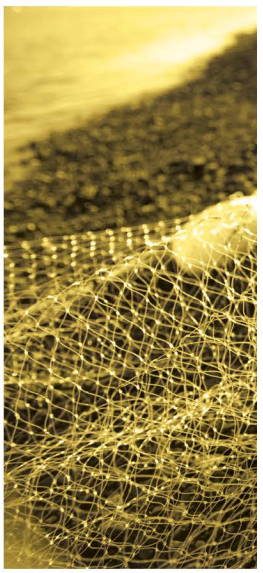
Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations

JULY 2020

PREPARED FOR:

Trust

Alaska Mental Health Trust Authority



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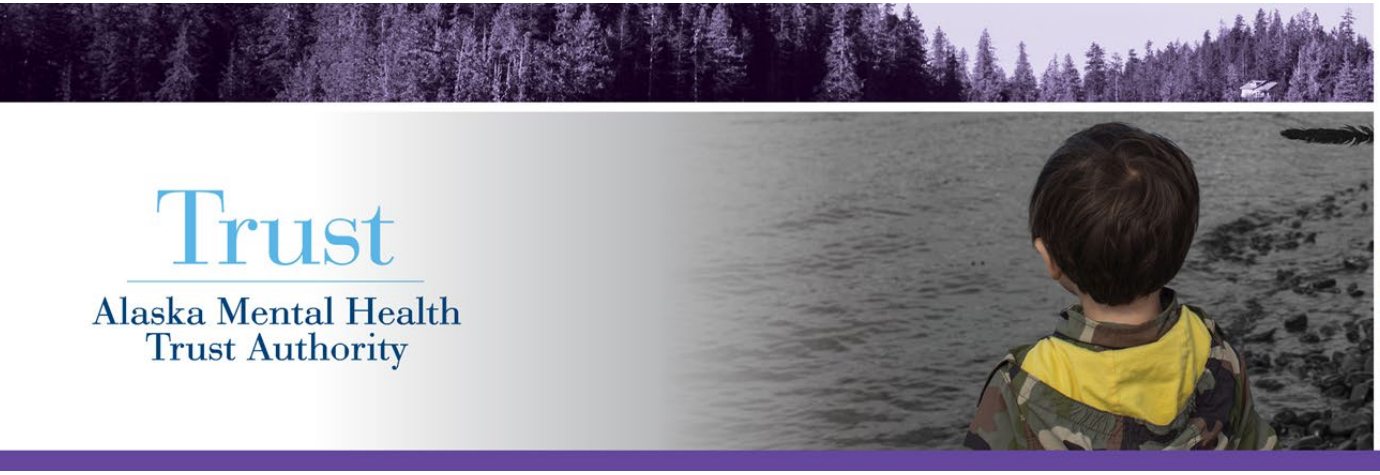

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Executive Summary

One of the significant aspects of alcohol misuse is drinking while pregnant. When asked about their maternal experiences before pregnancy, more than half of Alaskan women (57%) report drinking alcohol in the three months prior to becoming pregnant; 17% report binge drinking in the three months prior to conception.[1] Prenatal alcohol exposure at any time during the pregnancy can result in fetal alcohol spectrum disorders (FASD). FASD is a spectrum of disorders that can result in a range of disabilities. People with FASD can have lifelong physical, cognitive, and neurobehavioral symptoms that vary in severity.

Since about 1999, Alaska Department of Health and Social Services (DHSS) has coordinated and funded a statewide network of community-based, interdisciplinary FASD diagnostic teams, diagnosing FASD using evidence-based diagnostic guidelines formulated by the University of Washington. Over the past 20 years, diagnostic data has been collected by the Alaska Department of Health and Social Services. Recognizing these data can impart important information about FASD, the Alaska Mental Health Trust Authority (AMHTA) contracted with McDowell Group to analyze Alaska's FASD diagnostic team databases. This work included combining data from two databases into a single database. Once this was done, McDowell Group analyzed the data, including a breakdown of diagnosis by Alaska behavioral health regions and a comparison of the Alaska FASD diagnostic team network data to the University of Washington's Fetal Alcohol Syndrome Diagnostic & Prevention Network (FASDPN) data summary. These results and a policy literature review informed general and specific recommendations supporting primary, secondary, and tertiary prevention of FASD in Alaska. Finally, an FASD Data Scorecard (and Management Guide) was developed to present relevant FASD prevention indicators. Key findings are presented below.

FASD Diagnostic Data Findings

Assessment Data Summary

Between 1999 and May 2020:

[1] Alaska Pregnancy Risk Assessment Monitoring System (2017). http://ibis.dhss.alaska.gov/query/selection/prams23/PRAMSSelection.html. Accessed July 3, 2020.

The number of assessments varies by year and depends on the number of agencies performing assessments and seeking reimbursement through the State of Alaska. The number of assessments peaked in 2015 at 192. An annual average of 135 assessments were conducted between 2017 and 2019.

- Clients' average age at time of diagnosis was 10.1 years. Between 2017 and 2019, the average age of clients was 9.1 years.
- Males are overrepresented in the number of assessments compared to females (58% of assessments compared to 51% of the state's population). Between 2017 and 2019, 57% of the assessments were conducted with male clients.
- Alaska Natives are overrepresented in the number of assessments compared to other races (48% of assessments compared to 15% of the population). Due to select agencies not reporting assessments to DBH, this measure likely underestimates the magnitude of overrepresentation of Alaska Natives in all assessments performed statewide.
- More than half of the clients (57%) lived with a biological or adoptive parent, or other legal guardian at the time of assessment; another 29% lived in a foster home (July 2011-May 2020) and remaining 14% had other living arrangements.
- Among clients with known biological siblings, 31% had at least one sibling with a known FAS diagnosis between July 2011 and May 2020; this percentage was 24% between 2017 and 2019.
- Nearly one-quarter (24%) of referrals for assessment came from parents or foster parents. The Office of Children's Services (OCS), medical providers, and the probation office each accounted for an additional 15% of referrals. Between 2017 and 2019, 22% of the referrals came from OCS and less than 1.0% from the probation office.

Diagnoses Data Summary

- Out of 2,933 diagnoses made between 1999 and May 2020, the most common diagnostic outcomes are Static Encephalopathy/Alcohol Exposed (SE/AE) (32%) and Neurobehavioral Disorder/Alcohol Exposed (ND/AE) (26%).
- Analysis was conducted on:
    - Growth Deficiency Score – score of 1 (none) is predominant.
    - Facial Phenotype Score – score of 2 (mild) is generally more predominant, followed by a score of 1 (none).
    - Central Nervous System (CNS) Function Score – score of 3 (probable) is usually predominant, followed by a score of 2 (possible).
    - Alcohol Exposure Score – score of 4 (high risk) is usually predominant, followed by a score of 3 (some risk).
- The most common diagnosis for clients between ages 0 and 5 was ND/AE; for clients over age 5, the most common diagnosis was SE/AE.
- SE/AE and ND/AE were the most common diagnosis categories for male and female clients.
- The most prevalent diagnostic outcomes varied by the client's race; the most common diagnoses for white clients was SE/AE (30.0%) and PFAS (22.9%), while ND/AE (34.6%) and SE/AE (30.0%) were most common for Alaska Native/American Indian clients.

- SE/AE and ND/AE were the most common diagnostic outcomes among clients living with biological or adoptive parents, in other family placements, foster homes, residential treatment, and juvenile justice facilities. A higher percentage of those living independently (who were all adult clients) had a PFAS diagnosis (27%).
- The most common diagnoses with nearly all primary caregiver types were SE/AE and ND/AE.
- On average, clients diagnosed with a Normal/AE diagnosis have the highest number of known biological siblings with an FAS diagnosis (3.00). Clients diagnosed with FAS have the lowest average number of siblings with an FAS diagnosis (1.30).
- Diagnostic outcomes did not vary greatly by the type of person or organization who referred the client for assessment; the most common diagnoses were SE/AE and ND/AE.

Comparison with University of Washington FASDPN Data

- When Alaska FASD diagnostic data was compared to University of Washington FASDPN data:
    - A lower percentage of people assessed in Alaska were diagnosed with an ND/AE diagnosis (26%) compared to Washington clients (45%).
    - Conversely, a higher percentage of Alaska clients were diagnosed with an SE/AE diagnosis (32%) compared to Washington clients (24%).
    - These differences between SE/AE and ND/AE diagnoses in Alaska and Washington persist throughout age ranges and gender comparisons.
    - A higher percentage of Alaska clients received a score of 3 on their CNS function assessment (46%) compared to Washington clients (21%). Washington clients were more likely to receive a score of 2 on their CNS function assessment (53%) compared to Alaska clients (34%).

Prevention Policy Review Policy

Alaska Prevention Policy Overview

STRATEGIC PLANNING

- In 2017, the Governor's Council on Disabilities and Special Education (GCDSE) began developing and implementing the *Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022*. The strategic plan outlines a continuum of objectives and strategies identified to help decrease the prevalence of FASD, reduce the consequences of prenatal alcohol exposure, and improve the quality of life for individuals experiencing FASD. Six priorities areas are as follows; 2018-2019 objectives for each priority area were identified in the plan.

    1. Primary Prevention of FASD
    2. Screening for and Diagnosis of FASD
    3. Early Childhood and Education
    4. System Transformation and Navigation: Youth and Adults
    5. Workforce Development
    6. Community Outreach and Engagement

- Per Alaska Statute (AS) 47.30.660, DHSS, in conjunction with the AMHTA, has developed a plan for Alaska's Comprehensive Integrated Mental Health Program. *Strengthening the System: Alaska's Comprehensive Integrated Mental Health Plan 2020-2024* identifies priorities to inform state planning and funding decisions to meet the needs of Trust beneficiaries. The plan includes prevention strategies and objectives to promote practice-informed, universal screening efforts and early intervention services for FASD.

PREVENTION POLICIES

There are three levels of FASD prevention (Primary, Secondary, and Tertiary) addressed in policy:

Primary Prevention: ***Have no fetuses exposed to alcohol, thus eliminating the problems of FASD before they develop.***

- Since the late 1980s, the Alaska Legislature has passed several laws to develop public awareness of the FASD. These laws have largely focused on:
    - Distribution of written information.
    - Posting warning signs in locations that sell alcohol.
    - Training and public education.
    - Supporting trauma-informed approaches.

Secondary Prevention: ***Reduce the duration and severity of maternal drinking by identification of the person at risk.***

- Per state law (Alaska Statute (AS) 33.30.011), the DHSS commissioner must provide assessment or screening of the risks and need of offenders who may be vulnerable to harm, exploitation, or recidivism as a result of fetal alcohol syndrome, fetal alcohol spectrum disorder, or other brain-based disorder.
- In 2000, Alaska secured $29 million in federal funding to develop FASD infrastructure and services, including the statewide FASD diagnostic teams.
- In 2014, the Alaska Department of Corrections (DOC) replaced the Brief Jail Mental Health Screen and the Simple Screening Instrument for Substance Use – Revised, with the Alaska Screening Tool used by DHSS. This screening instrument includes one question regarding FASD.
- State law requires "practitioners of healing arts" to report cases in which substance abuse affects infants to the Office of Children Services (AS 47.17.024).

Tertiary Prevention: ***Reduce complications, impairments, and disabilities caused by FASD and include activities that prevent recurrence of the condition in subsequent children.***

- Since 2011, the State's operating budget has allocated funding for FASD case management and substance abuse treatment for pregnant women.
- In 2012, additional funding was allocated for the Complex Behavior Collaborative to provide consultation and training to providers and family members of people with complex behaviors and needs.

- In 2016, FASD was added to the Other Health Impairment special education eligibility category list of medical conditions, making Alaska the first state in the country to name FASD in education regulation.
- The state is required to provide quality learning and related early intervention family support services to eligible children under age 3 who have developmental delays or disabilities (subject to the availability of funding).
- In 2012, Alaska was the first state to make an FASD diagnosis a mitigating circumstance to be considered in sentencing for felony level criminal offenses (Alaska Senate Bill 151).

Additional Prevention Policy Review

A review of prevention policy initiatives in Australia, Canada, and elsewhere in the nation, including strategic plans, and primary, secondary, and tertiary prevention, revealed the following:

FASD Strategic Plans

- Few states besides Alaska have current FASD plans. Examples of states with plans include Michigan and Ohio.
- In Canada, four provinces and territories (Alberta, Manitoba, Ontario, and Yukon) have a specific prevention strategy or framework to address FASD.
- Australia's *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028* is structured around four key national priorities to catalyze national efforts in the prevention, diagnosis, support, and management of FASD.

Prevention Policies

Primary Prevention

- Research in Alberta identified that despite 20 years of public education programs, FASD remains a serious public health concern.
- States have passed many laws addressing alcohol use in pregnancy, despite limited evidence on the impact of such policies. A recent study revealed that despite evidence on the harm of alcohol use in pregnancy, most lawmakers did not express concern about this topic.
- To promote a common language about FASD and minimize misinterpretation on key issues, the Canada FASD Research Network developed a definition of FASD that used lay language to reach a wide audience.
- Australia's *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028* recognizes, among other things, a continued lack of public understanding about FASD, which can result in stigma. Inadvertent stigmatizing by public health FASD initiatives can limit the willingness of those affected by FASD to seek information, care, support, and assistance. Under the plan, policies are to be coordinated to ensure collaboration on implementation of evidence-based initiatives between all levels of governments and sectors, including health and human services, schools and teachers, and the legal system.

Secondary Prevention

- Many health professionals have not received guidance and training on how to discuss alcohol use and pregnancy with patients. Pregnant women are less likely to self-report if they feel they will be judged harshly by providers.
- A study by the Yukon Government revealed high rates of FASD and neurocognitive deficits among offenders. It was identified that concerted efforts specifically designed to both screen and comprehensively assess for FASD using validated tools were needed to inform offender risks and needs.
- Laws that discourage alcohol use during pregnancy through criminalization may reduce the likelihood that a pregnant woman would disclose her alcohol use to her doctor for fear of criminal sanction. While Alaska maintains mandatory reporting requirements, some states have removed them.
    - Colorado legislation makes the results of substance-abuse information discovered as part of pregnancy testing or the provision of prenatal care inadmissible in criminal proceedings.
    - Minnesota exempts health-care providers and social service professionals from required reporting of prenatal substance use, as long as the health-care provider or social service professional is providing the woman with prenatal care.

Tertiary Prevention

- Prevention of secondary conditions is dependent on broad system changes employing a public health approach to increase awareness and understanding of FASD, improve access to diagnostic and therapeutic services, and create responsive institutional policies to prevent secondary conditions.
- Systems-level barriers, such as delayed diagnosis, difficulty qualifying for services, limited availability of services, poor implementation of services, and difficulty maintaining services, can adversely impact outcomes and secondary condition development.
- The pervasive lack of knowledge and understanding of FASD is a primary source of these system-level barriers and contributes to the rates of secondary conditions in this population.

Estimating FASD Prevalence

- Estimating prevalence of FASD in Alaska is not possible with currently collected data, and it is likely many more individuals with FASD have not been (and will not be) diagnosed with FASD than what appears in the Alaska FASD Diagnostic Data.
- There is no national or international standard used for determining prevalence.
- Three main approaches to study the prevalence and patterns of FASD include: passive systems, clinic-based studies, and active case ascertainment. None of these methods is properly used to assess prevalence in Alaska.
- FASD diagnosis data are incomplete because of two reasons: many people are not screened for FASD, for a variety of reasons and the definition of FASD can be somewhat subjective (or variable depending on what definition is used).
- Barriers for estimating Alaska FASD prevalence include:
    - Stigma associated with “blame” of prenatal alcohol use by the biological mother.
    - Limited newborn screening tests, including alcohol byproduct assessment.

- Unawareness or inability to recognize FASD symptoms and complicating differential diagnosis.
- Overlooked assessments of less critical or severe cases.
- Unreported diagnoses to AKAIMS.
- Not all diagnostic assessments by all agencies are reported to the AKAIMS.
- No universal definition of FASD prevalence at the national and international level.

Evaluating Strategic Policy Performance

- Evaluation is important to measure outcomes and impacts of the work and inform what needs adjustment as the plan is implemented. Several of the strategic plans reviewed, including Alaska's, do not include implementation of a strategic performance evaluation plan.
- Evaluation strategies are considered and detailed in the Yukon FASD Action Plan and the Australian FASD Strategic.

Recommendations

Managing Continued FASD Diagnostic Database

- AKAIMS is the most appropriate repository for maintaining these data. At this time, no changes are recommended for the reporting form or the process of AKAIMS managing the data.
- Revise data entry to include the number of out-of-home placements captured in the data reporting form.
- During the strategic planning process, consider revisions to the diagnostic reporting tool to include additional demographic information of biological parents.
- Update FASD diagnostic data analysis to inform the strategic planning process each time the FASD strategic plan is updated.

Maintaining FASD Data Scorecard

- Establish scorecard performance targets when strategic goals are determined.
- Update the scorecard on a three-year cycle.

Develop Prevalence and Incidence Measures

- Establish a multi-sectoral epidemiological working group to build and coordinate statewide FASD surveillance strategies and review innovative and emerging approaches, measuring prevalence and incidence, and sharing lessons learned.

Prevention Strategies

PRIMARY PREVENTION

- Develop a new definition of FASD that can be used for consistent public messaging.
- Use the Alaska FASD Scorecard to increase public awareness and measure state performance to address the prevalence, incidence, and impacts of FASD.

- Update and enhance Alaska's FASD Strategic Plan. Consider available data when determining strategic direction, statewide priorities, and implementation strategies. Incorporate implementation and evaluation planning; establish performance targets. Align, coordinate, and leverage the FASD strategic plan with other related statewide efforts. Provide state support for U.S. Senate Bill S.2879 - Advancing FASD Research, Prevention, and Services Act, which provides resources for FASD strategic planning efforts.
- Advance mechanisms to support required FASD training for primary care providers and foster parents.
- Expand data collection on universal screening of alcohol use prior to pregnancy through additions and adaptions to Alaska PRAMS and BRFSS survey instruments.
- Develop funding sources to strategically advance public awareness and educational campaigns tailored for varied audiences. Emphasize positive messaging to promote awareness and discussion of alcohol use during pregnancy. Consider focusing on risk reduction, stigma, shared responsibility, and linkages to more information and help.

Secondary Prevention

- Bolster early detection and intervention for older youth and adults. Develop age-appropriate universal screening approaches with key public and private stakeholders including, among others, social service agencies, educational entities, and DOC.
- Expand the range and type of FASD early detection and intervention resources for all sectors, especially for professionals working in corrections, social services, OCS, and education. Expand training to address potential misdiagnosis of other conditions, such as autism, among others.
- Coordinate with OCS to maximize early detection and intervention opportunities.
- Establish a workgroup to review statewide diagnostic approach(s) on a systematic basis. Consider factors associated with long-term sustainability, availability of professional resources, geography and remoteness, and distribution of high-risk populations. Engage in conversation with other states or provinces positioned to share information regarding diagnostic approaches and lessons learned.

Tertiary Prevention

- Identify opportunities and seek resources to further align and coordinate FASD treatment services – including treatment of secondary conditions.
- Develop a FASD Transitioning Toolkit, which includes planning for case management, housing and employment assistance, education and training, treatment and health care, life skills, family support, and appropriate transitioning for youth leaving OCS and DOC custody.
- Clearly define post-diagnosis expectations and protocols. Develop a transparent process for communicating and integrating diagnostic results into service planning.
- Explore additional approaches to collecting more information on known siblings with FASD or undiagnosed, as this may be useful in developing wrap-around services for the child and family.

Alaska FASD Scorecard

Scorecards provide a high-level, (often) one-page overview of an entity's long-term, strategic outcomes and goals. Therefore, selected scorecard indicators are long-term and may be slow to change. Scorecards

leverage data from multiple sources to describe and reflect changes over extended periods of time. The Alaska FASD Scorecard was developed to provide information about the effectiveness of FASD initiatives in Alaska, including tracking progress and outcomes. Alaska FASD Scorecard indicators reflect relevant information from Alaska's FASD Diagnostic Team Network, state, and national data sources. These indicators align with the Alaska *Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022*, where possible.

FASD scorecard indicators are organized within three domains: primary, secondary, and tertiary prevention. These domains reflect a systematic approach to FASD prevention and intervention; indicators reflect maternal trauma, alcohol use, unintended pregnancy, alcohol-use screening and counseling, assessment referrals, diagnosis, out-of-home placement, and siblings with FASD. FAS/FASD prevalence estimates are not included, as neither an FASD prevalence nor incidence rate can currently be determined in Alaska. Indicator targets are also not included, as these have yet to be established by the Alaska FASD Strategic Plan Workgroup.

The *Alaska FASD Scorecard Data Management Guide* provides information essential to understanding the scorecard indicators, including an indicator definition and description of data source and methodology.

Next Steps

With guidance from the FASD Advisory Group, implications of this study and next steps include:

REVISIT STRATEGIC PLAN

Recognizing that a comprehensive strategic plan is the foundation for determining direction and priority, revisiting Alaska's *Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022* is a clear next step. Further work related to the strategic plan should:

- Consider FASD a public health issue rather than a behavioral health issue.
- Assess organizational and programmatic structure to reduce silos and expand agency collaboration for integrating and bridging of health, social, education, and justice services.
- Assess leadership structure to define a clear line of authority or oversight.
- Develop a new definition of FASD to inform the public in a nonclinical way and remove stigma.
- Evaluate the stability of the diagnostic tool; examine innovative and best-practice improvements in FASD diagnosis. Assess gender, agism, or cultural bias in diagnostic approaches, as well as sustainability of the chosen approach.
- Define strategic targets that can be integrated into the FASD Scorecard.

ASSESS BARRIERS TO PREVALENCE ESTIMATES

- Organize an epidemiological workgroup to investigate approaches and surveillance system gaps, including screening approaches across the lifespan and data management.
- Investigate the overlap with autism diagnoses and symptomology. This may advance access to additional funding sources.
- Invite the National Institute on Alcohol Abuse and Alcoholism (NIAAA) to offer support and advice.

Analyze Services and Supports

- Conduct a gap analysis of FASD prevention efforts and interventional services from preventive prenatal care through the pathway of care across the life span.
- Consider a longitudinal study of individuals diagnosed with FASD and their interaction with services and outcomes of these supports. This type of study over time may help identify individuals with FASD who then become parents of children with FASD, or other biological linkages to siblings with FASD. This work has not been done but may be possible through AKAIMS and linkages to other data systems, such as the court system.

Disseminate Findings

- Prepare a communications plan to impart the findings of this work. Identify key audiences, avenues, and established opportunities (i.e. Alaska's FASD Awareness month) for targeted distribution of this information.

Key Terms

Working definitions of key terms used in this study follow:

Behavioral health regions	State of Alaska's defined behavioral health reporting regions. Each of the 11 regions contains at least 20,000 individuals and complies with Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule for public dissemination of number of individuals who received behavioral health services.
FASD diagnostic team	An inter-disciplinary team specifically trained in select FASD diagnostic criteria and methodologies.
Incidence	Incidence refers to the number of individuals who develop a specific disease or experience a specific health-related event during a particular time period (such as a month or year).
Prevalence	The total number of individuals in a population who have a disease or health condition at a specific time period, usually expressed as a percentage of the population.
Prevention	A wide range of public health activities, known as interventions, aimed at reducing risks or threats to health. The three categories of prevention are primary, secondary, and tertiary.
Primary prevention	Primary prevention strives to eliminate the root causes of a problem by broad-based efforts to promote the health and well-being of a community.
Scorecard	A health scorecard provides a high-level, one-page overview of key indicators associated with a health system's long-term strategic goals.
Secondary prevention	Secondary prevention focuses on early detection and intervention of a health issue.
Tertiary prevention	Tertiary prevention engages interventions that advance recovery and reduce relapse risk and recurrence.

Acronyms and Abbreviations

AKAIMS	Alaska Automated Information Management System
AMHTA	Alaska Mental Health Trust Authority
ARBD	Other alcohol-related birth defects
ARND	Alcohol-related neurodevelopmental disorder
AS	Alaska Statute
CME	Continuing Medical Education
CNS	Central Nervous System
DBH	Alaska Division of Behavioral Health
DHSS	Alaska Department of Health and Social Services
DOC	Alaska Department of Corrections
FAS	Fetal alcohol syndrome
FASD	Fetal alcohol spectrum disorders
FASDPN	University of Washington's FAS Diagnostic & Prevention Network
GCDSE	Governor's Council on Disabilities and Special Education
HIPAA	Health Insurance Portability and Accountability Act
ND/AE	Neurobehavioral Disorder/Alcohol Exposed
NSDUH	National Survey of Drug Use and Health
OCS	Alaska Office of Children's Services
OSMAP	Alaska Office of Substance Misuse and Addiction Prevention
PFAS	Partial fetal alcohol syndrome
PRAMS	Pregnancy Risk Assessment Monitoring System
SAMHSA	Substance Abuse and Mental Health Services Administration
SE/AE	Static Encephalopathy/Alcohol Exposed
YRBS	Youth Risk Behavior Survey

Alcohol Misuse in Alaska

Alcohol misuse in Alaska is significant with incredible costs and harm. A 1998 study published in the *American Journal of Public Health* noted between 1977 and 1992 Alaska experienced the highest rate of alcohol consumption and alcohol-related hospitalizations in the nation, and Fetal Alcohol Syndrome (FAS) was highly prevalent in Alaska.[2]

The State of Alaska Department of Health and Social Services' (DHSS) 2019 Alaska Scorecard reports comparative state and national data reflecting alcohol misuse.[3] Alaska's alcohol-induced death rate is 26.3 (per 100,000 population), compared to the U.S. rate of 9.9. Among Alaska's adult population 16.4% engage in binge drinking and 7.1% engage in heavy drinking. An estimated 7.4% of Alaskan adults and 2.1% of youth, ages 12 to 17 years, are dependent upon or abuse alcohol. When asked about their maternal experiences before pregnancy, more than half of Alaskan women (57.2%) report drinking alcohol in the three months prior to becoming pregnant; 17.3% report binge drinking in the three months prior to conception.[4]

One of the significant aspects of alcohol misuse is drinking during pregnancy, which can cause a variety of birth defects ranging from morphological abnormalities to mental impairment. This range of birth defects are known as fetal alcohol spectrum disorders (FASD). Since the 1970s, Alaskans have been involved in efforts to identify and serve people affected by prenatal alcohol exposure. Advocates, including parents, medical professionals, teachers, justice professionals, policymakers, and others have been working to address this for more than four decades.

What is FAS/FASD?

Exposure to alcohol during pregnancy can cause a variety of birth defects, known as FASD, which include:

- Fetal Alcohol Syndrome (FAS)
- Partial FAS (PFAS)
- Alcohol-related neurodevelopmental disorder (ARND)
- Other alcohol-related birth defects (ARBD)

FASD was first identified in the United States in 1973. The effects of fetal alcohol exposure range from morphological abnormalities to mental impairment. Features of the syndrome include growth deficiency, anomalies of the brain structure and function (including intellectual deficits), and abnormalities of the head and face. FAS can also include neurological abnormalities, developmental delays, and behavioral dysfunction.

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[2] "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. Accessed June 2, 2020.
[3] http://dhss.alaska.gov/dph/HealthPlanning/Documents/scorecard/2019%20Trust%20Scorecard_full.pdf. Accessed June 25, 2020.
[4] Alaska Pregnancy Risk Assessment Monitoring System (2017). http://ibis.dhss.alaska.gov/query/selection/prams23/PRAMSSelection.html. Accessed July 3, 2020.

