June 15 Youth Conference

- Coast Salish acknowledgment and welcome YW's et al.

- My background – resiliency – cultural enrichment, community centres (various programming and camps), adult role models, family involvement, school and sports, positive encouragement from family and adult role models, assistance and guidance when needed.

- Healthy connections are important.

- Ask the youth non-judgementally about what interests them (school, employment, leisure, future goals, etc); encourage and promote this, as youth are experts ...

- They may struggle to appreciate what's best for them. Ask them to examine the positives and negatives.

- Elders and the Aboriginal community says Aboriginal people when involved in their culture(s) and or spirituality (a belief system or not) are more likely to be successful and working towards their goals. This applies to all human beings. Client examples...

- Professor Dr. Martin Brokenleg recommends Youth to use 4 themes in order to be successful. They are: a sense of belonging; mastery, independence (and interdependence), and generosity.

- Keep in mind the UN Convention on the Rights of the Child.
- Use the Asset model.
- Check out the Native Wellness Institute & Billy's Rogers tips.
- Those living with mental disabilities like Fetal Alcohol Spectrum Disorder (FASD) need accommodations made for them to be successful and thereby away from the CJS. Please thoroughly read the FASD materials I have provided.
- Liaise with others to see what programs and services may be best for each individual Youth. Transition to Adulthood Workers and healthy role models can help with change.
- What's worked for my clients: healthy adult and peer connections; feeling wanted and important; having a purpose and meaning goals; having an advocate and good community supports (counsellors, community centres, cultural and spiritual activities, etc); thinking positive; being resilient; exercising their bodies and minds; school or work options; recreational or other activities.
- Lastly, remember to walk in your future leader's shoes, value them and their voices or you could fail them!

You are welcome to contact me @:

Richard.Willier@gov.bc.ca or 604 660 6868

Dr. Brokenleg's Circle of Courage Model

- RW's notes from his Feb 6, 2008 Vancouver YJ Conference Presentation

1. **BELONGING**:
   - We all Need it; a person will not feel powerful if you don't belong
   - All Aboriginal people do better with lots of loved ones around them
   - Need positive places; to feel you belong, especially teens/adolescents
   - Heals Any Wounds
   - Give clients breaks & let them feel they belong (eg. How are you feeling? Or Tell my why questions)
   - NOTHING happens until belonging happens (with clients too)

2. **MASTERY**:
   - Need for Competency (Youth and all people need it)
   - Creates Strength of Spirit (discovering you can do it, to fix problems)
   - Kids issues (Adults have to learn to adjust to him or her)
   - Learning by Experience – let them struggle 1st. until gets it right
   - Focus on *Youth Assets*

3. **INDEPENDENCE**:
   - Self Responsibility (Empowerment)
   - *Discipline teaches responsibility; punishment does not*
   - Give Choices (they work)

4. **GENEROSITY**:
   - Needing to know ones own virtue (Restore the sense of Goodness)
   - Kids need to use this
   - Real Generosity has to hurt (give favourite possession away)
   - Court Sentence: To do a good thing, will bring good results

*****Need to allow all 4 themes to be used – for Youth's to be successful**

Spiritual involvement is the best work with kids-Power greater than oneself
Relationships are important! Emotional/spiritual especially
Children are important, & they need to feel important
Teach kids to use their mind and Heart (helps to be resilient & valued)
Focus on Wellness; Congratulate improvement; Use protective factors; Prevent problems and be Proactive

Investigate critical incidents: What happened? Why are you hurting?

PROBLEMS AS OPPORTUNITY

STRENGTHS GROWTH	PROBLEMS	GOALS FOR
Attachment	**Alienation**	**Belonging**
□ trust □ warmth □ friendship □ cooperation □ acceptance	□ distrust □ withdrawal □ detachment □ antagonism □ exclusion	a. b. c.
Achievement	**Incompetence**	**Mastery**
□ talent □ concentration □ comprehension □ organization □ coping	□ inadequacy □ disinterest □ confusion □ chaos □ defeat	a. b. c.
Autonomy	**Irresponsibility**	**Independence**
□ responsibility □ assertiveness □ self-confidence □ self-control □ optimism	□ undependability □ rebelliousness □ easily misled □ recklessness □ helplessness	a. b. c.
Altruism	**Selfishness**	**Generosity**
□ respect □ kindness □ empathy □ forgiveness □ purpose	□ disrespect □ indifference □ rancor □ vengeance □ emptiness	a. b. c.

40 Developmental Assets

Search Institute has identified the following building blocks of healthy development that help young people grow up healthy, caring, and responsible.

	CATEGORY	ASSET NAME AND DEFINITION
EXTERNAL ASSETS	**Support**	1. **Family support**—Family life provides high levels of love and support. 2. **Positive family communication**—Young person and her or his parent(s) communicate positively, and young person is willing to seek advice and counsel from parent(s). 3. **Other adult relationships**—Young person receives support from three or more nonparent adults. 4. **Caring neighborhood**—Young person experiences caring neighbors. 5. **Caring school climate**—School provides a caring, encouraging environment. 6. **Parent involvement in schooling**—Parent(s) are actively involved in helping young person succeed in school.
	Empowerment	7. **Community values youth**—Young person perceives that adults in the community value youth. 8. **Youth as resources**—Young people are given useful roles in the community. 9. **Service to others**—Young person serves in the community one hour or more per week. 10. **Safety**—Young person feels safe at home, at school, and in the neighborhood.
	Boundaries & Expectations	11. **Family boundaries**—Family has clear rules and consequences and monitors the young person's whereabouts. 12. **School boundaries**—School provides clear rules and consequences. 13. **Neighborhood boundaries**—Neighbors take responsibility for monitoring young people's behavior. 14. **Adult role models**—Parent(s) and other adults model positive, responsible behavior. 15. **Positive peer influence**—Young person's best friends model responsible behavior. 16. **High expectations**—Both parent(s) and teachers encourage the young person to do well.
	Constructive Use of Time	17. **Creative activities**—Young person spends three or more hours per week in lessons or practice in music, theater, or other arts. 18. **Youth programs**—Young person spends three or more hours per week in sports, clubs, or organizations at school and/or in the community. 19. **Religious community**—Young person spends one or more hours per week in activities in a religious institution. 20. **Time at home**—Young person is out with friends "with nothing special to do" two or fewer nights per week.
INTERNAL ASSETS	**Commitment to Learning**	21. **Achievement motivation**—Young person is motivated to do well in school. 22. **School engagement**—Young person is actively engaged in learning. 23. **Homework**—Young person reports doing at least one hour of homework every school day. 24. **Bonding to school**—Young person cares about her or his school. 25. **Reading for pleasure**—Young person reads for pleasure three or more hours per week.
	Positive Values	26. **Caring**—Young person places high value on helping other people. 27. **Equality and social justice**—Young person places high value on promoting equality and reducing hunger and poverty. 28. **Integrity**—Young person acts on convictions and stands up for her or his beliefs. 29. **Honesty**—Young person "tells the truth even when it is not easy." 30. **Responsibility**—Young person accepts and takes personal responsibility. 31. **Restraint**—Young person believes it is important not to be sexually active or to use alcohol or other drugs.
	Social Competencies	32. **Planning and decision making**—Young person knows how to plan ahead and make choices. 33. **Interpersonal competence**—Young person has empathy, sensitivity, and friendship skills. 34. **Cultural competence**—Young person has knowledge of and comfort with people of different cultural/racial/ethnic backgrounds. 35. **Resistance skills**—Young person can resist negative peer pressure and dangerous situations. 36. **Peaceful conflict resolution**—Young person seeks to resolve conflict nonviolently.
	Positive Identity	37. **Personal power**—Young person feels he or she has control over "things that happen to me." 38. **Self-esteem**—Young person reports having a high self-esteem. 39. **Sense of purpose**—Young person reports that "my life has a purpose." 40. **Positive view of personal future**—Young person is optimistic about her or his personal future.

Youth Self-Esteem Enhancers

- ♥ Listen with heart
- ♥ Acknowledge their presence
- ♥ Avoid calling teens "kids"
- ♥ Say, "I see good things in you."
- ♥ Be honest
- ♥ Respect them
- ♥ Appreciate their uniqueness
- ♥ Share your personal struggles with them – self-disclosure
- ♥ Give lots of compliments
- ♥ Give hugs when appropriate
- ♥ Ask for feedback
- ♥ Always encourage
- ♥ Avoid being judgmental – remember their behavior is a reflection of what they see
- ♥ Teach them life skills by modeling
- ♥ Give them reachable tasks and goals to accomplish
- ♥ Talk to them about healthy behavior and expectations
- ♥ Talk to them about unhealthy behavior
- ♥ Encourage healthy risk taking
- ♥ Nurture their Native cultural interests
- ♥ Show your care and concern by doing "little things" for them(e.g. cards, small gifts, acknowledgements)
- ♥ Be there for them – show them you are someone they can trust
- ♥ Love them unconditionally

• TRUST NEEDED
• PROTECTION "

Native Wellness Institute
January 2003

How To Talk To Native Youth So They'll Listen
How to Listen To Native Youth So They'll Talk

Body Language

- Be aware of too much eye contact
- Sit down when talking (LESS AGGRESSIVE)
- Keep arms unfolded
- Affirm listening with head nods
- Smile when appropriate (FOR SECURITY/SAFETY/COMFORT)

Talking

- Watch repeated probing questions – don't interrogate
- Ask open-ended questions that gather information; assist in processing
- Avoid using "should"
- Use "I' messages
- Avoid using "big" words
- Avoid telling the how they really feel or think
- Watch your tone of voice
- Avoid giving advice

Listening

- Use responses like "I see" and "umm"
- Use reflective questions such as "How did you feel during that experience?"
- It's OK to have extended "pause" time
- Be patient
- Don't interrupt
- Don't finish sentences for them
- Use lots of empathy to understand
- Don't be judgmental

Billy Rogers
December 2002

Traditional Values of Native People

Bravery and Courage

Bravery and courage are traits needed by native leaders of the past and of today. Bravery can be defined as conducting ourselves with strength of heart in the face of difficulties, dangers or adversity. Courage is a higher or nobler kind of bravery, enabling a person to face difficulties with firmness and without fear.

