



Fetal Alcohol Syndrome Update Summer 2001

Office of FAS, Department of Health & Social Services, State of Alaska

FACTS Project to Department of Education and Early Development

When you talk about fetal alcohol syndrome and other alcohol-related birth defects one issue that always comes up is how much FAS/ARBD impacts our state's educational system. But, it is also true that the educational system is the one system that most impacts our children and youth with FAS and ARBD. While we don't have any accurate data related to the number of children with this disability in our schools, anecdotal information tells us the number is great. We also know that many, if not most children and youth with this disability do not have an accurate diagnosis and many do not qualify for special education or other resources and accommodations to help them succeed.

The Fetal Alcohol Consultation and Training Services (FACTS) project has been a critical element of the state's FAS agenda for the past three years, under the coordination of Debra Evensen, first as a grant with Special Education Services Agency (SESA) and then through the University of Alaska Fairbanks. The goals of the project have been to increase the understanding of the disabilities associated with prenatal exposure to alcohol among educators and school personnel and to improve the educational outcomes for children and youth with these disabilities.

As the state's FAS efforts have grown, with the 5-year federal grant award, our focus has become more directed to improving, enhancing and developing our systems of service delivery to better understand and serve individuals with FAS or other alcohol-related birth defects. For this reason, we have decided that the best way to make educational change, at the systems level, is to work in collaboration and partnership with the Department of Education and Early Development (EED). Beginning with the new fiscal year, the FACTS project will be incorporated into EED, with the goal of developing a consistent and well-orchestrated effort to improve student outcomes, to address barriers to learning for students with FAS/ARBD and to provide school personnel with the knowledge and resources they need to improve educational services for this population. The Department is hiring a full-time FAS Education Specialist that will be located in the Juneau EED office, working within the section of Teaching and Learning Supports. The new staff person will work closely with the Office of FAS, the nine FAS Multidisciplinary Community Teams and the sixteen "Barriers to Learning" community sites. A start date for the new FAS Education Specialist is early to mid August.

We are very excited about this new partnership and look forward to working together with communities, school districts, schools, teachers and parents in developing a process for educational improvement for children and youth with FAS/ARBD. For further information you can contact Diane at the Office of FAS or Beth Shoher at EED. ▼

The dream catcher gracing this edition of our FAS Update was made by Marsha Thomason, Primary Counselor at Old Minto Recovery Camp, a program of Tanana Chiefs Conference. Following a 3-day FAS training conducted by Diane Worley, Marsha presented the dream catcher to represent the state's FAS project.

The five beads in the center represent the five years of our grant; the wolf claw represents the need for tenacity and determination to make systems change; the raven feather denotes the need for humor and cunning; and the willow branch represents the dawning of a new season.

Thank you Marsha and the entire Old Minto staff for a great 3-days and a wonderful reminder of the important work we are doing.

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Surveying Alaska's knowledge about FAS

The Office of FAS is currently developing a strategy to evaluate our statewide efforts to inform and educate Alaskans about FAS and its effects. Evaluation will be accomplished by looking at statewide knowledge, attitudes, behaviors and beliefs pertaining to FAS. This effort will focus on measuring both current and future statewide levels of FAS understanding and associated issues. The study will be directed at both the general public and special target populations (healthcare and other service providers). A baseline assessment is to be completed this year, with a follow-up study scheduled for five years from the date of the initial assessment.

In 1993 a similar evaluation was completed using the KABB (Knowledge, Attitudes, Behaviors & Beliefs) Survey. This study was limited however, as it was directed only at the Anchorage community and the initial survey instrument contained some questions that did not adequately measure the levels of FAS understanding in either targeted groups or the general public. The current effort uses the strengths and framework of the original KABB Survey for the development of a refined survey instrument that is more suitable for a broader audience.

