



## Enhancing and Sustaining Alaska's FASD Project

A report from Alaskans concerned about prenatal exposure  
to alcohol and its effects on the health of our state

**November 2005**

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**Alaska Statewide Plan – Honoring Our Past, Shaping Our Future:  
Enhancing and Sustaining Alaska's FASD Project**

November 2005

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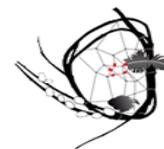
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## Alaska's response to Fetal Alcohol Spectrum Disorders

### ***FASD Regional Summits 2005***

Four regional summits brought Alaskans together in May and June of 2005 to share ideas, thoughts and strategies for continuing and enhancing the state's agenda on fetal alcohol spectrum disorders (FASD). A broad cross section of people came to the summits to shape the state's approach to services, prevention and advocacy for FASD in the next one to five years.

Almost 200 people participated in one or more of the regional meetings. People from the southcentral region met in Anchorage and those in the northern region met in Fairbanks. The southeast regional meeting was in Juneau, and the southwest region was held in Bethel. Several people attended meetings in regions different from the one in which they live.

Participants included parents, caregivers, educators, judges, law enforcement and corrections personnel. Those attending also included behavioral health, health care and disability service providers, policy makers and community advocates. During the registration process, forty participants indicated their lives have been directly impacted by an FASD.

After opening remarks from the State of Alaska Division of Behavioral Health Office of FAS, participants nominated topics to discuss in breakout session, using a meeting style known as Open Space Technology. People worked in small groups on the topics that they found most compelling; they moved among groups as interests and needs changed, providing cross-pollination of ideas. Several small groups drafted goals and action plans as time allowed. Many conference participants celebrated work that has begun, including progress in diagnosis and treatment for children.

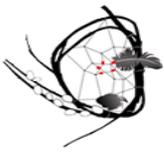
### ***Major themes for FASD planning***

With varied emphasis according to local circumstances and needs, the following four major themes surfaced at all four summits to form the backbone of planning for FASD in Alaska:

- Systems change: Continuum of services to support families and individuals, including those 18 and older, integrated across agencies and provider groups
- Training across systems
- Public awareness and advocacy
- Evaluation as an integral part of services

The importance of prevention, data gathering, integration of wrap-around services and sustainability were common concerns within many breakout sessions. Notes from the regional summits are available at [www.hss.state.ak.us/fas](http://www.hss.state.ak.us/fas)

*"Thank you for the conference and a chance to network; a lot of times we think we're alone in our places dealing with this stuff. I haven't been in loop, so it's nice to see what's going on and I'm positive about the future."  
Participant*



## **Foundation for FASD services in Alaska**

Among states collecting data related to births impacted by prenatal exposure to alcohol, Alaska continues to have high rates of FAS and other alcohol related birth defects. According to the Alaska DHSS, Division of Public Health, FAS Surveillance Project (using data from birth years 1995-1999) an average of 15 Alaskan infants are born each year with Fetal Alcohol Syndrome (1.5 per 1,000 live births). In addition, an average of 163 Alaskans are born being affected by maternal alcohol use during pregnancy and possibly resulting in related birth defects and disabilities. Among Alaska Native women the prevalence of FAS is more than 15 times that of whites.<sup>1</sup>

Over the past eight years Alaska has made great strides in addressing the critical issue of alcohol use during pregnancy and the devastating impact it has on individuals, families and communities. Alaska has been fortunate to have strong administrative, legislative and community support to move these efforts forward. Through the efforts of Senator Ted Stevens, a five-year \$29 million grant from SAMHSA provided an opportunity to establish a solid foundation of support, services and program development.

Beginning in October 2000, the SAMHSA grant provided an opportunity to examine the internal and external systems of prevention, intervention, diagnosis, treatment and data collection. The goal for this five-year grant award was to develop a comprehensive, integrated and sustainable system of services related to fetal alcohol spectrum disorders and to enhance the existing service delivery systems to better serve this issue. The funds provided Alaska with the resources to start some important new work, including initiatives to:

- Develop new materials
- Begin innovative community-based programs
- Create a system for statewide identification and diagnosis of FASD
- Develop a comprehensive public education campaign to change public norms about drinking during pregnancy and the outcome of those actions

## **SAMHSA grant launched training and public awareness initiatives**

With assistance from the Family and Youth Services Training Academy at the University of Alaska Anchorage, the state developed two training curricula:

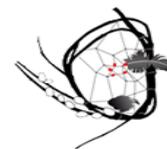
FAS 101—*Disabilities of Discovery: Insights into Brain-Based Disorders*

FAS 201—*Developing Successful Interventions and Supports*

As a result these of curricula, Alaska has a statewide total of 42 active FAS 101 trainers and 25 active FAS 201 trainers. Over 3,200 individuals have received the information, with a 31 percent increase of FASD knowledge documented statewide.

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<sup>1</sup> Race-specific estimates of FAS prevalence should be interpreted with caution. Increased awareness of maternal alcohol use and careful medical documentation by Alaska Native health organizations may result in more complete reporting of potential cases of FAS among Alaska Natives.



