

Attaining HUMAN RIGHTS, CIVIL RIGHTS, and CRIMINAL JUSTICE for People with **Fetal Alcohol Syndrome**

BY ANN STREISSGUTH, PH.D.

At a time in history when many people with disabilities are demanding their rights to be fully participating members of their communities, there is another group of people with disabilities who are demanding to be identified. At a time when people with disabilities are trying desperately to rise above their disabilities and be recognized for their basic humanity, people with Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), and other prenatal effects of alcohol are still struggling to be understood for the disabilities they do have. These disabilities are seldom recognized, seldom treated effectively, and seldom connected to service dollars. People with FAS/FAE have a somewhat "hidden" disability — not hidden from themselves, as they experience their disabilities all too acutely. Rather, their disabilities are "hidden" from those who may perceive them to be physically and sensorially intact, and thus fail to recognize their disabilities.

People with FAS and FAE have subtle birth defects of the brain. The brain is the organ of the body most vulnerable to the prenatal effects of alcohol. Children and adults can experience subtle brain dysfunction from prenatal alcohol exposure even without the characteristic growth deficiency and facial and physical anomalies associated with FAS in the prepubertal years. The central nervous system (CNS) dysfunction

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tion associated with prenatal alcohol exposure (also called Alcohol-Related Neurodevelopmental Disorders or ARND) can cause learning deficiencies, attention and memory difficulties, language, developmental, and motor delays, and problems with organization, speed of information processing and response modulation. These CNS dysfunctions impact social and behavioral interactions, judgment, task persistence and eventually employment and independent living as those affected reach adulthood.

As these problems can have other causes, knowledge that the child had significant alcohol exposure before birth, or that the child's mother had an alcohol problem, or was a regular or binge drinker around the time of pregnancy, is essential in proper identification of this disability. Due to the complexity of

linking prenatal alcohol history with subtle CNS dysfunctions, particularly in the absence of clear physical and sensory disability, most children and adults with ARND probably go through life undiagnosed. At this time, there are no biological markers for FAS or FAE, so the determination lies in the skill of the clinician. Yet, this disorder is not uncommon. A recently published epidemiologic study revealed that the prevalence of FAS and ARND was nearly 1 per 100.

Growing up without benefit of a diagnosis and without an obvious disability means that this group of people with disabilities has never had to fight for inclusion in society; they are considered to be already there (marginally). They have never had to fight for "service brokerage"; they have often never had services. They have never had to fight for "individualized funding"; they have often never had funding. Because they are seldom identified, they are seldom counted. When they are not counted, they are not included in master plans. When they are not included in master plans, their needs are not studied. Because they have not been studied, we as a society do not know how to help them.

This is probably what we have been doing for as long as pregnant women have been drinking. We have been treating their children as though their disabilities didn't exist because they weren't obvious. We've been expecting that they would be able to function normally if they just tried harder and applied themselves.

Finally, a large scale study of over 400 people with FAS and FAE, who ranged in age from 6 to 51 years, has been carried out. This new study has clear implications for the human rights, civil rights, and criminal justice of people with FAS/FAE across the lifespan. This study reveals how people with FAS/FAE are inadvertently the treatment failures of the very institutions set up to help people. In part this happens because people with FAS/FAE are often not identified as having disabilities. It also happens as a result of the pervasive belief that they should benefit from the same interventions as people with other

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Facilitate appropriate and effective

Fetal Alcohol Syndrome

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processing, and intervention facilities for children accused of community delinquency acts, status offenses, or who are alleged to have been victims of abuse or neglect. FAS/FAE will be systematically screened for, evaluated, and taken into consideration in the intervention process.

In Washington State, the legislature has funded the infrastructure for a network of FAS diagnostic and prevention clinics that are community based, and provided \$1.5 million dollars for the biennium for two model programs to work with the highest-risk women in the two largest communities. These women are at risk for abusing alcohol and/or drugs during pregnancy, have delivered a baby after receiving little or no prenatal care, and are not effectively served by other community agencies. This award-winning model program (originally called Birth to 3: the Seattle Advocacy Model for Paraprofessional Intervention, more recently termed P-CAP (Parent-Child Assistance Program)), significantly impacts 5 domains: maternal alcohol and drug treatment; abstinence from alcohol and drugs; effective family planning, child well-being; and connection to services. Washington State also has an exceptionally strong family support network, the FAS Family Resource Institute, which not only supports families but also advocates for prevention and intervention, and educates the community about FAS/FAE. Parent advocacy has been a powerful force for

bringing about greater awareness and understanding of FAS/FAE. And after all, understanding is the engine that powers change.

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The information found in this article is described in further detail in two recently published books: *Fetal Alcohol Syndrome: A Guide for Families and Communities* by Ann Streissguth, Paul H. Brookes Publishing Co. (phone: 1-800-638-3775); and *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*, edited by Ann Streissguth and Jonathan Kanter, University of Washington Press (phone: 1-800-441-4115). The research described here was funded by the Centers for Disease Control, Grant number R04/CCR008515.

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