

9 CORE MESSAGES:
**What Everyone Should Know
About Prenatal Alcohol Exposure**

Alaska FASD Strategic Plan Workgroup 2017-2022 | December 2021



Special Thanks

The Alaska FASD Strategic Plan Workgroup (2017-2022), coordinated by the Alaska Governor's Council on Disabilities and Special Education, is supported by multiple organizations, individuals, and agencies committed to addressing Fetal Alcohol Spectrum Disorders (FASD) in Alaska.

Participants include: Access Alaska, Advisory Board on Alcoholism and Drug Abuse, Alaska Center for Children and Adults, Alaska Center for FASD, Alaska Center for Human Development, Alaska Center for Resource Families, AK Child & Family, Alaska Department of Health & Social Services, Alaska FASD Partnership, Alaska Mental Health Board, Alaska Mental Health Trust Authority, Alaska Native Tribal Health Consortium, Anchorage School District, Denali Family Services, Fetal Alcohol Consultation & Training Services, Full Spectrum Health, Kenai Peninsula Borough School District, Kobuk Valley Consulting, Southcentral Foundation, Stone Soup Group, University of Alaska Anchorage Center for Behavioral Health Research & Services, Volunteers of America Alaska, Yukon Kuskokwim School District, Yupiit School District, and many individuals.

For contacts and other information, see Alaskan Resources page.

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DEFINITIONS

Prenatal Alcohol Exposure (PAE) is exposure to alcohol¹ before birth. **Fetal Alcohol Spectrum Disorders (FASD)** are a range of diagnoses that can result from prenatal alcohol exposure.

**The term fetal alcohol effects (FAE) has been replaced with the term FASD.*

- **Prenatal Alcohol Exposure (PAE)** is exposure before birth when alcohol is consumed during pregnancy. Alcohol passes through the placenta and causes changes to the cells of the developing baby, which can affect brain and physical development. Impacts can range from mild to severe and can last a lifetime.
- **Fetal Alcohol Spectrum Disorders (FASDs)** are a range of diagnoses resulting from prenatal alcohol exposure. They include: fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental disorder (ARND), alcohol-related birth defects (ARBD), neurobehavioral disorder alcohol-exposed (NBD-AE), and static encephalopathy-alcohol exposed (SE-AE). The term fetal alcohol effects (FAE) has been replaced with the term FASD.
- PAE/FASD most often impacts the brain, which manages behavior, judgment, memory, learning, emotions, attention, impulse control, understanding cause and effect, and more.
- Individuals with a PAE/FASD may present with a wide range of cognitive and/or physical differences determined by many variables—including when the alcohol was consumed (what was developing at that moment), how much was consumed, genetics, epigenetics, metabolism of the baby and pregnant person, stress level, etc. These variables contribute to how much and what kind of damage can occur, and inform the appropriate diagnosis and interventions.
- All populations of Alaskans where alcohol is used are at risk for FASD.

¹ Alcohol types include beer, wine, champagne, liqueurs, base alcohol (gin, vodka, whiskey, rum, brandy, tequila), home brew, mouth-wash, and some cleaning products.