This training continues to improve knowledge and understanding of FASD statewide, across discipline.

For a list of FAS trainers see <http://www.hss.state.ak.us/fas/Resources/trainers/default.htm>.

Since 2000 there has been a growing network of FASD Diagnostic Teams, with thirteen (13) teams currently serving the following communities: Sitka, Juneau, Ketchikan, Copper River, Tok, Kodiak, Anchorage (2- South Central Foundation and API), Wasilla, Fairbanks, Bethel, Dillingham, and Soldotna.

<http://www.hss.state.ak.us/fas/teams/default.htm>

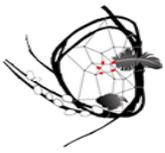


Through this effort over 145 Alaska professionals received training to conduct an FASD diagnosis utilizing the University of Washington's 4-Digit Diagnostic Code Model. Referrals to diagnostic teams for assessment and diagnosis have been received from many professions, including but not limited to:

- Caregivers (over 160 referrals)
- Social workers (over 170 referrals)
- Medical and mental health care providers (over 150 referrals)

From July 2000 through March 2005, the Alaska Team Network conducted 755 diagnostic assessments. Of the 755 individuals for whom a diagnosis was completed, 10 percent were diagnosed with FAS or atypical FAS and over 80 percent were diagnoses with some level of organic brain damage resulting from prenatal exposure to alcohol.

Beginning in 2001 the DHSS Office of FAS developed a statewide, multi-pronged public education/media campaign aimed at increasing knowledge about the dangers of drinking alcohol during pregnancy. The campaign developed two themes to reach specific populations:



- *I Have the Power to Prevent FAS* – This message is directed all women of child-bearing age
- *Thankfully There are People Who Will Help Her...Are You One of Them?* – Intended for family, friends and community members who know a woman who is pregnant and drinking

Television, radio and newspaper ads in three phases expanded the information and increased the knowledge Alaskans would receive regarding fetal alcohol spectrum disorders and the high-risk behavior of drinking alcohol during pregnancy. The last campaign highlighted Alaska medical providers to emphasize the role of primary care providers in giving women and their partners information, support and services related to the dangers of alcohol during pregnancy.

In 2006 the DHSS Office of FAS will conduct a second Knowledge, Attitudes, Beliefs and Behaviors (KABB) survey to document the change in perceptions about alcohol use and pregnancy. Selected service professionals and the general public will receive a telephone survey as part of documenting the success of the last eight years of the state's FASD project.

Educator training is available online through the Alaska Department of Education and Early Development. Learn more about the module from the following website: <http://www.hss.state.ak.us/fas/docs/multidisiplinary%20FASD%20module%20flyer1.pdf>

The \$29 million federal grant ended in September 2005. While this impacts project resources, it will not end the focus on building sustainable, community-based programs. To assist in the continuing FASD efforts, Governor Murkowski recommended \$1.096 million in new state funds for fiscal year 2006 to focus on prevention, diagnosis, service improvement and evaluation work as the foundations of ongoing efforts by the Office of FAS. At the end of the legislative session, \$596,000 remained in the FY06 budget designated specifically for the statewide diagnostic teams and the services they provide. This funding is a solid start to continuing Alaska's commitment to FASD and the needs identified in this report.

### ***Planning for the future***

The DHSS Division of Behavioral Health Office of FAS wanted to be sure that a state plan would reflect the strengths and needs of families and service providers statewide. To begin developing the state plan, the Office of FAS asked people to meet in regional groups in May and June 2005. Rather than conferences focused on training, the regional summit effort returned to the methodology employed in the first Statewide FAS Summit in 1997 – gathering information from those most involved and using their words, their concerns and their experiences to shape future plans.

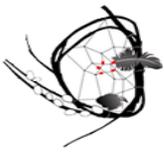
At each summit, participants suggested topics to discuss in breakout groups. Similar themes emerged at each of the four conferences, although notes from each summit reflect local characteristics and needs – we encourage readers of this report to visit of the Office of FAS website ([www.hss.state.ak.us/fas](http://www.hss.state.ak.us/fas)) to read direct proceedings from the regional summits.



This report incorporates actions recommended by summit participants within the framework of budgetary realities and departmental responsibilities of the DHSS, DBH, Office of FAS. The following sections of the report summarize major themes from the summits and provide recommended actions within each major theme. Tasks fall into two general arenas:

- Actions that will be addressed most effectively by groups and individuals at the regional or community level
- Actions that fall within core duties of the Office of FAS, or through partnering between the Office of FAS and state, regional or local entities

The State of Alaska continues to fund the Office of FAS within the DHSS Division of Behavioral Health, to continue statewide coordination, resources and advocacy.



