

REPORT:
CANADA NORTHWEST FETAL ALCOHOL SPECTRUM DISORDER CONFERENCE
Winnipeg, Nov.19-21, 2003

Conference Purpose:

This conference, the product of an FASD partnership among the governments of Saskatchewan, Alberta, British Columbia, Northwest Territories, Yukon and Nunavut, pulled together policy-makers, service providers, academics/researchers, parents, teachers, and care-givers involved in FASD education, research and services. Workshops and discussions provided the latest information regarding: etiology and diagnosis; strategies for home and classroom; strategies for community organization, awareness and education; counselling with FASD individuals and families; and sharing of experiences.

I focused on the research and diagnostic issues (Inuit communities have requested more information about diagnosis), and preventive strategies. I was especially interested in the latter, for it has been my experience at FASD workshops and conferences that we talk much about diagnosing and helping FASD children, and little about how to help women so that FASD does not happen. As noted below, this turns out to be a generally overlooked issue.

Terms:

FASD: Fetal Alcohol Spectrum Disorder – ‘umbrella’ term that covers all aspects of fetal alcohol-related injury

FAS: Fetal Alcohol Syndrome – damage that includes the full spectrum of brain, other physiological and characteristic facial abnormalities

ARND: Alcohol-Related Neurodevelopmental Disorder – focus on the brain-injury aspects of fetal alcohol damage (previously called FAE/Fetal Alcohol Effects)

Key Information Obtained:

Prevention:

- IMPORTANT POINT made by the experts: FASD has been, and continues to be, framed primarily as a child health and welfare issue, with much of the attention, programming and funding going towards identifying, treating and educating FASD children and providing information and help for their caregivers/educators. Much less attention and effort is given to actually helping women change risky drinking and risky lifestyles. Unless we help women stop drinking (or at least reduce their drinking to safer levels) and deal with the other factors that influence both drinking and FASD (malnutrition, stress, exposure to violence, etc.), they will continue to give birth to children damaged by alcohol.
- “Just say no” advice is neither sufficient nor effective. 3 levels of prevention needed:
 - awareness/health promotion/community development oriented to: change negative attitudes towards substance-abusing women, develop understanding of health determinants (i.e., what women need in order to not feel the need to drink); reduce barriers to care; develop community-based support systems, etc.

- a coordinated infrastructure of brief-intervention services and outreach for all women of child-bearing age: education re risks of substance use; brief motivational counselling re substance abuse (an early intervention strategy); referral to more specialized treatment and services when necessary.
- effective holistic services for pregnant women/mothers who have serious substance abuse problems and other health and social problems. The FUNDAMENTAL NEED IS A HOLISTIC, NON-JUDGMENTAL HARM-REDUCTION SERVICE ORIENTATION across collaborating agencies and services, individually tailored to allow women to feel safe and unjudged, and to make their own choices about kind of change and pace of change.
- Training in basic harm-reduction counselling, motivational interviewing and brief intervention is necessary for those working with pregnant women. (E.g., Dr. Leigh Wincott, a presenter in the Research stream, says he has established a reputation in his work area of northern Manitoba of asking *all* pregnant women direct and calm questions about their drinking; thus no one feels centred out or insulted. He doesn't ask "Do you drink?" but "How much do you drink?" Those who don't, say so; with those who do, he goes on to help them briefly assess their intake, and to provide guidelines and info.)
- Excellent resources:
 - Canadian Centre on Substance Abuse FASD Toolkit – all aspects of FASD work - <http://www.ccsa.ca/toolkit/introduction.htm>
 - Best Practices in FASD prevention (Health Canada) - <http://www.hc-sc.gc.ca/hecs-sesc/cds/pdf/BestpracticesEnglishclosed.pdf>
 - Urban Aboriginal women and primary care intervention - http://www.motherisk.org/JFAS/pdf/Urban_FASD.pdf

Research and Diagnosis:

- Binge drinking creates the greatest risk of FASD and the greatest damage. There is no known 'safe' level, or period, of drinking; pregnant women therefore should not drink at all. However, it is known that occasional small amounts of alcohol are unlikely to result in FASD.
 - Harm-reduction strategies for pregnant women who are unwilling or unable to completely stop alcohol use (due to addiction/dependence or social reasons) are therefore recommended. If they can cut back their drinking to 'safer' levels (no more than 1 or 2 per occasion, no more than 4 drinks a week), they significantly reduce the risk of damage to their babies.
- Evidence that other factors involved in fetal alcohol damage (e.g., malnutrition, stress). Prevention must therefore be holistic.
- Studies about Aboriginal FASD rates have generally been done in communities where alcohol consumption is known to be high. There is little research about how rates of alcohol use and FASD vary across communities. Demographic, socioeconomic and sociocultural research across communities is needed, in order to determine the protective factors (individual and social) in Aboriginal populations who have low alcohol use and FASD rates. Such knowledge will help in identification of and services for high-risk populations.

