

A Standard of Care for Children with FAS/E

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By the time children with FAS/E reach six years of age and begin elementary school, hopefully they are included in and bonded with a loving, healthy family. Naturally what is best for these children is for their birth families to start the recovery process and learn to parent their own children. However the sad fact is that over 80% of children with FAS/E who have been seen at the FAS Diagnostic Clinic were not living with their birth families. Therefore finding stable, permanent families for children with FAS/E becomes a critical intervention issue for foster care and adoption agencies. Dr. Ann Streissguth reported in the 1996 FAS/E Secondary Disability Study at the University of Washington, that the primary protective factors for the child with FAS/E were: living in a stable and nurturant home for over 72% of life and being diagnosed with FAS/E before age 6.

Consequently at the FAS Intervention Retreat in November 1997, when we started brainstorming with families about successful interventions we began with the assumption that the critical intervention foundation had been laid, i.e. that we were talking to healthy birth parents who were able to advocate as caregivers for their children, and to foster, adoptive, step and grandparents who had devoted their time, energy, wisdom and intelligence to providing for these children. We were not disappointed. As we finished sharing successful interventions for toddlers and moved into the discussion of children, ages 6 through 11, we facilitators were overwhelmed at the dramatic depth of love, patience and nurture that these parents had given to the children in their care. The toddler years of FAS/E are usually spent wondering at the developmental delays and worrying whether or not the child will "catch up," while the years of childhood begin to declare the depth of the brain damage. It is important for parents to understand that this issue is not unique to FAS/E. **In Washington State, developmental disabilities are defined as:** mental retardation, **developmental delays in ages birth to 6**, cerebral palsy, epilepsy, autism or other neurological conditions similar to mental retardation. It would seem logical that by the time children with FAS/E are six years old and the developmental delays are entrenched and permanent, (while their peers begin to blossom with physical, mental, and emotional maturation) that they would be shown the type of dignity and respect given to children with other disabilities - recognition and eligibility for services.

The mission of the Division of Developmental Disabilities* is to assist individuals with disabilities and their families to obtain services and supports based on individual preferences, capabilities and needs, and **which promote everyday activities and relationships common to most citizens**. Unfortunately, this is not the case for children with FAS/E. Two things are needed. First we must have a sound scientific "definition" that explains why FAS/E is as serious and catastrophic to the affected individuals as mental retardation.

The dream we have for children with FAS/E is that those precious, magical years before puberty can be as wonderful and carefree for them as for other children. The pursuit of happiness ... what a concept. The place to start? Again in Ann Streissguth's Secondary Disability Study, researchers list "being found eligible for services through the Division of Developmental Disabilities" as another universal protective factor. If our goal is to provide safety for individuals with FAS/E and the community, we need to provide appropriate intervention supports during childhood so they will not present as lacking remorse or a conscience during the adolescent years. The first interventions for the childhood years will be official recognition of FAS/E as a developmental disability and new funding appropriated into the Division of Developmental Disabilities to care for these children.

Secondly, we need an accepted medical protocol for diagnosing the organic brain damage which has been called fetal alcohol effects (FAE) over the past few years. Everyone understands the general concept of FAE but it is not a medical diagnosis and consequently does not open the door to any treatment or services. The exciting news is that the evolution of scientific research on this issue has brought us to the

*in the Department of Social and Health Services

point where doctors may have the tools to accurately diagnose FAS/E in the foreseeable future without being dependent upon the facial features as they have in the past. The current work of several researchers could have the potential for developing new diagnostic protocols or tests. Two of these researchers will be featured at the FAS*FRI conference in Everett, Washington on Oct 8-9, 1998, Dr. Sterling Clarren (University of Washington) and Sarah Mattson (San Diego State University). We believe their findings are indicative of the type of current front line research that has the potential to develop the necessary diagnostic tests to validate the existence of organic brain damage in all affected individuals. **This information is essential to policy makers, who need hard data to authenticate a medical condition and estimate the incidence and costs, in order to make informed decisions about appropriations for services.**

Diagnosis is also vital to the children and their families. The developmental delays of the toddler years must be understood and diagnosable as the children get older in order to provide them with appropriate care for a developmental disability instead of criticizing and shunning them as persons who have no conscience and are without remorse. If Dr. Ann Streissguth is correct in her Secondary Disability Study and it is important to diagnose the affected individual before age six, this new research information is a thrilling breakthrough for FAS/E.

This issue of FAS Times presents the collective family experience from the FAS Intervention Retreat for the childhood years. The good news is, there was so much information shared by parents for this age group, it will take two issues to present the interventions! So the interventions for children will be continued in the winter issue. We have had great feedback on the Summer issue which focused on interventions for toddlers. One mom called from California and said, "I'm desperate, can you send me the interventions for the adolescent years now?!" We understand her feelings of urgency. We've been there, too. However, we are compiling the data just as fast as we can. There is so much we can do to help individuals with FAS/E— isn't that a great place to be!

[Update: The complete Standard of Care is available by itself or in our book, The Best of FAS Times. Please see publications page for details and ordering information.]