## Summit themes, with results and recommendations

### I. Spearhead major systems change to improve services statewide

"I'm the type of young adult with FAE that you are all concerned about. I look normal and have great people skills I can get lots of jobs but can't keep them. Employers don't understand what I need to be able to keep a job."  
Participant

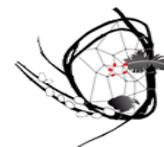
Alaska's Office of Fetal Alcohol Syndrome partnered with communities, agencies, family and individuals across the state to accomplish much in the past five years. More needs to be done to continue creating the most effective and efficient delivery system for people impacted by FASD. By integrating FASD into existing systems, early intervention and natural supports can help community members who experience the effects of alcohol-related birth defects to build upon their strengths and be engaged in a meaningful way.

All four regional summits highlighted urgent needs for major systems change. Alaska is a front-runner in addressing FASD nationally, but the needs and challenges that face Alaska are great. In many cases, the integration of services into existing service delivery systems can provide long-term solutions for individuals whose needs for support will continue throughout their lives.

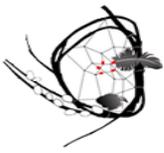
Participants repeatedly voiced concerns about dispelling a common myth – that although people with FASD *do not get better*, they *can do better* with the right supports, intervention and accommodations provided long-term. In other words, one cannot fix functional difficulties caused by prenatal alcohol exposure but supports can help people cope with their challenges as they and their communities focus on their strengths.

### Recommendations for integrating FASD into existing systems

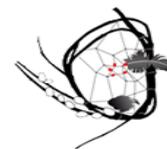
Strategies for systems change	State of Alaska Office of FAS with other state and regional partners	Regional and/or community responsibility
Coordinate and – as possible – integrate FASD services with other programs	<p>Expand networking opportunities by updating the website.</p> <p>Work with state departments, regional and community entities to incorporate FASD information into planning.</p> <p>Work with the Alaska Mental Health Trust, Governor's Council on Disabilities &amp; Special Education, and the Advisory Board on Alcoholism and Drug Abuse to recognize people with FASD as part of existing beneficiary groups.</p> <p>Develop partnership with DBH Traumatic Brain Injury (TBI) initiative to coordinate service planning and increase awareness of FASD as an acquired brain injury.</p>	<p>Advocate at the local and regional level for integrated services.</p> <p>Work with community, regional and state entities to incorporate FASD information into planning.</p> <p>Develop community-driven strategic plans to highlight FASD needs and service, including all existing service providers in the discussions.</p>



Strategies for systems change	State of Alaska Office of FAS with other state and regional partners	Regional and/or community responsibility
Train families to address needs	<p>Continue public education and awareness.</p> <p>Continue to refer inquiries to existing providers, trainers, and family support networks.</p>	<p>Provide community-wide training and outreach.</p> <p>Refer inquiries to existing providers, trainers, and family support networks.</p> <p>Develop community systems of referral for FASD services.</p>
Focus on best practices	<p>Integrate funding sources through interdivisional/departmental grant awards.</p> <p>Share information, examples and new research among the FASD community.</p> <p>Work with Medicaid on enhancing Medical billing for FASD services.</p>	<p>Develop and provide wrap-around services and family supports.</p> <p>Plan for provider turnover, with ongoing training opportunities.</p> <p>Share information, examples, and community successes in improved service delivery.</p>
Continue exploring classification issues and possibilities for FASD	<p>Continue discussions with Alaska Mental Health Trust, the Governor's Council on Disabilities &amp; Special Education and the Advisory Board on Alcoholism and Drug Abuse.</p> <p>Work in partnership with the Traumatic Brain Injury Council to discuss classification of FASD as a TBI.</p> <p>Engage in discussions with providers and families to evaluate usefulness of classification and next steps.</p>	<p>Continue discussions with Alaska Mental Health Trust, the Governor's Council on Disabilities &amp; Special Education and the Advisory Board on Alcoholism and Drug Abuse.</p> <p>Engage in discussions with providers and families to evaluate usefulness of classification and next steps.</p> <p>Contact legislators regarding necessary changes to regulations and eligibility for services.</p>
Encourage integration of rural services	<p>Continue offering FASD training and awareness/public education materials.</p> <p>Work with regional and local communities to identify key people to train and provide screening.</p> <p>Work with public health to implement mandatory FASD screening at well-child visits.</p> <p>Encourage regional and local entities to offer culturally relevant treatment centers, wellness teams, and tribal courts.</p>	<p>Coordinate delivery of consistent, accurate information.</p> <p>Provide a traveling diagnostic team and maximize use of telemedicine.</p> <p>Provide prevention education to clinics, schools, tribes, city councils.</p> <p>Identify key people to train and provide screening</p> <p>Create culturally relevant treatment centers, wellness teams and tribal courts.</p>



