



UAA College of Health
UNIVERSITY of ALASKA ANCHORAGE

Alaska Fetal Alcohol Spectrum Disorders Data Systems Development:

Gaps, Opportunities, & Recommendations

Prepared for:

Trust

**Alaska Mental Health
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Fetal Alcohol Spectrum Disorders Systems

Overview

There is not a significant amount of objective information documented on the impact of fetal alcohol spectrum disorders (FASDs) in Alaska. The available information on prevention and care services available to impacted persons is fragmented, with much of the publicly available information provided across myriad systems. This presents a significant challenge to persons in need of care to locate timely information, and for educators, healthcare providers, and policy makers to access relevant data.

Persons with an FASD receive services within the standard healthcare and behavioral healthcare systems. In addition to the healthcare system, individuals at risk of alcohol exposed pregnancy and persons experiencing an FASD are involved in a wide range of other systems such as the educational, child protection, court and correctional settings. This report sought to provide information about those systems to help guide policy and funding decisions making related to the prevention of FASD in three overall components.

The first component, entitled 'Systems of Care and Development', provides an oversight of the multiple systems which are most likely to be encountered by a person impacted by fetal alcohol exposure. In this section, services and programs are outlined, as well as barriers and recommendations. The second component, 'FASD and the Criminal Justice System', provides an in depth look at the impact and interaction with persons impacted by an FASD and the criminal justice system. Advocates for persons with an FASD have made a significant push to change the interactions with the criminal justice system. Finally, 'Fetal Alcohol Spectrum Disorders and the Alaska Education System' provides a detailed overview of the interaction of persons with an FASD and the education system in Alaska.

There are limitations to this report, which are primarily founded in the reason for this report, the lack of objective, timely, and systematic information available on multiple systems which could be faced by a person impacted by an FASD. For example, multiple educational, programmatic, and policy websites are out of date and include information

which is no longer relevant nor applicable. Some previous reports and publications in this area provide information without references or ties to replicable data or information.

This report was informed in large components by persons who advocate for persons impacted by fetal alcohol exposure. These persons were able to provide the most current, up to date information, and aided in the creation of this report by illuminating several the current challenges with the systems as applied to persons with an FASD. If it were not for these advocates, providers, educators, and persons working in systems of care, we would not have been able to provide report with this level of information and relevance. Unfortunately, not all persons impacted by an FASD nor their providers are able to access this network of persons to the extent which we were able. If they were, many of the gaps in the systems would be remedied.

One primary recommendation from this report is that there should be a concerted effort to connect the network of persons with the information and knowledge to the agency and provider organizations so that: public facing information (websites, educational materials, and agent knowledge) may be updated. Such an effort could be a low cost, high yield accomplishment which would not only improve many lives but could also increase access to care and prevention resources.

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Fetal Alcohol Spectrum Disorders Systems of Care and Development

Executive Summary Component 1

This report explores the common systems encountered by persons with a Fetal Alcohol Spectrum Disorders (FASD) and/or their caregivers. The focus is on systems most likely to be encountered over the lifespan from early childhood to adulthood. Given the range of expressions by an FASD, there is no way to predict every possible system of care and prevention an impacted person may encounter, we have explored the systems most likely to be experienced by most persons with an FASD. Our systems identification was informed by a literature review including research and policy publications, state and federal benefits, and persons working in the service delivery systems.

While focused on systems in Alaska, we documented not only the available resources specific to persons impacted by FASD, but also highlighted mainstream systems which can be accessed by and may enhance the life of persons with FASD. In addition to the identification of resources, we provided a gaps analysis and recommendations for consideration of policy and service enhancement. Recommendations were informed by key stakeholder interviews (n = 28) across all FASD systems of care identified in this report, including a focus group (n = 5) of caregivers and an adult with FASD.

This information is presented in a format which follows the idea of intervention: first focusing on prevention and then on systems of care and support. The systems of support are presented in a lifespan order, beginning with the initial systems which may be experienced by a person impacted by FASD as a child and adolescent and then through the stages of adulthood.

Systems of Prevention and Healthcare

According to the US Centers for Disease Control and Prevention (CDC), prevention is intended to prevent the acquisition of or the advancing of disease or other negative

health outcomes. (Prevention, 2019) Primary prevention focuses on removing risk factors or increasing personal knowledge to assist people in avoiding exposures which lead to disease development. Secondary prevention strives to identify persons with a disease or health condition so that treatment and/or services may be provided. Tertiary prevention are mitigation services which attempt to stop the advancement of disease or mitigate the impact of disease or negative health event on the persons impacted. As prevention tends to be less costly than treatment, it is commonly a preferred path for interventions.

Prevention

The US Centers for Disease Control and Prevention (CDC) provides extensive information on FASD across multiple domains, including prevention. Currently, there are two primary prevention approaches recommended to reduce the risk of alcohol exposed pregnancy. One is an alcohol screening and brief intervention (aSBI) and the other is an evidence-based counseling intervention for non-pregnant women to help reduce alcohol use and/or increase the use of birth control called CHOICES. (Curry et al., 2018; Interventions: FASD Prevention Efforts, 2020) Both approaches are validated and have been demonstrated to be effective. Much like counseling interventions, the cost of the aSBI may be billed in a patient healthcare setting to insurance and is covered under the Affordable Care Act.

In more than 30 years of development and use, the aSBI is an effective tool to determine alcohol risk among adults and is recommended by the US Preventive Services Task Force for use in primary care settings. The aSBI uses a validated set of screening questions to identify a patient's drinking patterns, which takes only a few minutes. A short conversation with patients reporting excessive drinking, and a referral to specialized treatment as appropriate.

CHOICES is an evidence-based intervention for women with high-risk drinking 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 motivation and 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 in two to four counseling sessions and a contraceptive counseling session.

Additional prevention information available from the CDC includes education and awareness campaigns as well as efforts to reduce stigma associated with FASD.

FASD Prevention in Alaska

There are numerous Alaska based organizations, including state agencies and workgroups, which highlight prevention work in fetal alcohol spectrum disorder (FASD). Among these organizations, a common refrain is the importance of primary and secondary prevention for FASD. The following list highlights the organizations and their programs and recommendations on FASD prevention.

1) The Alaska Department of Health and Social Services (DHSS) has a program within the Office of Substance Misuse and Addiction Prevention, charged with the oversight of the DHSS response in Alaska. Its mission is to prevent and reduce substance use disorders and support community-based activities across Alaska. It proposes to fulfill its mission through knowledge communication, community engagement, and collaboration.

2) The Alaska Center for Fetal Alcohol Spectrum Disorders is a non-profit organization formed in 2017 as ‘...a response to the lack of momentum’ on FASD in Alaska. (Ponka et al., 2020) Their mission is to reduce alcohol-exposed pregnancies, promote successful outcomes for affected individuals and families, and creates FASD-informed communities of care. The center indicates that its focus is to address:

- a. family & caregiver support
- b. create better informed ‘systems of care’ and communities
- c. provide a means for persons with FASD to connect with one another to avoid social isolation.

The AK Center for FASD has patient education information materials available for printing and some informational videos geared toward providers of women to address the risks of alcohol use during pregnancy. (Pottie et al., 2020)

Education and awareness in Alaska appear to be the tool for primary prevention efforts. While there are multiple levels of prevention in many health outcomes, with an outcome like FASD, once a person is born, there are no effective secondary or tertiary level preventions as FASD itself does not progress, does not transmit, and does not remit.

Care

While many of the medical needs of persons with an FASD are the same as persons without, persons with an FASD, the medical needs may be more complex. Given the diversity of disorders which fall under the umbrella of FASD and a universe of factors influencing their presentation, healthcare utilization will vary widely across persons. Factors such as the dose-response exposure to alcohol, the time in the pregnancy

when alcohol is used, singleton or multiple pregnancies, and access to prenatal care heavily influence health outcomes resulting in a wide variance in the severity and presentation of symptoms among and between persons with an FASD. (Lindinger et al., 2021; Miller et al., 2006) Depending on the severity of the FASD, a person may need access to highly specialized care, including plastic surgeons, gastroenterologists, neurologists, immunologists, and otolaryngologists, among others.



Persons with an FASD, like persons with other health concerns, may have a disadvantage in accessing healthcare in Alaska, especially among persons not located in or near a major population center. Even for persons in a population center, there are other factors which impact access to care, including housing, transportation, financial considerations, knowledge and understanding of healthcare navigation and service availability, and healthcare coverage.

The Alaska Office of Healthcare Access has identified four top priorities in their Strategic Map for 2018 – 2021 (OHA Strategic Plan: Strategic Map 2018 - 2021, 2017), including community health improvement, healthcare needs assessments, healthcare quality improvement, and healthcare workforce initiatives. Service needs for persons with FASDs could be enhanced through each of these four priorities and their corresponding objectives and strategies as presented in Figure 1. Statewide assessment of community healthcare needs, expansion of healthcare providers in key areas, community engagement to assess and improve outcomes, and identification of underserved populations and locations are the primary objectives which could increase care and remove barriers.

The distribution of healthcare and its support in a state the size of Alaska is a major undertaking (2019). While most of the population lives in relative proximity to one another, the lack of road system, remote areas, and other logistical issues, including shipping, impact healthcare delivery unlike any other place in the United States. There are two systems of care present in the state, one for persons of Alaska Native or Native Indian origin and one system for people who are not of First Nations origin.

The State of Alaska has developed an itinerant public healthcare system which provides care through a system of community health centers and relies heavily on public health nurses, public health aides, and behavioral health aides to provide care in more than 280 small communities and villages. There are many villages and settlements in remote and hard to access locations, Limited services are provided to individuals via the public health nursing model and include immunizations, family planning, prenatal counseling and postpartum outreach, well child exams, tuberculosis screening and treatment & school screenings, and HIV/STI testing.

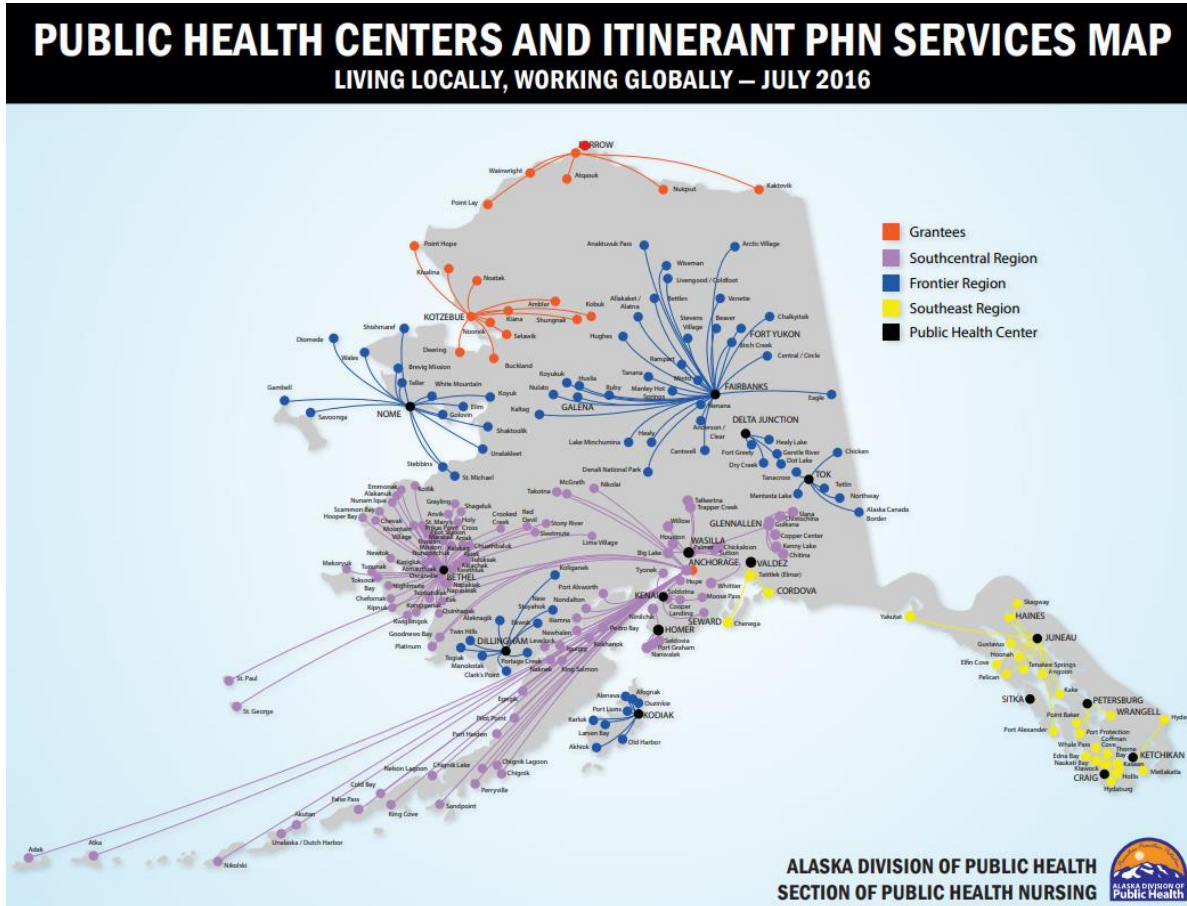
Figure 1. Alaska Office of Healthcare Access Strategic Map 2018 – 2021

 <p style="text-align: center;">DHSS, Division of Public, Health Rural & Community Health Systems</p> <p style="text-align: center;">Office of Healthcare Access Strategic Map 2018-2021</p> 			
<p>Vision: Vibrant health system in Alaska</p>			
<p>Mission: Improve the health of Alaskans by addressing health system issues.</p>			
<p>Guiding Principles: Communication is simple, accessible, and culturally competent.</p>			
Priorities			
Community Health Improvement	Healthcare Needs Assessments	Healthcare Quality Improvement	Healthcare Workforce Initiatives
Objectives & Strategies			
Foster collaboration between communities and partners	Assess statewide community healthcare needs	Evaluate and support critical access hospital quality improvement	Promote healthcare workforce incentive programs
Engage and empower communities to assess and improve health outcomes	Survey healthcare sites to accurately assess provider staffing	Advocate value based care transitions	Reduce healthcare provider shortages in key areas
Promote rural health resources	Identify underserved populations and locations	Initiate emergency medical and hospital quality care coordination	Pursue new funding opportunities
Performance Measures			
Publish rural health newsletter	Track key areas statewide with health provider shortage designations	Critical access hospital quality measure dashboards	Impact of workforce initiatives
Engagement in community health improvement activities	Publish updated statewide healthcare needs assessments	Publish statewide emergency medical services needs assessment	Provider job satisfaction and retention

The community-based services provided include Infectious diseases investigations, Community assessments, Community health improvement processes, Community organizing and development activities, Emergency preparedness, Health education

The following map shows the location of the public health centers and the itinerant public health nursing services provided statewide.

Figure 2. Alaska Public Health Centers and Itinerant PHN Services Map

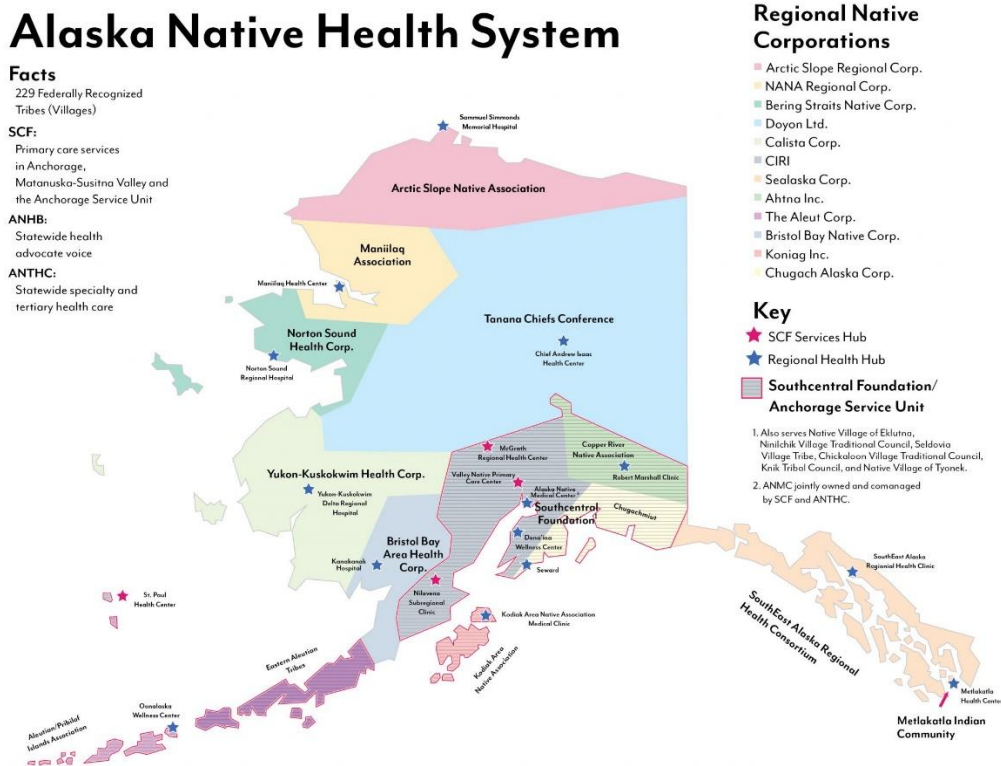


As of November 2020, there are 69 full time public health nurses employed to provide these services, not including 28 vacancies for full time positions. This map shows the hub model employed and the distances traveled to provide care from their base of locations. The health centers are also identified and while located near major population centers, there are large areas of the state where settlements and villages exist that are not covered by this system.

