



Free Executive Summary

Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment

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Executive Summary

Fetal alcohol syndrome (FAS), first described in the published medical literature in 1968, refers to a constellation of physical abnormalities, most obvious in the features of the face and in the reduced size of the newborn, and problems of behavior and cognition, in children born to mothers who drank heavily during pregnancy. These latter features lead to the most concern. The costs of FAS and related conditions can be quite high—for the individual, for the family, and for society. Rates of FAS in several of the most complete studies are similar—on the order of 0.5 to 3 cases per 1,000 births. Assuming an annual birth cohort of approximately 4 million, this translates into 2 to 12 thousand FAS births per year in this country. These incidence figures are offered not as established facts but to emphasize the magnitude of a problem that has serious implications—for the individual and for society.

In recognition of the seriousness of this problem, the U.S. Congress mandated in Section 705 of Public Law 102-321, the ADAMHA Reorganization Act, that the Institute of Medicine (IOM) of the National Academy of Sciences conduct a study of FAS and related birth defects. This report is in response to that mandate.

The charge to the committee was to improve the understanding of available research knowledge and experience on:

- tools and approaches for diagnosing FAS and related disorders
- the prevalence of FAS and related disorders in the general population of the United States
- the effectiveness of surveillance systems, and

- the availability and effectiveness of prevention and treatment programs for these conditions.

As part of its work, the committee reviewed and assessed U.S. Department of Health and Human Services agency research on the topic and provided guidance for the future.

FAS is caused by prenatal exposure to high levels of alcohol. FAS is not a "drunk" baby or a baby physically dependent on or addicted to alcohol. Although the manifestations of FAS might change with age, FAS never completely disappears and, as with many developmental disabilities, there is no cure, although there might be some amelioration in some individuals. The committee studied data on the relation between low or moderate levels of prenatal alcohol exposure and more subtle abnormalities associated with such exposure, but it was unable to conclude that these subtle abnormalities, as detected by statistical calculations from epidemiologic studies of defined populations, do or do not represent a distinct clinical entity. The clinical significance of these effects for an individual is not clear. The committee is cognizant of the grave concern of many pregnant or preconceptional women and their partners about possible effects of less than heavy consumption of alcohol. The lack of diagnostic criteria for or more definitive statements regarding possible effects of low to moderate exposure to alcohol should not be interpreted as contradictory to the Surgeon General's warning against drinking alcohol during pregnancy.

DIAGNOSIS AND CLINICAL EVALUATION OF FETAL ALCOHOL SYNDROME

A medical diagnosis serves several major purposes: to facilitate communication among clinicians; to facilitate communication between clinician and patient (including, in this instance, the parents of patients); to assist in the study of pathophysiology and etiology; and to guide treatment. In addition to the well-documented guidelines of good reliability and validity, a number of practical considerations also inform decisions about diagnostic criteria. Placing a patient in a diagnostic category confers both benefits and disabilities. For example, the diagnosis of FAS may validate a patient's disability and facilitate appropriate interventions and social benefits. On the other hand, the diagnosis may also be used to stigmatize and to create self-fulfilling prophecies about the future that could be detrimental to the patient and his or her family.

The key issues noted by the committee for identification of FAS include the following:

1. Should a documented history of exposure to alcohol be required for the diagnosis of FAS?
2. Which physical features should be used to define the disorder?

3. Can behavioral or cognitive features be used to define the disorder?
4. Is there a role for ancillary measures (e.g., magnetic resonance imaging [MRI]) in making the diagnosis?
5. Can criteria be designed to be used across the life span?
6. What is the relationship of so-called fetal alcohol effects to fetal alcohol syndrome?

