Promising Fetal Alcohol Spectrum Disorder Practices and Resources for American Indians and Alaska Natives in North America

Introduction

Description:
The "Promising Fetal Alcohol Spectrum Disorder Practices and Resources for American Indians and Alaska Natives in North America" is a central information repository for American Indian/Alaska Native (AI/AN) Fetal Alcohol Syndrome Disorder (FASD) best practices. In this newly developed repository, existing and desired prevention and intervention programs for each life stage (prepregnancy – elder) are organized in a table. The repository is accompanied by a detailed Appendix that provides a rich resource of contact information, website links, and training tools for programs listed in the table. Additional resources not mentioned in the table are included in the Appendix with journal article citations.

Methods:
The Indian Health Service (IHS) Maternal and Child Health Program and the Division of Behavioral Health Service Area and Headquarter staff were asked to provide input into those areas in the table where IHS, Tribal or AI/AN Urban programs have current or planned programs or activities that address FASD. In addition, information was also gathered through independent research, internet searches, literature reviews, interviews, and recommendations from IHS staff. Information collected from government, non-governmental (not for-profit organizations and universities), tribal entities, and other sources was compiled into this report in a format that is easily accessible.

The Substance Abuse and Mental Health Services Administration (SAMHSA) performed their research separately from the Indian Health Service. Their additions to this document are noted in green. To seek additional information for programs SAMHSA contributed, the document "Native American Programs within the United States with an FASD Prevention or Intervention Component," should be referenced.

Identified Need:
The table clearly identifies a need for more prevention/intervention programs targeting the adolescent, adult, and elder life stages. Additional needs include 1) an evaluation of all screening tools to develop a standardized prenatal health assessment form, 2) interventions for women who seek Emergency Care when they are intoxicated, 3) enhanced surveillance to track prenatal screenings, 4) family treatment programs, 5) training of labor and delivery nurses, 6) introduction of FASD as a substantive part of the medical school curriculum and medical boards, 7) classroom techniques designed for FASD children taught in schools of education, and 8) prevention programs for adolescents.

Similar needs for FASD programs were identified in a report published on March 2004 by SAMHSA, Fetal Alcohol Spectrum Disorders Center of Excellence. In this report, SAMHSA included data from site visits to 10 reservations and 5 Urban Indian Community Health Centers.

Organization:

The following document includes a table of contents; table of promising practices; and an appendix which includes descriptions of selected programs from the table, educational tools, biological screening tests, organizations, state programs, additional resources, related results from the 2001 Youth Risk Behavior Survey of High School Students, health assessment / screening tools, and selected journal articles. The information included in the appendix is not intended to be an exhaustive list of nationwide programs for AI/AN, but rather it is meant to serve as a sampling of potential resources that address the problem of FASD.

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Promising Fetal Alcohol Spectrum Disorder (FASD) Practices for American Indian and Alaska Natives (AI/AN) in North America

Life Stage	Existing
Pre-pregnancy (child bearing years)	
• **Prevention** (includes those affected and not affected)	**Screening:** Phoenix, Arizona (Georgia Butler[1]): Screening of women of childbearing age in hospitals and clinics. Baseline data being established via the Resource and Patient Management System (RPMS) for Government Performance and Results Act (GPRA[2]) reporting. California Area Indian Health Service (Dr. David Sprenger): Indian Health Service (IHS) Wide, data gathered will identify pregnant women (women of childbearing years) and RPMS will be used to look at multiple areas for screening. Code V79.1 can be used to document screening. **Education:** SIDS CJ Prevention Video

[1] Comments from G. Butler, FASD Coordinator - Phoenix Area Office, may have broader presence in I/T/U system but needs to be corroborated.

[2] GPRA FY05 Indicator for Alcohol Screening (FAS Prevention): During FY 05, increase the screening rate for alcohol use in women of childbearing age over the FY04 rate.

Life Stage	Existing
Pre-pregnancy (child bearing years)	
	Northwest Portland Indian Health Board's Northwest Tribal FAS Project: The goal is to reduce the level of FAS through the development of effective programs and multidisciplinary collaborative partnerships. Current project's scope, seeks to identify and track women of childbearing age who are potentially affected by fetal alcohol exposure in utero. The project includes 8 sites and conferences to share information with the community. See pg 28 App I Sec G. See SAMHSA Scan: Fetal Alcohol Syndrome (FAS) Program of the Navajo Nation. Louise Ashkie[3] is the only full-time FASD Coordinator in Indian Country. She works for the Navajo Nation Behavioral Health Department. She travels the reservation and provides education and training in FASD to social service providers. See SAMHSA Scan: Native American Women's Health Education is a public awareness campaign which uses brochures, booklets, reports, posters, and other health education materials.
Pre-pregnancy (child bearing years)	
	See SAMHSA Scan: Nome FAS Diagnostic Team is a grant that will fund ongoing training and resource development for health staff in the Nome service area. Funds will also be used to survey and collect local information about the frequency of drinking during pregnancy. Grant funds provide for a part-time FASD coordinator who will coordinate activities and link these grant projects to the work of the developing community diagnostic team.

[3] Louise Ashkie, Program Project Specialist, FAS Prevention Project, PO Box 709, Window Rock, AZ 86515, Phone: 928-871-6237, Email: louise.ashkie@nndoh.org

Life Stage	Existing
	Research: Research led by Dr. Philip May from the University of New Mexico (UNM) will measure the effectiveness of multi-site/system of comprehensive IOM-based FAS prevention for American Indians. Motivational enhancement therapy will be one of the types of interventions utilized. Performance sites include UNM Albuquerque NM UNM Flathead Reservation MT, UNM Sisseton Reservation SD; UNM Turtle Mountain Reservation ND; Cheyenne River Sioux Tribe SD; Fort Belknap Reservation MT; Blackfeet Nation MT; The City of Great Falls MT
• **Intervention** (includes those affected)	**Assuring/Follow-up:** Arizona (Georgia Butler): Referrals for counseling and/or treatment as needed.

Life Stage	Existing
Pre-pregnancy (child bearing years)	
	Evaluation: Tucson, Arizona (Theresa Cullen): RCIS can be used to track this information (referrals). **Education:** See SAMHSA Scan: The Native American Women's Health Education Resource is a program that provides services to women with alcohol problems and to their children with FASD. **Case Management:** See SAMHSA Scan: Chi Hullo Li is an inpatient alcohol and drug treatment center for American Indian women and their children. FASD is part of the alcohol education curriculum. Children who appear to have FASD are referred to the hospital in Talihina. Pregnant women have priority for treatment. See SAMHSA Scan: Effectiveness of a Culturally Focused Skills Enhancement Approach to Reduce Alcohol Use in Native Women. At least 280 participants will be recruited to be randomly assigned to an intervention (skills training) group or a placebo (education) group. Both groups consist of 12 weekly sessions. The focus will be developing support among the women and skills that will

Life Stage	Existing
Pre-pregnancy (child bearing years)	
	assist them in resisting and decreasing alcohol use. Effectiveness will then be evaluated. See SAMHSA Scan: Native American Community Health Center, Inc. (NACHC) is an urban American Indian Health center in Phoenix. Programs include Native women's wellness, health education, substance abuse, and Women, Infants, and Children (WIC). Health education includes an FASD curriculum provided to local treatment centers and other interested agencies. In the WIC and substance abuse programs, pregnant women are given information about FASD. Children with severe disabilities are referred to St. Joseph's Hospital for treatment. See SAMHSA Scan: Gila River Indian Community (ADAP). The ADAP program provides outpatient and prevention services. FASD is part of the treatment curriculum. ADAP also provides FASD awareness and prevention education. Contact Information: Della Sockyma at della.sockyma @gric.nsn.us or (520) 562-6048. See SAMHSA Scan: Jemez Behavioral Health Program provides outpatient alcohol and drug treatment services. FASD education is part of the treatment curriculum. Pregnant women are referred to inpatient treatment as needed. The staff also gives lectures in
Pre-pregnancy (child bearing years)	
	the schools about FASD. **Referrals:** See SAMHSA Scan: Eastern Band of Cherokee Indians Health and Medical Division. All women who come to the clinic are screened for alcohol and drug problems. Women are

Life Stage	Existing
	given information about FASD. Pregnant women who appear to be drinking are referred to treatment. Contact Information: Reggie McCaulley (?) (828) 497-9163. See SAMHSA Scan: Indian Health Care Resource Center (IHCRC) of Tulsa. IHCRC offers maternal and child health care, women's health, and substance abuse services. Women are screened in all programs, and those with alcohol problems are referred to the Substance Abuse Department for treatment. Children presenting with developmental problems are assessed and referred for services. In the Maternal and Child Health Care Department, all women receive education about the effects of alcohol on the fetus.
Pregnancy (from conception to birth)	
• **Prevention** (includes those affected and not affected)	**Screening:** Arizona (Georgia Butler): Screening of prenatals in hospitals/clinics. **Assessment / Screening:** IHS Wide: Prenatal Health Assessment

Life Stage	Existing
Pregnancy (from conception to birth)	
	Aberdeen Area IHS: developed "Screening Pregnant Women for Substance Use A Training Guide for Health Care Providers" http://forms.psc.gov/forms/IHS/ihs-866.pdf See pg 65 App VIII Sec A. TWEAK Test (Tolerance, Worry, Eye-Opener, Amnesia, K/Cut Down) See pg 72 App VIII Sec D. T-ACE (Tolerance, Annoyed, Cut-down, Eye Opener) Questionnaire. See pg 71 App VIII Sec C. CAGE Questionnaire See pg 70 App VIII Sec B. South Dakota: Prenatal Questionnaire (hard copy available) Minnesota: Minnesota Pregnancy Assessment Forms (no copy) – State's own version with one or two drug and alcohol related questions - Self reported Resource for screening tools that includes background of the tools mentioned above and others - pdf copies available, See: http://www.projectcork.org/clinical_tools/ See SAMHSA Scan: Ketchikan Indian Corporation Tribal

Pregnancy (from conception to birth)	
	Health Clinic. Grant provides for the screening of all newly pregnant women to determine if they are at risk for drinking during pregnancy. Grant funds will be used to support diagnosis and service planning through the newly established Community Diagnostic Team. Contact Information: Jasmine Nelson, Ketchikan Indian Corporation (907) 247-0429. **Education:** Arizona (Georgia Butler): Fetal Alcohol Syndrome (FAS) education is provided in prenatal classes, by Public Health Nurses (PHNs), and by other providers. Canada's Aboriginal Midwifery Services which includes prenatal education. See pg 44 App II Sec J. **Documentation/Data Collection:** IHS Patient and Family Education Protocols and Codes (nationally recognized method of documentation and coding) See pg 45 App II Sec K. See: www.ihs.gov (click on "Nationwide Programs and Initiative" then look to the upper right hand corner and click on "Patient Education Protocols and Code Manual") – Mary Wachacha **Assuring/Follow-up:** Arizona (Georgia Butler): Baby Arizona See pg 36 App II Sec A. Montana: MIAMI See pg 29 App I Sec B.

Life Stage	Existing
Pregnancy (from conception to birth)	
• **Intervention** (includes those affected)	**Assuring/Follow-up:** Arizona (Georgia Butler): Referrals for counseling and/or treatment. **Case Management:** Arizona (Georgia Butler): Limited case management is provided by PHNs and Community Health Representatives (CHR) Parenting classes. Alaska: Dena A. Coy Program, a residential treatment for substance abusing pregnant women supported by the State of Alaska, Southcentral Foundation, 3rd party Medicaid Billing, and SAMHSA. The Alaska Native Medical Center (ANMC) Services are available to all Alaska citizens and is well utilized. Screens almost 100% Alaska Native. See pg 51 App V Sec A. See SAMHSA Scan: FOCUS Program, Spokane Regional Health Districts. This program provides home visitation, advocacy, referral, and care management, as well as child development assessment for pregnant and postpartum women with alcohol and drug problems. See SAMHSA Scan: Guiding Star Lodge is a residential alcohol and drug treatment center for American Indian women and their children.
Pregnancy (from conception to birth)	
	Pregnant women have priority for treatment. Guiding Star provides education about FASD to all clients. Children or adults who need additional services are referred to Phoenix Indian Medical Center. Contact Information: Guiding Star Lodge 30W Portland Phoenix AZ 85003 Tel: (602) 254-5805 or (602) 254-7356 See SAMHSA Scan: Health Choices for Women and Children is a public health program that provides case management and home visitation to pregnant

Life Stage	Existing
	women with alcohol and drug problems and remains involved for 3 years postpartum. Contact Information: Liz Davis 95 Scovill Street, Ste. 100 Waterbury, CT 06706 (203) 597-3417. See SAMHSA Scan: Healthy Start Chugachimiut is funding the Ghugach Region Prenatal Health Promotion Project, which provides individual advocacy and services for pregnant women with alcohol and drug problems. Contact Information: **NAME** 4201 Tudor Centre Ste 210 Anchorage, AK 99508 Tel: (907) 562-4155. See SAMHSA Scan: Pasqua Yaqui Alcohol Treatment Program (PATH) is an inpatient alcohol and drug treatment center for American Indian women. FASD is a part of the treatment curriculum. Pregnant women have priority. Women who appear to have FASD are referred for developmental disabilities evaluation. Contact Information: 7474 S. Camino De Oeste Tucson, AZ 85746 Tel: 883-5016 See SAMHSA Scan: Spotlight on Aboriginal FAS/FAE Programs in Canada. Located in Winnipeg, Manitoba, this prevention program is offered by the Aboriginal Health and
Pregnancy (from conception to birth)	
	Wellness Centre. It offers both modern and Native traditional approaches of support to Aboriginal women who are using alcohol during their current pregnancies or who have a history of using alcohol during past pregnancies. See SAMHSA Scan: Tohono O'Odham Department of Behavioral Health. This department provides social services, psychological services, and substance abuse services. Pregnant women who come in contact with social services or psychological services are given FASD information. Women are referred to the substance abuse program as needed. See SAMHSA Scan: Yaqui Behavioral Health provides social services and substance abuse