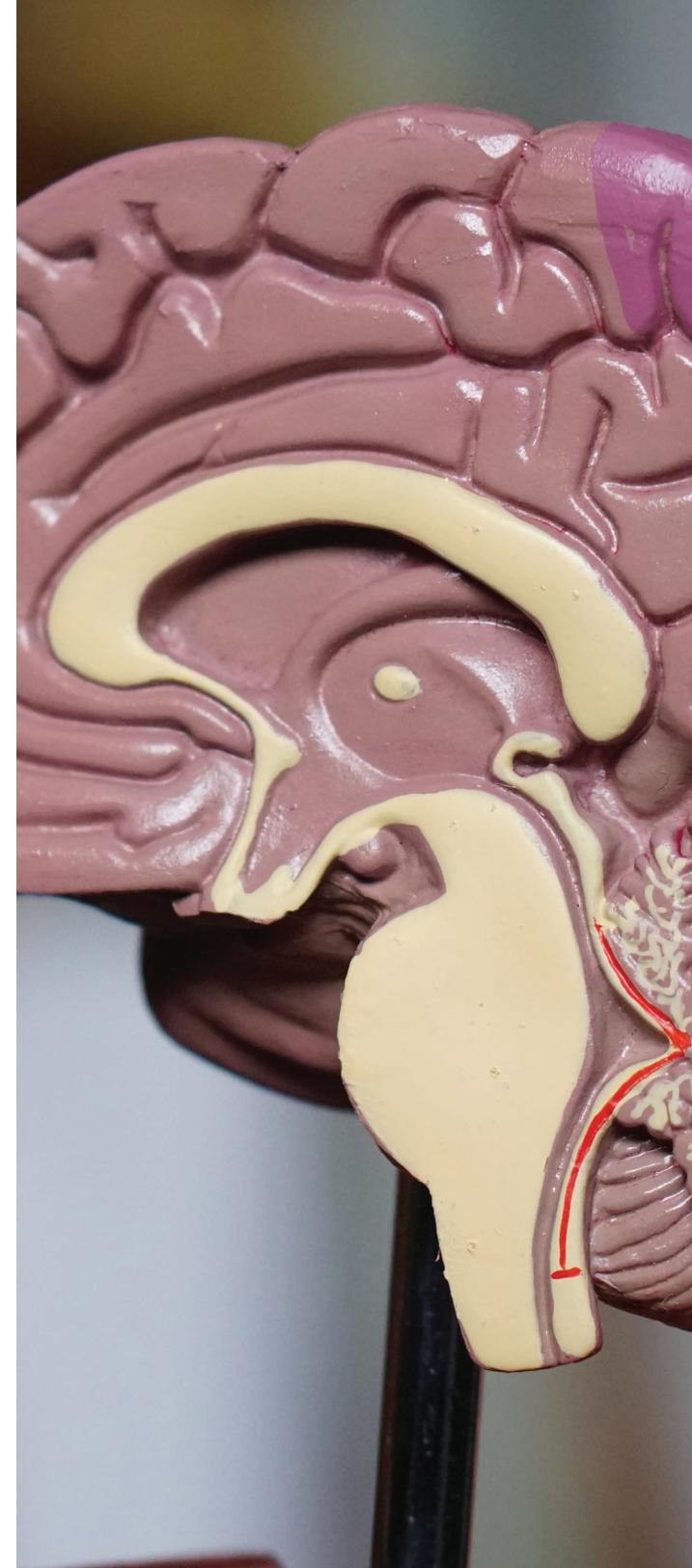
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FASD IS A BRAIN-BASED DISABILITY

Brain-based disabilities are not always physically visible. Prenatal alcohol exposure most commonly impacts the brain, which regulates behavior, judgment, memory, learning, emotions, attention, impulse control, and understanding cause and effect.

- The human brain is developing throughout an entire pregnancy. This puts it at higher risk of being impacted from alcohol exposure during any time in the pregnancy compared to other organs. The impacts vary, depending on how much and when the alcohol was consumed.
- Brain-based disabilities can be hidden, meaning they are not always physically visible. Brain-based disabilities commonly affect behavior, judgment, memory, learning, emotions, intelligence, and impulse control.
- Brain-based disabilities impact how a brain processes information resulting in slower or faster processing time, attention and memory challenges, sensory barriers, etc. People with FASD are often misperceived as willful or defiant, when the cause of their behavior is actually related to malfunctioning cognitive, emotional, and processing systems.
- About 90% of individuals diagnosed with an FASD have an average or higher intelligence quotient (IQ). Only about 10% experience an IQ below 70. Regardless of IQ, individuals with prenatal alcohol exposure often experience learning and intellectual difficulties, as well as challenges with behavior, memory, attention, judgment, and adaptive functioning.¹
- People with PAE, diagnosed or not, can benefit from individualized interventions that support appropriate care in their communities. Successful interventions might include intensive case management, education accommodations, supported living, group home, behavioral health treatment, housing and employment assistance—all of which may be necessary throughout an individual's life.
- The impacts to the brain from prenatal alcohol exposure can last a lifetime, however, with the right supports, accommodations, and services, individuals with PAE can live successfully in their communities and out of expensive institutional care (emergency, residential, psychiatric, or corrections).

¹ "Cognitive Aspects of Fetal Alcohol Spectrum Disorder" Davis, Kristin M; Gagnier, Karina Royer; Moore, Timothy E; Todorow, Michelle; National Library of Medicine (2013). <https://pubmed.ncbi.nlm.nih.gov/26304176/>





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PHYSICAL IMPACTS

Most people with prenatal alcohol exposure have no outward physical characteristics, but have hidden impacts to the brain and other organs and structures.