The committee studied the previous diagnostic criteria and felt that some of the issues confusing the clinical and research communities could be resolved with fairly minor changes (Table 1). The committee delineates five diagnostic categories. The rubric of Fetal Alcohol Syndrome contains criteria for (Category 1) FAS with a history of maternal alcohol exposure, (Category 2) FAS without a history of maternal alcohol exposure, and (Category 3) partial FAS with a history of maternal alcohol exposure. The naming of this diagnostic category was challenging for the committee, who found no perfect solution. The committee intends for this diagnostic category to include people with signs and symptoms attributable to significant prenatal alcohol exposure and who need medical, social services, and other attention. "Partial" denotes, to some people, that the condition might not be as severe, which the committee did not wish to imply. The committee settled on the use of "partial" despite these reservations.

Category 3 allows an FAS diagnosis to be given to someone who would not receive a Category 1 diagnosis, FAS with confirmed maternal alcohol exposure. A Category 3 diagnosis could be particularly useful, for example, for some patients who present for diagnosis as an adult. The natural history of FAS is such that some of the "hallmark" indicators used in infancy or childhood are not maintained into adolescence or adulthood. This diagnosis can also be used as a "holding" category as a means to defer a diagnosis of Category 1, FAS with confirmed maternal history of alcohol exposure, until more data collection or evaluation, including documentation as to whether behavioral and cognitive abnormalities persist over time, can support a more definitive diagnosis. In the newborn, for example, there is some controversy whether some behavioral abnormalities, such as abnormalities of state regulation, indicate or predict long-term dysfunction due to fetal alcohol exposure. In such cases, documentation of abnormalities over time would be important.

The committee has defined two other diagnostic categories: Category 4, alcohol-related birth defects (ARBD; physical anomalies only), and Category 5, alcohol-related neurodevelopmental disorder (ARND). Diagnostic categories 4 and 5 include clinical conditions for which clinical or animal research has linked maternal alcohol ingestion to an observed outcome. These final two diagnostic categories are intended to represent some degree of uncertainty whether prenatal alcohol exposure caused the adverse effects documented in an individual patient, or whether other factors were causative in this case. Because of the variability in the specific presentation of FAS, ARBD, or ARND, these diagnoses are most

TABLE 1 Diagnostic Criteria for Fetal Alcohol Syndrome (FAS) and Alcohol-Related Effects

Fetal Alcohol Syndrome
1. FAS with confirmed maternal alcohol exposure^a
A. Confirmed maternal alcohol exposure ^a
B. Evidence of a characteristic pattern of facial anomalies that includes features such as short palpebral fissures and abnormalities in the premaxillary zone (e.g., flat upper lip, flattened philtrum, and flat midface)
C. Evidence of growth retardation, as in at least one of the following: <ul style="list-style-type: none">— low birth weight for gestational age— decelerating weight over time not due to nutrition— disproportional low weight to height
D. Evidence of CNS neurodevelopmental abnormalities, as in at least one of the following: <ul style="list-style-type: none">— decreased cranial size at birth— structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)— neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
2. FAS without confirmed maternal alcohol exposure
B, C, and D as above
3. Partial FAS with confirmed maternal alcohol exposure
A. Confirmed maternal alcohol exposure ^a
B. Evidence of some components of the pattern of characteristic facial anomalies
Either C or D or E
C. Evidence of growth retardation, as in at least one of the following: <ul style="list-style-type: none">— low birth weight for gestational age— decelerating weight over time not due to nutrition— disproportional low weight to height
D. Evidence of CNS neurodevelopmental abnormalities, as in: <ul style="list-style-type: none">— decreased cranial size at birth— structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)— neurological hard or soft signs (as age appropriate) such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination
E. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment
Alcohol-Related Effects
Clinical conditions in which there is a history of maternal alcohol exposure,^{a,b} and where clinical or animal research has linked maternal alcohol ingestion to an observed outcome.
There are two categories, which may co-occur. If both diagnoses are present, then both diagnoses should be rendered:

Alcohol-Related Effects (continued)

4. Alcohol-related birth defects (ARBD)

List of congenital anomalies, including malformations and dysplasias

Cardiac	Atrial septal defects Ventricular septal defects	Aberrant great vessels Tetralogy of Fallot
Skeletal	Hypoplastic nails Shortened fifth digits Radioulnar synostosis Flexion contractures Camptodactyly	Clinodactyly Pectus excavatum and carinatum Klippel-Feil syndrome Hemivertebrae Scoliosis
Renal	Aplastic, dysplastic, hypoplastic kidneys Horseshoe kidneys	Ureteral duplications Hydronephrosis
Ocular	Strabismus	Refractive problems secondary to small globes
	Retinal vascular anomalies	
Auditory	Conductive hearing loss	Neurosensory hearing loss
Other	Virtually every malformation has been described in some patient with FAS. The etiologic specificity of most of these anomalies to alcohol teratogenesis remains uncertain.	

