddy parent for the family.
- Adjustment to long term foster care or adoption is cyclical in nature. Children revisit the stages of grief and loss at different developmental stages, which required managing behaviour and dealing the with acting out of grief and loss.
- Never discuss a family, the children or any problems with other persons, professionals, or system without the express permission of the parent, for the specific occasion. Confidentiality and the absence of *judgement* are the backbone of effective support.

The potential value of FAS/E knowledge that caregivers have to share cannot be overestimated — and sharing knowledge of strategies that work is one of the best ways that caregivers can help each other. Parents, adoptive or natural, teachers, doctors, psychologists, and social workers are among the groups who have and can contribute to the growing knowledge base of how best to live with FAS/E.

The book, *Fantastic Antoine Succeeds* was written out of frustration and concern over the prevailing opinion about FAS — that it is a condition with little hope. This is a damaging stereotype for a condition which covers such a broad range of characteristics and is heavily influenced by the home and community environment in which the child is raised. *Fantastic…* illustrates a number of situations where positive advances have been made in the lives of a number of children with FAS/E. Such achievements can become common. But only when families and care providers caring for FAS/E persons are consistently supported in their efforts.

For more information, contact:
FAS/E Support Network BC
13279–72nd Avenue
Surrey, BC V3W 2N5
Telephone: (604) 507-6675
Fax: (604) 507-6685
E-mail: info@fetalalcohol.com
Website: www.fetalalcohol.com

Communication Among Professionals

All professionals involved with FAS/E affected youth need to be knowledgeable about FAS/E and recognize the difficulties that the youth is likely to face in making the transition to adulthood. Specifically, she or he is likely to need supervision beyond the point when most youth are allowed independence. Recognizing that affected youth do not readily anticipate the consequences of their actions means a more gradual and supported transition toward independence is required.

This understanding becomes particularly significant when affected youth and adults find themselves in trouble with the law. All those associated with the justice system need to be well informed about FAS/E. The rights of victims must be respected. Similarly understanding of the legal process, intent, self-incrimination, and rehabilitation need to be evaluated and presented in terms of the disabilities associated with FAS/E.

Conclusion

Like the pebble hitting the water, the impact of FAS and FAE ripples through a community. It affects the local health care system, the schools, the justice system, child care and social services. But before all else, the impacts are felt on a deeply personal level by moms and dads, other family members and of course, the affected child.

Behaviours common to FAS/E, such as hyperactivity and impulsivity, can put heavy stress on families. This can increase problems within the family, and in turn compound the behavioural problems of the affected person. It is not possible to separate the extent to which the affected person's difficulties are added to by family problems or conversely how the family's stress is amplified by the affected person's difficulties.

It is likely that these factors interact, in many cases causing the situation to deteriorate for the whole family — a situation that is felt by the entire community, not just family members. A similar dynamic can develop in school classrooms where stress is on the teacher, other students and the affected child.

This observation underlines the importance of focussing the resources of the community on children with FAS/E as well as their families in a comprehensive prevention strategy.

Successful prevention can have only one result — no more FAS or FAE. Because both are entirely preventable. Prevention takes teamwork. The job of team building may seem daunting. Particularly in communities where there is no team concept. But the root causes of FAS/E demand a proactive, community wide response.

Successful interventions on behalf of persons with FAS/E are no different. They are often found in smaller communities where there is an "extended" family, consisting of a biological family and community groups such as a Native Friendship Centre or church ready to be part of the team. Each assumes a responsibility to provide support for the affected child, the family and the attending caregivers. The communities that care have the best chance of breaking the cycle of damage to the unborn. They must care enough to actively work to prevent FAS/E in their families. In cases where FAS/E is already present in the community, they must care enough to work with love, determination and the resourcefulness to undertake proper diagnosis, early intervention and train knowledgeable care providers. It is a fact that the FAS/E affected person, with proper support, can make positive advances in their lives, be contributing members of the community and live to their fullest capabilities.

