

A Training Manual for Trainers



Alcohol and the Fetus

by Carolyn Hartness, Educator/Consultant
Second Edition
October 2002

Children with Special Health Care Needs Program
Public Health - Seattle & King County
999 Third Avenue #900
Seattle, WA 98104-4039
(206) 296-4610



Acknowledgments

This manual is dedicated to our teachers: the children and adults affected by alcohol in utero. 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, the legal system, legislation, 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. This educational tool honors the teachings and the sacrifices offered to us in our capacities as parents, care givers, providers, and educators of children and adults with FAS and related conditions.

I want to acknowledge the countless individuals and programs that are making a difference in the lives of many people affected by alcohol in utero. Thank you to the parents, care givers, and professionals who are dedicating their lives and giving their love to these bright spirits.

Special thanks to everyone who contributed to the writing of this manual; Dr. Susan Astley, June Belefond, Dr. Donna Burgess, Chan Brisbois, Dr. Heather Carmichael Olson, Dr. Sandra Clarren, Dr. Truman Coggins, Linda Colfax, Sharon Cummings Beck, Jocie DeVries, Susan Doctor, Christine Evans, Dr. Robert Fineman, Julie Gelo, Jackie Jamero-Berganio, Suzie Kuerschner, Margaret Kuklinski, Dr. Robin LaDue, Linda LaFever, Chris Lair, Jan Lutke, Vicky McKinney, Dr. Wendy Mouradian, Rose Quinby, Sandra Randels, Public Health - Seattle & King County staff, Dr. Ann Streissguth, Marceil Ten Eyck, Lorri Verzola, Nancy White and to the staff at the Centers for Disease Control and Prevention. Special thanks to Dr. Sterling Clarren for reviewing the manual for medical accuracy, and to Lucia Mejeir for writing Appendix I; *Behavioral Interventions for Working with Chemical Abusing and Dependent Mothers*, and to Sue Spahr for bringing it to print.

The writing of this manual was funded in part by a cooperative agreement from the Centers for Disease Control and Prevention (grant # U50/CCU008566-04), Dr. Robert Fineman, Principle Investigator, Washington State Department of Health.

Endorsements



“This manual presents a comprehensive view of the field of fetal alcohol syndrome and its myriad of problems and issues. The work is current, accurate and presented in an easy to use format. I am not aware of any other source on the market that is comparable”.

Sterling K. Clarren, M.D.
Robert A. Aldrich, Professor of Pediatrics
University of Washington School of Medicine
Medical Director, Fetal Alcohol Syndrome Diagnostic and Prevention Network
State of Washington

“Thank you Carolyn, for writing a practical and useable manual for trainers on fetal alcohol syndrome and fetal alcohol related conditions. I have presented in this field and worked with adolescents and their families for many years. I am grateful to have a manual that is not only readable but also wise”.

Dr. Robin A. LaDue, Clinical Psychologist
Team Member at the FAS Diagnostic and Prevention Clinic
University of Washington
Seattle, WA

“Accessing information on children in particular developmental stages makes this manual easy to understand. The suggestions for interventions tested by caregivers was definitely a plus. The ideas for using the training materials assists the trainer in developing their own presentations. I found it useable and informative”.

Julie Gelo, LPN
Background in chemical dependency
Birth, adopt and foster parent of seven children affected by alcohol in utero
Family Resource Advocate for the FAS Diagnostic and Prevention Clinic
University of Washington
Seattle, WA



Necessary Information For Trainers

This is an advanced training manual for professional and paraprofessional trainers who want to expand their knowledge of the possible effects of alcohol on the fetus. Trainers who use this manual will be able to develop presentations for various types of audiences, i.e., parents, teachers, social service professionals, medical and treatment providers, as well as community groups. The manual contains modules that discuss seven major topics related to the effects of alcohol on the fetus. Each module includes training content ideas and suggested training materials and other resources related to the theme of the module. An extensive list of resources is found in the Bibliography of Resources section. Modules may be selected according to variables listed below.

New nomenclature continues to be challenging for trainers in the field of fetal alcohol syndrome (FAS). Even with the diagnosis of FAS, it is difficult to understand how the brain is affected by alcohol. Each person presents the results of the brain damage uniquely. The behavior of someone who does not exhibit the physical characteristics of FAS may be more affected than someone with FAS or vice versa. FAS, and particularly fetal alcohol effects (FAE), fetal alcohol related conditions (FARC), alcohol-related neurodevelopmental disorder (ARND), and other labels attempting to address the affects of alcohol in utero can be misleading and confusing. Therefore, this manual will refer to children and adults affected by alcohol in utero as just that. FAS is a medical diagnosis and will be referred to as such. Alcohol effects on the fetus that do not result in the diagnosis of FAS may be referred to as related conditions.

The design of this curriculum and the concept of the training modules are based on the belief that the best trainers:

- are passionate about their subject.
- have current knowledge of FAS diagnosis, prevention and intervention strategies.
- have had personal or professional experiences which give them anecdotal information that brings the subject to life.
- are able to update their teaching materials as new information becomes available.
- enjoy and are comfortable speaking to groups as a trainer.
- can organize presentations based on the needs of their audiences.
- allow their personalities to guide their training style.



The modules are not scripted. However, if you as a trainer work better with an outline or a script, you will be able to develop one with information provided in this manual. To be most effective, trainers should be familiar with the contents of the Bibliography of Resources section of the manual and you are encouraged to read as many of the listings as possible. As you become more knowledgeable and experienced, you will develop much of your own material. Information in the field is constantly being updated, so you will have to change your curriculum to include new and/or revised information.

Variables for you to consider in order to develop relevant trainings for teachers, medical providers, criminal justice workers, parents, social workers and other audiences include:

- Who is requesting a training
- The needs and goals of your audience
- Their level of knowledge about the effects of alcohol on the fetus
- Which training materials are appropriate
- The amount of time allowed for your presentation
- The training setting

A description of how the training modules are formatted and suggestions for their use, appears in the Module Organization section.

Many good curricula have been developed for specific purposes and audiences. They are listed in the Training Materials section of each module and/or the Bibliography of Resources section.

Thank you for your passion and desire to educate people about this very important subject. My final advice to trainers is to be you, be creative and have fun!



Table of Contents

Acknowledgments	i
Necessary Information For Trainers	iii
Table of Contents	v
Module Organization	vii

Modules

I. History of Alcohol Related Birth Defects	1
II. Alcohol Ingestion and the Possible Effects on the Fetus	7
III. Central Nervous System (CNS) Dysfunction: Cognitive and Behavioral Characteristics	20
IV. Early Identification and Referral for Diagnosis	32
V. Interventions for Children and Adults Affected by Alcohol in Utero..	45
VI. Alcohol and Society	82
VII. Prevention	89



Table of Contents (cont)

Appendix I

Behavioral Interventions for Working with Chemical Abusing and Dependent Mothers	110
---	-----

Presentation Materials

Presentation Preparation.....	122
Training Request.....	125
Training Survival Kit.....	126
Presentation Evaluation.....	128
Survey Packet.....	129
Ordering Instructions.....	134
Order Form.....	135

Bibliography of Resources

Assessment/Screening	1
Facts	3
Intervention	15
Prevention.....	21

Resources

Books	22
CD ROMs	25
Curricula	26
Newsletters	29
Organizations	31
Programs.....	32
Resource Guides	33
Resource Miscellaneous	34
Videos	35
Visual Aides - Miscellaneous	39
Web Sites	40



Module Organization

Each module is organized using the following format:

Module Training Goals

Overall training goals are listed for each module.

Module Contents

Each module is subdivided into units.

Unit Goals

Each module is broken into units which cover the important topics relating to the subject of the modules. Each unit describes one or more goals outlining the learning objectives for that unit.

Training Tips

Each unit has an introduction to the key issues relating to the topic and gives suggestions for presenting the material.

Training Contents

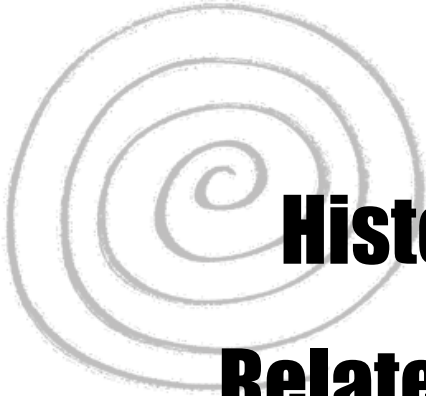
Training Contents contains a combination of facts, and anecdotal information that are important to the topic.

Training Materials

Some of the training materials available are suggested at the end of each unit of the modules. Additional resources and material descriptions may be found in the Bibliography of Resources section at the end of the manual. The numbers preceding each resource correspond to the alphabetical listings in the bibliography. Materials mentioned may include or refer to:

- books
- brochures
- curricula
- modules
- references
- video listings

MODULE I



History Of Alcohol Related Birth Defects

Module Training Goals

- To know there has been an awareness of the connection between drinking during pregnancy and fetal development for more than 2,000 years.
- To be aware of research conducted since the late 1800s.

Module Contents

Unit I	Historical References
Unit II	Early Findings and Experiments
Unit III	Recent Research Contributions



Unit 1

Historical References

Unit Goal

To know that there has been an awareness of the connection between drinking during pregnancy and fetal development for more than 2,000 years.

Training Tips

Including a discussion of the history of alcohol effects on pregnancy will be determined by the amount of time allowed for a training. This module is not pivotal to a discussion of the possible affects of alcohol on the fetus, but it will demonstrate to the audience that this is not a new phenomenon. Birth defects related to pregnancy have probably been around as long as people have been drinking alcohol.

Training Contents

1. Ancient Sparta and Carthage had laws prohibiting the use of alcohol by newly married couples in order to prevent conception during drunkenness.
2. Hundreds of years before the birth of Christ, the Greek philosopher Plato stated, "Children should not be made in bodies saturated with drunkenness; what is growing in the mother should be compact, well attached and calm."
3. In the Christian Bible, Judges 13:7, Sampson's mother is warned not to drink wine or strong drink during her pregnancy, "Behold, thou shalt conceive and bear a son: and now drink no wine or strong drink."
4. In the Middle Ages, Sir Francis Bacon warned women against using alcoholic beverages during pregnancy.
5. William Hogarth's 1751 painting depicts the devastation caused by the Gin Epidemic in England in the 1700s. Perhaps coincidentally, the child in the foreground appears to have the facial features of FAS.



Unit II

Early Findings and Experiments

Unit Goal

To learn about early theories and experiments around the use of alcohol during pregnancy relating to the characteristics of the children produced by drinking parents.

Training Tips

Birth defects resulting from alcohol have been noted by the medical community for centuries. Again, FAS is not a new phenomenon.

Training Contents

1. In 1734, during the Gin Epidemic in England, The British College of Physicians made reports to the House of Parliament suggesting that the prenatal use of alcohol was the cause of the decline in the birth rate and the increase in “weak, feeble and distempered children.”
2. In 1834, the British House of Commons Report stated that “Infants of alcoholic mothers often have a starved, shriveled and imperfect look.”¹
3. In the middle of the 19th century, a French physician, Dr. E. Lanceraux, described some of the characteristics of FAS - small head, peculiar facial features and “nervousness.”
4. In 1899, one of the first scientific studies on the effects of alcohol on the fetus occurred in an English prison. Dr. William Sullivan studied 120 female prisoners and their babies. The stillbirth rate and infant death was two and a half times higher for women who drank.



Unit III

Recent Research Contributions

Unit Goal

To be aware of research conducted since the early 1900s.

Training Tips

Research specific to birth defects related to alcohol consumption during pregnancy began in earnest in the late 60's and early 70's, mainly in France and the United States. Researchers around the world are now aware of the effects of alcohol on the unborn fetus. As people realize the consequences for the fetus caused by alcohol during pregnancy, more questions arise. As we ask more questions, the need for research increases.

Training Contents

1. It was well known that alcohol crossed the placenta for 100 years or more. However, it was thought to be safe.
2. An unpublished thesis written in the late 1950's in France reported the prenatal effects of alcohol on children born to alcoholic parents.
3. In 1968, Dr. Paul Lemoine published a study of 127 children from 69 French families in which he found that 25 of the children had the distinctive features which we now know to be related to *in utero* exposure to alcohol.
4. In 1973, Drs. Kenneth Jones Lyons and David W. Smith published their findings from Seattle and labeled the condition fetal alcohol syndrome.
5. The Lemoine, Jones and Smith reports were soon replicated in reports by Majewski and colleagues in western Germany (1976), by Dehaene and colleagues in northern France (1977), and by Olegard and colleagues in Sweden (1979). This knowledge stimulated the development of important programs in the late 1970's, designed to demonstrate methods to prevent FAS and to intervene in maternal alcohol abuse during pregnancy.²



6. In 1981, The Surgeon General recommended warnings against drinking alcoholic beverages during pregnancy or when planning pregnancy.
7. In 1988, Public Law 100-690, a federal law labeling alcoholic beverages with a warning about the risk of birth defects, was enacted.
8. During the past 30 years, a great deal of research has been done regarding the effects of prenatal alcohol exposure. This research, along with Native American activism and efforts in community education, spurred interest in alcohol related birth defects. A significant turning point came in 1989. A surge of media interest in prenatal alcohol exposure and publication of the book *The Broken Cord* by Michael Dorris brought the syndrome to the public. The book records his struggle to understand and cope with his adopted son's serious developmental and behavior problems caused by exposure to alcohol *in utero*.³
9. In 1993, the American Academy of Pediatrics published a discussion of alcohol consumption during pregnancy, as well as prevention, intervention, and policy recommendations, for pediatricians.
10. The Washington State Legislature responded to lobbying from concerned parents, wishing to develop a model for helping with the perceived unmet needs of people with FAS and their families, by adopting Senate Bill #5688. The Bill became a state law in 1995.
11. Senate Bill 5688 provides the development of the statewide FAS Diagnosis and Prevention Network in Washington State. Funding was available for development, training, and data management. The sites remain responsible for finding the resources needed to cover patient care costs. All the clinics will function similarly to the clinic established at the University of Washington by Drs. Clarren and Astley.
12. The growing interest in FAS around the world is generating more interest in research and services. In September of 1996, in Seattle, Washington, Dr. Ann Streissguth presented her research on secondary disabilities in FAS at a conference attended by people from six countries and 37 states including Alaska.
13. As we become aware of the scope of the effects on the individual, and society (i.e., educational, social service and legal systems, medical and mental health issues), we see the need for more research.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

26. Carmichael Olson, PhD, H. **The effects of prenatal alcohol exposure on child development.** *Infants and Young Children 1994.*
91. Streissguth, A.P., R. LaDue and S.P. Randels. **Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians.**
99. Streissguth, Ann P. **A Long-Term Perspective of FAS.** *Alcohol Health and Research World.*

Resources/Services:

Books:

1. **Alcohol Health and Research World.** (*Journal by: National Institute on Alcohol Abuse and Alcoholism (NIAAA)*).
4. Coles, C.D. **Prenatal Alcohol and Human Development. Development of the Central Nervous System: Effects of Alcohol and Opiates.**
6. Dorris, Michael. **The Broken Cord.** Harper & Row, New York. 1989

Resource Guides:

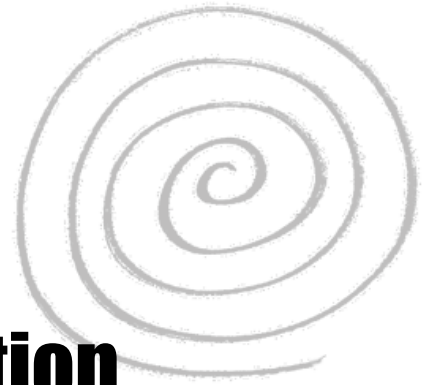
7. **Washington State Fetal Alcohol Resource Guide: Tools for Prevention and Information.**

¹Wegmann, Colfax, Gray & Reed. *Taken from the Assessment and Resource Guide for FAS/FAE.* Pen Print, Inc. Port Angeles, WA 1995.

