

FETAL ALCOHOL SYNDROME/ FETAL ALCOHOL EFFECTS

LEGAL ISSUES RESOURCE CENTER

Activity Report

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Introduction

One of the most serious harms caused by alcohol use is birth defects, Fetal Alcohol Syndrome and Fetal Alcohol Effects (FAS/FAE).

Although some victims have distinctive physical features, the more pervasive and disabling aspect of this birth defect is organic brain damage. More than a million people in the United States have FAS/FAE; current estimates are that each year approximately 60,000 babies are born in the United States with FAS alone.

There is no medical cure or treatment for the brain damage caused by FAS/FAE. The magnitude of the injury which FAS/FAE will cause an individual depends to a great degree on a range of legal issues and problems. Whether individuals with FAS/FAE will receive needed education and other services from federal, state and local government agencies depends on their ability to establish eligibility for those services under existing legal standards, and on the capacity of government officials to recognize and respond appropriately to the disabilities caused by FAS/FAE. In addition, a majority of individuals with FAS/FAE, for a variety of reasons, get in trouble with the law. Frequently the legal system operates to aggravate the problems caused by that disability, because officials in the criminal justice system are unaware of FAS/FAE, do not know how to identify individuals with that disability, and/or have no idea how to adapt the legal system to the circumstances of that disability.

The FAE/FAE Legal Issues Resource Center ("the Center") was

established to identify and develop legal policies and practices that will help to alleviate the harms caused by FAS/FAE. The Center does so by (1) analyzing recurring legal issues related to FAS/FAE in light of existing medical knowledge, (2) identifying changes in legal policies and practice necessary to respond appropriately to FAS/FAE, and (3) disseminating this information to FAS/FAE individuals and their parents and advocates, and to lawyers, judges, and other professionals involved in the administration of existing programs and of the legal system.

This Report summarizes the work of the Center since it began its activities in January, 2003, with a 12-month grant from the Robert Wood Johnson Foundation.

Analysis of Judicial Opinions

The Center has identified over a hundred federal and state judicial opinions dealing with FAS/FAE. We have organized these cases by subject matter and jurisdiction, and have begun the process of writing and putting on the Center's website summaries of the individual cases, in many instances with links to the full text of the opinions. The Center began to receive telephone calls for additional information about these cases within days of the first postings.

The decisions we have reviewed repeatedly rest on, or at least articulate, many misconceptions about FAS/FAE. There is a widespread but mistaken belief that only severe alcoholism can cause

FAS/FAE. A number of decisions assume that anyone with FAS/FAE would have a below average IQ, or would have the facial features characteristic of children with FAS. While any such scientific error would be regrettable, there are instances in which errors of this sort are part of the foundation of judicial decisions that have serious consequences for the disabled individual. It is manifestly of great importance that lawyers and judges become better educated about FAS/FAE.

There is an enormous variety in the subject matter of these decisions, including large numbers of civil as well as criminal cases. The greatest number of civil cases concern terminations of parental rights; termination is often ordered because a child has FAS/FAE based needs that a parent cannot meet, or because the parent has FAS/FAE and for that reason is not able to provide adequate care of the child. Litigation about termination of parental rights is particularly likely to result in reported decisions because the parents are often entitled to free legal representation, and these disputes (unlike a lawsuit over money) often cannot be resolved by settlement. Other civil cases in which FAS/FAE has arisen include "wrongful adoption" actions against adoption agencies which allegedly failed to provide information that a child might have FAS/FAE, as well as suits for education or disability benefits.

Most reported criminal law decisions related to FAS/FAE are capital punishment cases in which a defendant sentenced to death argued that he was denied the effective assistance of counsel

because his trial attorney failed to develop or introduce at the penalty phase mitigating evidence that the defendant had FAS/FAE. Many decisions reject these arguments somewhat curtly. These cases raise two particularly important recurring questions.

First, would a jury (or, sometimes, a judge) in deciding whether or not to impose the death sentence be significantly less likely to impose that sentence if the crime resulted in part from FAS/FAE organic brain damage. Some decisions hold that this evidence might have a great impact; others treat it as quite insignificant. None of the decisions yet offer a reasoned analysis of this question.