Generosity

Generosity was a traditional value of all native people and is still important today. It is being ready to give, being free of meanness and having a willingness to share.

Peacemaking

Traditional native leaders used peace making often, which is a "process" which guides people away from their differences with each other, creates agreements and restores harmony with one another. Patience, listening and compassion are building blocks for peacemaking.

Wisdom

Wisdom can be defined as knowledge of what is true or right, coupled with good judgment and sometimes experience. Wisdom was and is important for native leaders because when wisdom was present (often in elders), it conveyed respect. Wisdom is to be shared.

Humble

Being humble is not drawing attention to one, but to all – listening, not interrupting, sharing any honors and walking in a quiet way. One who is humble doesn't brag, but gives others credit.

Spirituality

Spirituality is being connected to the earth, to all things made by the creator. It is having purpose in life. It is knowing who you are and being with yourself in a good way. Spirituality is knowing when something is sacred. It is based on feeling, not thinking.

Billy Rogers
August 2002

Signs of Community Unbalance

Lack of Traditional Practices

High Rates of Alcohol/Drug Use

Aura of Negativity/Fear

Unhealthy Leaders

Rumors

Jealousy

Blaming

Nepotism

Violence

Elder Abuse

Child Sexual Abuse and Incest

Factional Groups

Exclusion

Lack of Celebrations

High Rates of Domestic Violence & Suicide

No Spiritual "Center"

Billy Rogers
November 2001

A Developmental Model of Unbalance

Personal

- Poor parenting
- Fear of abandonment
- Shame
- Abuse
- Low self-esteem
- Lack of attachment
- External locus of control
- Control issues
- Poor communication
- Anger
- Addictions

Family

- Scapegoat/savior roles
- Dependency
- Blaming

Billy Rogers 10/23/02

1. BELIEVE IN THEM Express positive expectations—confidence in their inborn ability and nobility. Notice particular talents and gifts. Honor who they are—unique in the entire world. Demonstrate your confidence by trusting them with responsibilities.

2. SHOW THAT YOU CARE "People don't care how much you know until they know how much you care." Love and kindness are powerful influences. Be genuinely friendly. Smile! Create a personal connection.

3. GET OFF THE FENCE Be specific about what "good" means. Cite timeless spiritual principles—the virtues—as standards. Everyone has these powers of the human spirit within them and can choose to use them.

4. SET CLEAR GROUND RULES a. Seek input from the recipients as you create the rules. b. Communicate the boundaries in advance. c. Teach the reasons for the rules, but don't indulge in constant explanations to defend them. d. Have a reasonable number of rules—everyone should be able to remember them. e. Be optimistic about compliance. Make it seem easy and enjoyable. f. Enforce the rules fairly and consistently.

5. TEACH THEM HOW Teach appropriate behavior step-by-step. Allow time for skills to develop. Keep expectations realistic for age, ability level and experience. Provide opportunities for practice. Allow "trial and error" learning when it's safe to do so.

6. TEACH POSTIVE SELF-TALK Teach the power of positive thinking and positive affirmations. Example, "I am courageous. I face my fears and overcome my doubts." If we can believe it, we can achieve it!

7. RECOGNIZE EFFORT Effort indicates a desire to do the right thing. Encouragement is most needed when new abilities are being developed. Don't wait for mastery. Tell them right away when you see them making a good start. Acknowledge patience and perseverance.

8. ACKNOWLEGE ACHIEVEMENT Reward excellence. Give approval, incentives, privileges, praise and rewards for achieving goals--for a "job well done".

9. CATCH THEM BEING GOOD Acknowledge moral courage. Cite particular virtues and be specific about the behavior that demonstrates the virtue. Example: "That was courageous when you gave a speech for 100 people."

10. PROMOTE COOPERATION Teach "winning people over, not winning over people." Working together is the basis of progress and prosperity—not unbridled competition.

11. SEE CRISIS AS OPPORTUNITY Convey the attitude that mistakes are opportunities for learning our "life lessons", for developing good character and strengthening our spirit. When people blunder, encourage them to try again. If there is a sincere desire to do better, give them a "second chance".

12. GIVE EDUCATIVE CONSEQUENCES a. When rules are deliberately broken, give fair, logical consequences that educate. Let the "punishment fit the crime" or withdraw associated privileges. b. Request the needed virtue and its associated behavior. Example: "Please be courteous. Take turns talking."

13. PROMOTE SELF ASSESSMENT Keep it positive and guilt-free. Ask questions that start with "what" and "how". "What did I do well today?" "How will I do even better tomorrow?" "What virtue did I need to use in that situation?" "How will I use that virtue next time?"

14. ACKNOWLEGE FEELINGS Take time for feelings. Listen with your heart. Acknowledge anger and fear. Feelings that are heard dissipate. Feelings held inside grow bigger. After strong feelings subside, the person will be able to "think straight" and come up with their own creative solutions .

15. PRACTICE RESTORATIVE JUSTICE Restore dignity by allowing the offender to make amends. Look for "win-win" solutions. Aim to heal the wounds created by the offence, to practice forgiveness and restore the person to loving relationships within the community, family or workplace.

16. BE INCLUSIVE Show each person that they are welcome and valuable to the group. Show them that they contribute something of worth just by being there and also by using their talents to serve.

17. SHOW THEM HOW Be an example of the behavior you wish to see. "Practice what you preach." Let your deeds match your words.

Native Youth & Law Gathering @ First Nations House of Learning (UBC)
on June 23, 2004

- Aboriginal Youth ~~were~~, and those who work with Aboriginal youth, ~~is~~ are encourage(d) to get an education to make life better for Aboriginal people.
- Remind Aboriginal youth they are descendants of strong survivors, who have been taught good things from strong willed people.
- Aboriginal youth were encouraged to think "Indian" but talk white (education).
- Today's warriors are those who fight for Aboriginal rights (encourage).
- Historical genocide through racial profiling is used against Aboriginal people, therefore Aboriginals need to be educated about this to stem this.
- Elder: Respect yourself/others, and that everything in life is beautiful; love must be in your heart to do well; courage-be as bold as a lion; understand we all make mistakes; talk to the Creator for he gives all to Native people, and he loves you no matter what you go through; communicate well with others; pray for another; give back to the community.
- Learn your language and culture; develop student employment programs, outdoor adventure programs, youth councils to make/develop community activities.
- Be a role model for younger people/siblings.
- Negative peer pressure comes from insecurities (deal with them).
- Don't be afraid to suggest doing good things with friends/others if ~~in~~ questioned (they may want to drink alcohol); TO DO BAD THINGS.
- Think positively, and have a good perception of things, even if facing adversity.
- Understand how things relate to other things.
- Understand physical things needed to survive-relate to environment, (do you need alcohol or drugs to survive?).
- Make sure rituals and memories of you (or Aboriginals in general) are positive ones, so no negativity comes about, or racism.
- Say how you feel in a positive way through listening, teaching, arts, writing, singing, proposals, to family/boss,etc.
- Govern yourself and remember your role to the community.
- Take care of your health and healing: eat right, drink right!
- Needs: balance all so 1 does not over consume any other needs. Find alternatives to anything that is questionable, or anything that is considered to be throwing you off.

MAY WANT TO PROVIDE TO ABORIGINAL CLIENTS
TO CONSIDER BETTERING THEIR LIFE SITUATIONS.

UN Convention on the Rights of the Child

In Child Friendly Language

"Rights" are things every child should have or be able to do. All children have the same rights. These rights are listed in the UN Convention on the Rights of the Child. Almost every country has agreed to these rights. All the rights are connected to each other, and all are equally important. Sometimes, we have to think about rights in terms of what is the best for children in a situation, and what is critical to life and protection from harm. As you grow, you have more responsibility to make choices and exercise your rights.

unicef

Article 1
Everyone under 18 has these rights.

Article 2
All children have these rights, no matter what they are, where they live, what their parents do, what language they speak, what their religion is, whether they are a boy or girl, what race they are, whether they have a disability, whether they are rich or poor. No child should be treated unfairly on any basis.

Article 3
All grown-ups should do what is best for you. When adults make decisions, they should think about how their decisions will affect children.

Article 4
The government has a responsibility to make sure your rights are protected. They must help your family to protect your rights and create an environment where you can grow and reach your potential.

Article 5
Your family has the responsibility to help you learn to exercise your rights, and to ensure that your rights are protected.

Article 6
You have the right to be alive.

Article 7
You have the right to a name, and this should be officially recognized by the government. You have the right to a nationality (to belong to a country).

Article 8
You have the right to an identity – an official record of who you are. No one should take you away from you.

Article 9
You have the right to live with your parents, unless it is bad for you. You have the right to live with a family who cares for you.

Article 10
If you live in a different country than your parents do, you have the right to be together in the same place.

Article 11
You have the right to be protected from kidnapping.