A study in 1994 found that approximately 58% of children born with FASD are later diagnosed as developmentally disabled.[5] Often, children with fetal alcohol disorders are not identified until they reach school age or later, as symptoms do not become apparent until later childhood developmental stages. As a result, FASD is often underreported. FASD symptoms can include difficulties with attention, memory, and problem solving. Heart, liver, and kidney disease, as well as vision and hearing problems, are also common among children with FASD.[6]

People affected by FASD experience lifetime effects, and the cost of caring for these individuals can be significant. Needs can range from neonatal care for low birth weight to special speech therapy, behavioral management, or residential care for adults with FASD. Based on a series of assumptions, the *2019 Economic Costs of Alcohol Misuse in Alaska* report estimates nearly 50,000 Alaskans experience a Fetal Alcohol Spectrum Disorder with an average annual cost for caregivers of children, youth, and adults with FASD from birth to 53 years of about $21,079 per person, suggesting a total annual cost of $1 billion dollars.[7]

Despite these significant costs involved, little is known about the primary, secondary, or tertiary prevention of FASD in Alaska, where programmatic and policy efforts should be targeted, or whether efforts are making a difference in reducing the prevalence of FASD.

Diagnosing FASD

Alaska's FASD Diagnostic Team Network

Since about 1999, DHSS has coordinated and funded a statewide network of community-based FASD diagnostic teams. The number and location of FASD diagnostic teams around the state has varied over time. Originally, 17 teams were trained to serve across the state. At present, there are six teams.

Diagnosis of FASD is conducted by these interdisciplinary teams using evidence-based diagnostic guidelines. This diagnostic model was first introduced by the University of Washington in 1993 and has been adopted as a best practice worldwide.[8] Ideally within this model, an interdisciplinary team of clinicians (i.e., medical provider, psychologist, speech language pathologist, occupational therapist, social worker, and family advocate) is required to diagnose FASD because the damage caused by prenatal alcohol exposure impacts all aspects of an individual's growth and brain development. The expertise of a medical doctor is required to assess the physical and neurological components of the disorder (i.e., growth deficits, facial anomalies, seizures). The expertise of a psychologist, speech language pathologist, and occupational therapist is required to assess the brain function component of the disorder. Deficits occur across multiple domains of brain function including attention, cognition, memory, language, and motor skills. More frequently seen are deficits in executive function and adaptive living skills.

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[5] Streissguth, A. (1994). A Long-Term Perspective of FAS. *Alcohol Health & Research World* 18(1):74-81. Accessed June 11, 2020.
[6] National Organization on Fetal Alcohol Syndrome, *What is FAS/FASD?* www.nofas.org/faqs.aspx?id=9. Accessed June 11, 2020.
[7] https://alaskamentalhealthtrust.org/wp-content/uploads/2020/01/McDowell-Group-Alcohol-Misuse-Report-Final-1.21.20.pdf. Accessed June 2, 2020.
[8] Substance Abuse and Mental Health Services Administration. Addressing Fetal Alcohol Spectrum Disorders (FASD). Treatment Improvement Protocol (TIP) Series 58. HHS Publication No. (SMA) 13-4803. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014. Accessed June 11, 2020.

Within the Alaska context, FASD diagnostic team composition has evolved over time. The early foundation for the diagnostic teams was rooted in state grant funding, which was then supplemented by a provider agreement from the state Division of Behavioral Health (DBH). As part of the requirements for funding, the diagnostic teams have been required to have a team coordinator, a parent navigator, medical provider, psychologist/neuropsychologist, speech language pathologist, and occupational therapist or physical therapist.

In practice, team composition has varied based on available resources — typically provider availability. Challenges with maintaining all these professionals on a team, especially in rural settings, has required flexibility in functioning. Currently, at a minimum, diagnostic teams include a coordinator, navigator, physician, and a psychologist — everyone having expertise in the functional domains assessed. The diagnostic evaluation may be supplemented with information from non-team affiliated professionals not formally part of the diagnostic team. For example, in the event a psychologist, speech language pathologist, occupational therapist, or physical therapist is not available, teams have been allowed to use testing and assessment information from professionals with similar assessment skills and from service entities that may be involved with the individual (e.g., school individualized education program (IEP) documents, other private practice professionals' reports, etc.). A team's evaluation of an individual may use results of a neuropsychological or psychological evaluation from an independent professional who is not a formal member of the team.

Alaska's FASD diagnostic teams are required to use the University of Washington's FAS Diagnostic & Prevention Network (FASDPN) 2004 FASD 4-Digit Diagnostic Code to diagnose the full spectrum of outcomes associated with prenatal alcohol exposure.[9] Over the past 20 years, there have been an estimated 3,000 to 4,000 individuals evaluated by the diagnostic team network; assessment data for about 3,000 individuals diagnosed with FASD were reported to the State of Alaska.

Study Background

Beginning in the early to mid-2000s, Alaska implemented a variety of prevention and intervention projects intended to reduce the prevalence or impacts of prenatal alcohol exposure. However, a limited range of data indicators, as well as a lack of coordinated data-gathering and monitoring, has contributed to mixed programmatic progress and outcomes, or appropriate allocation of resources. Factors relative to Alaska's current FASD landscape are integral to FASD data analysis. Some factors include:

- Systematic efforts for collecting Alaska's FASD-related data have changed markedly in the last several years. The Pregnancy Risk Assessment Monitoring System (PRAMS) is presently the only organized ongoing data collection mechanism.
- About 20 years of FASD diagnostic team network data are stored in more than one database.
- FASD Diagnostic Team Network assessment and diagnosis efforts statewide are ongoing, yet inconsistent over time.

[9] Astley, S. J. (2004). Diagnostic guide for fetal alcohol spectrum disorders: The 4-digit diagnostic code. Seattle, Washington, University of Washington. http://depts.washington.edu/fasdpn/pdfs/guide2004.pdf. Accessed June 2, 2020.

- Renewed statewide coordination of FASD prevention and intervention efforts is detailed in the Governor's Council of Disabilities and Special Education's (GCDSE) *Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022.*[10]
- For those at risk for prenatal exposure and individuals with an FASD, services are received through multiple systems — including standard healthcare and behavioral health-care systems, plus educational, child protection, court, and correctional settings.
- Expanding the continuum of data indicators may help improve progress and tracking of outcomes, including indicators in prevention, intervention, service, or systems of care domains.

[10] Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022. http://dhss.alaska.gov/osmap/Documents/fasd/FASD-Stategic-Plan-FY2017-2022.pdf. Accessed July 3, 2020.

Study Purpose

Data are needed to help guide policy and funding decision-making related to the prevention of FASD and implementation of secondary and tertiary prevention programs for individuals experiencing an FASD. This study's purpose is to analyze available Alaska's FASD Diagnostic Team Network data, FASD prevention program and data policies, and develop an FASD Data Scorecard to inform prevention policy and measure effectiveness of primary, secondary, and tertiary prevention efforts.

Study Scope

In April 2020, the Alaska Mental Health Trust Authority (AMHTA) contracted with McDowell Group to advance the study's purpose through a multi-faceted scope of work. The study's scope included four primary focuses:

1. **Alaska's FASD diagnostic team network database(s)**
    a. Combining FASD diagnostic team network data from existing databases
    b. Developing a single database with updated design elements for future use by DHSS
2. **Alaska's FASD diagnostic team network data**
    a. Analyzing about 20 years of FASD diagnostic team network data
    b. Summarizing diagnostic team data through descriptive and advanced analysis
    c. Completing a breakdown of diagnosis by Alaska behavioral health regions
    d. Providing a descriptive comparison of the Alaska FASD diagnostic team network data to the University of Washington's FASDPN data summary
3. **Alaska's FASD policy and programmatic recommendations**
    a. Using the results of the data analysis to identify general and specific recommendations supporting primary, secondary, and tertiary prevention of FASD in Alaska
    b. Conducting a literature review of policy and legislation to inform key policy and programmatic recommendations supporting the prevention of FASD
4. **Alaska's FASD Data Scorecard**
    a. Producing an Alaska-focused FASD data scorecard of relevant prevention performance indicators
    b. Providing recommendations on data management and scorecard updating
    c. Documenting how to access indicator and prevalence data

Methodology

Forming an FASD Advisory Group

An advisory group of FASD policy and programmatic leaders was formed for this study. The group met twice at the onset of the study and after draft data and the policy analysis and scorecard were submitted. The first meeting focused on understanding of data sources and infrastructure, as well as approach and expectations. The second meeting was a work session to discuss findings and their implications. Advice from the group helped refine the analytical findings and recommendations. Advisory group members included:

- Michael Baldwin, Senior Evaluation and Planning Officer, AMHTA
- Jessica Filley, Epidemiology Specialist, Office of Substance Misuse and Addiction Prevention, DHSS
- Hope Finkelstein, FASD Program Coordinator, Office of Substance Misuse and Addiction Prevention, DHSS
- Marilyn Pierce-Bulger, APRN, FASDx Services LLC, Interim President, Board of Directors, Alaska Center for FASD
- Patrick Swiger, Public Health Informaticist, Alaska's Automated Information Management System (AKAIMS), DBH, DHSS
- Jenn Wagaman, Fetal Alcohol Diagnostic Team Coordinator, Alaska Center for Children and Adults

Combining FASD Diagnostic Team Network Data with Update Design Elements

With support from AKAIMS data manager and others, the team developed a single database of FASD diagnostic team network data. The database was designed for continued updating with future diagnostic team data.

Conducting FASD Diagnostic Team Data Analysis

The team conducted a data analysis and evaluation of the FASD diagnostic team data. Data analyzed included diagnostic information and client demographics, as well as referral and background information; a regional analysis by State of Alaska's behavioral health regions was also conducted. Where possible, Alaska's FASD diagnostic data was compared to University of Washington's FASDPN data summary.

Recommending Policy and Programmatic Approaches

After analyzing the diagnostic team data, a literature review of data-related components to measure FASD policy and programmatic approaches was conducted. This analysis focused on implications for supportive policy and programmatic recommendations for primary, secondary, and tertiary prevention of FASD in Alaska. These recommendations centered on data management and infrastructure, organizational, and/or program-related issues.

Developing an Alaska FASD Scorecard

The study team produced an Alaska FASD Scorecard. Scorecard elements were developed after review of other scorecard models in Alaska and elsewhere. The GCDSE FASD Five-year Strategic Plan was considered when informing relevant and strategic indicators. A review of FASD literature and best practices also guided

indicator selection, as well as Alaska FASD Diagnostic Team, state, and national data sources. Scorecard domains reflect primary, secondary, and tertiary prevention constructs. Data presented in the FASD Scorecard were from readily available sources.

Key design features of the Alaska FASD Scorecard included:

- A summary of selected indicators organized by relevant prevention domains.
- Comparisons of the most appropriate current Alaska and U.S. data, with suggested indicator targets.
- Accompanying presentation of data sources for each indicator and prevalence estimate.
- Detailed sections for each indicator explaining the information source and methodology.

A scorecard data management guide with directions of how to update scorecard indicators and recommendations on the frequency and other information was developed.

In addition to the Alaska FASD Scorecard included in this report, a stand-alone version has been provided under separate cover to AMHTA.

Data Notes

FASD Diagnostic Team Data

Diagnostic data reflected in this study are comprised of assessment data reported by FASD diagnostic teams to DBH for purposes of seeking state reimbursement for assessment services as part of the State of Alaska FASD Diagnostic Team Provider Agreement network.

Not all diagnostic teams have a FASD Diagnostic Team Provider Agreement. At least one FASD diagnostic team has elected not to engage this agreement since about 2010. Hence, the FASD diagnostic team data set analyzed in this study is not comprehensive as it does not include data from this team since that time.

FASD Diagnostic Coding

The four digits of the FASD 4-Digit Code reflect the magnitude of expression of the four key diagnostic features of FASD, in the following order:

1. Growth deficiency
2. FAS facial phenotype
3. Central Nervous (CNS) structural/functional abnormalities
4. Maternal alcohol exposure (prenatal and postnatal)

The magnitude of expression of each feature is ranked independently on a 4-point Likert scale, with 1 reflecting complete absence of the FASD feature and 4 reflecting a strong classical presence of the FASD feature. The 4-Digit Code produces four diagnostic sub-classifications under the umbrella of FASD: FAS, PFAS, Static Encephalopathy/Alcohol Exposed (SE/AE), and Neurobehavioral Disorder/Alcohol Exposed (ND/AE).The 4-Digit Code is the only diagnostic system with an FAS facial phenotype confirmed to be highly specific to prenatal alcohol exposure and FAS.

In general, diagnostic classifications are defined as:

FETAL ALCOHOL SYNDROME (ALCOHOL EXPOSED)

Individuals with growth deficiency (height and/or weight at or below the 10th percentile); the full FAS facial phenotype (all three of the following features: palpebral fissure length at or below the third percentile, smooth philtrum and thin upper lip); significant structural, neurological, and/or functional CNS abnormalities; and confirmed prenatal alcohol exposure.

FETAL ALCOHOL SYNDROME (ALCOHOL EXPOSURE UNKNOWN)

Individuals with the growth, face, and CNS features of FAS, but the alcohol exposure is unknown.

PARTIAL FETAL ALCOHOL SYNDROME (ALCOHOL EXPOSED)

Individuals with significant structural, neurological, and/or functional CNS abnormalities, most of the growth or facial features of FAS, and a confirmed history of prenatal alcohol exposure.

STATIC ENCEPHALOPATHY/ALCOHOL EXPOSED

Individuals with confirmed prenatal alcohol exposure who present with severe CNS structural or functional abnormalities, but no FAS facial phenotype or growth deficiency.

NEUROBEHAVIORAL DISORDER/ALCOHOL EXPOSED

Individuals with confirmed prenatal alcohol exposure and moderate CNS dysfunction, but no facial phenotype or growth deficiency.

Methodology

Assessment Data Analysis

Assessment data analyzed is managed by DBH. The dataset includes assessment information entered from 1999 through May 20, 2020. Due to a time lag from assessment date to reporting date, this analysis likely excludes information on some assessments performed in May 2020.

This dataset includes only FASD assessments made by diagnostic teams reporting assessments to DBH for purposes of seeking state reimbursement for assessment services as part of the State of Alaska FASD Diagnostic Team Provider Agreement network. The number of diagnostic teams performing FASD assessments and seeking reimbursement varies from year to year. Therefore, this dataset does not represent the characteristics or diagnostic outcomes of all individuals assessed in Alaska.

From 1999 through June 2011, assessment data were entered by providers into a Microsoft Access database. In July 2011, providers began reporting assessment information in the AKAIMS application and use of the Access database was discontinued. Where possible, data from both databases were combined to provide assessment and diagnoses analysis over the entire 1999–May 2020 time period. Due to data quality issues related to the Access database, not all information from the 1999–July 2011 assessments could be combined with the AKAIMS database. Table titles throughout this report indicate the time period data were available.

Data on client background information not available prior to July 2011 period include:

- Living arrangement at time of assessment
- Clients' experience of an out-of-home placement at any time prior to assessment
- Race
- Data on the clients' biological siblings

For select client background data, some categories have been grouped due to confidentiality concerns (e.g, "*Other*" living arrangement includes those living in a receiving home or runaway shelter at the time of assessment). Table footnotes indicate where client background categories are combined.

Individual clients may undergo FASD assessment multiple times and may have different diagnostic outcomes between assessments. Due to data quality challenges in the Access dataset, this analysis could not identify unique clients in the 1999–July 2011 dataset, nor was it possible to identify clients with assessments in both the Access and AKAIMS datasets. A small percentage of clients in the AKAIMS dataset had multiple assessments over the August 2011–May 2020 period. This analysis attempts to provide diagnostic outcome indicators based on each client's most recent assessment. However, this analysis likely contains more than one diagnoses for a limited number of clients (less than 20 cases out of about 2,950) due to Access dataset issues previously discussed. Analysis of the number of assessments was performed using all assessments recorded in the datasets and includes all assessments for clients with more than one record.

DIAGNOSTIC CATEGORY

Diagnoses were categorized according to the University of Washington's Diagnostic Guide for FASD (as discussed above). The four-digit diagnostic system has 256 possible combinations. Specific diagnoses are grouped into 22 diagnostic categories and further consolidated into seven categories:[11]

- Fetal Alcohol Syndrome (FAS)
- Partial Fetal Alcohol Syndrome (PFAS)
- Static Encephalopathy/Alcohol Exposed (SE/AE)
- Neurobehavioral Disorder/Alcohol Exposed (ND/AE)
- Sentinel Physical Findings/Alcohol Exposed
- Normal/Alcohol Exposed
- All Other

BEHAVIORAL HEALTH REGIONS

Data are presented geographically based on behavioral health regions in Alaska. The following tables describe the boroughs and census areas within each region, and the FASD Diagnostic Teams serving each region.

[11] For more information on categorization of diagnoses, please see the University of Washington *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*.

Table 1. Alaska Behavioral Health Regions

Behavioral Health Region	Borough/Census Area
Anchorage Municipality	Anchorage Municipality
Fairbanks North Star Borough	Fairbanks North Star Borough
City and Borough of Juneau	City and Borough of Juneau
Kenai Peninsula Borough	Kenai Peninsula Borough
Matanuska-Susitna Borough	Matanuska-Susitna Borough
Northwest Region	Nome Census Area
	North Slope Borough
	Northwest Arctic Borough
Other Interior Region	Denali Borough
	Southeast Fairbanks Census Area
	Valdez-Cordova Census Area
	Yukon-Koyukuk Census Area
Other Southeast Region — Northern	Haines Borough
	Hoonah-Angoon Census Area
	Petersburg Borough
	Sitka City and Borough
	Skagway Municipality
	Wrangell City and Borough
	Yakutat City and Borough
Other Southeast Region — Southern	Ketchikan Gateway Borough
	Prince of Wales-Hyder Census Area
Y-K Delta Region	Bethel Census Area
	Kusilvak Census Area
Southwest Region	Aleutians East Borough
	Aleutians West Census Area
	Bristol Bay Borough
	Dillingham Census Area
	Kodiak Island Borough
	Lake and Peninsula Borough

Source: Alaska Division of Public Health

Table 2. FASD Diagnostic Teams Reporting to AKAIMS and Behavioral Health Regions Served, July 2011-May 2020

Behavioral Health Region	FASD Diagnostic Team	
	Team	Years Reporting to AKAIMS
Anchorage Municipality	Assets Inc.	2011-2014, 2016
	FASDx Services	2014-2020
Fairbanks North Star Borough	Alaska Center for Children & Adults	2011-2020
City and Borough of Juneau	REACH	2014-2017
	Tlingit & Haida Central Council	2011-2012
Kenai Peninsula Borough	Frontier Community Services	2011-2020
Matanuska-Susitna Borough	Mat-Su Services for Children & Adults	2013-2014
	Ptarmigan Connections	2017-2020
Northwest Region	Norton Sound Health Corporation	2017, 2019
Other Interior Region	-	-
Other Southeast Region - Northern	SEARHC (Sitka)	2012-2014
	Sitka Community Hospital	2015-2019
Other Southeast Region - Southern	-	-
Y-K Delta Region	Yukon Kuskokwim Corporation	2011-2017
Southwest Region	-	-

Report Organization

The report contains an Executive Summary, Key Terms and Abbreviations, Background, Purpose and Methodology, four chapters, references, and two appendices organized as follows:

- **Chapter 1: FASD Diagnostic Team Data Analysis** provides a summary of the data collected by FASD Diagnostic Teams from 1999 through May 2020.
- **Chapter 2: Prevention Policy Review** provides an overview of policy initiatives in Alaska and elsewhere to address FASD prevention.
- **Chapter 3: Alaska FASD Scorecard** provides a general description of the Alaska FASD Scorecard and selection of scorecard indicators.
- **Chapters 4: Recommendations** describes recommended considerations with a focus on data management and infrastructure and performance measures for primary, secondary, and tertiary prevention strategies.
- **References** outlines detailed information on key references cited within the report.
- **Appendix A: Alaska FASD Scorecard** reflects relevant data indicators from Alaska's FASD Diagnostic Team Network, state, and national data sources.
- **Appendix B: Alaska FASD Scorecard Data Management Guide** provides information essential to understanding the scorecard indicators.

Chapter 1: FASD Diagnostic Team Data Analysis

This chapter provides a summary of the data collected by FASD Diagnostic Teams from 1999 through May 2020. Depending on available data, data may include 1999-May 2020, 2003-May 2020, or July 2011-May 2020. Results are presented for assessments and diagnoses, by number and type, residency, demographics (i.e., age, gender, race/ethnicity), referral patterns, living arrangements, and family characteristics of individuals assessed and diagnosed.

Assessments

By Year

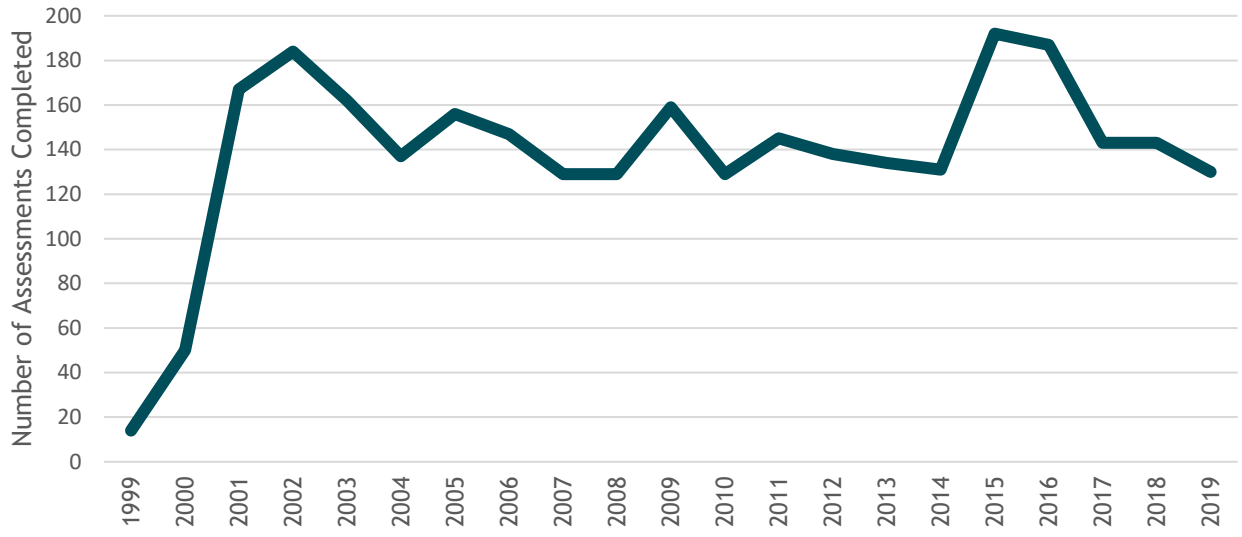
- The number of assessments varies by year and depends on the number of agencies performing assessments and seeking reimbursement through the State of Alaska. The number of assessments peaked in 2015 at 192.
- The number of diagnostic teams reporting FASD assessments to DBH has generally declined from highs between ten and 12 teams in the early 2000s. In 2019 (the last year for which complete annual data were available), only six teams reported data to DBH.

Table 3. Total Assessments and Number of Diagnostic Teams, by Year, 1999-May 2020

Year	Assessments Completed	Number of Diagnostic Teams
1999	14	2
2000	50	5
2001	167	7
2002	184	12
2003	162	10
2004	137	11
2005	156	11
2006	147	9
2007	129	6
2008	129	8
2009	159	8
2010	129	8
2011	145	6
2012	138	6
2013	134	6
2014	131	8
2015	192	6
2016	187	7
2017	143	8
2018	143	5
2019	130	6
2020*	41	4
Total	**2,947**	**-**

Notes: Based on data available as of May 20, 2020. Number of teams reporting data in 2011 is based on data reported to the AKAIMS systems following database cutover in July 2011. (*) indicates partial year (January-May) data.
Source: Alaska DHSS Dataset, May 2020. McDowell Group calculations.

Figure 1. Completed Assessments, 1999-2019



Source: Alaska DHSS Dataset, May 2020. McDowell Group calculations.

By Age

- Clients' annual average age at time of diagnosis generally ranges from age 8 to 12; the median age ranges from age 7 to 11. Between 1999 and May 2020, the average age at diagnosis is 10.1 years.
- The average age at diagnosis varies slightly year to year with no apparent trend.

Table 4. Annual Average and Median Age at Diagnosis, 1999-May 2020

Year	Average Age	Median Age
1999	9.9	7
2000	11.5	11
2001	10.7	10
2002	10.5	10
2003	10.2	10
2004	9.8	9
2005	11.1	10
2006	9.6	9
2007	10.3	9
2008	9.9	8
2009	10.4	9
2010	9.8	9
2011	12.0	9
2012	10.1	8
2013	10.3	9
2014	9.0	8
2015	10.6	9
2016	8.7	8
2017	8.6	7
2018	10.0	9
2019	8.6	8
2020	10.5	10
Total	**10.1**	**9**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Half (50%) of all assessments were performed when the client was between ages 6 and 12.
- About 20% of clients were age 13 to 17 at diagnosis, with an additional 19% between ages 3 and 5.
- Eight percent of assessments were conducted with adults.

Table 5. Assessments by Age Group, 1999-May 2020

Age Group	Number of Assessments	% of Total
0-2 years	68	2.3
3-5 years	566	19.2
6-12 years	1,464	49.7
13-17 years	617	20.9
18+ years	232	7.9
Total	**2,947**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Gender

- A higher percentage of clients assessed were male (58%), which suggests they are overrepresented in assessments compared to their share of the state population (51%).

Table 6. Assessments by Gender, 1999-May 2020

Gender	Number of Assessments	% of Total
Female	1,251	42.4
Male	1,696	57.6
Total	**2,947**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Race/Ethnicity

- Based on a 2018 estimate of Alaska's population, Alaska Natives are overrepresented in the number of assessments compared to other races (48% of assessments compared to 15% of the population). Due to select agencies not reporting assessments to DBH, this measure likely underestimates the magnitude of overrepresentation of Alaska Natives in all assessments performed statewide. Additionally, "two or more races" often includes Alaska Natives, further indicating over-representation.

Table 7. Assessments by Client's Race, July 2011-May 2020

Race	Number of Assessments	% of Total	% of Statewide Population (2018)
White (alone)	363	28.2	65.4
Alaska Native/American Indian (alone)	615	47.8	15.4
Black/African American (alone)	35	2.7	3.7
Other (alone)	19	1.5	8.0
Two or More Races	235	18.3	7.4
Unknown	19	1.5	-
Total	**1,286**	**100.0**	**100.0**

Notes: Due to rounding, some columns may not add to 100%. "Other race alone" includes Asian , Native Hawaiians and Pacific Islanders.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- The percentage of assessments by ethnicity is proportional to the statewide population.

Table 8. Assessments by Ethnicity, July 2011-May 2020

Ethnicity	Number of Assessments	% of Total	% of Statewide Population (2018)
Not Spanish/Hispanic/Latino/Mexican	1,160	90.2	92.8
Spanish/Hispanic/Latino/Mexican	77	6.0	7.2
Unknown	49	3.8	0
Total	**1,286**	**100.0**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Living Arrangement

- More than half of the clients (57%) lived with a biological or adoptive parent or other legal guardian at the time of assessment; another 29% lived in a foster home.

Table 9. Assessments by Client's Living Arrangement at Time of Diagnosis, July 2011-May 2020

Living Arrangement	Number of Assessments	% of Total
Biological / Adoptive Parents or Legal Guardian	735	57.2
Foster Home	371	28.8
Other Family Placement	65	5.1
Residential Treatment	42	3.3
Self/independent	26	2.0
Juvenile Justice Facility	13	1.0
Other	34	2.6
Total	**1,286**	**100.0**

Note: "Other" living arrangements include clients living in a receiving home or runaway shelter.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Most clients (82.5%) had experienced at least one out-of-home placement at the time of assessment.

Table 10. Assessments by Clients Having an Out-of-Home Placement, July 2011-May 2020

Out-of-Home Placement	Number of Assessments	% of Total
Yes	1,061	82.5
No	207	16.1
Unknown	18	1.4
Total	**1,286**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Primary Caregiver

- Most often (about 39%), adoptive parents or other legal guardians were the client's primary caregiver at time of assessment.
- Foster parents were also among the top primary caregivers with 28% of clients.
- One or both biological parents were the client's primary caregiver in 20% of cases.

