

# **Living with Fetal Alcohol Spectrum Disorder**



## **A Guide for Parents and Caregivers**



Drug Education Network Inc

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*This document is currently under review.  
The Drug Education Network Inc. are seeking feedback  
and suggestions on how this booklet might be improved  
or any information that might be added.  
We would welcome your contributions. If you have a  
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The Drug Education Network, 2011*

This document was developed by the Drug Education Network Inc in Tasmania. Your acknowledgement of our work will be much appreciated. We would also be pleased to receive feedback and to know how many copies of this resource have been distributed. Please contact Vicki Russell at the DEN via email [Vicki@den.org.au](mailto:Vicki@den.org.au) or telephone 1300 369 319 or 03 6211 2350

## **Foreword**

The 1<sup>st</sup> Conference on Fetal Alcohol Spectrum Disorder: Building Community Care (June 2007) was held in Launceston, Tasmania and this event marked the Drug Education Network's commitment to raising public awareness to prevent the risk of harms associated with fetal alcohol exposure in Tasmania. From consultations at the Conference, the need for a Guide for parents and caregivers emerged and *Living with FASD: A Guide for Parents and Caregivers* evolved. The Drug Education Network Inc. has been continuing a whole range of strategies in its prevention work to raise public awareness of FASD and in late 2009, a prenatal exposure to alcohol Prevention Handbook was launched and in early 2010, a prenatal exposure to alcohol Prevention Taskforce was established.

Since completion and distribution of the first edition of *Living with FASD: A Guide for Parents and Caregivers* in 2009, some minor changes to this second edition have been made based on the feedback received in the review period. Changes include the use of a larger font; increased space in setting out the document; and the inclusion of pictures. The term "secondary behaviours" has been changed to "secondary conditions" to reflect the reality that most outcomes are not about individual behaviour but the lack of understanding and inflexibility of service systems.

The author wishes to acknowledge the range of reference texts and resource materials on which the information in this Guide is dependent. Sincere gratitude and thanks are extended to the people living in the Northern suburbs of Launceston who supported the Steps Together Project, as well as caregiver groups like 'Grandpower' and Tasmanian Foster Carers Association who are challenged daily with the care of children and young people living with this largely 'invisible' spectrum of disabilities.

For children, young people and adults living with FASD, the experiences of daily life are fraught with systemic and community misunderstanding, the application of standardised

expectations which are invariably beyond their reach and against which their mistakes are measured. In this context of unfairness, they are often labelled recalcitrant, willful, lazy and unwilling to change their behaviour and are subjected to a variety of labels based on behaviour and not the underlying brain damage. Their true mantra is simply one that says they 'cannot do' rather than they 'won't do'<sup>1</sup>.



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<sup>1</sup> Malbin, D. FASCETS 2005

## **Introduction**

Very few children living with FASD continue to live in the care of their birth parents<sup>2</sup> and as many as 85% are suggested to be in the care of grandparents and/or other relatives, foster parents, or adoptive parents. These children can experience multiple 'out of home' care placements before securing permanent care and their complex behaviours and high range of needs makes supportive carers a priority. For children living with FASD, a stable and nurturing environment is one of the key protective factors<sup>3</sup>.

Caring for children living with FASD can be stressful, frustrating and tiring especially when support systems fail to acknowledge developmental disabilities as brain damage. Such children frequently require a multitude of specialist support services – education, counselling, social, legal and medical. Whilst many medical practitioners will recognise FAS, the assessment and diagnosis of FASD by experienced professionals can be problematic. Training in FASD assessment and diagnosis is not currently offered in Australia and the process requires the expertise of a multi-disciplinary team willing to share information with agreement to meet and plan for future care and intervention.

The assessment and diagnostic process is a particularly sensitive time for caregivers, especially for birth parents. This Guide is one step towards helping parents and carers accept the child's situation (which should never be considered as hopeless); identify strategies to improve outcomes for children; and increase public awareness of FASD. Carers are the experts in working with individuals living with FASD and are encouraged to share their experiences and any information and resources collected with other parents/caregivers and professionals.

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<sup>2</sup> Burd (2001) *Children with Fetal Alcohol Syndrome: A Handbook for Parents and Teachers*. Grand Forks. ND. North Dakota Fetal Alcohol Syndrome Center.

<sup>3</sup> Streissguth et al (2003) *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* University of Washington Press: Seattle.

In the preparation of this Guide, there are some resource materials and their producers who must be acknowledged:

1. National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) [www.nofasard.org](http://www.nofasard.org)
2. Teaching Students with Fetal Alcohol Spectrum Disorder, Alberta Learning
3. Burd, L., *Children with Fetal Alcohol Syndrome: A Handbook for Parents and Teachers*. Grand Forks. ND. North Dakota Fetal Alcohol Syndrome Center. (2001)
4. Malbin, D., *Trying Differently Rather Than Harder*, Tetric Northwest, FASCETS Inc. (2002)
5. *Identification and Care of Fetal Alcohol-Exposed Children: A Guide for Primary-Care Providers*, National Institute on Alcohol Abuse and Alcoholism, Office of Research on Minority Health, National Institute of Health. Online at [www.cme.wisc.edu/online/fas/info](http://www.cme.wisc.edu/online/fas/info). Downloaded 15/02/05
6. Graefe, S., *Living with FASD: A Guide for Parents* Groundwork Press: Vancouver 2006
7. Alton, H., & Evenson, D., *Making a Difference: Working with students who have Fetal Alcohol Syndrome*. Yukon Education, Government of Yukon 2006

#### Recommended reading

1. Liz Lawryk's book: *Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder*. OBD Triage Institute Inc. Canada (2005)
2. Malbin, D., *Trying Differently Rather Than Harder*, Tetric Northwest, FASCETS Inc. (2002)
3. Russell, E. *Alcohol & Pregnancy - No Blame, No Shame*; Zeus Publication  
This book is the sequel to *Alcohol and Pregnancy - A Mother's Responsible Disturbance*, by Elizabeth Russell (NOFASARD Qld Rep). Along with a short history of the author and her family it explores how prenatal alcohol exposure has affected the lives of sixteen Australians. Stories range from a mother challenged by symptoms consistent with FASD who has given birth to a baby, now a teenager, who was prenatally exposed to alcohol; to the exasperation of a young woman with pFAS trying to live her life based on the values with which she was raised, but falling short of her goal again and again. These stories highlight how they coped, strategies they used, mistakes they made, their pain and heartache and their triumphs and tragedies.
4. Russell, E. *Alcohol & Pregnancy - A Mother's Responsible Disturbance*; Zeus Publication  
Author, Elizabeth Russell (NOFASARD Qld Rep) This book is a must-read for parents and health professionals, and is an account of how prenatal alcohol exposure can have dramatic affects on children's health and wellbeing. Elizabeth Russell uncovers the circumstances that lead to both her children being diagnosed with Fetal Alcohol Spectrum Disorder, (FASD), a condition that occurs when a pregnant woman consumes alcohol.  
NB: Both books can be ordered through the NOFASARD Website.

## **Definitions**

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

FASD is an educational term which has been in use since 2003. FASD is not a diagnosis but rather, it is an umbrella term that covers the full range of possible birth defects and/or developmental disabilities that can be caused by prenatal exposure to alcohol. FASD is inclusive of Fetal Alcohol Syndrome (defined below) and is an effective way to indicate there is a spectrum of physical, cognitive and behavioural characteristics, unique to each individual living with FASD. The disabilities that fall within FASD are often 'hidden' because any physical characteristics can be subtle and may be unrecognised<sup>4</sup>.

### **Fetal Alcohol Syndrome (FAS)**

FAS is a diagnostic term first used in 1973 (Smith and Jones 1973). Those affected by FAS are often diagnosed in early life because they exhibit the features defined by a hallmark face which predicts brain damage and prenatal exposure to alcohol (Teaching Students with Fetal Alcohol Spectrum Disorder, Alberta Learning). The facial features typical of FAS can soften with age. A medical diagnosis of Fetal Alcohol Syndrome is based on pre or post natal growth restriction, central nervous system dysfunction and the presence of measurable physical characteristics, most commonly found in the measurement of facial features. FAS is clearly identified through hallmark physical characteristics and is most often recognizable to health and medical professionals because of the visible signs of prenatal exposure to alcohol, however this Syndrome is predicted as the least prevalent of the spectrum of birth defects. For diagnosis three criteria are used<sup>1</sup>:

1. A pattern of facial abnormalities
2. Growth deficiencies
3. Central nervous system impairment (brain damage).

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<sup>4</sup>Graefe, S. (2006), *Living with FASD: A Guide for Parents*. Groundwork Press: Vancouver.

