

we cares

practical skills for front-line
workers working with adults affected
by fetal alcohol spectrum disorder

specially designed for those working with people
who are homeless or at risk of homelessness
september 2004

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A. introduction

If you're working with the homeless, chances are you're working with people affected by FASD. This manual is designed for front-line workers working with people who are homeless and at risk of homelessness. It provides some practical, realistic and do-able ways to work with adults affected by FASD.

1. what you can expect from this manual

This manual is designed to help people working with those who are homeless and who are showing the same signs as someone who is affected by FASD. Whether the person you're working with has been diagnosed as affected by FASD or not, the manual will be helpful to you. In fact, participants in our workshop have found that it is helpful in working with adults with cognitive and developmental challenges that come from other causes, not necessarily only due to FASD.

- ❖ It helps you recognize some of the behavioural signs that are often shown by adults affected by FASD (see Section B).
- ❖ It will help you support yourself as a worker or caregiver with people who may be affected by FASD. It will tell you that there's no one formula for working with adults affected by FASD because each person is affected differently. So, the key is to "get curious" and discover what your client's reality is. Section C will help you find ways to do this, and to get the support of your peers.
- ❖ Section C also introduces the CARES approach (page 18), which gives you some very practical tips that you can try out. CARES stands for: Cues, Attitude, Repetition, Environment, and Supervision and Support.
- ❖ Section D gives you a list of things to work with using the CARES approach, related to different aspects of a person's life: physical, time and money management, thinking and behaviour, relationships, secondary disabilities, the environment, housing, and employment. With each workshop we do, more great tips come forward.

This manual is designed to help you:

- ❖ have more understanding of:
 - your own responses to a client affected by FASD
 - some of the behavioural signs of FASD
 - the strengths and challenges of a person affected by FASD
 - what helps adults affected by FASD
- you will strengthen your skills in helping adults affected by FASD by strengthening your ability to discover the unique strengths and needs of each client
- you will develop experience in getting support from your peers in working with people who may be affected by FASD

It will not help you to:

- diagnose or identify whether someone is affected by FASD

2. basic information about FASD

“Fetal Alcohol Spectrum Disorder”

(or sometimes you hear: “Alcohol-Related Neuro-Developmental Disorders (ARND)”, “Fetal Alcohol Syndrome (FAS)”, “Fetal Alcohol Effects (FAE)” or other terms¹)

It’s not Curable: Alcohol use during pregnancy can cause the baby to be born with permanent brain damage. FASD is theoretically 100% preventable, but there is no cure. The effects are life-long.

It’s a Spectrum: FASD does not affect any two people the same way -- some people are severely disabled, others seem almost unaffected. That’s why they call it fetal alcohol **spectrum** disorder. The effects can range from very severe to mild. Adults affected by FASD *may* have trouble with personal care, time and money management, decision-making, relationships, and understanding consequences.

This manual is geared to working with people who may be affected by FASD.

If Diagnosis and Understanding doesn’t Happen Early, More Damage can Be Done: If those affected by FASD are not given the support they need during childhood, by the time they reach adulthood, they may have developed “secondary disabilities”. Secondary disabilities that people affected by FASD can develop include mental health problems, academic difficulties, problems with the law, and substance use issues.

Chances are, a high percentage of people living in homeless shelters have been affected by FASD.

¹ for definitions, see “Section D: Glossary”.

FASD: How it Happens

Effects of Alcohol in Pregnancy

- If alcohol is in a pregnant woman's body, it freely gets into fetus' blood stream – it's not stopped by the placenta
- The fetus is not able to "metabolize" or get rid of alcohol from its system – so alcohol stays longer in the fetus' blood and in the "amniotic" fluid around the fetus
- Increased risk for low birth weight, birth defects, brain and central nervous system damage – which can lead to health problems
- Harm can be caused before a woman knows she is pregnant

Drinking Levels

- Where there's alcohol, there's FASD
- No safe time to drink during pregnancy
- No known safe limit
- All alcohol is harmful
- Safest approach is to not drink at all
- Binge drinking and heavy drinking are particularly harmful

Five Factors Involved in Alcohol-Related Developmental Disorders

- The stage in the pregnancy at which alcohol is consumed.
- The amount of alcohol consumed during the pregnancy
- The pattern of alcohol consumption – binge drinking is particularly harmful
- Individual susceptibility to alcohol.
- Other factors such as lack of nutrition, smoking, and the use of other drugs

Who Drinks During Pregnancy?

- Light/moderate/heavy drinkers
- Higher income, higher education, over age 30, successful
- Poor and isolated women
- Young women
- Multiple drug users and alcoholics
- Victims of violence (childhood, domestic)

Partners' Role: Social Effects

- Women most often drink with their partners
- Partners who drink heavily have trouble giving their pregnant partners the support they need
- A partner's drinking after the baby is born could hurt the child's care

Possibility of Misdiagnosis

- Alcohol Related Neuro-developmental Disorders (ARND) can look like many other mental health diagnoses or developmental disabilities
- Individuals may be diagnosed with a mental health disorder or a developmental disability
- ARND might not be considered or recognized – it's not an official "mental health diagnosis"
- Even when ARND is recognized, another diagnosis is often used in order to get reimbursement for treatment

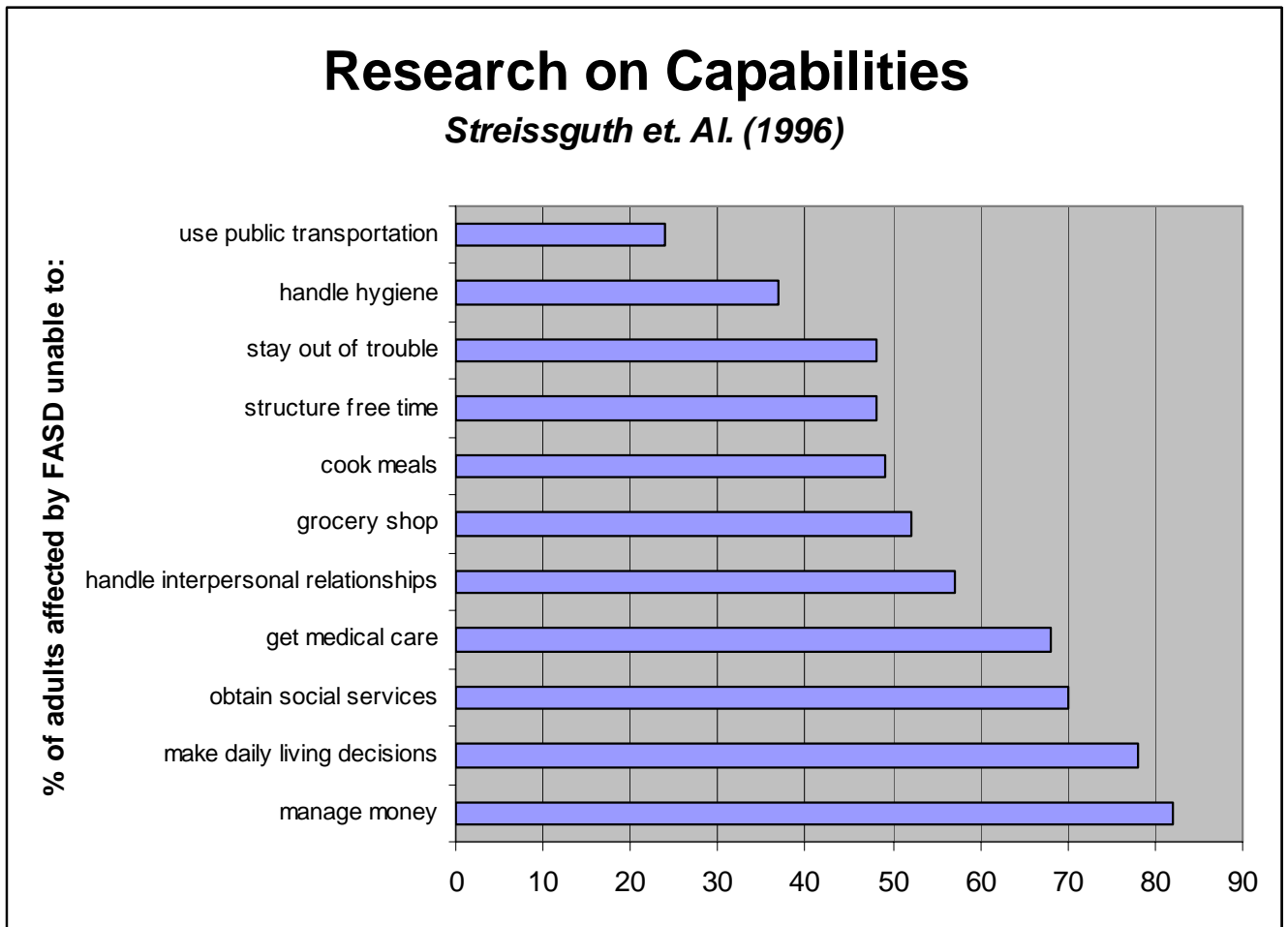
(Dubovsky, 2002)

Diagnostic Process

- Information is collected about – physical, social, academic, and adaptive skill history, and exposure to alcohol prenatally
- Seen by a medical doctor who may diagnose or refer for further assessment
- If possible, the physician, along with a psychologist and other specialists, will assess the individual in order to make an appropriate diagnosis

How are Homelessness and FASD related?

- The behaviours shown by someone affected by FASD can lead to
 - failure at school
 - stress within the family
 - difficulty keeping a job without support
 - difficulty with activities of daily living (ADL)
 - difficulty finding and keeping housing
 - Trouble with the law and difficulty adjusting to living outside of a correctional institution
- Repeated failure
 - loss of hope and self-esteem
 - substance use
 - loss of friends and family support
- All lead to higher risk of homelessness
- **Eighty percent of adults affected by FASD are unable to live independently**
(Streisguth et. al 1996).