5. Alcohol-related neurodevelopmental disorder (ARND)

Presence of:

A. Evidence of CNS neurodevelopmental abnormalities, as in any one of the following:

- decreased cranial size at birth
- structural brain abnormalities (e.g., microcephaly, partial or complete agenesis of the corpus callosum, cerebellar hypoplasia)
- neurological hard or soft signs (as age appropriate), such as impaired fine motor skills, neurosensory hearing loss, poor tandem gait, poor eye-hand coordination

and/or:

B. Evidence of a complex pattern of behavior or cognitive abnormalities that are inconsistent with developmental level and cannot be explained by familial background or environment alone, such as learning difficulties; deficits in school performance; poor impulse control; problems in social perception; deficits in higher level receptive and expressive language; poor capacity for abstraction or metacognition; specific deficits in mathematical skills; or problems in memory, attention, or judgment

^a A pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. Evidence of this pattern may include frequent episodes of intoxication, development of tolerance or withdrawal, social problems related to drinking, legal problems related to drinking, engaging in physically hazardous behavior while drinking, or alcohol-related medical problems such as hepatic disease.

^b As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

valuable clinically if accompanied by a description of the specific problems experienced at the time by the patient.

All diagnoses but Category 2, FAS without confirmed history of maternal alcohol exposure, require a history of maternal alcohol exposure. The committee defined the relevant history of maternal exposure as a pattern of excessive intake characterized by substantial, regular intake or heavy episodic drinking. As further research is completed and as, or if, lower quantities or variable patterns of alcohol use are associated with ARBD or ARND, these patterns of alcohol use should be incorporated into the diagnostic criteria.

Key Recommendations

Research recommendations include

- research to evaluate the utility, reliability, and validity of this scheme for classification and diagnosis;
- research, both cross-sectional and longitudinal, to assess the characteristics and clinical expression of these syndromes across the life span, particularly after adolescence;
- investigation of the differences in expression and specificity of behavioral and cognitive deficits in FAS and ARND;
- further clinical research, as well as research using animal models, to examine the adverse developmental effects of prenatal alcohol exposure, and to develop more specific biologic markers for diagnosis (e.g., biomarkers to confirm maternal alcohol exposure, endocrine signals, imaging techniques.)

EPIDEMIOLOGY AND SURVEILLANCE OF FAS, ARBD, AND ARND

The success of any public health program can be measured by comparing the incidence or prevalence of a particular societal problem before that program was implemented with its incidence or prevalence after implementation. Such data are also important for estimating the societal impact of these disorders and are crucial at the initial stages of planning, organizing, and implementing prevention programs aimed at the general population as well as at specific at risk populations.

The literature on the prevalence and epidemiology of FAS is far from consistent or conclusive. A limited proportion of mothers who are very heavy drinkers will have children with FAS. Various studies reporting the occurrence of FAS range from 0.5 to 3 births per 1,000 in most populations, with some communities having much higher rates. FAS and other diagnosable ARBDs or ARNDs may occur more frequently.

Passive surveillance is the strategy generally used to monitor birth defects.

A national passive surveillance system that includes FAS uses hospital discharge data on both live and stillborn newborns and has estimated the incidence of FAS at 3.7 per 10,000 births for 1992. Although passive surveillance is relatively inexpensive, it is notoriously inaccurate; given that FAS is a complex diagnosis, it may go unrecognized at birth. Thus, registry-based estimates of FAS prevalence can be expected to be gross underestimates. Data obtained passively from clinic-based studies, whether based on prospective epidemiologic studies or retrospectively of children referred for clinical evaluation, typically result in numbers that are higher than prevalence estimates derived by using standard surveillance methodologies.

