

# Alaska

## Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022

January 29, 2018 *(Revised 9.12.18)*



This strategic plan, organized by the Governor's Council on Disabilities and Special Education, is supported by multiple organizations, individuals, and agencies committed to addressing Fetal Alcohol Spectrum Disorders (FASDs) in Alaska. The Alaska FASD Strategic Plan Workgroup includes: Access Alaska, Advisory Board on Alcoholism and Drug Abuse, Alaska Center for Children and Adults, Alaska Center for Human Development, Alaska Child and Family, Alaska Department of Health & Social Services, Alaska FASD Partnership Alaska Mental Health Board, Alaska Mental Health Trust Authority, Alaska Native Tribal Health Consortium, Denali Family Services, FASDx Services, Full Spectrum Health, Kenai Peninsula Borough School District, Kobuk Valley Consulting, Northwest Resource Associates, Southcentral Foundation, Stone Soup Group, University of Alaska Center for Behavioral Health Research & Services, Volunteers of America Alaska, Yukon Kuskokwim School District, Yupiit School District, and many individuals.

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# I. Overview

The Alaska FASD Strategic Plan Workgroup was formed in 2017 by the Governor’s Council on Disabilities and Special Education (GCDSE) to address fetal alcohol spectrum disorders (FASD) in Alaska. Organized by the Governor’s Council on Disabilities and Special Education, a group of stakeholders from across the state from a variety of disciplines was formed to develop the 5-year strategic plan. After several in-person and telephonic meetings, the group determined six priority areas, which included: Primary Prevention, Screening and Diagnosis, Early Childhood and Education, System Transformation and Navigation for Youth and Adults, Workforce Development, and Community Outreach and Engagement. Workgroups were formed for each priority area and work began in late 2017. The strategic planning workgroup as a whole meets quarterly for reporting progress, and annually to update the plan. Individual priority workgroups meet regularly to address and carry out their objectives.

# II. Guiding Principles and Goals

## Vision

The prevalence of fetal alcohol spectrum disorders (FASDs) is reduced and individuals who experience FASDs and their caregivers are empowered to reach their unique and full potential. Through education, prevention, and provision of quality, relevant supports and services, Alaska is a FASDs- informed state.

## Goals

- Raise awareness of FASDs, a range of neurodevelopmental (brain-based) disabilities that can affect any person exposed to alcohol before birth.
- Reduce the incidence of alcohol-exposed pregnancies.
- Address the stigma associated with FASDs by educating Alaskans to understand the complexities of the disability in a way that honors the strengths of those impacted, to promote an inclusive, accepting culture.
- Reduce the co-occurrence of childhood trauma and FASDs by increasing supports for high-risk families, building resilience, and improving access to treatment for early childhood trauma.
- Define and promote FASD-informed care in Alaska.
- Advocate for fully fund appropriate services, supports and education for individuals and families with FASDs to increase self-advocacy, prevent crises, and reduce adverse outcomes, such as substance misuse, incarceration, and suicide.

## Purpose of Workgroup

- Focus on action.
- Bring advocates, self-advocates, and providers together.
- Break down silos.

- Share information.
- Develop and carry out a sustainable strategic plan.
- Recruit and mentor the next generation of advocates, self-advocates, facilitators, and leaders living with FASD.

## Implementing, Monitoring, & Revising the Plan

- This plan is the framework for guiding the FASD 5-year strategic planning effort.
- The GCDSE and its partners commit to facilitating, supporting, and advocating for the development and implementation of the plan.
- Partners will meet quarterly, with at least one annual meeting for revising and updating the plan.
- Workgroup leaders will convene workgroups that invite additional participants for drafting and implementing the action plans.