Using an appropriate sampling strategy, a contractor will administer both baseline and follow-up surveys statewide. It is expected that the baseline survey will be conducted in the fall of 2001 and then re-administered approximately five years later toward the end of our 5-year federal grant. The comparison of these two, time-dependent data sets will provide an important opportunity to evaluate the impacts of education, outreach and training on FAS awareness in Alaska. ▼

Prevention Symposium looking for presenters

This year's Prevention Symposium is scheduled for November 12-14, immediately preceding the FAS Summit 2001. As in past years, the Prevention Symposium and the FAS Summit will be scheduled back-to-back to allow out of town travelers to take advantage of both conferences. This year's Prevention Symposium theme is "Prevention: Within Our Reach." The Symposium planning committee has issued a **Call for Papers**, with emphasis on current research, effective prevention strategies and integrating traditional modalities and skills with innovative approaches. The four program tracks are Rural Focus; Environmental Strategies; General Information on Prevention; and Youth/Adult. Proposal submissions are due August 1. In addition, the Symposium is requesting nominations for four annual awards—the Barbara Bailey Prevention Award; Bette O'Moor Youth Prevention Award; Bill Brady Volunteer Prevention Award; and the Alaska Prevention Group Award. Copies of the criteria for both the **Call for Papers** and the award nominations can be accessed at www.akeela.org. Or you can call Jeeni Jurvig at (907)565-1219. ▼



Parent Navigator Network growing

This spring, parent navigators from seven of the state's nine community-based FAS diagnostic teams met in Anchorage

for specialized training. The two-part training opportunity was cosponsored by the Stone Soup Group and The Center for Psychosocial Development, with funding from the State of Alaska Office of FAS and the Far North Family Support Project of DMHDD.

On the first day of each session the parent navigators met with Cheri Scott, Stone Soup Group's Parent Navigator trainer and Kathy Fitzgerald, director of the Family Support Project, Center for Psychosocial Development to begin learning about the parent advocate's role of providing navigation and support services to families of children with prenatal alcohol exposure.

Trainees learned about the state's developmental disability and mental health systems, existing prevention programs and systems and how to help families access them. One key element of the training was to discuss how the process of parent navigation should be integrated into their local diagnostic team setting. The participants brainstormed a list of valuable attributes for parent navigators and listed and prioritized activities that they feel are important for parent navigators to be involved in as diagnostic team members.

The top ten activities identified were: 1) build positive working relationship with DFYS and other agencies; 2) have access to on-going training; 3) assist families in finding out about resources that will enhance their child's life; 4) get to know agency regulations for the agencies they work with and refer to; 5) meet with families before the team evaluation; 6) help family with paperwork before evaluation and afterward when applying for services; 7) advocate for needed changes in available services and for more and appropriate services where needed; 8) be able to problem solve with families solutions that will work for that family; 9) be assertive when working with professionals; 10) ICWA knowledge/connection.

During the last three days of each session the FAS parent navigators joined with a larger group of family support staff from a variety of programs throughout Alaska for extensive training in the concepts of family centered care and support. Presented by Dr. Susan Yuan of the University Affiliated Program, Vermont, the training was well received by all attending. Through Stone Soup Group and Cheri Scott, the Office of FAS has contracted for ongoing support, training and development of our FAS Team Parent Navigators. Thanks Cheri for a great kick-off activity! ▼

FAS Community Team Highlights

Southcentral Foundation, located in Anchorage, has been an Office of FAS Community Diagnostic Team since attending the University of Washington training in February of 2000. Beginning in the spring of 2000 the team has been holding regular, twice monthly clinics and have evaluated approximately 49 children. While many of the team staff have been working with the project since it's inception, they have recently added two new staff: Michael Baldwin, new team coordinator, will replace Nora Tobin who left the position earlier this month, and Parent Navigator Dora Moore, who works part-time providing team and family support. Michael and Dora each have recently signed on and each will bring their unique skills and energy to the Southcentral FAS effort. In addition to new staff, June marked a major community-based outreach and education event sponsored by the team. In an effort to provide ongoing FAS awareness to members of the community, the team organized a free one-day training that brought national presenters to Anchorage. Over 100 participants attended. If you would like to know more about Southcentral's FAS Multidisciplinary Community Team or to make a referral you can call them at (907) 729-4251 or call the Office of FAS. ▼