Impairments include structural impairments of the brain; neurological problems such as impaired motor skills; poor coordination and visual problems; and behavioural and/or cognitive problems such as mental disability; learning difficulties; poor impulse control; problems in social perception; and problems in memory, attention, reasoning and judgment.

### **Partial Foetal Alcohol Syndrome (pFAS)**

Partial FAS is a diagnostic term used when children present with some of the characteristics facial abnormalities of FAS and evidence of either growth deficiency or central nervous system impairment when significant prenatal alcohol exposure is documented.

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

Alcohol related birth defects (ARBI) describes malformations in the skeletal and major organ systems.

### **Alcohol related neuro-developmental disorder (ARND)**

ARND describes the functional or mental impairments linked to prenatal alcohol exposure.

## **Understanding FASD.**

Prenatal exposure to alcohol is one of the most common causes of developmental disabilities in developed nations and Fetal Alcohol Syndrome (FAS) was first named in 1973<sup>5</sup>. It took some time before the range of organic brain damage from prenatal exposure to alcohol was fully understood and the tragic implications for individuals to be appreciated. While FAS is estimated to affect 1 in 1000 children born, the broader spectrum of outcomes (FASD) is estimated to affect up to 1 in every 100 live births or about 1% of the population<sup>6</sup>. Recent research has indicated this rate might be even higher<sup>7</sup>, as May and Gossage (2010) point out;

FAS prevalence in the general population of the U. S. can now be estimated to be between 0.5 and 2 per 1,000 births, and the prevalence of FAS and ARBD combined is likely to be at least 10 per 1,000, or 1 percent of all births. This rate is too high for any population to accept.

FASD is often declared as an 'invisible' disability as the majority of individuals living with FASD do not necessarily have any or all of the physical characteristics of FAS. What is most often seen is behaviour and it is behaviour which can act as 'windows of opportunity' to understanding which kinds of support and interventions are most appropriate for each individual affected by FASD<sup>8</sup>.

Many individuals affected by FASD fail to achieve the best quality of life possible because their brain damage is undetected. Early diagnosis and assessment of needs is therefore crucial to understanding and helping individuals living with FASD. According to Liz Lawryk (2005:5), "a diagnosis of FASD identifies to the world the confidential and personal struggles of two people: a child and his or her biological mother. In isolating them we not only disrespect them but inadvertently chastise and hold them out for public judgment...we need to make every effort to shield our kids from unnecessary ridicule and boost their self-esteem."

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<sup>5</sup> Jones, K., Smith D.W., "Recognition Of The Fetal Alcohol Syndrome In Early Infancy". *Lancet* 2. (1973)

<sup>6</sup> Alberta Learning: Teaching Students with Fetal Alcohol Spectrum Disorder

<sup>7</sup> May, P.A. & Gossage, J. P Estimating the Prevalence of Fetal Alcohol Syndrome: A Summary.  
<http://pubs.niaaa.nih.gov/publications/arh25-3/159-167.htm>

<sup>8</sup>Malbin, D., *Trying Differently Rather Than Harder*, Tetrice Northwest, FASCETS Inc. (2002)

### **Primary Disabilities.**

The primary disabilities associated with prenatal exposure to alcohol are those that most clearly reflect underlying brain damage. There is wide variability in frequency and magnitude and none are exclusive to prenatal exposure to alcohol. This can lead to diagnoses based on observable behaviours that ‘mask’ the underlying brain damage. The aim here is to find an accurate explanation of where the child/children in your care fit within the wide spectrum of possibilities within FASD as a disorder – physiology, thinking abilities, expectations<sup>9</sup>. Caution needs to be taken to account for the previous life experiences of children which are sometimes traumatic – abuse, neglect, a sense of abandonment; isolation. The primary behaviours include:

### **Compromised Executive Functioning:**

- Difficulty planning, predicting, organising, prioritising, sequencing, initiating and following through.
- Setting goals, complying with contractual obligations, being on time, adhering to a schedule.

*Liz Lawryk explains how overall “executive functioning refers to the abilities that underline independent, purposeful, contextually appropriate behaviour.” Poor executive functioning is “clearly the essence of the disability” called FASD.*

### **Poor Memory:**

- Information input, integration, forming associations, retrieval and output are deficits.
- Difficulty learning from past mistakes - often the same mistakes are made over and over again despite increasingly severe consequences.
- Inconsistent memory or performance - remembering a task for two days then forgetting the task on the third day.

### **Difficulties with Abstract Concepts:**

- Difficulties in conceptualising time, understanding mathematical concepts and/or the value of money.

### **Impaired Judgement:**

- Inability to make decisions.
- Inability to recognise danger or distinguish danger from safety, friend from stranger, fantasy from reality.

<sup>9</sup> Lawryk, L.. *Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder*. OBD Triage Institute Inc. Canada (2005) p. 3

**Inability to Generalise Information:**

- Difficulty forming links and associations.
- Unable to apply a learned rule in a new setting, for example, understands not to take John's bike but then takes Jane's bike.

**Communication:**

- May seem to understand instructions and give agreement but is unable to comprehend.
- Often repeats rules exactly as said but cannot apply these same rules.

**Language:**

- Difficulty comprehending the meaning of language and accurately answering questions.
- May agree or confabulate (comply and fill in the blanks).
- May talk excessively but unable to engage in a meaningful exchange.
- The sheer volume of words used may create the impression of competence.

**Slow Cognitive Pace:**

- May think slowly, say "I don't know", appear to have 'shut down' or need minutes to generate an answer rather than seconds.
- This leads to the claim that people affected by FASD are "ten second people in a one second world."<sup>10</sup>

**Slow Auditory Pace:**

- Central auditory delays means language is processed more slowly and requires more time to comprehend.
- Many individuals affected by FASD can only grasp every third word from normally paced speech.

**Impulsivity:**

- Coupled with the inability to abstract (judgement and consequences) and to predict outcomes, the individual will act first. May be then able to see the problem after the action.

**Perseveration:**

- Rigid, stuck on an idea or thought.
- May have problems switching thoughts, stopping activities or transforming to a new task.
- Often reacts strongly to changes in setting, program or personnel (teachers/respite carers).

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<sup>10</sup> Malbin (2005) *Trying Differently Rather Than Harder*. Tetric Northwest, FASCETS Inc. (2002)

**Dysmaturity:**

- Often functions socially, emotionally, and in mentally at a much younger level developmental age than their chronological age.
- A 5 year old may be developmentally more like a 2 year old, a 12 year old like a 6 year old, and a 25 year old more like a 13 year old and so on.

**Sensory Systems Dysfunction:**

- May over-react to stimuli, for example, tactile defensiveness. Could react to different textures, smells, tastes, lighting, noise.
- May be overwhelmed by sensory input - unable to filter out extraneous stimuli - symptoms include increased agitation, irritability, and aggression.
- May also under-react to pain and not complain of earaches, broken bones, and be unable to experience painful stimuli like heat or cold.

*“Physical and sensory abnormalities are common so dental, hearing and vision testing are suggested” so it follows that speech and language assessments/therapy, occupational assessment/therapy and/or physiotherapy might be helpful. Some children living with FASD can have more than one disability. Physical anomalies: “lazy eye” (strabismus); decreased muscle tone (hypotonicity); poor hand-eye coordination and visual-spatial difficulties; difficulty verbalising concerns; transition difficulties (like sleep to awake); bone structural anomalies like fusing (scoliosis); ear infections; eating problems – too much or too little; respiratory tract infections should not be overlooked and treatment sought as soon as possible.<sup>11</sup>*

**Secondary Conditions**

These are behaviours that develop over time when there is a chronic poor fit between the individual and their environment. Defensive behaviours are normal protective reactions to frustration and are helpful clues for identifying points for intervention. Secondary behaviours are preventable when the environment is adjusted to suit the individual and are not necessarily exclusive to FASD but can develop in early childhood and frequently become patterns of behaviour by adolescence. There is a high cost for the individual, their family, and the community. Early identification of both primary disabilities and the onset of secondary behaviours are necessary in order to develop appropriate interventions that prevent or resolve secondary behaviours.

