

ADVERSE LIFE OUTCOMES ASSOCIATED WITH FETAL ALCOHOL SYNDROME- THE BENEFITS OF EARLY DIAGNOSIS

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A CRITICAL REVIEW of “Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects.”

Streissguth A, Bookstein F, Barr H, Sampson P, O'Malley K, Young J. J Dev Behav Pediatr. 2004 Aug;25(4):228-38.

Although the teratogenic effects of alcohol are well documented, the psychosocial milieu into which children with Fetal Alcohol Syndrome (FAS) are born and its effects on their development has not been as clearly elucidated. Living with an alcoholic parent, risks of child abuse and neglect, being raised by foster families are all factors that appear to further compound dysfunctions present from *in utero* alcohol exposure such as lower overall I.Q, deficits in academic performance, poor judgment, distractibility as well as difficulty understanding social cues. Shortcomings in adaptive living skills may have long term consequences and may in fact present the greatest challenge for the management of adolescents and adults with FAS.

Streissguth (1997) first showed that critically delayed or absence of diagnosis of FAS prevents the child from benefiting from interventions that may mitigate secondary damages of FASD¹. In this study, Streissguth and colleagues (2004) performed a follow up study on the emergence of these deficits and their consequences on the life outcomes of adolescents and adults with FAS/FAE. Employing a Life History Interview with knowledgeable informants of 415 patients with FAS or FAE, they examined five adverse outcomes in patients with FAS: inappropriate sexual behavior, disrupted school experience, trouble with the law, confinement and alcohol and drug problems. Ten associated risk/protective factors were examined including average years per household and quality of the homes in which they resided.

The analysis revealed a prevalence of 60 % of adolescents with FAS having trouble with the law; 50 % had completed some time in confinement in either prison, psychiatric or alcohol/drug inpatients and 61 % of adolescents had a disrupted school experience. As well, 49 % engaged repeatedly in inappropriate sexual behaviors while 35 % of FAS adolescents also struggled with alcohol/drug problems.

While these behaviors may be characteristic for adolescents and adults with FAS, the study does not attempt to compare the prevalence of these events to those in non-FAS populations. FAS children and teenagers may not be so different from an apparently healthy child in foster care. A 2001 study in the American School Board journal² found that foster children often repeat a grade, are twice as likely to drop out of school and perform poorly overall compared to their non-foster counterparts matched for socioeconomic class³. Thus whether disrupted school experience, confinement and alcohol/drug use is a result of FAS cannot be conclusively drawn from this study. Future studies should consider non-FAS, foster care comparison group.

Furthermore, some of the adverse life outcomes measured by the study appear to be interrelated. Clearly, if a child is having trouble with the law, he/she is more likely to have been in confinement. In this study, the families, whether biologic, adoptive or foster varied widely in both education and economic status.

Importantly, a protective factor against adverse life outcomes was the number of years lived in stable and nurturing home. It was calculated that on average, children who exhibited less adverse outcomes lived 75 % of their lives in a stable and nurturing home while the median years per living situations was 2.7 years. Each change requires the child to adjust to a new home, new family and often a new school. It is evident that the constant change in school may have been a factor that contributed to the 60% of FAS children who had a disrupted

school experience and decreased academic performance. Yet it is quite possible that the multiple home changes are not the reason for the worse outcome but rather their cause. It is possible that FAS children who are more maladaptive cause more foster families to pass them along.

With regards to social behavior, Streissguth grouped children who had suffered abuse whether it was physical, domestic or sexual. The response was recorded as a “yes” if any of these three was affirmed. However, these forms of abuse may differ substantially in terms of social and psychological consequences. Perhaps if more carefully grouped for these factors, there may have been significant correlations between the type of abuse and later adverse outcomes. Even then, these results would still have to be compared to a non-FAS control group in foster home to address the question whether FAS children and adolescents are actually more prone to adverse outcomes.

To quantify the social stability of the environment in which the FAS adolescent was raised, the authors designed a Life history interview. Streissguth et al (2004) justified that the use of a non-standardized interview was necessary due to the scope and magnitude of the study.

Age at diagnosis and a stable and nurturing home were found to be the most influential protective factors for children with FAS, reducing the risk of all five adverse life outcomes: disrupted school experience, inappropriate sexual behavior, and trouble with the law, alcohol/drug use and confinement. Streissguth and colleagues states: “*Adverse life outcomes can be reduced by families, communities and physicians working together to assure that children with FAS are raised in long-lasting, stable, nurturing homes with good stable families in the midst of enduring relationships.*” This study is an important continuation of the Seattle breakthrough work, showing that early diagnosis carries a substantial protective effect. With most high risk children today not having access to FAS diagnosis, providing diagnostic services became a major step toward primary prevention for the child’s future siblings by intervening with the mother. As Streissguth shows, it also provides secondary

prevention from the deficits that are often characteristic of children with FAS.

REFERENCES

1. Streissguth, A. Aase, J, Clarren S. Randels S, LaDue R, Smith D. Fetal alcohol syndrome in adolescents and adults. *JAMA*. 1991; 265:1961-67.
2. Finkelstein M, Wamsley M, Miranda D. What keeps children in foster care from succeeding in school? Views of early adolescents and the adults in their lives. *Vera Institute of Justice based on data from New York City Board of Education Annual School Reports*, 1 June 2002.
3. Wilwerth J. Should we take away their kids? Often the best way to save the child is to save the mother as well. *Time* (13 May 1991): 62.
4. Koren G, Nulman I. *The Motherisk Guide to Diagnosing Fetal Alcohol Spectrum Disorder*, Motherisk Program, Hospital for Sick Children, Toronto, Ontario, 2002.