

ALCOHOL AND THE FETUS

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Lecture and manual highlights:

The children and adults with fetal alcohol spectrum disorder (FASD) can be considered to be our teachers. Their lives make us painfully aware of the problems facing society today. The cracks they fall through reveal to us the inability of our systems to take care of all members of the "village." Reforms in education, criminal justice, social services and the medical community are needed to prevent isolation and loss of productivity suffered by people with organic brain damage.

A holistic, individualized approach to raising and interacting with our children and adults is the most valuable intervention tool and form of prevention currently available to us. Let us heed their message, that it takes all of us working together to provide opportunities for happy, healthy lives of the unborn and those who live among us affected by alcohol exposure in utero. The manual I have written is an educational tool, which honors the teachings and the sacrifices offered to us in our capacities as parents, care-givers, providers, and educators of children and adults with an FASD.

It is important to understand the organic effects of alcohol on the fetus. This is not a birth defect that can be "fixed". Drinking at any time during the pregnancy is a potential danger to the fetus. Planned pregnancies can insure an opportunity to create and experience a healthy pregnancy as well as time to prepare for the new member of the family and community. Because of the inability to predict the brain damage caused by alcohol, there is no safe amount of alcohol. People affected by alcohol in utero can exhibit particular physical features or not. What everyone with an FASD shares is damage to the central nervous system. People who do not have the physical characteristics may actually have a more difficult time finding services and acceptance than a person may with a visible disability.

Only trained physicians and dysmorphologists, psychologists, speech pathologists and occupational therapists and others related to the field of birth defects are able to conduct or decipher a neurodevelopmental assessment leading to a diagnosis of an FASD. They will also be able to recognize alternative syndromes and neurodevelopmental disorders.

There is research related to alcohol abuse and sperm in animals. Offspring of males given alcohol can have growth deficiencies and signs of central nervous system disorders. Even if father's drinking does not damage the fetus via his sperm, it is important that men support an alcohol free pregnancy for both parents. Planning a healthy pregnancy is the responsibility of both parents.

Alcohol causes physical damage to the central nervous system (CNS) in utero. Many caregivers feel that providing a good home and love will "cure" their child. These are indeed important aspects of intervention and success, but the organicity of the brain damage must be understood to establish realistic expectations for the caregivers and the person with an FASD. The difference between someone with FAS and those who have the brain damage but no or few physical features are minimized by the reality that someone can look "OK" but present with behaviors that are causing problems and stress for everyone involved. They may actually be more disadvantaged than someone who is identifiable because of physical characteristics that signify the presence of brain damage. Behavior is what drives caregivers to seek a diagnosis. After the diagnosis, affected people or their caregivers are left with the reality of the central nervous system (CNS) damage. Diagnosis and an understanding of child development are key in assessing behavior.

Research and experience reinforce that early diagnosis is essential to successful interventions for people with problems caused by alcohol exposure in utero. Establishing a history of alcohol use during pregnancy is paramount to diagnosis. Women do not drink to damage their unborn children. Refer to Appendix I in my manual for information and ideas on approaching the subject of alcohol use during pregnancy with mothers at risk of having children with an FASD. These can become labels for people who may already be identified as "problem children or adults." The label extends to the mother as well, so it is essential that trained professionals conduct diagnosis. Also, without diagnosis, FASD will not receive the recognition that will lead to more research and the establishment of appropriate services.

Each person affected by alcohol in utero will present central nervous system damage differently. How alcohol affects a particular part of the brain, in a particular way, at a particular point in the pregnancy is not known. The range of damage and the resulting behaviors will vary with each person. The spectrum of damage is minimal to severe. Therefore, each person must be looked at individually when creating interventions. Everyone affected by alcohol in utero has strengths that need to be incorporated into the interventions. Understanding the other contributing factors to behavior such as genetics must also be considered. There are no "recipes" that work for everyone, as each fetus is affected individually. Infants are particularly difficult to diagnose but early intervention leads to better outcomes for children exposed to alcohol in utero. As the child ages and is exposed to more environments and experiences, behaviors that might signal the presence of damage caused by alcohol may become more apparent. Again, remember that each child will present these behaviors differently depending on the amount of damage to the brain and what part of the brain is affected. IQ does not always indicate that there has been damage to the brain by alcohol exposure. IQs can range from 30 to over 130. Again, knowledge of child development is essential in assessing behavior.