Second, there is considerable uncertainty regarding when (and if so, how) an attorney has a professional obligation to inquire into whether a capital defendant might have FAS/FAE.

Courts appear more consistently sensitive to the impact of FAS/FAE in civil cases than in criminal cases. Where a trial court terminates the parental rights of an individual with FAS/FAE, the appellate courts almost invariably uphold that finding that that would affect his or her conduct and competence. But when a criminal defendant has FAS/FAE, the courts generally proceed as though the disability had no effect on his or her actions or competence to stand trial.

Assistance in Ongoing Cases

The Center receives an ever increasing volume of telephone, e-

mail and letters regarding the legal problems of particular individuals with FAS/FAE. Initially most of those requests for information and assistance came from family members and advocates. Inquiries from attorneys rose as we increased the legal content of the website; as of July 2003 attorney inquiries constitute about half of the overall volume.

These requests make clear that the concentrations of reported judicial decisions are quite different from the most common day-to-day problems. Although litigation about termination of parental rights and death penalty cases constitute the largest number of reported decisions, we have received no inquiries regarding the former, and only a few regarding the latter. By far the largest portion of calls, etc. that the Center has received concern sentencing decisions in non-death penalty cases. Most of these inquiries concern offenses in which the defendant's FAS/FAE apparently played a significant role in his or her conduct.

The most common inquiry the Center receives is from a parent whose (often adopted) son or daughter has already been diagnosed with FAS/FAE. The parent typically has been unable to persuade the child's attorney to raise that diagnosis as a defense or sentencing consideration. Some of that reluctance stems from a lack of understanding among attorneys about the nature of FAS/FAE; in addition, attorneys (perhaps understandably) instinctively resist suggestions from a parent about how to handle a criminal case. In some individual cases we have been able to solve this problem by

having an attorney on the faculty at the University of Washington School of Law contact the lawyer for the individual with FAS/FAE. But clearly that is not a long term solution to the problem.

Fashioning appropriate and creative dispositions for offenders with FAS/FAE is a recurring policy and practical problem. Although the (initial) offenses are often minor, in the absence of effective treatment more serious offenses are often likely. In a number of instances the Center has made suggestions to attorneys, or directly to judges, about treatment and probation techniques. Once they understand the diagnosis and the nature of FAS/FAE, judges have been responsive to the need for a carefully tailored disposition. In one instance, for example, we worked with the parent of a young man with FAS/FAE to find an appropriate faith-based out-of-state residential facility, to locate a full-time advocate for the young man, and to arrange for the advocate and facility staff to be trained about FAS/FAE by an expert located near the facility. We are obtaining transcripts of hearings on these issues, and will make them available on the Center's website.

In order to develop a better understanding of the recurring issues, and to obtain a body of experience from which to fashion more effective policies and practices, the Center in a limited number of cases has worked with attorneys or court officials in resolving specific cases. Courts and lawyers alike, somewhat understandably, have been unsure how (and when) to obtain a diagnosis regarding FAS/FAE. The Center has provided assistance in

identifying an appropriate expert to provide that medical evaluation. In one instance, we facilitated a court-ordered Magnetic Resonance Image of a defendant's brain. The test revealed significant brain defects.

Even the call-ins received by the Center, however, are not fully representative of the range of legal issues faced by individuals with FAS/FAE. Most of these inquiries involve a case that has reached a crisis stage (usually an arrest or conviction), an individual who has already been diagnosed, and an advocate (usually a parent) who is unusually persistent and aggressive. Even most criminal cases lack the latter two factors, and legal issues of a less urgent nature--such as the continuing ineffectiveness of a school's education program--are evidently getting relatively little legal attention.

Social Security Benefits for Individuals With FAS/FAE

The Social Security Administration administers a number of different benefit programs for individuals with disabilities. One of these programs is for children, and three are for adults. The eligibility standards (and benefits) of these programs vary. Although merely having FAS/FAE would not automatically render an individual eligible for benefits under one of these programs, an individual with FAS/FAE may be eligible if the impairments caused by that disability are sufficiently severe.

