Practical Strategies and Support for Families Affected by FASD

A presentation by
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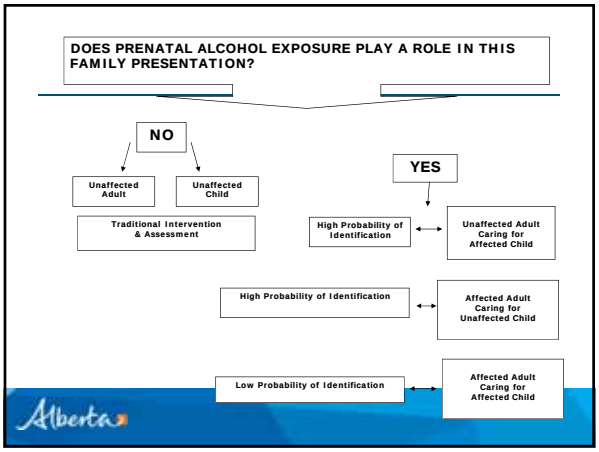
Alberta Government



UNAFFECTED ADULT/FASD AFFECTED CHILD

Presentation of the Unaffected Adult:

- Reports or demonstrates high frustration, exhaustion, isolation, and depression
- Uses crisis language
- May want child(ren) gone/out
- Looks very angry or sad
- Reports adult relationship problems
- Describes that "nothing works" and that previous attempts to find help were not helpful and/or damaging
- Describes all their efforts as useless
- May have addictions that need to be assessed and managed
- Financial crisis

Typical losses experienced by families/caregivers:

- Hopes and dreams
- The enjoyment of birth/infancy
- Self esteem and competence
- Balanced family system
- Support from family and friends - community
- Companionship
- Faith
- Financial Security
- Privacy
- Freedom
- Social network
- Ability to share in accomplishments
- May loose their loved one through separations, suicide, leaving the family

Presentation of the Affected Child:

Typical FASD behaviours/presentation (see primary/secondary disabilities lists below):

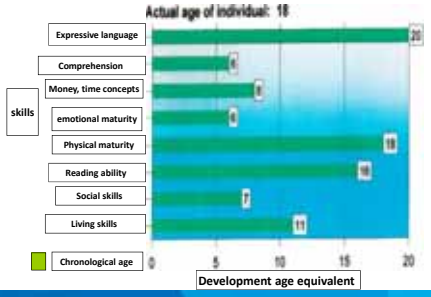
Possible Primary Disabilities

- ADHD
- auditory memory impairments for verbal recall
- decreased verbal and non verbal fluency
- spatial memory impairments
- executive function task impairments
- information processing disorders
- preservative behaviours
- learning impairments
- impaired vision/hearing
- impaired motor development and activity
- behavioural impairments
- impulsivity

Possible Secondary Disabilities

- mental health problems
- disrupted school experience
- trouble with the law
- need for confinement
- inappropriate sexual behaviour
- alcohol and other drug problems
- having children they can't care for
- problems with employment
- homelessness, transience
- lack of consistent ability to meet basic needs

Timelines and FASD



Adapted from research findings of Streissguth, Clarren et al by D. Malbin 94

Debolt

PARADIGM SHIFTS REGARDING TYPICAL FASD BEHAVIORS

BEHAVIOURS THAT CAUSE US CONCERNS AS PARENTS AND PROFESSIONALS

EATING AND SLEEPING

LEARNING AND REASONING

COGNITION

ATTENTION

SOCIAL SKILLS, EMOTIONS AND COMMUNICATION

PEER RELATIONS

SCHOOL ISSUES

TROUBLE WITH THE LAW

MONEY AND TIME CONCEPTS

HYGIENE

ASSESSMENT OF STRENGTHS AND LIMITATIONS

MANAGING PROBLEM BEHAVIOURS, LIKE LYING AND STEALING

PREPARING FOR A USEFUL FUTURE

Needs of the Affected Child(ren):

- Diagnosis
- Assessment of strengths and limitations
- Environment plan
- Increased and ongoing supervision and structure
- Living in a family that understands the disability
- Advocates for home and school
- Involvement of the Care Management Team:
  - Medicine
  - Rehabilitation (speech/language/occupational therapy)
  - Individual education plan
  - Ongoing neuro-psych evaluations
  - Functional skill building
  - Behaviour management focused on prevention of behaviours
  - Prevention of secondary disabilities

FASD AFFECTED ADULT / UNAFFECTED CHILD

Presentation of the Affected Adult:

- Have many children they cannot care for
- Being irresponsible/appearing unattached
- Denial of the problems
- Blaming others for problems
- Verbally compliant
- Behaviourally disorganized
- May be homeless/transient
- Can not manage time and money
- Poor or no delay of gratification
- Poor impulse control
- Positive self-report
- Highly verbal
- Looks manipulative
- Easily victimized/gullible
- Having problems with meeting basic needs of themselves and others
- History of sexual/violent victimization
- Likely to have positive descriptions of children's behaviours/achievements in the absence of tangible markers

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Needs of the Affected Adult (Sober):

- Diagnosis
- Functional skill assessments
- Pursue adult disability services eligibility
- A "do for" or mentor that offers:
  - Support
  - Guidance
  - Advocacy
- Long term service provision
- Structured environment
- Regular "temporary crisis management"
- Reliable reproductive health care
- Prevention of homelessness (reliable provision of food and shelter)

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Needs of the FASD Affected Adult (Non-Sober):

Same needs as above but additionally:

- Does addiction place the children at direct risk (safety)
  - When?
  - By whom?
- Do the needs of the child(ren) exceed the ability to provide through "do for" *(see below)
- Non-traditional addiction treatment: i.e. keep them away from substances

* Definition of a "Do-for": An individual who provides respectful remedies for the affected individual, including structure and supervision on an ongoing basis, and without the expectation that client compliance ensures the continuation of the service.

