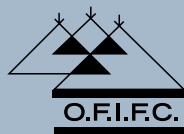


# FASD TOOL KIT

## for Aboriginal Families



Prepared by the Ontario Federation of Indian Friendship Centres  
September 2005

# FASD TOOL KIT

## for Aboriginal Communities

This Tool Kit was prepared as a “user-friendly” resource to help front line workers working with children, youth, adults and families affected by Fetal Alcohol Spectrum Disorder. It was prepared with the generous support of the Public Health Agency of Canada.

This document is available on the internet at: [www.ofifc.org](http://www.ofifc.org)

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## Who Are We?

The Ontario Federation of Indian Friendship Centres (OFIFC) is an Aboriginal organization representing the collective interests of twenty-eight member Friendship Centres located in towns and cities throughout Ontario. The OFIFC administers a number of programs delivered by Friendship Centres in areas such as health, justice, family support, and employment and training. Friendship Centres also design and deliver local initiatives in areas such as education, economic development, children's and youth initiatives, and cultural awareness.



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# FASD TOOL KIT

## for Aboriginal Communities

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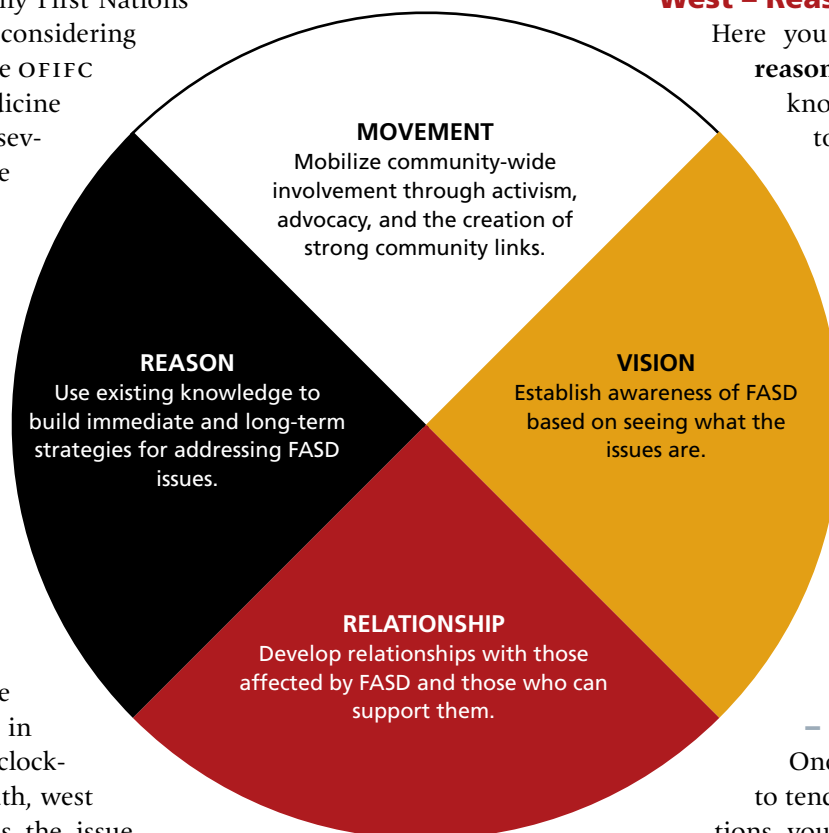
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# Preface

## Community FASD Wheel

The FASD Tool Kit uses a **Medicine Wheel** to help front-line community workers explore issues, and find and apply appropriate tools and supports to address FASD at the community level. The Medicine Wheel is greatly valued by many First Nations as a holistic model for considering a variety of issues. The OFIC has used the Medicine Wheel concept for several decades. The FASD Wheel below embraces a process through which we can see ourselves — where we are, where we have to go, and what we have to do. This Tool Kit is broken into four sections based on the four directions of the wheel. We will move through the wheel by beginning in the east and moving clockwise through the south, west and north to address the issue holistically.



### East – Vision

The Eastern Doorway houses the gift of **Vision**. As a front line worker, you need to establish a strong vision, beginning with a basic awareness of what the broad issues are related to FASD. This basic awareness will give you the foundation for moving to the south, where you can begin to establish relationships.

### South – Relationship

Once you have an awareness of FASD, you can begin to develop **relationships** with both clients and resource people. Establishing relationships means taking **time** to make connections with those affected by FASD, as well

as those who can support them. This process of sharing will lead you to the west, where you will be better prepared to develop an effective plan for addressing FASD in the community.

### West – Reason

Here you will use the gift of **reason**, based on existing knowledge around FASD, to develop strategies for dealing with the issue in your community or agency, including concrete ideas on how to access and develop community programs both for immediate guidance on FASD issues and for planning a community-wide response to FASD.

### North – Movement

Once you have been able to tend to the first three directions, you will be in a good position to **move** — to take action and help mobilize the community around the issue of FASD. Your activism and advocacy in the community, and the links that will be created in this process, will lead back to the east, where the gift of vision will have been made stronger and more inclusive of the wider community.

It is hoped that by moving through the wheel in this way, you will start to see results, be inspired, and inspire others to continue the journey. As the community begins to move through this process around the circle and uses the gifts from each direction, the struggle to both cope with and prevent FASD in our communities should gain momentum and have a lasting impact.

# Vision

To address the issue we must understand it. What is FASD? What are the symptoms and behaviours? Why is it such a problem in our communities, and when should I refer a person for FASD assessment?

## An Introduction to FASD

Exposure of the fetus to alcohol during pregnancy is considered to be one of the leading causes of mental and developmental disabilities in the Western World. The term **Fetal Alcohol Syndrome (FAS)** was introduced in 1973. The medical diagnosis of FAS is based on pre or post-natal growth restriction, central nervous system dysfunction and the presence of measurable physical characteristics, most commonly found in the measurement of facial features.

The term **Fetal Alcohol Effects (FAE)** was added to explain the existence of cognitive and behavioural FAS characteristics in people who do not display the physical symptoms of FAS. While FAS is clearly identifiable through physical characteristics, FAE has no physical features, although people suffering from FAE may have other symptoms as severe as a person with full FAS. As a result, in 2003, **Fetal Alcohol Spectrum Disorder (FASD)** was widely adopted as an umbrella term describing the range of effects that can occur in a person whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral and learning disabilities with lifelong implications.

## The Importance of Prevention

While this tool kit is designed to help those working with clients who have FASD and their families, it is always important to remember that ultimately, the most important factor in the struggle with FASD is the work that can be done to prevent its occurrence—in other words, working to raise awareness in the community about FASD, and the importance of not drinking or using drugs while pregnant. The focus on prevention through raising awareness is especially important in working with clients whom you suspect may be at risk of substance

abuse during pregnancy. It is also very important to raise general awareness in the community through publicity campaigns. The “movement” section of this document details some useful tactics for mobilizing awareness in the community.

## Symptoms of FASD

FASD is largely an invisible disability, since the majority of people exposed to alcohol in the womb do not necessarily exhibit the physical characteristics of FAS. As a result, many FASD sufferers are at great risk of failing to thrive because their disorder often goes undetected. As with any other lifelong disability, early identification is crucial to understanding and helping people who may be suffering from it. So what can we see? *Behaviour*. And if behavioral issues are identified and understood as symptoms of FASD, useful interventions may be developed. Professionals in the field are now using specific terms to describe behaviors associated with FASD. These include “primary” and “secondary” behaviors.<sup>1</sup>

### Primary Behaviours

Primary Behaviours are those that most clearly reflect underlying changes in brain structure and function. There is wide variability in their frequency and magnitude, and none are exclusive to FASD. Primary behaviours include:

#### ➤ Compromised executive functioning

Difficulty planning, predicting, organizing, prioritizing, sequencing, initiating, and following through. Difficulty setting goals, complying with contractual expectations, being on time, or adhering to a schedule.

<sup>1</sup> This breakdown of primary and secondary behaviours has been adapted from a presentation by Diane Malbin at the 2005 FASD National Conference, “Equality of Access: Rights and the Right Thing to Do.”

► **Difficulty with memory**

Information input, integration, forming associations, retrieval, and output. Difficulty learning from past experiences. Often repeat the same mistake over and over again in spite of increasingly severe punishment. Inconsistent memory or performance; may remember on Monday, forget by Tuesday.

► **Difficulty with abstract concepts**

Such as time, math, or money.

► **Impaired judgment**

Often unable to make decisions. Difficulty understanding safety and danger, friend and stranger, or differentiating fantasy from reality.

► **Inability to generalize information**

Difficulty forming links and associations, unable to apply a learned rule in a new setting; learns to not take Johnny's bike, but then takes Mary's bike.

► **Communication challenges**

Appears to understand instructions, nod and agree, but is unable to comprehend. Often repeats rules verbatim, then fails to apply the rules—"talks the talk" but doesn't "walk the walk."

► **Language problems**

Difficulty comprehending the meanings of language and accurately answering questions. May agree or confabulate—comply or fill in the blanks. Many talk excessively, yet are unable to engage in a meaningful exchange. The sheer volume of words creates the impression of competence.

► **Slow cognitive pace**

May think more slowly, say "I don't know," shut down, or require minutes to generate an answer rather than seconds. Those with FASD are "Ten-second people in a one second world."

► **Slow auditory pace**

Central auditory delays means language is processed more slowly, requiring more time to comprehend. Many only grasp every third word of normally paced speech.

► **Preservation**

May be rigid, get stuck, have difficulty switching gears, stopping an activity, or transforming to a new activity. Often react strongly to changes in setting, program or personnel.

► **Dysmaturity**

Often function socially, emotionally, and cognitively at a much younger level developmentally than their chronological age. A 5-year old may be developmentally more like a 2-year old, a 12-year old more like a 6-year old; and a 25-year old more like a 13-year old.

► **Impulsivity**

Coupled with inability to abstract and predict outcomes; acts first and then is able to see the problem after the fact.

► **Sensory systems dysfunctions**

May be over-reactive to stimuli—e.g. tactile defensiveness. May be easily overwhelmed by sensory input, may be unable to filter out extraneous stimuli; symptoms include increased agitation, irritability, and aggression. May under-react to pain—may not complain of earaches, broken bones, and be unable to experience painful stimuli.

## Secondary Behaviours

Secondary behaviours are defensive behaviours that develop over time when there is a chronic "poor fit" between the person and his environment. Defensive behaviors are normal protective reactions to frustration and are helpful cues for identifying points of intervention. By definition, these are preventable when a good fit is provided. Again, these are not exclusive of FASD.

- Inappropriate humor—the "class clown."
- Pseudo-sophistication; may echo words, phrases, manners, and dress in order to "pass" as competent beyond their actual ability, often to their detriment.
- Fatigued, irritable, resistant, argumentative.
- Anxious, fearful, chronically overwhelmed.
- Frustrated, angry, aggressive, destructive.
- Poor self-concept, often masked by unrealistic goals or self-aggrandizement.
- Isolated, few friends, picked on.
- Family or school problems including fighting, suspension, or expulsion.

- May run away, have other forms of avoidance.
- Trouble with the law, addictions.
- Depressed, may be self-destructive, suicidal.

Secondary behaviors often develop in early childhood, frequently becoming patterns of behavior by adolescence. Secondary conditions come at a high cost to the individual, their family, and the community. Early identification of both **primary symptoms** and **secondary behaviors** is necessary in order to develop appropriate interventions, or “accommodations” that prevent or resolve secondary behaviors.

Section 4 of this document (“Reason”) provides a useful table outlining primary and secondary behaviours and the kinds of interventions or “accommodations”

that work and don’t work in coping with them (“General Accommodation Strategies”).

## FASD From Infancy To Adulthood

Front line community workers will face the appearance of FASD in clients of all ages. The following breakdown of developmental life stages is an introduction to understanding some behavioral characteristics and patterns of FASD as they appear at different stages of life.<sup>2</sup> Caregivers who identify the symptoms of possible FASD early are better equipped to plan effective treatment and education strategies for the child and family.

