[Archived] Individuals Affected by Fetal Alcohol Spectrum Disorder (FASD) and Their Families: Prevention, Intervention and Support

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Introduction

Fetal alcohol syndrome (FAS) and a spectrum of associated disorders, sometimes called Fetal alcohol spectrum disorders (FASD), result from prenatal exposure to alcohol caused by maternal alcoholism or heavy drinking (including episodic or “binge” drinking) during pregnancy.

FAS is diagnosed based on four criteria[1]

1. growth retardation, (that is, below the tenth percentile for weight, height or head circumference at some point during development)

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2. characteristic facial dysmorphia, including absent or indistinct philtrum (groove in the upper lip), thinned upper vermillion (lip), and shortened palpebral fissures (eye openings)
3. damage to the central nervous system, manifested as developmental delays, and mental retardation and cognitive and/or behavioural problems[2]
4. evidence of maternal drinking during gestation.

It is estimated that one in every 1000 children has FAS and one in every 100 presents with the milder effects of prenatal alcohol exposure.[3]

Subject

Prenatal alcohol exposure is a significant problem, owing both to its worldwide frequency and the severity of its developmental effects on children. Families caring for affected children are considerably impacted by the consequences of this disorder. Both alcohol-exposed children and their parents therefore require effective support to ensure that the development of FAS children is optimal and to avoid secondary disabilities.[4] As with any developmental disability, children with FAS and their families require a range of support programs and services throughout their lifetimes.[5]

Problems

Several problems have been identified in the provision of services for FAS.

Identification of Guidelines

As the Institute of Medicine has noted,[2] currently, no standards of care exist for FAS and related disorders. Affected infants, children and adults who qualify for services do so because they meet other criteria for medical care, early intervention programs, or special education that is not based on their FAS diagnosis. Conversely, many affected individuals do not meet the existing criteria at all and fall through the cracks of the care network. Indeed, the development of appropriate standards of care is currently a major challenge.

Services/Programs Specific to FASD

While parents[6] argue that alcohol-affected individuals need specialized services and access to professionals who are knowledgeable about the special needs of children and families, such resources are rare. Recently, the Fetal Alcohol Syndrome Task Force, a Federal Advisory Board

established by the United States Congress, noted that services in this area are limited in the US and not designed to address the prevention and intervention needs of alcohol-using women and their children.[3]

Research on Effective Programs and Services

Although the need for intervention and treatment is recognized[3] and many attempts have been made to meet these needs on a clinical basis (see reference 7), no formal evaluation of programs and services has been conducted in this area to date.

Instability in the Caregiving Environment

Those affected by prenatal exposure to alcohol are often exposed to sub-optimal environmental conditions as well. Women who give birth to FAS have a high mortality rate in the years following childbirth. They are also more likely to lose custody of their children due to substance abuse or child abuse and neglect. As a result, many children with FAS are placed in foster care or adopted after a period of domestic instability during infancy. Those who remain with their birth mothers may experience stress if the mothers continue to drink. These environmental factors may interfere with the early identification of children's developmental needs and may prevent children from consistently receiving services.

Research Context

Evaluation of effective programs/services for prevention/intervention and treatment is still in its earliest stages. Although parents and some professionals have been aware of the need for services by alcohol-affected individuals for many years now, the provision of such services has not been a priority area for most providers and governmental organizations. However, now that advocacy efforts on the part of parents and other concerned citizens have raised the level of awareness among governmental agencies, funding has been increased and thereby allowed for the development and evaluation of programs. Recently, the Centers for Disease Control and Prevention (CDC) initiated a five-site collaborative study of educational and social interventions for school-aged children with FAS and alcohol-related neurodevelopmental disorders (ARND) but this project is still in its first year and results will not be available for several years to come. No other studies of this nature have been undertaken as of yet.

Key Research Questions

The US IOM (Institute of Medicine) report[2] outlined a number of questions to be addressed in evaluating programs and services for FAS patients. These questions are much like those found in any good evaluation (eg, Is the intervention effective? Does it generalize its findings?). Several other questions might also be raised, including:

1. For whom should programs/services be designed?

More specifically: Where are the greatest needs and where can resources be most effectively directed? For instance, is early diagnosis important in identifying infants with FAS so that secondary disabilities associated with caregiving deficits might be avoided? Do children with FAS have unique learning difficulties that make typical teaching methods ineffective?

2. *Where are the gaps in existing services?*

To the extent that individuals with FAS are underserved by existing systems, gaps should be identified and appropriate programs designed.

3. *What are the unique needs of alcohol-affected individuals?*

It would be important to examine the belief that alcohol-affected individuals have unique needs that require novel treatment solutions. Research efforts could be directed to examining the strengths and weaknesses of alcohol-affected individuals and comparing these outcomes to those of other groups of disabled individuals as well as to norms among the general population.

Recent Research Results

A comprehensive survey of the literature in this field indicates that none of the published studies of FAS intervention/service programs have included provisions for program evaluation or empirical research. However, a number of articles have been written by educators and parents[7,8] endorsing educational methods or describing interventions on an anecdotal basis. In addition, in a survey of patients' families, Streissguth et al.[4] reported that early identification, intervention and caregiving stability were correlated with a reduction in the frequency of secondary disabilities among clinically referred children and adolescents. Nonetheless, it should be noted that while this survey supported the need for early intervention and services for this group, it did not use contrast groups. Therefore it is unclear whether alcohol-affected patient outcomes differed from those of other patients with disabilities.

Conclusions

FAS was first described in North America in 1973[1] and over time this disorder and associated problems have had a major impact on public health, education and social problems. A review of the status of FAS services/programs suggests that there is likely an acute need for services to individuals and families. But more research is needed to further define these needs as available information on planning for services remains fragmentary and anecdotal; although some of the needs associated with FAS and alcohol exposure may be unique in nature, they have not yet been fully documented. Specific behavioural and educational intervention for the treatment of disorders associated with FAS and for the prevention of secondary disabilities are rare and those that do exist have not yet been effectively evaluated. In sum, these findings suggest that there is a perceived problem that has yet to be systematically explored and, consequently, we cannot make any data-based recommendations at this time.

Implications

A review of the current status of programs and services for individuals with FAS and other alcohol-related disabilities suggests that:

1. A comprehensive needs assessment should be carried out before future planning is drafted. FAS Individuals of all ages and their families must be surveyed to obtain descriptions of their functional and service needs.
2. Alcohol-affected individuals might best be compared to other disabled persons in order to identify the similarities and differences between the two groups. In this way, previous experience and knowledge may be effectively applied where similarities do exist; where differences are apparent, unique solutions may be developed.
3. Likewise, the resulting proposals for programs and services should be compared to other existing programs and services, allowing matches to be made where resources exist and unique services to be developed where necessary.
4. The evaluation of program/service effectiveness should be a major component of all the programs for prevention, intervention, and treatment.

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