## Core Values

- Respectful, comprehensive, collaborative and community-driven.
- We identify, promote and nurture strengths.
- We recognize formal and informal supports.
- No stigma, no shame.
- Supported independence.
- Full productive engagement in community.
- Resilience.
- Culture heals and supports all of us.
- Family.
- Support instead of punish.
- Acceptance.
- Compassion.
- Safety and health.
- Flexible to recognize individuals and individual needs.
- Trust between individuals, families and the service system.
- Trauma-informed
- Forward thinking and future planning.
- Creative, energetic and committed.
- Out of the box thinking.
- Do it! Get to action.
- Provide social and emotional support.
- Integrate all systems to work well together.
- Honor and address the grief and loss associated with trauma through healing relationships.
- Paradigm shift.
- Rural and Urban

# Brief History of FASD Efforts in Alaska

Since the 1970s, Alaskans have been involved in efforts to identify and serve people affected by prenatal alcohol exposure. A 1998 study published in the *American Journal of Public Health* on Fetal Alcohol Syndrome (FAS) prevalence in Alaska between 1977 and 1992, noted that the state experienced the highest rate of alcohol consumption and alcohol-related hospitalizations in the nation, and acknowledged that a high prevalence of FAS existed in Alaska.<sup>1</sup> Alaskan advocates, including parents, medical professionals, teachers, justice professionals, policymakers, and others have been working to address this for over four decades. The following offers a brief overview of some of their efforts:

- In the 1970s and 1980s, the Indian Health Service (IHS) screened women in Alaska for alcohol-exposed pregnancies.
- In the late 1980s and early 1990s, the Alaska State Legislature passed several laws addressing alcohol-related birth defects, including requiring distribution of written information about fetal health effects with marriage licenses and to public hospitals, clinics, and other health facilities; requiring warning signs in locations that sell alcohol about the risk of drinking alcohol during pregnancy; and requiring school districts to provide training teachers and other school officials on the needs of students with alcohol or drug related disabilities.
- In the early 1990s, the State of Alaska developed an Office of Fetal Alcohol Syndrome and sponsored several FASD conferences.
- In 1990, the State of Alaska developed the Alaska Fetal Alcohol Syndrome (FAS) Prevention Project to study and guide the state's future research and prevention activities. In 1997, the Project published a bulletin that outlines prevalence rates, risk factors and prevention strategies, to guide future activities.
- In 2000, the State secured a five-year (extended for a sixth year), \$29 million grant from Substance Abuse and Mental Health Services Administration (SAMHSA) to develop FASD diagnostic teams around the state, prevention for women of childbearing age and appropriate services for people impacted by FASD, data collection, monitoring, and analysis of impact, extensive curriculum development and training, much of which is still in use today. Alaska has gathered significant data from the work of the diagnostic teams that can be analyzed by the Division of Behavioral Health (DBH).
- In 2000, Volunteers of America-Alaska began coordinating summer camps for children with FASD, their families, and service providers in the Anchorage/Mat-Su area. VOA expanded the camps to Fairbanks, Sitka, Homer, and Juneau.
- In 2007, the State developed and gained approval for an 1115 Medicaid waiver to serve people with FASD. The five-year demonstration period did not result in a renewal of services.
- In 2008, University of Alaska Anchorage (UAA) Center for Behavioral Health Research and Services (CBHRS) was awarded a 3-year grant to establish the Arctic FASD Regional Training Center, with the mission of educating and training health and allied health care providers across the state about FASD prevention, assessment and diagnosis, and treatment and interventions
- In 2010, the Alaska FASD Partnership began a collaboration with Alaska CHARR (Cabaret, Hotel,

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<sup>1</sup> "Fetal Alcohol Syndrome in Alaska, 1977 through 1992: An Administrative Prevalence Derived from Multiple Data Sources;" Grace M. Egeland, PhD, Katherine A. Perham-Hester, MS, Bradford D. Gessner, MD, Diane Ingle, BA, James E. Berner, MD, and John P. Middaugh, MD; *American Journal of Public Health*, May 1998.

Restaurants, and Retailers) Association and many local volunteers, to provide FASD prevention information on table tents with an invitation for pregnant women to enjoy a free non-alcohol beverage in restaurants statewide. The effort has been conducted annually on September 9 “FASD Awareness Day,” and reached over 800 tables in 50 restaurants, in six communities, in 2015.