### Infancy

- Often tremulous and irritable; may cry a lot
- Weak sucking reflex and muscle tone
- Highly susceptible to illness
- Feeding difficulties; often disinterested in food; feeding can take hours
- Erratic sleep patterns; no predictable sleep-awake cycle
- Sensitive to sights, sounds, and touch
- Failure to thrive
- Slow to master developmental milestones (e.g. walking, talking, imitating sounds)
- Problems with bonding

### Preschool

- Disinterest in food and disrupted sleep continued
- Poor motor coordination
- Flits from one thing to another with ‘butterfly-like’ movements
- More interested in people than objects
- Overly friendly, highly social
- Unable to comprehend danger; does not respond well to verbal warnings
- Prone to temper tantrums and non-compliance
- Short attention span
- Expressive speech may be delayed; may have less in-depth language than peers or may be excessively talkative and intrusive, giving the superficial appearance that speech is not impaired
- Easily distractible or hyperactive
- Does not respond well to changes; prefers routines

<sup>2</sup> This breakdown was developed by Sara Graefe in *Parenting Children Affected by FAS: A Guide for Daily Living*, Vancouver Society of Special Needs Adoptive Parents, 1998.

## Early School

- Reading and writing skills during the first two years may not be noticeably delayed
- Arithmetic may be more of a problem than spelling and reading
- Attention deficits and poor impulse control become more apparent as demands for classroom attention increase
- Inability to transfer learning from one situation to another—to learn from experience
- Requires constant reminders for basic activities at home and school
- ‘Flow through’ phenomena—information is learned, retained for a while and then lost; poor performance of ‘learned’ tasks may appear deliberate
- gross motor control problems, i.e., clumsy
- fine motor problems (e.g. trouble with handwriting, buttons, zippers, shoe laces, etc.)
- difficulties with social skills and interpersonal relationships; may be unable to share, wait for turn, follow the rules or cooperate; may be inappropriately intrusive
- poor peer relations and social isolation may be noted; may prefer to play with younger children or adults rather than with peer group
- memory deficits
- exists in the ‘here and now,’ seems to lack an internal time clock
- unable to monitor his/her own work or pace him/herself

## Middle School

- Delayed physical and cognitive development
- Reading and spelling skills usually reach peak
- Increased difficulty maintaining attention, completing assignments and mastering new academic skills
- Usually a very concrete thinker, may have trouble working with ideas—tends to fall further behind peers as world becomes increasingly abstract and concept based
- Continuing fine motor problems may make volume work production impossible
- Good verbal skills, superficially friendly social manner and good intentions often mask the seriousness of the problem
- Psychological evaluation and remedial placement may be necessary
- A pattern of school suspensions may start

## Adolescence

- Increased truancy, school refusals and school dropouts
- Increased behavioral disruption in school
- Reading comprehension is poorer than word recognition
- Faulty logic; lacks basic types of critical thinking and judgement skills
- Math tends to be the most difficult task, suggesting poor memory, poor abstract thinking, and difficulty with basic problem solving

*Continued*

### Adolescence continued

- May be able to ‘talk the talk’ while unable to ‘walk the walk’—for example, they may tell you they understand your instructions, but are unable to carry them out. They may have learned to act as though they understand, but cannot follow through on their own
- Often misjudged as being lazy, stubborn and unwilling to learn
- Increased problems with abstract thinking and the ability to link cause and effect
- Impulsive, total lack of inhibition and easily influenced, subject to peer manipulation and exploitation
- Difficulty showing remorse or taking responsibility for actions
- Problems managing time and money
- High risk for problems with the law and involvement in the criminal justice system
- Difficulty identifying and labeling feelings
- Low motivation
- Low self-esteem
- Clinical depression may become evident
- Sexual boundary issues; sexual activity may begin at an earlier age.
- Will not exhibit the same signs or symptoms as a child with FASD but may display secondary disabilities (listed above).
- A need to develop social skills that are appropriate for their age
- High risk for exploitation and peer manipulation

### Adulthood (18+)

- Uncontrollable repetition of a particular response; with ideas or activities, may appear compulsive and rigid
- Difficulty holding down jobs
- May be unable to live independently or parent children
- Problems managing money
- Poor social skills
- Lack of reciprocal relationships
- Unpredictable behavior
- Depression/ suicidal ideation
- Withdrawal and isolation
- Drug or alcohol abuse; susceptible to chemical dependency

## FASD and Culture

### FASD is not an issue of Race or Culture

A common misconception is that FASD is associated with ethno-cultural background. In Canada, First Nations are the hardest hit by FASD, but this is not because of racial or cultural characteristics. It is important to remember that FASD is one symptom of the fallout from an assault on Indigenous cultures; if anything it is the *loss of culture* rather than the cultures themselves that is related to the predominance of FASD.

The underlying factors contributing to FASD are related primarily to *social background*, including: untreated

or under-treated mental health issues; social isolation; histories of abuse (including severe childhood sexual abuse); lower education levels; lower socioeconomic status; inadequate nutrition; a poor developmental environment; and reduced access to prenatal and postnatal care and services. All of these factors can aggravate prenatal exposure to alcohol, drug use and smoking.

Unfortunately, Aboriginal communities are particularly sensitive to the stigma associated with FASD because it is not often contextualized as the product of a social problem but as a racial stereotype related to the evils of “Indians and Drinking.” To work around this stigma, some frontline workers have used educational strategies

that gradually introduce the issue of FASD. For example, they may advertise a community event as “*Information on Developmental Difficulties with ADHD*” and add “*FAS, FASD, and Autism*” as sub-headings.

However, over the longer term, the more we are able to overcome the stigma, community sensitivity and shame associated with FASD, the better we can understand it and develop community-wide identification, prevention, diagnosis and intervention.

### **Aboriginal Cultures are Resources**

The recovery of our cultures has in fact been shown to have great positive effects for individuals, families and communities coping with FASD. These cultural ways may well be our best resources. The OFIFC has produced a magazine on using Aboriginal cultural methods to work with FASD clients, *Aboriginal Approaches to Fetal Alcohol Syndrome/ Effects*, available on our web site at <www.ofifc.ca>.

## **When to Refer**

Referrals for FASD diagnosis should be made in the following situations:<sup>3</sup>

- Presence of 3 characteristic facial features (short palpebral fissures, smooth or flattened philtrum, thin vermilion border—see “The Diagnostic Process” in the “Relationships” section of this document for a definition of these features).
- Evidence of significant prenatal exposure to alcohol at levels known to be associated with physical or developmental effects, or both.

- Presence of one or more facial features with growth deficits plus known or probable significant prenatal alcohol exposure.
- Presence of one or more facial features with 1 or more central nervous system deficits plus known or probable significant prenatal alcohol exposure.
- Presence of 1 or more facial features with pre- or post-natal growth deficits, or both, and 1 or more central nervous system deficits plus known or probable significant prenatal alcohol exposure.
- Individuals with learning or behavioural difficulties, or both, without physical or dysmorphic features and without known or likely prenatal alcohol exposure should be assessed by appropriate professionals or specialty clinics (i.e., developmental pediatrics, clinical genetics, psychiatry, psychology) to identify and treat their problems.

Remember: while most of the items in this checklist include physical characteristics, many people suffering from FASD won’t exhibit obvious physical symptoms. As suggested above, those without physical symptoms or a known history of prenatal alcohol exposure will need a great deal more observation and diagnostic support. Because diagnosis is so involved and resources limited, referrals in each community must be evaluated and their level of priority established.

But first, let’s talk about approaching people you see as potential referrals for FASD assessment, and who will need to be involved in the assessment process. In the next section we will look at the important process of developing appropriate relationships with clients and their families, then look at relating to diagnostic assessment teams and resource people in the community who can help implement practical interventions and supports.

<sup>3</sup> Taken from “Fetal alcohol spectrum disorder: Canadian guidelines for Diagnosis” (Albert E. Chudley, Julianne Conry, Jocelynn L. Cook, Christine Loock, Ted Rosales and Nicole LeBlanc, 2005)

# Relationship

The FASD assessment process starts by recognizing the need for diagnosis and ends by implementing appropriate recommendations. This process means building relationships on many levels, with the clients and their families, as well as various community resources.

## Developing Trust

Once you know a bit about FASD, you can begin to develop *relationships* with the most important people in a position to address the issue: the people directly affected and their families and primary caregivers. Based on what you know already from the first section of this tool kit, you have a sense of what to look for in the behaviours of clients potentially affected by FASD. But how do you even begin to approach this painful issue, let alone suggest an assessment?

Making a referral is not just a matter of confronting the person, picking up the phone and sending them off to the “experts.” Approaching the issue will be a huge emotional undertaking for the client and family, and the front line worker is in a position to set the stage for either a positive diagnostic process, or a distressing episode (or even avoidance of diagnosis); this all depends on the relationship you establish with the family, primary caregiver and client, and whether this relationship is sensitive to their needs.

To optimize the outcome of the diagnosis, the community and family must be ready to participate in the diagnostic assessment of their own free will, based on a relationship of trust and emotional safety. Getting to this stage will take *time*.

## So How Do I Approach the Family and Client?

To get started, look at the individual’s history. If their background and behaviour suggest that FASD may be an issue, you will need to find sensitive, creative ways to gently indicate this and suggest information about how to get a diagnosis.

Developing trust in Native communities means allowing the person to come to the teaching rather than imposing the teaching on the person. You may want, at least at first, to find *indirect* ways of getting the message across.<sup>4</sup>

Indirect approaches could mean disclosing information about FASD in the client or family’s presence without singling them out, simply by making it known in the community through educational and community events that you have some knowledge about FASD and are willing to work on the issue. Of course you eventually want to address the issue openly. Every situation is different, and ultimately, only you will know when it feels right to address the issue directly with the client and their family.

The following kinds of general messages are important in helping people approach this sensitive issue, and should break down some of the barriers they may have in facing up to it:

- Use educational strategies and send messages that reduce the stigma and shame surrounding FASD; for example:
  - › Gradually introduce the issue; e.g., advertise a community event as “Information on Developmental Difficulties with ADHT” and add “FAS, FASD, and Autism” as sub-headings;
  - › Always stress how this is a big community issue affecting many people, and that people are not alone;
  - › If possible, find people with FASD in the community who are willing to speak openly about the issue, or bring such people in from elsewhere (this will require a budget).

<sup>4</sup> The exception, of course, would be a situation where you identify the possibility of preventing FASD in a newborn, i.e., where you know of substance abusers that are pregnant or at risk of pregnancy. In this case, direct intervention is both urgent and necessary.

- Always remind families and clients that diagnosis has the benefit of identifying the possible source of many of the problems they may be having and that it can help improve their lives and reduce these problems.
- Never assign blame: the message should always be, “What can we do now and in the future?” rather than pointing fingers about the past.
- Discuss the common misconceptions around FASD; stress how the following statements are false and misleading:
  - › Behavior problems associated with FASD are the result of poor parenting or a bad environment.
  - › Admitting a child has FASD will result in society giving up on them.
  - › The child will eventually outgrow FASD. Diagnosis of FASD will thwart their development.
  - › It is useless to diagnose FASD because there is no “real” treatment approach.

## Approaching Assessment

Whether the client or family approaches you or you feel ready to approach them, they will likely need help to move confidently through the diagnostic process. This will include some preparatory education concerning FASD and linking them with community supports and resources.

### Supporting the education process

At this stage, the client and family will need and want information to start thinking about FASD. After all, they will become the best expert on the child or youth with FASD; they will be (and have been) dealing with the person on a daily basis.

As a front line worker, you should help the client to begin developing a basic awareness of FASD. The first section of this tool kit may be useful, and the Bibliography at the end of this tool kit lists some excellent information references. However, keep in mind that many people will have difficulty wading through more advanced documents written by academics, and that some may be struggling with lower literacy skills. It will be important for you to have videos available for clients to borrow, or to view privately in your community centre. For example, the Yellowknife Association for Community Living has produced two videos for families raising children

affected by FASD.<sup>5</sup> There are many other excellent grass-roots-oriented resources on FAS available through the FAS Bookshelf in British Columbia. Check them out at <www.fasbookshelf.com>.

### What to tell them about assessment

Whether approaching the older individual with FASD or the caregivers of the child or youth, one of the most important things they will need to know is that no one wants to just “pin a label” on them. Other things to keep in mind:

- They should be informed that the process of assessing and identifying FASD as a possible source of their difficulties will involve a range of professionals and community members, and will take time.
- Mention that at this point you only suspect FASD as a source of many of their difficulties, but that regardless of the results, the assessment process can be beneficial, as long as it is done in a sensitive manner. At the end of the process, the family and client will end up knowing more about their problems and about potential ways of addressing them.
- Always ensure that they are in agreement on the purpose of diagnosis.
- Make sure they are aware of the potential psychosocial consequences of an FASD diagnosis (e.g., increasing a sense of guilt and anger, especially with the birth mother, or potential stigmatization of the child).