As of May 2020, according to the American Hospital Directory, there are ten non-federal, short term, acute care hospitals in Alaska. This number includes a military hospital and a children’s hospital. The total number of staffed beds, excluding the military facility, is 1,274 providing a combined total of 45,403 discharges. Additionally, there are three psychiatric hospitals and nine critical access hospitals statewide.

The US Indian Health Service operates the Alaska Area Indian Health Service (IHS) partners with Alaska Native Tribes and Tribal Organizations (T/TO) to provide comprehensive health services to almost 175,000 Alaska Natives. (Indian Health Service: Alaska, 2017) Approximately 99% of the Alaska Area budget is allocated to Tribes and Tribal Organizations. The Alaska Tribal Health Compact (ATHC) is a comprehensive system of health care serving all 228 federally recognized tribes in Alaska including hospitals located in Anchorage, Bethel, Dillingham, Kotzebue, Nome, Sitka, and Utqiagvik.

Figure 3. Map of Alaska Native Health System



In addition to hospitals, this system includes 58 tribal health centers, 160 tribal community health aide clinics, and five residential substance abuse treatment centers. Referrals and specialty care are coordinated from the Alaska Native Medical Center in Anchorage. There are several other statewide health promotion and disease prevention programs operated by the Alaska Native Tribal Health Consortium (ANTHC), which is managed by representatives of all Alaska tribes. There are 36 positions in the Alaska Area IHS performing federal functions that cannot be contracted to T/TOs. The Alaska Area supports USPHS Commissioned Corps officers and civil service employees to T/TOs for the provision of health care services.

Opportunities for Prevention and Care

- Primary healthcare access is limited in Alaska. Specialist care is increasingly more difficult to access, especially among persons outside of population centers, such as Anchorage, Fairbanks, and Juneau.
- There does not appear to be a formal linkage system for care coordination of FASD services among providers more highly utilized among persons impacted by FASDs, including obstetrics, gynecology and pediatrics clinics, diagnostic clinics, neuropsychiatric clinics, occupational therapists, mental health providers, and substance misuse providers, among others.
- There are opportunities throughout Alaska to alter existing services which could provide surveillance data on the occurrence of FASDs and opportunities for screening of persons to determine if an FASD is present.
- At this time, there does not seem to be a coordinated effort to use the primary tools recommended by the CDC for primary prevention of FASD, including the alcohol brief screening and intervention tool nor CHOICES as an evidence-based intervention.

Recommendations to Enhance Systems of Prevention and Care

- Actively engage the Department of Health and Social Services to discuss opportunities for screening opportunities, especially among pregnant women and newborns across the state using the public health centers and public health nursing programs as a vehicle for change.
- Destigmatize FASD care and prevention by aligning the services with regular care provided through healthcare services. Routinization of care and prevention services will increase the uptake of services by removing barriers by using a population-based approach.
- Assess healthcare utilization data from hospitals or from Medicaid claims data to identify geographic areas for points of interventions through telemedicine or part time clinics to increase care access and reduce system costs and burden.

- Explore options for telehealth and telemedicine systems, including remote technology setup. This could address FASD and other health problems simultaneously.
- Service recommendations for individuals and families include post-diagnosis care coordination and case management services, educational assessment and intervention, caregiver support and respite services, community-based recreational programs, child counseling and psychiatric services, occupational and speech language therapy, and substance misuse prevention.
- Using existing Federal healthcare data, combined with State of Alaska data on healthcare utilization, map the location of all healthcare services statewide and compare to the mapped service utilization. This enables the determination of care access issues based on services accessed, distance traveled, provider to population ratio, and coverage needs among other key health access concerns.
- Implement a pilot program to measure the efficacy and outcomes of the alcohol brief screening and intervention tool at primary care and women's health centers.
- Implement a pilot program to measure the efficacy and outcomes of the CHOICES intervention at primary care centers and women's health centers.

Overview and Summary of Social Systems and Programs

In Alaska, there are many systems which a person impacted by FASD could interact within their life, while systems specific to serving persons with FASD is limited. The presented information includes systems which are most likely to impact persons with FASD based on information in scientific and public health literature. The purpose of this component is to outline the systems and identify major barriers, obstacles, and challenges. As with any system of care, there is no means by which an entirely exhaustive report can detail every challenge faced. Systems should be designed on the principle that every effort be made to allow efficient access to all persons who need those services.

To highlight an insider perspective, we include data collected from key informants. These informants are persons who work within the various systems and provided feedback on the gaps, strengths, and areas for potential enhancement of the systems. Given that persons who work within systems may know of methods to engage the system more successfully by persons using the system, the key informant inclusion appears to be a unique aspect compared to other published materials.

Disability Support Systems

In Alaska, the Intellectual and Developmental Disabilities (IDD) Unit provides support and oversees providers in the support systems for persons with disabilities. [12] Through the Senior and Disability Services through the Department of Health and Social Services, the IDD oversees:

- Developmental Disabilities (DD) eligibility program
- DD Registry (also known as the “Waitlist”)
- Individualized Supports Waiver (ISW)
- Intellectual and Developmental Disabilities (IDD) Waiver

To be eligible for services, a person must be determined through the Developmental Disability Determination Application to experience a developmental disability (DD) as defined by Alaska state law (AS 47.80.900(6)), where a person with a developmental disability is someone experiencing a severe, chronic disability that:

- is attributable to a mental or physical impairment or a combination
- is manifested prior to age 22
- is expected to be of an ongoing and indefinite period
- limits substantial functional in at least three of the following areas of life activity:
 - i. self-care
 - ii. learning
 - iii. mobility
 - iv. expressive and receptive language
 - v. self-direction
 - vi. capacity for independent living
 - vii. economic self-sufficiency

Once applied and approved, an applicant would be considered for either the ISW program, IDD waiver, or both. The ISW program focuses primarily on in home supports and has an annual cost cap. The following table compares these programs, both of which are likely to be accessed by persons with FASD and their family.

Table 1. Service eligibility in ISW Program, IDD Waiver, or Both

Service	IDD Waiver	ISW
Care Coordination*	X	X
Residential Habilitation (4 services)		
• Family Habilitation	X	
• Group Home	X	

• In-Home Supports < 18	X	X (limited)
• Supported Living >18	X	X (limited)
Day Habilitation	X	X
Respite	X	X
Supported Employment	X	X
Chore	X	X
Environmental Modifications	X	
Intensive Active Treatment (IAT)**	X	X
Meals	X	
Nursing Oversight and Care Management	X	
Specialized Medical Equipment	X	
Specialized Private Duty Nursing	X	
Transportation	X	X

Opportunities for Disability Support Systems

- The disability support systems seem to be under-resourced in terms of personnel and information technology systems which could expand access to services.

Recommendations

- Conduct a review and assessment of the successful engagement of this system by its constituency, including persons with an FASD and/or their caregivers and advocates.
- Post assessment, identify and implement cost and time savings actions which would increase the uptake and access of services by the persons in need of disability supports.

Foster Care

People of Color (POC) including Alaska Native persons and persons with lower income are disproportionately overrepresented in the child welfare system. Increased disparities in foster and adoptive placements lead to long-term family and community disconnect and increased likelihood of interactions with corrections and emergency service systems.

In Alaska, the foster care system may be the first non-medical system encountered by many persons with an FASD and persons without an-FASD alike. On average, there are

3,000 children in foster care each month in the state. (Alaska Office of Children's Services Statistical Information, 2020) For the month of October 2020, 3,142 children were in an 'Out of Home Care' placement through the Office of Children's Services (OCS). Of these, 2,047 were Alaska Native, representing 65.15% of the children in care, while Alaska Native persons represent approximately 19% of the total population in the State of Alaska. Also, during October, 88 children were removed from their home (64.77% Alaska Native) and 61 children were discharged from Out-of-Home Care of which 67.21% were Alaska Native.

For children and adolescents with an FASD, the likelihood of a successful, long term placement is reduced compared to a child without FASD and is more closely associated with children with behavioral disorders. (Paintner et al., 2012) Increased instability may result from displayed behavioral issues combined with the FASD associated stigma. If caregivers are not educated and trained for the special needs of a child with FASD, this can increase the probability of justice system and correctional systems engagement.

Opportunities for Foster Care

- There does not appear to be a reunification support program for children with an FASD to return to their caregivers as appropriate.
- No transitional skills programs have been identified for children and adolescents in foster care in Alaska with an FASD or a similar condition to assist in developing the necessary skills.

Recommendations

- Provide training to caregivers of children and adolescents with an FASD to reduce the engagement of the foster care system and to increase their knowledge of resources and systems of care which will benefit them in developing advocacy skills.
- Create a transitional program for adolescents and young adults with an FASD or similar health concern to increase the probability of their successful, independent living once they leave the foster care system.

Accommodated Education

Section 504 of the Rehabilitation Act of 1973 provides protection and equality of access for persons with disabilities in education and other programs, including persons with learning disabilities and FASD. Section 504 prohibits disability discrimination by any "program or activity" receiving federal funding. For educational institutions, this means any school, program, or institution that receives any type of federal funding must adhere to the protections of 504 and ensure that a person with a disability has access to an educational program equal to that of persons without disabilities. Under 504, a person

may be entitled to reasonable accommodation to access the including extra-curricular activities and school housing. ("Section 504, Rehabilitation Act of 1973," 1973)

Early intervention services (EIS) are federally governed by the Individuals with Disabilities Education Act (IDEA). A federal law passed in 1986, IDEA requires states to ensure that young children who may have disabilities or developmental delays receive an evaluation to identify the potential need for early intervention services. In Alaska, EI/ILP is administered by the Department of Health and Social Services (DHSS), Office of Children's Services, Early Intervention / Infant Learning Program. (Alaska Department of Health and Social Services, Senior and Disability Services, 2019) The IDEA requires states to develop and implement early intervention programs for infants and toddlers from birth to three years of age with disabilities or delayed development. Services for young children with developmental delays can often reduce the need for later special need services. EI/ILP encourages early identification and prompt referral of any infant or toddler with developmental delays in one or more areas of physical, cognitive, social/emotional, or adaptive development.

Certain diagnosed conditions pre-qualify children because of the high probability of developmental delays. Among the conditions which have a high probability of 50% developmental delays include syndromes and conditions associated with severe delays in development such as Fetal Alcohol Syndrome (FAS). Alaska's EI/IL program provides specialized services for children who have developmental delays and/or disabilities. It is a statewide system of professionals dedicated to serving all Alaskan families with children who are at risk for or experience developmental delay. The services are for children birth to three years of age. The mission is to build upon natural supports and provide resources that assist family members and caregivers to enhance children's learning and development through everyday learning opportunities.

EIS are designed to enroll qualifying children within 45 days from the day the agency is contacted. The statewide goal is to enroll 100% of all qualified children within 45 days from the initial referral. Alaska defines Part C eligible children as those children who experience a significant developmental delay (at or greater than 50% in one or more developmental domains: cognitive, physical, communication, social/emotional, or adaptive) or those children who have an identified condition that would result in a significant delay.

The Alaska EI/ILP partners with grantees around the state to provide services directly to families at a local level. EI/ILP grantees include school districts, mental health providers, Alaskan Native corporations, parent associations, and other nonprofit organizations. Programs vary widely by staff and region size. Service may include:

- developmental screening and evaluation
- individualized family service plans to outline goals for the family and child
- child development information
- home visits
- physical, occupational or speech therapy
- specialized equipment
- referrals to other needed services

Alaska's EI/ILP Program has 25 provider service areas with 18 agency providers statewide. Once referred to the program, the child receives an assessment by a multi-disciplinary team which may include a physical therapist, speech therapist, occupational therapist, and/or developmental therapist. An Individualized Family Service Plan (IFSP) is developed for eligible children. While no child is turned away due to inability to pay, Medicaid or private insurance may be billed for services.

Individualized Education Program

Alaska statute mandates the use of an individualized education program (IEP) in accordance with Federal requirements specifically for students receiving special education. ("Definition of individualized education program," 2007; "Individualized education program; transition services.," 2019) According to the Alaska Department of Education and Early Development, an individualized education program (IEP) details the educational plan for a student who receives special education services. All special education students in Alaska are required to have a current IEP.

The US Department of Education provides a more in-depth definition through the Federal Regulations which is adopted by multiple states. This definition includes that an IEP must make or provide the following:

- (1) A statement of the child's present levels of academic achievement and functional performance, including -
 - (i) How the child's disability affects the child's involvement and progress in the general education curriculum (i.e., the same curriculum as for nondisabled children); or
 - (ii) For preschool [children](#), as appropriate, how the disability affects the child's participation in appropriate activities;
- (2)
 - (i) A statement of measurable annual goals, including academic and functional goals designed to -

- (A) Meet the child's needs that result from the child's disability to enable the child to be involved in and make progress in the general education curriculum; and
 - (B) Meet each of the child's other educational needs that result from the child's disability;
- (ii) For [children](#) with disabilities who take alternate assessments aligned to alternate academic achievement standards, a description of benchmarks or short-term objectives;
- (3) A description of -
 - (i) How the child's progress toward meeting the annual goals described in paragraph (2) of this section will be measured; and
 - (ii) When periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report cards) will be provided;
- (4) A statement of the [special education](#) and [related services](#) and [supplementary aids and services](#), based on peer-reviewed research to the extent practicable, to be provided to the child, or on behalf of the child, and a statement of the program modifications or supports for school personnel that will be provided to enable the child -
 - (i) To advance appropriately toward attaining the annual goals;
 - (ii) To be involved in and make progress in the general education curriculum in accordance with [paragraph \(a\)\(1\)](#) of this section, and to participate in extracurricular and other nonacademic activities; and
 - (iii) To be educated and participate with other [children](#) with disabilities and nondisabled [children](#) in the activities described in this section;
- (5) An explanation of the extent, if any, to which the child will not participate with nondisabled [children](#) in the regular class and in the activities described in [paragraph \(a\)\(4\)](#) of this section;
- (6)
 - (i) A statement of any individual appropriate accommodations that are necessary to measure the academic achievement and functional performance of the child on [State](#) and districtwide assessments consistent with section 612(a)(16) of the [Act](#); and
 - (ii) If the IEP Team determines that the child must take an alternate assessment instead of a particular regular [State](#) or districtwide assessment of student achievement, a statement of why -
 - (A) The child cannot participate in the regular assessment; and
 - (B) The particular alternate assessment selected is appropriate for the child; and
 - (7) The projected date for the beginning of the services and modifications described in [paragraph \(a\)\(4\)](#) of this section, and the anticipated frequency, location, and duration of those services and modifications.
- (b) **Transition services.** Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must [include](#) -

(1) Appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills; and

(2) The [transition services](#) (including courses of study) needed to assist the child in reaching those goals.

(c) *Transfer of rights at age of majority.* Beginning not later than one year before the child reaches the age of majority under [State](#) law, the IEP must [include](#) a statement that the child has been informed of the child's rights under Part B of the [Act](#), if any, that will transfer to the child on reaching the age of majority under [§ 300.520](#).

To assist parents and educators in understanding the implementation, use, and transition of IEPs, the State of Alaska and many other organizations provide opportunities to learn about IEPs and their use.

Opportunities for Accommodated Education

- The lack of diagnostic teams and the extensive diagnostic process used in Alaska may present barriers to students who would be eligible for services to access services if services are contingent on an FASD diagnosis.
- Documenting the number of students who have an FASD and who receive these services, as well as the number of students who do not receive these services would provide insight into the engagement of students with an FASD.

Recommendations

- Identify and implement a targeted screening tool based on behavioral concerns through which a student could more readily access services as needed.
- Identify opportunities for augmented education and support for students, teachers, and caregivers to increase the probability of successful educational engagement.

