Fetal Alcohol Spectrum Disorders Healthcare Utilization Study

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PREPARED FOR:

Trust

Alaska Mental Health Trust Authority

McKINLEY RESEARCH GROUP, LLC

Formerly McDowell Group

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Executive Summary

What is FASD?

Exposure to alcohol during pregnancy can cause a variety of birth defects, known as Fetal Alcohol Spectrum Disorders (FASD), which include Fetal Alcohol Syndrome (FAS), partial FAS (PFAS), alcohol-related neurodevelopmental disorder (ARND), and other alcohol-related birth defects (ARBD). Effects of FASD are lifelong, numerous, varied, and often complex.

What are common impacts of FASD?

The most common developmental disabilities associated with FASD include cognitive and behavioral impairments associated with decreased intelligence quotient and deficits in motor skills, attention, executive function, language, visual perception, and adaptive functioning, among other neurological abnormalities. Emerging research indicates that individuals experiencing an FASD may be more susceptible to atypical aging and related health consequences, such as the early onset of chronic diseases and degenerative conditions. Common impairments include structural and skeletal anomalies, growth and sensory issues, dental anomalies, hearing and vision difficulties, organ system defects, immune system comprise, and chronic condition development.

In a recent Canadian survey of adults with FASD, these impacts are dramatic and serious:

- Autism/Asperger's Spectrum Disorder (ASD) was 6.6 was times higher than in the general population.
- Numerous musculoskeletal conditions occurred more frequently, including fused vertebrae in the neck (880.0 times), pectus carinatum (46.3) femoral rotation (44.0 times), and abnormalities of the digits such as pectus excavatum (36.0), syndactyly (20.5), and camptodactyly (19.9).
- Congenital heart defects and cardiomyopathy were 11.7 and 21.1 times higher than in the general population, respectively. Having heart surgery as a child occurred at a rate 10.8 times higher.
- Gastrointestinal and digestive system conditions were about two times higher.
- Clinically evident hypothyroidism was 186.7 times higher and hypoglycemia (not related to diabetes) 87.2 times higher.
- Chronic ear infections were 146.8 times higher; acute sinusitis 46.5 times, kidney infections 830.0 times, staph infections 80.0 times, and bone infections 200.0 times higher.

- Early onset dementia was 209.3 times higher, as was attempted suicide (49.5 times higher), agoraphobia (18.4), AHDH/ADD (18.1), panic disorder (17.1) and psychosis (10.5).

What is the purpose of this study?

The Alaska Mental Health Trust Authority contracted with McKinley Research Group to conduct an analysis of health services utilization to learn more about how expectant mothers with alcohol-use disorder, infants impacted by maternal alcohol use, and individuals experiencing an FASD used clinical and community health supports.

How was the research conducted?

Several research methods were used for this study, including secondary health service utilization data analysis (including data from Medicaid, Alaska Hospital Facilities Data Reporting, Federally Qualified Health Centers, and Division of Behavioral Health), a literature review regarding health utilization and policies, and executive interviews with subject matter experts and other stakeholders. Wherever possible, data were delineated using various life stages, including pregnancy and prenatal, infancy (birth to age 1), early childhood (ages 1 to 5), late childhood (ages 6 to 12), adolescence (ages 13 to 17), and adulthood (ages 18 to 64). Most data reported refer to 2019 (calendar or state fiscal year). For Medicaid indicators, data were calculated per geographic regions: Southcentral Alaska and All of the Alaska Boroughs/Census Areas.

What were the data challenges?

Data challenges identifying individuals with FASD stem from relying on self-reporting of alcohol use during pregnancy and an individual's access to FASD diagnostic services. Additionally, FASD is an umbrella term and not a specific diagnostic code. Therefore, only individuals with FAS and pregnant women with alcohol-use disorders were captured in the data analysis. With these and factors, it is highly likely data presented in this analysis underreport health services utilization for these populations. Additionally, the data analysis is limited to a one-year snapshot that does not capture the culmination of utilization patterns over a person's life span or transition between life stages, such as from adolescents into adulthood.

What are some data highlights?

Pregnant Women with Alcohol-use Disorders

- In SFY2019, 67 Medicaid beneficiaries were identified as pregnant women with alcohol-use disorders and receiving health services. The average annual number of claims for these beneficiaries was 64% higher than the comparison group (pregnant women with no substance use disorder) (77.1 and 46.8, respectively).
- For all Medicaid service categories, except therapy/rehabilitation, home health/hospice, laboratory/x-ray, early and periodic screening, and other services, pregnant beneficiaries with alcohol-use disorders used a higher percentage of services than the comparison group.
- In SFY2019, Alaska hospitals had 114 admissions by pregnant women with alcohol-use disorders receiving inpatient care, 198 outpatient visits, and 32 emergency department visits.

Top 5 Medicaid Services Used by Pregnant Women with Alcohol-use Disorders
(on a percentage basis)

1. Outpatient services & physician/practitioner services (both 95.5%)
2. Pharmacy (89.6%)
3. Health clinic (76.1%)
4. Inpatient hospital services (64.2%)
5. Transportation (56.7%)

Infants Impacted by Maternal Alcohol Use (birth to 1 year)

- In SFY2019, 71 Medicaid beneficiaries were identified as infants impacted by maternal alcohol use and receiving health services. The average annual number of claims for these beneficiaries was 227% higher than the comparison group (infants with no maternal substance use) (69.4 and 21.2, respectively).
- For all Medicaid service categories, except dental, early and periodic screening, and laboratory/x-ray, infants impacted by maternal alcohol use used a higher percentage of services than the comparison group.
- In SFY2019, Alaska hospitals had 35 admissions by infants affected by maternal alcohol misuse receiving inpatient care, 32 outpatient visits, and one emergency department visit.

Top 5 Medicaid Services Used by Infants Impacted by Maternal Alcohol Use
(on a percentage basis)

1. Physician/practitioner services (both 93.0%)
2. Inpatient hospital services (83.1%)
3. Early and periodic screening (81.7%)
4. Outpatient services (52.1%)
5. Pharmacy (46.5%)

Early Childhood (Ages 1-5)

- In SFY2019, 70 Medicaid beneficiaries were identified as children ages 1 to 5 with FAS and receiving health services. The average annual number of claims for these beneficiaries was 283% higher than the comparison group (those without FAS) (89.1 and 23.3, respectively).
- For all Medicaid service categories, children with FAS ages 1 to 5 used a higher percentage of services than the comparison group.

Top 5 Medicaid Services Used by Children Ages 1 to 5 with FAS
(on a percentage basis)

1. Physician/practitioner services (both 94.3%)
2. Outpatient services (75.7%)
3. Pharmacy (68.6%)
4. Early and periodic screening (64.3%)
5. Therapy/rehabilitation (55.7%)

- In SFY2019, Alaska hospitals had two admissions by individuals with FAS, aged 1 to 5, receiving inpatient hospital care, 79 outpatient visits, and three emergency department visits.

Late Childhood (Ages 6-12)

- In SFY2019, 243 Medicaid beneficiaries were identified as children ages 6 to 12 with FAS and receiving health services. The average annual number of claims for these beneficiaries was 431% higher than the comparison group (those without FAS) (151.9 and 28.6, respectively).
- For all Medicaid service categories, children with FAS ages 6 to 12 used a higher percentage of services than the comparison group.

Top 5 Medicaid Services Used by Children Ages 6 to 12 with FAS
(on a percentage basis)

1. Physician/practitioner services (both 86.8%)
2. Dental (72.8%)
3. Pharmacy (72.0%)
4. Outpatient services (57.2%)
5. Outpatient mental health (53.9%)

- In SFY2019, Alaska hospitals had 39 admissions by individuals with FAS, aged 6 to 12, receiving inpatient hospital care, 145 outpatient visits, and 11 emergency department visits.

Adolescents (Ages 13-17)

- In SFY2019, SFY2019, 175 Medicaid beneficiaries were identified as children ages 13 to 17 with FAS receiving health services. The average annual number of claims for these beneficiaries was 479% higher than the comparison group (those without FAS) (241.6 and 41.7, respectively).
- For all service categories, children with FAS, ages 13 to 17, used a higher percentage of Medicaid services than the comparison group.
- In SFY2019, Alaska hospitals had 75 admissions by individuals with FAS, aged 13 to 17, receiving inpatient hospital care, 64 outpatient visits, and 11 emergency department visits.

Top 5 Medicaid Services Used by Adolescent Ages 13 to 17 with FAS
(on a percentage basis)

1. Physician/practitioner services (both 90.3%)
2. Pharmacy (82.9%)
3. Dental (68.0%)
4. Outpatient mental health (63.4%)
5. Outpatient services (56.6%)

Adults (Ages 18-64)

- In SFY2019, 320 Medicaid beneficiaries were identified as adults ages 18 to 64 with FAS receiving health services. The average annual number of claims for these beneficiaries was 305% higher than the comparison group (those without FAS) (271.3 and 66.9, respectively).
- For all service categories, except laboratory and x-ray, adults with FAS, ages 18 to 64, used a higher percentage of Medicaid services than the comparison group.
- In SFY2019, Alaska hospitals had 105 admissions by individuals with FAS, aged 18 and above, receiving inpatient hospital care, 329 outpatient visits, and 92 emergency department visits.

Top 5 Medicaid Services Used by Adults Ages 18 to 64 with FAS
(on a percentage basis)

1. Physician/practitioner services (both 93.8%)
2. Outpatient services (84.7%)
3. Pharmacy (73.4%)
4. Health clinic (57.1%)
5. Dental (53.1%)

What are the implications for health utilization?

Population Health Approach

The varied scope and breadth of lifelong needs is best addressed through a multi-disciplinary, integrated population health approach. This interdisciplinary, customizable approach uses non-traditional partnerships among different sectors of the community – public health, industry, academia, health care, local government entities, etc., to achieve positive health outcomes.

Stigma

Stigma can 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. 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.

Knowledgeable Providers

Interventions for individuals experiencing an FASD have yet to capitalize on the skillset of providers, nurses, and other allied health professionals. These providers have unique opportunities to use information on family experience to support families in the reduction of potential primary effects related to PAE and prevention of secondary conditions. Survey-based studies of health professionals have documented insufficient knowledge about FASD and a lack of perceived competence when serving individuals with FASD.

Primary Prevention and Continuum of Care

Research literature suggests that women respond to prevention services aimed at improving their health, including efforts to decrease or stop substance use or to increase their safer use of substances. In Alaska, there does not appear to be a coordinated effort to use the CHOICES tools recommended for primary FASD prevention, including the brief alcohol screening and intervention tool. A comprehensive continuum of care approach has demonstrated the benefits of helping women plan their pregnancies, obtain prenatal care, improve their nutrition, reduce stress in pregnancy, and, in some cases, access treatment. Standard systems of care often do not meet the needs of women with prenatal or postnatal substance-use issues, especially women trying to raise children.

Standardized Screening

Standardized screening for alcohol use “is an ethical obligation” and provides high-risk women opportunities with advocacy support and primary prevention intervention. Alcohol use is often a difficult subject for providers to discuss with the patient, especially in a sensitive manner. 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).

FASD Diagnostic Limitations

FAS is a medical diagnosis with well-defined criteria, while the boundaries to normality and to other disorders within FASD are less clear. The typical link between diagnosis and a reasonably well-specified set of treatments is missing, which clearly diminishes the point of diagnosis. FASD

is often overlooked or misdiagnosed. Some clinicians perceive FASD to be primarily a problem for children of women with alcohol-use disorders or belonging to sub-populations of marginalized or oppressed groups. However, higher socioeconomic status is a strong predictor of PAE, and it is likely that FASD is underdiagnosed in educated, financially secure groups.

Early Diagnosis

Early diagnosis can increase the chances of obtaining early support that strengthens the individuals' ability over time and control over their own lives. Based on the literature, the odds of escaping adverse life outcomes (i.e., disrupted school experience, trouble with the law, sexual behaviors, and drug/alcohol problems) are increased two- to four-fold by receiving the FASD diagnosis at an earlier age and by being reared in good stable environments.

Post-Diagnosis Services

Service recommendations for individuals and families include care coordination and case management services, educational assessment and intervention, caregiver support and respite services, community-based recreational programs, child counselling and psychiatric services, occupational and speech language therapy assessments, and substance misuse prevention.

Classified Disability

Obtaining an FASD diagnosis, plus qualifying and maintaining services for FASD, is harder than for other developmental disabilities with similar symptoms, such as autism. FASD needs to be classified or recognized as a categorial developmental disability to ensure eligibility for Medicaid-funded services at the same level as autism or any developmental disabilities. A new definition of Intellectual Disability/Development Disability (ID/DD) is recommended.

Care Coordination

Care coordination and high-quality case management is essential from early childhood into adulthood. The risk for secondary conditions dramatically increases during adolescence and young adulthood, periods during which fewer community-based supports are generally available. A formal system for care coordination of FASD services does not appear to exist among providers more highly used among persons impacted by FASDs. Approaches that would support increased coordination and integration of care include a) electronic medical records; b) a client-centered medical home; and c) multidisciplinary primary care group practice models. Increased information sharing among both medical and non-medical service providers through eHealth may increase efficiency and system-level capacity.

Key Terms and Abbreviations

Key Terms

Working definitions of key terms used in this study follow:

Adolescence	Primarily ages 13 to 17.
Adulthood	Primarily ages 18 and over.
FASD diagnostic team	An interdisciplinary team specifically trained in select FASD diagnostic criteria and methodologies.
Early childhood	Primarily ages 1 to 5.
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).
Infancy	Birth to age 1.
Late childhood	Primarily ages 6 to 12.
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.
Primary effect	Impact to *in utero* fetal development, including adverse effects related to prenatal alcohol exposure.
Prenatal	Existing or occurring before birth.
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.
Secondary prevention	Secondary prevention focuses on early detection and intervention of a health issue.
Secondary conditions	Problems that a person is not born with but may develop because of an FASD.
Stigma	A mark of disgrace association with a particular circumstance, quality, or person.
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
AST	Alaska Screening Tool
CDC	U.S. Centers for Disease Control and Prevention
CNS	Central Nervous System
DBH	Alaska Division of Behavioral Health
DHSS	Alaska Department of Health and Social Services
FAS	Fetal alcohol syndrome
FASD	Fetal alcohol spectrum disorders
FQHC	Federally Qualified Health Centers
HFDR	Alaska Hospital Facilities Data Reporting
ICD	International Classification of Diseases
ND/AE	Neurobehavioral Disorder/Alcohol Exposed
OCS	Alaska Office of Children's Services
PAE	Prenatal alcohol exposure
PFAS	Partial fetal alcohol syndrome
SAMHSA	Substance Abuse and Mental Health Services Administration
SBIRT	Screening, brief intervention, and referral to treatment
SE/AE	Static Encephalopathy/Alcohol Exposed
SFY	State fiscal year
UDS	Uniform Data System

Methodology

Several research methods were used for this study, including secondary health service utilization data analysis, a literature review regarding health utilization and policies, and executive interviews with subject matter experts and other stakeholders.

Wherever possible, research was delineated using various life stages, including pregnancy and prenatal, infancy (birth to age 1), early childhood (ages 1 to 5), late childhood (ages 6 to 12), adolescence (ages 13 to 17), and adulthood (ages 18 to 64).

Data Limitations

The McKinley Research Group study team employed guidance from experts and data analysts, as well as careful consideration, to identify health services utilization associated with preventing alcohol harm among pregnant women and for individuals experiencing an FASD. Data challenges in identifying individuals with FASD stem from relying on self-reporting of alcohol use during pregnancy and an individual's access to FASD diagnostic services. To add even more complexity, FASD is an umbrella term and not a specific diagnostic code. Therefore, only individuals with Fetal Alcohol Syndrome (FAS) and pregnant women with an identified alcohol-use disorder were captured in the data analysis. Additionally, FAS and FASD is often misdiagnosed or missed. FAS/FASD is also excluded from the list of alcohol-related conditions for which alcohol-attributable fractions can be calculated because 1) mortality data due to FASD is not well recorded, as these harm estimates are based on prevalence estimates on drinking while pregnant; and 2) FASD is a condition that is not experienced by the alcohol consumer themselves and therefore falls into the category of harm to others. With these factors, it is highly likely data presented in this report underreports health services utilization data for pregnant women with alcohol-use disorders and individuals experiencing an FASD.

Additionally, the data analysis is limited to one-year (2019) and thereby only captures a limited snapshot of health utilization patterns and does not capture the cumulative impacts on health utilization over the entire life span or transitions between life stages such as from adolescents into adulthood.

Health Data

Sources of utilization data include Alaska's hospital facilities, federally qualified health centers (FQHC), behavioral health services, Medicare, and Medicaid. FQHC data were analyzed for calendar year (CY) 2019. For all other data sources, state fiscal year (SFY) 2019 data were analyzed as 2020 use patterns were considered atypical due to COVID-19 impacts.

Medicaid

Using alcohol-related International Classification of Diseases (ICD)-10 codes, Medicaid data for individuals with FAS primary and secondary diagnoses any time in SFY2019 were provided by Alaska Department of Health and Social Services through a special data request. Based on all reimbursements for claimants, indicators included:

- Total number of beneficiaries by study/comparison group
- Average number of claims per beneficiary
- Average dollar value per claim
- Average dollar value of all claims per beneficiary
- Total number of claims by study/comparison group
- Total dollar value of all claims by study/comparison group

Data were requested for three groups of claimants and a comparison group.

- **Study Group 1:** Pregnant Women with any alcohol-use disorder, including claimants who are pregnant women with any known alcohol use complicating pregnancy or with care due to damage to the fetus from alcohol. The following ICD-10 codes were used to identify these claimants.
    - O35.4 Maternal care for (suspected) damage to fetus from alcohol
    - O99.314 Alcohol use complicating childbirth
    - O99.311 Alcohol use complicating pregnancy, first trimester
    - O99.312 Alcohol use complicating pregnancy, second trimester
    - O99.313 Alcohol use complicating pregnancy, third trimester
    - O99.310 Alcohol use complicating pregnancy, unspecified trimester
    - O99.315 Alcohol use complicating the puerperium

  The comparison group for Study Group 1 included any pregnant woman without substance misuse complicating pregnancy or impacting the fetus. The following ICD-10 categories were used to exclude claimants from the comparison study group.
    - O35.4XX0-4XX9 Maternal care for (suspected) damage to fetus from alcohol
    - O99.314 Alcohol use complicating childbirth
    - O99.311 Alcohol use complicating pregnancy, first trimester
    - O99.312 Alcohol use complicating pregnancy, second trimester
    - O99.313 Alcohol use complicating pregnancy, third trimester
    - O99.310 Alcohol use complicating pregnancy, unspecified trimester
    - O99.315 Alcohol use complicating the puerperium
    - O35.5XX0-5XX9 Maternal care for (suspected) damage to fetus by drugs
    - O99.324 Drug use complicating childbirth
    - O99.321 Drug use complicating pregnancy, first trimester
    - O99.322 Drug use complicating pregnancy, second trimester
    - O99.323 Drug use complicating pregnancy, third trimester
    - O99.320 Drug use complicating pregnancy, unspecified trimester
    - O99.325 Drug use complicating the puerperium

- **Study Group 2: I**nfants (birth to age one) diagnosed at birth with FAS. The following ICD-10 codes were used to identify these claimants.
    - Q86.0 Fetal alcohol syndrome (dysmorphic)
    - P04.3 Newborn affected by maternal use of alcohol

  The comparison group included any infants without impacts from any substance misuse. The following ICD-10 categories were used to exclude claimants from the comparison study group.
    - Q86.0 Fetal alcohol syndrome (dysmorphic)
    - P04.3 Newborn affected by maternal use of alcohol
    - P96.1 Neonatal withdrawal symptoms from maternal use of drugs of addiction
    - P04.4 Newborn affected by maternal use of drugs of addiction
- **Study Group 3**: Individuals who have FAS at any time during SFY2019. This study group was further grouped by the following four age categories at time of FAS/FASD diagnoses on record.
    - Study Group 3a: Age 1 through 5
    - Study Group 3b: Age 6 through 12
    - Study Group 3c: Age 13 through 17
    - Study Group 3d: Age 18 through 64

  The following ICD-10 code were used to identify claimants in this study population group.
    - Q86.0 Fetal alcohol syndrome (dysmorphic)

  The comparison group for Study Groups 3a-3d included any claimant without a developmental disability. The following ICD-10 categories were used to exclude claimants from the comparison study group.
    - Q86.0 Fetal alcohol syndrome (dysmorphic)
    - G93.40 Encephalopathy, unspecified
    - F70-F79 Intellectual disabilities
    - F80-F89 Pervasive and specific developmental disorders
    - F90-F98 Behavioral and emotional disorders with onset usually occurring in childhood and adolescence

Indicators were calculated for residents of the following two geographic regions, considering statewide population distribution factors.

- **Region 1:** Southcentral Alaska – Municipality of Anchorage, Matanuska-Susitna Borough, Kenai Peninsula Borough
- **Region 2:** All Other Alaska Boroughs/Census Areas

Indicators were grouped by service categories as outlined below.

- Behavioral Health
    - Inpatient psychiatric hospital
    - Outpatient mental health

    - Residential psychiatric/behavioral rehab services
- Long-Term Care
    - Home and community-based waiver
    - Respite care
    - Home health/hospice
    - Nursing home
    - Personal care
- Medical/Other
    - Dental
    - Durable medical equipment/supplies
    - Early & periodic screening, diagnosis & treatment
    - Health clinic
    - Inpatient hospital
    - Laboratory/x-ray
    - Other services
    - Outpatient hospital
    - Pharmacy
    - Physician/practitioner services
    - Therapy/rehabilitation
        - Physical therapy
        - Occupational therapy
        - Speech therapy
    - Transportation
    - Vision

Alaska Hospital Facilities Data Reporting

The Alaska Hospital Facilities Data Reporting (HFDR) program SFY2019 dataset provided the number of admissions/visits, length of stay, and hospital charges for inpatient admissions, outpatient visits, and emergency department visits for admissions/visits for pregnant women with an alcohol-use disorder, infants affected by maternal alcohol use, and individuals with an FAS diagnoses.

The following diagnoses codes were used to identify hospital admissions/visits for individuals in this study, including records with a primary or secondary diagnosis in this set.

Table 1. ICD-10 Codes Used to Identify HFDR Records

Group	ICD-10 Code	Description
Pregnant women with alcohol-use disorders	O35.4	Maternal care for (suspected) damage to fetus from alcohol
	O99.314	Alcohol use complicating childbirth
	O99.311	Alcohol use complicating pregnancy, first trimester
	O99.312	Alcohol use complicating pregnancy, second trimester
	O99.313	Alcohol use complicating pregnancy, third trimester
	O99.310	Alcohol use complicating pregnancy, unspecified trimester
	O99.315	Alcohol use complicating the puerperium
Infants affected by maternal alcohol use	Q86.0	Fetal alcohol syndrome (dysmorphic)
	P04.3	Newborn affected by maternal use of alcohol
Individuals with FAS (ages 1 - 64)	Q86.0	Fetal alcohol syndrome (dysmorphic)

Charges presented by HFDR represent the amount charged by a facility for services, not the final amount paid.

Federally Qualified Health Centers

All FQHCs in the United States receive federal grants to support their work in bringing quality and culturally sensitive primary health care to underserved and vulnerable populations. As a condition for receiving federal funds, each FQHC must report specific data to the Health Resources and Services Administration every calendar year. The data is compiled and reported to the public through a system called the Uniform Data System (UDS).

Statewide data from UDS summary tables were identified to provide insight into health care system utilization at FQHCs. Every borough in Alaska has at least one site served by an FQHC.

The selected data from the 2019 annual report does not specifically represent patients with an FASD diagnosis but does represent patients receiving services identified as those rendered to individuals with an FASD diagnoses. National rates are included for comparison.

Pregnancy and prenatal services indicators include prenatal care entry, age of prenatal patient, and newborn birth weight. Selected childhood conditions that occur frequently in children with an FASD are included. Screening data for mental health and substance use disorders were included as well.

Complete definitions for indicators and methodologies can be found at https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/reporting/2019-uds-manual.pdf.

Lay of the Land Survey

Data from the Lay of the Land 2017 Canadian health survey (published in 2020) was compiled from *The Routledge Handbook of Social Work and Addictive Behaviours*. Collected under the direction of the Adult Leadership Committee of FASD Change Makers, data reflects the first extensive exploration of the broad health issues in individuals with FASD age ≤16 to 60+ years. Although the data are not specific to Alaska, it does reflect the type and frequency of the health issues self-reported among individuals with FASD as compared to prevalence rates in the general population reported in reliable sources (including the U.S. Centers for Disease Control and Prevention (CDC), Statistics Canada, National Institutes of Health (NIH), the World Health Organization (WHO), Mayo Clinic, Thyroid Foundation of Canada, Sjögren's Syndrome Foundation, and scientific journals listed in PubMed).

Division of Behavioral Health

Data on the number and results of FAS assessments, as well as demographic data on individuals who are screened FASD positive using the Alaska Screening Tool (AST), were provided by the Alaska Division of Behavioral Health (2019) in the AKAIMS – Alaska's Automated Information Management System (data file from AKAIMS FASD Screening Cost).

Medicare

Medicare databases, publicly available through the Centers for Medicare & Medicaid (medicare.gov and data.gov) were downloaded and searched for relevant utilization data, such as alcohol misuse screenings and counseling. Medicare data were not included in this report however, as it was considered too general and not useful for the FASD medical service utilization analysis.

Literature Reviews and Policy Scans

A review of literature related to FASD utilization patterns for pregnant women with alcohol-use disorders and individuals experiencing an FASD at all life stages was conducted. Internet searches were conducted as well as a review of articles and research recommended by subject-matter experts.

Executive Interviews

A total of 19 interviews were conducted using interview protocols customized to capture aspects of user experience; systems intersection, alignment and overlap; and the FASD-related continuum of prevention and treatment opportunities throughout an individual's lifespan. Interviewees represented:

- Researchers
- Clinical supports, i.e., pediatrics, obstetrics/gynecology, general practice, neuropathology, diagnostics team, and mental and behavior health
- Public health and prevention, i.e., public health nursing, substance misuse and addiction prevention and screening, and maternal and children health
- Tribal health organizations
- FASD programs
- Child protective services
- Parents/foster parents of children with FASD

Report Organization

The report contains an Executive Summary, Key Terms and Abbreviations, Methodology, nine sections, and two appendices organized as follows:

- **FASD Health Utilization Context** provides on overview of FASD and its cognitive and neurobehavioral and physical impacts, and health care utilization patterns.
- **Pregnancy and Prenatal Care** provides an overview of health impacts and health utilization data for pregnant women with alcohol-use disorders and their baby's prenatal care.
- **Infancy** provides an overview of health impacts and health utilization data for infants impacted by maternal alcohol misuse.
- **Early Childhood** provides an overview of health impacts and health utilization data for children ages 1 to 5.
- **Late Childhood** provides an overview of health impacts and health utilization data for children ages 6 to 12.
- **Adolescence** provides an overview of health impacts and health utilization data for children ages 13 to 17.
- **Adulthood** provides an overview of health impacts and health utilization data for adults ages 18-65.
- **All Life Stages** provides a summary of health utilization data across all ages.
- **Implications for Health Utilization** provides a summary of policy and health utilization issues impacting individuals with FASD and pregnant women who misuse alcohol; issues include access to care, level of support, and barriers to care, among others.
- **Appendix A: Additional Health Data** provides data on Medicaid spending, hospital facilities charges, and FQHC patient demographics and utilization.
- **Appendix B: List of Interviewees** provides a list of people interviewed during this study.

FASD Health Utilization Context

Exposure to alcohol during pregnancy can cause a variety of birth defects, known as fetal alcohol spectrum disorders (FASD), which include:

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

FASD is a pervasive, complex condition, often camouflaged and missed by health and social service professionals. FASD represents a continuum of effects encompassing physical, developmental, emotional, and behavioral consequences resulting from prenatal alcohol exposure (PAE). Although most frequently diagnosed in early childhood, FASD is not a "pediatric" disability, but a lifelong condition with lifelong implications.[1] FASD occurs all over the world, across all ethnic groups, and in every stratum of society, although higher risk groups are identifiable. The functional and health consequences of FASD are heterogeneous but, regardless of the individual's needs, FASD has impacts across the lifespan.

Obviously, prevention is imperative in addressing FASD. However, the reality is individuals experiencing an FASD require intervention with clinical and community health supports throughout their life span, from prenatal care through infancy, childhood, adolescence, and adult life.

This report focuses attention on the health consequences and related utilization of health care services throughout the life stages of individuals experiencing an FASD.

A Whole Body Disorder

The impacts of PAE and association with birth defects, including intellectual and neurodevelopmental disabilities, was first described in the United States in 1973.[2] In the ensuing 45 years, it has become evident that PAE results in a spectrum of lifelong manifestations, varying from mild to severe and encompassing a broad variety of physical defects and cognitive, behavioral, emotional, and adaptive functioning deficits.

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[1] Loock, C., Elliott, E., Cox, L.V. "Fetal alcohol spectrum disorder: Evidence, theory, and current insights," in The Routledge Handbook of Social Work and Addictive Behaviors, ed. Begun, A. L., Murray, M.M. (New York: Routledge, 2020), 173-189.

[2] Williams, J.F., Smith, V.C., and the Committee on Substance Abuse, Fetal Alcohol Spectrum Disorders, Pediatrics, November 2015, 136(5) e1395-e1406.

While much research, diagnostic practice, and interventional care has focused on cognitive and neurobehavioral deficits among individuals of minority age, the adverse consequences and outcomes beyond childhood and adolescence are an area of emerging attention. FASD is becoming recognized as a whole-body disorder with changing impacts and needs across the life span – including those within the physical health and adult care arenas.[3]

Cognitive and NeuroBehavioral Impact

According to the National Organization on Fetal Alcohol Syndrome, the most common developmental disabilities associated with FASD include cognitive and behavioral impairments associated with decreased intelligence quotient (IQ) and deficits in motor skills, attention, executive function (working memory, problem solving, planning, and response inhibition), language, visual perception, adaptive functioning (skills necessary for everyday living), among other neurological abnormalities. These are further described as follows:

- Intellectual functioning. IQ scores for individuals experiencing an FASD may fall in the borderline to low average range with reduced verbal and nonverbal performance. While recognized as one of the most common causes of developmental disability worldwide, the IQ range for all on the spectrum is from 20-130. IQ, however, is not the only measure of brain function and many people suffering from FASD can have an 'average' IQ but are seriously affected by deficits in their adaptive and executive functioning.[4]
- Executive function. Individuals experiencing an FASD display deficits on measures of verbal and nonverbal fluency, problem solving and planning, concept formation, and set-shifting.
- Learning and memory recall. Individuals experiencing an FASD may have deficits in learning and memory, including acquiring and recalling verbal and nonverbal information.
- Language skills. Individuals with heavy prenatal alcohol exposure display deficits in various basic language skills, including speech production, phonological processing, articulation, word ordering, and grammatical understanding.
- Visual-spatial function. Individuals with heavy prenatal alcohol exposure have also been shown to have a variety of visual-spatial deficits, including problems with basic figure copying, spatial learning, spatial working memory, spatial recall, visual-spatial reasoning, visual-perceptual matching and sustained visual attention.
- Attention. Attention deficits include the establishing and sustaining aspects of attention.
- Behavior problems and psychiatric disorders. Individuals experiencing an FASD are at a higher risk for problem behaviors that can interfere with their home, school, and social

[3] Himmelreich, M., Lutke, C.J., Hargrove, E. T., "The lay of the land: Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis," in The Routledge Handbook of Social Work and Addictive Behaviors, ed. Begun, A. L., Murray, M.M. (New York: Routledge, 2020), 190-214.

[4] Fetal Alcohol Spectrum Disorder Care Network, Understanding FASD, https://www.fasd-can.org.nz/understanding-fasd.

environments, including increased risk for mental health disorders, such as depression and suicidal ideation, alcohol and drug misuse. Such individuals frequently meet the diagnostic criteria for attention deficit hyperactivity disorder (ADHD). Further, they are less likely to live independently.

Physical Health impact

The physical effects and health implications among individuals experiencing an FASD are numerous, varied, and often complex. Much is known about the health consequences of FASD among infants, children, and adolescents. Emerging research indicates that individuals experiencing an FASD may be more susceptible to atypical aging[5] and related health consequences, such as the early onset of chronic diseases and degenerative conditions.[6] Common impairments include structural and skeletal anomalies, growth and sensory issues, dental anomalies, hearing and vision difficulties, organ system defects, immune system comprise, and chronic condition development. These are further described as follows:

- Facial anomalies. Distinctive facial features, including small eyes, an exceptionally thin upper lip, a short, upturned nose, and a smooth skin surface between the nose and upper lip.
- Small head circumference and brain size. Microcephaly indicative of brain damage which may result in cognitive and behavioral problems.
- Skeletal defects. Deformities of joints, limbs, and fingers such as fused bones in the arms, fingers, hands, and toes. Early onset osteoarthritis and osteoporosis.
- Growth deficiencies and sensory issues. Slow physical growth before and after birth complicated by difficulty nursing or eating and sensory issues (i.e., oral, touch, pain tolerance) throughout the lifespan.
- Dental anomalies. Cleft palate, over- and underdevelopment of the upper and lower jaw, as well as malformed, missing and/or misaligned teeth. Cavities occurring at a young age, weak muscles that prevent proper placement of food for chewing, late loss of baby teeth, and late eruption of permanent teeth.
- Hearing problems. Eustachian tube dysfunction and recurrent otitis media often resulting in hearing loss and complicating speech and language development.
- Vision difficulties. Ophthalmological abnormalities such as ptosis, refractive errors, strabismus, subnormal visual acuity, and optic nerve hypoplasia often resulting in visual perception problems throughout the life span.