### Helping families prepare

If the person you suspect may have FASD is a child or youth still in the care of their family, you will need to meet with the child’s caregiver to initiate the assessment process. When getting information from the birth parent it is important to ask questions skillfully and carefully. For example, you wouldn’t say, “Did you drink while you were pregnant?” Rather, you might try asking them, “When was your last drink?”

Mothers with FASD children are often adoptive parents or foster parents, so it is important to pursue initial parent interviews without jumping to unnecessary conclusions that could alienate the parent. Never assume that the current parent or guardian was the person responsible for drinking during pregnancy.

In any case, the objective is not to lay blame but to impart to the parents how important it is to get an early

<sup>5</sup> *Helping Families Helping Children* (parts 1 and 2), Yellowknife Association for Community Living, PIDO Productions and Yellowknife Films. Available through the FAS Bookshelf, <www.fasbookshelf.com>.

diagnosis and develop appropriate interventions for their child so they are not as severely affected by FASD, if that is what they have.

### Helping youth and adults prepare

Sometimes the client you think may have FASD will have already left their family home and be out on their own, or even if they are at home, they may still be old enough to play a big part in approaching the diagnostic process.

Understandably, the adult or youth will often have great difficulty in facing up to the possibility of an FASD diagnosis; remember, you are talking about their own brain and body. While it should be a relief for the client in the longer term to diagnose FASD and develop strategies for coping with it, considering the possibility that they may have it is likely to make them uncomfortable.

It will be very important to reinforce the fact that the client is not alone and that much can be done to improve the wellbeing and overall life quality of people with FASD, rather than focusing too much on symptoms and problems.

## The Team Approach

Now that we've looked at how to approach, support and relate to the family and client, whom do we relate to in the assessment process? As the frontline worker who has initiated the assessment, you will need to relate with and rely on a team.

The purpose of screening individuals at risk for FASD is to determine whether a pattern of learning and behavioral problems may be related to prenatal alcohol exposure.<sup>6</sup> The screening can be coordinated through the education system, mental health system, judicial system, or social services. The screening should facilitate referral to a diagnostic clinic and highlight the need for referral and support for the birth mother.

To create an environmental support for such referrals, it is important to understand the model of a **Coordinated Team Assessment and Follow Up Service**—who is involved in an analysis of FASD and how do they work together?

Proper assessment requires a multi-disciplinary approach. Due to the complexity of FASD and its expression in all facets of life, a core team of professionals in

the following fields is key to an accurate and comprehensive diagnosis:

- Coordinator for case management (front line worker)
- Physician specifically trained in FASD diagnosis
- Psychologist or Psychiatrist
- Occupational therapist
- Speech-language pathologist.
- Possibly, a neurologist or geneticist<sup>7</sup> trained in diagnosing FASD

Additional members may include:

- Addiction Counselors
- Childcare workers
- Cultural interpreters
- Mental health workers
- Parents or caregivers
- Probation officers
- Teachers and Vocational counselors
- Nurses
- Family therapists.

These experts all have different pieces of the puzzle that may help diagnose whether someone has FASD. A multi-disciplinary diagnostic team can be geographic, regional or virtual; it can also accept referrals from distant communities and carry out an evaluation using telemedicine.

## Gathering Information

Assessment will involve gathering documented information and records from various sources, including a medical examination, a full maternal history, and a neuropsychological report. These assessments often include an extensive review of assessment notes by various social service practitioners, as well as meetings with relevant professionals who know the patient (teachers, doctors, social workers, etc.).

Client consent and confidentiality practices for frontline community workers should always be in place and followed carefully - from the documentation of your own reasons for referral through to the process of accessing and managing information relating to all aspects of the client's developmental and social history. Wherever

<sup>6</sup> *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis*

<sup>7</sup> Sometimes a geneticist will suggest DNA tests to rule out genetic disorders.

possible, you will need to access information from the following kinds of sources:

### **Hospital and Medical Records**

- Maternal/ Neonatal History
- Birth and Pregnancy records
- Medical history
- Psychological/ psychiatric history

### **Social services**

- Adoption records
- Reasons for Referral
- Psychological and psychometric assessments
- Documentation of the family history
- Drug exposure history

### **School History**

- Day Care history
- Academic records
- Achievement tests

### **Other Previous assessments**

- Developmental assessments
- Legal reports

## **The Diagnosis**

### **Medical Assessments**

The term FASD is not meant as a clinical diagnosis; it is a classification for a range of disabilities associated with prenatal alcohol exposure. However, ultimately, the person who says, “this person has or doesn’t have FASD” is the doctor.

Unfortunately, most doctors are not trained to assess for FASD. It is important to inquire carefully about which doctors specialize in this area, how far or close they may be, and to develop a relationship with them.

A medical assessment for children may include:

### **Growth Parameters**

- Length
- Weight
- Head Circumference

### **Developmental Assessment**

- Cognitive ability
- Language ability
- Motor skills

### **Genetics Assessment**

- Dysmorphic (referring to a *dysmorphic feature*; for example, a body characteristic that is abnormally formed, such as an ear)
- Palp fissure (refers to the palpebral fissure length which is the measurement of the eye from one corner to the other)
- Philtrum (refers to measuring philtrum smoothness and upper lip thinness)
- Other Anomalies

Further Medical Assessments for children, youth, and adults may include:

### **Occupational Therapy Assessment**

- Motor Impairments
- Sensory processing difficulties/ sensory integrative dysfunction
- Learning difficulties
- Poor Social Skills
- Difficulty completing activities for daily living

### **Speech & Language Assessment**

- Auditory comprehension
- Auditory memory
- Auditory discrimination
- Auditory sequencing

### **Psychiatric Assessment**

FAS is not included in the DSM (*Diagnostic and Statistical Manual of Mental Disorders*), the diagnostic “bible” for psychiatrists. Psychiatrists who do forensic assessments for criminal cases have not generally been trained to recognize or diagnose the full spectrum of alcohol related birth disorders.

### **Building on the Diagnostic Process <sup>8</sup>**

The comprehensive assessment by the diagnostic team provides important information about the individual’s unique needs and allows interventions to be tailored to his or her strengths and challenges. The post-diagnostic report should state the basis for the diagnosis by includ-

<sup>8</sup> Adapted from FASD: *Canadian Guidelines for Diagnosis*, Chudley, Conry, Cook, Looch, Rosales, LeBlanc, 2005.

ing the history of alcohol use, the physical criteria and the psychological data that support it.

Following assessment, a report containing recommendations should be made available to caregivers, educators, and biological families, as well as other appropriate individuals who work with the child (i.e., daycare workers, early intervention workers, social workers, etc).

The multidisciplinary team findings should be discussed with the guardian or parent. Older children who possess the cognitive ability should have the opportunity to learn about their diagnosis from the team. The team might also take on the responsibility for facilitating and providing follow-up with the family and community resources regarding outcomes of the recommendations. Ultimately, the diagnostic process will result in concrete management recommendations to improve the lives of the affected individuals, their families and the communities.

## Advocacy

After diagnostic assessment has confirmed FASD, it is important to move beyond the label and begin the next level of relationship with the client and their family: advocacy. **Advocacy** is working for the best possible resources and supports for the person with FASD.

### Developing Family Advocates

Advocates can be a relative or good family friend. However, in the beginning, as the frontline worker who has helped the family identify FASD as a possibility, you may find yourself as the family's primary advocate until they have become more knowledgeable about supports and resources.

Validate the parents/ primary caregivers of an FASD child for their knowledge about the child's individual strengths and abilities. As a front line worker, you will need to work *with* parents to facilitate the best advocacy possible for the child. At first they will need a lot of help and support from you, but you can't do it all for them, or you will burn out very quickly. Ultimately you need to help *them* to become the best possible advocates they can be, rather than doing the work for them. Here are some tips for facilitating the development of parent/ family caregiver advocates:

- Encourage the parents to get involved with parent groups where they can find support and access community resources; if such a group doesn't exist in your community, look into finding a way to start one.
- Research and suggest resources and workshops in your community that can help parents expand their advocacy skills.
- Help them continue learning about FASD by building and sharing a library of books, magazines, journals, videos.
- Facilitate, advertise, attend and encourage workshops and conferences.
- Work beyond the label of FASD—there are many existing community resources that both parents and frontline workers can access that are not necessarily identified as an FASD service.
- Find additional, secondary advocates for the child and family—someone to champion their cause in specific settings, be it in the school system, the legal system, the medical field or social services.

**Remember:** each family, like each child, is unique. There is no key resource or approach that will work best for everyone, so everyone needs to work together.

# Reason

So we have an idea of what FASD is and how to approach clients and community supports. But it seems like such a big community problem, with so many challenges; how do we tackle it?

There is no single, easy, step-by-step method for addressing FASD; it requires a holistic approach that takes into account the unique needs of the person with FASD, their family, and the various sectors of the community that may have an impact on the client and family. However, there are some good general principles that can be seen as applicable to working with FASD clients as well as certain approaches developed in the education sector and the north that can inform most people looking for strategies.

## General Accommodation Strategies

The useful chart on page 20 lists:

1. Primary behaviours associated with FASD;
2. Standard social expectations;
3. How primary behaviours are often interpreted when these expectations are not met;
4. Standard interventions that prove ineffective and often lead to Secondary behaviours;
5. Secondary behaviours that arise when ineffective standard interventions are applied to people with FASD; and,
6. Accommodations which are sensitive to the needs of those with FASD and which help them to better respond and adjust to the environment.

This chart gives a good general overview of strategic principles to be applied in relating to and supporting the development of people with FASD.

## Strategies for Families

### Tracking Behaviour

Of course, the most important resource is the family itself. It is the primary ongoing caregivers for the per-

son with FASD who will ultimately make the most difference in how the child or youth is able to cope with their condition for the rest of their life. Parents and family advocates need to watch for development milestones in infants, children, and teens by keeping track of behaviours and basing their strategies on what they observe on a daily basis.

For parents and advocates working with children and youth who may have FASD it is important to keep Behavior Records. These are written records that note behavior problems in various environments, including what happened, what was the trigger, what was the behavior demonstrated, and what was the response to that behavior. Examining these notes will help produce a record of where the problems crop up and help identify what the common denominator is. Parents and advocates will then be better equipped to anticipate where the problems are and identify appropriate responses and changes to the environment.

For example, aggression can result from stimulus overload caused by sensory integration difficulties where the child's senses become overwhelmed. Noise, clutter, light levels, excessive movement or even the feel of certain types of clothing on the skin or the smell of fragrances can ignite an impulsive aggressive response among children and youth with FASD. Behaviour journals will help the caregiver to identify which environmental factors need to be eliminated.

### Strategies for the Home

Once patterns of behaviour are identified, practical strategies for addressing these behaviours can have great impact when applied daily in the family home.