Mainstream Education

Children and adolescents with an FASD may function at a high enough level to not meet the eligibility guidelines for special education services but may have other limitations which impede their ability to be successful in a mainstream educational setting. Despite not qualifying for special education, research indicates that children with an FASD process information differently than their non-disabled peers and peers with other disabling conditions. (Millar et al., 2017) School districts in the US attempt to address this issue in high schools by leveling courses, so that the same class will present content at a different speed and through different processes with the intent that students with different learning styles are grouped together. This may not benefit student learning

environment when the determination of students in these levels are based on performance, not on learning needs. Increasing the knowledge of educators on the impact of prenatal alcohol exposure is important. The Alaska Department of Education and Early Development has online trainings available. One of these trainings focuses on disabilities associated with prenatal alcohol and drug exposure. (Prenatal Alcohol and Drug Related Disabilities, 2021)

The National Organization on Fetal Alcohol Syndrome (NOFAS) partnered with the CDC to develop a curriculum focused on K-12 education targeting educators with an implementation action toolkit among other resources. (Fetal Alcohol Spectrum Disorders: Information for Educators, 2021) These tools are available free of charge and available to download from the CDC's website. Components include education on FASDs for educators, strategies for engaging and educating students with FASDs, and a training curriculum for educators and parents. As a comprehensive resource, the information available here could be used by schools or school districts to increase the competence and successful engagement of students.

Other site resources include a toolkit for reducing FASD associated stigma for healthcare providers and a separate module for addressing substance use disorder during pregnancy. There is an awareness curriculum geared toward Tribal justice center personnel which helps train personnel in working with persons who have an FASD and are justice system involved. Information is available on developmental milestones by which children aged three months to five years of age may be assessed to determine any delays. There is also a Science Ambassador program which provides information on the development of lesson plans on health concerns including FASDs. Part of this program offers a competitive application for participation in the CDC Science Ambassador Fellowship which is offered for STEM (science, technology, engineering, and math) teachers and educational leaders to learn how to introduce public health sciences into middle- and high-school classrooms. The fellowship includes a 1 week on site summer course at CDC headquarters in Atlanta, Georgia, and a 1-year distance-based professional development opportunity.

Opportunities for Mainstream Education

- Training of educators in mainstream classes to identify students with an FASD who may be functioning at the lower end of the success spectrum and who could benefit from augmented services in the mainstream educational setting.

Recommendations

- Establish, adapt, and promote CDC based FASD training for educators from K – 12 on recognizing FASD and how to appropriately engage a student and connect a student with specialized services as needed.

Higher Education

While we were unable to identify any college or university in the United States with programs specifically dedicated for students with FASD, there are many programs at colleges and universities which are structured to support students with learning and intellectual disabilities as well as behavioral disorders and cognitive impairments.

In addition to programs on college and university campuses for students with additional learning needs, there are a few colleges with emerging programs specifically designed for students needing a specifically tailored curriculum. One example is Beacon College, a private college in Leesburg, Florida, which was founded and evolved a multimodal pedagogy and unique learning-specialist education model. Beacon uses the concept of a social fabric, which meshes the college's global-leaning advocacy and innovation through narrative and personal reflections. The college reports itself to be the first accredited baccalaureate school to educate primarily students with learning disabilities, ADHD, dyslexia, and other learning differences in the United States. (Beacon College, 2020)

In the United States, there are many programs designed and implemented to assist students with disabilities to access higher education. One example are the Federal TRIO Programs, which are located at colleges and universities in each state and include outreach and student services programs designed to identify and provide services for individuals from disadvantaged backgrounds. TRIO includes eight programs targeted to serve and assist low-income individuals, first-generation college students, and individuals with disabilities to progress through the academic pipeline from middle school to postbaccalaureate programs. Given the broad scope of TRIO programs, persons with FASD could qualify for multiple programs based on their individual background, need, and disability. (Federal TRIO Programs, 2019)

The University of Alaska Anchorage and the University of Alaska Fairbanks each currently host two TRIO programs, including Student Support Services (SSS) and Upward Bound (UB). The program with the most relevance to students with an FASD at each campus would be SSS. This program offers services to students with limited income, whose parent(s) or guardian(s) have not earned a baccalaureate degree, and/or who experience a documented disability. SSS supports 160 students annually by

assisting them navigate their undergraduate program to graduation. There is no cost for eligible students accepted into the program.

The specific services provided by UAA's SSS program include:

- Academic Mentoring Support
- Assessment Testing including Accuplacer, Learning Styles and Strengths Quest Inventories
- Assistance with Degree Planning and Academic Mapping
- Bridging Program/Mentoring: Orientation to UAA and the College Experience
- College Survival Skills Instruction (3 Credits): Formal instruction on keys to successful college learning and degree completion
- Community and Campus Cultural Events: SSS Club, Cultural Exposé, Performing Art Culture Exposure, and Welcome Gatherings
- Financial Aid Assistance: financial aid application assistance, scholarship essay and referral assistance, tuition waivers, and Financial Literacy 101 Instruction
- Skill Development Workshops: Financial Literacy and Resume Development
- Tutorial Assistance such as individualized tutoring and referrals to campus tutoring

Opportunities for Higher Education

- Persons with an FASD or their caregivers who are seeking information on higher education opportunities should explore benefits and programs designed for all persons with disabilities or disabling conditions.
- Given the legal mandates from the Federal government, accommodations must be made at all educational organizations which accept Federal funds, thereby increasing the opportunities for persons to successfully obtain higher education, including persons with an FASD.

Recommendations

- Determine the prevalence of FASD among college and university students who are engaged with these programs within Alaska to determine the service connectivity among the FASD community and mainstream services.
- Itinerant or distance education-based teaching models with trained educators could provide services to students from anywhere using internet based technology.
- Increase family understanding of programs available to their adolescents for on campus support.
- Increase access to or expand services for adolescents and youth to improve social skills and to destigmatize FASD.

Vocational Rehabilitation and Employment Services

Vocational rehabilitation services are available to persons receiving Medicaid and persons who have documented disabilities. These services are provided to persons to assist in securing and maintaining employment. For persons who receiving supplemental income or disability income, the vocational rehabilitation system works with the person receiving their services to ensure there is a minimum impact on their income and to mitigate the risk of loss of healthcare coverage.

In the State of Alaska, to qualify for Vocational Rehabilitation services, a person must have:

- Medical records documenting the disability.
- Proof of receipt of social security disability.
- Documentation of work history.
- A completed application for services.
- An interview with a counselor from the vocational rehabilitation services.

Gaps in Vocational Rehabilitation

- There are very few programs focused on supportive employment for persons with an FASD or similar conditions to obtain and maintain employment.

Recommendations

- Link persons with an FASD to mainstream benefits and programs for vocational rehabilitation and supportive employment.
- Expand access to supportive employment programs, including job prospecting, shadowing, and employment mediation.

Legal System & Public Safety

The American Bar Association recognized the impact that FASD played on sentencing and in 2012, passed a resolution calling on attorneys and judges, as well as other members, to obtain education on FASD to better support their clients. In the same year, Alaska became the first state in the country to allow the presence of an FASD diagnosis to be considered in sentencing reduction for felony crimes. (Tibbett & Jeffrey, 2015) There are currently no recorded data on the use of this statute. Given the lack of understanding and knowledge of FASD among judges, attorneys, and others in the legal system, it is estimated this resolution is not used to its fullest advantage. Combine this with the theorized under diagnosed number of cases of an FASD in Alaska, and

there exists an opportunity to provide additional intervention points through which persons with an FASD could be better served in a system through which they are overrepresented.

In our review of published literature, in the last 22 years there were only five publications addressing this issue, all of which were from Canada. (Fast & Conry, 2004; Fast et al., 1999; Gagnier et al., 2011; Mela & Luther, 2013; Popova et al., 2015) Each of these investigations demonstrated how persons with an FASD are disproportionately represented in the legal system, most are likely to be of lower income and education, less likely to have privately or personally funded legal representation and are more likely to get more severe sentencing for similar crimes than persons with a better and higher level of education and a higher income.

In the United States, the National Council of Juvenile and Family Court Judges created an FASD resource for judges. (Fetal Alcohol Spectrum Disorders: Implications for Juvenile and Family Court Judges, 2015)

Opportunities for Legal System & Public Safety

- There is not available data on the use of the FASD statute for sentence reduction in Alaska.
- No programs or opportunities have been identified which provide formal training for judges or other legal system employees to increase their knowledge of this resolution.
- Increase training on conflict resolution and de-escalation techniques for public safety officers could benefit persons with behaviors which may be perceived as agitated, aggressive, or non-compliant behavior.

Recommendations

- Collect data on FASD statute utilization since implementation and estimate the number of “missed opportunities” for this statute to be implemented.
- Create and launch tailored FASD training opportunities for attorneys, judges, and public safety officers combined with similar conditions to appeal to a broader audience and help destigmatize FASD.

Corrections and Re-Entry

In Alaska as in the rest of the United States, persons in the corrections systems, both juvenile and adult, are disproportionately persons of color (POC) and persons with disabling conditions. (Wildeman & Wang, 2017) In addition to overrepresentation among POC, persons with serious and persistent mental illness, substance misuse disorders,

behavioral disorders, traumatic brain injuries, developmental disabilities, and persons who have been in the foster care system are at increased risk for incarceration. Therefore, it stands to reason that persons with FASDs are also overrepresented. The cumulative effect of being a POC and having an FASD further increases the incarceration risk. Some studies have found that up to 90% of incarcerated men have FASD related traits and / or characteristics. (Brintnell et al., 2019)

Interaction with the corrections system is an unfortunate outcome for many persons and more so for persons with developmental disabilities or birth defects. While access to healthcare within the criminal justice system, both jails and prisons, is guaranteed under the Eighth and Fourteenth Amendments of the Constitution of the United States, quality and connection are difficult to assess and more difficult to determine adequacy. (Ahalt et al., 2013; De Groot et al., 2001) For persons with a diagnosed FASD, the justice system is obligated to provide care. However, it is theorized that many persons with FASD are undiagnosed, and while diagnostics are part of the guaranteed healthcare, an FASD diagnosis does not directly lead to a cure nor necessarily an effective treatment plan for the myriad conditions. (Gert Helgesson et al., 2018) This results in the outcome that there may be no means by which to compel the justice system to test and then provide care especially as diagnosing FASD is a highly contentious issue especially among adults as most of the arguments for a diagnosis benefit the family, not the person with FASD.

Opportunities in Corrections

- The Alaska Department of Corrections is mandated to screen for the presence of an FASD which does not appear to be consistently deployed.
- There are no identified educational opportunities for corrections workers to understand and more effectively engage inmates with an FASD.

Recommendations

- The Alaska Department of Corrections might partner with an organization to assist them in identifying a current tool used by other corrections systems to screen incarcerated persons for an FASD and adapt this tool for use in their system.
- Collecting data and determining the role of an FASD on incarcerations in Alaska could prove beneficial as an intervention point for reducing recidivism as well as providing best discharge planning services.

Homeless Service Systems

Like the interaction with corrections and justice systems, persons with FASD are overrepresented among persons who are homeless and/or precariously housed. (Harding et al., 2020) Persons who have a lower income, including persons with disability, are more likely to be housing insecure given the lack of affordable housing in many areas, including Alaska. There are opportunities for housing specifically for persons with disabling conditions. As defined by Housing and Urban Development, a disabling condition is an event which is expected to be of long-term duration and impacts a person's ability to conduct the activities of daily living but can be improved by housing. ("HUD Final Rule," 2015)

One barrier to accessing care is documentation of disabling condition. While there is a significant lack of FASD diagnostic teams in Alaska, if persons were able to be screened as positive for FASD related attributes or characteristics, there would be the opportunity to reduce homelessness through multiple housing options including long term supportive housing options through the US Housing and Urban Development's (HUD) Continuum of Care homeless services systems. ("HUD Final Rule," 2015) If persons with FASD had an advocate to assist them, homelessness could be more easily remedied given the 'mainstream' services available to persons who are homeless and have disabling conditions. Provider awareness of FASD could also be helpful for establishing housing criteria.

Gaps in Homeless Systems

- FASD is currently not widely considered in homeless care systems.

Recommendations

- Provide information on FASD to persons who work in the homeless provider system, but advocacy and education on FASDs could increase housing access through documentation of a 'disabling condition'.

Elder Care Systems

As the US population ages and the numbers of persons in older age increases from large population generations, this will increase the number of persons with an FASD who are becoming elderly. For persons with an FASD and who have limited functioning, their own aging and the aging of their care givers could exacerbate negative outcomes. While there is not a lot of information available specifically for aging persons with FASD, there are opportunities within the mainstream systems for older persons, including

special considerations in healthcare, dietary needs, assistance with activities of daily living, independent living, behavioral challenges, and housing.

The Office of Senior and Disability Services through the Alaska Department of Health and Social Services has Aging and Disability Resource Centers (ADRCs) for older persons with disabilities. The ADRCs connect seniors, people with disabilities, and caregivers with long-term services and supports which are tailored to needs and choice. These services are provided statewide to Alaskans regardless of age or income. As part of a federal effort, these services are to increase community supports for aging persons to increase success in life outside of an institutionalized setting. Not only does this approach increase quality of life and health outcomes for many, but is less costly. Community supports vary but can include transportation, assistive technology, or in-home care. ADRC specialists counsel callers and visitors on long-term supports that fit their circumstances. People specify their needs and the ADRC specialists help people access those services. Services through ADRCs are provided in six regions, including: Anchorage; Fairbanks North Star, Southeast Fairbanks, Yukon-Koyukuk, Denali and North Slope Alaska; Kenai Peninsula, Valdez-Cordova, and Kodiak; the Mat-Su Valley; Southeast Alaska; and Western Alaska, which includes the Aleutian Islands, Lake and Peninsula, Bristol Bay, Dillingham, Bethel, Kusilvak, Nome, and Northwest Arctic.

For persons who are Alaska Native, the Older Americans Act Title VI Programs and Services Title VI (OAA) is a Federal Act which provides primary authority for funding nutrition and family caregiver support services to Native American (Indian, Alaskan, and Hawaiian) elders, who are one of the poorest senior minority populations in the nation.

Opportunities for Elder Care Systems

- Though not scientifically supported, FASD is currently discounted by many persons as not existing in the elderly community – educational opportunities exist for persons who work with the aging community.
- Ensure connection to caregiver training and resources as grandparents may be caregivers to children and adolescents with an FASD.

Recommendations

- Determining the prevalence and impact of an FASD on aging and health outcomes could provide indicators for healthcare interventions at earlier life stages as a point to mitigate disease progression, specifically, dementia.

Systems of Diagnoses and Screening

FASD Diagnostic Model

The current model adopted by the State of Alaska for FASD diagnosis is the FASD 4-Digit Diagnostic Code, developed by the Washington State FAS Diagnostic and Prevention Network in 1997, updated in 1999 and 2004. At the time, this process was the first widely used, evidence based diagnostic test was reported as replicable and stated as valid by the authors. ("Diagnostic Guide for Fetal Alcohol Spectrum Disorders, The 4-Digit Diagnostic Code," 2004) Due to these reasons, this diagnostic process became the gold standard in the United States and remains in use to the present day. This time intensive effort requires an extensive interview and evaluation process using a highly specialized, multidisciplinary treatment team, and has significant associated costs. The recommended participants for this team include a case coordinator, psychologist, speech language pathologist, physical therapist or occupational therapist, physician, and a family navigator.

Since development almost 25 years ago, the healthcare landscape and specifically the payor reimbursement schema has changed significantly. In Alaska, given the intensity of the diagnostic process and the highly specialized nature of the providers, there few teams available for the service, and the dispersed location of the service, accessing a team is challenging. There are currently five diagnostic teams in Alaska, located in Anchorage, Fairbanks, Nome, Soldotna, and Wasilla.

A recent analysis conducted by the McDowell Group found that in 21 years of operation, the network of teams produced 2,933 diagnoses with a peak of 192 in 2015, with an annual average of 135 assessments per year for 2017, 2018, and 2019. (Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations, 2020) While there are not many diagnoses, the denominator of persons who were assessed and not diagnosed is unknown at this time. While this report uses the terms 'assessment' and 'diagnosis' interchangeably, it appears the reported numbers are diagnoses exclusively. The numbers are further diminished as one of these teams discontinued participation in the shared data collection process in 2010, resulting in artificially decreased numbers in the report.

Screening Programs

In public health, as in clinical care, screening programs and diagnostic procedures are used when there is a benefit to the patient or in the case of infectious or environmental

exposures, to a close contact of the patient. (Delatycki, 2012) Because of this, diagnosing FASD is a controversial and contested topic in the healthcare setting and with many countries not acknowledging FASD as a diagnosis nor an umbrella term, it offers no clinical benefits to a patient, whereas diagnosing the individual aspects may lead to treatment and improved health. (G. Helgesson et al., 2018; Swedish Council on Health Technology, 2016) FASD diagnoses seem more important to families and persons with an FASD for peace of mind. Based on this, in part, screening may be a more appropriate avenue for providers and patients alike, but both should be evidence based. (Fields & Chevlen, 2006)

FASD Screening was identified as Priority Area 1 in a three-to-five-year plan in the Governor's Council on Disabilities and Special Education's Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan (2017 – 2022). (Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022, 2018) One recommended outcome from this document is to implement the use of validated screening tools with brief interventions and referrals among preconception and prenatal care providers. The use of screening tools should be tailored to the population being screened and the location of screening as well as provider type. The use of validated instruments should be prioritized for specific populations, such as newborns, children and adolescents potentially affected by FASD, neurobehavioral screening tools for maladaptive behaviors, and corrections settings including both juvenile and adult systems.

