

FAS/E: A Standard of Care for Adolescents

The Anti-Social Years

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Recently, policy makers in our state came together to address the issue of youthful antisocial behavior. Our Governor, Gary Locke, and the Superintendent of Public Schools, Dr. Terry Bergeson, took the lead in this endeavor and scheduled a "Youth Safety Summit" in August 1998. The goal was to discuss how to prevent school violence by troubled youth. The final report listed violence predictors (risk factors) and protective factors as follows.

PREDICTORS OF YOUTH VIOLENCE

Individual and Peer-Related Factors

- Interpersonal conflict
- Alienation and rebelliousness
- Poor peer relations
- Friends with problem behavior
- Early onset of problem behavior
- Impaired cognitive functioning
- Drug and alcohol abuse
- Psychological difficulties
- Constitutional factors, potentially including genetic factors

PROTECTIVE FACTORS AGAINST YOUTH VIOLENCE

I. Positive relationships with Family Members, Teachers and Friends

- Close bonds
- Encouragement
- Recognition of Youth's Competence

II. Healthy beliefs of school, families and friends

- Setting clear standards
- Encouraging performance at school
- Discouraging drugs and crime

In the conclusion of the final report, the specific recommendation for individual action was, "Adults should provide opportunities for youth to bond with them through mentoring, tutoring, job shadowing, internships and other volunteer activities."

Another effort to protect Washington's youth originated in the Washington State Department of Social and Health Services, Division of Alcohol and Substance Abuse (DASA). It is called the Communities That Care research program (1996-1998), a Risk and Protective Factor-Focused Approach to Reducing Adolescent Problem Behaviors. The program begins, "All across our county, adults concerned about the healthy development of young people are searching for answers to adolescent behavior problems. Although these problems have been with us for a long time, alarming increases in juvenile crime, particularly violent juvenile crime, have created a

renewed sense of urgency. Young people in record numbers are falling through the cracks and are failing to develop their potential to mature into healthy, productive citizens of our communities. Fear of and fear for our nation's youth is crippling our ability to nurture and support the next generation into adulthood." It goes on to say, "As our understanding of risk and protective factors has grown, we have searched for ways to address them. Communities That Care organizes what has been learned about prevention strategies into a comprehensive approach to addressing adolescent problem behaviors." The Communities That Care project cites bonding, attachment and commitment as the three critical issues which mold individual characteristics into Healthy Behaviors. The program presents the following.

INDIVIDUAL/PEER RISK FACTORS

- Alienation and Rebelliousness
- Friends Who Engage in the Problem Behavior
- Favorable Attitudes Toward the Problem Behavior
- Early Initiation of the Problem Behavior
- Constitutional Factors (such as developmental disabilities *[my comment]*)

SCHOOL RISK FACTORS

- Early and Persistent Antisocial Behavior
- Academic Failure Beginning in Late Elementary School
- Lack of Commitment to School

The key puzzle piece seems to be something so simple that mothers of drug affected babies notice it almost immediately ... bonding and attachment issues. Data generated at the FAS Intervention Retreat has shown that in the Collective Family Experience, bonding is not secure in those individuals with FAS/E until well into the adult years.

My husband and I accidentally stumbled on this understanding as we parented our four children through adolescence. When our 2 oldest children were about 12 years of age, I, in my mothering role, developed a little family coming-of-age ritual. Part of the ritual was that we had a special heart-to-heart talk and I, in essence, released them from my authority into their adolescent years. Please note that they were not released from my husband's authority. He was still ruler in the kingdom of adolescence in our household. (I know this sounds a little strange, but I'm going somewhere with this.) My insight, which I found in my Bible, was that I wanted to see if respect for women had been instilled in the heart of my kids during their childhood years.

Our household did not immediately turn into a chaotic swamp because my husband most assuredly did not release the kids from his authority. The question I wanted to answer was how bonded were they to me, as a woman and mother. Would they respect me and my advice or would they figuratively spit in my face as some other teenagers do to their mothers? Well, with my first two teenagers (who were not exposed to alcohol) everything turned out fine. They voluntarily listened to me and respected my wisdom and counsel and we had a lot of fun during their teenage years.

But when our kids with FAS/E reached twelve and thirteen, we were in a whole different ball game. Even though the family ritual was intact, the kids' brains weren't (so to speak). The respect

for my husband and me was still there and we all had many adventures together but the bonding process was somehow warped.