There is a wide range of behaviors that may be present in the child or adult who is affected. Here are a few:

- ❖ problems with fine and gross motor skills
- ❖ memory deficit or "quirky" memory
- ❖ easily over stimulated or distracted
- ❖ difficulty with cause and effect
- ❖ seeming lack of remorse
- ❖ learning difficulties
- ❖ attention deficit
- ❖ lack of boundaries
- ❖ overly affectionate
- ❖ hypersensitive or under sensitive to touch, sound, light and textures (even in food), hygiene problems and extreme generosity.

These are some of the behaviors observed at the FAS Diagnostic and Prevention Network at the University of Washington in Seattle, Washington.

Interventions must begin with nonjudgmental, unbiased observation. Get into the person's head not your own. Their view of life, events, ideas, etc., can be much more concrete than your view. Design environments and activities that are

structured, predictable and repetitive. Consistency is a key. Getting up, dressed, eating, bathed, etc. should be routine. *AVOID CHANGES AND REDUCE STIMULATION.*

It has been demonstrated in animal research and clinical settings that alcohol has a devastating effect on the unborn fetus. Why then, do pregnant women continue to drink during pregnancy, in many cases with the support of her family, friends and professionals? The answer is that alcohol is the number one drug of choice in the United States and it is a legal substance. In a consumer oriented society, marketing costs to industry are high but worth the investment. A large portion of liquor industry profits is put into advertising. It works. Alcohol consumption is presented in an aura of glamour, acceptability and prosperity. Everyone is the target, young and old alike.

Animal studies on FASD demonstrate that alcohol is the key variable in producing a damaged fetus. Therefore, women who do not drink during pregnancy will not produce children with an FASD. Reported prevalence rates of FAS vary widely depending on the population studied and the research methodology used. CDC studies have documented FAS prevalence rates ranging from 0.2 to 1.5 per 1,000 live births in different areas of the United States. Health Canada estimates that at least one child is born with FAS each day in Canada. An epidemiological study (American Journal of Public Health, Volume 90, Issue 12, 1905-1912) of a South African community found rates to be 18 to 141 times greater than in the United States. The most powerful prevention message is that FAS is 100% preventable.

Primary prevention activities focus on preventing mothers from drinking during pregnancy and on encouraging the use of family planning methods among drinking women of childbearing age. Many efforts target women who are at high risk for producing children with birth defects, including alcoholic women of childbearing age and birth mothers of children with an FASD. Planned pregnancy and education around the dangers of drinking during pregnancy are unequivocally the best strategies to prevent this birth defect. In 2001, approximately one-half of pregnancies in the United States were unintended (Finer 2006, Perspectives on Sexual and Reproductive Health).

This is a problem that crosses all racial, social and economic lines. Unintended pregnancies can have serious consequences. They are associated with late or inadequate prenatal care, low birth weight, neonatal death, poor child health and development, domestic violence, child neglect and abuse and exposure of the

fetus to alcohol, tobacco, and other harmful substances. Unintended pregnancy clearly is a common denominator of many of today's health and human service problems. Secondary prevention activities are early attempts at identification, intervention, and treatment to prevent further health problems. Tertiary prevention is designed to minimize long-term disability or reduce negative effects of drinking during pregnancy among people with an FASD.

Parenting is the oldest and most "natural" form of prevention for birth defects related to alcohol. Parenting strategies should focus on the risk factors which place future generations at risk for an FASD.

The Ethiopian proverb "It takes a village to raise a child" is more pertinent now than ever before in modern day society. Communities committed to bringing children into a safe, nurturing environment; seldom if ever experience something as devastating to the very fabric of a healthy society as fetal alcohol spectrum disorder. Children growing up in such communities understand the importance of alcohol free pregnancies and feel protected by the community at large. Women are encouraged and assisted by the other members of their group to remain sober. Children observe healthy pregnancies and parenting as a norm throughout the "village", and have a clear view of what good parenting means at a communal level.

Placing our children at risk for an FASD is a social problem borne by all of us. The impact on our society can be felt on many levels. Loss of life, productivity, human resources, and money are all issues relevant to all members of every community.

This information is from the training manual for trainers - Alcohol and The Fetus, by Carolyn Hartness. She is co-authoring a new manual with Suzie Kuerschner which should be available in 2008. Please contact Carolyn at P.O. Box 556, Indianola, WA 98342, (360) 297-0411, chartness@centurytel.net or visit her website, www.Seventh-Generation.com for more information on training and consulting availability.