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[5] Okazaki S, Otsuka I, Shinko Y, Horai T, Hirata T, Yamaki N, Sora I, Hishimoto A. Epigenetic Clock Analysis in Children With Fetal Alcohol Spectrum Disorder. Alcohol Clin Exp Res. 2021 Feb;45(2):329-337. doi: 10.1111/acer.14532. Epub 2021 Jan 22. PMID: 33296097.

[6] Himmelreich, M., Lutke, C.J., Hargrove, E. T., "The lay of the land: Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis," in The Routledge Handbook of Social Work and Addictive Behaviors, ed. Begun, A. L., Murray, M.M. (New York: Routledge, 2020), 190-214.

- Organ system defects. Congenital defects of the heart, intestines, liver, and kidney. Heart defects include atrial and ventricle abnormalities, issues with heart valve formation, and a potential increase in the risk of heart disease later in life. Individuals with damaged intestines, kidneys (i.e., structural anomalies and tubular dysfunction), and livers, have impaired ability to digest food, absorb nutrients, and eliminate toxins.
- Skin problems. Conditions such as atopic dermatitis and hemangiomas.
- Joint problems. Conditions such as clinodactyly, camptodactyly, and joint hypermobility.
- Immune system compromise. Disrupted fetal immune system resulting in an increased risk of infections and disease in newborns that may persist throughout the life span.
- Chronic disease and long-term health consequences. Potential early onset of chronic diseases and conditions such as hypertension, diabetes, cardiovascular disease, and cancer possibly associated with atypical aging.

Comorbidity

Specifying co-occurring disorders can provide the most complete picture of a child with FASD's strengths and weaknesses to determine treatment or referral course. Differential diagnoses can be particularly challenging because the disorder does not always present the same way in all children because of differences in timing and amount of prenatal alcohol exposure and differences in genetic predispositions or postnatal environment. In a sample of children with FASDs, comorbid mental health conditions include (in descending order) mental retardation (i.e., intellectual disability, sleep abnormalities, reactive attachment disorder, anxiety, posttraumatic stress disorder, oppositional defiant disorder, language disorder, learning disability, depression, bipolar, disorder, some features of autism, and specific phobias. Other health conditions, such as enuresis, encopresis, and eating disorders may be present depending on the age of the individual.[7]

Mortality

Mortality rates for children diagnosed with FASD are increased three- to four-fold. The mortality risk for siblings of a diagnosed case is also increased three- to four-fold. increased mortality rate is due to birth defects (e.g., congenital heart defects), sudden infant death syndrome, and infectious illness. Mortality risk for birth mothers of children with FASD is also increased. Thus, FASD is a severe syndrome with increased lethality for birth mothers, children with an FASD diagnosis, and their siblings.[8]

[7] Hagan, Joseph et al. "Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure," Pediatrics, October 2016, 138(4).

[8] Burd, Larry et al, "A court team model for young children in foster care: The role of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorders," Journal of Psychiatry & Law, 39/Spring 2011.

Health Utilization Patterns

When considering FASD, the use of health care and ancillary health-related services typically aligns with two service constructs:

- Prevention and early intervention
- Secondary effects mitigation

Prevention and early intervention focus on the prevention PAE, screening for prenatal substance use and/or mitigation of potential primary effects related to PAE – specifically adverse impact to *in utero* fetal development. This type of prenatal interventional care seeks to modulate FASD risk through approaches such as reduced alcohol consumption, optimal maternal nutrition, and reduced polysubstance use, including tobacco. Common primary effects of PAE include brain damage (with related behavioral dysfunction and learning disabilities) and alcohol-related birth defects – which may result in lifelong medical and health issues.

Secondary effects mitigation focuses on secondary conditions, which are problems that a person is not born with but may develop because of a FASD. These conditions are due to the impact of the FASD (recognized or unrecognized) on the child and family, not from the direct effect of alcohol. These conditions can be improved or prevented with appropriate treatment for children and adults with FASD and their families. Some of the secondary effects associated with FASDs include mental health problems (i.e., attention problems, conduct disorder, alcohol or drug dependence, anxiety, depression, eating disorders, posttraumatic stress disorder), disrupted school experience, trouble with the law, inappropriate sexual behavior, and, for those over 21 years, dependent living, and problems with employment.[9]

Types of treatment and care for individuals experiencing an FASD are generally broken down into five categories including:

- Medical and ancillary health care
- Medication
- Behavior and education therapy
- Parent training
- Alternative approaches (i.e., biofeedback, auditory training, relaxation therapy, etc.)

For the purposes of examining healthcare utilization patterns, this study focuses primarily on the utilization of medical and medication services, behavioral health, and ancillary health care services.

[9] FASDs: Secondary Conditions, Centers for Disease Control and Prevention, FASDs: Secondary Conditions | CDC, Accessed June 16, 2021.

Stigma and Bias

People affected by FASD are often stigmatized, including individuals experiencing an FASD and their family members and caregivers. This stigmatization can also affect diagnostic bias.

Stigma is perhaps best understood as a process that involves the endorsement by others of negative *stereotypes* (i.e., socially informed notions and impressions of particular groups), accompanied by *prejudice*, including emotion-based reactions (e.g., anger or fear), and potential *discrimination* (e.g., structural or personal forms of discrimination) or devaluation of persons.[10,11] Importantly, stigma rests on cultural patterns of behaving, thinking, and feeling about others that are also partly determined by the social discourse and power structures surrounding a particular group of individuals.[12]

Core elements of stigma for individuals with FASD, their biological mothers and families include:

- Personal responsibility and blame toward biological mothers.
- Felt and enacted stigma experienced by children and families.
- Anticipated life trajectories for individuals with FASD.

The following model emphasizes and explains the different 'loads' placed upon those affected by FASD, either because of popularly held negative beliefs, or attitudes towards the causes of FASD (i.e., who is to blame), towards the deficits displayed by those with FASD, and with regards to their potential to overcome these deficits. The model highlights that multiple stakeholders (biological parents, adoptive parents, kinship and foster caregivers, children and adults with FASD) may be subject to forms of stigma associated with drinking during pregnancy and FASD, and it recognizes that these relationships are important to understand how stigma might play out across a lifespan for each of these stakeholders.[13]

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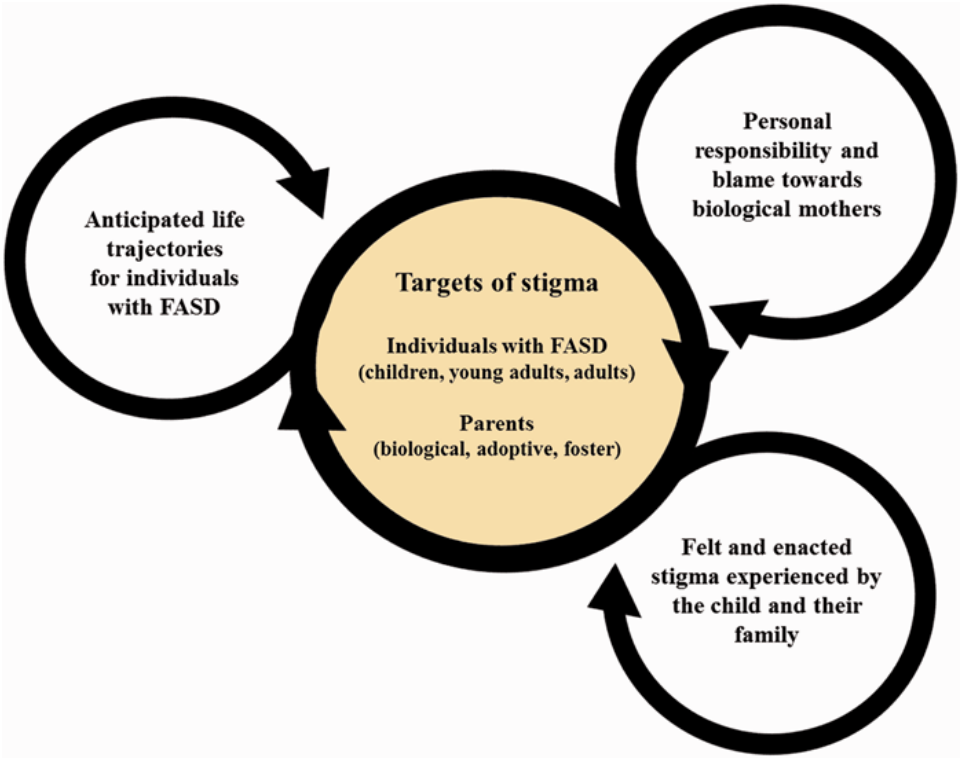
[10] Link, B. G., Phelan J. C., Conceptualizing Stigma, Annual Review of Sociology, 2001, vol. 27 (pg. 363-385).

[11] Corrigan, P. W., Watson, A. C., Understanding the Impact of Stigma on People with Mental Illness, World Psychiatry, 2002, vol. 1 (pg. 16-20).

[12] Rüsch, N., Angermeyer, M. C., Corrigan, P. W., Mental Illness Stigma: Concepts, Consequences, and Initiatives to Reduce Stigma, European Psychiatry, 2005, vol. 20 (pg. 529-539).

[13] Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., Reynolds, J.N., Racine, E., It's a Shame! Stigma Against Fetal Alcohol Spectrum Disorder: Examining the Ethical Implication for Public Health Practices and Policies, Public Health Ethics, Volume 9, Issue 1, April 16, Pages 65-77.

Figure 1. Descriptive Model of FASD Stigmatization



Source: Bell, E., et al. 2016.

Stigmatization related to FASD can have far-reaching consequences. First, women can be held responsible for drinking alcohol during pregnancy and can therefore be blamed for having a child with FASD. Biological mothers of children with FASD fear societal judgement and thus conceal having consumed alcohol during pregnancy. Women might also be reluctant to seek counselling or treatment for alcohol dependence. Second, nonbiological parents and guardians of individuals with FASD can be held responsible for a child with FASD's disability or behavioral difficulties. Third, individuals with FASD can be perceived as frequent users of social services due to their medical and social problems.[14]

One of the most important, but poorly documented, downstream effects around the stigma concurrent with a diagnosis of FAS or FASD is the fact that it results in a diagnostic bias. For example, the overrepresentation of FASD diagnoses in Alaska Natives and Canadian Aboriginal communities has been interpreted as stemming from a bias towards diagnosing indigenous

[14] Roozen, S., Stutterheim, S.E., Bos, A.E.R. et al. Understanding the Social Stigma of Fetal Alcohol Spectrum Disorders: From Theory to Interventions. Found Sci (2020). https://doi.org/10.1007/s10699-020-09676-y.

children more readily than non-indigenous children with FASD (where non-indigenous children may be diagnosed with a different neurobehavioral condition such as ADHD).[15,16]

Diagnostic biases may also be affected by a child's placement in the social care system. For instance, clinicians may more readily confirm a diagnosis of FASD for children placed in the foster care system. These forms of diagnostic bias are important to understand as they may lead to further marginalization and stigmatization of already disadvantaged groups. Moreover, the focus of the diagnosis being on maternal drinking behavior also obscures other potential reasons that prevalence differences might exist between groups (e.g., poor prenatal care, social or population health, or genetic factors).[17]

Life Stages

Individuals impacted by an FASD face ongoing and evolving health care service and support needs throughout their lifespan. These needs can vary greatly based on the extent of PAE impact and subsequent life experiences. Individuals affected by an FASD may experience a wide degree of challenges in their daily living, needing more support with their physical health, motor skills, learning skills, memory, attention, communication, emotional regulation, and social skills. Support at different stages of life differs based on developmental need and environment.

There is a growing understanding that FASD, as a whole-body and lifelong disorder, manifests itself differently throughout life stages.[18] Health issues and medical care needs evolve throughout the lifespan. An examination of health care utilization, including medical, behavioral health, and ancillary support services, must be considered through the life stage lens.

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[15] Ryan S., Ferguson D. L., The Person Behind the Face of Fetal Alcohol Spectrum Disorder: Student Experiences and Family and Professionals' Perspectives on FASD, Rural Special Education Quarterly, 2006, vol. 25 (pg. 32-40).
[16] Dej E. What Once Was Sick is now Bad: The Shift from Victim to Deviant Identity for Those Diagnosed with Fetal Alcohol Spectrum Disorder, Canadian Journal of Sociology, 2011, vol. 36 (pg. 137-160).
[17] Meurk C., Lucke J., Hall W., A Bio-social and Ethical Framework for Understanding Fetal Alcohol Spectrum Disorders, Neuroethics, 2014, vol. 7 (pg. 337-344).
[18] Moore, E.M., Riley, E.P. What Happens When Children with Fetal Alcohol Spectrum Disorders Become Adults? Curr Dev Disord Rep 2, 219–227 (2015).

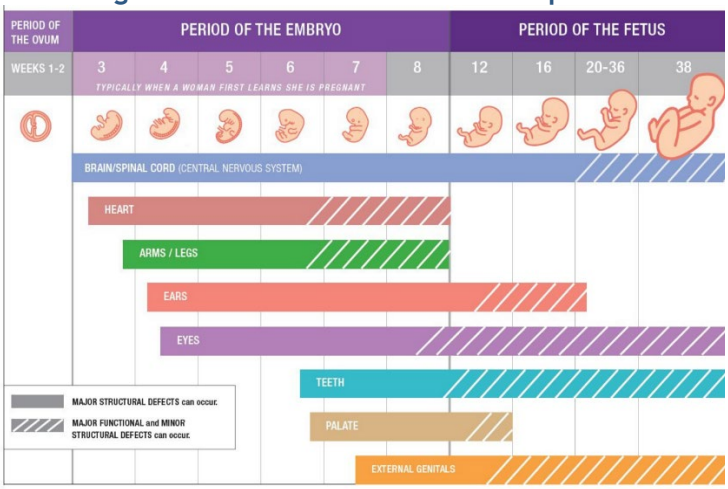
People drink during reproductive times.

—FASD Advocate

Common Effects

Prenatal alcohol exposure (PAE) can potentially impact normal development at almost any point in the pregnancy, from embryonic through fetal development. Prenatal development has two stages, the embryonic stage that compromises the first eight weeks of development after fertilization, and the fetal stage that encompasses the remainder of development.

Figure 2. Critical Periods of Development



Source: Adapted from Moore, 1993 and the National Organization of Fetal Alcohol Syndrome (NOFAS), 2009.

During the embryonic stage, the body plans are established; the precursors of what will be organ systems are determined. Alcohol introduced at this stage can result in development deviations, including a range of birth defects, or completely arrest the pregnancy. During the fetal stage, PAE still has the potential to negatively impact development, but much less than during the embryonic stage, when massive developmental defects can result from exposure.[19]

Alcohol exposure during pregnancy is a major known cause of birth defects, neurodevelopmental impairments, and learning problems. Impacts of alcohol on unborn babies during pregnancy can range from mild to severe, including:

[19] Developmental Timeline of Alcohol-Induced Birth Defects, The Embryo Project Encyclopedia, https://embryo.as.edu. Accessed June 18, 2021.

- Lower birth weights
- Miscarriage
- Stillbirth
- Premature birth
- Birth defects
- A range of conditions known as FASD

Emergent Health Care Needs

Unintended Pregnancy

Pregnancy is a powerful motivator for women to stop using alcohol; many women abstain or cut down on alcohol use once they know they are pregnant. However, unplanned pregnancy frequently results in unintended PAE during the first trimester after conception, before pregnancy recognition. That means women may have used alcohol in the weeks before they knew they were pregnant.

More than 40% of all pregnancies in Alaska (41.1%) are self-reported as mistimed, unwanted, or unsure if they were wanted by women who had recently given birth.[20] 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.[21]

Screening

Screening for substance use and mental health disorders should be part of comprehensive obstetric care and done at the first prenatal visit.

Data from a national survey showed that among pregnant women about 10% had at least one alcoholic drink in the past 30 days. Of those using alcohol, 40% also used other substances – most often tobacco and marijuana.[22] Routinely screening pregnant women for substance use (including alcohol and tobacco) - using a validated set of screening questions and combined with brief intervention efforts - is critical to identifying individuals who use substances at unsafe or risky levels and provide early interventions.

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[20] Prevalence of Selected Maternal and Child Health Indicators for Alaska, Pregnancy Risk Assessment Monitoring System (PRAMS), 2016-2017.
[21] Alaska Pregnancy Risk Assessment Monitoring System (2017). http://ibis.dhss.alaska.gov/query/selection/prams23/PRAMSSelection.html. Accessed July 3, 2020.
[22] National Survey on Drug Use and Health (NNSDUH), United States, 2015-2018. Alcohol use and co-use of other substances in pregnancy | CDC. Accessed June 18, 2021.

Women are at a higher risk for suffering from mental health disorders during pregnancy. Depression and anxiety during pregnancy have been associated with a variety of adverse pregnancy outcomes. Data indicate that about 10% to 15% of pregnant women experience clinically significant depressive symptoms during pregnancy.[23] Women who suffer from psychiatric illness during pregnancy are less likely to receive adequate prenatal care and are more likely to use alcohol, tobacco, and other substances known to adversely affect pregnancy outcomes.[24] Prenatal mental health screening, using a validated instrument, can initiate treatment or referral to mental health care providers to offer maximum benefit.

Prenatal Care

Early Entry into Care

Early entry into prenatal care is essential for monitoring for healthy pregnancies and decreases the probabilities of negative birth outcomes. Getting early and regular prenatal care improves the changes of a healthy pregnancy. Early entry into prenatal care can identify maternal risk factors for having a child with FASD. For example, women who drink and are older and have had multiple pregnancies and births are at greater risk of having a child with FASD.[25] However, research suggests that women who give birth to children with FASD have higher rates of inadequate prenatal care.[26]

Interventional Care

Prenatal interventional care may modulate FASD fetal risk and reduced low birth weight through approaches such as reduced alcohol consumption and substance use, and optimal maternal nutrition. Women with poor nutrition and inadequate prenatal care are at higher risk of having a child with FASD.[27] Interventional approaches, including nutritional supplements such as zinc, folate, chlorine, and iron, may protect the developing fetus from the harmful effects of alcohol.[28,29] Quality prenatal care and monitoring are essential to help reduce low birth weight outcomes. Babies born at lower birth weights experience higher rates of delayed or diminished intellectual and physical development.

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[23] Flynn, H.A., et al. Rates and predictors of depression treatment among pregnant women in hospital-affiliated obstetrics practices. Gen Hosp Psychiatry. 2006 Jul-Aug;28(4):289-95.
[24] Psychiatric Disorders During Pregnancy, MGH Center for Women's Mental Health: Reproductive Psychiatry Resource & Information Center. Psychiatric Disorders During Pregnancy (womensmentalhealth.org). Accessed June 22, 2021.
[25] May, P.A., et al. Maternal risk factors for fetal alcohol syndrome and partial fetal alcohol syndrome in South Africa: A third study. Alcoholism: Clinical and Experimental Research 32:738–753, 2008.
[26] Singal, D., et al. Prenatal care of women who give birth to children with fetal alcohol spectrum disorder in a universal health care system: a case-control study using linked administrative data. CMAJ Open. 2019 Feb 11;7(1): E63-E72.
[27] Fetal Alcohol Spectrum Disorders: Understanding the Effects of Prenatal Alcohol Exposure, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Alcohol Alert. Number 82. *Fetal Alcohol Spectrum Disorders: Understanding the Effects of Prenatal Alcohol Exposure (nih.gov). Accessed June 21, 2021.
[28] Helfrich, K.K., Saini, N., Kling P.J., Smith, S.M. Maternal iron nutriture as a critical modulator of fetal alcohol spectrum disorder risk in alcohol-exposed pregnancies. Biochem Cell Biol. 2018 Apr;96(2):204-212.
[29] Idrus., N.M., Thomas, J.D., Fetal Alcohol Spectrum Disorders: Experimental treatments and strategies for intervention. Alcohol Research & Health 34(1):76–85, 2011.

Utilization Patterns

FQHC UDS Utilization for All Prenatal Care

Less than half of a percent of prenatal care patients at Alaska FQHCs are under 15 years. About one-quarter of FQHC prenatal patients, in both Alaska and the entire United States, are age 20-24 years. Most prenatal patients of Alaska FQHCs (68%) are age 25-44 years. This is slightly higher than the U.S. FQHC percentage at 64%. (*Additional UDS data can be found in Appendix A.)*

About 79% of pregnant patients served through Alaska FQHCs began prenatal care in the first trimester of pregnancy, about 5% higher than all U.S. FQHCs. Only about 3% of Alaska FQHC prenatal patients began receiving care in their third trimester, compared to about 6% for U.S. FQHCs.

Table 2. Prenatal Care Patients by Age, Alaska and U.S., CY2019

Age in Years	Number of Patients* Alaska	Percentage of Patients Alaska	Percentage of Patients U.S.
Less than 15 Years	1	0.1%	0.2%
Ages 15-19	146	8.2%	9.1%
Ages 20-24	426	24.0%	26.1%
Ages 25-44	1,203	67.6%	64.3%
Ages 45+	3	0.2%	0.3%
Total Patients	**1,779**	**-**	**-**

Source: Uniform Data System (UDS), 2019.
Note: Percentages may not sum to 100% due to rounding.
* Patient counts are unduplicated patients receiving prenatal care.

Table 3. Prenatal Care Patients, Entry into Prenatal Care, Alaska and U.S., CY2019

Prenatal Care Patients*	First Trimester	Second Trimester	Third Trimester
Alaska			
Percentage of women having first prenatal visit with FQHC	69.0%	14.3%	2.0%
Count of women having first prenatal with FQHC	*1,228*	*254*	*36*
Percentage of women having first prenatal visit with another provider	9.4%	4.3%	1.0%
Count of women having first prenatal visit with another provider	*168*	*76*	*17*
Alaska Total	**78.5%**	**18.6%**	**3.0%**
U.S.			
Percentage of women having first prenatal visit with FQHC	68.2%	16.8%	4.4%
Percentage of women having first prenatal visit with another provider	5.6%	2.1%	1.1%
U.S. Total	**73.8%**	**20.7%**	**5.5%**

Source: Uniform Data System (UDS), 2019.
Note: Percentages may not sum to 100% due to rounding.
* Prenatal patients include unique patients who receive all their prenatal care at the FQHC, all those referred to other providers for their prenatal care, and those who transferred to or from the FQHC for their prenatal care.

Medicaid Utilization

In SFY2019, 67 Medicaid beneficiaries were identified as pregnant women with alcohol-use disorders receiving health services. The average annual number of claims per study group beneficiaries was 64% higher than the comparison group (77.1 and 46.8, respectively). Of the pregnant women with alcohol-use disorders, 46% (31 beneficiaries) were from Southcentral Alaska. Southcentral Alaska beneficiaries with alcohol-use disorders averaged 86.6 claims in 2019 compared to 68.9 claims for All Other Alaska beneficiaries. (*Medicaid spending data can be found in Appendix A.)*

Table 4. Medicaid Claims and Average Annual Claims per Beneficiary, Pregnant Women with Alcohol-use Disorders, and Comparison Group, Southcentral Alaska and All Other Alaska, SFY2019

	Southcentral Alaska		All Other Alaska		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	31	2,606	36	1,959	67	4,565
Total claims	2,684	123,675	1,480	89,954	5,164	213,629
Average Number of Claims per Beneficiary	86.6	47.5	68.9	45.9	77.1	46.8

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019. The comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium.

For all service categories, except therapy/rehabilitation, home health/hospice, laboratory/x-ray, early and periodic screening, and other services, pregnant beneficiaries with alcohol-use disorders used a higher percentage of Medicaid services than the comparison group. On a percentage basis (see table and graph below), the top five services used by the study group were:

1. Outpatient services and physician/practitioner services (both 95.5%)
2. Pharmacy (89.6%)
3. Health clinic (76.1%)
4. Inpatient hospital services (64.2%)
5. Transportation (56.7%)

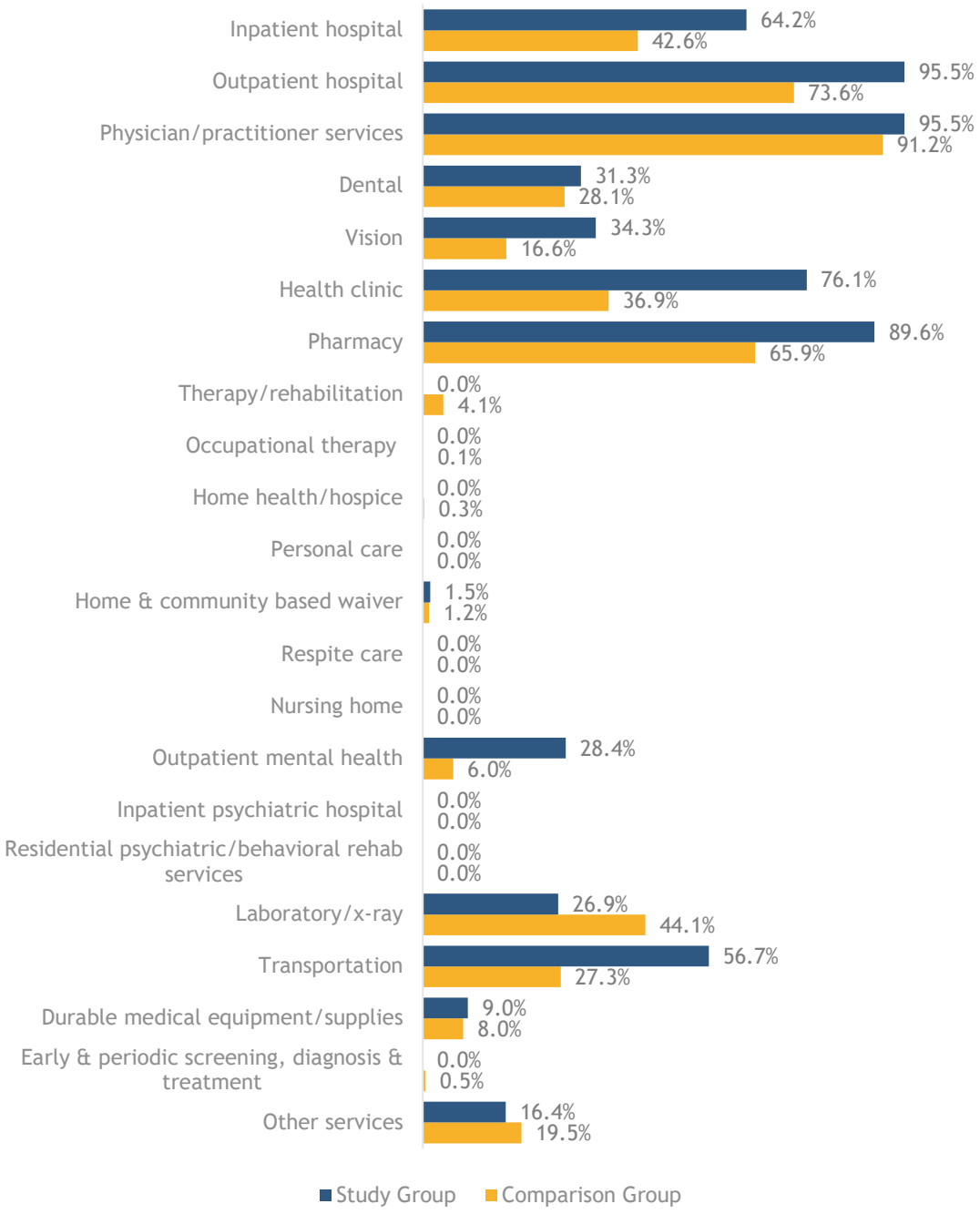
(See table next page.)

Table 5. Service Recipients, Medicaid Beneficiaries, and Total Claims by Service Category, Pregnant Women with Alcohol-use Disorders and Comparison Group, SFY2019

	Beneficiaries Receiving Services		Total Beneficiaries		Total Claims	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Inpatient hospital	43	1,945	67	4,565	74	2,341
Outpatient hospital	64	3,359	67	4,565	1,245	55,912
Physician/practitioner services	64	4,164	67	4,565	1,147	59,180
Dental	21	1,283	67	4,565	93	6,388
Vision	23	757	67	4,565	84	3,068
Health clinic	51	1,683	67	4,565	471	12,728
Pharmacy	60	3,010	67	4,565	685	19,572
Therapy/rehabilitation	0	187	67	4,565	-	1,764
Occupational therapy	0	4	67	4,565	-	22
Home health/hospice	0	13	67	4,565	-	123
Personal care	0	0	67	4,565	-	-
Home & community-based waiver services	1	56	67	4,565	2	98
Respite care	0	0	67	4,565	-	-
Nursing home	0	0	67	4,565	-	-
Outpatient mental health	19	275	67	4,565	341	9,149
Inpatient psychiatric hospital	0	1Be	67	4,565	-	2
Residential psychiatric/behavioral rehab services	0	0	67	4,565	-	-
Laboratory/x-ray	18	2,014	67	4,565	180	19,553
Transportation	38	1,248	67	4,565	813	21,098
Durable medical equipment/supplies	6	365	67	4,565	12	957
Early & periodic screening, diagnosis & treatment	0	23	67	4,565	-	25
Other services	11	892	67	4,565	17	1,649

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019. The comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium.

Figure 3. Percentage of Beneficiaries Receiving Each Service, Pregnant Women with Alcohol-use Disorders, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019. The comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium.

Hospital Facilities Utilization

In SFY2019, 114 admissions by pregnant women with alcohol-use disorders received inpatient hospital care; 46% (53 admissions) were in Southcentral Alaska facilities. The average length of stay per admission was three days.

A total of 198 outpatient visits occurred; 30% (60 visits) were in Southcentral Alaska facilities. The average annual visits per patient were 1.58.

Emergency departments had 32 visits from pregnant women with alcohol-use disorders; 25% (8 visits) were in Southcentral Alaska hospitals. The average annual number of visits per patient were 1.23. (*Hospital Facilities charge data can be found in Appendix A.)*

Table 6. Inpatient, Outpatient, and Emergency Department Hospital Admissions/Visits and Length of Stay for Pregnant Women with Alcohol-use Disorders, Primary or Secondary Diagnoses, SFY2019

Category	Number of Admissions (Inpatient)/Visits (Outpatient & ED)	Average Annual Admissions/Visits per Patient	Length of Stay (days)	Average Length of Stay per Admission/Visit (days)
Inpatient Admissions				
Southcentral Alaska	53	1.10	154	3
All Other Alaska	61	1.13	179	3
Total	114	1.12	333	3
Outpatient Visits				
Southcentral Alaska	60	1.62	60	1
All Other Alaska	138	1.57	138	1
Total	198	1.58	198	1
Emergency Department Visits				
Southcentral Alaska	8	1.00	8	1
All Other Alaska	24	1.33	24	1
Total	32	1.23	32	1

Source: Alaska Hospital Facilities Data Reporting Program.

The top diagnosis (primary or secondary) for inpatient admissions of pregnant women with alcohol-use disorders was delivery of their child (73% of all their admissions). The next top diagnoses were behavioral health diagnoses related to alcohol, tobacco, or drug misuse.

The top five diagnoses for outpatient visits were behavioral health-related addressing alcohol misuse and tobacco dependency.

For emergency department visits, the top three diagnoses were behavioral health-related, addressing alcohol and tobacco misuse issues. To round out the top five diagnoses, the remaining two diagnoses were medically related to the pregnancy.

Table 7. Top Inpatient, Outpatient, and Emergency Department Diagnoses for Pregnant Women with Alcohol-use Disorders, Primary or Secondary Diagnoses, SFY2019

Category	Type	Count	% of Total
Inpatient Admissions			
Single live birth	Medical	83	72.8%
Alcohol use complicating childbirth	Behavioral Health	75	65.8%
Smoking (tobacco) complicating childbirth	Behavioral Health	42	36.8%
Drug use complicating childbirth	Behavioral Health	34	29.8%
Other problems related to lifestyle	Behavioral Health	31	27.2%
Outpatient Visits			
Alcohol use complicating pregnancy, first trimester	Behavioral Health	66	33.3%
Alcohol use complicating pregnancy, second trimester	Behavioral Health	66	33.3%
Alcohol use complicating pregnancy, third trimester	Behavioral Health	49	24.7%
Alcohol abuse, uncomplicated	Behavioral Health	33	16.7%
Nicotine dependence, cigarettes, uncomplicated	Behavioral Health	30	15.2%
Emergency Department Visits			
Alcohol use complicating pregnancy, first trimester	Behavioral Health	15	46.9%
Alcohol use complicating pregnancy, second trimester	Behavioral Health	14	43.8%
Nicotine dependence, cigarettes, uncomplicated	Behavioral Health	8	25.0%
Other specified pregnancy related conditions, second trimester	Medical	7	21.9%
Less than 8 weeks gestation of pregnancy	Medical	7	21.9%

Source: Alaska Hospital Facilities Data Reporting Program.

Infancy

With our fragmented, high-turnover, multi-systems health care in Alaska, we reinvent the wheel with each child.

— FASD Clinical Specialist

Common Effects

Common FASD impacts in newborns and infants (birth through age 1) include:

- Jitteriness and/or tremors
- Seizures and/or EEG abnormalities
- Unpredictable, disruptive, fitful sleep/wake cycle
- Decreased vigorous bodily activity/low muscle tone
- Hypercousis (low hearing threshold)
- Failure to thrive (given adequate opportunity)
- Weak sucking response/poor feeding
- Irritability
- Hyperexcitability
- Slow physical growth
- Slower rate to learn new skills
- Touch and sensory issues, i.e., stiffens when held, startles easily, sensitive to touch, sound, and light

Emergent health care needs include early intervention services, sensory integration therapy, neonatal inpatient and outpatient services, and screening and diagnostic testing, pharmacy services, among others.

Utilization Patterns

FQHC Utilization for All Infants

In Alaska in 2019, 5.3% of deliveries of Alaska FQHC patients were low or very low birth weight babies. This is about three percent lower than for the United States. FQHCs percentage of 8.1%.