- While the brain is most often affected by prenatal alcohol exposure, other parts of the body are commonly affected—including the heart, kidney, spine and joints, teeth and jaw, palate, hearing and speech.
- Brain and physical abnormalities are determined by what was developing at the time of alcohol consumption.
- About 90% of individuals who experience prenatal alcohol exposure will show no outward physical symptoms. Only 10% will present with the facial abnormalities of the upper lip, philtrum, eyes, and nose¹ common in fetal alcohol syndrome.
- It is important to note that facial features develop between the 18th and 21st days of pregnancy, prior to when most people recognize they're pregnant. The facial characteristics associated with prenatal alcohol exposure will only occur if the alcohol consumption occurs during this narrow time period.² Additionally, since facial features change over time, what appeared in childhood may be less obvious after puberty.
- Tools that measure adaptive function (how a person handles common life demands and independence compared to others of a similar age and background), such as neuropsychiatric examinations and pragmatic language assessments, are more likely to reveal the deficits attributed to prenatal alcohol exposure. These tools, which measure communication, social skills, relationships, hygiene, etc., are important for informing the individual interventions needed.

¹ In *Teratology Primer, 3rd Edition "What Are the Effects of Alcohol Use During Pregnancy?"* Miguel del Campo, MD, PhD, Kenneth Lyons Jones, MD <https://birthdefectsresearch.org/primer/fas.asp>

² "Magnetic Resonance-based imaging in animal models of Fetal Alcohol Spectrum Disorder" Sulik, K., O'Leary-Moore, S., Parnell, S. and Lipinski, R. *Neuropsychology Rev.* 2011 Jun; 21(2): 167-185. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3445286/>

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COMMON CHARACTERISTICS ACROSS THE SPECTRUM: STRENGTHS & CHALLENGES

People with PAE/FASD can experience a wide range of challenges and strengths that vary from individual to individual.

Executive Function

- **Strengths:** Concrete thinker, lives in the moment, “every day is a new day.”
- **Challenges:** Managing impulses and emotions, planning and organizing, procrastinating, difficulty shifting between tasks (transitions), understanding cause and effect, keeping something “in mind” long enough to carry it out, and understanding abstract concepts.

Attention, Focus

- **Strengths:** Hyper-focus when engaged, ability to carry out tasks and responsibilities with targeted focus, multi-tasking.
- **Challenges:** Easily distracted, memory challenges, difficulty staying attentive or engaged.

Sensory

- **Strengths:** Discerning sense of smell, hearing, touch, and attention to details, imaginative, “out of the box” thinking, athletic, artistic, musical, drumming, dancing, skin sewing, carving.
- **Challenges:** Heightened sensitivity or avoidance of certain smells, sounds, touch, tastes, or the opposite, a heightened seeking of certain sensory information.

Adaptive Living

- **Strengths:** Responds to structure and routine, prompts and reminders, attention to detail, concrete explanations.
- **Challenges:** Functions at varying developmental levels (may act younger than chronological age), difficulty maintaining jobs, school, friendships, making safe decisions, maintaining hygiene and self-care, managing time and money.





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COMMON CHARACTERISTICS ACROSS THE SPECTRUM: STRENGTHS & CHALLENGES (CONTINUED)

People with PAE/FASD experience a wide range of challenges and strengths that vary from individual to individual.

Communication

- **Strengths:** Friendly, outgoing, not afraid to interact with new people, trusting, direct, expressive, sensitive to non-verbal communication.
- **Challenges:** Talks a lot (verbose), interrupts, longer processing time to respond, difficulty following a series of instructions or telling a story in sequence, social cues. Can repeat instructions given to them, but may lack the capacity to comprehend or remember them.

Social Skills

- **Strengths:** Helpful, kind, friendly, “young at heart,” relates well with younger people and animals, empathy and concern for others.
- **Challenges:** Socially immature, difficulty interpreting and responding to social cues, relating to same age peers, discerning safe or unsafe relationships, participating on a team, increased vulnerability to exploitation and victimization (financial, trafficking, abuse).

Visual Perception

- **Strengths:** Enhanced eye-hand coordination, learns easily by watching and doing.
- **Challenges:** Difficulty with spatial awareness (bumping into things), recognizing people’s “space,” eye-hand challenges.

Fine Motor

- **Strengths:** Enhanced coordination for sports, drawing, music, mechanics, hunting, fishing, carving, skin sewing, beading, ulu, puzzles, etc.
- **Challenges:** Difficulty with buttons, zippers, tooth brushing, dressing, handwriting, painting, athletics, etc.

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IMPORTANCE OF DIAGNOSIS AND EARLY INTERVENTION

Recognizing prenatal alcohol exposure early increases the likelihood a person with an FASD will have access to appropriate supports that promote a balanced, manageable, and successful life. Diagnosis and early intervention help prevent more serious and costly problems later on.

