



Fetal Alcohol Exposure: Time to Know, Time to Act

Ontario's Provincial Conference
April 10-11, 2003

Working with Young Children

Judy Kay, Consultant
Sioux Lookout & Hudson Association
for Community Living

Judy Kay

Sioux Lookout & Hudson Association for Community Living
Box 1258
Sioux Lookout, ON P8T 1 B8
Telephone: 807-737-4600 Fax: 807-737-3833

Judy Kay has both personal and professional experience with Fetal Alcohol Syndrome. Her educational background is in Early Childhood Education/Resource Teaching. More than 10 years of foster-parenting children with FAS has given Ms. Kay a passion to carry forth the FAS issue. Ms. Kay has coordinated local programs that conducted public education, professional development for all sectors, and supports for families. She helped develop a provincial FAS training program for early intervention programs. Presently, Ms. Kay coordinates the Healthy Generations Family Support Program in Sioux Lookout. This program supports families raising young children with FAS or related conditions.

Support & Advocacy for Parents Raising Children With FAS and related conditions

It Takes a Village to Raise a Child.

The Need for Family Support Is Great

- ✓ Information to combat confusion
- ✓ Appropriate professional services to combat deterioration of the family
- ✓ Understanding to combat isolation

Where to Begin

- ✓ If you haven't lived it, you don't know it!
- ✓ Learn from parents.
- ✓ Learn all you can about FAS.
- ✓ There is no quick fix or easy solution.
- ✓ Parents often feel defensive and don't trust that professionals understand FAS.

Where to Begin

- ✓ The behavior of the parents has not caused the misbehavior of the child. The root of the behavior may have neurological roots, possibly compounded by other issues. The parents may be reacting to the disability.
- ✓ Listen, "hear" what is being said..not being said.
- ✓ Provide services pro-actively.
- ✓ Don't under-rate the problems parents are expressing.

Identification & Diagnosis

- ✓ Early diagnosis is only the beginning.
- ✓ Information about FAS is not a sentence, it is a building block.
- ✓ Support and help parents through the process.
- ✓ Ensure the process is up to date and useful.
- ✓ Help families set up a supportive system.

Grief, Loss, Acceptance

- ✓ Birth parents feel grief, guilt and shame. We may or may not have the capacity to understand, but at least we must come to terms with our feelings in order to not judge.
- ✓ All parents experience grief and loss as they adjust to reality of their child's situation.
- ✓ Grief and loss is not just at the beginning, it comes and goes throughout the journey.

Grief, Loss, Acceptance

- ✓ Many parents feel responsible for how they have disciplined or parented because of not understanding FAS and inappropriate services.
- ✓ The biggest challenge is changing their expectations for their child and family.

Parent's Experiences

- ✓ Constant vigil (protectiveness, hyper-vigilance)
- ✓ Effects on marriages (stress and strain)
- ✓ Child management
- ✓ Parental issues
- ✓ Interactions with professionals
- ✓ Emancipation concerns (independent living)
- ✓ Medical implications

Issues of Families of Children With FAS

- ✓ Validation
- ✓ Guilt
- ✓ Frustration
- ✓ Fear for the future
- ✓ Family-centered care
- ✓ Family strategies

Help Parent Strategize and Advocate

- Ask the question, "If I really believed this child's problem is a result of an organic brain problem, what would I do different?"
- Begin and end with the question, "what is needed in order for this child to be successful (external brain)?"
- Interventions need to focus on creating an environment that works best for the child.
- Parents may need you to advocate for them depending on their energy levels at that time.
- Case management is vital.

Help Parents Strategize and Advocate

- Provide access to training for understanding FAS and specific parenting techniques.
- Track down resources and aid families in using them, sort out red tape.
- Help parents interpret and track, difficulties, successes, talents and solutions.
- Help parents to consider & access respite.

Help Parents Strategize and Advocate

- Provide training to all involved in the child's life, don't assume they "get it."
- A support group or buddy system may help.
- Longer term planning and parenting is common.
- There are good and bad days for children living with FAS. What we want is to have more good days.

"In my early recovery I blamed myself terribly for what I had done to my son. I try not to do that anymore. I try to focus on the here and now. What's done is done and now I like to stay in the solution if possible."

Traci (birth mother)

Young Children with Fetal Alcohol Syndrome and related disorders

Infants

- Failure to thrive (low birth weight)
- Jittery
- Exaggerated startle reflex
- Problems with sleep patterns
- Problems with sucking and feeding
- React poorly to change, problems with regulation
- Over or under reactive to stimulus, difficult to calm
- Delayed milestones or development
- Medical problems
- Loose muscle tone
- Problems with hearing, vision, and other organs

Toddlers

- Become over-stimulated in stimulating environments
- React strongly to transitions, change in routine and environment
- Poor attention span, impulsive, poor judgement
- Unaware of consequences of behavior (risky behavior)
- Be indiscriminate with strangers
- May not pick up subtle information
- Behavior may need constant monitoring
- May act younger
- May get stuck on certain behaviors (perseveration)
- Sleeping and eating difficulties
- Memory problems

Interventions for Infants

- ✔ Speak softly, hold gently, don't rush
- ✔ Observe for signs of over-stimulation and control environmental stimulus
- ✔ Notice what upsets them and what calms them
- ✔ Reduce stimulus, bundle
- ✔ Introduce one sensation at a time if necessary
- ✔ Avoid letting the baby get to a state of frantic crying
- ✔ Stroke lips and gums before feeding
- ✔ Bundling, Pacifier, Gentle motion
- ✔ Comforting sounds
- ✔ Ease infant back to sleep or aid with transition to awake
- ✔ Keep routine constant

Interventions for Toddlers

- ✔ Activities to enhance development
- ✔ Activities that enhance communication/speech
- ✔ Create structure, routines and predictable schedules
- ✔ Use concrete teaching strategies
- ✔ Use simple, concrete language
- ✔ Accommodate for slower auditory processing time
- ✔ Use visual cues to teach and remind
- ✔ Careful supervision
- ✔ "prescribe" the environmental stimulation

"Fetal Alcohol Syndrome is primarily an invisible handicapping condition – one whose only manifestation may be behavioral."
(Ann Streissguth)

If a child does not have the capacity to adapt to the environment then the onus is on the environment to adapt to the child.