Article 12
You have the right to say what you think, and for adults to listen and take it seriously.

Article 13
You have the right to find out things and share what you think with others, by talking, drawing, writing or in any other way unless it harms or offends other people.

Article 14
You have the right to choose your own religion and beliefs. Your parents should help you decide what is right and wrong, and what is best for you.

Article 15
You have the right to choose your own friends and join or set up groups, as long as it isn't harmful to others.

Article 16
You have the right to privacy.

Article 17
You have the right to get information that is important to your well-being. There should be books, newspapers, computers and other sources. Adults should make sure that this information is not harmful, and help you find and understand the information you want.

Article 18
You have the right to be raised by your parent(s) if possible.

Article 19
You have the right to be protected from being hurt and mistreated, in body or mind.

Article 20
You have the right to special care and help if you cannot live with your parents.

Article 21
You have the right to care and protection if you are adopted or in foster care.

Article 22
You have the right to special protection and help if you are a refugee (if you have been forced to leave your home and live in another country), as well as all the rights in this Convention.

Article 23
You have the right to special education and care if you have a disability, as well as all the rights in this Convention, so that you can live a full life.

Article 24
You have the right to the best health care you can get, safe water to drink, nutritious food, a clean and safe environment, and information to help you stay well.

Article 25
If you live in care or in other situations away from home, you have the right to have these living arrangements looked at regularly to see if they are the most appropriate.

Article 26
You have the right to help from the government if you are poor or in need.

Article 27
You have the right to food, clothing, a safe place to live and to have your basic needs met. You should not be disabled by poverty.

Article 28
You have the right to a good quality education. You should be encouraged to go to school to the highest level you can.

Article 29
Your education should help you use and develop to your talents and abilities. It should also help you learn to live peacefully, protect the environment and respect other people.

Article 30
You have the right to practice your own culture, language and religion – or any you choose. Minority and indigenous groups need special protection of their rights.

Article 31
You have the right to play and rest.

Article 32
You have the right to protection from work that harms you and is bad for your health and education. If you work, you have the right to be safe and paid fairly.

Article 33
You have the right to protection from harmful drugs and from their illegal trade.

Article 34
You have the right to be free from sexual abuse. Article 4 (the one that allowed a kidnap or sell you.

Article 35
You have the right to protection from anyone who might harm you.

Article 36
You have the right to protection from any kind of exploitation (taking advantage of).

Article 37
No one is allowed to punish you in a cruel or harmful way.

Article 38
You have the right to protection and limitation from war. Children under 15 cannot be forced to go into the army or take part in war.

Article 39
You have the right to help if you've been hurt, neglected or badly treated.

Article 40
You have the right to legal help and fair treatment in the justice system that respects your rights.

Article 41
If the laws of your country provide better protection of your rights than the articles in this Convention, those laws should apply.

Article 42
You have the right to know your rights. Adults should know about these rights and help you learn about them, too.

Articles 43 to 54
These articles explain how governments and international organizations like UNICEF will work to ensure children are protected and their rights.

QUEEN ALEXANDRA FOUNDATION FOR CHILDREN

Canadian Heritage / Patrimoine canadien

FETAL ALCOHOL SPECTRUM DISORDER

I Hear and I Forget
I See and I Remember
I Do and I Understand - **Proverb**

Fetal Alcohol Spectrum Disorder (**FASD**) is a range of neurological [brain dysfunction primarily] & perhaps some physical disabilities/conditions that affect children who are born to women who consume alcohol during pregnancy. Conroy 2000, says it "is a life-long disorder". Only a doctor can diagnose FASD. Graefe in 2006 said, "FASD is 100% preventable ... [and] is found in all economic and racial groups".

"Poor fit = Problems"

Primary Disabilities

- Cognitive and physical disabilities caused by prenatal alcohol exposure
- These are related to the biological developmental affects of alcohol on brain cells growth, cell division & migration in the developing embryo/fetus - Byrne 2008
- Are the *learning*, developmental and/or physical responses to the environment and other behavioural symptoms

Examples:

- Poor short term memory; and difficulty making good decisions
- Planning and setting goals is difficult
- Upset by changes to their environment; and impulsive
- Short attention span; and inconsistent behaviour and competency

Secondary Disabilities

- Are those that result from the primary disabilities & external factors after birth
- Impact or severity or frequency of secondary disabilities may be decreased by appropriate interventions/prevention of those external factors - Streissguth 1996
- Are the *defensive* behaviours that develop over time as a result of chronic frustration, trauma, and/or failure

Examples:

- Lonely/isolated
- Poor self-esteem
- Easily manipulated

Tertiary Disabilities

- Are the *net effect* of chronic failure and frustration

Examples:

- Trouble at home - runs away from home
- Problems with school - drops out of school
- Trouble with work - quits job

"Expectation needs to match ability"

Visible Effects of FASD (Most don't have, so examine using caution)

- Those with no visible signs are the most common Annis 2008

A Useful list to Recognize FASD Behaviour in your Clients/Children

- Follows others and is impulsive; poor planning
- Dysmaturity; younger than biological age
- May not understand personal space or boundaries
- Easily over stimulated and over sensitive, and slow to settle
- Has difficulty answering questions; takes time to respond
- Talks better, than understands
- Difficulty retrieving and exchanging information
- Slow auditory pace (hears every 3rd word)
- Easily distracted
- Acts out when overwhelmed; consequences are not thought of
- Easily fatigued and sleeping issues
- Acts fast but thinks slowly
- Difficulty communicating emotions and thoughts
- Does not understand: danger; similarities and differences
- Forgets things, remembers others
- Hyperactive behaviour and poor coordination

Common difficulties in brain functioning for those with FASD

- "Planning and organizing, starting/initiating
- Predicting, seeing outcomes [and consequences]
- Integrating information: Gets the piece, not the picture
- Thinking and reasoning: Weighing/evaluating, comparing/contrasting
- Understanding cause and effect
- Stopping, changing direction
- Perseverating: Gets stuck, can't stop

- Making links: translating between modalities (Hearing into doing; Seeing into writing; Thinking into speaking; Speaking into action: Talks the talk but doesn't walk the walk)" Malbin 2008

What can YOU do to help your client/child on Probation/At home

- Break tasks into steps
- Give MORE time to complete tasks and lessen expectations
- Create a plan that will fit the needs of the client in order to ensure success. Adapt counselling to how they do and say things. Use music therapy? Art, play or dance therapy?
- Repeat instructions (written is very helpful) and keep it simple (pictures can be helpful to some who don't like reminders)
- FASD clients are visual learners, SHOW them what they need to do
- Teach them how to schedule their appointments in a day planner, illustrate the importance of being organized
- Go SLOW, use less words
- Think younger. Most FASD clients are younger mentally than their biological age
- Encourage them to ASK questions, and teach them to not be afraid to ask for HELP
- When there is anger and frustration, there is usually missing information
- See the pattern of behaviours and understand where the 'fit' is poor
- Time Management Gotowiec & VPD training manual 2008
- Visual Learner...[use] Visual cues Malbin 2008
- Slower processing...[use] Slow down, fewer words Malbin 2008
- Needs simplicity...[use] One or two steps
- Be Patient & Be [or find] A Life Long Advocate if you can!
- Limit sensory stimuli, as they see and hear everything
- Manage caregiver fatigue (emotional, physical, intellectual, spiritual) - meditate or take small short breaks Castaldi 2008
- Use respite if/when you can
- As Malbin 2008 puts it, be an "External Brain Support"
- Focus on their strength's! Malbin 2008 says, "Recognize Ability"; & as McMillan 2008 puts it "focus on their gifts"
- "Combine mind and heart = wisdom"; use "many supportive people are best" McMillan 2008

- Use consistency, stability and predictability Gotowiec & VPD training manual 2008
- Long term support and structured programming Gotowiec & VPD training manual 2008
- "Let go of yesterday...live the present...create the future...honor the past" McMillan 2008
- "Believe in change, acceptance, growth & new beginnings ... If we undermine their best to be successful, they won't try anymore" McMillan 2008
- [perhaps] medication Gotowiec & VPD training manual 2008

"FASD is an invisible disability"

FASD (an umbrella term) consists of a wide spectrum of Neurobehavioral effects, ranging from the least subtle to severe neurodevelopmental problems:

- **FASD (Full FAS) with confirmed maternal alcohol exposure**

Those people who exhibit facial features, growth retardation, and central nervous system neurodevelopment abnormalities are defined as having full-blown "Fetal Alcohol Syndrome" [now called Fetal Alcohol Spectrum Disorder] Koren & Nulman 2006

- **FASD (FAS) without confirmed maternal alcohol exposure**

If persons have the disabilities described as full FASD, a diagnosis is possible even without confirming maternal drinking Koren & Nulman 2006

- **Partial FASD (pFAS) with confirmed maternal alcohol exposure**

In this category people may have some "facial anomalies, and either growth retardation, central nervous system neurodevelopmental abnormalities, or behavioural or cognitive abnormalities" Koren & Nulman 2006

- **Alcohol-related birth defects (ARBD)**

"Clients [physical effects Annis 2008] who fall into this category will have congenital malformation and dysplasia (abnormal growth or development of cells, tissue, and bone) as result of alcohol toxicity" Koren & Nulman 2006; "Those with ARBD may have problems with their heart, kidneys, bones and/or hearing" McMillan 2005

- **Alcohol-related neurodevelopment disorder (ARND)**

"Patients in this category will have evidence of complex patterns of behavioural and/or cognitive toxicity" Koren & Nulman 2006

