



Fetal Alcohol Exposure: Time to Know, Time to Act

Ontario's Provincial Conference
April 10-11, 2003

Learning the Dance

Reframing our Perception of how Children with
FAS Sense the WORLD

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GUIDELINES TO INTERVENTION WITH FAMILIES

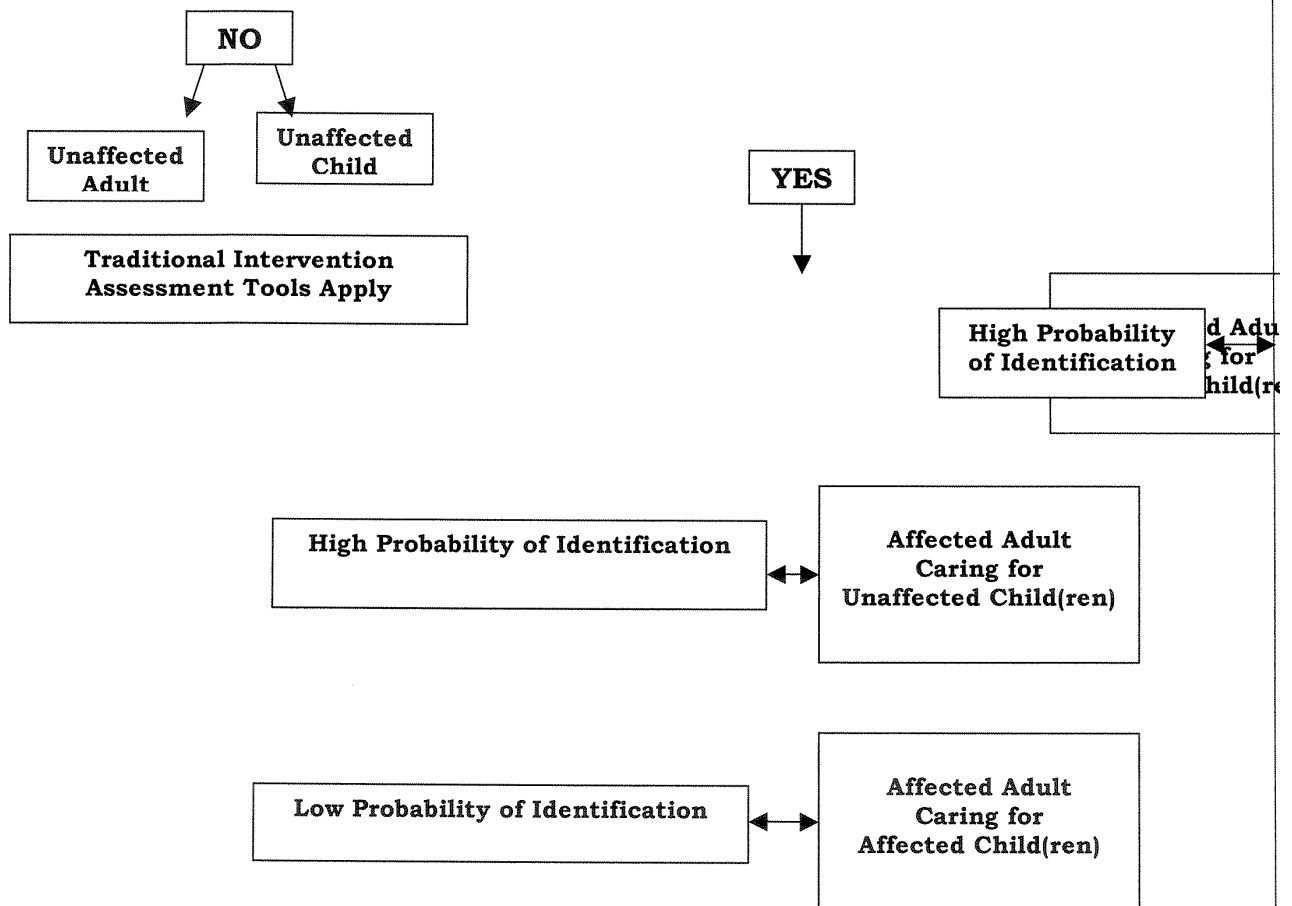
Revised 03/17/03

ASSESSMENT OF NEEDS

Assessment tells us:

- What to do
- When to do it
- Rationale for intervention

QUESTION TO BE CONSIDERED: DOES PRENATAL ALCOHOL EXPOSURE PLAY A ROLE IN THIS FAMILY PRESENTATION?