Currently, the only consistently applied screening program reported in Alaska which could be used to determine the presence of an FASD is for newborns. The only mandated screening program for adults is within the Department of Corrections. According to a recent report by the McDowell Group for the AK Mental Health Trust Authority, the Alaska Department of Corrections completes a single question screening at intake and contingent upon the response, additional questions may be asked. (Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations, 2020)

Early & Periodic Screening, Diagnostic & Treatment Program (EPSDT)

In Alaska, for children eligible for Medicaid and Denali-KidCare (Alaska Well Child Program) this program focuses on the timely provision of health care for children as needs are identified. This includes physical, mental, social, emotional, and behavioral health needs.

The goal of EPSDT is to provide early healthcare as defined 'Children should receive quality health care beginning at birth and continuing throughout childhood and adolescence including the identification, diagnosis and treatment of medical conditions as early as possible.' This includes minimal expectations based on a timeline as

established by the American Academy of Pediatrics and other best practices. (Delaney et al., 2021)

These early intervention services are recommended to include services of a health history, developmental and behavioral screening and assessment, physical exam, immunizations, lab tests, and screenings for dental, vision, and hearing. Blood lead screening is also indicated at 12 and 24 months. Diagnostics should be conducted for treatment evaluation for health, developmental, and emotional problems during well-child visits.

Gaps in Diagnostic & Screening Programs

- Of the five diagnostic teams in the State of Alaska, the team in Anchorage is operated by the Southcentral Foundation, which is accessible by persons eligible for services to Indian Health Services programs. This means there are four treatment teams available in the state open to all residents.
- There are no universal nor widely available screening programs outside of the Department of Corrections which offers the opportunity for piloting and adaptation of validated instruments for statewide deployment.
- If a validated screening tool could be identified and deployed throughout Alaska, the number of people who would need to access a diagnostic team could be greatly reduced. This would greatly reduce associated costs and lead to a better understanding of the prevalence.

Recommendations

- Institutionalize KABB (Knowledge, attitude, beliefs, and behaviors) surveys to assess provider knowledge about FASD identification. Develop and require trainings to address gaps through continuing education units (CEUs).
- Identify screening tools which would be appropriate and have a high level of specificity so that they could more correctly identify persons without an FASD, which would decrease the number of persons who would need a diagnostic team.
- Identify and implement a risk assessment tool for use in areas where people are engaging in high risk behaviors that increase the potential for prenatal exposure to alcohol or other drugs. Train behavioral health aides and other providers to increase their use. Focusing on high risk behaviors (drinking and drug use) can decrease the stigma of women as the sole contributor to prenatal alcohol and drug exposure and increase the understanding that men contribute to these exposures.
- If a validated screening tool is identified for Alaska, a validation study could be conducted comparing persons diagnosed through the gold standard four-digit diagnostic process with persons assessed by the instrument.

- Implement universal screening where persons are most likely to be available for screening, such as emergency departments, hospital inpatient, outpatient clinics, substance misuse and mental health services, as well as an enhanced screening in corrections.

Potential Funding for FASD Systems of Care, Identification, and Prevention

Funding opportunities are difficult to identify and recommend at this point for a few reasons. As there is no solid understanding of the prevalence of FASDs, the distribution throughout the State of Alaska, and the populations most impacted, a focus on resolving these gaps of knowledge are recommended to prioritize for action and funding.

General funding opportunities available to persons with FASDs and similar health conditions are based on the project initiative and organization deploying the project. Examples of funding include: State of Alaska's 1115 Behavioral Health Medicaid Waiver Demonstration Project; a funding reserve from an alcohol tax; Centers for Medicaid and Medicare Services programs to reduce expenses for persons with an FASD by focusing on preventative treatment and prevention; Patient Centered Outcomes Research Institute; and the Agency for Healthcare Research and Quality.

A diagnostic impression or screening tool could greatly reduce the cost of FASD diagnosing, which would expand the scope of eligible services as well as provide a more precise understanding of the prevalence and occurrence of FASD in Alaska.

Summary of Targeted Interviews

Drawing upon the knowledge of experts across multiple systems of care, the project team engaged with key FASD stakeholders to identify systems-level gaps and inform the recommendations in this report. A total of 28 interviews were completed with stakeholders from the following sectors: early intervention, child welfare, foster care, education (K-12), intellectual/developmental disability, mental/behavioral health, higher education, vocational rehabilitation, corrections, homeless services, public safety, eldercare, and direct healthcare/clinical services.

In addition, one focus group was conducted (n = 5) consisting of caregivers from both rural and urban communities statewide and an adult with FASD. Participants had opportunities to reflect on lived experiences accessing FASD systems in their communities and offer feedback on barriers and areas in need of improvement.

Summary of Discussions:

Among providers who offer in home, early intervention services, for example, physical therapy, occupational therapy, and speech language therapy, along with program administrators, several major issues were consistently noted during the exchanges.

First, families may interact with providers that may not fully understand the implications of FASD for the child and the family. Provider education was identified as a key element. Family and caregiver training, including generational training, can help families advocate for services and navigate service systems.

Second, it was universally noted that it is essential for services to be based on the child's needs. Given the time to reach a diagnosis, it was reported that the family's current needs must be addressed. Meeting the immediate needs should be the highest priority whether the child has a diagnosis, is being evaluated by a FASD Diagnostic Team, has a suspected diagnosis, or has not been referred to a FASD Diagnostic Team. In tandem with addressing present needs, a common issue noted was that due to the length of time from referral to receiving a diagnosis, the family having support to navigate the entire process [diagnosis, needing care, needing assistance, finding resources] is crucial. In addition, families need support while they are on multiple, extensive waiting lists for services. Further, restrictive eligibility guidelines for programs can lead to families not receiving services.

Third, especially in rural areas, it was noted that providing and maintaining consistent levels of services is a challenge. This is multifactorial and may be influenced by staffing, funding, and standardized professional preparation.

Fourth, from a systems perspective, it was described that preparing for transition is an ongoing process. Whether the transition is from the early intervention to the school system to post-secondary education, families can benefit from support in preparing for transition.

Finally, stigma and trust in existing systems were described as overarching issues. Stigma was discussed as an issue with many layers often based on assumptions. As a result, it was noted that families may be hesitant to seek services.

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Fetal Alcohol Spectrum Disorder and the Criminal Justice System

FASD Criminal Justice Resource Guide and Toolkit

Executive Summary Component 2

Fetal Alcohol Spectrum Disorder (FASD) costs the U.S. billions of dollars and causes lifelong neurobehavioral deficits in adaptive behavior, language, attention, reasoning, memory, and other facets of central nervous system functioning, as well as sometimes causing the distinct pattern of facial dysmorphias often called the “FAS face”. With the exception of facial dysmorphism, these deficits are not unique to FASD, which causes difficulty in diagnosis. One attribute common among persons with FASD is increased impulsivity. Impulsivity, in turn, is among the most robust predictors of crime and delinquency.

The effects of FASD also impact a defendant’s ability to understand and comply with complex instructions. In particular, language deficits can manifest as reduced verbal reasoning. When combined with impulsivity and weak memory also associated with FASD, defendants may appear to be willfully noncompliant with criminal justice actors when, in fact, they simply do not understand or recall the instructions.

Across the entire criminal justice system, professionals should receive training and increase awareness of FASD. Access to screening and diagnostics should be improved, so that criminal justice actors can adapt processes in a way that is consistent with each individual defendant’s risks, needs, and responsivity to treatment. Specialized units with exclusively behavioral health caseloads should be considered to supplement broad-based training. While difficult, data sharing frameworks should be developed that allow service providers and criminal justice agencies to provide a continuum of care that enhances the likelihood of positive outcomes.

The key to adaptation of existing practices is recognition that a defendant should be assessed for FASD. After a review of existing diagnostic systems, we recommend that Alaska continue to use the 4-Digit Diagnostic Code. While there are different diagnostic

systems in use — and they do produce different results when tested head-to-head — there is no external standard that can be used to validate FASD diagnostic systems. One key advantage of the 4-Digit Diagnostic Code relative to other diagnostic systems is that it does not require confirmed maternal alcohol use. Particularly when diagnosing adults, confirmation of maternal alcohol use can be difficult.

Diagnostic systems for FASD are expensive due to their requirements for multi-disciplinary teams of medical professionals. Screening tools can be used to ensure efficient use of diagnostic resources, and while they cannot substitute for full diagnostics, screening tools can be implemented in criminal justice settings by professionals and paraprofessionals.

While several brief screening tools have been designed to detect FASD and each generally has an initial validation study, none have robust support in the scientific literature; some brief screening tools have conflicting evidence in the literature. These screening tools are promising, but implementation of any screening tool should include a local validation study to ensure predictive validity. At the individual level, it may be more fruitful to implement enhanced screening and diagnostics for intellectual and developmental disabilities more generally, with FASD as one cause among many.

Prior active case ascertainment research among correctional populations (mostly in Canada) suggests that between 10% and 20% of the correctional population falls somewhere on the FASD spectrum. If that holds for Alaska, we estimate that between 500 and 1,000 offenders in Alaska DOC institutions and an additional 350 to 700 persons under community supervision may have an FASD. We emphasize that this is a coarse estimate based solely on applying prior research findings from elsewhere to Alaska's 2019 population counts. More accurate prevalence estimates require active case ascertainment studies within these populations, the results of which would be useful for directing primary prevention efforts.

Among persons with an FASD diagnosis, prior research suggests that 60% will be justice-involved in their lifetimes. An analysis of limited FASD diagnostic data and Alaska Court System data suggests that 21% of persons with an FASD diagnosis between 2011 and 2021 had an adult criminal case filed against them within a five-year period (2016-2021). Most of these cases involved misdemeanors only, with violation of conditions of release, assaults, and disorder charges being the most common. Among persons with an FAS or pFAS diagnosis, 85% of cases resulted in a guilty disposition on one or more charges.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a group of disorders caused by maternal alcohol use during pregnancy that manifests in a pattern of central nervous system abnormalities, growth deficits, a distinct pattern of facial dysmorphias, impulsivity, memory problems, language problems, inability to empathize with others, and adaptive behavior problems (Bertrand et al., 2004; Clarke & Gibbard, 2003). The most serious form of FASD is Fetal Alcohol Syndrome (FAS); a variety of terms have been used to describe less serious presentations of FASD.

FAS is a relatively new condition. Developmental deficiencies in children stemming from the effects of maternal alcohol use during pregnancy were first detailed in the late 1960s (Lemoine et al., 1968) and the constellation of symptoms we now recognize as FAS were described in the early 1970s (Jones & Smith, 1973). Research progressed quickly, and in 1981, the U.S. Surgeon General advised women to avoid drinking during pregnancy (Armstrong, 1998). Current guidance from the CDC suggests women avoid alcohol consumption entirely during childbearing years when they are sexually active and not using contraception to avoid accidental fetal alcohol exposure (Centers for Disease Control and Prevention, 2018). Alcohol use during pregnancy remains a public health concern. Globally, about 10% of women consume alcohol while pregnant, and roughly 1 in 67 women who did so gave birth to a child with FAS (Popova et al., 2017).

FAS and FASD, beyond the detrimental effects on public health, are also enormously costly to the justice system in particular and society in general. The total cost of FASD in the US in 1998 was estimated to be \$4 billion (Fast & Conry, 2009). In Alaska, The McDowell Group (2020b) estimated that the State of Alaska spends approximately \$1.7 million annually to house offenders who screened positive for FASD on the Alaska Screening Tool.

The State of Alaska has focused on addressing FASD in recent years. The creation of the FASD Partnership in 2010 led to the creation of the Alaska FASD mitigating statute. In 2012 this group released a list of recommendations for the state to improve services for people with FASD (Alaska FASD Partnership, 2012). More recently, the Governor's Council of Disabilities and Special Education FASD Workgroup has created a 2017-2022 five-year plan to address changes across six areas: prevention, screening and diagnosis, early childhood education, system transformation, workforce development, and community outreach (Alaska Governor's Council on Disabilities & Special Education FASD Strategic Plan Workgroup, 2018). Additionally, the FASD Program

housed in the Alaska Department of Health and Social Services Office of Substance Misuse and Addiction Prevention maintains diagnostic sites across the state.

This report describes the intersection of FASD and the criminal justice system. We begin by describing how individuals with an FASD become justice-involved, using SAMSHA's Sequential Intercept Model as a guide to the criminal justice process. To add to this discussion, we conducted key informant interviews with criminal justice professionals to gain Alaska-specific descriptions of the impacts of FASD. Next, we discuss diagnostic and screening tools for FASD with a particular focus on how these tools could be implemented in criminal justice contexts. We then discuss how the differing diagnostic criteria make it difficult to estimate prevalence, again with a focus on prevalence within the criminal justice system. Finally, we provide estimates of justice involvement among FASD-diagnosed persons in Alaska.

FASD, criminal behavior, and the sequential intercept model

The cognitive deficits caused by FASD can impact not only the propensity to offend but also how defendants interact with every aspect of criminal justice processing. Conry and Fast (2000) describe the cognitive deficits caused by FASD using the mnemonic device ALARM: adaptive behavior, language, attention, reasoning, and memory. These aspects are not unique to FASD, but they are common among persons diagnosed with FASD:

A — Adaptive Behavior

- Ineffectiveness in meeting personal and social skill expectations for age and cultural group.
- Poor life skills such as self-care, personal relationships, independence, appropriate judgement in social/work situations.

L — Language

- May appear to possess good verbal skills but with a comprehension level considerably lower than word use.
- There may be speech or language delays and difficulty processing verbal directions.
- May use superficial language expression.

A — Attention

- Attention deficit disorder – inability to concentrate for long periods of time on one topic.

- Highly impulsive with few internal controls.

R — Reasoning

- Inability to link actions with consequences or to respond appropriately.
- Unable to empathize with others or understand how their actions affect others.

M — Memory

- May show weak short-term memory.
- May have trouble with “working memory” (i.e., “spotty”, uneven, inconsistent long-term recall of information).
- Confabulation – recalling details/events that didn’t actually happen. (p. 13)

There are multiple well-tested criminological theory domains that are implicated by these deficits. A recent retrospective chart review conducted at the Asante Center in Canada found that of 161 individuals diagnosed with FASD had high rates of substance use (50%), involvement in child welfare (75%) and criminal justice systems (30%) (Popova et al., 2021). Prior research found that 60% of adults and juveniles with FASD disorder experienced some trouble with the law (Fast & Conry, 2009). Among the cognitive deficits common among persons with FASD, impulsivity may be the most important to the commission of crimes. The link between impulsivity (sometimes called low self-control) and criminal behavior is well-documented (Gottfredson & Hirschi, 1990; Pratt & Cullen, 2006; Vazsonyi et al., 2016). The link between school performance and delinquency (Maguin & Loeber, 1996) is also well-established, and is likely due to impulsivity (Felson & Staff, 2006). Impulsivity also impacts the ability to weigh costs and benefits of actions in the moment (Clarke & Cornish, 2000). High impulsivity is therefore linked not only to criminal propensity but also to the decision to commit a particular crime in a particular place. Additionally, social issues and problems maintaining relationships mean that FASD sufferers are more likely to associate with delinquent peers (Fast & Conry, 2009). Social learning theory suggests that criminal behavior is learned through peer groups and is further reinforced through social means within those peer groups (Agnew, 2001; Akers et al., 1979; Burgess & Akers, 1966; Pratt et al., 2010).

The cognitive deficits associated with FASD can also impact correctional rehabilitation. The risk-needs-responsivity (RNR) model has become the dominant framework for correctional rehabilitation in the US (Muhlhausen, 2016). Correctional rehabilitation following the RNR model involves: 1) identifying an offender’s level of risk of reoffending, 2) tailoring an individualized treatment menu to the offender’s needs, and 3) analyzing the level of responsivity the offender will have to treatment to ensure that it is provided in the method in which it will be most effective (Bonta & Andrews, 2007; Ogloff & Davis, 2006).