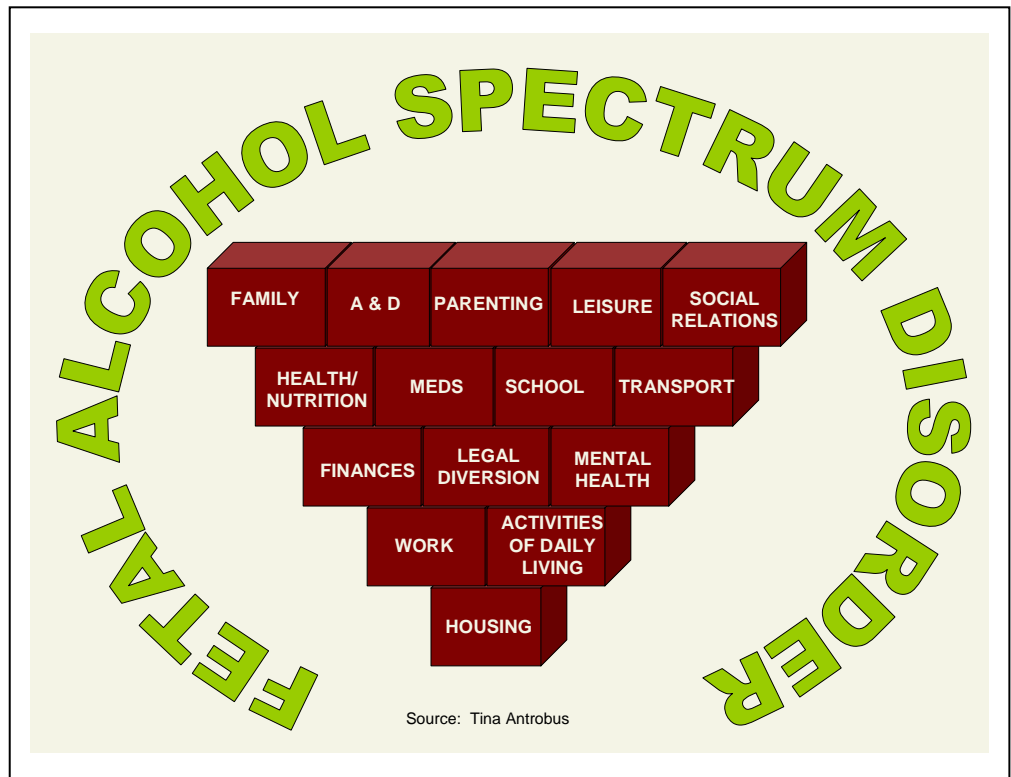


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(Streisguth et al 1996).

Adequate and stable housing is essential to everyone's health and well being. If you've been affected by FASD, housing is even more essential.

For someone affected by FASD, having reliable housing provides a place where daily routine, predictability, and structure can be provided. For someone affected by FASD, routine and structure are essential and other parts of daily living depend on them.



The Economics of FASD and Homelessness

(source: Ottawa's Community Action Plan to Prevent and End Homelessness 2002 – 2005)

Options for the Homeless

- Emergency Shelter
 - with most supports: \$60-\$85/day
 - With some support: \$30 - \$43/day
- Drug and Alcohol Treatment
 - Detox Centre \$80 - \$185/day
 - Recovery \$40 - \$65/day
- Prison/Detention Centre \$90 - \$250/day; avg: \$124
- Psychiatric Hospital \$200 - \$600/day (avg: \$380)

VS

Permanent Housing Options

- Mental health residential facility \$140 – 191/day
- Enhanced apartments (self contained with support on site and collective meal options) \$67 – 88/day
- Boarding House (housekeeping with daytime or 24 hour staffing) \$32 - \$38/day
- Public housing apartment \$14 – 20/day
- Group/shared home \$13+/day
- Non profit rooming house \$12 – 15/day

FASD and Homelessness

The homeless use 33% more government services than those with permanent shelter, and are such heavy users of services that it would be more cost effective to provide them with decent stable housing.

Government of British Columbia (2001) *Homelessness-- Causes and Effects, Vol III: The Cost of Homelessness in British Columbia*, www.hvl.ihpr.ubc.ca/pdf/EberleCosts2001.pdf (link provided by Tina Antrobus)

source of these slides: Government of British Columbia (2001) *Homelessness-- Causes and Effects, Vol III: The Cost of Homelessness in British Columbia*, www.hvl.ihpr.ubc.ca/pdf/EberleCosts2001.pdf

The 7 S's of Supportive Housing

SELECTION
STRUCTURE
SUPPORT
STABILITY
SAFETY
SECURITY
SUPERVISION

B. life affected by FASD

1. a glimpse through the eyes of someone affected by FASD

Each person who's affected by FASD has a different experience -- it's not accurate to generalize. But, to give you a little peek into what it is like to have words and meaning not connect to each other, try this exercise.

Look at the chart and say the COLOUR not the word

YELLOW	BLUE	ORANGE
BLACK	RED	GREEN
PURPLE	YELLOW	RED
ORANGE	GREEN	BLACK
BLUE	RED	PURPLE
GREEN	BLUE	ORANGE

Left – Right Conflict

Your right brain tries to say the colour but your left brain insists on reading the word.

2. some clues of FASD

❖ **memory**

- memory may skip from day to day
- may need to hear something many times before it can be remembered -- if ever

❖ **decisions**

- think in "black and white" -- don't understand "grey"
- may have trouble making decisions and understanding outcomes of those decisions
- may have difficulty understanding "responsibility" and taking responsibility for their own actions

❖ **people-skills**

- may have trouble reading other people's signals -- or body language
- may have different "boundaries" than others
 - may take things that don't belong to them, without viewing it as stealing, i.e. if you leave your coat at the table and get up to use the washroom – the coat may not be viewed as yours anymore
 - may touch others in a way that's crossing "boundaries"

❖ **time and place**

- may become upset when routines are changed, i.e. changing meal times or coffee break routines
- may have trouble understanding "yesterday" and "tomorrow" or "before" and "after"

❖ **communication**

- may talk a lot but say little
- may take things literally and not understand the double meaning of some words

If you tell someone affected by FASD to "break a leg", they may think you're wishing that they'd hurt themselves.

3. case examples of people affected by FASD

Donna

Donna is a 26 year old woman who often visits the Drop In Centre a couple of times per week. She is a prostitute in the downtown area and although she lives with her 'boss', she sometimes needs to come to the Drop In for safety, a rest or because of a fight with her pimp. She also sometimes eats, showers and receives health care when needed. Staff know her well and often encourage her to "be careful" when working. Donna is an avid alcohol and drug user, with cocaine being her first drug of choice. Donna's pimp will often provide her with drugs and alcohol to ease her long nights of working. Donna has confided in staff before that she often engages in unprotected sex with her clients in order to increase her price. As a staff at the Drop In Centre, what sort of opportunities do you think you have to discuss safe drinking and safe sex with Donna? What key pieces of information would be important to provide to Donna? What might you try?

David

David is a 25 year old man who grew up in foster care and group homes. At 14 he ran away - surviving by couch surfing, accessing local shelters, panhandling and cleaning car windows at city intersections. During the past few years he has been the client of several agencies who assist homeless individuals find housing or employment. Although a highly verbal, friendly and compliant man, no agencies to date have been successful in assisting him to stay housed or maintain employment. Several shared housing arrangements broke down when David failed to pay his share of the rent, attend to personal hygiene or keep his personal space clean. He is often labelled as immature, lazy and a liar by people who live with him.

David is currently living in a rooming house and in danger of eviction due to drinking and difficulty paying rent on time. Other tenants also take advantage of him. He often lends belongings or money to them, most of which are never returned.

You are a worker at a centre that provides both housing and employment support to people at risk of homelessness. David is a new client, referred by his rooming house landlord. You were to meet with David for the first time yesterday but he showed up today instead. Although it is snowing outside, David seems impervious to the cold and is only wearing a light spring jacket. You ask him why he arrived a day late. He seems surprised, but quickly explains that a friend wanted to see him yesterday.

In reviewing David's employment history, he tells you that he has had two jobs in the past year. He was fired last week. David says he was fired because he asked his employer for a date after she "encouraged him". He was also let go from the other job and charged with theft by his employer. Charges are still pending.

Melissa

Melissa is a 55 year old woman who is well known to the shelter system. She has lived off and on the streets for most of her adult life and has been in some trouble with the law – trespassing, theft under a \$1000.00 and loitering. Staff report that Melissa is extremely demanding, often wanting their attention and exhibiting behaviours such as shouting, temper tantrums, etc. Staff are extremely frustrated with Melissa and believe she is manipulative and belligerent to the rules at the Shelter. When staff ask her to clean her room, shower and get ready for dinner she often sits in her room looking at magazines, talking to other residents and walking around. She may change her pants or make her bed, but her overall lack of completion of tasks often causes problems for her and the staff. What could staff do differently when asking Melissa to prepare for dinner, shower and tidy her room?

Jessica

Jessica is a 33 year old mother of three. Her three children are in care of child welfare authorities and she has no contact with them. She used to have regular visits, but she lost her visits when she was unable to meet the 'parenting class' requirements that were placed on her by the child welfare worker. Jessica has made many attempts to get her life together, signing leases on apartments and holding occasional jobs at fast food restaurants and in sports bars. Often Jessica will leave the shelter full of smiles and anticipation for her new life, new apartment and new job. She receives support and encouragement from the shelter staff and praise for getting things on track and 'making it on her own'. She appears confident and happy, but usually returns a few months later very quiet, disappointed and discouraged. What could staff do differently or say differently when Jessica makes plans for leaving the shelter?

Arnold

Arnold is 36 years old and was recently living in the Psychiatric Facility in a nearby city. Due to funding cuts and an increase in the community integration model, Arnold was released. With no known family, or supports in the area, there were no plans made for housing for Arnold. He made his way to your shelter with little knowledge of where he came from, no understanding of why he was in hospital and no plans for the future. Arnold indicated that he was taking several medications while in the hospital, but was not sure why or what they were. Arnold exhibits signs of depression and isolates himself from others. He finds it difficult to follow simple instructions and often has loud outbursts when he is frustrated or unsure of what he is doing. Arnold is often very impulsive in his behaviour and has poor judgement. For example, he will punch someone for jumping ahead of him in line or start shouting and swearing at the phone when he reaches voice mail. Staff suspect he has schizophrenia and refer him to the outreach nurse.

One quiet evening, a staff member sits with Arnold and probes about his history – he tells staff that he was taken from his family at a young age because his parents were

"druggies" and that he moved around a lot. He cannot remember much about the homes he lived in, but knows that when he turned 18 years old he moved to the hospital and lived there ever since. When asked about his ability to follow instructions in the past, he admits that he has always had trouble understanding what is expected of him. How can staff better support him to function within the shelter? What should staff be aware of in assisting Arnold to make future housing plans?