Consistency is very important for any kind of developmental disorder. For this reason, understanding and establishing routines that meet the specific needs of the child or teen is key to creating a nurturing and supportive environment. Routines are very important for children and youth with FASD because they are so negatively

## FASD neuro-cognitive characteristics, expectations, secondary behaviors and examples of accommodations

Primary behavioral characteristics of FASD	"Fit" within environments: Values and Expectations	Interpretation of behaviors when expectations are not met	Standard Interventions	Secondary behaviors	Environmental Accommodations to prevent challenging behaviors
Slow auditory pace, goes blank	Think fast pay attention stay on task	Ignoring me, resistant personalize	Talk fast Therapy Punish	Anxiety Frustration Shut down	Slow down Give time Adjust workload
Slow cognitive pace, doesn't answer	Think fast, timed tests, finish work within time allotted in schedule	Controlling, avoidant, not trying, holding others up on purpose	Take away privileges, shame, ridicule	Anxiety, frustration, tantrums	Give time. Slow down. Reduce work load Accept slow pace
Difficulty generalizing, gets the piece not the picture	Follow the rules, learn inferentially, "get it" by watching	Willful, on purpose, Intentional. He knew what the rule was!	Punish	Fear Frustration Anger	Accept need to re-teach a concept in different settings
Dysmaturity: Developmentally younger than their age	Act your age Be responsible Be appropriate	Poor social skills, acting like a baby, inappropriate, overprotective parents	Teach age-based skills Punish "inappropriate" behaviors	Lonely, Isolated Depressed	Think younger Establish developmentally appropriate expectations
Memory problems "on days and off days"	Learn the first time and remember from day to day	"He/she doesn't care", lazy, needs to try harder	Punish, ground Shame	Anxiety, fear, no confidence, eroded esteem	Recognize and allow for variability, prevent anxiety
Sensory issues: Over stimulated, Overwhelmed, distractible	Pay attention, sit still, ignore distractions	Not trying, undisciplined, off task, ADD	Punish More work, Medicate No recess	Agitation, overactive, avoidance, anger, anxiety tantrums	Evaluate the environment, adjust accordingly, provide breaks
Easily fatigued	Keep up, try harder	Not trying, lazy work avoidant, unmotivated	Punish More work	Anger, tantrums	Adjust work load, provide breaks and snacks
Impulsive, inability to predict outcomes, acts fast but thinks slowly	Think ahead, plan, set goals rein in impulses	Willful, Disobedient, Inappropriate, Doesn't care	Punish	Avoidance Defiance	Prevent problems, build on strengths, use visual cues
Concrete thinker, Learns by doing	Abstract, sit still, pay attention, listen and learn	Lazy, unmotivated and/or poor parenting	More hours on homework, no recess therapy	Burnout Shut down Give up	Provide kinesthetic, Experiential Relational options for learning
Rigid, perseverative, difficulty stopping or changing activities	Stop what you're doing when you're told, transition easily, don't resist	Controlling wants all the power, bossy, oppositional	Interrupt, assert control, require transitions	Resistance Anger <b>Big Tantrums</b>	Adjust workload to achieve closure Provide adequate time

affected by change and because they struggle with attention deficit difficulties and memory problems.

For example, a common routine like brushing teeth in the morning is difficult for children with developmental issues because they will not remember. So a strategy to help remember may consist of using visual signs, constructed out of velcro and felt, where the child can be reminded of brushing their teeth, taking a shower, changing into street clothing, or whatever the morning routine might be. As the child completes each task, they take the reminder felt symbol and put it in the velcro sign's pocket below.

Strategies like the one above help FASD children and youth maintain schedules by creating visual patterns that help trigger routines. For more ideas on what can be done to create a proactive environment for the FASD child and youth, see the "Strategies for Educators" section.

### **Working with Parents**

Biological parents of children with FASD often themselves have undiagnosed brain damage, i.e. FASD. Their histories may include early school failure, multiple diagnoses, abuse, neglect, and addictions. Their behavioral symptoms are often viewed as volatile or resistant. Understanding that the parents may also have a problem is useful for a few reasons. First, it helps understand family dynamics. Second, identification at any age reframes problems and expands options for interventions.

Parents with FASD often face numerous personal challenges that may include addiction, domestic violence, poverty, lack of education, lack of support and isolation. No doubt these factors affect their ability to parent. But for many parents affected by FASD knowing can be become a door opening. Once they have had time to process the initial stigma of shame, guilt and grief they can become more attuned to how their own experience of FASD has impacted upon their life. It can take months or even years but eventually parents who can come to terms with their own FASD are better equipped to then deal with their children's possible diagnosis, opening a door to recovery for the entire family.

Whether affected with FASD or not, parents require ongoing support for themselves and their children who are diagnosed with FASD. As a frontline worker you will need to help them identify a safety net of support and services that may include accessing disability allowance and respite services.

### **Support Services**

Depending on a variety of factors, clients and families struggling with FASD may or may not have the ability to support themselves through employment. Once diagnosis has been made, it may be possible for those in need to access supports and services designed for people with disabilities.

Look up disability programs offered in your province. A list of national resources is available in the final section (bibliography) of this tool kit. Supports and services will vary from province to province. In Ontario, for example, these services are available through the Ontario Disability Support Program (ODSP) and Ontario Works Program (OW). ODSP provides financial assistance for persons with physical, intellectual and/or mental health disabilities.

### **Strategies from the North**

Some of the best community strategies for coping with FASD have come from more isolated northern regions. However, these strategies are applicable in any region, since FASD is always best addressed by working with a front line, community-based approach. For this reason, we view the work done in northern communities to address FASD not only as strategies for the north, but also as strategies from the north, which can be applied at the grassroots level in any community, whether you're in Windsor or Moosonee. We are indebted to the Northwestern Ontario FASD Clinic for their contribution to this manual, and for the information that has been included below.<sup>9</sup>

### **Case Management with FASD Children in Northern Isolated Communities**

The major challenge for the North is overcoming the vast distances between communities, some of which are remote and isolated. Unlike major urban centres, remote northern communities have few experts in the field of FASD. As a result, the frontline worker has to become the specialist. To do this they often have to be self taught and then, if funding can be found, must locate training for FASD, which often means traveling outside of their community. Once trained, the caseworker in turn becomes a teacher for other frontline workers as they assemble

<sup>9</sup> Northwestern Ontario FASD Clinic, 21 Wolsley Street, Kenora, ON P9N 3W7, <[www.fasdnorthwest.org](http://www.fasdnorthwest.org)>.

a community response and referral system among the other social service agencies in their community.

### **Developing a community response**

For frontline workers in the North, developing a community response is key to addressing the needs of families with FASD. Through a coordinated effort, across several distant communities, frontline workers are able to access diagnosis, effective treatment planning and resources and services for their clients. For example, Kenora and Sioux Lookout have coordinated efforts under the auspices of the Lake of the Woods District Hospital to form “The Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Team.”

The purpose of this team is to improve the quality of life for the children and families of North Western Ontario through the provision and coordination of the Northwestern Ontario FASD Clinic. The clinic’s purpose is to enhance the quality of life for the children and families of North Western Ontario through diagnostic assessment and facilitation of services.

This team of frontline workers recognized the need to work together and the need to access and coordinate their existing programs. They did this by reaching out to the human services field of their various communities. Consequently they have worked with an initial advisory committee made up of Community based Health Centres, the District’s School Board, Addiction Service Agencies, Infant and Family Support Services, Special Education Coordinator, a Speech Language Pathologist, a Neuropsychologist, Occupational Therapist, Child and Youth Coordinators and representatives from the Association for Community Living. The result is an effective referral system that is reaching the far north.

And yet the team of the Northwestern Ontario FASD clinic has identified many barriers to working in the North, through their strategic planning meetings. Determined to succeed, they have also come up with possible strategies to overcome these barriers. The following list has been shared with the purpose of educating other communities about how to coordinate and organize a community response to FASD in the North.

**BARRIER:** Limited Access And Underdeveloped Capacity for Follow-Up Resources Causes Frustration

**STRATEGIES:**

- Inventory of community resources
- Community support group

- Training of community based social development staff in FASD follow-up
- Develop community resources (lay people, parents, day care/school staff)
- Web based access tele-medicine
- Tap into informal supports
- Use information to document need

**BARRIER:** Varying Degrees Of Understanding FASD Limits Utilization Of Services

**STRATEGIES:**

- Partner with other service providers to have education plan
- Develop learning modules and circulate
- Provide simple ways of explaining and understanding info
- Access available resources, i.e. videos
- Identify where parents are at in understanding what diagnosis means and what changes they will make
- Consider doing a community readiness scan

**BARRIER:** Unsure of long term funding support, which limits what we can offer in diagnosis, assessment and facilitation of services

**STRATEGIES:**

- Form a committee to work on future funding (Sustainability Working Group)
- Include a back up plan so money is not the sole deciding factor in sustainability
- Write proposals for ongoing funding

**BARRIER:** Cross-Cultural Language Barriers Prevents Clear Communication

**STRATEGIES:**

- Invite community workers and educators to training
- Have information on FASD translated into syllabics
- Translate/ distribute glossary of technical terms re FASD
- Check perceptions to ensure effective communication
- Develop partnerships with various communities
- Simplify assessment language (user friendly)
- Make assessment easy to read (size of print)
- Provide info to translate into dialect with 2 other opinions
- Try to use the same translators they will become more familiar with technical medical terminology

**BARRIER:** Insufficient Planning Will Result In Underutilization Of Service

**STRATEGIES:**

- Build in screening at intake for client readiness
- Provide training for alternates
- Build in a mentoring system for team members
- Use existing resources and or train others to do education in FASD issues
- Develop a list of short notice clients who could fill last minute cancellation no show

**BARRIER:** Limited Experience With A New Innovative Model Is Scary

**STRATEGIES:**

- Build in consultation advice
- Spend time creating clear policy manual
- Clarify roles & job descriptions
- Build in time for reflection, “lessons learned” analysis as we go
- Follow communication policy
- Evaluation team should track implementation issues if and when they arise

**BARRIER:** Fear Of Not Making The Correct Diagnosis

**STRATEGIES:**

- Gather criteria checklist and use
- Use of 4 digit diagnostic code<sup>10</sup>
- Prepare family for all scenarios

It is clear that there are no easy answers to addressing issues of FASD in the far North and that the field of FASD presents a learning curve for all communities. However, as demonstrated by the success of the Northwestern FASD Clinic, a favorable outcome can be attained through intensive case management process that incorporates an effective interdisciplinary approach.

The establishment of close working relationships with allied service providers and other community supports in the region means stronger connections with child welfare agencies, schools, children’s mental health facilities, addictions agencies, and health care providers, which will prove invaluable both for referral and case management services.

In the North, learning how to access programs means learning how to work with them. This is also true of North’s relationship to centers in the South where they are linking up to provide specialized training in FASD

assessment and diagnosis. Currently, a number of tools are being developed to implement distant diagnosis through the use of telemedicine.

The North, while challenging, is in a unique position to adjust the nature and pattern of service delivery in the field of FASD through creatively meeting the changing needs of children and families in remote communities.

## Education Strategies

Learning how a child learns will facilitate a better learning environment that will validate the child and help the educator understand the child’s needs. Often FASD is not recognized by the schools and therefore it is important for the parent and their advocate to approach the school together in order to speak to the need to tailor a learning program around the child’s ability rather than impose a curriculum of learning that is not right for them. For this reason and many others, frontline workers must encourage direct parent advocacy and involvement; success for the FASD child depends on the caregiver’s understanding of different approaches and specific needs of the child.

### Success for Students with FASD: Strategies for Educators

The strategies below have been developed by Mary K. Cunningham (PHEc), a retired secondary school teacher with 30 years teaching experience. She has served as Educational Consultant for Toronto District School Board—Social Science and Humanities; co-authored a Student text—Parenting in Canada; is Past President of FASworld Toronto; and co-founder of the Ontario Coalition for Mandatory Parenting Education (OCMPE). She is currently working as a Parenting Education Consultant and FASD Advocate.

The strategy will become the basis for an “FASD 101 for Educators—Success for Students with FASD. It is applicable for anyone involved with students and is not just for teachers. It will be presented in September 2005. It is also likely to be used when presenting to school staffs as part of professional development sessions, and will form part of the Teacher Backgrounder for an Ontario Curriculum Prevention Package for students in Elementary/Secondary schools in Ontario. This is being planned by the FASD Steering Committee for Waterloo,

<sup>10</sup> For complete information refer to the *Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis*, Chudley, Conry, Cook, Look, Rosales, LeBlanc.

Wellington and Dufferin regions. (Grades 5, 8, 9, 11 and 12 to begin with.)

There are seven sections:

1. Introduction
2. What Usually Happens to Students with FASD
3. Adapted Environments where Students with FASD Can Succeed
4. Changing the Parameters
5. Whole School Strategies
6. Classroom Strategies
7. Resources for Educators

## 1. Introduction

As young children with FASD enter the school system at kindergarten or grade one, their educators face new challenges. This includes their teachers and classroom assistants, administrators, office staff, custodians, bus drivers and any others working with students. All are left wondering how to meet the educational needs of these students, keep other students and themselves safe and meet all the other expectations that society has for its schools.

Although they present challenges to the education system it is possible for FASD children and youth to be successful within different parameters. For these students to achieve success all educators must change their expectations of these students. Parameter change is a critical concept—things must change for these students to succeed.

This part of the FASD toolkit describes broad strokes just to get educators started. You will learn as you go and there are many other good sources of information. Some will be listed at the end of this section. FASD makes education challenging but not impossible.