The main diagnoses for FASD are: Full FAS; Partial FAS, ARND and ARBD (with or without alcohol exposure known, except full FAS has confirmed maternal alcohol use). Of note, there are other many lesser types of diagnosis given by the University of Washington's 4-digit FASD code - and other Canadian guidelines diagnosis given - that are not on the spectrum, such as Neurobehavioural Disorder or Neurodevelopmental Disorder (alcohol exposure unknown)

Celebrate the Strengths in those with FASD

- Strong visual strength, musical strength, writing strength Opie 2008
- Hands on: see, touch, move
- Artistic, creative, hard-working, determined, willing, kinesthetic - [movement] Malbin 2008
- "Games (age appropriate) with therapeutic purpose" Opie 2008
- "Strong long-term memory; loyal; friendly; loving; eager to please; concrete, experiential, contextual learners; learn by doing; work well with their hands; learn by being shown rather told; learn through relationship, learn through consistency; continuity and relevance; may be visual, kinaesthetic, learn best when all modalities are involved; perserverative; willing to work, though may require more time to finish, to achieve closure" Malbin 2002

Possible School & Employment Tools/Opportunities

- Inform staff to better utilize person and her/his abilities
- Adapt style that works for the person
- Provide reminders and consistent structure; predictable routine
- Supportive work with animals, art, music, cooking, mechanics Gotowiec & VPD training manual 2008
- Artist, musician, warehouse person, electrician, boat builder, mechanic, child care worker, animal rescue worker, drummer, dancer, office worker, special education teacher, counsellor, massage therapist, truck driver, delivery person, farmer, adult care worker Malbin 2008
- Singer; play instruments; compose music; speller; reader; writer; poet; computer work; welder; woodworker; teacher; alcohol and drug counsellor; parent; community leader Malbin 2002
- FASD lecturer, speaker or specialist

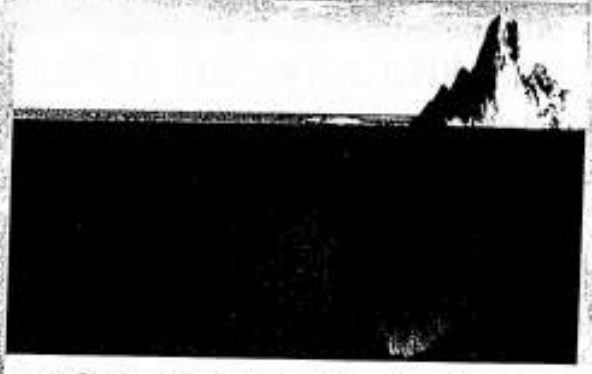
"Good fit = Environmental Accommodations with Comprehensive Supports = Solution" Annis 2008

In Conclusion

- It is vital that when working/living with those with FASD that we always acknowledge their strengths and accommodate wherever possible
- If you are working with (or parenting) a child who has FASD, be patient and stay educated
- If you know someone who is pregnant, or is trying to get pregnant, inform them of the dangers in consuming alcohol while pregnant
- As Lutke (2009) puts it, "the family is the institution and need to accept the person, otherwise the system fails them ... parents need training to understand how FASD works with systems [and be an] advocate, and brain for their kids". Kee Warner (White Crow camp) adds, "Our platform is interdependence ... People with FASD need family support and the family needs to transfer that support".
- Lastly more tips: create a day plan, week plan, year and life plan for the person – and a 24-7 plan; life-long supportive and compassionate people are important and needed, along with understanding supports tailored to the person's needs and wants; educate people on FASD and strategies they could use or consider using - focus on gifts and positives and create strategies that avoid negative outcomes/possibilities; seek programs with FASD understanding, and ask each area of the FASD person's life to have an FASD knowledgeable person as the go to person to assist and educate them to do a better job with the person

Prepared by Richard Willier, Aboriginal Youth Probation Specialist for Vancouver, BC, CANADA (with some initial assistance from Andrea Cruz)

26 JohnHoward SOCIETY OF ONTARIO FactSheet



Fetal Alcohol Spectrum Disorder and the Criminal Justice System: A Poor Fit

Inside

What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is the most common type of developmental delay in Canada. There is increasing data to suggest that a disproportionate number of people in conflict with the law have FASD. Some researchers estimate the rate of FASD to be ten times higher inside Canadian prisons than in the general population.

Given this high rate, it is clearly important for service providers to be knowledgeable about this issue. When working with people with FASD, it is important to be aware of the following facts:

"Some researchers estimate the rate of FASD to be 10 times higher inside Canadian prisons"

- FASD is a brain-based *physical* disability. As such, FASD is permanent and cannot be cured.
- FASD is an umbrella term used to describe any neurological, physical and behavioural effects that result from exposure to alcohol in utero.
- The key characteristics of FASD are: difficulty with assessment, judgment and reasoning; poor memory; misunderstanding cause and effect; inability to generalize or think abstractly; difficulty planning; trouble at school; self-medicating.
- Often the effects of FASD do not present themselves in a person until they are several years old.
- Numerous aspects of fetal development can be affected depending on when the mother drank alcohol, how much and what she drank during pregnancy.
- The Public Health Agency of Canada asserts that there is no known safe time or amount to drink when pregnant.
- FASD cannot be inherited from either parent; it is not genetic. A child cannot get FASD from his or her mother who has been diagnosed with FASD, unless she drinks during her pregnancy.
- Despite being so widespread, FASD is significantly under-diagnosed among the Canadian population.
- The neurological and behavioural effects of FASD create challenges at all stages of the criminal justice process for those affected by it.

FASD Fetal Alcohol Spectrum Disorder

FAS	Fetal Alcohol Syndrome
pFAS	Partial Fetal Alcohol Syndrome
ARND	Alcohol-Related Neuro-developmental Disorder
ARBD	Alcohol Related Birth Defect

FASD by the Numbers

The statistics show that FASD is one of the most common and expensive types of developmental delays. Estimates are:

300,000 (or 1:100)
The number of Canadians affected by FASD. Since FASD often goes undiagnosed, the actual prevalence is likely much greater.

>80%
Percentage of people with FASD who are raised by someone other than their parents.

95%
Percentage of people with FASD who also have a mental illness.

60%
Percentage of people with FASD over 12 years old who have been charged with, or convicted of, a crime.

55%
Percentage of people with ARND who will be confined in prison, drug/alcohol treatment centres, or psychiatric institutions.

$21,642
The total annual adjusted costs associated with each person with FASD.

$5.3 billion
The annual cost to the country of those with FASD from day of birth to age 53.

FASD and the Criminal Justice System: A Poor Fit

Given the characteristics of FASD, it is no surprise that affected people face challenges at all stages of the criminal justice system.

The differences of those with FASD must be better understood and accommodated, both in terms of human rights as well as the goal of a just and effective criminal justice system.

Trouble with Assessment, Judgment and Reasoning: These characteristics make it difficult for people with FASD to make choices that seem 'smart' or consider long-term goals, and can result in conflict with the law. FASD also makes affected individuals more vulnerable to manipulation and coercion, placing them at higher risk of giving false confessions.

"People with FASD face challenges at all stages of the criminal justice system"

Poor Memory: Many people with FASD struggle with memory challenges. It can be difficult for others to understand that a person with FASD may not merely be choosing to forget certain events, but are truly unable to recall what happened. Poor memory can make a person extremely vulnerable when trying to recall events during a criminal investigation. Therefore, people with FASD may be at risk of incriminating themselves during a police interrogation or court hearing.

Misunderstanding of Cause & Effect: People with FASD generally have significant challenges connecting cause and effect. This skill is, of course, central to the concept of deterrence. Thus, punishments are unlikely to have any impact on deterring future similar behaviour. As such, if a person with FASD commits a crime and is later convicted, they may not be able to draw a connection between the two events.

Inability to Generalize: Most adults are able to draw connections between two similar but separate events. This requires somewhat sophisticated executive functioning, namely being able to apply knowledge gained from one situation to a new situation that may have some key differences. Individuals with FASD frequently struggle with this skill. For example, a woman with FASD may learn she will go to jail for cocaine possession. However, unable to apply this fact to other situations, she may not understand that she will also go to jail for heroin possession.

Inability to Think Abstractly: Because individuals with FASD usually have difficulty understanding abstract concepts, they generally struggle to understand basic concepts in math, money, and time. Also, all rules and laws are inherently abstract, and as such, are difficult for individuals with FASD to understand and internalize.

As a result, the meaning behind stealing someone's money is different than it is to a person who is able to understand the meaning and value of money. This difficulty with abstraction means that many persons with FASD cannot imagine or consider the future. This disability places them at risk during stages of court processing, such as plea bargaining, sentencing or parole hearings.

Difficulty Planning: Often people with FASD struggle with planning, as it requires the ability to envision an abstract view of the future, and achieve goals through a series of complex steps. This disability can lead to highly impulsive behaviour and makes it difficult for people with FASD to be deterred from committing a crime. Recidivism rates are consequently very high.

Trouble in School: Due to no diagnosis or misdiagnosis, people with FASD frequently struggle in school. Over 60% of people with ARND between the ages of 12-51 will have disrupted school experiences. The research shows that education is strongly correlated with preventing criminal behaviour and recidivism.

Self-Medicating: Since FASD is often improperly diagnosed or missed entirely, many individuals with FASD develop secondary behaviour problems due to a chronic "poor fit" with their environment. In order to alleviate or cope with these secondary problems, such as depression, some people with FASD self-medicate with illegal drugs. Rarely successful, self-medicating may lead to addiction and conflict with the law.

