



## **Fetal Alcohol Spectrum Disorder (FASD)**

Fetal Alcohol Spectrum Disorder (FASD) is a general term that describes the range of disabilities that may affect an individual if his or her birth mother drank alcohol while she was pregnant. FASD is a major cause of preventable birth defects and the leading form of developmental delay in North America. FASD is not in itself a diagnosis. The possible diagnoses within the range of disabilities include:

- Fetal Alcohol Syndrome (FAS)
- Partial FAS (pFAS)
- Alcohol-Related Neuro-developmental Disorder (ARND)
  
- Although not a medically identified term until 1968 (France) and 1973 (Washington), this disability has been around since women began to drink alcohol while pregnant.
  
- Alcohol is a toxin; a poison that may impair the developing brain of a fetus.
  
- A child's brain develops throughout pregnancy and continues to develop into adulthood.
  
- Individuals live with a range of, or differing effects of prenatal alcohol exposure depending on when mom drank, what parts of the brain were developing at that time, etc. These varying effects are known as the Spectrum of fetal alcohol.
  
- Living with an FASD is like:
  - The early onset of Alzheimer's
  - Living in a different culture with a different language and different social expectations
  - A Traumatic Brain Injury (TBI)
  
- There are no statistics on the number of individuals who live with this disability in Canada as diagnoses are very limited.
  
- No woman intentionally drinks alcohol to harm her baby.
  
- FASD occurs in all countries of the world. Individuals from all cultures, economic status, education levels, income, etc. can be affected.
  
- A child may only be born with an FASD IF mom drinks alcohol while she is pregnant.
  
- A woman with an FASD WILL NOT give birth to a child with an FASD if she does not drink alcohol while she is pregnant.



- If dad drinks alcohol, his child will not be born with an FASD. However, the baby, if carried to term, may have other problems.
- FASD is a primary disability (what a child is born with).
- If appropriate supports ARE NOT put in place (the earlier the better), secondary disabilities could develop and follow the individual throughout life. Some examples are:
  - disrupted school experience
  - trouble with the law
  - go to jail or an institution
  - inappropriate sexual behaviour
  - substance abuse
  - unable to live independently
  - problems with employment
  - mental health problems
- Some aspects of FASD are visible; we can see them, for example, facial features (which occurs during a very short time period of pregnancy).
- Many aspects of FASD are invisible, we cannot see them, for example, brain injury (we cannot see the brain).
- People are more likely to help others with disabilities that can be seen. The majority of people with invisible impacts of FASD do not receive support; they fall through the cracks, are expected to behave like individuals who do not live with disabilities.
- Youth and adults who live with an FASD live with varied characteristics.
- Fetal Alcohol Disorders are developmental disabilities; a person's chronological age and developmental capabilities may not be equal:
  - Individuals may function at a much younger age
- Characteristics or difficulties may be similar to other members of society. However they are exaggerated:
  - Characteristics are more significant
  - Challenges and difficulties occur more frequently
- Many of these characteristics are contributing factors to these individuals becoming involved in the legal system. People who live with this disability are over represented in the justice system.



## Fetal Alcohol Spectrum Disorders and the legal system

- Our brain has many components: One component is Executive Functioning (E.F.):
  - Planning
  - Time (from investigation to completion of court process)
  - Ordering
  - Memory (recalling events for investigators and/or during testimony)
  - Emotions

All are needed at different times during the legal process.

- Think of E.F. like:
  - The Chairperson of a Board of Directors
  - The head of a company or department
  - School principal or community leader

If that individual is not functioning effectively, the organization experiences challenges and difficulties.

Therefore, for an individual who may live with an FASD, focus on Adaptive Functioning (A.F.) or Daily Living Skills'

- Independent living: We should not expect an adult who functions at the same level as an eleven year old to live independently and carry out all responsibilities of adults.
- Individuals who live with an FASD are vulnerable throughout the legal process.
- Someone living with this disability can be:
  - A victim one week
  - An offender the next
  - A victim at a later time
- It is important that legal personalities do not get frustrated if they see the same client on successive occasions.
- We need to learn all we can about this disability and identify clients.



- Information needs to be shared with successive individuals throughout the legal process to enable equal access to justice and allow personnel to be prepared and accommodating.
- Individuals may have difficulties with:
  - Understanding the legal process
  - Language used throughout the legal process; much of it is abstract
  - Roles of individuals within the legal process
  - Staying focussed
  - Understanding procedures and documents
  - Recalling events
- Communication is important!
- Use plain language.
- Communicate at clients' capabilities; do not talk down to them.
- Ensure clients understand what you are saying. How they are interpreting what you are saying?
  - For example, there is a Supreme Court of Canada ruling that police must ensure youths understand their rights
- Ensure that you understand what clients are saying. How are you interpreting what they are saying?
- Many words have more than one meaning: Say what you mean, mean what you say!
- Explain what will happen and what has happened before and after each phase of the legal process:
  - Investigative stage
  - Restorative Justice
  - Court/Trial
  - Probation
- We need to RALLY around people with this disability just as we rally around famous people, sports personalities, and others who acquire brain injuries
- Valarie Massey states: You can't do everything, BUT you can do something!