Table 11. Assessments by Client's Primary Caregiver, 2003-May 2020

Primary Caregiver	Number of Assessments	% of Total
Adoptive Parents / Legal Guardian	1,016	39.4
Foster Parent(s)	718	27.8
Biological Mother Only	190	7.4
Biological Father Only	192	7.4
Other Family	128	5.0
Both Biological Parents	109	4.2
Self	89	3.4
Social Service Agency	71	2.8
Other	53	2.1
Unknown	14	0.5
Total	**2,580**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Sibling Characteristics

- More than three-quarters (77%) of clients had biological siblings at the time of assessment.
- For 17% of clients, it was unknown if the client had biological siblings at the time of assessment.

Table 12. Assessments by Clients with Biological Siblings, July 2011-May 2020

Biological Siblings	Number of Assessments	% of Total
Yes	991	77.1
No	74	5.8
Unknown	221	17.2
Total	**1,286**	**100.0**

Note: Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- On average, clients with known biological siblings had 2.93 biological siblings at the time of assessment.
- Of clients with known biological siblings, 17% did not know the actual number of biological siblings.

Table 13. Number of Known Biological Siblings, July 2011-May 2020 (Base: Clients with Known Biological Siblings)

Number of Biological Siblings	Number of Assessments	% of Total
1	240	24.2
2	192	19.4
3	143	14.4
4-5	157	15.8
6+	87	8.7
Unknown	172	17.4
Total	**991**	**100.0**
Average number of siblings	**-**	***2.93***
Median number of siblings		***2.00***

Notes: Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Among clients with known biological siblings, 31% had at least one sibling with a known FAS diagnosis. In nearly half (45%) of cases where the client had biological siblings, it was unknown whether any of the siblings had an FAS diagnosis.
- If excluding biological siblings with an unknown FAS diagnosis, 57% of clients with a known biological sibling have at least one sibling with an FAS diagnosis.

Table 14. Clients with Known Biological Siblings Diagnosed with FAS, July 2011-May 2020 (Base: Clients with Known Biological Siblings)

Biological Siblings with FAS	Number of Assessments	% of Total	Number of Assessments (Excluding siblings with unknown FAS diagnosis)	% of Total (Excluding siblings with unknown FAS diagnosis)
Yes	307	31.0	307	56.7
No	234	23.6	234	43.3
Unknown	450	45.4	--	--
Total	**991**	**100.0**	**541**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Of the 991 clients with a known biological sibling, 31% have at least one biological sibling who is also diagnosed with FAS and 46% do not know if any of their biological siblings have been diagnosed with FAS. Only 23% of these clients have no biological siblings diagnosed with FAS.
- Analysis suggests that the percentage of clients with at least one sibling who has an FAS diagnosis increases as the client's total number of biological siblings increase.

Table 15. Proportion of Client With At Least One Sibling Diagnosed with FAS, July 2011-May 2020 (Base: Clients with Known Biological Siblings)

	Clients with at Least One Siblings with Known FAS Diagnosis	Clients without at Least One Siblings with Known FAS Diagnosis	Clients who do not know if at least one sibling has an FAS Diagnosis[a]	Clients with At Least One Known Biological Sibling
Number of Clients	307	230	454	991
Percentage of Clients	31.0	23.2	45.8	100.0

Note: a. Includes clients for whom the number of biological siblings is unknown, but data indicated no siblings with an FAS diagnosis.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- On average, clients with known biological siblings with an FAS diagnosis have 1.93 siblings with FAS.

Table 16. Number of Siblings with FAS Diagnosis, July 2011-May 2020 (Base: Clients with Known Biological Siblings Who Have an FAS Diagnosis)

Number of Biological Siblings with an FAS Diagnosis	Number of Assessments	% of Total
1	142	46.3
2	46	15.0
3	34	11.1
4-5	10	3.3
6+	17	5.6
Unknown	58	18.9
Total	**307**	**100.0**
Average number of known biological siblings with FAS	**-**	***1.93***
Median number of known biological siblings with FAS	**-**	***1.00***

Note: Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Of clients with at least one known biological sibling with a known FAS diagnosis, most clients (37%) had one older biological sibling with an FAS diagnosis.
- Another 32% of clients with a known biological sibling with an FAS diagnosis had no older siblings with an FAS diagnosis.

Table 17. Number of Older Siblings with FAS Diagnosis, July 2011-May 2020
(Base: Clients with Known Biological Siblings Who Have an FAS Diagnosis)

Number of Older Biological Siblings	Number of Assessments	% of Total
0	98	31.9
1	114	37.1
2	29	9.4
3	12	3.9
4-5	9	3.0
6+	5	1.6
Unknown	40	13.0
Total	**307**	**100.0**
Average number of older known biological siblings with FAS	**-**	***1.67***
Median number of older known biological siblings with FAS	**-**	***1.00***

Note: Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Of clients with at least one sibling with a known FAS diagnosis, most clients (36.8%) had no younger siblings with an FAS diagnosis.
- Another 34.5% of clients with at least one sibling with an FAS had one younger siblings with an FAS diagnosis.

Table 18. Number of Younger Siblings with FAS Diagnosis, July 2011-May 2020
(Base: Clients with Known Biological Siblings Who Have an FAS Diagnosis)

Number of Younger Biological Siblings	Assessments	% of Total
0	113	36.8
1	106	34.5
2	26	8.5
3	14	4.6
4-5	5	1.6
6+	3	1.0
Unknown	40	13.0
Total	**307**	**100.0**
Average number of younger known biological siblings with FAS	**-**	***1.56***
Median number of younger known biological siblings with FAS	**-**	***1.00***

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Referral

- Nearly one-quarter (24%) of referrals for assessment came from parents or foster parents.
- The Office of Children's Services (OCS), medical providers, and the probation office each accounted for an additional 15% of referrals.

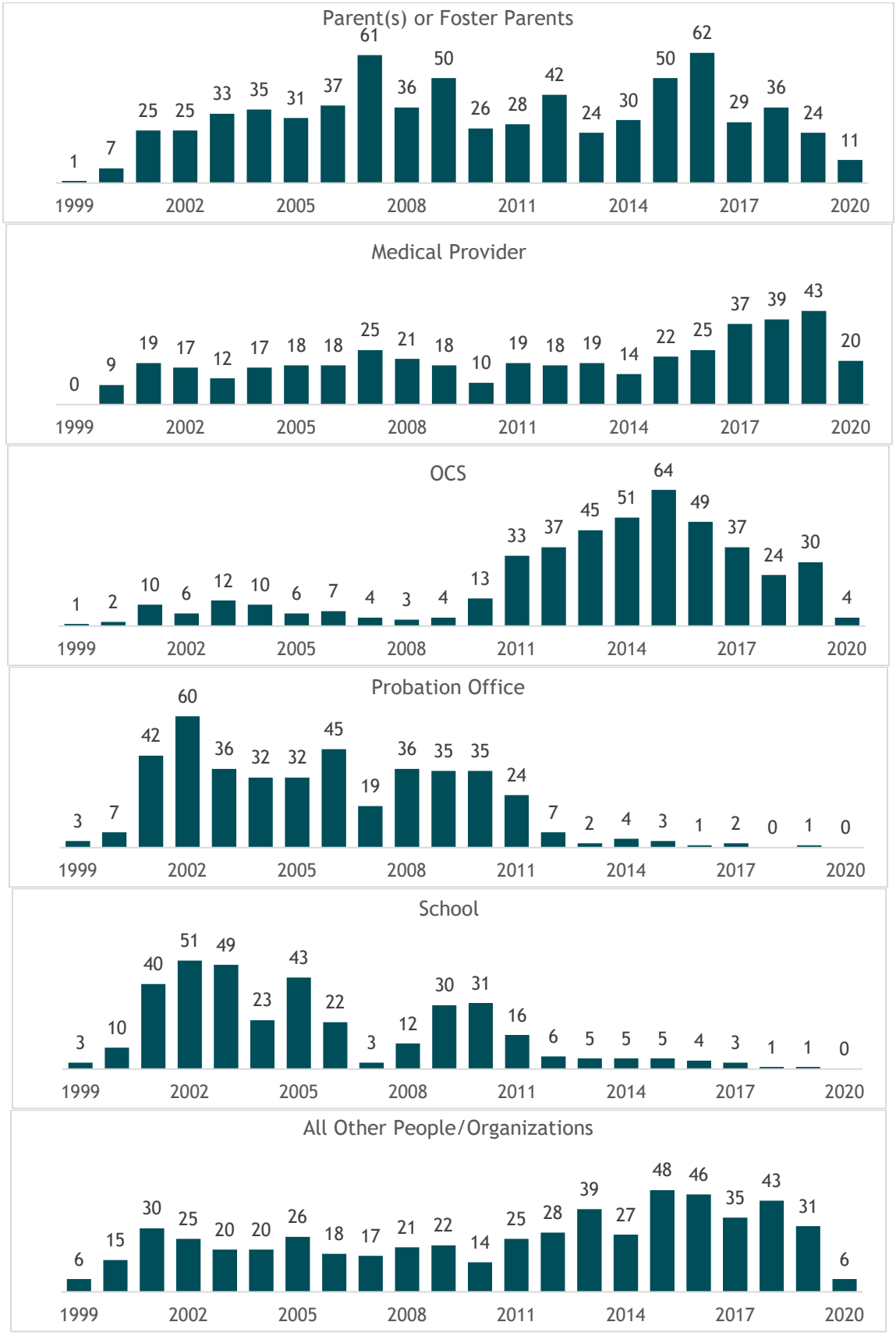
Table 19. Assessments by Referral Person/Organization, 1999-May 2020

Referral Person/Organization	Number of Assessments	% of Total
Parent(s) or Foster Parents	703	23.9
OCS	452	15.3
Medical Provider	440	14.9
Probation Office	427	14.5
School	363	12.3
Mental Health Provider	210	7.1
Self	41	1.4
Other	276	9.4
Unknown	35	1.2
Total	**2,947**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

The figures (next page) display the number of annual assessments since 1999 by select referral person or organization.

Figure 2. Number of Assessments by Referral Person/Organization, 1999-May 2020



Note: "All Other People/Organizations" includes mental health providers, self-referrals, and others.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Behavioral Health Region

While some clients can be assessed in their home communities, several behavioral health regions have no FASD diagnostic team. Therefore, the number of assessments by clients' residency is related to FASD Diagnostic Team access.

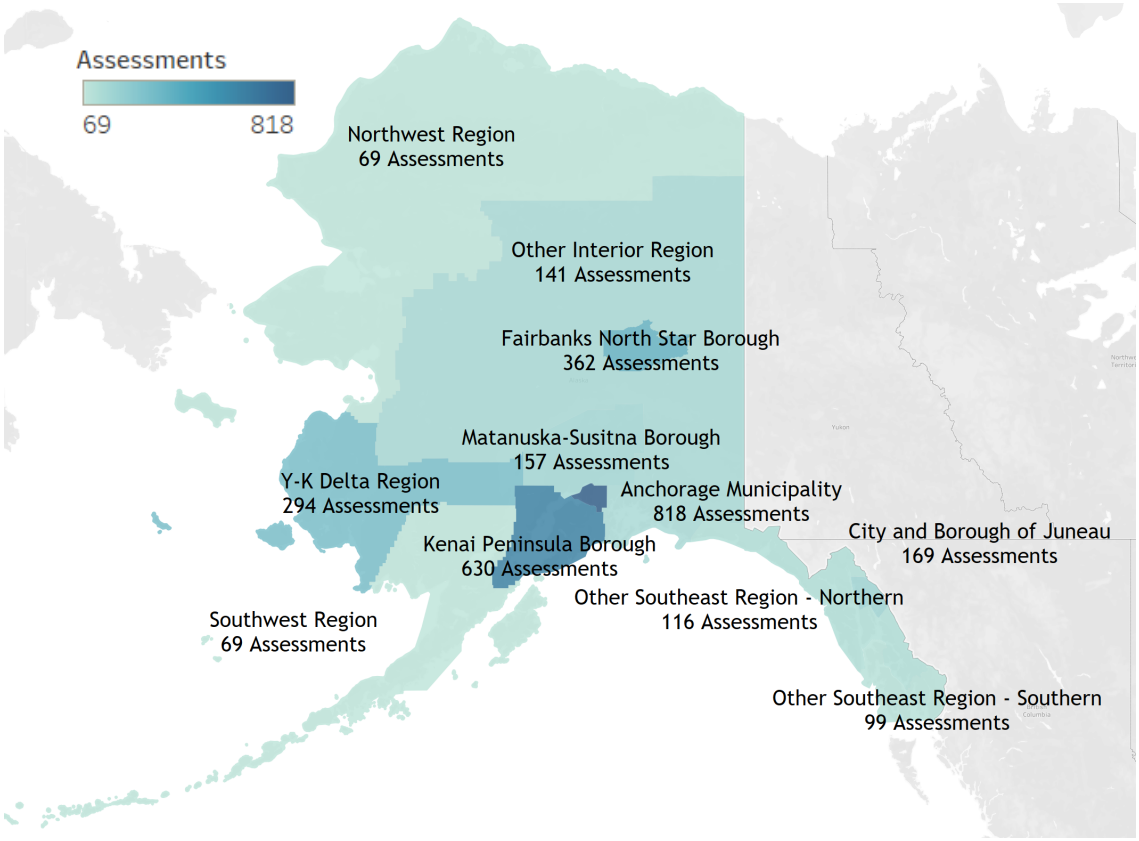
- Anchorage residents comprise the highest percentage of all assessments reported to DBH (28%). Compared to Anchorage's share of the statewide population (40%), Anchorage residents appear underrepresented in assessments reported to DBH. This underrepresentation is likely a factor of select FASD-diagnostic teams in the Anchorage area not reporting data to DBH (such as Southcentral Foundation since 2011).
- While the Kenai Peninsula Borough (KPB) has only 8% of the statewide population, KPB residents comprised more than 20% of assessments reported to DBH.
- Similarly, Yukon-Kuskokwim Delta residents comprise 10% of all assessments reported whereas the region has only 3.6% of the statewide population.
- Matanuska-Susitna Borough residents comprise only 5.3% of total assessments reported to DBH, despite the borough being the second largest population center in the state.

Table 20. Assessments by Behavioral Health Region, 1999-May 2020

Behavioral Health Region	Number of Assessments	% of Total	% of Statewide Population (2019)
Anchorage Municipality	818	27.8	39.9
Kenai Peninsula Borough	630	21.4	8.0
Fairbanks North Star Borough	362	12.3	13.1
Y-K Delta Region	294	10.0	3.6
City and Borough of Juneau	169	5.7	4.4
Matanuska-Susitna Borough	157	5.3	14.6
Other Interior Region	141	4.8	3.2
Other Southeast Region - Northern	116	3.9	2.8
Other Southeast Region - Southern	99	3.4	2.7
Northwest Region	69	2.3	3.8
Southwest Region	69	2.3	4.0
Unknown	23	0.8	-
Total	**2,947**	**100.0**	**100.0**

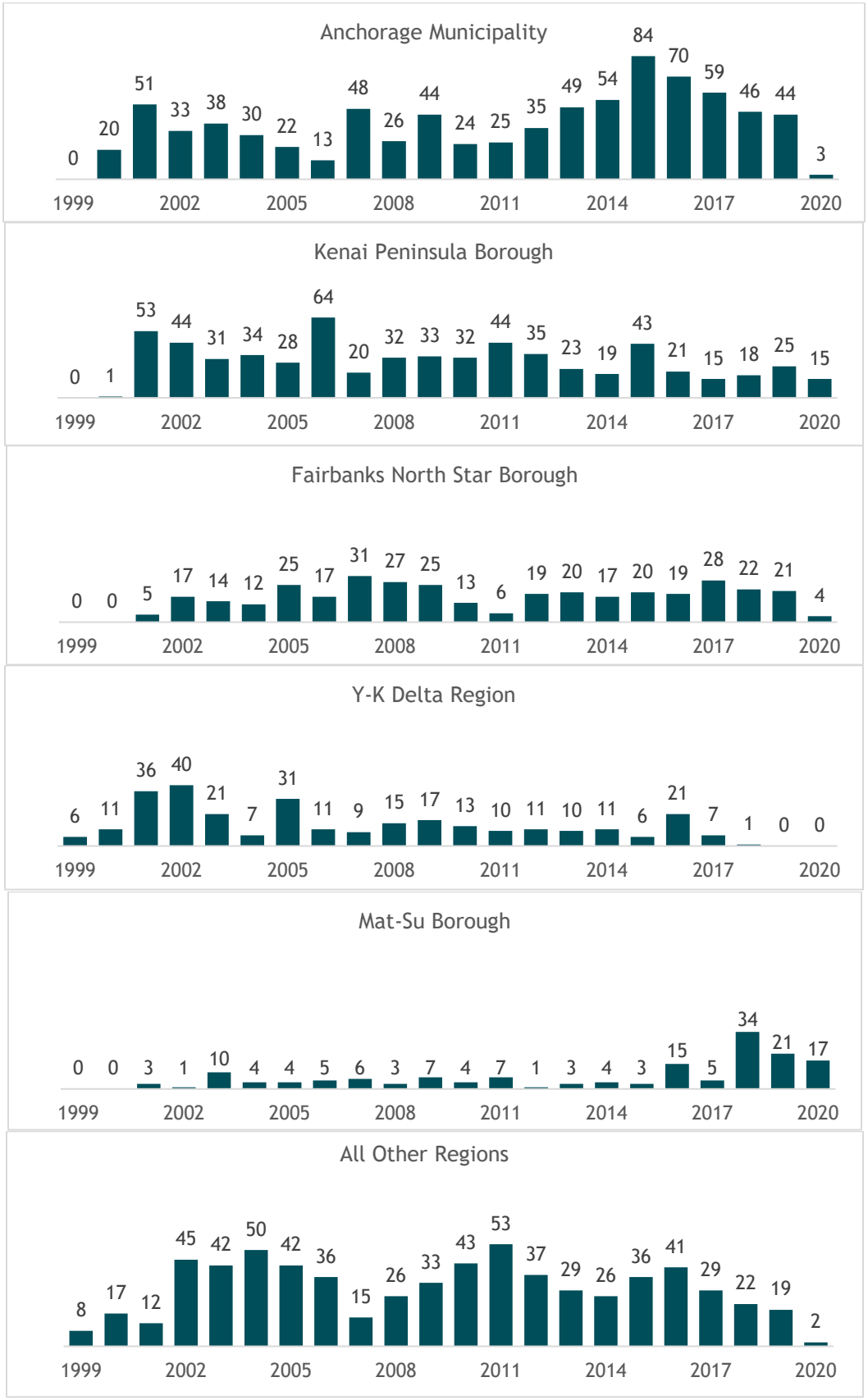
Note: Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; Alaska DOLWD, 2019; McDowell Group calculations.

Figure 3. Number of Assessments by Client Community



The figures (next page) display the number of annual assessments since 1999 by select behavioral health regions.

Figure 4. Number of Assessments by Behavioral Health Region, 1999-May 2020



Note: "All Other Regions" includes the City and Borough of Juneau, Northwest Region, Other Interior Region, Other Southeast Region – Northern, Other Southeast Region – Southern, and Southwest Region.
Source: Alaska DHSS Dataset, May 2020; Alaska DOLWD, 2019; McDowell Group calculations.

By Diagnostic Teams

- Three diagnostic teams composed about 70% of all assessments: FASDx Services (Municipality of Anchorage), Frontier Community Services (Kenai Peninsula Borough), and Alaska Center for Children and Adults (Fairbanks North Star Borough).

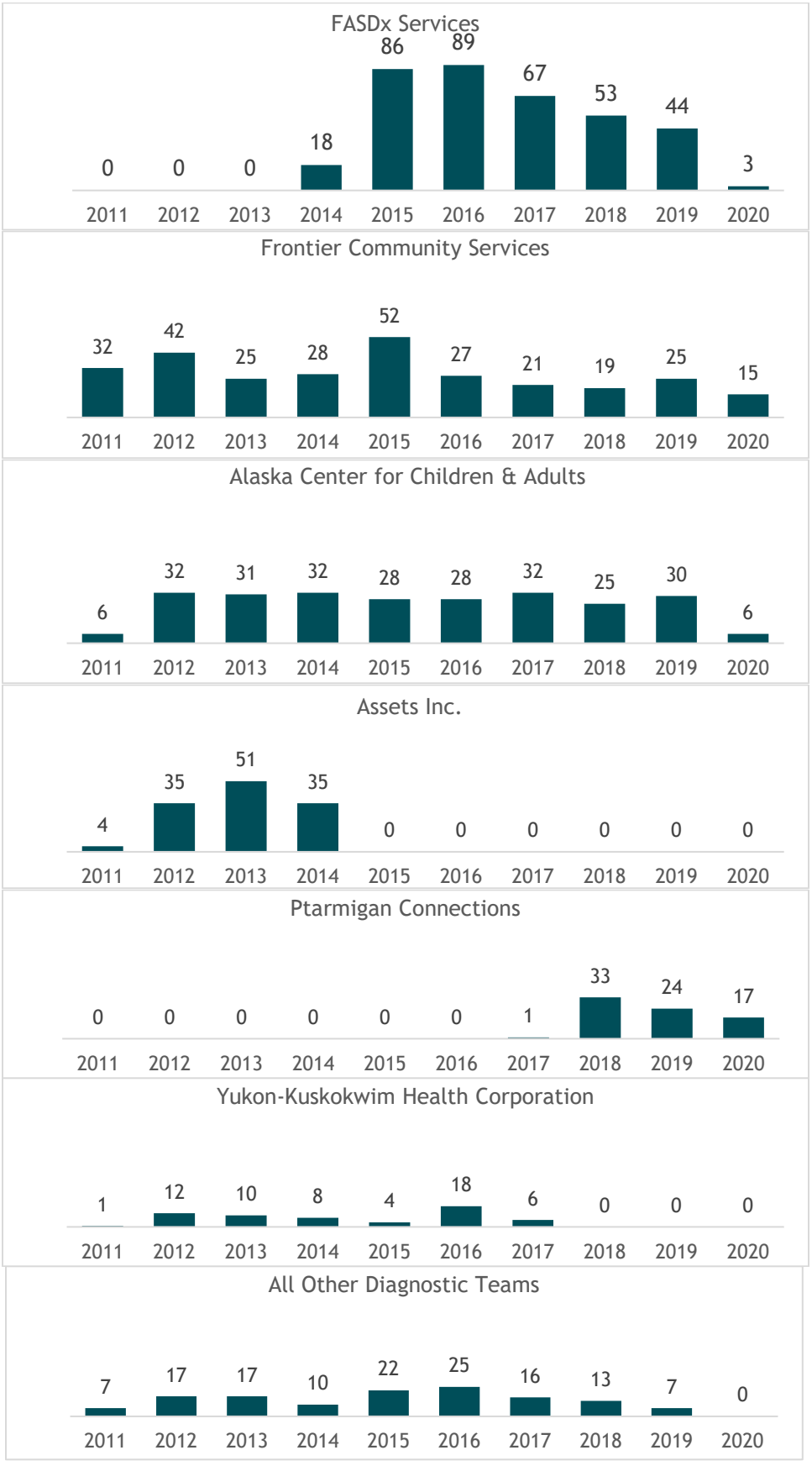
Table 21. Assessments by Diagnostic Team, July 2011-May 2020

Assessing Agency	Behavioral Health Region Served	Number of Assessments	% of Total
FASDx Services	Municipality of Anchorage	359	27.9
Frontier Community Services	Kenai Peninsula Borough	284	22.1
Alaska Center for Children & Adults	Fairbanks North Star Borough	250	19.4
Assets Inc.	Municipality of Anchorage	126	9.8
Ptarmigan Connections	Mat-Su Borough	75	5.8
Yukon-Kuskokwim Health Corporation	Yukon-Kuskokwim Delta Region	59	4.6
All Other	Juneau, Northwest, Other Interior, Other Southeast (Northern), Other Southeast (Southern), and Southwest Regions	133	10.4
Total		**1,286**	**100.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

The figures (next page) display the number of annual assessments since 2011 by Agencies/Diagnostic Teams.

Figure 5. Number of Assessments by Diagnostic Team, July 2011-May 2020



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

Diagnoses

By Diagnostic Outcome

- Out of 2,933 diagnoses made between 1999 and May 2020, the most common diagnostic outcomes are Static Encephalopathy/Alcohol Exposed (SE/AE) (32%) and Neurobehavioral Disorder/Alcohol Exposed (ND/AE) (26%).

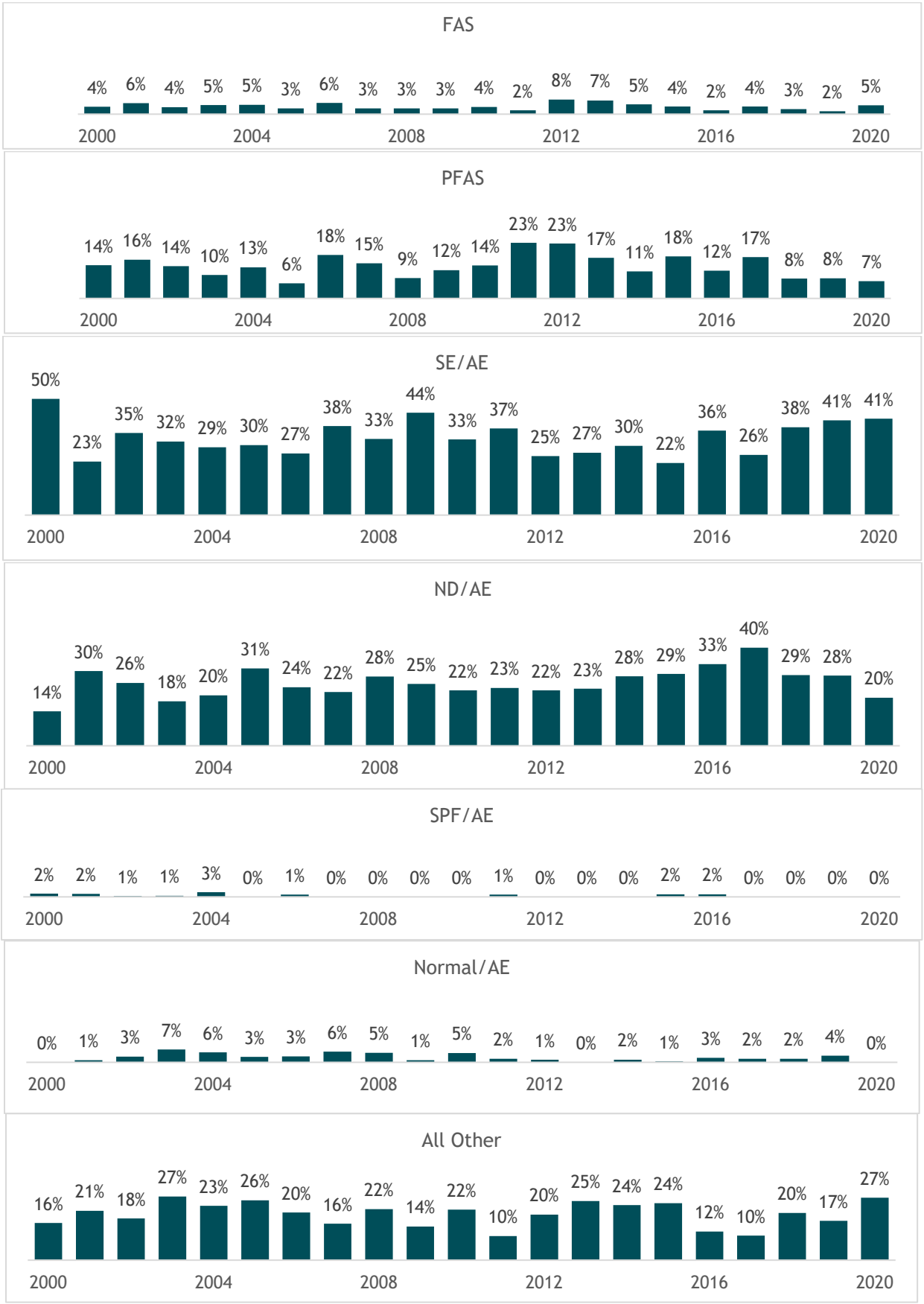
Table 22. Diagnoses by Group, 1999-May 2020

Diagnostic Group	Diagnoses	% of Total
FAS	123	4.2
PFAS	411	14.0
SE/AE	948	32.3
ND/AE	769	26.2
SPF/AE	20	0.7
Normal/AE	86	2.9
All other	572	19.5
Unknown	4	0.1
Total	**2,933**	**100.0**

Notes: Based on data available as of May 20, 2020. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

The figures (next page) display diagnostic outcomes between 2000 and May 2020.