The Center has created on its website a summary of the

different Social Security disability programs for which individuals with FAS/FAE might be eligible, together with an explanation of the eligibility standards and application process. This part of the website includes links to informative publications by the Social Security Administration and private groups, a method of locating the nearest Social Security Administration office, information about applying for benefits on line, and names of attorneys who specialize in Social Security disability cases.

There are only a handful of judicial opinions regarding eligibility of individuals with FAS/FAE for Social Security disability benefits; they are summarized in this portion of the website. It seems likely that there are useful unreported administrative decisions by the Social Security Administration regarding this disability. The Center will attempt to obtain copies of decisions of that sort, and make them available on or through the website.

"Medical Information for Police" Card

One of the most common concerns expressed by parents of individuals with FAS/FAE is that their sons and daughters do not know how to deal appropriately with the police. More than half of all adolescents and adults with FAS/FAE have been in trouble with the law at some point in their lives. Because of their disability, these individuals often do not understand how to conduct themselves in dealing with the police. Frequently that lack of understanding

aggravates their problems with the criminal justice system.

In response to this recurring problem, the Center devised a "Medical Information for Police" card that individuals with FAS/FAE can carry with them and give to the police. The card and related materials were developed in consultation with a number of attorneys, judges, police officials, and FAS/FAE organizations. The card explains to the police the need to contact a relative or advocate before questioning the individual. It is our hope that use of the card will reduce litigation about the admissibility of statements made by individuals with FAS/FAE. The card also alerts police (and prosecutors, should they become involved) of the existence of a disability which needs to be dealt with differently. The text of the card is as follows:

Medical Information for Police

I have the birth defect Fetal Alcohol syndrome/Fetal Alcohol Effects, which causes brain damage. If I need assistance, or if you need my cooperation, you should contact the person listed on the back of this card. Because of this birth defect, I do not understand abstract concepts like legal rights. I could be persuaded to admit to acts that I did not actually commit. I am unable to knowingly waive any of my constitutional rights, including my Miranda rights. Because of my disability, I do not wish to talk with law enforcement officials except in the presence of and after consulting with an attorney. I do not consent to any search of my person or property.

The back of the card has a place to write in the name of an appropriate family member or advocate, and to identify the individual's physician or diagnostician.

The card is available on the Center's website in a PDF format,

so that it can be downloaded and printed on any home or office printer. The Center's website invites interested organizations or individuals to reproduce the card and related materials, or to place them on their own websites. A number of organizations have chosen to do so, including NOFAS (the National Organization on Fetal Alcohol Syndrome). The Center has been asked to prepare a Canadian version of the card, and is working with several Canadian attorneys on that project.

Website

The Center's website has been the primary method of broad dissemination of information and policy recommendations. The website is part of the overall website of the Fetal Alcohol and Drug Unit, which is among the top-rated FAS/FAE websites on Google. The website includes the Social Security explanation and links, the Medical Information for Police card and related materials, and the growing list of summaries of judicial opinions.

In addition, the website contains an archive of articles related to FAS/FAE and the law. Although they contain a wide range of important information for family members, advocates, lawyers and policy makers, these articles as a practical matter have not been generally available until now. The existence of these articles is not widely known, and in many instances they originally appeared in publications with very limited circulation. Authors and publishers have generally acceded to our request to put the text of the

articles up on the website. Expansion of this archive continues.

In 2000 the Department of Health and Human Services published a detailed state-by-state directory of organizations, physicians and advocates concerned with FAS/FAE. Although the information in this directory would often be invaluable to family members, advocates or policy makers in any given state, it was highly unlikely that they would have a copy. In the past the Fetal Alcohol and Drug Unit has used the directory in responding to phone, e-mail and written requests for information and referrals. The Center obtained from the author an electronic version of the directory, and has put it on the website. We are in the process of telephoning every person and organization in the directory to update the listings.