- Fetal damage may be the result of alcohol metabolism effects that result in oxidative (free radicals) damage to cells, leading to cell death. Maternal malnutrition probably intensifies the effects of the alcohol. Antioxidant treatment with, e.g., medical levels of antioxidant vitamins C and E during pregnancy may protect against this damage. *(Note: I had heard of such research a couple of years ago, and had a brief discussion with someone. Their view was that this was a dangerous finding, since it would encourage women to drink if they could just take vitamin therapy to offset damage. A potential discussion with ethical overtones.)*
- Alcohol may affect the dilation and constriction of placental and umbilical blood vessels: leads to constriction, resulting in reduced blood flow to fetus. Mouse studies showed that mouse moms which had been given alcohol had impaired blood flow to the fetus; and the fetuses were smaller and less developed than normal.
- Prenatal exposure to alcohol can be detected in an analysis of a baby's first fecal movement (called *meconium*). Although alcohol is excreted from the body quite quickly, it produces Fatty Acid Ethyl Esters (FAEEs) which remain in the body much longer. All humans naturally produce alcohol in their bodies and therefore show FAEEs; but these FAEEs (if they show at all) are at low levels in the baby. Drinkers also produce different kinds of FAEEs. Presence of higher levels FAEEs in the baby's first feces is evidence of the baby's prenatal exposure to alcohol consumed by the mother; and presence of certain types of FAEEs may indicate heavy drinking.
 - Meconium starts forming in the 2nd trimester of pregnancy, so it will not indicate if mom drank in the first trimester.
 - This is important in early FASD diagnosis. Information about a mother's drinking is not always accurate. If testing can be done immediately, both health-providers and families can take steps to minimize the effects of possible fetal-alcohol damage. The earlier steps can be taken, the more effective intervention may be.
 - The test is established. An ethics committee has now been established to determine its ethical uses in early diagnosis.
 - **The organization Motherisk has a lab at the Hospital for Sick Children in Toronto, and will do testing if samples are shipped to their lab. There is a fee which varies according to the analysis/service required. They can be contacted at 1-877-327-4636.**
- Functional magnetic resonance imaging (fMRI) studies of FAS adults and children have shown brain activity that is different from non-FAS individuals. May thus become a useful diagnostic tool.
- Current diagnosis generally uses 2 diagnostic tools (alone or in combination):
 - Institute of Medicine Diagnostic Criteria (IMDC): Uses 3 main "yes/no" criteria (FAS facial characteristics, prenatal maternal drinking, additional criteria (e.g., growth retardation, brain abnormalities, cognitive and behavioural abnormalities) to generate 5 diagnoses –
 - FAS with confirmed maternal drinking
 - FAS without confirmed maternal drinking
 - Partial FAS with confirmed maternal drinking
 - Alcohol-related birth disorder
 - Alcohol-related neurodevelopmental disorder

- 4-Digit Diagnostic Code: uses 4 ranked criteria to produce a diagnosis:
 - growth deficiency (significant, moderate, mild, none) FAS facial characteristics (severe, moderate, mild, absent)
 - brain dysfunction (definite, probable, possible, unlikely)
 - gestational alcohol [prenatal exposure to alcohol] (high risk, some risk, unknown, no risk)

NOTE: FAS facial characteristics are considered a definite sign of FAS and exposure to alcohol, even if maternal alcohol use is unconfirmed.

Recommendation by all: need to develop a standardized diagnostic tool. Differences in diagnoses may lead to differences in and inadequate interventions, and differences in funding for services (potential for inadequate funding).

- Effective diagnosis and intervention planning needs input from multiple partners: medical, family, community.
- Telemedicine has been shown to have great potential as an effective tool in FASD diagnosis, planning and training, when used in partnership with family and community resources.

Conclusion and Follow-up:

Excellent conference, providing the latest in research and evidence, as well as identifying gaps. The speakers on preventive strategies were dynamic, experienced and knowledgeable. The presentations from all workshops will apparently be posted on the conference website (?)...I shall find out and pass on that information.

Early in the new year, I shall be writing a series of FASD fact-sheets, based on information gathered here and elsewhere, for inclusion on the Ajunnginiq Centre's website. The focus will be on diagnostic issues and prevention, which are areas in which Inuit communities have indicated a need for more information.

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