- In 2011, FASD advocates successfully advocated for funding in the state’s operating budget for FASD case management and substance abuse treatment for pregnant women.
- In 2011, UAA CBHRS was awarded a further 3 year grant (extended by one year) to continue their work training and educating health and allied health care providers about FASDs through the Arctic FASD Regional Training Center.
- In 2012, the Alaska State Legislature was the first state in the United States to make FASD a mitigating factor in sentencing. With substantial support from an ad hoc workgroup of the Alaska FASD Partnership, SB 151 made an FASD diagnosis a mitigating circumstance to be considered in sentencing for felony level criminal offenses.
- Also, passed in 2012, SB 127 permanently recognized September 9 as Fetal Alcohol Spectrum Disorders Awareness Day in Alaska. Additional funding was allocated for the Complex Behavior Collaborative, established in the Division of Behavioral Health to provide consultation and training to providers and family members of people with complex behaviors and needs.
- In 2013, UAA CBHRS hosted a statewide FASD conference in Anchorage, in collaboration with the State of Alaska Office of FAS and other organizations, and funding from the Centers for Disease Control (CDC).
- In 2014, the Alaska State Legislature passed HB 210 related to crisis intervention training for school personnel and restricting the use of restraint and seclusion of students in public schools
- In 2014, the Alaska State Legislature funded “Empowering Hope” which provided funds to the Alaska Mental Health Trust Authority to conduct a 3-year FASD media campaign, and to the University of Alaska to study the use of pregnancy tests in bar bathrooms for reducing alcohol-exposed pregnancies. The media campaign, which targeted 18 to 34 year olds, involved researching local and national data, conducting Alaskan focus groups, outreach to medical professionals, service providers, and the public, and development of a “messaging” toolkit called “Let’s Talk.” The results of the pregnancy test study, released in 2017, showed a 61% response rate from 2,147 women in four Alaskan communities, with 42 reporting they learned they were pregnant from the test and stopped drinking alcohol.
- In 2014, UAA CBHRS was awarded a 4-year CDC grant to establish an FASD Practice and Implementation Center to leverage what was learned working with public health nurses in Alaska to a national level through collaborations with national nursing organizations, other PICs and the CDC. Alaska participated in the development of online training courses for health professionals, implementation of alcohol screening and brief intervention programs in clinic settings, and raising awareness of FASD prevention among nurses nationwide.
- In 2016, FASD was added to the Other Health Impairment (OHI) special education eligibility category list of medical condition, making Alaska the first state in the U.S. to name FASD in education regulation. Advanced Nurse Practitioners (ANP) were also added to who may diagnose and treat medical conditions in this category.
- In 2017, the first FASD training for professionals and summer camp and families and professionals in Alaska using the Canadian Whitecrow Village model was held in Juneau.

- In 2017, the program coordinator for the state’s FASD efforts moved to the Office of Substance Misuse and Addiction Prevention (OSMAP) to work with community stakeholders and continue management of the state-funded diagnostic teams.
- In 2017, work began developing and implementing a 5-year strategic plan for addressing FASD in Alaska, organized by the Governor’s Council on Disabilities and Special Education.
- In 2018, the Alaska Center for FASDs, a statewide non-profit is formed with the mission to reduce alcohol-exposed pregnancies, promote successful outcomes for affected individuals and families, and be a catalyst for creating FASD-involved communities of care.
- In 2018, DHSS sponsored Dr. Ira Chasnoff’s training in 4 P’s prenatal substance use screening for hospital staff in Fairbanks, Anchorage, and Juneau. Dr. Chasnoff also presented at community film showings of “Moment to Moment: Teens Growing Up With FASDs,” which features Dr. Chasnoff.

### III. Workgroup Priorities and Objectives

Priority Area I: Primary Prevention of FASDs	
<i>Workgroup leaders: Alexandra Edwards, Sherrell Holtshouser</i>	
3-5 Year Priorities	2018-19 Objectives
<ul style="list-style-type: none"> <li>• Identify and reduce barriers and stigmas that interfere with effective fetal alcohol spectrum disorders (FASDs) prevention and intervention.</li> <li>• Compile information or evidence about the co-occurrence of FASDs and childhood trauma.</li> <li>• Develop risk reduction public awareness strategies tailored to varied audiences.</li> <li>• Implement evidence-based interventions and strategies in pre-conception and prenatal care among providers and agencies to prevent unintended and alcohol-exposed pregnancies, including use of validated screening tools and brief intervention with referral.</li> <li>• Assure evaluation is incorporated into all strategies.</li> </ul>	<ul style="list-style-type: none"> <li>• Identify best practices for policy adoption and training of health care workers to universally screen all women of reproductive age, especially those who are pregnant, for risky alcohol use. Ensure collaboration between relevant entities and to pair FASDs prevention messages and strategies with resilience building.</li> <li>• Work with community partners and the Alaska Medicaid program and Alaska Department of Health and Social Services 4P's Plus project to advocate for Medicaid reimbursement of long-acting reversible contraceptives (LARC) at time of birth.</li> <li>• Develop evaluation plan for prevention efforts.</li> </ul>