The Center's website can be accessed at:

<http://depts.washington.edu/fadu/legalissues/>

Papers and Presentations

In February 2003 Project Director Kay Kelly gave a paper on FAS/FAE and education during her presentations on two panels about legal remedies at a conference about Fetal Alcohol Spectrum Disorder held in Vancouver, British Columbia under the sponsorship of the University of British Columbia and several other organizations.

Also in February 2003, Ms. Kelly, Dr. Keiran O'Malley of the Fetal Alcohol and Drug Unit, and Professor Eric Schnapper of the School of Law made a joint presentation about FAS/FAE and the law to fifty Canadian family law attorneys. The attorneys were in Calgary

and Edmonton, and the conference and presentations were made by telephone.

In March 2003 the Project Director spoke in Los Angeles at a Town Hall meeting on FAS/FAE organized by the Center for Excellence; contacts made at that meeting have become important sources of additional information and activity.

An article by Ms. Kelly, "The Victimization of Individuals With Fetal Alcohol Syndrome: Fetal Alcohol Effects", will appear in the August, 2003 issue of Tash Connections, published by the Public Interest Law Center of Philadelphia (PILCOP).

Police Training

Family members of individuals with FAS/FAE, and organizations that deal with that disability, have long been concerned about the lack of training about FAS/FAE for law enforcement officials. Police officers need to be able to distinguish an individual who is confused, frustrated or angry because of FAS/FAE from someone who poses a serious threat. The police can avoid creating a dangerous problem if they understand that individuals with FAS/FAE tend to overreact if physically startled. Law enforcement officials must make important discretionary decisions in dealing with members of the public, such as whether to arrest a troubled youth or simply take him home; police can do a better job in making those decisions if they understand disabilities like FAS/FAE.

There is little familiarity with FAS/FAE among police officers

in the United States. The long-time Americans With Disabilities Act coordinator for the police department in a major American city told the Center that he had heard no mention of FAS/FAE since he was in college. In part that may be because it would often be difficult for a police officer to know that an individual had FAS/FAE, particularly if an officer had not come into repeated contact with such individuals. Police training regarding FAS/FAE is likely to be particularly valuable (a) in helping the police understand and deal with repeat offenders, since the pattern of offenses may itself be an indication of FAS/FAE, and (b) in smaller communities.

The Royal Canadian Mounted Police has developed a significant degree of familiarity with this disability, in part because it polices some rural areas where the incidence of FAS/FAE is high and the population low and stable. In preparation for conducting its own training program on FAS/FAE, the RCMP drafted a power-point presentation, which at the request of the RCMP was reviewed by the Center and by Dr. Ann Streissguth of the Fetal Alcohol and Drug Unit. In September 2003 the RCMP will be holding a two-day training session for Canadian law enforcement officials. At the request of the Center, the RCMP has agreed to let a number of American police officers attend its training program. The Center has been recruiting law enforcement officials from the United States to attend this Canadian training program, and is assisting those American officials in obtaining the necessary approval from the RCMP.

Work With Native American Tribes and Officials

FAS/FAE raises often distinct legal issues in Indian Country, because the tribal legal systems differ from the federal and state systems, because the prevalence of FAS/FAE may be unusually high, and because the nature of the tribal community may offer unique treatment possibilities.

The Center has held meetings to discuss FAS/FAE with the Washington State Tribal/County Justice Task Force, the Northwest Indian Bar Association, and representatives of tribal and federal officials concerned with criminal justice issues in the northwest. At our urging, the intake process for criminal cases at the Tulalip reservation in Washington has been altered to include an inquiry about maternal alcohol use. As a result of the Center's work, the President of the Tribal Police chiefs Association of Washington, who is also the Police chief for the Lower Elwha Klallam Tribe, will be attending the RCMP training in September 2003.

Use of MRI Analyses in Diagnosis

In the past diagnosis of FAS/FAE has been based largely on neuropsychological testing, together with information about maternal alcohol use and physical appearance. In litigation this has at times raised practical problems. Reliable information about maternal alcohol use during pregnancy may not be available. The number of experts on FAS/FAE is limited, and the subjective nature

of the evaluation process has led to a number of disputes.