Common secondary behaviours include:

- Inappropriate humour;

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<sup>11</sup> Lawryk, L., (2005:10-14)

- Pseudo-sophistication – echo words or phrases, manners and dress in order to ‘pass’ as competent beyond actual ability. Often this is to the detriment of the individual;
- Fatigued, irritable, resistant, argumentative;
- Anxious, fearful, chronically overwhelmed;
- Frustrated, angry, aggressive, destructive;
- Poor self-concept, often masked by unrealistic goals or self-aggrandisement;
- Isolated, few friends, bullied;
- Family or school problems including fighting, suspension or expulsion;
- May run away, have other forms of avoidance;
- Trouble with the law;
- Addictions;
- Depressed, self-destructive, suicidal.

**Physical abnormalities:**

1. Facial appearance – usually soften with age, by late adolescence may have disappeared.
2. Body system functions (refer Table below):

<b>Eyes</b>	Crossed, near sightedness, poor vision, optic nerve abnormalities, astigmatism, curved/twisted retina.
<b>Ears</b>	Outer ear malformations, sensorineural hearing loss, inner ear malformations, frequent ear infections.
<b>Mouth and Jaw</b>	Dental problems (crowded teeth, gum deviations), cleft palate, soft palate, dysfunctional movements of tongue and larynx, obstruction to upper airways causing respiratory problems (at night).
<b>Skeleton</b>	Missing bones, hip dislocation, scoliosis, clubfoot, incomplete nail development.
<b>Organs</b>	Heart, urogenital and genital anomalies, malformed and/or misplaced kidney.
<b>Other sensory</b>	Tactile defensiveness (not wanting to be touched), or tactile stimulation (wanting to touch or be touched), hypersensitive or hyposensitive to light, sound, taste, smell and/or touch.
<b>Immune system</b>	Allergic reactions, altered susceptibility to infections.

Source: Saskatchewan Learning 1996

## **FASD From Infancy To Adulthood**

A breakdown of the developmental life stages is helpful to understand some behavioural characteristics and patterns of FASD as these present. Some symptoms often observed by parents and carers include:

### **Infancy**

- Unusual posturing of hands;
- Chronic constipation;
- Unable to support head;
- Small head;
- Often tremulous and irritable and may cry a lot;
- Weak sucking reflex and muscle tone;
- Highly susceptible to illness;
- Feeding difficulties, often disinterested in food with feeding taking a very long time;
- Erratic sleep patterns, no predictable sleep-wake cycle;
- Sensitive to light, sound and touch;
- Failure to thrive;
- Slow to master developmental milestones – walking, talking, imitating sounds; and or,
- Problems with bonding.

### **Preschool Age**

- Disinterest in food and disrupted sleep continues;
- Poor motor co-ordination;
- Moves from one thing to another with 'butterfly – like' movements;
- More interest in people than objects;
- Overly friendly and highly social;
- Unable to comprehend danger, does not respond well to verbal warnings;
- Prone to temper tantrums and non-compliant;
- Short attention span;

- Expressive speech may be delayed, may have less in depth language than peers, may be excessively talkative and intrusive - superficial appearance that speech is not impaired;
- Easily distractible or hyperactive; and/or,
- Does not respond well to changes, prefers routine and structure.

### **Early School Age**

- Reading and writing skills during the first two years may not be noticed as delayed;
- Arithmetic may be more of a problem than spelling/reading;
- Attention deficits and poor impulse control become more apparent as demands for classroom attention increase;
- Inability to transfer learning from one situation to another or to learn from experience;
- Requires constant reminders for basic activities at home or school;
- Information is learned, perhaps retained for a while and is then lost and poor performance of 'learned' tasks may appear deliberate;
- Gross motor control problems – clumsy;
- Fine motor control problems – handwriting, buttons, shoe laces;
- Difficulties with social skills and interpersonal relationships, be unable to share, wait for a turn, follow the rules or cooperate, be inappropriately intrusive;
- Poor peer relationships and social isolation, may prefer to play with younger children or adults rather than peers;
- Memory deficits;
- Exists in the here and now and seems to lack an internal time clock; and/or,
- Unable to monitor his/her own work or to pace self.

### **Middle School Age**

- Delayed physical and cognitive development;
- Reading and spelling skills usually peak;

- Increased difficulty maintaining attention, completing tasks and mastering new academic skills;
- Usually very concrete thinking, may have trouble working with ideas or concepts, tends to fall further behind peers as world becomes increasingly abstract and concept based;
- Continuing fine motor problems may make volume work production impossible;
- Good verbal skills, superficially friendly social manner and good intentions often mask the seriousness of the problem;
- Psychological evaluation and remedial placement may be necessary; and/or,
- A pattern of school suspensions may begin.

### **Adolescence**

- Increased truancy, school refusal and dropout;
- Increased behavioural disruption in school;
- Reading comprehension is poorer than word recognition;
- Faulty logic, lacks basic types of critical thinking and judgement skills;
- Mathematics tends to be the most difficult task suggesting poor memory, poor abstract thinking and difficulty with basic problem solving;
- May be able to 'talk the talk' while unable to 'walk the walk', for example, may indicate an understanding of instructions but are unable to carry these out, may have learned to act as though there is understanding of instructions but cannot follow through;
- Often misjudged as being lazy, stubborn, and unwilling to learn;
- Increased problems with abstract thinking and the ability to link cause and effect;
- Impulsive, total lack of inhibition and easily influenced, subject to peer manipulation and exploitation;
- Difficulty showing remorse or taking responsibility for actions;
- Problems managing time and money;
- High risk for problems with law and involvement with criminal justice system likely;
- Difficulty identifying and labelling feelings;

- Low motivation;
- Low self-esteem;
- Clinical depression may be evident;
- Sexual boundary issues with sexual activity beginning at an earlier age;
- May not exhibit primary symptoms of FASD but may display secondary disabilities;
- Have a need to develop social skills appropriate to their age group; and/or,
- High risk for exploitation and peer manipulation.

**Adulthood (18 years +):**

- Uncontrolled repetition of a particular response - ideas or activities may appear compulsive and/or rigid;
- Difficulty holding jobs;
- Unable to live independently or parent children;
- Problems managing money;
- Poor social skills;
- Lack of reciprocal relationships;
- Unpredictable;
- Depressed/ suicidal ideation;
- Withdrawn and isolated; and/or,
- Alcohol and other substance misuse.

## **Referral**

While most of the items in the following checklist include physical characteristics, most individuals affected by prenatal exposure to alcohol do not exhibit any obvious physical symptoms. Those without physical symptoms or a known history of prenatal exposure to alcohol will need a great deal more observational and diagnostic support.

Referrals should be made where there are characteristic facial features:<sup>12</sup>

- short palpebral fissures [crease around the eyes]
- a flattened midface including a smooth or flattened philtrum [absence of a dent between top lip and bottom of nose]
- a thin vermilion border [a thin top lip] and
- evidence of significant prenatal exposure to alcohol.

Individuals with learning or behavioural difficulties, or both, without physical or hallmark facial features and without known or likely prenatal exposure to alcohol should be assessed by appropriate professionals, or speciality clinics (for example: developmental paediatrics, clinical genetics, psychiatry, psychology) to identify and treat problems. Multiple assessments over time through encounters with a range of medical and non-medical specialists without a satisfactory outcome can be an indicator of FASD.