## 2. What Usually Happens to Students with FASD

As an educator you will have already encountered students with FASD. Virtually **all** schools in Ontario have from a few to many students with FASD. A regular classroom with 1 or 2 students with undiagnosed FASD generally presents extreme management problems even for seasoned educators. It must be noted that for the brain damage of FASD to occur there must have been alcohol use in pregnancy and that not every student with problems has FASD. That being said FASD is very common in Ontario's schools as social and heavier drinking during pregnancy has been almost acceptable until very recently. Many pregnant women still drink. FASD is now

acknowledged as the most common birth defect seen in children.

Generally children with the permanent brain damage caused by FASD enter school undiagnosed and, therefore, unrecognized and needing special treatment. FASD brain damage causes an enormous and complicated sensory processing disorder and frequently the stimuli are coming at these children so hard and fast that they simply cannot deal with them. One little girl told her mother to “just make it stop, just make it stop.” Nothing unusual was happening to this child but the stimuli were still too great. This sensory overload is at the bottom of what almost always becomes an inability to learn and/or behave in acceptable ways at school. Early professional diagnosis is a key to school success for these children.

**The General Effects of FASD on Students** Unlike children with typical cognitive delays, children with FASD tend to show the greatest difficulty in areas that require the use of abstract thought. Written performance is noticeably affected. Students with FASD frequently have serious memory deficits (e.g., forgetting rules) and poor judgement (e.g., foolish or dangerous decisions) along with poor impulse control. Many children with FASD show difficulties in social/family relationships, memory and attention, which also affects their ability to function well in school. These problems all result from the destruction or rearrangement of brain neurons by alcohol use during pregnancy. This brain damage is permanent.

**Types of Students with FASD** These students generally present in two ways, the quiet and seemingly well behaved little person who “just doesn't seem to get it” as well as his or her peers (looks like ADD) and the acting out, uncontrollable child who bites, kicks and punches peers and school staff. (looks something like ADHD) The latter type of children are quickly identified as troublemakers and often face “Safe School” suspensions even in kindergarten. Neither child learns as well as their peers and achievement deficits are either immediately apparent or appear by the end of the junior division or grade 4. There is a third, less likely, variant of the child with FASD who has a fairly high IQ but poor behaviour and attitude. They never appear to meet their potential and can be very disruptive. Most of these students do not display facial abnormalities.

**Test Results** Many children with FASD have an IQ in the low normal range. Some will be below normal IQ. A

few will have a higher IQ. A full battery of psycho-educational testing will almost always also reveal a great variation in various scores and the performance related scores will usually be much higher. Using the innate aptitudes revealed by these higher scores is the basis of successfully educating a student with FASD. These students will be most successful when their strengths are maximized through skill development and their weaknesses are minimized. They will **not** be able to fully meet the educational expectations of the new Ontario Curriculum. It must be adapted for any kind of success. You, as an educator, must change the parameters for these students to succeed.

**The Usual Story** Many students with FASD slide through the first years of school (“slip through the cracks”) with weaker achievements in the academic areas. Art and physical prowess may appear to make up the difference for many. However, almost all fall behind badly by grade 5 or 6. If they had previously fit in with their peers until this time a growing gap now develops as their undamaged friends realize that this one is different and leave him or her behind. Since all children crave peer approval children with FASD will usually turn to similar mates (those with FASD or other psychological troubles) for approval. As these students become reinforced by their new and negative peer group, educators should expect to see them show a steady decline into increased rudeness and misbehaviour and even less school success. This is the usual progression. Some FASD “experts” think that this may be the beginning of the development of serious clinical psychosocial problems emerging later in life.

By high school these students often achieve very low marks and frequently skip school, start smoking, abuse alcohol and drugs to control their pain, and engage in crime (eg. shop-lifting, stealing, drug dealing) and sexual promiscuity. They tend to do “everything a parent or teacher wouldn’t want them to do.” Depression is common. Conduct disorders are then often diagnosed along with many other co-occurring psychiatric conditions. Early school dropout is common and is now recognized as the first of the many “secondary disabilities” of FASD. (Streissguth, 1996)

### **3. Adapted Environments where Students with FASD Can Succeed**

An early diagnosis of FASD is considered essential for success. Children with full FAS (facial dysmorphism is evident) receive the best service in Ontario, as their

disability is obvious. Most children with FASD **do not have facial dysmorphism** and do not qualify for special treatment in Ontario schools without some kind of diagnosis.

Doing nothing or maintaining the ‘status quo’ of what we are doing now in education will almost ensure a lifetime of failure for these students and huge social costs for Canadians. It is generally recognized that adults with undiagnosed FASD make up a disproportionate part of the homeless, drug and alcohol addicted, sexually deviant and violent crime-prone portions of our population. All of these characteristics are considered as “secondary disabilities” of FASD. As educators, if we can keep them in school and developing skills these secondary disabilities can often be avoided or at least minimized. Educators, therefore, play a pivotal role in the life-long success of a student with FASD.

Three adapted educational environments can be identified which will help almost all students with FASD, diagnosed or not, succeed and develop their inherent skills. All of these work, but none are easy or inexpensive.

1. A special class or school just for students with FASD using dedicated FASD techniques
2. Home schooling for one or two children with FASD using FASD techniques
3. Regular classroom with integrated Special Education or Special Education withdrawal for FASD techniques

**Special Class** An example of a school that has special classrooms for students with FASD is the David Livingstone Community School in Winnipeg, Manitoba.

“This is an Early Childhood Behavioural Treatment Program...designed for students who display severe behaviour resulting from FAS/FAE or other neurological difficulties. A description of the program is as follows: low stimulus environment, low enrolment classroom, focus on social skills, behaviour and academics, strong consistent classroom agenda, individual education plans, predictable routines and expectations, behaviour plan consistently reinforced by Teacher Assistants and Support personnel, consistent consequencing, speech therapy on site two times a week, occupational therapy on site once a week.”

This program has had demonstrated success with students seriously affected with FASD.

**Home Schooling** Some parents and caregivers will opt for home schooling for their children with FASD. Students who are frequently on school suspension for “misbehaviour” resulting from stimulus overload and an inability to control impulses may do much better at home in a safe, predictable and low stimulus environment. The Ontario Ministry of Education provides some support to adults who home school children at <[www.edu.gov.on.ca/extra/eng/ppm/131.html](http://www.edu.gov.on.ca/extra/eng/ppm/131.html)>. There are other resources available (print, internet) for adults who decide to home school. FASD techniques described in this tool kit can be adapted for home educational use.

**Integrated FASD Special Education** Since the special classroom described above is expensive and most people cannot home school their children, reality dictates that most students with FASD will need to be accommodated in regular classrooms with some Special Education integrated into their program in a way that meets site-based school plans (Program Adaptation, Classroom Assistant, Withdrawal etc.)

Any student who has been assessed as possibly having FASD should receive a thorough medical and psycho-educational assessment in early childhood. Ideally, the child’s Parents/Caretakers, Physician, Educators, Therapists and Social Support Workers will meet and begin to develop a realistic, lifelong plan of communication and care to minimize the development of secondary disabilities.

All students with FASD receiving Special Education should have a diagnosis and an IEP describing appropriate educational strategies. The IEP should reflect individual student strengths and deficits identified from psycho-educational and other FASD assessments. These assessments should include speech/language, occupational therapy and developmental levels. Educational plans resulting from testing are described in the IEP that should focus on functional skills that will have broad applications. The IEP must be re-evaluated yearly in the Identification, Placement and Review Committee (IPRC) process.

At this time (June 2005) Ontario does not yet identify FASD as a Special Education category so in-school Special Education funding will need to be based on another label. Students with FASD, no matter how they are labelled, will not succeed without effective Special Education support. It is critical that educators understand the range

of effects of FASD on students and which students probably have FASD even if it is labelled as something else.

Educational professionals should never try to diagnose a student, only assess and recommend a professional diagnosis if FASD (or any other serious condition) is suspected.

#### **4. Changing the Parameters for Students with FASD**

Ever since schools have existed their goal has been to help students grow steadily into independent, socially useful adults who think and reason effectively on their own. This goal must be changed for students with FASD.

Children with FASD are “10-second children in a 1-second world” according to Diane Malbin, a respected FASD researcher and therapist. They need longer to process cognitive tasks and may need other people, called “external brains” to do much of their important thinking and cueing for them for the rest of their lives. Socially useful independence is not a realistic goal for many people with FASD. However, using socially useful skills in interdependent relationships with “external brains” is a definite and positive possibility “External brains” can be parent(s), caregiver(s), educators, partners, friends and many other social supporters. The most successful adults with FASD surround themselves with a “circle of support.”

All children with FASD will have innate skills. Many of them will be found in the hands-on and technical fields, computers, the arts, childcare and working with animals. Howard Gardner’s Theory of Multiple Intelligences is very helpful for educators working with these students. Educators who can determine and develop the functional skills of students with FASD have the most success.

#### **5. Whole School Strategies** (this represents a minimum)

- All staff in the school trained to understand how FASD affects students
- Substitute personnel trained to understand and deal with students with FASD
- Emergency support for substitute personnel and students if “the wheels fall off.”
- Teachers and aides with realistic expectations of functional development
- Ideal staff will have nurturing, flexible personalities and a sense of humour
- Full-time Educational Assistants

- Make student records easily accessible (understandable) to professionals within privacy limits
- Whole school behaviour expectations, eg. Tribes™ or “With All Due Respect” <www.realdiscipline.com>
- Mark boundaries on floors, hallways if inappropriate touching and poking is a problem
- Direct supervision of all meals, snacks, recess, bathrooms, on the bus – 24/7 supervision
- Structure program as much as possible, no surprises, structure all routines and be consistent
- Buddy Program of FASD-affected student with unimpaired peer
- Direct supervision, if required, of all transit from place to place within the school
- Each FASD student should have an adult “buddy” within the school
- Be overcautious with safety—expect the unexpected—lock up all dangerous items
- Have these students “do in-school errands” (if capable) to use energy acceptably
- Prepare students carefully for assemblies, guest speakers or fire drills (provide ear protection)
- Communication books that go home and come back every day
- Work closely with parent(s)/caregiver(s)—“everyone on the same page”—“iron-clad” consistency
- The same teacher or EA for more than one school year, minimizing transitions
- “Time-in” spots that are private, safe, easily supervised, low-stimulus and comfortable
- Aim for fun and enjoyment, enjoy good times with all students, *Carpe diem*.
- Staff need to learn to like the students with FASD as people
- Remember that students who are impaired teach life lessons to those who are less challenged
- Remember that students with FASD do not know why they do things, don’t ask!
- Foster interdependence not independence in the FASD affected, learn to use ‘external brains’
- When things are going poorly try something different, don’t try harder
- Life skills curriculum blending academic, daily living, personal/social and occupational skills
- Focus on helping students function well in the community with a minimal amount of supervision
- Work within the community to establish supportive and understanding school to work links

## 5. Classroom Strategies (this list is a start)

- Work with student’s developmental age not his chronological age
- Repeat, repeat, repeat. Repeat, re-teach, repeat, re-teach. Adapt the curriculum expectations
- If she repeatedly has outbursts look for the inciting stimuli and steer her away from them
- Alternate times of calm with activity, mini breaks for “brain gym” activities could be helpful
- Reduce stimuli in classroom. Have him looking at a blank wall up near you, not a colourful display
- Use a ruler, paper to cover everything except what is being read at that moment
- Colourful, attractive displays are very, very distracting for children with FASD. Low stimulus works
- Be prepared to handle clothes that itch (distract)— turn t-shirt inside out and tell parent/caregiver
- Figure out what she is good at and build on these functional skills
- Hands-on learning
- Small class size if possible
- Minimize transitions and prepare him for them in advance, “we are going to get out the red book”
- Transitions—forewarn, auditory cue (same song), visual cue (coat), action cue (hold coat open)
- Laminated visual cues—eg. coat, bathroom sink, lunch are helpful—visual learners
- Easy read labels—symbols, be organized, aim for an uncluttered classroom
- Create a personal bubble with tape, carpet square etc. to minimize poking, hitting, touching
- Lots of time, “10-second children in a 1-second world.” (Diane Malbin)
- Use only one book for writing in to minimize trying to find the right book in a disordered desk
- If he can handle it colour code books, get out your yellow book not Language Arts
- Have a quiet, soft place for de-stressing (not punishment)—bean bag chair, pillows, pup tent etc.
- If an assembly will be too stimulating, provide muted ear phones or keep child out of environment
- Do not ask why she did something or moralize. She does not know and morals are meaningless



A special classroom for students with FASD features small class size, “personal bubbles” marked off with carpeting or tape, a low stimulus environment, easy read labels and laminated cues, private spaces for de-stressing, private “time-in” spaces, and large bean bags for use as weighted blankets.

