



Fetal Alcohol Syndrome Update

Fall 2001
Office of FAS, Department of Health & Social Services, State of Alaska

FAS Summit 2001



Carolyn Hartness,
Summit 2001 keynote speaker

FAS Summit 2001 “Beyond Diagnosis: Grief, Healing and Community Collaboration” is fast approaching! This year’s Summit is scheduled for November 15–16, 2001 at the Anchorage Hilton Hotel, immediately following the annual Prevention Symposium. The Summit will include a combination of national and local presenters as we expand to two days of presentations, workshops and resource sharing about fetal alcohol syndrome and its impact on the state of Alaska.

Featured national speakers will include Carolyn Hartness, author, health educator and FAS advocate from Washington state; Kathryn Shea, an adoptive parent of a child with FAS and a social worker presenting on developing around the clock interventions for children with

FAS; Dr. Robin LaDue, clinical psychologist and author of *A Practical Native American Guide for Caregivers of Children, Adolescents and Adults with FAS*; Tracy Jirikowic, an Occupational Therapist for the FAS Diagnostic and Prevention Network at the University of Washington; and Craig Lesley, former foster parent of a child with FAS and author of the novel *Storm Riders* based on his experiences with his foster child.

A limited number of travel stipends to attend the FAS Summit 2001 will once again be available for birth, adoptive and foster parents dealing with raising a child affected by prenatal exposure to alcohol. Stipends can cover travel, lodging, meals, registration and childcare. Funds are limited and selection will be made through a lottery system, until all available funds have been used. The Alaska Foster Parent Training Center will be coordinating this effort. For information contact Vinnie at (800) 478-7307. The deadline for application is October 23. In addition, there will be a parent meeting beginning at 5:30 P.M. on Thursday providing time for parents to gather, network and provide information and support to one another.

The registration fee for the 2-day conference is \$50.00. For additional information call the H&SS Office of FAS at (877) 393-2287 (statewide) or (907) 465-3033 in Juneau. Or you can go to our Summit web site for on-line information and registration at

www.hss.state.ak.us/fas/summit2001.

H&SS has new Commissioner

Deputy Commissioner Jay Livey has been tapped by Governor Tony Knowles to be the new Commissioner of Health and Social Services.



Governor Knowles made the announcement in a press conference on Thursday, September 27 praising Jay’s experience and commitment to the department’s mandate for excellence. Jay comes to this position with a wealth of experience, skills and understanding of the multitude of issues facing the department, as well as the social and health issues across our state.

Congratulations Commissioner Livey!

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Funds available for home modifications

The Anchorage Neighborhood Housing Services, Inc. is currently offering grant funds up to \$10,000 for home modifications to improve access and provide needed adaptations for Alaska Mental Health Trust beneficiaries. Eligibility includes:

- Households with at least one member who is an eligible Mental Health Trust beneficiary.
- The home can be owned by the occupant or rented (as long as the landlord agrees to participate).
- Properties must be located within the Municipality of Anchorage.

Staff at the Anchorage Neighborhood Housing Service are ready to assist beneficiaries, their families, or care providers with the application process, and their Rehab Specialist can help with the scope of work, hire a contractor and oversee the job to completion. To request an application or for more information call (907) 243-1558.

AHELP - online access to health information

The Alaska Health Education Library Project (AHELP) is an electronic clearinghouse of current health promotion and health education resources that are specific to and available in Alaska. It contains information on health promotion and health education programs, projects and materials. Topic areas include tobacco, heart health, nutrition, diabetes, substance abuse, fetal alcohol syndrome, community-based programs and more. AHELP is designed to assist Alaskans working in the areas of health and social services and to promote sharing, networking and collaboration. To access AHELP go to their website at www.ahelp.org or call them at (800) 879-7033.

Fetal alcohol exposure and brain function: An overview of the UW diagnostic process

The office of FAS is coordinating a day-long training event, slated for February 6th 2002 in Anchorage. This training is designed for Psychologists, Speech and Language Therapists, and Occupational Therapists who are interested in the FAS Team Diagnostic process. Experts in each field from the University of Washington FAS Diagnostic and Prevention Network will be on hand to discuss the UW model and the nuances of FAS assessment for each area of expertise. Registration will be free, and will be open to practicing professionals in any of the three fields. Stay tuned for more information, or call Heidi at the Office of FAS at (877) 393-2287.

