[Archived] FAE/FAS: Prevention, Intervention and Support Services: Commentary on Burd and Juelson, Coles,and O'Malley and Streissguth

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Introduction

Fetal Alcohol Spectrum Disorder (FASD) is one of the leading preventable causes of intellectual impairment and other disabilities. It is also one of the most under-identified. While decades of research have documented the developmental consequences of prenatal alcohol exposure, we have accumulated very little information on effective remediation strategies for affected children. Key to developing effective programs is the ability to identify affected children while they are young, so that they can benefit from educational and other support services that are currently available. The community-based screening approach described by Larry Burd and

Timothy Juelson[1] holds considerable promise as a way to identify FASD children so that schools and other social-service agencies can begin to understand their needs and develop services and programs that address them.

Research and Conclusions

The existing body of research on FASD is very consistent regarding the correlation between clinical signs of prenatal alcohol exposure and the risk for impairments in health and normal development.[2-4] However, despite what is known about the developmental outcomes in children exposed to alcohol prenatally, many of these children remain undiagnosed, even when maternal alcohol use during pregnancy is documented in the medical record.[5]

One of the greatest challenges to identifying FASD children in need of intervention has been developing methods for population-based screening that are cost-effective, require minimal training to perform and are sufficiently non-invasive to be acceptable to parents and caretakers. Until very recently, it was believed that FASD could only be diagnosed by highly trained medical professionals familiar with the constellation of facial features and developmental problems associated with prenatal alcohol exposure. However, work by Clarren et al.[6] has demonstrated the feasibility of community-based screening through the public schools, using public-health or school-based nurses to conduct the screening. A particularly important finding from this study was that the majority of FASD children identified through this process had not been previously identified. Moreover, once the diagnosis was made, children were re-classified as having a health-related disability and became eligible to receive intervention services.

The screening process described by Burd and Juelson[1] can be done in eight to 11 minutes and is based upon accepted diagnostic criteria.[7] The results presented by Burd and Juelson[1] indicate that the weighted checklist is a valid and sensitive instrument for screening for FAS. As a result of implementing this screening protocol, 28 previously undiagnosed FASD children were identified. Clearly, there is research support for both the feasibility and the effectiveness of community-based screening for FASD.

An important issue not addressed by Burd and Juelson[1] is the matter of cost. While the social benefits of early identification of FASD children are quite clear, it will be difficult to convince many policy-makers that the benefits outweigh the costs associated with conducting large-scale community-based screening. Although Burd and Juelson[1] state that “the cost (of screening) is

low," they do not translate that statement into economic terms. As an example of a screening project, Burd and Juelson[1] cite a nine-year study in which 98% of children enrolled in kindergarten were screened (1,384 children). Of these, 69 (5%) were referred for further diagnostic assessment. Of these, only eight (.5%) children were diagnosed with FASD. Obviously, this was a very time-consuming endeavour for a putatively small return. It is also important to note that the estimated prevalence of FASD in this community is 4.4 per 1,000, higher than the national estimate of one to three per 1,000.[8] The yield would be lower in a community with fewer at-risk individuals.

Another consideration in conducting population-based screening is participant protection and confidentiality. The diagnosis of FASD cannot be made without a diagnosis of maternal alcohol abuse. Thus, it becomes important that appropriate confidentiality safeguards be in place for the families of children who are still living with their biological parents. Identifying women at risk of having additional FASD children would be an added benefit of community-based screening. However, in some communities violation of confidentiality could also lead to embarrassment and increased social stigma for both the child and his/her family.

In the study conducted by Clarren et al.,[6] the inconsistency of policies around securing parental consent for screening also presented challenges. While one school system was comfortable with a passive consent procedure (i.e. parents were instructed to notify the school if they *did not* wish to have their child screened), another school system insisted on receiving signed consent from each parent or caregiver. As a result, only 25% of the children in the second community could be screened. Public education on the importance of prevention and early identification of FASD children could help make many communities more willing to participate in this type of effort.