Figure 6. Diagnosis by Diagnostic Outcome, 2000-May 2020

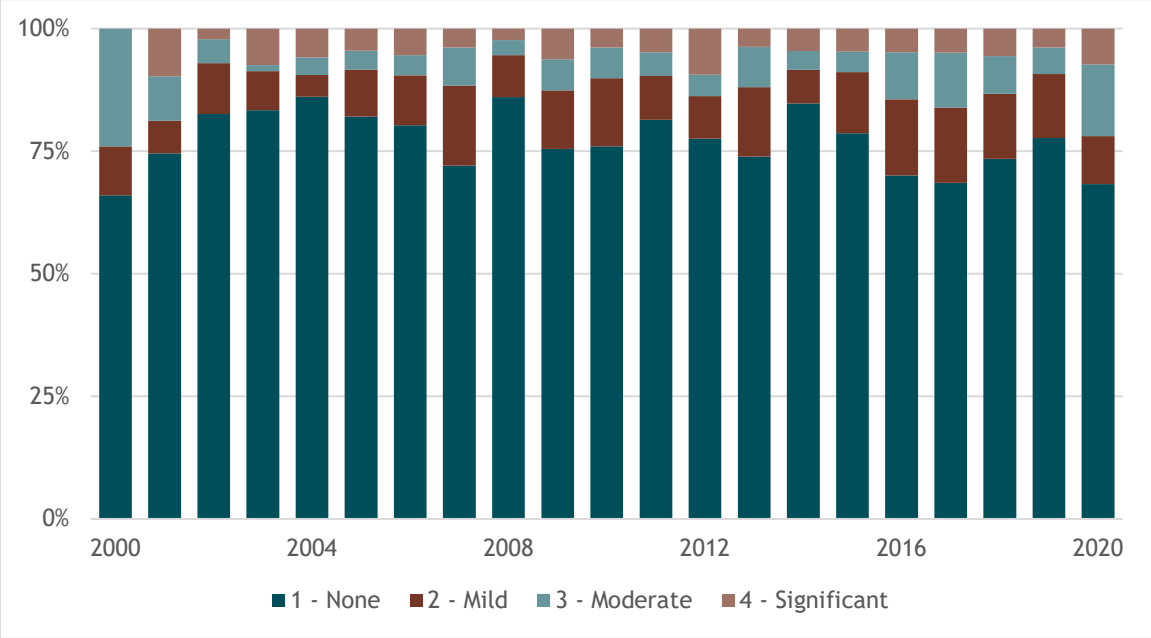


Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Growth Deficiency Score

- The figure below displays the proportion of assessed growth deficiency scores (1: None, 2: Mild, 3: Moderate, and 4: Significant) between 2000 and May 2020. The score of 1 is predominant, consistently representing most of all assessments.

Figure 7. Percent of Assessments by Growth Deficiency Score, 2000-May 2020

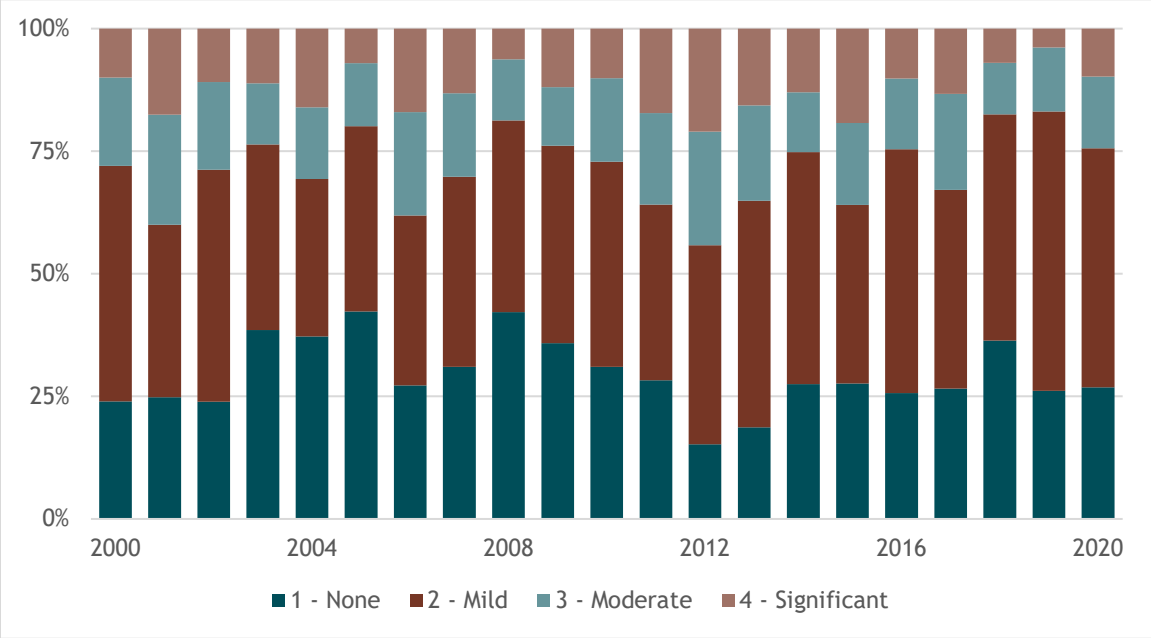


Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Facial Phenotype Score

- The figure below displays the proportion of assessed facial phenotype scores (1: None, 2: Mild, 3: Moderate, and 4: Significant) between 2000 and May 2020. The score of 2 is generally more predominant, followed by a score of 1.

Figure 8. Percent of Assessments by Facial Phenotype Score, 2000-May 2020

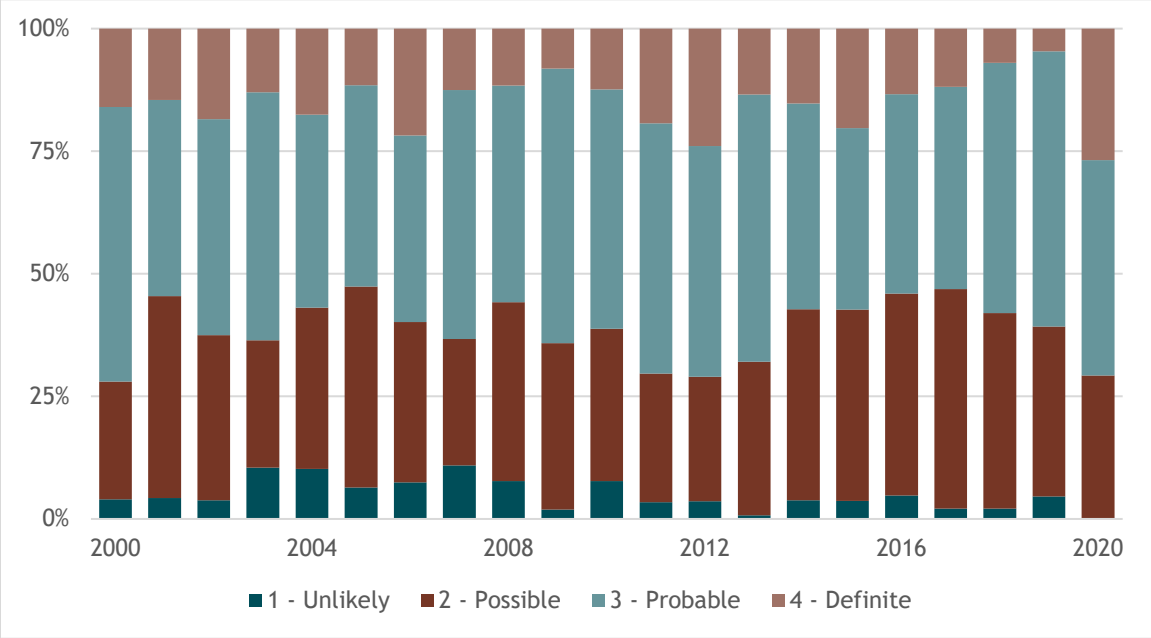


Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By CNS Function Score

- The figure below displays the proportion of assessed CNS function scores (1: Unlikely, 2: Possible, 3: Probable, and 4: Definite) between 2000 and May 2020. The score of 3 is usually predominant, followed by a score of 2.

Figure 9. Percent of Assessments by CNS Function Score, 2000-May 2020

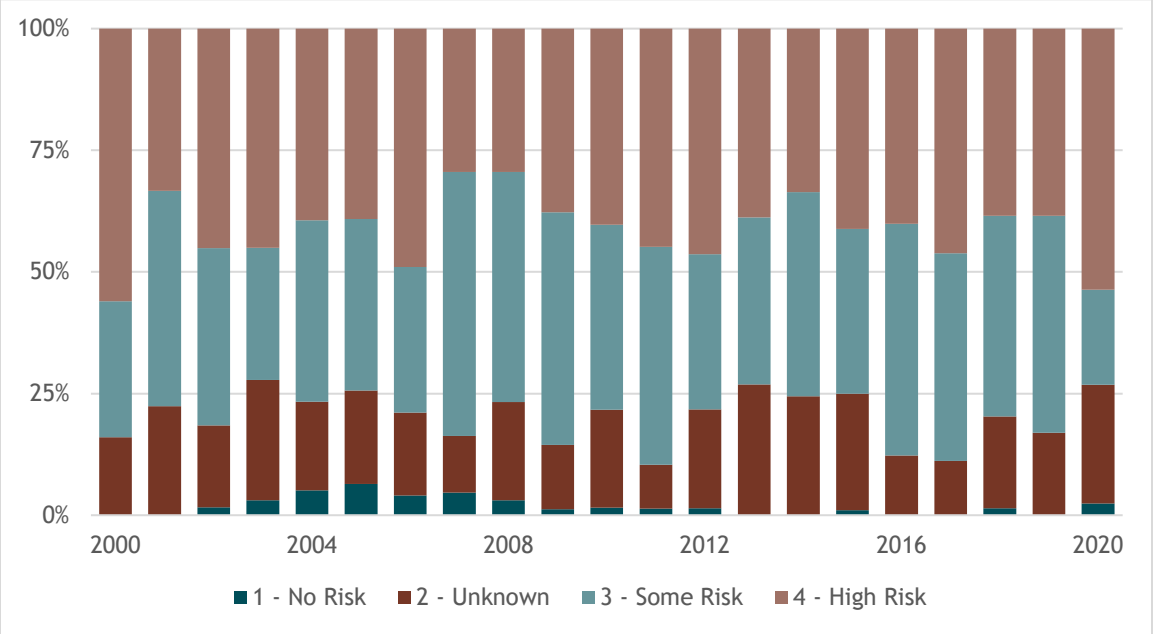


Notes: 1999 diagnoses excluded due to low number of assessments.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations

By Alcohol Exposure Score

- The figure below displays the proportion of assessed alcohol exposure scores (1: No risk, 2: Unknown, 3: Some risk, and 4: High risk) between 2000 and May 2020. The score of 4 is usually predominant, followed by a score of 3.

Figure 10. Percent of Assessments by Alcohol Exposure Score, 2000-May 2020



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations

By Age

- The most common diagnosis for clients between ages zero and 5 was ND/AE.
- For clients over age 5, the most common diagnosis was SE/AE.

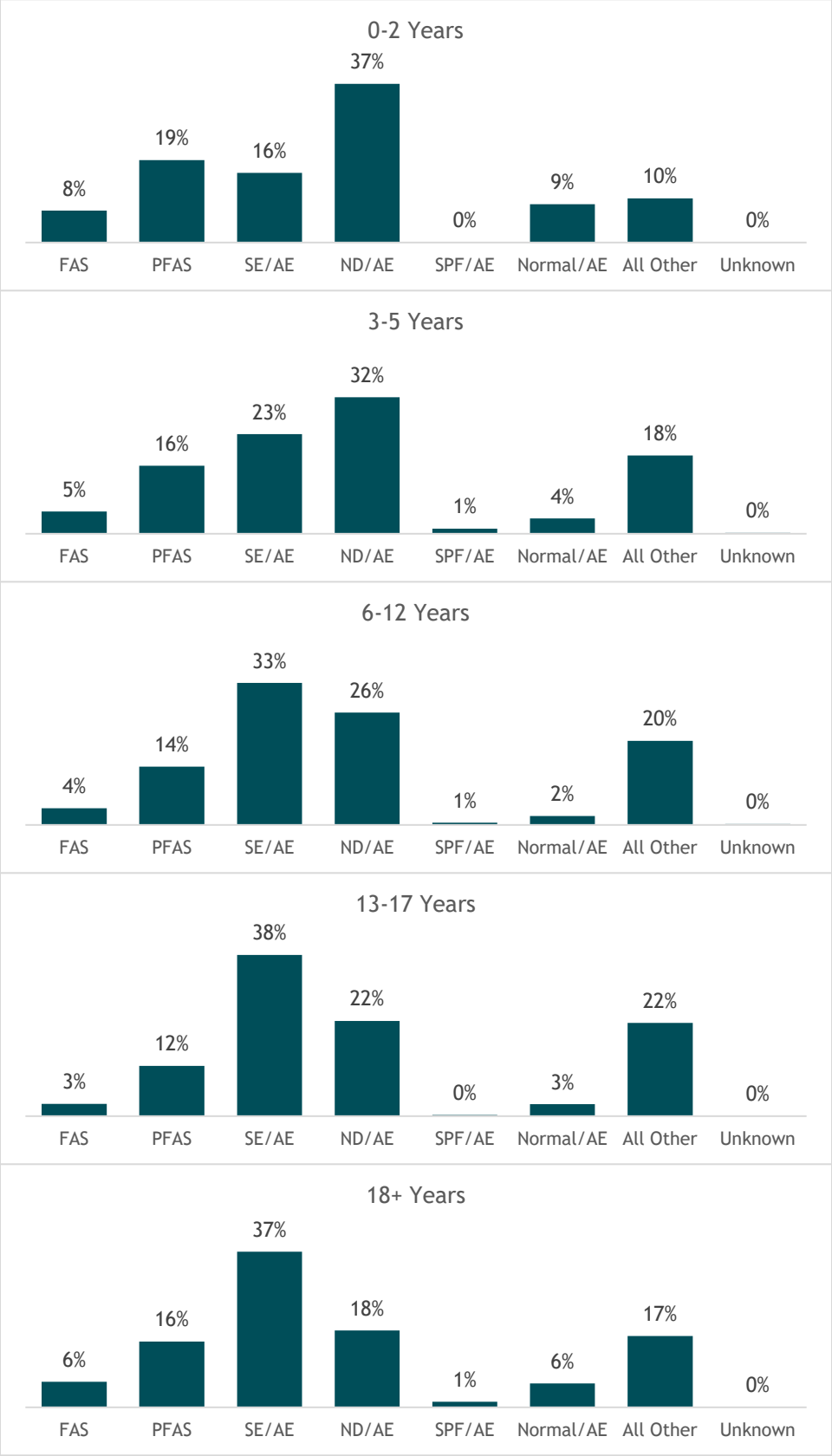
Table 23. FASD Diagnoses Categories by Age Range of Client at Diagnoses, 1999-May 2020

Diagnosis Category	Age 0-2		Age 3-5		Age 6-12		Age 13-17		Age 18+	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	5	7.5	29	5.2	57	3.9	18	2.9	14	6.0
PFAS	13	19.4	90	16.0	199	13.7	73	11.8	36	15.5
SE/AE	11	16.4	131	23.4	487	33.4	234	37.9	85	36.6
ND/AE	25	37.3	180	32.1	384	26.4	138	22.4	42	18.1
SPF/AE	0	0.0	7	1.2	8	0.5	2	0.3	3	1.3
Normal/AE	6	9.0	20	3.6	30	2.1	17	2.8	13	5.6
All Other	7	10.4	103	18.4	288	19.8	135	21.9	39	16.8
Unknown	0	0.0	1	0.2	3	0.2	0	0.0	0	0.0
Total	**67**	**100.0**	**561**	**100.0**	**1,456**	**100.0**	**617**	**100.0**	**232**	**100.0**

Notes: Gold highlighted cells denote top two diagnosis categories for each age group. If an individual had multiple diagnoses, the most recent diagnosis was used in analyzing diagnoses data. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations

The figures (next page) display the type of diagnostic outcomes by age between 1999 and May 2020.

Figure 11. FASD Diagnoses Categories by Age Range of Client at Diagnoses, 1999-May 2020



Notes: If an individual had multiple diagnoses, the most recent diagnosis was used in analyzing diagnoses data.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Gender

- SE/AE and ND/AE were the most common diagnosis categories for male and female clients.

Table 24. Diagnoses by Gender, 1999-May 2020

Diagnostic Group	Male		Female	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	74	4.4	49	3.9
PFAS	251	14.9	160	12.9
SE/AE	590	35.0	358	28.8
ND/AE	408	24.2	361	29.0
SPF/AE	8	0.5	12	1.0
Normal/AE	35	2.1	51	4.1
All Other	320	19.0	252	20.2
Unknown	2	0.1	2	0.2
Total	**1,688**	**100.0**	**1,245**	**100.0**

Notes: Gold highlighted cells denote top two diagnosis categories for each gender. If an individual had multiple diagnoses, the most recent diagnosis was used in analyzing diagnoses data. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Race/Ethnicity

- The most prevalent diagnostic outcomes varied by the client's race.
- The most common diagnoses for white clients was SE/AE (30.0%) and PFAS (22.9%), while ND/AE (34.6%) and SE/AE (30.0%) were most common for Alaska Native/American Indian clients.

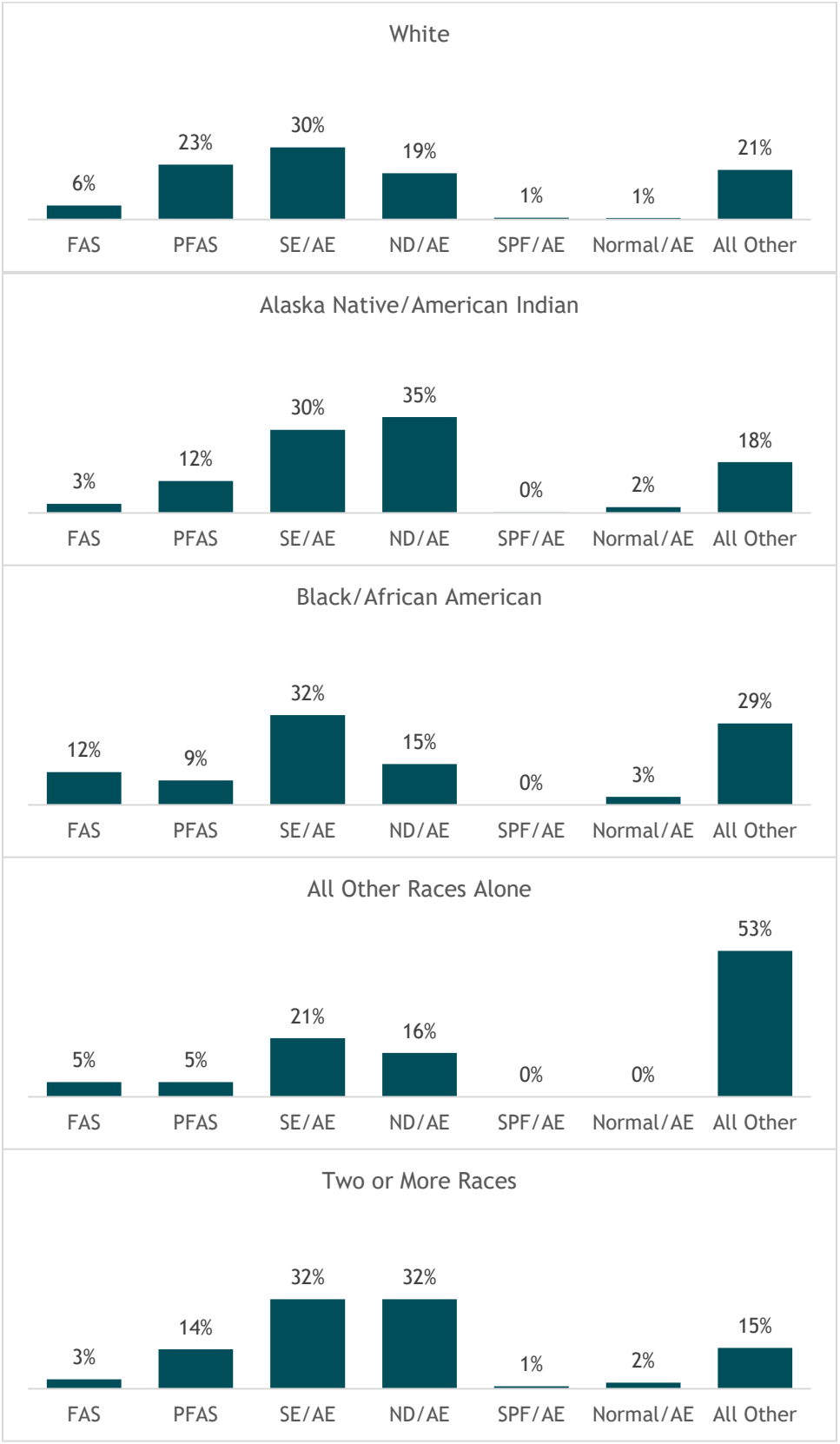
Table 25. Diagnoses by Race, July 2011-May 2020

Diagnostic Group	White (alone)		Black/African American (alone)		Alaska Native/American Indian (alone)		All Other Races (alone)		Two or More Races		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	21	5.8	4	11.8	20	3.3	1	5.3	8	3.4	0	0.0
PFAS	83	22.9	3	8.8	70	11.5	1	5.3	33	14.2	6	31.6
SE/AE	109	30.0	11	32.4	182	30.0	4	21.1	75	32.3	10	52.6
ND/AE	70	19.3	5	14.7	210	34.6	3	15.8	75	32.3	2	10.5
SPF/AE	3	0.8	0	0.0	1	0.2	0	0.0	2	0.9	0	0.0
Normal/AE	2	0.6	1	2.9	13	2.1	0	0.0	5	2.2	0	0.0
All Other	75	20.7	10	29.4	111	18.3	10	52.6	34	14.7	1	5.3
Total	**363**	**100.0**	**34**	**100.0**	**607**	**100.0**	**19**	**100.0**	**232**	**100.0**	**19**	**100.0**

Notes: "All other races (alone)" includes Asian, Native Hawaiians and Pacific Islanders. Gold highlighted cells denote top two diagnosis categories for each race. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

The figures below display the type of diagnostic outcomes by race between July 2011 and May 2020.

Figure 12. Diagnoses by Race, July 2011-May 2020



Note: "All Other Races Alone" includes Asian, Native Hawaiians and Pacific Islanders.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- The most common diagnoses types for Spanish/Hispanic/Latino/Mexican clients were SE/AE (34%) and PFAS (25%), while SE/AE (30%) and ND/AE (29%) were most common for clients not of Spanish/Hispanic/Latino/Mexican heritage.

Table 26. Diagnoses by Ethnicity, July 2011-May 2020

Diagnostic Group	Not Spanish/Hispanic/Latino/Mexican		Spanish/Hispanic/ Latino/Mexican		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	50	4.3	1	1.3	3	6.2
PFAS	171	14.9	19	25.0	6	12.5
SE/AE	348	30.3	26	34.2	17	35.4
ND/AE	333	29.0	16	21.1	16	33.3
SPF/AE	6	0.5	0	0.0	0	0.0
Normal/AE	18	1.6	1	1.3	2	4.2
All Other	224	19.5	13	17.1	4	8.3
Total	**1,150**	**100.0**	**76**	**100.0**	**48**	**100.0**

Note: Gold highlighted cells denote top two diagnosis categories for each ethnicity. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Living Arrangement

- SE/AE and ND/AE were the most common diagnostic outcomes across clients living with biological or adoptive parents, in other family placements, foster homes, residential treatment, and juvenile justice facilities.
- A higher percentage of those living independently (who were all adult clients) had a PFAS diagnosis (27%).

Table 27. Diagnoses by Living Arrangement, July 2011-May 2020

Diagnostic Group	Biological / Adoptive Parents or Legal Guardian		Other Family Placement		Foster Home		Residential Treatment		Juvenile Justice Facility		Self/independent		Other	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	34	4.7	1	1.6	13	3.5	0	0.0	0	0.0	3	11.5	3	8.8
PFAS	108	14.9	11	17.5	59	16.0	4	9.5	2	15.4	7	26.9	5	14.7
SE/AE	233	32.0	16	25.4	99	26.8	19	45.2	5	38.5	8	30.8	11	32.4
ND/AE	203	27.9	20	31.7	118	32.0	13	31.0	3	23.1	5	19.2	3	8.8
SPF/AE	2	0.3	1	1.6	3	0.8	0	0.0	0	0.0	0	0.0	0	0.0
Normal/AE	9	1.2	0	0.0	9	2.4	0	0.0	0	0.0	0	0.0	3	8.8
All Other	138	19.0	14	22.2	68	18.4	6	14.3	3	23.1	3	11.5	9	26.5
Total	**727**	**100.0**	**63**	**100.0**	**369**	**100.0**	**42**	**100.0**	**13**	**100.0**	**26**	**100.0**	**34**	**100.0**

Notes: "All Other" living arrangements include clients living in a receiving home or runaway shelter. Gold highlighted cells denote top two diagnosis categories for each living arrangement type. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Diagnostic outcomes did not vary based on client placement. The most common diagnoses were SE/AE and ND/AE.
- For clients with an unknown out-of-home placement, SE/AE and "All Other" were the most common diagnoses types.

Table 28. Diagnoses by Out-of-Home Placements, July 2011-May 2020

Diagnostic Group	Yes - Out-of-Home Placement		No - No Out-of-Home Placement		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	36	3.4	15	7.3	3	16.7
PFAS	172	16.4	22	10.7	2	11.1
SE/AE	324	30.8	62	30.2	5	27.8
ND/AE	300	28.5	62	30.2	3	16.7
SPF/AE	6	0.6	0	0.0	0	0.0
Normal/AE	20	1.9	1	0.5	0	0.0
All Other	193	18.4	43	21.0	5	27.8
Total	**1,051**	**100.0**	**205**	**100.0**	**18**	**100.0**

Notes: Gold highlighted cells denote top two diagnosis categories by home placement. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Primary Caregiver

- The most common diagnoses with nearly all primary caregiver types were SE/AE and ND/AE.
- A higher percentage of those whose primary caregiver was both biological parents (36%) were diagnosed with an All Other diagnosis compared to clients with different primary caregiver types.

(See table next page.)