Table 8. Prenatal Care Patients, Live Births and Birth Weights, Alaska and U.S., CY2019

Live Births	Birth Weight < 1500 grams	Birth Weight 1500-2499 grams	Birth Weight >= 2500 grams	Low or Very Low Birth Weight Babies*	Patients Who Delivered During the Year†
Alaska					
# of live births	11	45	998	56	1,075
% of live births	1.0%	4.3%	94.7%	5.3%	-
U.S.					
# of live Births	4,023	20,988	285,759	25,011	312,956
% of live births	1.3%	6.8%	92.0%	8.1%	-

Source: Uniform Data System (UDS), 2019.
Note: Percentages may not sum to 100% due to rounding.
* Low or very low birth weight babies are those born weighing less than 2500 grams.
† Includes all women who had deliveries regardless of birth outcome. Miscarriages are not included as deliveries.

Medicaid Utilization

There were 71 Medicaid beneficiaries identified as infants impacted by maternal alcohol use and receiving health services in SFY2019. The average annual number of claims per study group beneficiaries was 227% higher than the comparison group (69.4 and 21.2, respectively). Of the study infants, 51% (36 beneficiaries) were from Southcentral Alaska. Southcentral Alaska beneficiaries impacted by maternal alcohol use averaged 60.8 claims in 2019 compared to 78.3 claims for all other Alaska beneficiaries.

Table 9. Medicaid Claims and Average Annual Claims per Beneficiary, Infants Impacted by Maternal Alcohol Use, and Comparison Group, Southcentral Alaska and All Other Alaska, SFY2019

	Southcentral Alaska		All Other Alaska		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	36	3,836	35	2,748	71	6,584
Total claims	2,189	78,350	2,740	60,905	4,929	139,255
Average Number of Claims per Beneficiary	60.8	20.4	78.3	22.2	69.4	21.2

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to infants (under age 1) who were Medicaid beneficiaries in SFY2019 and diagnosed at birth with FAS. The comparison group refers to Medicaid beneficiaries in SFY2019 who were under age 1 and without FAS, not affected by maternal use of alcohol or drugs of addiction, and infants not experiencing withdrawal symptoms from maternal substance use.

For all service categories, except dental, early and periodic screening, and laboratory/x-ray, infants impacted by maternal alcohol use received a higher percentage of Medicaid services than the comparison group. On a percentage basis, the top five services used (see table and graph below) by the study group were:

1. Physician/Practitioner services (both 93.0%)
2. Inpatient hospital services (83.1%)
3. Early and periodic screening (81.7%)
4. Outpatient services (52.1%)
5. Pharmacy (46.5%)

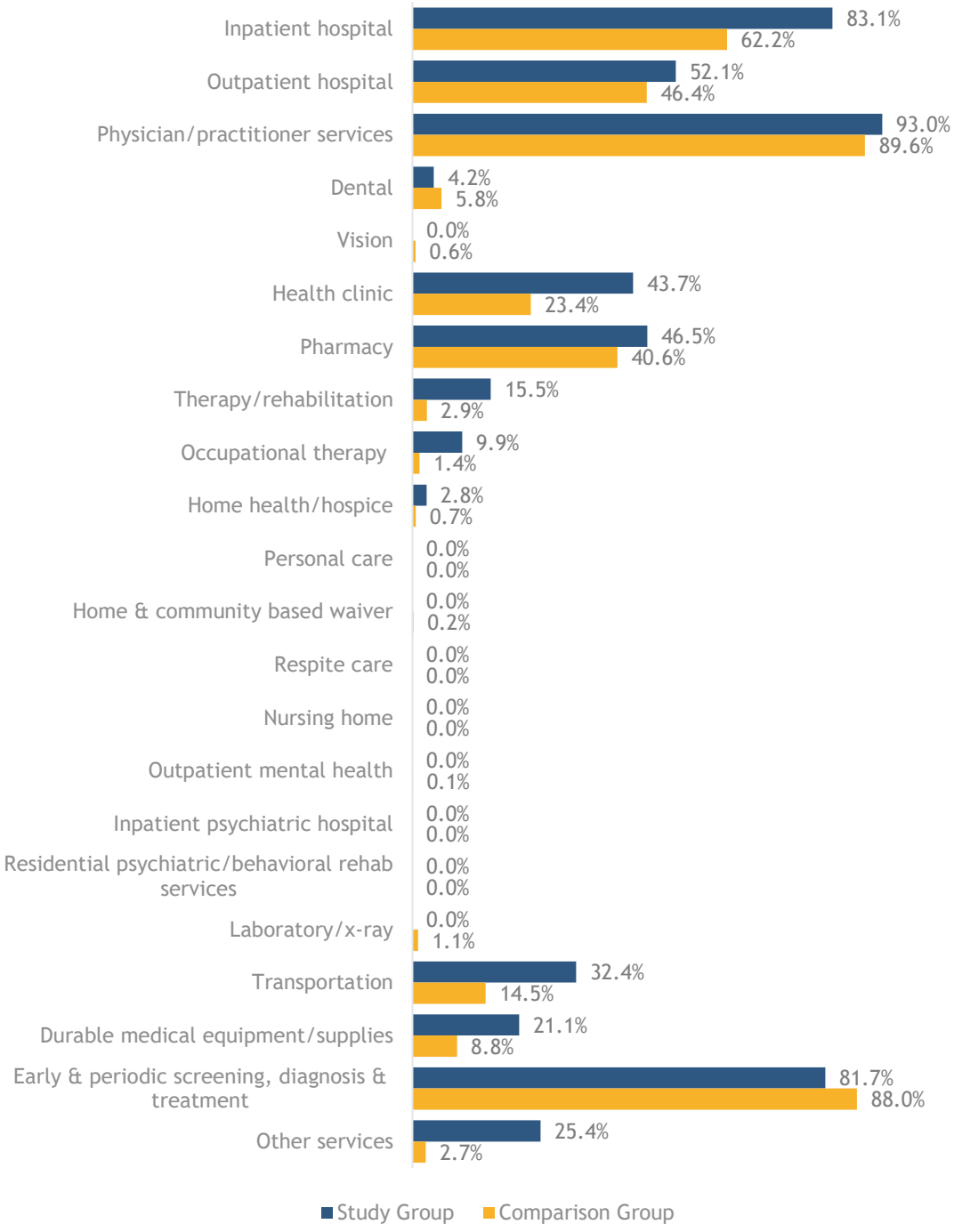
(See table next page.)

Table 10. Service Recipients, Medicaid Beneficiaries, and Total Claims by Service Category, Infants Impacted by Maternal Alcohol Use and Comparison Group, SFY2019

	Beneficiaries Receiving Services		Total Beneficiaries		Total Claims	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Inpatient hospital	59	4,098	71	6,584	118	5,142
Outpatient hospital	37	3,053	71	6,584	211	16,879
Physician/practitioner services	66	5,896	71	6,584	2,964	64,417
Dental	3	379	71	6,584	5	715
Vision	0	41	71	6,584	-	92
Health clinic	31	1,541	71	6,584	179	5,775
Pharmacy	33	2,670	71	6,584	127	8,575
Therapy/rehabilitation	11	189	71	6,584	76	1,858
Occupational therapy	7	93	71	6,584	41	709
Home health/hospice	2	43	71	6,584	85	179
Personal care	0	0	71	6,584	-	-
Home & community-based waiver services	0	13	71	6,584	-	47
Respite care	0	0	71	6,584	-	-
Nursing home	0	0	71	6,584	-	-
Outpatient mental health	0	5	71	6,584	-	49
Inpatient psychiatric hospital	0	0	71	6,584	-	-
Residential psychiatric/behavioral rehab services	0	0	71	6,584	-	-
Laboratory/x-ray	0	74	71	6,584	-	191
Transportation	23	953	71	6,584	497	10,569
Durable medical equipment/supplies	15	580	71	6,584	376	2,993
Early & periodic screening, diagnosis & treatment	58	5,791	71	6,584	192	20,354
Other services	18	175	71	6,584	58	711

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to infants (under age 1) who were Medicaid beneficiaries in SFY2019 and diagnosed at birth with an FAS. The comparison group refers to Medicaid beneficiaries in SFY2019 who were under age 1 and without FAS, not affected by maternal use of alcohol or drugs of addiction, and infants not experiencing withdrawal symptoms from maternal substance use.

Figure 4. Percentage of Beneficiaries Receiving Each Service, Infants Impacted by Maternal Alcohol Use, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to infants (under age 1) who were Medicaid beneficiaries in SFY2019 and diagnosed at birth with FAS. The comparison group refers to Medicaid beneficiaries in SFY2019 who were under age 1 and were without FAS, not affected by maternal use of alcohol or drugs of addiction, and infants not experiencing withdrawal symptoms from maternal substance use.

Hospital Facilities Utilization

In SFY2019, 35 infants affected by maternal alcohol misuse received inpatient hospital care; 54% (19 admissions) were in Southcentral Alaska facilities. The average length of stay per admission was seven days.

A total of 32 outpatient visits occurred; 68% (22 visits) were in Southcentral Alaska facilities. The average annual number of visits per patient was 1.52.

Emergency departments had one visit from an infant affected by maternal alcohol misuse.

Table 11. Infants Affected by Maternal Alcohol Misuse, Hospital Inpatient, Outpatient, and Emergency Department, Admissions/Visits and Length of Stay, Primary or Secondary Diagnoses, SFY2019

Category	Number of Admissions (Inpatient)/Visits (Outpatient & ED)	Average Annual Admissions/Visits per Patient	Length of Stay (days)	Average Length of Stay per Admission/Visit (days)
Inpatient Admissions				
Southcentral Alaska	19	1.06	129	7
All Other Alaska	16	1.00	111	7
Total	35	1.03	240	7
Outpatient Visits				
Southcentral Alaska	22	1.47	22	1
All Other Alaska	10	1.67	10	1
Total	32	1.52	32	1
Emergency Department Visits				
Southcentral Alaska	0	-	-	-
All Other Alaska	1	1.00	1	1
Total	1	1.00	1	1

Source: Alaska Hospital Facilities Data Reporting Program.

The top diagnosis (primary or secondary) for inpatient admissions was for newborns affected by maternal use of alcohol (behavioral health-related) (100% of all their admissions). The next top two diagnoses were medical diagnoses related to immunization and live births.

The top five diagnoses for outpatient visits were medical-related; however, a diagnosis of FAS was the fifth diagnoses (13% of all outpatient visits).

There was only one emergency department visits with four medical diagnoses.

Table 12. Infants Affected by Maternal Alcohol Misuse, Top Hospital Inpatient, Outpatient, and Emergency Department Diagnoses, Primary or Secondary Diagnoses, SFY2019

Category	Type	Count	% of Total
Inpatient Admissions			
Newborn affected by maternal use of alcohol	Behavioral Health	35	100.0%
Encounter for immunization	Medical	30	85.7%
Single liveborn infant, delivered vaginally	Medical	24	68.6%
Newborn affected by maternal use of tobacco	Behavioral Health	10	28.6%
Newborn affected by maternal use of other drugs of addiction	Behavioral Health	7	20.0%
Outpatient Visits			
Newborn affected by maternal use of alcohol	Medical	28	87.5%
Encounter for routine child health examination without abnormal findings	Medical	6	18.8%
Encounter for immunization	Medical	5	15.6%
Preterm newborn, unspecified weeks of gestation	Medical	4	12.5%
Fetal alcohol syndrome (dysmorphic)	Medical	4	12.5%
Emergency Department Visits			
Viral infection, unspecified	Medical	1	100.0%
Candidal stomatitis	Medical	1	100.0%
Newborn affected by maternal use of alcohol	Medical	1	100.0%
Fever, unspecified	Medical	1	100.0%

Source: Alaska Hospital Facilities Data Reporting Program.

Early Childhood

Obtaining diagnostic services takes a lot of parental persistence. It's a fight. Diagnosis at an early age AND periodic reassessment is key to obtaining services; however, services are not always available.

—Adoptive parent of children with FASD

Common Effects

Common FASD impacts in early childhood (age 1-5) include:

- Poor hand-eye coordination and/or balance, clumsiness
- Skills, such as walking, are delayed
- Central auditory dysfunction
- Hyperactivity, impulsivity, attention problems
- Language development delays, i.e., good talking skills, but poorer understanding
- Hearing and vision anomalies as common
- Short-term memory for simple sentences is delayed
- Inability to manage stimuli simultaneously and shift attention during task (e.g., cognitive flexibility)
- IQ range varies – ranging from intellectual disability to average intelligence
- Overlapping symptoms with autism and trauma
- Touch and sensory issues, i.e., sniffs everything, stiffens when held, startles easily, child removes clothes because they are irritating
- Needs to hear things repeatedly

Emergent health care needs include early intervention services, speech therapy, occupational therapy, outpatient health and mental health services, sensory integration therapy, dental services, screening and diagnostic testing, and pharmacy services, among others.

Utilization Patterns

Medicaid Utilization

In SFY2019, 70 Medicaid beneficiaries were identified as children ages 1 to 5 with FAS receiving health services. The average annual number of claims per study group beneficiaries was 283% higher than the comparison group (89.1 and 23.3, respectively). Of the children with FAS, 58%

(41 beneficiaries) were from Southcentral Alaska. Southcentral Alaska beneficiaries with FAS averaged 108.6 claims in 2019, compared to 61.4 claims for all other Alaska beneficiaries.

Table 13. Medicaid Claims and Average Annual Claims per Beneficiary, Individuals with FAS age 1 through 5, and Comparison Group, Southcentral Alaska and All Other Alaska, SFY2019

	Southcentral Alaska		All Other Alaska		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	41	14,081	29	10,540	70	24,621
Total claims	4,453	322,092	1,781	252,518	6,234	574,610
Average Number of Claims per Beneficiary	108.6	22.9	61.4	24.0	89.1	23.3

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study Group refers to Medicaid beneficiaries who were ages 1 through 5 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 1-5 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

For all service categories, children with FAS ages 1 to 5 used a higher percentage of Medicaid services than the comparison group. On a percentage basis, the top five services used (see table and graph below) by the study group were:

1. Physician/Practitioner services (both 94.3%)
2. Outpatient services (75.7%)
3. Pharmacy (68.6%)
4. Early and periodic screening (64.3%)
5. Therapy/rehabilitation (55.7%)

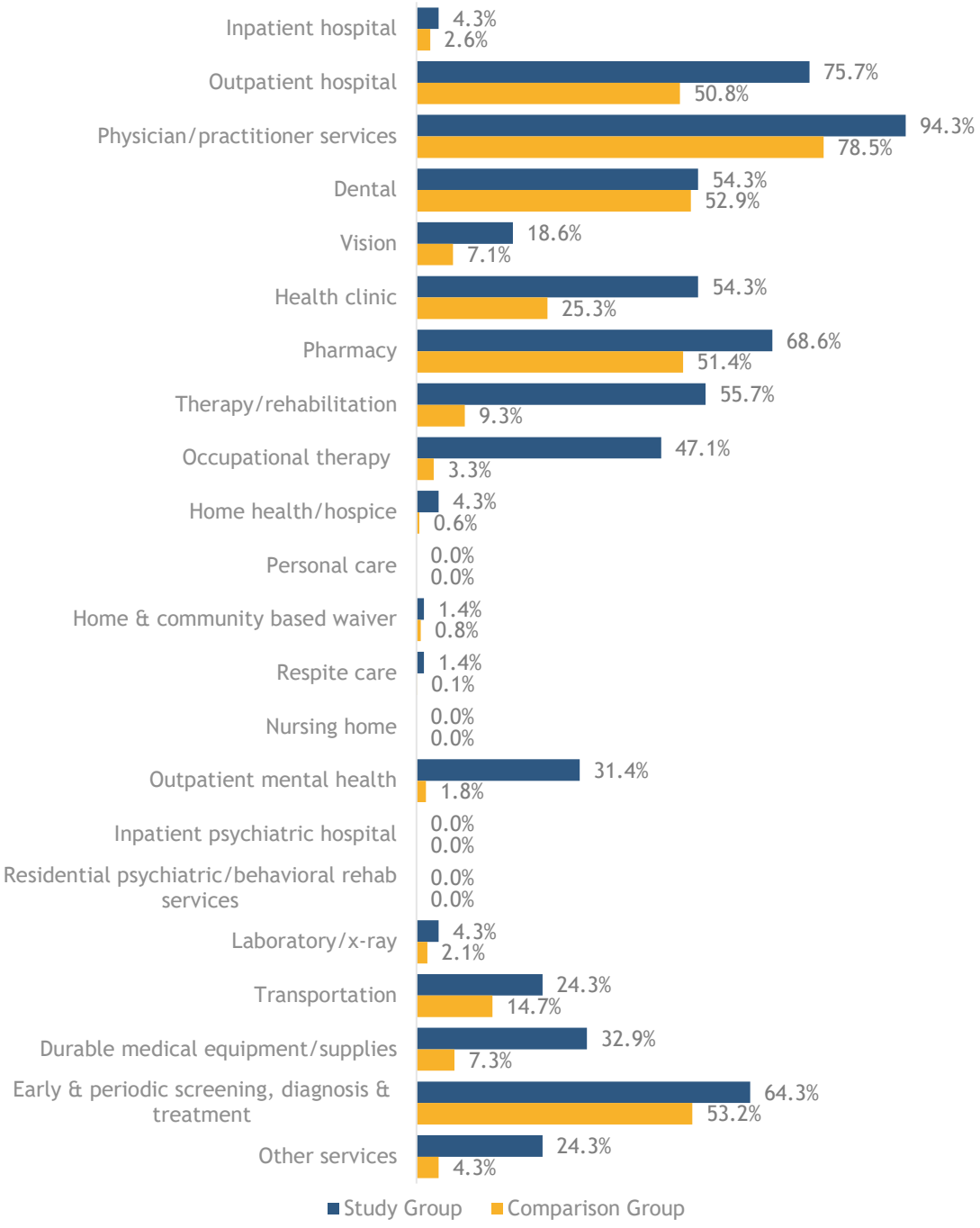
(See table next page.)

Table 14. Service Recipients, Medicaid Beneficiaries, and Total Claims by Service Category, Infants Impacted by Maternal Alcohol Use and Comparison Group, SFY2019

	Beneficiaries Receiving Services		Total Beneficiaries		Total Claims	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Inpatient hospital	3	646	70	24,621	9	960
Outpatient hospital	53	12,504	70	24,621	466	79,153
Physician/practitioner services	66	19,320	70	24,621	758	121,349
Dental	38	13,018	70	24,621	223	96,492
Vision	13	1,737	70	24,621	64	5,983
Health clinic	38	6,220	70	24,621	253	20,923
Pharmacy	48	12,645	70	24,621	330	50,321
Therapy/rehabilitation	39	2,290	70	24,621	1,549	49,402
Occupational therapy	33	811	70	24,621	771	17,454
Home health/hospice	3	139	70	24,621	80	4,832
Personal care	0	0	70	24,621	-	-
Home & community-based waiver services	1	201	70	24,621	172	3,931
Respite care	1	25	70	24,621	119	119
Nursing home	0	0	70	24,621	-	-
Outpatient mental health	22	453	70	24,621	487	23,232
Inpatient psychiatric hospital	0	0	70	24,621	-	-
Residential psychiatric/behavioral rehab services	0	0	70	24,621	-	-
Laboratory/x-ray	3	517	70	24,621	6	1,407
Transportation	17	3,608	70	24,621	319	59,208
Durable medical equipment/supplies	23	1,801	70	24,621	442	13,136
Early & periodic screening, diagnosis & treatment	45	13,092	70	24,621	67	19,847
Other services	17	1,048	70	24,621	119	5,581

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 1 through 5 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 1-5 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Figure 5. Percentage of Beneficiaries Receiving Each Service, Individuals with FAS Age 1 Through 5, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 1 through 5 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 1-5 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Hospital Facilities Utilization

In SFY2019, two admissions by individuals with FAS aged 1-5 received inpatient hospital care; all admissions were in Southcentral Alaska facilities. The average length of stay per admission was four days.

A total of 79 outpatient visits occurred; 63% (50 visits) were in Southcentral Alaska facilities. The average annual number of visits per patient was 1.84; in Southcentral Alaska facilities, the average annual number of visits per patient was 1.56 and in all other Alaska facilities, the average annual number of visits per patient was 2.64.

Emergency departments had three visits from individuals with FAS aged 1-5; two visits were in Southcentral Alaska hospitals. The average annual number of visits per patient was 1.00.

Table 15. Individuals with FAS Age 1 Through 5, Hospital Inpatient, Outpatient, and Emergency Department, Admissions/Visits and Length of Stay, Primary or Secondary Diagnoses, SFY2019

Category	Number of Admissions (Inpatient)/ Visits (Outpatient & ED)	Average Annual Admissions/Visits per Patient	Length of Stay (days)	Average Length of Stay per Admission/Visit (days)
Inpatient Admissions				
Southcentral Alaska	2	1.00	8	4
All Other Alaska	0	-	-	-
Total	2	1.00	8	4
Outpatient Visits				
Southcentral Alaska	50	1.56	51	1
All Other Alaska	29	2.64	257	9
Total	79	1.84	308	4
Emergency Department Visits				
Southcentral Alaska	2	1.00	2	1
All Other Alaska	1	1.00	1	1
Total	3	1.00	3	1

Source: Alaska Hospital Facilities Data Reporting Program.

There were only two inpatient facility admissions for children with FAS aged 1-5; both received medical diagnoses (primary or secondary) of FAS and muscle carnitine palmitoyltransferase deficiency.

The top six diagnoses for outpatient visits were medically related; the top diagnosis was FAS (100%) followed by conditions related to developmental issues.

All three visits to the emergency department the diagnosis was FAS.

Table 16. Individuals with FAS Age 1 Through 5, Top Hospital Inpatient, Outpatient, and Emergency Department Diagnoses, Primary or Secondary Diagnoses, SFY2019

Category	Type	Count	% of Total
Inpatient Admissions			
Muscle carnitine palmitoyltransferase deficiency	Medical	2	100.0%
Fetal alcohol syndrome (dysmorphic)	Medical	2	100.0%
Outpatient Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	79	100.0%
Unspecified lack of expected normal physiological development in childhood	Medical	17	21.5%
Other disorders of psychological development	Medical	13	16.5%
Developmental disorder of speech and language, unspecified	Medical	11	13.9%
Specific developmental disorder of motor function	Medical	9	11.4%
Encounter for routine child health examination without abnormal findings	Medical	9	11.4%
Emergency Department Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	3	100.0%

Source: Alaska Hospital Facilities Data Reporting Program.
Note: Any diagnosis with less than two counts is not listed.

Late Childhood

The disease drives the behavior.

—FASD Advocate

Common Effects

Evidence of FASD impact in late childhood (age 6-12) includes:

- Increased difficulty with math, time, money (abstract concepts), and reading comprehension
- Difficulty with inflexible approaches to problem solving, organizational skills and task completion, short term visual and verbal memory deficits
- Around third to fourth grade, more isolation due to challenges in forming successful peer relationships (i.e., difficulty making friends with peers/prefers younger children)
- Hyperactive and/or impulsive
- Distractible, which may be due to sensory problems
- Inattentive (~60% have ADHD diagnosis first)
- Overlapping symptoms with autism and trauma
- Uncooperative or obstinate
- Extropia – abnormal turning of one or both eyes outward
- Good talking skills, but poorer understanding
- Eating disorders

Emergent health care needs include behavior health, occupational therapy, outpatient health and mental health services, vision services, dental services, inpatient psychiatric treatment, and screening and diagnostic testing, and pharmacy services, among others.

Utilization Patterns

Medicaid Utilization

In SFY2019, 243 Medicaid beneficiaries were identified as children ages 6 to 12 with FAS and receiving health services. The average annual number of claims for those in the study group was 431% higher than for those in the comparison group (151.9 and 28.6, respectively). Of these children with FAS, 58% (142 beneficiaries) were from Southcentral Alaska. Southcentral Alaska

beneficiaries with FAS averaged 146.9 claims in 2019 compared to 158.9 claims for all other Alaska beneficiaries.

Table 17. Medicaid Claims and Average Annual Claims per Beneficiary, Individuals with FAS age 6 through 12, and Comparison Group, Southcentral Alaska and All Other Alaska, SFY2019

	Southcentral Alaska		All Other Alaska		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	142	17,616	101	13,772	243	31,388
Total claims	20,861	530,533	16,050	367,511	36,911	898,044
Average Number of Claims per Beneficiary	146.9	30.1	158.9	26.7	151.9	28.6

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 6 through 12 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 6-12 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

For all service categories, children with FAS ages 6 to 12 used a higher percentage of Medicaid services than the comparison group. On a percentage basis, the top five services used (see table and graph below) by the study group were:

1. Physician/Practitioner services (both 86.8%)
2. Dental (72.8%)
3. Pharmacy (72.0%)
4. Outpatient services (57.2%)
5. Outpatient mental health (53.9%)

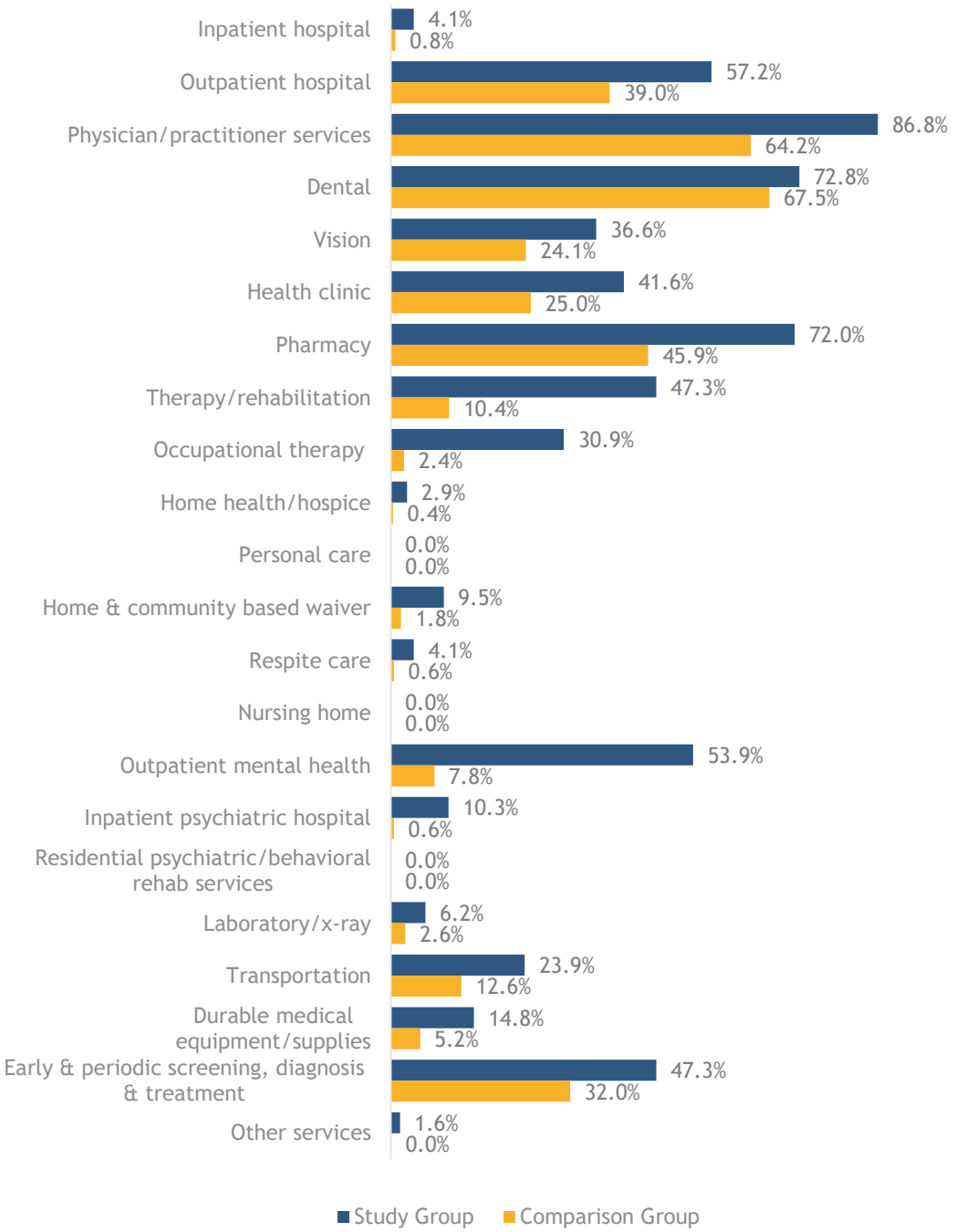
(See table next page.)

Table 18. Service Recipients, Medicaid Beneficiaries, and Total Claims by Service Category, Individuals with FAS age 6 through 12, and Comparison Group, SFY2019

	Beneficiaries Receiving Services		Total Beneficiaries		Total Claims	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Inpatient hospital	10	258	243	31,388	16	322
Outpatient hospital	139	12,239	243	31,388	1,312	69,118
Physician/practitioner services	211	20,148	243	31,388	2,879	96,386
Dental	177	21,179	243	31,388	1,540	163,997
Vision	89	7,563	243	31,388	493	35,344
Health clinic	101	7,832	243	31,388	438	20,442
Pharmacy	175	14,405	243	31,388	3,002	79,923
Therapy/rehabilitation	115	3,260	243	31,388	4,098	95,507
Occupational therapy	75	750	243	31,388	2,160	22,699
Home health/hospice	7	117	243	31,388	400	5,849
Personal care	0	9	243	31,388	-	1,332
Home & community-based waiver services	23	574	243	31,388	2,633	42,127
Respite care	10	177	243	31,388	591	13,479
Nursing home	0	0	243	31,388	-	-
Outpatient mental health	131	2,437	243	31,388	14,460	143,454
Inpatient psychiatric hospital	25	177	243	31,388	118	987
Residential psychiatric/behavioral rehab services	0	2	243	31,388	-	22
Laboratory/x-ray	15	813	243	31,388	58	3,051
Transportation	58	3,944	243	31,388	1,344	73,335
Durable medical equipment/supplies	36	1,639	243	31,388	1,220	19,496
Early & periodic screening, diagnosis & treatment	115	10,034	243	31,388	137	11,123
Other services	4	14	243	31,388	12	51

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 6 through 12 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 6-12 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Figure 6. Percentage of Beneficiaries Receiving Each Service, Individuals with FAS Age 6 Through 12, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 6 through 12 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 6-12 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Hospital Facilities Utilization

In SFY2019, 39 admissions by individuals with FAS, aged 6-12, received inpatient hospital care; 76% of all admissions (30 admissions) were in Southcentral Alaska facilities. The average length of stay per admission was 14 days.

A total of 145 outpatient visits occurred; 71% (103 visits) were in Southcentral Alaska facilities. The average annual number of visits per patient was 1.67; in Southcentral Alaska facilities, the average annual number of visits per patient was 1.51 and in all other Alaska facilities, the average annual number of visits per patient was 2.21.

Emergency departments had 11 visits from individuals with FAS aged 6-12; nine visits were in Southcentral Alaska hospitals. The average annual number of visits per patient was 1.00.

Table 19. Individuals with FAS Age 6 Through 12, Hospital Inpatient, Outpatient, and Emergency Department, Admissions/Visits and Length of Stay, Primary or Secondary Diagnoses, SFY2019

Category	Number of Admissions (Inpatient)/ Visits (Outpatient & ED)	Average Annual Admissions/Visits per Patient	Length of Stay (days)	Average Length of Stay per Admission/Visit (days)
Inpatient Admissions				
Southcentral Alaska	30	1.20	418	14
All Other Alaska	9	1.00	138	15
Total	39	1.15	556	14
Outpatient Visits				
Southcentral Alaska	103	1.51	110	1
All Other Alaska	42	2.21	396	9
Total	145	1.67	506	3
Emergency Department Visits				
Southcentral Alaska	9	1.00	9	1
All Other Alaska	2	1.00	2	1
Total	11	1.00	11	1

Source: Alaska Hospital Facilities Data Reporting Program.

The top diagnosis (primary or secondary) for inpatient facility admissions for children with FAS aged 6-12 was FAS (100%), followed by four behavioral health-related diagnoses.

The top diagnosis for outpatient visits was FAS (100%), followed by two behavioral health-related conditions related to ADHD and autism.

All emergency department visits received a diagnosis was FAS, followed by three behavioral health diagnoses related to ADHD, autism, and oppositional defiant disorder.

Table 20. Individuals with FAS Age 6 Through 12, Top Hospital Inpatient, Outpatient, and Emergency Department Diagnoses, Primary or Secondary Diagnoses, SFY2019

Category	Type	Count	% of Total
Inpatient Admissions			
Fetal alcohol syndrome (dysmorphic)	Medical	39	100.0%
Attention-deficit hyperactivity disorder, combined type	Behavioral Health	28	71.8%
Oppositional defiant disorder	Behavioral Health	25	64.1%
Borderline intellectual functioning	Behavioral Health	18	46.2%
Reactive attachment disorder of childhood	Behavioral Health	15	38.5%
Post-traumatic stress disorder, chronic	Behavioral Health	15	38.5%
Outpatient Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	145	100.0%
Attention-deficit hyperactivity disorder, unspecified type	Behavioral Health	40	27.6%
Autistic disorder	Behavioral Health	26	17.9%
Encounter for immunization	Medical	15	10.3%
Encounter for routine child health examination without abnormal findings	Medical	15	10.3%
Emergency Department Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	11	100.0%
Attention-deficit hyperactivity disorder, unspecified type	Behavioral Health	5	45.5%
Autistic disorder	Behavioral Health	4	36.4%
Oppositional defiant disorder	Behavioral Health	3	27.3%

Source: Alaska Hospital Facilities Data Reporting Program.

Adolescence

As our son approaches puberty, we are very nervous because of his heightened sexual awareness combined with his younger cognitive age. I don't want him to end up in the criminal system.