Active surveillance involves direct prospective collection of data using experimentally driven protocols rather than using available data such as medical charts. Two classic types of active surveillance are prospective epidemiologic studies of the infant outcomes associated with maternal alcohol use and population-based active FAS case ascertainment. In general, these rates are higher by an order of magnitude than those estimated from passive surveillance studies. These studies can be very expensive and labor intensive. The populations studied in epidemiologic studies of maternal alcohol abuse frequently do not include sufficient women who abuse alcohol at levels that produce offspring with FAS. Population-based studies can assist in addressing some of the criticisms of passive surveillance systems and may be useful for linking identified individuals to treatment programs and for evaluating comprehensive prevention efforts.

An alternative to passively monitoring the incidence of FAS at birth is to develop proxy measures of FAS, such as one facial anomaly and one indicator of growth deficiency, and use these as surveillance criteria for active case ascertainment that would identify a group of newborns with a high probability of having FAS. One would then need to develop a means to estimate from these kinds of data an approximation of the incidence or prevalence of FAS. Population-based studies in a variety of populations might be useful in determining such an estimation factor.

Key Conclusions and Recommendations

The committee concludes that FAS, ARBD, and ARND are a completely preventable set of birth defects and neurodevelopmental abnormalities, that FAS is arguably the most common known nongenetic cause of mental retardation, and that FAS, ARBD, and ARND constitute a major public health concern. To address the lack of baseline data and the wide variation of prevalence estimates for subpopulations, including ethnic minorities, the committee recommends that:

- an interagency plan be developed for a national survey to estimate the prevalence and incidence of FAS, ARND, and ARBD, which could utilize active surveillance techniques;

- improved data collection and surveillance be implemented to identify specifically children with FAS, ARND, and ARBD in various social and educational environments (e.g., maternal and child health block grant programs, Head Start programs, and Early Intervention and Special Education Services); and
- when active surveillance strategies are employed that identify children with FAS, ARND, or ARBD, appropriate linkages should be in place among agencies and local clinics to facilitate treatment.

EPIDEMIOLOGY AND SURVEILLANCE OF DRINKING DURING PREGNANCY

Approximately 60 percent of adult women in the United States drink alcohol at least occasionally. Approximately 4 percent of women would be considered to have alcohol abuse or alcohol dependence, as defined by the fourth edition of the Diagnostic and Statistical Manual (DSM-IV). Available data indicate substantially lower rates of both drinking (approximately 20 percent according to national surveys) and heavy drinking (less than 1 percent) among pregnant women, relative to nonpregnant women of childbearing age. (By comparison, a national survey estimates that 20 percent of pregnant women smoked, 5.5 percent used any illicit drugs, 0.9 percent used crack cocaine, and 10 percent used psychotherapeutics for medically-indicated conditions.) Although the percentages are small in *relative* term, the large *absolute numbers* of women who continue to engage in heavy and hazardous drinking throughout pregnancy make it imperative to understand the personal and social factors that make women more likely to continue drinking heavily during pregnancy.

Although researchers have seen some encouraging changes in drinking patterns during pregnancy over the years, there is no substantive evidence of any change in drinking behavior among women who drink more heavily or abuse alcohol, either in terms of proportions of heavy drinkers at the time of conception or in terms of consumption levels during pregnancy.

Current clinic-based studies of drinking in pregnant women include relatively small numbers of women who are heavier drinkers, alcohol abusers, or alcohol dependent and few studies of drinking during pregnancy assess personality or social-environmental variables associated with drinking. Because only a small percentage of women are pregnant at any point, only general population surveys with very large samples will allow reliable analysis of drinking correlates among women pregnant at the time of the survey.