- Minimize homework. If it is causing too much stress it should not be done
- Let him have quiet “fiddle” toys — squishy balls, pocket full of rubber bands
- Sipping water from a sports bottle (straw attached, no spills) may help her attend to lesson
- If he can’t sit still a weighted blanket (large bean bag) may help him anchor his body in space
- Ensure you have eye contact with her when giving instructions, ask her to repeat simple directions
- Simplify complex directions and avoid multiple commands
- Make directions clear and concise and be consistent with daily instructions
- Develop some quiet cues (signs) to help him settle down, go to the quieting place when overstimulated
- Be firm when needed and give only limited choices.
- Make students feel comfortable with seeking assistance (most children will not ask for help)
- These children will need more help for a longer period of time than the average child
- Remember he is not “misbehaving” on purpose to make you mad, “think brain not blame” (7)
- Analyzing, moralizing and traditional disciplinary methods do not work
- Behaviour modification and /or rewards/punishment will not work!
- Communication, patience, compassion, understanding and creativity do work — think FASD first!
- Provide transition help when switching over to middle, junior or high school
- Focus on life skill training, health and nutrition, job skills not higher academics
- Focus on communication, problem-solving, social and life skills — reality based education
- Try to incorporate math and literacy skills into life skills, eg. cooking, shopping, advertising etc.
- Continue to address high school student’s developmental, not chronological age (35)
- Routines are critical, these students may benefit from an “external brain buddy” to get to next class
- Fewer classrooms, classrooms close to each other works best
- Help her organize her locker and backpack
- Colour code subjects, yellow-math, red-English, blue-Family Studies — coloured stickers on texts

- Same locker and adult “external brain” year after year is helpful
- Use technology wherever practicable with these students—usually technologically savvy
- Provide FASD-aware tutors
- If what you are doing is not working, don’t try harder, try differently!

## 7. Resources for Educators

Educators, parents/caregivers can learn a great deal on their own to help them help students with FASD be successful. The Internet has an abundance of good sources and there is a lot of print media available on the subject of the education of students with FASD. The list that follows is a good start but is far from complete. You will find many other excellent resources that you should share with others working with individuals with FASD.

Stick to a few good sources to start. Try not to surf too far out into the “internet sea” at first. It is all very tempting. You will discover other favourites that work well for you. Then nobody will be able to stop you helping these students. Students with FASD are fascinating people who need you. The “pay” for being successful is great. Good luck, Mary K. Cunningham (519-893-7393).

- Conry, Julie, Johnson, B. Tamboline, A. Williams, L. Wright, L. (1996). *Teaching Students with Fetal Alcohol Syndrome/Effects, A Resource Guide for Teachers*, Ministry of Education, Skills and Training. British Columbia, Canada.
- George, Anne. (1993). *Guide for Parents, Teachers and Others Caring for Children with FAS/FAE and NAS*, Vancouver YWCA Crabtree Corner. Vancouver, BC. (604-895-5790) (Pages 40-49—excellent)
- Lasser, Peggy. (1999), *Challenges and Opportunities. A Handbook for Teachers of Students with Special Needs with a focus on Fetal Alcohol Syndrome (FAS) and partial Fetal Alcohol Syndrome (pFAS)*, District Learning Services, Vancouver School Board. (This publication pretty well covers everything and more.)
- Tanner-Halverson, Patricia. (1996). *Strategies for Educating Children with FAS/FAE*, Indian Oasis School District, PO Box 248, Sells Arizona 520-383-2601 (212) (FAS Bookshelf)
- FAS Bookshelf Inc. #438-6540 Hastings Street, Burnaby, B.C. V5B 4Z5, 604-942-2024 or 604-942-2041, <[www.fasbookshelf.com](http://www.fasbookshelf.com)>. Has many of these print resources plus much more.
- <[www.betterendings.org/FASE/teachers/edguide.htm](http://www.betterendings.org/FASE/teachers/edguide.htm)>—Better Endings, New Beginnings: help for families with special needs and high risk children
- <[www.acbr.com](http://www.acbr.com)>—Advanced Communications and Business Resources
- <[www.arbi.org](http://www.arbi.org)>—American Research Bureau

# Movement

Nobody can tackle FASD alone. Indigenous philosophies recognize that it takes a village to raise a child. This is more so the case for children with FASD.

## Mobilizing Communities

Addressing the issue of FASD is best achieved through an agency-wide—or even better, community-wide—approach. Ultimately, FASD can only be addressed effectively if whole communities are ready to face the issue and support campaigns, activities and programs aimed at interventions and prevention.

### Starting an FASD Task Force

One of the most effective ways to mobilize community is to initiate an FASD Task Force. A Task Force will help your agencies work together to plan and deliver better services. These improved services will contribute to an improvement in the quality of life for people living with FASD. The task force should aim to:

- Show service gaps and identify what needs to be done regarding FASD;
- Lead to greater coordination and accountability of service agencies in addressing FASD;
- Create links that better serve and address the needs of FASD clients;
- Make sure people and communities are genuinely engaged in the decisions made on public services affecting FASD;
- Gain a commitment from organizations to work together in providing better public services for families and clients struggling with FASD.

### Environmental Scan

Start by making a list based on questions that will help you do an environmental scan of existing FASD services in your community. Ask yourself:

- What services does my organization offer?
- Are there aspects of FASD that touch upon these other services?
- Who in my community is directly involved with issues of FASD? Look at community health agencies, adult

literacy, children's and youth programs, Children's Aid Services, Employment and Training Initiatives, Parent Groups, and so on.

Once you have done this, call an agency or community meeting with relevant groups to explore the various services and ask:

- How can we help each other to address FASD by building on existing programs?
- What services do our programs work with in the surrounding community? Do any of these outside programs deal with issues of FASD? What are the referral processes?
- What is offered beyond our immediate community? Are there provincial and federal organizations that we can join or access?

### Target Core Services

Once you have done an environmental scan, begin to approach core services in your community for commitment to ongoing membership on the task force. Consider the following areas:

**Health** FASD diagnostic clinics, hospital clinics, neighborhood clinic, nurses association, A representative from an Aboriginal Health clinic, Aboriginal programs specializing in parenting programs and healthy baby initiatives, etc.

**Education** District School Board Representative, Special Education Teacher, an assessor for Literacy and Special Education, etc.

**Justice** Youth and family court workers, probation officer, a representative from Aboriginal Legal services, etc.

**Employment** Aboriginal Training programs and other services targeting employment preparation.

## The Work of the Task Force

Once you have assembled a task force, you can begin to focus on the steps you need to take together to address FASD in your community. The following breakdown gives you an idea of the things you will have to consider.

### What is our mandate?

Develop a broad statement that identifies your fundamental job as a task force. The statement should be clear and reflect a shared vision that genuinely reflects the group and community's needs and aspirations.

### What are the core objectives?

Brainstorm with the members of your task force about what you want to achieve. Try to include concrete, achievable goals you can reach in a measurable way. Consider and prioritize things like promoting effective community engagement in the planning process of FASD Day, building assessment teams, FASD workshops and other initiatives.

### Who is our target audience?

Consider staff in various service agencies you haven't reached yet, the general public, and specific community and government sectors such as health, education or corrections. Priorities will vary depending on the make-up of your community.

### What are our key messages and media?

Based on your target audience, craft a communication strategy that clearly addresses their needs and concerns and reaches them in ways that are sure to engage. Consider community gatherings/ special events as well as print media.

### Connect your team with broader public service organizations

Create a framework for community planning that builds on key resources, linking with existing national, regional and local groups with expertise on FASD. Build genuine partnerships that effectively engage the broader FASD community. Consider ways to link and improve services at all levels.

### Implement an action plan

Finally develop and implement strategies aimed at building knowledge and expertise, raising skills, charting progress and planning for change around FASD.

## Broadening Awareness: FASD Day<sup>11</sup>

### The Importance of FAS Day

FAS Day is the short name for International Fetal Alcohol Syndrome Awareness Day, which was observed for the first time on September 9, 1999, with a "Minute of Reflection" at 9:09 am. Bells rang out around the world marking the "magic minute" of 9:09 am as "The FAS Bell Concordance." Since then bells have rung around the world, from the historic 56-bell carillon in Cape Town, South Africa, to tiny bells rung by school children in Toledo, Ohio, and wind chimes and rain sticks in Sioux Lookout, Ontario.

The Minute of Reflection symbolizes the worldwide circle linking everyone who cares about FAS/FASD, is working towards it's prevention, and is helping children and adults struggling with fetal alcohol disorders to reach their full potential.

There is a purity about bells that reminds us of the innocence of children, and they are a powerful auditory reminder that we are all connected to the planet, and each other. In that "magic minute," we affirm that FAS/FASD can be beaten, by working together.

FAS Day provides an ideal opportunity to connect with other organizations and programs in our community. Together we can build an awareness of FAS/FASD for families and professionals, politicians, local government and the media. Newspaper, radio and TV reporters tend to be more inclined to report on an internationally recognized event, especially when it represents an important human-interest story related to the wellbeing of the community. Further, the contacts and partnerships we make leading up to FAS Day will have a remaining impact on our future endeavours.

Community partnerships throughout the world on FAS Day have included cultural events such as:

- A Pow Wow or pipe ceremony and prayer;
- An information evening for Social Services;
- Having a well known restaurant give away free non-alcoholic drinks to pregnant women
- Having an art exhibit featuring work donated by famous artists;
- Distributing posters to family physicians;
- Offering curriculum to teachers;
- Doing presentations with key stakeholders, such as local government agencies and ministers;

<sup>11</sup> Adapted from FASWORLD's Online manual for International FAS Awareness Day 2000 (see bibliography)

- Up north, one community used information brochures on FAS/FASD as place mats in local restaurants, whereas another community organized a nine-block march to symbolize 9 months of pregnancy.

### How to Plan International FASD Day

To begin planning, start by making a list:

- Do you need to recruit an FASD Task Force? (People are your most important resources. Each person is a wealth of ideas, contacts, skills and creative energy. Once you have their interest and commitment, send out a formal request to their organization inviting them to join the FASD Task Force. *(See sample letter.)*)
- Who might be interested in helping the FASD Task Force? (Small business, corporate donors, other organizations in your field, service agencies, neighbors, etc.)
- Who would be interested in promoting the event? (Community based radio, colleges, universities, reporters who write or broadcast on social issues.)
- What are your timelines? (This will depend on the Task Force, so getting organized early is key to success.)
- What is your budget? (Examine the size and nature of the event and the amount of resources you have generated from fundraising. *(See attached sample budget.)*)

### Making a Public Splash

Once you have set up your FASD Task Force you can begin going public. Start by having a clear agenda, knowing who you are and what you want to achieve.

- State Mission, Vision and Values
- State your Purpose
- List your Terms of Reference
- Meeting once a month
- Advisory Committee
- Once a year strategic development Day— FASD Day
- Coordination of events in your community on FASD
- Formalized minutes
- Report bi-annually
- Create an FASD proclamation

### What is an FASD Proclamation?

An FASD Proclamation is a formal and official announcement. In 1999, FAS Day volunteers from all over the world managed to get civic proclamations. In Toronto the Mayor was contacted and the proclamation was drafted with the assistance of the city's protocol office. Versions of the 1999 proclamation were then used in many towns,

cities and states around the world. *(See Letter to Mayor/ Proclamation attached.)*

### Working the Media

As a not for profit organization it is key to understand the difference between advertising and publicity. Advertising is paid information to be distributed to the public. Publicity is information that will interest the public and therefore costs nothing. No legitimate media outlet would ever charge for running a story because they would then be in violation of media ethics. For organizations with limited resources, publicity is the best media strategy.

### So what makes good publicity?

All media whether it is television, radio, magazines, or newspapers all have one thing in common. They want to offer their audiences information of value. They want to report breaking news, report on trends, amuse and entertain. And they want to respond to community concerns.

### Steps to Contacting the Media:

Editors are always demanding that reporters do stories about events/issues that have an impact on the lives of ordinary people. They want real people as “characters” in stories, not just officials and spokespersons. Find people from among your clients or your supporters who are willing to tell their story to the media.