Six Common Myths about FASD

1. *Myth:* You can tell if someone has FASD by the way they look.

The majority of people with FASD have no physical characteristics of the disability. FASD and other such "invisible disabilities" that affect behaviour are often under-diagnosed because behaviour is frequently assumed to be a choice.

Research shows that there is a small period during a pregnancy when alcohol use can affect the child's facial features. This is very unlike the brain, which develops throughout the entire pregnancy and can therefore be affected at any point.

2. *Myth:* FASD only occurs when mothers binge drink or are alcoholics. Drinking in moderation won't cause FASD.

The Public Health Agency of Canada makes it very clear that, "***There is no known safe amount of alcohol during pregnancy.*** *There is* ***no safe time*** *to drink alcohol during pregnancy.*"

3. *Myth:* Behaviour is a choice. People with FASD just need to *try harder!*

Most healthy adults can control their own behaviour and follow societal norms. This is not true for many people with FASD. Experts stress that the brain damage associated with FASD often prevents people from being capable of controlling their behaviour. For that reason, it is important to change the assumption that "they won't behave" to the understanding that "they can't."

4. *Myth:* FASD only affects children and adolescents. Adults don't have it.

Although the majority of resources and information about FASD are directed to those under 18, FASD is a permanent, lifelong disability. Rather than being able to "outgrow" FASD, many adults face *greater* challenges as they get older because their behaviour becomes less acceptable as adults. As a person ages, the FAS-related facial features they may have can become less apparent, making it even harder for people to receive proper diagnosis.

5. *Myth:* FASD is an Aboriginal disease. All Aboriginals have FASD.

FASD is solely and directly the result of prenatal exposure to alcohol. Therefore, FASD can affect people of all races, ages, cultures, classes, genders and sexualities.

6. *Myth:* FASD is just the latest trendy disability.

Although there have always been people affected by FASD, only recently have we been able to recognize the enormous prevalence of this developmental delay. FASD is frequently misdiagnosed as one of its secondary characteristics (e.g. Oppositional Defiance Disorder). FASD has been routinely absent from criminal justice discourse, despite the high prevalence of people with FASD in conflict with the law.

Ways to Make the Environment Work for People with FASD

FASD challenges the ways that service providers, whether inside or outside the criminal justice system, work with their clients. Many of the ways we practice, and the things that workers say they "know works," simply do not apply to those with FASD.

What then? FASD experts talk of **modifying the external world** to work for the FASD brain. The field of Disability Studies similarly provides a useful model, demanding that we recognize the ways in which society constructs disabilities. A prominent advocate for FASD, Diane Malbin, explains that,

> People with FASD are not broken and do not need fixing, they require those in society to accommodate their different ways of viewing the world.

The FASD Ontario Justice Committee suggests several techniques one can adopt to successfully accomplish this, including:

Reframing Behaviours: It is vital to distinguish between what someone with FASD *won't do* and what he or she *can't do.* Often, people confuse the two and assume that the person with FASD is choosing to act a certain way. It may be helpful to remember that FASD is a form of physical brain damage and has very little to do with personal choice.

Setting up an External Brain: Depending on the level of damage to the brain, a person with FASD will likely benefit from the support of someone able to assist with decision-making as well as advocating for his or her rights and well- being. One excellent service of this kind is the Gateway Mentoring Program at the John Howard Society of Central and South Okanagan in British Columbia. The Gateway Mentoring Program is a one-to-one mentorship to those who have – or have symptoms of – FASD, and are involved in, or at risk of involvement in, the Criminal Justice System.

Early Diagnosis/Any Diagnosis: The earlier an individual receives a proper diagnosis of FASD, the better he or she will fare. Living without a diagnosis can be confusing for affected individuals and the people in their lives trying to understand their behaviour. Often, not being diagnosed will increase a person's likelihood of developing secondary disabilities that stem from the frustration and confusion of not being understood. As well, many of the services, treatments and medications can only be offered after a formal diagnosis.

Further Readings on FASD

- "Damaged Angels" by Bonnie Buxton
- "Trying Differently, Not Harder" by Diane Malbin
- "The Broken Cord" by Michael Dorris
- "It Takes a Community" by the First Nations and Inuit FASD Initiative
- "The Canadian FASD Training Online Database" found at www.ccsa.ca
- "Fetal Alcohol Syndrome and the Criminal Justice System" by Julianne Conry and Diane Fast
- "Fetal Alcohol Spectrum Disorder (FASD): A Framework for Action" by the Public Health Agency of Canada
- www.fasdontario.ca
- www.fasdjustice.on.ca
- www.faslink.org
- www.fasalaska.com

Fact Sheets are a publication of the John Howard Society of Ontario on a variety of social and criminal justice issues, intended for our Affiliate staff and community partners. All Fact Sheets are available on our website.

Eight Ways Clients with FASD Need You to Respond

Deb Evensen, Director of Fetal Alcohol Consultation and Training Services, identifies eight strategies to adopt when working with people with FASD. By using these techniques, service providers can limit feelings of anxiety, frustration and misunderstanding, and can modify the external world to work for the FASD brain.

1. Concrete. Talk in concrete, clear terms. Avoid sarcasm, figurative language, abstract terms and metaphors. Be sensitive to the possibility that someone with FASD may not understand you at first, and you may need to repeat your message with different words.

2. Consistency. People with FASD function best in stable environments. Consistency helps reduce anxiety over having to "guess" what is going to happen next. When working with someone with FASD, it is important that your behaviour and interactions are predictable and consistent.

3. Repetition. Memory loss is an ongoing challenge for those with FASD. It's common for people with FASD to forget things they've learned and known for some time. Remind people multiple times, in order to make it more likely that they will remember.

4. Routine. Stable routines coincide with consistency and repetition. It is important for people with FASD to have a set routine that rarely changes. This way, people with FASD can feel more secure as they know what to expect from each day and are not anxious of the unknown.

5. Simplicity. Many people with FASD can be overstimulated. As a result, they may have difficulty sorting through their environment and selecting what is relevant and important at any given moment. For that reason it is important to keep one's interactions as simple as possible.

6. Specific. People with FASD require others to say exactly what they mean. Subtlety in language can often be mistaken or missed. It is best to give step by step directions, removing the need to fill in the blanks. Instead of saying "That judge doesn't like when people are late," say: "At 12:30, take Bus 15A to the court house, go through security and sit inside the court room, don't take any breaks along the way. I'll meet you there at 1:20, please don't be late." In some cases, you may need to simplify instructions even further, or write them down. Having clients with FASD carry an emergency contact number, so they can seek assistance if needed, could also be helpful.

7. Structure. Like routine, structure is extremely important for people with FASD. Structure often lowers the anxiety of these individuals by allowing them to better predict and understand what to expect from their environment.

8. Supervision. It is difficult to offer supervision to adults with FASD, without feeling patronizing. However, it is important to reach a cautious balance between respecting the person as an individual, and recognizing his or her challenges and capacity.

The John Howard Society Position

The John Howard Society's mission statement calls for "effective, just and humane responses to crime and its causes." The John Howard Society supports the idea that *"it is fundamentally unjust to imprison an individual in response to acts committed as a result of brain-based physical disability."* We strongly believe that the criminal justice system must recognize and respond effectively to people with FASD.

The estimated rate of people in our correctional system and the disproportionate rates of recidivism amongst people with FASD suggest that the current approach of the criminal justice system is inadequate. From policing through to prisons, the system fails those with FASD. Specialized courts, diversion programs and prison services, which exist for other groups, would be highly beneficial in accommodating the unique needs of those with FASD.

The John Howard Society argues that comprehensive programs that can demonstrate their success in meeting the specific needs of people with FASD must be available. Such services must be broadly and consistently accessible, supported through stable funding and staffed by trained service providers. Education is imperative. A thorough understanding of the complexities of FASD would assist all service providers to recognize possible signs that their client may have FASD. Once identified, service providers can modify their own interactions, advocate for a formal diagnosis, and encourage others to use more appropriate techniques.

Meaningful governmental responsibility must be taken to prevent FASD in Canada.

Only through these changes can we reduce the frequency and prevalence of criminal justice system involvement for people with Fetal Alcohol Spectrum Disorder.

Understanding FASD: Basic Information

What is FASD?

Fetal Alcohol Spectrum Disorder (FASD) is a complex disability and one that is not quickly explained. The term Fetal Alcohol Spectrum Disorder is an **umbrella term** referring to the continuum of effects that can occur in children, youth or adults prenatally exposed to alcohol. The spectrum of effects includes mild to severe cognitive, behavioural, physical and sensory disabilities. The disabilities caused by alcohol exposure are present from birth but, in many cases, are not identified until later in life. FASD is considered the leading cause of developmental and cognitive disabilities among children in Canada. (Health Canada 2006). FASD is a life-long disability for which there is no cure. This means that people do not grow out of their unique disabilities and the brain injury cannot be fixed.

How does alcohol harm a fetus?

Alcohol is a **teratogen**, meaning that this substance is toxic to, and can negatively influence, prenatal development. When a woman is pregnant and drinks alcohol, the alcohol not only enters her system, but also passes freely through the placenta and enters the system of the developing fetus. Alcohol remains in the system of the fetus longer than that of the mother. The alcohol injures the body systems and organs that are developing at that stage of the pregnancy. The **Central Nervous System (CNS)** is particularly vulnerable for two reasons **1.** The CNS develops throughout the entire pregnancy so injury to neurological functions can occur over the entire nine months **2.** Alcohol acts as a solvent on the rapidly developing cells of the CNS and causes significant injury, primarily to the brain. Our brain continues to develop after birth, so alcohol should also be avoided when breastfeeding. Many factors influence the amount of injury resulting from prenatal exposure, including the amount of alcohol consumed, how often alcohol is consumed, the timing of consumption, the general health of the mother, stress levels, exposure to other substances and genetic makeup.