Darcy

Darcy is a 24 year old man who was dually diagnosed with a learning disability and depression. He left his parents home at 19 years of age and went to live in a group home with people with disabilities. It quickly became clear that Darcy was too high functioning for a group home, but also unable to follow house rules and guidelines. It was decided that he would be better off living on his own with supports and was put on the list for Supportive Independent Living. Luckily, Darcy receives a disability pension, so he can afford more than if he was on social assistance. As his support worker, you have arranged for his rent to be automatically deducted from his cheque and have gone over menu planning, budgeting and grocery shopping with him. Darcy is a quick learner and you are excited to see that he enjoys cooking and cleaning. Because of your busy schedule, you can only see Darcy once per week and over the past month you have noticed a decline in his personal care, the cleanliness of his apartment and are shocked to learn that he has no money and no food. You go over the goals to plan menus and shop for groceries and Darcy tells you that he "understands" the process. He states that he has made some new friends and that they "borrowed" some money from him. As well, he has decided to treat himself to dinners at Swiss Chalet and Red Lobster. As his support worker, what are some clues that might indicate that Darcy does not fully "understand" the goals set for him? What are some of the signs that he needs more regular support to get through the week? As a support worker, what other methods could be used to help Darcy with his finances and meal planning?

Derek

Derek is a 28 year old who has been in trouble with the law since he was about 15 years old. His charges were mostly for theft and a lot of breaches. He has trouble keeping a job and did not finish high school. The first time he shows up for court, it is on the wrong day at the wrong time and he is not aware of what he has been charged with. He is not showered and he is angry at his lawyer for the confusion. He relies on the Courtworker to speak for him and to remind him of his Court dates. Derek appears to have good verbal skills but his comprehension is low and he can only answer one plain language question at time. When Derek answers questions he tries to answer the way he thinks you want him to which makes the information he gives inconsistent. When Derek's case is ready to be heard, he is disrespectful in the courtroom and has trouble sitting still and making eye contact with the court members. The Judge orders that Derek reappear before him one month later. How can Derek's Courtworker better prepare him for his next court appearance?

C. the keys to working with someone affected by FASD

This section is all about how you as a worker can support yourself in working with someone affected by FASD. The keys are:

- *shift your own attitude so that you drop your assumptions and are in a “get curious” mode*
- *use the CARES model to think about working differently*
- *get support from your peers.*

This section includes:

1. ***what you think and what may really be going on***, to help you get beyond common assumptions about what motivates behaviour
2. ***attitude: it starts with you***: a questionnaire to help you check your own attitude
3. ***CARES: the basics of working with someone affected by FASD***, a summary of the CARES model -- and a good thing to post on the wall as a reminder
4. ***what if you don't have a diagnosis?***
5. ***peer lightening process***: a 40 minute process to get support from other workers in working with someone with FASD
6. ***case worksheet***: to use in planning interventions with someone who may be affected by FASD
7. ***supporting staff and caregivers***: summarizing the importance of seeking support from others.

1. what you think and what may really be going on

what you might think ²	what may really be going on
<ul style="list-style-type: none"> o won't co-operate 	<ul style="list-style-type: none"> o doesn't get it -- memory problems
<ul style="list-style-type: none"> o repeat offender 	<ul style="list-style-type: none"> o may be impulsive o not able to learn from consequences
<ul style="list-style-type: none"> o takes the blame 	<ul style="list-style-type: none"> o easily led by others o wants to please
<ul style="list-style-type: none"> o lazy 	<ul style="list-style-type: none"> o tries and is exhausted or o can't start, disorganized o does not want to fail again
<ul style="list-style-type: none"> o lies 	<ul style="list-style-type: none"> o fills in the blanks o willing and compliant -- tells you what s/he thinks you want to hear, <i>i.e. how was the doctor's appointment? It was great! Even though they may have forgotten the appointment</i> o slow pace of hearing -- may only get every third word o can say words but doesn't connect words with meaning
<ul style="list-style-type: none"> o doesn't care/shuts down 	<ul style="list-style-type: none"> o defensive o hurt

² adapted from RCMP Division D (2002) *Fetal Alcohol Spectrum Disorder: A Message to Police Officers about FASD*, Direct Focus Marketing Communications Inc, fas@directfocus.com

what you might think ²	what may really be going on
	<ul style="list-style-type: none"> ○ abused ○ frustrated
<ul style="list-style-type: none"> ○ looks uncomfortable 	<ul style="list-style-type: none"> ○ can't show feelings
<ul style="list-style-type: none"> ○ resisting 	<ul style="list-style-type: none"> ○ doesn't understand ○ has trouble paying attention
<ul style="list-style-type: none"> ○ trying to make others mad 	<ul style="list-style-type: none"> ○ can't remember ○ over-excited
<ul style="list-style-type: none"> ○ immature, acting younger 	<ul style="list-style-type: none"> ○ an adult affected by FASD may have same skills as a normal eight year old ○ being late for supper and missing out on dessert can be absolutely devastating and a reason to have a tantrum
<ul style="list-style-type: none"> ○ thief 	<ul style="list-style-type: none"> ○ doesn't understand value and ownership ○ has trouble predicting consequences

2. attitude: it starts with you

thinking about a client you've worked with who's showing signs related to FASD...

1. what kinds of thoughts have gone through your head when you encounter someone showing signs like those described on page 14?
2. what kinds of feelings have you had?
3. what have you found yourself doing?
4. what have you observed in others -- say, other workers and other service providers?
5. in general, how does your program deal with behaviours such as those listed on page 10?
6. what would you personally like to know more about related to working with people affected by FASD?

3. CARES: the basics of working with someone affected by FASD

According to Kellerman, the strategies for success in dealing with adults affected by FASD are what we've summarized as the **CARES** strategy: *Cues, Attitude, Repetition, Environment, Structure and Supervision.*

Cues

- ❖ use visual and voice cues
- ❖ give simple, clear and concrete instruction, *i.e. take a shower now; use this soap on your body and this shampoo on your hair.*
- ❖ Avoid a long list of steps that may be difficult to remember. Give no more than 3 steps at a time, and only when the individual is about to undertake the activity.
- ❖ focus on what's happening now
- ❖ help with list-making
- ❖ help with transition, *i.e. after you eat your ice cream, we will begin to clean up and you will sweep the floors*

Attitude

- ❖ try differently not harder
- ❖ drop your own assumptions and get curious
- ❖ look for strengths
- ❖ check your goals and expectations as you learn more about this person
- ❖ work within your agency to develop and implement a consistent care plan. Discuss and document results with your work team and with your client

Repetition

- ❖ repeat yourself using the same words each time
- ❖ probe for understanding -- have them show how they understand what you've said or *"tell me what I've just said in your own words"*
- ❖ keep mood calm and distraction levels as low as possible
- ❖ provide reminder tools and aids as needed
- ❖ post schedules – reinforce the client to follow the schedule when they ask repetitive questions
- ❖ keep consistent

Environment

- ❖ keep safe spots - where someone can go to calm down
- ❖ create special evacuation and safety procedures (alarms can be over-stimulating)
- ❖ help community members to understand

Structure and Supervision

- ❖ structure substitutes for supervision when you can't be there
- ❖ be consistent
- ❖ limit choices and the need for decision-making
- ❖ keep to routines as much as possible -- when you change routine, anticipate problems, tell your client what's happening and work with him/her to adapt
- ❖ give immediate feedback
- ❖ provide or arrange supervision for when you're not around -- intensive case management to support semi-independent living is often needed; peer support and mentoring can be useful

4. what if you don't have a diagnosis?

Most adults affected by FASD are not diagnosed with FAS or FAE. A diagnosis is often difficult to make. Only a specially trained team of professionals (usually comprised of: coordinator/case manager (nurse or social worker), physician, psychologist, occupational therapist, and speech and language pathologist) can make a diagnosis. Because many people affected by fetal alcohol are adopted or placed in foster care, it's sometimes difficult to verify the prenatal history.

if you see a client who's behaving like someone affected by FASD -- then use the strategies in the manual -- whether they're diagnosed or not.

A diagnosis is a helpful door-opener to the services that an adult affected by FASD often needs. A diagnosis may be needed before someone can get services such as:

- disability support payments
- supportive housing
- job coaching.

It can also be a relief for an adult who's struggled to keep up with expectations all their lives to realize that there may be a physiological reason why they are different from other people.

get curious about the way they see the world

No two people affected by FASD are the same. So, the most important thing you can do is find out about what this particular person is capable of.

- ❖ **first, notice your own reactions** if you're feeling confused by a client -- and you're seeing lots of contradictions -- that's a clue that you might be working with someone affected by FASD
- ❖ **second, catch yourself in the act** of assuming that you know what's going on with your client. Get to know your own particular signs of when you're jumping to conclusions. As much as you can, drop your assumptions and get curious.
- ❖ **next, observe and ask**
 - watch to see how they respond to disruption of routine
 - ask them to show you how they understand by walking through the steps
 - observe them interacting with others --
 - do they take things literally?
 - do they pick up on unspoken signals from others?

5. peer lightning round

This process is designed to generate fresh ideas for a worker who's "stumped" with a case -- it's a little different than a brainstorm because there are times when the person who's asking for support is quiet and listens to their peers talk about ideas for their case. The purpose of this is to clear the way for fresh thinking. Later on, there'll be a chance for you to come back in and provide more information or ask more questions.

Start the process off by inviting peers to take 40 minutes to work with you on a challenging case. Then, take a few minutes to prepare yourself and get clear on one or two burning questions.

Time allotted	Activity	Notes
5 minutes	Ask one of your peers to facilitate. The worker provides peers with a summary of the case and where you're challenged as a worker Worker asks 1-2 questions for peers to help you with	
5 minutes	Peers ask clarification questions and worker responds	
10 minutes	peers brainstorm and worker takes notes	<i>this is the hard part -- because you'll want to jump in and give them more information -- and the peers may want to ask you questions</i>
5 minutes	worker gives information on what's helpful about what they've heard, where they want more discussion, and provides more info if needed	
10 minutes	Second round: peers brainstorms, worker takes notes	
5 minutes	Wrap up round -- were there any ah-hah's for anyone in the process?	

6. case worksheet

The client's and worker's goal with this case:

Challenges in reaching the goal

What you might try

use the manual

*Cues, Attitude, Repetition,
Environment, Structure and
supervision*

physical

thinking and behavior

relationships

Challenges in reaching the goal

What you might try

use the manual

*Cues, Attitude, Repetition,
Environment, Structure and
supervision*

time and money management

mental illness and substance use

environment

housing

employment

Complete this exercise by listing the agencies and/or professionals in your area that could be helpful in working with this client.