The RNR model is flexible and effective (Andrews, 2012; Andrews & Bonta, 2010; Dowden & Andrews, 1999; Hanson et al., 2009; Lipsey, 2009; Serin et al., 2010; Turner & Petersilia, 2012). As a model, RNR has the adaptability and agility to address a variety of offenders and their risks, needs, and responsivity to treatment, including FASD. While some research has shown that offenders with mental illness generally have more risk factors than offenders without mental illness (Peterson et al., 2010), many of these risk factors are the same for both groups. Presentations of FASD vary greatly, and the needs of persons with FASD vary accordingly. Those needs can include a variety of life skills and coping mechanisms to minimize the detrimental impacts of FASD — but again, these needs are not entirely dissimilar from those that are common among correctional populations (Andrews & Bonta, 2010). Responsivity is also implicated by learning, attention, and memory deficits, suggesting that FASD-informed care plans may be necessary to ensure understanding and program compliance.

System-level recommendations to improve criminal justice outcomes for people with FASD

The cognitive deficits associated with FASD also have impacts on criminal justice processing and how actors within the system respond to defendants. We review each step of the criminal justice system and provide details in the sections below, but four recommendations are applicable across the entire system:

Training and awareness for all criminal justice system actors is necessary. Service providers, police officers, correctional officers and jail staff, defense attorneys, prosecutors, judges, probation/parole officers and associated staff should all receive practical training to identify patterns of behavior associated with intellectual and developmental disabilities, including FASD. These trainings should be tailored for specific roles in the criminal justice system and ideally made part of the standard training curriculum for each role.

Our discussions with juvenile and criminal justice professionals repeatedly surfaced the importance of professional and clinical judgement in detecting suspected FASD cases. Despite the lack of a validated screening tool, our key informants each discussed situations where agency staff realized that a person “just wasn’t getting it,” as it was often described. This kind of professional judgement relies on an environment where staff are both appropriately trained and are able to tailor responses to the risk, needs, and responsivity of each individual.

Access to screening and diagnostics for intellectual and developmental disabilities should be improved.

Although brief screening tools for FASD have not received strong support in the scientific literature (see the Fetal Alcohol Spectrum Disorder Diagnosis and Screening section for more detail), there are methods that can be implemented to help criminal justice practitioners identify not only FASDs, but also other disabilities that negatively impact the offender's journey through the SIM. Increased access to individual education plans from defendants' school years, for example, could be helpful in tailoring responses to individual needs. Ultimately, neuropsychological evaluations are likely the best tool to determine the unique needs of the individual, regardless of the cause.

Processes and explanations of those processes should be adapted to ensure defendants can understand them.

The cognitive deficits associated with FASD can impact a defendant's ability to understand and comply with conditions of release and other rules. Processes should be adapted when an FASD is confirmed or suspected, with shorter instructions, more written instructions, and more frequent meetings. These changes are likely to benefit other defendants as well.

Specialized units, including units with exclusively behavioral health caseloads, should be considered and their use expanded in addition to broad-based training for all criminal justice system actors.

Mobile crisis units trained to provide a non-law enforcement response to behavioral health crises are a key component of Crisis Now, and mobile crisis units show promise in improving outcomes for persons experiencing a mental health crisis. In law enforcement, crisis intervention teams (CIT) receive specialized training to handle incidents involving mental health crises. Mental health court staff receive specialized training as well, and many probation/parole offices throughout the US have teams with reduced caseloads who serve clients with mental health concerns. These specialized units should be expanded, and lessons learned from these units should be communicated throughout the system.

Data sharing frameworks should be developed.

Sharing data efficiently is a difficult technical challenge in any context. The problem is compounded in this context by privacy concerns. Individually identified criminal justice information and protected health information are both heavily regulated, and data sharing in some circumstances requires a release of information from the individual. Some defendants may not know that certain data exists, and therefore may not seek its

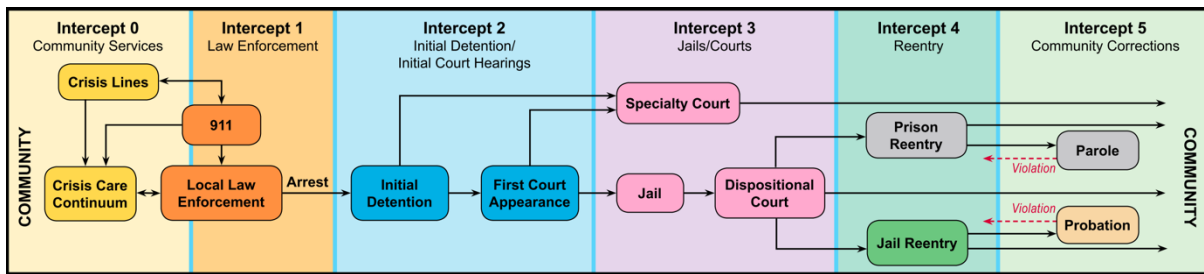
release. Other defendants may not want to share data among service providers for a variety of reasons, including the stigma attached to FASD. There are few easy solutions to the problem of data sharing; technical and regulatory hurdles vary by agency. Service providers should be proactive when seeking releases of information from clients, and methods for securely sharing data between service providers should be developed.

The Sequential Intercept Model and FASD

We used the Sequential Intercept Model (SIM) as a framework to describe the stages of the criminal justice system. We provide a brief overview of each intercept, then describe how FASD could impact decisions made by both offenders and criminal justice actors. As shown in Figure 4, progress through the intercepts is generally — but not always — sequential. We discuss each intercept as a separate stage for ease of presentation, but there can be overlap between them for any given defendant. For example, a person on probation may be arrested for technical violations and be remanded to a correctional institution.

For a more thorough description of SIM as it generally applies to persons in mental health crisis, see Substance Abuse and Mental Health Services Administration (2019) and Griffen et al. (2015).

Figure 4: The Sequential Intercept Model



a. Figure adapted from Substance Abuse and Mental Health Services Administration (2019).

Intercept 0: Community Services

Intercept 0 includes community services that encompass a range of services prior to criminal justice system involvement. A detailed review of these services is outside of the scope of this report; we offer this brief discussion due to the importance of community services in avoiding the criminal justice system entirely. Common elements in this

system are 23-hour crisis stabilization/observation beds, short-term crisis residential stabilization services, mobile crisis services, peer crisis services, 24/7 hot and warm lines, and emergency departments (Substance Abuse and Mental Health Services Administration, 2014). We also include education and other community services at this intercept.

Early intervention improves the odds of avoiding lifetime adverse effects for persons with an FASD diagnosis by a factor of two to four (Streissguth et al., 2004), and many of the treatments for a child with FASD are delivered in the school system (Chasnoff et al., 2015). Deficits of adaptive functioning (such as improper socialization and poor life skills), language comprehension, and attention will likely show themselves during school years. When the need for additional care is identified, the child with FASD should receive an individualized education plan (IEP). Deficiencies in adaptive functioning can be aided by an IEP, since the lacking skills involve improving social skills, understanding what is expected in social environments, and skills needed for personal independence. At their best, an IEP combined with skilled educators will gather together a multidisciplinary team consisting of not only educators but also physicians, psychologists, speech language pathologists, occupational therapists, social workers, physical therapists, school guidance counselors, and family/caregivers (Millar et al., 2017).

There is evidence that FASD is underdiagnosed among children. A study of children in a foster care environment found alarmingly high rates of missed FASD diagnosis. Out of 156 children who met criteria for a FASD diagnosis 80.1% (n=125) had not been previously diagnosed with FASD; the most common prior diagnosis was Attention Deficit Hyperactivity Disorder (ADHD) Chasnoff et al. (2015).

Adults with FASD may struggle to seek, receive, and maintain community-based services. Non-compliance with program instructions or rules is likely to occur due to deficiencies in adaptive function, attention, and language comprehension. Over time, fewer and fewer resources may be available when non-compliance results in disqualification from the program or service. The same deficits may also wear out family and/or other community support. Lacking resources, the person with an FASD may become more likely to enter a state of crisis.

Recommendations at Intercept 0

School systems should have robust systems for identifying intellectual and developmental disabilities, including FASD. The development and use of IEPs provides greater potential for direct support in the child's development of coping strategies that will pay lifelong dividends. Individual education plans can also assist indirectly, by giving

other support services and criminal justice actors needed indicators regarding the person's history. Criminal justice professionals at each intercept discussed the importance of IEPs in our key informant interviews. IEPs were repeatedly discussed as a means for identifying possible mental and behavioral issues. Even when the details are years old, the presence of an IEP can serve as an indicator for criminal justice actors to further investigate mental health issues.

Service providers should receive training that can enable identification of patterns of behavior that are likely caused by FASD. Program non-compliance may be due to language, reasoning, or attention deficits that are not under the control of program participants with FASD. This non-compliance may appear to be willful and lead to disqualification or other service refusals when providers are untrained. The need for service provider training was reinforced during our interviews with practitioners across the SIM. A likely trajectory for the FASD afflicted individual is that they will cycle through available service provider and fail to comply with treatment protocols at each. That failure can be used to deny admission at a later date, creating barriers to diversion and treatment.

Intercept 1: Law Enforcement

Intercept 1 includes law enforcement officers, who act as the “gatekeepers” to the rest of the criminal justice system (Reuland & Yasuhara, 2015). Patrol officers are often the first criminal justice actors to come into contact with a person with FASD. Over the past two decades, police departments have recognized the need for specialized responses to mental illness. Nearly all departments surveyed by Fiske et al. (2020) utilized a specialized police response for mentally ill suspects, typically trained in Crisis Intervention Team (CIT) procedures. The extent to which police departments receive FASD-specific training nationwide is unknown. Anchorage Police Department recruits receive two days of training designed to help officers detect and appropriately respond to persons with disabilities, including intellectual and developmental disabilities. This training includes both classroom and scenario-based elements, but has no FASD-specific content (Capt. Sean Case, personal communication 5/1/2021).

The cognitive deficits associated with FASD such as impulsivity and difficulties interpreting language make people more likely to not only commit crimes, but also to respond to police officers in ways that will be interpreted as willful non-compliance. Willful non-compliance has traditionally been met with force — sometimes called street justice — because officers perceived that a person could have acted differently but simply disobeyed the officer (Van Maanen, 1978). While empirical studies of policing using 1970's and 1990's data found that officers were not more likely to arrest mentally disordered suspects (Engel & Silver, 2001), the subtle nature of FASD's effects almost

certainly would not have been measured as mental disorder in the few large-scale studies of police behavior that have examined related questions¹.

Recommendations at Intercept 1

The use of mobile crisis units should be explored more fully. Recent work suggests that models that allow police officers and the community to involve mobile crisis units specially trained in mental illness can reduce the likelihood of adverse outcomes (Lord & Bjerregaard, 2014). This is part of the Crisis Now model currently in the planning phase in Alaska (Alaska Mental Health Trust Authority, 2021), along with expanded crisis lines and expanded capacity for short-term involuntary commitment. In the language of SIM, implementation of the Crisis Now model will likely strengthen the link between Intercept 0 and Intercept 1 services.

Police officer training should include training to enable the identification of patterns of speech and behavior that are common among persons diagnosed with FASD. While there is not robust research on this topic, there is some evidence that police officers agree and would welcome additional training in FASD identification and strategies for improving outcomes for persons with FASD (Stewart & Glowatski, 2014). Additional specialized training is available for mental health in policing. Common models of this are the Crisis Intervention Team (CIT) model and the specialized policing responses (SPR) model (Dempsey et al., 2020; Reuland & Yasuhara, 2015). Both models promote the use of special teams of officers or civilian personnel, creating connections to community resources for those suffering from mental illness, and diversion of such suspects out of the formal criminal justice process when appropriate. Line officers could be trained to identify the deficits using the ALARM mnemonic, and specialized policing teams or mobile crisis units could be called in to respond further as appropriate. According to our conversations with CIT officers in the Anchorage Police Department and Alaska State Troopers, there is likely support among officers for both more basic training for all officers and having more specialized responders who can focus on mental health and disabilities.

Intercept 2: Initial Detention/Initial Court Hearings

Intercept 2 begins after an individual has been arrested. It typically occurs at a police station in a holding cell, at a court lock-up, or at a local jail. At this intercept the individual is waiting for an initial hearing presided over by a judge or magistrate. Many different stakeholders can be involved at this stage including mental health

¹ Engel & Silver (2001) measured whether citizens were unable to “perceive situations as a reasonable person would or to control their emotions and actions” (p. 234). They explicitly excluded from their measure two persons who were “mentally retarded but had been incorrectly coded as mentally disordered” (p. 235) which suggests that persons with cognitive deficits who were not in an immediately obvious crisis would not have been included in “mentally disordered.”

professionals, public defenders, private defense attorneys, magistrates and judges, jail-based case managers, jail liaisons to the court, and other jail mental health staff. While individuals wait for court proceedings to occur, the key elements of Intercept 2 may take place: 1) screening for mental or substance use disorders, 2) data linkage, and 3) pretrial diversion can be presented (Abreu et al., 2017).

Language deficiencies can impede the ability of the defendant to understand questions about their mental health history. The presence of an IEP during school years can be a valuable piece of information for jail diversion programs among adults, since it provides evidence of a chronic condition. Prior diagnoses from medical professionals are also useful. Information sharing is a key element, but the defendant has to choose to disclose their prior history in most cases. Privacy considerations for both education and health records generally prohibit automatic information sharing. But where prior records are available, our interviews with key informants suggested they are helpful.

Whether self-disclosed or through prior diagnoses or an IEP, not all defendants with a prior diagnosis will want to disclose the diagnosis to criminal justice professionals due to social stigma associated with FASD. This is likely due in part to the impact of negative stereotypes that persons with FASD are unable to do certain tasks and have negative life trajectories (Aspler et al., 2021)². The benefit of access to mental health history was brought up among our interviews with public defenders and other legal actors at Intercept 2, but is usually gated by the defendant choosing to disclose their history.

Deficiencies in language comprehension and memory can also cause challenges while in a courtroom setting. Courtroom hearings are difficult to comprehend generally (Broner et al., 2002-2003), and since a person with FASD may struggle to comprehend language more than the general population, the problem is compounded. The issues go beyond mere confusion. Persons with intellectual disabilities have been found to be more likely to recall incorrectly based on leading questions (Milne et al., 2002). Furthermore, deficiencies in memory can cause a person with FASD to struggle to give accurate accounts of events and participate in their own defense. Their language patterns and word choice may come across as intentionally deceitful when the defendant is merely mistaken or confused.

Pretrial release often involves some degree of court/jail supervision and specific conditions of release. Noncompliance with these conditions typically results in detention until trial. The effects of FASD may cause people to not understand these conditions

² Aspler et al, 2021 interviewed 19 adults with FASD, 20 caregivers, and 23 relevant healthcare and allied professionals (i.e., physicians, nurses, social workers, psychologists) to derive themes of stereotypes associated with having a FASD, and how those stereotypes impacted outcomes.

when they are explained. Increased impulsivity can also cause persons with FASD to be noncompliant, which can result in remand to a jail pending the resolution of the case.

Individuals with FASD will likely have difficulties in detainment. Jails often lack resources that a person with FASD would need. An arrestee who has undiagnosed FASD will also not have the resources to help them while housed with the general inmate population. Jail is a stressful and disorienting environment, and deficits in adaptive functioning make the FASD afflicted individual susceptible to victimization, and/or self-harm while detained. In addition to the issues of the jail environment itself, individuals with FASD who were receiving treatment prior to arrest will have their provision of services interrupted by the detention (Broner et al., 2002-2003; Clark, 2004; National GAINS Center, 2007).

Recommendations at Intercept 2

Improve and institutionalize FASD awareness and training among criminal justice actors. In particular, deficiencies in language make it more likely that individuals with FASD will not understand directions, although they will respond with affirmations that they do (Deere et al., 2018). Subsequent noncompliance therefore appears willful.

Improve and institutionalize intellectual and developmental disability screening, including FASD, at DOC and among the criminal defense bar. Screening and evaluation is the most essential step in post-booking diversion programs (Lattimore et al., 2003; National GAINS Center, 2007). Screening may use treatment histories, direct observation, nonclinical interviews, self/family referrals, or the use of standardized instruments/surveys. Screening could occur either in a court or jail setting or in both (Lattimore et al., 2003). After initial screening, an evaluation by mental health professionals should take place for eligible individuals. After diagnosis, a variety of options such as diversion, plea bargaining, reduced charges, or reduced pretrial detention could be appropriate, depending on the alleged crime and extent of the defendant's disability (Steadman et al., 1994). Alaska DOC currently employs the SAMHSA Brief Jail Mental Health Screen during intake (see Appendix IV: Brief Jail Mental Health Screen).

Adapt explanations of court processes and conditions of pretrial release to compensate for reduced language skills. In addition to changing outcomes for defendants, diagnosis or suspicion of FASD should cause the Court, defense bar, and pretrial supervision staff to adapt their processes and how they are explained. This has been done in Alaska courtrooms before, but on an ad-hoc basis (Jeffery, 2010). Jeffery (2010) describes adaptations he made in his Utqiagvik (then Barrow) courtroom in an attempt to make the process more understandable. We discuss this in more detail below, in Intercept 5,

but providing instructions to defendants in a way that is likely to be understood is important at every stage of the criminal justice process.