If possible the groundwork for successful support begin at birth. Patterns of relationships between infants and their caregivers are established very early in life. The attachment of infant to caregiver and caregiver to infant is critical to the promotion of healthy emotional and physical development. This bonding can help overcome barriers that work against strong mutually supportive relationships — particularly when the child does not consistently demonstrate behaviours that are predictable or responsive.

The home, school and community environments play a significant role in the growth and development of all children. It can either enhance or hinder development. Early intervention in the environment

can reduce the impact of developmental delay. In some situations, it can prevent secondary problems from occurring.

Ultimately the goals of prevention are to eliminate further cases of FAS/E and help already affected persons live a healthy, safe and enjoyable life, to their fullest potential. The foundation for successful prevention and intervention strategies is formed when action taken within the community is done with the support of everyone and given with respect and care for the persons with FAS/E, their families and the caregivers, in other words — *It Takes a Community.*

Bibliography

Abel, E.OL., *Fetal Alcohol Syndrome,* Medical Economics Co. Ltd., Oradell, N.J., USA, 1990.

Bray, D.L., Anderson, P.D., *Appraisal of the Epidemiology of Fetal Alcohol Syndrome Among Canada's Native People,* Canadian Journal of Public Health, Vol. 80, Canada, Jan/Feb, 1989.

Ervin, C.S., Little, R.E., Streissguth, A.P., Beck, D.E., *Alcoholic Fathering and Its Relation to Child's Intellectual Development: A Pilot Investigation,* Alcoholism: Clinical and Experimental Research, Vol. 8, No. 4, USA, July/Aug, 1984.

Government of Canada, *Fetal Alcohol Syndrome, Government Response to the Fifth Report of the Standing Committee of the House of Commons on Health, Welfare, Social Affairs, Seniors and the Status of Women, From Awareness to Prevention,* Canada, December, 1992.

House of Commons. Report of The Standing Committee on Health and Welfare, Social Affairs, Seniors and The Status of Women, House of Commons, *Fetal Alcohol Syndrome, A Preventable Tragedy,* Canada, June, 1992.

Jones, K.L., Smith, D.W., *Pattern of Malformation in offspring of chronic Alcoholic Mothers,* Lancet 1: pg. 1267–1271, 1973.

Kleinfeld, J., *Fetal Alcohol Syndrome in Alaska: What the Schools Can Do,* A Background Paper prepared for the Alaska Department of Education, USA, January, 1991.

Loock, C.A., unpublished submission to the Royal Commission on Health Care and Costs, *Prevention of Fetal Alcohol Syndrome and Alcohol Related Birth Defects,* Canada, 1991.

National Institute on Alcohol Abuse and Alcoholism, Alcohol Alert, No. 13, *Fetal Alcohol Syndrome,* U.S. Department of Health and Human Services, USA, July, 1991.

Robinson, G.C., Armstrong, R.W. (Ed), *Alcohol and Child/Family Health: A Conference with particular reference to the prevention of alcohol-related birth defects,* B.C. FAS Resource Society, 1988.

Robinson, G.C., Conry, J.L., Conry, R.F., *Clinical Profile and Prevalence of Fetal Alcohol Syndrome in an Isolated Community in British Columbia,* Canadian Medical Association Journal, Vol. 137, Canada, August, 1987.

Streissguth, A.P., LaDue, R.A., Rondelo, S.P., *A Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians,* University of Washington, Seattle, Washington, 1988.

Streissguth, A.P., Zagon, I.S., Slotkin, T.A. (eds), *Fetal Alcohol Syndrome and Fetal Alcohol Effects: A Clinical Perspective of Later Developmental Consequences,* Substance Abuse and the Developing Nervous System, San Diego Academic Press, Inc., USA, 1992.

Stewart, C.A., Barber, W.H., *FAS Characteristics, Prevention, Treatment and Long Term Outlook,* B.C. Journal of Special Education, Vol. 15, No. 2, Canada, 1991.