7. supporting staff and caregivers

Caring for one or more people who are affected by FASD demands patience, perseverance, creativity and both peer and professional support. Here's what is suggested to prevent burn-out and optimal care:

- create a **circle of support** with peers who you can do "peer lightning rounds" (see previous section) before you are at your wits end with someone who you are supporting
- **use your circle of support** – it only takes 40 minutes of the group's time to do a peer lightning round. It works well over the phone. You can put out the word to your circle that you're requesting a peer lightning round at a certain time and ask whoever's available and interested to join you on the phone. Use the telephone company's three-way calling process to inexpensively connect people.
- **Identify a network of people** in your community who have expertise about FASD and bring them into a staff meeting to help your colleagues develop awareness. Conclude with a discussion about what you can do differently within the program.

Use local specialists for case consultations -- have them come in and coach you in working with challenging clients.

D. more details about working with FASD

This section reviews what you often see happening with people affected by FASD and provides specific tips for working with them. The sections are:

- 1. physical signs of FASD*
- 2. thinking and behaviour*
- 3. relationships*
- 4. time and money management*
- 5. secondary disorders: mental illness and substance use*
- 6. environment*
- 7. housing*
- 8. employment.*

Within each section, there's a brief introduction to this aspect of a person's life. Then, on the left side of the page is a section describing what you might see in someone who is affected by FASD (remembering that every person is affected differently. On the right side of the page is a section describing what you might try with someone who is challenged in this aspect of their lives. What you might try is organized using the CARES framework. The tips on the right do not necessarily provide answers to the signs on their left. So, the easiest way to read these pages are to read down the left side first to get a picture of how someone affected by FASD may be affected in this area. Then, scan the tips on the right side to get ideas for what you might try.

1. physical signs of FASD

The amount of brain damage to a person who's been exposed to alcohol before birth can depend on many things. It can depend on

- ❖ *the amount of alcohol drank*
- ❖ *when the alcohol was in the system and what stage of development the fetus was at then*
- ❖ *use of other substances such as tobacco, street drugs, prescription and over-the-counter drugs*
- ❖ *access to good nutrition before and during pregnancy.*

what you might see

No two people are affected by FASD in the same way. You might notice:

- ❖ disturbed sleep
- ❖ difficulties with staying clean (hygiene – may believe one shower per week is enough)
- ❖ difficulty telling when they're hungry or full
- ❖ seizures
- ❖ learning and behavioural problems such as attention deficit/hyperactivity disorder and/or developmental delays
- ❖ poor co-ordination -- may be inconsistent -- for example someone may be outstanding in running and jumping but have trouble with tying shoe laces; others have poor gross motor skills
- ❖ hearing and vision problems -- may hear but information may not get through
- ❖ may be able to stand lots of pain and yet react strongly when touched or bumped

what you might try

Cues

- ❖ **post a list of steps** to talk around personal hygiene – use pictures and clock faces

attitude

- ❖ **adjust your expectations** to what you observe is possible

repetition

- ❖ **find different ways** to say things – use pictures or practice by doing

environment

- ❖ **adapt routines** and tools to help with tasks needing fine motor skills such as chewing, dressing, and/or employment. An occupational therapist can help here.

Structure

- ❖ **arrange a medical assessment** with a physician with experience with FASD
- ❖ **closely supervise medication**

2. time and money management

what you might see

- ❖ **time telling:**
 - may have trouble judging how much time has passed
 - sayings like: “quarter to” and “half past” can be confusing

- ❖ **predicting:** may not plan for things that will take time -- like walking back to the shelter to be in on time; may get distracted along the way

- ❖ **estimating:** may have trouble figuring out the value of money

- ❖ **vulnerable:** easily taken advantage of by others around money

- ❖ **impulse control:**
 - may have trouble with credit card or ATM
 - may not be reliable working with cash

“When Jim missed his bus, he decided to run to work so he’d get there as fast as he could. He arrived an hour late for work, out of breath and sweaty. Had he waited for the next bus, he would have arrived 10 minutes late for work. His boss, knowing about his condition, thanked him for making the extra effort to get to work as fast as he could.”

what you might try

Cues

- ❖ **help plan ahead** about what to do when -- write the schedule for the day down – use symbols
- ❖ **prepare for upcoming transitions**
- ❖ **anticipate and prevent problems** by sitting down at the beginning of the day to **review** what’s coming when

Attitude

- ❖ **look for successes** and recognize them

Repetition

- ❖ **at the end of an activity**, review what happened and declare it done before moving on

Environment

- ❖ **post schedules** and use **calendars and timers** – pictures as well as words

Structure

- ❖ **supervise spending:** provide money needed for each day at beginning of day. Avoid ATM cards.
- ❖ **trusteeship:** arrange for monthly cheques to go to a trustee or direct deposit

3. thinking and behaviour

what you might see

- ❖ **meaning not always connected to words:** someone affected by FASD may use lots of words, but doesn't seem to connect words with meaning or action
- ❖ **hyperactive:** has trouble sitting still
- ❖ **gaps in memory:** memory skills are often affected by FASD. You might see:
 - forgetting or losing things then making up stories to fill in the gaps
 - knowing something one day but not the next but may know it again a few days later
 - ability to read words but not understand them
 - what seems like "lies", but with no intent to be dishonest (sometimes this is referred to as "confabulation")
- ❖ **learning limited:** repetition of behaviour patterns without learning -- they may make the same mistakes over and over no matter how many times they suffer as a result
- ❖ **impulsive:** behaviour can be impulsive. They may say "I knew I shouldn't do it, but I couldn't help myself"

what you might try

Cues

- ❖ *be your client's "external brain": help them make lists and decisions and keep step by step instructions*
 - ❖ *use **pictures** as reminders, for example on drawers so they can see where dishes go*
 - ❖ *teach "**self-talk**" to help stay focused, for example: "first, I have to do ..." and to stop impulses "stop and think"*
- ❖ **agree on signals** provide him/her with a signal to show when a time out is needed
- ❖ **think ahead:** give time to adapt to a change

attitude

- ❖ *let go of **blame***
- ❖ *be prepared to **move in to intervene***
- ❖ *let go of **frustration***

what you might see

- ❖ **striking out:** may strike out with words or physically -- sometimes with apparent little reason
- ❖ **change can be difficult:** changes in routine can be confusing or upsetting -- even ones that peers find exciting
- ❖ **no action may indicate confusion:** may seem to be unmotivated or lazy when they really do not understand what is going on
- ❖ **cause and effect:** may have trouble connecting cause and effect or seeing how their actions led to results; may not easily make connections from one situation to another
- ❖ **over-stimulation can be stressful:** can be easily distracted and overwhelmed by noise, commotion, or stress
- ❖ **all or nothing:** all or nothing patterns or black and white thinking, leading to extremes in behaviour, such as obsessive thinking patterns

"I know I have to pay bus fare on the #18 bus, but I didn't know I had to pay on the #2"

what you might try

Repetition

- ❖ use **simple language and reminders**, such as the use of "stop" hand signal, to help change problem behaviours.
- ❖ Don't use figures of speech or sarcasm
- give **immediate feedback** and consequences

Environment

- ❖ **minimize visual stimulation** such as lots of colours, posters particularly in eating and sleeping areas

Structure

- ❖ provide **close supervision** and move in immediately, to defuse situations
- ❖ be **specific and concrete**
 - ❖ keep **activities brief**

4. relationships

Relationships with others can sometimes be a source of stability for people affected by FASD. They can bring a sense of joy and spontaneity to others. Having friends and being accepted by others is as important or even more important for someone affected by FASD as it is for anyone else. However, sometimes they do things that lead such important relationships to end.

what you might see

- ❖ **vulnerable:** learning and memory can be limited, s/he can be easily hurt and taken advantage of
 - can be sensitive and caring
 - can be easily bullied and victimized
 - want to be accepted by peers
- ❖ **boundaries:** don't understand personal boundaries and ownership
 - may be overly friendly and not see the difference between friends and strangers
 - behaviour may be seen as bugging people, going too far, or acting silly
 - may take things that don't belong to him/her
 - may touch others inappropriately
 - unable to "take a hint", even when others say things pretty directly such as "I'm getting angry"
 - at work, they may overstep boundaries (such as rank)
- ❖ **responsibility:** tend to see whatever happens as someone else's fault -- don't see their own responsibility in what happens

what you might try

Cues

- ❖ *when touching inappropriately, or not reading someone else's signals, give **immediate feedback** and explain what happened*

attitude

- ❖ *help the client take the other person's point of view*

repetition

- ❖ *if a client takes something that doesn't belong to them, **simply state** "This ... belongs to ..." and return the object*

Environment

- ❖ *use individual chairs rather than couches in the common area*

Structure

- ❖ **protect everyone from harm:** *don't put someone affected by FASD in a situation where they could inadvertently take something or hurt someone else*
- ❖ **don't leave items** *lying around*

how to help build social skills

Build skills in the place where the skill will be used. Use a 3-step process to build skills.

1. **modelling** -- show by doing yourself
2. **practice with guidance** -- explain how this will help and encourage him/her to try. Be beside and giving immediate feedback while s/he's trying. Be prepared to do this over and over.
3. **reinforcement of behaviour** -- watch her/him in real life and when s/he uses the new skill, point it out and praise. Do this repeatedly and often.

The **key skills** to build in working with people who are on the street are:

- how to get someone's attention
- how to handle frustration, disappointment and fear
- how to ignore someone who is bothering you
- how to negotiate for what you want
- how to accept criticism
- how to show someone you like them

5. secondary disabilities: mental illness and substance use

Many people affected by FASD who are using services for the homeless have "secondary disabilities" like mental illness and substance use problems. These conditions have developed often as a result of growing up in a world that doesn't understand FASD and doesn't offer the right kinds of support.

what to be alert for

- ❖ **usual signs:** an increase or worsening of depression, anxiety, mood swings, suicidal thoughts or compulsive behaviours
- ❖ **more confusion** or memory problems than usual
- ❖ **changes in personal hygiene**, health or weight
- ❖ **dropping out** of activities, avoidance of others
- ❖ **unusual budgeting problems** with panic attempts to get money
- ❖ **trouble with the law**
- ❖ **unusual aggressive** or bizarre behaviour involving conflict with others
- ❖ **inappropriate sexual behaviour**
- ❖ **changes in alcohol and drug** use. Be on the lookout for syringes and pill bottles containing street, prescription and over the counter medication, use of alcohol and alcoholic products such as mouth wash and shoe polish
- ❖ **loss of job or housing**

your advocacy skills are needed

- ❖ **help others understand:** don't assume that family members, community members such as bank staff, police officers, store personnel or others know what to expect from or how to support someone who's affected by FASD. Help them interpret behavior and understand your client's needs.
- ❖ **find out about resources:** know what resources are available in your area and how to refer. Think about how you might help your client access, for example: supported housing, assisted employment and job coaching, personal supports for shopping, banking and home management.
- ❖ **explain your concern** to your client and describe what you'd like to do to assist them to get help. They may be relieved to think that the difficulty they've been having all their lives may be due to a medical condition.
- ❖ **provide orientation with referral:** when referring someone affected by FASD, make an appointment with the other professional to orient them to the client and their particular strengths and limitations -- don't assume they know; negotiate with the professional for an advocate to be welcome to all appointments.
- ❖ **arrange an advocate or be there as one yourself:** arrange for your client to be accompanied by an advocate to appointments; make sure the advocate writes down what happened and instructions for follow up and reviews with client.
- ❖ **if appropriate, engage case management:** People affected by FASD often have a number of people involved in helping them, including: family members, community health workers, outreach workers, addictions treatment workers, physician, probation officer, and others. "Wraparound" and other forms of case management have been very helpful in providing ongoing and co-ordinated support to people affected by FASD. Start by checking to see if there are other workers involved with this person and arrange to meet with them.