Commissioner Perdue—Leaving a legacy of child, family and community advocacy

On October 8th, the Department of Health and Social Services said good-bye to Commissioner Karen Perdue. In August, Commissioner



Perdue announced that she had resigned her position with H&SS and would move to a new position within the University of Alaska in Fairbanks. In the words of Karen, “it is time to go home.” The Office of FAS, along with everyone in Alaska who is associated with health and social service issues will truly miss the vision, leadership and incredible energy of Karen Perdue. She has guided the Department of Health and Social Services since her appointment in

December of 1994—always leading with the one goal of improving the health and welfare for all citizens of the state of Alaska. Commissioner Perdue spearheaded efforts to improve the state’s response to the devastating effects of prenatal exposure to alcohol, securing our 5-year federal grant to address FAS in Alaska. We will all miss Karen and her constant drive to make things better! Good luck Karen and thank you for all that you have given.

FAS Community Team highlights

Copper River Native Association is host to one of the State’s longest running FAS Diagnostic teams, and has developed one of the most unique team models to address the needs and challenges of the Copper River area. Trained at the University of Washington in January of 1999, the team faced one of it’s most difficult challenges early on – that the Copper River Area did not have a doctor, a position that is required for diagnostic team development because FAS is a medical diagnosis. Some quick and creative planning led the Copper River team to identify an out-of-town doctor who was willing to travel to Copper River monthly to do the necessary medical assessment. A similar arrangement has been made for the team psychologist. These two team members now travel monthly to the community, and work hand in hand with other team members who reside full time in the area. To date the team has provided services to 74 individuals, including diagnosis, case planning and service provision in an on-going process. To learn more about the Copper River team process plan on attending their workshop “The Copper River Basin Experience: Adapting a Model that Works for Rural and Remote Alaska” offered at this years FAS Summit, or contact coordinator Gay Wellman at (907) 822-5241.

Respite for parents!

Anchorage Center For Families (ACF) is adding a second Intermision Crisis Nursery, located in Mountain View, to provide services to the Anchorage community. The new center opened its doors for referrals on October 1st. Through the use of FAS Innovative Grant funds, the new center will provide one respite bed reserved for families with children affected by fetal alcohol spectrum disorders (FASD). Parents and other caretakers of children affected by FAS can now access ACF for short term respite breaks! For more information about this new service for families dealing with FASD call ACF at (907) 276-4994.

Statewide support for parents

The Alaska FAS/FAE Parent Support Group is offering a variety of services for parents across Alaska. A 24-hour Parent Warmline can be accessed by calling (877) 786-7327, where another parent will answer questions, listen and provide available resources. Their new website is on-line at www.alaskafas.com, with resources and up-to-date information about alcohol-related birth defects and strategies for caregivers. In addition, a FAS Parent List Serve is now available for parents in Alaska and the Yukon only. To subscribe to this on-line e-mail support service go to <http://groups.yahoo.com/group/alaskafas>.

New Publication for Educators and Caregivers

Watch for the Rainbows: True Stories for Educators and Other Caregivers of Children with Fetal Alcohol Spectrum Disorders is the result of a collaboration between an educator and a psychiatrist. Drs. Frances M.E. Kapp (the educator) and Kieran D. O'Malley (the child psychiatrist) share true stories told to Dr. Kapp during interviews with parents, teachers and physicians of children with FASD, while gathering research for her doctoral dissertation. Each vignette is related with love and sometimes humor and is followed by insightful commentary by Dr. O'Malley. The vignettes are intended to illustrate both the uniqueness and the similarities often found in children with fetal alcohol syndrome and other alcohol-related birth defects. The book also includes an excellent selection of recommended books on fetal alcohol syndrome, as well as other resources in both the United States and Canada. To order send \$14.95 (plus \$5.00 shipping/handling) to:

Dr. Kieran D. O'Malley
University of Washington
Dept. of Psychiatry & Behavioral Sciences
Fetal Alcohol & Drug Unit
180 Nickerson St., Suite 309
Seattle, WA 98109