Life Stage	Existing
	outpatient treatment. FASD is part of the treatment curriculum. Pregnant women who are drinking and come into contact with social services are referred to treatment.
Birth (birth to first few weeks)	
• **Prevention** (includes those affected and not affected)	

Life Stage	Existing
Birth (birth to first few weeks)	
• **Intervention** (includes those affected)	**Assessment:** MecStat-EtOH Fetal Alcohol Monitor which utilizes a panel of 7 fatty acid ethyl esters to identify fetal alcohol exposure in the last 20 weeks of term pregnancy (samples 2-3 grams of meconium). The Unites States Drug Testing Laboratories (USDTL) is the only commercial reference laboratory offering this screening test on a routine basis. See pg 47 App III Sec A. CDC studies are designed to devise and test sensitive and specific biomarkers to help identify alcohol-exposed pregnancies and/or newborns exposed to alcohol prenatally. See pg 47 App III Sec B. **Case Management:** Arizona (Georgia Butler): AZ Early Intervention Program-a statewide system of supports and services for families of children birth to 3 yrs with disabilities or developmental delays. See pg 31 App I Sec E. Child Find [4] screens, evaluates, and provides supports and services to children from birth to 21 with delays or disabilities

[4] Child Find should be included under existing interventions for life stages birth-21. Child Find screens, evaluates, and provides services to children from birth to 21 with delays or disabilities, preschool education services for ages 3-5, and special education services for K-21. For more information on Child Find: http://www.childfindidea.org/overview.htm

Life Stage	Existing
Infant – 6yrs (infancy to early childhood)	
• **Prevention** (includes those affected and not affected)	**Education:** Arizona (Georgia Butler): Beginning Alcohol and Addictions Basic Education Studies (BABES) is a primary prevention program for children ages 5 to 8. See pg 30 App I Sec C. **Screening:** See SAMHSA Scan: Brandywine Counseling Inc., Bridge Perinatal Unit is a program that is an outpatient drug and alcohol treatment facility that does FASD screening at birth. Contact Information: Ginny LanczKowski 2713 Lancaster Ave. Wilmington, DE 19805 Tel: (302) 655-9889 ext. 16 or (302) 656-2348 See SAMHSA Services: Shodair Children's Hospital provides FASD diagnostic services. **Referrals:** See SAMHSA Scan: Local Alaskan Native Health Corporation Providers - refer to Anchorage for FASD diagnostic services. Contact Information: See Appendix [???] for Alaska Native Diagnostic Teams information
• **Intervention** (includes those affected)	**Education:** See SAMHSA Scan: Aberdeen Area Indian Health Service Indian Hospital Health Education Unit is a source of expert advice on FASD for families and professionals. A FASD training manual was developed for use in the Area. Contact Information: • Valborg Kvigne (Mary-Lynn Eaglestaff) (605) 226-7278 • Phillip May University of New Mexico – FASD Research

Life Stage	Existing
Infant – 6yrs (infancy to early childhood)	
	Case Management: Arizona (Georgia Butler): Genetic Clinics are held at the service units in Arizona to evaluate children for FAS/FASD. See pg 33 App I Sec F. (Roy Teramoto): Phoenix Area IHS has a contract with the University of Arizona to provide Genetic Clinics. Genetic consultants travel to the Phoenix Indian Medical Center (PIMC), Salt River Clinic, Whiteriver, San Carlos, Parker, Peach Springs, Ft. Yuma, and Hopi Health Care Center. Clinics, which include a team, are held once a month at the PIMC and every two or three months at other sites. Treatment plans are developed. Arizona (Georgia Butler): Division of Developmental Disabilities provides services for those who meet eligibility criteria. See pg 56 App V Sec D. See Resource like Fetal Alcohol Syndrome Practical Suggestions and Support for Families and Caregivers. NOFAS. Kathleen Tavenner Mitchell, 2002. See pg 40 App II Sec C. See SAMHSA Scan: Chugachumuit Community
Infant – 6yrs (infancy to early childhood)	
	Health Aide Program provides support services for individuals with FASD. Contact Information: Annette Siemens, Program Director; 4201 Tudor Centre Ste 210 Anchorage, AK 99508 Tel: (907) 224-3076
6 – 12 yrs (childhood)	
	Education:

Life Stage	Existing
• **Prevention** (includes those affected and not affected)	FAS curriculum will be developed by NOFAS this year for grades K-12. See pg 43 App II Sec I. Beyond The 7th Generation: A Native American Fetal Alcohol Syndrome Program – A 3-year (2001-2004) project to implement and test the scientifically developed award winning 7th Generation FAS and FAE Prevention Curriculum, "Faces Yet to Come" is designed for AI students in grades 6-8. Additional materials for 9-12 grades are the presentation kit and video, "Remembering What We Know" See pg 38 App II Sec B.
• **Intervention** (includes those affected)	**Case Management:** Arizona (Georgia Butler): Genetic clinics are held at the service units. See pg 33 App I Sec F. Arizona (Georgia Butler): Treatment plans are developed. Minnesota: Clinic Assessment
6 – 12 yrs (childhood)	
	Teams provide evaluations for children with significant behavior difficulties which may be related to fetal alcohol exposure. See pg 52 App V Sec B. South Dakota: Interdisciplinary Diagnostic Clinics provide an appropriate diagnosis of a Fetal Alcohol Spectrum Disorder. On-site consultation to assist with the implementation of recommendations as a result of this diagnosis is available. See pg 53 App V Sec C. See SAMHSA Scan: Alaska Native Medical Center, FAS-IT Program provides case coordination for children with FASD and their families. The Center also screens all pregnant women (~ 100% Alaska Native) and refers women who are drinking to Dena A. Coy

Life Stage	Existing
	Screening: Visual exams for children with special needs (includes FASD). Inclusion of an eye doctor in the diagnostic team. 90-100% of FAS children have specific ocular problems and eye exam findings are very specific for FAS. Diagnosis, treatment, intervention can significantly increase child's functional ability. See pg 75 & 78 App IX Ref # 19 and 20.
12- 18 years (adolescence)	
• **Prevention** (includes those affected and not affected)	**Education:** Arizona (Georgia Butler): Education is provided by counselors, health educators, providers, and CHRs. Arizona (Georgia Butler): Youth conferences are held in the communities. Topics of conferences range and are dependent on communities, one of the conferences focused on alcohol and substance abuse, self respect, nutrition, setting goals, staying healthy. Arizona (Georgia Butler): After school youth programs for adolescents. Arizona (Georgia Butler): Teen Life Center at one of the reservations provides counseling, youth activities, trips, etc.
12- 18 years (adolescence)	
• **Intervention** (includes those affected)	**Case Management:** Arizona (Georgia Butler): Genetic clinics are held at the service units. See pg 33 App I Sec F. Minnesota: Clinic Assessment Teams provide evaluations for children with significant behavior difficulties which may be related to fetal alcohol exposure. See pg 52 App V Sec B.

Life Stage	Existing
	South Dakota: Interdisciplinary Diagnostic Clinics. See pg 53 App V Sec C. Arizona (Georgia Butler): Treatment plans are developed. Arizona (Georgia Butler): On site counseling provided at some schools.

Life Stage	Existing
12- 18 years (adolescence)	
	Arizona (Georgia Butler): Residential treatment centers for adolescents. Arizona (Georgia Butler): Transition services for students 14 and up (provided by Arizona DOE) which connects students and families with appropriate agencies, program and services to make the transition from school to post-school activities such as vocational training, employment, independent living, adult services, etc. See SAMHSA Scan: Medical University of South Carolina – hospital that provides FASD diagnostic and referral services for all individuals who are referred, including American Indians. Contact Information: Pediatric Child Development Dr. Shashidhar Pai (843) 876-1516. See SAMHSA Scan: Thunder Spirit Lodge, joined with Chrysalis, a Center for Women this program provides specialized program support services within a family-driven organization to children (4-22 not set up for older adults) and young adults diagnosed with fetal alcohol spectrum disorders and their families. Diagnostic services performed at the University of Minnesota Fetal Alcohol Diagnostic Center and St Joseph's Children Hospital. The center serves American Indians. Contact Information: Chrysalis –Cindy Murphy Kelly, Director (612) 870-2417; Janet Lang, Director of Fetal Alcohol Diagnostics Program (serves all ages), Duluth, MN (218) 726-4858. **Research:** See SAMHSA Scan: American Indian Rehabilitation Research and Training Center, University Center on Disabilities, Institute of Human Development NAU, AZ - conducts research and training for American Indian and Alaska Natives with disabilities. Special focus is on culturally relevant rehabilitation programs for individuals with FASD.

Life Stage	Existing
Adults	
• **Prevention** (includes those affected and not affected)	**Education:** Arizona (Georgia Butler): Education is provided to the community members, parents, caregivers through trainings, conferences, health fairs, sobriety festivals, etc.
• **Intervention** (includes those affected)	**Services:** Arizona: Division of Developmental Disabilities services for those who meet eligibility criteria. Arizona (Georgia Butler): Vocational Rehabilitation services
Elder	
• **Prevention** (includes those affected and not affected)	**Services:** Arizona (Georgia Butler): Same as above
• **Intervention** (includes those affected)	

Life Stage	Existing
Community	
• **Prevention** (includes those affected and not affected)	**Education:** 3 day FAS training for IHS participants at the University of Washington Primary care provider training in chemical dependency for physicians / nurses sponsored by IHS Women wellness conferences/ Gathering of Native Americans (promotes community healing) Alaska: In addition to the primary clinical emphasis, training and education of community, parents/caregivers, and professionals (e.g., physicians, mental health, educators, child advocates etc) are conducted. A **3rd Annual Community Workshop on FAS**, in 2003 focused upon legal issues. Robin Ladue Ph.D. gave the keynote. National FAS Awareness day prevention/education activities are held in the service community. A team was selected by State of Alaska to develop, over the next two years, an **in-state diagnostic training program based upon the University of Washington's FAS team model and diagnostic system,** See http://depts.washington.edu/chdd/ucedd/CCS/CCSFAS.html
Community	
	Alaska Indian Health Care System which includes FAS / FAE / alcohol-related neurodevelopment disorder (ARND) Screening, Diagnosis, Treatment, and perinatal alcohol exposure prevention activities. Contact Information: See Alaska FASD Team Network grid for contacts. Appendix [???] See SAMHSA Scan: Fetal Alcohol Syndrome Prevention Program. This program provides

Life Stage	Existing
	FAS prevention services for the community, such as identifying and studying children with alcohol-related birth defects (ARBD) and working with birth mothers and pregnant women at high risk. Contact Information: **Mike Baldwin**, Southcentral Foundation (907) 729-4251. See SAMHSA Scan: Yukon-Kuskokwim Health and Social Services. A librarian responds to requests for FASD information and resources. Contact Information: See Alaska FASD Team Network grid for contacts. Appendix [???] **Awareness:** FAS World (www.fasworld.com/home/ihtml) is an international alliance of parents and professionals who don't want to see any more children, teenagers, and adults struggle with birth defects caused when their mothers drank alcohol during pregnancy. Co-founded by volunteers in Toronto, Canada, and Tucson, Arizona, this led to the creation of FAS World Canada (www.fasworld.com/about.ihtml) which works with the Fetal Alcohol Community Resource Center
Community	
	(www.come-over.to/FASCRC/) See pg 61 App VI Sec F. See SAMHSA Scan: Kodiak Area Native Associations Compass Project is a grant that provides a comprehensive needs assessment of FASD services in the Kodiak area. Funds will be used to provide workshops addressing FASD community training needs. Contact Information: Nancy Wells Kodiak Area Native Association3449 East Rezanof Kodiak, AK 99615 (907) 486-4643
• **Intervention** (includes those affected)	NOFAS (Lisa Neel): Interventions including both community wide and targeted approaches have shown moderate success in reducing drinking behaviors. See pg 77 App IX Ref # 14. **Case Management:** See SAMHSA Scan: American Indian

Life Stage	Existing
	Community House (AICH) is an urban community health center in New York City that provides outpatient substance abuse treatment and prevention services. They also provide information about FASD to pregnant women. Children, individual, or families with developmental difficulties are referred to community services. See SAMHSA Scan: Brandywine Counseling Inc., Bridge Perinatal Unit: Outpatient drug and alcohol treatment facility that does FASD screening at birth.
Community	
	See SAMHSA Scan: The Choctaw Nation Recovery Center is an inpatient alcohol and drug treatment center for men and women. FASD is part of the treatment center curriculum. Contact Information: Bert Holt, Clinical Director Choctaw Nation Recovery Center RR 2 Box 1600 Talihina, OK 74571 (918) 567-2389 http://oasis.ouhsc.edu/Directory/oilc0516aa.html See SAMHSA Scan: The Cordova Family Resource Center provides community FASD education. Grant funds will be used to purchase resources such as "Baby Think It Over" curriculum used to address the high teen pregnancy rate in Cordova. The program serves the neighboring villages. Contact Information: Nicole Songer, Exec. Director (907) 424-5674. See SAMHSA Scan: Salt River Behavioral Health Department. This alcohol and drug program provides outpatient treatment for the community. Pregnant women who are drinking and present for any behavioral health services are referred to treatment. FASD awareness efforts take place in **the High School.** Contact Information: Sherilla McKinley, Health Educator (480) 850-8430

Life Stage	Existing

Appendix I:

Selected Programs from the Scan:

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

A. Project CHOICES (Changing **H**igh-Risk Alc**O**hol Use and **I**ncreasing **C**ontraception **E**ffectiveness **S**tudy**)**
See: http://www.cdc.gov/ncbddd/fas/choices.htm

Purpose: To Prevent Alcohol-Exposed Pregnancies Among High-Risk Women in Special Community-Based Settings

In September 1997, CDC awarded cooperative agreements to three university grantees to develop brief interventions aimed at preventing alcohol-exposed pregnancies among women of childbearing age in special settings. The selected settings (see below) have access to relatively large numbers of women of childbearing age who drink at high-risk levels and do not use contraception effectively.