6. the environment

This section addresses the physical environment – the building where your program is located. It also addresses the “social” environment – family, friends and community.

If your program is designed for people who are homeless or at risk of homelessness, chances are you will have several clients who are affected by FASD. Here are some tips for designing programs. These tips are also applicable to housing and employment situations.

❖ **the daily plan should include:**

- **consistent routines for each activity within schedule** -- the same sequence of tasks for each activity
- **start each day with a schedule review** -- identify what’s going to be the same and what’s going to be new today. If there’s going to be a change in the schedule, let the person know as soon as possible
- **a few simple rules** -- use language that is concrete *“Cigarette break is at 10:30”*. Keep consistent and immediate consequences for breaking rules
- **prepare for transitions** -- when a new activity is coming up, let him/her know how much time is left before it starts - *“Expect a breakdown if you move the smoking area”*

❖ **the facility and room:**

- **provide acceptable options for repetitive movement**, such as a rocking chair while the individual is reading or learning about a new activity
- **calm the mood** (as much as possible) avoid fluorescent lights where possible (*their buzzing noise is distracting*) and replace with full spectrum lights, soothing colours
- **minimize clutter** by helping clients to keep room clean and free of junk – may take daily checks by staff to enforce
- **have a quiet area** to use when the person is over-stimulated
- use **cues**, such as tape on the floor and pictures on drawers to give reminders about what goes where

calming colours

soft yellow
soft green
sage green
light orange
light green
blue green
peach,
salmon orange
brown
white is not recommended due to glare effect

“At the shelter, we had to work with Sarah to help her understand that when staff had the office door closed, they were busy and not to be disturbed unless there was an emergency. We asked her to go and wait on the chair downstairs until one of us came to get her.”

- A worker in a busv shelter

❖ **Family and friends**

Many adults who are affected by FASD and who are homeless have lost contact with family and friends, but some may still have contact or may, in adulthood, be renewing contact with family.

- **Helping understanding:** FASD may be a particularly difficult condition for a family to accept, particularly the biological mother, who may feel responsible.
 - It's not essential to name the condition, only to help people who are in your client's life better understand what to expect and how to help.
 - You could talk about what you've found helpful in working with your client – introduce basic concepts such as:
 - They need help to remember the most basic things – cues and pictures, timetables help
 - One day you might think they remember and the next day it's gone
 - When it may seem that they aren't co-operating or are being sneaky, it may be that they just don't understand
 - They need support in housing and activities of daily life.

❖ **Community:**

Within neighbourhoods and small communities, the more people who understand what to expect from your client and how to help, the better. Think about who they will be in contact with on a regular basis and seek your client's permission to talk to people about what to expect and how to help. Labels about the condition are not important. You don't even need to use the term "FASD". Think about educating:

- Neighbours
 - Landlord
 - Confectionary store staff
 - Taxi drivers and bus drivers
 - Bank personnel
 - Police
 - Probation officers
 - Ambulance
 - Hospital emergency staff
 - Doctors
 - Outreach workers
 - Natural community leaders (such as faith leaders, people who have large friendship networks)
 - Local restaurant and bar owners and staff.
- If there are several people in your community who may be affected by FASD, you may want to consider organizing something to publicize how FASD affects adults as well as children. Bring a speaker to town and invite key people to come; get the local newspaper to run a story about it.
 - Connect your client with services that may provide needed support.

7. housing

For someone affected by FASD, having a consistent, predictable and calm environment is very important to coping with their condition. Living in shelters, or living rough is likely to be disorienting to someone affected by FASD. As Tina Antrobus notes³,

- Housing is essential to be able to do any further programming around, for example, addiction or employment. If housing is unstable, all other programming will break down.
- For people affected by FASD, supportive housing is needed, including round-the-clock support from people knowledgeable with FASD. They should provide support in money management, cooking and food security, health, medication, housekeeping, maintenance.
- A zero tolerance policy (particularly around substance use) does not work for people affected by FASD – guidelines should be individualized to each resident.

³ Tina Antrobus (2004) *personal communication*

what you might see

accessing housing

- may not understand how to access housing leading those affected by FASD to seek shelter under bridges and abandoned buildings or become chronic shelter users
- may have a hard time securing housing because they have no credit, job credibility or co-signer

maintaining housing

- may forget when rent is due
- may impulsively spend rent money on something else

neighbours

- may have unrealistic expectations of neighbours *i.e. knock on door and want to watch TV with the people next door*
- may trespass - going into other people's backyards or entering into another's private space leading to interaction with the police
- may be overly friendly or hostile, leading to neighbours avoiding them or taking advantage of them
- may inappropriately interact with children including sexual approaches

what you might try

Cues

rent reminders: give reminders about when rent is due -- one week, 4 days then 2 days in advance, then a reminder on due date; have a consistent reminder schedule each month

cleaning instructions and reminders: give consistent reminders about storing garbage, food and "cleaning" their room. "Cleaning" needs to be described step-by-step *i.e. wash the floor with soap and water and when you're done that, look on the fridge to find out what step 2 is...*

label belongings: Mark and label personal belongings clearly

landlord tips: provide a list of when they can call the landlord for help, and what for

attitude

"Interdependence" rather than "independence" is a realistic goal for people more affected by FASD.

repetition

Model behaviour: For the first while, go side by side with your client while they go through their daily routine. Model appropriate behaviour, for example, with neighbours.

what you might see

sanitation

- may have rotting food due to difficulty understanding how to properly store food
- living space may be dirty with garbage piling up - may not understand how to clean, garbage schedules

house-mates

- may often change house-mates
- may choose inappropriate house-mates -- frequently fighting with them or becoming their victim

landlord relations

- may be confused about how to treat the landlord -- and consider him or her a friend who can lend money, or share a meal, etc.
- may not understand landlord/tenant responsibilities and relationships
- may have a pattern of frequent eviction
- unable to understand when they have been wrongly evicted or where to seek help

what you might try

Environment

- ❖ The **ideal housing** situation for someone affected by FASD would include:
 - ❖ structured setting
 - ❖ small group
 - ❖ communal meals and responsibilities
- ❖ some ongoing supervision, advocacy and support provided by staff trained in the challenges of FASD

Structure

- ❖ **Firm boundaries with housemates** -- support them to set firm boundaries at the start
- ❖ Some people are able to live on their own with **ongoing** supports. They will need:
 - ❖ **financial support:** a system for guaranteeing payment of rent such as direct payment or trusteeship
 - ❖ **housing advocacy:** help to find housing and develop agreements with landlord
 - ❖ **orientation for the landlord** about how to interact with their new tenant
 - ❖ **ongoing support in landlord/tenant relations** and/or in roommate and neighbour relations
 - ❖ **training and ongoing support in basic life skills** such as shopping, cooking, transportation, laundry and personal hygiene as well as time and money management

8. employment

what you might see

Some people may be capable of keeping a job, if the job is appropriate and they and their employer are provided with support all along the way. The support required is long-term and ongoing.

Finding a Job

- may have trouble finding a job, as most will have few academic qualifications

Handling Cash

- may not be able to give proper change
- may be tempted to take cash

Being on Time

- may often be late, take unscheduled breaks or leave at the wrong time
- may miss shifts or come to work at the wrong time

"Fred was a likeable guy who was affected by FASD. With the help of a job coach, he'd been working on a construction site for a month. His boss, Ted, noticed that whenever he gave Fred a ride in the truck, any small change that he had on the dashboard would disappear. Once he noticed that, he stopped leaving small change lying around.

what you might try

Cues

- ❖ **timing reminders** give reminders of when break time is over, and when the work day is over
- ❖ **job roles:** give clear list of what they are expected to do in their job. Be prepared to repeat examples and directions often. Each task may need to be described in steps with pictures and diagrams.

attitude

- ❖ **help colleagues** to understand FASD
- ❖ **help the client** have the words to explain how FASD affects them and what's helpful

repetition

- ❖ **on the job training** and daily repetition of routines is important

environment

- ❖ **limit access** to money or other things that the individual is susceptible to not being able to handle

Structure

- ❖ **A vocational service** with experience working with people affected by FASD is needed to match the individual to the right job. The service should provide:
- ❖ **employability assessment** and screening to identify interests and skills
- ❖ **education and outreach to employers** to recruit people willing to work with people affected by FASD

what you might see

Getting Along with Co-Workers

- may have outbursts and tantrums when work tasks and routines are changed without warning
- may overstep boundaries with other employees or management

Getting Along with the Public

- may not be able to talk with customers appropriately i.e. *may act silly, mimic or respond negatively; may ask a customer for a cigarette*

❖ what you might try

❖ **S**tructure (continued)

- ❖ ***a menu of employment options*** with FASD friendly employers
- ❖ ***task analysis of available jobs*** -- that breaks down duties into simple, manageable steps
- ❖ ***matching -- individual to opportunity*** this should include job placement, which involves multiple trials of work to identify the best placement
- ❖ ***on-site job training, coaching and support*** (pre-vocational preparation is less useful to people affected by FASD)
- ❖ ***wrap-around support*** involving links with other community agencies as well as supportive neighbours, family members and friends
- ❖ ***follow-along support to employee, employer and co-workers***, with periodic assessment, for as long as required (usually ongoing)

E. Summary of Key Messages

It's a Spectrum: No two people affected by FASD will show the same behaviour. Some people will be affected mildly and will develop creative ways to accommodate to their condition. Others will be significantly affected and will need the kinds of supports we've been describing here.