Much of this about how you portray your work or issue, what the media call framing. Think about your agency's work in terms of the benefit it has on the community. Frame your issue in a way that shows how and why it matters.

Proximity is one of the elements of relevance: editors search for news that is close to home. As a local agency, this will be to your advantage with the local media.

Is there a particular local publication that writes about your community? A radio or TV program that deals with related issues? Figure out which reporter at a particular media outlet is most likely to cover your community? Give them a call let them know who you are and where your expertise might be helpful to them. Share your expertise. Share your information. Tell them about websites where they can find statistics about your community. Tell them about trends developing in your area of expertise.

Ask the media people you contact for the names and numbers of local freelancers who write about and report on your community.

Establish yourself as a source, an expert that news people can call for a quote or information when they're working on a story about your community or field.

Keep in mind that when you call a reporter that they are probably getting calls from at least ten other people that day. Be efficient. Have your pitch down. Present your credentials and tell them your idea. Maintain contact. Be friendly, upbeat, businesslike, and brief. Always respect their time.

### **Contact Protocol**

- Send a Pitch Letter
- Send your Biography or CV
- Follow up with your News Release
- Special Events News Release or PSA

### **Pitch Letter**

- Your first sentence must make a case—immediately—for why the person reading what you've sent should read on.
- Present the conclusion at the top. Inverted pyramid style of writing. Then provide supporting facts, figures and arguments.
- Keep it short, no more than 1 page. Simplicity is a plus.
- Let them know why they should care
- Keep it clean
- All writing is rewriting—use active voice as opposed to passive voice
- Let it sit and read again
- Be precise—address to a specific person it's better to try to sell the story to the person who'll report on it.
- Can use pitch letters as stand alones to gage interest.
- Best way to present your pitch letter is to call ahead and find out the preferences of the media person(s) you've targeted. Be brief and explain that you've got an idea for a story and that you would like to send a letter with the details. Would they prefer an email, fax or snail mail?
- Calling and asking is a good way to begin building a relationship.

### **Your Biography**

A biography presents your credentials and your most recent and or key accomplishments – as they relate to the story you are pitching. What makes you different – and what makes you the right person to interview for this story? What makes you an authority in your field? Your bio should answer these questions.

You can include an interesting quote in you bio, one that shows you understand what makes for a lively news

story—and that you're quotable. This is one time when you can quote yourself at your wittiest, most profound or most engaging best.

Your bio should be written in third person. It should be one to one and half pages long at most. A well-done bio should present you as an appealing personality. Like a well written news-release, the first sentence of your bio (your lead sentence) should grab the reader's attention immediately.

### **News Release and Special Events News Release**

Media appreciate an "inverted pyramid" style. In this style of writing the conclusion or summary is presented first. The second most important fact or supporting material is presented second. The third most important fact is presented third, etc.

The inverted pyramid style is the way journalists compose their own news stories. As news people have limited space in their papers and on their programs, they often have to shorten a story. The inverted pyramid style allows them to do this easily and quickly, while retaining the most important information. *(See attached samples.)*

### **Public Service Announcements**

Radio and television provide a certain amount of airtime on a no-charge basis to serve the public interest. This means your local broadcast media will report on meetings and events sponsored by nonprofit organization, or by for profit businesses if the event benefits a nonprofit organization.

The trick to writing a good PSA is to make it sound like something a person would say out loud. It is usually one minute long or less. Speakers generally talk at a rate of 125 words per minute, so a one-minute PSA should be about 125 words long, a thirty second PSA should be about 62 words long etc.

PSA's should include the Who, What, When, Where, Why and How. Be sure to include a contact person and his or her address, telephone, and email address. Send you PSA 2-3 weeks before the date you want the announcement broadcast. Be sure to include a brochure or cover letter that highlights the work of your organization, especially is your organization isn't well known.

Call ahead to see who to address it to. Ask for the Public Service Director. *(See attached sample.)*

NOTE: If your release contains any hard to pronounce foreign names, include the phonetic pronunciation (in capital letters in parentheses) next to the words.

## Sample PR Kit

### Sample Letter

#### FASD Task Force Recruitment Letter (on your letterhead)

Date

Manager's Name  
and Official Title  
Organization's Name  
Address

Dear 'Manager's Name'

Please accept this letter as formal request that Jane Doe sit on the FAS Task Force Committee which has been organized by 'your organization name.' This committee consists of parents and professionals who are interested in enhancing services to FAS/FASD children, youth and families within the community.

Jane Doe's experience and knowledge about issues within the 'identify/name the' community will be very beneficial to the FASD Task Force. The task force will convene on a monthly basis and all minutes/information will be available to you.

If you would like to discuss this further please call.

Sincerely,

Your name  
and Title

### Sample Budget

PROJECT EVENT BUDGET		
Submitted by:		
Date:		
Sponsor Name	Income	Expenditures
Kodak	(1000 disposable cameras)	
Health Canada	\$3000.00	
Subtotal of Actual Income to date		
<b>Projected Costs to Date</b>		
Program printing		\$150.00
Subtotal of projected costs to date		

## Letter to the Mayor

(Date and address)  
Mayor Mel Lastman  
Toronto City Hall  
100 Queen Street West  
Toronto, ON M5H 2N2

Dear Mr. Lastman,

I am writing to request that you officially proclaim International Fetal Alcohol Syndrome Awareness on September 9, 2000. We were pleased that you proclaimed International FAS Day on September 9, 1999, and would be grateful if you could read this year's proclamation at our observance on September 9 at 8:30 a.m. at Metropolitan United Church.

Fetal Alcohol Syndrome is the leading cause of mental retardation in Canada and the industrialized nations of the world. FAS is not just a "disease of the week" but a major root cause of numerous social disorders, including the homelessness/street kid issue that currently plagues Toronto. People with FAS also are at high risk of learning disabilities, early school drop-out, juvenile delinquency, drug addiction and alcoholism, mental illness, crimes against property, vandalism, child and spousal abuse, unemployment and poverty. Some researchers believe that as many as 1 in 100 people are affected with fetal alcohol disorders, and each of these individuals can cost the taxpayers \$2 million per year for social services.

My husband Brian Philcox and I are coordinators of "FASWORLD," an informal alliance of parents and professionals around the world who are working to build awareness of the dangers of drinking in pregnancy, and the desperate plight of individuals with FAS and their families.

Why September 9 at 9:09 a.m.? On the ninth minute of the ninth hour of the ninth day of the ninth month, our alliance asks the world to remember that during the nine months of pregnancy, a woman should not drink alcohol. We also want the world to remember those millions of individuals who will not reach their genetic potential because their mothers drank in pregnancy. People around the world are working at getting their local bells to ring at 9:09 a.m.

Various organizations with an interest in FAS issues are supporting us in our FAS Day program here in Toronto. Among them are Breaking the Cycle (which works with pregnant women with alcohol/drug issues) and Native Children and Family Services (which works with native street youth.)

I've enclosed documentation about FAS and the FASWORLD alliance. My husband and I are adoptive parents of Colette, now 19, who was diagnosed with Fetal Alcohol Effects in November, 1997. Colette spent most of 1997 on the street, surviving by squeegeeing and addicted to crack. We now believe that many squeegee kids struggle with undiagnosed fetal alcohol disorders, and would welcome an opportunity to meet you and other City Council members who would be interested in learning more about FAS.

We would welcome any assistance you and Council can give us in encouraging the people of this great city to ring every bell in Toronto at 9:09 a.m. on September 9. Also enclosed is a "FAS Knot," our symbol of connection around the world.

Yours truly,  
Bonnie Buxton

## Sample Proclamation

### **PROCLAMATION**

#### **Fetal Alcohol Syndrome Awareness Day September 9, 2000**

WHEREAS: children are our most important resource and it is our responsibility to care for, nurture and protect them; and

WHEREAS: statistics indicate that individuals with Fetal Alcohol Syndrome and Effects (FAS/E) in Canada and industrial nations throughout the world, face the risk of mental retardation or learning disabilities, early school drop-out, homelessness, addictiveness, trouble with the law and mental illness; and

WHEREAS: to reduce the incidence of FAS/E, it is essential that women in pregnancy are provided with support and information; and

WHEREAS: parents, professionals, individuals living with FAS/E and other people around the world will observe the second International FAS Awareness Day on Sept. 9, 2000, with a Minute of Reflection at 9:09 a.m.

NOW THEREFORE: I, Mel Lastman, Mayor of the City of Toronto, on behalf of Toronto City Council and the more than 2.3 million people of our great city, do hereby proclaim September 9, 2000 as "Fetal Alcohol Syndrome Awareness Day" in the City of Toronto. I encourage everyone to act with compassion and understanding towards those individuals whose lives were affected by alcohol before they were born.

(signed) Mel Lastman, Mayor

## Standard News Release Format

### NEWS RELEASE

**Contact Information:** Name of Organization, Address, Contact Person, telephone number, and email address.

**Release Date:**

**Attention:** (specify which editors or reporter) may help to avoid a quick trip to the recycling bin.

**Headline:** (straightforward and provoke interest) a grabber.

**Dateline:** is the city where your office is located or the location of an event and date the release is distributed. **Lead:** The first sentence provides the gist of the story. **Body:** The body of a news release provides supporting facts and information. In general news releases are written in third person and not first person, unless conveying a personal anecdote.

**Story Prep Information:** List other potential interviews. Their name, contact number and type of personality and what they can offer. Providing story prep information alerts the media that you know the process involved in “making” a news story. In other words, you understand their needs and will be easy to work with.

**Photo Opportunity:** List where, when, who and what time. Assignment editors: Camera crews welcome. Providing this information in release signals to TV media that there is a story here that will work well on camera. Adding the “Camera crews welcome” signals that you know how the media operate and will be easy to work with.

**Optional or where appropriate:**

**Seasonal Tie-In:** Mention of a seasonal tie-in does a lot to strengthen your news. Think how often you hear stories on the TV news that start with seasonal tie-in openers.

## Special Events News Release Format

### SPECIAL EVENTS NEWS RELEASE

**Contact Information:** Name of Organization, Address, Contact Person, telephone number, and email address.

**Release Date:**

**Attention:** (specify which editors or reporter) may help to avoid a quick trip to the recycling bin.

**Headline:** (straightforward and provoke interest) a grabber.

**WHAT:** Explain the significance of what is happening.

**WHO:** Explain who is involved.

**WHEN:** List Date and Time.

**WHY:** Explain why this event is happening.

**WHERE:** List the Place and Address.

## Public Service Announcement Format

**Contact Information:** Name of Organization, Address, Contact Person, telephone number, and email address.

### PUBLIC SERVICE ANNOUNCEMENT

**List time:** for example, 30 Seconds or 1 minute

**List Organization:** who you are

**Announcement:** The trick to writing a good PSA is to make it sound like something a person would say out loud. It is usually 1 minute long or less. Speakers generally talk at a rate of 125 words per minute, so a one-minute PSA should be about 125 words long, a thirty second PSA should be about 62 words long. PSA's should include the Who, What, When, Where, Why and How. If your release contains any hard to pronounce names, include the phonetic pronunciation (in capital letters in parentheses) next to the words.

**Remember:** Call ahead to see who to address the PSA to. Ask for the Public Service Director.

# Bibliography

The resources below should be helpful in learning more about FASD and how to approach it at all levels (individual, family, community, and nation).

## Resources

### National Resources

The following list of *National Resources* has been cited from the *Directory of Fetal Alcohol Syndrome Information and Support Services in Canada*. This directory is a listing of national and provincial organizations and individuals that provide FAS-related services or initiatives in Canada. Some of the organizations provide services exclusively for FAS, for example, in terms of intervention, diagnosis or support for families while others may provide an FAS service as one of many services. The directory is available in both print and electronic form at no charge. Contact the FAS Information Service:

#### FAS Information Service

##### Canadian Centre on Substance Abuse (CCSA)

300 – 75 Albert St., Ottawa ON K1P 5E7  
TEL: 1.800.559.4514 (toll free in Canada) or  
613.235.4048 ext. 223  
FAX: 613.235.8101  
E-MAIL: fas@ccsa.ca  
WEBSITE: www.ccsa.ca/fasgen.htm

#### Aboriginal Nurses Association of Canada

Ms. Claudette Dumont-Smith, Executive Director  
56 Sparks St. Suite 502  
Ottawa ON K1P 5A9  
TEL: 613.724.4677  
FAX: 613.724.4718  
E-mail: info@anac.on.ca Web Site: www.anac.on.ca  
SERVICES: The Aboriginal Nurses Association of Canada (ANAC) is a professional organization working toward making a positive difference in the health of Aboriginal people in Canada.