Table 29. Diagnoses by Primary Caregiver, 2003-May 2020

Diagnostic Group	Both Biological Parents		Biological Mother Only		Biological Father Only		Adoptive Parents/ Legal Guardian		Foster Parent(s)	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	1	0.9	3	1.6	5	2.6	55	5.5	25	3.5
PFAS	18	16.5	29	15.3	24	12.6	131	13.0	108	15.1
SE/AE	23	21.1	61	32.1	76	39.8	334	33.2	213	29.7
ND/AE	26	23.9	54	28.4	51	26.7	265	26.4	198	27.7
SPF/AE	0	0.0	1	0.5	1	0.5	3	0.3	7	1.0
Normal/AE	2	1.8	9	4.7	7	3.7	19	1.9	28	3.9
All Other	39	35.8	33	17.4	26	13.6	196	19.5	137	19.1
Unknown	0	0.0	0	0.0	1	0.5	2	0.2	0	0.0
Total	**109**	**100.0**	**190**	**100.0**	**191**	**100.0**	**1,005**	**100.0**	**716**	**100.0**

Diagnostic Group	Social Service Agency		Self		Other Family		Other		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	3	4.2	5	5.6	5	3.9	1	1.9	1	7.1
PFAS	8	11.3	18	20.2	22	17.2	3	5.7	2	14.3
SE/AE	22	31.0	29	32.6	36	28.1	28	52.8	2	14.3
ND/AE	15	21.1	15	16.9	36	28.1	10	18.9	5	35.7
SPF/AE	2	2.8	0	0.0	1	0.8	0	0.0	0	0.0
Normal/AE	5	7.0	6	6.7	2	1.6	1	1.9	1	7.1
All Other	16	22.5	16	18.0	26	20.3	10	18.9	3	21.4
Unknown	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Total	**71**	**100.0**	**89**	**100.0**	**128**	**100.0**	**53**	**100.0**	**14**	**100.0**

Notes: Gold highlighted cells denote top two diagnosis categories for each primary caregiver type. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Sibling Characteristics

- The most common outcome types did not vary based on the client having biological siblings. However, a higher percentage of clients where it was unknown if a client had biological siblings had an All Other diagnosis.

Table 30. Diagnoses by Biological Siblings, July 2011-May 2020

Diagnostic Group	Yes - Biological Siblings		No - No Biological Siblings		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	37	3.8	3	4.1	14	6.4
PFAS	149	15.2	12	16.2	35	16.1
SE/AE	290	29.5	24	32.4	77	35.3
ND/AE	301	30.7	26	35.1	38	17.4
SPF/AE	3	0.3	2	2.7	1	0.5
Normal/AE	19	1.9	0	0.0	2	0.9
All Other	183	18.6	7	9.5	51	23.4
Total	**982**	**100.0**	**74**	**100.0**	**218**	**100.0**

Note: Gold highlighted cells denote top two diagnosis categories for sibling relationships. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Among clients with known biological siblings, the average number of siblings was highest for clients diagnosed with an All Other diagnosis (3.32 siblings) and was lowest for those diagnosed with FAS (1.88 siblings).

Table 31. Average and Median Number of Siblings by Client Diagnoses, July 2011-May 2020 (Base: Clients with Known Biological Siblings)

Diagnostic Group	Average Number of Biological Siblings	Median Number of Biological Siblings
FAS	1.88	1.5
PFAS	2.69	2.0
SE/AE	2.84	2.0
ND/AE	3.04	2.0
SPF/AE	3.00	3.0
Normal/AE	3.13	3.0
All Other	3.32	3.0
Total	**2.93**	**1.0**

Note: Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- SE/AE and ND/AE were the most common diagnosis types regardless of having a known biological sibling with an FAS diagnosis.

Table 32. Clients with Known Biological Siblings Diagnosed with FAS by Client Diagnoses, July 2011-May 2020
(Base: Clients with Known Biological Siblings)

Diagnostic Group	Yes - Biological Siblings Diagnosed with FAS		No - No Biological Siblings with FAS Diagnosis		Unknown if Any Biological Siblings have FAS Diagnosis	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	11	3.6	8	3.4	18	4.0
PFAS	71	23.5	32	13.7	46	10.3
SE/AE	75	24.8	71	30.3	144	32.3
ND/AE	94	31.1	69	29.5	138	30.9
SPF/AE	2	0.7	1	0.4	0	0.0
Normal/AE	6	2.0	5	2.1	8	1.8
All Other	43	14.2	48	20.5	92	20.6
Total	**302**	**100.0**	**234**	**100.0**	**446**	**100.0**

Note: Gold highlighted cells denote top two diagnosis categories for each sibling by FASD diagnoses. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- On average, clients diagnosed with a Normal/AE diagnosis have the highest number of known biological siblings with an FAS diagnosis (3.00).
- Clients diagnosed with FAS have the lowest average number of siblings with an FAS diagnosis (1.30).

Table 33. Average and Median Number of Siblings with FAS Diagnosis by Client Diagnoses, July 2011-May 2020
(Base: Clients with Known Biological Siblings)

Diagnostic Group	Average Number of Siblings with an FAS Diagnosis	Median Number of Siblings with an FAS Diagnosis
FAS	1.30	1.0
PFAS	2.20	1.0
SE/AE	1.86	1.0
ND/AE	1.73	1.0
SPF/AE	2.00	2.0
Normal/AE	3.00	2.0
All Other	2.08	2.0
Total	**1.93**	**1.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Among clients with at least one known biological sibling with an FAS diagnosis, those diagnosed as Normal/AE on average had the highest number of older siblings diagnosed with FAS (3.33 siblings) while those diagnosed with FAS had the lowest number of older siblings (1.33).

Table 34. Average and Median Number of Older Siblings with FAS Diagnosis by Client Diagnoses, July 2011-May 2020
(Base: Clients with Known Biological Siblings with an FAS Diagnosis)

Diagnostic Group	Average Number of Older Siblings with an FAS Diagnosis	Median Number of Older Siblings with an FAS Diagnosis
FAS	1.33	1.0
PFAS	1.95	1.0
SE/AE	1.69	1.0
ND/AE	1.58	1.0
SPF/AE	1.00	1.0
Normal/AE	3.33	1.0
All Other	1.39	1.0
Total	**1.67**	**1.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

- Among clients with at least one siblings with an FAS diagnosis, those diagnosed with an All Other diagnosis on average had the highest number of younger siblings diagnosed with FAS (2.05 siblings) while those diagnosed with ND/AE had the lowest (1.36).

Table 35. Average and Median Number of Younger Siblings with FAS Diagnosis by Client Diagnoses, July 2011-May 2020
(Base: Clients with Known Biological Siblings with an FAS Diagnosis)

Diagnostic Group	Average Number of Younger Siblings with an FAS Diagnosis	Median Number of Younger Siblings with an FAS Diagnosis
FAS	1.67	2.0
PFAS	1.50	1.0
SE/AE	1.57	1.0
ND/AE	1.36	1.0
SPF/AE	2.00	2.0
Normal/AE	1.67	2.0
All Other	2.05	1.5
Total	**1.56**	**1.0**

Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Referral

- Diagnosis outcomes did not vary greatly by the type of person or organization who referred the client for assessment.
- The most common diagnoses by nearly all referral group categories were SE/AE and ND/AE.

Table 36. Diagnoses by Referral Person/Organization, 1999-May 2020

Diagnostic Group	Parent(s) or Foster Parents		Medical Provider		Mental Health Provider		Probation Office		OCS	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	36	5.2	16	3.7	7	3.3	14	3.3	13	2.9
PFAS	90	12.9	48	11.0	22	10.5	62	14.5	78	17.3
SE/AE	257	36.9	169	38.6	82	39.2	111	26.0	103	22.8
ND/AE	171	24.6	91	20.8	54	25.8	120	28.1	153	33.9
SPF/AE	1	0.1	2	0.5	1	0.5	6	1.4	4	0.9
Normal/AE	17	2.4	14	3.2	6	2.9	17	4.0	8	1.8
All Other	120	17.2	98	22.4	37	17.7	97	22.7	92	20.4
Unknown	4	0.6	0	0.0	0	0.0	0	0.0	0	0.0
Total	**696**	**100.0**	**438**	**100.0**	**209**	**100.0**	**427**	**100.0**	**451**	**100.0**

Diagnostic Group	School		Self		Other		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	16	4.4	3	7.3	15	5.5	3	8.6
PFAS	51	14.1	5	12.2	50	18.2	5	14.3
SE/AE	116	32.1	17	41.5	81	29.5	12	34.3
ND/AE	92	25.5	9	22.0	68	24.7	11	31.4
SPF/AE	5	1.4	0	0.0	1	0.4	0	0.0
Normal/AE	13	3.6	4	9.8	6	2.2	1	2.9
All Other	68	18.8	3	7.3	54	19.6	3	8.6
Unknown	0	0.0	0	0.0	0	0.0	0	0.0
Total	**361**	**100.0**	**41**	**100.0**	**275**	**100.0**	**35**	**100.0**

Notes: Gold highlighted cells denote top two diagnosis categories for each referral person/organization type. If an individual had multiple diagnoses, the most recent diagnosis was used in analyzing diagnoses data. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Behavioral Health Region

- In most behavioral health regions, SE/AE and ND/AE are the most common diagnoses outcomes.
- Over half (56%) of clients who were residents of the *Other Southeast Region – Northern* region had a diagnosis of All Other.

Table 37. Diagnoses by Behavioral Health Region, 1999-May 2020

Diagnostic Group	Anchorage Municipality		City and Borough of Juneau		Fairbanks North Star Borough		Kenai Peninsula Borough		Matanuska-Susitna Borough		Northwest Region	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	%	# of Diagnoses	% of Total	# of Diagnoses	%	# of Diagnoses	% of Total
FAS	33	4.1	1	0.6	19	5.3	44	7.0	5	3.2	2	2.9
PFAS	59	7.2	3	1.8	54	15.0	179	28.4	15	9.6	6	8.7
SE/AE	330	40.5	68	40.2	106	29.5	139	22.1	60	38.5	29	42.0
ND/AE	214	26.3	64	37.9	142	39.6	92	14.6	34	21.8	25	36.2
SPF/AE	3	0.4	0	0.0	2	0.6	11	1.7	0	0.0	0	0.0
Normal/AE	22	2.7	5	3.0	4	1.1	22	3.5	7	4.5	2	2.9
All Other	153	18.8	28	16.6	31	8.6	142	22.5	34	21.8	5	7.2
Unknown	0	0.0	0	0.0	1	0.3	1	0.2	1	0.6	0	0.0
Total	**814**	**100.0**	**169**	**100.0**	**359**	**100.0**	**630**	**100.0**	**156**	**100.0**	**69**	**100.0**

Diagnostic Group	Other Interior Region		Other Southeast Region - Northern		Other Southeast Region - Southern		Southwest Region		Y-K Delta Region		Unknown	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	8	5.7	2	1.7	0	0.0	1	1.4	6	2.0	2	8.7
PFAS	26	18.4	3	2.6	9	9.5	16	23.2	37	12.6	4	17.4
SE/AE	54	38.3	19	16.5	35	36.8	27	39.1	72	24.6	9	39.1
ND/AE	33	23.4	19	16.5	36	37.9	14	20.3	93	31.7	3	13.0
SPF/AE	0	0.0	1	0.9	1	1.1	0	0.0	2	0.7	0	0.0
Normal/AE	4	2.8	7	6.1	1	1.1	0	0.0	11	3.8	1	4.3
All Other	15	10.6	64	55.7	13	13.7	11	15.9	72	24.6	4	17.4
Unknown	1	0.7	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Total	**141**	**100.0**	**115**	**100.0**	**95**	**100.0**	**69**	**100.0**	**293**	**100.0**	**23**	**100.0**

Notes: Gold highlighted cells denote top two diagnosis categories for each region. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

By Diagnostic Team

- SE/AE was the first or second highest diagnosed category for all diagnostic teams, except the Yukon Kuskokwim Health Corporation.

Table 38. Diagnoses by Diagnostic Team, July 2011-May 2020

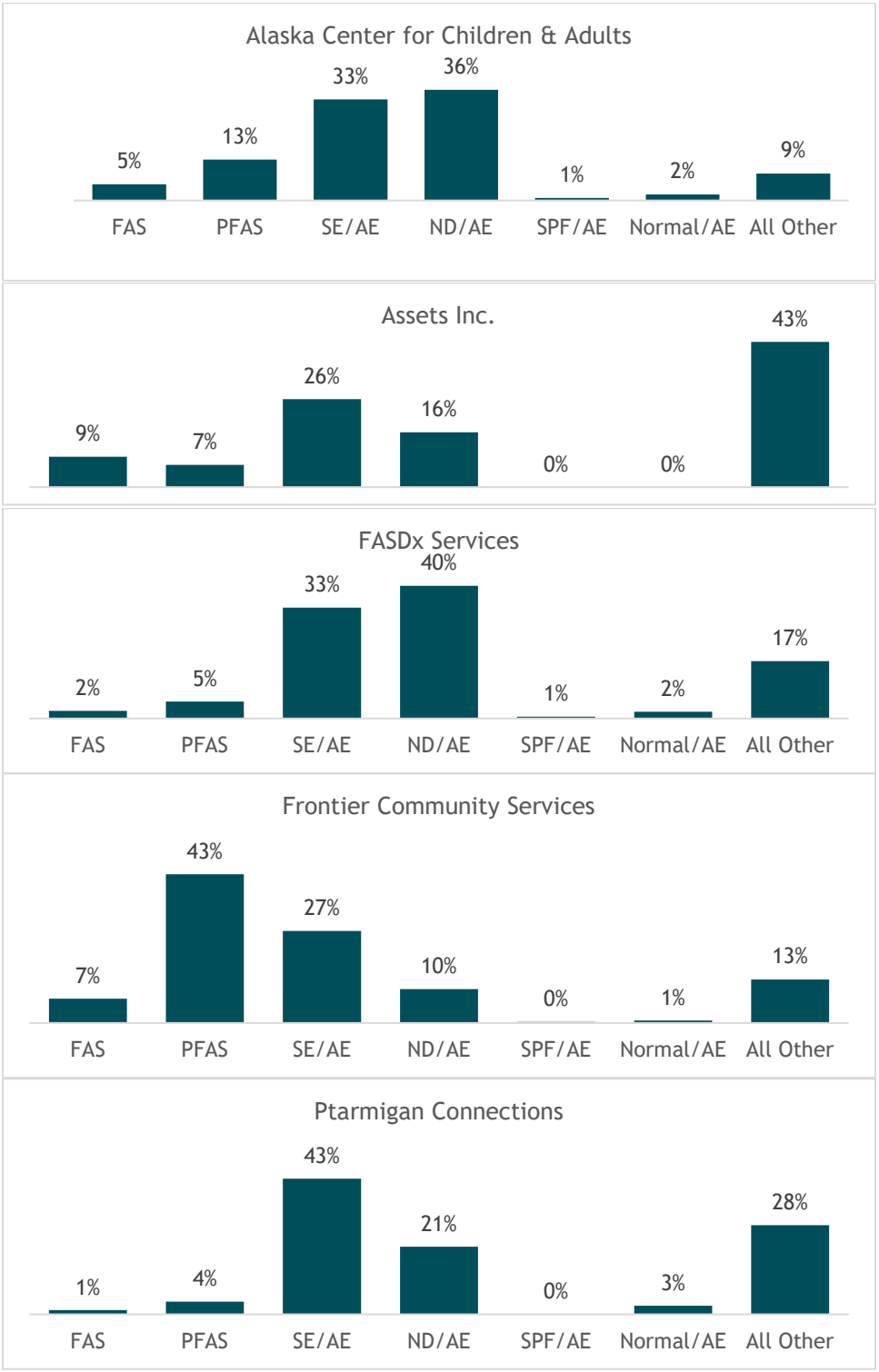
Diagnostic Team	Alaska Center for Children & Adults		Assets Inc.		FASDx Services		Frontier Community Services	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	13	5.3	11	8.9	8	2.3	20	7.0
PFAS	33	13.4	8	6.5	18	5.1	123	43.0
SE/AE	82	33.2	32	25.8	117	33.0	76	26.6
ND/AE	90	36.4	20	16.1	142	40.0	28	9.8
SPF/AE	2	0.8	0	0.0	2	0.6	1	0.3
Normal/AE	5	2.0	0	0.0	7	2.0	2	0.7
All Other	22	8.9	53	42.7	61	17.2	36	12.6
Total	**247**	**100.0**	**124**	**100.0**	**355**	**100.0**	**286**	**100.0**

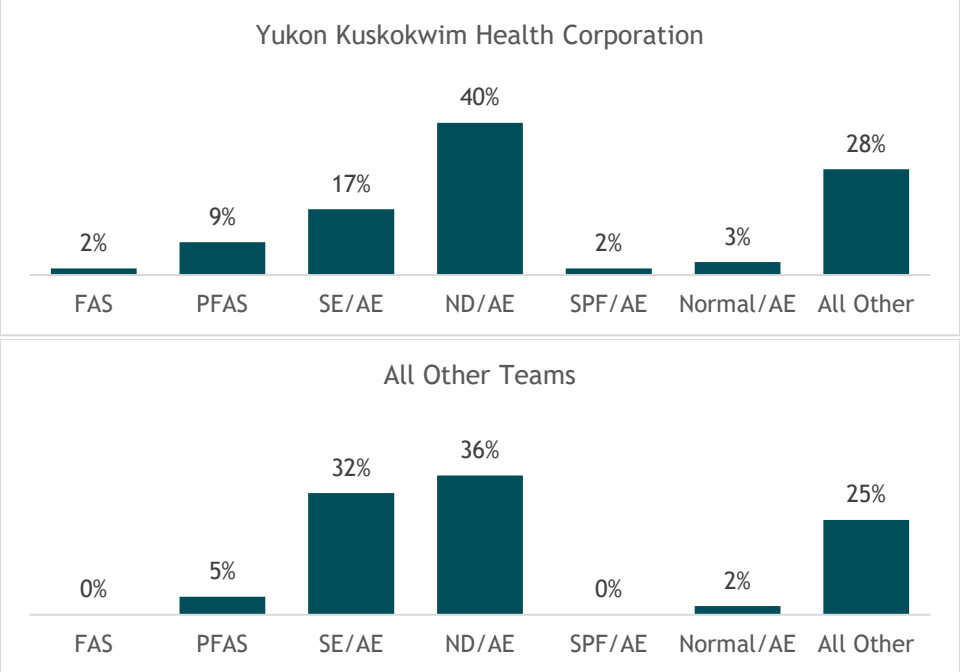
Diagnostic Team	Ptarmigan Connections		Yukon Kuskokwim Health Corporation		All Other Diagnostic Teams	
	# of Diagnoses	% of Total	# of Diagnoses	% of Total	# of Diagnoses	% of Total
FAS	1	1.3	1	1.7	0	0.0
PFAS	3	4.0	5	8.6	6	4.7
SE/AE	32	42.7	10	17.2	41	31.8
ND/AE	16	21.3	23	39.7	47	36.4
SPF/AE	0	0.0	1	1.7	0	0.0
Normal/AE	2	2.7	2	3.4	3	2.3
All Other	21	28.0	16	27.6	32	24.8
Total	**75**	**100.0**	**58**	**100.0**	**129**	**100.0**

Notes: "All Other Diagnostic Teams" includes seven additional teams. Gold highlighted cells denote top two diagnosis categories for each diagnostic team. Due to rounding, some columns may not add to 100%.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculations.

The figures below display the type of diagnostic outcomes by diagnostic team between July 2011 and May 2020.

Figure 13. Diagnoses by Diagnostic Team, July 2011-May 2020





Note: "All Other Teams" includes seven additional teams.
Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation

Comparison with University of Washington FASDPN Data

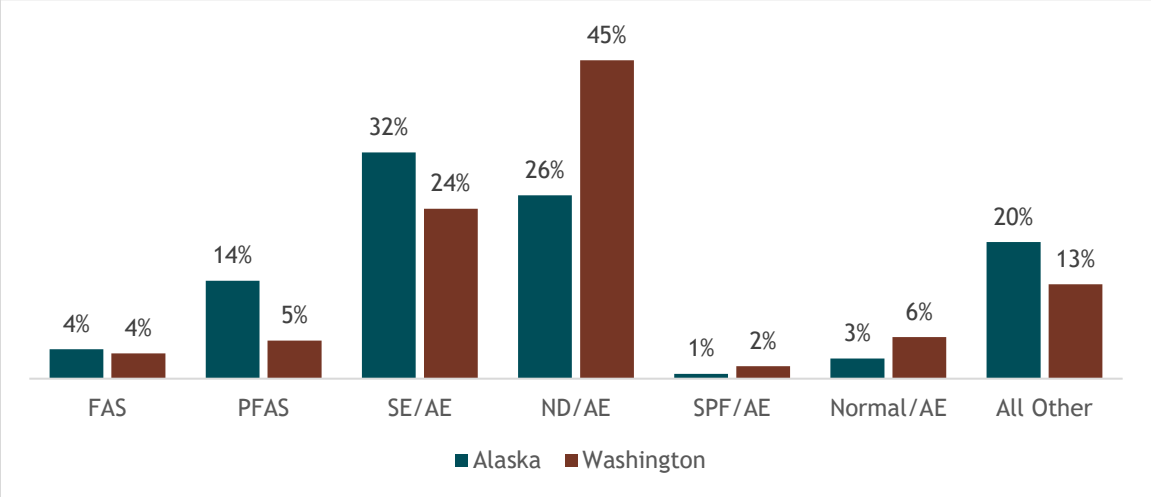
The figures below provide a comparison of Alaska's FASD diagnostic team data (1999-May 2020) with the University of Washington FASDPN data (1993-2016) and by 4-digit code ranks and diagnoses by age and gender.

By Diagnostic Outcome

- A lower percentage of people assessed in Alaska were diagnosed with an ND/AE diagnosis (26%) compared to Washington clients (45%).
- Conversely, a higher percentage of Alaska clients were diagnosed with an SE/AE diagnosis (32%) compared to Washington clients (24%).
- These differences between SE/AE and ND/AE diagnoses in Alaska and Washington persist throughout age ranges and gender (see sections below).

The figures (next page) display the comparison of diagnostic outcomes between Alaska and Washington clients.

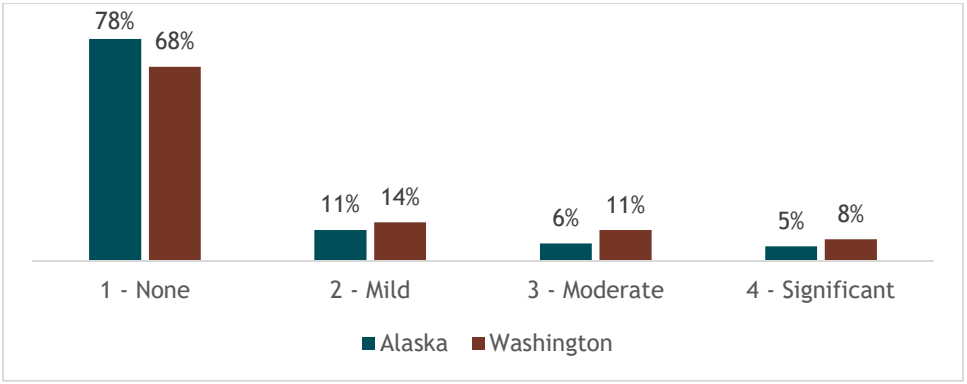
Figure 14. FASD Diagnostic Outcome Comparison, Alaska (1999-May 2020) and Washington (1993-2016)



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

By Growth Deficiency Score

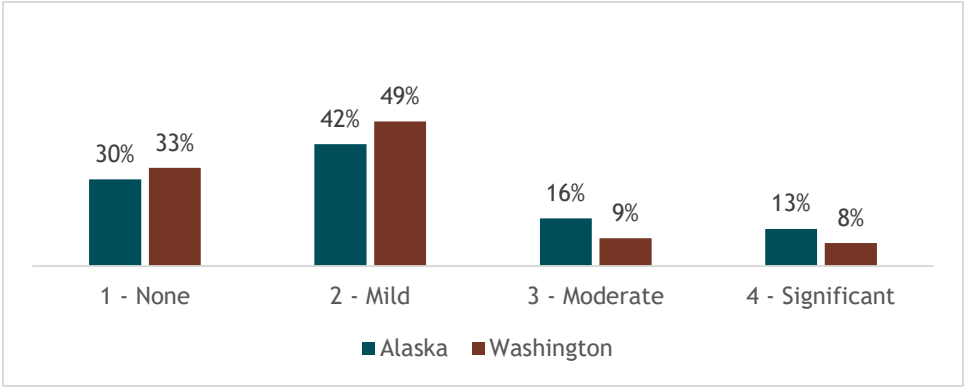
Figure 15. Growth Deficiency Score Comparison, Alaska (1999-May 2020) and Washington (1993-2016)



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

By Facial Phenotype Score

Figure 16. Facial Phenotype Score Comparison, Alaska (1999-May 2020) and Washington (1993-2016)

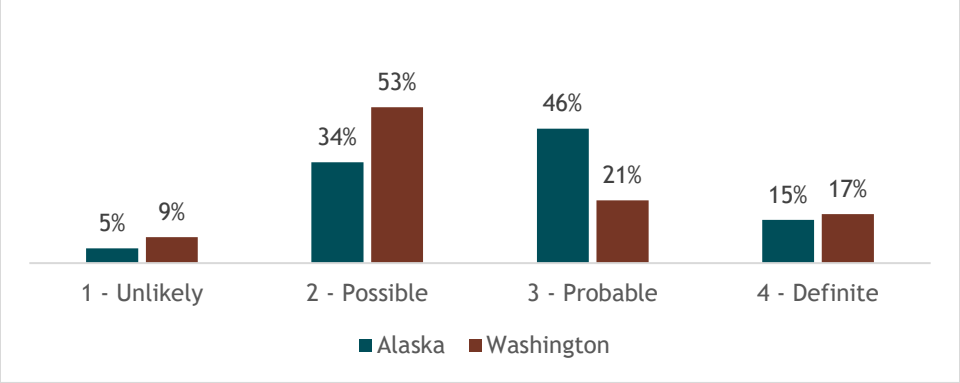


Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

By CNS Function Score

- A higher percentage of Alaska clients received a score of 3 on their CNS function assessment (46%) compared to Washington clients (21%).
- Washington clients were more likely to receive a score of 2 on their CNS function assessment (53%) compared to Alaska clients (34%).