Systems change Strategies con't.	State of Alaska Office of FAS with other state and regional partners	Regional and/or community responsibility
Coordinate support for children with FASD and their families	<p>Continue providing a current and user-friendly FASD website for families and providers.</p> <p>Incorporate nutritional strategies into training and website information.</p> <p>Partner with funders and existing providers to expand the network of parent navigators.</p> <p>Partner with childcare services and licensing to assure caregivers are trained to work with children who have fetal alcohol exposure.</p> <p>Encourage regional entities to plan or support local efforts to provide needed services such as crisis intervention respite, camping experiences, dental care.</p>	<p>Encourage use of the Office of FAS website for resources and training information.</p> <p>Train respite providers in FASD and strategies for intervention.</p> <p>Broaden access to respite for all families dealing with FASD.</p> <p>Plan or support needed services such as crisis intervention respite, camping experiences, dental care.</p> <p>Expand the network of parent navigators through partnerships with funders and existing providers</p>
Launch diagnostic team(s) for adolescents and adults	Encourage and assist Office of Children's Services, Division of Juvenile Justice and the Department of Corrections to implement broad-based screening.	<p>Provide screenings in small communities through regional planning.</p> <p>Expand and diversify funding resources.</p> <p>Implement broad-based screening through the Office of Children's Services, Division of Juvenile Justice and Department of Corrections.</p>
Ensure service availability for people in high school and throughout adulthood	<p>Develop employer awareness materials related to FASD and its impact on affected employees.</p> <p>Encourage the Office of Children's Services to partner with others to transition supervision into young adult life.</p> <p>Encourage development of a continuum of services for families and individuals affected by prenatal alcohol exposure.</p> <p>Advocate for development of FASD therapeutic models.</p> <p>Expand work with the state's education system, to improve services to children and youth with an FASD.</p>	<p>Develop supportive networks such as safe havens, life coaches and smooth transition from child protective services supervision.</p> <p>Work to develop vocational programs specifically geared for individuals with FASD.</p> <p>Strengthen employer awareness of FASD and its impact on youth and adults.</p> <p>Encourage development of a continuum of services for families and individuals affected by prenatal alcohol exposure.</p> <p>Advocate for development of FASD therapeutic models.</p>



## **Regional summit examples: Major systems change outcomes or strategies**

### **Southwest Region**

Year 1: Start an FASD parent support group that could eventually serve as a resource for villages in the area.

Year 3: Each village will have a parent-driven FASD support group.

### **Southeast Region**

Year 1: Provide training to begin transition planning, including partial guardianships, by age 14 so caregivers know the steps to complete before age 18 – for all caregivers, such as Office of Children’s Services, schools, professionals, Division of Vocational Rehabilitation.

Year 3: System in place includes trained advocates for all individuals with FASD. Caregivers know how to provide gentle supports based on needs/strengths; parent support groups exist in all rural and urban communities. Training available for teens, caregivers, schools, all state service providers, medical professionals, and law enforcement in all rural and urban areas.

### **Northern Region**

Fairbanks Fetal Alcohol Community Evaluation Services (FACES) supports efforts to develop a team for adolescents and/or young adults.

### **Southcentral Region**

The Anchorage Council on FASD formed to serve as a cooperative network of individuals and organizations committed to advocacy for people impacted by prenatal alcohol exposure and to the prevention of FASD.

## **Examples of success or best practice in Alaska**

- Several school districts received funding to implement FASD innovative school-based programs through the Department of Education and Early Development.
- The Anchorage School District identified and trained an FASD specialist in each school.
- Maniilaq staffs an FASD specialist in each village school in the Northwest Arctic School District
- Alaska Court System is working to train judges, attorneys and staff to better understand FASD and the relationship to criminal activity.
- Division of Juvenile Justice has developed an ongoing FASD Advisory group to address FASD issues as they relate to juveniles and their involvement with the juvenile justice system.
- Alaska DHSS Division of Behavioral Health has included screening for potential FASD in the required Alaska Screening Tool.



## II. Foster a network of FASD training for all systems

In the past we never knew what was wrong with our children and they ended up in jails. Their minds are not like our regular brain. It's not that they are bad. It's just that their brain is not functioning right.

Participant

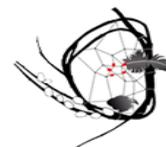
Lack of understanding about the wide range of effects of FASD creates chaos in classrooms, at worksites and in service systems. The number of school drop outs, inmates and chronically unemployed adults could be reduced if people had a better understanding of FASD and how to provide the supports necessary to help affected individuals function to their capacity.

Because Fetal Alcohol Spectrum Disorders manifest differently for each person and in many cases effects are not visible to the eye, there is no easy test or checklist to follow. This makes it extremely difficult for teachers, parents, employers, public safety officers, and service providers to recognize symptoms and choose appropriate strategies and effective interventions.