Recent studies done by the Fetal Alcohol and Drug Unit, in conjunction with Professor Fred Bookstein of the University of Michigan, has identified a method for detecting FAS/FAE using an MRI of the corpus callosum. This new methodology has the potential to provide a basis for a diagnosis that will be faster, less expensive and less subject to dispute than the traditional methods.

The Center is working to encourage attorneys and judges to use this new methodology. In the one case in which a judge agreed to order this test, it demonstrated quite decisively the existence of severe brain damage. We believe that increasing use of this scientific method will over time have a profound impact on the manner in which the legal system deals with FAS/FAE.

Screening

Effective policies and legal practices for dealing with individuals with FAS/FAE cannot exist unless officials know which individuals actually have FAS/FAE. Because existing diagnostic methods--whether based on neuropsychological testing or MR images--involve significant expense or delay, methods have to be developed to screen from the general population those individuals whose chances of having FAS/FAE are sufficiently high to warrant a formal diagnosis. In practice perhaps the most common screening mechanism has been the frustration of parents who conclude over time that nothing else seems to explain the difficulties their children are experiencing.

Manifestly better screening methods have to be found. In part because officials or others will have different types of information about individuals who may have FAS/FAE, different types of screening tools will have to be developed. Some scattered institutions have fashioned their own screening standards; most rely in part on physical appearance, which necessarily misses FAE and many cases of FAS as well, depending on the age of the subject.

The Center has developed for use in the criminal justice system a set of factors related to a defendants' offense history which may tend to indicate the presence of FAS/FAE. We have provided that list to a number of attorneys and organizations, and are monitoring its utility. We have noted the existence of at least one somewhat unusual offense which may signal the existence of FAS/FAE; we continue to look for reports regarding this particular problem. The Center has also identified a relatively simple set of factors (not involving facial features) in a child's background that are being used by Los Angeles officials to identify children who should be given a diagnostic evaluation. We intend to share that approach with officials and parents in other areas.

Future Activities

The balance of the Center's work in 2003 will be devoted to a continuation of many of the activities described in this report. Analysis of the large number of identified cases will be a significant part of that effort. We anticipate that the ever-increasing number of calls and e-mails for information and

assistance will raise new legal issues, and provide greater understanding of already identified problems. The Center will develop and put on its website information about the rights of students with FAS/FAE under the federal Individuals With Disabilities Education Act (IDEA). We will be conducting a Continuing Legal Education program for attorneys in Seattle, Washington, a presentation that should be a prototype for educating attorneys in other parts of the country.

The Center's current grant from the Robert Wood Johnson foundation will end in January, 2004. The needs which the Center is meeting will remain, and we hope to obtain funding to continue and expand the Center's activities. In many subject matter areas the reported judicial decisions we have found are too few or incomplete to provide a basis for understanding the relevant legal issues; additional (and usually more time-consuming) research will be required. There are important problems which will require substantial empirical investigation or the development of pilot programs--screening for FAS/FAE in the infants and children who come into state dependency court, responding to the unique problems and opportunities that arise in Indian Country, assessing the competence to stand trial of defendants with FAS/FAE, assisting school officials in complying with the IDEA with regard to students with FAS/FAE, and helping judges and attorneys with the difficult sentencing problems posed by offenders with FAS/FAE.

The research that the Center has completed, and that remains to

be done, will be of little value unless it is translated into practical terms and disseminated to parents and advocates, and to lawyers, judges, prosecutors, police and corrections officers, and others. That can only be achieved through an ongoing, multi-faceted education and outreach program, involving publications, CLE programs, training for police and corrections officials, responses to telephone and e-mail requests for information, and an ever-expanding and more widely known website. Far too little can be done by parents and advocates who do not know how to invoke applicable legal principles, or by lawyers or government officials who do not understand FAS/FAE. But law and medicine, in combination, can provide to both groups the tools they need to ameliorate the harm of this all too common disability.

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