## Priority Area 2: Screening for and Diagnosis of FASD

**Workgroup Leader: Marilyn Pierce-Bulger, Jenn Wagaman**

### 3-5 Year Priorities

- Coordinate with and leverage existing efforts in Alaska to increase use of standardized screening tools and health care provider training in best practices for alcohol/substance use screening, Adverse Childhood Experiences (ACEs)/trauma exposure, and child development.
- Create a sustainable FASDs-informed diagnosis system that includes quality assurance measures to ensure consistency and longevity across State-funded teams.
- Collaborate with agencies that work with 'high risk' groups to identify children and adults with prenatal alcohol exposure (PAE) so that they will receive appropriate intervention and diagnosis in a timely manner.
- Increase prenatal alcohol history information sharing between obstetric and pediatric providers.

### 2018-2019 Objectives

- Partner with key public and private stakeholders, especially the Office of Children's Services (OCS) and Division of Juvenile Justice (DJJ), to promote universal developmental/FASD screening and referral for FASD diagnosis, when indicated.
- Support current State of Alaska FASD team network through data analysis process and explore possible options for a sustainable FASD diagnosis system in partnership with current teams and relevant public/private entities.
- Identify best practices for policy adoption and training health care providers to universally screen patients for alcohol use (or exposure in the case of children)
- Coordinate with existing efforts related to screening for Adverse Childhood Experiences (ACEs) as symptoms overlap with and complicate FASD diagnosis
- Support the UAA Institute of Circumpolar Health effort for a National Institute on Alcohol Abuse and Alcoholism (NIAAA) FASDs prevalence study.

## Priority Area 3: Early Childhood and Education

**Workgroup Leaders: Erin Johnson, Clayton Holland**

### 3-5 Year Priorities

- Provide compassionate, effective, and ongoing assistance for parents and families impacted by FASD.
- Help educators focus on developmental age along with chronological age in the school system.
- Increase ongoing peer supports and education about FASD for children in the school system for elementary, middle, and high school-age.
- Increase ongoing training and support for frontline providers/advocates on how to work with children with FASD and increase practical behavioral supports.

### 2018-2019 Objectives

- Implement promising practices, such as those of the Whitecrow Village FASD Society, as the state-wide training models to provide enriching experiences and education for individuals and family impacted by FASD, paraprofessionals, educators, and healthcare providers. Identify and training leaders who are affected by FASD to be facilitators and coaches for state wide training.
- Prioritize healthcare providers, educators, and DJJ/OCS system, personnel to be 'FASD-informed' so that they can recognize behavioral manifestations and symptoms of FASD.
- Add 'significant alcohol exposure' as a risk factor to be eligible for early intervention and developmental services.
- Increased parent advocacy with teachers and administrators to ensure appropriate educational supports for children.
- Target administrators, teachers, paraprofessionals, school staff and school board members with in-depth training on FASD, thereby aiding and encouraging compliance with the Binkley law that requires teacher-training related to FASD.

## Priority Area 4: System Transformation and Navigation - Youth and Adults

**Workgroup Leaders: Teri Tibbett, Vicki Tinker**

### 3-5 Year Priorities

- Identify a central entity for FASDs prevention, intervention and supports to ensure people who do not currently qualify for services are served.
- Collaborate with agencies that work with ‘high risk’ groups to increase lifelong support services for individuals and families impacted by FASDs including case management, housing and employment assistance, education and training, treatment and health care, life skills, family support, and appropriate transitions for youth leaving OCS and DJJ custody. Must work locally, as these services look different in different communities.
- Integrate services and supports for people with FASDs into existing health and wellness systems to provide cyclical, safety net support for individuals and families, and ensure that wrap-around services are accessible and easy to navigate.
- Provide appropriate supports for justice-involved individuals with FASDs including diversion programs at the pre-trial level, interventions during incarceration, and long-term supports after release into the community.
- Protect existing FASDs services and resources, such as the FASDs diagnostic teams and case management, 1915(c) Medicaid home and community-based services waiver, media funds managed by the Alaska Mental Health Trust Authority, and research and funding at the Institute of Circumpolar Health Studies.