Key Recommendations

Therefore, the committee recommends special attention to the following research questions and issues:

- expansion of studies of pregnant women, where possible, to include measurement of psychological, social-environmental, dietary, and other factors that may influence women's drinking behavior or fetal outcome;
- inclusion of questions regarding alcohol consumption and pregnancy status in appropriate future national health surveys;
- focus on protective factors that may decrease women's drinking or prevent fetal injury from alcohol consumption;
- continued and increased epidemiological study of women's drinking patterns, including efforts to maximize the validity of self-report measures, efforts which could include the use, where and when appropriate, of a biomarker for alcohol exposure.

PREVENTION

Because prenatal alcohol exposure most likely is associated with a spectrum of effects ranging from negligible to severe, a number of different drinking patterns with various characteristics and etiologies need to be addressed. Cultural, sociological, behavioral, public health, and medical disciplines are relevant to the prevention of FAS and related conditions.

The committee thought about the prevention of FAS and related problems within a conceptual framework that would encompass a broad spectrum of prevention measures and that acknowledges that prevention of FAS includes treatment and maintenance for alcohol abuse in the mother. A woman's partner and her community are appropriate targets for preventive interventions and subjects for preventive intervention research. After the birth of an FAS child, there are two targets for intervention—the mother and the child. Each of them is a patient in need of care; each is a target for treatment and maintenance to improve their health and well-being as well as for preventive intervention for the birth of another FAS child. The hallmark of this framework is that one enters into the continuum of interventions in a manner proportional to the certainty and severity of the risk involved. That is, the intervention becomes more specific and intensive as the risk is defined less by general population characteristics and more by individual characteristics.

Universal prevention intervention strives to ensure that all members of society understand that drinking alcohol can have hazardous consequences, particularly during pregnancy. The universal prevention message for FAS is a conservative one that encourages abstinence prior to conception and throughout pregnancy as the safest alternative. One of the basic techniques used in universal prevention is public education. Visits to family practitioners and to obstetrician gynecologists offer the opportunity for brief messages about the importance of responsible alcohol use and for providing general information about the risks of alcohol to the fetus.

Selective prevention interventions target people who are at greater risk for a

particular outcome because they are members of a subgroup known to be at higher risk than the general population. These interventions involve different levels of targeting and intensity compared to universal preventive interventions. Targets of selective prevention for FAS, ARBD, and ARND include women who drink alcohol and are in the reproductive age range and their partners. Although paternal alcohol exposure does not cause FAS, the important supportive role that the male partner plays in a healthy pregnancy is well established and cannot be emphasized too strongly. However, many women who are at high-risk for FAS are unmarried, in very unstable relationships, or both.

Physicians or other health care providers should be prepared to talk to women about their alcohol use, screen women for indication of alcohol abuse, conduct further assessments as necessary, and be prepared to offer brief interventions. If appropriate, referral for formal treatment of alcohol dependence should be made. In general, the strength of the intervention should be proportional to the level of risk. There are studies showing that some pregnant women who drink moderately or heavily are amenable to interventions offered in conjunction with prenatal care. However, there are no consistent data to predict who will respond to such interventions and who will continue to drink.

Indicated prevention interventions target high-risk individuals. A small proportion of women within some populations given birth to most of the FAS children. The committee therefore considers the target for indicated prevention interventions to be a woman who engages in heavy drinking while pregnant or at risk for being pregnant, particularly a pregnant or preconceptional woman who drinks alcohol and who has already given birth to a child with FAS, ARBD, or ARND. As with selective interventions, the committee would also include interventions aimed at the partner, significant friends, or family members of a woman who fits the profile just described. Indicated *prevention of FAS* includes *treatment* for alcohol abuse or dependence for a pregnant woman or for a woman highly likely to become pregnant. The committee identified little controlled research into the most effective ways to treat pregnant women who drink.

Because, in many cases, women do not seek obstetric services until delivery, any health care provider who comes in contact with women who abuse alcohol should consider brief intervention therapies and referral to more formal alcohol abuse treatment, if appropriate. Women of reproductive age who abuse alcohol should also be offered referral and access to birth control information and services.