Nova Southeastern University in Ft. Lauderdale, Florida

- Adult and Pediatric Primary Care Centers in the North Brossard Hospital District of Ft. Lauderdale
- Recruitment of a cohort of women concerned about problem drinking through media advertisement in the Ft. Lauderdale area

University of Texas Health Sciences Center at Houston, School of Public Health in Houston, Texas

- Harris County Jail
- Houston Recovery Campus

Virginia Commonwealth University, Medical College of Virginia in Richmond, Virginia

- Gynecology Outpatient Clinic of the Medical College of Virginia
- South Richmond Health Center

A common protocol for a behavioral intervention was developed, implemented, and evaluated in each of the six settings. A feasibility study designed to test the behavioral intervention was conducted from March 2000 until May 2001. Study participants (50 women from each of the six special settings) were provided a brief intervention of four sessions delivered over the course of eight weeks. The intervention consists of the following:

- In-depth assessment of alcohol use and contraceptive use patterns.
- Counseling about the consequences of alcohol use during pregnancy.
- Brief advice and counseling for moderate-to-heavy drinkers to reduce intake levels, or referral to community treatment services for alcohol-dependent drinkers.
- Reproductive health education about contraceptive methods, provision of contraceptive services, and client follow-up.

To read more about the feasibility study see

Ingersoll K, Floyd L, Sobell M, Velasquez MM; Project CHOICES Intervention Research Group. Pediatrics. 2003 May; 111 (5 Part 2): 1131-5.

B. MIAMI

See: http://www.dphhs.state.mt.us/hpsd/pubheal/healsafe/famheal/homevis/miami.htm

MIAMI, (**M**ontana's **I**nitiative for the **A**batement of **M**ortality of **I**nfants) was passed in the 1989 Montana Legislature to:

- Ensure that mothers and children receive access to quality maternal health services
- Reduce infant mortality and the number of low birth weight babies (5½ pounds or less)
- Prevent the incidence of children born with chronic illnesses, birth defects, or severe disabilities as a result of inadequate prenatal care

MIAMI projects are intended to serve only high risk pregnant women, which account for approximately 20 percent of the pregnant population in Montana.

Local MIAMI projects provide nursing, dietitian and social services, health education and advocacy for pregnant women. Professionals at each MIAMI site monitor the woman's pregnancy and outcome. A woman needing assistance will be referred to an agency or agencies that can help.

Directives for improving birth outcome for pregnant women and decreasing the incidence of infant death are firmly grounded in the Federal Title V Maternal and Child Health mandates. The State is also committed to improved pregnancy outcomes in Montana. The four components of MIAMI are:

II. Provision of services in local communities (MIAMI projects are found in 33 Montana communities).
III. Public education campaigns regarding the importance of early and continuous prenatal care.
IV. Review of the causes of fetal infant and child deaths at both local and state level to identify preventable cause of death and implement policy change to impact those deaths that can be prevented. See FICMR.
V. Improving services for Medicaid eligible women who are pregnant.

MIAMI Sites

- Beaverhead MIAMI — Barrett Memorial Hospital
- Cascade MIAMI — City-County Health Department/ Better Beginnings
- Chouteau MIAMI — Chouteau County Health Department
- Crow Reservation MIAMI — Crow Tribal Health
- Dawson MIAMI — County Health Department
- Fergus MIAMI — Fergus County Public Health Nurses
- Flathead MIAMI — City-County Health Department
- Gallatin MIAMI — City-County Health Department
- Hill MIAMI — County Health Department
- Jefferson MIAMI — County Health Department
- Lewis and Clark MIAMI — City County Health Department
- Missoula MIAMI — City County Health Department
- Park MIAMI — County Health Department
- Ravalli MIAMI — Marcus Daly Memorial Hospital
- Butte/Silver Bow MIAMI — City County Health Department
- Tri-County MIAMI — Toole, Teton, and Pondera County Health Departments
- Yellowstone MIAMI — City County Health Department

C. Baby Arizona

See: http://www.azwellness.com/babyarizona.html

GOAL

To increase the number of women who receive early and continuous prenatal care.

MISSION

To increase the percent of healthy babies born to Arizona women and to improve the health of expectant mothers through a public/private partnership that focuses on outreach to low-income pregnant women and reduces barriers to early prenatal care.

D. Parent-Child Assistance Program† (P-CAP)

See: http://depts.washington.edu/chdd/ucedd/CO/co_PCAP.html

The goal of P-CAP is to prevent births of children with alcohol and drug effects by identifying women who abused alcohol or drugs during pregnancy, by helping them become clean and sober and stay in recovery, and by convincing women who abuse substances not to become pregnant.

The project provides trained and supervised advocates to work with a caseload of 15 mothers and their families for three years beginning with the birth of the target child. The advocates assist clients in identifying personal goals, obtaining alcohol/drug treatment, staying in recovery and choosing a family planning method. They also may help with such matters as child health care, transportation to appointments, housing, domestic violence or child custody problems, and they connect clients with needed community services.

P-CAP is funded by the Washington State Legislature with four sites statewide (Seattle, Tacoma, Yakima, Spokane). State funding has allowed the program to broaden its focus to include women who have a child with fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE) or who themselves have been diagnosed with FAS/FAE.

The four-site program is coordinated by a training and evaluation component at the UW School of Medicine's Fetal Alcohol and Drug Unit.

E. AZ Early Intervention Program

See: http://www.de.state.az.us/azeip/pdf/AzEIPNotesIssue1.pdf

Eligibility Determination for AZ Early Intervention Program:
The State of Arizona defines as eligible a child between birth and 36 months of age, who is developmentally delayed or who has an established condition, which has a high probability of resulting in a developmental delay, as outlined in the state's definition.

A child from birth to 36 months of age will be considered to exhibit developmental delay when that child has not reached 50 percent of the developmental milestones expected at his/her chronological age, in one or more of the following domains:

- physical/fine and/or gross motor/sensory
- cognitive/adaptive
- language/communication
- social/emotional
- self-help/adaptive

Determination that a child is developmentally delayed will be based on professional evaluation or assessment and will include parental involvement and input.

Established conditions which are deemed to result in a high probability of developmental delay include, but are not limited to:

- chromosomal abnormalities
- metabolic disorders
- hydrocephalus
- neural tube defects (e.g., spina bifida)
- intraventricular hemorrhage
- periventricular leukomalacia
- cerebral palsy
- significant auditory impairment
- significant visual impairment
- failure to thrive
- severe attachment disorders

The Department of Health Services (DHS) assumes the primary agency role for:

- Metabolic Disorders
- Neural Tube Defects (spina bifida)
- Severe Attachment Disorders
- Other conditions where CRS provides extensive medical services

Referral for AZEIP Eligibility Determination:
Children may be referred for AzEIP eligibility determination by any concerned individual or organization, such as parents, primary care physicians, community health nurses, other child care providers, AzEIP management teams or other agencies and service providers. The developmental services coordinator will receive and review all referrals (including medical information), initiate family contact, and assess child's readiness for testing. The coordinator, in collaboration with other team members, including the interim service coordinator, will develop an evaluation/testing strategy. The child will be scheduled for the evaluation/s that best meets the presenting concerns.

DHS Developmental Services to be rendered:

1. An assessment of physical parameters
2. Developmental evaluation and/or discipline specific evaluation
3. Initiation of the identification of family resources, priorities and concerns
4. Parent education and support
5. Assistance with referrals for community-based services
6. A written developmental report.
7. Multi-disciplinary case conferences as indicated
8. Transportation assistance to families having financial or transportation difficulties.
9. Developmental evaluations completed in the home by clinic staff.
10. Nutrition and Social Service evaluations.
11. Provision of bi-lingual services when needed.
12. Communication of the team findings regarding the child's developmental strengths, needs, medical issues, and eligibility to parents, primary care providers and any other team members the family identifies.

Community Collaboration:

Developmental services:

- Provides opportunities to educate and train various disciplines such as physicians, therapists, nurses, psychologists, etc., in the area of pediatric developmental assessments.
- Provides opportunities for hospitals, universities, and other institutions to give feedback to hospital staff and early intervention programs. The feedback will serve to improve the care of critically ill infants as well as the support given to families.
- Collaborates and networks with community referral agencies.
- Collaborates with community referral and/or social services, when available, to ensure responsive action in the high risk population including participation in multi-disciplinary, family-focused team conferences.
- Assures the completion of the referral process to appropriate community resources.
- Identifies and/or interfaces with infants and families in critical social situations to ensure their involvement in the early intervention programs.

F. Genetic Clinics

ARIZONA:

See: http://www.ahsc.arizona.edu/opa/horizons/1997/pediatric.htm
and http://www.mostgene.org/dir/diraz.htm

Background

- More than 10 years ago Dr. Eugene Hoyme, MD a pediatric-geneticists from the University of Arizona sought funding to take pediatric genetics services to Native American children who were in need of them. The University Department of Pediatrics received a Special Project of Regional and National Significance (SPRANS) grant to set up a pilot project for the Native American community. The original grant provided clinics at all service units within the Navajo, Phoenix, and Tucson Areas. With the termination of the SPRANS grant funding, each IHS Area decided how to continue this service.

Clinic Services

- Currently, in the Phoenix Area IHS, services continue to be provided at all Arizona Service Units under a contractual agreement with the University of Arizona (in both Phoenix and Tucson). Services include definitive medical evaluation, diagnosis, treatment, and referral. IHS Contract Health Services funds are utilized to provide these services.
- Full spectrum of genetic services is available in Arizona including prenatal, pediatric, adult, and cancer genetics.
- Team approach to providing care for kids. Includes physicians, nurses, social workers, and genetic counselors.
- Currently the State of AZ and IHS continued this program that was initially designed to be short term. IHS and the State Children's Rehabilitative Services (CRS) provide funds to ensure that genetic programs continue.

- Try to build long term relationship with families to help children and families deal with genetic diseases and conditions.

MICHIGAN:

NW Community Health Agency of Michigan or Munson Medical Center (University of Michigan)
Phone: 734-764-0579

Healthy Start Nurse, Vivian Le Grand, reports that the doctor the Little Traverse Bay Bands of Odawa Indians Healthy Start Program refers families to a Dr. Daniel Verburg from Petoskey for Amniocentesis and Genetic Counseling.

Vivian Le Grand, RN, BA
vlerand@ltbbodawa-nsn.gov
Healthy Start Nurse
Little Traverse Bay Bands of Odawa Indians Healthy Start Program
7500 Odawa Circle
Harbor Springs, MI 49740
231-242-1614

Dr. Daniel Verburg, OB/GYN
Bayview Obstetrics and Gynecology
560 W. Mitchell
Suite 530
Petoskey, MI 49770

NEW MEXICO:

See: http://www.mostgene.org/dir/dirnm.htm

University of New Mexico Health Sciences Center / Department of Pediatrics / Division of Genetics/Dysmorphology, Provides field clinic at the Gallup Indian Medical Center and Northern Navajo Medical Center

3rd Floor Ambulatory Care Center
Albuquerque, NM 87131-5311
Director: Carol Clericuzio, MD
Phone (505) 272-6631
FAX (505) 272-6823
Email ccleri@salud.unm.edu

Regional Genetic Clinic Sites: Carlsbad, Clovis, Farmington, Gallup, Las Cruces, Las Vegas, Roswell, Santa Fe, Shiprock, Silver City, Taos, Zuni

ADDITIONAL GENETIC CLINIC INFORMATION:

See: http://www.mostgene.org

The MoSt GeNe is the Mountain States Genetics Network which provides information on medical genetics knowledge and resources from other health care practitioners, patients, and caregivers. The website allows you to search by topic which include genetic services, chromosome analysis, DNA analysis, prenatal diagnosis, patient and family issues, education, newborn screening, and other links.

G. Northwest Fetal Alcohol Syndrome Project

See: http://www.npaihb.org/epi/fas/fas.html

Project Goal:

Reduce the level of FAS through the development of effective programs and multidisciplinary collaborative partnerships.

Project Information:

The project seeks to identify and track women of childbearing age who are potentially affected by fetal alcohol exposure in utero, so that prevention strategies can be appropriately designed to meet their cognitive and social emotional needs. The FAS project is in its fourth year of operation. Two Project Specialists, Carolyn Hartness for the Washington and Northern Idaho tribes and Suzie Kuerschner for the Oregon and Southern Idaho tribes, meet with tribes as needed to educate the community on FAS. Conferences are held regularly to share FAS information with the community.