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<sup>12</sup> Chudley et al (2005) *Fetal Alcohol Spectrum Disorder: Canadian Guidelines For Diagnosis*"

## **FASD Screening & Assessment**

*In a situation where FASD in a newborn can be prevented, direct intervention is both urgent and necessary<sup>13</sup>.*

Remember, FASD is not a clinical diagnosis. Rather, it is an educational term used as a way of classifying a range of disabilities associated with prenatal exposure to alcohol. Ultimately, the person who claims the position of validating a diagnosis of FAS (rather than FASD) is a medical doctor or medical specialist and only a few have training to make such assessments. It is important to know which doctors in your region or state have the requisite skills, their geographical location, their requirements for accepting a referral, their availability and their openness to building the kind of relationship required to progress an individual through the assessment process.

Screening is not the same as making a diagnosis especially in respect to neurodevelopmental behaviours. The causes of these observed behaviours will not be known until the child is old enough for assessment and some behaviours may not be acute until the child is 7-10 years old. Most children who are diagnosed with fetal alcohol exposure problems are:

- Not identified before they reach school age.
- Are noted by teachers and parents to have a learning disability or an attention deficit disorder.

Screening and assessment are opportunities to discover whether FASD is a possible explanation of the underlying cause of developmental and behavioural difficulties that the person in your care is experiencing. Assessment is not just about finding a label but can lead to finding new or different ways of dealing with these problems. It should involve a range of professionals and community members and as a result, will take time.

There are possible psychosocial consequences of an FASD assessment and diagnosis and for birth mothers, in particular, great sensitivity needs to be assured. There can be an increased

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<sup>13</sup> Wemigwans, J. FASD Tool Kit for Aboriginal Communities, Ontario Federation of Indian Friendship Centres, Ontario (2005)

sense of guilt and anger or concern about the potential stigmatising of the affected individual once diagnosed. Early intervention still remains the best option for identifying future needs and can minimise the potential impact of these effects on early childhood development and offset the development of secondary behaviours.

### **A Multi-Disciplinary Approach**

Assessment begins with risk screening to determine whether a pattern of learning and behaviour may be related to prenatal exposure to alcohol<sup>14</sup>. The screening process is coordinated through the education, mental health, judicial and social services systems. In the case of a birth mother, a referral should be made to enable access to supports especially if there is a chance of another pregnancy.

#### **Who Is Involved?**

Due to the complexity of FASD and its expression across a variety of domains, a core team of professions should include:

- A coordinator for case management;
- A doctor who has trained in FASD diagnosis;
- A psychologist or psychiatrist;
- An occupational therapist;
- A speech-language pathologist;
- Perhaps a neurologist or geneticist.

Others (dependent on client age) may include:

- Addiction counsellors;
- Child carers;
- Cultural interpreters;
- Mental health workers;
- Parents or caregivers;
- Corrective services officers;
- Teachers/vocational counsellors; nurses/health workers; and, family therapists.

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<sup>14</sup> Chudley et al (2005) *Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis*"

### **Preparation**

1. Learn all you can about FAS and the spectrum described as FASD.
2. Recognise that as a parent/caregiver you are the expert in understanding your child's needs and/or behaviours.
3. Recognise that you have a wealth of information about which responses to the child, young person or adult behaviours work best.
4. Develop relationships with the most important people in a position to address the problem – teachers, GPs, specialist medical professionals, respite workers, extended family members and other community supporters.
5. Risk screening and assessment will probably constitute a huge emotional undertaking by the individual affected by the problem and their parents/caregivers/family.
6. The community and family need to be ready to participate in the assessment and if old enough, the individual should participate with their consent. The assessment process will take time.
7. Be prepared. Gather as much history as you can.

### **Gathering Information.**

Assessment will involve gathering of all sorts of documented information and records from a range of sources – medical maternal history, neuropsychological reports – with an extensive review often in place from social services personnel. There may be documents from other relevant professionals who have had ongoing contact with the client including information relating to developmental and social history (Source: teachers, medical practitioners, social workers, youth workers etc).

Client consent is crucial and confidentiality should be adhered to. This includes documentation of the initial concerns and the reasons for referral through to accessing and managing all client information. Make up a file and take this to any relevant assessment or discussion situation. Do not be discouraged.

## **Possible Sources of Information**

### **Hospital and Medical Records:**

Maternal/neonatal history

Birth and pregnancy records

Medical history

Psychological/psychiatric history

### **Social services:**

Adoption records

Foster placement records

Reasons for referral

Source of referral

Psychological assessments

Psychometric assessments

Family history

Drug exposure history

### **School history:**

Day care history

Achievement tests

Academic records (including reports and results)

### **Other assessments:**

Developmental assessments

Legal reports

Parents/caregivers and families are already experts in caring for children living with FASD, even if they don't realise it. They will have been responding to behaviours and dealing with the child's needs on a daily basis and it is not surprising how much knowledge they have to guide interventions. Older children, adolescents and adults living with FASD should be made aware, appropriate to their developmental age, of FASD. Many will have difficulty managing all the available information especially articles and resources prepared and written by academics. Literacy skills may be an issue. Use videos or DVDs from a lending library or make contact with someone who can offer help.

**Possible Sources of More Information**

Drug Education Network Inc. Phone 1300 369 319 or [www.den.org.au](http://www.den.org.au)

National Association for FAS and Related Disorders [www.nofasard.org.au](http://www.nofasard.org.au)

British Columbia FASD Bookshelf [www.fasbookshelf.com](http://www.fasbookshelf.com)

## **Helping Young People and Adults Prepare For Assessment**

Sometimes young people living with suspected FASD are not in the care of their parents/caregivers or if they do live at home are essentially independent. They may be living in a shelter or with supportive families. Facing up to the possibility of FASD means thinking about the way their own brain and body works and this may invoke discomfort and stress. Reinforce the fact that they are not alone and that much can be done to improve their health and well being and quality of life.

All of these experts hold different pieces of the puzzle that may help determine if FASD is the problem. A multi-disciplinary team can be geographical, regional or virtual and can accept referrals from rural and remote communities.

*As an individual living with FASD, a parent or caregiver you have the right to ask your preferred medical practitioner's for details of his/her training and expertise in FASD risk screening, diagnosis and assessment.*

### **Building on the Assessment**

The individual's unique needs are an outcome of the assessment process and allow for intervention strategies to be tailored to suit strengths and challenges. The post-diagnostic assessment report should advise of the basis from which the diagnosis is made including the history of maternal alcohol use, any physical criteria noted and psychological data that supports the outcome.

The report should provide recommendations made available to carers, educators and biological families as well as other appropriate professionals or non-professionals who work with children in particular. The findings should be discussed with the guardian or parent. Older children who possess cognitive ability need to be provided with the opportunity to learn about their condition from the team who provided the assessment and diagnosis.

The team, or at least some of the key members, should take on the responsibility for facilitating follow-up with the family and identify any community resources connected with the recommendations.

### Assessment Domains

Assessment Type	Yes	No	Assessment Type	Yes	No
<b>Growth parameters</b>			<b>Speech &amp; Language Assessment:</b>		
Length or height			Auditory comprehension		
Weight			Auditory memory		
Head circumference.			Auditory discrimination Auditory sequencing.		
<b>Developmental Assessment</b>			<b>Occupational Therapy Assessment</b>		
Cognitive ability			Learning difficulties		
Language ability			Poor social skills		
Motor skills			Difficulties completing activities for daily living.		
			Sensory processing difficulties/sensory integrative functioning		
			Motor impairments		
<b>Genetics Assessment - Dysmorphic (facial) features</b>			<b>Other</b>		
Palpebral fissure length measurement					
Philtrum measurement (smoothness and thinness)					
Any other anomalies					

## Assessment Checklist <sup>15</sup>

This checklist has been adapted from Liz Lawryk's book *Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder*.(2005:18-26)

Type	Behaviour	Check
Impulsivity	Do they do things impulsively without thinking?	
	Does their tendency to be impulsive compromise their safety?	
Attention	Do they have a diagnosis of ADD?	
	Do they have difficulty making a transition from one activity to another?	
	Do they have difficulty sustaining focus on a task?	
Distractibility	Do they have trouble keeping their attention on something other than TV or computer games?	
	Are they easily sidetracked from tasks?	
Hyperactivity	Do they have a diagnosis of ADHD?	
	Are they often restless, fidgety, wriggle, or constantly moving?	
	Do they have difficulty engaging in an activity, which requires concentration and staying in one place?	
Memory	Have they been diagnosed with short-term or long term memory impairments?	
	Is their memory sporadic?	
	If an activity is interrupted, are they able to recall where they stopped?	
	Are they able to recall events according to personal interest or importance rather than in chronological order (how they happened)?	
	Do they require visual reminders?	
	Do they have trouble remembering some parts of an instruction?	
	Are they concrete thinkers and take things literally?	
	Do they have trouble realising that things are similar to each other?	
	Do they have trouble problem solving?	