Using the Fact Sheets

The fact sheets in the back cover pocket of *It Takes a Community* are for community caregivers who are planning public information sessions in their communities. The sheets summarize some of the health, social, behavioural and educational issues facing persons affected with FAS/E and their families. When doing an information session the presenter may want to have access to other more in-depth information, from *It Takes a Community* or other sources, to complement the fact sheets. The sheets can be photocopied for handouts or used as overheads. Here are some things to remember when planning your information session.

Disclosures

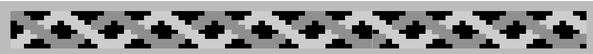
An FAS/E community information session could bring forward people who believe they or someone they care for have FAS/E. This could cause a personal or family crisis. People making such disclosures need an informed and caring support network.

The organizer should have a support network identified and ready to receive referrals. This means working as a team with other caregivers in the community, like the CHR, Nurse, Alcohol and Drug Counsellor, physician or elder prior to, during and after the information session. People making disclosures may need follow-up support from qualified careproviders. The support team should be ready to provide on-going support.

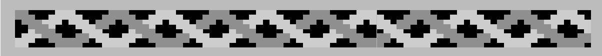
Training

Public information needs to be clear and accurate. Presenting information about FAS/E requires someone with skills in communicating and an in-depth knowledge of FAS/E.

Ideally, resource workers should have training in workshop presentation, public speaking or attended a train-the-trainers program.



Traditional knowledge regarding conception, pregnancy, birth and parenting can be a good basis for community education.



Presentation

Present FAS/E information with respect and care. Someone in the audience could be taking your words very personally. Participants should be left with a sense of hope.

Cultural Knowledge

Traditional knowledge regarding conception, pregnancy, birth and parenting can be a good basis for community education. Participants may have an easier time understanding FAS/E issues if they are introduced using a familiar and positive subject.

1

Pregnancy and Alcohol Use

PREGNANCY

Rapid organ development occurs in the early stages of pregnancy. Organ growth continues throughout the pregnancy but at a slower pace than the earlier stage.

HOW ALCOHOL IS ABSORBED BY THE BODY

- Alcohol is absorbed into the blood, from the stomach and intestines and transferred to the liver. The alcohol is broken down in the liver by two enzyme systems.
- In the pregnant woman, alcohol easily crosses the placenta to the circulatory system of the fetus. The placenta does not act as a barrier.
- The fetus cannot rid itself of alcohol as quickly as the mother because of its small and underdeveloped liver and enzyme system. The fetus is exposed to alcohol for longer periods than the drinking mother.

WHAT DOES THIS MEAN FOR MOM AND BABY

- Drinking at anytime during pregnancy could possibly affect the normal development of the baby.
- Not drinking at all is one sure way to increase the likelihood of a healthy baby.
- If the mother is drinking, interventions to stop drinking at any time during pregnancy will help the chances of a healthier baby.

2

What Happens When the Mother Drinks During Pregnancy?

How does alcohol affect the fetus?

- Alcohol is a toxic agent which can damage the cells in developing organs.
- Damage to the cells cause malformations to growing organs.
- All fetal organs can be adversely affected, to some degree, at any time if alcohol is consumed throughout the pregnancy.
- The more the mother drinks, the greater exposure to alcohol and the greater risk of fetal damage.

Effects on the fetal brain

- Fetal brain development occurs throughout pregnancy. During the late stages of pregnancy the brain develops more rapidly. Therefore drinking at any time during pregnancy can damage the brain.
- The fetus is forced to divert its energy to metabolize the alcohol instead of using energy to grow healthy cells and tissues.
- Alcohol affects the ability to organize and communicate information within the brain. This impairs the ability to use good judgement and reason later on in life.

What Happens When the Father Drinks?

Effects on the fetus

- The effects of paternal drinking on the fetus are not fully known.
- Some children of alcoholic fathers have defects in learning and memory and tend to be more hyperactive than children of non-alcoholic biological parents.
- It is not known if these effects are the result of genetic transmission or the result of paternal alcohol consumption on the father's sperm prior to conception.
- There is no conclusive evidence that paternal drinking before conception causes direct adverse effects on the fetus.