Provide a framework for linking data diversion programs, behavioral health providers, schools, and other community resources such as homelessness services. Data linkage and information sharing is challenging, both technically and from a regulatory compliance standpoint, but is worth attempting. Data linkage can improve the likelihood of Intercept 2 diversion for an individual with FASD. For example, Maricopa County (Phoenix), AZ implemented a data linking system where jail admission data was sent to a mental health provider, then it was scanned to find name matches, and a curated list of names were sent back to the jail diversion staff (National GAINS Center, 2007). By connecting services criminal justice practitioners can learn that an individual has received behavioral health services, or even a FASD diagnosis, in the past.

Intercept 3: Jails/Courts

Intercept 3 involves corrections officials at all levels of correctional institutions – municipal/county, state, and federal. At this intercept, the suspect is either awaiting trial or serving a sentence after having been arrested, booked, and has had their initial appearance in court. Officials at this intercept are routinely involved in correctional rehabilitation. Existing frameworks to serve this goal can be utilized and adapted to treat persons with FASD.

The cognitive deficits caused by FASD put individuals detained in courts or jails at risk from both inmates and corrections officials. Much in the same way that high impulsivity, a lack of empathy for others, and an inability to link actions with consequences put persons with FASD at risk of running afoul of the law, they would likely do the same in regards to rules and regulations inside a jail or courtroom. Memory deficits could additionally make these rules difficult for defendants to retain. Trouble understanding legal proceedings would cause them to not comprehend their legal options, such as appeals, the usefulness of being represented by an attorney, and the nuances of plea agreements (Gagnier et al., 2011).

It is crucial for criminal justice actors to understand how the cognitive deficits caused by fetal alcohol exposure impact a defendant's responses in the courtroom and prison because jails and courts have a prominent role to play in the administration of both legal responsibility and potential treatment of offenders with FASD. Furthermore, courts are the last chance for an offender with mental illness to be diverted from the formal legal process before sentencing and conviction (Liu & Redlich, 2015).

The same risks of pretrial detention for persons with an FASD described above in intercept 2 also apply to longer stays in correctional institutions. Additionally, the social deficits persons with FASD often experience can also put persons with FASD at higher risk of embedding with gangs while in jail. Executive function deficits as well as language issues can make it difficult for persons with FASD to take advantage of GED or work programs that might improve their life outcomes after they are released.

Comorbid mental health issues in the incarcerated population make any type of progress inherently difficult – one study showed a prevalence of serious mental illness of 14.5% for males and 31% for females in a sample of Maryland and New York Jails (Steadman et al., 2009). In the Alaska correctional population between 2008 and 2012, 30.4% of inmates were identified as Trust Beneficiaries, with 61.3% of these individuals found to have more than one Axis 1 mental health diagnosis, and 30.8% to have both Axis 1 disorder(s) and Axis II personality disorders (Hornby Zeller Associates, 2014, p. 3).

Recommendations at Intercept 3

Increase use of therapeutic courts with a focus on mental health. Currently, the State of Alaska operates three mental health courts in Anchorage, Juneau, and Palmer. Mental health courts use a rehabilitative lens that focus on mental illness as an underlying causal factor (Castellano & Anderson, 2013) and have generally been found to reduce recidivism (Anestis & Carbonell, 2014; Burns et al., 2013; Herinckx et al., 2005; Hiday et al., 2013; McNiel & Binder, 2007; Sarteschi et al., 2011; Snedker et al., 2017; Steadman et al., 2011). While there is variation in how they are implemented, a national survey found several traits are present in nearly all therapeutic courts: they target a portion of the docket that contains offenders with mental illness, divert defendants from jails and prisons into community-based mental health treatment, monitor for program compliance, and sanction non-compliance as well as provide rewards for compliance (Redlich et al., 2006). The defendant plays a more significant role in this type of court, which fosters an agility and variety of solutions that a traditional court may not be able or willing to provide. A 2017 study of Alaska service providers found mental health courts to be expensive, costing the state \$11,416 per person, but effective in reducing recidivism with savings calculated at \$13,246 per person (Valle, 2017, p. 110).

Ensure that existing screenings in DOC contexts capture intellectual and developmental disabilities, including FASD, that can impact risks, needs, and responsiveness to treatment. We discuss these below, in Intercept 4, and the concepts in institutional settings are similar.

Intercept 4: Reentry

Most inmates will be released from DOC custody. There exists a broad range of programs designed to make this process a positive one for offenders, but these programs have varying rates of success. The propensity of offenders to leave and reenter the criminal justice system has been described as a “revolving door” (Snedker et al., 2017). Offenders with mental illnesses have been shown to exhibit higher rates of recidivism (Baillargeon et al., 2009; Messina et al., 2004). In Alaska, within the first year after release 40.9% of Trust Beneficiaries will recidivate, nearly twice the rate of those who are not Trust Beneficiaries (22.0%) (Hornby Zeller Associates, 2014, p. 33). A tailored approach designed to address the risks, needs, and responsiveness to treatment of offenders a mental illness is required. Any correctional rehabilitation program that accepts patients with any intellectual or developmental disability, including FASD, in a corrections setting must have a number of characteristics to be successful: a long duration, concrete examples of concepts taught, small groups, considerations for anxiety of patients, a focus on one problem at a time, aftercare, short directions, appropriateness of treatment, and an understanding of how to cope with impairments for which there is no treatment (Burd, Fast, et al., 2010).

The Assessment, Planning, Identification, and Coordination (APIC) model currently used by the Alaska Department of Corrections is heavily influenced by the RNR model and is derived from similar principles (Alaska Department of Corrections, 2020b; Osher et al., 2003). The APIC model emphasizes planning and coordinating linkages between probation officials and community organizations to ensure the smoothest transition from corrections to community. This emphasis can improve the RNR approach to individuals with FASD by more explicitly focusing on how community resources can help the individual prior to release.

Recommendations at Intercept 4

Ensure continuity of care as offenders transition from pretrial, adjudication, institutional corrections, community corrections, and out of correctional system care. Interviews with practitioners reiterate this need for a “warm handoff” between juvenile and adult justice systems, and between service providers. A general lack of service providers that are willing and able to work with FASD-affected clients was often cited as a hinderance for both initial care and proper handoff between systems.

Intercept 5: Community Corrections

The final step in the SIM is Intercept 5, community correction services. It includes individuals who are on some form of supervised release, typically probation or parole.

Probation is non-custodial supervision served in lieu of incarceration, whereas parole occurs after an individual has served part of their sentence in a correctional facility. In the framework of the SIM they function similarly: supervising officers work to enable service provision to address the risks and needs of offenders and provide supervision to keep the community safe (Klockars, 1972). Community corrections agencies work to reduce the likelihood that the individual will recidivate and re-enter the criminal justice system by addressing their risks, needs, and responsivity to treatment.

Probation and parole are tenuous states of existence for justice-involved individuals. Technical violations of the conditions of release can mean being remanded to prison or jail. Common technical violations include failure to appear at court at specified times, failure to maintain continued employment, failed drug testing, and failure to adhere to treatment requirements set by the court upon release. Persons with an FASD are more likely to commit technical violations because they struggle to understand and follow rules — but they are also likely to tell the court and probation officers that they understand instructions (Fast & Conry, 2009).

Deficiencies in reasoning, including executive function, are likely to impair an individual with FASD's ability to follow through on probation or parole conditions of release. A deficit in language abilities and adaptive functioning could damage the offender-parole officer (PO) relationship because the PO may interpret affirmative responses from a client with FASD as confirmation that they understand and wish to follow-through on instructions. Persons with FASD, especially when it goes undiagnosed, may also fail out of a number of community reentry and rehabilitation programs for similar patterns of noncompliance, further reducing the possibility of successfully completing a community corrections sentence. Finally, memory deficits may make what seems to be an obvious link between behavior and consequence difficult to understand. For this reason, memory deficits will make it seem like individuals with FASD do not learn from their mistakes, and are not deterred by repeated consequences associated with their criminal actions (Conry & Fast, 2000).

Recommendations at Intercept 5

Develop specialized community corrections programs with smaller caseloads and expanded training. Many states have developed specialized community corrections programs in which officers deal with smaller caseloads and are trained in mental health issues, including FASD, as they pertain to the criminal justice system, the provision of services, and case management (Council of State Governments, 2002; Skeem & Manchak, 2008). These programs have been shown to reduce both technical violations and recidivism (Louden et al., 2010; Skeem et al., 2009).

Provide a framework for adapting processes and explanations to different learning styles. Orders from the court, including conditions of release, should be adapted to ensure that defendants can understand them. This idea is not new to Alaska and has been described by a (now-retired) judge in detail (Jeffery, 2010). Judge Jeffery suggested that paper forms include initials next to each section, and that sections be shortened, and language simplified to aid in comprehension. Case management should also include more frequent meetings to provide additional structure for people diagnosed or suspected of having FASD.

Fetal Alcohol Spectrum Disorder Diagnosis and Screening

The prior section largely assumed that FASD was diagnosed or suspected. While FASD symptomology and the life course of those who suffer from this disorder are well documented (Clarke & Gibbard, 2003; Streissguth et al., 1998), diagnosis of FASD is complex. Most symptoms of FASD are not unique to FASD — the ALARM deficits discussed above are certainly not unique to FASD. There are disagreements regarding the diagnostic criteria for FASD. These disagreements have centered around the similarity of symptoms, the causality of alcohol, and the seeming lack of a simple dose-response curve, as many women who drank heavily during pregnancy did not have offspring with the worst symptoms (Armstrong, 1998).

From the identification of FAS as a distinct diagnostic category of intellectual and developmental disabilities in the early 1970s through the late 1990s, the prevailing method of diagnosing FAS has been called the ‘Gestalt Method’ by some researchers (Astley, 2013; Astley & Clarren, 2000). This method, as the name implies, requires a medical professional to look at the broad, holistic presentation of all symptoms and decide on a diagnosis in a dichotomous fashion (Sokol & Clarren, 1989). While this was a step forward in the sense that FASD could be diagnosed, modern research has shown the need for both objective criteria and diagnosis on a spectrum instead of a binary decision. FASD has a wide range of symptoms, many of which overlap with other disorders such as Aarskog syndrome, Dubowitz syndrome, Cornelia de Lange syndrome, and many others. The presentation of FASD and related deficits and disabilities also varies considerably (Astley & Clarren, 2000).

Several FASD diagnostic systems were developed roughly contemporaneously in the 1990s and early 2000s, revised versions of which remain the most commonly used tools today (Astley & Clarren, 2000; Chudley et al., 2005; Hoyme et al., 2005). The 4-Digit

Diagnostic Code was developed in 1997 and revised in 1999 and 2004 (Astley, 2004). The 4-Digit Diagnostic Code considers the four broad diagnostic subcategories that patients typically display— 1) growth deficiency, 2) facial phenotype (thin upper lip, palpebral fissure length, smooth philtrum), 3) central nervous system dysfunction, and 4) gestational alcohol exposure, and places patients on a spectrum (Astley & Clarren, 2000). Validation of the 4-Digit Diagnostic Code in a 10-year foster care program showed favorable performance to holistic diagnostic methods (Astley, 2013). The 4-Digit Diagnostic code has also enjoyed broad popularity due to its portability and availability of online training (FAS Diagnostic & Prevention Network, n.d.). Alaska's FASD diagnostic teams use the 4-Digit Diagnostic Code.

Other diagnostic criteria exist. While there is considerable overlap in the conceptual domains covered by each diagnostic system, the systems are not identical. Table 2 summarizes selected domains covered by each of these diagnostic systems to show the similarities and differences among the systems, and Appendix I describes each of these other systems in more detail.

One notable advantage of the 4-Digit Diagnostic Code is that it measures maternal alcohol use but does not require confirmed prenatal alcohol exposure. Confirmation of maternal alcohol use is often difficult (Bakhireva et al., 2018; Freeman et al., 2019). Diagnostic systems that require confirmed maternal use can lead to underdiagnosis (Coles et al., 2016; Petryk et al., 2019).

It is not possible to objectively assess the performance of FASD diagnostic systems because no external standard exists. Researchers have compared FASD diagnostic systems against one another, however. In general, these studies have found that the 4-Digit Diagnostic Code tends to produce lower estimates of FAS than other systems but produces estimates of other aspects of FASD such as partial FAS (pFAS) and alcohol-related neurodevelopmental disorder (ARND) similar to other diagnostic tools (Coles et al., 2016; Hemingway et al., 2019).

Table 2. FASD Diagnostic Systems Compared

	<i>3rd Edition 4-Digit Diagnostic Code</i>	<i>Revised Institute of Medicine Guidelines</i>	<i>2016 Canadian Guidelines</i>	<i>DSM-V ND-PAE</i>	<i>Australian Guidelines</i>	<i>German Guidelines</i>	<i>CDC Guidelines</i>
Criteria	(Astley, 2004)	(Hoyme et al., 2016)	(Cook et al., 2016)	American Psychiatric Association (2013)	Bower et al. (2017)	Landgraf et al. (2013)	Bertrand et al. (2004)
Sentinel facial features and/or other physical defects	x	x	x		x	x	x
Cognition/IQ	x	x	x	x	x	x	x
Adaptive behavior	x		x	x	x		
Language/social deficits	x	x	x	x	x	x	x
Memory problems		x	x	x	x	x	x
Visuo-spatial ability		x		x		x	
Neuropsychological/neuroanatomical deficits	x	x	x		x	x	x
Academic deficits	x		x	x	x	x	x
Motor/sensory evaluation	x		x	x	x	x	x
Mental health and other psychiatric conditions	x						
Family history			x				
Executive function & hyperactivity	x	x	x	x	x	x	x
Cognitive development	x	x	x			x	
Growth Deficits	x	x				x	x
Maternal alcohol consumption required	No	Yes	Yes	Yes	Yes	No	Yes

Notes:

1. CDC Guidelines provide recommendations for the diagnosis of FAS, not FASD.
2. All diagnostic systems except the DSM-V ND PAE require multi-disciplinary teams.

Screening for FASD

Given the multi-disciplinary nature of most diagnostic systems, universal FASD diagnostic assessment for all offenders in a criminal justice context is cost prohibitive. As a practical matter, a screening or referral protocol that can be administered at a comparatively low cost would be beneficial (Boland et al., 2002). In the broader public health literature, screening children for FASD prior to diagnosis has been shown to be cost effective, with one study showing a savings per 100 children screened of \$89,895 compared to conducting complete diagnostics for FASD (Berrigan et al., 2019). FASD screening should be carried out early on—ideally, during the intake assessment during booking, although other authors have noted that screening can also aid in offender’s legal defense by raising issues of competency to stand trial, culpability for criminal behavior, and sentence mitigation (Boland et al., 2002; Gagnier et al., 2011).

Screening tools specializing in FASD, experts trained to use them, opportunities to train existing mental health professionals in usage of those tools, and the number of screens done overall are all low in the United States. In a survey of correction systems in each state and four major cities in the US, Burd et al. (2004) found that only one of their respondent correctional systems had any screening program for FAS. Just four programs had access to FAS diagnostic services, and just one offender out of the 3,080,904 offenders covered by respondent correctional systems was reported to have a diagnosis of FAS.

We found four screening tools designed for use in adult or juvenile correctional settings: the Canadian Brief Screen Checklist (BSC), the Fetal Alcohol Behavior Scale (FABS), a forensic FASD screen developed by Brown and colleagues in 2010, and the Asante Center Tool (Brown et al., 2010; Burd et al., 2004; MacPherson et al., 2011; Streissguth et al., 1998). Appendix II describes these tools in more detail and describes other screening tools that could be adapted to a criminal justice context.

No brief FASD screening tool has robust scientific support

Screening tools remain a developing area. Most show promise, and some are in active use in jurisdictions throughout the US and Canada. Yet we found no screening tool with universal support among technical reports and published scientific literature. The four tools listed in Table 3 each had initial validation studies conducted that showed the tools were effective. In general, however, few studies other than this initial validation have been published regarding the tools. With some tools, such as the BSC, follow-up studies found that the original scale required extensive modification to item scaling

(McLachlan, 2017) to be predictive at all, or required substantial changes to screening criteria (McLachlan et al., 2020) to balance sensitivity and specificity.