—Adoptive parent of a child with FASD

Common Effects

Evidence of FASD impact in adolescence (age 13-17) includes:

- Physical/sexual maturity with emotional/social immaturity
- Frustration/depression at their inability to fit in
- Eating disorders
- Early onset osteoarthritis and osteoporosis
- Cognitive deficits persist long term:
  - Distractibility, impulsivity, defiant/uncooperative, and inattention challenges often persist
  - Difficulty with judgment, decision-making, and understanding consequences of actions, transparent lying
  - Overlapping symptoms with autism and trauma
- Difficulty with identifying and understanding social norms:
  - May not understand verbal or nonverbal cues ("social" language)
  - May not have many same-age friends; connects better with younger/older age group
  - Vulnerable to influences of those who might take advantage of them, no sense of "stranger danger"
- Common adaptive living behavior problems
  - Failure due to "bad environmental match" at school/work
  - Difficulty with self-direction, money management, and living independently without support

Emergent health care needs include understanding of sexual development and behavior, behavior health, occupational therapy, outpatient health and mental health services, vision services, dental services, inpatient psychiatric treatment, screening and diagnostic testing, and pharmacy services, among others.

Utilization Patterns

Medicaid Utilization

In SFY2019, 175 Medicaid beneficiaries were identified as children, ages 13 to 17, with FAS receiving health services. The average annual number of claims per study group beneficiaries was 479% higher than those for the comparison group (241.6 and 41.7, respectively). Of these children with FAS, 62% (109 beneficiaries) were from Southcentral Alaska. Southcentral Alaska beneficiaries with FAS averaged 195.4 claims in 2019 compared to 318.1 claims for all other Alaska beneficiaries.

Table 21. Medicaid Claims and Average Annual Claims per Beneficiary, Individuals with FAS age 13 through 17, and Comparison Group, Southcentral Alaska and All Other Alaska, SFY2019

	Southcentral Alaska		All Other Alaska		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	109	10,947	66	8,226	175	19,173
Total claims	21,295	444,081	20,993	354,909	42,288	798,990
Average Number of Claims per Beneficiary	195.4	40.6	318.1	43.1	241.6	41.7

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 13 through 17 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 13-17 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

For all service categories, children with FAS ages 13 to 17 used a higher percentage of Medicaid services than the comparison group. On a percentage basis, the top five services used (see table and graph below) by the study group were:

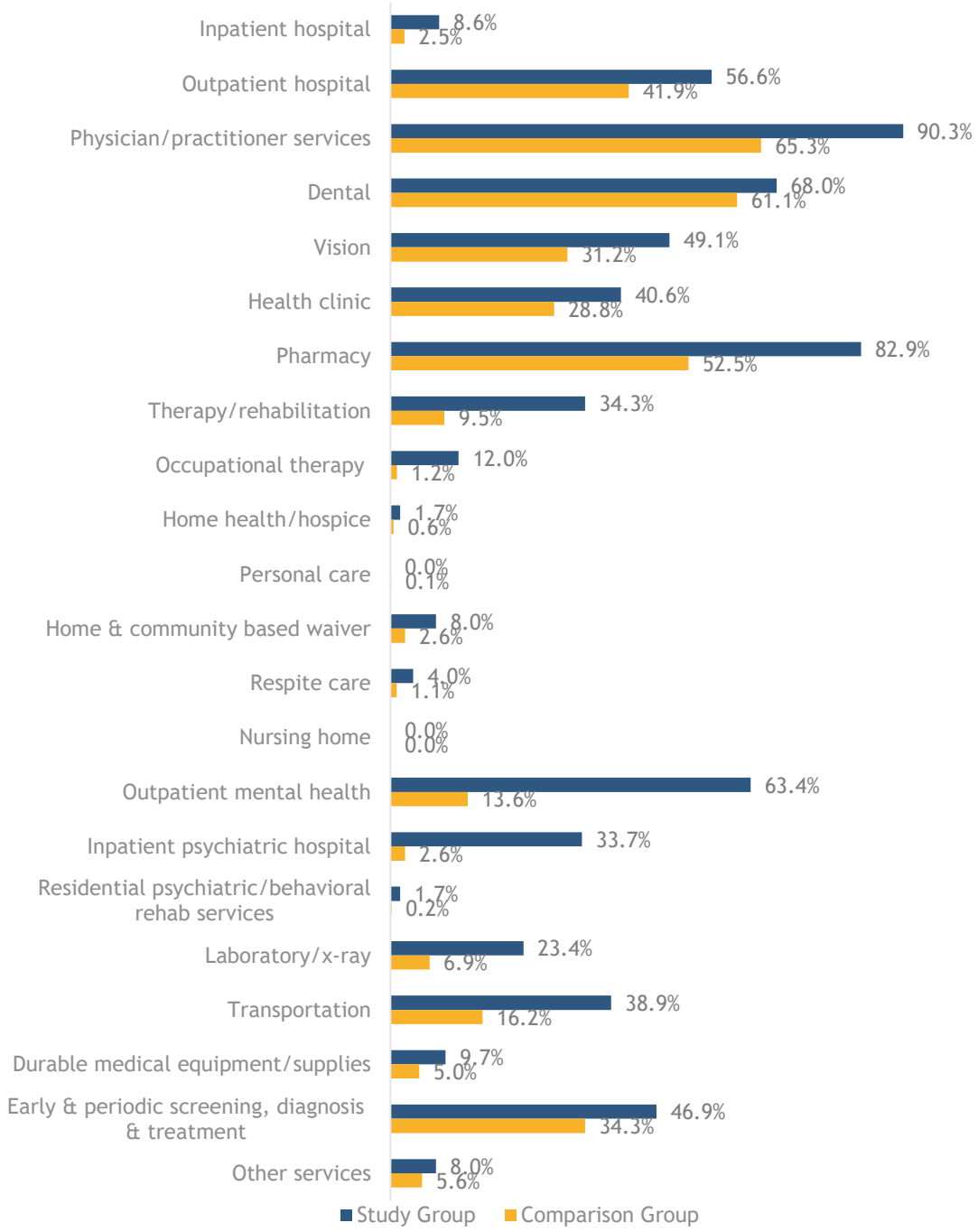
1. Physician/Practitioner services (both 90.3%)
2. Pharmacy (82.9%)
3. Dental (68.0%)
4. Outpatient mental health (63.4%)
5. Outpatient services (56.6%)

Table 22. Service Recipients, Medicaid Beneficiaries, and Total Claims by Service Category, Individuals with FAS age 13 through 17, and Comparison Group, SFY2019

	Beneficiaries Receiving Services		Total Beneficiaries		Total Claims	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Inpatient hospital	15	475	175	19,173	20	631
Outpatient hospital	99	8,043	175	19,173	1,232	60,711
Physician/practitioner services	158	12,518	175	19,173	3,119	83,109
Dental	119	11,706	175	19,173	1,146	93,874
Vision	86	5,975	175	19,173	448	27,441
Health clinic	71	5,527	175	19,173	281	16,935
Pharmacy	145	10,062	175	19,173	4,390	79,107
Therapy/rehabilitation	60	1,825	175	19,173	2,767	43,476
Occupational therapy	21	221	175	19,173	488	5,430
Home health/hospice	3	106	175	19,173	1,092	2,873
Personal care	0	27	175	19,173	-	6,061
Home & community-based waiver services	14	497	175	19,173	2,138	53,727
Respite care	7	210	175	19,173	312	14,717
Nursing home	0	1	175	19,173	-	396
Outpatient mental health	111	2,609	175	19,173	22,564	218,696
Inpatient psychiatric hospital	59	495	175	19,173	481	4,935
Residential psychiatric/behavioral rehab services	3	32	175	19,173	20	608
Laboratory/x-ray	41	1,318	175	19,173	260	8,161
Transportation	68	3,112	175	19,173	719	55,070
Durable medical equipment/supplies	17	968	175	19,173	652	12,152
Early & periodic screening, diagnosis & treatment	82	6,571	175	19,173	100	7,395
Other services	14	1,067	175	19,173	59	3,485

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 13 through 17 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 13-17 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Figure 7. Percentage of Beneficiaries Receiving Each Service, Individuals with FAS Age 13 Through 17, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 13 through 17 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 13-17 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Hospital Facilities Utilization

In SFY2019, 75 admissions by individuals with FAS aged 13-17 received inpatient hospital care; 64% (45 admission) of all admissions were in Southcentral Alaska facilities. The average length of stay per admission was 16 days.

A total of 64 outpatient visits occurred; 76% (49 visits) were in Southcentral Alaska facilities. The average annual number of visits per patient was 1.21; in Southcentral Alaska facilities, the average annual number of visits per patient was 1.17 and in all other Alaska facilities, the average number of annual visits per patient was 1.36.

Emergency departments received 20 visits from individuals with FAS aged 13-17; 11 visits were in Southcentral Alaska hospitals. The average annual number of visits per patient was 1.18.

Table 23. Individuals with FAS Age 13 Through 17, Hospital Inpatient, Outpatient, and Emergency Department, Admissions/Visits and Length of Stay, Primary or Secondary Diagnoses, SFY2019

Category	Number of Admissions (Inpatient)/ Visits (Outpatient & ED)	Average Annual Admissions/Visits per Patient	Length of Stay (days)	Average Length of Stay per Admission/Visit (days)
Inpatient Admissions				
Southcentral Alaska	45	1.10	775	17
All Other Alaska	30	1.07	437	15
Total	75	1.09	1,212	16
Outpatient Visits				
Southcentral Alaska	49	1.17	125	3
All Other Alaska	15	1.36	26	2
Total	64	1.21	151	2
Emergency Department Visits				
Southcentral Alaska	11	1.00	12	1
All Other Alaska	9	1.50	20	2
Total	20	1.18	32	2

Source: Alaska Hospital Facilities Data Reporting Program.

The top diagnosis (primary or secondary) for inpatient facility admissions for children with FAS aged 13-17 was FAS (100%), followed by four behavioral health-related diagnoses.

The top diagnosis for outpatient visits was FAS (100%), followed by five behavioral health-related conditions related to ADHD, post-traumatic stress disorder, depression, attachment disorder and suicidal ideation.

All emergency department visits received a diagnosis was FAS, followed by five behavioral health diagnoses related to ADHD, depression, autism, post-traumatic stress disorder, and drug therapy.

Table 24. Individuals with FAS Age 13 Through 17, Top Hospital Inpatient, Outpatient, and Emergency Department Diagnoses, Primary or Secondary Diagnoses, SFY2019

Category	Type	Count	% of Total
Inpatient Admissions			
Fetal alcohol syndrome (dysmorphic)	Medical	75	100.0%
Post-traumatic stress disorder, unspecified	Behavioral Health	33	44.0%
Oppositional defiant disorder	Behavioral Health	28	37.3%
Reactive attachment disorder of childhood	Behavioral Health	28	37.3%
Attention-deficit hyperactivity disorder, combined type	Behavioral Health	25	33.3%
Outpatient Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	64	100.0%
Attention-deficit hyperactivity disorder, unspecified type	Behavioral Health	25	39.1%
Post-traumatic stress disorder, unspecified	Behavioral Health	12	18.8%
Major depressive disorder, single episode, unspecified	Behavioral Health	10	15.6%
Reactive attachment disorder of childhood	Behavioral Health	6	9.4%
Suicidal ideations	Behavioral Health	6	9.4%
Emergency Department Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	20	100.0%
Attention-deficit hyperactivity disorder, unspecified type	Behavioral Health	10	50.0%
Major depressive disorder, single episode, unspecified	Behavioral Health	7	35.0%
Autistic disorder	Behavioral Health	4	20.0%
Post-traumatic stress disorder, unspecified	Behavioral Health	4	20.0%
Other long term (current) drug therapy	Behavioral Health	4	20.0%

Source: Alaska Hospital Facilities Data Reporting Program.

Adulthood

When they are children, they have help. But as adults they need supports.

—FASD Researcher

Common Effects

Emerging research suggest that adverse events during childhood development may permanently alter physiologic function, leading to a higher risk of adult-onset diseases. Evidence of FASD impact in adulthood (ages 18-64) includes:

- Eating disorders
- Early onset of chronic diseases and conditions such as hypertension, diabetes, cardiovascular disease, and cancer possibly associated with atypical aging.
- Cognitive deficits persist long term:
  - Distractibility, impulsivity, and inattention challenges often persist
  - Difficulty with judgment, decision-making, understanding consequences of actions
- Difficulty with identifying and understanding social norms:
  - May not understand verbal or nonverbal cues ("social" language)
  - May not have many same-age friends; may connect better with younger/older age group
  - Vulnerable to those who might take advantage of them
- Common adaptive living behavior problems
  - Failure due to "bad environmental match" at school/work
  - Difficulty with self-direction, money management, and living independently without support
  - Difficulty keeping job

Lay of the Land Survey

The following "Lay of the Land" survey data represents individuals with FASD who participated in a health survey in Canada.[30] While this utilization study is focused on Alaska, the Canadian

[30] Himmelreich, M., Lutke, C.J., Hargrove, E. T., "The lay of the land: Fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis," in The Routledge Handbook of Social Work and Addictive Behaviors, ed. Begun, A. L., Murray, M.M. (New York: Routledge, 2020), 190-214.

study provides a contextual backdrop complementing Alaska data. It provides a unique insight into the cumulative impacts of FASD on adult health conditions and the health services utilization context. Overall, the survey results indicate higher frequencies among individuals with FASD of almost every health issue reported, and in many cases, many times higher than prevalence rates in the general population.

Congenital Disorders and Growth/Developmental Alterations

Survey results reflect an increased frequency of cleft lip or palate, spina bifida, and cerebral palsy. Autism/Asperger's Spectrum Disorder (ASD) was 6.6 was times higher than in the general population. More than one third (38.2%) of respondents reported growth delay during childhood. Being underweight as an adult was 12.1 times higher than the general population.

Table 25. Congenital Disorders and Growth/Developmental Alterations, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Congenital Disorders			
Cleft lip or palate	0.1	2.6	26.0
Cleft palate	0.05-0.06	-	-
Spinal (sacral) dimple	4.8	5.3	1.1
Spina bifida/spina bifida occulta	0.1	1.9	19.0
Cerebral palsy	0.15-0.4	3.4	12.4
Growth and Development Alterations			
Growth delay as child	-	38.2	-
Treated for GH deficiency	-	1.6	-
Low weight (i.e., lose weight easily or can't gain weight)	1.5	14.7-21.5	12.1
Overweight/obese	-	27.4	-
Overweight	31.8	-	-
Obese	40.0	-	-
Severe obesity	8.0	-	-
Autism/Asperger's (ASD)	2.24	14.7	6.6

Source: Himmelreich, Lutke, & Hargrove (2017).

Musculoskeletal System Conditions

Numerous musculoskeletal conditions occurred more frequently than within the general population. Most notable were fused vertebrae in the neck (880.0 times), pectus carinatum (46.3) femoral rotation (44.0 times), and abnormalities of the digits such as pectus excavatum (36.0), syndactyly (20.5), and camptodactyly (19.9).

Table 26. Musculoskeletal System Conditions, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Musculoskeletal System*			
Osteoarthritis	-	13.2	3.7‡
Ages 20-29 (PHAC)	0.2-2.2	-	-
Ages 40-49 (PHAC)	3.6-6.9	-	-
Adult (CDC)	9.2	-	-
Osteoporosis	10.0	3.4	0.3
Male	4.0	-	-
Female	16.0	-	-
Osteopenia	48.0	5.7	0.1§
Sciatica	13.0-5.3	17.2	1.9
Shin splints	-	23.0	-
Flat feet	20.0†	34.9	1.7§
Plantar fasciitis	8.3-10.0	14.3	1.6
Congenital hip		5.9	
Adult hip dysplasia	5.0-11.0	4.9	0.2
Bone spurs		6.3	
Femoral rotation	0.05	2.2	44.0
Abnormalities of digits	-	-	-
Clinodactyly	1.0-19.0	25.0	2.5
Camptodactyly	<1.0	19.9	19.9
Syndactyly	0.05-0.33	3.9	20.5
Radioulnar synostosis	350 cases in literature	1.0	-
Scoliosis	2.5†	19.5	7.8§
Missing vertebrae in neck	Rare	1.2	
Fused vertebrae in neck	0.0025	2.2	880.0
Odontoid anomaly	Rare	2.2	
Pectus excavatum	0.25-0.1	6.3	36.0
Pectus carinatum	0.067	3.1	46.3

Source: Himmelreich, Lutke, & Hargrove (2017).
*Other chronic complaints included joints always hurt, joints make noise, joints lock, joints swell, and cartilage problems such as grinding or "crunching" with movement.† Adults.‡ Compared to adults 20-49.§ Times higher calculated using FASD frequency and incidence in general population

Cardiovascular System Conditions

Congenital heart defects and cardiomyopathy were reportedly higher than in the general population at 11.7 and 21.1 times, respectively. Having heart surgery as a child occurred at a rate 10.8 times higher.

Table 27. Cardiovascular System Conditions, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Cardiovascular System*			
Heart disease (all types)	10.6-11.5†	-	-
Congenital heart defects (CHD)	0.3-1.0	7.6	11.7
Coronary heart disease	1.2‡	1.9	1.6
Hypertension	8.4‡	16.1	1.9
Valvular heart disease	0.7‡	2.7	3.9
SVT (supraventricular tachycardia)	2.0	5.7	2.9
Cardiomyopathy	0.036-0.04	0.8	21.1
Heart murmur	10.0†	21.0	2.1
Heart failure	20.0§	0.4	0.0
Heart attack	1.0-1.8**	2.1	1.5
Heart surgery	-	-	-
As child	0.25	2.7	10.8
As adult	-	0.8	-

Source: Himmelreich, Lutke, & Hargrove (2017).
*Other heart problems occurring less frequently included bundle branch block, stents, mitral valve prolapse, bradycardia, pulmonary stenosis, enlarged heart, enlarged aorta, Lown-Ganong-Levine syndrome, and Wolff-Parkinson-White syndrome. † Adult, ‡ Ages 18-44. § Lifetime risk. ** Ages 20-59.

Gastrointestinal and Digestive System Conditions

Respondents experienced gastrointestinal and digestive system conditions about 2 times higher than the general population.

Table 28. Gastrointestinal and Digestive System Conditions, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Gastrointestinal/Digestive			
Stomach ulcers (all types)	1.0-6.2	8.4	2.3
Esophageal reflux (GERD)	20.0	42.1	2.1
Irritable bowel syndrome (IBS)	11.2	20.0	1.8
Chronic diarrhea	5.0	12.7	2.5
Chronic constipation	2.0-27.0	26.3	1.8

Source: Himmelreich, Lutke, & Hargrove (2017).
*Wide variance. † Times higher calculated using FASD frequency and incidence in general population.

Endocrine and Metabolic Disorders

Clinically evident hypothyroidism was 186.7 times higher and hypoglycemia (not related to diabetes) 87.2 times higher than the general population.

Table 29. Endocrine and Metabolic Disorders, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Endocrine and Metabolic			
Diabetes Type 1	-	1.9	5.0*
Ages 20-39	0.34-0.42	-	-
Ages 40-59	0.31-0.49	-	-
Diabetes Type 2	8.5	6.0	0.7
Thyroid disease	-	-	-
Hypothyroidism (clinically evident)	0.03	5.6	186.7
Hyperthyroidism	0.5	1.3	2.6
Parathyroid disease	0.03-0.7	2.1	5.8
High cholesterol	-	-	-
Total	12.9	16.5	1.3
LDL	31.7	-	-
Hypoglycemia (not related to diabetes)	0.36	31.4	87.2

Source: Himmelreich, Lutke, & Hargrove (2017).
*Times higher calculated using FASD frequency and incidence in general population.

Immune Disorders, Diseases, and Infections

For almost every disease, disorder, or infection, except for sexually transmitted infections, frequencies in adults with FASD were higher than prevalence rates in the general population. Chronic ear infections were 146.8 times higher than the general population; acute sinusitis 46.5 times, kidney infections 830.0 times, staph infections 80.0 times, and bone infections 200.0 times higher.

Table 30. Immune Disorders, Diseases, and Infections, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Immune Disorders			
Sinusitis	12.5-14.0	-	-
Chronic	14.0	35.4	2.5
Acute	1.3	60.4	46.5
Ear infections (chronic)	0.25*	36.7	146.8††
Chest infections	3.3-3.6	41.9	-
Chronic bronchitis	23.65	-	-
Colds/year (all ages)	36.0	-	-
Flu/year (all ages)		-	-
12+ years	27.3		
Allergies	7.7-8.1	59.1	2.2††
Hay Fever	7.7-8.1	-	-
Asthma	7.7-8.3†	35.9	4.7††
Carry EpiPen	0.08-2.4	9.6	7.7
Eczema	10.1-10.7‡	27.7	2.7††
Fungal infections	-	25.2	-
Pneumonia	1.62	34.8	21.5
Kidney infections	-	16.6	830.0
Women	0.01-0.03		
Bladder infections	20.0-50.0	41.1	2.1
Influenza B	11.37-13.05§	11.1	1.0††
Strep	3.4**	40.2	11.8††
Staph	0.24-0.41*	19.2	80.0††
Eye infections	-	54.4	-
Bone infections	0.01-0.1*	2.0	200.0††
Skin infections	34.48	29.3	-
STDs/STIs	-	19.5	-
Hepatitis (all)	-	4.7	-
A	0.00044-0.00062§	-	-
B	0.0065§	-	-
C	0.745§	-	-
Difficulty with wound healing	-	24.6	-

Source: Himmelreich, Lutke, & Hargrove (2017).
* Incidence (adult).† 13.6% ever had.‡7.2% (adult).§Incidence. ** Incidence (non-invasive). †† Times higher calculated using FASD frequency and incidence in general population.

Autoimmune Disorders

Overall autoimmune disorders are 4.1 times higher among respondents, as compared to the general population. Sjögren's syndrome, a chronic autoimmune disease affecting salivary glands and tear glands, was 181.8 times higher. Sarcoidosis was higher at 16.0 times and Goodpasture's syndrome 13.3 times.

Table 31. Autoimmune Disorders,2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Autoimmune Disorders			
Overall autoimmune	5.0-8.0	35.0	4.1
Rheumatoid arthritis	0.6-1.3	6.6	5.4
Lupus	0.05	0.8	6.9
Sarcoidosis	0.05*	0.6	16.0‡
Angiodema	0.5	1.4	12.0
Celiac	0.75-1.0	2.2	2.8
Psoriasis	2.4-3.0	7.4	2.5
Ulcerative colitis	0.3-0.95	2.2	2.7
Crohn's disease	0.14-0.83	2.4	3.5
Fibromyalgia	2.0-3.3	5.9	4.9
Gout	3.76-3.9	3.4	2.2
Kawasaki disease	0.001-0.01	1.0	0.9
Sjögren's syndrome	1.2	0.3	181.8
Scleroderma	0.024	0.32	0.3
Anti-GBM antibody disease (Goodpasture's syndrome)	0.0001-0.00016†	0.16	13.3‡

Source: Himmelreich, Lutke, & Hargrove (2017).
* Among Caucasians. † Incidence – Prevalence Unknown. ‡ Times higher calculated using FASD frequency and incidence in general population.

Dental and Oral Health

Absence of natural teeth is 1.2 times higher than the general population. Among survey respondents, 7.6% never had baby teeth, 10.7% never had adult teeth. Compared to the general population, the occurrence of many cavities was 1.4 times higher.

Table 32. Dental and Oral Health, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Dental and Oral Health			
Absence of all natural teeth	6.4	-	1.2
Never had baby teeth	-	7.6	-
Never had adult teeth	-	10.7	-
Extra adult teeth	-	13.36	-
Fused teeth	-	3.3	-
Hypoplastic enamel	-	19.3	-
Simple (1 tooth)	9.8-93.0	-	-
Severe (multiple teeth)	2.2-21.6	-	-
Cavities	-	-	-
Many	35.0*	50.6	1.4†
Few/none	-	37.1	-
High arched palate	-	22.0	-
Tori (overgrowth of bone in the mouth)	7.0-10.0	4.0	0.5
Had braces	33.0	41.7	1.3
Never had but needed braces	20.0	26.37	1.3

Source: Himmelreich, Lutke, & Hargrove (2017).
*Ages 25-44. † Times higher calculated using FASD frequency and incidence in general population.

Vision Conditions

Difficulties with a range of vision conditions occurred with greater frequency among survey respondents, as compared to the general population. Of note are esotropia (9.5 times higher), ptosis (9.1), amblyopia (8.6), and astigmatism (7.6).

Table 33. Vision Conditions, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Vision			
Myopia	30.0	48.2	1.6
Astigmatism	4.7	35.6	7.6
Amblyopia	2.0-3.0	21.6	8.6
Ptosis	0.97	8.8	9.1
Strabismus	-	-	-
Esotropia	1.2	11.4	9.5
Exotropia	2.1	5.1	2.4
"Jittery" vision when reading (Nystagmus?)	-	20.8	-
Problems with depth perception	-	30.9	-
Wear glasses/contacts	-	64.9	1.6*
Ages 20-40	40.0-42.0	-	-
Ages 40-50	60.0	-	-
Eye surgery	-	12.4	-

Source: Himmelreich, Lutke, & Hargrove (2017).
* Times higher calculated using FASD frequency and incidence in general population.

Hearing Disorders

Hearing disorders were reported among survey respondents. Experiencing hearing loss as a child was 58.4 times higher as compared to the general population. Hearing problems beginning after age 20 occurred in 8.1% of respondents.

Table 34. Hearing Disorders, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Hearing			
Hearing loss (as a child)	0.2-0.3	14.6	58.4
Tubes in ears (as a child)	7.0	22.2	3.2
Hearing problems beginning after age 20	-	8.1	-

Source: Himmelreich, Lutke, & Hargrove (2017).

Executive Function Issues

A range of executive function issues are reported by the super-majority of survey respondents (67.5% - 90.2%). Examples include problems paying attention (90.2%), problems with short- and long-term memory (81.5% and 67.5%, respectively), problems making decisions (85.8%), difficulty with judgement (82.8%), and problems managing money (87.4%). Difficulty understanding what is being said to you was reported by almost three quarters of respondents (71.5%).

Table 35. Executive Function Issues, 2017

Disease/Disorder/Condition	FASD Frequency (%)
Executive Function Issues	
Problems with short-term memory	81.5
Problems with long-term memory	67.5
Difficulty with math or numbers	82.8
Difficulty with calculation	80.0
Difficulty with estimation	82.8
Problems paying attention	90.2
Problems managing money	87.4
Problems making decisions	85.8
Difficulty with judgment	82.8
Difficulty following directions (especially verbal)	85.2
Problems with time management	81.5
Difficulty understanding what is said to you	71.5
Difficulty reading	48.1
Difficulty understanding what you read	69.0
Dyslexia	13.9

Source: Himmelreich, Lutke, & Hargrove (2017).

Other Sensory Issues

A range of sensory issues was reported by survey respondents with relatively high frequency overall. About half of respondents (53.1%) report a high pain tolerance, cannot tolerate bright light (57.5%), have difficulty feeling temperature like others do and regulating temperature (54.1% and 49.9% respectively); do not like the texture of some/many foods (58.2%), and report their skin is very sensitive to stimuli (52.2%). About two-thirds are over-reactive to some body sensations and under-reactive to others (68.8%) and do not like loud noise (63.4%). Three quarters of respondents do not like tags, wrinkles, socks, etc. (74.8%) and are easily overwhelmed by crowds/large groups (75.7%).

Table 36. Other Sensory Issues, 2017

Disease/Disorder/Condition	FASD Frequency (%)
Sensory Issues	
Do not feel pain the way others do – high pain tolerance for major things	53.1
Feel more pain than others do even for minor things	33.6
Do not like tags, wrinkles, socks, etc.	74.8
Clothes need to be very tight	16.1
Clothes need to be very loose	46.0
Do not like loud noise (hyperacusis)	63.4
Cannot tolerate bright light	57.5
Difficulty feeling temperature (hot or cold) like others do	54.1
Difficulty regulating temperature (go from too hot to too cold quickly and often)	49.9
No sense of smell	10.1
Disordered sense of smell (things smell different than to others [dysosmia])	28.3
Poor or no sense of taste for many foods (hypoaguesa or aguesa)	10.9
Do not like texture of some/many foods	58.2
Really like spicy hot foods (can taste)	39.1
Like to eat lemons	33.1
Do not feel hunger much	36.6
Skin is very sensitive to stimuli	52.2
Skin itself (not muscles) hurts with use	16.3
Easily overwhelmed (panicky) by crowds, large groups (noise, light, movement, touch)	75.7
Over-reactive to some body sensations and under-reactive to others	68.6

Source: Himmelreich, Lutke, & Hargrove (2017).

Sleep Disorders

Some sleep disorders occurred more frequently among survey respondents. Most noted was narcolepsy and problems falling asleep at 12.0 and 4.0 times higher, respectively.

Table 37. Sleep Disorders, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Sleep Disorders*			
Narcolepsy	0.025-0.05	0.45	12.0
Problems falling asleep	11.9-22.8	70.0	4.0
Problems staying asleep	17.0-26.9	57.6	2.6
Problems sleeping too much	-	41.7	-
Problems sleeping at night	-	65.7	-
Need to sleep during the day	-	47.4	-
Problems waking up in the morning	-	57.6	-
Tired all the time	-	34.8	-
Sleep apnea	-	15.2	0.6
≥5 events per hour	9.0-38.0	-	-
≥15 events per hour	6.0-17.0	-	-
Restless leg syndrome	7.0-10.0	18.5	2.2
Night sweats	-	24.7	-
Parasomnias	-	-	-
Night terrors	-	2.7	-
Sleep walking	-	1.7	-
Sleep talking	-	17.7	-
Nightmares	-	19.4	-

Source: Himmelreich, Lutke, & Hargrove (2017).
*Other sleeping problems included incontinence due to sleep and heart stops while asleep. Times higher calculated using FASD frequency and incidence in general population.

Reproductive Health Conditions

Female respondents indicated premature menopause at 6.6 times higher than the general population. In males, undescended testicles were more common at 3.5 times higher. Among individuals who had children, recurrent miscarriages were 5.6 times higher; having a child with special needs was 1.2 times higher.

Table 38. Reproductive Health Conditions, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Reproductive Health			
Dysmenorrhea	5.0-59.0*	34.8	1.1†
Ovarian cysts	20.0	12.9	0.6
Premature menopause	-	6.6	6.6†
Ages <40	1.0	-	-
Ages 41-45	5.0	-	-
Undescended testicles	1.0-2.0	5.2	3.5
Infertility	6.0-6.7	4.7	0.7
For those who had children			
Recurrent miscarriage	-	11.1	5.6
Two miscarriages	2.0	-	-
Three miscarriages	1.0	-	-
Premature baby	10.0	9.5	-
Breast feeding problems	-	21.3	-
Child with special needs	13.0-15.0	16.4	1.2

Source: Himmelreich, Lutke, & Hargrove (2017).
*Wide variance. † Times higher calculated using FASD frequency and incidence in general population.

Mental Health Disorders

Early onset dementia was 209.3 times higher, attempted suicide (49.5 times higher), agoraphobia (18.4), AHDH/ADD (18.1), panic disorder (17.1) and psychosis (10.5) than in the general population.

Table 39. Mental Health Disorders, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Mental Health			
Dementia (early onset)		0.9	209.3
Ages 25-64	0.00-0.0086		
Mood disorder (any)	8.6-99.7	52.6	5.7
Depression (including MDD)	7.6	67.4	8.9
Anxiety or agitation	19.1*	88.4	4.6
Panic disorder	2.7	46.2	17.1
ADHD/ADD	4.4	79.7	18.1
Schizophrenia	0.25-1.1	3.1	4.6
Bipolar disorder	2.8	17.0	6.1
Agoraphobia	0.9	16.6	18.4
Personality disorder	9.1	16.5	1.8
Oppositional defiant disorder	9.7	27.3	2.8
OCD	1.2	4.4	3.7
Psychosis	0.749	7.9	10.5
Suicide			
Attempted	0.6	29.7	49.5
Suicidal thoughts	4.3		

Source: Himmelreich, Lutke, & Hargrove (2017).
*Any anxiety disorder among U.S. adults. †Median lifetime risk.

Substance Use Disorders

Cigarette and marijuana use was 2.3 and 3.3 times higher, as compared to the general population.

Table 40. Substance Use Disorders, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Substance Use Disorders			
Alcohol or drugs	-	37.1	-
Alcohol	8.5-25.1	-	-
Drugs	2.0	-	-
Both	1.1	-	-
Cigarettes	14.0-19.4	37.8	2.3
Marijuana	-	31.5	3.3
Use	9.5	-	-
Disorder	2.9	-	-

Source: Himmelreich, Lutke, & Hargrove (2017).

Other Diseases, Disorders, Conditions, and Cancer

Cancer among individuals 18-44 years old was 1.9 times higher. Lifetime risk of seizures was 5.0 times higher, and kidney disease 4.8 times higher than in the general population.

Table 41. Other Diseases, Disorders, Conditions, and Cancer, 2017

Disease/Disorder/Condition	General Prevalence (%)	FASD Frequency (%)	Times Higher
Other			
Cancer	9.4	3.75	0.4
Ages 18-44	2.0	-	1.9
Ages 45-64	9.9	-	-
Migraine headaches	11.7-16.2	32.8	2.4
Seizures (lifetime risk)	4.0	20.1	5.0
Hernias	-	3.0-5.0	-
Umbilical	2.0	5.0	2.5
Hiatal	15.0	3.0	0.2
Inguinal	-	4.5	
Appendicitis	-	45.5	4.3
Ages 20-29	13.0	-	-
Ages 30-39	10.8	-	-
Ages 40-49	7.8	-	-
Tourette syndrome	0.3-0.6	4.4	-
Kidney disease	2.1	10.1	4.8

Source: Himmelreich, Lutke, & Hargrove (2017).
Note Other diseases, disorders, and conditions named included Ehlers Danloss syndrome, Fetal Dilantin syndrome, Reiter's syndrome, neurofibromatosis, thalassemia, Prader Willi syndrome, Thalidomide syndrome, central core myopathy, balance translocation chromosomes 2 & 3, Caroli syndrome, Noonan's syndrome, hemophilia, Klinefelter syndrome, Williams syndrome, Turner's syndrome, Cyclic neutropenia, Duane syndrome, Short Gut syndrome, Proteus syndrome, and several unspecified chromosomal anomalies.

