



Fetal Alcohol Exposure: Time to Know, Time to Act

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Adolescent Issues

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Chris Margetson initiated and has been the Executive Director of FASAT (Ontario) for 5 years. Throughout Ontario and beyond Chris has been a speaker, facilitator or trainer at hundreds of workshops, conferences and forums on Fetal Alcohol Spectrum Disorder (FASD). She has also facilitated and supported a number of communities to develop a community response to FAS. Her expertise in providing initial support and training to communities, to begin a parent support program is in high demand. In 1992 Chris was awarded the Bicentennial Medal of Canada and in 2000, the Ontario Medal for Citizenship for dedicating her career and life to the betterment of family, community and country. In 1997, she was the recipient of the Woman of Distinction Award for Training and Development and in May 2000, she was appointed to the FAS National Advisory Committee to Health Canada

SEVEN PROTECTIVE FACTORS FOR SECONDARY DISABILITIES

Stable nurturing home for 72% of life

Definitive Diagnosis before age 6

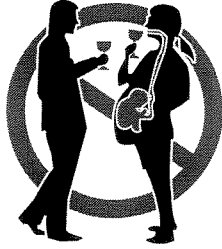
Never experiencing violence

More than 2.8 years in each living situation

Good quality home from 8-12 years

Developmental Disability Eligibility

Aggressive and early interventions



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COMMON MISINTERPRETATIONS IN FAS/E INDIVIDUALS

BEHAVIOURS

MISINTERPRETATION

ACCURATE INTERPRETATION

Noncompliance

Willful misconduct
 Attention seeking
 Stubborn
 Everyone does this at times

Difficulty translating verbal directions into action. Doesn't understand. Pattern & frequency of behaviours denote organicity.

Repeatedly making the same mistakes

Willful misconduct
 Manipulative

Can't link cause to effect
 Can't see similarities
 Difficulty generalizing

Often late or doesn't attend at all

Lazy, slow
 Poor parenting
 Willful misconduct
 Lots of people are late

Can't understand the abstract concept of time. Needs assistance organizing. Needs ongoing support/reminding

Not sitting still / fidgeting

Seeking attention
 Bothering others
 Willful misconduct
 Normal for this age

Neurologically based need to move while learn/listening. Sensory overload. Pattern & frequency of behaviours denotes organicity

Poor social judgement

Poor parenting
 Willful misconduct
 Neglected/abused childhood

Unable to interpret social cues from peers/others. Can't control impulses

Overly physical

Willful misconduct
 Deviancy

Hyper or hypo—sensitive to touch & environment. Can't understand social cues regarding boundaries

Doesn't work independently

Willful misconduct
 Poor parenting

Chronic memory problems. Can't translate verbal directions into action

These guidelines are particularly important when dealing with adolescents and young adults. Adapted from: Debra L. Evensen, MA., About FASE, Surrey B.C. 1996.





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FAS/E ADOLESCENTS/YOUNG ADULTS

How can I recognize adolescents/adults affected by FAS?

Following puberty, the characteristic facial features and growth deficiency are less apparent. Adolescents and adults, however may have limited reasoning and judgement abilities. They act impulsively, repeat mistakes and fail to consider consequences. They usually use time poorly and seek immediate gratification. They may also have deficits in abstract thinking.

These limitations mean that the FAS adolescent/young adult may continue to need supervision and support and that some are unable to hold jobs, live independently, manage their own money or parent children. Withdrawal and isolation are common, as is unpredictable behaviour, depression and a higher level of mental illness than would be expected. Abuse of drugs and/or alcohol, which frequently begins in adolescence, may compound the problems.

Unfortunately, many of these adolescents have the uncanny ability to present well enough to convince people that their behaviour is deliberate, thought out, and within their ability to control and determine outcomes. It has been said that what most marks the young adult is **the appearance of capability without actual ability**. In order to accommodate the diverse needs of adolescents/adults with FAS, interventions must address their intrinsic cognitive and behavioural deficits. Although, we have given information regarding identification above, it is important to note that the diversity of affects make it necessary, to some extent, to give general descriptions. Some individuals may have developed more severe and others less severe secondary disabilities, often depending on the level of support and/or health in the family in which they were raised and the availability/access of community supports.