Communities Promote FAS Awareness Day Statewide

In addition to Governor Tony Knowles proclaiming September 9th as FAS Awareness Day in Alaska, several communities across the state found different ways to recognize International FAS Awareness Day. Some of the many activities included:

- Dena A Coy in Anchorage sponsored a day-long informational/awareness booth at the Alaska Native Medical Center.
- In Kodiak, the FAS Team produced a FAS Awareness Day button and distributed them around the community with a FAS information card.
- The Juneau office of the Alaska Foster Parent Training Center distributed FAS knots and information in its September newsletter.
- The Mat-Su Valley FAS Planning Committee sent a mass e-mail with education and information on International FAS Awareness Day.
- The Salvation Army Day & Residential treatment programs made 100 knots and passed them out with brochures at the Northway Mall in Anchorage.
- RuralCAP made FAS Day knots and distributed them with information to Head Start programs across the state.
- Several members from the Barrow Diagnostic Team participated in a local radio show on FAS & International FAS Awareness Day.
- Pat Cochran at Volunteers of America, Anchorage coordinated the taping of channel 2 news segments highlighting the stories of families dealing with FAS.
- Haines held a small gathering for community members to share in baked goods and discuss local issues surrounding FAS.
- The Kenai Peninsula Team made more than 1,000 knots and distributed them to families and social service agencies throughout the Peninsula. In addition the Peninsula Clarion featured a 2 page article on FAS.

FAS Day kits made available

To help communities organize FAS Awareness Day events, the Office of FAS developed a community resource kit filled with ideas, information and suggestions for FAS Day activities. The kits were sent to FAS grantees, various community agencies and to all divisions in H&SS. The colorful kits included background information on how FAS day evolved, the meaning of FAS Knots, and how to make them, information on Proclamations, media messages and community activity ideas.

Thanks to all of you who marked this important day with creativity and action!

Welcome to EED FAS Education Specialist



Jenny Huntley and Todd Brocius
in the FAS Office in Juneau

We are pleased to announce the hiring of Todd Brocius as the new FAS Education Specialist within the Department of Education and Early Development (EED). This new position is the offspring of collaborative efforts between EED and the Office of FAS, and was created to address the educational needs of Alaska's children who are affected by fetal alcohol spectrum disorders (FASD). Todd comes to EED from the Division of Family and Youth Services where he

worked as a social worker in the Juneau field office. Todd's other work history includes coordinating the Alaska Youth Initiative Program in Juneau, counseling in multiple residential treatment facilities with intervention focuses on developmental and emotional disabilities, and tutoring at several universities.

While the role of the FAS Education Specialist has not yet been fully developed, several immediate areas of need have been identified. These include:

- The need to create a user-friendly statewide FAS training module for teachers. This may emerge as a web-based delivery course, a CD-Rom, or more traditional learning curricula. This will assist schools in meeting Alaska Statute 14.20.680 which mandates training for all "teachers, administrators, counselors, and specialists on the needs of individual students who have alcohol or drug related disabilities."
- The need to connect existing *Barriers to Student Learning Teams* to existing *FAS Multidisciplinary Community Teams* or other community resource teams to promote FAS information exchange and to establish holistic student supports.
- The need to provide regional and/or statewide trainings for educators to model and disseminate education specific teaching strategies and interventions to provide optimal learning environments and to maximize the learning potential of students with FASD.

As part of the EED FAS Education project, scholarships for teachers to attend the FAS Summit 2001, November 15-16 in Anchorage, are available. These scholarships are being offered to any Alaskan teacher who feels he/she is currently working with students affected by prenatal exposure to alcohol. \$25,000 in scholarship money has been procured and selection will be made through a lottery system to ensure fairness. Scholarships will include the following: airfare (where applicable); lodging, per diem, registration fees and substitute teacher coverage costs. The deadline for application is October 17th. Application forms are available through school administrators and lead teachers at all 527 public schools across the state. For more information contact Todd at (907) 465-2825

Congratulations Diane

On Sunday, September 2, 2001 Diane Worley, Program Manager for the Office of FAS, was married to Joel Casto. As a heads-up, Diane has changed her name from "Worley" to "Casto"!