<sup>15</sup> Lawryk, L. *Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder*. OBD Triage Institute Inc. Canada (2005).

Abstract concepts	Do they have trouble recognising that there is more than one way to symbolise numbers and letters?	
	Do they have a poor concept of time?	
	Do they have trouble managing money or appreciating the value of items?	
	Do they struggle to learn multiplication tables?	
	Do they have trouble answering abstract questions about “why” something happened or if told to “wait” or if told that there will be consequences to their behaviour?	
Sequencing	Is it difficult for them to make a decision from two or more options?	
	Does the concept of priority have any meaning to them?	
	Is it difficult for them to organise themselves for activities?	
	Do they know where to start?	
	Do they have trouble doing things in logical order?	
	Is it difficult for them to see patterns?	
	Are they able to follow through without assistance?	
Problem solving	Do they play ‘imagination’ games?	
	Do they find it hard to come up with solutions?	
	Do they repeat the same mistakes until frustrated or giving up?	
	Do they repeat the same mistakes even after numerous consequences have been tried?	
	Do they rely on signals to gain your attention?	
Communication	Do they over-react in the extreme when things are taken away, like toys?	
	Do they seem to have trouble expressing appropriate feelings?	
	Do they have trouble recalling words as names for things?	
	Do they have trouble following instructions?	
	Are they able to remember instructions but not be able to explain or apply?	
	Do they have trouble retelling an event in the correct order?	
	Is it difficult for them to follow a conversation and do they make out of context comments?	
	Are they unable to differentiate double meaning?	
Do they perseverate (thought, topic, experience repeated over and over)?		

	Do they hear another person's experience and repeat as their own?	
Soft neurological signs	Do they have visual depth perception problems – bump into things, poor eye-hand co-ordination?	
	Do they have difficulty filtering out stimuli like bright lights, loud sounds, touch, being in groups etc?	
	Do they tire easily?	
	Do they have a high or low tolerance for pain?	
	Are they constantly making odd or unusual sounds or movements?	
	Do they have sensitivities to combination foods (several textures together)?	
	Do they have disrupted sleep patterns?	
	Do they eat until stopped or are they particularly uninterested in foods?	
Social rules	Is the child a collector of other people's things or have trouble with the concept of ownership?	
	Do they have difficulty sharing?	
	Are they imitators of peer behaviours without being able to discriminate between appropriate and not appropriate behaviours?	
	Do they stand too close, demonstrate inappropriate affection or misinterpret other people's intentions?	

## **Advocacy**

When a parent/caregiver raises the issue of FASD and seeks an assessment for their child/adolescent or adult in their care, medical specialists may be unable or unwilling to confirm this condition. This does happen despite the strongest belief that organic brain damage is the problem. At this time, parents and carers often need access to additional support. Non-conformation when parents/caregivers believe strongly that FASD is likely can leave them feeling frustrated, disbelieved and/or disempowered. It is helpful to make contact with support groups like the National Organisation for Foetal Alcohol Syndrome and Related Disorders (NOFASARD) or FASLink.

FASD is a new problem for the community to come to terms with and it will take some time for the formal system to develop ways to help individual children, adolescents and adults and their families and carers.

It is important to remember that having a diagnosis of FASD does not limit the kind of expertise that will benefit the individual/s you care for but marks a time for advocacy. Advocates can be relatives, family friends or frontline worker (who may have initiated the referral and assessment process). The latter may have this role until the family/supporters are more confident and knowledgeable about the range of support and resource options in the community.

The advocate validates the parents/caregivers of an individual affected by FASD for their knowledge about the individual's strengths and abilities. The advocate works with the parents/caregivers to facilitate the best advocacy possible. The aim is to help families/caregivers become the best possible advocates they can be.

If you are an advocate for another individual, parent, or family:

- Encourage parents/caregivers to be involved with parent groups to access support and community resources. If such a group does not exist, then look for ways to initiate one;
- Research and suggest resources and workshops that can help parents/caregivers expand their advocacy skills;
- Help parents/caregivers expand their learning – build and share a library of resources;
- Facilitate, advertise, attend and encourage workshops and conferences;
- Work beyond the label of FASD – there are a whole lot of opportunities in the community that can be accessed which don't identify as a specific FASD service;
- Find additional, secondary advocates for the individual and their family. some people will champion their cause in the school system, the legal system, the medical system and in social services.

## **Understanding the Context of FASD**

There is no doubt that FASD is a complex problem, bound up with issues like the social acceptance of alcohol use in society, an under-estimation of the true incidence of the problem in Australia, the amount of alcohol consumed to cause a level of harm in the unborn child and the need to blame something or somebody for the problem. These barriers should not deter a parent or caregiver from seeking the best level of assistance for the individual living with the problem.

Birth parents are often dealing with an unbearable load of shame and grief<sup>16</sup>. Too often the response about the birth parent from the community is negative and carers (and professionals/community workers) need to acknowledge their own individual attitudes and biases.

To prepare for this, it is important to find out about:

- The impact of alcohol use in the community.
- What it means to be dependent on alcohol.
- Why women use alcohol, especially in pregnancy and understanding the barriers that stop women seeking help? Mothers of children, adolescents and adults living with FASD are not always 'alcoholic'. Some are social drinkers, some have FASD themselves, and many are survivors of personal violence.
- What happens when a man drinks, whose partner is pregnant and how community attitudes might differ towards him.
- What role alcohol plays in your own life or the life of the family.

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<sup>16</sup> Yukon Education p.2:3

## **Care Strategies**

### **Understanding behaviour**

Learning and behavioural models of intervention seldom work with children living with FASD. There is an understanding that behaviour will be repeated or reduced through positive or negative consequences (punishments or rewards) and this is often the foundation for school education, work training, discipline and behavioural management programs. It is also most parents own experience of childhood and schooling. Learning assumes a rule can be followed. For example, respect for other people's property; that people can understand the underlying concepts of that rule; that people can remember the rule; and that the rule can be applied in different settings. Children can usually understand abstract social concepts and are able to remember and follow the rule and that with practice, recall the rule as needed and generalise it to other situations.

Children living with FASD try hard but experience the barriers of information processing. They cannot interpret instructions, are unable to consistently retain information already learned and then use it in daily life. They are constantly in trouble for getting it wrong and worse, cannot understand why. The child may have a developmental age that is much less than their chronological age.

Abstract concepts, generalising information, understanding cause and effect, and poor memory place their social understanding at a much reduced developmental age. This is a key to developing strategies that work for the child living with FASD.

According to Maureen Murphy (1991) the following core factors need to underpin caring for individuals living with FASD:

1. Structure (choices within clear and predictable routines);
2. Supervision (care to offset trouble and dangerous situations);
3. Simplicity (simple directions and simple language use);
4. Steps (break down tasks into small steps and teach through repetition and reward for positive behaviours); and,
5. Context (teach in settings skills are to be used, there is no value in assuming individuals can generalise or understand across contexts).

**REMEMBER TO**

1. Determine the individual's developmental age.
2. Use repetition, repetition, repetition.
3. Advocate for early intervention.
4. Apply multi-modal learning.
5. Apply natural not created consequences.
6. Use properly prescribed and monitored medications.
7. Play a role in community education.
8. Use positive role models.
9. Create a structured environment.

**The Importance of Structure**

Structure allows the child living with FASD to behave in appropriate ways and a child will be more successful in environments that provide a high degree of structure or consistent routines. Over time, these routines bring about patterns for daily life which the child can follow leading to greater independence and success.