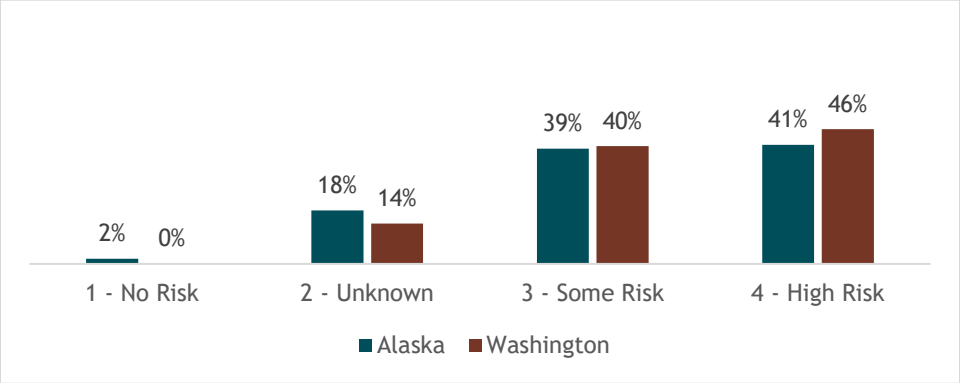
Figure 17. CNS Function Score Comparison, Alaska (1999-May 2020) and Washington (1993-2016)



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

By Alcohol Exposure Score

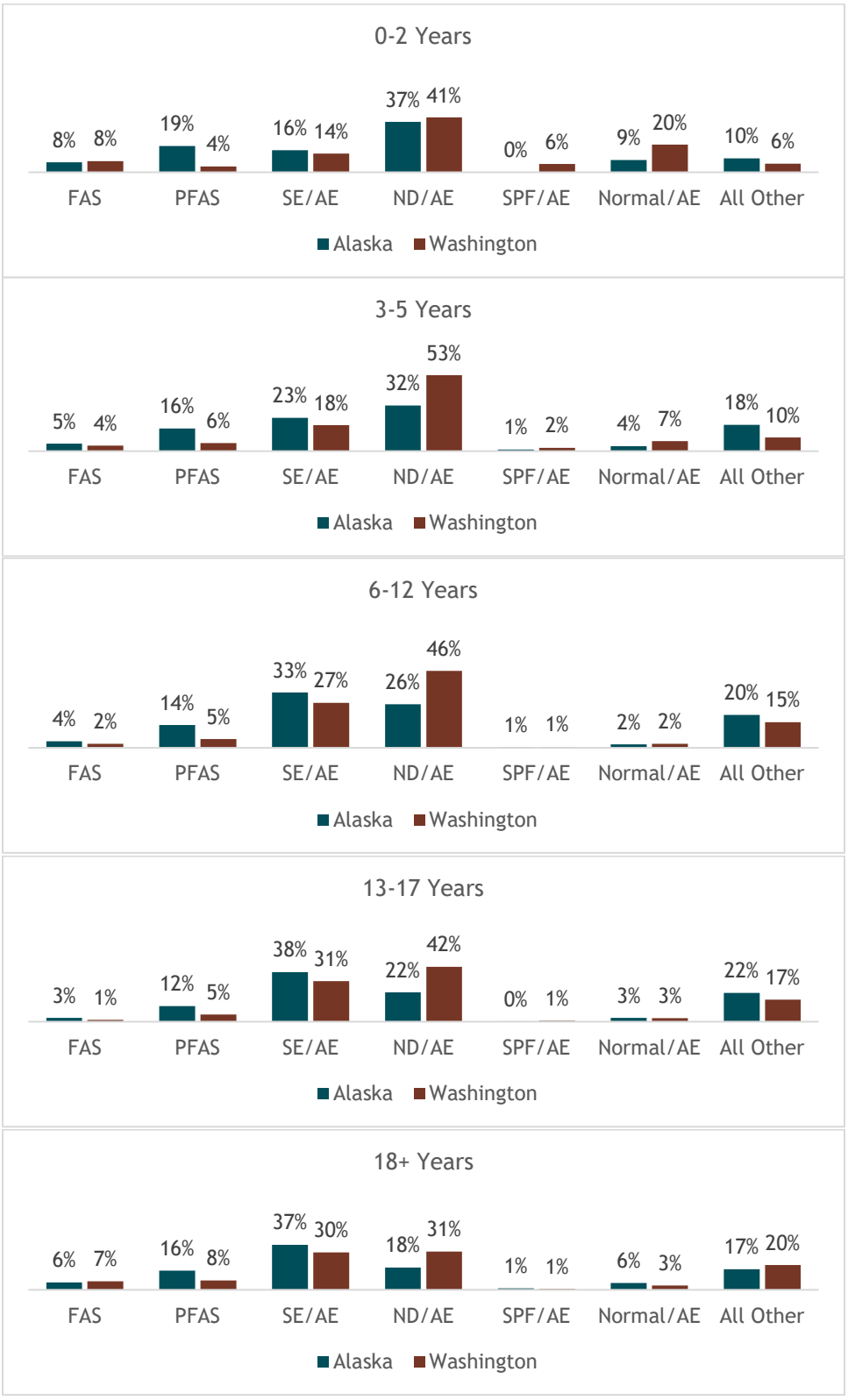
Figure 18. Alcohol Exposure Score Comparison, Alaska (1999-May 2020) and Washington (1993-2016)



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

By Age

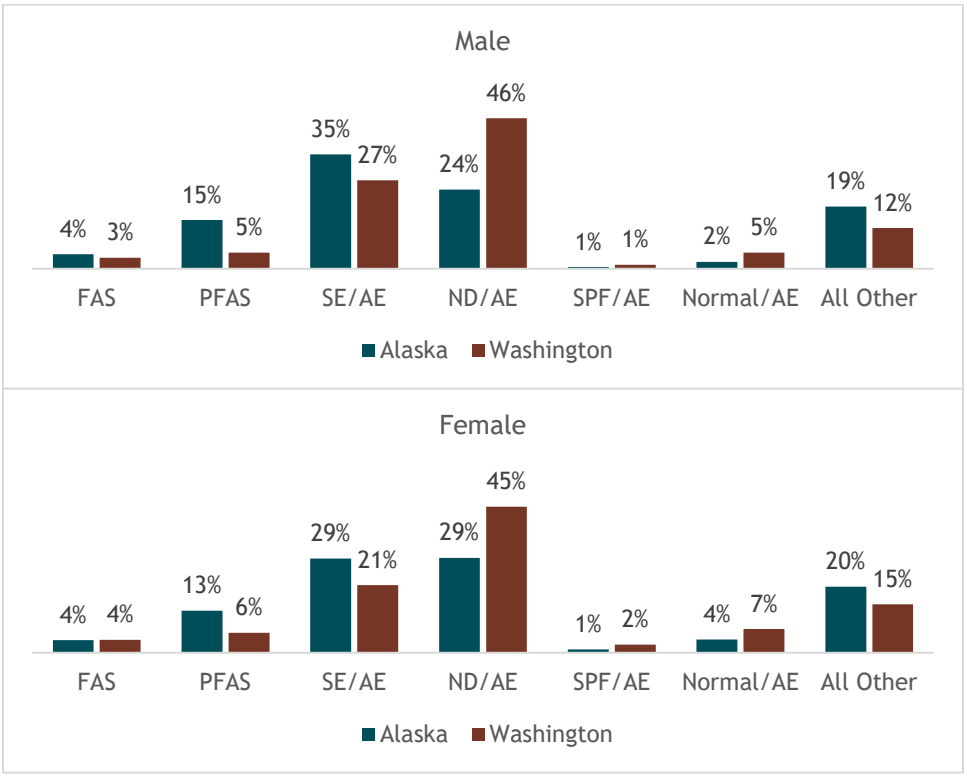
Figure 19. FASD Diagnoses Categories Comparison by Age Range of Client at Diagnoses, Alaska (1999-May 2020) and Washington (1993-2016)



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

By Gender

Figure 20. FASD Diagnoses Categories Comparison by Gender, Alaska (1999-May 2020) and Washington (1993-2016)



Source: Alaska DHSS Dataset, May 2020; McDowell Group calculation; Washington State FAS Diagnostic & Prevention Network, July 2020

Chapter 2: Prevention Policy Review

This section provides an overview of policy initiatives in Alaska and elsewhere to address FASD prevention. The table below outlines the three levels of FASD prevention (Primary, Secondary, and Tertiary), the goal of each level, and typical strategies used.

Table 39. FASD Prevention Categories

Goal	Strategies
Primary Prevention - Elimination of the problem's root causes with broad-based efforts to promote the health and well-being of a community	
Have no fetuses exposed to alcohol, thus eliminating the problems of FASD before they ever develop	• Engage in education regarding FASD and the adverse effects of alcohol on the fetus with all women and their partners • Ask all female patients of childbearing age the basic question about their use of alcohol • Be aware of and use promotional materials in offices and as handouts for patients • Be aware of and access community resources • Discuss and enhance access to contraceptive strategies with all women and their partners
Secondary Prevention - Early detection and intervention	
Reduce the duration and severity of maternal drinking by identification of the person at risk.	• Identify women who are using alcohol during pregnancy and assess level of risk • Counsel pregnant women who are using alcohol about the effects on the fetus and their own health • Counsel pregnant women regarding the benefits of stopping or reducing the use of alcohol at any time during pregnancy • Refer women who are using alcohol for appropriate treatment • Provide contraceptive counselling and enhanced contraception access
Tertiary Prevention - Targeting for advance recovery and relapse risk	
Reduce complications, impairments, and disabilities caused by FASD and include activities that prevent recurrence of the condition in subsequent children	• Identify those women at high risk in future pregnancies • Ask the woman why she drinks? • Refer at-risk women, especially during pregnancy, for appropriate treatment • Counsel women about the benefits of stopping or reducing alcohol consumption at any time during pregnancy • Provide contraceptive counselling and enhanced contraception access

Source: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2582740/. Accessed June 11, 2020.

Alaska Prevention Policy Overview

Below is a summary of Alaska's statutes, regulations, and strategies specifically related to the prevention of FASD.

Strategic Planning

In 2017, the GCDSE began developing and implementing a five-year strategic plan for addressing FASD in Alaska. The plan, Alaska Fetal Spectrum Disorders (FASD) Strategic Plan 2017-2022, included a vision, goals, core values, three- to five-year targets, and workgroup priorities and objectives. Six priority areas were as follows:

1. Primary Prevention of FASD
2. Screening for and Diagnosis of FASD
3. Early Childhood and Education
4. System Transformation and Navigation: Youth and Adults
5. Workforce Development
6. Community Outreach and Engagement

2018-2019 objectives for each of the priority areas were identified in the plan. The plan stipulated partners meet quarterly, with at least one annual meeting for revising and updating the plan. Workgroup leaders with invited participants were to draft and implement action plans.

AMHTA also prepared the *Strengthening the System: Alaska's Comprehensive Integrated Mental Health Plan 2020-2024* to identify priorities to inform state planning and funding decisions to meet the needs of Trust beneficiaries.[12] The plan includes prevention strategies and objectives to promote practice-informed, universal screening efforts and early intervention services for FASD. This plan is a response to a statutory requirement, Alaska Statute (AS) 47.30.660, which requires DHSS, in conjunction with the Trust, to develop and revise a plan for Alaska's Comprehensive Integrated Mental Health Program.

Primary Prevention

Since the late 1980s, the Alaska Legislature has passed several laws to develop public awareness of the FASD. These laws have largely focused on:

- Distribution of written information.
- Posting warning signs in locations that sell alcohol.
- Training and public education.
- Supporting trauma-informed approaches.

DISTRIBUTION OF WRITTEN INFORMATION

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 alcohol and pregnancy to public hospitals, clinics, and other health facilities. State law also required FASD-related information be provided when issuing marriage licenses in Alaska. AS 25.05.111 states, "(b) With a license issued under (a) of this section, the licensing officer shall also give to the parties written information about fetal alcohol effects and the fetal health effects of chemical abuse and battering during pregnancy. The Department of Health and Social Services shall prepare or obtain this information and submit it in distributable form to each licensing officer in the state."

[12] http://dhss.alaska.gov/Commissioner/Documents/MentalHealth/StrengtheningSystem-CompPlan_2020-24.pdf. Accessed July 22, 2020.

In the early 1990s, the Office of Fetal Alcohol Syndrome was developed, several FASD conferences were sponsored, and the Alaska FAS Prevention Project was formed. In accordance with state law, the project published a bulletin that outlined prevalence rates, risk factors, and prevention strategies. AS 18.05.037 stipulates, "The Department [of Health and Social Services] shall prepare or obtain distributable information on fetal alcohol effects and the fetal health effects of chemical abuse and battering during pregnancy. The department shall make this information available to public hospitals, clinics, and other health facilities in the state for distribution to their patients."

POSTING WARNING SIGNS

Some of the legislation has focused on increasing awareness at locations that sell alcohol. For example, AS 04.11.150 specifies, "The package store license, agent, or employee shall include written information on fetal alcohol syndrome and fetal alcohol effects resulting from a woman consuming alcohol during pregnancy in a shipment of alcoholic beverages sold in response to a written solicitation." Similarly, AS 04.21.065 (b) mandates the posting of warning signs by all alcohol license or permit holders to post on the licensed or designated premises. One of the warning signs must be "at least 11 inches by 14 inches, and the lettering must be a least one-half inch high and in contracting colors. The first sign must read, "WARNING: Drinking beverages such as beer, wine, wine coolers, and distilled spirits or smoking cigarettes during pregnancy can cause birth defects."

Additionally, according to Alaska Administrative Code (3 AAC 304.465), "While selling or serving alcoholic beverages, a person required under AS 04.21.025 to complete an alcohol server education course…(c)…Subjects covered by alcohol server education courses must include:…(4) effects of alcohol consumption including…(D) fetal alcohol syndrome and fetal alcohol effect."

TRAINING AND PUBLIC EDUCATION

Due to legislative action in the late 1980s and early 1990s, the state began requiring school districts to provide training teachers and other school officials on the needs of students with alcohol or drug related disabilities.[13]

In 2012, the Legislature established "FASD Awareness Day" (SB 127), and since then, annual events throughout the state are held on September 9. The day's designation was made to promote "awareness that there is no known safe level of alcohol consumption during pregnancy, to promote awareness of the effects of prenatal exposure to alcohol, to increase identification of children with fetal alcohol spectrum disorders, and to improve the lives of those affected by fetal alcohol spectrum disorders."[14]

In 2014, the Alaska State Legislature funded "Empowering Hope," which provided funds to AMHTA to conduct a three-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.[15] The media campaign, which targeted 18 to 34-year-olds, involved research on local and national data; focus group research; outreach to medical professionals,

[13] http://dhss.alaska.gov/osmap/Documents/fasd/FASD-Stategic-Plan-FY2017-2022.pdf. Accessed June 2, 2020.
[14] http://www.akleg.gov/basis/Bill/Detail/27?Root=SB%20127. Accessed June 2, 2020.

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 Alaska communities, with 42 women reporting they learned they were pregnant from the test and stopped drinking alcohol.

As part of professional staff development at residential psychiatric treatment centers, Alaska Administrative Code (7 AAC 50.820) requires at least 40 hours of staff training and development each year, which must include (among other issues), "the theory and treatment of fetal alcohol syndrome and fetal alcohol effect."

SUPPORTING TRAUMA-INFORMED APPROACHES

With compelling evidence that links women's substance use to experiences of violence and trauma, a significant shift in the fields of addiction has been the awareness of trauma's impact on infants, children, women, their families, and communities. The State of Alaska supports trauma-informed approaches to care and services as demonstrated in AS 47.05.060, relating to children the state serves. In 2018, the Alaska Legislature added statutory language stating, "It is the policy of the state to acknowledge and take into account the principles of early childhood and youth brain development and, whenever, possible, consider the concepts of early adversity, toxic stress, childhood trauma, and the promotion of resilience through protective relationships, support, self-regulation, and services."

Secondary Prevention

In the 1970s and 1980s, the Indian Health Services conducted alcohol-exposure screening of Alaska Native women. According to AS 33.30.011, the Commissioner of Health and Social Services shall "provide necessary…assessment or screening of the risks and needs of offenders who may be vulnerable to harm, exploitation, or recidivism as a result of fetal alcohol syndrome, fetal alcohol spectrum disorder, or other brain-based disorder."

In 2000, the State secured a $29 million multi-year grant from Substance Abuse and Mental Health Services Administration (SAMHSA) to develop statewide FASD diagnostic teams; prevention for women of childbearing age; services for people impacted by FASD; data collection; monitoring and analysis of impact; and extensive curriculum development and training, much of which is still in use today. Collected data are housed by AKAIMS (DBH) and were analyzed in the *Chapter 1: FASD Diagnostic Team Data Analysis*.

In 2014, AMHTA recommended the Alaska DOC change its screening tool used when inmates are booked in correctional facilities. As a result, it replaced the *Brief Jail Mental Health Screen and the Simple Screening Instrument for Substance Use – Revised*, with the *Alaska Screening Tool* used by DHSS. This screening instrument includes one question regarding FASD but could be supplemented with additional screening questions if FASD is suspected.[16]

[16] http://www.ajc.state.ak.us/acjc/docs/resources/Behavorial/hornby_zeller_mh_trust_beneficiaries_in_doc.pdf. Accessed June 2, 2020.

Requiring Mandatory Reporting

State law requires "practitioners of healing arts" to report cases in which substance abuse affects infants to the Office of Children Services. AS 47.17.024. stipulates the "(a) A practitioner of the healing arts involved in the delivery or care of an infant [defined as a child who is less than age one] who the practitioner determines has been adversely affected by, or is withdrawing from exposure to, a controlled substance or alcohol shall immediately notify the nearest office of the department of the infant's condition."

Tertiary Prevention

Supporting Treatment

In 2007, the State developed and gained approval for an 1115 Medicaid waiver to serve people with FASD, but the five-year demonstration period did not result in a renewal of services. In 2011, FASD activists successfully advocated for funding in the State's operating budget for FASD case management and substance abuse treatment for pregnant women. In 2012, additional funding was allocated for the Complex Behavior Collaborative, established in the DBH to provide consultation and training to providers and family members of people with complex behaviors and needs.

Supporting Special Education and Disability Services

In 2016, FASD was added to the Other Health Impairment special education eligibility category list of medical conditions, making Alaska the first state in the country to name FASD in education regulation. As reported in a notice from the Alaska Department of Education, Alaska passed an education regulation change to include FASD as one of the possible health conditions to qualify for special education (4 AAC 52.130 – Criteria for determination of eligibility). The change also expanded who can diagnose a health condition from "physician" to "physician or advanced practice registered nurse." As a result, diagnoses from Alaska's FASD Diagnostic Clinics headed by Advanced Nurse Practitioners are recognized when an individual is seeking special education in the state. In part, the regulations govern the qualifying requirements for the special education category.[17]

The state is required to provide quality learning and related early intervention family support services to eligible children under age three who have developmental delays or disabilities (subject to the availability of funding). The term "disability" is defined under AS 47.20.290 as "having an identifiable physical, mental, sensory, or psychosocial condition that has a probability of resulting in developmental delay even though a developmental delay may not be exhibited at the time the condition is… identified, including…(B) other syndromes and conditions associated with delays in development, such as fetal alcohol syndrome."

[17] https://www.nofas.org/alaska-students-with-an-fasd-eligible-for-special-education/ Accessed June 12, 2020.

MITIGATING OTHER SECONDARY CONDITIONS

In 2012, Alaska was the first state to make an FASD diagnosis a mitigating circumstance to be considered in sentencing for felony level criminal offenses (Alaska Senate Bill 151).[18] This legislation passed with substantial support from an ad hoc workgroup of the Alaska FASD Partnership. AS 12.55.151, regarding criminal sentencing, provides the exception, "(A) as a fetal alcohol spectrum disorder, the fetal alcohol spectrum disorder substantially impaired the defendant's judgment, behavior, capacity to recognize reality, or ability to cope with the ordinary demands of life, and the fetal alcohol spectrum disorder, though insufficient to constitute a complete defense, significantly affected the defendant's conduct; in this subparagraph, "fetal alcohol spectrum disorder" means a condition of impaired brain function in the range of permanent birth defects caused by maternal consumption of alcohol during pregnancy."

Additional Prevention Policy Review

The following presents some prevention policy initiatives in Australia, Canada, and elsewhere in the nation, including strategic plans, and primary, secondary, and tertiary prevention. A discussion of determining prevalence follows.

FASD Strategic Plans

Few states besides Alaska have current FASD plans. Below are a few examples from states that have plans.

MICHIGAN

The prevention objectives of the Michigan Five-Year Plan (2015-2020) include:

- Increase public awareness and knowledge among Michigan's general population – especially among women of reproductive age, 15–44 years, and their families – that no amount of alcohol is safe during pregnancy.
- Implement prevention strategies targeted to women of child-bearing age before, during, and between pregnancies; women's health care providers; and the general population.
- Develop and implement early screening, diagnosis, assessment, interventions, and support services across the life cycle for individuals affected by FASD.
- Increase readiness of the workforce to prevent alcohol exposure during pregnancy; identify, implement, and provide effective, efficient. and lifelong support services for individuals affected by FASD in the key support and service systems: health care, behavioral health care, education, social services, and criminal justice.

While the plan spells out objectives and activities, evaluation of the plan's effectiveness is not considered.

[18] http://www.akleg.gov/basis/Bill/Detail/27?Root=SB%20151. Accessed June 12, 2020.

OHIO

The Ohio FASD Steering Committee developed a Strategic 5-Year Plan (2016-2021) (revised in 2019) that includes:[19]

- Goal One - Reduce alcohol-exposed pregnancies (Prevention)
  - Objective #1: Provide information and education
  - Objective #2: Research best practices
- Goal Two - Increase availability and awareness of services for FASD
  - Objective #1: Identify and provide resource and supports for individuals with FASD, parents, caregivers, and professionals supporting an individual with FASD
  - Objective #2: Build knowledge and capacity of professionals to identify individuals with a possible FASD diagnosis
  - Objective #3: Promotion and sharing of information/resources/practices being done with FASD
- Goal Three - Develop mobilization and sustainability strategies
  - Objective #1: Identify a state champion team for FASD
  - Objective #2: Increase capacity to maintain longevity of the FASD Steering Committee

CANADA

In Canada, four provinces and territories (Alberta, Manitoba, Ontario, and Yukon) have a specific prevention strategy or framework to address FASD. Other provinces have strategies; however, they are outdated or are still in development.[20]

Yukon

Informed by foundational initiatives and sources, The *Yukon FASD Action Plan* aims to address FASD and support families and communities using a holistic approach. The action plan identifies key contributors, guiding vision statements, principles, and seven priority areas. Each area of priority outlines an overarching goal, followed by immediate and/or intermediate actions, as well as desired outcomes. Given the recent execution of the action plan, a separate plan delineating lead individuals, partners, resources (both human and financial), and timelines to further support the implementation of the action plan is being created.

Primary prevention is about broad-based awareness and health promotion activities that support girls' and women's health and promote community wellness. The Government of Yukon in its *Yukon FASD Action Plan (September 2019)* highlights this goal, with immediate action to broadly release its *Action Plan* and intermediate action to "implement a territory-wide public awareness campaign developed through community-based partnerships that are tailored according to different audiences, cultures, and linguistic groups."[21] The campaign also includes building on sexual health, contraception and planned pregnancy information and curricula, and initiating awareness and education campaigns on FASD targeting elementary and high school-aged youth.

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[19] https://mha.ohio.gov/Portals/0/assets/FamiliesChildrenandAdults/Healthy%20Babies/AlcoholandPregnancy/FASD-Steering-Committee-Strategic-Plan-Short-Version.pdf. Accessed July 13, 2020.
[20] https://canfasd.ca/wp-content/uploads/publications/Provincial-Strategies-Issue-Paper-Final.pdf Accessed June 23, 2020.
[21] https://yukon.ca/sites/yukon.ca/files/hss/hss-yukon-fasd-action-plan-2019.pdf. Accessed June 12, 2020.

Outcomes of this awareness campaign include Yukoners being aware that FASD is a lifelong condition caused by prenatal alcohol, no amount of alcohol is safe while pregnant, FASD is preventable, and a number of complex reasons contribute to prenatal alcohol exposure, among other messages.

The *Yukon FASD Action Plan* recognizes that FASD is complex and involves more than providing information about the risks of alcohol use during pregnancy. Other primary preventions strategies include:

- Giving girls and women of childbearing years the opportunity for safe discussion about reproductive health, contraception, pregnancy, alcohol use, and related issues with their support network and healthcare providers; the goal is to equip women to make informed choices and identify resources to support healthy pregnancies.
- Providing supportive services that are specialized, culturally safe, and accessible to women with alcohol problems and histories of violence and trauma; the goal is to tackle the pervasive barriers to accessing care and takes a trauma-informed and harm-reduction perspective.
- Supporting new mothers to maintain health changes in their alcohol use and related health and social choices made during pregnancy.
- Reducing instances of prenatal alcohol exposure by providing ongoing support in the form of a home visit program and intensive case management.

Outcomes of this prevention program include providing women supportive advice about FASD prevention and maternal child health; reducing alcohol consumption among women who plan to become or are pregnant; and helping women feel supported, safe, and informed about making health choices while pregnant and after pregnancy.

Alberta

Alberta's current FASD strategy is comprehensive in its approach to FASD, focusing on five strategic pillars that include:

- Awareness: Public awareness and education initiatives.
- Prevention: Safe discussion with women about FASD and parent-child assistance programs.
- Assessment and Diagnoses: Assessment for intervention to provide a continuum of supports across the lifespan with planned transitions and diagnosis to support surveillance and research.
- Support for Individuals and Caregivers: Coordinated access to the right services at the right time, across the lifespan with planned transitions.
- FASD Learning Organization: Training and information, strategic planning, research and evaluation, and stakeholder engagement.

The strategy is built on the success and learnings of the *Alberta FASD 10-Year Strategic Plan 2007-18*. In addition to providing detailed definitions of what is included in each area of focus, the Alberta strategy delineates the target population, the desired outcomes of the plan, and existing gaps in services and supports

related to each specific area. The Alberta Plan underwent two formative evaluations at five years and at seven years, and one final summative evaluation.[22]

These evaluations provided key findings and recommendations which have helped to guide policies and practices for supporting Albertans with FASD while improving Alberta's strategic model and the province's supports and services. In the seven-year evaluation, one of the overarching recommendations was to streamline FASD outcomes, indicators, and key performance indicators and continue to enhance Alberta's online reporting system, expanding the system to capture contributions to outcomes made by all FASD initiatives, and making data collection and reporting a requirement for all funded FASD initiatives.

The vision of a coordinated response to prevent future alcohol exposed pregnancies and a continuum of culturally informed supports across the lifespan is achieved through cross-ministerial collaboration and 12 FASD Service Networks. The strategy continues to evolve to include initiatives to support employment for individuals with FASD, explore the use of a telehealth model, development of an FASD Workforce Development Framework to enable an FASD-informed workforce across sectors, and an FASD policy framework. Research developed an FASD prevalence of 1.2% (or approximately 46,000 Albertans).

Manitoba

The province of Manitoba first implemented an FASD strategy in 2007 and has continued to invest and expand on this strategy since its inception. Developed within an interdepartmental partnership, the Manitoba FASD Strategy functions across a wide range of areas (e.g., health, education, employment, justice, housing). Employing a lifespan approach to FASD, and guided by five main goals (i.e., Knowledge, Prevention, Intervention, Evidence, and Quality), the province outlines numerous successes across each sector from these ongoing strategic efforts in the *Together we are Stronger: Continuing the Success of Manitoba's FASD Strategy* document. Manitoba has indicated its desire to include evidence-based prevention strategies, in addition to the strategies which focus on post-diagnosis.

Ontario

In 2017, the Ontario provincial government announced that it was committed to investing more than $26 million dollars over four years to increase awareness and prevention of FASD in the province. Six initiatives were outlined in the budget including: funding for FASD support workers; investing in parent support networks; increasing access to Indigenous-led FASD initiatives; establishing a consultation group to provide advice and feedback to inform implementation planning and prioritization efforts; and creating a research fund and investing in knowledge mobilization. Despite these commitments, as well as recognized funding in some of these areas, no formal Ontario FASD strategy has been released to the public to date.

[22] https://open.alberta.ca/dataset/51b16a7f-ad76-44c1-b57b-424d6e3c783c/resource/10396740-2863-4c4f-be45-d138489cde4c/download/year-7-evaluation-progress-report.pdf. Accessed June 23, 2020.

Saskatchewan

While outdated, the *Saskatchewan FASD Prevention Framework 2014* developed by the Government of Saskatchewan recognizes the prevention of FASD requires a multi-pronged approach to ensure effective and sustainable progress towards reducing the incidence of FASD.[23] Their research findings underscored that FASD prevention efforts must extend beyond the singular focus on alcohol use in pregnancy to address the complex web of social determinants that mediate the outcome of alcohol-exposed pregnancies. Access to good nutrition, pre-and post-natal medical care, safe housing, and social support are vital to help women to care for themselves and their children. Their strategic approach delineates four levels of prevention activities to comprehensively address FASD prevention:

- Broad awareness building health promotion efforts
- Discussion of alcohol use and related risks with all women of childbearing years and their support networks
- Specialized, holistic support of pregnant women with alcohol and other health/social problems
- Postpartum support for new mothers and support for child assessment and development

The Saskatchewan Government is conducting an evaluation of current and new programs that are part of the FASD Prevention Framework, collaborating with the Canada FASD Research Network. The research evidence is intended to inform ongoing policy and program development in Saskatchewan.