- Screening and diagnosis for prenatal alcohol exposure is recommended for children and adults with characteristics of prenatal alcohol exposure and/or known exposure.
- An FASD diagnosis can be given by a medical doctor, psychologist, nurse practitioner, physician's assistant, or multidisciplinary diagnostic team.
- The State of Alaska provides funding and support for multidisciplinary FASD diagnostic teams statewide.¹
- Diagnosis from a multidisciplinary team offers a comprehensive assessment, with recommendations for interventions appropriate for the person's individual needs.
- A professional diagnosis and intervention plan assists parents, schools, medical and justice professionals, and others in providing appropriate supports and interventions to reduce the risk of more severe problems later.
- Early interventions help prevent adverse outcomes, such as failure in school or work, depression, addiction, criminal justice involvement—which can develop when primary disabilities are not appropriately addressed.
- A confirmed diagnosis helps individuals with FASD understand their disability, learn coping skills and strategies for success, and understand that their challenges are “not their fault.”
- Early intervention services can include wrap-around family or community support, speech and occupational therapy, learning and life skills support, care coordination, training, and more.
- When disability needs are not met, individuals with FASD are more likely to end up needing more costly services down the road, such as emergency or hospital care, child protective services, criminal justice, or other institutional care.
- Early diagnosis and intervention is less costly than institutional care.

¹ State of Alaska FASD Diagnostic Team Network: <http://dhss.alaska.gov/osmap/Pages/fasd-team.aspx>. Webpage: <http://dhss.alaska.gov/osmap/Pages/fasd.aspx>.





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PREVALENCE

In Alaska, the prevalence of fetal alcohol syndrome, one of the diagnoses on the FASD spectrum is estimated to be 1.7 per 1,000 live births, about 10% of the total FASD diagnoses. Prevalence for the other 90% diagnosed is estimated to be 65 per 1,000.

- The Alaska Department of Health & Social Services (DHSS) reports that for the years 2007-2013, based on information from medical charts and data reported from Alaska's FASD Diagnostic teams, approximately 1.7 of every 1,000 live births in Alaska annually may experience fetal alcohol syndrome (FAS).¹
- In Alaska, FAS accounts for 10% of the total FASD diagnoses. Individuals with other diagnoses on the FASD spectrum are estimated to be 65 per 1,000, accounting for about 90% of the diagnoses.²
- About 1 in 20 children are born with an FASD every year in the United States. The U.S. Centers for Disease Control and Prevention (CDC) estimates that 2% to 5% children ages six and seven experience prenatal alcohol exposure, based on community studies taken from physical examinations in four regions of the U.S.³
- Other data from the CDC Behavioral Risk Factor Surveillance System (BRFSS) indicates that 1 out of 9 pregnant women surveyed in the U.S. reported drinking in the past 30 days. Of those reporting drinking alcohol during pregnancy, a third reported binge drinking.⁴
- It is estimated that only 1 out of every 600 individuals impacted by PAE will receive an FASD diagnosis.⁵

¹ Health Impacts of Alcohol Misuse in Alaska (May, 2018). http://www.epi.alaska.gov/bulletins/docs/rr2018_02.pdf

² <https://alaskamentalthrust.org/wp-content/uploads/2020/06/1949-AMHTA-Drugs-and-Alcohol-FASD-Summary-Report-Final-Revised-6.12.2020.pdf>

³ May PA, Chambers CD, Kalberg WO, Zellner J, Feldman H, Buckley D, Kopald D, Hasken JM, Xu R, Honerkamp-Smith G, Taras H, Manning MA, Robinson LK, Adam MP, Abdul-Rahman O, Vaux K, Jewett T, Elliott AJ, Kable JA, Akshoomoff N, Falk D, Arroyo JA, Hereld D, Riley EP, Charness ME, Coles CD, Warren KR, Jones KL, Hoyme HE. Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities. *Journal of American Medical Association*. 2018;319(5):474-482. <https://jamanetwork.com/journals/jama/fullarticle/2671465?redirect=true> or https://www.cdc.gov/ncbddd/fasd/documents/fasd_english-508.pdf.