New videos available

The Office of FAS has purchased two (2) great new videos from Vida Health Communications. *Straight from the Heart: Stories of Mothers Recovering from Addiction* is designed as a motivational program for women with histories of substance abuse. This video is 28 minutes long and features 6 mothers from various backgrounds telling their stories of recovery. The video provides a touching approach and features one mother dealing with her son's recent FAS diagnosis.

Our second video, *A Challenge To Care* is a staff-training program for providers working with childbearing women. This 38-minute video offers specific, practical interventions to be used with mothers who are chemically dependent and how to assist them seek recovery. It also offers tips on providing support after a child is born.

To borrow any of our videos for a two-week period please contact the Office of FAS at (907)465-3033 or 877-393-2287 or via e-mail at sherrie_stears@health.state.ak.us. A complete listing of our library can be found on our web-site.



March of Dimes announces requests for proposals

The March of Dimes Alaska Chapter Community Grants Program is designed to invest in projects that support one of the following important strategies: access to and quality of health care for women and infants, availability of prevention services and folic acid education. Agencies that support these issues are encouraged to request a 2002-funding brochure from the March of Dimes. Awards will range from \$10,000 to \$25,000 and proposals must be received by Sept. 12, 2001. Proposals must address one of March of Dimes funding priorities. A listing of these priorities can be received by contacting:

Leslie Linton, Regional Program Director
March of Dimes, Alaska Chapter
(907) 276-2290
(800) 478-5245 toll-free
e-mail: llinton@modimes.org.

Staff changes at office of FAS

Jenny Huntley, our first Administrative Assistant, has moved into the position of Grants Administrator for the Office of FAS. Jenny will be responsible for monitoring over 40 grants and contracts for the Office as well as overseeing the procurement process for all new office grants, contracts and RSAs. Additionally, Jenny will assist in creating the RFP for our media campaign and monitoring this process and contract over the 5-year period. On July 20th Jenny will be providing training for all FAS grantees on the grant process, repeating this training at the FAS Summit. Jenny can still be reached by calling the main FAS phone numbers.

Sherrie Stears has accepted Jenny's previous position of Administrative Assistant for the Office of FAS and began her new duties on July 11th. Sherrie transfers to our office from the Division of Family and Youth Services where she worked for the past six years, primarily with subsidized adoptions. As the Administrative Assistant Sherrie will be responsible for daily management of the office, all front desk duties and is the first point of contact for the Office of FAS. She will also maintain the library, process staff travel, assist in producing the newsletter and help with coordinating the annual Summit. Sherrie has extensive experience working with parents and will be a great asset to the FAS Office.

On Monday, July 16 Louise Champagne will join the FAS staff as our new part-time Project Assistant. Louise will be charged with two specific projects, and of course, "other duties as assigned"; to develop and distribute a FAS International Day (September 9) Community Activities packet; and coordination of the FAS Summit 2001 planning. Louise is a longtime Juneau resident with experience in program design and development, writing, editing, public speaking and graphic design and publication development.

We welcome both Sherrie and Louise to the Office of FAS! ▼

VOA offers great FAS Family Camp!

Article provided by
Cheri Scott

VOA staff and camp volunteers all did a fantastic job with their FAS Summer Camp June 6–10. All involved did a great job of caring for the kids and nurturing the parents. They provided such a wonderful gift to the families!

Camp was great and the weather couldn't have been better. Both kids and parents made new friends, and almost everyone wished it could go on longer! Massage (choice of chair or table style) was one of the highlights for parents, and the kids all seemed to love getting out on the lake in the paddle boats and canoes. Some even braved the cold water and went swimming. Several caught fish and shared them at dinner. YUM! We all did a family tie-dye shirt project—with only a few accidents. One mom went back to Fairbanks with some very colorful shorts! The best part was the opportunity for parents and children to have several days to relax and play in a totally accepting and understanding environment.