Table 3. Comparison of Fetal Alcohol Spectrum Disorder Screening Tools Designed for Criminal Justice Contexts

	<i>Brief Screen Checklist (BSC)</i>	<i>Fetal Alcohol Behavior Scale (FABS)</i>	<i>Brown et al., 2010</i>	<i>Asante Center Tool</i>
	MacPherson et al. (2011)	Streissguth et al. (1998)	Brown et al. (2010)	Conry and Asante (2010)
<i>Number of items</i>	48	36	35	11
<i>Maternal Alcohol Use</i>	x		x	x
<i>Behavioral Questions</i>	x	x	x	x
<i>Family History Questions</i>	x		x	x
<i>Past Psychiatric Illness</i>				x
<i>Facial Analysis</i>	x			
<i>Age Group</i>	Adults and juveniles	Adults and juveniles	Adults and juveniles	Juveniles

Due to the overall lack of consistent evidence in support of any screening tool, any screening tool deployed in Alaska criminal justice contexts would likely require a local validation as part of its deployment. Given the mixed results in the extant literature, substantial revision may be required to arrive at a valid tool. Periodic revalidation may require yet further revisions. With each revision, staff training on the new tool would be required.

Part of the difficulty in creating and validating a screening tool is the general lack of agreement on the more complete diagnostic criteria. The set of intellectual and developmental deficits and disabilities associated with FASD are also not unique to FASD. Moreover, in discussions with criminal justice professionals, we were repeatedly reminded that knowing that an FASD is confirmed or suspected is useful information — but that alone is not sufficient to craft accommodations and adaptations of programs and processes that are likely to improve outcomes for persons with FASD. The presentation of FASD varies so widely from one person to the next that more detail is required.

In terms of the treatment of individuals in the criminal justice system, then, a more fruitful approach may be to abandon the goal of a brief FASD-specific screening tool. Instead, enhanced screening for intellectual and developmental disabilities and their related deficits/disabilities more broadly should be conducted, regardless of cause. Such screening can rely on professional judgement, as it is today, augmented with screening tools designed to detect intellectual and developmental disabilities.

Prevalence of Fetal Alcohol Spectrum Disorder

There are not universally-accepted methods for estimating FASD prevalence (May & Gossage, 2001; McDowell Group, 2020a). As discussed elsewhere in this report, diagnostic criteria and preferred terminology both vary. While the diagnostic tools are similar, they are not identical and prevalence estimates are sensitive to the diagnostic criteria used. Contemporary studies of FASD prevalence have strayed from examining FAS as a standalone syndrome, and instead place FAS on a spectrum that includes related disorders. Terminology also varies, with studies discussing one or more of FAS, FASD, partial fetal alcohol syndrome (pFAS), fetal alcohol effects (FAE), alcohol-related birth defects (ARBD), and alcohol-related neurodevelopmental disorder (ARND).

May et al. (2009) determined that less severe cases of FASD are particularly likely to be missed in prevalence estimates for three reasons: first, FASD is less likely to be screened for when there are comorbid neurodevelopmental disorders; second, there is not one standardized battery of tests that clinicians and researchers agree most effectively diagnoses FASD; and third, diagnostic methodology has historically focused on physical growth and development deficiencies which are less likely to be present in less serious cases of FASD. Diagnosing FASD often requires the coordination of a team of investigators, which also complicates estimating prevalence (Clarren & Lutke, 2008; Eriksson, 2007).

The variation in diagnostic criteria, terminology, and study methodology explains some of the variation in prevalence estimates discussed below. A complete review of FASD prevalence literature is outside of the scope of this report; we suggest interested readers see Abel (1995), May and Gossage (2001), and Popova et al. (2017). This report does, however, discuss prevalence among justice-involved individuals. A brief review of prevalence estimates is therefore relevant.

Three methodologies are common among studies of FASD prevalence: clinic-based studies, passive surveillance, and active case ascertainment. Clinic-based studies are typically conducted in hospitals or maternity clinics and are advantageous because hospitals and clinics are good places to collect a sample of pregnant women and their children. Gathering maternal history and personal health habits are typical steps in the pre-natal healthcare process, making data collection less obtrusive. The disadvantage of clinic-based studies, however, is that participants are self-selecting, and the individuals who have the highest risk to produce offspring with FASD are also less likely to visit maternity clinics or agree to participate in clinical research (May & Gossage, 2001). Clinic-based studies have typically found FAS prevalence rates between 0 and 3

cases per 1,000 live births (Abel, 1995; Abel & Sokol, 1987). Prevalence estimates of other diagnoses on the FASD spectrum are rare in the literature; our review found just one study, Sampson et al. (1997), that estimated the combined rate of FAS and ARND to be 9.1 per 1,000 live births. The large difference between this study and other studies illustrates how diagnostic and definitional differences impact prevalence estimates.

Another common method for estimating FASD prevalence is passive surveillance. Passive surveillance involves establishing which diagnostic criteria will be used to define FASD and reviewing available records in order to find births that meet those criteria. Historically, these records have included birth certificates, developmental disability registries, and hospital records. Additionally, several states, Alaska among them, have broad birth-defect tracking systems. Passive surveillance is the easiest and cheapest means of estimating prevalence, as it involves the analysis of existing data. However, the major disadvantages of passive surveillance are that FASD is more difficult to diagnose than some other birth defects (Aase, 1994; Clarren et al., 2001; Little et al., 1990) and that they typically underestimate FASD prevalence compared to other methodologies (Popova et al., 2017). Prevalence estimates from passive surveillance studies have typically found FAS prevalence rates between 0.2 and 2.9 per 1,000 live births (Burd et al., 1996; Centers for Disease Control and Prevention, 1993, 1995, 1997; Chavez et al., 1988; Egeland et al., 1998; Weiss et al., 2004). Passive surveillance studies examining FAS have found prevalence rates approximately 10 times higher among American Indian and Alaska Native populations compared to the general population (Chavez et al., 1988; Egeland et al., 1998).

Active case ascertainment is another method for estimating FASD prevalence. Active case ascertainment involves researchers entering the community under study and actively seeking out children who may have FASD. After establishing screening criteria, researchers typically refer candidates to clinicians for diagnosis. This method benefits from involving community outreach, which improves the likelihood that researchers will uncover individuals who would otherwise be less likely to self-identify. However, it is a time consuming and costly method of study, which also relies on a high level of cooperation not just within the research team, but from many community members as well (May & Gossage, 2001). Active case ascertainment studies have found prevalence rates between 1.4 and 18.4 per 1,000 live births (Clarren et al., 2001; May et al., 1983; Quaid et al., 1993).

FASD Prevalence Among Justice-Involved Persons in the Scientific Literature

There is reason to believe that the prevalence of FASD is higher among justice-involved persons than the general population. Mental health issues are more common among justice-involved persons than the general public. The prevalence of serious mental illness is approximately 5.5% in the US adult population (Hudson, 2009), while 13.8% of male prisoners and 18% of female prisoners suffered from a serious mental illness (Fazel & Seewald, 2012). Using a more expansive definition, Hornby Zeller Associates (2014) found that more than 30% of individuals who entered, exited, or resided in an Alaska DOC facility between July 1st 2008 and June 30th 2012 were beneficiaries of the Alaska Mental Health Trust, and that over 40% of incarcerations per year are likely to be Trust beneficiaries (Hornby Zeller Associates, 2014).

It is simply too costly to attempt FASD diagnostics for all justice-involved persons. The lack of validated brief screening tools suggests that targeting diagnostic resources for the purposes of individual diversion and case management is difficult (at best). At the population level, however, estimating prevalence is key to primary prevention efforts. Active case ascertainment studies are the most accurate way to produce estimates of the prevalence of FASD among justice-involved persons at various stages of the criminal justice process. In the absence of active case ascertainment, however, we can use prior studies to estimate the prevalence of FASD among Alaska correctional populations.

Despite widespread concern about the impact of FASD on justice-involved persons (see SIM discussion for details of how FASD impacts each step of the criminal justice process), we could find no published studies of FASD prevalence among arrestees or court defendants. We are limited to studies of correctional populations, and studies from outside the US.³ Studies of FASD prevalence among justice-involved juveniles have generally used active case ascertainment and were conducted in Canada or Australia. Estimates vary but are typically between 10% and 20% of the juvenile correctional population. Estimates are similar among adult populations, with active case ascertainment studies generally finding that between 10% and 20% of adult correctional populations have a diagnosable FASD. Other studies also suggest that FASD impacts justice-involved youth. For example, in a meta-analysis, Popova et al. (2011) found that youth with FASD were roughly 19 times more likely to be incarcerated than youth without FASD. Table 4 shows the results of these prevalence studies among correctional populations. Overall, studies of correctional populations show higher prevalence than studies of the general population — but as discussed above,

³ Burd et al. (2004) cites Streissguth et al. (1998) as having estimated the prevalence of FAS in the Washington State corrections system. However, we were unable to find such an estimate in this work.

differences in methodology may explain at least some of the differences between correctional populations and the general population, especially when the differences are large. Given the variation in time periods, diagnosis, diagnostic criteria, and specific population under study, it is notable that estimates for both juveniles and adults converge around 10-20%.

We can use this to provide a rough estimate of FASD among correctional populations in Alaska. In 2019, Alaska DOC's adult population included 4,997 persons. Given the prior literature suggesting that approximately 10-20% of correctional populations have FASD, it is reasonable to estimate that between 500 (10%) and 1,000 (20%) offenders in Alaska DOC institutions could be diagnosed with an FASD. An additional 3,460 persons were on probation or parole, adding between 350 (10%) and 700 (20%) persons under DOC supervision who may have had an FASD (Alaska Department of Corrections, 2020a).

This estimate is substantially higher than was recently estimated by McDowell Group. Based on recorded screenings using the Alaska Screening Tool (AST), the McDowell Group reported that 29 individuals living in correctional or detention facilities in Alaska had screened positive for FASD on the AST in 2017 (McDowell Group, 2020b). While the numbers are not directly comparable to the prevalence estimates from Canadian studies due to differences in methodology, it is suggestive that FASD may be underdiagnosed among persons under Alaska DOC supervision.

Table 4. Estimated Prevalence of FASD for studies conducted with correctional populations

Study	Data Collection Period	Correctional Population	Diagnosis ¹	Diagnostic Criteria	Rate per 1k Population
Fast et al. (1999)	1995-1996	Juvenile, 12-18, Inpatient Assessment Unit of Youth Forensic Psychiatric Services, Burnaby, British Columbia, Canada	FAE	Clarren & Smith (1978)	220
Fast et al. (1999)	1995-1996	Juvenile, 12-18, Inpatient Assessment Unit of Youth Forensic Psychiatric Services, Burnaby, British Columbia, Canada	FAS	Sokol & Clarren (1989)	10
Murphy et al. (2005)	2004	Juvenile, three youth custody centers in British Columbia, Canada	FAE or FAS	Unspecified	120
Bower et al. (2018)	2015-2016	Juvenile, 10-18, Banksia Hill Detention Centre	FASD	Australian Guide to the Diagnosis of FASD	360
Rojas and Gretton (2007)	1985-2004	Juvenile, two sites for juvenile sexual offenders in British Columbia, Canada	FAS or FAE	Unspecified	109
MacPherson et al. (2011)	2005-2006	Adult Male, 30 and under, federal inmates from Winnipeg, Manitoba, Canada	FASD	Brief Screening Checklist	100

Study	Data Collection Period	Correctional Population	Diagnosis ¹	Diagnostic Criteria	Rate per 1k Population
MacPherson et al. (2011)	2005-2006	Adult Male, 30 and under, federal inmates from Winnipeg, Manitoba, Canada	Some characteristics of FASD	Brief Screening Checklist	150
Forrester et al. (2015)	2011-2012	Adult Female, 35 and under, one federal institution for women in Canada	FASD	Brief Screening Checklist for Women	170
Forrester et al. (2015)	2011-2012	Adult Female, 35 and under, one federal institution for women in Canada	Some characteristics of FASD	Brief Screening Checklist for Women	220
McLachlan (2017); (McLachlan et al., 2019)	2013-2015	Adult, 18-40, institutional and community corrections in Yukon Territory, Canada	FASD	2005 Canadian Diagnostic Guidelines	175
Brintnell et al. (2019)	2009- unspecified	Adult Male, one provincial correctional site in Canada	Neurobehavioral disorders with PAE	2005 Canadian Diagnostic Guidelines	370
Brintnell et al. (2019)	2009- unspecified	Adult Male, one provincial correctional site in Canada	Static encephalopathy with PAE	2005 Canadian Diagnostic Guidelines	200

¹Language used to describe disorders varies as diagnostic criteria are different across time and geography. FAE: Fetal Alcohol Effects; FAS: Fetal Alcohol Syndrome; FASD: Fetal Alcohol Spectrum Disorder; PAE: Prenatal Alcohol Exposure

Linking FASD Diagnostic Data to Adult Criminal Justice Data

In addition to estimates of the prevalence of FASD among correctional populations from the scientific literature, it is important to estimate justice involvement among persons with an FASD diagnosis. Prior literature has found that youth with FASD are roughly 19 times more likely to be incarcerated than youth without FASD (Popova et al., 2011). One study estimated that 60% of adolescents and adults with FAS or FAE have been charged with a crime, arrested, convicted, or otherwise in trouble with the law in their lifetimes, and 35% have been incarcerated for a crime in their lifetimes (Streissguth et al., 2004).

To estimate justice involvement among Alaskans with FASD diagnoses, we linked FASD diagnostic data maintained by the Alaska Department of Health and Social Services (DHSS) to Alaska Court System (ACS) criminal case dispositions. The diagnostic data provided by DHSS include FASD diagnoses from January 2011 through March 2021. The case disposition data contains all adult criminal cases disposed (completed) from January 2016 through March 2021. The two datasets were linked using a probabilistic matching procedure⁴ on name and date of birth.

Two limitations of the data and methods used will tend to underestimate the number of FASD-diagnosed persons who had criminal justice involvement in this analysis. First, the diagnostic data are not complete — there are FASD diagnoses in Alaska that are not recorded in DHSS's database. In general, DHSS has information only on diagnoses funded by the state. Second, we do not have any data from the Alaska Division of Juvenile Justice (DJJ). This second point is particularly salient because the median age of persons in the FASD data was 13 years old on March 21, 2021, the date the available Alaska Court System data ends. Minors are generally not processed through the adult criminal justice in Alaska.⁵

Despite these limitations, the available data provide useful information. We received FASD diagnostic data for 1,360 distinct persons, 346 of whom were 18 or older as of March 31, 2021. We were able to match 75 persons⁶ (6% of the total, 21% of adults) to adult criminal justice cases disposed of between January 2016 and March 2021.

There were 266 cases among the 75 persons. These cases were not equally distributed, with 30 persons having just one case. Six persons had more than 10 cases

⁴ Our procedure first created separate fields for first name, middle name, last name, name suffix (Jr., III, etc), and month, day, and year of birth. Name fields were passed through a phonetic algorithm to account for spelling variations and typographical errors. Each data source was deduplicated, then each field and its phonetic code was compared to the other data, with matching and non-matching scores attached to each field. Potential matches were reviewed clerically until a suitable cutoff score for matches between datasets was found.

⁵ While youths *can* be waived to adult court (see AS 47.12.100) and some offenses are automatically waived, only 0.67% of court dispositions between January 1, 2016 and March 31, 2021 involve persons under 18 years of age at the time the case was filed.

⁶ This includes two persons with an FASD diagnosis who were minors.

in the Court System data analyzed. In three cases, the defendant was found incompetent; these cases all involved the same defendant and were filed in the same month. A quarter (26%) of cases were dismissed for various reasons after a complaint was filed. In an additional 12% of cases, a complaint was never filed. Defendants were guilty in 62% of cases. The defendant pleaded guilty in 163 cases; in one case the defendant was found guilty at trial. In no case was the defendant acquitted.

Table 5 shows the case disposition by FASD diagnosis. Eight out of nine persons diagnosed with FAS pleaded guilty; the ninth was found guilty at trial. Eighty percent (40 out of 49) of persons diagnosed with pFAS pleaded guilty.

Table 5. FASD diagnosis by case disposition

	Case disposition				Total
	Def. found incompetent	Dismissed	Compliant not filed	Guilty	
FASD diagnosis					
FAS				9	9
Partial FAS		8	1	40	49
Sentinel physical finding(s) / static encephalopathy		8	5	11	24
Static encephalopathy	3	41	18	68	130
Sentinel physical finding(s) / neurobehavioral disorder		4	1	4	9
Neurobehavioral disorder		7	5	28	40
No physical findings or CNS abnormalities detected			1	4	5
Total	3	68	31	164	266

Each case can contain multiple charges. Sixty percent of cases (161) had a single charge, and 92% of cases had four or fewer charges. Just under a quarter (23%, 61 cases) of cases included any felony charges. Table 6 shows the number of cases by crime type. Crime types are not mutually exclusive (i.e., cases can have more than one

crime type). The most common crime type was violation of conditions of release, present in 69 cases (26%). Assaults were nearly as common and were present in 63 cases; disorder charges were present in 57 cases.

Table 6. Number of cases by crime type

Crime type	Number of cases
Alcohol	7
Assault	63
Burglary	12
DUI	14
DV protective order	7
Disorder	57
Escape	1
False reporting	5
MICS	13
Other property	6
None (no complaint filed)	30
Other violence	4
Robbery	6
Sexual assault	4
Sex offender registry	2
Theft	48
Traffic	19
Trespass	21
VCOR	69
Vehicle theft	13
Weapons	2

Note: Number of cases does not sum to total; each case can have more than one crime type.