AUSTRALIA

Australia's *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028* is structured around four key national priorities to catalyze national efforts in the prevention, diagnosis, support, and management of FASD.[24] Australia does not have national FASD prevalence data due to several factors, including a lack of routine assessment and screening for maternal alcohol use and FASD, a lack of national diagnostic criteria until recent times, a lack of nationally consistent data collection reporting, and a lack of awareness of the full spectrum of disorders in FASD.

In their prevention strategies, it is recognized that research shows drinking during pregnancy appears to be consistently associated with women's pre-pregnancy alcohol consumption (i.e. quantity and frequency of typical drinking) as well as exposure to abuse or violence. Prevention strategies must be formulated to respond to potential influences on women's alcohol consumption during pregnancy and identify women who may be at a higher risk and require targeted interventions. Additionally, stigma and fear of negative consequences cause women to underreport alcohol consumption during pregnancy. Efforts to prevent and eliminate stigma must continue to be embedded across all activities. This requires careful consideration to the nature of any messaging – tone of voice and language, employing women-centered and compassionate support for all pregnant women, and avoiding stories that blame or shame mothers of children with FASD.

[23] Saskatchewan FASD Prevention Framework 2014, https://pubsaskdev.blob.core.windows.net/pubsask-prod/99283/99283-FASD-prevention-framework-2014.pdf Accessed July 8, 2020.
[24] National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028. *https://www.nofasd.org.au/blog/strategic-action-plan/*. Accessed June 1, 2020.

Primary Prevention

PUBLIC AWARENESS

Researchers in Alberta conducted an analysis of measuring the level of FASD awareness in the province.[25] A variety of public education programs developed over the last 20 years have promoted alcohol abstention during pregnancy, yet FASD remains a serious public health concern. In 2011, 18% of men and 10% of women did not know about FASD; this decreased somewhat by 2017, with 15% of men and 6% of women unaware of FASD. The data indicated the education focus on women of childbearing age continues to make sense. It further concluded that in addition to targeting women in prevention messages, formal (health care providers for example) and informal support (partner, spouse, family, and friends) could improve prevention. In the 2011 and 2017 surveys, both informal and formal support were reported as sources of encouragement, and ensuring they understand risks, as well as effective ways to encourage abstinence or harm reduction, may be beneficial for both the woman and her pregnancy.

[25] Fetal alcohol spectrum disorder: What does public awareness tell us about prevention programming? https://documentcloud.adobe.com/link/track?uri=urn%3Aaaid%3Ascds%3AUS%3Acde9fdd7-9364-4cb1-8b6a-6ab3db66d911#pageNum=1. Accessed July 8, 2020.

LEGISLATOR AWARENESS

States have passed many laws addressing alcohol use in pregnancy, despite limited evidence on the impact of such policies. A recent study explored how state legislators used evidence when making policy on alcohol use in pregnancy.[26] Despite evidence on the harms of alcohol use in pregnancy, most lawmakers did not express concern about this topic. Instead, they expressed concern about opioid use in pregnancy. Personal experiences, anecdotes, and known contacts influenced legislators' views on substance use in pregnancy, whereas evidence, for the most part, did not. The intermediaries who typically bring evidence about problems and solutions to legislators did not appear to be raising the issue of alcohol use in pregnancy on legislators' agenda. Basic evidence on the prevalence and harm of alcohol use in pregnancy did not appear to influence state lawmakers' policy priorities. It is suggested concern over opioid use may provide a window of opportunity to educate legislators on the relative scope and harm of both alcohol and opioid use in pregnancy.

DEFINING FASD

To promote a common language about FASD, and to minimize misinterpretation of key issues, Canada FASD Research Network developed a definition of FASD that used lay language to reach a wide audience, emphasizing the whole-body implications of FASD and highlighting that each individual with FASD is unique, with individual strengths and challenges.[27]

> *Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term used to describe impacts on the brain and body of individuals prenatally exposed to alcohol. FASD is a lifelong disability. Individuals with FASD will experience some degree of challenges in their daily living, and need support with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills to reach their full potential. Each individual with FASD is unique and has areas of both strengths and challenges.*

Prior to the recommended definition, they had found some positive definitions that spoke to the range of effects of prenatal alcohol exposure, the invisible nature of FASD, the need to consider FASD across the lifespan, the strengths of individuals with FASD, and those that considered the social determinants of health. Neutral statements referred to alcohol use during pregnancy (e.g., "any type, any amount, at any time") and factual statements, such as FASD prevalence. There were also negative components referring to birth defects, identifying that there is "no cure" for FASD, emphasizing FASD as a disability that occurs only in infants and children, and those that drew particular attention to the perceived fault and blame of mothers.

[26] "Alcohol During Pregnancy? Nobody Does that Anymore": State Legislators' Use of Evidence in Making Policy on Alcohol Use in Pregnancy. https://pubmed.ncbi.nlm.nih.gov/31250804/ Accessed July 8, 2020.
[27] https://canfasd.ca/wp-content/uploads/2019/08/Toward-a-Standard-Definition-of-FASD-Final.pdf. Accessed June 23, 2020.

ELIMINATING STIGMA

The Australia's *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028* includes a section entitled "Enablers."[28] The plan recognizes FASD is under-recognized, which represents a substantial barrier to early detection, diagnosis, support, and assistance. This prevents significant improvement of outcomes for individuals and their families. Further, despite a broad range of efforts to date, there is still a lack of public understanding about FASD. Media portrayals and community attitudes can result in stigma. Consequently, those affected by FASD (including children diagnosed with FASD and their mothers and families) may feel shamed and blamed.

Stigma can also influence the prevention and identification of FASD. Inadvertent stigmatizing by public health FASD initiatives can limit the willingness of those affected by FASD to seek information, care, support, and assistance. Community and public education should embed the message that everyone has responsibility for prevention of alcohol-exposed pregnancies, not just women themselves. All approaches to dealing with alcohol consumption during pregnancy must consider the range of socio-economic needs and pressures which affect women's behaviors. Services for pregnant women who are alcohol dependent or have problematic alcohol use must be provided by trained specialists in a compassionate and sensitive manner. The success of other destigmatizing health campaigns, particularly mental health campaigns to address myths and tackle stigma, can provide useful lessons for FASD anti-stigma strategies going forward.

The Australian plan recognizes that coordination and collaboration across jurisdictions and communities is essential to achieving its aim to reduce the prevalence of FASD and the impact it has on individuals, families, caregivers, and communities. Policies are to be coordinated to ensure collaboration between all levels of governments and sectors, including health and human services, schools and teachers, and legal system, on implementation of evidence-based initiatives.

Secondary Prevention

EFFECTIVE PRE-NATAL SCREENING

Due to stigma and unawareness, it is well accepted alcohol use during pregnancy is underreported. Pregnant women are less likely to self-report if they feel they will be judged harshly by providers; there is often shame involved. Along with stigma, many women who drank during pregnancy claimed they did not know about the negative health implications for a fetus. Combined with these factors, many health professionals have not received guidance and training on how to discuss alcohol use and pregnancy with patients. It is often a difficult subject to bring up and discuss with the patient especially in a sensitive manner that would best produce truthful answers and best educate the patient as to the dangers of alcohol. For example, in the U.S. 82% of obstetricians asked their pregnant patients about alcohol use only during their initial visit, 66% indicated occasional alcohol consumption is not safe during any period of pregnancy, 58% did not use a validated alcohol risk screening tool, and there was no consensus when asked if alcohol's effect on fetal development is clear (47% thought it was clear and 46% did not) [29] In Australia, only 45% of doctors said they

[28] National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028. https://www.nofasd.org.au/blog/strategic-action-plan/. Accessed June 1, 2020.
[29] https://pubmed.ncbi.nlm.nih.gov/21769028/ Accessed June 2, 2020.

always ask their pregnant patients about their alcohol use and only 25% routinely provide information on the effects of alcohol on a fetus.[30]

In 2014, SAMHSA issued a treatment improvement protocol addressing FASD, which states screening for alcohol use "is an ethical obligation" and further states, "it would be unethical to ignore [high-risk women and their children] existence and ignore opportunities to provide them with advocacy support and primary prevention intervention.[31] Screening gives the client permission to talk about drinking, helps to identify and/or clarify co-occurring issues, minimizes surprises in the treatment process, and can mean more effective treatment. The SAMHSA treatment protocol provides sample policy for screening and procedures for all women of childbearing age regardless they are pregnant or not. The treatment protocol also provides a policy and procedures section to help state's plan and implement other policies (i.e., clinical staff training and competency (intervention and prevention), recruitment, training, and supervision of FASD-capable clinical staff, observation and referral of clients exhibiting signs of an FASD, treatment planning, service recording, discharge planning, and continuity of care, counselor performance appraisal, and evaluation of service effectiveness and quality assurance.

USING SCREENING IN CORRECTIONAL FACILITIES

The Yukon Government spearheaded a study to estimate the prevalence of FASD in their justice system as well as evaluate FASD screening tools, including the Asante FASD Screening and Referral Tool for Probation Officers and the Correctional Service of Canada's Brief Screening Checklist (BSC), for use in the adult criminal justice context.[32] A Prevalence Partnership Board was created that provided community, expert, and stakeholder oversight and guidance during the development, implementation, interpretation, and dissemination stages of the prevalence research. Given the study's high rates of FASD and neurocognitive deficits, further efforts to validate efficient and cost-effective approaches to FASD screening remains an important goal. Screening continues to play an important role in developing an evidence base to inform offender risks and needs. However, it should be coupled with access to more comprehensive assessment resources in cases of positive screening using validated tools. The sample-optimized BSC may benefit from future evaluation, in addition to alternative approaches to identifying neurocognitive deficits. Screening cannot replace assessment and diagnosis, which should follow the recently updated Canadian Guidelines for FASD Diagnosis[33]

[30] National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028. https://www.nofasd.org.au/blog/strategic-action-plan/. Accessed June 1, 2020.
[31] https://store.samhsa.gov/sites/default/files/d7/priv/sma13-4803.pdf Accessed June 2, 2020.
[32] *FASD in Yukon Corrections,* http://www.justice.gov.yk.ca/pdf/Corrected_McLachlan_Final_Report_to_Yukon_August_2017.pdf Accessed June 23, 2020.
[33] Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., Rosales, T. (2015). Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. Canadian Medical Association Journal, 188(3), 191-197. http://doi.org/10.1503/cmaj.141593 Accessed June 2, 2020.

LINKAGES BETWEEN FASD AND AUTISM

Children with FASD exhibit difficulties in many cognitive and behavioral domains and also have high comorbidity with other disorders, such as attention deficit/hyperactivity disorder (ADHD) and conduct disorder as well as autism. Although the FASD profile is shown to be distinct from ADHD and conduct disorder, far less is known about the commonalities with autism. FASD and autism share similarities regarding social and communicative functioning, which may be useful in specifying the particular interventions children need.[34]

The essence of the overlapping clinical presentations comes in the expressive and receptive language area. The qualitative impairments in social awareness, social cognition, and social communication are not uncommonly hard to differentiate, whether using clinical assessment by an experienced child psychiatrist or psychologist. In many countries, the ambivalence to accept the true prevalence of FASD leads school systems and physicians to 'hide' many FASD patients under an Autism Spectrum Disorder or Asperger's Disorder diagnosis because of the expediency of receiving school learning disability services. This is slowly changing in Canada and the U.S. The United Kingdom is acknowledging FASD are the current biggest challenge for teaching as these pupils display complex learning disabilities with co-morbid psychiatric disorders for which there is no regular curriculum.[35]

REMOVING MANDATORY REPORTING

While Alaska requires mandatory reporting of healthcare providers to the Office of Children Services, other states have removed this requirement as mandatory reporting may not be beneficial; laws that seek to discourage alcohol use during pregnancy through criminalization may reduce the likelihood that a pregnant woman would disclose her alcohol use to her doctor for fear of criminal sanction. For example, Colorado legislation makes the results of information related to substance abuse discovered as part of pregnancy testing or the provision of prenatal care inadmissible in criminal proceedings and Minnesota exempts healthcare providers and social service professionals from required reporting of prenatal substance use, provided that the healthcare provider or social service professional is providing the woman with prenatal care.[36]

Tertiary Prevention

PREVENTING SECONDARY CONDITIONS

Individuals with FASD have high rates of secondary conditions, including mental health problems, school disruptions, and trouble with the law. Broad system changes using a public health approach are needed to increase awareness and understanding of FASD, improve access to diagnostic and therapeutic services, and create responsive institutional policies to prevent secondary conditions. These changes are essential to

[34] https://www.tandfonline.com/doi/full/10.1080/09297049.2012.727791?src=recsys. Accessed July 22, 2020.
[35] https://www.intechopen.com/books/recent-advances-in-autism-spectrum-disorders-volume-i/clinical-implications-of-a-link-between-fetal-alcohol-spectrum-disorders-fasd-and-autism-or-asperger. Accessed July 22, 2020.
[36] Colorado House Bill 21-1100 and Minnesota Senate Bill 2695.Accessed June 2, 2020.

improve outcomes for individuals with FASD and their families and facilitate dissemination of empirically supported interventions.[37]

Systems-level barriers include delayed diagnosis, difficulty qualifying for services, limited availability of services, poor implementation of services, and difficulty maintaining services. Barriers are all related to a pervasive lack of knowledge about FASD that penetrates multiple systems and the community as a whole.

The lack of knowledge about FASD permeates all aspects of society, including medical and mental health professionals, the education system, religious communities, the judicial system, and extended family members and friends. The pervasive lack of knowledge and understanding of FASD is a primary source of these system-level barriers and contributes to the rates of secondary conditions in this population.

Parents stated that they constantly must educate others about FASD and explain their child's behavior. Many parents described feeling stigmatized and isolated from their community by their child's behavior and the lack of understanding by others. Families also often feel frustrated by the challenges of obtaining an appropriate diagnosis and services for their children. They report feeling especially frustrated by providers who they feel should be knowledgeable about FASD, such as medical providers, mental health providers, and teachers. Providers have little significant coursework or formal education on FASD during their training; many learned about FASD when they began working with a client with FASD and educated themselves to try to help the individual.[38]

Additionally, obtaining adequate services is a challenge for many individuals with developmental disabilities, but may be especially difficult for individuals with FASD as they do not easily fit within the qualification categories utilized in most service systems (i.e., special education, developmental disabilities).

Estimating FASD Prevalence

Prevalence refers to the proportion of persons in a population who have a condition at or during a particular time period and is often used to reflect the burden of FASD. However, estimating prevalence of FASD in Alaska is not possible with currently collected data. It is likely many individuals with FASD have not been (and will not be) diagnosed with FASD; these individuals are therefore not represented in the Alaska FASD Diagnostic Data (*for more detail see next chapter, FASD Diagnostic Team Data Analysis)*. Alaska is not alone – there is no national or international standard used. For example, in Michigan's FASD Five-Year State Plan (2015-2020), it states, "defining the prevalence of FASD has been difficult because of the lack of awareness of its existence and impact, the lack of screening and limited diagnosis of the conditions that make up the spectrum, and the poor/underreporting of alcohol consumption during the prenatal period.[39]

There are three main approaches to study the prevalence and patterns of occurrence of FASD[40]:

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[37] *Prevention of Secondary Conditions in Fetal Alcohol Spectrum Disorders: Identification of Systems-Level Barriers.* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4007413/ Accessed June 23, 2020.
[38] Ibid.
[39] https://www.michigan.gov/documents/mdhhs/Michigan_FASD_Five_Year_State_Plan_2015-2020_516784_7.pdf. Accessed June 20, 2020.
[40] https://pubs.niaaa.nih.gov/publications/arh25-3/159-167.htm. Accessed July 2, 2020.

1. **Passive Systems** – Researchers must first establish the criteria for defining a diagnosis of FASD and then a team of reviewers looks for documented or probable cases of children born with FASD and diagnosed in a particular time period. Three types of records are generally reviewed: birth certificates, special registries for children with developmental disabilities or birth defects, and/ or the medical charts of hospitals and physicians. The major advantage of passive methods is they efficiently use existing health care systems, programs, and records that are already funded by other sources. But there are also major disadvantages. FASD diagnoses are complex, involving multiple indicators of physiology, development, and behavior, many of which are not obvious at all or are at least more difficult to identify at particular ages (e. g., birth). Therefore, passive systems, which generally depend on the diagnoses of many hundreds of non-specialist physicians, educators, and other service providers (who may miss FASD symptoms because of the circumstances of examination or the age at which the child is presented), lack the rigor and consistency of diagnoses that characterize other systems.
2. **Clinic-based Studies** – Clinic-based studies are generally conducted in prenatal clinics of large hospitals where researchers can collect data from mothers as they pass through the various months of their pregnancies. Control groups are easy to obtain, since all consenting women in the clinics are screened. However, most women report abstaining alcohol use, providing an adequate comparison group. Clinic-based studies provide the opportunity to gather maternal history data and study a large number of pregnancies with various levels of alcohol exposure. Health services are often provided, offering incentives for participants. However, subjects are self-selected and the women at highest risk for FASD offspring are less likely to attend prenatal clinics regularly (or none), making access to the highest risk cases less regular or impossible with these methods. Additionally, many, if not most, of the clinic-based studies conducted in the United States have been carried out in publicly funded hospitals and clinics where disadvantaged populations predominate. Therefore, clinic studies and the data obtained may over-represent the prevalence of FASD and the characteristics of these selected populations and under-represent middle-and upper-class populations. Also, since FASD is not most accurately diagnosed at birth, and often until ages 3 to 12, these studies likely underestimate the prevalence of FAS in the population studied.
3. **Active Case Ascertainment** – Active case ascertainment studies actively seek, find, and recruit children who may have FASD. Once criteria are established for referral to clinical examination and testing, a referral network and referral procedures are defined. Clinical specialists examine possible cases and assess the physical growth and development, dysmorphology, and psychosocial characteristics of the children for a final diagnosis. Advantages of this approach is the primary focus is on finding children with FASD at appropriate ages for accurate diagnosis by clinical specialists. Active, effective, and comprehensive outreach in a large general population is most likely to uncover children with FASD and alcohol-abusing mothers at the highest risk. By studying entire communities or populations, this method can eliminate much selectivity and generally ensure wide representation. Therefore, an efficient active case ascertainment approach may produce the most complete access to children with FASD and the most complete assessment of the prevalence and population-based characteristics of FAS in a particular population. However, there are substantial disadvantages: 1) such research is labor intensive, time consuming, and costly. The outreach process involves gaining permission to access a community for study, training people to recognize symptoms and refer

children suspected of having FASD, locating and securing permission for maternal and child subjects, hiring specialists for the clinical assessments, and holding special developmental clinics that may require 2 to 3 hours to completely diagnose a single child; 2) studies of this type require cooperation from many non-researchers (e.g., community, political, health, and education officials, parents, social welfare personnel, etc.). If a vital community constituency does not support a study, case finding may be incomplete or selective, resulting in under representation of the prevalence or a skewed understanding of the true characteristics of the problem. High levels of cooperation with research on stigmatized topics such as FASD and maternal drinking are often difficult to achieve; 3) access to particular populations may be selective, and frequently only high-risk populations have been studied using these methods. In other words, these studies have been most frequently carried out where FASD cases are more likely to be found. If such selective populations are studied and these findings projected to the general population, then the prevalence of FAS may be overestimated.

Recent approaches have included prevalence of alcohol consumption in pregnancy by measuring ethanol biomarkers in meconium. Meconium samples or cord tissue samples of a newborn can identify alcohol byproducts that represent alcohol exposure during pregnancy (meconium samples are only indicative of alcohol in the 2nd and 3rd trimester, unlike cord samples, but are presumably easier and less expensive to obtain and analyze).[41,42]

In Alaska, none of these methods are used to assess prevalence. Additionally, diagnosis of FASD is incomplete because of two reasons: many persons are not screened for FASD, for a variety of reasons, and the definition of FASD can be somewhat subjective (or variable depending on what definition is used). Other barriers for estimating Alaska FASD prevalence include:

- *Stigma associated with "blame" of prenatal alcohol use by the biological mother.* Only a small proportion of persons diagnosed in the FASD Diagnostic Database have been referred by their biological parents. This suggests parents may be reluctant to obtain screening for their children.
- *Limited newborn screening tests.* Current newborn screening tests most often do not include alcohol byproduct assessment (e.g., meconium samples, cord tissue samples). Therefore, alcohol exposure documentation may not be available, especially if there is sole reliance on maternal history transfer from the prenatal record to newborn record.
- *Unawareness or inability to recognize FASD symptoms.* Apart from facial characteristics, many symptoms of FASD overlap with conditions such as autism and others which complicates the differential diagnosis if alcohol-use history is not known or disclosed. If a person (usually a child) is never diagnosed, children (and their families) may not understand the basis for their behavioral issues and receive less effective or no treatment.
- *Overlooked assessments of less critical or severe cases.* Cases may go undiagnosed if the capacity for in-depth evaluation by diagnoses teams has been reached or referrals for seemingly less critical or severe cases are delayed or dropped. Additionally, in some people, FASD manifestations may be subtle and may never be referred for diagnosis or seek treatment.

[41] https://pubmed.ncbi.nlm.nih.gov/30783158/ Accessed July 2, 2020.
[42] https://pubmed.ncbi.nlm.nih.gov/28676561/ Accessed July 2, 2020.

- *Unreported diagnoses to AKAIMS*. Some caregivers and evaluation teams do not report their diagnosed cases to the AKAIMS database (i.e., Southcentral Foundation practitioners).
- *No universal definition of FASD prevalence at the national and international level*. There currently is no national or international gold-standard for the definition of an FASD diagnosis.[43] While several attempts have been made (e.g. University of Washington, American Academy of Pediatrics, Canadian government, Australian government, World Health Organization, Centers for Disease Control and Prevention), each definition is slightly different or not universally accepted.

Evaluating Strategic Policy Performance

Several of the strategic plans reviewed, including Alaska's, do not include an implementation process to evaluate the performance of the strategies. Below are a few examples where more consideration is made on research and evaluation of prevention strategies.

The *Yukon FASD Action Plan* promotes research and evaluation to ensure the incidence and prevalence of FASD are better understood and interventions are evidence-based and effective. Evaluation is also important to measure outcomes and impacts of the work and to understand what is working and informed what needs adjustment as the plan is implemented.

The Australian plan also recognizes the gaps in data and research, and supports evaluative strategies to:

- Support of further epidemiological research to better understand prevalence rates, particularly in at-risk groups.
- Build the availability of data on alcohol consumption during pregnancy to better monitor progress in reducing maternal alcohol consumption through improving data collections.
- Amend data collections to collect country of birth and language spoken at home information.
- Support the continuation of national FASD surveillance and the national FASD Register as tools that enable collection of epidemiological data and monitoring of prevalence trends and prognosis.
- Support systems-based research to prevent risky alcohol use and related harm, including FASD.
- Prioritize translational and implementation research to drive adoption of FASD diagnostic guidelines, diagnostic activity, and therapy support models.
- Evaluate the effectiveness of new therapies and novel diagnostics, such as 3D facial imaging, epigenetics, genetics, eye movements and biomarkers.
- Review the Australian Guide to the Diagnosis of FASD and associated training.
- Conduct health economic modelling of FASD to assess the full costs and the value to Australian society and the community if FASD was adequately identified, managed, and prevented.
- Build opportunities for policy development and evaluation and reporting of progress to be informed by those with lived experience and outcome measurements where possible.[44]

[43] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4960726/. Accessed July 23, 2020.
[44] National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028. https://www.nofasd.org.au/blog/strategic-action-plan/. Accessed June 1, 2020.

Chapter 3: Alaska FASD Scorecard

Overview

Report cards of performance are a helpful accountability instrument, facilitating improvements in service and effectiveness. Report cards are also used for advocacy and performance research, including evaluation of health care programs, managerial practices, and systems of care. Within Alaska, performance report cards are already in practice or development in many public health, health care, and social service sectors. Measures, or indicators, reflected on a report card provide insight into how well an organization's or system's structure, resources, and activities align with its core functions and strategic objectives. The most common type of report cards are dashboards and scorecards.

Scorecards

Scorecards provide a high-level, (often) one-page overview of an entity's long-term, strategic outcomes and goals. Selected scorecard indicators are therefore long-term and may be slow to change. They leverage data from multiple sources to describe and reflect changes over extended periods of time.

Scorecards are typically organized by program priority or strategy measure and performance against described goals using simple visualizations (e.g., raw numbers, arrows, and stoplights). Entities use scorecards to direct ownership and accountability by assigning key stakeholders to each strategic goal.

Alaska FASD Scorecard

In recent years, the GCDSE worked with key stakeholders to develop a statewide 5-year *Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022*. The strategic plan outlines a continuum of objectives and strategies identified to help decrease the prevalence of FASD, reduce the consequences of prenatal alcohol exposure, and improve the quality of life for individuals experiencing FASD.

The FASD Strategic Plan identifies key FASD-related prevention and intervention needs, and guiding stakeholder efforts. As the strategic plan's implementation proceeds, it is important to show progress towards FASD prevention with demonstrated outcomes. Currently, the main method of determining progress is an ongoing evaluation that tracks completion of plan objectives and strategies. While beneficial in documenting accomplishments, a process evaluation is unable to provide any information about the effectiveness of the initiatives and whether there is a reduction in the prevalence or consequences of prenatal alcohol exposure.

Over time, a limited range of data indicators, as well as a lack of coordinated data gathering and monitoring, has contributed to mixed programmatic progress and outcomes, or appropriate resource allocation. Increasing the continuum of data indicators should help improve the scorecard's effectiveness. An FASD data scorecard, with domains relevant to prevention and intervention, would benefit tracking progress and outcomes.

Scorecard Indicators

Alaska FASD Scorecard indicators reflect relevant information from Alaska's FASD Diagnostic Team Network, state, and national data sources. Where possible, indicators are aligned with the goals, priorities and objectives described in the *Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022*. A review of FASD literature and best practices also informed the selection of FASD scorecard indicators. This includes indicators related to maternal trauma and life stressors, out-of-home placement, age of diagnosis, and gender at diagnosis.

For reasons described in the *Prevention Policy Review* (Chapter 2), neither an FASD prevalence nor incidence rate can be determined in Alaska. When the ability to determine these rates is available, both rates should be included in the Scorecard.

According to the Alaska Longitudinal Child Abuse and Neglect Linkage Project (ALCANLink), the presence of adverse life events, such as multiple maternal stressors in the 12 months prior to birth, may be linked with household dysfunction and increased contact with child welfare services.[45] Data also show the number of past-year stressors experienced was related to any current drinking, current binge drinking (i.e., consuming five or more drinks for men or four or more drinks for women at least once in the past year), and current alcohol-use disorders. Among women, the relationship was generally linear, with increases in prevalence at each increase in past-year stressors.[46] Data on maternal stressors may be a useful indicator associated with FASD prevention strategies.

In general children with disabilities, including FASD, are at a greater risk of maltreatment and neglect than children without disabilities. Children with FASD are often placed in the care of child protection service agencies and frequently end up in out-of-home placement such as foster care.[47] Scorecard indicator data on out-of-home placement may be useful in developing FASD screening and interventional strategies within the child protection agencies.

A correct diagnosis early in life and a community network that understands FASD are important first steps to ensuring the right support systems can be accessed. Some experts identify diagnosis before age 6 as a "protective factor."[48] Scorecard data on age of diagnosis may inform screening and diagnostic approaches.

Certain evidence indicates that effects of prenatal alcohol exposure may vary by fetal gender. Males may have higher rates of diagnosis because of their increased likelihood to show certain diagnostic criteria earlier in life.[49] Data on gender at diagnosis may serve as an indicator to gender-specific evaluate diagnostic trends.

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[45] https://alaskamentalhealthtrust.org/wp-content/uploads/2018/06/HandOut-Jared-Parrish-ALCANLink-Presentation-080118-FINAL.pdf. Accessed June 30, 2020.