Effects on pregnancy

- At the time of conception, alcohol can result in a lower sperm count and abnormal sperm, making the likelihood of pregnancy remote.
- If pregnancy occurs, the likelihood of miscarriage is high.

Social effects

- The social effects of the father's drinking are enormous, since women most often drink with their partners.
- Fathers who drink heavily are unlikely to provide the necessary emotional support and care for their pregnant partners.
- A father's drinking after the baby is born could adversely affect the nurturing home environment needed to raise a child.

What is Fetal Alcohol Syndrome?

FETAL ALCOHOL SYNDROME

Fetal Alcohol Syndrome or FAS: A cluster of birth defects caused by heavy consumption of alcohol during pregnancy.

- The damage caused by fetal alcohol exposure is permanent. FAS is entirely preventable.
- FAS should be determined by a medical diagnosis which confirms a number of birth defects associated with drinking during pregnancy.

FEATURES OF FAS

Growth retardation — Babies may grow at a slower than normal rate during pregnancy and after birth. Children are typically small and skinny, growing into short adults.

Appearance — The FAS child has distinct facial features. These could include shortened eye slits, flattened mid-face, a flattened midline ridge between nose and lip, thin upper lip and other features. An FAS child may have some or all of these features.

- Facial features may fade as the child grows. Using facial features alone to identify FAS is not advised. This can promote a stereotypical image of the FAS affected person.

Brain and central nervous system — The most critical effect of alcohol on the fetus is the permanent damage to the brain and central nervous system.

- This includes small brain and head circumference, brain malformations, developmental delay, intellectual impairment, behavioural disorders, learning disabilities, attention deficit disorder and hyperactivity.

What is Fetal Alcohol Effects?

FETAL ALCOHOL EFFECTS

Fetal Alcohol Effects or FAE: Refers to an individual who has been exposed to maternal drinking and has one or two FAS characteristics.

- FAE is entirely preventable.
- FAE is not the less severe form of FAS.
- FAS and FAE are known as the leading causes of birth defects and developmental delay in North American children.

FEATURES OF FAE

Appearance — A child with FAE may look normal but still suffer damage to the brain and nervous system.

Behaviour and learning — The most critical effect of alcohol is permanent damage to the fetal brain and central nervous system. The learning and behavioural characteristics of FAS and FAE are similar.

- FAE will show itself in the child as developmental delay, intellectual impairment, behavioural disorders, learning disabilities, attention deficit disorder and hyperactivity.
- Persons with FAE may function far below their actual age in school and socially.
- Poor judgement, learning difficulties, impulsive behaviour and poor social and communication skills are common characteristics.

Understanding Infants with FAS/E

CHARACTERISTICS OF INFANTS WITH FAS/E

Infants may have some or most of the following characteristics.

HEALTH

- In the first months, severely affected infants may require hospitalization from disorders affecting major organs such as the heart or kidneys.
- Infants with FAS/E are prone to infections. Generally, they develop more slowly than other infants.
- Motor skills are affected. Infants may be “floppy” babies because of poor muscle tone or have too much muscle tone, making them rigid.

SLEEPING

- Infants with FAS/E may have difficulty sleeping. Routine sleep patterns take longer to develop. This makes care giving difficult because unpredictable sleep patterns effect all family members.

FEEDING

- Infants may have difficulty sucking and swallowing. Keeping food down and gaining weight may be problems. Some babies take a long time to feed and do better with many short meals over the course of a day.

BEHAVIOUR

- Some infants are irritable and unpredictable. Be patient.
- Some infants become over-stimulated when with a caregiver. Know the level of stimulation that the infant can tolerate and the infant’s ways of tuning out the environment — for example, by turning away or blinking.

7

Understanding Young Children with FAS/E

Characteristics of young children

From toddler through preschool, children with FAS/E may be slow to develop. This may not be readily noticeable due to their young age and small stature.

Health

- Severely affected children will continue to have health problems due to organ damage or being prone to infections.

