Fetal Alcohol Syndrome

Discussion Date: **August – October 2004**
Discussion Moderator: **George Brenneman, MD**

This discussion was initiated August 24 and, through October 4, 2004, received comments from eight respondents. Each respondent made very thoughtful points. Many were very detailed. It is quite obvious that Fetal Alcohol Spectrum Disorder (FASD) continues to be an important t multidisciplinary health issue in Indian Country and one that requires coordinated and cooperative interventions across professional and agency boundaries.

This summary will include the original questions followed by bullets extracted from responses.

Original Questions:

Indian Health SIG ListServ Discussion: Fetal Alcohol Syndrome

My work in South Dakota keeps me very aware of health conditions and issues related to prenatal alcohol exposure. In spite of health education activities and heightened awareness, I sometimes wonder how effective prevention efforts have been.

I confront a number of issues related to prenatal alcohol exposure:

- Identification and appropriate intervention of at-risk pregnancies
- Diagnosis and terminology
- Multidisciplinary follow up and intervention
- Interdisciplinary communication and sharing information

One recent experience here vividly focused the complexity of the issue of preventing prenatal alcohol exposure and failure of satisfactory multi-disciplinary communication. In a zealous effort to prevent FAS, State social services petitioned Tribal court to incarcerate (jail) a pregnant woman who allegedly continued to drink. But she also had gestational diabetes and was on insulin.

Have you confronted similar, and how did you manage the situation?

Another area; in arranging for a competent level of evaluation for infants and children who have a history of prenatal alcohol exposure, the nearest available is an academic center 150 away from the family's community and location of the child's primary services. Evaluations are often not relevant or culturally effective, and follow up is difficult to arrange.

What success have you had in bringing multi-disciplinary evaluation and follow-up services to the community where direct health care providers, teachers, and family can be involved in evaluation, diagnosis, and follow up?

Responses:

- Important steps in prevention must focus on mother's mental health needs and should include inpatient care.
- Schools need to be more aware and have realistic expectations for affected children.
- Periodic multidisciplinary (outreach) clinics for evaluation and diagnosis are particularly important for most Indian Health sites, which are often remote from immediate specialty services.
- Raise awareness of possible presence of FASD:
  - Any history suggestive of prenatal alcohol ingestion by a mother should be a trigger to observe carefully for evidence of FASD in her offspring and to initiate early evaluation and intervention as indicated.
  - Missed appointments for evaluations and essential services by dysfunctional family with a child who has developmental or cognitive delay or has a behavioral disorder may be an indication of prenatal alcohol exposure.
  - Mothers who received little of late prenatal care.
  - Child in foster care, living with father only, or living with grandparents for unexplained reasons.
  - Delinquent immunizations.
- Clinicians need to improve documentation of prenatal use of alcohol.
- The issue of pregnant women who continue to drink prompted a number of comments:
  - It is very difficult
  - Incarceration is not a good idea, for women will hide their drinking and be reluctant to seek help.
  - Significant partners of pregnant women need to be involved.
  - Safe housing with a complete range of social, counseling, and mental health services are needed the mother, her partner, and family.
  - Dena A Coy is a model residential and ambulatory program in Anchorage, AK for treatment of pregnant women who abuse alcohol.
- Many women are well aware of the toxic fetal effects of alcohol and will avoid alcohol when they are pregnant, but, to ensure prevention, alcohol must be avoided before conception as well as throughout pregnancy:
  - Critical window is frequently wide open between conception and first awareness of possible pregnancy.
  - Important to continually address the importance of "fertility awareness" and availability of family planning.
- Important facets in addressing FASD include,
  - Diagnosis

    The use of FASD is useful and practical. The University of Washington approach is good and provides good training for providers. This program receives funding from IHS.
  - Clinical intervention

    Clinicians must go beyond making a diagnosis and also address co-morbidities, development, and behavior. To do this effectively, agency and discipline boundaries need to be breached.
  - Community intervention

Families and communities must be included as partners in the provision of FASD intervention. Schools must be held accountable for providing appropriate services to FASD children under Individuals with Disabilities Education Act mandates.

    - Evaluation

      Additional community-appropriate qualitative, quantitative, and evidence-based research is needed.

- Failure in prevention of prenatal alcohol exposure is often the fault of the system not providing the "required 'dose' of the right 'therapy'."
- Good resources:
    - "FETAL ALCOHOL SYNDROME, Diagnosis, Epidemiology, Prevention, and Treatment," Institute of Medicine, National Academy Press. Washington, DC 1996
    - CDC National Center on Birth Defects and Developmental Disabilities Web site at: http://www.cdc.gov/ncbddd/
    - SAMHSA Web site, www.samhsa.gov Go to "FAS Center of Excellence."