Are there behaviours common to FAS/E adolescents/young adults?

The following behaviours are often noticed in adolescents or adults with FAS/E:

- no sense of personal space
- rigid thinking or approach to a problem
- seems unmotivated
- difficulty waiting
- emotional volatility
- lying and/or stealing
- defiance of authority
- grandiose aspirations

- not responsive to subtle facial expressions & body language
 - unable to organize own activities
 - always losing possessions, forgetful
 - agitated when presented with options or need to make a choice
 - seems to disregard consequences of behaviour even when consequences are known/understood
- squirms, fidgets, restless
 - reacts badly to changes in routine



What is the formula for success when working with FAS adolescents & young adults? Remember these are general suggestions and may need to be adapted or changed for each individual's situation.

- access to service and support based on diagnosis (organic damage), **NOT I.Q.**
- adequate living situations: supported and structured
- some form of consistent, daily reliable, trained, in-home support
- on-going life skills training
- unvarying routine/schedule to follow
- routines for all possible events
- access to assisted work-not a sheltered workshop
- one-to-one buddy or peer support person
- social opportunities
- supervision "chaperone"
- remove/lessen the need to make choices
- financial trusteeship for basic needs
- family involvement

What is it important to avoid, when working with FAS adolescents/young adults?

The skills to achieve many of the following can be developed over time, through ongoing support and teaching but they should be avoided until there is an expectation for successful transition. Those adolescents/adults who have not been blessed with a definitive early diagnosis/intervention may have a more difficult time in achieving consistent independent success in these areas:

- unstructured time
- unscheduled time
- unsupervised time (i.e. to and from activities)
- parenting -without extensive, intensive, comprehensive and continuing in - home support
- alcohol or drug use
- driving
- direct access to money
- social isolation

Adolescents and Young Adults with Alcohol and Drug Problems

People with FAS have a shocking level of secondary disabilities that severely impair their quality of life and are extremely costly to society. As secondary disabilities of FAS, alcohol and other drug problems could presumably be ameliorated through better

understanding and appropriate interventions. In the 1996 Study of Secondary Disabilities of FAS, 35% of those 12 years and older reported alcohol and other drug problems but none were reported for those children under 12. Many reported that they did not drink at all. Alcohol problems were much more prevalent than illicit drugs.



Although alcoholism itself reduces the ability to cope, for those FAS individuals struggling with alcohol abuse, prenatal brain damage also contributes significantly to their dysfunctional life. Alcoholism presents special problems for persons with developmental disabilities igniting more major behaviour and disruptive problems than if they abstained from alcohol. Feelings of worthlessness, anger, depression, and panic as well as suicidal ideation are typical of young men with FAS. Yet, treating them for their secondary disability (alcoholism) rather than their primary disability (FAS) only proves to be problematic.

Advocacy treatment strategies oriented toward helping with seemingly insurmountable problems such as housing, employment, social isolation, following through etc. will be far more therapeutic than “insight-oriented” psychotherapy or group therapy. In addition, recognizing primary symptoms (i.e. memory problems, disorientation in time and space, impaired judgement, impulsivity) arise from a specific organicity, will help professionals to avoid **mistakenly interpreting** an individual’s actions as “manipulative”.

In addition to the advocacy model, feasible alternatives include network therapy for alcohol and other drug abuse, a treatment model that involves active utilization of designated professionals, family members, friends or supporters who become an important part of the treatment team, under the guidance of the therapist, and a harm-reduction model, which teaches individuals to invent rules to keep themselves out of harm’s way. Rules, especially when self-imposed, are a great strategy for FAS individuals to learn to employ and can provide the structure that they will need for success. Much reminding and practicing, as well as supportive encouragement will be required to achieve this success.