² Streissguth, A.P. 1994. A Long-Term Perspective of FAS. *Alcohol Health & Research World Vol. 18, No. 1, 1994: 74-81.*

³Dorris, Michael. *The Broken Cord.* New York, Harper & Row, 1989.

MODULE II



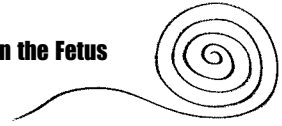
Alcohol Ingestion and the Possible Effects on the Fetus

Module Training Goals

- To understand that there is no known safe amount of alcohol consumption during pregnancy by understanding the following:
 - alcohol as a teratogen
 - route of ingestion
 - dose
- To understand how fetal development is affected by alcohol and how prevalent FAS and related conditions are in the population.

Module Contents

Unit I	Agent, Route of Ingestion and Dose
Unit II	The Effects of Alcohol on the Fetus
Unit II	The Father's Role



Unit I

Agent, Route of Ingestion and Dose

Unit Goals

- To learn that alcohol has a teratogenic effect on the fetus.
- To understand how alcohol reaches the fetus.
- To know that there is no safe amount or timing of alcohol consumption during pregnancy.

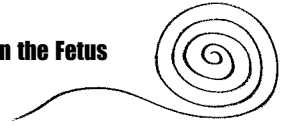
Training Tips

It is important for the audience to understand the organic effects of alcohol on the fetus. This is not a birth defect that can be “fixed”. Discussing the physical damage to the fetus will bring home the importance of not drinking at any time during the pregnancy. It is also an opportunity to emphasize the importance of planned pregnancies.

Training Contents

Agent

- I. Alcohol is a teratogen (environmental cause of birth defects). In lay terms, alcohol can cause physical damage to the embryo and/or fetus resulting in organic brain damage. Central nervous system damage can also result in or lead to behavior and learning problems. In some cases, growth deficiencies, specific facial abnormalities and malformations of organs like the heart or kidneys are also present.



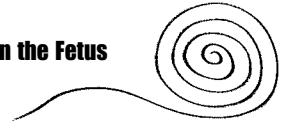
2. Alcohol reaches the embryo and fetus by passing through the mother's blood, crossing the placenta and entering the embryo fetal blood stream. It can then pass into all developing tissues.

Route

1. Alcohol passes easily through the placenta. Autopsies of stillborn babies born to women using alcohol prior to delivery have shown that the amount of alcohol in the fetus's blood is the same or slightly higher than the mother's.
2. Alcohol may also be transmitted to the baby during breast feeding.¹ Because the central nervous system and some of the organs are not fully developed at birth, women should not drink alcohol while breast feeding. Many women have reported that they are still being told to have a beer to assist in beginning the flow of breast milk. This is not good advice!

Dose

1. It is impossible to state with absolute assurance that any amount of alcohol consumed during pregnancy will not damage the fetus. The only statement which can be made with complete accuracy is "zero exposure equals zero risk." Therefore, drinking should be discouraged at any point during the pregnancy.
2. Research shows that the more a pregnant mother drinks the more at risk the fetus is for some kind of damage which could lead to an alcohol-related diagnosis such as FAS.
3. An ounce of alcohol is an ounce of alcohol, regardless of the type of alcoholic drink consumed. Many people believe that drinking wine or beer is less harmful to the fetus than hard liquor. Alcohol can be teratogenic whether it is in a bottle of beer, a glass of wine, a wine cooler or hard liquor. A five ounce glass of wine, a nine-ounce wine cooler, one and 1/2 ounces of liquor or two cordials all contain approximately the same amount of alcohol (0.6 ounces). The equation for alcohol content in beer is not as consistent. Most beers contain 6% alcohol, so a twelve ounce can has 0.7 ounces of alcohol, about the same as a mixed drink of hard liquor. Some beer, however, contains twice the amount of alcohol as other beer, i.e. malt liquors. In any event, alcohol is alcohol is alcohol! See Module VII: *Alcohol and Society*, for more information.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Assessment/Screening:

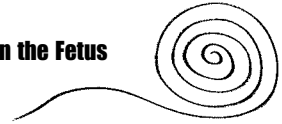
1. Astley, S. and Clarren, S.K. **A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome.** *Journal of Pediatrics*. 129: p33-41. 1996. (FASRES: 262)

Facts:

12. Anderson, P.O. **Drug use during breast-feeding.**
34. Clarren, K. and Smith, D.W. **The Fetal Alcohol Syndrome.**
108. Wall, RN, Ginna. **Breastfeeding: Is it OK for Women Who Consume Illicit Drugs?**

Modules:

Module VI: *Alcohol, and Society*



Unit II

The Effects of Alcohol on the Fetus

Unit Goals

- To understand alcohol's impact on the fetus by studying the effects on the following areas of fetal development:
 - a. Growth
 - b. Facial features
 - c. Central nervous system
- Estimated prevalence of FAS in the population.

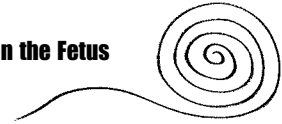
Training Tips

This unit should be included in every presentation, or at least reviewed for more advanced trainings. Here is an opportunity to emphasize the impact of alcohol on the brain, whether the diagnosis is FAS or a related condition. Many people feel that FAS is “worse” than a related condition. Because of the inability to predict the brain damage caused by alcohol, this is not true. In fact, someone who has suffered brain damage as a result of exposure to alcohol during pregnancy and does not have the physical characteristics of FAS may have a more difficult time finding services and acceptance than someone with a visible disability.

Training Contents

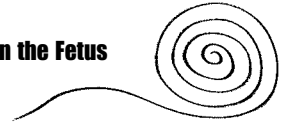
Alcohol and the Fetus

- I. Alcohol damage to the fetus can result in fetal alcohol syndrome which is a combination of growth deficiencies, facial abnormalities and central nervous system damage.²



2. Individuals **may** have evidence of organic brain damage such as structural problems like a small head (microcephaly), neurologic problems (like seizures), mental retardation or patterns of dysfunction on batteries of psychometric tests. These problems can lead to learning and behavior problems. When these types of problems are associated with a positive history of substantial alcohol exposure during gestation but without the physical characteristics of FAS (growth deficiency and the complete cluster of facial anomalies), fetal alcohol effect or fetal alcohol related conditions or other similar terms have been applied.³
3. It is believed that the metabolism of the mother has some impact on whether or not the fetus will be damaged by alcohol consumption. Genetic susceptibility is another factor in each fetus which may explain variability in outcomes. Dizygotic (fraternal) twins exposed to equal amounts of alcohol can be differently affected at birth and show different degrees of later impairment. Monozygotic twins are much more likely to be similarly affected by gestational alcohol exposure.⁴
4. To date, research shows that only alcohol consumption during pregnancy can cause FAS. Many people are concerned that their drinking prior to conception will put the fetus at risk for FAS or a related condition. This is not true. FAS and related conditions are completely preventable. This is an opportunity to emphasize the importance of planning pregnancy *and* not drinking after conception.
5. FAS is a specific medical diagnosis.
6. Cell division begins immediately after the egg is fertilized. Therefore, alcohol consumption in the early stages of cell division could be a critical factor to the healthy production of cells as the embryo develops.
 - a. **Growth**

Based on current knowledge, growth is more affected during the last trimester than any other time during the pregnancy. Although alcohol consumption at any point in the pregnancy can put a fetus at risk for growth deficiencies, a woman who drinks moderately to heavily during the third trimester is even more at risk of having a child with growth deficiencies.



b. Facial Development

Refer people to a fetal development chart. Using the chart, ask the audience whether a woman who does *not* drink in her first trimester will have a child with FAS. The answer is no. The face is fully developed by the tenth week. There may be minor anomalies, but not the cluster needed for a diagnosis of FAS. Intermittent and binge drinking can contribute to related conditions.

c. Central Nervous System

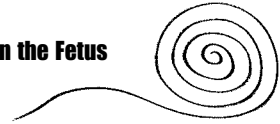
The central nervous system can be damaged at any time during the pregnancy as it is one of the first systems to form after conception and is still developing after birth. Module III: *Central Nervous System Dysfunction*, for behaviors and Module V: *Interventions For Children And Adults Affected By Alcohol In Utero*, for interventions.

There is no known test to tell us what part of the brain is damaged by alcohol when it occurs. All parts of the brain are at risk for damage.

Alcohol is a neurobehavioral teratogen which can damage brain cells. Children may have developmental delays, intellectual deficits, academic and behavioral problems as a result of exposure to alcohol during pregnancy.

Prevalence

1. There is no indication that the gender of the fetus plays a role in the incidence of FAS or related conditions in the general population. No research to date documents that the risk of FAS or related conditions is associated with race alone.
2. The national incidence of FAS is 1 to 3 per 1,000 live births. Current studies show that related conditions are thought to far exceed the incidence of FAS.



Training Materials

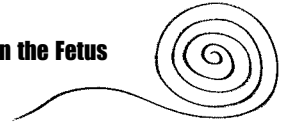
There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Assessment/Screening:

2. Astley, S. and Clarren, S.K. **Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: The Four-Digit Diagnostic Code.** 2nd Edition, University of Washington Press, Seattle, WA 1999.

Facts:

12. Anderson, P.O. **Drug use during breast-feeding.**
14. Author Unknown. **Brain Development and Brain Injury.**
27. Chasnoff, I.J. **Fetal alcohol syndrome in twin pregnancy.**
34. Clarren, K. and Smith, D.W. **The Fetal Alcohol Syndrome.**
48. Hogan, Brigid L.M. and Barnes, Joseph. **The Instruction Manual for Making an Embryo: How does Alcohol Affect Embryonic Development.**
71. NOFAS. **Fetal Alcohol Syndrome Fact Sheet.**
74. Oscar-Berman, Marlene. **Alcoholism and Asymmetries of Brain Function.**
85. Russel, M., Czarnecki, D.M., Cowan, R., et al. **Measures of maternal alcohol use as predictors of development in early childhood.**
90. Streissguth, A.P. and Dehaene, P. **Fetal Alcohol Syndrome in Twins of Alcoholic Mothers: Concordance of Diagnosis and IQ.**
108. Wall, RN, Ginna. **Breastfeeding: Is it OK for Women Who Consume Illicit Drugs?**



Modules:

- Module III: *Central Nervous System (CNS) Dysfunction - Cognitive and Behavioral Characteristics*
- Module IV: *Early Identification and Referral for Diagnosis, for information about the characteristics of FAS and related conditions.*
- Module V: *Interventions For Children And Adults Affected by Alcohol in Utero*

Resources/Services:

Books:

6. Dorris, Michael. **The Broken Cord.**
10. Kleinfeld, Judith and Siobhan Wescott. **Fantastic Antoine Succeeds!**
11. Kleinfeld, Judith and Siobhan Wescott. **Antoine Grows Up**

Organizations:

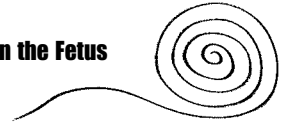
4. March of Dimes Birth Defects Foundation.

Visual Aides - Miscellaneous:

2. Healthy Mothers, Healthy Babies Coalition of Washington. **Brain Poster.**

Videos:

6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
11. **Mary's Choice.**
15. **Preventing F.A.S.**
19. **What is FAS?**



Unit III

The Fathers Role

Unit Goals

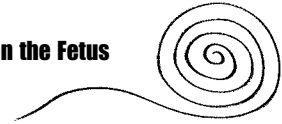
- To learn what is known about the father's role in pregnancy
- The importance of sobriety for both parents.
- The importance of family planning.

Training Tips

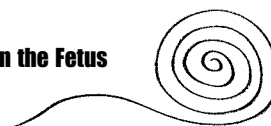
Although there is little research related to alcohol abuse and sperm, the trainer can emphasize the importance of the male's role in supporting an alcohol free pregnancy for both parents. Planning a healthy pregnancy is the responsibility of both parents.

Training Contents

1. FAS occurs after fertilization and is not caused by sperm. Only maternal alcohol use in gestation can cause FAS.
2. There is little research on the effect drinking has on the egg or the sperm. To date, research in rodents suggests that a drinking father can contribute to low birth weight which may cause death, growth deficiencies, failure to thrive, and mental retardation.
3. The March of Dimes reports that some researchers now suspect reproduction and fetal development may be affected even if a biological father has been exposed to certain lifestyle or occupational hazards. The "macho sperm" theory—that damaged sperm could not fertilize an egg—has been dispelled by research that shows sperm are vulnerable and that even when damaged, they may still fertilize an egg. Dad's diet, habits, and lifestyle can play a part in how healthy a baby will be. But no evidence on alcohol specifically is available.



4. Diane Malbin reports in the notes from “Coming Together to Meet the Challenges of FAS/NAS” conference in Vancouver, BC, November 1996, that in the absence of maternal use of alcohol or other substances the following characteristics have been scientifically observed as outcomes of paternal drinking or using substances prior to conception: low birth weight (Little, Sing, NEJM 314 1986) and neurophysiological alterations in sons of alcoholic fathers and abstinent mothers. Impaired cognitive skills, greater likelihood of hyperactivity (Hegedus 1994, Tartar, 1989).
5. Ms. Malbin also cited the following research: changes in behavior of offspring-i.e., sons of alcoholic fathers (Abel, 1988); abnormal EEGs (Bergleiter and Projesz, 1988); low count and altered structure of sperm may be related to spontaneous abortion. (Joffe and Soyka, 1982); paternal alcohol exposure resulted in offspring with decreased activity and testosterone levels (Abel and Lee, 1988); cocaine attaches to sperm prior to conception (Yazigi et al, JAMA 166, 1991); and possible intergenerational/genetic effects (Friedler, AHRW 1990). She also reported lower rates of pregnancies, increased rates of preterm fetal mortality, sons were less fertile, and had higher rates of fetal deaths in their offspring.
6. Use this unit as an opportunity to emphasize the importance of planning for pregnancy to insure a healthy baby. A strong support system through the family structure results in healthier, happier children whether or not they are affected by alcohol in utero.
7. The father’s support of the mother is key to her sobriety. See Module VII: *Alcohol and Society*, for information on women and alcohol abuse and the role of her partner. Appendix I: *Behavioral Interventions for Working with Chemically Abusing and Dependent Mothers*, gives ideas on interventions for the mother that involve her partner.

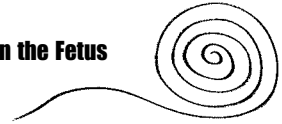


Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module.

Facts:

2. Abel EL. **Paternal and maternal alcohol consumption: effects on offspring in two strains of rats.** Alcohol Clin Exper Res 1989 Aug;13(4):533-41 (ADAJ jl).
3. Abel EL. **Paternal alcohol consumption affects grooming response in rat offspring.** Alcohol 1991 Jan-Feb;8(1):21-3 (ADAJ jl).
4. Abel EL. **Paternal exposure to alcohol.** In: Sonderegger TB (ed.) PERINATAL SUBSTANCE ABUSE : RESEARCH FINDINGS AND CLINICAL IMPLICATIONS. Baltimore : The Johns Hopkins University Press, 1992, pp.132-160 (ADAJ bk) Call No: RG 627.6 D79 P443 1992.
5. Abel EL. **Effects of physostigmine on male offspring sired by alcohol-treated fathers.** Alcohol Clin Exp Res 1994 Jun;18(3):648-52 (ADAJ jl).
6. Abel EL. **A surprising effect of paternal alcohol treatment on rat fetuses.** Alcohol 1995 Jan-Feb;12(1):1-6 (ADAJ jl).
7. Abel EL, Hazlett LS, Berk RS, Mutchnick MG. **Neuroimmunotoxic effects in offspring of paternal alcohol consumption.** Prog Clin Biol Res 1990;325:47-55. (ADAJ bk) Call No: RA 644 A25 A369 1989.
8. Abel EL, Lee JA. **Paternal alcohol exposure affects offspring behavior but not body or organ weights in mice.** Alcoholism (NY) 1988 Jun;12(3):349-55 (ADAJ jl).
9. Abel EL, Moore C. **Effects of paternal alcohol consumption in mice.** Alcoholism (NY) 1987 Dec;11(6):533-5 (ADAJ jl).
28. Cicero, T.J. **Effects of paternal exposure to alcohol on offspring development.**



Resources/Services:

Videos:

6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
15. **Preventing F.A.S.**
19. **What is FAS?**

¹Anderson, P.O. Drug use during breast-feeding. *Clinical Pharmacy*, 10:p594-624. 1991.