So, when you see "Diane Casto" listed as the FAS Program Manager, know that it is really the same person!

Prevention Specialist training available in FY02

The *Alaska Substance Abuse Prevention Specialist Training (ASAPST)* is a five day certificated training sponsored by the Alaska Division of Alcoholism and Drug Abuse, Akeela, Inc. and the Western Regional Center for the Application of Prevention Technologies (WestCAPT). The ASAPST curriculum was developed by WestCAPT and adapted to meet the unique needs of Alaska. The ASAPST is designed for both experienced professionals and those new to the prevention field. This is an ideal training opportunity for prevention providers, regional health providers, youth workers, tribal leaders, teachers, counselors, suicide prevention coordinators, village alcohol counselors, and community coalition members. The training will assist participants in building an effective prevention program and an understanding of how to develop community needs assessments. A certificate of completion will be given to those attendees who complete all five days. Regional trainings are available throughout the state of Alaska during the next eight months in Anchorage, Juneau, Fairbanks, Kotzebue and Nome. The 5-day registration fee is \$150.00. For more information and specific training dates contact Akeela, Inc. at (888) 290-3850 (toll-free statewide) or (907) 565-1226 (Anchorage) or visit them online at www.akeela.org.

FAQ: What is FAE?

There is much confusion about the varied terminology used to describe an individual affected by prenatal exposure to alcohol. Fetal alcohol syndrome (FAS) and other conditions associated with prenatal exposure to alcohol refer to a group of physical and mental birth defects. These birth defects are medical and disability conditions diagnosed by a physician, in partnership with other trained professionals. As we all know, securing a diagnosis can be difficult because the characteristics associated with prenatal exposure to alcohol are often subtle and may go unrecognized or be misdiagnosed or mislabeled. Fetal alcohol effects (FAE) is a term that has traditionally been used to categorized all of those individuals affected by prenatal exposure to alcohol that did not meet the criteria for fetal alcohol syndrome (FAS). FAS is a medical diagnosis that requires the presence of the following four criteria:

1. Delayed prenatal and/or postnatal growth (resulting in height and/or weight below the tenth percentile).
2. Central nervous system abnormalities (e.g. small head circumference, developmental delay, intellectual function delay, mental retardation, attention deficit disorders).
3. Characteristic facial features including short palpebral fissures (small eyes), abnormal philtrum (groove above the lip), and thin upper lip.
4. Reasonable knowledge that individual was prenatally exposed to alcohol.

While it is often assumed that other alcohol-related birth defects, including FAE are less severe than FAS, this is not always the case. Most often individuals with other alcohol-related conditions do not have the associated facial features. However, they can have neurological abnormalities, delays in development, intellectual impairments and learning/behavior disabilities or other types of CNS impairment. Often times FAE is more severe than FAS and the lifelong impacts can be greater.

In an effort to begin clarifying this confusing terminology, a new term has come to the forefront—Fetal Alcohol Spectrum Disorders (FASD). FASD is the most recent attempt to more clearly capture the essence of the clinical problem, acknowledging the reality that prenatal alcohol exposure causes a wide range of effects. FASD has three subtypes: fetal alcohol syndrome (FAS), partial FAS and alcohol related neurodevelopmental disorder (ARND).

The most important thing to remember is that alcohol is a teratogen and can cause lifelong, permanent birth defects for any child exposed to alcohol prenatally. The effects for each individual are varied due to the tremendous variability associated with consumption of alcohol during pregnancy. The more we learn about FASD, the better we can serve those already affected and the better our prevention efforts will be.

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 life-time outcomes for individuals with this disability.

