

Cataloging of Historical and Current Legislative Decisions, Medical Practices and Agency Policies Regarding FAS

*Prepared by ACSES Staff
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Background

As part of the conditions of funding the statewide Alaska FAS Prevention Project, SAMHSA requested that the project be evaluated by an independent team of evaluators. This evaluation contract was awarded to the Center for Human Development (CHD) at the University of Alaska Anchorage (UAA), with the request that the evaluation be conducted by an interdisciplinary team of evaluators from across the UAA campus. Staff at CHD subsequently selected various professionals from the UAA community to build the Evaluation Team and to divide the work involved in the evaluation of the FAS Prevention Project. The FAS Project Principal Evaluation Team selection began in February 2001 (3rd Quarter of FY 01 of the grant). In August 2001, a comprehensive evaluation plan was submitted to the FAS Advisory Team and State Office of FAS for review and approval. Following submittal of the evaluation plan application to the University of Alaska Institutional Review Board (IRB) and receipt of funding from the state in August 2001, the detailed actions defined in the Diagnostic Evaluation Plan were initiated in October 2001 (2nd Quarter of FY 02 of the grant).

The *Alaska Comprehensive and Specialized Evaluation Services (ACSES)* was one of the groups approached by CHD to participate as a member of the FAS Project Principal Evaluation Team. ACSES was honored to take on the evaluation of diagnosis-related activities, committing to activities to meet five overarching goals. One of these goals was the development of a catalog of historical and current legislative decisions, medical practices, and agency policies regarding FAS and ARBDs in Alaska. This report provides an update on activities and findings about this goal to date.

Activities

In the Year One Diagnosis Evaluation Plan (DEP), we proposed to take four specific steps toward the development of a catalog of historical and current legislative decisions, medical practices, and agency policies regarding FAS and ARBDs in Alaska. These steps are as follows:

1. Identification of Data Sources
2. Requests for Information
3. Development of a Repository System
4. Development of a Continuous Tracking System

During the first year of implementing the DEP, our intent was to tackle the first three steps, with the intent being that the fourth step would evolve over subsequent years in collaboration with the

State Office of FAS. To date, we have made progress on the first three steps toward meeting this goal. Specifically, in the process of completing other DEP Year One goals, (specifically, the ethnographic analysis of each diagnostic team and review of diagnostic methods), ACSES staff began to discover and document the rich history of past and current FAS intervention efforts within the state. Additionally, a few preliminary interviews were conducted to outline the scope and extent of the history of FAS activities in Alaska, and to identify additional key individuals to interview and pertinent source materials to collect. Finally, some materials were collected and added to a growing repository of information currently housed at ACSES.

Findings

A brief timeline of the primary historical events related to FAS prevention and treatment activities in Alaska is included in Figure One. As indicated, significant FAS-related activities date back to as early as 1985 and have included major efforts by the Indian Health Services (IHS) and the State of Alaska. More specifically, beginning in the 1980s, the Alaska Native Health Board (funded through IHS) developed an elaborate system that focused on FAS recognition, awareness, data collection, and programming. This system was targeted at Alaska Natives and Native Americans throughout the state of Alaska. In 1990, IHS and the Alaska Department of Health and Social Services (DHSS) requested the Centers for Disease Control (CDC) and Prevention to provide assistance in developing an FAS surveillance methodology and the generation of epidemiological data to develop and evaluate prevention strategies within the state. This surveillance system was implemented shortly thereafter, and continues today. However, with the implementation of compacting in the late 1990's, the IHS FAS system became decentralized and many of the components were discontinued.

Today's FAS Project, a five-year, \$29 million grant from the federal Substance Abuse and Mental Health Services Administration (SAMHSA), incorporated numerous aspects of earlier Alaska-based FAS programs (namely, the IHS Prevention Program, State of Alaska efforts, and cooperative projects among the CDC, State of Alaska, and IHS) and suggestions generated from four working groups at the 1997 FAS Summit. These common program elements include, but are not limited to: 1) designation of a central contact person to coordinate FAS-related activities within the state; 2) use of specially-trained FAS diagnostic teams; 3) implementation of a survey designed to evaluate knowledge, attitudes, beliefs, and behaviors (KABB); 4) provision of education programs for multiple populations (e.g., medical providers, service agency staff, parents, students) within the community; 5) identification of women at risk; and 6) a system for reporting data from diagnosed individuals to a central agency for surveillance purposes. Major differences between the previous systems and the current FAS Project include, but are not limited to: 1) diagnostic services are available for individuals of all races and ethnicities in Alaska, 2) operations that are global rather than limited to a "closed" health system and, 3) implementation of a statewide, multimedia campaign.