For the comparatively small group of women who continue to drink heavily during pregnancy, formal treatment of alcohol dependence may be needed. Treatment programs described are typically broad, multimodal interventions that are intended to address the complex problems exhibited by this population. However, systematic data collection on characteristics of women who drink heavily during pregnancy has been rare. Thus, treatment programs for pregnant women who abuse alcohol have been based primarily on the availability of services and

on clinical judgment, and in the relative absence of empirical data that could inform the conceptualization and development of treatments targeted to address the specific problems of this population.

The literature in recent years suggest that one effective way to help alcohol abusing women who had FAS children might be through intensive case management. Case management involves all members of the extended family and should include enlisting the positive action of the male partner. Children benefit from such efforts, too. Often children of FAS-producing mothers are in foster placement because of neglect or abuse. A major motivator for maintenance and aftercare is to improve the social and health status of the mother so that she can regain or retain custody of her children.

Key Recommendations

- The committee recommends that until such time as clear dose-response relationships are established, pregnant women and those about to become pregnant be counseled to avoid alcohol consumption throughout pregnancy.
- The committee recommends greatly increased attention among sponsors of prevention initiatives, independent of the target population, to evaluating the effectiveness of programs implemented. This recommendation applies to all levels of prevention interventions.
- The committee recommends that research efforts include comparisons of prevention methods at all levels in order to provide information to policy makers about relative costs and benefits.

Indicated Prevention Interventions

- The committee recommends that a high priority be placed on research efforts to design, implement, and evaluate prevention interventions that can effectively guide pregnant women who drink heavily to alcohol treatment. Research or programs should also include:
- assessment of methods to involve women's partners and family members in interventions to decrease or stop drinking;
- implementation of appropriate screening tools, including biomarkers of alcohol exposure, to identify women who are drinking moderate to heavy amounts of alcohol during pregnancy;
- incorporation of comprehensive reproductive counseling and contraceptive services in prevention and treatment programs for substance abusing women;
- development of training programs for professionals in the identification of heavy drinking, and referral to appropriate regional centers or prevention services;
- basic research in animal models to elucidate further the mechanisms of

alcohol teratogenesis, which might lead to pharmacologic or other strategies for amelioration of the effects of alcohol exposure in utero.

Selective Prevention Interventions

- The committee recommends increased research efforts to design, implement, and evaluate selective prevention interventions to decrease risks of FAS, ARND, and ARBD through programs aimed toward women who are pregnant or may become pregnant, and who drink alcohol.
- Where the utility of specific intervention programs has been established, the committee recommends broad implementation of successful prevention interventions. Programs developed or studied should include the following:
 - intervention targeted to specific demographic groups that have been demonstrated to be at higher risk for FAS, ARBD, and ARND, as well as those who exhibit risk factors associated with moderate to heavy alcohol consumption during pregnancy.

Universal Prevention Interventions

- The committee recommends that although data are insufficient regarding the effectiveness of universal prevention interventions, such interventions should be continued to raise awareness about the risks of FAS, ARBD, and ARND. However, the most important approach to universal prevention is probably the development of a medical environment in which concepts of the risk of FAS, ARBD, and ARND are incorporated into routine health care.

TREATMENT OF THE AFFECTED INDIVIDUAL

Many prenatally exposed individuals do not receive correct diagnosis or treatment for their alcohol-related disabilities. There has been a curious lack of enthusiasm for targeted efforts directed at the prevention of secondary disabilities. The view that intervention may not be useful in children affected by alcohol is inconsistent with the attitude taken toward other groups of high-risk and disabled children. Few systematic attempts have been made to intervene with alcohol-affected children to test the possibility that such strategies would be effective in producing more positive outcomes.

In understanding how to meet the needs of individuals with FAS, it is first necessary to describe the behavioral characteristics of affected children as well as the social environment in which many affected children live. Information about affected children is derived mainly from two sources: (1) retrospective and uncontrolled, descriptive clinical studies of clinically referred children with FAS and fetal alcohol effects, and (2) prospective research studies of children exposed

to alcohol in utero due to maternal drinking. In most such prospective studies, maternal drinking is in the light to moderate range, with only a few women drinking in the heavy range. As a result, most of the children in these prospective studies are not dysmorphic and would not, therefore, qualify for a diagnosis of FAS, although in some cases they may have milder effects that are observable through focused testing or the statistical analysis of group data.