A Diagnosis may not be Available: Don't wait for a diagnosis to start trying some of the strategies in this manual. Many people affected significantly with FASD are not diagnosed. A diagnosis won't lead to a cure. It can lead to more appropriate expectations -- of self and from others. It can also open the door to services. The longer a person lives with significant impacts from FASD without appropriate support, the more likely it will be that they will develop secondary disabilities such as mental illness and substance use.

Get Curious: Because there's no one pattern of challenges faced by people affected by FASD, the best way to work with someone is to get curious and see what you can observe about how they're experiencing the world.

Be Prepared to Try Differently: Someone who's severely affected by FASD will not be able to learn in a reliable way -- it is not realistic to expect them to change. It's up to us to change what we are expecting and how we're offering support. It's up to us to work with others to help them understand too.

Specifically, you can:

- ❖ ***try differently*** by using
 - cues
 - attitude
 - repetition
 - environment
 - structure and supervision.
- ❖ ***help others try differently*** by
 - explaining what you know to colleagues and help your team members see other ways of working
 - accompanying the client to professional appointments and taking time with each referral to explain FASD and what you've found helpful
 - educating policy makers about how essential supportive housing and employment are for people significantly affected by FASD.

D. glossary

Alcohol Related Neuro-Developmental Disorders (ARND) describe the functional and mental impairments caused by prenatal alcohol exposure. Individuals with ARND display behaviour and learning difficulties indicative of central nervous system damage but do not usually have the physical characteristics or disabilities. It is widely accepted that ARND is the most common within the spectrum. These individuals often have normal or above-normal IQ's and lack the characteristic facial features. Due to the invisibility of their disability they are often not properly assessed or diagnosed.

Alcohol Related Birth Defects (ARBD) are the malformations in the skeletal and major organ systems caused by prenatal exposure to alcohol.

Concurrent Disorders Individuals with Fetal Alcohol Spectrum Disorder may also have concurrent disorders, i.e. a second condition in addition to the alcohol related developmental disorder. The primary cause, organic brain dysfunction (brain damage due to prenatal exposure to alcohol), may go unrecognized. The most common co-existing diagnoses are:

- < Attachment Disorder
- < Attention Deficit/Hyperactivity Disorder
- < Autism
- < Oppositional Defiant Disorder
- < Sensory Integration Dysfunction
- < Language Learning Disorder
- < Conduct Disorder
- < Developmental Delays

Fetal Alcohol Effects (FAE) is a term that is used to describe individuals who do not show all the signs of FAS (usually the characteristic facial features observed in those with FAS as described below are absent).⁴

Fetal Alcohol Spectrum Disorder (FASD) is a term that describes the range of clinical conditions associated with prenatal exposure to alcohol. It is not a diagnostic term. Alcohol related developmental disorders are not genetic or inherited – they are the result of prenatal exposure to alcohol.

⁴In 1996 the American Medical Institute replaced FAE with ARND, pFAS and ARBD.

Fetal Alcohol Syndrome (FAS) is a medical diagnosis and the most easily diagnosed alcohol related developmental disorder. Individuals with FAS display characteristics from three areas:

- ❖ characteristic facial features including a flat looking face, thin upper lip, wide set eyes and a wide groove in the upper lip,
- ❖ small growth both pre and post-natally (height and weight) and,
- ❖ damage to the central nervous system which is indicated by poor fine and gross motor control, poor impulse control, behavioural and learning impairments.

FAS is considered the most common preventable/non hereditary cause of developmental delays. Most individuals with FAS function in the borderline or slow learner range.

Partial-FAS (pFAS) is a term used to describe some but not all of the physical features found in FAS, as well as learning and behavioural problems suggesting central nervous system damage.

E. resources

1. top resources relevant to FASD and homelessness

Websites

Heath Canada

www.hc-sc.gc.ca/english/lifestyles/fas.html

BC Ministry of Education - Special Education (which can be adapted for adults)

www.bced.gov.bc.ca/specialed/ppandg/toc.htm

Canadian Centre on Substance Abuse

www.ccsa.ca

Calgary Fetal Alcohol Network

www.calgaryfasd.com -- document summarizing best practices in support of adults affected by FASD.

Publications

Ontario Federation of Indian Friendship Centres, *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects (2002)* www.ofifc.org

Malbin, D. (1993). *Fetal Alcohol Syndrome/Fetal Alcohol Effects: Strategies for Professionals*. Center City: Minnesota; Hazelden Educational Materials.

Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living, 2nd Edition, revised and updated by Sara Graefe, Society of Special Needs Adoptive Parents (SNAP), British Columbia: Victoria, 1994. ISBN: 0-9698617-2-9.

Streissguth, A. & Kanter, J. (1997). *The Challenges of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. Seattle and London: University of Washington Press.

2. canada's diagnostic centres

Note: The following is contact information for FASD clinics with mutlidisciplinary teams that provide diagnostic services. It is up to date as of September 1, 2004. There are several similar clinics preparing to open across Canada; this list should be updated on a regular basis.

Clinic	Contact Information
British Columbia	
Asante Centre for FAS	22326 (A) McIntosh Ave, Maple Ridge, BC V2X 3C1 Contact: Audrey Salahub E-mail: asalahub@asantecentre.org URL: www.asantecentre.org Tel: (604) 467-7101
Children's and Women's Health Centre of British Columbia;	4500 Oak Street Vancouver, BC V6H 3V4 Contact: Dr. Christine Loock E-mail: cloock@cw.bc.ca Tel: (604) 875-2000
Sunny Hill Health Centre	3644 Slocan Street Vancouver, BC V5M 3E8 Contact: Dr. Christine Loock E-mail: cloock@cw.bc.ca Tel: (604) 453-8300
Alberta	
Alberta Children's Hospital	Alberta Children's Hospital 1820 Richmond Road S.W. Calgary, Alberta T2T 5C7 Contact: Dr. Margaret Clarke E-mail: Margaret.clarke@calgaryhealthregion.ca
Glenrose Rehabilitation Hospital	11132 102 ST NW, Edmonton, AB T5G 2M3 Contact: Dr. Gail Andrew E-mail : gandrew@cha.ab.ca
Lakeland FAS Clinic	Box 479 Cold Lake, AB T9M 1P1 Contact: Audrey MacFarlane E-mail: pwfascen@telusplanet.net URL: www.lakelandfas.com Tel: (780) 594-9905 Toll Free #: 1-877-594-5454 Fax: (780) 594-9907
Saskatchewan	

Clinic	Contact Information
Saskatoon	Alvin Buckwold Child Development Program, Kinsmen Children's Centre, 1319 Colony St, Saskatoon, SK S7N 2Z1 Contact: Dr. Patricia Blakley E-mail: patricia.blakley@saskatoonhealthregion.ca Tel: (306) 655-1070
<i>Manitoba</i>	
Clinic for Drug and Alcohol Exposed Children (CADEC)	Children's Hospital CK 275840 Sherbrook Street Winnipeg, Manitoba R3A 1S1 Contact: Mary Cox-Millar E-mail: mmillar@hsc.mb.ca Tel: (204) 787-1822 Fax: (204) 787-1138
Thompson	Contact Info: Leigh Wincott email: lwincott@brha.mb.ca
<i>Ontario</i>	
Toronto Hospital For Sick Children	Motherisk Program 555 University Avenue, Toronto, ON M5G-1X8 Contact: Dr. Gideon Koren E-mail: gkoren@sickkids.ca Tel: (416) 813-7500
St. Michael's Hospital	FASD Diagnostic Clinic 61 Queen Street Toronto, ON M5B 1W8 Contact: Brenda Stade Tel: (416) 864-6060 ext. 8275
<i>Newfoundland and Labrador</i>	
The General Hospital, Health Sciences Centre	Janeway Child Health Centre 300 Prince Philip Drive, St. John's, NF A1B 3V6 Contact: Dr. Ted Rosales E-mail: torosales@nf.sympatico.ca Tel: (709) 777-4345 Fax: (709) 777-4190

3. other materials

FAS and Law Enforcement Power Point Presentation & Training Manual:

A 4-hour power point presentation covering FASD – definitions, features, characteristics, strengths, effects and influencing factors and more. FASD & the law – Canadian Charter of Rights and Freedoms, statements, case law, investigations, restorative justice and more, and **A Community Approach** – networking, prevention, resources.

FASD Train the Trainers course: A 2-day course created for experienced instructors on FASD. Officers with this training are required to partner with health or FASD workers in their respective communities and deliver FASD training to fellow police officers and community partners.

Different Directions: Includes cassettes, videos and a training manual -- contact Laura Whelan, Our Children Our Future

4. organizations and agencies

Contact information for the following organizations and agencies is up to date as of September 1, 2004.

Canadian Centre for Substance Abuse

75 Albert Street
Suite 300

Ottawa, ON
Canada K1P 5E7
T: (613) 235-4048
F: (613) 235-8101

www.ccsa.ca

The Canadian Centre on Substance Abuse (CCSA), Canada's national addictions agency, was established in 1988 by an Act of Parliament. CCSA provides a national focus for efforts to reduce health, social and economic harm associated with substance abuse and addictions.

national resources

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)

Web Site: 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, counselling 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 pediatricians. 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 Web Site: 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 Web Site: 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 Web Site: www.cich.ca

Services: Funded through Health Canada's FAS/FAE Strategic Project Fund, FASE out 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.

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); (613) 235-4048, ext. 223 Fax: (613) 235-8101

E-mail: fas@ccsa.ca Web Site: www.ccsa.ca/fasgen.htm

Services: Through its National Clearinghouse on Substance Abuse, information resources are provided in answer to individual requests through the 1-800 number, fax, email and written request. Since April 2003, the National Database of FAS and Substance Use during Pregnancy Resources have been available. Funded through Health Canada's FAS/FAE Strategic Project Fund, this is a database of Canadian resources that have been authored, produced or published in Canada or that have Canadian content but have been published outside of Canada and are currently available to be ordered or purchased from the organization responsible. Search the database at www.ccsa.ca/fas.

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 Web Site: 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.

Health 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 Web Site: 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.

Centre for Addiction and Mental Health (CAMH)

Ms. Sheila Lacroix, Library Coordinator
Library
33 Russell St.
Toronto ON M5S 2S1
Tel: (416) 535-8501, ext. 6982 Fax: (416) 595-6601
E-mail: sheila_lacroix@camh.net; library@camh.net Web Site: www.camh.net

Services: With the back-up of an extensive collection of resources on the topics of Alcohol and Pregnancy and FAS/E, the CAMH Library reference service responds to requests for information and referrals from professionals, students and the general public. In addition, many of the library resources are available through inter-library loan within Canada.

ontario resources

FASAT (Ontario)

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 Web Site: 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.