Wall RN, Gina. Breastfeeding: Is it OK for Women Who Consume Illicit Drugs? *Handout by MOMS Project*, Seattle, WA. 1994.

²See Module IV, *Early Identification and Referral for Diagnosis* for characteristic facial anomalies and growth deficiencies, and a list of overheads, and other materials to assist people in recognizing FAS.

³See Module III, *Central Nervous System (CNS) Dysfunction - Cognitive and Behavioral Characteristics*, for information on organic brain damage and its consequences and training materials which describe and/or show examples of behavior related to FAS and related conditions.

⁴Streissguth, A. P., Ph.d and Little, R.E., Sc.D., Unit 5, Alcohol, Pregnancy, and The Fetal Alcohol Syndrome, Second Edition.

MODULE III

Central Nervous System (CNS) Dysfunction



Cognitive And Behavioral Characteristics

Module Training Goals

- To understand the organicity of central nervous system damage to the fetus as a result of alcohol exposure in utero.
- To recognize the behaviors associated with exposure to alcohol *in utero* at different stages of an individual's development.

Module Contents

Unit I Organic Brain Damage

Unit II Cognitive and Behavioral Characteristics



Unit 1

Organic Brain Damage

Unit Goal

To recognize the brain damage caused by alcohol exposure in utero as organic in origin.

Training Tips

It is important to recognize the physical damage caused by alcohol to the central nervous system (CNS). Many care givers 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 care givers and the person affected by alcohol in utero. Here is an opportunity to stress the difference between these diagnoses. The difference is minimized by the reality that someone who looks “OK” can 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.

Training Contents

1. Alcohol is a teratogen, which means that the embryo or fetus can suffer birth defects when exposed to alcohol.
2. “As many studies of alcohol teratogenesis have demonstrated, the brain is the most vulnerable organ in the body to the effects of prenatal alcohol exposure.”¹
3. “...perinatal exposure to alcohol produces a variety of damaging morphological alterations in the developing brain. ...damage can occur both in the form of developmental delays and in permanent anomalies...consider the likelihood that developing neurons exhibit variations in susceptibility to the adverse effects of alcohol as a consequence of the timing of the alcohol insult.”²
4. “Death in children with FAS has been due to severe cardiac or central nervous system (CNS) problems.”³



5. One indication of central nervous system damage is microcephaly or a small head, usually below the 10th percentile. When the head is small, the brain is small, which increases the risk for mental retardation.
6. Another possible birth defect associated with FAS in some people is hydrocephalus, an abnormal accumulation of cerebrospinal fluid causing the brain and the skull to enlarge, sometimes called “water on the brain.”⁴
7. About half of the people with fetal alcohol syndrome are not considered mentally retarded by virtue of an I.Q. above 70. The reported I.Q. range is somewhere around 30 to 130. The Full Scale I.Q. average for people with FAS is around 74. Their Verbal I.Q. scores are around 77 and the Perceptual I.Q. is around 76, according to the FAS Diagnostic and Prevention Clinic at the University of Washington.
8. Extreme abuse of alcohol during pregnancy can cause holes in the brain. The absence of large parts of the brain is called anencephaly. Life is usually not sustainable in this situation.
9. Abnormal cysts or cavities in the brain can be a result of alcohol abuse during pregnancy. MRI's have shown areas of the brain that are completely missing in functioning individuals with FAS.
10. Not all brain damage is detectable with current imaging technologies. The lesions may be at a chemical or microcellular level.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

16. Berg, S., Kinsey, K., Lutke, J. and Wheway, D. **A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects.**
30. Clarren, S.K. **Neuropathology in Fetal Alcohol Syndrome.**
99. Streissguth, Ann P. **A Long-Term Perspective of FAS.**
111. West and Pierce. **Alcohol and Brain Development. Perinatal Alcohol Exposure and Neuronal Damage.**

Resources/Services:

Curricula:

2. FAS/E Support Network (Berg, Kinsey, Lutke, Wheway). **FASNET Assessment Tools.**
5. Kuerschner, M.S., Suzie. **Fetal Alcohol Syndrome/Fetal Alcohol Effect: BEYOND THE GLOOM AND DOOM.**
6. Kuerschner, MS, Suzie. **The Native American Family Resource Curriculum Guide.**
14. The FAS Family Resource Institute. **The FAS Family Resource Institute Packet.**
16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**



Unit II

Cognitive and Behavioral Characteristics

Unit Goal

To recognize the cognitive and behavioral characteristics associated with exposure to alcohol in utero at different stages of an individual's development.

Training Tips

Behavior drives care givers to seek a diagnosis. After the diagnosis of FAS or a related condition they are left with the reality of the central nervous system (CNS) damage, which presents as behaviors that usually cause a variety of concerns and problems for everyone involved. An understanding of child development is key in assessing behavior. The trainer can focus on a specific age group depending on the needs of the audience. "Real life" examples are very effective in demonstrating cognitive and behavioral characteristics associated with FAS and related conditions. Members of the audience may also have stories that will demonstrate the behaviors you are describing.

Training Contents

General

- I. Alcohol is a behavioral teratogen, meaning that the effects of alcohol on the development of the central nervous system can "be expressed through deficits in cognition, arousal and attention, fine and gross motor control, auditory processing, language sequencing, expressive versus receptive abilities and social and emotional development."⁵



2. At this point in time, we do not have a comprehensive list of behaviors associated with alcohol exposure. This is impossible because the range of effects and the severity is spread over a large continuum of alcohol exposure. We do not know which part of the central nervous system is damaged at what particular time. However, there are a cluster of behaviors that are beginning to emerge that may signal central nervous system damage from alcohol exposure in utero.
3. Signs of CNS damage, such as a small head, developmental delays, hyperactivity, problems with attention or learning, intellectual deficits or seizures change in form over the course of development and are expressed among affected individuals in many different ways.⁶
4. IQ is only one measure of brain processing and ability. People can have serious organic brain damage and have normal or even above average IQ's.
5. People with organic brain damage have positive behaviors and strengths. Module V: *Interventions for Children and Adults Affected by Alcohol in Utero*, will discuss these strengths and opportunities for affected people to improve their outcomes based on consistent interventions in structured environments.
6. More than anything else, fetal alcohol related conditions are a neurological contributor to social and adaptive living skills retardation.⁷

Infancy - birth to 5 years

1. Infants are often irritable and do not respond to holding and rocking. Frequently, unless there has been polydrug involvement, these infants have low tone and are floppy, with poor spacial awareness, resulting in a failure to cross midline and a failure to meet normal developmental milestones for sitting, crawling (may even bypass) and walking.⁸ Care givers have reported success with swaddling. Native American programs, as well as some hospitals, are promoting cradle boards and swinging the infant in a hammock or a device that mimics this motion. Rocking back and forth with the infant on your shoulder or in a rocking chair may aggravate the child.
2. Poor sucking reflex is an issue often reported by hospital nurseries and care givers. Nursing is advisable for increased immunization and bonding. There are also implications for problems with fine motor development in the future as well as bonding issues. If women cannot stop drinking, perhaps pumping their breast milk when alcohol is not in their system is advisable.



3. The following are some of the issues and concerns associated with FAS and related conditions during the first five years of the affected child's life as reported by Dr. Robin LaDue: poor habituation, sleep disturbances, failure to thrive, difficulty following directions.
4. Affected children are often seen as affectionate, in spite of aberrant bonding patterns. They can also be social, happy and gregarious. These are qualities we tend to reward in young children. Behavior not appropriate to their developmental stage is more often detected in school where teachers can compare the affected child's behavior with other children in that developmental stage or age group.
5. Complex speech development is often slow, and the child may have much less in-depth language than peers. Problems with word meanings and sentence structure show up early, and anomia (the inability to find the word you need - "tip of the tongue feeling") is common.⁹ Again, primary language deficit occurs as a result of the discrepancy between expressive and receptive language skills. Echolalic patterns may begin to emerge in the pre-school years. Even though children can repeat (echo) what has been said, they may not be able to process the information and "understand" what the words mean.¹⁰
6. During the preschool period, behavioral effects are usually more apparent than are cognitive deficits.¹¹ Suzie Kuerschner, FAS educator/consultant, has noted consistent cognitive difficulties in some preschoolers including difficulty with preschooler's ability to identify and retrieve attributes of color, rote counting, and letter recognition.
7. Lack of physical boundaries and overly friendly behavior can be overlooked as "cute". However, this can be dangerous for the child and/or tiresome for care givers and parents. Inability to recognize who is safe and familiar and who is not can be cause for concern.

Childhood - 6 to 11 years

1. Verbal behavior and rote language skills are often less affected than areas requiring abstract thinking (math) or memory. These are often not fully detected until children enter the 3rd and 4th grade where they are required to use abstract concepts for math and story problem solutions.



2. As Streissguth, et al. (1989 a,c) reported, binge and heavy drinking patterns (more than 5 drinks per occasion) were associated with a variety of deficits in cognitive functioning at 7 years.
3. Dr. Robin LaDue has identified some of the issues and concerns associated with FAS and related conditions during what she calls the “latency period,” 6 - 11 years. Children in this age range are easily influenced and have difficulty predicting and/or understanding consequences. They give an appearance of capability without actual abilities.
4. There is an excellent discussion of the significant social and behavioral problems that children with FAS and related conditions begin to encounter during this period in A Layman’s Guide to FAS/E. “During this stage a pattern of vulnerability to environment, both physical and peer, results in an affect that could be behavioral echolalia which extends into adolescence and adulthood.”¹²
5. The combination of academic deficits and behavioral and social problems that begin to emerge at this point can be a recipe for disaster in adolescence.

Adolescence - 12 to 17 years

1. The following are some of the issues and concerns associated with FAS and related conditions between 12 and 17 years: behavior we interpret as lying, stealing and passivity to requests, low motivation, self-esteem and depression.
2. The happy young child may as an adolescent become depressed and sometimes hostile, aggressive, or withdrawn. This is not likely due to a change in the organicity of the brain damage but is rather prompted by misunderstanding, isolation, rejection and for many, chaotic lifestyles, as well as hormonal changes.
3. Puberty, learning and behavior problems, impulsivity, the inability to connect action and consequence, inappropriate sexual behavior and the potential for victimization and exploitation, put adolescents with brain damage at risk for rejection, isolation and in worse cases, incarceration.



4. Again the expressive/receptive discrepancy and the fact that the adolescent with FAS or related conditions can talk “better” than they can think causes misinterpretation of their behavior in many instances. Parents report that children can repeat back the rule, even tell what might happen if it is broken, and then break it one minute later. When they are reprimanded, they don’t understand why the parent is so upset.
5. Our legal system is based on our ability to connect action and consequence and to predict what will happen next. Many teenagers with FAS or related conditions have put themselves or others in danger without truly understanding the outcome of their actions. Here is an example of a child’s inability to predict danger from the video, “Fetal Alcohol Syndrome and Effects, Stories of Health and Hope”. A father and his daughter were sledding. The father alerted his daughter of an oncoming truck which would intersect her ride down the hill. She assured her father that she saw the oncoming vehicle and agreed that she would wait until it passed to come down the hill. She slid under the truck and when the astounded father could speak, he asked her if she had seen the truck. Her reply was, yes, but she didn’t know it would go there. Her ability to predict what would happen next was compromised.

Adulthood - 18+

1. The following are some of the issues and concerns in adulthood associated with FAS and related conditions according to Dr. Robin LaDue (18+ years): residential placement, depression, pregnancy/fathering a child, unpredictable behavior.
2. This population’s cognitive and behavioral characteristics may propel some affected adults into the correctional system. Interestingly, once incarcerated, for some the structure provided within the correctional setting often provides relief and results in little motivation to leave.¹³
3. Other affected adults can hold down jobs for many years, graduate from high school and even college, and have successful relationships. These adults have usually had early interventions, a strong support network and a great deal of supervision and advocacy in areas that may trouble them, i.e. managing finances, appropriate friends, etc.
4. Many adults are thought to be “bad”, or lazy, or manipulative. The truth is that they appear more capable than they are and are operating at a level well below their age group.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

16. Berg, S., Kinsey, K., Lutke, J. and Wheway, D. **A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects.**
25. Carmichael Olson, H., Sampson, P.D., Barr, H., et al. **Prenatal exposure to alcohol and school problems in late childhood: A longitudinal prospective study.**
26. Carmichael Olson, PhD, H. **The effects of prenatal alcohol exposure on child development.**
37. Coles, C.D., Raskind-Hood, C.L. et al. **A comparison of information processing in children with fetal alcohol effects and attention deficit condition.**
53. Kodituwakku, P.W., Handmaker, N.S. et al. **Specific impairments in self-regulation in children exposed to alcohol prenatally.**
69. Morse, Ph.D., Barbara A. **Understanding the Behavioral Conditions of FAS. Unpublished(?)**.
91. Streissguth, A.P., R. LaDue and S.P. Randels. **Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians.**
92. Streissguth, A.P., Barr, H., Kogan, J. and Brookstein, F.L. **Understanding occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects. Final Report.**
94. Streissguth, A.P., et al. **Fetal Alcohol Syndrome in Adolescents and Adults.**
95. Streissguth, A.P., K. Kopera-Frye and H.M. Barr. **Primary and Secondary Disabilities in Patients with FAS.**



100. Streissguth, Ann P. **The Behavioral Teratology of Alcohol: Performance, Behavioral, and Intellectual Deficits in Prenatally Exposed Children.**
103. Streissguth, Ann P. and Carole T. Guinta. **Patients with Fetal Alcohol Syndrome and their Caretakers.**
108. Wall, RN, Ginna. **Breastfeeding: Is it OK for Women Who Consume Illicit Drugs?**

Modules:

Module V: *Interventions for Children and Adults Affected by Alcohol in Utero*

Resources/Services:

Books:

4. Coles, C.D. **Prenatal Alcohol Exposure and Human Development. Development of the Central Nervous System: Effects of Alcohol and Opiates.**

Curricula:

5. Kuerschner, M.S., Suzie. **Fetal Alcohol Syndrome/Fetal Alcohol Effect: BEYOND THE GLOOM AND DOOM.**
6. Kuerschner, MS, Suzie. **The Native American Family Resource Curriculum Guide.**



¹West 1986; Goodlett and West 1992; Streissguth et al. 1993, *A Long-Term Perspective of FAS*

²West (editor), 1989. Alcohol and Brain Development; with article by West and Pierce, Perinatal Alcohol Exposure and Neuronal Damage

³West (editor), 1989. Alcohol and Brain Development; with article by Clarren, Neuropathology in Fetal Alcohol Syndrome

⁴Lutke, J. 1993. A Layman's Guide to Fetal Alcohol Syndrome & possible Fetal Alcohol Effects.

⁵Vorhees, 1986. Development of the Central Nervous System, Effects of Alcohol and Opiates, edited by Miller.

⁶Carmichael Olson, Ph.D, H., 1994. The effects of prenatal alcohol exposure on child development. See *Module I Training, Unit III, footnote 3*

⁷Lutke, J. 1993. A Layman's Guide to Fetal Alcohol Syndrome & possible Fetal Alcohol Effects.