- The Alaska Foster Parent Training Center (AFPTC) is an innovative grantee that is using its grant funds to provide statewide support to foster and adoptive parents to attend fetal alcohol syndrome training across the state. The initial project goal was to provide travel, lodging and child care scholarships to families attending one of three trainings in the communities of Bethel and Dillingham. In addition to these originally planned trainings, AFPTC was able to host and provide parent travel scholarships for trainings in Fairbanks and Juneau. Upcoming plans for AFPTC include providing travel scholarships to the 2001 FAS Summit for birth, foster and adoptive parents. Recently, the AFPTC welcomed aboard new Director Deborah Hayes, who brings a DFYS background and excellent leadership to the program. For more information about this innovative grant call the Alaska Foster Parent Training Center at (800) 478-7307.
- An innovative grant program sponsored by the Salvation Army of Anchorage is another exciting project working toward the prevention of fetal alcohol syndrome. Grant funds are used to support a community health educator who provides FAS training and awareness to high-risk populations like women's substance abuse programs, vocational rehabilitation programs, teen groups, and others. Utilizing their already existing program structure and clients, FAS educational information and resources are provided in a variety of ways, incorporating education about fetal alcohol syndrome and the dangers of drinking during pregnancy to all high-risk populations they work with. We are pleased to see FAS grant funds being used to enhance and improve programs that are already reaching high-risk populations—maximizing the educational and outreach efforts that the Salvation Army already does so well! For information about this project call Joyce Guest at (907) 279-0522.
- The Resource Center for Parents and Children in Fairbanks, is using its Innovative Community Grant to fund the *Aurora Project*, a parent training and support model for parents with children affected by fetal alcohol syndrome. *Aurora Project* coordinator Mary Lou Canney, a longtime advocate for FAS and parent support services, facilitates an 8–10 week course modeled on principals developed by Diane Malbin, a nationally recognized professional and birth mother working in the field of fetal alcohol syndrome. To learn more about this program contact the Resource Center for Parents and Children at (907) 456-2866.

FAS: Alaska Educator's Guide ready for distribution

The Office of FAS is please to announce the publication of our newest guide – *Fetal Alcohol Syndrome: Alaska Educator's Guide (The Educator's Guide)*. This is the third in a four-part series of guides for specific service disciplines working with individuals with FAS and other alcohol related birth defects and their families. The first two guides were aimed at Alaska's medical providers and providers offering prevention and intervention services. The fourth guide, still in production, will be geared toward Alaska's judicial system. *The Educator's Guide* was developed in collaboration with the Department of Education and Early Development, to provide Alaska's teachers with current information on fetal alcohol syndrome and other alcohol related birth defects. *The Educator's Guide* includes information on what school districts can do, what teachers can do, supporting families, Alaska's response to FAS, suggested classroom strategies and available resources.

A copy of the new *Educator's Guide*, along with a copy of the video *Students Like Me: Teaching Children with Fetal Alcohol Syndrome*, will be sent to every school district and every Head Start program across the state. If you would like a copy of *The Educator's Guide* or our two other guides, *Alaska Medical Provider's Guide* or *Alaska's Guide to Prevention, Intervention & Services*, please call Sherrie at the Office of FAS or send us an e-mail with your name, mailing address and which guides you would like to have.

Dates to Remember

October

4-5, Thursday and Friday: FAS Steering Committee meeting, Fairbanks.

11-13, Thursday-Saturday: 15th Annual NASW Conference. "Exciting Challenges to Consider in a Diverse Alaska and Changing World," Anchorage. (800) 478-6279.

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

November

7, Wednesday: Infant Learning EI/ILP Annual Conference, Anchorage. (907) 269-3440.

8-10, Thursday-Saturday: "Steps to Unity." 8th Biennial Pathways Conference, Anchorage. (800) 478-7678.

12-14, Monday-Wednesday: Prevention Symposium 2001, Anchorage. (888) 653-4478.

15-16, Thursday and Friday: "Beyond Diagnosis: Grief, Healing and Community Collaboration." FAS Summit 2001, Anchorage. (877) 393-2287.

December

4-6, Tuesday-Thursday: Alaska Health Summit, Anchorage. (907) 269-3457.

7-8, Friday and Saturday: Children and Adolescent Psychiatry Conference, Anchorage. (907) 261-3011.

February 2001

6, Wednesday: FAS Specialty Training for Psychologist, Occupational and Speech Therapists, Anchorage. (877) 393-2287

March

4-6, Monday-Wednesday: Early Years, Critical Years II: The Science of Early Childhood from 0 to 8 years, Anchorage. (907) 269-4681

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