Can FASD be prevented?

Clearly, prevention of FASD is important. The public requires clear and accurate information about the harmful affects of alcohol on a fetus. There is no known safe amount of alcohol or a known safe time during pregnancy to consume alcohol. For these reasons, it is best for women to abstain from alcohol throughout the entire pregnancy. This information needs to be widely available in the community and through health-care services. Women will need support from family, friends and partners to abstain from alcohol. This can be difficult as alcohol use is accepted and common in our culture. Women and families affected by addictions need specialized services during pregnancy. We very well know that many in our communities have an addiction to alcohol. People become addicted to alcohol for a variety of reasons, and the nature of addictions makes it extremely difficult for women to stop drinking when they become pregnant.

How many people are affected by FASD?

In Saskatchewan, it is believed that 1 in 100 people may be affected by prenatal alcohol use. (Saskatchewan Prevention Institute, 2005). However, it is difficult to know just how many families are affected as FAS has only been recognized in the last 30 years and the idea of a spectrum of disorders resulting from prenatal alcohol exposure is even more recent. In addition, the signs and symptoms of FASD often go unnoticed, are masked by other factors in the individual's life or are attributed to other causes. This is why FASD is often called an **invisible disability**. Individuals with invisible disabilities in many cases do not receive the support and accommodation they need to succeed in life. Research shows that those most at risk are individuals with no visible signs of disability (Malbin 2006). Many people with FASD have an IQ in the normal range, but the various cognitive processes have been altered. With appropriate supports and changes to their environment, individuals can be productive and successful members of society.

Diagnostic Terms and Criteria

In 2005, a team of professionals developed the ***Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis.*** This was a major accomplishment that will aid many families and individuals in the journey to access diagnosis. Diagnosis and assessment of prenatal exposure is a complex process best completed by a multi-disciplinarian team of professionals that must include a physician specially trained in diagnosis and assessment. Diagnostic and assessment services are available throughout the province but families continue to face barriers to these services. Barriers include long wait lists, services that are more widely available to children and youth rather than all age groups, lack of trained professionals, difficulty for families in remote and rural regions to access diagnostic and assessment services due cost of travel and long distances to services.

Despite the problems accessing diagnostic and assessment services, this is an important process that can improve outcomes for individuals and families. A common area of confusion for families and professionals is the language used around diagnosis. The term Fetal Alcohol Spectrum Disorder (FASD) is not a diagnostic term. FASD is an umbrella term used to describe the range of disabilities caused by drinking alcohol during pregnancy. The following are some commonly used terms associated with diagnosis within the spectrum of FASD. The criteria for diagnosis are those used across Canada.

Fetal Alcohol Syndrome (FAS)

1. Information showing the birth mother drank during pregnancy
2. Characteristic facial features
3. Below normal weight, height and small head
4. Problems with learning and /or problems with behaviour

Fetal Alcohol Syndrome (FAS) without Confirmed Maternal Exposure

Sometimes the fact that the mother drank during the pregnancy cannot be proven but there is good reason to believe she did. If the other 3 characteristics for FAS are present then the diagnosis of FAS without confirmed maternal exposure can be made.

Partial Fetal Alcohol Syndrome (pFAS)

Information showing the birth mother drank during pregnancy and two out of three of the following characteristics:

1. Some of the characteristic facial features found in FAS are present.
2. 'Much' below normal weight, height and small head
3. Problems with learning and/or problems with behaviour

Alcohol Related Neurodevelopmental Disorder (ARND)

1. Information showing the birth mother drank during pregnancy
2. Problems with learning and/or problems with behaviour

A term used in the past that is no longer used as a diagnostic term is **Fetal Alcohol Effects (FAE).** This is a term has been replaced by the diagnostic terms **pFAS** and **ARND.**

Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis is available online at www.cmaj.ca/cgi/content/full/172/5_suppl/S1

Developed by FASD Support Network of Sakatchwan (2003; Revised 2005)
Adapted from Chudley, A.E., Conry, J., Cook, J., Loock, C., Rosales, T., Leblanc, N. Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. Canadian Medical Association Journal (March 2005).

Paradigm Shifts and People with FASD

Fetal Alcohol Spectrum Disorder describes a range of disabilities caused by prenatal alcohol exposure. The disabilities are brain based. When families, caregivers, professionals and community members change their own understanding or perception of the individual with FASD, this is called a "paradigm shift."

The following chart shows how we can shift our understanding of FASD. With realistic expectations we can give individuals with FASD every opportunity to be successful.

From seeing the child as...	To understanding the child as...
Won't	**To Can't**
Bad, annoying	Frustrated, challenged
Lazy, unmotivated	Trying hard, tired of failing
Lying	Story telling , filling in the blanks
Fussy	Oversensitive
Acting young, babied	Being younger
Trying to get attention	Needing contact, support
Inappropriate	Displays behaviours of a younger child
Doesn't try	Exhausted or can't get started
From personal feelings of...	**To feelings of...**
Hopelessness	Hope
Fear	Understanding
Chaos, confusion	Organization, comprehension
Power struggles	Working with
Isolation	Networking, collaboration
Professional shifts from...	**To...**
Stopping behaviours	Preventing problems
Behaviour modification	Modeling, using visual cues
Changing people	Changing environments

"The first step toward change is awareness. The second step is acceptance."
Nathanial Branden

Prepared by FASD Support Network of Saskatchewan Inc. (2006).
Chart reprinted with permission from Malbin, Diane V., (2002, 1999) Trying Differently Rather Than Harder, Second Edition. Portland, Oregon: FASCETS. p.42. Permission granted March 2006.

Common Beliefs about FASD that are NOT TRUE

1. **Belief:** All people who have FASD have below average IQ. This is NOT true.

What is true is that:

- Some children with FASD have below average IQ.
- Some children with FASD have average or above average IQ's.
- Their brain has been injured.
- Children who have FASD do some things well and but can have difficulties with some things.
- It can be helpful to think of your child as having difficulties similar to someone who has brain injury because of an accident.

2. **Belief:** The behaviour problems of children who have FASD happen because their parents are not doing a good job of parenting. This is NOT true.

What is true is that:

- Brain damage can lead to behaviour problems. This is because a person with brain damage does not think the same way most people do. They don't always behave as others expect them to.
- Children with brain damage are difficult to parent.
- As a parent of a child who has FASD you need the support of your family, friends and the community. It is very difficult to go it alone.

3. **Belief:** Children with FASD will out grow their difficulties. This is NOT true.

What is true is that:

- FASD lasts a life time.
- The difficulties children face change as they grow older.
- Your child will continue to need your support well into adulthood.

4. **Belief:** Because a person with FASD has brain damage there is no point helping them. This is NOT true.

What is true is that:

- Children with FASD can learn if we give them help and if we teach them in the way they learn best. We can adjust our teaching style to match their learning style.
- Children with FASD learn best in a quiet place where they can practice skills. They need a routine that seldom changes.
- You can help your child by talking about FASD with family, friends, and professionals. This should help them understand your child's behaviour.

Common Beliefs about FASD that are NOT TRUE

5. **Belief:** A diagnosis of FASD is a label that will make people want to give up on the individual. This is NOT true.

What is true is that:

- A diagnosis tells you what the problem is.
- A diagnosis helps you figure out what to do to help your child.
- A diagnosis can be a relief to a child because now he or she will know the reason for difficulties.
- You can use the diagnosis to help you find supports for both you and your child. For example your child may qualify for extra help in school or you may be able to get respite care for your child so you can stay well and strong.

6. **Belief :** People with FASD are unmotivated or unwilling to take responsibility for themselves. This is NOT true.

What is true is that:

- Children with FASD are not trying to be difficult. They often have difficulty paying attention or remembering instructions. This is usually the reason for the behaviour.
- It is important to understand that people with FASD suffer from brain damage and that this affects their ability to be responsible for their behaviour. It's not that they won't, it's that they can't.

7. **Belief :** Mothers had an easy choice not to drink while they were pregnant and that they purposely set out to damage their baby. This is NOT true.

What is true is that:

- Pregnant women do not purposely harm their baby.
- Family, friends and the community all play a role in helping the pregnant mother overcome problems with addiction.
- Stopping drinking at any time during pregnancy will be helpful for the development of the baby.
- Changing drinking patterns during pregnancy is not a simple matter. There are many reasons why drinking alcohol is a part of a person's life at a particular time. Addiction can be a way of trying to manage an unmanageable life. For many mom's drinking and started long before they became pregnant. In fact, the pregnancy may be happening within a well developed addiction.

Prepared by FASD Support Network of Saskatchewan Inc. (2005) Adapted from Streissguth, A. (1997). Seven Common Misconceptions about FAS/FAE. Permission granted September 2005.

Primary Disabilities and Secondary Disabilities

Fetal Alcohol Spectrum Disorder (FASD) describes a range of lifelong disabilities resulting from prenatal alcohol exposure. Maternal alcohol consumption injures the structure, function and design of the brain, resulting in a physical disability, that is mostly invisible to us. What is visible to us are the behavioural signs and symptoms for which accommodations need to be made. (Malbin 2006). It can be helpful to understand the various primary disabilities as well as the secondary disabilities associated with FASD.