Structure is a framework that supports or reinforces positive behaviour. It allows the child to move, step by step through learning processes. The structure can always be

modified if necessary to support success. Structure gives each child a path to follow towards an outcome like road signs to point the way.

### **Effective Communication**<sup>17 18</sup>

1. Begin all conversations with the child, adolescent or adult's name and make eye contact.
2. Be specific when giving an instruction – “sit on that chair” instead of “leave the kitchen” or “hang up your coat” instead of “put your coat away”.
3. Use the same words to express directions for daily routines.
4. Realise that many of the same words or expressions have more than one meaning. Individuals living with FASD can be very literal in their understanding.
5. Be brief and keep directions short. A short attention span might be a problem even when the individual appears to be listening.
6. Offer individual instructions using their name (especially if caring for more than one affected child). Group directions may be too difficult to understand.
7. Speak slowly and pause between sentences to allow for information processing. Auditory processing may lag behind the rate of speech. Repeat and restructure information as needed.
8. Keep the environment as free from distractions as possible, especially when a task requires focussed attention.
9. Step by step simple instructions on how to do things can be useful for both common and unexpected situations. Teach the older child/adolescent or adult how to use a list and practice role plays and simulation games.
10. Jog the memory. Tell, demonstrate, show and then find a visual way to tap into memory. If this does not work, remind and move on. Gentle reminders help develop a positive attitude.

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<sup>17</sup> Parenting Children Affected by Fetal Alcohol Syndrome: A Guide for Daily Living, Ministry for Children and Families Edition, British Columbia

<sup>18</sup> Graefe, S. *Living with FASD: A Guide for Parents* Groundwork Press: Vancouver 2006

11. Link tasks together with another event to build sequences (dinner follows homework, bus after breakfast).
12. Use expressive gestures when talking – loud and soft speech, hand signals;
13. Use as many visual cues as possible to aid comprehension and trigger memory. Be specific when labelling inappropriate behaviour with an exaggerated shaking of the head and add visual cues to emphasise the desired action.
14. Touch can be useful for teaching appropriate distance and personal space. Place your outreached hand on the child/adolescent or adult's shoulder and say "This is where we stand when we talk to others."
15. Use a visual or verbal cue to begin or end a task or activity. Make sure these cues are consistently used for starting or finishing and add exaggerated facial or body language.
16. Help with identifying social and behavioural cues through the behaviours and actions of others. For example: "Jo looks happy, she is smiling."
17. Encourage the use of positive self-talk: "I can do this!"
18. Help develop skills for safe expression of feelings – metaphor, art, play, anger management strategies.
19. When an activity is not resulting in desired behaviour it is important to stop the activity, observe the current behaviour, and assess the situation and then plan for something different.

### **Impulsivity, Attention, Distractibility and Hyperactivity**

According to Liz Lawryk<sup>19</sup> Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder "with or without medication...[are]...real and quite likely responsible for some major challenges" for individuals living with FASD. She recommends the following:

1. Get organised.
2. Clean out all unwanted paraphernalia from school bags etc. as a daily ritual.

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<sup>19</sup> Lawryk, L. : *Finding Perspective...Raising Successful Children Affected by Fetal Alcohol Spectrum Disorder*. OBD Triage Institute Inc. Canada (2005).

3. Arrange activities that individuals living with FASD are likely to be successful at.
4. If over stimulation is a problem, undertake a disarray check in their bedroom and slowly (not as a consequence) remove items like murals, books videos, stuffed toys. Show where these things are being moved to and encourage charitable donation.
5. Check out how much computerised back ground noise/lights etc. affects the family home environment – turn off what you can.
6. Learn relaxation exercises together and practice these before challenging activities are started.
7. Plan for losing things.
8. Ensure regular bathroom breaks, drinks and good choice snacks.
9. Limit homework to an appropriate amount of time.
10. Try 'swaddling' with a heavy blanket if hyperactive.

### **Difficulty Understanding Cause and Effect**

Individuals living with FASD may disobey instructions due to a lack of comprehension skills, memory impairment or like other people, have times when their behaviours are simply disobedient. The trick is to work out which.

1. Language disabilities have difficulty with 'why' questions. Ask these questions in a different way – "What made this happen?"
2. Show cause and effect – demonstrate, draw pictures, role play.
3. Tell the individual what to do and not what not to do. Telling what to do gives direction and gives a focus to the positives.
4. Encourage their help and participation in even the smallest ways. Begin with simple instructions and work up to determine their ability to understand and follow through.
5. In particular, give immediate rewards and tell why the reward is happening. Often rewards are noticed to be ineffective over a time period. Stars and stickers

are useful rewards for younger children as is time on computers or watching videos/DVDs for older children.

6. If there are consequences, act immediately and tell why. There is little advantage in speaking about the same behaviour the day before without prompting memory.
7. Be firm and consistent in setting limits – no debate, no argument. Family rules can be written or drawn in pictures.
8. Separate the individual from the problem behaviour. The action may not be great but the individual is never a problem person – “Your behaviour makes me think you need time out.” When calm, always reinforce that he/she is a good person.
9. Do not make threat that cannot be carried out. The individual may take your comments literally and there is no learning about consequences when the threat is not carried out.
10. Be very specific with praise or criticism. Always accompany with name, eye contact and touch so that they understand the praise or criticism is for them.
11. Intervene if possible to avoid an escalation in behaviour. This is demanding for parents/caregivers because there is a need to be vigilant and tuned in all the time.
12. Find a place for a ‘quiet time’ for when feelings are overwhelmed. Let the individual choose the place where comfort and safety is maximised. Validate their use of this space.

### **Dealing with Change**

Sometimes change in routines is unavoidable. Changes, even small ones can be traumatic and transitions from one activity to another for some people can be difficult. Change may represent a major challenge for the child living with FASD. A replacement respite carer, for example, may be called in or a daily routine could be changed because of a medical appointment. Children with FASD are usually highly rigid or

concrete thinkers<sup>20</sup> and cannot work out what is going to happen next. Anxiety increases. An example is provided in Alton et al (2006:4:2):

*Debbie decided to rearrange the living room after her son had gone to bed. In the morning she awoke to her son's sobbing and found him in the living room standing next to the couch. He had urinated on himself and told her, "I can't find the bathroom."*

### **Strategies for Establishing Routines**

1. Write down or diagram what needs to be done – pictures of each step in brushing teeth might be necessary.
2. Break down tasks into steps. Try to do everything in the same way every day and in the same order.
3. Avoid situations that will lead to over-stimulation by people, places, sound, light or movement.
4. Be organised with a place for everything and everything in its place. Allow one item at a time and store with a system of colour, size, type etc.
5. Place labels on the outside of drawers, cupboards, shelves etc and mark with single words or pictures.
6. Mark off areas (for privacy etc.) with masking tape.
7. Create quiet homework corners. Have the equipment needed there and call it a name – office, work library.
8. Make sure relaxation alternates with busy times.
9. Help build relationships with positive role models.
10. Establish routines so that life is more predictable.
11. Offer structured but limited choice. Encourage decision-making among a couple of options.
12. Teach verbal cues to end and begin tasks and let them know if a change of tasks will happen soon. Egg timers can be useful.

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<sup>20</sup> Alton et al p. 4:2 Yukon Education

13. Prepare for school or an event the night before and allow the individual the scope to pack and prepare – what to wear, what to take etc.
14. Develop rituals for greeting and farewells.
15. Use photographs of actual people in the person's/family's life, places they go and things they need for certain events – moving house, visits to doctor or dentist, hospital or a new school.
16. If a family member will be absent, use photographs of the person and where they will be.
17. If entering a new placement or a period of respite make sure their routine changes as little as possible.
18. Acknowledge any fears especially about abandonment. Be reassuring and honest.
19. Try to begin with advanced warning about a possible change.

### **Strategies for Introducing Change to Routines**

Even if steps in a routine are changed, the individual who cannot generalise from one setting to another sees it as a new routine.