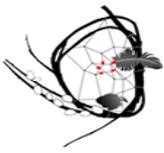
Workers in all systems need training to create a common understanding of FASD. Training should include opportunities to share strategies that have been successful in helping individuals function to their full potential. Involving those impacted in training reinforces the philosophy of: *Nothing about me without me.*

### Recommendations for expanding the network of FASD training

Strategies	State of Alaska Office of FAS with other state and regional partners	Regional and/or community responsibility
Advocate for inclusion of FASD into training curricula across systems and disciplines	<p>Continue sharing and developing curricula for various systems, and expand content.</p> <p>Maintain website updates to include a current list of certified trainers and their locations as well as the nonprofits that have certified trainers.</p> <p>Partner with the 73 state certified trainers to expand distribution of information.</p>	<p>Send local people to FASD trainings and share information with others.</p> <p>Contact certified FASD trainers to schedule presentations and training.</p> <p>Share FASD curricula and expand content.</p> <p>Contribute information to DHSS Office of FAS for inclusion on website.</p>
Education system	<p>Develop ongoing process for school districts to utilize existing online FASD training for educators.</p> <p>Share examples of how Alaska school districts are addressing FASD.</p> <p>Identify information sources for planning classroom strategies for individuals with an FASD.</p> <p>Partner with appropriate associations and universities to expand FASD training and encourage/model change in the education system.</p>	<p>Provide school district level FASD training to accommodate staff turnover.</p> <p>Partner with local service providers and families.</p> <p>Share classroom FASD strategies with local schools and educators.</p> <p>Partner with appropriate associations and universities to expand FASD training and encourage/model change in the education system.</p>



Strategies	State of Alaska Office of FAS with other state and regional partners	Regional and/or community responsibility
Human services	<p>Monitor available information and implementation of FASD training for employees.</p> <p>Continue monitoring infusion of FASD information and training into UAF Rural Programs and Community Health.</p> <p>Negotiate training opportunities with Public Assistance staff and offices.</p>	<p>Include FASD issues in continuing education given to health aides, educators, social workers, elected leaders, medical officials and others.</p> <p>Provide FASD training and discussion opportunities for all community-based service providers.</p>
Justice System	<p>Monitor integration of FASD into RADCAT training, as well as training provided in the Division of Juvenile Justice, Department of Corrections and the Alaska Court System</p> <p>Encourage Office of Children's Services to implement changes in service delivery based on training received.</p> <p>Encourage FASD awareness training and provide information if needed, including strategies.</p> <p>Continue to work with Alaska State Trooper Academy in Sitka to incorporate FASD into VPSO and Trooper training.</p>	<p>Implement training and information sharing among peers in the Justice System.</p> <p>Link with local FASD trainers and providers to provide integrated services.</p> <p>Encourage local staff of the Office of Children's Services to implement changes in service delivery based on training received.</p> <p>Integrate FASD training and awareness across the public safety and justice communities.</p>
Families	<p>Continue to provide accurate and relevant information on the FASD website.</p> <p>Continue to search for new funding sources.</p> <p>Continue to refer families to existing resources.</p>	<p>Provide training and education to families on issues related to mental/substance abuse as well as individual roles in a child's life.</p> <p>Teach children to advocate for themselves and/or their peers.</p> <p>Implement systems of FASD training for parents, public health workers, Head Start and those working in villages.</p>
Employers	<p>Develop and provide FASD information appropriate for employers.</p> <p>Seek statewide employer networks to raise awareness about FASD.</p> <p>Partner with the Division of Vocational Rehabilitation to increase job skills/training for individuals with an FASD.</p>	<p>Encourage supported employment opportunities and share successful strategies.</p> <p>Encourage employer networks to raise awareness about FASD.</p>



## Regional summit examples: Network of FASD training outcomes or strategies

### Southwest Region

Year 1: Identify existing trainers and piggyback training with annual district in-services, annual health aide training, and behavioral health aide trainings. Individuals attending the Summit commit to introduce FASD in their own communities.

Year 3: FASD 101 and 201 in Yupik language with trainers available in every village.

### Southeast Region

Year 1: Short curriculum for professional provider groups; curricula tailored for various professionals and employers. Ensure school districts inform parents about the steps to take as children reach age 18. Integrated family support systems for parents with FASD and parents raising children with an FASD – across the board supports. Functional assessment in use for FASD instead of IQ score.

Year 3: A community group system will provide mentoring for adults with FASD. Independent living skills and services in schools for transitioning adults.

Year 5: Individual advocates/mentors with long-term relationships. FASD training mandated for certain professional groups such as law, public safety, and education.

### Examples of success or best practice in Alaska

- FASD 101 and 201 curricula and training system
- FASD for Educators – online training
- Online FASD 101 training for providers, paraprofessionals and families/caregivers
- Alaska Center for Resource Families—providing training and resources for foster families caring for children with an FASD
- RurALCAP's *Early Decisions: Addressing Alcohol and its Effects on the Unborn Child* – an FASD prevention curriculum for youth and young adults
- Statewide FASD Summit

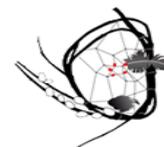
### III. Build awareness of FASD issues and rationale for funding

Funders, policy makers and communities need greater understanding of the dynamics around Fetal Alcohol Spectrum Disorders. Blaming or punishing the mother will not help the child. Instead, resources should focus on prevention as well as how best to help the child or adult affected by prenatal alcohol exposure.