Upon reflection I now realize that our expectations were based on our knowledge and expertise of the natural maturing cycle of the adolescent years. We thought we could trust their behavior to be within the civilized norm for mischievous teenagers. When they would exhibit normal teenage social blunders, we expected them to at least alter their behavior a little and learn from whatever discipline or restriction would be imposed as consequences, but that didn't happen. That's the bad news.

The good news is when we understand the Core Disability issues of adolescents and adults with FAS/E, the life altering result is that we change. The kids don't change, but our expectations change and become realistic. This turning point (in our attitude as parents and guardians) is absolutely critical. You see, they are not really antisocial at all. Individuals with FAS/E appear antisocial when they are compared to their peers who are meeting developmental milestones. This disability is hidden deep inside the central nervous system in their brains. At this time there is not enough education and public awareness to recognize the disability of FAS/E when the IQ scores are normal. So it is easy to jump to a faulty conclusion, i.e. that they are untrustworthy and antisocial. Parents, schoolteachers, counselors, judges etc. say things like, "I told you what the consequences would be if you stole another car. Now your actions prove to me that I can't 'trust' you, so ..." But the issue is not trust.

The cold hard fact of reality is that we, as a society, cannot help adolescents with FAS/E unless we change our good adolescent programs to include alternative interventions to motivate these individuals. They cannot work the plan. They cannot follow the 12 steps. They cannot follow the sequence of rules expected in the adolescent developmental process of maturing. They are disabled and it is we, as a society, who must change to respect their virtues and include them as honorable, loving individuals.

In this issue of FAS Times we share with you our Standard of Care for adolescents with FAS/E. Please remember that even if you have not had time to use our interventions for toddlers and children, those interventions may still be effective for teens with FAS/E. So review this information often (printed in our three previous editions of FAS Times), as you reflect on the challenges and successes along the way. It is sometimes helpful to me to view the disability of FAS/E in three primary stages.

The first stage is the Teachable Years, ages birth through age nine. When the IQ is normal, toddlers and children with FAS/E can learn almost anything any other child can learn. While they may have subtle developmental delays, the normal IQ usually masks the severity of the disability to parents, doctors, teachers, counselors and other professionals.

The second stage is the Antisocial Years, roughly ages 10 through 18. We believe the primary goal in this stage is to keep the affected individuals safe, bonded with the family, and living within the community norms which in turn will keep the community safe. In order to accomplish this, it is absolutely critical that families, communities and courts have a basic understanding of the Core Disability traits of FAS/E for this age group (especially when the IQ is normal).

The adolescent years are difficult at best. But when the teen is been disabled by FAS/E and appropriate interventions do not occur, it can be disastrous for the individual, family and community if their disability is misunderstood or ignored.

The Dysfunctional Years comprise the third stage which is during adulthood. We will explore this stage in the next issue of FAS Times.

Who, What, When, Where, Why and How to Help Teens With FAS/E

Who: The individual at the highest risk for violent, antisocial behavior is the child who has been disabled by FAS/E, but has not had the benefit of diagnosis and specific FAS/E intervention support services.

What: Intervention services. A secure bond and attachment to family, school and society is the most important protective factor for keeping the individual with FAS/E and his/her community safe, according to research gathered by The Communities That Care Program, The Washington State Youth Safety Summit, The University of Washington/Centers for Disease Control study of The Secondary Disabilities of FAS/E and the FAS Family Resource Institute's Standard of Care. Without support unique to the Disability of FAS/E, these individuals may be (or may appear to be) unbonded and detached from compassion, empathy and morality.

When: Every community will determine it's own destiny. If individual citizens ignore the consequences of prenatal alcohol exposure, we (as a culture) will allow a tragic preventable disability to multiply exponentially in successive generations. Interventions can happen now or whenever we decide as a culture that this is an important issue.

Where: The where is in communities who have people that will absolutely insist that their social service policymakers recognize and care for individuals that "constitutionally" cannot care for themselves.

Why: Why is for prevention. The consequences of ignoring individuals with FAS/E (according to research from Dr. Ann Streissguth at the University of Washington) is that they are extremely vulnerable to the self medication of alcohol abuse, making them at highest risk to produce another generation of children with FAS/E.*

How: Muster the courage to face reality. Accept and grieve over the risk factors. Then join in the work with others who are determined to take action and implement the protective factors in your community.

[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.]

* Baer, John S., Barr, Helen M., Bookstein, Fred L., Sampson, Paul., & Streissguth, Ann P., (1998, September). Prenatal Alcohol Exposure and Family History of Alcoholism in the Etiology of Adolescent Alcohol Problems, Journal of Studies on Alcohol.