Primary disabilities

Primary disabilities are those disabilities that one is born with that are directly caused by the prenatal exposure to alcohol. Primary disabilities may impact cognitive, physical, behavioural, or sensory functioning. The most significant primary disabilities are those that result from neurological injury to the central nervous system. Some examples of primary disabilities are impaired **cognitive functioning** (how we think, mental tasks, intellectual functioning) including:

- slower cognitive pace and reduced ability to pay attention
- difficulty with judgment, perception, prediction, and planning
- trouble with abstract thought and generalizing information from one setting to another
- difficulty with learning and memory, leading to story telling, filling in the blanks

In addition to impaired cognitive functioning, **behavioural disabilities** are an issue. Some examples are:

- problems with interpersonal skills and reading social cues
- impulsive actions along with a lack of inhibitions
- poor understanding of boundaries and ownership
- struggles with regulating emotion
- rigid and inflexible behaviour patterns
- being easily influenced, overly trusting and **dysmaturity,** meaning individuals act younger than they are
- sleep problems and being overly active

While many of the disabilities relate to cognitive functioning and behavioural issues, there are some **physical and sensory disabilities** that are worth noting, such as:

- delayed motor development and poor motor control
- lower height and weight along with characteristic facial features
- hearing impairments and auditory processing problems
- injury to body systems, skeletal, renal, and circulatory systems
- high or low pain tolerance, sensitivity to light, sound, texture or stimulation

This is a rather long list. Keep in mind that no two people are alike and each person will experience varying affects; some individuals will be affected mildly and others will be significantly affected.

"Keep in mind that no two people are alike and each person will experience varying affects."

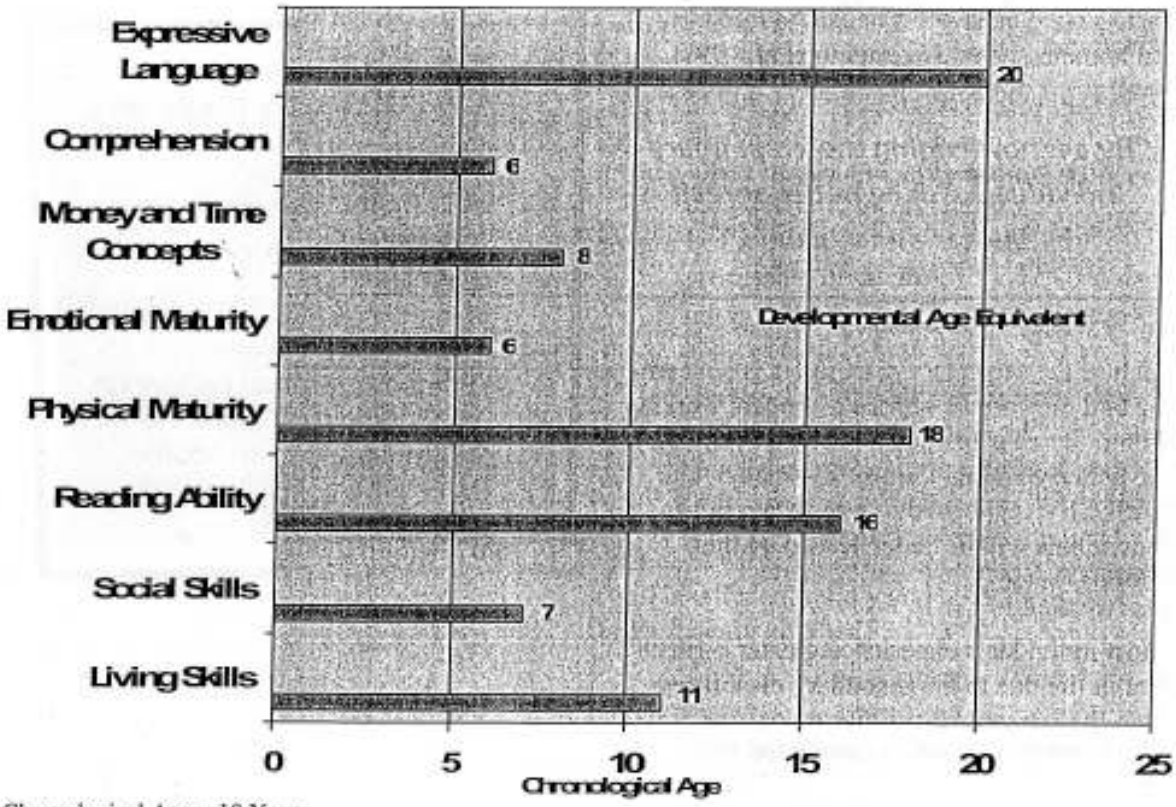
Developmental Age and FASD

Research has shown that people with Fetal Alcohol Spectrum Disorder (FASD) are developmentally much younger than indicated by their chronological age. To further complicate this, there is often a noticeable difference in development or ability in the various areas. Most of us, whether professionals or parents, expect children and youth to develop and grow according to an accepted chronological schedule and for physical, cognitive, and psychosocial development to occur at about the same rate. Unfortunately for individuals affected by prenatal alcohol exposure, these assumptions about development create a "poor fit" between abilities and the expectations placed upon individuals.

In the example below, the chart indicates the development of a youth of 18 years. You can see that the physical development seems to be "on time" yet emotional maturity and social skills lag far behind. This is not uncommon and can create difficulties.

Think about the amount of supervision you might typically provide for an 18 year old, yet consider the emotional maturity and comprehension skills of the 18 year old affected by FASD. Clearly, additional structure and supervision would be required. Another example, picture an 18 year old, articulate and clear in her ability to express herself, yet unable to complete and submit assignments by the due date or get to school on time.

Diane Malbin suggests that we adjust our expectations and "think younger" when we assign responsibilities, intervene, and support those with FASD. By adjusting our expectations, thinking younger, and making accommodations in the environment for the existing brain injury, we create a good fit and promote better outcomes for individuals with FASD. Each of us, regardless of our area of service provision can engage in this process of creating a "good fit."



Chronological Age = 18 Years

Source: Malbin, D. (2002) *Trying Differently Rather than Harder*. 2nd Edition. Portland, Oregon: FASCETS.

FASD: Primary Disabilities and Secondary Disabilities

Secondary disabilities

Secondary disabilities are those difficulties that arise later in life due to a poor fit between the individual's needs, level of functioning and the environment. Complications arise most often because of:

- undiagnosed primary disability,
- lack of intervention,
- lack of services,
- ineffective strategies,
- and unrealistic expectations.

Some common secondary disabilities and characteristics related to FASD are mental health problems, low self esteem, difficulties with school, trouble with the law, being a victim of crime, substance use and abuse, addictions, employment problems, inappropriate sexual behaviour, housing problems and homelessness (Streissguth et al. 1997).

"By acknowledging the brain injury individuals will be better served by the various systems."

Each of the secondary disabilities is concerning and the various service providers working within these sectors must become aware of the underlying brain injury associated with FASD. By acknowledging the brain injury individuals will be better served by the various systems.

Most individuals experience greater difficulties in life due to the secondary disabilities than the primary disabilities associated with FASD. Fortunately, secondary disabilities can be prevented. The presence of protective factors like a stable nurturing home, early diagnosis, effective support and environmental accommodations will help to prevent secondary disabilities and help to minimize the impact of the secondary factors. With the recognition that FASD is a disability there is a greater likelihood that accommodations will be made and therefore the outcomes for youth and adults can be improved.

Common Secondary Disabilities

- Mental health problems
- Substance use
- Addictions
- Legal problems
- Employment problems
- Inappropriate sexual behaviours
- Emotional problems and violence
- Housing problems and homelessness

Streissguth, A. (1997) *Fetal Alcohol Syndrome: A Guide for Families and Communities*. Baltimore, MD: Paul H. Brookes Publishing. pp 270 -275.

8 Magic Keys to Supporting Individuals with FASD

While there is no recommended "cookbook approach" to working with individuals with FASD there are strategies that work, based on the following guidelines:

Concrete – Individuals with FASD do well when people talk in concrete terms; do not use words with double meanings, or idioms. Because their social-emotional understanding is far below their chronological age, it helps to "think younger" when providing assistance and giving instructions.

Consistency – Because of the difficulty individuals with FASD experience trying to generalize learning from one situation to another, they do best in an environment with few changes. This includes language. For example, teachers and parents can coordinate with each other to use the same words for key phrases and oral directions.

Repetition – Individuals with FASD have chronic short-term memory problems; they forget things they want to remember as well as information that has been learned and retained for a period of time. In order for something to make it to long-term memory, it may simply need to be re-taught and re-taught.

Routine – Stable routines that don't change from day to day will make it easier for individuals with FASD to know what to expect next and decrease their anxiety, enabling them to learn.

Simplicity – Remember to Keep it Short and Sweet (KISS method). Individuals with FASD are easily over-stimulated, leading to "shutdown" at which point no more information can be assimilated. Therefore, a simple environment is the foundation for an effective school program.

Specific – Say exactly what you mean. Remember that individuals with FASD have difficulty with abstractions, generalization, and not being able to "fill in the blanks" when given a direction. Tell them step by step what to do, developing appropriate habit patterns.

Structure – Structure is the "glue" that makes the world make sense for an individual with FASD. If this glue is taken away, the walls fall down! An individual with an FASD achieves and is successful because their world provides the appropriate structure as permanent foundation.

Supervision – Because of their cognitive challenges, individuals with FASD bring a naiveté to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behaviour.

Not Working?