Participants at regional summits said they continue to hear many circumstances like the following – stories that can be changed with greater public awareness:

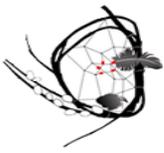
- Women who have an occasional drink before realizing they are pregnant, but who did not intend to hurt their child.
- Women who are chemically dependent who do not drink to intentionally cause harm to the child – they are unable to stop due to their addiction.
- Pregnant women whose abusive partners force them to drink choose alcohol use rather than receiving physical abuse they fear could hurt the baby more.

*I'd like to see research on prevalence of FASD among state prison population – to reinforce the need for community based, life-long support.*  
Participant



## Recommendations for increasing awareness of FASD among policy makers and the public

Strategies for awareness	State of Alaska Office of FAS with other state and regional partners	Regional or community responsibility
Develop and use a method of advocacy like Key Campaign	<p>Compare costs of people with FASD in jail to those receiving supports in communities.</p> <p>Share FASD information with funders and policy makers.</p> <p>Work with departments and service providers to focus on alcoholism as a disease.</p>	<p>Build broad FASD awareness, education and advocacy.</p> <p>Integrate community health planning.</p> <p>Implement FASD advocacy plans and share FASD information with funders and policy makers.</p> <p>Work with service providers and departments to focus on alcoholism as a disease.</p>
Coordinate delivery of consistent information about FASD	<p>Clarify and standardize statutes, regulations and practices related to services, disabilities and substance abuse.</p> <p>Continue working with providers and policymakers to break the stigma of FASD and birth mothers.</p>	<p>Coordinate treatment models to utilize appropriate FASD strategies and accommodations.</p> <p>Always use person first language and encourage others to also.</p> <p>Develop and implement local campaigns to break the stigma of FASD and birth mothers.</p>
Continue work on prevention of FASD	<p>Continue FASD public awareness efforts and update materials, including rural friendly and culturally appropriate.</p> <p>Underscore relationship between FASD and child abuse, and how early identification can prevent secondary disabilities.</p> <p>Help people understand that lack of diagnosis does not always mean lack of effects.</p> <p>Provide FASD tools and information to share with schools and communities that reach people at different ages and levels.</p> <p>Work with public health and medical professions to make the family planning connection and to counsel women to “not drink a drop’ during pregnancy.</p> <p>Continue funding travel budgets for FASD trainers around the state.</p>	<p>Network, coordinate and communicate FASD efforts at the community level.</p> <p>Incorporate cultural sensitivity into all FASD materials.</p> <p>Work with local media and other outreach sources to focus on FASD.</p> <p>Share information that lack of diagnosis does not always mean lack of effects.</p> <p>Work with public health and medical professionals to increase their awareness and response to the dangers of alcohol during pregnancy.</p> <p>Continue FASD public awareness efforts.</p>



## **Regional summit examples: Public awareness outcomes or strategies**

### **Northern Region**

Outline a specific legislative plan and work with all agencies who share concern for individuals and families affected by FASD. Advocate for state funding for FASD services and specialized policy development related to FASD.

### **Anchorage**

Anchorage Council on FASD – a cooperative network of individuals and organizations committed to advocacy for people impacted by prenatal alcohol exposure and to the prevention of FASD. FASD Awareness Day event at Covenant House was well attended.

The Council met with staff from Senator Murkowski’s Anchorage office to inform them about various projects, and to discuss the senator’s bill on FASD support and prevention. Prevention messages are attached to candy bars to be distributed at Halloween or at conferences, carrying the slogan, “This candy will be gone in a minute, but the effects of prenatal exposure to alcohol last a lifetime.”

### **Southeast Region**

Year 1: SAFE, WISH, AWARE, and SEARHC will include FASD information in their existing systems of care and service delivery. A speaker’s bureau will be established to become a base of knowledge in the community. Public awareness group will conduct needs assessments for gaps in services and for existing resources. A group will plan a targeted youth awareness efforts about FASD in and out of school.

Years 3 and 5: Build upon past success; strengthen and expand efforts and continue to evaluate effectiveness.

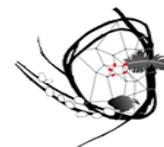
## **Examples of success or best practice in Alaska**

- International FASD Awareness Day, September 9 – communities across Alaska participate each year; the Governor issues a Proclamation each year.
- Multi-pronged media campaign – radio and television public service announcements, posters and print ads to increase awareness, understanding and available resources.
- Informational brochures distributed to public health office, treatment providers, WIC offices and Vital Statistics—targeting high-traffic areas for women of childbearing age.

*We’ve come  
a long way,  
but we still  
have a very  
long way to  
go.  
Participant*

## **IV. Plan and evaluate services**

Collecting and analyzing statewide FASD data will help to prioritize resources and guide the state and communities to most effectively develop services to positively impact people’s lives. Long-term studies of trends, needs, impact, and evaluation are needed for long range planning. FASD data collection must be integrated into existing systems and service delivery.