Appendix II:

Educational Tools

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

Curricula:

A. Beginning Alcohol and Addictions Basic Education Studies (BABES)

See http://www.aodc.org/BABES.html

THE BABES FAMILY:
Buttons & Bows McKitty, Myth Mary,
Early Bird, Donovan Dignity,
Recovering Reggie and Rhonda Rabbit

The BABES Philosophy:
"Today's children are tomorrow's future. Hope for this future is dependent upon the existence of an environment which is strong, healthy, nurturing and safe, effectively addressing the problems of today's youth, such as dropouts, pregnancy, suicide and alcohol and other drug use."

The BABES program uses believable, cuddly puppets to tell 6 story lessons. The curriculum includes:

Lesson #1 – Self Image
Lesson #2 – Peer Pressure & Good Decisions
Lesson #3 – Coping Skills
Lesson #4 – Alcohol & Drug Information
Lesson #5 – Getting Help
Lesson #6 – Chemical Dependency

The major concepts are expressed through animal puppets who are humanized to be like men, women and children we all know. The BABES puppet characters are:

- **Buttons & Bows McKitty** are brother and sister kittens. They reflect the same feelings and emotions that real children experience and are used to demonstrate effective, acceptable ways of making decisions, coping and handling other life situations.
- **Myth Mary** is a squirrel who repeats everything she hears without knowing if it is factual or appropriate for the occasion, much of what she says and does is based on myths and misconceptions, not only about alcohol, alcoholism and drug dependency, but also about every other life situation she experiences. Through her character, children come to realize how misguided some of their own beliefs are, I.e., "It's wrong to feel angry" or "Alcoholics are bad people", and other myths.
- **Early Bird** gives a "honk-honk" early warning signal for self defeating behavior in general and gives the consequences for decisions that are not healthy for the mind and body.
- **Donovan Dignity** is a wise owl who corrects Myth Mary's misconceptions and shares a lot of other good information about ways of having a happy, healthy life. He presents things in a factual, non-judgmental manner in ways children understand.
- **Recovering Reggie** is a dog who is a recovering cross-addicted alcoholic. He tries to erase the stigma attached to chemical dependency and to pass on the lessons in living he has learned a part of his recovery.
- **Rhonda Rabbit** lives in a home with two cross-addicted alcoholics. She is also an abused child. She is the "voice of experience" and can tell children first-hand what has happened to her and how she copes.

This 6 week program is a primary prevention program designed to assist children ages 5 to 8 in developing positive living skills. BABES accomplished this goal by providing the children with accurate, non-judgmental information.

THE BABES COMMITMENT

BABES (Beginning Alcohol and Addictions Basic Education Studies) are founded on one belief. Children are entitled to have happy, healthy lives, free from substance abuse. In this very vane, BABES is committed to providing children with healthy living skills and information needed for a lifetime of protection from substance abuse.

By being sensitive to and approaching children at specific developmental level, BABES presents complex concepts in a simple, factual, non-threatening manner.

BABES is committed to remaining state-of-the-art by constantly updating its curriculum, consistent with new research regarding the long term effects of substance abuse prevention on the lives of young people.

Through your caring and guidance along with the BABES commitment, we can change the world.

B. Beyond the 7th Generation Project

See: http://tel.occe.ou.edu/aii/Faces.htm

Description

The Beyond the 7th Generation (B7Gen) Project is a 3 year (2001-2004) science-based project which is piloting the 7th Generation Curricula (Faces Yet to Come and Remembering What We Know) developed during a 2-year 1995 SAMHSA Center for Substance Abuse Prevention (CSAP) funded for 3 years but cut back to 2 years. B7Gen's proposed objectives included the testing of these curricula and revision of the existing curricula for the purposes of updating information and developing more teacher-friendly technological and other educationally-sound curricular changes in accordance with culturally appropriate and sensitive elements as well as input form the Teacher/Trainers and Advisory Board members.

7th Generation Curriculum Guide:

The 7th Generation **Fetal Alcohol Syndrome** (FAS) **and Fetal Alcohol Effects** (FAE) prevention curriculum is designed for American Indian students in the 6th through 8th grades. The curriculum is designed to be utilized in conjunction with the 7th Generation **video, "Faces Yet to Come."**.

This curriculum is designed to be incorporated into grades 6th, 7th, and 8th as a series of ready-to-use activities that support Fetal Alcohol Syndrome prevention efforts through education.

This curriculum combines structure and flexibility. Each lesson includes the presentation of information and experiential learning activities. Students are active participants in the learning process. In addition, students are encouraged to include family members, tribal elders, and community leaders as valuable resources for the learning process.

This curriculum is organized in nineteen lessons. For maximum benefit, it is recommended that the lessons be presented as numbered. Each lesson begins with a *Goal* and learning *Objectives* which clearly state the purpose of each lesson and desired student outcomes.

Most of the lessons require little preparation. If materials that are not usually found in a classroom are needed for student activities, *Materials Needed* will be listed after Objectives. *Background Information* contains information to be disseminated to the students. This information is presented as a handout to be copied and distributed to each student. *Student Activities* enhance the learning process and include research projects, experiential learning activities, and class discussion. *Evaluation Activities* measure learning outcomes.

The bibliography provides a listing of resources used in the development of this curriculum. Teacher/facilitators are encouraged to add community-specific resources to this listing for future use.

Remembering What We Know:

Target group Grades 9-12

Includes a Presentation Kit and Video

The Presentation Kit includes FAS facts and consequences and contains

- Presentation-ready lecture notes
- Colorful, informative overheads
- Handouts ready for duplication

Video:

12 minute movie for informing and stimulating discussions with High School and Young Adult groups which is divided into three Parts:

Part I is the message using Native themes to speak about universal values of caring for the next generation and the dangers of FAS.

Part II is the play that dramatizes the situation of whether a pregnant friend drinks or not.

Part III is the questions where each character asks the viewers a discussion question.

For more information on B7Gens description of the implemented interventions / activities contact:

Judy Salinas, Ph.D., Director
Beyond the 7th Generation Project
American Indian Institute
University Outreach
University of Oklahoma
555 Constitution St., Ste. 237
Norman, OK 73072-7820
Phone: 405-325-7087/405-325-4127
Fax: 405-325-7757
Email: jsalinas@ou.edu

Training Manuals:

C. Northern Arizona University. **Fetal Alcohol Syndrome: A Training Manual to Aid in Vocational Rehabilitation and Other Non-Medical Services.** LaDue RA, Schacht RM, Tanner-Halverson P, McGowan M. Flagstaff, AZ, 1999.

Purpose: To aid trainee in

1) Understanding what fetal alcohol syndrome is and what it is not
2) Recognizing and assessing primary and secondary disabilities
3) Screening for FAS or FARC
4) Developing an individualized plan
5) Designing and aiding the implementation of an individualized plan
6) Evaluate how a plan is working and make adjustments

D. National Organization on Fetal Alcohol Syndrome. **Fetal Alcohol Syndrome Practical Suggestions and Support for Families and Caregivers.** Mitchell KT. Washington, DC 2002.

Description: A handbook to help families as they go through the many stages of accepting that their family member has FAS or other alcohol related birth disorders.

Purpose: To assist families to better plan, strategize, and cope with family members with FAS

E. Hartness C. **Alcohol and the Fetus: A Training Manual for Trainers.** Second Edition: October 2002.

Description: Advanced training manual for professional and paraprofessional trainers who want to expand their knowledge of the possible effects of alcohol on the fetus. After reviewing the manual, trainers will be able to develop presentations for various types of audiences, i.e., parents, teachers, social service professionals, medical and treatment providers, and community groups. The manual is divided into 7 major topic areas (1. History of Alcohol Related Birth Defects; 2. Alcohol Ingestion and the Possible Effects on the Fetus; 3. Central Nervous System (CNS) Dysfunction; 4. Early Identification and Referral for Diagnosis; 5. Interventions for Children and Adults Affected by Alcohol in Utero; 6. Alcohol and Society; and 7. Prevention) and includes an extensive list of resources.

F. Journey Through the Healing Circle, Series on Fetal Alcohol Syndrome: Love, respect, structure, and laughter – these are the keys to parenting a child with FAS. Washington State Alcohol/Drug Clearinghouse

Includes:

- Set of 4 books separated into age groups beginning with birth to age 22
- Two Video tapes separated into 2 age groups beginning with birth to age 22
- Books and Video tapes can also be purchased in CD format
- Poster
- Coloring Book

G. LaRue RA. **A Practical Native American Guide for Professionals working with children, adolescents, and adults with FAS and FASD.** IHS/PHS NPAIHB, 2002.

LaRue RA. A Practical Native American Guide for Caregivers working with children, adolescents, and adults with FAS and Alcohol related conditions. IHS/PHS Date Unknown.

Education Tools:

H. Fetal Alcohol Syndrome Awareness and Education Project

See: http://www.cdc.gov/ncbddd/fas/awareness.htm for more details on other funded projects

Purpose: To (1) develop, implement, and evaluate materials to educate parents and professionals working in school systems, public health service agencies, social service agencies, and judicial systems about FAS and other fetal alcohol-related disorders and (2) identify how to secure access to appropriate diagnostic and treatment services for affected children and their families.

Funded Projects:

The Arc of the United States—Silver Spring, Maryland
This project is developing and testing a comprehensive curriculum that can be presented to adult learners in a workshop format. The modules address general information about FAS, components of care for the affected child, and family stressors and coping strategies. The Arc's team of seven chapters is using available resources and printed materials and creating new materials as part of the development of the comprehensive curriculum.

Double ARC—Toledo, Ohio
This project is developing and testing a training curriculum for parents that describe the core deficits of children with FAS; teaches effective parenting techniques; and informs how to access service resources for children, including school programs. The training curriculum for teachers describes FAS, ways to recognize children who might have the condition, and approaches to enhancing school performance for children with FAS.

Education Development Center—Newton, Massachusetts
This project is developing an online education package targeting teachers and parents about FAS and related disorders, and an online education package for training the trainer. Content includes a comprehensive review of the physical, neurodevelopmental, and behavioral characteristics of children with FAS; secondary disabilities; needed services; family stressors and coping strategies; and what schools can do with limited community resources.

National Indian Justice Center—Santa Rosa, California
This project is developing and testing a training curriculum for three-day regional training sessions focusing on medical and psychological aspects of FAS/ARND, with breakout sessions that provide information more specifically geared toward various subgroups such as tribal court judges, state court judges, and tribal leaders. Focus groups and a community needs assessment are being conducted to inform materials development.

Future Curriculum:

I. NOFAS - Medical school curriculum

In development by NOFAS. These curriculums are currently implemented at Northwestern and Georgetown universities and they introduce students to FASD by combining scientific understanding of the disease with personal, familial and societal dimensions, and legal and ethical considerations as well. It focuses on the need for medical professionals to practice effective communication, counseling and leadership skills to identify and prevent FASD.

NOFAS – K-12 curriculum

In development by NOFAS. To be implemented in grades K-12.

For more information contact:

Lisa C. Neel, MPH
Program Associate
Native American Programs
National Organization on Fetal Alcohol Syndrome
900 17th Street, NW
Suite 910
Washington, DC 20006
202-785-4585 X. 212
202-466-6456 fax
neel@nofas.org
www.nofas.org

Prenatal Education:

J. Canada: Six Nations Maternal and Child Centre

Reported by Ruby Miller, R.N. (Aboriginal Midwifery Services, Hagersville, Ontario) at the IHS 16th Annual Research Conference, 5/11-5/13:
Contact Info:
Maternal and Child Centre Supervisor, R. R. # 6
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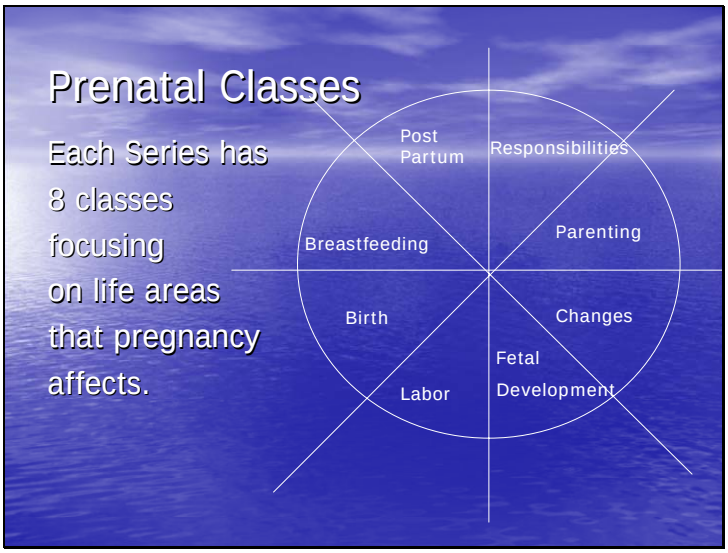
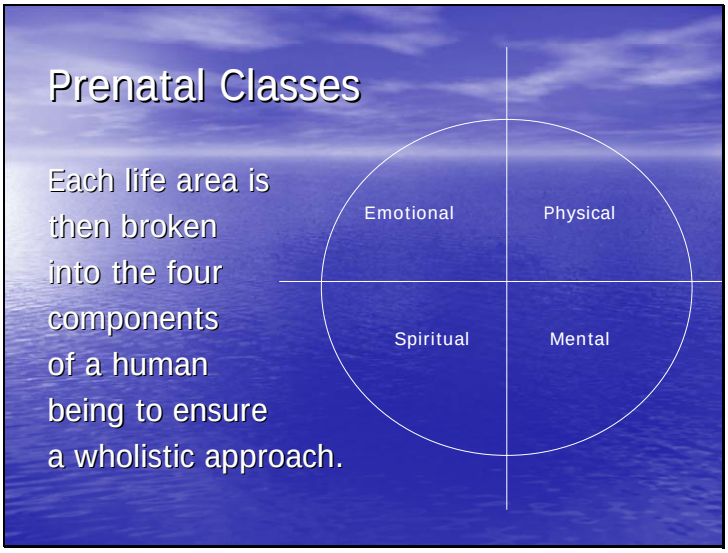
N0A 1H0
519-445-4922 FAX 519-445-4032
tsinonwe@sixnationsns.com





K. Indian Health Service Patient and Family Education Protocols and Codes:

PATIENT EDUCATION PROTOCOLS: PRENATAL

PN-1T FIRST TRIMESTER

OUTCOME: The first trimester patient will understand the progression of pregnancy as related to fetal growth and development and changes in her body.