#### Adoption Council of Canada (ACC)

Bronson Centre  
210 – 211 Bronson Ave.  
Ottawa ON K1R 6H5  
TEL: 613.235.0344 1.888.542.3678 (toll free in Canada)  
FAX: 613.235.1728  
E-MAIL: acc@adoption.ca  
WEBSITE: www.adoption.ca  
SERVICES: The ACC raises public awareness of adoption, promotes placement of waiting children and stresses the importance of post-adoption services. These services are provided through the Canada's Waiting Children Program which recruits families for waiting children, the 1.888.54-ADOPT adoption information line, the ACC's Resource Centre, the publication of a quarterly newsletter and other resources, conference planning, and information and referrals in answer to adoption inquiries.

#### Alcohol and Substance Use in Pregnancy Helpline

Motherisk, The Hospital for Sick Children  
555 University Ave.  
Toronto ON M5G 1X8  
TEL: 1.877.327.4636 (toll free in Canada)  
WEBSITE: www.motherisk.org  
SERVICES: By dialing the toll free number in Canada, individuals who have questions or concerns related to alcohol and drug use during pregnancy and lactation will receive information, counseling and access to care in their home communities. Motherisk counselors can also make referrals for FAS diagnosis at the Motherisk Clinic, and can arrange hair and meconium tests for drug and alcohol exposure in newborn babies. Members of the medical profession who have questions or concerns about specific clients and their use of alcohol and/or drugs during pregnancy and while breastfeeding may also wish to consult this team of experts which includes pharmacologists, toxicologists, neurologists and pediatri-

cians. This telephone service is available from 9:00 a.m. to 5:00 p.m. from coast to coast, Monday to Friday.

### **Association for the Neurologically Disabled of Canada**

59 Clement Rd.  
Etobicoke ON M9R 1Y5  
TEL: 416.244.1992 1.800.561.1497 (toll free in Canada)  
FAX: 416.244.4099  
E-MAIL: [info@and.ca](mailto:info@and.ca)  
WEBSITE: [www.and.ca](http://www.and.ca)

SERVICES: A.N.D. Canada provides functional rehabilitation programs to individuals with non-progressive neurological disabilities. The programs are home-based, non-institutionalized and are individualized to meet the needs of each client and family. Individuals with a broad range of disabilities, including fetal alcohol syndrome, may benefit from the program.

### **Canadian Association for Community Living (CACL)**

Ms. Monica Misra  
Kinsmen Building, York University Campus  
4700 Keele St.  
North York ON M3J 1P3  
TEL: 416.661.9611  
FAX: 416.661.5701  
E-MAIL: [info@cacl.ca](mailto:info@cacl.ca)  
WEBSITE: [www.cacl.ca](http://www.cacl.ca)

SERVICES: CACL is Canada's national association dedicated to promoting the participation of people with intellectual disabilities in all aspects of community life. Please contact for information or referral to local associations and programs.

### **Canadian Institute of Child Health**

Dr. Miriam Levitt, Executive Director  
FASEout  
300-384 Bank St.  
Ottawa ON K2P 1Y4  
TEL: 613.230.8838 ext. 232  
FAX: 613.230.6654  
E-MAIL: [mlevitt@cich.ca](mailto:mlevitt@cich.ca)  
WEBSITE: [www.cich.ca](http://www.cich.ca)

SERVICES: Funded through Health Canada's FAS/FAE Strategic Project Fund, FASEout is a three-year, national Health Canada project designed to take current Best Practices related to FASD off the bookshelves and into

use across Canada. Pilot sites from the health, education, judicial and social service sectors will be participating at the national, provincial and regional level, working through an Implementation Guide designed to assist organizations in linking research to policy and practice. By modifying policies and practices this project seeks to enhance national FAS/FAE information, resource networks and programs to provide needed support to children and families affected by FAS/FAE.

### **FASworld Canada**

Ms. Bonnie Buxton  
Brian Philcox, Founders  
1509 Danforth Ave.  
Toronto ON M4J 5C3  
TEL: 416.465.7766  
FAX: 416.465.8890  
E-MAIL: [fasworldcanada@rogers.com](mailto:fasworldcanada@rogers.com)  
WEBSITE: [www.fasworld.com](http://www.fasworld.com)

SERVICES: FASworld Canada is a pro-active, non-profit organization which strives to dramatically reduce the incidence of fetal alcohol disorders, reduce the incidence of secondary disabilities among individuals living with mental or physical damage caused by maternal drinking in pregnancy and to assist families and caregivers of people with fetal alcohol spectrum disorder (FASD). FASworld Canada works with health units, family support groups and other interested organizations who form the chapter network in communities across the country. Individuals and groups are invited to apply for membership or chapter status.

### **International FAS Awareness Day**

Ms. Bonnie Buxton  
Brian Philcox, Founding Coordinators  
1509 Danforth Ave.  
Toronto ON M4J 5C3  
TEL: 416.465.7766  
FAX: 416.465.8890  
E-MAIL: [fasworldcanada@rogers.com](mailto:fasworldcanada@rogers.com)  
WEBSITE: [www.fasworld.com](http://www.fasworld.com)  
SERVICES: FASworld, an alliance of individuals and organizations in many countries, observe FAS Day on September 9 each year. The goal of the alliance is to inform the general public and professionals worldwide about fetal alcohol disorders. Contact Bonnie or Brian for further information.

### **Public Health Agency of Canada, FASD Team**

Ms. Mary Johnston, Manager  
Division of Childhood and Adolescence  
Room C967, Jeanne Mance Building  
Tunney's Pasture, Postal Locator: 1909C2  
Ottawa ON K1A 1B4  
TEL: 613.946.1779  
FAX: 613. 946.2324  
E-MAIL: mary\_johnston@hc-sc.gc.ca  
WEBSITE: www.healthcanada.ca/fas  
SERVICES: In 1999, funding of \$11 million over three years was allocated to enhance activities related to: Public Awareness and Education, FAS/FAE Training and Capacity Development, Early Identification and Diagnosis, Coordination, Integration of Services, Surveillance, and a Strategic Project Fund. Health Canada's Division of Childhood and Adolescence role is to implement activities outlined in the initiative.

### **Pauktuutit Inuit Women's Association**

Ms. Jennifer Dickson, Executive Director  
131 Bank St., 3rd Flr.  
Ottawa ON K1P 5N7  
TEL: 613.238.3977  
FAX: 613.238.1787  
E-MAIL: pauktuut@pauktuutit.on.ca  
WEBSITE: www.pauktuutit.on.ca  
SERVICES: Pauktuutit develops resources and provides educational awareness on Fetal Alcohol Syndrome for Inuit communities.

### **Provincial Resources, Ontario**

#### **FASAT**

Ms. Chris Margetson, Executive Director  
C/O Homewood Health Center CADS  
100 – 49 Emma St.  
Guelph, ON N1E 6X1  
TEL: 519.822.2476  
FAX: 519.822.4895  
E-MAIL: fasat@golden.net  
WEBSITE: home.golden.net/~fasat  
SERVICES: This organization has been developed in order to meet the needs of children across Ontario with FAS/FAE by providing training for the professionals and parents who work with and care for them, by advocating

and supporting families and by being involved in activities related to prevention.

### **Community Living Ontario**

<http://www.communitylivingontario.ca/about/wwa.html>

Provides direct services and support to individuals and their families so that people may plan their future as productive, fully participating citizens in the community.

Community Living Ontario supports this activity by linking local associations and their members with the resources and information they need, and by offering training and consultation in the areas of family support, education, employment, human rights, community participation, advocacy and self-planning.

Community Living Ontario also works to shape public policy by developing position papers on current issues, by analyzing and responding to legislation, and by advocating for change through public education and awareness campaigns.

In addition, Community Living undertakes pilot projects that demonstrate Community Living at work. These range from "Building Inclusive Schools," a three-year project to help school districts adopt inclusive education, to "Opening New Doors," a project designed to help communities welcome people out of institutions.

Community Living Ontario is also a member of the Canadian Association for Community Living, which in turn is an active participant in the international movement in support of people with intellectual disabilities.

## **References**

The references below have been used in the development of this tool kit:

### **Literature**

- Canadian Centre on Substance Abuse (CCSA), *Directory of FAS/FAE Information and Support Services in Canada*, Ottawa: Canada, May 2002.
- Graefe, Sara, "Living with FASD," *A Guide for Parents*, Vancouver: Ben Simon Press, 2003.
- Graefe, Sara, "Parenting Children Affected by Fetal Alcohol Syndrome," *A Guide for Daily Living*, Vancouver: Society of Special Needs Adoptive Parents (SNAP), 1998.

- Rutman, Deborah, Normand, Claude Louise, *Working with Families Affected by Fetal Alcohol Syndrome/Effects*, Child Family & Community Research Program and School of Social Work University of Victoria, May 1996.
- Mayer, Lorna, *Living and Working with Fetal Alcohol Syndrome/ Effects*, Winnipeg: Interagency FAS/E Program, 1999.
- McCreight, Brenda, *Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook*, Washington: Child Welfare League of America, 1997.
- Mountford, E. Allan, "The Golden Hoop of Life—A Community of Hope," *A Handbook for Caregivers of children ages 3 to 6 with Fetal Alcohol Spectrum Disorder*, Ontario: Fetal Alcohol Spectrum Education Support.
- Normand, Claude Louise, Rutman, Deborah, *Caring for Children with Fetal Alcohol Syndrome*, Child Family & Community Research Program and School of Social Work University of Victoria, March 1996.
- Turpin, Jeanette, Schmidt, Glen, "Fetal Alcohol Syndrome/Effect," *Developing a Community Response*, Halifax, Fernwood Publishing, 1999.

## Conference presentations

### The 2005 FASD National Conference

#### Equality of Access: Rights and the Right Thing to Do

Referenced the Conference Syllabus:

- Linking "Brain" With "Behavior" and Improving Outcomes: Interventions for FASD as a Physical Disability, by Diane Malbin
- Fetal Alcohol Spectrum Disorder (FASD) and the role of the family court judges in improving outcomes for children and families, *Juvenile and Family Court Journal*, Vol. 55 No. 2, by Diane Malbin

### For the Children

February 22-24, 2005, Toronto, Ontario

Ontario Federation of Indian Friendship Centres

Referenced the workshops:

- FASD Environmental Strategies  
Kim Meawasige, FASD Policy Analyst – OFIFC
- Traditional/ Contemporary Aboriginal Children's Games and Alternatives for Special Needs Children  
Joan Chalifoux, CAP-C Trainer – OFIFC

- What an Assessment Involves  
Dr. Brenda Stade, RN, Program Director, St Michael's Hospital Fetal Alcohol Spectrum Disorder Clinic

## Powerpoint Presentation

### ODSP & OW Extras: The Untold Story

Catharine Allan, Community Legal Worker  
HIV & AIDS Legal Clinic (Ontario)  
65 Wellesley Street East, Suite 400  
Toronto, ON M4Y 1G7  
(416) 340-7790/1-888-705-8889  
allanc@lao.on.ca  
www.halco.org

## Websites

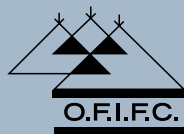
[http://www.cmaj.ca/cgi/content/full/172/5\\_suppl/S1](http://www.cmaj.ca/cgi/content/full/172/5_suppl/S1)  
*Fetal alcohol spectrum disorder: Canadian Guidelines for Diagnosis*

Albert E. Chudley, Julianne Conry, Jocelynn L. Cook, Christine Loock, Ted Rosales, Nicole LeBlanc.

### [www.come-over.to/FASDAY/manual.htm](http://www.come-over.to/FASDAY/manual.htm)

FASWORLD's *How to do FAS Day: An Online Manual for International FAS Awareness Day 2000*.

Prepared by Bonnie Buxton, Brian Philcox, and Teresa Kellerman, co-founders of FASWORLD, an international alliance formed to raise global awareness about the dangers of drinking alcohol during pregnancy and the special needs of individuals affected by prenatal exposure to alcohol.



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