For the clinician, as well as the research scientist, there are several important questions that must be answered in order to plan interventions for individuals with FAS, partial FAS and possible ARND. The first question is whether there are discernible patterns in the development of prenatally exposed children. A review of existing information about the development of these children suggests the following conclusions: *The data base is limited, there is a great deal of variability in outcome. Early identification is possible in some cases. Effects of prenatal exposure appear to become more significant later in the child's development, perhaps due to the nature of a disorder that may affect behaviors associated with more mature social functioning.*

The second significant question is whether developmental problems seen in alcohol-exposed children should be attributed solely to the effects of the teratogen on neurological functioning, solely to the effects of environmental factors such as social class and dysfunctional families, or to some combination of the two. At present, there is no easy answer to this question. Because children develop within a family and a community, their caregiving environment must be given careful consideration as well. However, the social and environmental factors that may affect the development of individuals with FAS or ARND have not been adequately investigated.

Anecdotal evidence suggests that children with FAS, ARBD, or ARND are more likely to have negative caregiving environments than are typical children or children with other disabilities. The first risk for these children is loss of their biological parents. Clinical observation also suggests that children with FAS or possible alcohol-related effects often come to the attention of protective service agencies and frequently may enter foster care or be placed for adoption. Some children receive a stable placement; others are shifted repeatedly because their behavior is hard for some foster or adoptive families to manage.

The third question concerns specificity. It is not clear that the behaviors reportedly shown by alcohol-affected individuals are different from those shown by other persons who are mentally retarded, have specific learning disabilities, are diagnosed with ADHD, or have been reared in dysfunctional families. Rarely have these groups been compared to other clinically diagnosed groups to identify factors specific to those who have been exposed to alcohol. If it is true that there are specific problems in children with FAS and RAND, it may be possible to design targeted prevention efforts that will help to avoid the more negative outcomes that have been observed.

Although in some cases the prenatal exposure may have had permanent

effects, it still might be possible to avoid the development of secondary disabilities in these individuals by early identification and appropriate treatment over the life span. There is no systematically compiled information available describing the number of people with FAS receiving services or the kinds of services received by individuals with FAS or other alcohol-related deficits. At the present time, there are no empirical studies available of the effects of educational intervention, either generalized (the standard services offered to all qualifying children) or specific (programs specifically designed for those with FAS or ARBD), on alcohol-affected children. Faced with a lack of published information about teaching methods and the effectiveness of treatment for alcohol-exposed children, some teachers and parents have turned to the "wisdom of practice." When these teachers' methods are examined, it is clear that their suggestions are well grounded in an understanding of young children and in practical knowledge about teaching. It is not clear, however, that these methods are of relatively greater value in alcohol-affected children than in other groups. However, to determine whether they are more or less effective with children with fetal alcohol effects, evaluation of methods and programs will be required.

In addition to medical and educational interventions directed at affected individuals, other strategies have been considered to improve outcomes for alcohol-affected children and adults. Research suggests that few professionals working with children have adequate training in identifying and treating the effects of fetal alcohol exposure in children, although some programs that have provided professional education have been successful. Because the child is being reared within a family, whether the biological family or an adoptive or foster family, intervention for the prevention of secondary disabilities in alcohol-affected children must address the needs of the family as well. The way in which this support is provided will depend on the age of the child and the kind of family situation that exists.

Key Recommendations

The committee concludes that there are no specific programs to treat children with FAS, ARBD, or ARND, and other efforts to prevent secondary disability in these children are insufficient and inadequate. Given the known value of early intervention for other conditions, however, it is important to identify children with FAS, ARBD, or ARND as early as possible. Thus, in the committee's view, action to bring needed programs and efforts to an acceptable level must proceed on a number of fronts. The committee, therefore, recommends the following actions to address these needs:

- Clusters of high-quality diagnostic and treatment services should be available locally and regionally.
- Programs serving children with FAS, ARND, or ARBD should meet the

special, complex needs of such children, including consideration of the families involved and increased availability of parenting training for caretakers (birth parents, foster parents, and adoptive parents).