Respondent Demographics

A total of 541 individuals participated in the survey. Respondents ranged in age from ≤16 to greater than 60 years, with the greatest number of individuals in the 16–40-year range, and an average age of 27.5 years. A range of FASD diagnoses was reported by these individuals: 47.8% had been diagnosed with FAS and 17% with ARND; the remaining ~35% were diagnosed with pFAS (8.0%), FAE (fetal alcohol effects, 9.9%), static encephalopathy PAE (7.9%), and other (9.8%, including FASD, FAS Atypical, and Neurobehavioral Disorder PAE).

Table 42. Respondent Demographics, 2017

Category	%
Diagnosis	
FAS	47.8
pFAS	8.0
ARND	17.4
FAE	9.9
Static encephalopathy	7.9
Other	9.8
Age	
<16	7.6
16-19	20.3
20-30	43.4
31-40	16.3
41-50	5.7
51-59	4.4
>60	2.2

Source: Himmelreich, Lutke, & Hargrove (2017).

Emergent health care needs include behavior health, occupational therapy, outpatient health and mental health services, vision services, dental services, home health services, inpatient health and psychiatric treatment, and pharmacy services, among others.

Utilization Patterns

Medicaid Utilization

In SFY2019, 320 Medicaid beneficiaries were identified as adults, ages 18 to 64, with FAS receiving health services. The average annual number of claims per study group beneficiaries was 305% higher than the comparison group (271.3 and 66.9, respectively). Of these adults with FAS, 70% (223 beneficiaries) were from Southcentral Alaska. Southcentral Alaska beneficiaries with FAS averaged 306.8 claims in 2019 compared to 189.8 claims for all other Alaska beneficiaries.

Table 43. Medicaid Claims and Average Annual Claims per Beneficiary, Individuals with FAS age 18 through 64, and Comparison Group, Southcentral and All Other Alaska, SFY2019

	Southcentral		All Other Alaska		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	223	59,761	97	40,321	320	100,082
Total claims	68,419	4,535,131	18,406	2,162,153	86,825	6,697,284
Average Number of Claims per Beneficiary	306.8	75.9	189.8	53.6	271.3	66.9

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 18 through 64 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 18-64 and without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

For all service categories, except laboratory and x-ray, adults with FAS ages 18 to 64 used a higher percentage of Medicaid services than the comparison group. On a percentage basis, the top five services used (see table and graph below) by the study group were:

1. Physician/Practitioner services (both 93.8%)
2. Outpatient services (84.7%)
3. Pharmacy (73.4%)
4. Health clinic (57.1%)
5. Dental (53.1%)

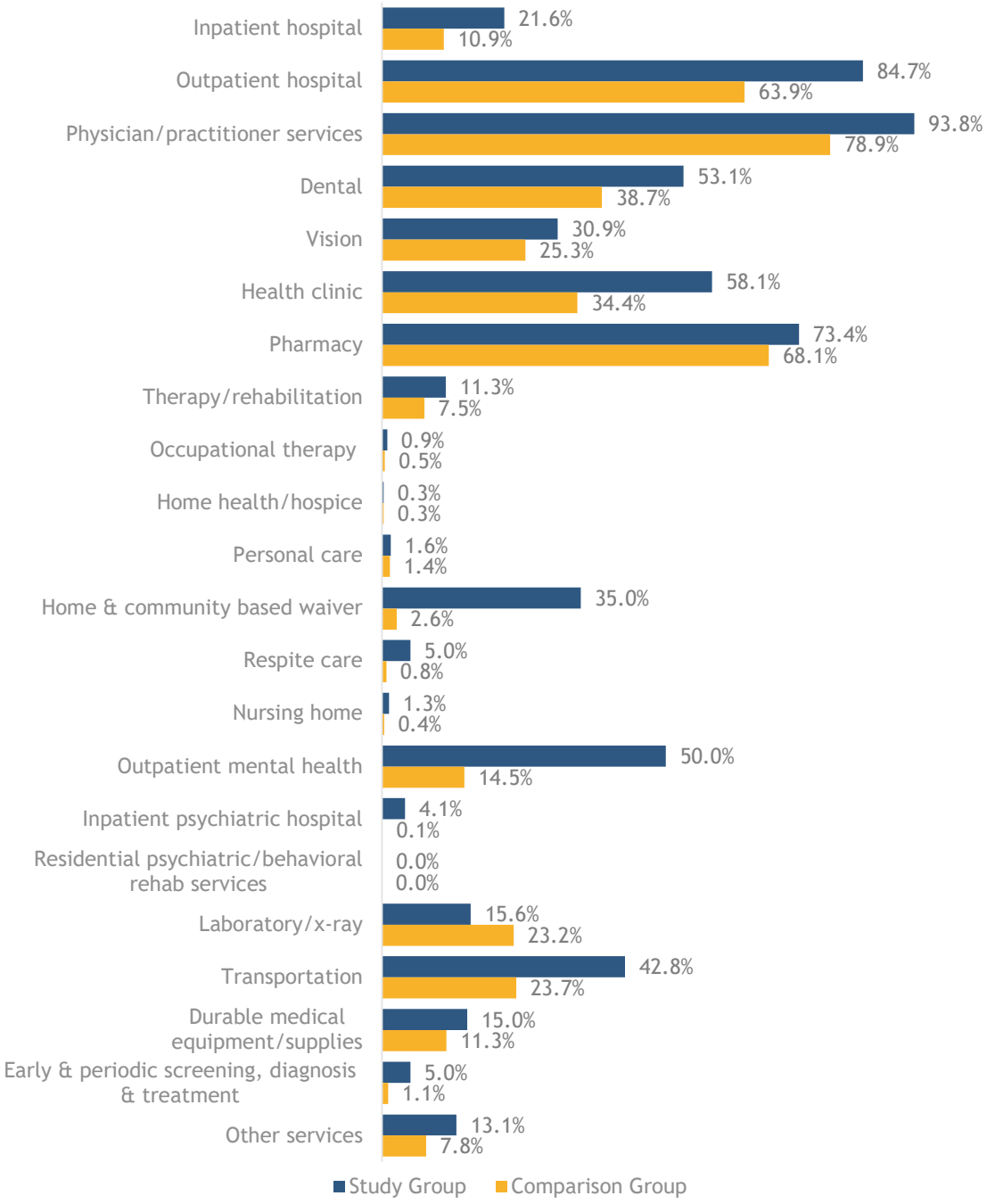
(See table next page.)

Table 44. Service Recipients, Medicaid Beneficiaries, and Total Claims by Service Category, Individuals with FAS age 18 through 64, and Comparison Group, SFY2019

	Beneficiaries Receiving Services		Total Beneficiaries		Total Claims	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Inpatient hospital	69	10,907	320	100,082	130	16,687
Outpatient hospital	271	63,907	320	100,082	7,097	1,076,568
Physician/practitioner services	300	79,013	320	100,082	6,462	1,093,111
Dental	170	38,778	320	100,082	995	241,184
Vision	99	25,297	320	100,082	407	108,932
Health clinic	186	34,433	320	100,082	1,381	180,963
Pharmacy	235	68,171	320	100,082	9,571	1,154,813
Therapy/rehabilitation	36	7,485	320	100,082	803	137,645
Occupational therapy	3	508	320	100,082	11	8,277
Home health/hospice	1	309	320	100,082	25	8,265
Personal care	5	1,378	320	100,082	1,240	298,030
Home & community-based waiver services	112	2,603	320	100,082	42,645	881,960
Respite care	16	783	320	100,082	1,045	78,239
Nursing home	4	391	320	100,082	214	3,715
Outpatient mental health	160	14,505	320	100,082	10,837	641,333
Inpatient psychiatric hospital	13	88	320	100,082	51	433
Residential psychiatric/behavioral rehab services	0	3	320	100,082	-	39
Laboratory/x-ray	50	23,225	320	100,082	457	204,985
Transportation	137	23,673	320	100,082	2,141	390,292
Durable medical equipment/supplies	48	11,356	320	100,082	1,127	147,567
Early & periodic screening, diagnosis & treatment	16	1,081	320	100,082	19	1,172
Other services	42	7,795	320	100,082	167	23,074

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 18 through 64 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 18-64 and were without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Figure 8. Percentage of Beneficiaries Receiving Each Service, Individuals with FAS Age 18 Through 64, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: Study group refers to Medicaid beneficiaries who were ages 18 through 64 in SFY2019 and were diagnosed with FAS at any time in SFY2019. The comparison group includes Medicaid beneficiaries in SFY2019 who were ages 18-64 and were without a developmental disability, encephalopathy, other intellectual disabilities, pervasive, and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Hospital Facilities Utilization

In SFY2019, 105 admissions by individuals with FAS aged 18 and above received inpatient hospital care; 66% (69 admission) of all admissions were in Southcentral Alaska facilities. The average length of stay per admission was six days.

A total of 329 outpatient visits occurred; 79% (261 visits) were in Southcentral Alaska facilities. The average annual visits per patient were 1.61; in Southcentral Alaska facilities, the average annual visits per patient were 1.69 and in all other Alaska facilities, the average annual visits per patient were 1.36.

Emergency departments had 92 visits from individuals with FAS aged 18 and above; 88% (81 visits) were in Southcentral Alaska hospitals. The average annual number of visits per patient was 1.44.

Table 45. Individuals with FAS Age 18 and Above, Hospital Inpatient, Outpatient, and Emergency Department, Admissions/Visits and Length of Stay, Primary or Secondary Diagnoses, SFY2019

Category	Number of Admissions (Inpatient)/ Visits (Outpatient & ED)	Average Annual Admissions/Visits per Patient	Length of Stay (days)	Average Length of Stay per Admission/Visit (days)
Inpatient Admissions				
Southcentral Alaska	69	1.41	400	6
All Other Alaska	36	1.33	199	6
Total	105	1.38	599	6
Outpatient Visits				
Southcentral Alaska	261	1.69	778	3
All Other Alaska	68	1.36	81	1
Total	329	1.61	859	3
Emergency Department Visits				
Southcentral Alaska	81	1.50	84	1
All Other Alaska	11	1.10	11	1
Total	92	1.44	95	1

Source: Alaska Hospital Facilities Data Reporting Program.

The top diagnosis (primary or secondary) for inpatient facility admissions for adults (aged 18 and over) was FAS (100%), followed by four behavioral health-related diagnoses (suicidal ideation, post-traumatic stress disorder, medication noncompliance and borderline personality disorder).

The top diagnosis for outpatient visits was FAS (100%), followed by four behavioral health-related conditions related to tobacco use, post-traumatic stress disorder, depression, and suicidal ideation.

All emergency department visits received a diagnosis was FAS, followed by four behavioral health diagnoses related to tobacco use, ADHD, suicidal ideation, and bipolar disorder.

Table 46. Individuals with FAS Age 18 and Above, Top Hospital Inpatient, Outpatient, and Emergency Department Diagnoses, Primary or Secondary Diagnoses, SFY2019

Category	Type	Count	% of Total
Inpatient Admissions			
Fetal alcohol syndrome (dysmorphic)	Medical	105	100.0%
Suicidal ideations	Behavioral Health	18	17.1%
Post-traumatic stress disorder, unspecified	Behavioral Health	17	16.2%
Patients' other noncompliance with medication regimen	Behavioral Health	17	16.2%
Borderline personality disorder	Behavioral Health	16	15.2%
Outpatient Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	329	100.0%
Nicotine dependence, cigarettes, uncomplicated	Behavioral Health	67	20.4%
Post-traumatic stress disorder, unspecified	Behavioral Health	47	14.3%
Major depressive disorder, single episode, unspecified	Behavioral Health	40	12.2%
Suicidal ideations	Behavioral Health	33	10.0%
Emergency Department Visits			
Fetal alcohol syndrome (dysmorphic)	Medical	92	100.0%
Nicotine dependence, cigarettes, uncomplicated	Behavioral Health	38	41.3%
Attention-deficit hyperactivity disorder, unspecified type	Behavioral Health	17	18.5%
Suicidal ideations	Behavioral Health	16	17.4%
Bipolar disorder, unspecified	Behavioral Health	14	15.2%

Source: Alaska Hospital Facilities Data Reporting Program.

Services for All Life Stages

Unlike other substances, prenatal alcohol exposure can have life-long developmental consequences.

—FASD Clinical Specialist

This section presents health utilization data that bridge all life stages.

FQHC Populations Served By Age

More than a quarter of patients served by Alaska FQHCs are children under 18 years (27%), compared to 31% served by all U.S. FQHCs. More than half of patients served by both Alaska and all U.S. FQHCs (60%) are age 18-64 years. Slightly more adults over age 64 re served by Alaska FQHCs, as compared to all U.S. FQHCs (13% versus 10%, respectively).

Table 47. Patients by Age and Sex, Alaska and U.S., CY2019

Age In Years	Number of Patients* Alaska	Percentage of Patients Served Alaska	Percentage of Patients Served U.S.
Under Age 1	1,936	1.7%	2.3%
1-5	8,235	7.2%	8.3%
6-12	11,827	10.3%	12.0%
13-17	8,915	7.7%	8.2%
18-64	68,733	59.7%	59.5%
65+	15,470	13.4%	9.6%
Total	**115,116**	**100%**	**100%**
Total Children under 18	**30,913**	**26.9%**	**30.8%**

Source: Uniform Data System (UDS), 2019.
* Patient counts are unduplicated patients.

FASD Diagnosis

Diagnosis of FASD can occur at any time during an individual's life. Since 1999, Alaska Department of Health and Social Services 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. An interdisciplinary team of clinicians (i.e., medical provider, psychologist, speech language pathologist, occupational therapist, social

worker, and family advocate) is required because the damage caused by prenatal alcohol exposure impacts all aspects of an individual's growth and brain development. A medical doctor is required to assess the physical and neurological components of the disorder (i.e., growth deficits, facial anomalies, seizures). A psychologist, speech language pathologist, and occupational therapist are 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 executive function and adaptive living skills. Summary results of an analysis conducted on Alaska's FASD diagnostic team data (1999 to May 2020) include:

- Clients' average age at time of diagnosis was 10.1 years.
- Males are overrepresented in the number of assessments compared to females (58% of assessments compared to 51% of the state's population).
- Alaska Natives are overrepresented in the number of assessments compared to other races (48% of assessments compared to 15% of the population).[31]
- 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 the 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.
- 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.
- Out of 2,933 diagnoses made, the most common diagnostic outcomes are Static Encephalopathy/Alcohol Exposed (SE/AE) (32%) and Neurobehavioral Disorder/Alcohol Exposed (ND/AE) (26%).
- 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.[32]

Alaska Screening Tool

The Alaska Screening Tool (AST) screens for substance misuse, mental illness, co-occurring substance misuse and mental illness, traumatic brain injury, and FASD. Between 2013 and 2017, 72,964 screenings were conducted, of which 5,833 (8%) were positive for FASD. As of January 1, 2018, the AST was removed from the Division of Behavioral Health's Minimal Data Set with grantees no longer mandated to utilize the AST and report associated data.

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[31] 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.

[32] McDowell Group, Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Data Analysis and Data Scorecard. July 2020. Prepared for Alaska Mental Health Trust Authority.

The Alaska Screening Tool (AST) screens for substance misuse, mental illness, co-occurring substance misuse and mental illness, traumatic brain injury, and FASD.[33] Between 2013 and 2017, 72,964 screenings were conducted, of which 5,833 (8%) were positive for FASD. These screenings were conducted with 4,876 individuals, some of whom had multiple intakes, and therefore multiple screenings.[34]

Table 48. Alaska Screening Tool (AST): Total Screenings, Total Screened FASD Positive, Percentage of Screenings Positive for FASD, and Unique Number of Clients, 2013-2017

Year	Total Number of AST Screenings	Total AST with FASD Screened Positive	Percentage of FASD Screening Positive Overall All Screenings	Number of Unique Clients
2013	16,259	1,301	8.0%	1,209
2014	14,727	1,159	7.9%	1,062
2015	13,529	1,061	7.8%	995
2016	13,797	1,128	8.2%	1,034
2017	14,652	1,184	8.1%	1,054
Total	**72,964**	**5,833**	**8.0%**	**4,876**
Average Per Year	**14,593**	**1,167**	**8.0%**	**1,876**

Source: Alaska Division of Behavioral Health. (2019). AKAIMS- Alaska's Automated Information Management System [Data file from AKAIMS FASD_Screening_Cost]. Retrieved from https://akaimsreports.dhss.alaska.gov/Reports/report/FASD%20Diagnostic%20Team/FASD_Screening_Cost.

A third of people screened (33%), were under age 18. For this sector, 47% were females. Sixty-six percent of those screened were adults, of which 56% were females.

[33] Note that a screening is not the same as an assessment.

[34] Additional cost and demographic data on the Alaska Screening Tool can be found in Summary of the Economic Costs of Fetal Alcohol Syndrome/Fetal Alcohol Spectrum Disorder in Alaska. https://alaskamentalhealthtrust.org/wp-content/uploads/2020/06/1949-AMHTA-Drugs-and-Alcohol-FASD-Summary-Report-Final-Revised-6.12.2020.pdf

Table 49. Age and Gender Distribution Among Persons Screening Positive on the Alaska Screening Tool, 2013-2017

Age at Screening	Females	Female % of Total	Males	Male % of Total	Total	Distribution by Age
Under age 18	724	47.4%	802	52.6%	1,526	32.5%
18 years or older	1,770	55.8%	1,404	44.2%	3,174	67.5%
Total	2,494	53.1%	2,206	46.9%	4,700	100.0%

Source: Alaska Division of Behavioral Health. (2019). AKAIMS- Alaska's Automated Information Management System [Data file from AKAIMS FASD Screening Cost]. Retrieved from https://akaimsreports.dhss.alaska.gov/Reports/report/FASD%20Diagnostic%20Team/FASD_Screening_Cost.

Medicaid Utilization Summary

In SFY2019, 67 Medicaid beneficiaries were identified as pregnant women with alcohol-use disorders receiving health services. The average annual number of claims per study group beneficiaries was 64% higher than the comparison group (77.1 and 46.8, respectively). In the same year, 879 Medicaid beneficiaries were infants impacted by maternal alcohol use or individuals with FAS ages 1 to 64 receiving health services. The average annual number of claims per study group beneficiaries was 302% higher than the comparison group (201.6 and 50.1, respectively). In total, 946 Medicaid beneficiaries were in the study group, their average annual number of claims per all study group beneficiaries was 286% higher than the comparison group (192.8 and 50.0, respectively).

Table 50. Medicaid Beneficiaries, Claims, and Claims per Beneficiary, Pregnant Women with Alcohol-use disorders, Infants Impacted by Maternal Alcohol Use, and Individuals with FAS, and Comparison Groups, SFY2019

	Pregnant Women		Infants and Individuals		Total	
	Study Group	Comparison Group	Study Group	Comparison Group	Study Group	Comparison Group
Beneficiaries	67	4,565	879	181,848	946	186,413
Total claims	5,164	213,629	177,187	9,108,183	182,351	9,321,812
Average Number of Claims per Beneficiary	77.1	46.8	201.6	50.1	192.8	50.0

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

In all life stages, except for children with FAS aged 1-5 and adults ages 18-64, the study group represented a disproportionately higher number of beneficiaries than their comparison group.

Table 51. Medicaid Beneficiaries, **Pregnant Women with Alcohol-use Disorders, Infants Impacted by Maternal Alcohol Use, and Individuals with FAS, and Comparison Groups, SFY2019**

Life Stage	Study Group		Comparison Group	
	Number of Beneficiaries	% of Total Beneficiaries	Number of Beneficiaries	% of Total Beneficiaries
Pregnant Women	67	7.1%	4,565	2.4%
Infants (Less than 1 year)	71	7.5%	6,584	3.5%
Ages 1-5	70	7.4%	24,621	13.2%
Ages 6-12	243	25.7%	31,388	16.8%
Ages 13-17	175	18.5%	19,173	10.3%
Ages 18-64	320	33.8%	100,082	53.7%
Total Beneficiaries	946	100.0%	186,413	100.0%

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

The following tables and graphs provide snapshots of Medicaid service utilization by individuals with an FASD and a comparison group for each category of service; data are presented by life stages, percentage of utilization and average number of claims per beneficiary receiving this service in SFY2019. Medicaid eligibility criteria and official definition of services were applied.[35]

[35] For more information on Medicaid service categories and eligibility, refer to Alaska Department of Health & Social Services, Division of Health Care Services, Alaska Medicaid Recipient Handbook. http://dhss.alaska.gov/dhcs/documents/pdf/recipient-handbook.pdf. Accessed June 29, 2021.

Inpatient Hospital Services

Inpatient hospital services were mostly used by pregnant women with alcohol-use disorders (64.2%) and infants affected by maternal alcohol use (83.1%) in SFY2019. Inpatient hospital services, by percentage dropped off dramatically and started to increase in adulthood (21.6%). While 4.3% of children with FAS ages 1-5 received services, their average number of claims was the highest of all life stages (3.00).

Figure 9. Percentage of Medicaid Beneficiaries Receiving Inpatient Hospital Services, SFY2019

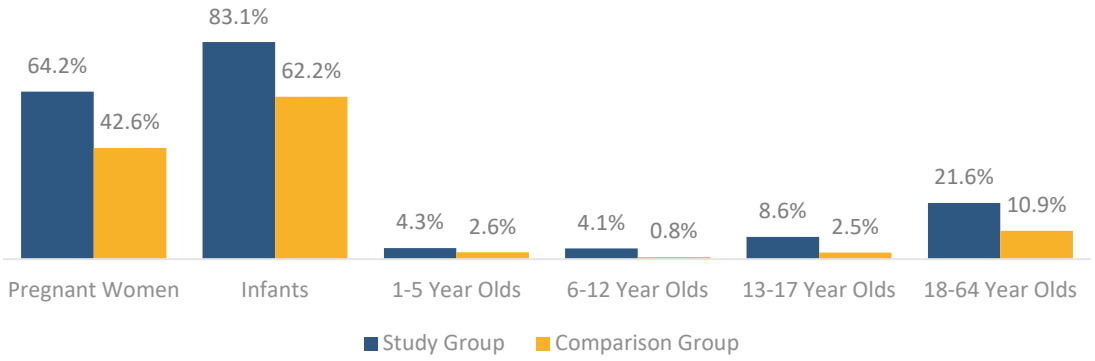
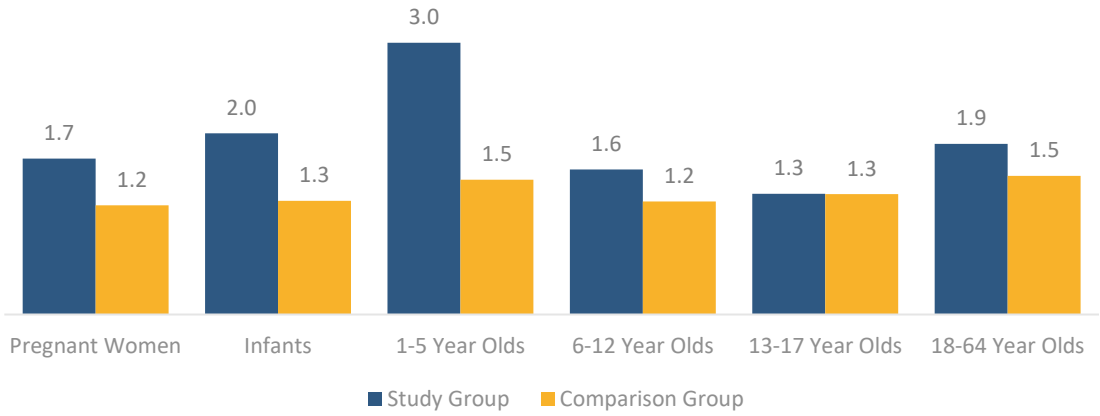


Figure 10. Average Number of Medicaid Claims per Recipient, Inpatient Hospital Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Outpatient Hospital Services

Outpatient hospital services were used throughout all life stages, but most often by pregnant women with alcohol-use disorders (95.5%) and adults with FAS (84.7%) in SFY2019. With 84.7% of adults with FAS receiving services, their average number of claims was the highest of all life stages (26.2 claims).

Figure 11. Percentage of Medicaid Beneficiaries Receiving Outpatient Hospital Services, SFY2019

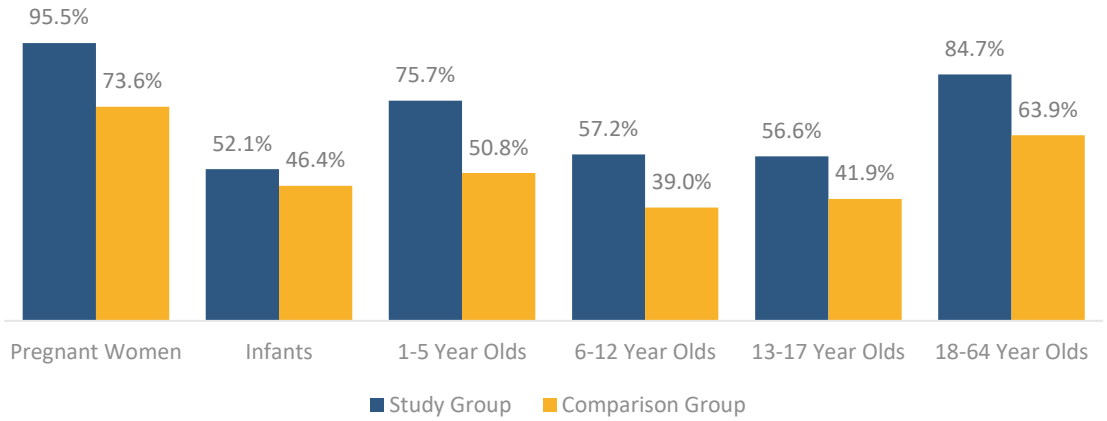
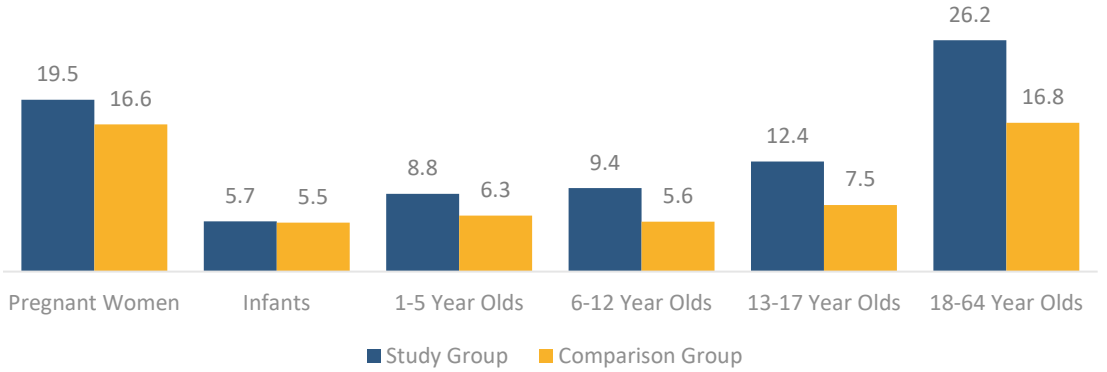


Figure 12. Average Number of Medicaid Claims per Recipient, Outpatient Hospital Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Physician/Practitioner Services

Physician/practitioner services were used throughout all life stages, but slightly most often by pregnant women with alcohol-use disorders (95.5%) and children with FAS ages 1-5 (94.3%) in SFY2019. With 93.0% of infants impacted by maternal alcohol use receiving services, their average number of claims was the highest of all life stages (44.9 claims).

Figure 13. Percentage of Medicaid Beneficiaries Receiving Physician/Practitioner Services, SFY2019

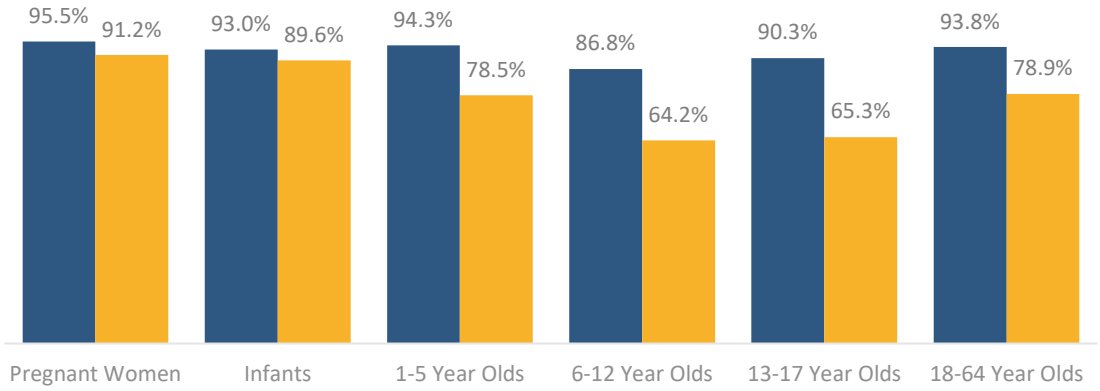
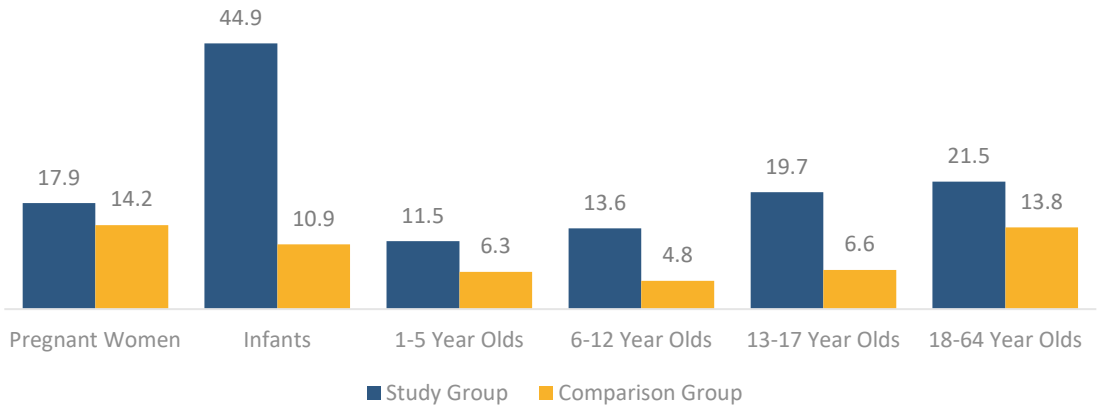


Figure 14. Average Number of Medicaid Claims per Recipient, Physician/Practitioner Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Dental Services

Dental services were used throughout all life stages, but most often by children with FAS ages 6-12 (72.8%) and ages 13-17 (68.0%) in SFY2019. With 68.0% of adolescents with FAS ages 13-17 receiving services, their average number of claims was the highest of all life stages (9.6 claims).

Figure 15. Percentage of Medicaid Beneficiaries Receiving Dental Services, SFY2019

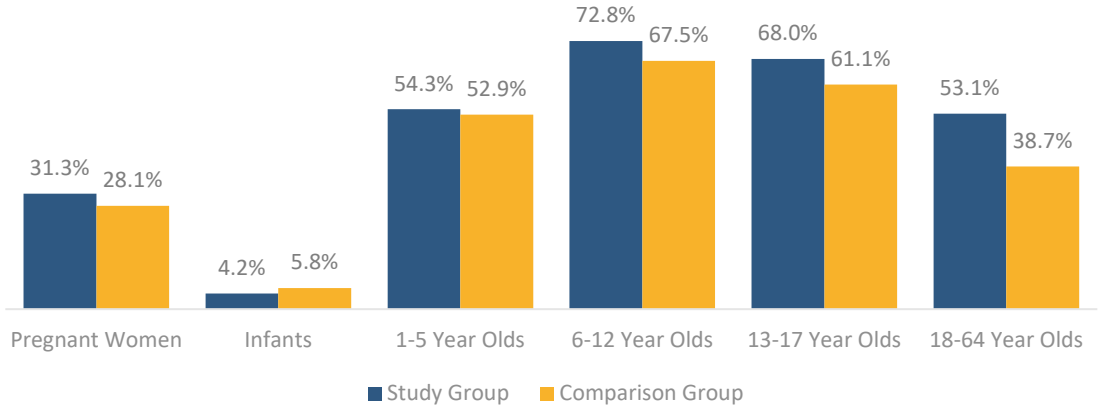
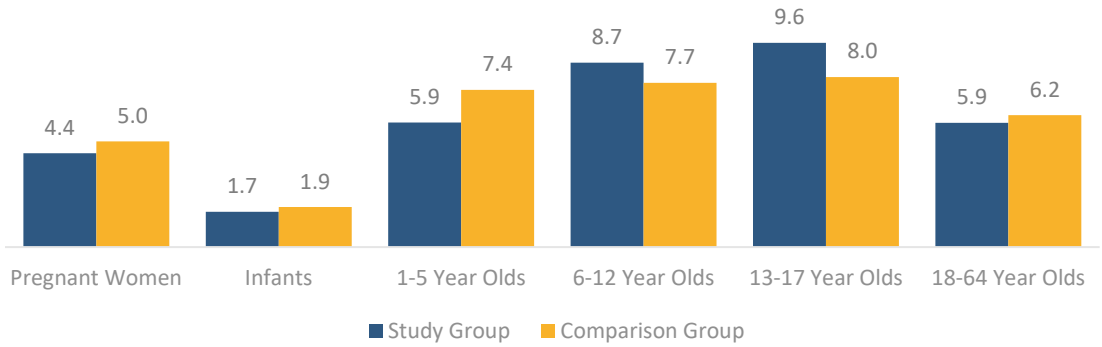


Figure 16. Average Number of Medicaid Claims per Recipient, Dental Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Vision Services

Vision services were used throughout all life stages, except by infants impacted by maternal alcohol use, but most often by adolescents with FAS ages 13-17 (49.1%) and children with FAS ages 6-12 (36.6%) in SFY2019. With 36.6% of children with FAS ages 6-12 receiving services, their average number of claims was the highest of all life stages (5.5 claims).