Implications for Development and Policy Perspectives

The incidence of FASD is low compared to other health issues that may receive more attention from both the media and the public-health community. However, the potential costs associated with the disabilities that are a consequence of this disorder are enormous. Early identification of FASD children will help to secure needed intervention services to remediate some of the developmental challenges faced by affected children and potentially provide intervention opportunities in families where alcohol abuse creates a risk for the birth of additional FASD children.

The cost/benefit of community-based screening needs to be clearly articulated in economic terms. The social benefits of identifying FASD children are clear. However, these benefits need to be translated into language that will appeal to legislators and other policy-makers concerned with the proverbial “bottom line.” It may also be useful to consider implementing screening for FASD in the context of other health-related screening that already occurs in schools and community public-health settings.

Issues of confidentiality and participant protection will need to be addressed on a policy level. FASD is a significant and costly public-health problem. It is of crucial importance to identify affected children early so that they can reach their full developmental potential. However, this goal should not over-shadow the importance of protecting the confidential medical information of affected children and their families.

Individuals Affected by Fetal Alcohol Spectrum Disorder and Their Families: Prevention, Intervention and Support. Commentary on Coles

Introduction

Although most children affected by FASD can now be identified early in infancy, some children may have significant behavioural and psychosocial problems even in the absence of the facial features commonly associated with FAS.[9] Moreover, the range and variability in the medical, psychosocial and developmental problems such children exhibit make it difficult to establish consistent standards of care. As Dr. Coles[10] points out, FASD children who do qualify for services do so because individual manifestations of FASD meet the criteria for specialized medical, educational or psychosocial intervention programs. The diagnosis of FASD alone, in most cases, does not automatically result in access to intervention and treatment services.

Research and Conclusions

This manuscript is well grounded in current research on FASD. Clinical research with individuals affected by FASD has documented a continuum of developmental problems, ranging from physical birth defects to a higher incidence of psychological and behavioural problems.[11,12] Most of these effects persist throughout the lifetime of the individual. The variability in developmental outcomes highlights the need for early diagnosis and appropriate medical and developmental screening of FASD children with the goal of developing individualized and coordinated intervention/treatment plans. Such treatment plans should be comprehensive in scope and

address medical, psychological and social needs of affected individuals and their families.

Another area of research that has been neglected is the pattern and economic impact of service utilization for FASD children and their families. Information on the types of intervention and support services used by families with FASD children would be very helpful in formulating policy and identifying potentially effective programs and services for this population. To date, most of the information on service utilization has come from single case studies or anecdotal research. While suggestive, this type of research can do little to convince policy-makers of the need for increased funding for program development or third-party support.

Implications for Development and Policy Perspectives

There is a need to compile information on what services FASD families perceive to be most beneficial. As Dr. Coles[10] also points out, although these needs of FASD children are well recognized by parents and clinicians experienced in working with FASD children and their families, the political will is often not as evident, with few resources allocated to the development and evaluation of intervention and treatment services for this population. Systematic and objective research that examines intervention strategies in relation to FASD developmental outcomes and family functioning is needed to help support policy-level decisions that are data-driven.

Developmental problems observed in FASD children are very similar to those seen in children with other congenital syndromes, such as intellectual deficits, hyperactivity and attention deficit disorder. There are existing intervention strategies that have been found to be effective in mediating these disorders. What remains unclear is whether there are more comprehensive approaches that may yield greater benefit than isolated interventions that target specific disabilities without considering the environmental context of the FASD child.

There is a growing body of literature that suggests that even non-FASD children who are raised in an alcoholic or drug-using family environment face considerable challenges to normal development. The instability of the home environment, increased risk of neglect and abuse, as well as the social isolation and psychological impact that can result often lead to poor school performance, emotional and behavioural problems in children without prenatal alcohol exposure. These environmental risks are compounded for FASD children. Early identification, as early as infancy but certainly before school age, would increase opportunities for early intervention.