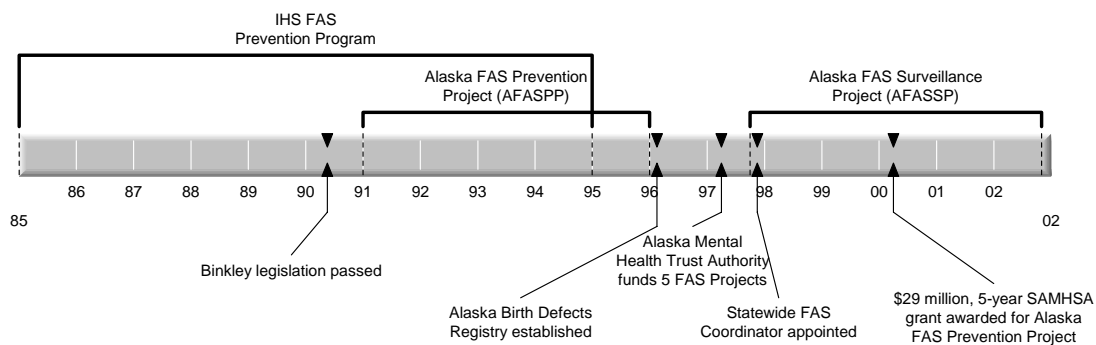
Relative to legislative decisions, through the investigation of several sources (including the internet, copies of legislative memos, Department of Health and Social Services [DHSS] FAS Status Updates, a monograph written regarding FAS in Alaska, and an interview with the State Office of FAS's Statewide FAS Coordinator), it became apparent that the 12 pieces of legislation

on FAS-related issues introduced by Senator John Binkley in 1990 were the most recent and significant FAS-related legislative acts to be signed into law. Specifically, nine of the 12 proposals were passed while eight became law. This legislation included:

- A resolution designating Mother’s Day Week as Alcohol Related Birth Defects Awareness Week
- A resolution asking for continuing medical education opportunities for doctors and nurses,
- A bill giving treatment priority to pregnant women who abuse substances,
- A bill to train teachers and other school personnel on working with children exposed prenatally to alcohol
- Two bills mandating the format of warning signs about the effects of alcohol consumed during pregnancy to be posted on all liquor stores
- A bill mandating all marriage license applications be accompanied by a brochure warning about the damages of drinking during pregnancy

The information provided above only begins to describe the rich and extensive history of FAS-related activities in Alaska.

Figure One



Potential Interviewees

Following is a preliminary list of professionals who have engaged in FAS-related treatment and prevention activities in Alaska. This is not intended as an all-inclusive list, but rather should be considered as a starting point. Undoubtedly, for each interview conducted, several more individuals with invaluable information will be identified.

- Bailey, Marvin, CDC, Alaska Environmental Health Program
- Baxter, Susan, M.S., former IHS FAS Psychologist
- Berner, Jim, MD, Alaska Native Health Consortium (ANTHC)
- Bruce, Patti, Alaska DHSS Division of Alcoholism & Drug Abuse
- Burgess, Donna, Ph.D, University of Alaska, Anchorage (UAA), Institute of Circumpolar Health Studies
- Caldera, Debra, Division of Public Health, Section of Maternal Child & Family Health