Reinvigorate and revise Division of Behavioral Health’s (DBH) FASDs case management program to make it less cumbersome for case managers and families, and make the program more likely to be utilized. Focus on recruiting qualified FASDs case managers statewide.

### 2018-2019 Objectives

- Research evidence-based approaches that have worked in other states to effectively serve high-functioning people with FASD and how they might qualify for Medicaid-funded services and supports. Explore Canadian models, including practices used by the FAS Society of the Yukon in Whitehorse, and others.
- Develop/support efforts to serve justice-involved individuals with FASD during incarceration and at the pretrial and reentry levels in the following ways:
  - a) engage with the Alaska Community Reentry Program, community reentry coalitions, and the diversion efforts of Department of Corrections (DOC) and Department of Health & Social Services (DHSS).
  - b) engage DHSS/DOC to implement an effective screening tool, such as the Inter-RAI Functionality Assessment, to ensure more effective treatment for justice-involved individuals with FASD. Also, look at Whitehorse Correctional Center in Canada for new standardized practices.
- Support DHSS’s Medicaid 1115 Waiver application to include serving people with FASD appropriately.

## Priority Area 5: Workforce Development

**Workgroup Leader – Christy Knight**

### 3-5 Year Priorities

- Develop an FASDs-informed workforce in all systems of care and levels of education across Alaska.
- Increase opportunities for people impacted by FASDs to succeed in the workforce.
- Investigate including FASDs training in licensure requirements for selected professions.
- Develop inter-professional and paraprofessional team support that values the roles of all members, including family members, caregivers and self-advocates.

### 2018-2019 Objectives

*This workgroup is on hold as a stand-alone for now - Priorities will be incorporated into other focus areas as appropriate.*

## Priority Area 6: Community Outreach and Engagement

**Workgroup Leader: Teri Tibbett, Tami Eller**

### 3-5 Year Priorities

- Establish a clearinghouse with a resource library and searchable online repository of information where people can share and receive information. Promote shared resources between groups to include Alaska Center for FASDs, the State’s Office of FASDs, Alaska FASDs Partnership, Alaska Mental Health Trust Authority, and other resource agencies.
- Establish network of the next generation advocates and self-advocates who have the desire and technical skills to carry on outreach efforts.
- Promote inclusion and develop peer supports among individuals impacted by FASDs and broader communities.
- Collaborate with other workgroups to expand awareness of FASDs prevention and intervention among medical and behavioral health providers, school and early childhood personnel, university and college campuses and other local and state agencies and partners.

### 2018-2019 Objectives

- Establish baseline information from past outreach strategies and evaluate them using evidence-informed practice to build on successes and learn from what has and has not worked. Understand the level of readiness among target audiences.
- Develop an informed effort to expand FASD education and outreach across Alaska, including the following:
  - a) update and create new FASD education materials;
  - b) establish speakers’ panels for presentations to school boards, Rotary Clubs, city and village councils, assemblies, community councils, town halls, constituent meetings, and the Alaska State Legislature;
  - c) identify statewide conferences to promote FASD message through exhibit tables, break-out sessions, and keynote speakers;
  - d) collaborate with the Early Intervention and Education workgroup to promote awareness of the requirements of the Binkley Law to school administrators and school boards statewide;
  - e) create advocacy “cookbook” offering steps advocates can take for successful meetings with policymakers and testifying at public meetings;
  - f) engage advocates for writing letters and emails, public testimony, and other acts of advocacy, highlighting personal stories, to educate policymakers about the needs of people

	<p>with FASD, families, and providers;</p> <p>g) gather position papers, resolutions, and letters of support for specific legislation from organizations across the state;</p> <p>h) develop distribution list of advocates willing to receive alerts and reminders to communicate with policymakers;</p> <p>i) identify champions and famous Alaskans to carry FASD message.</p> <ul style="list-style-type: none"><li>• Recruit new advocates with lived experience of FASD, family members, providers to join the statewide FASD effort. Reach out to Peer Power and Self-Advocates for FASDs in Action (SAFA), foster families, OCS, schools, service providers, state and private entities, etc. Offer supports as needed.</li></ul>
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