Families attended from all over the state including Fairbanks, Bethel, Port Heiden, Barrow, Dillingham, Anchorage, Eagle River, Chugiak.

The next camp hosted by VOA with funding from the Office of FAS will be on the Kenai Peninsula in January 2002. Everyone that attended this summer's camp will automatically get information on the winter camp when it becomes available, and all team coordinators will also be sent camp information. Once again, travel assistance will be available for families interested in attending. If you have questions about the camp or would like to make suggestions for camp activities please call Cheri Scott at (907) 561-3701 or Pat Cochran or Deena Wiggins at Volunteers of America: (907) 279-9634. ▼



Farrah and Justin enjoying camp

Director leaves Foster Parent Training Center

We bid a fond farewell to **Jeanne Gonzales**, the Director of the AFPTC since November of 1988. In Jeanne's 13 years with the Training Center, she oversaw the development and growth of a critical element for our state's foster care system—training. Jeanne has been dedicated to ensuring foster parents received quality and informative training and was also instrumental in coordinating FAS funding for parents to travel to the FAS Summit and other training. We will miss Jeanne's hard work, her great smile and her undying commitment to Alaska's families. We look forward to continuing to work with her great staff and the new director. Good luck Jeanne and have fun. ▼

FAQ: Diagnosis vs. Labeling

One question we continually hear is “should we diagnosis an individual with an alcohol-related birth defect or does that just label the person unnecessarily?” Clearly there is a difference between “labeling” and “diagnosing.”

Webster’s defines label as: *An object serving as a means of identification; a descriptive term.* Diagnosis is defined as: *The act or process of identifying or determining the nature of a disease by examination—a critical analysis.*

The state believes that an accurate diagnosis of all medical conditions is critical to understanding the condition, the root cause of the condition, what type of services, interventions or treatment are needed to improve outcomes and to increase our knowledge and ability to develop strategies for prevention.

Fetal Alcohol Syndrome (FAS) is a medical diagnosis of a permanent birth defect syndrome caused by maternal consumption of alcohol during pregnancy. For those individuals with alcohol-related birth defects that do not meet the FAS diagnosis, there are a number of other specific diagnoses that provide a clear understanding of the condition and its cause. These are not labels, these are diagnoses. Accuracy in diagnosing disabilities related to prenatal exposure to alcohol will provide us with the ability to improve our services, better understand the needs of the individual with these disabilities, accuracy in data about the extent of this problem in our state and to promote an active and focused effort to prevent the birth of children with disabilities related to maternal drinking during pregnancy. Accurate diagnosis is the critical core of our state’s ongoing FAS efforts.

In the words of Dr. Ann Streissguth: *“Diagnosis provides visibility, and visibility prompts solutions.”* ▼



RuralCap produces new posters!

The Rural Community Action Program, a grantee of the Office of FAS, has initiated distribution of four new posters designed to educate women about the dangers of drinking during early pregnancy. The posters feature pictures of healthy children representing a variety of Alaska Native cultures.

If you would like posters for your agency contact RuralCap at (800) 478-7225.

Grantees educating communities about FAS

Over the last few months communities across the state of Alaska have had the opportunity to learn about fetal alcohol syndrome, how alcohol consumption impacts pregnancy, the areas of functionality impacted in an individual with alcohol-related organic brain damage and strategies for improved service delivery. FAS Teams and Innovative grantees in Nome, Kodiak, Bethel, Kenai, Anchorage and Dillingham have all offered community-wide training to service providers, medical providers, policy makers, parents and caregiver, educators and the general public. Using both local and national experts, including Diane Malbin, Carolyn Hartness, Deb Evensen, Dr. Phil Matthies, Cheri Scott and Daniel Dubovsky, communities have had a wonderful opportunity to begin community-wide discussions about alcohol-related birth defects, the impact of alcohol on community health, the need for improved services for individuals with FAS/ARBD and the next steps to develop community planning around this issue. Thanks to all of our grantees for their hard work, energy and commitment to improving our efforts related to all alcohol-related birth defects. ▼