Seemingly hopeless situations can be turned around by an astute, educated intake worker or therapist who takes responsibility for getting the FAS person through the diagnostic process, when necessary and for using the acquired FAS information to structure after-care needs with a permanent case manager or therapist rather than taking a “transition” approach to aftercare. This may be a lifelong struggle for those with FAS and many “slips” or relapses are common. The necessity of relearning should be expected. Again, it is extremely important to treat an adolescent/young adult’s addiction or substance abuse in the context of their FAS, in order to achieve successful results.

What is “best practice”?

Current research points to, all professionals working as members of an integrated team including teachers, doctors, mental health and other community workers to provide ongoing support to the family and/or caregivers and the adolescent. Families, friends and the professionals in their lives, can work together to build an environment at home, school, employment and in the community that nurtures the development of FAS adolescents and young adults to their potential.

Many families have felt abandoned and blamed by professionals for the problems associated with their daughter/son’s FAS. Their experience with receiving conflicting advice and support from different individuals with varying degrees of FAS expertise has often left them feeling bewildered and inadequate. Bringing all professionals and support people together to offer an integrated plan, can help to alleviate these feelings and provide hope for success. Receiving the same message from different perspectives in different environments can make a significant difference in the family’s/caregivers ability to provide support to FAS adolescents and young adults.

SAMPLE TIME LINES FOR FAS/E ADOLESCENTS

People with FAS/FAE may present a complex portrait of competencies and delays. It is not uncommon to encounter a mix of abilities and lags in any one person. The profile of maturation and strengths vary significantly between people with FAS/FAE. This chart is intended to provide a visual cue for gaps, which may be masked by abilities (i.e., emotional immaturity may be hidden by strong expressive language skills.)

It is when the expectation that a person is “on time” when they are actually developmentally much younger that conflict develops. ‘Why don’t you act your age?’ “Grow up” and “Get your act together! ” are common comments which reflect frustration where immaturity and organicity have not been recognized as part of a normal variability in development. One parent said his feeling about his child changed after he was reminded to “Think younger” and “Have more reasonable expectations”.

SAMPLE TIME LINES FOR FAS/E ADOLESCENTS

Actual age of individual: Skill	19 Developmental age equivalent
Expressive Language =====>	21
Comprehension =====>	7
Money, time concepts =====>	8
Emotional maturity =====>	6
Physical maturity =====>	19
Reading ability =====>	15

Social skills =====> 8

Living skills =====> 12



A gradual catch up is noted in young adults with FAS/FAE. Rather than being able to leave home at 18, a more realistic time line may be 25 to 30 or so. Ask yourself what responsibilities would be reasonable to expect from a 10 year old when confronted by a tall, verbal 19 year old with FAS/FAE. Adjust expectations accordingly. The necessity of consistent reminding and supportive and nurturing reteaching makes more sense when seen in the context of this sample timeline.

Time line Adapted from: Research findings of Streissguth, Clarren et al 1996, Washington

Thanks for valuable contributions to this handout:

Robin LaDue, Ph.D. (Fetal Alcohol & Drug Unit, University of Washington); Conference Presentation, Portland Oregon 1996

FASNET Assessment Tool for Adults 1995

Ann Streissguth Ph.D., Fetal Alcohol Syndrome, A Guide For Families & Communities, Brookes

Publishing, 1997

Galanter, M. Network therapy for alcohol and drug abuse: A new approach in practice. New York: Basic Books 1993

Streissguth, Barr, Kogan, Bookstein Understanding the Occurrence of Secondary Disabilities in Clients with FAS/E, Center for Disease Control and Prevention, 1996

SECONDARY DISABILITIES OF FAS/E

Mental Health Disrupted School Trouble with Law

Confinement (re: mental health, addiction, and crime)

Inappropriate Sexual Behavior Alcohol/ Drug Problems

Re: 1996 Report, Understanding the Occurrence of Secondary Disabilities in Clients with FAS and FAE, University of Washington, School of Medicine, Dept of Psychiatry & Behaviour Sciences

SEVEN COMPONENTS OF THE ENVIRONMENT

Attitudes

Perceptions

Physical Layout

Sensory Stimuli

Time Lines

Expectations

Process

CHANGE THE ENVIRONMENT NOT THE INDIVIDUAL!!!