FASD Aboriginal Support Group

Ms. Marja George, R.N.

Kettle and Stony Point Health Center

P.O. Box 670

Forest ON N0N 1J0

Tel: (519) 786-5647 Fax: (519) 786-4541

E-mail: marjag@ksphs.on.ca

Services: Provides support and information to families and individuals affected by prenatal alcohol exposure. Support group meetings are held on the last Thursday of each month.

FASD Durham

Ms. Marian Cook

6 Hogan Cres.

Bowmanville ON L1C 4X9

Tel: (905) 697-9064

E-mail: bcook0459@rogers.com

Services: FASD Durham provides training to service providers and parents and works within the community to meet the needs of children with FAS in the Durham Region; also coordinates a parent support group and the development of an identification and assessment team for Durham Children & Youth.

Allan Mountford, B.A., B.P.E., M.Ed

106 Coleman Crescent,

Janetville, ON L0B 1K0

Tel: (705) 324-7801

E-mail: mountfrd@allstream.net

Services: Fetal Alcohol Spectrum Education Support provides support to educators and parents of children affected by FASD. From individual advocacy to Professional Development, the objective of FASES is to increase awareness of the pedagogical & behavioural implications of FASD and to provide educators with a paradigm and strategies to maximize the school experience for a student affected by FASD

FASD Ontario Region Lead

Ms. Sharri Kimberley

Healthy Child Development Team

55 St. Clair Ave. East, 3rd Flr.

Toronto ON M4T 1M2

Tel: (416) 973-5659; (905) 690-7913 Fax: (905) 690-7917

E-mail: sharri_kimberley@hc-sc.gc.ca

FASlink (Fetal Alcohol Spectrum Disorders Information, Support &

Communications Link)

Mr. Bruce Ritchie , Moderator
2445 Old Lakeshore Rd.
Bright's Grove ON N0N 1C0
Tel: (519) 869-8026 Fax: (519) 869-8026
E-mail: fas@acbr.com Web Site: www.acbr.com/fas

Services: FASlink is a moderated email discussion group that provides support and information for individuals, families and professionals who are working with and caring for those affected by prenatal alcohol exposure. FASlink serves more than 200,000 visitors to its website annually. The FASlink Archives contain more than 70,000 letters and articles on FAS issues. FASlink's online discussion forum is the primary Canadian FAS communications network and includes members worldwide. FASlink publishes the FASlink CD-ROM and FAS InfoDisk (for download from the website). To join the list serv, send an email message to: majordomo@listserv.rivernet.net and, leaving the subject line blank, type -- subscribe faslink -- in the body of the message.

FASworld - Hamilton and District

Ms. Margaret Sprenger, President
#2 - 241 Queen St. South
Mississauga ON L5M 1L7
Tel: (905) 821-1590
E-mail: margsprenger@sympatico.ca

Services: FASworld - Hamilton and District supports individuals and families affected by FASD, holds monthly meetings in Hamilton, disseminates knowledge and understanding of FASD and assists in the establishment of FASD diagnostic centers. You may also contact Rick and Martha Bradford at (905) 578-9091 or Barry and May Stanley at (905) 849-3860.

Ontario

FASworld Toronto

Ms. Mary Cunningham, President
Brian Philcox, Executive Director
1509 Danforth Ave.
Toronto ON M4J 5C3
Tel: (416) 465-7766 Fax: (416) 465-8890
E-mail: fasworldcanada@rogers.com Web Site: www.fasworld.com

Services: Originally founded as Fetal Alcohol Support Network (Metropolitan Toronto and Peel), the group has changed its name in order to become the first chapter of FASworld Canada. The group meets on the second Saturday of the month at St. Michael's Hospital in Toronto in order to support families with members struggling

affected by FASD. Membership is open to parents, care givers, professionals and others interested in FASD prevention. Call Brian for further information.

Fetal Alcohol Information Support Network

Ms. Theone Collins

P.O. Box 20022

150 Churchill Blvd.

Sault Ste. Marie ON P6A 6W3

Tel: (705) 946-0638 Fax: (705) 946-3004

E-mail: the1collins.fassm@sympatico.ca Web Site: www.soonet.ca/faisn

Services: The Network undertakes activities to help prevent alcohol related birth defects and provides support and information to those affected.

Fetal Alcohol Spectrum Disorder (FASD) Program

Ms. Maureen Parkes, FASD Coordinator

NorWest Community Health Centres

525 Simpson St.

Thunder Bay ON P7C 3J6

Tel: (807) 622-8235 Fax: (807) 622-3548

E-mail: fas@norwestchc.org

Services: The program provides support for families, individuals of all ages and offers education to families and professionals in the community and offers non-medical assessments, resources, training, and advocate for programs and services for individuals affected by FASD. Referrals are made as necessary for clients to various organizations in the area.

Fetal Alcohol Spectrum Disorder Group of Ottawa

Ms. Elspeth Ross, Co-facilitator
Jill Courtemanche, Co-facilitator
Box 915
Rockland ON K4K 1L5
Tel: (613) 737-1122; (613) 446-4144 Fax: (613) 446-4144
E-mail: rosse@freenet.carleton.ca

Services: The group provides support for families, and information and education for families and professionals on the effects of alcohol on people of all ages, and importance of prevention. Monthly meetings are held from October to June at the Children's Hospital of Eastern Ontario (CHEO). Please contact Elspeth Ross for further details.

Fetal Alcohol Support and Information Network (F.A.S.I.N.)

Mr. & Mrs. Dave and Margie Fulton
P.O. Box 100
Murillo ON P0T 2G0
Tel: (807) 935-3168 Fax: (807) 935-2198
E-mail: fulton@northroute.net

Services: F.A.S.I.N. provides support for families and individuals affected by FASD, education and training for professionals and the general community and a resource library for families, students and professionals.

Fetal Alcohol Syndrome Treatment and Education Centre Inc.

Ms. Jill Dockrill
202 Farley Ave.
Belleville ON K8N 4L5
Tel: (613) 968-8129 Fax: (613) 968-5263
E-mail: jillfastec@netscape.net

Services: This is a registered nonprofit organization with a mandate of awareness and prevention of FAS and advocacy for programs and services for individuals affected by prenatal alcohol exposure and is currently working towards establishing a Supportive Living Environment and Education Centre. A support group for primary caregivers, parents and individuals with FAS/FAE called 'Circle of Friends' meets off-site, the first Tuesday of every month.

Healthy Generations Family Support Program

Ms. Judy Kay
Sioux Lookout and Hudson Association for Community Living
Box 1258
Sioux Lookout ON P8T 1B8

Tel: (807) 737-1447, Ext. 224 Fax: (807) 737-3833
E-mail: healthy@slhacl.on.ca Web Site: www.slhacl.on.ca/fasd

Services: Healthy Generations Family Support Program provides services to families raising children affected by FASD.

FASD Network of Sudbury

(info to be inserted (Laura Whelan))

Kenora and area FAS/FAE Committee

Ms. Patti Dryden Holmstrom

c/o Addiction Services Kenora Youth Program Lake of the Woods District Hospital
12 Main St. South

Kenora ON P9N 1S7

Tel: (807) 467-3575 Fax: (807) 468-6093

E-mail: pdryden@lwdh.on.ca

Services: The Committee undertakes activities related to prevention and community awareness.

Motherisk, Hospital for Sick Children

Dr. Irena Nulman, Associate Director

555 University Ave.

Toronto ON M5G 1X8

Tel: (416) 813-7887 Fax: (416) 813-7562

E-mail: inulman@sickkids.on.ca

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

Native Child and Family Services of Toronto

201 - 464 Yonge St.

Toronto ON M4Y 1W9

Tel: (416) 969-8510 Fax: (416) 969-9251

Services: The following programs are available: Youth with FAS Support Group offers traditional and contemporary approaches to support aboriginal youth affected by FASD between the ages of 16-24; Children affected by FASD five day summer camp offers a safe and structured environment for children between the ages of 8 - 12, providing respite for caregivers; Parents affected by FASD Support Group is offered once a week and provides ongoing support for parents living with FAS (diagnosed or undiagnosed); Parenting Children affected by FASD is a ten week session that looks at education, behavioural and environmental techniques for caregivers and parents.

New Choices

Ms. Marilyn J. Guest, Program Manager
138 Herkimer St.
Hamilton ON L8P 2H1
Tel: (905) 522-5556 Fax: (905) 522-6046
E-mail: mguest@interlynx.net

Services: New Choices is an innovative, collaborative, inter-agency program that offers single access services of information, support, treatment and advocacy to women who are pregnant or parents of young children (0-6 years). The goal of the program is to empower women to make new choices that will reduce the incidence and impact of child development delays caused by prenatal exposure to drugs/alcohol and/or the impacts of a woman's poverty, substance use, mental health, and abuse survivor issues upon her ability to optimally parent, provide and care for, her children. The flexible services are provided in a safe, welcoming environment and include parenting, lifeskills, social recreational, addiction/mental health, and child development assessment, education and therapy. Child care is provided on site.

North Bay Indian Friendship Centre

Mrs. Shelly Sawyer, FAS/FAE Child Nutrition Community Support
980 Cassells St.
North Bay ON P1B 4A6
Tel: (705) 472-2811, Ext. 27 Fax: (705) 472-5251
E-mail: ssawyer@nbifc.org; fas-fae@nbifc.org Web Site: www.nbifc.org

Services: The FAS/FAE Child Nutrition program provides one-on-one support, referrals to health care providers and programs that are offered at the Centre, awareness workshops and presentations and includes a nutritional component for the Aboriginal community.

Northumberland Family Respite Services Inc.

Ms. Yvonne Brydges, Director
72 Walton St., Suite 1
Port Hope ON L1A 1N3
Tel: (905) 885-6671 Fax: (905) 885-9758
E-mail: nfrs@eagle.ca

Services: This agency provides support to families of children with FAS/FAE through its respite care program.

Ontario Federation of Indian Friendship Centres

Ms. Kim Meawasige, FAS/FAE Policy Analyst
219 Front St. East
Toronto ON M5A 1E8
Tel: (416) 956-7575 Fax: (416) 956-7577
E-mail: kmeawasige@ofifc.org Web Site: www.ofifc.org

Services: This program will assist with FAS/FAE resources available to urban Aboriginal people in Ontario. It offers both a traditional and contemporary approach to FAS, on-site training and consultations as well as intervention, prevention and programming including community development regarding FAS/FAE.