STANDARDS:

1. Explain the reproductive cycle. Identify and explain the functions of: the ovaries, ova, fallopian tubes, uterus cervix, placenta and vagina as it relates to pregnancy.
2. Discuss fetal growth and development during the first trimester. Emphasize the importance of regular prenatal care, rest, prescribed vitamins, iron and good nutrition. Relate adequate folate intake to fetal neural tube health.
3. Discuss the importance of appropriate weight gain. Review the food pyramid, suggest foods that should be increased, i.e., those high in folic acid, iron, vitamin A, calcium; and those to be limited or avoided, i.e., those high in salt, fat, caffeine and empty calories.
4. Emphasize the importance of complete abstinence from drugs, alcohol and tobacco. Point out that use of drugs and/or alcohol during pregnancy can result in birth defects or other complications. Evaluate the patient's use of substances and refer for treatment as appropriate. **Refer to CD**.
5. Teach the patient to inform all health care providers of her pregnancy prior to obtaining treatment (x-rays, medications, etc.).
6. Discuss the importance of good personal and dental hygiene as it relates to good health and positive self-image. Discuss the dangers of fetal overheating in relation to hot baths, jacuzzis, sweat lodges, etc. **Refer to WL-HY**.
7. Discuss relief measures for the discomforts of pregnancy.
8. Discuss sex during pregnancy. Encourage the patient to ask questions.
9. Explain the clinical procedures (exams, lab, sonograms etc.).
10. Emphasize the patient's responsibilities to herself and her growing child. Discuss the dangers of exposure to infectious diseases (measles, toxoplasmosis, STDs, parvovirus, etc.).
11. Emphasize the importance of prepared childbirth classes and parenting classes. Encourage the patient to enroll at the appropriate times.

PATIENT EDUCATION PROTOCOLS: PRENATAL

PN-CD CHEMICAL DEPENDENCY

OUTCOME: The patient/family will understand the disease process of chemical dependency/substance abuse and its relationship to fetal development and develop motivation for change.

STANDARDS:

1. Emphasize the importance of complete abstinence from alcohol, inhalants, other drugs and tobacco. Point out that use of alcohol, inhalants and other drugs during pregnancy are associated with birth defects or other complications. Evaluate the patient's use of substances and refer for treatment as appropriate. **Refer to CD.**
2. Administer CAGE or other screening instrument.
3. Discuss that alcohol use during pregnancy is directly associated with an identifiable syndrome in the child. This syndrome can cause developmental delay, hyperactivity, emotional and behavioral problems, mental retardation, learning disabilities, and decreased ability to function independently as an adult. This syndrome has been called fetal alcohol syndrome, fetal alcohol effect and pervasive developmental delay.
4. Review treatment options available.
5. Refer to community resources as available or appropriate.

Videos:

L. Students Like Me

See: http://www.vida-health.com/product_menu.php?uid=1088175422

Students Like Me Teaching Children with Fetal Alcohol Syndrome. (2000). [Video]. Massachusetts: Vida Health Communications.

Students Like Me Raising Children with Fetal Alcohol Syndrome. (2000). [Video]. Massachusetts: Vida Health Communications.

Description:

Vida's award-winning programs on FAS are designed to help clinicians, educators, and caregivers cope with the challenges of this wholly preventable problem. All three programs were produced with an SBIR grant award from the National Institute on Alcohol Abuse and Alcoholism and have been professionally researched, reviewed and evaluated in accordance with accepted research practice.

Appendix III:

Biological Screening

(The following list provides information on useful resources and is not intended to be comprehensive)

A. USDTL Newsletter

United States Drug Testing Laboratories
1700 South Mount Prospect Road
Des Plaines, IL 60018-1804

USDTL Notes

Volume 1 Issue 2 | Quarterly Newsletter | April 2004

MecStat-EtOH^{sm} Fetal Alcohol Monitor

USDTL introduced the MecStat-EtOH^{sm} assay in 1999. The assay utilizes a panel of 7 fatty acid ethyl esters to identify fetal alcohol exposure in the last 20 weeks of a term pregnancy. USDTL is the only commercial reference laboratory offering this screening test on a routine basis.

The assay is done by GC/MS analysis. This method provides great sensitivity in correctly identifying ethanol exposure.

Results are available 3 days after the sample is received in the laboratory.

Sample requirement is 2-3 grams of meconium (one teaspoon).

B. Biomarkers – CDC:

See: http://www.cdc.gov/ncbddd/fas/biomarkers.htm

Identifying Alcohol-Exposed Pregnancies through Biomarkers

Moderate-to-heavy alcohol use by pregnant women is known to be harmful to the developing fetus. Currently, there is no specific laboratory marker to indicate fetal alcohol syndrome. Obtaining such a marker could lead to the identification and treatment of women at risk for an alcohol-exposed pregnancy, who may not otherwise provide this information because of the stigma associated with prenatal alcohol use. Also, research has shown that early identification of children with fetal alcohol exposure reduces

secondary disabilities resulting from the condition. Possible biomarkers include maternal blood and meconium (first stool of the newborn infant) testing. The studies described below are designed to devise and test sensitive and specific biomarkers to help identify alcohol-exposed pregnancies and/or newborns exposed to alcohol prenatally.

Funded Projects:

University Hospital of Cleveland—Cleveland, Ohio

It is estimated that 1% of all newborns are affected by prenatal alcohol exposure. However, identifying alcohol-exposed newborns is difficult. Currently, there is no systematic approach, nor definitive laboratory tool that can be used for such identification. A biological marker, fatty acid ethyl esters (FAEE), would allow earlier identification and intervention for affected infants, and recognition of women at risk for alcohol abuse. This also facilitates research on dose-response relationships between alcohol exposure and alcohol-related birth defects. The project proposes that FAEE in meconium is a useful biological marker for exposure of low-to-moderate maternal alcohol use during pregnancy, and for identification of a group of infants at high risk for poor neurodevelopmental outcomes. The study seeks to validate FAEE in meconium as a biomarker of prenatal exposure to alcohol.

University of Maryland—Baltimore, Maryland

The purpose of this study is to investigate the use of biochemical tests and ultrasound findings to identify women who abuse alcohol and are at risk for having a child affected adversely by prenatal alcohol exposure. Criteria, derived from alcohol-use questionnaires, biochemical markers and ultrasound studies, are being developed to identify at-risk, pregnant women who need special counseling or intervention. This information will be correlated with infant development indices taken at birth and at 6 and 12 months of age to predict the prenatal risk for fetal alcohol syndrome (FAS) and other prenatal alcohol-related conditions. Eliminating or reducing alcohol consumption during pregnancy would have a significant effect on the incidence of fetal alcohol syndrome and other prenatal alcohol-related conditions.

Massachusetts General Hospital—Boston, Massachusetts

The goals of this project are to: (1) identify women at risk for having an alcohol-exposed pregnancy through a combination of questionnaire screening and biochemical markers of alcohol use, and (2) motivate the women at risk to decrease their alcohol intake through brief intervention meetings and results of their blood marker levels throughout their pregnancies. Previous studies show that certain blood markers can be used to identify alcohol-using pregnant women more accurately than women's self-reported use. This study will use a combination of blood markers and self-report to identify women at risk of having an alcohol-exposed pregnancy. Pregnant women receiving prenatal care at obstetric clinics at several sites in the Boston area receive a questionnaire to determine if they are risk drinkers. The women who are not identified as risk drinkers on the questionnaire serve as the comparison group for the study. Women who are identified as risk drinkers are asked to provide a blood sample and a series of blood markers of alcohol use are assessed. Women with positive blood markers are then asked to participate in a series of brief interventions and agree to ongoing monitoring of and feedback on the blood markers throughout their pregnancy. Infant outcomes will be assessed on all women participating in the study and the role of specific markers on the achievement of alcohol abstinence or reduction will also be explored.

Appendix IV:

Organizations

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

A. National Organization on Fetal Alcohol Syndrome (NOFAS)

See: http://www.nofas.org/main/index2.htm

NOFAS focuses on the following program areas:

- national and community-based public awareness campaigns;
- a curriculum for medical and allied health students;
- training workshops for professional and lay audiences;
- peer education and youth outreach initiatives;
    - A three-year program is underway to train Indian Youth from the Navajo Nation, Standing Rock Sioux Tribe, Native American Rehabilitation Association, and Mississippi Band of Choctaw Tribes to plan alcohol and pregnancy awareness campaigns within schools and after school programs
    - Teen advisors will serve as peer counselors and recruiters in outreach and community-based activities within schools and after-school programs
    - Other initiatives include developing a teen curriculum guide, hosting teen town-hall meetings on reservations, and creating an interactive web site on the NOFAS home page
- and the NOFAS information, resource and referral clearinghouse.

Some of the other Activities include dissemination of a monthly newsletter, and partnership activities such as the Low-Literacy FAS Project with the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and the formation of the National Task Force in partnership with the IHS in 1993.

Other projects include the development of a K-12 curriculum.

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neel@nofas.org
www.nofas.org

Appendix V:

State Programs

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

A. Alaska Indian Health Care System

See: http://health.hss.state.ak.us/fas/AKfiveyrgoal/default.htm

and

http://www.gov.state.ak.us/omb/Audit03/dhss_62.pdf

and

http://www.fasarizona.com/fazresources.htm

- In 1998 the State of Alaska established the Office of Fetal Alcohol Syndrome within the Department of Health and Social Services (DHSS)
- In October 2000 the state entered into a 5-year $29 million cooperative agreement with the Department of Health and Human Services Substance Abuse and Mental Health Service Administration (SAMHSA) to initiate a statewide comprehensive, integrated approach to FAS prevention and systems improvement (agreement ended on September 29, 2003). These funds reach many Native communities.
- During these 5 years, DHSS focused their attention on the development of screening, diagnosis and service planning, at the community level.
- In working toward a goal to increase AK diagnostic capacity the state developed a network of statewide FAS Multidisciplinary Community Teams
- The Alaska Native Medical Center (ANMC) is one of 13 FAS Multidisciplinary teams, many of which are in primarily Native Communities
    - Some of the Native Communities which are served include Anchorage, Nome, Kotzebue, Bethel, Kodiak, Dillingham, Fairbanks, Tok, Copper Center, Kenai Peninsula, Sitka, Ketchikan, Mat-Su Valley, and Juneau
    - As a clinical program focused on the multidisciplinary diagnostic evaluation of Alaska Native Children prenataly exposed to alcohol that are between the ages of 3-18 years, priority is given to beneficiaries who reside within our service area – that includes Anchorage and approximately 55 rural villages. Second priority is given to accepting referrals from around the state.
- Multidisciplinary evaluation is based on a system developed by the University of Washington's FAS Diagnostic and Prevention Network
    - Team comprises of 4 pediatricians, 2 psychologists, 1 parent navigator/advocate, 1 speech/language pathologist, 1 physical therapist, a social worker, and 1 mental health FAS case manager.
    - Upon team evaluation, considerable energy is spent in developing intervention/care plan recommendations for the child and family

- Limited case management follow-up is provided directly, with the majority of support (through consultation) given to other health care providers as they provide on –going care and follow-up
- Parent/caregiver support groups for the families on the waitlist, and those already diagnosed is provided
- Reduction or prevention of the well known secondary disabilities that arise with this population is being addressed to improve client and their families overall quality of life

- In addition to the primary clinical emphasis training and education of community, parents/caregivers, and professionals (physicians, mental health, educators, child advocates, etc) is conducted
- **3rd Annual Community Workshop on FAS, in 2003**, focused on legal issues. Robin Laude, Ph.D gave the keynote. National FAS Awareness Day prevention/education activities are held in the service community.
- The State of Alaska, over the next two years, has selected the diagnostic team to develop an in-state diagnostic training program based upon the University of Washington's FAS team model and diagnostic system
- South-central Foundation which is part of the Native Health consortium oversees the Alaska Native Medical Center (ANMC) has a number of collaborative programs that are directed at FAS prevention through clinical activities. There is an entry level Pregnancy Support Staff person(s) in women's health clinic and prenatal clinic who provide one on one on-the-spot prenatal alcohol/substance abuse risk assessment and referrals.
- **The Dena A Coy program** (residential treatment for substance abusing pregnant women providing a continuum of services supported by the State of Alaska) is available to all Alaska citizens and is well utilized by the ANMC serviced population (~100% Alaska Native).