- Educational materials should be developed for professionals who deal with school age children to increase their awareness of FAS, ARND, or ARBD as a potential cause of ADHD-like behaviors, including hyperactivity, and to facilitate their referral of such children to other appropriate or needed services.
- Clinical practice guidelines should be developed for follow-up and treatment of children with FAS, ARND, or ARBD.

A necessary complement to the above actions is an expanded knowledge base. The committee, thus, views further research as essential to providing adequate treatment of children affected by FAS, ARND, and ARBD. The committee recommends additional research in the following areas:

- research to distinguish the role of the postnatal environment in modifying the effects of fetal alcohol exposure, including research on adopted versus non-adopted children with these disorders;
- research on the social and emotional status of school age children affected by FAS, ARND, or ARBD and research on the existence of specific impairments associated with these syndromes, particularly impairments in attention, language, sensory integration, and other behavioral problems;
- evaluation of the effectiveness of educational interventions on children with FAS, ARND, or ARBD, possibly beginning with the examination of educational interventions that look promising in case studies or in studies of children exposed to illicit drugs in utero.

INTEGRATION AND COORDINATION

There is no single, organized discipline within medicine that can, at this time, logically be held responsible or accountable for the development of a comprehensive approach to preventing and treating fetal alcohol syndrome (FAS), alcohol-related birth defects (ARBD), or alcohol-related neurodevelopmental disorder (ARND). Nor is there a single discipline in the broader arena of health and health care appropriate for this role. No group has yet shown any interest in the management of FAS, ARBD, or ARND patients as adults. Therefore, these disorders lie within the purview of many groups but are clearly not the full responsibility of any one. Like any problem that falls between organized disciplines, progress is unavoidably hampered. Both FAS research and service delivery suffer.

Such structural marginalization is also evident in government, where it is difficult to find a local, state, or federal government system that is positioned to address these disorders in a comprehensive manner. It is clear that neither governmental

structures nor the organization of modern medicine and health care can be redesigned. Thus, the challenge is to improve communication and cooperation among health, education, developmental disabilities, and social services disciplines and government agencies.

RECOMMENDATION

Therefore, the committee recommends that an interagency task force, or other entity comprised of representatives from the relevant federal research, surveillance, and services agencies, be established to coordinate national efforts in FAS, ARBD, and ARND. Lead responsibility for heading this task force should be assigned to NIAAA, because it is experienced at encouraging research and at incorporating research methodologies into all activities and has had the longest history in addressing FAS. However, all member agencies should be willing and able to translate research findings into service delivery and policy development activities and be expected to contribute to and be consulted with about achieving the overall goals of preventing and treating FAS.

It is suggested that one of the top priorities of such a coordinating body should be to forge interagency cooperation in the adoption of a common terminology and set of definitions related to these disorders, such as proposed in this report, and the design and implementation of national surveys to estimate the true prevalence of FAS, ARND, and ARBD. At the same time, prevention and treatment of secondary disabilities associated with FAS, ARND, and ARBD, as well as prevention and treatment of alcohol abuse and dependence by pregnant women and by women at risk of becoming pregnant, should be a high, and long-term, priority of this coordinating body. Additional important areas of focus should include consideration of basic research and communication among the basic and clinical research communities and the health services community. Recommendations for research in all aspects of FAS can be found in this report and should serve as guidance for the coordinating body. Finally, the coordinating body should take active steps to encourage and facilitate the rigorous evaluation of all intervention programs.

FETAL ALCOHOL SYNDROME

Diagnosis, Epidemiology, Prevention, and Treatment

Kathleen Stratton, Cynthia Howe, and Frederick Battaglia, *Editors*

Committee to Study Fetal Alcohol Syndrome

Division of Biobehavioral Sciences
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