Ottawa Children's Treatment Centre (OCTC)

Ms. Margo Belanger-Deleo, Intake Coordinator
René Walinga, Intake Administrative Support
395 Smyth Rd.
Ottawa ON K1H 8L2
Tel: (613) 737-0871; 1-800-565-4839 (toll free in Ontario) Fax: (613) 738-4841
E-mail: pahearn@octc.ca Web Site: www.octc.ca

Services: OCTC provides specialized bilingual ambulatory services to children, youth and certain adults with physical and/or developmental disabilities and their families. Clients eligible for the services at OCTC can receive, as required, diagnostic assessment, treatment, consultation and education from specialists like: physiotherapists; occupational therapists; speech-language pathologists; nurses; school, preschool and liaison teachers; psychologists; social workers; technical and medical specialists; developmental pediatricians; neurologists; psychiatrists; orthopedic surgeons; behaviour consultants, early childhood consultants and recreation therapists. Referrals are made to community resources as appropriate.

Sarnia/Lambton FAS/FAE Support Group

Ms. Deborah Dunn
388 Confederation St.
Sarnia ON N7T 2A8
Tel: (519) 336-1576 Fax: (519) 336-7150
E-mail: deb000@hotmail.com Web Site: www.rivernet.net/~fas

Services: The purpose of this group is to support, educate and inform. A poster is available for purchase entitled 'Give your baby the best possible start in life'.

South West Regional Fetal Alcohol Parent Advisory Group

Mrs. Susan Kampers

R.R. #3
23141 Thames Rd.
Appin ON NOL 1A0
Tel: (519) 289-0155 Fax: (519) 289-0635
E-mail: susan.kampers@sympatico.ca

Services: This group provides support and education to families with children diagnosed with FAS and is involved in public speaking within the community.

Thunder Bay Indian Friendship Centre

Ms. Kelly Hicks, Community Support Worker

401 North Cumberland St.
Thunder Bay ON P7A 4P7
Tel: (807) 345-5840, Ext. 253 Fax: (807) 344-8945
E-mail: kelly.hicks@shawcable.com Web Site: www.tbifc.com

Services: Provides support, information and education to families, professionals and community members on the effects of alcohol on people of all ages and the importance of prevention. Also provides referrals and support through the diagnostic process.

Timiskaming Brighter Futures

Ms. Darlene Grossinger

OR Pat Spadetto
6 Hudson Bay Ave.
Kirkland Lake ON P2N 2H4
Tel: Darlene: (705) 567-5626; Pat: (705) 567-5926 Fax: (705) 567-2466
E-mail: dgrossinger@timiskamingchildren.org; pspadetto@timiskamingchildren.org
Services: To speak to the prenatal worker, please contact Darlene or Pat as listed above or for Englehart: (705) 544-2422; North Cobalt: (705) 672-3333.

Union of Ontario Indians - Anishinabek Health Commission

P.O. Box 711
North Bay ON P1B 8J8
Tel: (705) 497-9127, Ext. 2296; 1-877-702-5200, Ext. 2296 (toll free in Ontario)
Fax: (705) 497-9135
E-mail: mcllau@anishinabek.ca

Services: Provides culturally-based training to aboriginal frontline workers located throughout the Anishinabek Nation. Four regional FASD program workers are available for First Nation workshops and health fairs. An FASD resource library is maintained and a number of culturally-based resources have been developed.

Waterloo FAS Support Group

Ms. Bonnie May

Regional Municipality of Waterloo Infant Development Program
P.O. Box 1612
99 Regina St. South, 5th Flr.
Waterloo ON N2J 4G6
Tel: (519) 883-2223 Fax: (519) 883-8102

Services: This is a support group for parents raising children suspected of prenatal alcohol exposure. Requests for information and for participation in workshops are responded to.

5. more resources

Presentation on FASD and Housing was shared by:

Tina Antrobus, B.A.
FASD Consultant
Connections - The Society Serving Adults with FASD
Email: tinaantrobus@shaw.ca

Burd, L. et al., (2003) Fetal Alcohol Syndrome in the Canadian Correction System. J FAS Int. e14. Toronto, On: The Hospital for Sick Children.

Canadian Pediatric Society Statement. (CPS). (2002). Fetal Alcohol Syndrome. *Pediatric Child Health, 7*(3), 161-174.

Grant, T. (1996). When case management isn't enough: A model of paraprofessional advocacy for drug and alcohol abusing moms. *Journal of Case Management, 5*(1), 20-29.

Kleinfeld, J., Morse, B. & Wescott, S. *Fantastic Antone Grows Up: Working with Adolescents and Adults with Fetal Alcohol Syndrome*. University of Alaska Press.

Malbin, D. (1993). *Fetal Alcohol Syndrome/Fetal Alcohol Effects: Strategies for Professionals*. Center City: Minnesota; Hazelden Educational Materials.

Mayer, L. (1999). *Living and Working with Fetal Alcohol Syndrome/Effects*. Interagency FAS/E Program: Winnipeg, MB. To order (204-582-8658).

Murphy, M. (1993). "Shut Up and Talk to Me". In J. Kleinfeld & Wescott (eds.), *Fantastic Antone Succeeds*. University of Alaska Press.

- Roberts, G. & Nanson J. (2000). *Best Practices: fetal alcohol syndrome/fetal alcohol effects and the effects of other substance use during pregnancy*. Canada's Drug Strategy Division, Health Canada.
- Streissguth, A. (1991). Fetal Alcohol Syndrome in adolescents and adults. *American Medical Association Journal*, 15, 265.
- Streissguth, A. & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. *Neuropsychiatry*, 5(3), 177-90.
- Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., (1996) "Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE)," Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06.
- Turpin, J. & Schmidt, G. (1999). *Fetal Alcohol Syndrome/Effects Developing a Community Response*, Halifax: Fernwood Press.

6. videos

FAS FORWARD: A Fresh Look at Fetal Alcohol Syndrome Alberta: Distribution Access, 2001. 30 min. Access/Alberta Learning, Canadian Learning Television, Program Sales and Distribution, 1-888-440-464-0440 - 7729 crystalh@incentre.net

Ray, Sadie, Naomi and Sindy live with Fetal Alcohol Syndrome. The media often portrays the situations of people with FAS to be hopeless. However these individuals, together with the support of people who love and care for them, lead rich and meaningful lives. Stories of hope, stories of compassion and love. The video explores some of the strategies and approaches that make a difference in these people's lives. It gives voice to those who live with the disability and others who support them. It also examines some of the very real challenges that FAS presents, and debunks some of the many myths and misconceptions that exist about the disability.

David with FAS (1996) Kanata Productions, National Film Board of Canada & CBC

A 45-minute video about David Vandenbrink, a 21-year-old man with FAS whose condition went undiagnosed for 18 years.

Video can be ordered by phone, (867)920-2644 or fax, (867)920-2348.

Fetal Alcohol Syndrome/Fetal Alcohol Effect: Stories of Help and Hope

Good for understanding brain differences related to presenting behaviors. Information and experiences from professionals, biological, foster, and adoptive parents, and adolescents who have prenatal alcohol exposure.

To Order Contact:

Hazelden 1-800-328-9000

Fetal Alcohol Syndrome: Life Sentence

Fetal alcohol syndrome is the result of permanent organic injury to the brain of the fetus, caused by maternal drinking during pregnancy. That injury leads to learning disabilities, poor judgment, antisocial behavior, and worse, if a recent study is correct. This program discusses FAS within the context of that study which suggests that 20 to 25 percent of all prison inmates may suffer from the condition. The program examines how early identification and treatment of children with FAS can help prevent extreme antisocial behavior in adulthood. (24 minutes, color).

To Order Contact:

Cambridge Educational's (1-800-468-4227)

Honour of All, Part 1 and 2; The Story of Alkali Lake (56:40 minutes)

Stripped of their native culture and religion after the coming of the white men, the people of Alkali Lake were left with a void in their lives that begged to be filled. Thus they were ripe for the introduction of the devastating force of alcohol. This story of heartfelt recovery from almost complete cultural and spiritual destruction is true. All the incidents depicted occurred between 1940 and 1985.

To Order Contact:

Four Worlds International Institute For Human and Community Development
Four Directions International
347 Fairmont Boulevard
Lethbridge, AB T1K 7J8
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Phone: (403) 320-7144

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Journey Through the Healing Circle; an innovative series on Fetal Alcohol Syndrome (2000)

Produced by the Washington State Department of Social and Health Services (DSHS)

"Journey Through the Healing Circle" is a series of videotapes, video CDs, and professionally illustrated workbooks. The series is narrated by Native American Storyteller Floyd Red Crow Westerman, who uses animal stories to talk about children with Fetal Alcohol Syndrome (FAS) and the problems families face with these effects.

"Journey Through the Healing Circle" is now available to parents, schools, and other social service agencies as a series of videotapes, video CDs, and professionally illustrated workbooks.

To Order Contact:

Washington State Alcohol/Drug Clearinghouse
3700 Rainier Avenue South, Suite A
Seattle, WA 98144

Telephone: (206) 725-9696 or (800) 662-9111

Fax: (206) 722-1032

Email: clearinghouse@adhl.org

"What is FAS?"

"What is FAS?" (24 min., 1990), is designed for families, educators and health care professionals and examines the cause, treatment and prevention of alcohol-related birth defects. Highlights include interviews with mothers and families of F.A.S. children, and commentary from international experts.

To Order Contact:

Altschul Group, 1560 Sherman Avenue, Suite 100, Evanston, Illinois 60201.
Tel. 1-800-323-9084 or 1-800-232-3263.

Worth The Trip

Worth the Trip is the first comprehensive video resource about the health, development and learning styles of children and adolescents affected by fetal alcohol. The film presents strategies for meeting the developmental and behavioral challenges faced by children and adolescents with FAS and the parents and professionals who care for them.

To order Contact:

Vida Health Communications
6 Bigelow Street
Cambridge, MA 02139
Telephone: (617) 864-4334
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What is FAS? (1989) Program 1

Preventing FAS (1989) Program 2

Living and Learning with FAS (1990) Program 3

Produced by BC FAS Resource Society

To Order Contact:

Available from Image Media Services

Phone: (604) 272-7797 Fax: 272-7798

F. articles

- Doug Anderson and Jennifer Wemigwans, "Healing with a Deep Heart: A Community-based Approach to Living with FAS/E", *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects: A Special Report by the Ontario Federation of Indian Friendship Centres* pp 6-12.
- Francis Perry, "Coming out of the Box", *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects: A Special Report by the Ontario Federation of Indian Friendship Centres* pp 20 - 25.
- Bonnie Buxton, "Society's Child" *Elm Street* (also appeared in *Reader's Digest*, March 2000, pp 114 - 120)