  (See http://www.southcentralfoundation.org/index.cfm?pg=29)

  - Referrals are made from the clinics and postpartum care includes PHN follow-up, well baby checks and referral to the FAS clinic as warranted.
  - ANMC staff are seeing second generation FAS issues and undiagnosed FAE that require as much attention to parenting of children and care to themselves
  - High risk women can be referred for a 45 day treatment who are not pregnant or do not wish to fulfill on the criteria for admission and retention that the Dena A Coy treatment team has set up
  - Women can also be referred from Labor and Delivery if a positive urine drug screen is obtained.

  Contact:
  Katie Johnson
  Phone: 907-729-5070

- Alaska also receive funding from the CDC to become one of the 5 states to part of the Fetal Alcohol Surveillance Network (FASSNet)

B. Minnesota Department of Health

See: http://www.health.state.mn.us/fas/servicesforchild.html the following list does not include all services listed on Minnesota Department of Health's website

Minnesota Children with Special Health Needs Behavior Clinics (MCSHN)

The Clinic Assessment Teams:
Provide evaluations for children with significant behavior difficulties which may be related to fetal alcohol exposure.

- A multi-disciplinary team consists of a physician, behavior analyst, social worker, psychologist, occupational therapist and a speech language pathologist.
- The assessment team and parents develop and discuss management strategies for home and school Minnesota Department of Health
- MCSHN Behavior Clinics are located in: Bemidji, Cass Lake, New Ulm, Detroit Lakes, Virginia, and Willmar.
- Telephone: (651) 215-8956 (voice or TDD) or (800) 728-5420 (voice or TDD)

Early Childhood Services Directory of Services Available To Children with Disabilities

This directory lists Minnesota State, county and tribal government services available to help families in the three areas of Early Learning, Family Support, and Financial Resources. The directory includes a local contacts and a partial list of websites which may be of interest to health professionals and families seeking reliable information and resources.

Child Diagnostic and Evaluation Services

Cass Lake Indian Hospital, Cass Lake, MN
Telephone: (218) 335-2293

Education and Family Support Organizations

Native American Community Clinic FASD Intervention Program
Provides FAS/FAE assessments, follow-up, counseling and support. Provides education, support, and referrals for women at risk for alcohol use during pregnancy. Provides primary medical prenatal, pediatric, and adult care for American Indians and the general public.
Minneapolis, MN
Telephone: (612) 872-8086

C. South Dakota

Current FASD Programs:

1) 4-State FASD Consortium (congressional earmark funded through SAMHSA): South Dakota, North Dakota, Minnesota, & Montana collaborated on developing an infrastructure to implement and evaluate prevention, intervention, and surveillance activities
2) FASD Diagnostic Clinic: An interdisciplinary diagnostic clinic held in Sioux Falls, SD using the IOM diagnostic method and seeing approximately 4 children each month
3) Research Projects: NIH funded research project exploring relationship between prenatal alcohol exposure and stillbirth/SIDS ; CDC funded translationsl research to incorporate individual and community-based prevention efforts in the community and FAS surveillance efforts

More on South Dakota Diagnostic Clinics:

See: http://www.usd.edu/cd/fasdi/clinic.htm

Fetal Alcohol Spectrum Disorders Institute
Fetal Alcohol Spectrum Disorders Clinic

Clinic Goal
To provide an appropriate diagnosis of a Fetal Alcohol Spectrum Disorder with on-site consultation to assist with the implementation of recommendations as a result of this diagnosis. The diagnosis will allow professionals and families to develop strategies to improve the educational and health outcomes for the individual with a Fetal Alcohol Spectrum Disorder. The ultimate outcome of this approach is the development of a more productive life for the individual with a Fetal Alcohol Spectrum Disorder.

Referrals
Referrals may be made by anyone for individuals of any age. An intake packet, including an authorization for evaluation and a release of information, will be sent out after a referral is received. The referred individual will be scheduled into the clinic once the necessary paperwork is completed. School/program/agency personnel and families are invited to participate in any or all of the evaluation process.

To request an intake packet, contact the Center for Disabilities at (605) 357-1439 or 1-800-658-3080 (Voice/TTY) or at the address listed at the bottom of this page.

Clinic Information
Clinics are held on the 2nd and 4th Tuesdays of each month on the campus of Augustana College in Sioux Falls, South Dakota. The Educational Strategist will make a pre and post clinic visit to the classroom/program and/or home of the individual as part of the evaluation process.

Clinic Components
The clinic consists of evaluations/interviews with professionals from the following disciplines.

- Clinical Psychology
- Education
- Genetics
- Psychiatry
- Social Work

In addition, if needed, professionals from the following disciplines may be utilized.

- Audiology
- Chemical Dependency
- Neurology
- Nutrition
- Occupational Therapy
- Physical Therapy
- Speech/Language Pathology
- Other Medical Specialties as needed

Clinic Cost

Clinic cost will vary depending on the disciplines involved. Please contact the Center for Disabilities for more information.

Family Services and Student Training

Family services and student training are the foundation of this clinic. Certified and licensed professionals who have experience in the area of Fetal Alcohol Spectrum Disorders from the faculty of The University of South Dakota School of Medicine & Health Sciences will supervise students throughout the evaluation process. Results, recommendations, and diagnosis are made through the utilization of an interdisciplinary team approach.

Diagnosis

Diagnosis will be made utilizing the Institute of Medicine's Fetal Alcohol Spectrum Disorders classification system, as appropriate to the individual being evaluated.

For More Information

For more information contact the Center for Disabilities by phone at (605) 357-1439 or 1-800-658-3080 (Voice/TTY) or at the address listed at the bottom of this page.

Or

Amy Elliott, Ph.D
Center for Disabilities / Department of Pedicatrics
University of South Dakota School of Medicine
1400 W. 22nd Street
Sioux Falls, SD 57105-1570
(605) 357-1439 or 1-800-658-3080

D. Arizona Division of Developmental Disabilities

See:
http://www.de.state.az.us/ddd/EligibilityReferral/frm_EligibilityRequirements.aspx?Visited=true

Background:
The Arizona Department of Economic Security/ Division of Developmental Disabilities provide needed supports to people who meet the following eligibility requirements. Please click on the links below and review the definitions of the terms.

- Is a resident of the state of Arizona
- Voluntarily applies
- Is at risk of having a developmental disability (up to age six) or
- For people over the age of six years, has a diagnosis of
    - epilepsy,
    - cerebral palsy,
    - mental retardation or
    - autism
- The disability occurred prior to the age of 18 and
- Has a substantial functional limitation in three of the seven major life areas.

On the website listed above, the underlined eligibility requirements are hyperlinked to information which provides detailed definitions for each requirement. If eligibility requirements are met, a person can refer the child by clicking on the “Continue” button which then links to a page that asks for further information. The information is then submitted to the Department for follow-up.

Appendix VI:

Additional Resources

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

A. Fetal Alcohol Surveillance Network (FASSNet)

See: http://www.cdc.gov/ncbddd/fas/fassurv.htm

Purposes of FAS Surveillance Network

- Enhance an existing system or develop and implement a new system that uses a multiple-source surveillance methodology to enable researchers to determine the prevalence of FAS within a geographically defined area (statewide, multiple states, or regions within a state);
- Improve the capacity to ascertain true cases of FAS and generate population-based surveillance data;
- Establish relations with facilities or programs where FAS is likely to be diagnosed or children with FAS receive services, such as high-risk newborn registries, special diagnostic units, special education programs, special needs registries, and other programs or settings for children with developmental disabilities;
- Evaluate the completeness of the surveillance system methodology, the system's ability to generate a prevalence rate for FAS, and the potential for monitoring trends; and
- Implement health-care provider training and education on FAS to improve case ascertainment, referral and case-management practices, and prevention activities.

FASSNet Sites

FASSNet projects are in five states. Click on a state listed below to learn more about its program. This cooperative agreement will end September 29, 2003.

B. Institute of Medicine
Fetal Alcohol Syndrome
Executive Summary, 1996

See: http://www.nap.edu/readingroom/books/fetal/summary.html

C. Historic Agreement Heralds New Era for Prevention and Treatment of Fetal Alcohol Spectrum Disorders

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For Immediate Release
April 15, 2004

Contact: Adam Litle
(202) 785-4585

WASHINGTON – At an historic summit hosted by the National Organization on Fetal Alcohol Syndrome (NOFAS), national experts – including for the first time representatives from the Centers for Disease Control, National Institutes of Health, Substance Abuse and Mental Health Services Administration, and Health Canada – came together to produce and sign onto a unanimous agreement on terminology for Fetal Alcohol Spectrum Disorders (FASD).

"There is so much confusion around what to call the broader effects of prenatal alcohol exposure when a diagnosis of Fetal Alcohol Syndrome cannot be made," said summit co-chair Dr. José Cordero, Director of the National Center on Birth Defects and Developmental Disabilities. "Acceptance of this new terminology will go a long way toward getting individuals with the wide range of Fetal Alcohol Spectrum Disorders the recognition, treatment, and services they need."

Summit participants stressed the importance of having a term that communicates the range of issues surrounding Fetal Alcohol Syndrome. "The terminology should serve the individual with the disorder, their parents and those who seek services for the affected individual," said summit co-chair Dr. Kenneth Warren, Office of Scientific Affairs Director, National Institute of Alcohol Abuse and Alcoholism. NOFAS Chairman, Terry Lierman, expanded on this by saying, "Our chief concern is that parents, families, and public policy officials speak with one voice when it comes to treatment and prevention."

The Consensus Statement is as follows:

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.

For a full list of summit participants, contact Adam Litle, NOFAS Director of Government Affairs, at (202) 785-4585.

NOFAS is a 501 (c)(3) nonprofit organization founded in 1990 dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those individuals and families affected by FASD.

D. National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

See: http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5114a2.htm

Recommendations Defining the National Agenda for Fetal Alcohol Syndrome and Other Prenatal Alcohol-Related Effects

Summary Notes Prepared By Teresa Kellerman Based on Report Published In CDC Morbidity and Mortality Weekly Report September 20, 2002

Formation of the Task Force:

Established by Public Health Service Act, Section 399G (42 U.S.C. Section 280f, as added by Public Law 105-392), by direction from Congress in 1999 to the Department of Health and Human Services. The Task Force was chartered in 2000 and is managed by the CDC's National Center on Birth Defects and Developmental Disabilities, Fetal Alcohol Syndrome Prevention Team

Function of the Task Force:

• To advise federal, state, and local programs and research activities regarding awareness, education, diagnosis, prevention, and intervention
• To coordinate activities with the federal Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS); and
• To submit reports on current and planned activities.

Recommendations:

1) Develop clinical definition of Fetal Alcohol Syndrome (FAS) and other alcohol related neurodevelopmental disorders (ARND).

2) Develop surveillance case definition for FAS and ARND.

3) Review relevant research on prevalence, risk, and diagnosis.

4) Review evidence of effective prevention and treatment strategies.

5) Develop research agenda that focuses on the affected individuals and their families

6) Develop research agenda that focuses on clinical findings of susceptibility

7) Develop profile of existing services for affected individuals and women at risk

8) Develop agenda for standard of care for affected individuals

9) Endorse a national media campaign

10) Endorse Surgeon General's warning statement to be reissued

11) Urge inclusion of FAS/ARND info by Office of National Drug Control Policy

12) Develop checklist of services needed by affected individuals

13) Develop education plan for professionals and service providers

14) Develop a K-12 curriculum about FAS/ARND/prenatal alcohol use

15) Investigate inclusion of FAS/ARND info in credentialization process.

Next Steps:

1) Work closely with CDC, collaborate with ICCFAS

2) Identify which agencies will carry out which recommendations

3) Develop guidelines for diagnosing FAS/ARND and incorporate into medical curriculum.

4) Fund four regional training centers for medical professionals, implement surveys

5) Develop educational curricula for medical professionals for diagnosis of FAS/ARND.

6) Gather information from FAS Center for Excellence Town Hall Meetings.

7) FAS Center for Excellence will identify model programs for prevention and treatment.

8) FAS Center for Excellence will identify gaps in service programs.

E. Substance Abuse and Mental Health Services Administration (SAMHSA) Information Resource Center

See: http://fascenter.samhsa.gov/resource/index.cfm

- Rich resource of journal articles, reports, books, news stories, and other publications. Copies aren't available through this site but can be ordered from the Bill Dubovsky Memorial FASD Lending Library (http://come-over.to/FAS/booklend.htm), 339 Coolwater Driver, Bastrop, TX 78602, e-mail ckbarker@ev1.net.

F. FAS Community Resource Center

See: http://www.come-over.to/FASCRC/

- Provides links to resources like featured articles, PowerPoint presentations, books, recent research and surveillance studies, clinical information, websites, intervention materials, posters, parent materials, online support groups, home school help, and much more.
- Also See: http://www.come-over.to/FAS/ for additional resources

G. American Journal of Medical Genetics

- American Journal of Medical Genetics Part C. (2004). Seminars in Medical Genetics Fetal Alcohol Syndrome. Guest Editor: Larry Burd. 2004 May 15; 127C (1): 1-58.

Description:

Special Issue of the Seminars in Medical Genetics on Fetal Alcohol Syndrome, Contents include the following articles

Contents:

Burd L. Introduction: Fetal Alcohol Syndrome. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 1-2.