⁸Kuerschner, MS, Suzie. **The Native American Family Resource Curriculum Guide.** Curriculum, Native American Rehabilitation Assoc. of the Northwest, Inc., Gresham, OR

⁹Lutke, J. 1993. A Layman's Guide to Fetal Alcohol Syndrome & possible Fetal Alcohol Effects.

¹⁰Kuerschner, S., 1995. Juvenile Justice Conference, Warm Springs, OR.


¹¹Coles, Claire. *Prenatal Alcohol Exposure and Human Development.* In Development of the Central Nervous System; Miller, editor.

¹²Kuerschner, S., 1995. Juvenile Justice Conference, Warm Springs, OR.

¹³Kuerschner, S., 1995. Juvenile Justice Conference, Warm Springs, OR.

MODULE IV

Early Identification And Referral For Diagnosis



Module Training Goals

- Learn to establish a history of exposure to alcohol during pregnancy.
- Learn to identify physical, and behavioral characteristics indicative of the effect of alcohol on fetal development
- Identify referral resources for diagnosis

Module Contents

- Unit I** Importance of and Procedures for Establishing Prenatal Alcohol Exposure
- Unit II** Screening Tools For Medical And Health Care Providers, Parents, Nonmedical Care Givers And Other Professionals
- Unit III** Referral for Diagnosis



Unit I

Importance of and Procedures for Establishing Prenatal Alcohol Exposure

Unit Goals

- To know that a documented or substantiated history of drinking during pregnancy is extremely important to the diagnostic process. Labeling an individual without a diagnosis, also labels the mother as someone who drank during her pregnancy.
- To use assessment tools and intervention strategies that are non-judgmental, i.e. do not blame women who may not be able to control their drinking, for abusing alcohol during pregnancy.

Training Tips

Research and experience show early diagnosis is essential to successful interventions for people affected by alcohol 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 for information and ideas on approaching the subject of alcohol use during pregnancy with mothers at risk of having affected children. 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 people are diagnosed by trained professionals. Also, without diagnosis, FAS will not receive the recognition that will lead to more research and the establishment of appropriate services.



Training Contents

1. All women, including women who drink during pregnancy, want healthy babies. Blaming women will not result in a clear history of drinking during pregnancy. It takes courage and care to bring a child in for diagnosis or even begin a dialogue which may lead to a referral. It is imperative to assume a nonjudgmental attitude about women drinking during pregnancy.
2. Emphasize the disease concept of alcoholism.¹
3. Establishing a clear history of drinking during pregnancy, preferably reported by the birth mother, is an important part of the diagnostic process. On the occasion, however, that someone has all of the characteristics of FAS, without an available history of exposure, a diagnosis of FAS can be given.²
4. Diagnoses for alcohol-related birth defects of any type *must* be accompanied by a documented history of fetal alcohol exposure.
5. A history of mother's drinking may be available from medical records, family members, reports from CPS workers or other professionals. Releases may be needed for some of this information.³
6. Diagnoses resulting from alcohol exposure in utero always labels two people in a way, the mother and her child.

Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Appendix I: *Behavioral Interventions for Working with Chemically Abusing and Dependent Mothers* addresses alcohol abuse and working with at risk and drinking pregnant women. You may have information or materials that can be included in this unit. See footnotes for possible materials that can be used as well.



Assessment/Screening:

6. D'Apolito RN, Ph.D., Karen. **Illicit Drug Use During Pregnancy: Consequences for Infants, Mothers & Children.**

Facts:

49. Hughes, T.L. & Fox, M.L. **Patterns of Alcohol & Drug Use among Women: Focus on Special Populations.**
56. Landry, Mim. **Chemical Dependency: The Impaired Nurse.**
73. Normand, PhD, Claude L. **What's in a Name? Issues of Labeling and Fetal Alcohol Syndrome.**
85. Russel, M., Czarnecki, D.M., Cowan, R., et al. **Measures of maternal alcohol use as predictors of development in early childhood.**

Modules:

Module II: *Alcohol Ingestion and the Possible Effects on the Fetus*, should be reviewed in order to answer questions about the facial anomalies, growth deficiencies and central nervous system damage characterizing a diagnosis of FAS or conditions related to alcohol exposure in utero.

Module VI: *Alcohol and Society*. Understanding the use of alcohol in our society is important when working with women around alcohol related birth defects.

Prevention:

2. Kopera-Frye, Karen, et al. **Preventing FAS by Empowering Native American Chemical Dependency Counselors.**



Unit II

Screening Tools For Medical And Health Care Providers, Nonmedical Care Givers And Other Professionals

Unit Goals

- Identify facial characteristics
- Recognize growth characteristics
- Identify central nervous system damage

Training Tips

This is also a unit that should be included or referred to in all trainings. People must be reminded that they can not diagnose for FAS or other alcohol-related birth defects. They can, however, recognize the characteristics of someone effected by alcohol in utero and refer them to the appropriate professionals for diagnosis.



Training Contents

1. Emphasize that you are training people to screen for FAS and not diagnose other effects of alcohol exposure in utero. A brief introduction to the facial and growth characteristics and central nervous system damage of someone suspected to have FAS can lead to a misdiagnosis. Labeling can seriously impact their lives and those of their care givers.
2. Emphasize that only specialists trained in dysmorphology and neurodevelopmental assessment and who understand the effects of prenatal alcohol exposure are qualified to diagnose FAS. They will also be able to recognize alternative syndromes and neurodevelopmental conditions.
3. Stress that the difference between FAS and related conditions is based on the presence of a cluster of physical characteristics with FAS that are not all present in the diagnosis of related conditions.
4. Damage to the central nervous system can have a range of effects resulting in mental retardation and/or behavioral problems. The severity of the behavioral and learning problems is often similar in cases of FAS and related conditions. One is not “worse” than the other.
5. Physical and central nervous system damage from FAS and related conditions covers a large spectrum, from death to mild behavioral, emotional, physical and learning problems.
6. Many variables are considered in the diagnosis. FAS is a medical diagnosis, therefore, a trained physician (i.e. dysmorphologist, pediatrician, geneticist, etc.) must diagnose this syndrome. Ideally, input and/or testing by specialists such as speech pathologists, occupational and physical therapists, psychologists, psychiatrists, social workers, teachers, parents and care givers should also be obtained for an accurate diagnosis and understanding the patient’s specific pattern of effects and needs.
7. It may be difficult to diagnose infants with FAS because of indistinct facial features and their inability to demonstrate most aspects of cognitive delays.



8. Many children with FAS lose the physical characteristics such as growth deficiencies and facial characteristics of FAS at puberty. There have also been cases where the physical characteristics have been identified, disappeared for a number of years and then reappear in adolescence.
9. The optimum window of diagnosis is usually between the ages of four and ten.
10. Early diagnosis provides parents, care takers and others working with children affected the opportunity to create an effective environment for learning and success.

Diagnostic Criteria

Based on procedures followed for FAS diagnosis at the Diagnostic and Prevention Clinic at the University of Washington, Drs. Astley and Clarren.

Identify Facial Characteristics

1. For a diagnosis of FAS a particular cluster of minor facial characteristics is necessary. People diagnosed with central nervous system damage due to alcohol exposure in utero may have some or none of these features but not all, or none of these features.
2. The facial characteristics are a thin upper lip, the absence of a philtrum and short eye slits.
3. Asians and some Native and African Americans have epicanthal folds. Therefore, this characteristic is not part of the official diagnosis according to Drs. Astley and Clarren (see their screening guide listed at the end of the unit). Some Native Alaskan peoples naturally have short palpebral fissures (eye slits). The point to make is that unless you know the ethnicity of someone you can not assume that any of these characteristics indicate alcohol abuse during pregnancy. This is another opportunity to remind people that you must have the full complement of facial characteristics to receive the diagnosis of FAS.



Recognize Growth Deficiencies

1. Growth deficiencies may be seen at birth and in childhood. Some children reach normal weight and height for their age after puberty.
2. During diagnosis people are weighed, measured and compared to their age group. Experts determine how the outcomes relate to exposure to alcohol during pregnancy.
3. Weight and height for children and adults that are below the norm for the appropriate age group may be considered as a characteristic leading to a diagnosis of FAS.
4. Genetic makeup should be considered in the diagnosis of FAS. Someone who is below their group norm for weight and height may be within the normal range for their family.

Identify Central Nervous System Damage

1. The brain “is the most important organ that is damaged by alcohol teratogenesis. No one problem is universal. Evidence of damage may be structural, neurologic, and/or behavioral”⁴
2. The most common indicator of central nervous system damage is behavior. A set of behaviors is beginning to emerge around alcohol exposure during pregnancy. However, there is no “cookbook” recipe for identifying behavior related to conditions caused by alcohol exposure. Some of the training materials listed in this section contain screening tools which are helpful but should not be used in isolation or without training.
3. There are no two cases of alcohol exposure that are identical.
4. Many of the training materials listed in this module, discuss behaviors that are seen in many affected people. See Module III: *Central Nervous System (CNS) Dysfunction - Cognitive and Behavioral*.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Assessment/Screening:

1. Astley, S. and Clarren, S.K. **A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome.**
2. Astley, S. and Clarren, S.K. **Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: The Four-Digit Diagnostic Code.** 2nd Edition, University of Washington Press, Seattle, WA 1999.
3. Astley, S. and Clarren, S.K. **Diagnosing Fetal Alcohol Syndrome: Introducing the Four-Digit Diagnostic Code, Alcohol and Alcoholism.** 35: 400-420, 2000.
11. Wegmann, Colfax. **Diagnostic Process (relating to FAS/E).**

Facts:

13. Astley, S.J. and Clarren, S.K. **A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome.**
26. Carmichael Olson, PhD, H. **The effects of prenatal alcohol exposure on child development.**
32. Clarren, S.K. and Astley, S.J. **Critical gestational periods and threshold doses for ethanol teratogenesis.**
43. Ernhart, C.B., Green, T., Sokol, R.J. et al. **Neonatal diagnosis of fetal alcohol syndrome: not necessarily a hopeless prognosis.**
62. Malbin, Diane B. **Why bother to identify these kids? Identifying fetal alcohol syndrome and effect: Barriers and potentials.**



73. Normand, PhD, Claude L. **What's in a Name? Issues of Labeling and Fetal Alcohol Syndrome.**
87. Sampson, P., Streissguth, A., Bookstein, F., Little, R., Clarren, S., et al. **The incidence of fetal alcohol syndrome and the prevalence of alcohol-related neurodevelopmental condition.**
90. Streissguth, A.P. and Dehaene, P. **Fetal Alcohol Syndrome in Twins of Alcoholic Mothers: Concordance of Diagnosis and IQ.**
101. Streissguth, Ann P. **10 Common Misconceptions about Fetal Alcohol Syndrome and Fetal Alcohol Effects.**

Modules:

Module III: *Central Nervous System Dysfunction - Cognitive and Behavioral Characteristics*, will also give you a great deal of information and material.

Resources/Services:

Books:

4. Coles, C.D. **Prenatal Alcohol Exposure and Human Development. Development of the Central Nervous System: Effects of Alcohol and Opiates.**
9. Institute of Medicine. **Fetal Alcohol Syndrome. Diagnosis, Epidemiology, Prevention, and Treatment.**

Curricula:

16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**



Videos:

6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
11. **Mary's Choice.**
15. **Preventing F.A.S.**
19. **What is FAS?**



Unit III

Referral for FAS Diagnosis

Unit Goal

To refer identified individuals for diagnosis

Training Tips

It will be necessary for the trainer to compile a list of resources and diagnostic centers in the area. The list will likely be comprised of individuals with expertise in FAS rather than FAS diagnostic clinics. Again, emphasize that only trained professionals can diagnose, but educated individuals can refer people for diagnosis. Asking people why they feel diagnosis will be useful can bring up questions and reinforce the idea of referral. Most care givers are relieved after diagnosis to find that it wasn't "bad parenting" and the person diagnosed usually says that they knew they weren't "stupid", they just didn't know why certain things were so difficult.

Training Contents

1. Emphasize that you are training people to screen and not diagnose. Diagnosis is done by trained specialists.
2. Develop a list of people in your area who can assist in the psychological, developmental, educational and medical testing necessary for an accurate diagnosis.
3. Develop a list of people in your area who can assist in talking with birth parents and care givers about referral.⁵
4. There are few fetal alcohol syndrome diagnostic clinics in the United States. Your referral list will probably be trained physicians and other experts who can assist in diagnosis and intervention strategies.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Resources/Services:

Videos:

10. **One For My Baby.**

¹See Module VI, *Alcohol and Society*.

²PFAS (Partial fetal alcohol syndrome) or A typical fetal alcohol syndrome is a diagnosis in cases of central nervous system damage, some or no growth deficiencies, and some (90%) facial anomalies. A documented history of alcohol abuse during pregnancy is not necessary for this diagnosis; Clarren, 1995.

³See Appendix I, *Identification and Referral of At Risk and Drinking Pregnant Women in Various Settings*, for ideas on assisting women who may have abused alcohol during pregnancy with treatment and/or diagnosis.

⁴Clarren and Astley *A Screening Guide for fetal alcohol syndrome*, 2nd Edition, 1999.

⁵See appendix I, *Identification and Referral for Diagnosis and Treatment of At Risk and Drinking Pregnant Women in Various Settings*.



MODULE V

Interventions For Children And Adults Affected by Alcohol in Utero

Module Training Goals

- To learn the importance of identifying the specific needs of each child and adult with FAS or related conditions.
- To create and identify age appropriate interventions specific to each person with FAS or related conditions and apply them in various settings.
- To recognize and utilize the strengths of people with FAS and related conditions when creating interventions.
- To understand that there may be other factors influencing behavior in addition to brain damage caused by exposure to alcohol during pregnancy.

Module Contents

Unit I	Overview
Unit II	Infancy and Early Childhood
Unit III	Childhood
Unit IV	Puberty
Unit V	Adolescence
Unit VI	Adulthood



Unit I

Overview

Unit Goals

- To understand the need for individualized interventions at all ages in any setting.
- To recognize strengths which can be used to create effective interventions appropriate for each individual.
- To understand that even with the diagnosis of FAS, behaviors may not be explained totally by exposure to alcohol without considering other factors.

Training Tips

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 severe to minimal. Therefore, each person must be looked at individually when creating interventions. Everyone affected by alcohol in utero has strengths which 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. Encourage a discussion of interventions that care givers are using and finding to be successful. This stimulates conversation and allows care givers to experience themselves as effective.

Training Contents

- I. There are unique patterns of behavioral and cognitive characteristics that identify someone with the effects of alcohol exposure in utero, as discussed in Module III: *Central Nervous System Dysfunction - Cognitive and Behavioral Characteristics*. However, the neurodevelopmental damage caused by alcohol exposure in utero presents itself differently in each person, depending on the type and amount of brain damage.