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[47] Caley, L., et al., What human service professionals know and want to know about fetal alcohol syndrome. Canadian Journal of Clinical Pharmacology, 2008. 15(1): p. e117-e123. Accessed July 6, 2020.

[48] https://www.fasdcenter.org/ask-expert-diagnose-not-whats-benefit-fasd-diagnosis. Accessed June 23, 2020.

[49] DiPietro, J. A., & Voegtline, K. M. (2017). The gestational foundation of sex differences in development and vulnerability. *Neuroscience*, *342*, 4–20. https://doi.org/10.1016/j.neuroscience.2015.07.068 Accessed June 23, 2020.

Scorecard Domains

FASD scorecard indicators are organized within three domains: primary, secondary, and tertiary prevention. These domains reflect a systematic approach to FASD prevention and intervention. Where available, comparisons with the most appropriate U.S. data are provided. Indicator targets are not included, as these have yet to be established by the Alaska FASD Strategic Plan Workgroup. The Alaska FASD Scorecard is found in Appendix A.

Data Management Guide

The Alaska FASD Scorecard Data Management Guide provides information essential to understanding the scorecard indicators. The guide includes an explanation of each indicator, as well as a description of each data source and methodology. The guide can be found in Appendix B.

Chapter 4: Recommendations

Recommendations were developed in collaboration with the Advisory Council and focus on data management, infrastructure, and performance measures for primary, secondary, and tertiary prevention strategies.

Data Recommendations

Managing Continued FASD Diagnostic Database

- Until the diagnostic process is revised, no changes are recommended for the diagnostic reporting form or the process of AKAIMS managing the data. AKAIMS is the most appropriate repository for maintaining these data.
- Consider revising data entry to include the number of out-of-home placements. Currently, the diagnostic reporting form includes a question for the number of out-of-home placements, but these data are not included in the FASD Diagnostic Database. While in many cases, this data may be unknown, what is known should be collected.
- During the strategic planning process, consider revisions to the diagnostic reporting tool to include additional demographic information of biological parents.
- Timing for an updated analysis of the FASD diagnostic data should occur at a minimum each time the FASD strategic plan is updated to inform the strategic planning process (the current plan expires in 2022).

Maintaining FASD Data Scorecard

- Until strategic goals are determined, there are no performance targets in the proposed scorecard. These targets could be established through a strategic planning or data committee process.
- The scorecard should be updated on a three-year cycle. This schedule will make it is easier to observe shifts in trends. This cycle also recognizes internal capacity may not be sufficient, sustainable, and cost-efficient on an annual update schedule.
- Most of the data in the scorecard are owned by DHSS and should be available (published or unpublished) for the foreseeable future and at no cost. However, some data will require special request and calculations to determine rolling averages, particularly the FASD Diagnostic Data.

Establishing an Epidemiological Working Group to Develop Prevalence and Incidence Measures

- Measuring FASD prevalence and incidence is admittedly complex and difficult and requires statewide collaboration. Opportunity exists to build statewide FASD surveillance strategies integral to developing prevalence estimates and incidence measures. An epidemiological working group could be established to strengthen this work. The multi-sectoral epidemiological working group should include, among others, member representation from DHSS (e.g., state epidemiologist, Alaska Birth Defects Registry), AMHTA, and FASD diagnostic teams and/or service agencies - including tribal health entities such as Southcentral Foundation. This working group could provide a platform to

strategically coordinate and enhance surveillance efforts and share lessons learned from sectoral perspectives.

- The epidemiological working group could review innovative and emerging approaches to measure prevalence, incidence, and other surveillance. For example, one innovative approach is conducting a representative sample of the population for a marker of alcohol exposure. Quantified alcohol use during pregnancy is one such marker. Regular screening of a representative sample of all newborn infants (in fact, of their mothers) is currently conducted in Alaska in the form of the PRAMS survey. Questionnaires asking about alcohol use during pregnancy have been shown to be unreliable (likely due to the associated social stigma). However, meconium samples or cord tissue samples of a newborn can accurately quantify the amount of and patterns of alcohol consumption by the mother during pregnancy. It may be possible to periodically piggyback on to the PRAMS survey to obtain meconium or cord tissue samples from this cohort (or a subset of the cohort) of new mothers and babies. Annual estimates of prevalence of alcohol levels during pregnancy based on this cohort could be obtained and tracked semi-regularly (perhaps collected every three years) to assess changes over time. These estimates of prevalence of alcohol use during pregnancy could be extrapolated to indicate changes in likely FASD prevalence over time.

Prevention Strategy Recommendations

Primary Prevention

Defining FASD

- FASD is not universally nor well understood. Like Canada, Alaska should develop a new definition of FASD that can be used for consistent public messaging. The definition should include no medical jargon (such as "teratogen" or "neurobehavioral disorder"), be easily understood by non-clinicians, and be crafted with the intent of removing stigma. The definition could be developed by staff or through a strategic planning process and tested to gauge consistent understanding by the public.
- An FASD definition could be included as a preface to the scorecard. The definition would set the context of the data and reflect the strategic objective of positive performance.

Promoting the FASD Scorecard

- The scorecard should be used to increase public awareness and measure state performance to address the prevalence, incidence, and impacts of FASD. It should be integrated into a public awareness campaign or messaging.

Updating the State's FASD Strategic Plan

- Alaska's state plan expires in 2022, so work for updating should start in 2021.
- The current plan is underdeveloped and does not include an implementation or evaluation plan. These two features are essential for accountability and collaborative effort.
- The strategic plan should establish performance targets, of which the scorecard can be used to measure performance.

Statewide alignment, interagency coordination, and leveraging opportunities to further FASD prevention efforts are critical. The Alaska FASD Strategic Plan should reflect coordination with other related statewide efforts, including strategic plans and/or identified priorities among DBH, Office of Substance Misuse and Addiction Prevention (OSMAP), Board of Medicine, Departments of Public Health, Corrections, and Education & Early Development, the Alcoholic Beverage Control Board, and tribal health entities. Strategic planning should address efforts to leverage existing opportunities to advance primary prevention through policy and legislation. For example, evidence on the prevalence and dangers of alcohol in pregnancy appears to have limited influence on state lawmakers' policy priorities when compared to concern over opioid use. Piggybacking on opioid efforts may provide a window of opportunity to further educate legislators on the consequences of both alcohol and opioid use in pregnancy.

- Ongoing and effective statewide strategic planning takes resources. The state should actively support U.S. Senate Bill S.2879 -- The Advancing FASD Research, Prevention, and Services Act introduced by Sen. Lisa Murkowski (Alaska) and Sen. Amy Klobuchar (Minnesota) in the Senate Health, Education, Labor, and Pensions Committee. This act would amend the Public Health Service Act to reauthorize and extend the Fetal Alcohol Spectrum Disorder Prevention and Services Program. The bill supports research, surveillance, building state FASD systems, promoting community partnerships, development of best practices and models of care, transitional services, funding, prevention, intervention, and services in the education and justice systems, among other items. It authorizes grants, contracts, or cooperative agreements to states for the purpose of *developing and implementing a statewide FASD strategic plan*, establishing or expanding statewide programs of surveillance, screening and diagnoses, prevention, and clinical intervention for individuals with FASD and their families.[50]

REQUIRING FASD TRAINING

- Primary care providers who care for women at risk for alcohol-exposed pregnancy and for those who work with individuals living with FASD should be required to complete continuing medical education (CME) directly related to FASD prevention and intervention. Training should emphasize the importance of discussing alcohol use with all females of child-bearing age and pregnant patients, whether or not risk factors are identifiable, and screening for alcohol use before and during pregnancy. Trainings should involve instructing healthcare professionals on how to talk to their patients in a nonjudgmental, culturally sensitive fashion that promotes the greatest honesty from patients. This should help eliminate the "not in my practice mentality."
- Foster parents should be required to be trained on FASD. Requiring foster parents to be trained on FASD, as a condition of licensure, can provide foster parents with tools and strategies for effectively caring for children with an FASD. Model legislation from Minnesota references a training curriculum that addresses the causes, symptoms, and key warning signs of mental health disorders; cultural considerations; and effective approaches for dealing with a child's behaviors.[51]

[50] https://www.congress.gov/bill/116th-congress/senate-bill/2879/text Accessed July 13, 2020.
[51] https://www.fasdcenter.org/wp-content/uploads/2017/10/FASDFosterCareTrainingRequirement.pdf Accessed July 14, 2020.

Expand Universal Screening

- Screening for alcohol use prior to pregnancy is critical to prevention. Collecting data on screening efforts is central to directing and monitoring prevention strategies. Alaska PRAMS currently asks multiple questions about what health care workers discuss with women during health care visits prior to becoming pregnant – including tobacco use. However, inquiry regarding alcohol use is not included. Alaska PRAMS should include the following question: *During any of your health care visits in the 12 months before you got pregnant, did a doctor, nurse, or other healthcare worker ask if you drank alcohol?*
- In 2017, Alaska BRFSS included the optional module Alcohol Screening and Brief Intervention (ASBI), which included questions such as: "At that checkup, were you asked in person or on a form if you drink alcohol?" and " Were you offered advice about what level of drinking is harmful or risky to your health?" However, this optional module was not included before 2017 and has not been included since. The ASBI module should be consistently included in the Alaska BRFSS as an indicator of screening efforts.

Public Awareness and Education

- Develop funding sources to strategically advance public awareness and educational campaigns tailored for varied audiences. Efforts should focus on positive messaging to promote awareness and discussion of alcohol use during pregnancy. Emphasis on risk reduction, stigma, a shared responsibility, and linkages to more information and help should be considered.

Secondary Prevention

Early Detection and Intervention

- Screening across the lifespan is an essential component of secondary prevention. Alaska FASD diagnostic team data indicates that the average age at diagnosis is 10.1 years. To bolster early detection and intervention for older youth and adults, age-appropriate universal screening approaches should be developed with key public and private stakeholders, including, among others, social service agencies, educational entities, and the Alaska Department of Corrections.
- Continue to expand the range and type of FASD early detection and intervention resources for all sectors. Professionals working in corrections, social services, OCS, and education (e.g., teachers and paraprofessionals) and other key individuals can play an important role in recognizing, screening, and assisting individuals with FASD. Training should also be conducted to reduce misdiagnoses of other conditions, such as autism, which may present similarly but with less stigma than FASD.
- Coordinate with OCS to maximize early detection and intervention opportunities. Child protection workers should have training that equips them to screen for FASD as part of case assessment, familiarity with the FASD diagnostic process, and knowledge of how to obtain a diagnosis for their clients.

Diagnostic Approaches

- Establish a workgroup to review statewide diagnostic approach(s) on a systematic basis, such as once every five years in association with strategic planning efforts. Specifically consider factors associated with long-term sustainability, availability of professional resources, geography and remoteness, and distribution of high-risk populations. Other entities have done this periodically throughout the last 20 years as a touchstone for ongoing capacity, quality, and sustainability.
- Engage in conversation with other states and/or provincial entities who are positioned to share information regarding review of diagnostic approaches and lessons learned in advancing diagnostic efforts in similar environments.

Tertiary Prevention

Coordination and Continuum of Care

- Identify opportunities and seek resources to further align and coordinate FASD treatment services – including treatment of secondary conditions (e.g., mental health issues, disruptive school experience, and trouble with the law). Treatment planning and approaches should reflect interagency coordination with special education and child development, mental health, substance misuse, legal, and disability resources.
- The transition to adulthood can be a challenging experience for individuals with FASD because of the expectation of increased responsibility and independence in adulthood. This can be further complicated if the individual is transitioning out of foster care. Consider developing a FASD Transitioning Toolkit, which includes planning for case management, housing and employment assistance, education and training, treatment and health care, life skills, family support, and appropriate transitioning for youth leaving OCS and Department of Corrections custody.

Service Planning

- Clearly define post-diagnosis expectations and protocols. Develop a transparent process for communicating and integrating diagnostic results into service planning. Ensure that the results of diagnostic testing are provided to key stakeholders (e.g., responsible party, primary care provider, and education system), along with other relevant diagnostic information. Such information is essential to developing an integrated treatment approach and mitigating the development of secondary conditions.
- Explore additional approaches to collecting more information on known siblings with FASD. This information may be useful in developing wrap-around services for the child and family.

Next Steps

With guidance from the FASD Advisory Group, implications of this study and next steps include:

Revisit Strategic Plan

Recognizing that a comprehensive strategic plan is the foundation for determining direction and priority, revisiting Alaska's *Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022* is a clear next step. Further work related to the strategic plan should:

- Consider FASD a public health issue rather than a behavioral health issue.
- Assess organizational and programmatic structure to reduce silos and expand agency collaboration for integrating and bridging of health, social, education, and justice services.
- Assess leadership structure to define a clear line of authority or oversight.
- Develop a new definition of FASD to inform the public in a nonclinical way and remove stigma.
- Evaluate the stability of the diagnostic tool; examine innovative and best-practice improvements in FASD diagnosis. Assess gender, agism, or cultural bias in diagnostic approaches, as well as sustainability of the chosen approach.
- Define strategic targets that can be integrated into the FASD Scorecard.

Assess barriers to prevalence estimates

- Organize an epidemiological workgroup to investigate approaches and surveillance system gaps, including screening approaches across the lifespan and data management.
- Investigate the overlap with autism diagnoses and symptomology. This may advance access to additional funding sources.
- Invite the National Institute on Alcohol Abuse and Alcoholism (NIAAA) to offer support and advice.

Analyze Services and Supports

- Conduct a gaps analysis of FASD prevention efforts and interventional services from preventive prenatal care through the continuum of care across the life span.
- Consider a longitudinal study of individuals diagnosed with FASD and their interaction with services and outcomes of these supports. This work has not been done but may be possible through AKAIMS and linkages to other data systems, such as the court system.

Disseminate Findings

- Prepare a communications plan to impart the findings of this work. Identify key audiences, avenues, and established opportunities (i.e. Alaska's FASD Awareness month) for targeted distribution of this information.

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Appendix A: Alaska FASD Scorecard

Primary Prevention *Eliminating root causes of FASD by broad-based efforts*	Most current Alaska data	Most current U.S. data	Alaska FASD Strategic Plan
ALCOHOL USE			
1. Female adolescents who report alcohol use (1+ drinks last month) (%)	23.5%	31.8%	
2. Females who report alcohol use before pregnancy (1+ drinks/week) (%)	58.6%	56.9%	
3. Females who report binge drinking before pregnancy (1+ times) (%)	17.4%	--	
4. Females who report alcohol dependency or abuse within past year (%)	7.4%	6.0%	
UNINTENDED PREGNANCY			
5. Females who report unintended pregnancy (%)	42.4%	44.4%	✓
Secondary Prevention ***Early detection and intervention***	**Most current Alaska data**	**Most current U.S. data**	**Alaska FASD Strategic Plan**
TRAUMA EXPOSURE			
6. Females who report multiple life stressors (4+ in 12 months before delivery) (%)	15.8%	15.7	✓
SCREENED WHILE PREGNANT			
7. Females who report being screened for alcohol use while pregnant (%)	97.5%	93.8%	✓
COUNSELED WHILE PREGNANT			
8. Females who report being counseled about alcohol use while pregnant (i.e. advised not to drink) (%)	89.3%	--	✓
ALCOHOL USE WHILE PREGNANT			
9. Females who report alcohol use while pregnant (1+ drinks/week) (%)	5.4%	8.0%	
10. Females who report binge drinking while pregnant (1+ times) (%)	0.7%	--	
ASSESSMENT REFERRALS			
11.Assessment referrals from Office of Children's Services (%)	21.9%	--	✓
12.Assessment referrals from Probation Office (Dept. of Corrections) (%)	0.7%	--	✓
NUMBER OF DIAGNOSIS			
13.Average annual number of clients diagnosed with FASD	135	--	
AGE AT DIAGNOSIS			
14. Average age at diagnosis (years)	9.1	--	
GENDER AT DIAGNOSIS			
15. Male gender at diagnosis (%)	56.5%	--	
OUT-OF-HOME PLACEMENT			
16.Individuals in out-of-home placement when diagnosed (%)	39.9%	--	✓
Tertiary Prevention ***Targeting advance recovery and relapse risk***	**Most Current Alaska Data**	**Most Current U.S. Data**	**Alaska FASD Strategic Plan**
SIBLINGS WITH FASD			
17.Clients with 1+ known biological sibling diagnosed with FAS (%)	23.9%	--	✓

Appendix B: Alaska FASD Scorecard Data Management Guide

Overview

The Alaska FASD Scorecard Data Management Guide provides information essential to understanding scorecard indicators. The guide includes a full description of each indicator, data source, methodology, and guidance for accessing data.

Description of Scorecard Indicators

Primary Prevention Indicators

Alcohol Use

1. Percentage of females ages 15-18 years who report having at least one drink of alcohol during the past 30 days. (Alaska YRBS 2019, U.S. 2017).

2. Percentage of females ages 18-44 years who report consuming at least one alcoholic drink in an average week during the three months prior to becoming pregnant (Alaska PRAMS 2017-2019, U.S. 2017-2019).

3. Percentage of females ages 18-44 years who report binge drinking alcohol at least one time during the three months before pregnancy. Binge drinking is defined as consuming four alcoholic drinks or more in a two-hour time span (Alaska PRAMS 2017-2019, no comparable U.S. available).

4. Percent of females ages 15-44 years who report alcohol dependency or abuse within the past year (Alaska NSDUH 2017-2018, U.S. 2017-2018).

Unintended Pregnancy

5.Percentage of females ages 18-44 years who report not trying to get pregnant when they became pregnant (Alaska PRAMS 2017-2019, U.S 2017-2019).

Secondary Prevention Indicators

Trauma Exposure

6.Percentage of females ages 18-44 years who report experiencing four or more life stressors in the 12 months prior to delivery (Alaska PRAMS 2017-2019, U.S. 2017-2019).

Screened while Pregnant

7. Percentage of females ages 18-44 years who report being asked by a healthcare worker if they use alcohol during any prenatal visit (Alaska PRAMS 2017-2019, U.S. 2017-2019).

Counseled While Pregnant

8. Percentage of females ages 18-44 years who report being advised by a healthcare worker regarding alcohol use during any prenatal visit (Alaska PRAMS 2017-2019, no comparable U.S. available).

Alcohol Use While Pregnant

9. Percentage of females ages 18-44 years who report consuming at least one alcoholic drink in an average week during the last three months of pregnancy (Alaska PRAMS 2017-2019, U.S. 2017-2019).

10. Percentage of females ages 18-44 years who report binge drinking alcohol at least one time during the last three months of pregnancy. Binge drinking is defined as consuming four alcoholic drinks or more in a two-hour time span (Alaska PRAMS 2017-2019, no comparable U.S. available).

Assessment Referrals

11. Percentage of all clients referred for assessment by Alaska OCS (Alaska FASD data 2017-2019).

12. Percentage of all clients referred to assessment by Alaska Division of Probation and Parole, DOC (Alaska FASD data 2017-2019).

Number of Diagnosis

13. Number of clients diagnosed annually with FASD by Alaska FASD diagnostic teams (FASD diagnostic team data 2017-2019).

Age at Diagnosis

14. Clients' annual average age at the time of diagnosis (FASD diagnostic team data 2017-2019).

Gender at Diagnosis

15. Percentage of clients diagnosed who were male at the time of diagnosis (FASD diagnostic team data 2017-2019).

Out-of-Home Placement

16. Percentage of all clients living in an out-of-home placement at time of diagnosis (FASD diagnostic team data 2017-2019).

Tertiary Prevention Indicators

Siblings with FASD

17. Percentage of clients with known biological siblings having at least one known biological sibling diagnosed with FAS (FASD diagnostic team data 2017-2019).

Data Sources

FASD Diagnostic Team Network Data

General Description

Alaska's FASD Diagnostic Team Network began collection data in 1999. Beginning in 2011, data has been maintained in AKAIMS. This dataset includes FASD assessment data made by diagnostic teams reporting assessments to DBH for purposes of seeking state reimbursement for assessment services as part of the State of Alaska FASD Diagnostic Team Provider Agreement network.

Specific FASD diagnostic team data questions associated with scorecard indicator data include:

- *What percentage of assessment referrals came from OCS?*
- *What percentage of assessment referrals came from DOC?*
- *What is the average annual number of clients diagnosed with FASD?*
- *What was the clients' annual average age at time of diagnosis?*
- *What percentage of clients diagnosed were male at time of diagnosis?*
- *What percentage of all clients were living in an out-of-home placement at time of diagnosis?*
- *What percentage of clients with a known biological sibling had at least one known biological sibling diagnosed with FAS?*

Data Considerations

The number of diagnostic teams performing FASD assessments and seeking state reimbursement varies from year to year. Not all diagnostic teams in Alaska seek state reimbursement for assessment services as part of the State of Alaska FASD Diagnostic Team Provider Agreement network. Therefore, this dataset does not represent the characteristics or diagnostic outcomes of all individuals assessed in Alaska.

FASD Diagnostic Team Network Data reflected in the Alaska FASD Scorecard is a three-year rolling average (2017-2019). No national U.S. comparative data is available on these indicators.

Data Access

FASD diagnostic team data in AKIMS can be accessed by special request to DHSS. However, scorecard indicator data will need to be analyzed and three-year averages will need to be calculated.

Pregnancy Risk Assessment Monitoring System (PRAMS)

General Description

Alaska Pregnancy Risk Assessment Monitoring System (PRAMS) Project is an on-going survey of mothers of newborns and was initiated by the State of Alaska Division of Public Health, Section of Maternal, Child and Family Health in 1990. PRAMS collects state-specific, population-based data on maternal attitudes and experiences before, during, and after pregnancy.

The PRAMS questionnaire includes core questions that are asked by all participating states and state-specific questions that are chosen or developed by individual states. The core portion of the questionnaire includes questions on content of prenatal care, use of alcohol before and during pregnancy, and psychosocial stress, among others.

Specific PRAMS core questions associated with scorecard indicator data include:

- *During the three months before you got pregnant, how many alcoholic drinks did you have in an average week?*
- *During the three months before you got pregnant, how many times did you drink four alcoholic drinks or more in a two-hour time span?**
- *When you got pregnant with your new baby, were you trying to get pregnant?*
- *This question is about things that may have happened during the 12 months before your new baby was born. For each item, check No if it did not happen to you or Yes if it did.*
    a. *A close family member was very sick and had to go into the hospital.*
    b. *I got separated or divorced from my husband or partner.*
    c. *I moved to a new address.*
    d. *I was homeless or had to sleep outside, in a car, or in a shelter.*
    e. *My husband or partner lost their job.*
    f. *I lost my job even though I wanted to go on working.*
    g. *My husband, partner, or I had a cut in work hours or pay.*
    h. *I was apart from my husband or partner due to military deployment or extended work-related travel.*
    i. *I argued with my husband or partner more than usual.*
    j. *My husband or partner said they didn't want me to be pregnant.*
    k. *I had problems paying the rent, mortgage, or other bills.*
    l. *My husband, partner, or I went to jail.*
    m. *Someone very close to me had a problem with drinking or drugs.*
    n. *Someone very close to me died.*
- *During the last three months of your pregnancy, how many alcoholic drinks did you have in an average week?*
- *During the last three months of your pregnancy, how many times did you drink four alcoholic drinks or more in a two-hour time span?**
- *During any of your prenatal care visits, did a doctor, nurse, or other health care worker ask you if you were drinking alcohol?*
- *During any of your prenatal care visits, did a doctor, nurse, or other health care worker advise you not to drink alcohol while you were pregnant?**

DATA CONSIDERATIONS

On an annual basis in Alaska, approximately one of every six mothers of newborns is selected for PRAMS. Mothers are randomly selected from birth records at the Health Analytics and Vital Records. Women from some groups are sampled at a higher rate to ensure adequate data are available in smaller but higher risk

populations. Data collection procedures and instruments are standardized to allow comparisons between states.

PRAMS indicator data as reflected in the Alaska FASD Scorecard is a three-year rolling average. U.S. national comparative data are available, except for above questions marked with an asterisk (*).

DATA ACCESS

PRAMS data are available free of charge. Select data query modules can be accessed through Alaska IBIS, the State of Alaska's DHSS Indicator-based Information System for Public Health. Additional data may be obtained through a special request to DHSS. Scorecard indicator data will need to be analyzed and three-year averages will need to be calculated, where not available in per standard query modules. National data is available upon special request.

National Survey of Drug Use and Health (NSDUH)

GENERAL DESCRIPTION

The National Survey on Drug Use and Health (previously referred to as the National Household Survey on Drug Abuse) is an annual nationwide survey on the use of legal and illegal drugs, as well as mental disorders, that has been conducted by the United States government since 1971. It is funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) and is supervised by the SAMHSA's Center for Behavioral Health Statistics and Quality. Data are collected from individuals residing in households, noninstitutionalized group quarters (e.g., shelters, rooming houses, dormitories) and civilians living on military bases. The survey interviews about 70,000 Americans ages 12 and older, through face-to-face interviews conducted where the respondent lives. The NSDUH, along with the Monitoring the Future, is one of two main ways the National Institute on Drug Abuse measures drug use in the United States.

NSDUH alcohol dependence criteria questions associated with scorecard indicator data include:

- *Spent a great deal of time over a period of a month or more getting, using, or getting over the effects of alcohol.*
- *Used alcohol more often than intended or was unable to keep set limits on alcohol use.*
- *Needed to use alcohol more than before to get desired effects or noticed that same amount of alcohol use had less effect than before.*
- *Inability to cut down or stop using alcohol every time tried or wanted to.*
- *Continued to use alcohol even though it was causing problems with emotions, nerves, mental health, or physical problems.*
- *Alcohol use reduced or eliminated involvement or participation in important activities.*
- *Reported experiencing two or more alcohol withdrawal symptoms at the same time that lasted longer than a day after alcohol use was cut back or stopped. Symptoms include (i) sweating or feeling that heart was beating fast; (ii) having hands tremble; (iii) having trouble sleeping; (iv) vomiting or feeling nauseous; (v) seeing, hearing, or feeling things that were not really there; (vi) feeling like could not sit still; (vii) feeling anxious; and (viii) having seizures or fits.*

DATA CONSIDERATIONS

NSDUH alcohol dependence or abuse questions are based on the criteria in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV); American Psychiatric Association, 1994. To be defined with alcohol dependence, a survey respondent must have met three or more alcohol dependence criteria.

NSDUH indicator data as reflected in the Alaska FASD Scorecard is a two-year average. U.S. national comparative data is available.

DATA ACCESS

NSDUH indicator data may be accessed through the Substance Abuse & Mental Health Data Archive's (SMHDA) Public-Use Data Analysis System. The system allows crosstab analysis; there is no cost associated with obtaining this data.

Youth Behavior Risk Survey (YRBS)

GENERAL DESCRIPTION

The Youth Risk Behavior System (YRBS) surveys high school students nationwide regarding risk behaviors. As a school-based survey, the Alaska YRBS provides important information about the health of Alaska teens, including health risk behaviors that contribute to social problems, disabilities, and even death. Alaska students take the YRBS every other year in odd-numbered years in public traditional, alternative (associated with at-risk students, and juvenile justice and correctional high schools.

The YRBS question associated with scorecard indicator data is:

- *During the past 30 days, on how many days did you have at least one drink of alcohol?*

DATA CONSIDERATIONS

From January through March, more than 7,000 high school students from more than 100 Alaska schools complete the YRBS. Participation in the YRBS is anonymous, voluntary, and requires written parental consent. The YRBS Program rarely releases the raw data. Statewide data may be broken down by traditional/alternative schools, gender, race, and school grade.

YRBS data as reflected in the Alaska FASD Scorecard is the most current data available for Alaska females ages 15-18 in traditional high school (does not include alternative high schools). U.S. national comparative data are available.

DATA ACCESS

Statewide and national data are easily accessible on the CDC's Youth Online tool (https://nccd.cdc.gov/Youthonline/App/Default.aspx) or by special request. No fee is required at this time.