1. Don't skip bits of the routine or combine two routines into one.
2. If the routine is interrupted, start the existing routine again.
3. Let the child know ahead of time if there is to be a change in the daily schedule. Provide clear, concise, concrete and short instructions. Use visual cues.
4. Ensure carers or replacement teachers know anxiety management strategies based on the individual child's past reactions and successful interventions.
5. Create a schedule of pictures or words so that the child can refer to this as often as is needed to bring about reassurance. Review this schedule with the child throughout the day.
6. Colour code material if necessary to connect materials to specific activities.

## Supervision

Because individuals living with FASD have trouble understanding behaviour and consequences, they are often the person who gets caught doing the wrong thing. They might not even be the person who initiated or acted in a particular way.

1. Keeping their bedroom fairly empty of things, decreases the potential for accidents if the child wanders in the night.
2. An alarm for night wanderers might be necessary.
3. If an approach is made to strangers, deal with it straight away in front of the stranger. It might be embarrassing but is essential to teach protective behaviours. Tell them, "this is a stranger and we do not talk to strangers."

### **REMEMBER S.O.A.P.**

**STOP** the activity.

**OBSERVE** or become aware of your judgements on the situation; take note of all sensory input – what the child hears, sees, feels, smells; the level of energy or fatigue, hunger, anxiety, fear; what is the current behaviour accomplishing.

**ASSESS** the child's behaviour in terms of differences in his/her brain function (child is not being bad, brain is damaged); academic strengths and challenges and learning problems; reframe – view current negative actions in terms of child's brain dysfunction.

**PLAN** creatively. Clarify what need to be done in the child's environment. Include a new set of possible solutions. Accommodate child rather than trying to 'fix' the child.

## Typical FASD Behaviours and Misinterpretation.

*The following table is adapted from Deb Evensen (2000) in Making a Difference Yukon Education*

<b>BEHAVIOUR</b>	<b>MISINTERPRETATION</b>	<b>ACCURATE INTERPRETATION</b>
<b>Non-compliance</b>	<ul style="list-style-type: none"> <li>▪ Wilful misconduct</li> <li>▪ Attention seeking</li> <li>▪ Stubborn</li> </ul>	<ul style="list-style-type: none"> <li>▪ Difficulty translating verbal directions into action</li> <li>▪ Doesn't understand</li> </ul>
<b>Repeatedly making same mistakes</b>	<ul style="list-style-type: none"> <li>▪ Wilful misconduct</li> <li>▪ Manipulative</li> </ul>	<ul style="list-style-type: none"> <li>▪ Can't link cause and effect</li> <li>▪ Can't see similarities</li> <li>▪ Difficulty generalising</li> </ul>
<b>Not sitting still</b>	<ul style="list-style-type: none"> <li>▪ Seeking attention</li> <li>▪ Bothering others</li> <li>▪ Wilful misconduct</li> </ul>	<ul style="list-style-type: none"> <li>▪ Neurologically based need to move while learning</li> <li>▪ Sensory overload</li> </ul>
<b>Doesn't work independently</b>	<ul style="list-style-type: none"> <li>▪ Wilful misconduct</li> <li>▪ Poor parenting</li> </ul>	<ul style="list-style-type: none"> <li>▪ Chronic memory problem</li> <li>▪ Can't translate verbal directions into action</li> </ul>
<b>Does not complete homework</b>	<ul style="list-style-type: none"> <li>▪ Irresponsible</li> <li>▪ Lazy</li> <li>▪ Unsupportive parents</li> </ul>	<ul style="list-style-type: none"> <li>▪ Memory deficits</li> <li>▪ Unable to transfer what is learned in class to homework assignment</li> </ul>
<b>Often late</b>	<ul style="list-style-type: none"> <li>▪ Lazy, slow,</li> <li>▪ Poor parenting style</li> <li>▪ Wilful misconduct</li> </ul>	<ul style="list-style-type: none"> <li>▪ Cannot understand the abstract concept of time</li> <li>▪ Needs assistance in organising</li> </ul>
<b>Poor social judgment</b>	<ul style="list-style-type: none"> <li>▪ Poor parenting</li> <li>▪ Wilful misconduct</li> <li>▪ Abused child</li> </ul>	<ul style="list-style-type: none"> <li>▪ Not able to interpret social cues from peers</li> <li>▪ Doesn't know what to do</li> </ul>
<b>Overly physical</b>	<ul style="list-style-type: none"> <li>▪ Wilful misconduct</li> <li>▪ Deviancy</li> </ul>	<ul style="list-style-type: none"> <li>▪ Hyper-sensitive or hypo-sensitive to touch</li> <li>▪ Doesn't understand social cues regarding boundaries</li> </ul>
<b>Stealing</b>	<ul style="list-style-type: none"> <li>▪ Deliberate dishonesty</li> <li>▪ Lack of conscience</li> </ul>	<ul style="list-style-type: none"> <li>▪ Doesn't understand concept of ownership over time and space</li> <li>▪ Immature thinking (finders keepers)</li> </ul>
<b>Lying</b>	<ul style="list-style-type: none"> <li>▪ Deliberate</li> <li>▪ Sociopath behaviour</li> <li>▪ Lack of conscience</li> </ul>	<ul style="list-style-type: none"> <li>▪ Problems with memory and/or sequencing</li> <li>▪ Unable to accurately recall events</li> <li>▪ Try to please by telling you what they think you want to hear</li> </ul>
<b>Self-centredness</b>	<ul style="list-style-type: none"> <li>▪ Selfishness</li> <li>▪ Only cares about self</li> </ul>	<ul style="list-style-type: none"> <li>▪ Only see the superficial or concrete level of social behaviour</li> <li>▪ Doesn't link cause and effect</li> </ul>

<b>Volatile</b>	<ul style="list-style-type: none"> <li>▪ Poor parenting</li> <li>▪ Aggressive nature</li> <li>▪ Short-tempered</li> </ul>	<ul style="list-style-type: none"> <li>▪ Exhausted from stress of trying to keep up</li> <li>▪ Extremely over-stimulated</li> </ul>
<b>Inconsistent performance</b>	<ul style="list-style-type: none"> <li>▪ Manipulating</li> <li>▪ Sneaky</li> <li>▪ Not trying hard enough</li> </ul>	<ul style="list-style-type: none"> <li>▪ Chronic memory problems</li> <li>▪ Inability to generalise learning from one situation to another</li> </ul>
<b>Unmotivated</b>	<ul style="list-style-type: none"> <li>▪ Poor parenting</li> <li>▪ Lazy</li> <li>▪ Doesn't care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Can't project into the future and see what will happen</li> <li>▪ Doesn't connect today's decision with future opportunities</li> <li>▪ Doesn't understand cause and effect</li> </ul>

## **Talking to a Child or Older Person about Living with FASD**

According to Graefe (2006:113-116) openness is important. Any child, adolescent or adult living with FASD needs to have information to understand themselves and be prepared for the challenges of the future. Often these individuals recognise their differences from peers and self-esteem and frustration can be profound.

Language use and concepts need to be developmental and age appropriate with the introduction similar to a general introduction to FASD – common characteristics for example conveys an understanding that FASD is not an isolated problem.

**Young children** are immediate in their needs and respond best to reassuring support through the use of concrete language. Use animals to describe differences – some cats hear better than others, owls like the dark and being awake at night, flowers have soft petals and like soft touch etc. Continue to make associations through nature – differences are normal, different leaf shapes, stones on the beach, and colours of cows. When behaviour goes wrong, talk about what happened, not about the child and how the differences got in the way.

**School-aged children** may be able to understand some simple descriptions of FASD, especially what causes the differences. Link the unique characteristics of FASD with what caused the problems and then with their unique strengths and successes. Visual metaphors can be helpful for a child to describe their experiences – like a wall in my head that sometimes light can get through.

Share stories about other individuals living with FASD to make it more real and reduce isolation. Be honest about what might or might not change – you might always be clever at drawing or writing but not quite able to do maths or remember what comes next. Reassure that this is OK and that there are things that can be done to help – calendars, photos,

pictures, lists and extra time and practice. Ask the child if they can think of other things that might help.

If the discussion becomes focussed on why the birth mother used alcohol during pregnancy, do not blame the mother. This can be a time of sadness and the child needs encouragement and reassurance not negativity and a sense of hopelessness. Try to use simple answers and ask what it is like for them.