2. Though the brain damage is permanent, behavior can look different at various stages in the life of someone affected by alcohol in utero. The happy, affectionate child may become the aggressive or depressed teenager.
3. Our interpretation of children's behavior becomes more critical as they grow. Our expectations may not fit the abilities of an affected child regardless of their age. The child's behavior, without appropriate interventions, has more than likely remained constant. Our expectations and our interpretation of the child's behavior have probably changed more than the child.
4. Consistency and structure should be the focus of all interventions at any age in any setting. Observation and assessment must determine the level of expectation appropriate for the individual.
5. Children and adults affected by alcohol in utero have many strengths. Direction from care givers is necessary to utilize these strengths and maximize their success.
6. Observation, consistency, creativity, patience, unconditional love and recognizing the uniqueness of each child or adult are the building blocks to successful intervention.
7. Most affected children are loving, happy, and concerned. They often enjoy music, have good visual memories and are highly verbal. These positive attributes can be utilized when developing interventions. Assess the child's strong points and build interventions that highlight their abilities.
8. The behavior associated with alcohol exposure in utero seems to have a particular "feel" to it. However, even with the diagnosis of FAS, accompanied with a documented history of alcohol abuse during pregnancy, other factors must be examined when creating interventions.
9. Contributing causes of behavior may be related to other teratogen use such as cocaine, genetic factors causing learning difficulties, mental retardation, emotional problems, environmental effects such as exposure to lead or toxins, physical abuse during pregnancy, and physical, sexual, mental and emotional abuse after birth.
10. Interventions must be developed with the idea that healing and change are possible. A child must be led to the edge of their potential without pushing them into failure because of an inability to sustain long term or total mastery of a skill as a result of brain damage caused in utero.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

16. Berg, S., Kinsey, K., Lutke, J. and Wheway D. **A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects.**
19. Burgess, D.M. & Streissguth, A.P. **Fetal Alcohol Syndrome & Fetal Alcohol Effects: Principles for Educators.**
20. Burgess, Donna M. **Educating Children Affected by Alcohol & Drugs.**
21. Burgess, Lasswell and Streissguth. **Educating Children Prenatally Exposed to Alcohol and Other Drug.**
26. Carmichael Olson, PhD, H. **The effects of prenatal alcohol exposure on child development.**
29. Clarren, S.G.B., Clarren, S.K., Astley, S.J., Shurtleff, H., et al. **A psychoeducational, neuropsychological profile in children with FAS.**
35. Clarren, Streissguth, et al. **The Positive Side of FAS/FAE.**

Interventions:

Refer to the Training Materials sections after each unit in this module for age specific interventions. Also, the Intervention section of the Bibliography of Resources lists 56 resources for information on interventions.



Resources/Services:

Books:

5. Davis, Diane. **Reaching Out to Children with FAS/FAE.**
6. Dorris, Michael. **The Broken Cord.**
8. Hannaford, Carla. **Smart Moves (Brain Gym).**
9. Institute of Medicine. **Fetal Alcohol Syndrome. Diagnosis, Epidemiology, Prevention, and Treatment.**
10. Kleinfeld, Judith and Siobhan Wescott. **Fantastic Antoine Succeeds!**
11. Kleinfeld, Judith. **Fantastic Antoine Grows Up.**
20. Wallace PhD, Rosella. **Rappin' and Rhymin': Raps, Songs, Cheers, and Smartrope Jingles for Active Learning.**

Curricula:

5. Kuerschner, M.S., Suzie. **BEYOND THE GLOOM AND DOOM.**
6. Kuerschner, MS, Suzie. **The Native American Family Resource Curriculum Guide.**
7. LaDue, Robin A. **A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions.**
14. The FAS Family Resource Institute. **The FAS Family Resource Institute Packet.**
16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**



Newsletters:

1. **FASTIMES Newsletter: Fetal Alcohol Syndrome/Adolescent Task Force Newsletter.**
4. **Growing with FAS.**

Organizations:

1. CH.A.D.D.: Children and Adults with Attention Deficit Disorders.
4. Parents Anonymous Washington State.
5. Washington State Independent Living Council (SILC).

Programs:

Check this section of the Bibliography of Resources for relevant resources.



Unit II

Infancy and Early Childhood

Unit Goal

To learn interventions for infants, toddlers and young children affected by alcohol in utero in various settings that are appropriate to their level of functioning.

Training Tips

A discussion of child development is important when considering interventions for various age groups. Infants are particularly difficult to diagnose but early intervention leads to better outcomes for children exposed to alcohol in utero. Use your audience for ideas on interventions and emphasize the fact that they do not work with every child and that creativity and persistence is the key to success.

Training Contents

A. Interventions in Care Giving Settings for Infants

The most commonly noted problems in affected infants are inconsolableness, poor feeding and sleep patterns, bonding problems, and developmental delays. Many infants, however, appear normal.

Inconsolableness

Inconsolableness is common in affected infants, as well as children whose mothers were cocaine or poly drug users. Here are some suggestions:

- I. Swaddling, rocking the infant in a hammock, keeping visual and auditory stimulation to a minimum may help. A darkened room, a blank wall, nothing in the crib and sheets that are the same neutral color can contribute to a calm environment with minimum distractions.



2. Experimentation is the key to reducing over stimulation, i.e., bouncing vertically instead of side to side, applying light, steady pressure across the chest, playing a rhythmic drum sound with a steady beat, Native American drum music, Celtic lullabies, anything with an even, repetitive rhythm.
3. Some infants can only handle stimulation from one source. Pick one interaction, such as talking to the child but not touching them, or holding and not talking. Mothers report that placing the infant on the floor and talking from a distance of two feet allows the infant to focus on the social interaction with the mother without being distracted by touch.

Feeding

Low birth weight is a component of the FAS diagnosis and is often found in cases of late gestational alcohol exposure. Feeding becomes critical to many of these babies who are not always interested in food and are difficult to feed. Here are some intervention ideas given by the mothers and care givers of affected infants:

1. Regular feeding patterns must be established and adhered to.
2. Feeding on demand is usually not successful as the infant may not *feel* hungry. One mother said that her four month old diagnosed with FAS, after eleven hours of sleep showed no interest in food until she initiated a feeding after 15 hours.
3. Over stimulation may make infants too hyper to feed. Consistently feeding in the same quiet, darkened room, holding the baby in the same position can work well.
4. Experiment with feeding positions. One mother sang while feeding to keep the baby focused. The infant may respond better if the same person administers food at each feeding.
5. Poor suck and problems with swallowing are common. The infant can suck too much and choke, and their pacing can be erratic.
6. The care giver must be relaxed in order for the infant to eat.



Sleep

Irregular sleep patterns are reported by parents and care givers from infancy through childhood. The following interventions and observations will help everyone in the family:

1. It is very important to establish specific sleep routines, i.e. consistent bed times and procedures.
2. Remove everything from the bed. Putting the child to bed with a bottle may be a problem if the infant wakes up in the night and can't find the bottle. They have programmed themselves to go to sleep with the bottle and finding it gone may confuse and irritate them.
3. Rocking the baby until drowsy but not asleep is reported to be a successful sleep routine.

Bonding

Many affected children are affectionate and loving but have trouble bonding and feeling connected to care givers.

1. As infants they may not want to be held, this can be very difficult for mothers and care givers, especially when the infant is irritable.
2. Providing continuity and a structured, nurturing, loving environment will provide the child with a sense of safety. This environment will enhance bonding.
3. Eliminate unnecessary moves. Many children placed in foster care with this diagnosis can have a very difficult time adjusting on many levels. Bonding becomes even more of an issue for them when they are moved from one home to another.

Developmental Delays

It is difficult to detect developmental delays in infants, so observation and knowledge of developmental stages are keys to successful and early intervention.

1. Seek developmental information and services as early as possible, i.e., occupational, physical and speech therapy. Pathologists, neurologists, behavioral management specialists, family support services for counseling, respite, someone to handle medication trails and other specialists may be needed.



2. Become informed about infant developmental stages in order to recognize potential problems as soon as possible. Readjust your expectations accordingly.

B. Interventions in Care Giving Settings for Toddlers and Young Children

It is important to understand developmental stages and recognize the role of the child's personality and abilities when assessing their behavior. At this stage the "honeymoon" begins to fade into the reality of raising what is beginning to be seen as a "difficult child". Observation and knowledge are key to recognizing the difference between behaviors related to an organic brain syndrome and those related to the child's normal development as an individual. Some behaviors related to organic brain damage are temper tantrums, low frustration tolerance, perseveration, difficulty with physical, emotional, mental and social transitions, fearlessness, over reacting to minor stimuli and repeating harmful behavior without an awareness of the consequences of their actions. The holistic approach of a team made up of parents, care givers, teachers, counselors, therapists, and medical providers can produce the best results. Although each intervention must be developed specifically for each child, there are practical ideas in the resource section of the manual which references the many sources drawn from in this section. Here are a few:

Behavior

1. Early identification is the most valuable intervention. Consult with other care givers and professionals who understand child development and related birth defects.
2. Developing the child's self-esteem is critical to their success. Restructure the environment to optimize their achievements by recognizing what causes them stress, i.e. too much noise, too many objects, people or directions, too much color, etc. .
3. Transitions should be discussed in simple steps. Multi-task instructions are not always understood or remembered. Break activities down into manageable sequences.
4. Repetition in conjunction with visual reminders works well.



5. Rewards must be immediate and accompanied by plenty of hugs, smiles and positive attention for appropriate behavior. Punishment is not usually effective. Stress discipline based on adhering to a structured environment and routine. Consequences must be immediate. Watch for signs of stress and redirect the child's energy into a positive activity.
6. Children affected by alcohol in utero exhibit many behaviors that we consider to be desirable in youngsters such as being friendly, eager, engaged, humorous, and talkative. Build on these strengths in your interventions.
7. Care givers must have a holistic approach to interventions. Parents, teachers, counselors, medical personnel, service providers and therapists working together to structure a consistent, positive environment based on the strengths of everyone concerned will produce positive results.

Development

There may be physical, cognitive and social delays during this stage. Early identification and diagnosis is the best intervention.

A. Possible Physical Delays

1. There may be delays in walking and talking.
2. Motor skills can be enhanced through play activities, balance, games like follow the leader and using music with a repetitive beat.
3. Fine motor development can be enhanced with wooden puzzles, legos, water and sand play, dipping and filling activities, etc.
4. Toilet training may be delayed until 4 or 5 years of age, and later before the child is trained during the night. Be diligent and patient.
5. Careful monitoring of physical development and health is necessary.

B. Possible Cognitive Delays

1. They may have difficulty following directions. Lessons need to be restructured and individualized. Break instructions down into simple steps and give them one at a time.



2. Play word games, name body parts, feelings, etc. Make it fun!
3. Most of these children are visual and will learn faster through doing and seeing.
4. Place child in front of you when giving instructions, away from distractions.
5. Close contact allows immediate reward and intervention. One-on-one is the optimum learning setting.
6. Preschool placement should meet the needs of the child. Some children need a great deal of time and attention from care givers. Placing them in large classrooms with one teacher, a room with many distractions and too many choices may be a disaster for the child and the teacher.
7. Assess the need for an occupational or physical therapist, and/or a speech therapist.
8. Limit volume of work, breaking down each task into individual steps.
9. Limit the amount of noise, interruptions, lights, toys, activities and transitions.
10. Provide regular scheduled play, learning and rest activities.
11. Alert child of transitions, providing advance notice.
12. Do not assume that the child has generalized the lesson they just learned from one environment or situation to another.

C. Possible Social Delays

1. Impulsivity can cause problems with adults and peers.
2. Hyperactivity and temper tantrums are common. Intervene before it escalates and redirect the behavior.



3. “Time out” is usually not useful for disciplining our affected children. Children are supposed to understand what they have done wrong. Incorporate the lesson into future behaviors and reward the correct behavior in the next or similar situation. This level of abstract thinking is usually difficult or even impossible for our child. One mother asks her daughter to get her body under control. The child has learned that this means to put “her body” in a chair. This is very concrete and she can calm herself. The child knows exactly what getting her “body under control” means and this phrase is also used at school or by any other care giver interacting with the child.
4. Help the child recognize feelings and integrate their feelings into everyday situations.
5. Assist the child in self-control, maintain eye contact, verbally reassure them through the behavioral problem.
6. Maintain good nutrition and rest.
7. Set the child up for success behaviorally by assessing their abilities and strengths, as well as their environment.
8. Separate the behavior from the child, reinforcing what is appropriate and assuring the child that they are always loved in spite of their behavior.
9. Close contact allows immediate reward and intervention. One-on-one is the optimum learning setting. One therapist reports that wearing very dark lipstick helps the children she works will focus on what she is saying. The message is be creative.
10. Plenty of praise, smiles and positive attention for good behavior.
11. Help them develop a sense of trust and mutual respect by listening and being consistent.
12. Encourage the child to help with chores and include them in family activities as a valued member.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

35. Clarren, Sandy. **Learning Strengths, Challenges and Solutions for Students with FAS/E.**

Interventions:

Refer to the Training Materials sections after each unit in this module for age specific interventions. Also, the Intervention section of the Bibliography of Resources lists 56 resources for information on interventions.

3. Bays, J. **The Care of Alcohol & Drug-Affected Infants.**
16. Griffith, D.R. **Caring for disorganized/low threshold infants.**
18. Kvigne, V., Struck, J. & West, T. **Education Techniques for Preschool Children with FAS/E.**
26. Maloney, S.M. **Interventions for the Drug Exposed Infant.**
50. Weiner, Lyn and Morse, Barbara A. **Facilitating development for children with fetal alcohol syndrome.**

Modules:

Module III: Central Nervous System Dysfunction - Cognitive and Behavioral Characteristics



Resources/Services:

Books:

6. Dorris, Michael. **The Broken Cord.**
10. Kleinfeld, Judith and Siobhan Wescott. **Fantastic Antoine Succeeds!**

Videos:

3. **Cocaine Kids Training Tape: New Strategies, New Solutions.**
18. **Training tapes for living with FAS and FAE: The early years, birth through age 12.**



Unit III

Childhood

Unit Goal

To understand the principals used to create individual interventions for children affected by alcohol in utero in family, social and educational settings.

Training Tips

Children's behavior at home is often "forgiven" and attributed to similar behaviors inherited or modeled by a parent or relative. When the child enters the educational system, behaviors are many times identified as problematic by teachers and not parents. The reverse can be true as well. Parents have reported that the problems they see in their children are often attributed to "bad parenting" by professionals who do not feel the child is exhibiting behavior attributable to brain damage. Cooperation between everyone involved with the child is essential to developing and implementing successful interventions. Creativity, persistence, continuity, and consistency continue to be the building blocks for success.

Training Contents

A. Interventions in Care Giving Settings for Children

The most commonly noted problems in children affected by alcohol in utero is their inability to recognize the consequences of their actions, appearing more capable than they actually are, tantrums, lying, stealing, defiance of authority, delayed physical and cognitive development, hyperactivity, memory deficits, impulsive behavior, attention difficulties, and poor comprehension of social rules and expectations. The resource section includes several listing ideas for interventions in various settings. Here are a few:

Education

- I. Develop an individual educational plan, (I.E.P.)



2. Mainstreaming provides positive role models but affected children may also need a contained learning center. Allow them to interact with all students, but develop a specialized learning program.
3. Dividing children completely sets up an “us and them” way of looking at children with special needs. In the long run, children affected by alcohol in utero need friends more than almost anything else. Learning to accept others should be part of the educational process to insure adults who have compassion for anyone seen as “different”.
4. Activities in small groups work best.
5. If something is working at home implement it at school when appropriate and vice versa.
6. Because affected students have trouble with verbal instructions and information, a multi-sensory approach to teaching which integrates visual and kinesthetic methods is ideal.
7. Repetition of instructions, review of material and using visual cues such as color coding, charts, videos and photos or drawings to refresh a child’s memory about the steps involved in a particular activity will reduce the impact of memory deficits.
8. Lack of good judgment, the inability to generalize and ineffective incidental learning can be aided by modeling and self-talk routines to stay on task
9. Reading and writing skills during the first few years may not be noticeably delayed. Students appear to be achieving quite well relative to their I.Q. scores. Teachers may have to use other tests to determine the impact of the brain damage on their ability to learn. Their ability to talk better than they think can lead to unrealistic expectations.
10. Arithmetic and other subjects requiring abstract thinking usually present more of a problem for students than reading and writing. Rappin’ and Rhymin’ features learning activities that highlight whole-brain, group activities that can be used in any setting and are fun and easy to remember.