⁴ Denny CH, Acero CS, Naimi TS, Kim SY. Consumption of Alcohol Beverages and Binge Drinking Among Pregnant Women Aged 18-44 Years — United States, 2015-2017. *MMWR Morb Mortal Wkly Rep* 2019;68:365-368. DOI: <http://dx.doi.org/10.15585/mmwr.mm6816a1> and https://www.cdc.gov/mmwr/volumes/68/wr/mm6816a1.htm?cid=mm6816a1_w

⁵ Popova. S., Dozet, D., and Burd, L. Fetal Alcohol Spectrum Disorder: Can We Change the Future? *Alcoholism, Clinical and Experimental Research*, 2020 (4): 815-819.

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STRATEGIES FOR SUCCESS

There is no one-size-fits-all approach for working with people with prenatal alcohol exposure. Each person is impacted differently, which requires an individualized and lifelong approach.

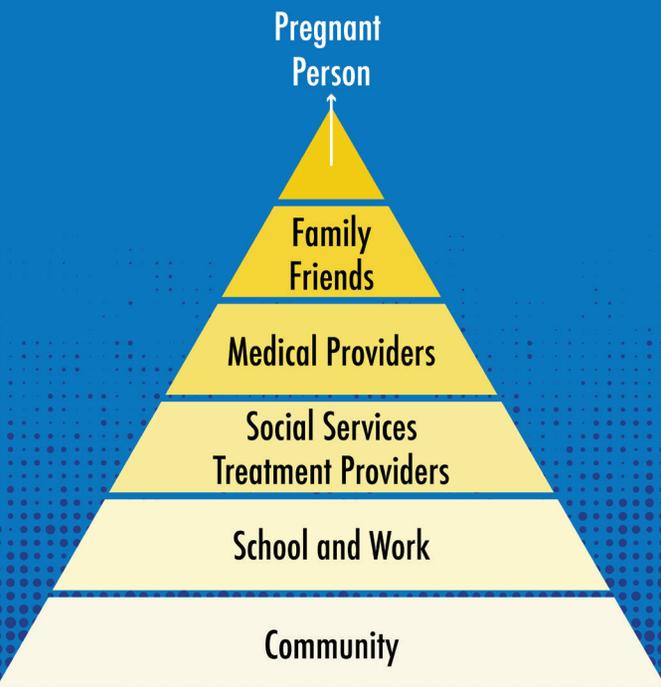
- Try differently, not harder.
- Offer proactive supports and accommodations, rather than punishments.
- Use concrete language and simple instructions. Say what you want someone to do, instead of what not to do.
- Think stage not age, adapt to developmental age, not chronological age.
- Plan for lifelong supports as with other developmental disabilities.
- Be patient and give time to process.
- If the person doesn't learn in the way we teach, teach in the way they learn. Modify the environment.
- Focus on and develop strengths, move away from only seeing what's wrong with the person.
- Understand that traditional behavioral interventions, including talk therapy and cognitive behavioral approaches, can be ineffective with people impacted by prenatal alcohol exposure. Offer interventions that are individualized and appropriate for the individual.
- Educate people with PAE about their disability and offer tools for managing it. Teach self-advocacy skills and self-coping skills.
- Acknowledge individual milestones. Look for accomplishments to celebrate.
- Encourage caregivers to engage in informed support, including self-care and respite, to help reduce secondary trauma.
- Use the "Eight Magic Keys" chart and video to teach: concrete, consistency, repetition, routine, simplicity, specific, structure, supervision.
- Educate individuals, families, caregivers, and professionals using '9 Core Messages: What Everyone Should Know About Prenatal Alcohol Exposure' toolkit.
- See **ALASKAN RESOURCES** at the end of this document for additional suggestions and links to resources.



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PREVENTION

Promote universal alcohol screening at medical appointments and education about the impacts of drinking alcohol during pregnancy. Access to treatment and services are essential for prevention.



- There is no known safe amount of alcohol and no safe time to drink alcohol during pregnancy. While it is possible for some people to drink during pregnancy and not give birth to an affected child, it is also possible that even a mild exposure can cause noticeable impacts. Advocates ask, “Is it worth the risk?”
- Reducing or stopping alcohol exposure at any point in pregnancy is better than continuing to drink at the same levels.
- Reduce shame and stigma by not blaming birth parents. Support access to substance use treatment and recovery services, intensive case management, and wrap-around services.
- Recognize that unintentional pregnancies are common and that alcohol exposure can happen unknowingly. Plan to stop alcohol and substance use when pregnancy is possible, suspected, or confirmed. Seek treatment from a medical or behavioral health providers if stopping alcohol or substances is difficult.
- Promote not drinking after an episode of unprotected sex to reduce the risk of an alcohol-exposed pregnancy.
- Promote universal alcohol screenings at medical appointments for early identification and intervention, normalize conversations about not drinking during pregnancy, adopt screening questions that reduce shame or guilt.
- Promote awareness, education, and access to birth control, as appropriate.
- Promote awareness of the role of family, partners, friends, and community in preventing prenatal alcohol exposure. Recognize that a safe and sober home environment, with alternatives to alcohol and alcohol-related activities, are important for people who may struggle with alcohol dependence or addiction.
- Consider emerging research on the impacts of genetics, epigenetics, and the role of males in a healthy pregnancy and baby.