**Characteristics of adolescents (12-17) and adults (18 and over)  
who are diagnosed with, or suspected of having an FASD;  
Individuals may live with one or more of the following:**

- ✓ Alcohol and drug use/misuse
- ✓ Appears to have capacity but may not have actual ability
- ✓ Co-dependence
- ✓ Co-occurring disabilities or disorders
  - Developmental disability
  - Cognitive impairment
  - Intellectual disability
  - Learning disability
  - Mental health issues
  - Social development issues
  - Behavioural issues
- ✓ Difficulty accessing, participating in positive leisure activities
- ✓ Difficulty drawing conclusions
- ✓ Difficulty learning from mistakes
- ✓ Difficulty making decisions
- ✓ Difficulty managing relationships and/or parenting
- ✓ Difficulty processing information
- ✓ Difficulty reasoning (thinking in a logical, clear way)
- ✓ Difficulty seeing another person's viewpoint
- ✓ Difficulty taking daily medication or birth control pills on a regular effective basis
- ✓ Difficulty transferring learning from one situation to another (generalizing)
- ✓ Difficulty understanding abstract concepts (rules, values ownership, honesty, responsibility, etc.)
- ✓ Difficulty understanding money and its value)
- ✓ difficulty understanding safety issues for self and others
- ✓ Difficulty understanding the limits of their disability
- ✓ Difficulty understanding which actions might get them into trouble
- ✓ Distractible
- ✓ Does not want structure, but needs it
- ✓ Easily bored
- ✓ Easily influenced
- ✓ Easy for others to take advantage of
- ✓ Employment difficulties
- ✓ Fearless
- ✓ Gullible and vulnerable
- ✓ Homelessness
- ✓ Hygiene issues
- ✓ Impulsive
- ✓ Inappropriate sexual activity



- ✓ intrusive
- ✓ Lack social sensitivity
- ✓ Limited independent living or daily living skills
- ✓ Manipulative (survival tactic)
- ✓ Memory deficits
- ✓ Mental health issues
  - Anxiety Disorders
  - Bi-polar Disorder
  - Depression
  - Mental and emotional overload
  - Panic Attacks
  - Perseveration
  - Schizophrenia
  - Sleep Disorders
  - Suicide
  - Suicide by “impulse”
- ✓ Mood disorders including depression
- ✓ Needs supervision
- ✓ Quick recovery from a crisis (may not understand the seriousness, which puts them at risk)
- ✓ Poor communication and/or language skills
- ✓ Poor judgment
- ✓ Poor reflective skills
- ✓ Poor understanding of personal boundaries
- ✓ Problem solving difficulties
- ✓ Risk takers
- ✓ Self-esteem issues
- ✓ Talk much better than they can think
- ✓ Time (time of day, passage of time, or past, present, future)
- ✓ Transition or change difficulties
- ✓ Unable to think about the consequences of their actions
- ✓ Uneven sleep patterns
- ✓ Uninhibited
- ✓ Unpredictable
- ✓ Vulnerable to gangs
- ✓ Vulnerable to ideas in movies, videos, music, TV and advertisements

***Note: These characteristics may appear to be typical behavior in a normal person, but in individuals who have been disabled by prenatal exposure to alcohol, these traits occur in grossly exaggerated form and do not respond to typical interventions.***



*A Developmental Overview of FAS/E through the Eyes of Parents*  
*1998 FAS Family Resource Institute*

Compiled by Doreen Reid, Department of Justice, Government of the Northwest Territories 2009

## **Hints for Communicating Clearly with Persons with FASD**

by Beverly Palibroda

*Network News Summer 2006*

FASD Support Network of Saskatchewan Inc.

When we interact with others we continuously send and receive messages. The words and actions we use to send messages are powerful and can either help or hinder communication. For people affected by FASD, communication can be difficult due to the many chances for miscommunication and misunderstandings of words and actions. There are a number of things that parents, caregivers and service providers can do to help improve communication with persons affected by FASD. Here are just a few ideas for you to try.

**Use clear concrete words and short sentences.** If you say exactly what you mean with fewer words 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 in a way that is clear and brief. The individual with FASD can grasp the meaning of the message and she or he does not need to sort out the meanings of large or unfamiliar words or try to understand complex sentences. 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. Write the steps down and have the list posted in a convenient spot.

**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. Some 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/id-mngs.html> ESL Idiom page). Persons with FASD may feel lost in a conversation that includes figures of speech because they can not decipher the subtle meanings of these phrases. They may respond in ways that do not make sense. They may stay quiet because they do not want to feel they are not part of the group or seem like they are not paying attention to what is going on.

**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. The service providers might know exactly what they mean when they use jargon specific to their area of knowledge, but the rest of us usually don't understand!

**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 when this was not the intention. It is very 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 works such as eye contact, touch, gestures and facial expressions. This will differ with each individual. Nonverbal skills can ensure that you are both paying careful attention to the conversation.

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

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