Figure 17. Percentage of Medicaid Beneficiaries Receiving Vision Services, SFY2019

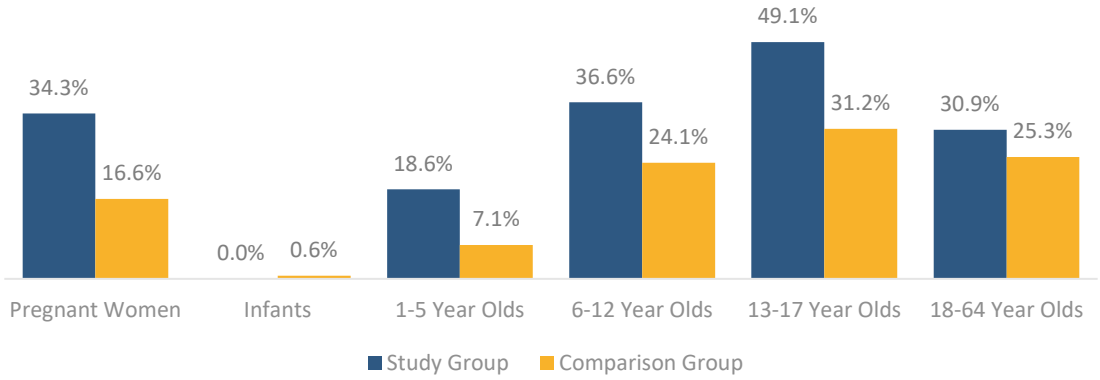
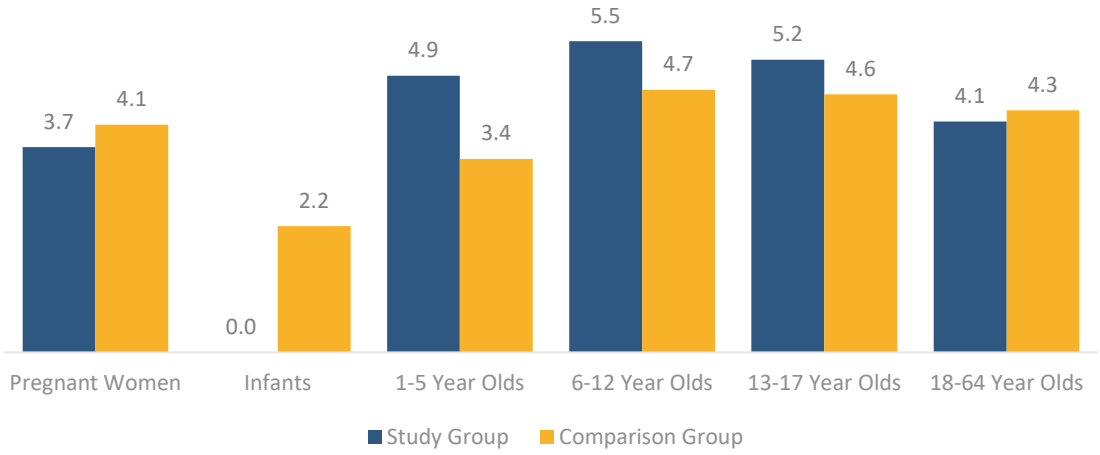


Figure 18. Average Number of Medicaid Claims per Recipient, Vision Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Health Clinic Services

Health clinic services were used throughout all life stages, but most often by pregnant women with alcohol-use disorders (76.1%) and adults with FAS (58.1%) in SFY2019. With 76.1% of pregnant women with alcohol-use disorders receiving services, their average number of claims was the highest of all life stages (9.2 claims).

Figure 19. Percentage of Medicaid Beneficiaries Receiving Health Clinic Services, SFY2019

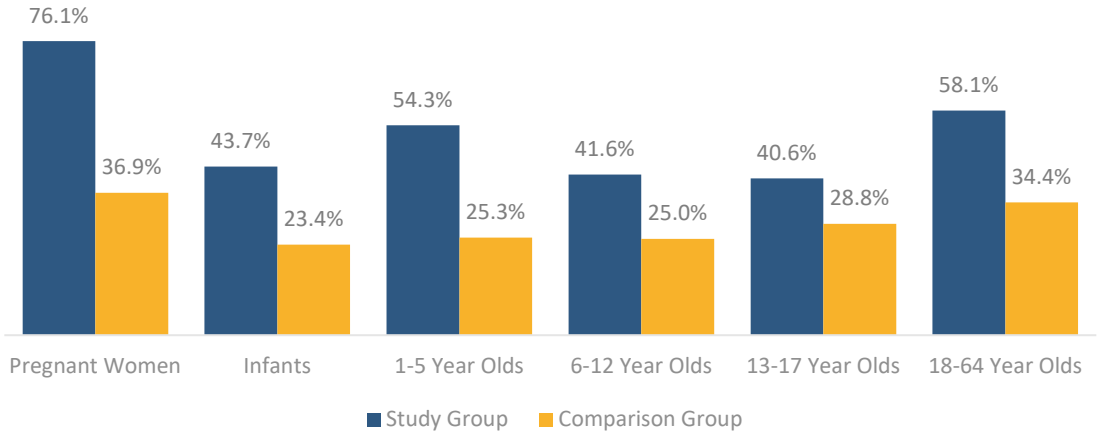
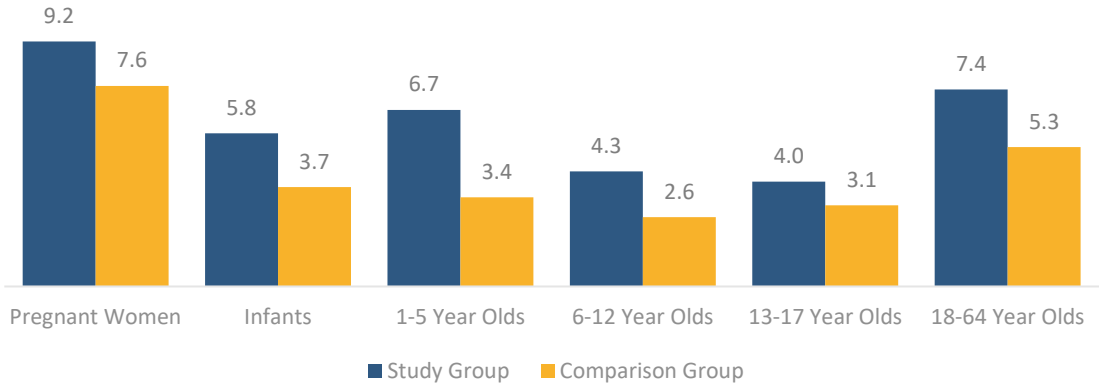


Figure 20. Average Number of Medicaid Claims per Recipient, Health Clinic Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Pharmacy Services

Pharmacy services were used throughout all life stages, but most often by pregnant women with alcohol-use disorders (89.6%) and adolescents with FAS ages 13-17 (82.9%) in SFY2019. With 73.4% of adults with FAS receiving services, their average number of claims was the highest of all life stages (40.7 claims).

Figure 21. Percentage of Medicaid Beneficiaries Receiving Pharmacy Services, SFY2019

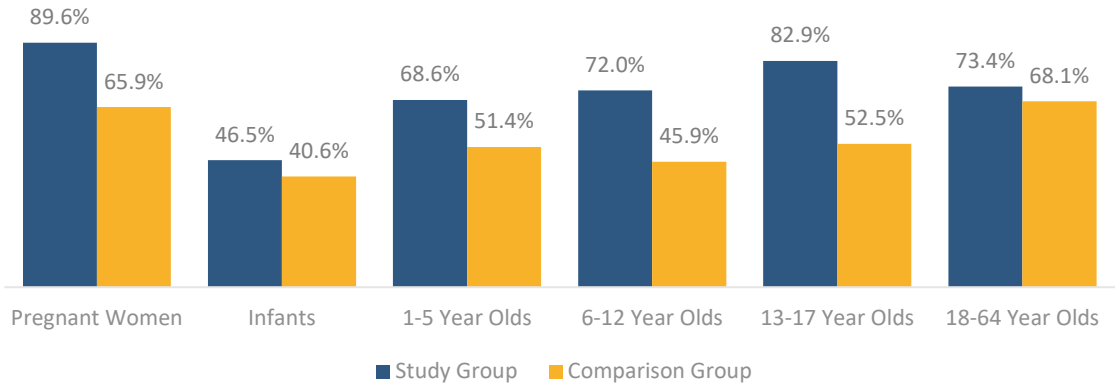
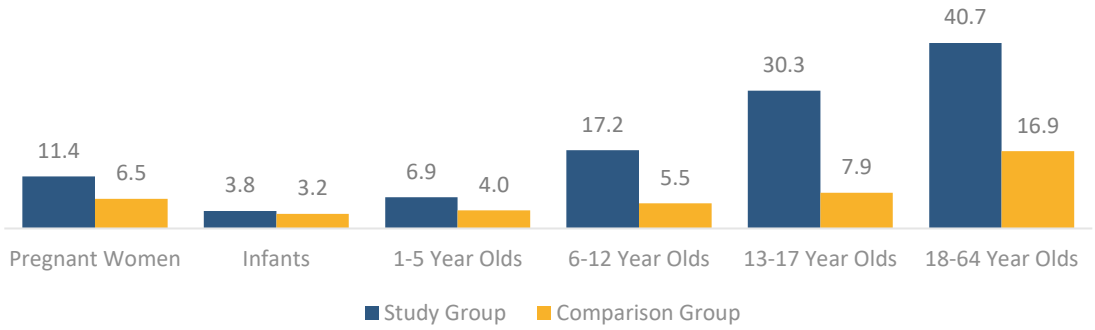


Figure 22. Average Number of Medicaid Claims per Recipient, Pharmacy Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Therapy/Rehabilitation Services

Therapy/Rehabilitation services were used throughout all life stages, except by pregnant women with alcohol-use disorders, but most often used by children with FAS ages 1-5 (55.7%) and ages 6-12 (47.3%) in SFY2019. With 34.3% of adolescents with FAS ages 13-17 receiving services, their average number of claims was the highest of all life stages (46.1 claims).

Figure 23. Percentage of Medicaid Beneficiaries Receiving Therapy/Rehabilitation, SYF2019

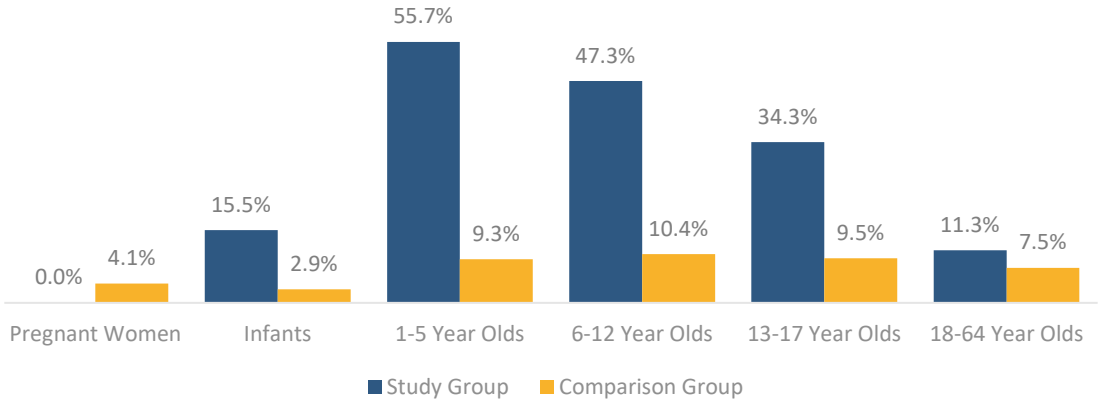
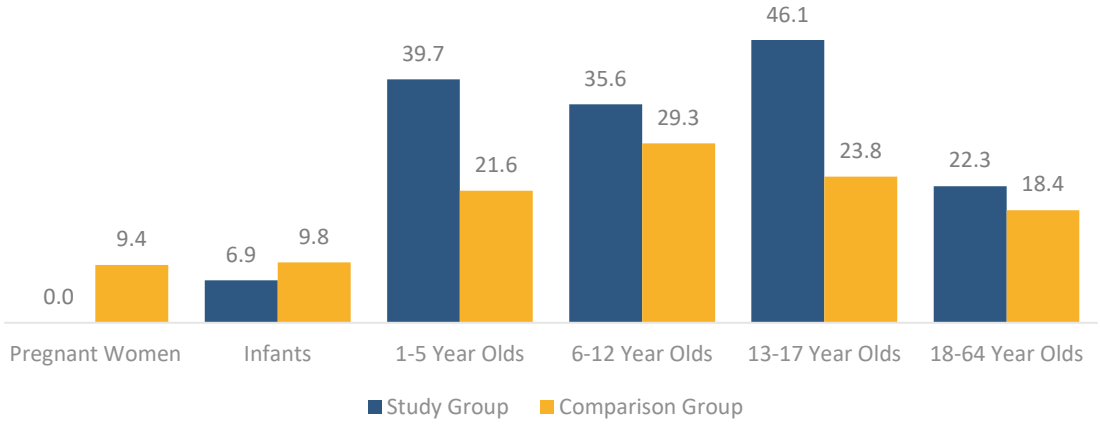


Figure 24. Average Number of Medicaid Claims per Recipient, Therapy/Rehabilitation Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Occupational Therapy Services

Occupational therapy services were used throughout all life stages, except by pregnant women with alcohol-use disorders and infants impacted by maternal alcohol use, but most often by children with FAS ages 1-5 (47.1%) and ages 6-12 (30.9%) in SFY2019. With 30.9% of children with FAS ages 6-12 receiving services, their average number of claims was the highest of all life stages (28.8 claims).

Figure 25. Percentage of Medicaid Beneficiaries Receiving Occupational Therapy Services, SFY2019

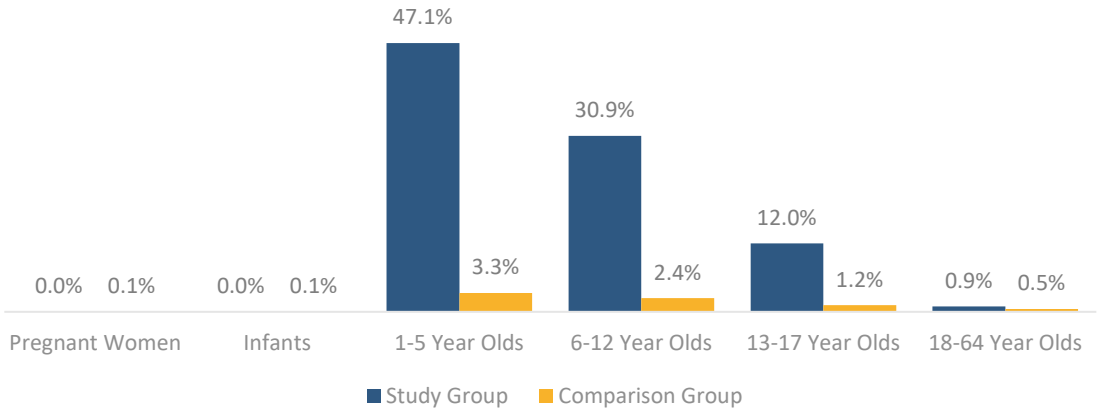
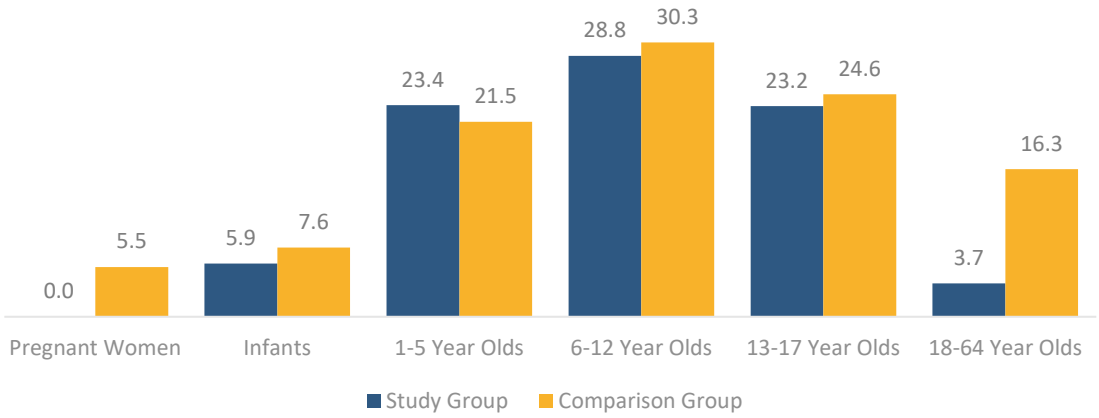


Figure 26. Average Number of Medicaid Claims per Recipient, Occupational Therapy Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Home Health/Hospice Services

Home health/hospice services were used throughout all life stages, except by pregnant women with alcohol-use disorders, but most often by children with FAS ages 1-5 (4.3%) and ages 6-12 (2.9%) in SFY2019. With 1.7% of adolescents with FAS ages 13-17 receiving services, their average number of claims was the highest of all life stages (364 claims), suggesting high acuity recipients.

Figure 27. Percentage of Medicaid Beneficiaries Receiving Home Health/Hospice Services, SFY2019

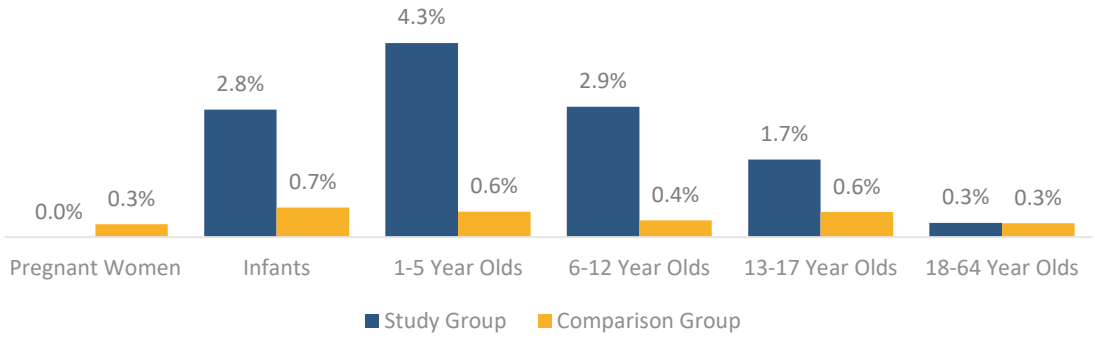
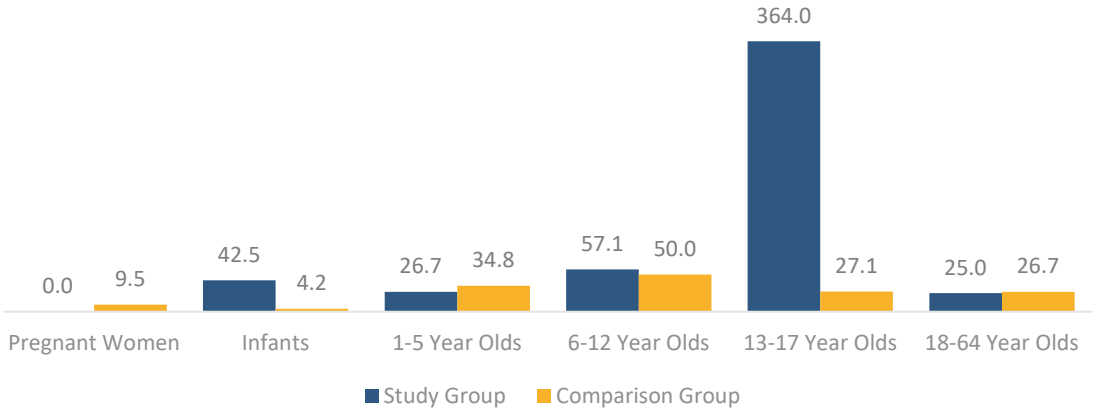


Figure 28. Average Number of Medicaid Claims per Recipient, Home Health/Hospice Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Personal Care Services

Personal care services were only used by adults with FAS (1.6%). For the 1.6% of adults with FAS receiving services, their average number of claims was 248.0 in SFY2019.

Figure 29. Percentage of Medicaid Beneficiaries Receiving Personal Care Services, SFY2019

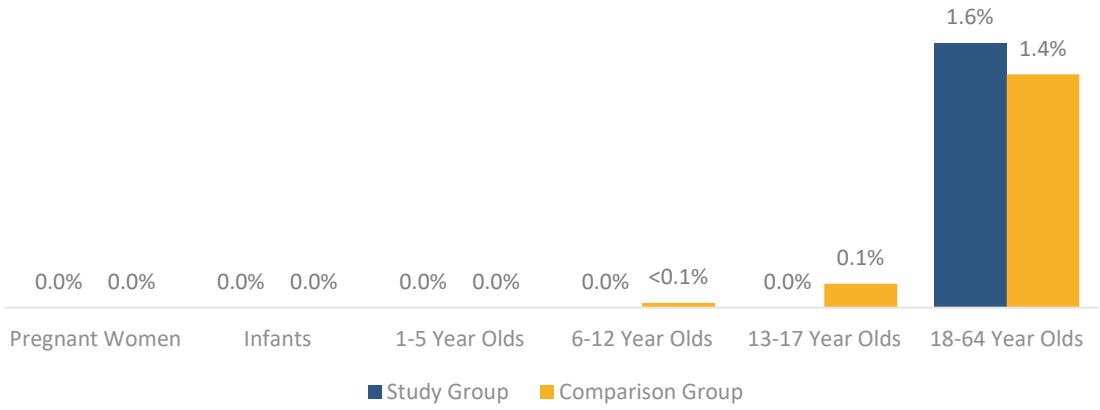
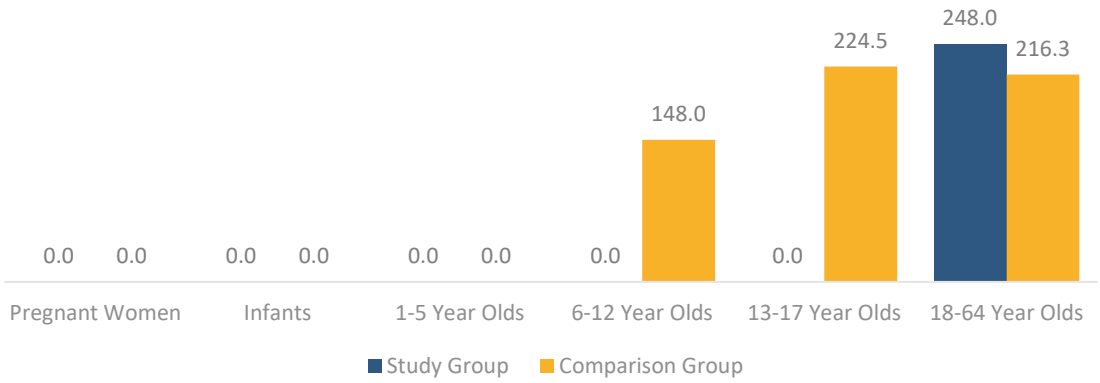


Figure 30. Average Number of Medicaid Claims per Recipient, Personal Care Systems, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Home & Community-Based Waiver Services

Home and community-based waiver services were used throughout all life stages, except for infants impacted by maternal alcohol use, but most often by adults with FAS (35.0%) and children with FAS ages 6.12 (9.5%) in SFY2019. With 35.0% of adults with FAS receiving services, their average number of claims was the highest of all life stages (380.8 claims).

Figure 31. Percentage of Medicaid Beneficiaries Receiving Home & Community-based Waiver Services, SFY2019

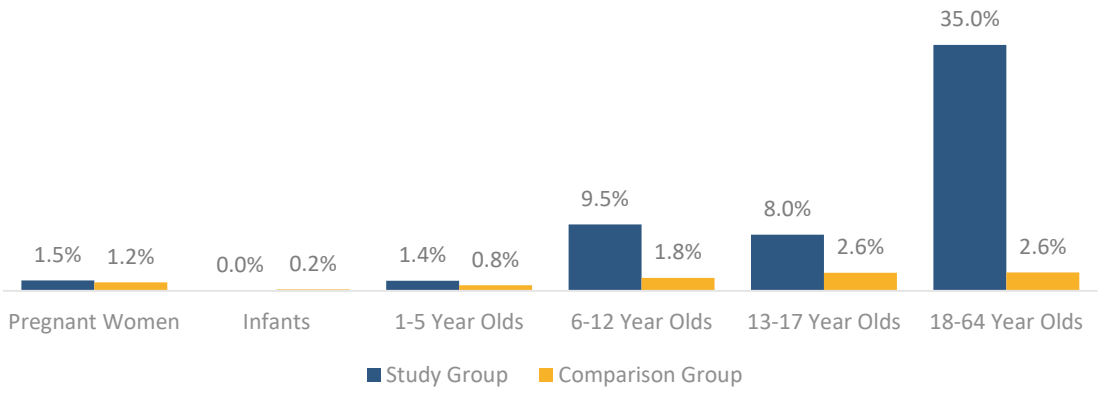
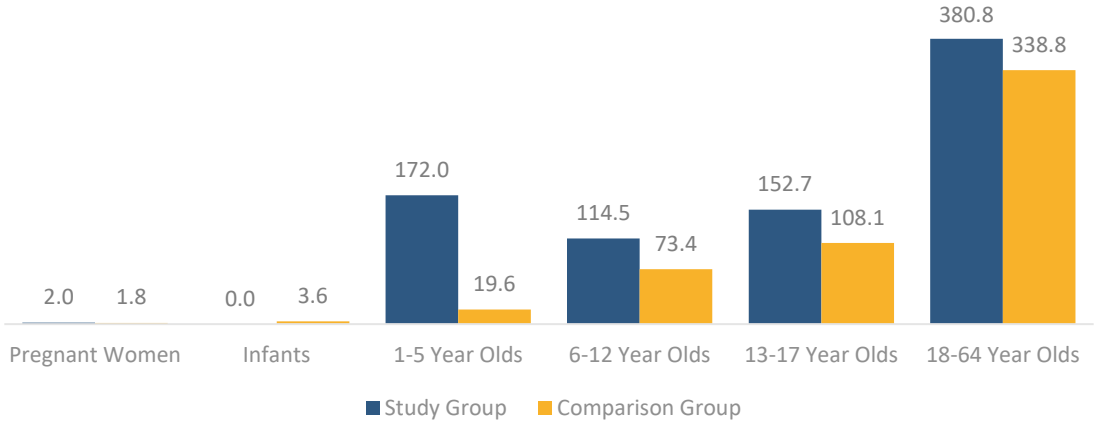


Figure 32. Average Number of Medicaid Claims per Recipient, Home & Community-based Waiver Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Respite Care Services

Respite was used throughout all life stages, except for pregnant women with alcohol-use disorders and infants impacted by maternal alcohol use, but most often by adults with FAS (5.0%) and children with FAS ages 6-12 (4.1%) in SFY2019. With 1.4% of children with FAS ages 1-5 receiving services, their average number of claims was the highest of all life stages (119.0 claims).

Figure 33. Percentage of Medicaid Beneficiaries Receiving Respite Care Services, SYF2019

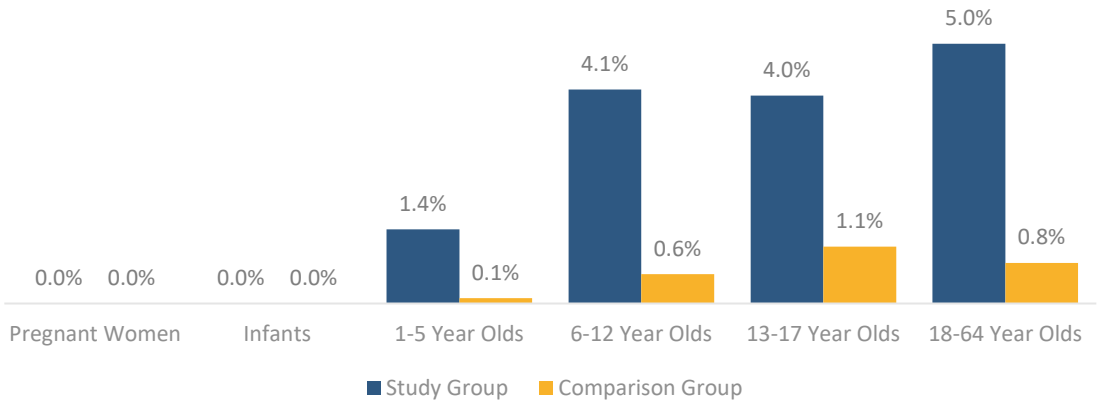
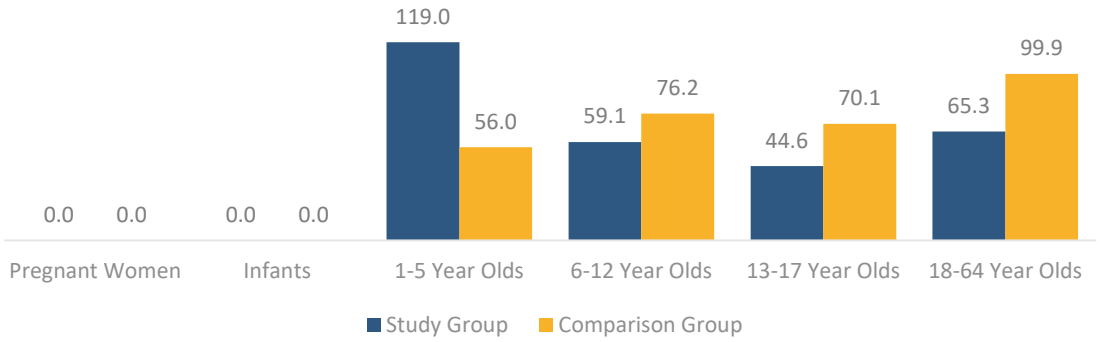


Figure 34. Average Number of Medicaid Claims per Recipient, Respite Care Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Nursing Home Services

Nursing home services were only used by adults with FAS (1.3%), with 53.5 average claims in SFY2019.

Figure 35. Percentage of Medicaid Beneficiaries Receiving Respite Care Services, SFY2019

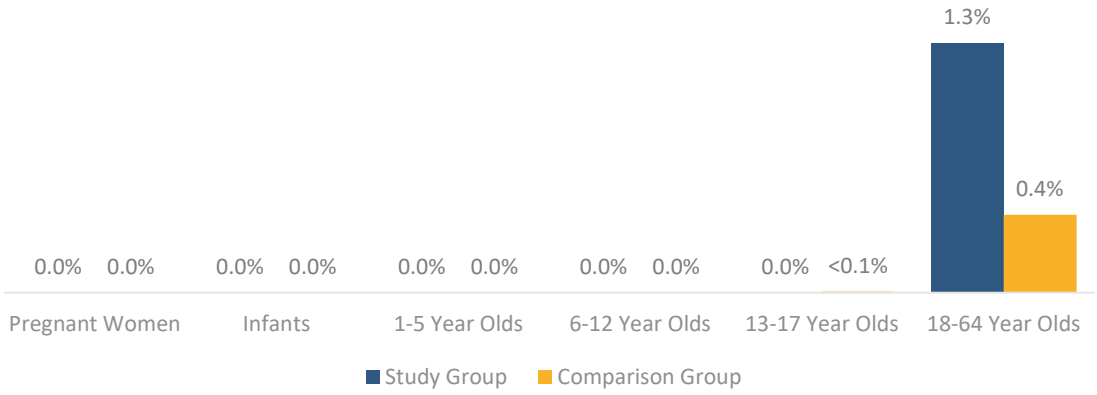
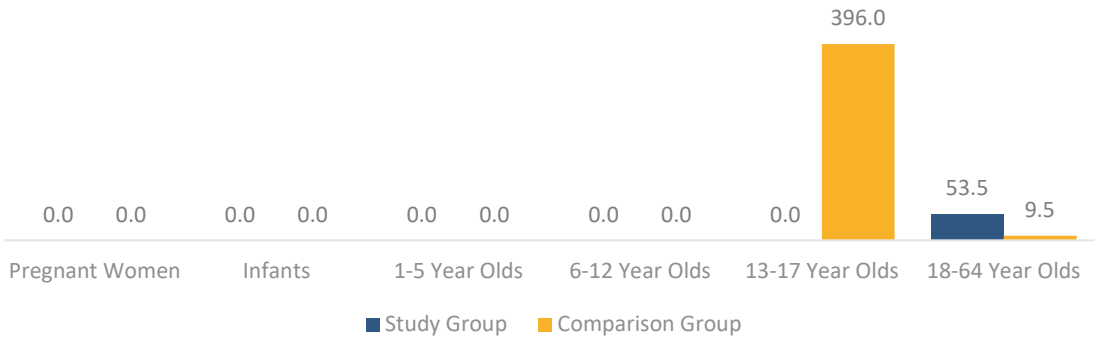


Figure 36. Average Number of Medicaid Claims per Recipient, Respite Care Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Outpatient Mental Health Services

Outpatient mental health services were used throughout all life stages, except infants impacted by maternal alcohol use, but most often by adolescents with FAS ages 13-17 (63.4%) and children with FAS ages 6-12 (53.9%) in SFY2019. With 63.4% of adolescents with FAS ages 13-17 receiving services, their average number of claims was the highest of all life stages (203.3 claims).