When a situation with an individual with FASD is confusing and the intervention is not working, then:

Stop Action!
Observe.
Listen carefully to find out where he or she is stuck.
Ask: What is hard? What would help?

Reprinted with Permission. Evensen, D. & Lutke, J. (1997). 8 Magic Keys. Adapted version, (2005) Minnesota Organization on Fetal Alcohol Syndrome.

Hints for Communicating Clearly

Clear communication is important when supporting individuals with FASD. The words and actions we use to send messages can help or hinder communication. For people affected by FASD, communication can be difficult due to the many chances for misunderstandings of words and actions. There are a number of things that parents, caregivers and support people can do to improve communication. Here are a few ideas for you to try.

Use clear concrete words and short sentences. Say exactly what you mean with fewer words and you will find your messages are better understood. This is sometimes referred to as using plain language. Plain language does not mean that you talk down to someone; you simply speak clearly and briefly. Try to keep sentences to 10 words or less.

Be specific. General terms and abstract concepts are difficult to understand. Be precise and specific especially with times, locations, and tasks. When giving directions, or teaching a skill, tell the person step by step exactly what to do, in the order that the tasks need to be done.

Use repetition in your words and language. Key phrases used in the same way for the same activities are helpful. Regular use of key phrases helps to ensure understanding, builds routines and creates predictability in a world that is often chaotic and unpredictable.

Avoid puns, metaphors and words or phrases with double meanings. The use of figures of speech, phrases where the literal meaning is very different than the intended meaning, causes confusion and frustration. Equally confusing are idioms. Idioms are phrases with a meaning that seems unrelated to the actual words that are used. Examples of commonly used idioms: It's raining cats and dogs out there! This is as easy as pie. Let's ditch class. I feel antsy. (Source: http://www.eslcafe.com/idioms/idmngs.html ESL Idiom page). Individuals with FASD may feel lost in a conversation that includes figures of speech because they can not decipher the subtle meanings of these phrases.

Avoid jargon and acronyms. Terms and acronyms that are known only to groups with specialized knowledge exclude others from the conversation. This is an especially important reminder for those who are having meetings with teens or adults with FASD.

Sarcasm, exaggeration and jokes can be puzzling. What is intended as light humour or a joke may leave a person with FASD feeling hurt or angry. It is uncomfortable when others are laughing and you do not understand what is funny. An offhand comment may be taken as an insult or a joking comment might be understood as the truth.

Keep questions short and clear; calmly prompt for answers. Questions, by their very nature, require thought in order to give an answer. If a person with FASD needs to think hard to figure out what is being asked or if they forget the question, they will not be able to come up with an
answer. This is not because they do not know the answer, but because they could not figure out the meaning of the question.

Use a calm and clear voice. Messages can be lost when given in a highly emotional or excited tone. Simple gestures along with clear and direct phrases may be helpful.

Use varied nonverbal language. Figure out the nonverbal language that works such as eye contact, touch, gestures and facial expressions. This will differ with each individual.

Listen carefully. You can pick up on lack of understanding, miscommunication or confusion more quickly and address the problem rather than letting things escalate.

Source: *Network News* (2006) FASD Support Network of Saskatchewan Inc.

FASD – Vancouver Based Resources

MCFD & Aboriginal Organizations have FASD Key Workers around BC. They assist FASD clients, parents, relatives, & foster parents to access services. Locally there are FASD Key Workers at the South Vancouver Youth Centre @ 604 325 2004; Vancouver's Crabtree Corner @ 604 216 1656; The Children's Foundation (Vancouver) @ 604 434 9101 or 604 721 6855; Pacific Community Resources Society (PCRS, Vancouver & Surrey) @ 604 412 7950; The Vancouver Aboriginal Friendship Centre @ 604 251 4844 ext. 311; BC Centre for Ability (Vancouver & Burnaby) @ 604 451 5511; The Squamish Nation (North Vancouver) @ 604 985 4111; The Centre for Child Development in Langley @ 604 533 3088; in Maple Ridge/Pitt Meadows @ 604 463 0881 ext 302; and many others in the lower mainland of BC

Lower Mainland based PLEA community services has FASD expert workers @ 604 871 0450, and KidStart has 1 to 1 volunteer mentors @ 604 629 3360. The Vancouver PLEA CUE Employment Program assists clients to gain employment and educates employers @ 604 629 3368 (referrals from Youth Probation Officers)

Vancouver's Hey Way Noqu @ 604 874 1831 has FASD day program for 16+

Vancouver's Urban Native Youth Association counselling staff (and all UNYA staff) have FASD training @ 604 254 7732, & UNYA has Kinnections 1 to 1 volunteer mentors

Vancouver Native Courtworkers with FASD knowledge are: Flora Raynes @ Youth Court @ 604 660 7455 & Lyle Dixon @ Adult Court @ 604 660 1101; Surrey Crown Counsel Jodie Harris has FASD knowledge @ 604 572 2360; Vancouver Youth Justice Crown Counsel Linda Selbie and Carol Konkin @ 604 660 9123 have FASD knowledge

Vancouver Police has trained many officers; Corey Bech @ 778 837 7243 (VSB school liaison officer); Inspector John de Haas @ 604 717 3295

MCFD has Vancouver Youth Probation Officers with FASD expertise: Michael Truscott, Alix Devlin & Richard Willier @ 604 660 6868. Fiona Pardy (Fraser Valley Youth Justice Consultant) @ 604 951 5879 and Sandra Manzardo (Vancouver Youth Justice Clinical Supervisor) @ 604 660 9235 have FASD knowledge

BC Centre for Ability has seasonally adapted family programs and teen programs in Burnaby. Contact Joni Petrica @ 604 630 3030 or Rosanna Battista @ 604 451 5511 ext 460

MCFD has Youth Justice Intensive Support and Supervision Program (ISSP) workers in BC for those involved in the Youth Criminal Justice System – these workers can be accessed by a Youth Probation Officer, and can assist those living with FASD

Vancouver's Crabtree Corner has mother & grandparent support groups @ 604 216 1659; Vancouver Native Health has a caregivers group Tuesdays 10am-12pm @ 717 Princess St. @ 604 251 4844 ext 311; The Children's Foundation in Vancouver @ 604 434 9101 has parent support groups and FASD awareness info

Vancouver Island's FASD camp for a person and families/workers to attend: Whitecrow Village Camp in Nanaimo @ 1 888 716 3231

PCSR has Vancouver's Westcoast Alternate High School, along with FASD experts in Vancouver mainly @ 604 412 7950 & at the Broadway Youth Resource Centre @ 604 709 5720; some Vancouver schools are sensitive to those affected by FASD; Vancouver School Board contact is Debra Martel (Aboriginal Principal for Vancouver) @ 604 713 5000; Surrey's Fastrack Program @ Creekside Elementary @ 604 543 9132 & Surrey's Fastrack High School Program @ 778 578 4439 (referrals are needed for both schools)

Vancouver's Tim Harrison (Employment Assistance Worker for a FASD Pilot Project-for those diagnosed & Youth to adult transitioning clients who are referred by Social, Probation or Support Workers) has federal government funding applications information @ 604 376 6508

Vancouver Native Health's Circle of FASD Trained Elders are seeking further funding to re-open; Blair Harvey is the team leader @ 604 722 8542. They offer a caregivers group. Additionally, some Elders are open to work individually with those affected with FASD-this is ongoing

Surrey's The C.R.E.W. Inclusive Social & Learning Group has a 6 week program for 17-26 year old young men, & a 6 week program called The Totally Beautiful Inclusive Social & Learning Group for 16-24 year old young woman. Both are for those, "having difficulty finding inclusive social activities". Contact Sarah Phillips @ 604 320 1960 (daytime) or 604 583 8440 (evening).

Assessment sites/helpers: Dr. Christine Loock or nurses @ Vancouver's Sunnyhill Hospital, Ray-Cam Community Centre, Vancouver Native Health or Crabtree Corner; The Asante Centre in Maple Ridge does free Youth Justice & pre-adoption in care assessments, and paid assessments for all others; private psychologists in BC provide fee for service assessments too

The Justice Institute of BC has some online FASD courses; Sunnyhill Hospital has FASD workshops; Pacific Community Resources Society @ 604 412 7950 does presentations; The Asante Centre @ 604 467 7101 does team training, workshops, individual presentations, & have an online resource centre called the Minga Market Place – and learning materials on their website; Lethbridge College (Alberta) and The College of New Caledonia (BC) have online FASD courses; The Vancouver Police have offered training to their members and others previously; Vancouver Aboriginal Youth Probation Specialist Richard Willier provides presentations @ 604

660 6713; Vancouver Native Courtworker Lyle Dixon offers presentations @ 604 660 1101; Vancouver's Gladys Evoy at Crabtree Corner supplies presentations @ 604 216 1659

ADULTS:

John Howard Society of BC and the Lower Mainland @ 604 872 5651 has adult housing and outreach services for those meeting Community Living BC requirements; housing for adult parolee's in Vancouver and Abbotsford

Circle of Eagles Lodge Society (for adult parolees) @ 604 874 9610 (Leah Dan, FASD manager); Westcoast Genesis and Mariah Carrie Cottage in New Westminster have housing for adult parolees and some adult homeless folks @ 604 515 2950 & 604 636 3590

FASD National Screening Tool available online @ www.ken.caphc.org

FASD Experts: Jan Lutke @ info...@fasdconnections.ca; Dr. Sterling Clarren @ 604 875 2996 ; Dr. Julie Conroy @ 604 467 7101