There is a need for both formative and summative evaluation research on prevention and intervention strategies. Formative research is needed to provide information on how existing programs and services can be enhanced to provide more effective treatment for FASD children and their families. Examples of formative research might include surveys of families of FASD children to elicit information on their service needs and the perceived effectiveness of available services. Summative evaluation research is also necessary to examine the comparative long-term benefits of various intervention strategies on improving developmental outcomes and family functioning.

Clinical Intervention and Support for Children Aged Zero to Five Years with Fetal Alcohol Spectrum Disorder and Their Parents/Caregivers. Commentary on O'Malley and Streissguth

Introduction

Research on FASD children suggests that a stable, nurturing home environment can help to prevent or ameliorate many secondary disabilities and behavioural problems.[13] Therefore, early identification and access to intervention services for the FASD child are critical. However, as O'Malley and Streissguth[14] point out, there is a lack of research on comprehensive, evidence-based interventions for young FASD children, specifically those from zero to five years of age. Education and support services for parents and other caregivers are also rare.

Research and Conclusions

O'Malley and Streissguth[14] present a compelling argument in support of prevention, early intervention and support services for FASD children and their caregivers. Historically, prevention efforts have focused on universal strategies such as public-health education that were directed toward young women of childbearing age. Although there have been few evaluation studies of these programs, there is some evidence that such programs are effective in reducing alcohol consumption rates among low-risk populations.[15,16]

Intervention and outreach programs based in prenatal clinics have also shown promise in encouraging reduced alcohol and drug use among pregnant women.[16-19] Once identified, women are receptive to the information provided and even heavy drinkers are able to decrease or discontinue their alcohol use during pregnancy. It is important to note, however, that women with a history of alcoholism or chronic alcohol abuse will require additional follow-up and support. Residential programs that provide an array of services, such as group and individual

psychotherapy, parenting education, child care and vocational training, have shown promise in treating drug-dependent women.[20]

The greatest challenge to successful intervention with alcohol-abusing women is early identification. Most of the programs described above relied heavily on self-report to identify women at risk. More recent research has identified potential biological markers for alcohol abuse during pregnancy that may enhance our ability to identify and intervene early with pregnant alcohol abusers.[21] What is clear from FASD prevention research is that we have both the knowledge and the tools to identify and effectively intervene with pregnant alcohol users. What is often lacking is the political will to put them to use.

Once an FASD child is born, early identification and intervention become critical. These children remain at risk for developing secondary psychological and behavioural problems as a result of exposure to non-optimal home environments. FASD children who are removed from the custody of their biological parents often experience multiple foster-care placements. Exposure to physical or sexual abuse, neglect and other forms of domestic violence can lead to lasting emotional scars, which if left untreated can significantly impair social and emotional functioning. Clinical studies of FASD children have documented a higher incidence of psychological and behavioural problems when compared to non-FASD children.[11]

There is also a sizable body of literature that documents the familial nature of alcohol and drug addiction. Children of alcoholic parents are far more likely to develop alcohol problems as adults than are children with non-alcoholic parents. This risk also extends to FASD children. Information from case studies and other anecdotal research has documented that both alcoholism and FASD are multi-generational problems.[22,23] It is important for interventions with FASD children to incorporate family-focused interventions that provide support to both parent and child, addressing the full spectrum of needs presented.

Implications for Development and Policy Perspectives

FASD is a preventable disorder. Early identification of women who use alcohol during pregnancy or who have previously given birth to an FASD child creates opportunities for prevention. Promising intervention techniques include clinic-based counselling, outreach and comprehensive addiction treatment for alcohol-dependent women. There is ample evidence that these strategies are effective in promoting abstinence and other positive life changes in alcohol- and drug-

dependent women.

There is a gap between what we know about the needs of FASD children and our knowledge of effective interventions to address them. FASD is a lifelong disorder. The earlier the diagnosis is made, the more likely it is that we will be able to successfully remediate existing problems and prevent the development of secondary disabilities in these individuals. O'Malley and Streissguth[14] have identified a number of promising early-intervention approaches. What is needed now is systematic research to evaluate the effectiveness of these and other strategies.

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