Floyd RL, Sidhu JS. Monitoring Prenatal Alcohol Exposure. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 3-9.

May PA, Gossage JP, White-Country M, Goodhart K, Decoteau S, Trujillo PM. Kalberg WO, Viljoen DL, and Hoyme HE. Alcohol Consumption and Other Maternal Risk Factors for Fetal Alcohol Syndrome among Three Distinct Samples of Women before, during, and after Pregnancy: The Risk is Relative. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 10-20.

Stoler JM, Holmes LB. Recognition of Facial Features of Fetal Alcohol Syndrome in the Newborn. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 21-27.

Day NL, Richardson GA. An Analysis of the Effects of Prenatal Alcohol Exposure on Growth: A Teratologic Model. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 28-34.

Riley EP, McGee CL, Sowell ER. Teratogenic Effects of Alcohol: A Decade of Brain Imaging. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 35-41.

Lupton C, Burd L, Harwood R. Cost of Fetal Alcohol Spectrum Disorders. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 42-50.

Burd L, Wilson H. Fetal, Infant, and Child Mortality in a Context of Alcohol Use. American Journal of Medical Genetics Part C. 2004 May 15; 127C (1): 51-58.

Appendix VII:

Selected Results from the 2001 Youth Risk Behavior Survey of High School Students Attending Bureau Funded Schools

See: http://www.oiep.bia.edu go to the 'Studies and Reports' link and on this page click on the '2001 YRBS' link.

Tobacco Use

Tobacco use is the chief preventable cause of death nationwide. One million teenagers begin smoking each year and 3,000 begin smoking each day. Ninety percent of smokers begin before the age of 21 and 50% begin before the age of 14. The 1997 YRBS for Bureau high school student's report 11% smoked their first cigarette by age 8.

- 88% of students report to have ever tried cigarette smoking. This is a decrease from the 1997 survey, which reported 93% to have ever tried cigarette smoking.
- 34% of students report to smoke cigarettes everyday.
- 3% of students report smoking 10 or more cigarettes per day.
- 57% of students report smoking cigarettes on one or more of the 30 days preceding the survey. This reflects a decrease from 1997 when 64% reported to have smoked a cigarette on one or more days preceding the survey.
- 67% of current student smokers have tried to quit within the thirty days preceding the survey. In 1997, 65% reported have tried to quit and in 1994, 46% report having tried to quit.

- 20% of students report using smokeless tobacco. Males report this activity at 26% and females at 14.5%.

- Cigar use is reported by 19% of students. Males at 25% and females at 12%.

Alcohol Use

Alcohol is a major contributor to all homicides, suicides and motor vehicle crashes. The National Highway Safety Administration reports that 35% of all motor vehicle fatalities for youth nationwide are alcohol related.

- 81% of students report ever having a drink of alcohol. The 1997 reported 85% ever having a drink of alcohol.

- 49% of students report current use of alcohol within thirty days of the survey.

In 1997, 53% students reported this activity.

- 38% of students report that within 30 days preceding the survey he/she participated in episodic heavy drinking which is described as having five or more alcohol drinks in a row. In 1997, heavy episodic drinking was reported at 43%.

Appendix VIII:

Health Assessment / Screening Tools

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

A. Prenatal Health Assessment

See: http://forms.psc.gov/forms/IHS/ihs-866.pdf

Prenatal Health Assessment Form, IHS -866

- Designed to identify pregnant women who abuse alcohol and other substances so that appropriate treatment can be provided during pregnancy to reduce adverse effects on developing fetus
- Self-administered questionnaire
- Preliminary results from its use in several IHS facilities in the Northern Plains indicate that the proportion of women identified with substance abuse problems increases several fold through the use of this tool compared to the usual prenatal interview
- This tool should be scored by a nurse or other health professional and appropriate counseling and treatment should be provided

Aberdeen Area Indian Health Service (IHS)

- Developed "Screening Pregnant Women for Substance Use A Training Guide for Health Care Providers"
- Available to Service Units within the Aberdeen Area
- Training manual is divided into 5 sections: 1) Need for maternal screening; 2) Using the Prenatal Health Assessment on the first prenatal visit; 3) Using the Prenatal Health Assessment to interview the prenatal patient; 4) Development of an Intervention Team Plan; and 5) Evaluation of the Intervention Team Plan
- Training guide will be available on the IHS web site.
- Training provided in the following Aberdeen Area IHS clinics/hospitals: Lower Brule, SD; Wagner, SD; Sisseton, SD; Pine Ridge, SD; Belcourt, ND; Eagle Butte, SD; and the Native Women's Health Clinic in Rapid City, SD. Training scheduled for Rosebud, SD; Winnebago, NE; and Fort Yates, ND in June 2004.

Contact person:

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Center for Disabilities, USDSM
1400 W. 22nd Street
Sioux Falls, SD 57105-1570
(605) 357-1439

vkvigne@usd.edu

IHS-866 (5/99)

PRENATAL HEALTH ASSESSMENT

Please answer these questions honestly so we can help you receive the best possible care for you and your baby. Ask the nurse for help if you have difficulty with these questions. **Your answers will be a confidential part of your medical record.**

"Drink"= one 12 ounce bottle or can of beer, or one 4 ounce glass of wine, or one shot (one ounce) of hard liquor. **Remember!!! "Drinks" do not mean "sips"!!**

1. How many drinks does it take for you to first feel the effects of alcohol? **Refer to box above.**

   Number of Drinks: _____

2. When was your last drink? **Please check just one answer.**

   ☐ Within the last week ☐ Within the last year ☐ More than a year ago
   ☐ Within the last month Number of months ago: _____ ☐ Never

3. Do you ever feel that you should cut down on your drinking?

   ☐ Yes ☐ No

4. Do any friends or family ask you to drink less?

   ☐ Yes ☐ No

5. Does anyone in your house get drunk or use drugs?

   ☐ Yes Is it a problem? ☐ Yes ☐ No
   ☐ No

6. Have you ever been treated for problems from alcohol or drugs?

   ☐ Yes How many years ago was that? _____
   ☐ No

7. Has anyone hit or physically abused you in the last year?

   ☐ Yes ☐ No

   Has anyone hit or physically abused you during this pregnancy?

   ☐ Yes ☐ No

8. Have you ever been sexually abused?

   ☐ Yes ☐ No

	Just before this pregnancy	During this pregnancy
9. When you drink, how much do you usually drink?	Number of Drinks: _____	Number of Drinks: _____
A. How many times per month do you drink that much?	Times Per Month: _____	Times Per Month: _____
10. When you drink more than your usual amount, how many drinks do you have?	Number of Drinks: _____	Number of Drinks: _____
A. How many times in a month?	Times Per Month: _____	Times Per Month: _____
11. How many cigarettes do you smoke in a day?	Cigarettes per day: _____	Cigarettes per day: _____
12. Do you use smokeless tobacco?	☐ Yes ☐ No	☐ Yes ☐ No
13. Do you huff or sniff gasoline, glue or other substances to get high?	☐ Yes ☐ No	☐ Yes ☐ No
14. Do you use other drugs (PCP, marijuana, cocaine, heroin, speed)?	☐ Yes ☐ No Which ones? _____	☐ Yes ☐ No Which ones? _____
15. Do you use needles to inject drugs to get high?	☐ Yes ☐ No	☐ Yes ☐ No

16. How much alcohol can a pregnant woman drink each day?

    Number of Drinks: _____

17. When was you last menstrual period?

    _____
    Month Day Year

18. What is today's date?

    _____
    Month Day Year

19. What do you think is the most important thing you can do to have a healthy baby?

    _____

    _____

Thank you for completing this assessment. It will help us provide better prenatal care.

HR # SSN #

NAME

B DATE SEX TRIBE

RESIDENCE

FACILITY DATE

REVISIT/ REFERRAL TO: DATE TIME

PURPOSE:

INSTRUCTIONS: TO PATIENT: ☐ SIGN RELEASE RECORDS

PROV. SIGNATURE

Created by: PSC Media Arts Branch (301) 443-2454 EF

INSTRUCTIONS FOR COMPLETING THE IHS-866 PRENATAL HEALTH ASSESSMENT FORM

This questionnaire is designed to identify pregnant women who abuse alcohol and other substances so that appropriate treatment can be provided as soon as possible during the pregnancy to reduce the adverse effects on the developing fetus. This is a self-administered questionnaire that takes only a few minutes of nursing time to administer and collect. Preliminary results from its use in several IHS facilities in the Northern Plains indicate that the proportion of women identified with substance abuse problems increases several fold through the use of such a tool compared to the usual prenatal interview. The results of the questionnaire provide useful clinical information for the primary care provider to tailor appropriate health education messages and to refer prenatal patients for treatment when indicated. In order to be fully effective as a clinical and educational tool, it should be scored by a nurse or other health professional and appropriate counseling and treatment provided.

Using the Prenatal Health Assessment to Determine Prenatal Alcohol Consumption and Risk Factors for Drinking During Pregnancy

Follow the steps below to determine whether the woman drank or is at risk for drinking alcohol during pregnancy:

Step 1: In questions 9 and 10, is there any alcohol use indicated DURING THIS PREGNANCY?
If yes, review entire questionnaire with patient.
If no, **CONTINUE.**

NOTE: If the answer to question 10 is 5 OR MORE DRINKS, the woman should be counseled about binge drinking.

Step 2: Determine how many months pregnant the woman is by using the following process:

1) Add 14 days to the date of the last menstrual period (question 17)
   Example: 10/12/98 + 14 days = 10/26/98 (date of conception)

2) Starting with today's date (question 18), count back to the date of conception to determine the number of months pregnant
   Example: From 1/6/99 to 10/26/98, the woman is 2 months 11 days pregnant

Step 3: Comparing the answer calculated in step 2 to the woman's answer to question 2, did the woman drink during pregnancy?

If yes, review entire questionnaire with patient.
If no, **CONTINUE.**

Step 4: Is the answer to question 1 "3 or more drinks"?

If yes, the woman is at risk for drinking during pregnancy.
Review entire questionnaire with patient.
If no, **CONTINUE.**

Step 5: Is there one or both questions answered "yes" in questions 3-4?

If yes, the woman is at risk for drinking during pregnancy.
Review entire questionnaire with patient.
If no, **CONTINUE.**

Step 6: Is the answer to question 5 "yes"?

If yes, the woman is at risk for drinking during pregnancy.
Review entire questionnaire with the patient
If no, **CONTINUE.**

Step 7: Is the answer to question 6 "yes"?

If yes, the woman is at risk for drinking during pregnancy.
Review entire questionnaire with patient.

NOTE: Women who answer "yes," but also indicate that they have received treatment and have remained sober for two years have a good chance of remaining sober.

If no, **CONTINUE.**

Step 8: Did the woman indicate that she drank JUST BEFORE this pregnancy in either question 9 or 10?

If yes, the woman is at risk for drinking during pregnancy.
Review entire questionnaire with patient.
If no, **CONTINUE.**

Step 9: Is the answer to question 16, 1 OR MORE DRINKS?

If yes, the woman is at risk for drinking during pregnancy.
Review entire questionnaire with patient.
If no, the woman is not drinking during pregnancy and does not have risk factors for drinking during pregnancy. Routine prenatal care should be provided.

NOTE: Patients who have positive responses to questions 11-15 may have exposed the fetus to these substances. Appropriate counseling and treatment should be provided for tobacco use cessation and avoidance of illicit drugs and inhalants to improve fetal outcome.

The following procedures are recommended for its use:

1. Stamp the patient's addressograph card on the bottom left hand corner of the first page of the questionnaire.

2. The prenatal clinic nurse asks the prenatal patients to complete the questionnaire at the time of their first visit. The prenatal nurse or clerk may administer it to those patients who cannot read or understand the questionnaire. The questionnaire could be given or administered to the patients either before or after the usual prenatal interview that is conducted by the nurse.

3. The responsible health care provider reviews the questionnaire and completes any questions that have been left blank. This could be done by the clinic nurse, public health nurse, chemical dependency counselor, mental health/social services worker, physician, midwife, or appropriately trained community health worker. The questionnaire should then be scored and discussed with the patient. The completed questionnaire should be filed in the patient's medical record so that confidentiality is maintained.

4. The responsible health care provider should confirm all risk factors detected by this questionnaire, counsel the patient, and refer the patient for appropriate treatment, if she gives consent. The responsible health care provider should have a list of treatment resources available for the area.

5. If appropriate treatment is not available at the facility, this should then be documented. If the unmet need justifies additional services, these data can be used to help justify additional resources to meet those needs. In such a situation, the primary care providers and supportive health care workers would need to provide counseling to the best of their abilities.

6. Confidentiality of this information should be maintained as specified in the Privacy Act.

7. The problem lists of the mother and infant should indicate "maternal antepartum alcohol use" for women and infants identified with alcohol consumption during pregnancy.

RATIONALE FOR INCLUSION OF QUESTIONS ON THE PRENATAL QUESTIONNAIRE

(T= TOLERANCE A=ANNOY C=CUT DOWN E=EYE-OPENER)

The TACE questionnaire has been widely used and validated as a screening tool for alcohol abuse in prenatal populations and for that reason is included in this questionnaire with some modifications based on our pilot experience as follows:

1. Question #1: Tolerance - This question was initially asked, "How many drinks does it take you to get high?"

   We found that some of the prenatal patients thought being "high" meant totally drunk and for that reason the wording has been changed. Any patient answering 3 or more drinks is felt to be tolerant to the effects of alcohol.