Development

- Delays affecting speech and vocabulary may be noticeable in the preschool years, indicating later learning disabilities. Referral to therapy and special needs preschool may counter any possible learning disability.
- Late development of motor skills means children with FAS/E can be clumsy and accident prone for their age. They may require more intense supervision.
- Learning through experience, seeing and hearing may be delayed. They rely more on touch to explore their surroundings. Hot stoves, camp-fires, electrical outlets or eating non-edible substances can be dangerous for the unsupervised child with FAS/E.

Preschool

- Over-stimulation or changes in daily routines can lead to tantrums and destructive behaviour. A gradual introduction to preschool may ease this situation.
- Interacting with other children can be a problem. Adapting to class routines can be difficult. Special needs preschool with low pupil/teacher ratios provide speech therapy and other support programs.
- As the child nears school age, an assessment is needed to determine what special services should be in place to ensure a successful transition to school.

Understanding School-Age Children with FAS/E

CHARACTERISTICS OF ELEMENTARY SCHOOL-AGE CHILDREN

There are physical, learning and behavioural difficulties common to most children with FAS/E. Parents, teachers and careproviders are better prepared to provide nurturing and support if they understand the nature and extent of these difficulties.

LANGUAGE DEVELOPMENT

- Development of speech and language may be delayed.

MEMORY

- Children with FAS/E may have problems mentally "registering" information and once information has been learned it cannot be "retrieved."

REASONING

- The ability to understand that consequences are the results of action is often impaired.

LEARNING DISABILITIES

- An impaired capacity to mentally process and use information affects the child's ability to learn.

ATTENTION DEFICIT AND HYPERACTIVITY DISORDER

- A child with FAS/E may have a short attention span. They are easily distracted. Complicating this is the abundant and seemingly unending energy of the child.

MOTOR SKILLS

- Children may have difficulty coordinating large muscle movements used for running or climbing and/or lack the small muscle control essential for handwriting.

ADAPTIVE AND SOCIAL BEHAVIOUR

- Reasoning and learning disabilities mean that inappropriate behaviour is a constant concern.

9

Understanding Adolescents and Young Adults with FAS/E

CHARACTERISTICS OF ADOLESCENTS AND YOUNG ADULTS

Youths with FAS/E and their care providers are dealing with normal teenage issues plus the concerns of FAS/E. Compared to preteens with FAS/E, parents say the support and structure for teenagers is as needed and often more difficult to provide.

BEHAVIOUR

- The youth with FAS/E can be easily misled by messages from TV and videos. Social skills interventions, a supervised environment and appropriate school programming can lessen problems.
- Affected youth have problems making friends because of unacceptable or immature behaviour, such as the need to touch when it is inappropriate.

SCHOOL

- There will be difficulty in communicating and understanding instruction. Abstract thinking is slow to develop. Reading, math, and spelling will be below their age and grade level. Success in secondary school will require modified curriculum materials.
- Attention deficit and hyperactivity will affect learning and relationships with peers. Hyperactivity often subsides at adolescence, but attention deficit and impulsivity may remain. Excess energy needs to be directed.
- Some affected youth become skilled in individual sports like swimming or running. Sports can help build self-esteem and social skills. In team sports they may have difficulty following the rules and interacting with teammates.

PREPARING FOR ADULTHOOD

- The youth with FAS/E will have difficulty with daily living skills that lead to independent living in adulthood. These include personal care, household skills, managing time and money. Life skills need to be reinforced from an early age.

Basic Needs of Persons Living with FAS/E

The FAS/E affected person

- 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 with FAS/E.
- 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.

The family

- 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, limited work skills and parenting skills.
- Caregivers should be respectful and non-judgmental toward families living with FAS/E and acknowledge that the parents of FAS/E affected children 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.
- Family members and friends need a good understanding of the FAS/E child's behaviour, limitations and potential. Knowing that behaviour can be changed for the better gives hope and is the basis for coping and growing.

"We owe our future to our unborn"

Marion Mussell

Health Canada Santé Canada