Figure 37. Percentage of Medicaid Beneficiaries Receiving Outpatient Mental Health Services, SFY2019

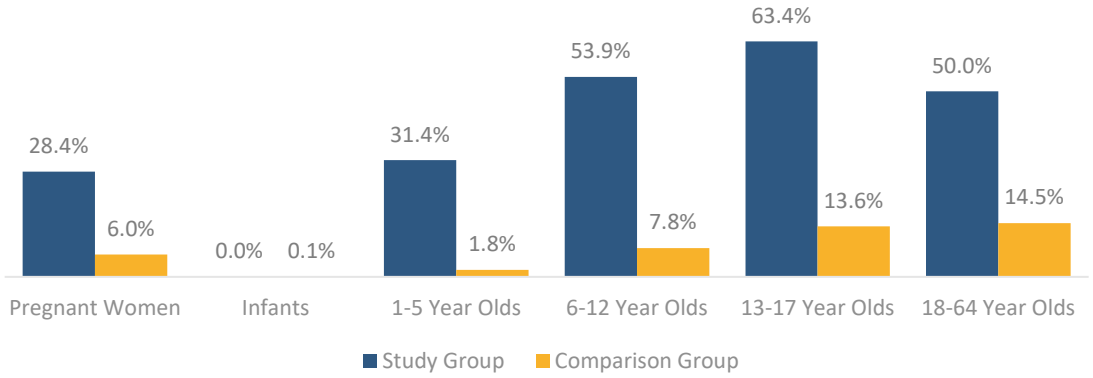
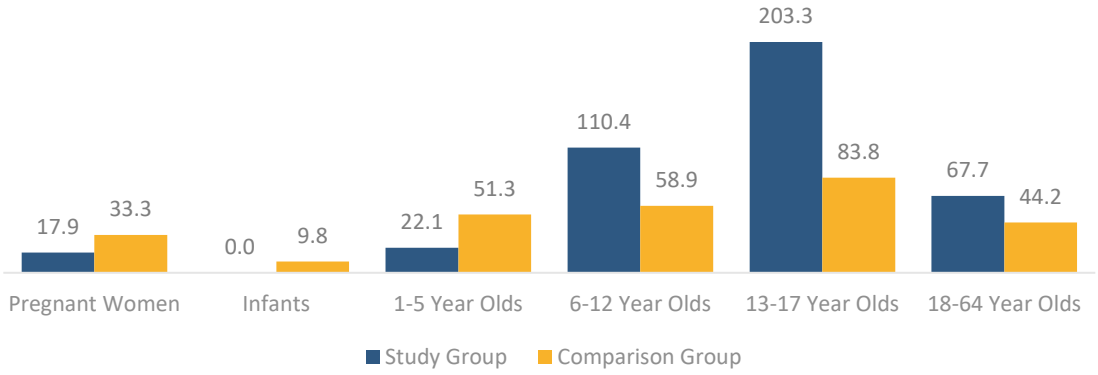


Figure 38. Average Number of Medicaid Claims per Recipient, Outpatient Mental Health Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Inpatient Psychiatric Hospital Services

Inpatient psychiatric hospital services were used by individuals with FAS ages 6 and older, but most often by adolescents with FAS ages 13-17 (33.7%) and ages 6-12 (10.3%) in SFY2019. With 33.7% of adolescents with FAS ages 13-17 receiving services, their average number of claims was the highest of all life stages (8.2 claims).

Figure 39. Percentage of Medicaid Beneficiaries Receiving Inpatient Psychiatric Hospital Services, SFY2019

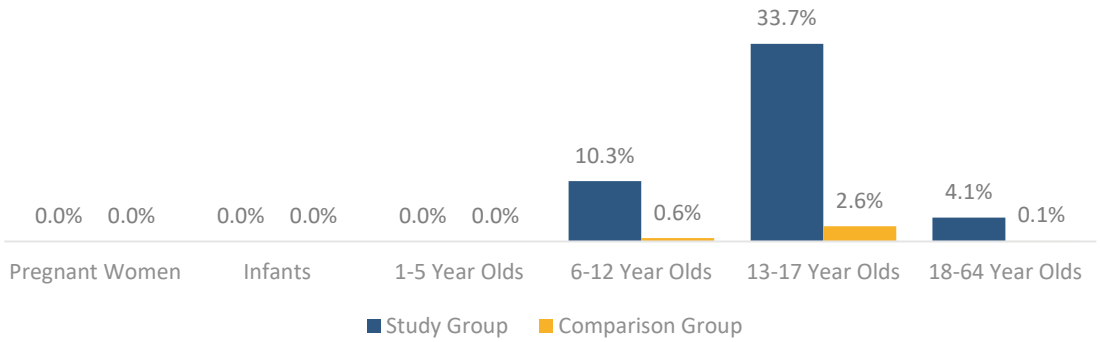
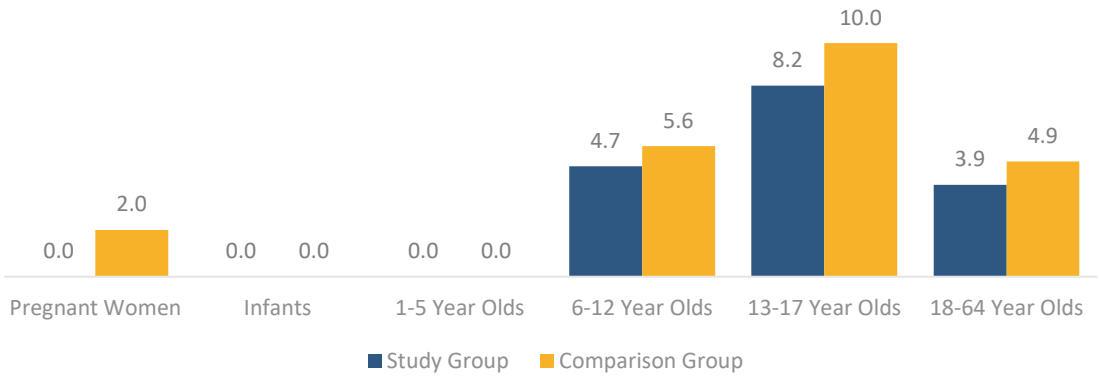


Figure 40. Average Number of Medicaid Claims per Recipient, Inpatient Psychiatric Hospital Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Residential Psychiatric/Behavioral Rehabilitation Services

Residential psychiatric/behavioral health rehabilitation services were only used by adolescents with FAS ages 13-17 (1.7%) with an average number of 6.7 claims in SFY2019.

Figure 41. Percentage of Medicaid Beneficiaries Receiving Residential Psychiatric/Behavioral Rehabilitation Services, SFY2019

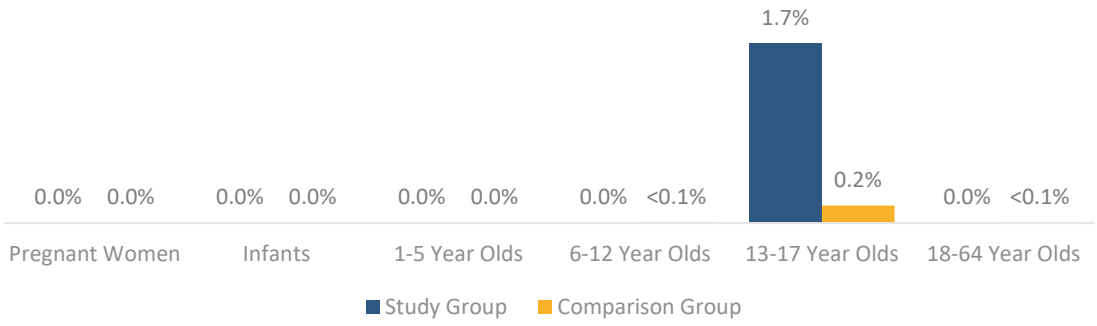
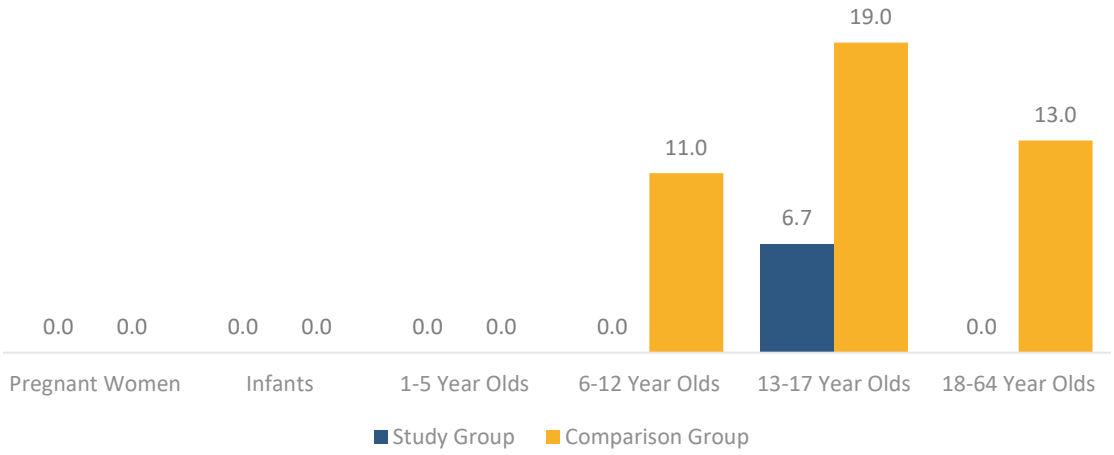


Figure 42. Average Number of Medicaid Claims per Recipient, Residential Psychiatric/Behavioral Rehabilitation Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Laboratory/X-Ray Services

Laboratory/x-ray services were used throughout all life stages, except by infants impacted by maternal alcohol use, and were most often used by pregnant women with alcohol-use disorders (26.9%) and adolescents with FAS ages 13-17 (23.4%) in SFY2019. With 26.9% of pregnant women with alcohol-use disorders receiving services, their average number of claims was the highest of all life stages (10.0 claims).

Figure 43. Percentage of Medicaid Beneficiaries Receiving Laboratory/X-Ray Services, SFY2019

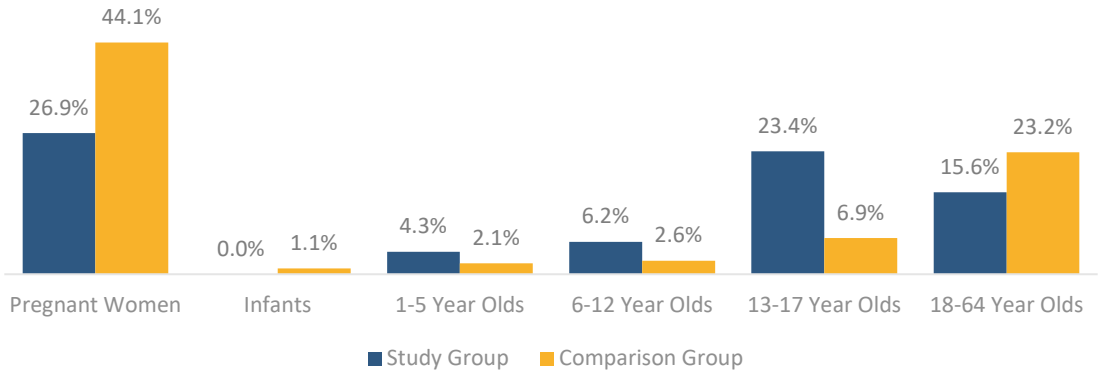
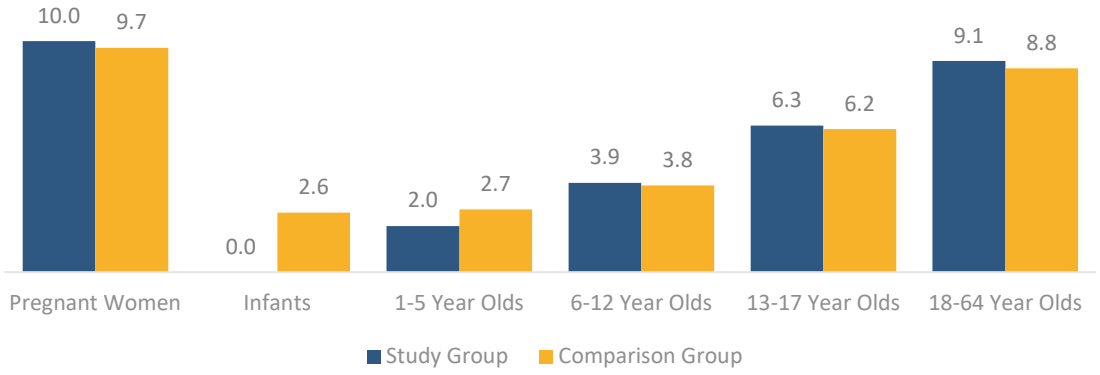


Figure 44. Average Number of Medicaid Claims per Recipient, Laboratory/X-Ray Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Transportation Services

Transportation services were used throughout all life stages, but most often by pregnant women with alcohol-use disorders (56.7%) and adults with FAS (42.8%) in SFY2019. With 23.9% of children with FAS ages 6-12 receiving services, their average number of claims was the highest of all life stages (23.2 claims).

Figure 45. Percentage of Medicaid Beneficiaries Receiving Transportation Services, SFY2019

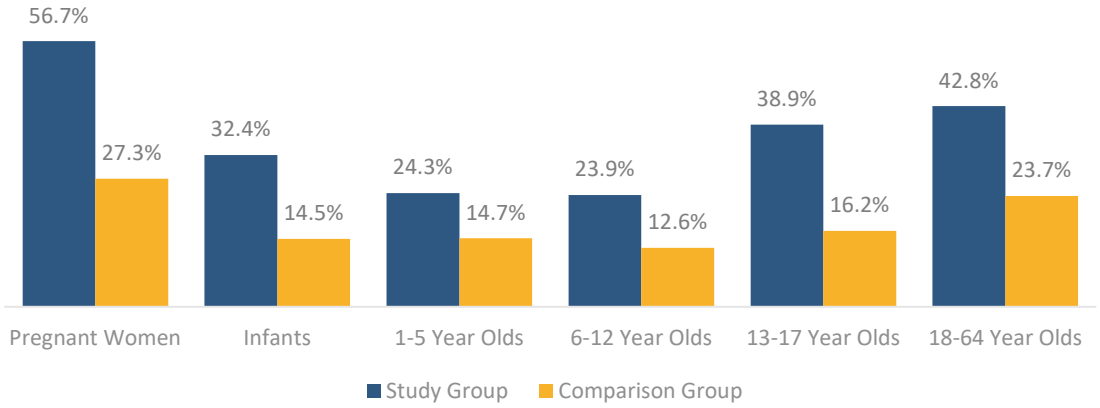
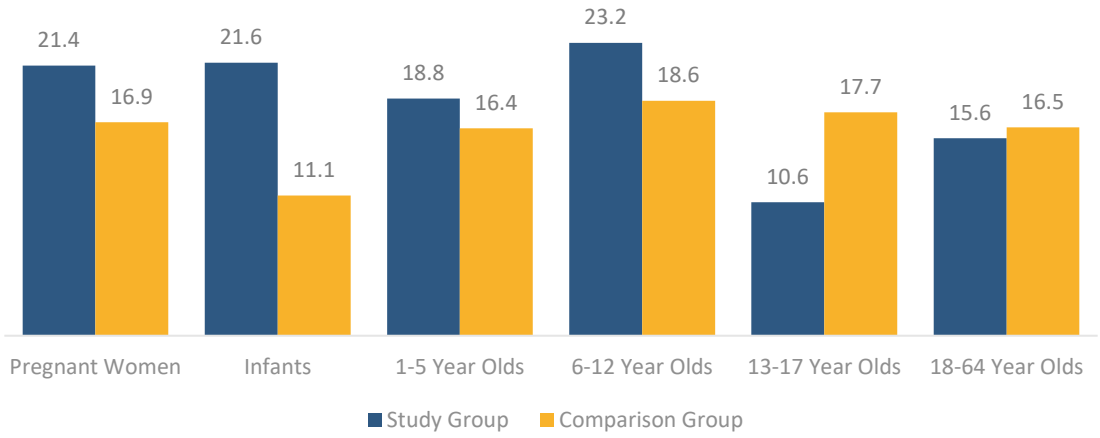


Figure 46. Average Number of Medicaid Claims per Recipient, Transportation Services, SFY2019

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Durable Medical Equipment/Supplies Services

Durable medical equipment/supplies services were used throughout all life stages, but most often by children with FAS ages 1-5 (32.9%) and infants impacted by maternal alcohol use (21.1%) in SFY2019. With 9.7% of adolescents with FAS ages 13-17 receiving services, their average number of claims was the highest of all life stages (38.4 claims).

Figure 47. Percentage of Medicaid Beneficiaries Receiving Durable Medical Equipment/Supplies Services, SFY2019

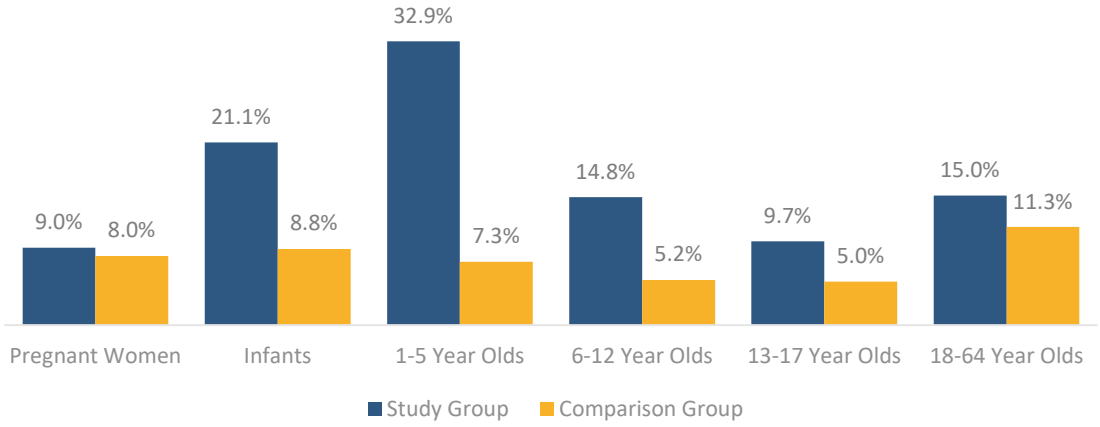
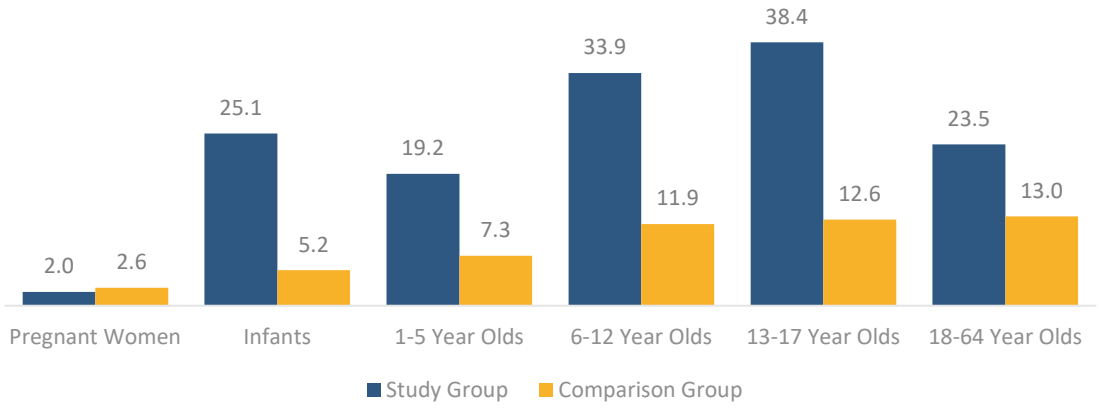


Figure 48. Average Number of Medicaid Claims per Recipient, Durable Medical Equipment/Supplies Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Early and Periodic Screening, Diagnosis, and Treatment Services

Early and periodic screening, diagnosis, and treatment services were used throughout all life stages, except by pregnant women with alcohol-use disorders, but most often by infants impacted by maternal alcohol use (81.7%) and children with FAS ages 1-5 (64.3%) in SFY2019. With 81.7% of infants impacted by maternal alcohol use receiving services, their average number of claims was the highest of all life stages (3.3 claims).

Figure 49. Percentage of Medicaid Beneficiaries Receiving Early and Periodic Screening, Diagnosis, and Treatment Services, SFY2019

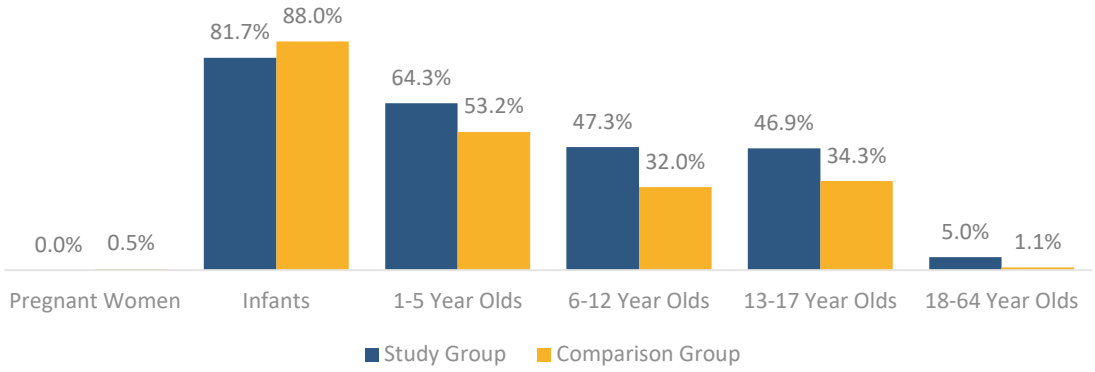
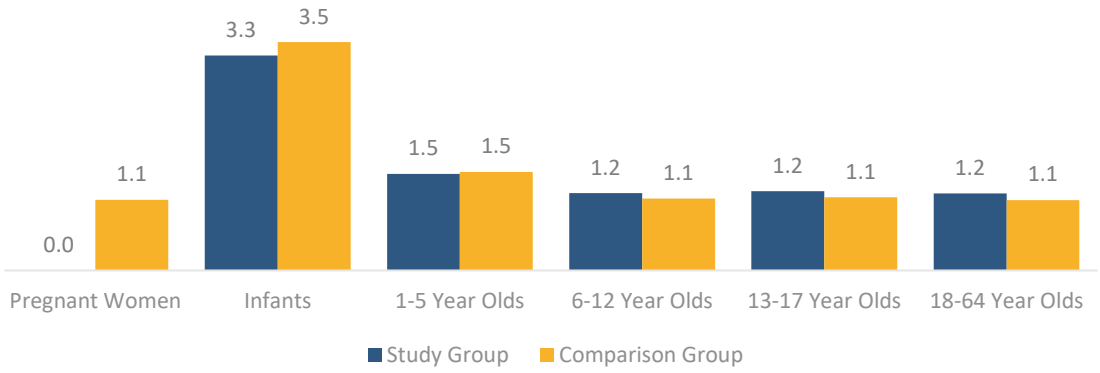


Figure 50. Average Number of Medicaid Claims per Recipient, Early and Periodic Screening, Diagnosis, and Treatment Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Other Services

Other services were used throughout all life stages, but most often by infants impacted by maternal alcohol use (25.4%) and children with FAS ages 1-5 (24.3%) in SFY2019. With 24.3% of children with FAS ages 1-5 receiving services, their average number of claims was the highest of all life stages (7.0 claims).

Figure 51. Percentage of Medicaid Beneficiaries Receiving Other Services, SFY2019

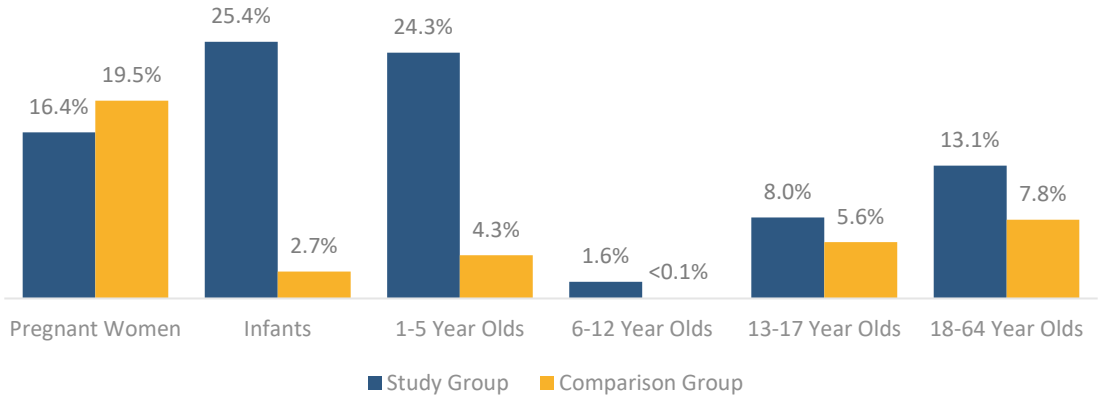
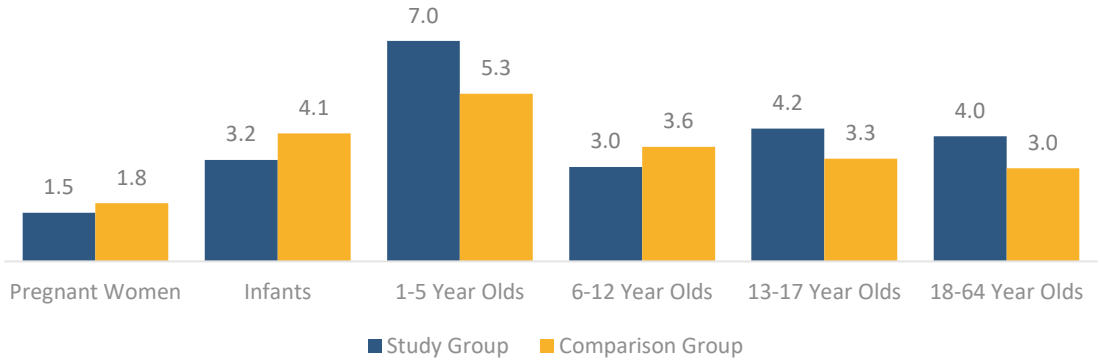


Figure 52. Average Number of Medicaid Claims per Recipient, Other Services, SFY2019



Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The pregnant women study group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the comparison group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. The infants and individuals study group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the comparison group includes SFY2019 Medicaid beneficiaries who were infants under age 1 and were not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Implications for Health Utilization

Population Health Approach

Ideally, the diagnosis and management of FASD requires a population health approach considerate of progressive life stages. Population health brings significant health concerns into focus and considers comprehensive implications related to the social determinants of health. It is an interdisciplinary, customizable approach using nontraditional partnerships among different sectors of the community – public health, industry, academia, health care, local government entities, etc., to achieve positive health outcomes.[36]

Lifelong support is required to assist with navigating physical health, mental health, disability, employment, legal, and family services, as well as challenges in adaptive skills, including activities of daily living (ADL), such as self-care, employment, and housing. The varied scope and breadth of lifelong needs is best addressed through a multi-disciplinary, integrated population health approach.

FASD care and prevention can be destigmatized by aligning FASD services with regular health care. Routinization of care and prevention care will increase the uptake of services by removing barriers and using a population-based approach.[37]

Stigma

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 that 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, can provide useful lessons for FASD anti-stigma strategies going forward.

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

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[36] Centers for Disease Control and Prevention, What is Population Health? https://www.cdc.gov/pophealthtraining/whatis.htm. Accessed June 15, 2021.

[37] UAA College of Health, Alaska Fetal Alcohol Spectrum Disorders Data Systems Development: Gaps, Opportunities, & Recommendations, March 2021. Prepared for the Alaska Mental Health Trust Authority.

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. As one FASD advocate stated, "It isn't about reducing stigma. It's about addressing the broader picture and stopping the perpetuation of harm."

Knowledgeable Providers

Interventions for individuals experiencing an FASD have yet to capitalize on the skillset of providers, nurses, and other allied health professionals. These providers have unique opportunities to use information on family experience to intervene and support families in reducing potential PAE primary effects and preventing secondary conditions. Nurses and other health care providers should acknowledge that although families of individuals with FASD may experience similar or greater levels of stress as families of children with other developmental disabilities, the source of that stress may be different and may therefore require different kinds of intervention. Improved education and training on FASD for health professionals appears a clear priority based on parents' experiences of having difficulty in finding knowledgeable providers. Survey-based studies of health professionals have documented insufficient knowledge about FASD and lack perceived competence in serving individuals with FASD. Increased awareness among professionals is also an important step toward modifying policies and other systems-barriers (e.g., delayed diagnosis, access, and availability of services) that compromise the success of individuals with FASD.[38]

Primary Prevention and Continuum of Care

Beyond simplistic advice to not drink while pregnant, a comprehensive approach has demonstrated the benefits of helping women plan their pregnancies, obtain prenatal care, improve their nutrition, reduce stress in pregnancy, and, in some cases, access treatment.

The U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA) uses the Institute of Medicine continuum of care model to define three types of prevention for alcohol-exposed pregnancies:

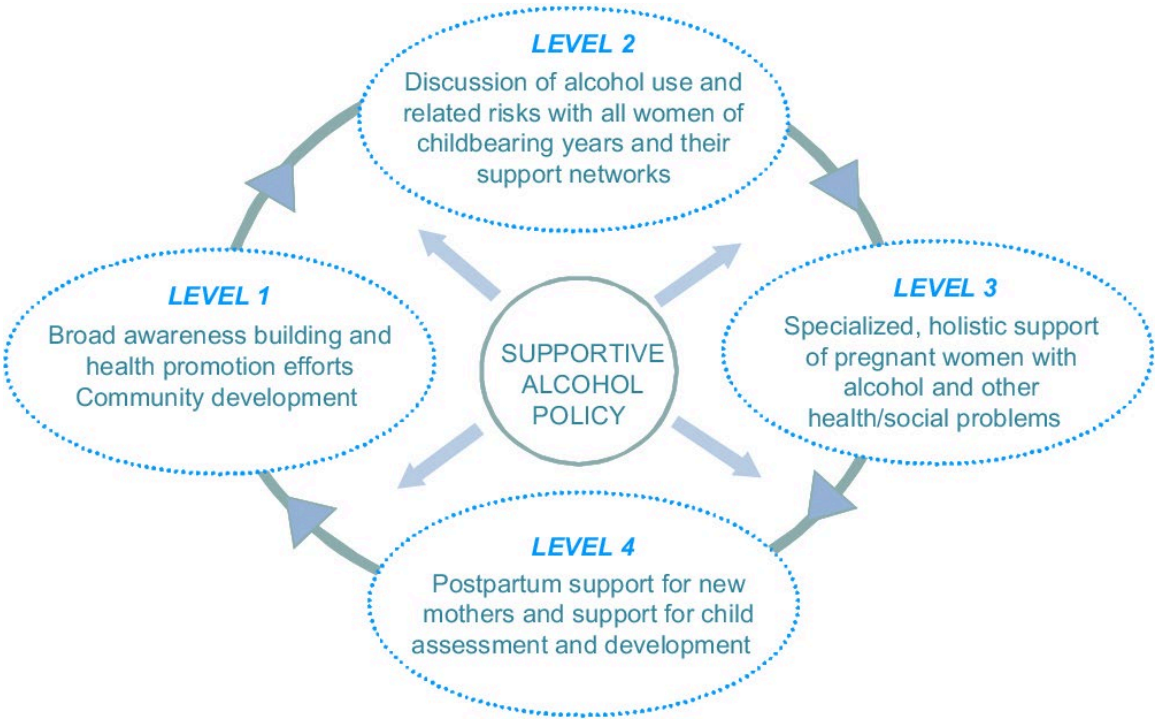
1. *Universal prevention* addressing the segment of population with average probability, risk, or condition of developing a disorder. It can take a variety of forms, including media campaigns, large-scale health initiatives, etc. This population segment would include a woman who is not pregnant and reports no alcohol use or does not screen positive for at-risk alcohol use.

[38] Christie L.M. Petrenko, et al, ""I'm doing my part, I just need help from the community": Intervention Implications of Foster and Adoptive Parents' Experience Raising Children and Young Adults with FASD,"" Journal of Family Nursing 2019 May: 25(2): 314-347.

2. *Selective prevention* addressing a specific sub-population with risk significantly above average; this can include screening for women for alcohol use, working with family members of pregnant women who misuse alcohol, brief interventions, and referrals, etc. This would include a woman of childbearing age who reports alcohol use but has only one of the two indicators for an indicated intervention; she is either pregnant but does not screen positive for at-risk alcohol use, or she screens positive for at-risk alcohol use, but is not pregnant.
3. *Indicated prevention* addressing individuals with minimal but detectable signs or symptoms suggesting a disorder, such as a woman who has already given birth to a child with FASD and continues to drink, etc. This would include a woman of childbearing age who screens positive for at-risk alcohol use and is pregnant.
4. For many vulnerable women, pregnancy is a time of increased motivation to contemplate significant life changes, particularly prompted by women's desire to keep their newborns in their care. Indeed, the research literature suggests that women will respond to prevention services that are aimed at improving their health, including efforts to decrease or stop substance use or to increase their safer use of substances. Strong evidence also indicates that outcomes for mothers and infants improve when accessible, women-centered substance-use services or treatment are offered in conjunction with prenatal care; moreover, care also tailored to the specific and evolving needs of women, their children, and the mother–child dyad is viewed as the most effective. Programs that integrate practical and social supports with prenatal and postnatal health services, such as culture, transportation, childcare, and meals, and that address the fear of child apprehensions may have an advantage in engaging women who otherwise have few reasons to trust the formal health care system. Moreover, programs that use nonjudgmental, relationship-based, trauma-informed, and harm-reduction approaches and that acknowledge women's unique realities when it comes to the mother–child relationship have been found to be most effective in reaching vulnerable pregnant and parenting women with substance-use issues.[39]

[39] Hubberstey, Carol et al, "Multi-service Programs for Pregnant and Parenting Women with Substance Use Concerns: Women's Perspectives on Why They Seek Help and Their Significant Changes," International Journal of Environmental Research and Public Health, 2019, 16, 3299.