UNAFFECTED ADULT CARING FOR AFFECTED CHILD(REN)

Presentation of the Unaffected Adult:

- Reports or demonstrates high frustration, exhaustion, isolation, and depression
- Uses crisis language (looks “crazy”, says “crazy things”)
- May want child(ren) gone/out
- Looks very angry or sad
- Reports adult relationship problems
- Lost sense of humour
- Describes that “nothing works”
- Reports previous attempts to find help as not helpful and/or damaging
- Describes all their efforts as useless (black hole)
- May have addictions that need to be assessed and managed
- Financial crisis

Needs of the Unaffected Adult (Sober):

- Initial education about FAS/E
- Will require ongoing learning opportunities and training regarding FAS/E
- Care-giving strategies
- Normalizing the behaviours within the context of the disability
- Support:
 - Primary to diagnosis
 - Ongoing for coping
 - Respite/even when not asked for
 - Therapy for grief/loss work at many stages of development*
 - A “case manager”(may not be the obvious person)
 - Clarity of expectations
 - Connections to other care givers

Needs of the Unaffected Adult (Non-Sober):

- Family planning may need to be addressed
- Addiction treatment/management, may need a “mentor” for several years
- Primary education about FAS/E
- Will require ongoing learning opportunities and training about FAS/E
- Care-giving strategies
- Normalizing the behaviours within the context of the disability
- Support:
 - Primary to diagnosis

- Ongoing for coping
- Respite/even when not asked for
- Therapy for grief/loss work*
- A “case manager”(may not be the obvious person)
- Clarity of expectations
- Connections to other care givers

*See losses below

Typical losses experienced by families and 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
- The affected loved one through separations, suicide, leaving the family

Presentation of the Affected Child(ren):

Typical FAS/E behaviours/presentation see primary/secondary disabilities list 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
- behavioral 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

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

AFFECTED ADULT CARING FOR 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

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"
- Prevention of additional children
- Prevention of homelessness (reliable provision of food and shelter)

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”
* (see below) services
- Non-traditional addiction treatment: i.e. keep them away from substances

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

*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.

AFFECTED ADULT CARING FOR THE 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)
- Prevention of additional children
- Prevention of homelessness (reliable provision of food and shelter)

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

Presentation of Affected Child(ren)

Typical FAS/E behaviours/presentation, see primary/secondary disabilities list above.

Needs of the Affected Children):

- 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 the 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

Consideration 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

Issues to Consider:

- Caregivers of FAS/E child(ren) can look more competent than they really are
- Issues around FAS/E are complex, although strategies may be quite simple
- Strategies readily available through revised traditional interventions
- Build/strengthen resiliency in the unaffected individuals and community
- Pick “hills to die on”
- 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)

Parent *support* strategies

Outline for presentation in Toronto

- Welcome and introductions
- What do parents really want?
- Who *is* the helper? Being “Colombo’ like
- Barriers to providing support
- Hopes and dreams; Inuvik vs. Hawaii
- Losses
- Gains, preventing secondary disabilities
- Coaching as a tool for change
- Building family strength
- Alternate family structures
- Laughter and fun
- Paradigm shifts

Coaching Families

The Coaching Families program was initiated to provide coaching and mentoring to families living with children aged 0-18 who have been prenatally exposed to alcohol.

The goals of Coaching Families are to:

- build on family strengths
- ensure the children are in a safe and stable environment
- increase understanding and knowledge of FASD among families, caregivers, and other community supports
- provide families with strategies and tools to decrease the risk of secondary disabilities (e.g. financial or legal difficulties)
- provide consultation to teams involved with a parent who themselves have FASD

As of June 30, 2002, 87 referrals were made to the program. The average time a client is actively involved in our program is 21.5 weeks. In April 2002 a waitlist was established. During the first 6 months, we closed 28 files. (Client initiated closure in all cases so far).