**Adolescents and adults** are often dealing with the dilemmas faced on a daily basis and they need constructive feedback about what to do about these situations. Discuss possible options and try to encourage their input, affirming their suggestions and never patronising.

Adolescents will want to know what to do in more specific situations – what to tell friends for example. Young people might be asked what is wrong with them. One example that might be suggested is “I do it this way because it works better.” Use situations in other people’s lives to explore ideas. Explain that the young person has control over how much others need to know about living with FASD so that they can set the boundaries for disclosure. Peer support groups might be helpful.

## **Educating Children & Adolescents Living With FASD.**

The most challenging areas for primary interventions include:

Impulsiveness	Conflict with siblings
Concentration difficulties	Sleep disturbances
Poor memory	Mental health issues
Sensory integration	Education and learning

### **Be aware of brain function deficits**

1. Neurological impairment – small head and underdeveloped brain.
2. Information processing deficit – gaps and inconsistencies in understanding, sequencing and auditory processing of information.
3. Memory and attention deficits – faulty memory and limited attention span.
4. Delay or dysfunction of language – limited vocabulary and comprehension, problems with clarity of speech or speech impairment.
5. Delayed development – delays in meeting developmental milestones, tremors, balance and coordination problems, fine motor skills problems.
6. Intellectual development, learning ability or social judgement may be affected.
7. Impulsivity, distractibility, perseverance (continue to respond to a stimulus after it has ended) can be problematic.

### **Planning for education programs**<sup>21</sup>

Unfortunately in Australia, there is a limited professional understanding of FASD as causal to children's behaviour and developmental disabilities. Adoptive and foster parents/caregivers can be deprived of family; social and medical background information, let alone the

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<sup>21</sup> Teaching students with FASD, Alberta Learning p.15

awareness that the child is living with FASD. The lack of understanding of the child's needs and the application of traditional parenting approaches can and does result in failure. This same conundrum can challenge teachers until their awareness is raised.

With or without awareness of FASD, educators spend a lot of time with children and adolescents in school. From their observations, educators have valuable information about specific patterns of behaviours and other characteristics. This information may be valuable for FASD assessment and their documentation of any concerns is therefore important.

Children living with FASD have complex disabilities – learning, behavioural, expression and understanding language and brain damage can affect how new information is perceived and understood, how information is memorised, how each child learns new skills and ideas and how information is recalled across a range of settings. Some children have reading and written language difficulties and/or mathematical reasoning difficulties. Intellectual functioning can range from severe to above average. Many children have poor social skills compromised further by poor speech articulation and memory impairments.

Children living with FASD do the best they can with the challenges they face and the understanding they have. When the same mistakes are made over and over again, it is time to do something different. Their repeated mistakes (social, academic, behavioural) can often result in punishments as if their actions are intentional. If the child is not progressing in school or repeated behaviour is happening, then something needs to change in the environment. Children living with FASD are aware they are not meeting expectations and can develop unrealistic expectations of themselves. This exacerbates the sense of failure.

According to Yukon Education (2006) the best a child can do can vary from day to day. Inconsistencies can create situations where prior success at a task can reinforce the teacher expectation that the child simply need to work harder. Because the child does not understand their limitations, harder work as a remedy is believed.

Higher expectations have been linked to a more 'normal' physical appearance. Children with visible physical abnormalities tend to attract increased compassion and understanding. Because FASD is more commonly an invisible disability, it is easy to assume children can do better if they try harder. A slow cognitive pace as children struggle to understand, means they are invariably left behind as the teacher moves to the next subject. Children living with FASD are reported to understand only every third word and slow pace cognition may be perceived as disinterest and resistance.

Slower instructions, concrete language, visual cues and reminders, adjustment of time lines and realistic expectations can bring success. It is important that generalisation of expectations in one setting is not translated to another. Doing well is only relevant to the task at hand.

### **Suggestions**

- Make up an information folder of reference materials that explain FASD – the common characteristics and behaviours;
- Meet regularly with teaching staff;
- Share information about the child/young person's particular strengths and the areas in which additional assistance will be needed;
- Share information on which strategies work and do not work at home;
- Negotiate for a daily home-school journal to be put in place so that information from both spheres of the child/young person's life can be shared.
- Look for strengths at school. A strategy for one young person who struggled with frustration at school and was on occasions, aggressive was to make him responsible for restocking supplies, messages and other structured activities that could be introduced when the onset of stressful times was observed.

#### **Recommended reading:**

*Trying Differently: A Guide for Daily Living and Working with FASDs and other Brain Differences, FASSY Yukon*



## **Care Of The Parents, Carers And Families**

Caring for a child or children who live with FASD means experiencing challenges and pressures.<sup>22</sup> The predominant feeling expressed by parents and caregivers of an individual affected by FASD is anger, especially in the absence of a diagnosis which might explain a particular behaviour. The hidden disabilities that mark FASD are not generally understood or accepted. Children living with FASD are often stigmatised or regarded as less than perfect. To compensate, children will try to mask their problems. Health and relationships within the carer family can be compromised.

Parents and caregivers may display:

- Exhaustion from lack of sleep;
- Shock from learning that normal parenting skills and discipline techniques are ineffective for the child living with FASD;
- Struggle with their own personal histories and/or current use of alcohol;
- Frustration with the lack of understanding by health and social service providers;
- Continual reports on negative behaviours from family members, schools and community workers ( and multiple trips to the school to sort issues out);
- Frustration and tiredness because the experience of obtaining an accurate assessment might be difficult in the absence of appropriately trained health providers and in fact, parents and carers may need to be the educators.
- Blame for the (misunderstood) behaviours of their child resulting from their poor parenting skills.
- Hurt and disbelief when trying to secure understanding from service providers.

Foster and adoptive parents may experience additional frustration from the lack of social, medical and mental health histories for their child.

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<sup>22</sup> Identification and Care of Fetal Alcohol-Exposed Children: A Guide for Primary-Care Providers, National Institute on Alcohol Abuse and Alcoholism, Office of Research on Minority Health, National Institute of Health. Online at [www.cme.wisc.edu/online/fas/info](http://www.cme.wisc.edu/online/fas/info). Downloaded 15/02/05

## **How to Tackle the Problem of FASD in Communities**

The prevention of prenatal exposure to alcohol; reducing the incidence of FASD in communities; and reducing the risk of secondary conditions development requires a whole of community approach that accounts for the unique needs of those directly affected by FASDs including the individual child adolescent or adult; their family; caregivers; supporters; and members of the community who have an important influence on each individual and family.

### **Become informed**

1. Learn about the primary disabilities and secondary conditions most commonly associated with FASD.
2. Understand accepted social expectations for children, adolescents and adults and think about how these are applied to individuals who cannot possibly meet these kinds of expectations without appropriate levels of support.
3. Take into account the spectrum of primary disabilities individuals living with FASD might be managing on a daily basis and how these adverse outcomes of prenatal exposure to alcohol might be impacting on all they do and participate in. Take into account each individual's potential lowered developmental age in contrast to their chronological age.
4. Understand how primary disabilities and related behaviours are often interpreted when these expectations are not met (refer p.46).
5. Understand how standard and accepted interventions prove usually are ineffective for individuals living with FASD and if applied, can often promote the development of secondary conditions.

### **Promote change**

6. In environments at home, school and workplaces which are sensitive to the needs of those living with FASD and which help them to better respond and adjust to the environment – picture charts that support established routines; photos of support

people; inclusion of digital clocks; personal time out areas (dimmed lights, soft music, a blanket to roll in) or time out activities (option of a walk); ready access to water and the availability of nutritious snacks in between meals.

7. Ask any professional who works with people if they know about FASD. If not, direct them to a contact – email, website, resource, telephone number.
8. Form a support group in your local community.
9. Take information on FASD with you to all professional appointments.
10. Join NOFASARD online [www.nofasard.org.au](http://www.nofasard.org.au).
11. Partner with DEN through joining a reference groups. Contact the Drug Education Network Helpline.

Free Call: 1300 – 369 – 319

Or e-mail: [dutyofficer@den.org.au](mailto:dutyofficer@den.org.au)