## Recommendations for evaluation

Strategies for evaluation	State of Alaska Office of FAS with other state and regional partners	Regional and/or community responsibility
Implement planning across systems to improve community health	Consistently involve people impacted by FASD in planning, education and advocacy. "Nothing about me without me." Develop and support FASD community planning strategies. Advocate for people with FASD to be recognized within existing beneficiary groups of the Alaska Mental Health Trust Authority.	Collect and provide available and needed FASD data. Implement and track FASD community planning strategies. Consistently involve people impacted by FASD in all planning, education and advocacy efforts.
Collect data	Use FASD data results for public awareness, prevention, funding, grants, and programming. Plan and establish FASD data collection for multiple purposes.	Plan for sustainable FASD efforts. Continue and enhance community-based FASD advocacy. Use FASD data to improve services and public awareness.
Create systems to measure outcomes.	Make electronic and print program evaluation tools available. Study/track FASD information from families and services available as well as gaps in services. Create templates/tools to measure provider effectiveness in working with individuals with an FASD.	Implement FASD evaluation and data tracking processes.

### Regional summit examples: Planning and evaluation

#### Northern Region

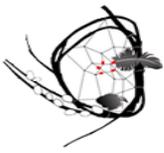
Work with ACCA to support the existing team, evaluate strengths and needs of the team, and assist with quality assurance efforts to determine the impact of the transition of the team to a new agency.

#### Southeast Region

Year 1: Conduct needs assessments, not only for gaps but also for existing resources to help the cause. Collect statistics to determine funding needs; reevaluate later.

### Examples of success or best practice in Alaska

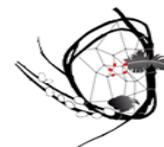
- State of Alaska FAS Surveillance Project, DHSS Division of Public Health – working in partnership with Alaska Birth Defects Registry, diagnostic teams and the Office of FAS
- Statewide FASD Diagnostic Team Network data collection and analysis by the UAA Behavioral Health Research and Services
- Training and support for all Alaska DHSS Division of Behavioral Health FASD grantees to develop outcome measures and program evaluation at the community level



## Resources identified at FASD regional summits

Participants in each regional summit brainstormed lists of resources – the following compilation is not exhaustive, but will provide a good indication of the types of resources available. Many of the websites listed here will take people to numerous other resources. For more detailed information or contacts, contact the DHSS, DBH, Office of FAS at (877) 393-2287 or 907/465-3033.

Family and individual supports	Training and information
<p>Alaska Center for Children and Adults (Fairbanks)</p> <p>Alaska Center for Resource Families and Alaska Adoption Support Center <a href="http://www.acrf.org/">http://www.acrf.org/</a></p> <p>Alaska Family Resource Center (Mat-Su)</p> <p>Alcoholics Anonymous sponsors and meetings</p> <p>Anchorage School District – SteP Center (<a href="http://www.asdk12.org/depts/step/anchorage/">http://www.asdk12.org/depts/step/anchorage/</a>)</p> <p>Attendance at regional and state summits</p> <p>Cook Inlet Tribal Council – New Beginning – Healthy Families (Alaska Native)</p> <p>Governor’s Council on Disabilities and Special Education (model and support) <a href="http://www.state.ak.us/gcdse">http://www.state.ak.us/gcdse</a></p> <p>Elders</p> <p>Fairbanks Community Mental Health Center</p> <p>Fairbanks Resource Agency</p> <p>Family Centered Services of Alaska</p> <p>Family Outreach Center for Understanding Special Needs (FOCUS)</p> <p>Head Start programs in many communities</p> <p>Infant Learning Programs – many communities</p> <p>Maniilaq FAS program</p> <p>MAT-SU Services for Children and Adults</p> <p>Medical contacts in Alaska communities <a href="http://family.addresses.com/yellow_pages/health~and~medicine/individual~and~family~services/8/627/AK/A.html">http://family.addresses.com/yellow_pages/health~and~medicine/individual~and~family~services/8/627/AK/A.html</a></p> <p>Native corporations</p> <p>Support for/by parents: <a href="mailto:fasalaska@lists.sesa.org">fasalaska@lists.sesa.org</a></p> <p>Program for Children of Incarcerated Parents</p> <p>Resource Center for Parents and Children, (Fairbanks) and their toll-free parent support line</p> <p>Salvation Army women’s and men’s programs</p> <p>School-based mental health programs</p> <p>Southcentral Foundation support groups around the state</p> <p>STAR programs at many agencies (DHSS grants)</p> <p>Stone Soup and related support groups</p> <p>Tribal councils, community groups</p> <p>Volunteers of America, based in Anchorage</p>	<p>Alaska DHSS, Division of Behavioral Health <a href="http://www.hss.state.ak.us/dbh/">http://www.hss.state.ak.us/dbh/</a></p> <p>Alaska DHSS Office of Children’s Services: adoption</p> <p>Alaska Office of FAS <a href="http://www.hss.state.ak.us/fas/">http://www.hss.state.ak.us/fas/</a> lists of resources, websites; material available for loan; training opportunities</p> <p>Alaska Office of FAS – FASD 101 and 201 trainers: <a href="http://www.hss.state.ak.us/fas/Resources/trainers/default.htm">http://www.hss.state.ak.us/fas/Resources/trainers/default.htm</a> and trainers Chalkboard (add link for teachers)</p> <p>Alaska Family Directory, a statewide directory for parents of children with special needs. <a href="http://www.asd.k12.ak.us/AFD/">http://www.asd.k12.ak.us/AFD/</a></p> <p>Anchorage School District STEP Center library (Students, Teachers, and Parents Center)</p> <p>Department of Education and Early Development— FASD resources for educators <a href="http://www.eed.state.ak/tls/asd">http://www.eed.state.ak/tls/asd</a></p> <p>Canadian Lake model</p> <p>Cottonwood Rehabilitation</p> <p>Fetal Alcohol Consulting and Training Services (Deb Evensen) <a href="http://www.fasalaska.com">http://www.fasalaska.com</a></p> <p>Faces of FAS – Canadian model</p> <p>FASCETS - Fetal Alcohol Syndrome Consultation, Education and Training Services, Inc. (Diane Malbin) – four-part video and <i>Trying Differently</i> <a href="http://www.fascets.org">http://www.fascets.org</a></p> <p>Mannequin baby with FASD (\$250)</p> <p>Oregon Study (accommodations that build on strengths: reducing secondary disabilities)</p> <p>University of Alaska – various programs/resources via University of Alaska Fairbanks (UAF) and University of Alaska Anchorage (UAA)</p> <p>UAA Center for Human Development – self-advocacy tools/resources includes multi-step process</p> <p>University of Washington Diagnostic and Prevention Network (birth mom model) <a href="http://www.depts.washington.edu/fasdpn">http://www.depts.washington.edu/fasdpn</a></p>