2. Question #3: This is the "cut-down" question of the TACE questionnaire.

3. Question #4: Originally this was the "annoy" question in the TACE questionnaire. This was re-worded since some of our patients did not understand the word "annoy".

4. The "eye-opener" question of the TACE questionnaire was found to be ineffective and was eliminated from the Self-Administered Questionnaire.

Question #2 was included to determine when the patient last drank alcohol.

Question #5 is included to assess, the home environment of the patient which may be very important in determining the patient's support system.

Question #6 is included because of women who have previously been treated for alcohol or drugs may be at risk of resuming alcohol use during pregnancy. They should be evaluated more thoroughly by the primary care provider and referred for treatment if appropriate.

Question #7 is included to determine physical abuse experienced by the prenatal patient in the last year and during pregnancy. Women who have been abused should be counseled to obtain help in avoiding or ending abusive relationships. Abusive relationships are frequently associated with alcohol or other substance use. This question was included on the Pregnancy Information Program, a computerized assessment of a prenatal patient's lifestyle, that has been used as part of routine prenatal care at the IHS Hospital in Albuquerque, NM.

Question #8 is included to determine sexual abuse to the patient. Women who have been sexually abused may not be able to stop drinking or using drugs until issues related to the sexual abuse are assessed and treated by professional counselors. This question has not been validated or field tested but was felt by several reviewers to be the best way to assess sexual abuse. If the question is not useful or is inappropriate, it should be removed from the questionnaire. Each clinic using the Prenatal Health Asessment should develop plans on how to refer and follow-up with women who have been physically or sexually abused.

Question #9 - #10 are important to include because they assess both the frequency of drinking and binge drinking (defined as 5 or more drinks at a time). Binge drinking is felt to be a greater risk factor for FAS than drinking the same amount of alcohol in smaller amounts over a longer period of time.

Question #11 is included because cigarette smoking has been associated with an increasing number of adverse pregnancy outcomes, including higher rates of SIDS, birth defects and low birth weight babies. Thus, all women who are smoking during pregnancy should be counseled frequently by the primary care provider to quit and referred to smoking cessation programs, if they are available. Primary care providers, in a non-judgmental manner, should assess current cigarette use for prenatal patients at each visit and reinforce the recommendation to stop or cut down on smoking.

Question #12. The effect of smokeless tobacco use on the fetus is not known, but the elevated nicotine levels resulting from its use may have an adverse impact on the fetal development. Women who are using smokeless tobacco during pregnancy should be advised to quit for their own benefit as well as for the potential benefit of the fetus.

Question #13. Inhalants: The fetal impact of maternal inhalation of solvents is not known. Most of these substances are known to have a central nervous system toxicity and women who use them during pregnancy should be counseled or referred for treatment immediately.

Questions #14 - #15. Use of illicit drugs in pregnancy has well known harmful effects on both the mother and the fetus. Such women should be referred for treatment, if they are detected through this screening questionnaire. Drug related street terms and slang words for drugs can be found on the internet at http://www.addictions.com/slang.htm. Street terms for drugs change frequently and local terms for some drugs may not be included in this list.

Question #16. According to the Surgeon General, no amount of alcohol can be considered safe in pregnancy. Therefore, if women answer this with any amount, discuss with the patient that there is not a safe amount of alcohol that can be drunk during pregnancy.

Question #17. A question on the last menstrual period is included to help determine the gestational age at the time this questionnaire is completed.

Question #18. The date is included so we can determine the gestational age of the fetus at the time the questionnaire is completed based on the date of the last menstrual period.

Question #19. This is included so that women can tell us what they feel is important to have a healthy baby. This can then be reinforced and expanded as part of the first prenatal and subsequent prenatal visits.

In order to effectively use this screening questionnaire, it is important to establish a smooth referral process for women who are identified at risk or have consumed alcohol during pregnancy. Ideally, this should be done at the time of the first visit but in reality this may not be possible in many facilities. Referrals to the public health nurses or mental health/social services may be the optimal method of follow-up in some communities. In others, the patient will need to make her own appointment for the recommended treatment. Issues related to patient confidentiality and informed consent need to be carefully considered when setting up such referral systems.

B. CAGE Questionnaire

See: http://www.niaaa.nih.gov/publications/cage.htm and

See: http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/Cage.pdf and

See: http://www.mentalneurologicalprimarycare.org/downloads/primary_care/11-1_CAGE_questionnaire.pdf and

Ewing JA. Detecting Alcoholism: The CAGE Questionnaire. JAMA. 1984 Oct 12; 252 (14): 1905-7.

CAGE questionnaire - screen for alcohol misuse

Alcohol dependence is likely if the patient gives two or more positive answers to the following questions:

- Have you ever felt you should **C**ut down on your drinking?
- Have people **A**nnoyed you by criticising your drinking?
- Have you ever felt bad or **G**uilty about your drinking?
- Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (**E**ye-opener)?

The combination of CAGE questionnaire, MCV and GGT activity will detect about 75% of people with an alcohol problem.

C. T-ACE Questionnaire

(Tolerance, Annoyed, Cut down, and Eye-opener)

See: Sokol RJ, Martier SS, Ager JW. The T-ACE questions: practical prenatal detection of risk-drinking. Am J Obstet Gynecol 1989; 160 (4): 863-8.

The T-ACE Questionnaire for Problem Drinking in Women

2. Have you ever felt you ought to Cut Down on your drinking? (One point if yes).
3. Have people annoyed you by criticizing your drinking? (One point if yes).
4. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (Eye-opener)? (One point if yes).
5. How many drinks does it take to make you feel high/feel the effect of alcohol? (Two points if a woman needs more than two drinks to get high).

* Total scores of 2 or more points: evidence of problem drinking.

D.TWEAK Test

(Tolerance, Worry, Eye-Opener, Amnesia, K/Cut Down)

See below:

Prenatal Intervention

Name_____ Date of Birth_____ Date_____

SCREENING FOR ALCOHOL ABUSE

TWEAK Test (Russell 1984)

TOLERANCE - **T** — *How many drinks can you hold?* If more than 5 drinks = **2 points**

WORRY - **W** — *Have close friends or relatives worried or complained about your drinking in the past year?* Yes = **2 points**

EYE-OPENER - **E** — *Do you sometimes take a drink in the morning when you first get up?* Yes = **1 point**

AMNESIA - **A** — *Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?* Yes = **1 point**

K/CUT DOWN - **K** — *Do you sometimes feel the need to cut down on your drinking?* Yes = **1 point**

A score of 2 or above places the woman in a risk category and requires further assessment.

SMOKING©

ASSESSMENT OF EXPOSURE DURING PREGNANCY

On average how many days per week do you smoke? _____(a)

On an average day how many cigarettes do you smoke? _____(b)

How many days have you smoked 10 or more cigarettes in the last month? _____

What is the most cigarettes you smoked on any one day during this pregnancy? _____

EXPOSURE PARAMETERS (Cumulative exposure)

Smoking Days = **(a x 40) =** _____(c)
Estimates number of smoking days during this pregnancy.

Percent of Days Exposed = **(c ÷ 280 x 100) =** _____ %
Estimates days exposed during this pregnancy.

Number of Cigarettes = **(axbx40) =** _____(d)
Estimates cumulative number of cigarettes during this pregnancy.

Number of Packs = **(d ÷ 20) =**
Estimates cumulative exposure in packs during this pregnancy.

ALCOHOL©

ASSESSMENT OF EXPOSURE DURING PREGNANCY

On average how many days per week do you drink? _____(a)

On an average drinking day how many drinks do you have? _____(b)

How many days in the last month have you had 5 or more drinks? _____(c)

What is the most you had to drink on any one day in the last month? _____

EXPOSURE PARAMETERS (Cumulative exposure)

Drinking Days = **(a x 40) =** _____(d)
Estimates number of drinking days during this pregnancy.

Percent of Days Exposed = **(d ÷ 280 x 100) =** _____ %
Estimates days exposed during pregnancy.

Number of Binge Days = **(c x 9) =** _____
Estimates number of binge days (5 or more drinks in one day) during this pregnancy.

Number of Drinks = **(axbx40) =** _____(e)
Estimates cumulative number of drinks during this pregnancy.

Ounces of absolute alcohol = **(e ÷ 2) =** _____
Estimates cumulative absolute alcohol exposure during this pregnancy.

MATERNAL RISK SCORE

SCORE

____Age Over 25 years
____Unmarried, Divorced, Widow, Living with Partner
____On AFDC, WIC, Social Security or Income < $16,000 Per Year
____Did not graduate from high school
____Poor Diet
____Smokes More Than ½ Pack per Day
check any one, add 5

____Heavy drinker (drinks 3 or more drinks/day for 3 or more days per week, or more than 5 drinks/day on 6 or more occasions
____Uses inhalants, sniffs, huffs, or illegal drugs
check any one, add 45

____Drinks, but less than criteria for heavy drinker *check, add 20*

____Age first drunk less than 15 years
____In treatment over three times
____In treatment in last 12 months
____Previous child with FAS, FAE, Birth Defect, or Developmental Disability
____Previous child died
____Children out of home (foster care or adopted)
check any one, add 35

Alcohol: ___ total drinks ___ binge days
Smoking: ___ total cigarettes ___ days exposed

Total Score

Score	Risk Category	Recommendations
0	None	Standard Prenatal Care
5	Low	Standard Prenatal Care
20-40	Moderate	Standard Prenatal Care and Patient Education on FAS
45-50	High	High Risk Pregnancy, Alcohol-Drug Abuse Treatment
55-85	Very High	High Risk Pregnancy, Inpatient Treatment

CJ FOUNDATION® for SIDS
Tel: 1.888.8CJ.SIDS | Website: www.cjsids.com

Provided by
Larry Burd, Ph.D., North Dakota Fetal Alcohol Syndrome Center
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701-777-3683 www.online-clinic.com

A component of the **Face up to wake up™** Resource Kit to help reduce the risk of Suddent Infant Death Syndrome, produced by the CJ Foundation for SIDS.

PRENATAL INTERVENTION PLAN

Alcohol use: _____counseled _____referred _____attended _____quit _____date monitored

Smoking: _____counseled _____referred _____attended _____quit _____date monitored

Drug use: _____counseled _____referred _____attended _____quit _____date monitored

Abuse: _____counseled _____referred _____attended _____quit _____date monitored

E. Eye Exams

Alaska:

- An Optometrist is examining children with special needs to identify children with FAS and or FASD
- Eye doctor is part of the FAS Diagnostic Team
- The reason and importance for performing eye exams is that 90-100% of FAS children have specific ocular problems, ocular and visual abnormalities can be as specifically diagnostic for FAS as many other criterion, eye exam findings are often very specific for FAS and invaluable if diagnosis of FAS is in question, many of the eye problems can be fixed or managed and if treated can increase a child's ability to function
- The vision of people with FAS is tested for visual acuity, refraction, eye teaming, eye structural integrity, eye health, visual reactions, and visual processing.

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Appendix IX:

Selected Journal Articles

(The following list provides information on useful resources recommended by representatives from Indian Health Service Areas, state officials and university faculty and not intended to be comprehensive)

1) Abel, E.L. (1995). An Update on Incidence of FAS: FAS is Not an Equal Opportunity Birth Defect. *Neurotoxicology and Teratology*, 17 (4), 437-443.

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3) Branco, E.I., & Kaskutas, L. A. (2001). 'If It Burns Going Down…': How Focus Groups Can Shape Fetal Alcohol Syndrome (FAS) Prevention. *Subst Use Misuse*, 36 (3), 333-345.

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5) Egeland, G.M., Perham-Hester, K.A., Gessner, B.D., Ingle, D., Berner, J.E., & Middaugh, J.P. (1998). Fetal Alcohol Syndrome in Alaska, 1977 through 1992: An Administrative Prevalence Derived from Multiple Data Sources. *American Journal of Public Health*, 88 (5), 781-786.

6) Ewing, J.A. (1984). Detecting Alcoholism: The CAGE Questionnaire. *JAMA,* 252 (14), 1905-1907.

7) Ingersoll, K., Floyd, L., Sobell, M., & Velasquez, M.M. (2003). Project CHOICES Intervention Research Group. Reducing the Risk of Alcohol-Exposed Pregnancies: A Study of a Motivational Intervention in Community Settings. *Pediatrics*, 111 (5), 1131-1135.

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14) Masis, K.B, & May, P.A. (1991). A Comprehensive Local Program for the Prevention of Fetal Alcohol Syndrome. *Public Health Reports*, 106 (5), 484-489.

15) May, P.A., McCloskey, J., & Gossage, J.P. (2002). Fetal Alcohol Syndrome Among American Indians: Epidemiology, Issues, and Research Review. In Mail, P.D., Heurtin-Roberts, S., Martin, S.E., Howard, J. (Eds.), *Alcohol Use Among American Indians and Alaska Natives: Multiple Perspectives on a Complex Problem*. (pp. 321-369) Bethesda: US Department of Health and Human Services.

16) May, P.A. (1996). Overview of Alcohol Abuse Epidemiology for American Indian

Populations. In National Research Council (U.S.) Committee on Population Sandefur, G.D., Rindfuss, R.R., and Cohen, B. (Eds.), Changing Numbers, Changing Needs: American Indian Demography and Public Health. (1st ed, pp. 235-261). Washington, D.C.: National Academy of Sciences.

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Appendix X:

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