

Introducing. . . A Standard of Care
for Toddlers, Children, Adolescents and Adults with FAS/E
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A Crisis in America

The epidemic of kids killing kids in the school yards and classrooms of America may be more understandable than most people think. According to Michael Dorris, a featured author on ABC's 20/20 program a few years ago, fetal alcohol syndrome (FAS) leaves many individuals without remorse, without a conscience and unable to distinguish right from wrong. For thousands of years, many of these babies died soon after birth because they often have "failure to thrive" and/or they are premature. However, with the discovery of penicillin and the invention of incubators and various other dramatic lifesaving techniques, babies now born with FAS/E usually survive.

According to the National Association for Families and Addiction Research and Education, over 750,000 alcohol or other drug exposed babies are now born every year in the USA. While this is not to say that all of these children have FAS/E, it is obvious that the addictions of their mothers were so out of control that when they went to deliver their babies, they tested positive for alcohol and/or other drugs. It is quite possible that for many of these children, remorse, conscience and the ability to distinguish right from wrong has been diminished. Of course many complex factors converge when a child turns violent and many of these factors may have nothing to do with fetal alcohol exposure. But research has shown that individuals with FAS/E are very naive, vulnerable, volatile and easily drawn into anti-social behavior. Truly, we have a crisis in America.

Protecting People with Disabilities from an Overload of Stress

One of the most basic and fundamental issues of human rights should be caring for people in our culture that cannot take care of themselves: babies, people who are physically or developmentally disabled and those with serious mental disorders. In some situations we, as a society, have developed interventions that really are effective but in other areas serious work is still needed.

The good news is that interventions for individuals with FAS/E have been known for many years by parents struggling to care for these children. The problem was that there had been no systematic effort to gather up this "collective family experience" until November 19-21, 1997 at Rainbow Lodge in Washington State. Dr. Tim Brown and Mr. Kenneth Stark (Directors of the Divisions of Developmental Disabilities and Alcohol and Substance Abuse in the Department of Social and Health Services) funded an FAS Intervention Retreat for families. It is important to realize that this event was initiated by families in crisis and these men responded to those needs.

Most professionals still testify to the fact that no one knows which strategies will develop into interventions that will work for individuals with FAS/E. But a strategy is a theory. Interventions are actions which alter the course of otherwise inevitable events. According to Dr. Ann Streissguth's Secondary Disability Study at the University of Washington (1996), the natural course of the disability of FAS/E is catastrophic to the individual, family and society.

Consequently, as a community we are forced to provide interventions - either out of compassion for a developmental disability or out of fear through the criminal justice system. Unless we make a conscious, compassionate choice, and learn how to protect individuals with FAS/E from stress that they do not understand and are unable to cope with, we will end up serving them out of fear as is currently being experienced across America.

The Difference Between Strategy and Intervention

Accepting the necessity for serving these individuals and understanding the unique wisdom and experience of the families we've had the privilege to meet over the past nine years, we decided to hold a family FAS Intervention Retreat. We sent out invitations to all the parents in Washington State on our mailing list. The one requirement for attendance was that they have a medical diagnosis of FAS/E on a child they are raising or have raised.

We brought as many families together as we could (28 total) from all over the state who represented children in all four of the developmental

stages. We spent three days brainstorming about all the positive, successful interventions we've devised for our children. This was not a strategy session nor was it a time to whine. It was a work session to share and collect interventions that have already altered the negative course of FAS/E. We families were focused and determined.

Our emotions were real, so we were able to acknowledge the grief that will always be a part of our lives. The grief is strong not only because FAS/E is a life-long disability but also because it is totally preventable. Our children could have been saved from this birth defect if society had been educated and committed to the best intervention - prevention. (See related article, p. 11.) Because of the intervention data generated at this event and others over the years, we have the necessary information to develop an FAS/E "Standard of Care" from the collective family experience. We now understand:

- * The developmental deficits of toddlers, children, adolescents and adults with FAS/E (FAS/E Developmental Overview through the Eyes of Parents brochure. Also see p. 4 for Toddler Deficits.)
- * The adolescent behavioral profile that presents itself even when the IQ is normal (as described in the We Love Children brochure);
- * This behavioral profile is reflective of the developmental deficits and the resulting symptoms should not be treated separately or apart from a basic understanding of FAS/E.
- * There is a recognizable pattern of conduct that can be catastrophic to families (Survey of Stress and Grief, see p. 5);
- * The proven interventions which can be done within the resources of the families (See Family Interventions, pages 6-8);
- * The successful interventions that families have initiated within public service delivery systems (Systems Interventions, see pages 6-8).

We are very grateful for the funding that was made available for this special gathering. We were also humbled and excited that Dr. Louise Floyd and Dr. Jacqueline Bertrand from the federal Centers for Disease Control called to ask us if they could attend the FAS Intervention Retreat. What a testimony of their interest and respect for the collective family experience!

This issue of FAS Times is devoted to the foundational introduction of the FAS/E Standard of Care and the presentation of the specific Standard of Care for Toddlers with FAS/E. The Fall and perhaps Winter issues will present the Standard of Care for children (ages 6-11), adolescents (ages 12-19) and adults (ages 20 and over).

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(Editor's note: The complete Standard of Care is available by itself or in our book, The Best of FAS Times. Please see publications page.)