Figure 53. Four Levels of Supportive Alcohol Policy for Pregnant Women with Alcohol-use disorders



Source: "Prevention of Fetal Alcohol Spectrum Disorder: Current Canadian Efforts and Analysis of Gaps," Substance Abuse: Research and Treatment 2016:10(S1)

Women's reasons for prenatal substance use are both complex and gendered. Research suggests that women's prenatal substance use is often driven by a host of social determinants of health factors such as deep poverty, a history of physical or sexual abuse and neglect or other forms of trauma, intimate partner violence, mental health concerns, precarious living conditions including homelessness, child welfare involvement including maternal–child separation, and physical health problems. Moreover, women who are struggling with substance use are typically isolated, are more likely to be living with a partner with problematic substance use, experience lower levels of social support, and have fewer resources at their disposal relative to their male counterparts. These factors contribute to women's reluctance to reveal the full extent of their substance use.

Systemic barriers compound the situation as standard systems of care often do not meet the needs of women with prenatal or postnatal substance-use issues, especially women trying to raise children. As a result, when seeking help for their substance use, vulnerable, marginalized women commonly experience numerous barriers, including stigmatization, lack of mental health supports, negative attitudes of health care providers, and adversarial approach of child welfare authorities. Not surprisingly, fear of child welfare authorities is another factor in women's avoidance of services, as is inadequate transportation and/or lack of child care. These factors together make the decision to seek addiction treatment and support services even more

challenging. For service providers this also makes it more important that the programs they offer meet women's needs.[40]

According to a recent study by University of Alaska Anchorage, there does not appear to be a coordinated effort to use the CHOICES tools recommended by CDC for primary FASD prevention, including the brief alcohol screening and intervention tool in Alaska.[41] CHOICES is an evidence-based intervention for high-risk women who are not pregnant, but who could become pregnant. This intervention helps women reduce drinking and/or increase the effective use of contraception. Motivational interviewing is used to increase a woman's commitment to change by allowing the participant to decide which behavior to focus on to reduce the risk of an alcohol-exposed pregnancy. The intervention is carried out through two to four counseling sessions and a contraceptive counseling session.[42]

The Parent-Child Assistance Program (PCAP) is an award-winning, evidence-informed home visitation case-management model for pregnant and parenting women with substance-use disorders. PCAP strives to help mothers build healthy families and prevent future births of children exposed prenatally to alcohol and drugs. PCAP provides support and linkages to needed services to women for three years following enrollment. The goal is to reduce future alcohol-exposed pregnancies by increasing abstinence from alcohol and/or improving regular use of reliable contraception among enrollees.

Standardized Screening

It is well-accepted that alcohol use during pregnancy is underreported due to stigma and lack of awareness. Pregnant women are less likely to self-report if they feel they will be judged harshly by providers. 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 United States, 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). [43] In Australia, only 45%

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[40] Hubberstey, Carol et al, "Multi-service Programs for Pregnant and Parenting Women with Substance Use Concerns: Women's Perspectives on Why They Seek Help and Their Significant Changes," International Journal of Environmental Research and Public Health, 2019, 16, 3299.

[41] UAA College of Health, Alaska Fetal Alcohol Spectrum Disorders Data Systems Development: Gaps, Opportunities, & Recommendations, March 2021. Prepared for the Alaska Mental Health Trust Authority.

[42] UAA College of Health, Alaska Fetal Alcohol Spectrum Disorders Data Systems Development: Gaps, Opportunities, & Recommendations, March 2021. Prepared for the Alaska Mental Health Trust Authority.

[43] https://pubmed.ncbi.nlm.nih.gov/21769028/ Accessed June 2, 2020.

of doctors said they always ask their pregnant patients about their alcohol use and only 25% routinely provide information on the effects of alcohol on a fetus.[44]

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."[45] 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 of whether they are pregnant. The treatment protocol also provides a policy and procedures section to help states 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).

4P's Plus Screen for Behavioral Health Risk© tool, also known as 4P's Plus©, is a screening tool that has been validated to screen pregnant women for all substances with potential to harm a pregnancy. Screening questions are organized around family history questions (i.e., parents, partner, and past) which help to normalize the process of asking the sensitive questions about substance use during pregnancy. The fourth "P" section (i.e., pregnancy) then asks about substance use prior to the woman's knowledge of her pregnancy. Report of use of any quantity of alcohol during the month prior to the woman's knowledge of her pregnancy constitutes a positive screen indicating heightened risk for substance use during pregnancy.

Alaska Substance Exposed Newborns Initiative (SENI) is an Alaska program focused on improving the quality of clinical care and community-based resources needed to optimize the health and well-being of pregnant women, babies, and their families. It is working to integrate 4P's Plus© into inpatient and outpatient practice settings. The four Alaska hospitals participating in SENI began using the 4P's Plus© screening tool in July 2017. Although the tool was developed for use during routine outpatient prenatal care, SENI has focused screening efforts primarily around the time the woman presents for delivery. This approach aims to provide universal screening that includes screening of women who do not access early or routine prenatal care. Between July 1, 2017, and July 11, 2019, based on the 4P's Plus© tool, 19.5% of pregnant women reported use of alcohol only in the month before knowledge of their pregnancy; 6.6% reported tobacco and alcohol use; 4.6% reported marijuana and alcohol use; and 4.6% of women used tobacco,

[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.
[45] https://store.samhsa.gov/sites/default/files/d7/priv/sma13-4803.pdf Accessed June 2, 2020.

marijuana, and alcohol use. Combined, 35.2% of women used alcohol in the month before knowledge of their pregnancy.[46]

When substance use during pregnancy is reported, a brief and supportive counseling intervention and referral to care is completed. This evidence-based process is called "SBIRT", or screening, brief intervention, and referral to treatment. SAMHSA defines SBIRT as follows:

- Screening — a health care professional assesses a patient for risky substance-use behaviors using standardized screening tools. Screening can occur in any health care setting.
- Brief Intervention — a health care professional engages a patient showing risky substance use behaviors in a short conversation, providing feedback and advice.
- Referral to Treatment — a health care professional provides a referral to brief therapy or additional treatment to patients who screen in need of additional services.

FASD Diagnostic Limitations

FAS is a medical diagnosis with clearly well-defined criteria, while the boundaries to normality and other disorders within FASD are less clear. FASD is an umbrella term, not a clinical diagnosis. FASD as a diagnosis is of little use since knowing that someone has FASD does not specify which symptoms they have. Therefore, the typical link between diagnosis and a reasonably well specified set of treatments is missing, which clearly diminishes the point of diagnosis. A general FASD diagnosis would still have the point of placing the individual in a context of related disabilities and difficulties. Apart from that, there would be no positive consequences for the concerned individuals unless resources were allocated based on the diagnosis.[47]

Additionally, FASD is often overlooked or misdiagnosed. Some clinicians perceive FASD to be primarily a problem for children of women with alcohol-use disorders or belonging to sub-populations of marginalized or oppressed groups. However, higher socioeconomic status is a strong predictor of PAE, and FASD is likely underdiagnosed in educated, financially secure groups.[48]

Based on a recent study on FASD prevalence, a conservative prevalence estimation is that 11.3 to 50.0 persons per 1,000 have FASD.[49] Another study reflected the size of misdiagnosis; out of 156 children, 125 had never been diagnosed as affected by prenatal alcohol exposure, a missed diagnosis of 80.1%. Among 31 children who had been recognized before referral as affected by

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[46] Alaska Department of Health and Social Services, Alaska Substance Exposed Newborns Initiative, Report Covering Data Generated from Form Version 1 (July 1, 2017-July 11, 2019).
[47] Helgesson, Gert, et al, "Ethical aspects of diagnosis and interventions for children with FASD and their families" BMC Medical Ethics 19, 1 (2018).
[48] McCormack, C., et al. 2017 "Prenatal alcohol consumption between conception and recognition of pregnancy," Alcohol: Clinical & Experimental Research, *41*(2), 369–378.
[49] May et al. 2018 "Prevalence of Fetal Alcohol Spectrum Disorders in 4 US Communities," JAMA vol. 3019 (5).

prenatal alcohol exposure, 10 children's FASD diagnoses were changed within the spectrum, representing a misdiagnosis rate of 6.4%.[50]

Early Diagnosis

Clinical descriptions of patients with FASD suggest major problems with adaptive behavior. In a study of 415 patients, 80% were not raised by their biological mothers. For adolescents and adults, the life span prevalence was 61% for disrupted school experiences, 60% for trouble with the law, 50% for sexual behaviors on repeated occasions, and 35% for alcohol/drug problems. The odds of escaping these adverse life outcomes are increased two- to four-fold by receiving the diagnosis of FASD at an earlier age and by being reared in good stable environments.[51] Early diagnosis can increase the chances of obtaining early support that strengthens the individuals' ability over time and in that way strengthen the control over their own lives.[52]

Post-Diagnosis Services

Service recommendations for individuals and families include care coordination and case management services, educational assessment and intervention, caregiver support and respite services, community-based recreational programs, child counselling and psychiatric services, occupational and speech language therapy assessments, and substance misuse prevention.[53]

Classified Disability

The term "Intellectual Disability (ID) equivalence" refers to accommodations that are made by legal and other governmental entities when they provide services, supports, or protective arrangements to people who – because of brain impairment – function as if they had ID but failed to qualify for their ID label, which is needed for access to many programs because their IQ scores are a few points too high. FASD is a logical candidate for such an accommodation as a) it (like ID) involves brain impairment, b) people with FASD have adaptive deficits and support needs that are identical to those with ID, and c) while many people with FASD do qualify as having ID, the majority do not, because full-scale IQ scores are too high.[54]

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[50] Chasnoff, Ira et al. 2015 "Misdiagnosis and Missed Diagnosis in FASD," Pediatrics, Volume 135 (2).

[51] Streissgurth, Ann P. Risk Factors for Adverse Life Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects. Journal of Developmental Behavior Pediatrics 25:228-238, 2004.

[52] Helgesson, Gert, et al, "Ethical aspects of diagnosis and interventions for children with FASD and their families" BMC Medical Ethics 19, 1 (2018).

[53] UAA College of Health, Alaska Fetal Alcohol Spectrum Disorders Data Systems Development: Gaps, Opportunities, & Recommendations, March 2021. Prepared for the Alaska Mental Health Trust Authority.

[54] Greenspan, Stephen et al, "FASD and the Concept of "Intellectual Disability Equivalence" in Fetal Alcohol Spectrum Disorder in Adults: Ethical and Legal Perspectives, International Library of Ethics, Law, and the New Medicine 63.

Parents and providers anecdotally indicate that obtaining a FASD diagnosis, plus qualifying and maintaining services for FASD, is harder than other developmental disabilities with similar symptoms, such as autism. This results in scenarios in which parents and providers opt for a diagnosis of autism to obtain disability services more readily. As one experienced Alaska clinical health provider stated, "Autism is a savior for many families. It is easier to get services and families avoid stigma."

FASD needs to be classified or recognized as a categorial developmental disability so that people who become eligible for Medicaid-funded services are treated at the same level as people with autism or any developmental disabilities.[55] Advocates have been suggesting a new definition of Intellectual Disability/Development Disability (ID/DD): "ID/DD is a developmental condition that involves incomplete development of brain function and which is reflected in significant deficiencies relative to peers in the acquisition of intellectual, cognitive, and executive skills needed to succeed in various age-relevant community roles and to cope with every day as well as unique challenges and dangers in physical, academic, and social realms." Using a definition like this would allow for more people with FASD achieving Development Disability eligibility.[56]

Care Coordination

Although researchers have highlighted the significance of strength- and ecological-based approaches for children and youth with FASD, significantly less work has been done addressing the needs of youth and adolescents with FASD transitioning out of care or into emerging adulthood. This transition to adulthood is a critical period that warrants particular attention, especially regarding life planning.[57]

A formal system for coordination of FASD services is lacking among providers, including those in obstetrics, gynecology, pediatrics, diagnostics, neuropediatrics, occupational therapy, mental health, and substance misuse treatment.[58] Care coordination and high-quality case management is essential from early childhood through emerging adulthood and into adulthood. The risk for secondary conditions dramatically increases during adolescence and young adulthood, when fewer community-based supports are generally available.[59] Approaches that would support increased coordination and integration of care include a) electronic medical records; b) a client centered medical home; and c) multidisciplinary primary care group practice models. Increased

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[55] Christie L.M. Petrenko, et al, ""I'm doing my part, I just need help from the community": Intervention Implications of Foster and Adoptive Parents' Experience Raising Children and Young Adults with FASD,"" Journal of Family Nursing 2019 May: 25(2): 314-347.

[56] Greenspan, Stephen et al, "FASD and the Concept of "Intellectual Disability Equivalence" in Fetal Alcohol Spectrum Disorder in Adults: Ethical and Legal Perspectives, International Library of Ethics, Law, and the New Medicine 63.

[57] Badry, Dorothy and Kelly Harding, "Fetal Alcohol Spectrum Disorder and Child Welfare," Canada FASD Research Network Technical Report, January 2020.

[58] UAA College of Health, Alaska Fetal Alcohol Spectrum Disorders Data Systems Development: Gaps, Opportunities, & Recommendations, March 2021. Prepared for the Alaska Mental Health Trust Authority.

[59] Petrenko, Christie. "Positive Behavioral Interventions and Family Support for Fetal Alcohol Spectrum Disorders," Curr Dev Disord Rep, 2015 Sep: 2(3): 199-209.

information sharing among both medical and non-medical service providers through eHealth would increase efficiency and system-level capacity.[60]

[60] Masottti, Paul, Sally Longstaffe, Holly Gammon, Jill Isbister, Breann Maxwell, and Ana Honlon-Dearman. 2015. "Integration care for individuals with FASD: results from a multi-stakeholder symposium." *BMC health services research*, *15*, 457. https://doi.org/10.1186/s12913-015-1113-8.

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Appendix A: Additional Health Data

Additional data tables on Medicaid claim spending, hospital facilities charges, and FQHC patient demographics and utilization start on the next page.

Medicaid Claims Spending Data

All Alaska Beneficiaries

Table 52. Medicaid Beneficiaries, Claims, and Claim Spending, Pregnant Women with Alcohol-use Disorders, Infants Impacted by Maternal Alcohol Use, and Individuals with FAS and Comparison Groups, All Alaska Beneficiaries, SFY2019

Group	Beneficiaries (Number)	Claims (Number)	Spending on Claims	Average Number Claims/ Beneficiary	Average Spending/ Claim	Average Spending/ Beneficiary
Pregnant Women with Alcohol-use Disorders						
Study Group	67	5,164	$1,741,251	77.1	$337	$25,989
Comparison Group	4,565	213,629	$53,581,627	46.8	$251	$11,737
Infants Impacted by Maternal Alcohol-use (Age <1)						
Study Group	71	4,929	$6,268,302	69.4	$1,272	$88,286
Comparison Group	6,584	139,255	$92,012,752	21.2	$661	$13,975
Individuals with FAS (Age 1-5)						
Study Group	70	6,234	$1,457,666	89.1	$234	$20,824
Comparison Group	24,621	574,610	$123,815,812	23.3	$215	$5,029
Individuals with FAS (Age 6-12)						
Study Group	243	36,911	$8,059,335	151.9	$218	$33,166
Comparison Group	31,388	898,044	$164,768,203	28.6	$183	$5,249
Individuals with FAS (Age 13-17)						
Study Group	175	42,288	$11,261,746	241.6	$266	$64,353
Comparison Group	19,173	798,990	$183,612,636	41.7	$230	$9,577
Individuals with FAS (Age 18-64)						
Study Group	320	86,825	$20,147,948	271.3	$232	$62,962
Comparison Group	100,082	6,697,284	$1,310,821,179	66.9	$196	$13,097
All Beneficiaries						
Study Group	946	182,351	$48,936,249	192.8	$268	$51,730
Comparison Group	186,413	9,321,812	$1,928,612,208	50.0	$207	$10,346

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The Pregnant Women Study Group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the Comparison Group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. Infants and Individuals Study Group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the Comparison Group includes Medicaid beneficiaries in SFY2019 who were infants under age 1 not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

All Alaska Beneficiaries

Table 53. Medicaid Beneficiaries, Claims, and Claim Spending, Pregnant Women with Alcohol-use Disorders, Infants Impacted by Maternal Alcohol Use, and Individuals with FAS and Comparison Groups, Southcentral Alaska Beneficiaries, SFY2019

Group	Beneficiaries (Number)	Claims (Number)	Spending on Claims	Average Number Claims/ Beneficiary	Average Spending/ Claim	Average Spending/ Beneficiary
Pregnant Women with Alcohol-use Disorders						
Study Group	31	2,684	$694,378	86.6	$259	$22,399
Comparison Group	2,606	123,675	$25,738,873	47.5	$208	$9,877
Infants Impacted by Maternal Alcohol Use (Age <1)						
Study Group	36	2,189	$2,366,538	60.8	$1,081	$65,737
Comparison Group	3,836	78,350	$44,516,638	20.4	$568	$11,605
Individuals with FAS (Age 1-5)						
Study Group	41	4,453	$1,095,275	108.6	$246	$26,714
Comparison Group	14,081	322,092	$58,242,432	22.9	$181	$4,136
Individuals with FAS (Age 6-12)						
Study Group	142	20,861	$4,905,349	146.9	$235	$34,545
Comparison Group	17,616	530,533	$85,523,308	30.1	$161	$4,855
Individuals with FAS (Age 13-17)						
Study Group	109	21,295	$6,445,916	195.4	$303	$59,137
Comparison Group	10,947	444,081	$97,058,835	40.6	$219	$8,866
Individuals with FAS (Age 18-64)						
Study Group	223	68,419	$14,935,196	306.8	$218	$66,974
Comparison Group	59,761	4,535,131	$789,500,363	75.9	$174	$13,211
All Beneficiaries						
Study Group	582	119,901	$30,442,651	206.0	$254	$52,307
Comparison Group	108,847	6,033,862	$1,100,580,450	55.4	$182	$10,111

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The Pregnant Women Study Group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the Comparison Group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. Infants and Individuals Study Group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the Comparison Group includes Medicaid beneficiaries in SFY2019 who were infants under age 1 not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

All Alaska Beneficiaries

Table 54. Medicaid Beneficiaries, Claims, and Claim Spending, Pregnant Women with Alcohol-use Disorders, Infants Impacted by Maternal Alcohol Use, and Individuals with FAS and Comparison Groups, All Other Alaska Beneficiaries, SFY2019

Group	Beneficiaries (Number)	Claims (Number)	Spending on Claims	Average Number Claims/ Beneficiary	Average Spending/ Claim	Average Spending/ Beneficiary
Pregnant Women with Alcohol-use Disorders						
Study Group	36	2,480	$1,046,873	68.9	$422	$29,080
Comparison Group	1,959	89,954	$27,842,753	45.9	$310	$14,213
Infants Impacted by Maternal Alcohol Use (Age <1)						
Study Group	35	2,740	$3,901,764	78.3	$1,424	$111,479
Comparison Group	2,748	60,905	$47,496,115	22.2	$780	$17,284
Individuals with FAS (Age 1-5)						
Study Group	29	1,781	$362,392	61.4	$203	$12,496
Comparison Group	10,540	252,518	$65,573,380	24.0	$260	$6,221
Individuals with FAS (Age 6-12)						
Study Group	101	16,050	$3,153,986	158.9	$197	$31,228
Comparison Group	13,772	367,511	$79,244,894	26.7	$216	$5,754
Individuals with FAS (Age 13-17)						
Study Group	66	20,993	$4,815,830	318.1	$229	$72,967
Comparison Group	8,226	354,909	$86,553,801	43.1	$244	$10,522
Individuals with FAS (Age 18-64)						
Study Group	97	18,406	$5,212,753	189.8	$283	$53,740
Comparison Group	40,321	2,162,153	$521,320,815	53.6	$241	$12,929
All Beneficiaries						
Study Group	364	62,450	$18,493,597	171.6	$296	$50,807
Comparison Group	77,566	3,287,950	$828,031,759	42.4	$252	$10,675

Source: Alaska Department of Health and Social Services, Division of Healthcare Services.
Note: The Pregnant Women Study Group refers to Medicaid beneficiaries who were pregnant and diagnosed with alcohol use complicating childbirth, pregnancy, or the puerperium in SFY2019; the Comparison Group refers to Medicaid beneficiaries who were pregnant in SFY2019 excluding pregnant women who were diagnosed with drug or alcohol use complicating childbirth, pregnancy, or the puerperium. Infants and Individuals Study Group refers to Medicaid beneficiaries who were infants impacted by maternal alcohol use or diagnosed with FAS between the ages of 1-64 at any time in SFY2019; the Comparison Group includes Medicaid beneficiaries in SFY2019 who were infants under age 1 not affected by maternal use of alcohol or drugs of addiction, withdrawal symptoms; and individuals ages 1-64 without a developmental disability, encephalopathy, other intellectual disabilities, pervasive and specific developmental disorders, and behavioral and emotional disorders with onset usually occurring in childhood and adolescence.

Hospital Facilities Charge Data

The tables below present inpatient, outpatient, and emergency department charge data for pregnant women with alcohol-use disorders, infants affected by maternal use of alcohol, and individuals identified with FAS (primary or secondary diagnoses) for SFY2019. The data are also presented by region (Southcentral Alaska and All Other Alaska).

Pregnancy and Prenatal

Table 55. Pregnant Women with Alcohol-use Disorders, Hospital Inpatient, Outpatient, and Emergency Department Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$1,616,299	$30,496
All Other Alaska	$1,483,876	$24,326
Total	$3,100,175	$27,195
Outpatient Visits		
Southcentral Alaska	$173,065	$2,884
All Other Alaska	$262,135	$1,900
Total	$435,200	$2,198
Emergency Department Visits		
Southcentral Alaska	$75,295	$9,412
All Other Alaska	$84,609	$3,525
Total	$159,904	$4,997

Source: Alaska Hospital Facilities Data Reporting Program.

All Individuals Experiencing an FASD

Table 56. Individuals with FAS, Hospital Inpatient, Outpatient, and Emergency Department Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$10,351,134	$62,734
All Other Alaska	$4,378,519	$48,116
Total	$14,729,652	$57,538
Outpatient Visits		
Southcentral Alaska	$1,922,433	$3,964
All Other Alaska	$552,341	$3,368
Total	$2,474,774	$3,813
Emergency Department Visits		
Southcentral Alaska	$446,351	$4,334
All Other Alaska	$106,642	$4,443
Total	$552,994	$4,354

Source: Alaska Hospital Facilities Data Reporting Program.

Infancy

Table 57. Infants Affected by Maternal Alcohol Use, Hospital Inpatient, Outpatient, and Emergency Department Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$1,195,661	$62,930
All Other Alaska	$973,251	$60,828
Total	$2,168,913	$61,969
Outpatient Visits		
Southcentral Alaska	$6,618	$301
All Other Alaska	$4,763	$476
Total	$11,381	$356
Emergency Department Visits		
Southcentral Alaska	-	-
All Other Alaska	$1,556	$1,556
Total	$1,556	$1,556

Source: Alaska Hospital Facilities Data Reporting Program.

Early Childhood

Table 58. Individuals with FAS Age 1 Through 5, Hospital Inpatient, Outpatient, and Emergency Department Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$146,099	$73,049
All Other Alaska	-	-
Total	$146,099	$73,049
Outpatient Visits		
Southcentral Alaska	$139,218	$2,784
All Other Alaska	$44,073	$1,520
Total	$183,290	$2,320
Emergency Department Visits		
Southcentral Alaska	$3,370	$1,685
All Other Alaska	$594	$594
Total	$3,964	$1,321

Source: Alaska Hospital Facilities Data Reporting Program.

Late Childhood

Table 59. Individuals with FAS Age 6 Through 12, Hospital Inpatient, Outpatient, and Emergency Department Hospital Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$1,266,967	$42,232
All Other Alaska	$397,026	$44,114
Total	$1,663,993	$42,666
Outpatient Visits		
Southcentral Alaska	$260,982	$2,534
All Other Alaska	$58,974	$1,404
Total	$319,956	$2,207
Emergency Department Visits		
Southcentral Alaska	$36,829	$4,092
All Other Alaska	$3,306	$1,653
Total	$40,135	$3,649

Source: Alaska Hospital Facilities Data Reporting Program.

Adolescence

Table 60. Individuals with FAS Age 13 Through 17, Hospital Inpatient, Outpatient, and Emergency Department Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$2,495,412	$55,454
All Other Alaska	$1,473,209	$49,107
Total	$3,968,621	$52,915
Outpatient Visits		
Southcentral Alaska	$211,187	$4,310
All Other Alaska	$59,675	$3,978
Total	$270,861	$4,232
Emergency Department Visits		
Southcentral Alaska	$68,878	$6,262
All Other Alaska	$53,206	$5,912
Total	$122,083	$6,104

Source: Alaska Hospital Facilities Data Reporting Program.

Adult

Table 61. Individuals with FAS Age 18 and Above, Hospital Inpatient, Outpatient, and Emergency Department Charges, Primary or Secondary Diagnoses, by Region, SFY2019

Category	Total Charges	Average Charge per Admission
Inpatient Admissions		
Southcentral Alaska	$5,246,994	$76,043
All Other Alaska	$1,535,032	$42,640
Total	$6,782,026	$64,591
Outpatient Visits		
Southcentral Alaska	$1,304,428	$4,998
All Other Alaska	$384,858	$5,660
Total	$1,689,286	$5,135
Emergency Department Visits		
Southcentral Alaska	$337,275	$4,164
All Other Alaska	$47,981	$4,362
Total	$385,255	$4,188

Source: Alaska Hospital Facilities Data Reporting Program.

Uniform Data System

Patient Demographics

Alaska FQHC patients are predominately white (40%) or Alaska Native/American Indian (38%). Alaska FQHCs serve comparatively fewer white patients than all U.S. FQHCs (58%). Alaska FQHCs serve a greater percentage of American Indian and Alaska Native patients than all U.S. FQHCs, 38% versus 1%, respectively.

Table 62. Patients by Race and Ethnicity, Alaska and U.S., CY2019

Race or Ethnicity*	Number of Patients† Alaska	Percentage of Patients Served Alaska	Percentage of Patients Served U.S.
Race			
White	45,501	39.5%	57.7%
Alaska Native/American Indian	43,495	37.8%	1.2%
Asian	4,582	4.0%	3.6%
Black/African American	2,453	2.1%	18.4%
Native Hawaiian/Other Pacific Islander	1,544	1.3%	1.0%
More than one race	3,032	2.6%	2.9%
Unreported / Refused to report race	14,509	12.6%	15.3%
Ethnicity (of those with reported race)			
Hispanic/Latino	5,946	5.7%	36.8%
Non-Hispanic/Latino	97,743	94.3%	63.2%

Source: Uniform Data System (UDS), 2019.
Note: Percentages may not sum to 100% due to rounding.
* Race and ethnicity are self-reported.
† Patient counts are unduplicated patients.

Childhood Conditions

Children with middle and inner ear disorders have higher visit rates Alaska FQHCs compared to all U.S. FQHCs, 2.0 versus 1.5 annual visits, respectively. Children experiencing physiological developmental delays and/or nutritional deficiencies had lower annual visit rates to Alaska FQHCs compared to all U.S. FQHCs, with 1.4 visits per Alaska patient statewide and 1.6 visits nationally.

Table 63. Selected Childhood Conditions, Alaska and U.S., CY2019

Condition	Number of Patients with Diagnosis* Alaska	Number of Visits by Diagnosis† Alaska	Visits Per Patient Alaska	Visits per Patient U.S.
Otitis media and Eustachian tube disorders	4,686	9,562	2.04	1.48
Lack of expected normal physiological development and nutritional deficiencies in children only. ^	1,084	1,524	1.41	1.63

Source: Uniform Data System (UDS), 2019.
* Patients counts are unduplicated patients; they may be counted in multiple diagnostic categories. Patients with multiple occurrences of the diagnosis are reported only once for each diagnosis during the year.
† Number of visits are all visits in which the indicated diagnosis is listed regardless of diagnostic primacy for that visit.
^Examples of diagnostic inclusion: delayed milestone, failure to gain weight, failure to thrive. Does not include sexual or mental development.

Preventive Services

Visits for the health supervision of an infant or child occur at about the same rate for Alaska children receiving care at an FQHC as compared to all U.S. FQHCs, 1.6 annual visits per Alaska patient statewide and 1.5 visits nationally. These visits involve monitoring and screening children for development benchmarks to ensure early interventions for physical and intellectual development problems; visits also ensure routine vaccinations and health screenings happen on time.

Table 64. Health Supervision of Infant or Child, Diagnosis and Visits, Alaska and U.S., CY2019

Preventive Services	Number of Patients with Diagnosis* Alaska	Number of Visits by Diagnosis† Alaska	Visits Per Patient Alaska	Visits per Patient U.S.
Health supervision of infant or child (ages 0 through 11)	8,362	13,353	1.6	1.53

Source: Uniform Data System (UDS), 2019.
* Patients counts are unduplicated patients.
† Number of visits are all visits where the indicated diagnosis is listed regardless of diagnostic primacy for that visit.

Mental Health and Substance Use Disorders

The visit rate per patient for alcohol-related and tobacco use disorders was higher at Alaska FQHCs than FQHC national rates. Alaska rates for alcohol-related disorders was 3.65 visits per patient, compared to 3.25 visits per patient nationally. Alaska visit rates for tobacco use disorders are 2.14 visits per patient, compared to 1.91 visits per patient nationwide.

For selected mental health disorders, Alaska FQHCs had higher visit rates per patient, compared with U.S. FQHC rates, for depression and other mood disorders (3.73 versus 3.45 visits per patient), and a comparable rate for anxiety disorders, including PTSD (3.29 versus 3.26 visits per patient, respectively). Visit rates for attention deficit and disruptive behavior disorders were slightly lower per patient at Alaska FQHCs than nationally with 3.63 versus 3.9 visits, respectively.

SBIRT substance use screening rates were lower at Alaska FQHCs, compared to all U.S. FQHCs, 1.18 versus 1.69, respectively.

Table 65. Mental Health and Substance Use Disorders, Diagnosis and Visits, Alaska and U.S., CY2019

Disorders and Screening	Number of Patients with Diagnosis* Alaska	Number of Visits by Diagnosis† Alaska	Visits Per Patient Alaska	Visits per Patient U.S.
Selected Substance Use and Mental Health Disorders				
Alcohol-related disorders	4,240	15,469	3.65	3.25
Tobacco-use disorder	9,129	19,541	2.14	1.91
Depression and other mood disorders	8,314	30,984	3.73	3.45
Anxiety disorders, including post-traumatic stress disorder (PTSD)	8,918	29,315	3.29	3.26
Attention deficit and disruptive behavior disorders	1,463	5,311	3.63	3.9
Substance Use Screening				
Screening, Brief Intervention, and Referral to Treatment (SBIRT)	3,701	4,376	1.18	1.69

Source: Uniform Data System (UDS), 2019.
* Patients counts are unduplicated patients; may be counted in multiple diagnostic categories. Patients with multiple occurrences of the diagnosis are reported only once for each diagnosis during the year.
† Number of visits are all visits where the indicated diagnosis is listed regardless of diagnostic primacy for that visit.

Tobacco use screenings were administered for 82% of Alaska FQHC patients, about 5% lower than all U.S. FQHC patients Just under three quarters of patients were assessed for depression (73%) at Alaska FQHCs, about 1.5% higher than the national percentage.

Table 66. Screening, Tobacco Use and Depression, Alaska and U.S., CY2019

Screening	Number of patients aged 18 and over*	Number of patients assessed	Percent of patients assessed for and provided support as needed
Tobacco Use Screening			
Alaska	50,868	41,661	81.9%
National	12,688,867	11,060,418	87.2%
Depression Screening			
Alaska	66,984	49,061	73.2%
National	16,155,702	11,569,790	71.6%

Source: Uniform Data System (UDS), 2019.
* Patients counts are unduplicated patients.
Note: Incidence of condition is not reported.

Appendix B: List of Interviewees

- Larry Burd (PhD, MD), Director, North Dakota Fetal Alcohol Syndrome Center and FAS Clinic, and Professor, Department of Pediatrics, University of North Dakota School of Medicine
- Ira Chasnoff (MD), Professor of Clinical Pediatrics, University of Illinois College of Medicine
- Dan Dubovsky (MSW, LSW, FASD Specialist), Consultant, past FASD Specialist, SAMHSA FASD Center for Excellence.
- Jean Gerhardt-Cyrus, Program Coordinator, Maniilaq Association
- Hope Finkelstein, Program Manager, FASD, Alaska Department of Health and Social Services
- Grant and Lenna Funk, Parents/Foster Parents (McGrath)
- Kim Guay, Director, Office of Children Services, Alaska Department of Health and Social Services
- Cathy Heckenlively (MSN, MHA, RN, CENP), Executive Director, The Children's Hospital at Providence and Women's Services
- Matt Hershfeld (MD), Medical Director of Maternal Child Health Services, Alaska Native Medical Center
- Sherrill Holtshouser (RN, MPH), Women's & Reproductive Health Nurse Consultant, State of Alaska, Department of Health and Social Services, Division of Public Health, Substance Exposed Newborns Initiative (SENI)
- Kay Kelly, Project Director, FASD Legal Issues Resource Center; Research Coordinator, FASD in Adults: Health and Behavior, Fetal Alcohol and Drug Unit, University of Washington
- Karen Lomack, Parent Navigator, Stone Soup Group, and Parent (Anchorage)
- Marilyn Pierce-Bulger (FNP, CNM, MN) Interim President, Board of Directors, Alaska Center for FASD
- Evelyn Rider (MD) Alaska Neonatology Associates
- Rhonda Sparks, Parent/Foster Parent (Nome)
- Sarah Spencer (DO) Family Practice and Addiction Medicine Specialist (Ninilchik)

- Susan Stoner (PhD), Research Scientist, University of Washington Alcohol and Drug Abuse Institute
- William Trawick (NNP-BC), Executive Director, Alaska Center for Substance Use in Pregnancy and the Newborn, Inc.