Casto, Diane, Alaska DHSS Office of FAS
Clarren, Sterling, MD, University of Washington (UW) FAS Diagnostic Prevention Network (DPN)
Clarson, Sheila, Ph.D., Psychologist, Psychology Resources
Dawn, Rebecca, RN, Kodiak Area Native Association (KANA)
Gessner, Brad, MD, MPH, Pediatric epidemiologist, Neighborhood Health Center
Heart, Victoria, Alaska Native Health Consortium
Hild, Vickie, former IHS FAS Coordinator
Hymbaugh, Karen, MAPA, MPH CDC/NCBDDD
Kronowitz, Muriel, MSW, author of the 1992 *Fetal Alcohol Syndrome in Alaska: A Monograph*
Merrick, Susan, M.P.H., FAS Surveillance Project Coordinator
Perdue, Karen, former Commissioner of Alaska DHSS
Perham-Hester, Kathy, MS, MPH, Alaska PRAMS Coordinator, State of Alaska, DHSS, DPH, MCFH
Prinz, Scot, M.S., Alaska Native Tribal Health Consortium (ANTHC)
Ressler, Mildred, R.N., Crossroads Medial Center, Copper Center, Alaska

Other Sources of Information

Following is a list of resources on FAS-related issues in Alaska. This is not intended as an all-inclusive list, but rather should be considered as a starting point. Undoubtedly, through review of each these resources, several additional sources with invaluable information will be identified.

Publications

- Alaska Department of Health and Social Services. (1999). *1999 status update: Fetal alcohol syndrome, Alaska's #1 preventable birth defect*. Juneau, AK: Author.
- Alaska Department of Health and Social Services. (1998). *An update on the status of Alaska's response to fetal alcohol syndrome, Alaska's #1 Preventable Birth Defect*. Juneau, AK: Author.
- Alaska Department of Health and Social Services, Division of Public Health; Section of Maternal, Child, and Family Health, MCH Epidemiology Unit Family Health. (2001). Fetal alcohol syndrome prevalence in Alaska: New findings from the FAS surveillance project. *Family Health Dataline*, 7(1), 1-3.
- Alaska FAS Prevention Steering Committee. (1996). The Alaska fetal alcohol syndrome prevention project. *Federal Practitioner*, 13(8), 54-59.
- Centers for Disease Control. (1993). *Linking multiple data sources in fetal alcohol syndrome surveillance – Alaska*. MMWR, 42, 312-314.
- Department of Health and Social Services. (1993). *Alaska FAS prevention project*. *Alaska Medicine*, 35(2), 179.
- Institute of Medicine. (1996). *Fetal alcohol syndrome diagnosis, epidemiology, prevention, and treatment*. Washington, D.C. National Academy Press.
- Kronowitz, M. (1992). *Fetal alcohol syndrome in Alaska: A monograph*. in conjunction with CDC Contract #BD283-91

Namyniuk, L., Worley, D., FAS Summit Steering Committee. (1998). *Fetal Alcohol Syndrome A Time for Action*. Juneau, AK

Memoranda & Other Correspondence

Alaska State Legislature Memorandum. To Senator John Binkley, From Maureen Weeks, Senate Advisory Council, February 17, 1989, Economic impact of FAS; IR # 89-100015

Alaska State Legislature Memorandum. To Senator John Binkley, From Maureen Weeks, Legislative Analyst, April 24, 1990, Number of Alaska Newborns Affected by Alcohol and Other Drugs Research Request 90.205 (Revised)

1990 Memo to Maternal and Child Health Coordinator, IHS, Area FAS Activities FY 1990 Southcentral Foundation Proposal for FAS Multidisciplinary Community Team Training Grant. (1999).

Website Information

<http://www.hss.state.ak.us/fas/>. Alaska's response to FAS

Places to Obtain More Information

Native Health organizations (especially those who have maintained FAS programs beyond the 1980's IHS funding)

Obstetric, gynecological, and pediatric medical office practices

Conclusion

Through the process of cataloging sources of FAS information, it became evident that a rich history of FAS activities exists in the state of Alaska. This history of FAS prevention and intervention activities is of such an extensive nature that providing a thorough documentation is beyond the scope of the diagnosis evaluation plan. However, there may be value to documenting this history to provide a context for current activities and to learn from these past efforts. Such a history document would more than likely also contribute significantly to the preparation of the final report to SAMHSA by the State of FAS at the end of the five-year funding period.