11. Implement a functional curriculum teaching daily living skills, i.e. how to clean up after an activity.
12. Most children affected by alcohol in utero can be impulsive and distractible. Reducing the environmental stimuli will assist these children to stay on task. A second grade teacher constructed an “office” in the back of the classroom out of appliance boxes for a boy with FAS. He had spent most of his time in the hall until his mother explained the syndrome and suggested some interventions. The teacher reported that eventually the boy would announce to the class that they were too distracting, go back to his “office”, containing nothing but a desk and chair, and complete the assignment.
13. Children affected by alcohol in utero often have a high level of activity. Schedule times for appropriate movement and arrange nondistracting ways to move. A teacher put red tape around the classroom. The child could trace the tape with his finger around the room until he was calmed down. Suzie Kuerschner’s “white wall” (one blank wall in the classroom) is reported to help children refocus and calm themselves.¹
14. “A behavioral intervention such as time out relies on the ability of the person to perform the following cognitive tasks: remember a behavior, associate the consequence with it, compare one behavior to another, and predict a different outcome based on a new behavior in a different environment at some time in the future. People affected by alcohol in utero often have gaps in just the areas required for this otherwise good intervention to be effective. They have trouble storing and remembering information, forming associations, comparing and contrasting, abstracting, and predicting.”²

Social

1. Personal space begins to be a problem for children with no sense of boundaries at this stage. Use a hula hoop to visually remind them of the appropriate space needed for them and others.
2. Shake hands in greeting and good bye instead of a hug and kiss. There is an inability to differentiate between friends and strangers and they may initiate or participate in inappropriate conversation or behavior. An agreed upon signal such as holding a hand up when it is not appropriate to interrupt, telling them what they can be doing instead or simply telling them to wait can be effective as long as it is consistent.



3. Perseveration is often the cause of irritation to other people in their environment. They may simply want your attention, a drink, or something else. Behavior is a form of communication.
4. It is very important to understand that this age group can be exploited. Care givers must control the environment. Tell others what the rules are for the child and monitor interactions.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

There are several references in the Facts section of the Bibliography. Here are a few:

19. Hayne, B. **FAS Kids Respond Well to Special Strategies.** *Western Center News*, Portland, Or. 1993.20. Burgess, Lasswell and Streissguth. **Educating Children Prenatally Exposed to Alcohol and Other Drug.**
37. Coles, C.D., Raskind-Hood, C.L. et al. **A comparison of information processing in children with fetal alcohol effects and attention deficit disorder.**
52. Kleinfeld, Judith. **Fetal Alcohol Syndrome in Alaska: What the Schools Can Do.**

Interventions:

Refer to the Training Materials sections after each unit in this module for age specific interventions. Also, the Intervention section of the Bibliography of Resources lists 56 resources for information on interventions. Here are a few:

5. Blaine, K.L. **Management Interventions for the Young Child Prenatally Exposed to Drugs and Alcohol.**
6. Burgess, Donna M. **Helping Prepare Children with FAS or FAE for School and Beyond.**
11. Clarren, S. & Clarren, S.K. **Working with Children with Fetal Alcohol Syndrome and Fetal Alcohol Effects: Practical Applications for Social and School Needs.**
12. Clarren, Sandy. **Learning Strengths, Challenges and Solutions for Students with FAS/E.**



13. Clarren, Sandra G. B., Jirikowic, Tracy. **Intervention Ideas For Individuals with Prenatal Alcohol Exposure and Organic Brain Damage.** Washington State Fetal Alcohol Syndrome diagnostic and Prevention Network. Children's Hospital and Regional Medical Center, 4800 Sand Point Way N.E., CH-47, Seattle, WA 98105. (2000)
18. Hartness, C.L. **Intervention Mapping for Children Affected by Alcohol in Utero.** (2001), (360) 297-0411.
19. Hayne, B. **FAS Kids Respond Well to Special Strategies.** *Western Center News*, Portland, Or. 1993.

Modules:

Module III: Central Nervous System Dysfunction - Cognitive and Behavioral Characteristics

Resources/Services:

Books:

6. Dorris, Michael. **The Broken Cord.**
10. Kleinfeld, Judith and Siobhan Wescott. **Fantastic Antoine Succeeds!**

Curricula:

2. FAS/E Support Network (Berg, Kinsey, Lutke, Wheway). **FASNET Assessment Tools.**
5. Kuerschner, M.S., Suzie. **BEYOND THE GLOOM AND DOOM.**
6. Kuerschner, MS, Suzie. **The Native American Family Resource Curriculum Guide.**
7. LaDue, Robin A. **A Practical Native American Guide for Caregivers of Children, Adolescents, and Adults with Fetal Alcohol Syndrome and Alcohol Related Conditions.**



13. Northern Plains Native American Chemical Dependency Assoc., Inc. **FAS/FAE Curriculum for Native Americans.**
14. The FAS Family Resource Institute. **The FAS Family Resource Institute Packet.**
16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**

Videos:

18. **Training tapes for living with FAS and FAE: The early years, birth through age 12.**
20. **What's wrong with my child?**



Unit IV

Puberty

Unit Goal

To understand the problems facing adolescents related to changing expectations in the world around them in various settings.

Training Tips

Puberty is a challenging time for children and parents. Hormonal changes, possible academic struggles, feelings of failure, blame, alienation and increased expectations can cause behaviors that become more and more difficult for the child and the care givers to manage. Many children lose the physical characteristics of FAS during this time. The tendency of adults in their lives is to expect more because they appear more grown up. Their body may have caught up developmentally but the brain damage is consistent throughout their lives. A twelve year old may be operating at the level of a seven year old. Emphasize the importance of early intervention, diagnosis and the team approach to each child in each situation.

Training Contents

Contributing Factors to Changes in Attitude and Perceived Changes in Behavior of Adolescents exposed to alcohol in utero

Puberty, according to Barbara Sommer's Puberty and Adolescence³, refers more specifically to the physiological changes involved in the sexual maturation of the person. Puberty consists of a sequence of changes which occurs over a span of up to eight or nine years, described as either an event or a process. The onset of the physical and hormonal changes in children with FAS or related conditions may not follow the normal developmental curve. This and other factors should be considered when looking at interventions for children during puberty.



Several issues contribute to the perceived change in behavior of children with FAS and related conditions when they reach puberty. Hormonal changes raise issues relating to sexual behavior. Years of educational failure and social isolation begin to erode the happy, outgoing appearance of the young affected child. Depression, and aggression can cause emotional and behavioral acting out.

1. Early childhood intervention can reduce problems at this stage. The elementary school setting provides a fairly consistent environment for the affected child. The same teacher, classmates and room for a year are more stabilizing than the structure of the middle school educational system. Changing teachers, classrooms, classmates and subjects can cause the child to be overstimulated and therefore overwhelmed and confused.
2. Sex education and appropriate social behavior focusing on boundaries and safety need to be addressed.
3. STD and AIDS education using visual and tactile aids are important.



Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Facts:

There are several references in the Facts section of the Bibliography. Here are a few:

16. Berg, S., Kinsey, K., Lutke, J. and Wheway D. **A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects.**
22. Caldwell, S. **FAS Shut Down: One Parent's Perspective.**
35. Clarren, Streissguth, et al. **The Positive Side of FAS/FAE.**
37. Coles, C.D., Raskind-Hood, C.L. et al. **A comparison of information processing in children with fetal alcohol effects and attention deficit disorder.**
64. Malbin, Rathbun. **Rethinking Behaviors: Integrating Understanding of "Organic".**

Interventions:

Refer to the Training Materials sections after each unit in this module for age specific interventions. Also, the Intervention section of the Bibliography of Resources lists 54 resources for information on interventions. Here are a few:

7. Carmichael Olson, H. **Fetal Alcohol Syndrome & Fetal Alcohol Effects: A Lifespan View, with Implications for Early Intervention.**
12. Clarren, Sandy. **Learning Strengths, Challenges and Solutions for Students with FAS/E.**



13. Clarren, Sandra G. B., Jirikowic, Tracy. **Intervention Ideas For Individuals with Prenatal Alcohol Exposure and Organic Brain Damage.** Washington State Fetal Alcohol Syndrome diagnostic and Prevention Network. Children's Hospital and Regional Medical Center, 4800 Sand Point Way N.E., CH-47, Seattle, WA 98105. (2000)
19. Hayne, B. **FAS Kids Respond Well to Special Strategies.** *Western Center News*, Portland, Or. 1993.
24. Lutke, Jan. **Fetal Alcohol Syndrome/Effect and Children in the "System".**
25. Lutke, Jan. **Fetal Alcohol Syndrome/Effect: Role of FAS/E Caregivers in Relationship to Other Children in the Home.**
26. Malbin, Diane. **FAS/FAE and Traditional Behavior Modification Interventions.**
27. Malbin, Diane. **Adolescents and Young Adults with FAS/E: Tips for Success Toward Building Self-Esteem.** *FASETS: Improving the Outcome Newsletter*, Winter. 1995.
47. Turnbull, Anna. **Beach Center How To: Start Group Action Planning.** *Handout*, Beach Center on Families and Disability, Lawrence, Kansas. 913-864-7600. (1996).

Modules:

Module III: Central Nervous System Dysfunction - Cognitive and Behavioral Characteristics

Resources/Services:

Books:

6. Dorris, Michael. **The Broken Cord.**
8. Hannaford, Carla. **Smart Moves (Brain Gym).**



10. Kleinfeld, Judith and Siobhan Wescott. **Fantastic Antoine Succeeds!**
15. Lesley, Craig. **Storm Rider.** Picador USA, 175 5th Ave., New York, NY 10010 (2000).
Note: Available at B. Dalton, Borders, and other book stores. Excellent book based on author's personal experience of raising a child to adulthood with FAS.

Curricula:

2. FAS/E Support Network (Berg, Kinsey, Lutke, Wheway). **FASNET Assessment Tools.**
5. Kuerschner, M.S., Suzie. **BEYOND THE GLOOM AND DOOM.**
13. Northern Plains Native American Chemical Dependency Assoc., Inc. **FAS/FAE Curriculum for Native Americans.**
14. The FAS Family Resource Institute. **The FAS Family Resource Institute Packet.**
16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**

Videos:

1. **Adolescence and the Future.**



Unit V

Adolescence

Unit Goal

- To understand that most of the behaviors discussed in earlier stages of childhood are still seen in adolescence and that interventions continue to be created around the need for structure, consistency and expectations based on the child's abilities.
- To understand the need for a team approach to intervention and a focus on functional learning.

Training Tips

Adolescence continues to be a challenging time for children and parents. Brain development contributes to the maturation process that leads us to expect more of adolescents. We begin to see them as young people preparing for adulthood. Many adolescents affected by alcohol in utero are depressed. They begin to see clearly that they are not progressing at the same speed or at the same level as their peers. Again, interventions must include everyone touching the life of the adolescent and they must be individualized based on the behavior, setting and strengths of the child.

Training Contents

Adolescence, according to Barbara Sommer's Puberty and Adolescence, covers the entire transition from child to adult in a psychological and sociological sense. Adolescents must learn to manage body image changes, sexual impulses and increased sexual energy. Feelings and experiences become more differentiated and complex, awareness of both self and the world outside of self and ethical concerns increase. From age 7 to 12, children understand the concept of action and consequence and rational thinking should be evident in the early teens. Moral development, an understanding of sex roles, formation of educational and vocational expectations begin to be defined. Adolescents exhibit a need for independence often shifting their alliance from family to peers. They have a greater need to establish their identity than the young child.



The child affected by alcohol in utero faces these developmental changes in addition to the impact of organic brain damage on their ability to successfully cope with these transitions. Here are a few suggestions taken from the resources listed for this module:

Sex Education

1. Sex education is important for all teens. The child with poor judgment, a propensity for alcoholism, difficulty connecting action and consequence, and memory deficits is at risk of choosing an unhealthy relationship and not using protection during intercourse. Many of these children can become victims and may become predators because of the above mentioned difficulties and boundary issues. Close supervision and repeated education regarding choice of partners and safe sex is even more important for an adolescent affected by alcohol in utero.

Learning/Education

1. Structured, safe environments with a minimum of changes continue to be the most optimum learning settings.
2. Continued difficulty with math can be assisted with a calculator and an emphasis on functional applications. Writing skills may be improved with the use of a computer.
3. Academic testing may be needed to determine appropriate learning levels in various areas. It is common for our child to have academic strengths in certain subjects and few in other areas.
4. Shifting focus from academic to vocational and daily living skills may assure success in adulthood if appropriate.
5. Begin planning for residential placement or vocational training if needed.



Social

1. Negative and inappropriate behavior may be the result of not understanding verbal or social information. Intervene immediately pointing out the behavior to be changed and demonstrate appropriate behavior. Role plays can be useful.
2. Adjust your expectations about age appropriate behavior. Many parents report that they and other adults have an increased tendency to interpret “confabulation” as lying as the child reaches adolescence due to their expectations about moral development. Remember the teen may often be missing pieces of information and what appears to be “lying” can be a symptom of faulty memory, the desire to make you happy and/or the inability to discern fantasy from fact.
3. Institute routines to teach children about proper hygiene.
4. Mental health assessments may be needed.
5. Peer pressure is the biggest influence on behavior of any adolescent. Children affected by alcohol in utero are often easily recruited into gangs. “Healthy” friends can model and guide the child through potentially harmful influences. Group Action Planning, instituted by Anna Turnbull, involves peers and adults in identifying strengths to develop supportive friendships. In the end analysis, many of these children need friends more than a class in calculus.
6. The ability to discern fantasy from fact can cause many problems for the child affected by alcohol in utero with their peers as well as adults. Unrealistic expectations of themselves may appear as bragging or egocentricity. Influences of movies and television can mold unsavory or even antisocial behavior. Checking their perception of reality and helping them to recognize consequences through role play and immediate intervention is useful.



Training Materials

Facts:

There are several references in the Facts section of the Bibliography. Here are a few:

54. LaDue, R.A. and Dunne, T. **Legal Issues and the Fetal Alcohol Syndrome.**
55. LaDue, Robin, Streissguth, A.P. & Randels, S.P. **Clinical Considerations Pertaining to Adolescents and Adults with Fetal Alcohol Syndrome.**
61. Malbin M.S.W., Diane. **Fetal Alcohol Syndrome and Fetal Alcohol Effects: Strategies for Professionals.**
91. Streissguth, A.P., R. LaDue and S.P. Randels. **Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians.**
92. Streissguth, A.P., Barr, H., Kogan, J. and Brookstein, F.L. **Understanding occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects. Final Report.**
93. Streissguth, A.P., Barr, H.M., Carmichael Olson, H. et al. **Drinking during pregnancy decreases word attack and arithmetic scores on standardized tests: Adolescent data from a population-based prospective study.**
94. Streissguth, A.P., et al. **Fetal Alcohol Syndrome in Adolescents and Adults.**
95. Streissguth, A.P., K. Kopera-Frye and H.M. Barr. **Primary and Secondary Disabilities in Patients with FAS.**



Interventions:

Refer to the Training Materials sections after each unit in this module for age specific interventions. Also, the Intervention section of the Bibliography of Resources lists 54 resources for information on interventions. Here are a few:

13. Clarren, Sandra G. B., Jirikowic, Tracy. **Intervention Ideas For Individuals with Prenatal Alcohol Exposure and Organic Brain Damage.** Washington State Fetal Alcohol Syndrome diagnostic and Prevention Network. Children's Hospital and Regional Medical Center, 4800 Sand Point Way N.E., CH-47, Seattle, WA 98105. (2000)
21. LaDue, PhD, Robin. **Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents & Caretakers.**
24. Lutke, Jan. **Fetal Alcohol Syndrome/Effect and Children in the "System".**
25. Lutke, Jan. **Fetal Alcohol Syndrome/Effect: Role of FAS/E Caregivers in Relationship to Other Children in the Home.**
26. Malbin, Diane. **FAS/FAE and Traditional Behavior Modification Interventions.**
27. Malbin, Diane. **Adolescents and Young Adults with FAS/E: Tips for Success Toward Building Self-Esteem.** *FASETS: Improving the Outcome Newsletter*, Winter.
35. Rathbun, Antonia. **Practical Approaches to Working and Living with FAS/E children and Adults.** *FAS/FAE/Fetal Drug Effect: Educational Implications*, Unknown.
37. Rothwell, Mary Ann. **FAS/FAE Intervention Strategies.** *Unpublished.*
47. Turnbull, Anna. **Beach Center How To: Start Group Action Planning.**



Modules:

Module III: Central Nervous System Dysfunction - Cognitive and Behavioral Characteristics

Resources/Services:

Books:

6. Dorris, Michael. **The Broken Cord.**
11. Kleinfeld, Judith. **Fantastic Antoine Grows Up.**

Curricula:

2. FAS/E Support Network (Berg, Kinsey, Lutke, Wheway). **FASNET Assessment Tools.**
4. Kuerschner, M.S., Suzie. **BEYOND THE GLOOM AND DOOM.**
13. Northern Plains Native American Chemical Dependency Assoc., Inc. **FAS/FAE Curriculum for Native Americans.**
14. The FAS Family Resource Institute. **The FAS Family Resource Institute Packet.**
16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**

Videos:

1. **Adolescence and the Future.**
6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
7. **Healing the Broken Cord.**
9. **The Little Fox, The Little Mask, Sees No Danger, and Travels in Circles.**
13. **Precious Gift.**



Unit VI

Adulthood

Unit Goal

- To understand the importance of continued services and job training for adults affected by alcohol in utero.
- To realize that the most important and lasting interventions are based on a circle of friends as well as a network of support services, life skills education and appropriate job training.