FAS Summit 2001

Planning for the FAS Summit 2001 is underway! The theme for this year's Summit is *Beyond Diagnosis: Grief, Healing and Community Collaboration*. Several national FAS experts have already committed to presenting during the November 15th and 16th Summit including Carolyn Hartness, Robin LaDue, Kathryn Shea, and Craig Lesley, author of the recently published book *Storm Riders*.

In addition to our national speakers the Office of FAS is seeking workshop and presentation proposals from individuals and groups across the state for the Summit 2001. Proposals can be submitted by mail, fax or email, and are due to the office no later than July 31.

The Summit planning committee will also be selecting two individuals to honor at the FAS Summit 2001 for their work and dedication to the issue of FAS/ARBD. Nominations will be accepted for individuals who have advanced the cause of prevention of FAS/ARBD or advocacy for individuals living with this disability. For more information on the Call for Workshops or the Nominations you can give us a call or checkout our Summit website at www.hss.state.ak.us/fas/summit2001.

Stay tuned for more information on the Summit plans in our next quarterly update. ▼

Spotlight on FAS Innovative Grantees

Each quarter the FAS Update will highlight three (3) of our FAS Innovative grantees. By sharing information and progress about our grantees we hope to generate partnerships, collaborations and ideas for continuing the state's progress to prevent FAS and to improve lifetime outcomes for individuals with this disability.

- The Chugachmuit Healthy Start Project, an FAS prevention effort, is in full swing in the Chugach Region. Through this project, Coordinator Ruthe Schoder-Ehri is providing outreach, education and community awareness to pregnant women and their families in five communities, including Tatitlek, Chenenga Bay, Port Graham, Nanwalek, and to the Qutekcak Tribe in Seward. Ruthe brings her background in Public Health Nursing to the project, and has the ability to work one on one with expectant mothers and their families to promote healthy pregnancies. In addition, the project will provide materials and general awareness training to interested community groups and individuals in the area.
- Two innovative grants have been funded in the Ketchikan area, and the two projects are working hand in hand to promote education, awareness and to develop area wide diagnostic capacity. **Gateway Center for Human Services** is in the process of building an FAS resource library, and has begun to identify individuals interested in working with the community team in Metlakatla, Prince of Wales Island, and Petersburg. **Ketchikan Indian Corporation** (KIC) has also begun to work on issues of community readiness, team development, and systems change in their community. KIC is in the process of developing and printing informational brochures, t-shirts, calendars, and other items to "get the word out" about healthy behaviors during pregnancy. The two groups participated in the local health fair, and will be trained as a diagnostic team at the University of Washington in September 2001. ▼



Craig Lesley, author of Storm Riders and featured speaker for Summit 2001 at the National Conference in April.

Dates to Remember

July

31, Tuesday: Deadline for Call for Workshops and Presentations.

August

31, Friday: Deadline for FAS Awards Nominations.

– RFP for FAS Multidisciplinary Community Team Training issued.

September

5 & 7, Wednesday and Thursday: “Gathering to End Sexual Assault in Alaska” conference, Anchorage.

9, Saturday: International FAS Awareness Day

20 – 22, Thursday through Saturday: University of Washington FAS Diagnostic Team Training.

October

12, Friday: Deadline for FAS Multidisciplinary Community Team Training proposals.

November

8 & 9, Thursday and Friday: Pathways Conference, Anchorage.

12 – 14, Monday through Wednesday: Prevention Symposium, Anchorage.

14, Wednesday: Team Coordinator and Parent Navigator Meetings, Anchorage.

15 & 16, Thursday and Friday: FAS Summit 2001, Anchorage.

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