## Resources, continued

Justice System and related resources	Resident programs/housing/employment
<p>Adult therapeutic courts, State of Alaska Court System</p> <p>Alaska DHSS, Office of Children’s Services www.hss.state.ak.us/ocs</p> <p>Alaska DHSS, Division of Juvenile Justice www.hss.state.ak.us/djj</p> <p>Court Appointed Special Advocate (CASA) and Guardians Ad Litem</p> <p>Disability Law Center of Alaska www.dlcak.org</p> <p>Family courts, youth courts – limited</p> <p>Gastineau Community Residential Center (Juneau)</p> <p>Judges (some will send individuals with DD/FASD to SA programs such as Clitheroe, Akeela, Bryon Mawr, Hudson Lake healing camp (Copper River Native Association)</p> <p>Tribal Courts</p> <p>VINElink <a href="http://www.vinelink.com/index.jsp">http://www.vinelink.com/index.jsp</a> how to locate an individual in correction facility, see if on probation)</p>	<p>Access Alaska <a href="http://www.accessalaska.org">http://www.accessalaska.org</a></p> <p>Adult Learning Programs of Alaska – Fairbanks</p> <p>Alaska Division of Public Assistance www.hss.state.ak.us/dpa</p> <p>Alaska Division of Vocational Rehabilitation www.labor.state.ak.us/dvr/home.htm</p> <p>Alaska Women’s Resource Center (Anchorage)</p> <p>Cook Inlet Tribal Council residential services</p> <p>Dena A Coy House (Southcentral Foundation)</p> <p>Fairbanks Native Association</p> <p>Fairbanks Resource Agency (housing)</p> <p>Fairbanks Community Mental Health Center</p> <p>Habitat for Humanity</p> <p>Interior Alaska Center for Nonviolent Living</p> <p>PASS (Social security)</p> <p>Passage House (Covenant House)</p> <p>Rescue Mission – Fairbanks</p> <p>State of Alaska Job Centers <a href="http://www.labor.state.ak.us/home.htm">http://www.labor.state.ak.us/home.htm</a></p> <p>Tanana Chiefs Conference – Interior Alaska</p>
<p><b>Diagnosis; treatment; associated finances</b></p>	
<p>Alaska Division of Public Assistance <a href="http://www.hss.state.ak.us/dpa">www.hss.state.ak.us/dpa</a></p> <p>Alaska Resource Center</p> <p>Aligned Trust Beneficiary Initiative (SSI &amp; Medicare)</p> <p>FASD Diagnostic Team Network <a href="http://www.hss.state.ak.us/fas/teams/default.htm">www.hss.state.ak.us/fas/teams/default.htm</a></p> <p>Jennifer Lewis, Traumatic Brain Injury (TBI) Coordinator, Division of Behavioral Health (Anchorage)</p> <p>Medicaid</p> <p>Nonprofit organizations in many communities provide developmental disabilities services</p> <p>North Star Hospital (bringing 2 psychiatrists July, looking into FASD)</p> <p>Provider agreements</p> <p>Substance abuse/mental health programs</p> <p>Substance abuse treatment program within correction facility</p> <p>Temporary Assistance for Needy Families, Alaska Division of Public Assistance <a href="http://www.hss.state.ak.us/dpa">www.hss.state.ak.us/dpa</a></p> <p>Third party reimbursements</p> <p>Volunteers Of America Camp Hope, positive four-day family camp</p>	