Training Tips

There is little information about adults with FAS or related conditions. Recent studies say that homelessness and incarceration are common outcomes for adults. Success again must depend on a team approach to intervention over a lifetime. Adults who have had life skills training and job training which considers limitations and strengths of the individual are more successful. Friends and support systems are crucial.

Training Contents

1. It is most important to have a support system which focuses on friendships based on shared interests.
2. Services that assist in dealing with depression are a must.
3. Group Action Planning, created by Anna Turnbull, is a concept that can be applied to people with FAS and related conditions. Forming a support group of friends who focus on the person's strengths will raise self-esteem, give respite to care givers and builds interventions based on friendships and mutual respect.
4. Dr. Ann Streissguth's work on secondary disabilities highlights homelessness and incarceration as common outcomes for adults with FAS.



5. Adults affected by alcohol in utero need adequate living situations that offer structure and in-home support. Some adults need a protective payee or someone to supervise their finances.
6. Extended family systems which can include relatives, volunteers, foster parents, proprietary care homes, church groups and other volunteer organizations.
7. Government sponsored programs through which adults can find employment are needed.

Training Materials

Facts:

55. LaDue, Robin, Streissguth, A.P. & Randels, S.P. **Clinical Considerations Pertaining to Adolescents and Adults with Fetal Alcohol Syndrome.**
61. Malbin M.S.W., Diane. **Fetal Alcohol Syndrome and Fetal Alcohol Effects: Strategies for Professionals.**
63. Malbin, Diane B. **Sexuality Issues for Teens and Young Adults with FAS/E.**
75. Phelan, PhD, Thomas. **The Adult Experience of A.D.D.**
91. Streissguth, A.P., R. LaDue and S.P. Randels. **Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians.**
92. Streissguth, A.P., Barr, H., Kogan, J. and Brookstein, F.L. **Understanding occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects. Final Report.**
93. Streissguth, A.P., Barr, H.M., Carmichael Olson, H. et al. **Drinking during pregnancy decreases word attack and arithmetic scores on standardized tests: Adolescent data from a population-based prospective study.**
94. Streissguth, A.P., et al. **Fetal Alcohol Syndrome in Adolescents and Adults.**
95. Streissguth, A.P., K. Kopera-Frye and H.M. Barr. **Primary and Secondary Disabilities in Patients with FAS.**



Interventions:

12. Clarren, Sandy. **Learning Strengths, Challenges and Solutions for Students with FAS/E.**
21. LaDue, PhD, Robin. **Psychosocial Needs Associated with Fetal Alcohol Syndrome: Practical Guidelines for Parents & Caretakers.**
22. LaDue, Robin. **Psychosocial Needs Associated with Fetal Alcohol Syndrome and Fetal Alcohol Effects.**
23. Lutke, Jan. **Working with Adults (with FAS/E).**
27. Malbin, Diane. **Adolescents and Young Adults with FAS/E: Tips for Success Toward Building Self-Esteem.**
35. Rathbun, Antonia. **Practical Approaches to Working and Living with FAS/E children and Adults.**
47. Turnbull, Anna, **Beach Center How To: Start Group Action Planning.**

Resources/Services:

Curricula:

2. FAS/E Support Network (Berg, Kinsey, Lutke, Wheway). **FASNET Assessment Tools.**

Visual Aides - Videos:

6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
9. **The Little Fox, The Little Mask, Sees No Danger, and Travels in Circles.**



¹ Kuerschner, MS, Suzie. **The Native American Family Resource Curriculum Guide.** *Curriculum*, Native American Rehabilitation Assoc. of the Northwest, Inc., Gresham, OR.

² Malbin, Diane. Reframing perceptions, rethinking understanding. *Prevention Forum*, Illinois Prevention Resource Center. v15:n4, p9-12. 1995

³ Sommer, Barbara, Puberty and Adolescence. Oxford University Press, New York 1978.

MODULE VI

ALCOHOL & SOCIETY



Module Training Goals

- To be aware of alcohol's impact on our society.
- Identify markets for alcohol consumption.

Module Contents

Unit I	Our Number One Choice
Unit II	Alcohol Marketing



Unit I

Our Number One Choice

Unit Goal

To be aware of alcohol's importance and acceptability in our society.

Training Tips

It has been demonstrated in animal research and clinical settings that alcohol has a devastating affect 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.

Training Contents

1. Even with increased prevention efforts in FAS, drinking during pregnancy continues.
2. Many Americans refer to their drinking as "social". Alcohol is used to celebrate and commemorate many occasions in the lives of Americans. It is also in many cases a vehicle to forget or escape the harsh realities of life.
3. We celebrate birthdays, graduations, weddings, anniversaries, victories and sometimes pregnancy and birth with alcohol. Progressive birthing centers can be found that suggest bringing a bottle of champagne and glasses, which they will chill, to celebrate the new arrival. In a setting which promotes breast feeding, and natural childbirth, this seems ludicrous.
4. In a society that denies having a problem with alcohol abuse in general, this situation is not unbelievable.



5. “Social” drinking may be defined quite differently by different people. To one person a glass of wine on a special occasion is “social” drinking. To someone else a drink or two every night after work may be considered “social” drinking.
6. Amounts of alcohol may vary with each drink and person making the drink. One drink may contain more than one ounce of alcohol, but the consumer still refers to it as a drink.
7. Peer pressure among all age groups is compelling. Youth are even more affected by peer pressure than adults. A child raised in a loving, nurturing environment may not be immuned to the pressures of his or her peer group to drink.
8. Drinking for many women is not about emptying the bottle but filling up the holes in their lives according to Linda LaFever, author, educator and birth mother.
9. Sobriety is not a relief from the pressures of life and many women can not leave their children to seek treatment.
10. The grief and guilt associated with being the birth mother of a child with FAS or related conditions can keep women addicted.
11. Women need the support of family, friends and professionals to become and remain sober.
12. Men must take an active role in supporting the healthy pregnancy of their partner.

Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. See the Training Materials section or Unit II for some suggestions.

Resources/Services:

Books:

14. LaFever, Linda. **Cheers! Here’s to the Baby.**



Unit I I

Alcohol Marketing

Unit Goal

To be aware of consumer audiences targeted by the liquor industry.

Training Tips

In a consumer oriented society, marketing costs to industry are high but worth the investment, as advertising works. Alcohol consumption is presented in an aura of glamour, acceptability and prosperity. Everyone is the target, young and old alike. Ask your audience to think of some advertisements for alcohol. Discuss the target audience and the values associated with the ads.

Training Contents

1. The liquor industry has a strong lobby that has in some cases denied that alcohol causes FAS.
2. Younger and younger audiences are being targeted by the liquor industry. Advertisements associated with toys, cartoon characters or scenarios that appeal to children and adolescents feature alcohol.
3. Some ads do not specifically encourage young people to drink but they are grooming the next generation of consumers.
4. Alcohol consumption is linked to beauty, success, and prosperity by the liquor industry.



5. Magazines advertise in liquor industry publications in order to entice liquor companies to advertise with them. A very popular magazine among young women took out an ad displaying a beautiful young woman. The ad boasted that its readers had consumed millions of glasses and bottles of alcohol in the past weeks and months. The last line said, “Isn’t it time you gave (the name of the magazine) a shot?”. This ad implied that women who read their magazine and drink are young and beautiful.
6. The images created by these ads are far from the reality of drinking in a person’s life.

Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Appendix I:

Appendix I: *Behavioral Interventions for Working with Chemically Abusing and Dependent Mothers* addresses alcohol abuse and working with at risk and drinking pregnant women. You may have information or materials that can be included in this unit. See footnotes for possible materials that can be used as well.

Assessment:

6. D’Apolito RN, Ph.D., Karen. **Illicit Drug Use During Pregnancy: Consequences for Infants, Mothers & Children.**

**Facts:**

16. Berg, S., Kinsey, K., Lutke, J. and Whewey D. **A Layman's Guide to Fetal Alcohol Syndrome and Possible Fetal Alcohol Effects.**

Resources/Services:**Curricula:**

2. FAS/E Support Network (Berg, Kinsey, Lutke, Wheway). **FASNET Assessment Tools.**
14. The FAS Family Resource Institute. **The FAS Family Resource Institute Packet.**
16. Wegmann, M., Colfax, L., Gray, M. and Reed, B. **Assessment and Resource Guide for FAS/FAE.**

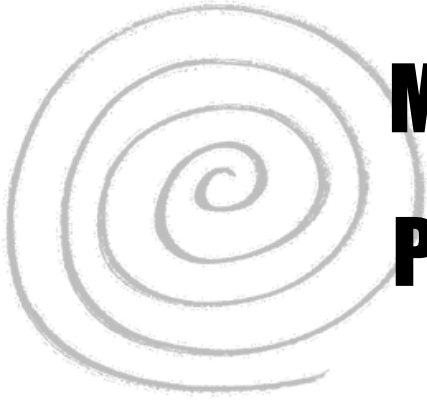
Resource Guides

1. **Alcohol and other drugs can harm an unborn baby: A resource list.**
3. **Early Childhood Substance Abuse Directory: Curricula Directory.**
4. Kvigne, Valborg, Engelhart, E. and Burke, K. **Fetal Alcohol Syndrome Resource List.**
5. **National Clearinghouse for Alcohol and Drug Inf. CATALOG (NCADI).**
6. Snyder, Lisa (developed by). **Fetal Alcohol Syndrome: Resource Guide.**
7. **Washington State Fetal Alcohol Resource Guide: Tools for Prevention and Information.**



Videos:

2. **Babies in Waiting.**
4. **The Fabulous FAS Quiz Show.**
6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
7. **Healing the Broken Cord.**
10. **One For My Baby.**
11. **Mary's Choice.**
16. **Sacred Trust - Protect Your Baby Against Fetal Alcohol Syndrome.**
15. **Preventing F.A.S.**



MODULE VII

Prevention

Module Training Goals

- To recognize various approaches to the prevention of FAS and other alcohol related conditions, their components and the need for comprehensive, holistic approaches to prevention.
- Learn what prevention strategies have been used and are needed in the future.
- To recognize good parenting as a “natural” form of prevention.
- To create motivation among audiences to form “contemporary villages” for the protection of the next generation.

Module Contents

Unit I	Prevention Overview
Unit II	Prevention Strategies
Unit III	Parenting as Prevention
Unit IV	Creating Villages



Unit I

Prevention Overview

Unit Goal

- To recognize various approaches to the prevention of FAS and related conditions and their components.
- To understand the need for comprehensive, holistic approaches to prevention linked with education, intervention and treatment for women at risk of producing children affected by alcohol, their support networks and the population in general.

Training Tips

Animal studies on FAS demonstrate that alcohol is the key variable in producing a fetus with FAS or related conditions. Women who do not drink during pregnancy will not produce children with FAS. The most powerful prevention message is that FAS is 100% preventable. Lead your audience through a discussion of other levels of prevention activity that can be focused on the individual in a variety of settings. Encourage examples from “real life” situations. Role plays of interventions with pregnant women may be useful.

Training Contents

A. Primary Prevention

Primary prevention activities focus on preventing mothers from drinking during pregnancy and on encouraging the use of family planning methods among drinking women of child bearing age. Many efforts target women who are at high risk for producing children with birth defects, including alcoholic women of child bearing age and birth mothers of children with FAS.



Planned pregnancy and education around the dangers of drinking during pregnancy are unequivocally the best strategies to prevent FAS and related conditions. The Department of Health in Washington State reports in epi TRENDS, Vol. I No.4, that 55% of all pregnancies and 44% of all births in the United States are unintended in that they are identified by the mother as either unwanted or mistimed at conception. 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.

- Dr. Sterling Clarren is identifying women at risk of producing children affected by alcohol in utero through the FAS Diagnostic and Prevention Clinic in Seattle, Washington. He and Dr. Susan Astley are developing a socioeconomic and demographic profile of these women and are identifying practical problems that confront women in terms of seeking, entering and benefiting from treatment, and remaining sober.
- Target audiences should include youth and people that make up the network of friends and family for women of child bearing age.
- Motivating women and at risk families to develop positive self-esteem and coping skills for a healthy lifestyle are important to prevention.
- Increase education about abstinence and contraception methods.
- Public information campaigns such as Healthy People 2000 are critical. Delaying the onset of drinking, reducing access of alcohol to minors, creating alternatives to drinking are some of the topics for such campaigns.
- Refer women and families to counseling or other appropriate services.
- Educate expectant mothers about the harm of alcohol use during pregnancy.
- For many people Alcoholics Anonymous has been an effective form of prevention.
- Services for women need to be developed and provided by treatment, social service and medical providers.



B. Secondary Prevention

Secondary prevention activities are early attempts at identification, intervention, and treatment to prevent further health problems.

1. Secondary prevention activities lessen the impact of the primary disability. For example, children with FAS have brain damage but they do not have to become depressed or oppositional. These secondary emotional problems can be prevented.
2. Early detection through proper screening, assessment and evaluation are very important.
3. Identifying children and adults with FAS and related conditions may assist them in reducing the risk of producing children with birth defects.
4. Individual and group therapy, family and marital therapy and social skills education emphasizing practical daily living skills for people with FAS are effective.
5. Pharmacological therapy, vocational rehabilitation and culturally sensitive interventions and programs should be developed for people with FAS and related conditions.

C. Tertiary Prevention

Tertiary prevention is designed to minimize long-term disability or reduce negative effects of drinking during pregnancy among people affected by alcohol in utero.

1. Tertiary prevention activities provide information. They are the basic tools for prevention of further cases of alcohol-related birth defects, education and intervention.
2. Provide appropriate, culturally relevant, treatment for drinking mothers.
3. Women in treatment could be screened for alcohol-related birth defects, tested for pregnancy and provided appropriate counseling and referrals. Establish consistent and accurate diagnosis and intervention early on in the pregnancy.
4. Follow-up for mother and child must be provided.



5. Resource information for families and life-long services are necessary.
6. Safe, accepting, and culturally appropriate environments are needed in which birth parents can explore and grieve their roles in, often unknowingly, creating a child with FAS or related conditions.

Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Assessment:

6. D'Apolito RN, Rh.D., Karen. **Illicit Drug Use During Pregnancy: Consequences for Infants, Mothers & Children.**

Facts:

18. Bowman (James Bowman Associates) and Quinby, R. **Seattle-King County Needs Assessment Survey on Fetal Alcohol Syndrome/Effects.**
41. Dufour, M.C., Williams, G.D., Campbell, K.E. and Aitken, S.S. **Knowledge of FAS and the Risks of Heavy Drinking During Pregnancy, 1985 and 1990.**
54. LaDue, R.A. and Dunne, T. **Legal Issues and the Fetal Alcohol Syndrome.**
63. Malbin, Diane B. **Sexuality Issues for Teens and Young Adults with FAS/E.**
65. March of Dimes Birth Defects Foundation. **Public Health Education Information Sheet: Drinking During Pregnancy.**
72. NOFAS. **Fetal Alcohol Syndrome Fact Sheet.**
91. Streissguth, A.P., R. LaDue and S.P. Randels. **Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians.**



92. Streissguth, A.P., Barr, H., Kogan, J. and Brookstein, F.L. **Understanding occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects. Final Report.**
96. Streissguth, A.P., Moon-Jordan, A. and Clarren, S.K. **Alcoholism in Four Patients with Fetal Alcohol Syndrome: Recommendations for Treatment.**

Interventions:

6. Burgess, Donna M. **Helping Prepare Children with FAS or FAE for School and Beyond.**

Prevention:

2. Kopera-Frye, Karen, et al. **Preventing FAS by Empowering Native American Chemical Dependency Counselors.**
3. Maloney, Susan K. and Susan S. Buell. **Toward Preventing Preinatal Abuse of Alcohol, Tobacco, and Other Drugs.**
6. Streissguth, A.P. **Today I Visited an Aleut Village: Observations on Preventing Fetal Alcohol Syndrome.**
7. Streissguth, A.P. **Fetal Alcohol Syndrome: Implications for Native American Communities.**
8. Western Regional Center for Drug-Free Schools and Communities. **Fetal Alcohol/Drug Effects Prevention Grid.**



Resources/Services:

Books:

3. Blume, Sheila B. **What you can do to prevent fetal alcohol syndrome: A professional's guide.**
9. Institute of Medicine. **Fetal Alcohol Syndrome. Diagnosis, Epidemiology, Prevention, and Treatment.**

Newsletters:

3. **FAS and Other Drugs Update.**
9. **Northwest Prevention Quarterly.**

Organizations:

4. **March of Dimes Birth Defects Foundation.**
6. **National Association for Prenatal Addiction Research and Education.**

Programs:

6. **Parent to Parent Support in Washington State.** *Programs throughout Washington, King County Parent-to-Parent contact: 206-364-4645, ext. 122.*



Unit II

Prevention Strategies

Unit Goal

To become aware of prevention strategies.

Training Tips

There are many excellent prevention programs focusing on individuals, families and communities. Dr. Ann Streissguth and her colleagues at the University of Washington in Seattle, Washington have developed models for intervention with women who abuse alcohol during pregnancy since the 1970's. The approach they have taken has been public education, professional training and providing services. These are still at the core of prevention in the field of FAS. The training content suggestions listed below are taken from "Preventing Fetal Alcohol Syndrome By Working With High Risk Mothers And Other Strategies: the Seattle Advocacy Model", by Ann P. Streissguth, Ph.D., Therese M. Grant, M.Ed., and Cara C. Ernst, M.A. The trainer must become aware of prevention activities in the area as resources for the audience. They may also be aware of successful intervention strategies to be shared with everyone. Refer to Appendix I for ideas in working with pregnant abusing women.

Training Contents

- Dr. Streissguth's team produced public service announcements for television and radio, an audio tape, a dysmorphology manual and a "Drinking for Two" cookbook.
- Frequent newspaper coverage was generated on alcohol and pregnancy.
- Informational brochures and a twelve hour a day dedicated hot-line was established.
- Over 6,300 professionals were trained.



Services provided to at various levels of risk included discussing their drinking and children of family members suspected to be affected and alcohol treatment and referral.

Training Materials

There are many references and materials listed in the Bibliography of Resources section that have not been included here. The following are a few selections relevant to the themes of this module:

Appendix I

Facts:

- 65. March of Dimes Birth Defects Foundation. **Public Health Education Information Sheet: Drinking During Pregnancy.**
- 71. No More Labels. **Fetal Alcohol Fact Sheet.**
- 72. NOFAS. **Fetal Alcohol Syndrome Fact Sheet.**
- 108. Wall, RN, Ginna. **Breastfeeding: Is it OK for Women Who Consume Illicit Drugs?**

Modules:

Module VI: Alcohol and Society

Prevention:

- 4. No More Labels. **SCENARIOS (for role playing).**
- 5. Streissguth, A.P. **Fetal Alcohol Syndrome: Understanding the Problem; Understanding the Solution; What Indian Communities Can Do.**



Resources/Services:

Books:

3. Blume, Sheila B. **What you can do to prevent fetal alcohol syndrome: A professional's guide.**

Curricula:

9. McKinney, Victoria. **FAS: Prevention at Its Earliest.**
10. McKinney, Victoria. **Prevention: From the Inside Out.**
11. McKinney, Victoria. **FAS: The Path to Prevention.**
15. Unknown. **Prevention 101 Training of Trainers.**
17. White, Nancy and Ruth Francis. **The Fabulous FAS Quiz Show.**

Newsletters:

3. **FAS and Other Drugs Update.**
6. **Iceberg Newsletter.**
9. **Northwest Prevention Quarterly.**

Organizations:

4. **March of Dimes Birth Defects Foundation.**
6. **National Association for Prenatal Addiction Research and Education.**

Programs:

2. **The Family Resource Institute (former The FAS Adolescent Task Force).**
3. **FAS Education Program, Boston.**



Resource Guides:

1. **Alcohol and other drugs can harm an unborn baby: A resource list.**
3. **Early Childhood Substance Abuse Directory: Curricula Directory.**
4. Kvigne, Valborg, Engelhart, E. and Burke, K. **Fetal Alcohol Syndrome Resource List.**
5. **National Clearinghouse for Alcohol and Drug Inf. CATALOG (NCADI).**
6. Snyder, Lisa (developed by). **Fetal Alcohol Syndrome: Resource Guide.**
7. **Washington State Fetal Alcohol Resource Guide: Tools for Prevention and Information.**

Videos:

1. **Adolescence and the Future.**
2. **Babies in Waiting.**
4. **The Fabulous FAS Quiz Show.**
6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
7. **Healing the Broken Cord.**
10. **One For My Baby.**
11. **Mary's Choice.**
16. **Sacred Trust - Protect Your Baby Against Fetal Alcohol Syndrome.**

Visual Aides - Miscellaneous:

2. Healthy Mothers, Healthy Babies Coalition of Washington. **Brain Poster.**



Unit III

Parenting as Prevention

Unit Goal

To recognize the elements of parenting that can be viewed as prevention strategies.

Training Tips

The intergenerational transmission of FAS is 100% preventable. 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 alcohol-related birth defects. Ask your audience for parenting ideas that are prevention strategies. Parents as role models is an example.

Training Contents

1. Parenting that leads to prevention needs the support of everyone in the community and should be culturally relevant.
2. Alternative forms of parenting may be required or determined to be the best case scenario for the child, i.e., extended family settings.
3. Prevention should address all youth, not just those at risk.
4. Begin early and continue good parenting throughout the life of the individual.
5. Establish a variety of strategies for children with FAS and related conditions. Each child must be viewed individually. Using all the senses and trying several approaches to learning, intervention and discipline result in the most success.



6. Activities should be integrated into family, classroom, school, and community life. Such activities encourage the participation of the whole community and fosters a sense of community responsibility.
7. Parents must take an active role in setting up or assisting with evaluations and intervention strategy planning for their children. This may involve schools, service agencies or interactions with appropriate professionals.
8. Positive role modeling from parents and consistent and appropriate expectations are elements of good parenting.
9. Identifying and providing a culturally relevant environment will promote self worth and provide a healthy framework for the child and family to relate to the community.

Training Materials

The resources below and others are found in the Bibliography of Resources at the back of the manual. The numbers preceding each resource correspond to the alphabetical listings under each section of the Bibliography of Resources. Review each section before each training.

Facts:

54. LaDue, R.A. and Dunne, T. **Legal Issues and the Fetal Alcohol Syndrome.**
63. Malbin, Diane B. **Sexuality Issues for Teens and Young Adults with FAS/E.**
65. March of Dimes Birth Defects Foundation. **Public Health Education Information Sheet: Drinking During Pregnancy**
72. NOFAS. **Fetal Alcohol Syndrome Fact Sheet.**
96. Streissguth, A.P, Moon-Jordan, A. and Clarren, S.K. **Alcoholism in Four Patients with Fetal Alcohol Syndrome: Recommendations for Treatment.**



Interventions:

6. Burgess, Donna M. **Helping Prepare Children with FAS or FAE for School and Beyond.**

Prevention:

3. Maloney, Susan K. and Susan S. Buell. **Toward Preventing Perinatal Abuse of Alcohol, Tobacco, and Other Drugs.**
4. No More Labels. **SCENARIOS (for role playing).**
8. Western Regional Center for Drug-Free Schools and Communities. **Fetal Alcohol/Drug Effects Prevention Grid.**

Resources/Services:

Books:

3. Blume, Sheila B. **What you can do to prevent fetal alcohol syndrome: A professional's guide.**
9. Institute of Medicine. **Fetal Alcohol Syndrome. Diagnosis, Epidemiology, Prevention, and Treatment.**

Curricula:

9. McKinney, Victoria. **FAS: Prevention at Its Earliest.**
10. McKinney, Victoria. **Prevention: From the Inside Out.**
11. McKinney, Victoria. **FAS: The Path to Prevention.**
15. Unknown. **Prevention 101 Training of Trainers.**
17. White, Nancy and Ruth Francis. **The Fabulous FAS Quiz Show.**



Newsletters:

3. **FAS and Other Drugs Update.** *Biannual, gratis*, Prevention Resource Center, Springfield, Ill.
9. **Northwest Prevention Quarterly.**

Organizations:

4. **March of Dimes Birth Defects Foundation.**
6. **National Association for Prenatal Addiction Research and Education.**

Programs:

6. **Parent to Parent Support in Washington State.**

Videos:

2. **Babies in Waiting.**
11. **Mary's Choice.**



Unit V

Creating Villages

Unit Goal

To recognize the importance of community building and all of its members' responsibility in the rearing of our children.

Training Tips

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 syndrome and related conditions. 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. This shared view reinforces their role as a parent striving to have and raise healthy, happy children.

Placing our children at risk for birth defects is a social problem which is 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. Discuss ways of building “villages” in today’s society. You may start with the family setting.

Training Contents

Assessment

1. In a screening study of first graders in two counties in Washington State conducted by the Washington State Department of Health and the University of Washington Medical School found an FAS rate of 1.9 per 1,000 and combined FAS and related conditions rate of 5.2 per 1000 (Randels and Fineman, 1995).



2. The Washington State Governor's FAS Advisory Panel reported that these rates are low estimates because not all of the children who were screened and referred were seen for the full evaluation. They conservatively estimate that there are approximately 5,000 people with FAS living in Washington State as of 1995. By the year 2000, the figure will reach 5,750 to 6,000 people, assuming a rising birth rate and no increase in prevention efforts.
3. The Seattle-King County Department of Public Health's Fetal Alcohol Syndrome Prevention Project, coordinated by Rose Quinby, conducted a needs assessment in 1994.
4. In 1989, the State of Alaska estimated that each person with FAS costs the state \$1.4 million during his/her lifetime (Binkley, 1989). A more recent estimate is more than \$2 million.
5. It is currently difficult for families and individuals to access assistance such as SSI unless the person with FAS or related conditions has an I.Q. below 70. Most people with related conditions have an I.Q. in the normal range.

Education

Education campaigns are necessary to heighten public awareness of FAS and related birth defects, but it is unlikely that such information will change the behavior of alcoholics. Thoughtful expansion of services for alcohol treatment and contraception options for women of child bearing age are needed.



Training Materials

The resources below and others are found in the Bibliography of Resources at the back of the manual. The numbers preceding each resource correspond to the alphabetical listings under each section of the Bibliography of Resources. Review each section before each training.

Facts:

18. Bowman (James Bowman Associates) and Quinby, R. **Seattle-King County Needs Assessment Survey on Fetal Alcohol Syndrome/Effects.**
41. Dufour, M.C., Williams, G.D., Campbell, K.E. and Aitken, S.S. **Knowledge of FAS and the Risks of Heavy Drinking During Pregnancy, 1985 and 1990.**
54. LaDue, R.A. and Dunne, T. **Legal Issues and the Fetal Alcohol Syndrome.**
63. Malbin, Diane B. **Sexuality Issues for Teens and Young Adults with FAS/E.**
72. NOFAS. **Fetal Alcohol Syndrome Fact Sheet.**
91. Streissguth, A.P., R. LaDue and S.P. Randels. **Manual on Adolescents and Adults with Fetal Alcohol Syndrome with Special Reference to American Indians.**
92. Streissguth, A.P., Barr, H., Kogan, J. and Brookstein, F.L. **Understanding occurrence of secondary disabilities in clients with fetal alcohol syndrome and fetal alcohol effects.**
96. Streissguth, A.P., Moon-Jordan, A. and Clarren, S.K. **Alcoholism in Four Patients with Fetal Alcohol Syndrome: Recommendations for Treatment.**

Interventions:

6. Burgess, Donna M. **Helping Prepare Children with FAS or FAE for School and Beyond.**



Prevention:

2. Kopera-Frye, Karen, et al. **Preventing FAS by Empowering Native American Chemical Dependency Counselors.**
3. Maloney, Susan K. and Susan S. Buell. **Toward Preventing Preinatal Abuse of Alcohol, Tobacco, and Other Drugs.**
4. No More Labels. **SCENARIOS (for role playing).**
5. Streissguth, A.P. **Fetal Alcohol Syndrome: Understanding the Problem; Understanding the Solution; What Indian Communities Can Do.**
6. Streissguth, A.P. **Today I Visited an Aleut Village: Observations on Preventing Fetal Alcohol Syndrome.**
7. Streissguth, A.P. **Fetal Alcohol Syndrome: Implications for Native American Communities.**
8. Western Regional Center for Drug-Free Schools and Communities. **Fetal Alcohol/Drug Effects Prevention Grid.**

Resources/Services:

Books:

3. Blume, Sheila B. **What you can do to prevent fetal alcohol syndrome: A professional's guide.**
9. Institute of Medicine. **Fetal Alcohol Syndrome. Diagnosis, Epidemiology, Prevention, and Treatment.**



Curricula:

9. McKinney, Victoria. **FAS: Prevention at Its Earliest.**
10. McKinney, Victoria. **Prevention: From the Inside Out.**
11. McKinney, Victoria. **FAS: The Path to Prevention.**
15. Unknown. **Prevention 101 Training of Trainers.**
17. White, Nancy and Ruth Francis. **The Fabulous FAS Quiz Show.**

Newsletters:

3. **FAS and Other Drugs Update.**
9. **Northwest Prevention Quarterly.**

Organizations:

4. **March of Dimes Birth Defects Foundation.**
6. **National Association for Prenatal Addiction Research and Education.**

Programs:

6. **Parent to Parent Support in Washington State.**



Videos:

1. **Adolescence and the Future.**
2. **Babies in Waiting.**
4. **The Fabulous FAS Quiz Show.**
6. **Fetal Alcohol Syndrome and Effect: Stories of Help and Hope.**
7. **Healing the Broken Cord.**
10. **One For My Baby.**
11. **Mary's Choice.**
15. **Preventing F.A.S.**
16. **Sacred Trust - Protect Your Baby Against Fetal Alcohol Syndrome.**
18. **Training tapes for living with FAS and FAE: The early years, birth through age 12.**
19. **What is FAS?**