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ADVOCACY

Advocacy is needed to raise awareness, promote education, identification, and access to services. People with prenatal alcohol exposure often go undiagnosed and untreated because of misdiagnosis, stigma related to alcohol, and the hidden nature of the disability.

- Support community services that provide early diagnosis and intervention, intensive case management, life skills training, parenting, peer support, job coaching, behavioral health treatment and recovery support, supportive housing and employment assistance, and other community supports.
- Promote community education and outreach to inform key community members about the causes, impacts, and strategies for success. Target direct service workers, educators, medical and behavioral health providers, justice and correctional professionals, businesses, policymakers, peers, families, and individuals with an FASD.
- Promote FASD awareness in school districts to increase opportunities for early detection and intervention, recognizing that early intervention can reduce the likelihood of developing other disabilities that lead to more serious and costly problems down the road.
- Promote universal alcohol screening and brief intervention by health care professionals to help identify patterns of alcohol use and risk for alcohol-exposed pregnancies. Provide guidance and referral when prenatal alcohol exposure is identified.
- Engage advocates, including people impacted by prenatal alcohol exposure, in educating policymakers, writing letters and emails, providing public testimony, and other acts of public advocacy that highlight personal stories about the real life impacts of prenatal alcohol exposure to individuals, families, providers of services, and communities.
- Promote regular training for staff and appropriate interventions for people with FASD and other neurodevelopmental disabilities within the justice system—including Department of Corrections, juvenile justice, therapeutic courts, and Office of Children's Services.



ALASKAN RESOURCES

- **Alaska Center for FASD:** <https://alaskacenterforfasd.org/>
- **Alaska FASD Partnership:** <http://dhss.alaska.gov/abada/Pages/fasdPartnership.aspx>
- **State of Alaska Fetal Alcohol Spectrum Disorders (FASD) Resource Webpage:** <http://dhss.alaska.gov/osmap/Pages/fasd.aspx>
- **Alaska FASD Diagnostic Team Network:** <http://dhss.alaska.gov/osmap/Pages/fasd-team.aspx>
- **Governor's Council on Disabilities and Special Education FASD Workgroup:** <http://dhss.alaska.gov/gcdse/Pages/committees/fasd/default.aspx>
- **Alaska FASD Strategic Plan (2017-2022):** <http://dhss.alaska.gov/osmap/Documents/fasd/FASD-Strategic-Plan-FY2017-2022.pdf>
- **Stone Soup Group:** <https://www.stonesoupgroup.org/?s=fasd>
- **Fetal Alcohol Community Evaluation and Services (FACES) - Alaska Center for Children and Adults:** <https://alaskacenter.org/faces/>
- **Alaska Mental Health Trust - Joint Advocacy:** www.alaskamentalhealthtrust.org/jointadvocacy
- **Prenatal Alcohol and Drug Related Disabilities Training Module, Alaska Department of Education & Early Development,** <https://education.alaska.gov/elearning/padrd>
- **Alaska Training Cooperative Trainings on FASD:** <https://aktclms.org/Training/Topic?cid=16539>
- **NPs, Midwives, and Nurses: Partnering to Prevent Fetal Alcohol Spectrum Disorders:** <https://sites.google.com/view/nursesmidwivespreventfasds/home>
- **Eight Magic Keys** (a video for educators) developed by the FASD Committee of the Anchorage School District, based on concepts by Deb Evensen and Jan Lutke <http://www.cde.state.co.us/cdesped/fasd-8magickeys>
- **Let's Talk About Alcohol & Pregnancy:** <https://letstalkfasdak.org/>
- **FASD Across the Lifespan**, sponsored by the Alaska Center for Children and Adults and the Alaska Center for Resource Families: <https://www.acrf.org/self-study/fasd-across-the-lifespan>
- **Alaska FASD Research**, scroll to the bottom of the page for FASD research <https://alaskamentalhealthtrust.org/alaska-mental-health-trust-authority/resources/>