- Of referrals, 72% were referred through mandated services (Child Welfare); 28% were community referrals.
- Of the 21.5 weeks on average a client is actively involved, and average of 8.3 weeks is time spent in the assessment phase of our work, and average of 13.2 weeks is time spent in what we refer to as the work phase (where specific strategies are taught).
- During this reporting period, 7 clients had their files 'on hold'. Of this 7, 4 files were pending confirmation of diagnosis, 2 were busy with other services, and 1 family's child temporarily moved out of our region.
- Of the closed files, 50% withdrew, were not interested, or contact was not established; 21% did not meet the criteria of our program; 11% withdrew due to placement breakdown.
- When on the waitlist, the average time until an opening became available was 30 days.
- The primary caregivers are largely comprised of Foster Parents, Adoptive Parents, Birth Parents, and Grandparents.

Coaching Families engages in a lengthy and intense needs and strengths assessment of the family and of the child(ren). This assessment often determines eligibility into our program. It may be concluded that a child has not, in fact, been prenatally exposed to alcohol, or that the family does not wish to pursue services for a variety of reasons.

The information in this report is gathered from:

- Client demographics derived from the Referral Interview, the Family Telephone Interview, and the Initial Home Visit.

- This information is input into our database, Canadian Outcomes Institute (COI), which provides services through Hull Outcomes Monitoring & Evaluation System (HOMES)
- The Referral Interview is in addition to the intake interview and conducted with the referring source
- The Family Telephone Interview is conducted with the primary caregiver and is the client's self-report
- The Initial Home Visit Interview is conducted with the caregiver(s) and may take several sessions to complete, and is the client's self-report
- Progress
 - Goals are determined by the client and measured at 6 months and/or at the end of involvement
 - Progress is determined by the Mentor and represented as an Interim Needs and Issue List through HOMES
- Stress Scales
 - Completed by clients at the outset of services, and at the end of our involvement
 - Only 4 pre and post stress scales were completed during this period, and of those 4 the majority showed definite improvement in their physical health and mental state, in their sense of hope, and in accessing resources, including respite.
- Client Satisfaction Questionnaire
 - This information is based on Client Satisfaction Surveys completed by the clients at the end of their involvement with the program

The coaches/mentors were asked to respond to some basic questions about the program, and one underlying theme was the need for families to have a better understanding of FASD.

What did as mentors we learn in first 6 months?

- families need respite
- families need a much deeper understanding of FASD
- families need support and people to talk to
- many foster families on case load
- we got a much better understanding of what it is we are doing

- we approach biological families a bit differently than the other families, as we need to be very sensitive and ensure that we are not blaming in any way
- sometimes we are not able to meet with both parents in a family
- just because an individual makes a self referral does not necessarily mean that they will follow through with the program
- families need lots of understanding, a safe place/person to vent with and are very grateful for our listening and support
- each family has distinct needs
- it is a big challenge to transform knowledge into everyday practice
- when you start a new program there are lots of wrinkles to work out
- the program works well for those who are committed to it
- it is important to find the method of learning that works best for each family
- we have successfully made the move to using HOMES right from the start and once we got used to it, learned it is very helpful

Are we going to do anything differently?

- we need to revise our FASD Stress Scale in order to use it more efficiently and effectively
- we will work with the parent that wants to work with us and help him/her to teach the other parent

Patterns noted by the Mentors:

- step mothers/common law partners of birth dads often refer their own family-for help
- families split up when partner forces one parent to choose between him/her and the affected child
- highly educated professional parents have difficulty accepting help from our program for various reasons (family should be able to handle their own problems / see us as more for child welfare families)
- clients want to cut back on being involved in our program during the summer months
- couples disagree on how child should be treated, what should be expected from child
- **caregivers have a lot of theoretical knowledge about FASD but have a problem remembering to implement into daily activities**
- it seems to be hit and miss with birth moms; I think it really depends where they are at when they are referred
- adoptive families are unaware of special needs child when adopted
- birth families tend not to stay in program due to addiction issues and crisis situations
- respite is a key issue
- **some families think they understand FASD but continue to be frustrated with children**
- ~ number of grandparents caring for the grandchildren; are unable to enjoy retirement

***THIS INFORMATION WAS TAKEN FROM OUR Summary of Statistics — December 2001 through June 2002**