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FASD AND ADDICTIONS TREATMENT

FASD affected persons are at increased risk of alcohol and drug problems, and substance abuse or misuse is one of the major secondary disabilities associated with having this disability.

There are several primary hurdles to successful treatment of FASD clients:

1. recognition and diagnosis do not occur with enough frequency
2. unhelpful philosophic approaches of therapists do not support individuals with FASD
3. precipitate discharge and inadequate post treatment supports
4. belief of therapists that client is able to follow through at discharge

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FASD AND ADDICTIONS TREATMENT

- disabled persons with alcohol/drug problems have many more serious problems and disruptions than others, they are more debilitated by substance use and may as a consequence exhibit violent, unpredictable, or unexplainable behaviours, and higher frequency of conduct disorders
- it requires alert workers to spot affected individuals at intake and look for FASD diagnostic criteria
- inconsistent attendance is a problem for these persons, usually present as manipulative, unmotivated, depressed, thought disordered, in denial, or dishonest
- group therapy and dredging up past may cause enormous trauma and be overwhelming for these persons

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FASD AND ADDICTIONS TREATMENT

- addressing practical needs and the almost insurmountable problems of living is far more beneficial than insight work for these clients
- dysfunction is generally due to organicity, not alcoholism per se, though it further reduces functioning, and requires coaching to ameliorate it's effects
- worthlessness, depression, suicidal thoughts and panic are typical for a young person with FASD, which are further exacerbated by substance use and abuse
- client may state strong desire to change and become self-sufficient, but this goal is frequently not realistic without support

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FASD AND ADDICTIONS TREATMENT

- affected individuals who have learning disabilities and low IQ are at risk to be turned down for treatment
- those clients that are seen as non-compliant are frequently turned away from treatment
- primary treatment goals should be: realistic living arrangements and sheltered work environments, life skills enhancement
- relapse prevention should focus on increased supervision and community supports rather than increased self-monitoring by client

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Presentation of the Unaffected Child(ren):

- Parentified
- Anxious
- Poorly cared for
- Less tolerant of the problems
- Amazing strengths within the context
- Make gains when placed in improved surroundings
- May demonstrate reliable indicators of victimization

Needs of the Unaffected Child(ren):

- Have safety and basic needs met
- Resiliency strengthening/building
- Traditional interventions (eg.therapy)
- Benefits of a "do for"
- Relationship with biological parent

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FASD AFFECTED ADULT/FASD AFFECTED CHILD

Needs of the Affected Adult:

- Diagnosis
- Functional skill assessments
- Pursue for adult disabilities services eligibility
- A "do for" or mentor that offers:
  - Support
  - Guidance
  - Advocacy
- Long term service provision
- Structured environment
- Managing the ongoing "temporary crisis" situations (e.g. running out of rent money, problems with law, exploitation by others)
- Reliable reproductive health care
- Prevention of homelessness (reliable provision of food and shelter)

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Needs of the Affected Adult (Non-Sober):

Same needs as above but additionally:

- Does addiction place the children at direct risk (safety)
  - When?
  - By whom?
- Do the needs of the child(ren) exceed the ability to provide through "do for" (external caring for) services
- Non-traditional addiction treatment: i.e. keep them away from substances

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Needs of the Affected Child(ren):

- Diagnosis
- Assessment of strengths and limitations
- Environment plan
- Increased supervision and structure
- Living in a family that understands the disability
- Advocates for home and school
- Involvement of a Management Team:
  - Medicine
  - Rehabilitation (speech, language, occupational therapy)
  - Individual education plan
  - Ongoing neuro-psych evaluations
  - Functional skill building
  - Behaviour management focused on prevention of behaviours
  - Prevention of secondary disabilities

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Considerations for Termination of Parental Rights:

- Legal authority may have less to do with relationship than decision making abilities
- Legal authority (level of intrusion) must address how to provide "do for" ing (e.g.) consider removal of decision making Vs relationship
  (E.g.) non-competent Vs non-compliant
- Needs of children may exceed ability of in-home services
- Parent may not allow involvement (safety needs may be compromised)
- Parent brings/allows dangerous people into home environment

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Issues to Consider:

- Issues around FASD are complex, although strategies may be quite simple
- Strategies readily available through revised traditional interventions
- Build/strengthen resiliency in the unaffected individuals and community
- The needs of the children dictate the case plan, not the competency of the parents
- Assessment should always consider the risk of non-involvement
- Always provide respite (even when parents are not sure they are interested)

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FASD is a Diagnosis for Two…

- Where are the mothers of persons that have FASD?
- What do we know about these mothers?
- Should we assume that mothers are able to change their behaviors without our intervention?

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FASD is a Diagnosis for Two…

- What would it take to make it possible in our community for every woman to get through her pregnancy without using drugs or alcohol?
- Would every woman need the same intervention?

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FASD

Although we know that adults who have been affected by prenatal exposure to alcohol face limitations and barriers, we believe that they have strengths on which to build.

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FASD: Needs

Those affected by FASD may need an external system of support to enable them to manage challenging situations and daily living skills. These issues may include parenting, employment, housing, educational training and social behaviour.

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