These findings should be viewed with caution given the limitations of the data. What we can say, however, is that a reasonable lower bound for an estimate of adult criminal justice involvement among adults who have been through the FASD diagnostic process is approximately one in five. Cases typically resulted in the defendant pleading guilty to

one or more charges, but a quarter of cases were dismissed. Complaints were never filed in another 12%. Among persons with the most serious FASD diagnoses, FAS and pFAS, 85% of cases resulted in a guilty disposition on one or more charges.

Finally, three-quarters of cases were for misdemeanors only. Among persons with FAS or pFAS diagnoses, 62% of cases were for misdemeanors only. Alaska's sentencing mitigator for FAS applies only to felonies. While the available data do not contain sufficient sentencing details to determine whether this mitigator was actually used in any of the cases in our analysis, these results suggest that relatively few cases could qualify.

Conclusion and recommendations

This report summarized how the cognitive deficits associated with FASD are likely to impact justice-involved persons. Deficits in adaptive behavior, learning, attention, reasoning, and memory (ALARM) are likely to impact criminal behavior and understanding of the criminal justice process. These deficits can also impact the efficacy of correctional rehabilitation programs when adaptations are not made to programming. Accommodations for a disability such as FASD cannot be made when the disability remains unknown (perhaps even to the justice-involved person themselves).

We offer several recommendations that cut across the entire criminal justice system. We suggest increased training and awareness for all criminal justice actors and increased access to screening and evaluation services. We also recommend adapting processes and explanations to the learning style of each defendant. The increased use of specialized units with additional training in FASD (among other diagnoses) is also recommended as supplementary support for particularly difficult to serve individuals. Finally, we recommend creating data sharing frameworks, and providing incentives for their use by criminal justice actors.

We recommend no change to the diagnostic criteria in use by the State of Alaska (the 4-Digit Diagnostic Code). While there are different criteria available, there is no external standard by which the various criteria can be judged. Comparisons to other diagnostic criteria suggest that the 4-Digit Diagnostic Code may underdiagnose FAS, but its identification of FASD is similar to other tools.

Given the overall lack of validated brief screening tools, we can recommend no existing brief screening tool for immediate deployment in criminal justice contexts. Any tool would likely require extensive local validation. At the individual level, it may be more

impactful to focus on screening and diagnostics for intellectual and developmental disabilities more broadly among justice-involved persons.

Prior research, mostly from Canada, suggests that between 10% and 20% of Alaska DOC populations may have had an FASD. In the absence of active case ascertainment studies, this is likely the best estimate available. Prior research suggests that the lifetime justice involvement among those diagnosed with FASD may be as high as 60%. Our analysis of Alaska FASD diagnostic data and Alaska Court System data suggested that 21% of adults with an FASD diagnosis had one or more criminal cases filed during a relatively short period, from January 2016 through March 2021.

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Appendix I: Other diagnostic systems

The Institute of Medicine's (IOM) 1996 guidelines were developed pursuant to a congressional mandate and were made into a true diagnostic system with updates in 2016 (Hoyme et al., 2016; Hoyme et al., 2005). The IOM Guidelines take a different diagnostic approach to FASD than the 4-Digit Diagnostic Code (Hoyme et al., 2005). The IOM guidelines delineate four distinct categories of the effects that stem from fetal exposure to alcohol, as opposed to the more spectrum-based 4-Digit diagnosis. These categories are FAS, partial FAS (pFAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). Each requires a different presentation of largely the same four symptom categories described within the 4-Digit Diagnostic Code (Hoyme et al., 2016; Hoyme et al., 2005). Validation research has shown the 2005 version of the guidelines to have a high degree of agreement with other diagnostic systems (Coles et al., 2016).

The Public Health Agency of Canada's National Advisory Committee on Fetal Alcohol Spectrum Disorder developed the Canadian Guidelines in 2005. These guidelines sought to harmonize the 4-Digit Diagnostic Code and the IOM guidelines (Chudley et al., 2005). The Canadian Guidelines recommended keeping the objective assessment tools of the 4-Digit Diagnostic Code along with the four diagnostic categories and terminology of the IOM guidelines. The revised 2016 Canadian Guidelines cover screening and referral, the various types of assessments required for diagnosis, and use of the same four diagnostic domains described by the 4-Digit Diagnostic code as well as the IOM guidelines (Cook et al., 2016). Validation research of the Canadian Guidelines showed favorable interrater reliability and sensitivity compared to the DSM-V diagnosis of neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE), a diagnostic method described later in this report (Sanders, Breen, et al., 2017).

The Center for Disease Control and Prevention FASD diagnostic guidelines were developed in coordination with the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect in 2004 (Bertrand et al., 2004). Like the Canadian Guidelines, the intention of the CDC guidelines was to harmonize various systems in use at the time, and thus many of the features of referral and diagnosis the CDC recommends look similar to those that were already in use by 2004. The diagnostic features that the CDC guidelines list as indicative of FASD are much the same as those of the previous three diagnostic systems (4-digit, Canadian, and IOM), and include facial dysmorphia, central nervous system dysmorphology and dysfunction, and growth deficits. This includes a multidisciplinary evaluation team, similar diagnostic criteria, and a screening

methodology intended to capture potential cases for formal diagnostic procedures, as well as recommendations for prevention and risk factors (Bertrand et al., 2004).

The Australian guidelines, developed in 2017 as a result of the efforts of the Commonwealth Department of Health, recommend a diagnostic system that looks similar to those already discussed—brain structure, cognitive ability, executive function, facial dysmorphology, as well as adaptive behavior (or lack thereof) and academic achievement (Bower et al., 2017). Confirmed prenatal alcohol exposure is not required for diagnosis, and this system has been used for children as old as 17 (Bower et al., 2017). The German FAS guidelines, developed in 2013, propose the usage of similar diagnostic features for diagnosis, and do not focus on diagnosing the entire range of FASD, but rather the most serious manifestations of the disease that result in FAS (Landgraf et al., 2013).

Lastly, the DSM-V includes a diagnostic category named neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) (American Psychiatric Association, 2013). The proposed criteria require more than minimal gestational alcohol exposure, at least one neurocognitive function impairment, at least one self-regulatory impairment, at least one adaptive function impairment, onset in childhood, and presence of clinically significant distress or impairment in various life domains (American Psychiatric Association, 2013). In one major validation study, the DSM-V diagnosis of ND-PAE showed weak construct validity (Sanders et al., 2020). Further, recent research has shown that ND-PAE diagnosis is too strict and requires more adaptive dysfunction than is necessary compared to other diagnostic systems (Kable & Coles, 2018; Sanders, Hudson Breen, et al., 2017).

In the absence of an external standard, it is impossible to determine which diagnostic system is most accurate, or whether any one system is more accurate than any other. FASD is a complex and relatively new condition, with rapidly progressing developments in screening, diagnosis, and treatment (Coles et al., 2016). What is possible, however, is to compare various systems on how they perform when diagnosing the same treatment group. Overall, these studies find at best modest agreement among commonly-used diagnostic systems. When multiple systems are used to retrospectively diagnose the same sample of patients, there are differences in the percent of the sample that is positive for FAS or FASD according to each system.

Table 7, reproduced from Coles et al. (2016), shows the extent of disagreement among a study of five diagnostic systems. The same sample of patients was diagnosed with the differing criteria. Using Cohen's Kappa, only modest agreement was found between the five systems examined, indicating problems with convergent validity (Coles et al., 2016).

Table 7. Percent of Alcohol-Related Diagnoses by Diagnostic System (n= 1,581)

System	FAS	pFAS	ARND	Any alcohol Dx	No diagnosis
Emory-20	13.73%	16.13%	15.94%	45.79%	54.21%
4-Digit Code	0.25%	12.97%	24.29%	37.51%	62.49%
Canada	1.83%	10.31%	13.03%	25.17%	74.83%
IOM	12.21%	22.83%	24.54%	59.58%	40.42%
CDC	4.74%	N/A	N/A	4.74%	95.26%

Note – Reproduced from Coles et al. (2016, p. 17)

Similarly, another study of diagnostic performance confirmed that there are differences in diagnostic inclusion between commonly-used systems, with variable performance on both FAS and FASD diagnoses. Hemingway et al. (2019) found that the percent of a sample diagnosed with FAS and FASD using the 4-Digit Code (2.1% and 79%), IOM Guidelines (6.4% and 44%), Australian Guidelines (1.8% and 29%), and Canadian Guidelines (1.8% and 16%) show large differences in convergence and divergence. The percentage of the clinical sample diagnosed with FASD by all four systems was just 11% (Hemingway et al., 2019). Other analyses show that relaxing the criteria for the “FAS face” lead to increases in the percentage of patients diagnosed with FASD (Astley, 2006).

Appendix II: Brief screening tools

Screening Tools Designed for a Justice Context

While no single tool has a robust evidence base, our review found four screening tools designed for adults in justice settings: the Fetal Alcohol Behavior Scale (FABS), the Canadian Brief Screen Checklist (BSC, included as Appendix III), a four-tier screening method outlined by Burd and colleagues in 2004, and a forensic FASD screen developed by Brown and colleagues in 2010 (Brown et al., 2010; Burd et al., 2004; MacPherson et al., 2011; Streissguth et al., 1998). For juvenile populations in justice settings, both the Asante Center's Youth Probation Officer's Guide to FASD Screening and Referral, and a method used in Manitoba by the Manitoba Youth Justice FASD Program have been used (Conry & Asante, 2010; Singal et al., 2018).

For adults and juveniles in justice settings, the FABS uses 36 questions about an individual's behavior in a yes/no format and adds the resultant scores. Some examples of the items include "Overreacts to situations", "Often demands attention or monopolizes a conversation", and "Makes 'off the wall' comments" (Streissguth et al., 1998, p. 326). The scale has been shown to have high test-retest and item-to-scale reliability in a series of 5 studies (Streissguth et al., 1998).

The Canadian Brief Screen Checklist was developed by MacPherson et al. (2011) to flag juvenile and adult offenders in a correctional population for further assessment for FASD. Family members and the individuals with suspected FASD fill out the BSC and answer questions in a number of domains found to be predictive of an FASD-related diagnosis. MacPherson and colleagues found that the psychometric properties of this screening tool were very favorable – when participants in their study were both screened and diagnosed by a multidisciplinary team, the BSC was found to have high predictive utility (78% sensitivity and 85% specificity), a high degree of accuracy (84%), and high internal consistency (Cronbach's alpha = .89). Additionally, the BSC was able to discriminate between three distinct groups: those with an FASD, participants with neuropsychological issues that were unrelated to prenatal alcohol exposure, and those with no deficits (MacPherson et al., 2011).

In 2010 Brown and colleagues proposed a primarily behavioral screening assessment intended for use with criminally-involved adults entering the courts. It is a 35-item form that obtains information about 5 domains—three of which deal specifically with the criminal history of the suspect or the circumstances of the incident which brought them before the court. These sections ask questions that attempt to tease out the kind of

behavior that is indicative of the pattern of neurological damage caused by exposure to alcohol in utero, such as whether the suspect acted in an illogical, impulsive way with a high risk of detection, had a poor exit strategy, and exhibited a willingness to confess to suggestible questioning (Brown et al., 2010). The remaining items are about the suspect's personal history and the nature and interpersonal communication abilities. These items are grounded in the FASD literature and are derived from empirically validated factors and deficits associated with FASD, although formal validation research on this tool has not been done.

For juvenile offenders, research in Canada with two different methodologies has shown some promise. The Asante Center, with consultation with an FASD expert, developed a checklist for probation officers with indicators proven predictive of FASD and asked questions about social factors (such as family history with FASD, alcoholism of mother, and whether the youth has been involved with child protection services) and personal factors (such as growth deficiencies, history of learning difficulties in school, and other mental health diagnoses) (Conry & Asante, 2010). Researchers showed that it was possible to train non-experts in the field of FASD in a brief screening methodology using plain language and accessible information to provide a potential list of candidates for formal diagnosis.

The Manitoba Youth Justice FASD program uses what they term a "red flag method" that screens candidates (selected through numerous interactions with justice professionals who note behavior that indicates potential FASD) for physical characteristics, behavioral and attention problems, trouble with understanding consequences of behavior, difficulties with empathy, and impulsiveness, and refers candidates who have not been previously diagnosed with FASD to diagnosis in an FASD diagnostic clinic. This red flag method has shown to have higher sensitivity than the Asante method (Singal et al., 2018). However, neither the Asante screen nor the "Red Flag Method" have undergone validation analysis.

Screening Tools Adaptable to a Justice Context

Four additional tools worthy of consideration are the Life History Screen, Fetal Alcohol Syndrome Diagnostic Checklist (FASDC), Neurobehavioral Screening Tool (NST), and the FAS Screen. All of these tools are used with children and not in justice settings, although there is a possibility to adapt them to this use with juvenile justice settings (Davis et al., 2013; Grant et al., 2013; Poitra et al., 2003).

Grant et al. (2013) developed the FASD Life History Screen to be used with adults in non-correctional settings with 28 questions that span life history, maternal alcohol use, education, criminal history, and many adaptive variables. This tool has the advantage

that it does not require a 3rd party nor anyone familiar with the individual to complete. Further, it was shown to be an efficient screening method with items that were significantly associated with FASD (Grant et al., 2013).

While only used with children and not yet adapted for justice settings, three tools deserve consideration for their potential to be adapted for such a purpose. The FASDC developed by Burd, Klug, et al. (2010) uses criteria developed from the IOM diagnostic guidelines and shows an impressive ability to distinguish FAS from non-FASD subjects (as determined by IOM diagnosis concurrent with screening), with 99% accuracy, 99% specificity, and 99% sensitivity. The NST is a psychometric tool that asks caregivers to provide information on a variety of behavioral factors centered around empathy, lack of consideration of consequences, disobedience, attention, and many others to screen for potential FASD. The NST shows excellent specificity (100% discrimination between FAS and control), and good sensitivity (62.5%) for participants with FASD (LaFrance et al., 2014). The FAS Screen is a rapidly-administered school-based screen that asks questions about physical and developmental characteristics that sent those with a score above 20 to diagnostic clinics for further evaluation. Research has shown that broad-based screening in a school system is a method of screening large numbers of people quickly (Poitra et al., 2003). The FAS Screen showed high sensitivity (100%), specificity (95.43%), and accuracy (95.44%) in an analysis of the tool's ability to distinguish between FAS and non-FAS children.

See Table 8 for a comparison of the selected screening tools in this paper.

Table 8. Comparison of Fetal Alcohol Spectrum Disorder Screening Tools

	<i>Fetal Alcohol Behavior Scale (FABS)</i>	<i>Brief Screen Checklist (BSC)</i>	<i>Brown et al., 2010</i>	<i>Asante Center Tool</i>	<i>Manitoba "Red Flag Method"</i>	<i>Life History Screen</i>	<i>FAS Diagnostic Checklist (FASDC)</i>	<i>Neurobehavioral Screening Tool (NST)</i>	<i>The FAS Screen</i>
Features	Streissguth et al. (1998)	MacPherson et al. (2011)	Brown et al. (2010)	Conry and Asante (2010)	Singal et al. (2018)	Grant et al. (2013)	Burd, Klug, et al. (2010)	LaFrance et al. (2014)	Poitra et al. (2003)
<i>Number of Items</i>	36	48	35	11	N/A	28	41	10	
<i>Commonly Used In Corrections?</i>	x	x	x	x	x				
<i>Maternal Alcohol Use Questions</i>		x	x	x	N/A	x	x		
<i>Behavioral Questions</i>	x	x	x	x	x	x	x	x	x
<i>Family History Questions</i>		x	x	x	N/A	x			
<i>Questions about past psychiatric illness</i>				x	N/A	x	x		
<i>Facial Analysis</i>		x			N/A		x		x
<i>Physical Measurements</i>							x		x
<i>Age Group</i>	Adults and juveniles	Adults and juveniles	Adults and juveniles	Juveniles	Juveniles	Adults and Juveniles	Juveniles	Juveniles	Juveniles
<i>Completed by self-report or 3rd Party</i>	3 rd party	Both	Both	3 rd party	3 rd party	Self-report	3 rd party	3 rd party	3 rd party

Appendix III: BSC

Source: MacPherson et al. (2011)

Fetal Alcohol Spectrum Disorder Brief Screen Checklist –Revised

Case ID: _____

Date: _____

Part 1 Behavioural Indicators

The first set of questions is about your behavior and abilities.

Directions: Please rate yourself on the following questions. There are no right or wrong answers. I will begin asking you the first set of questions now.

Would you say you are someone who:	Yes	No
1. Acts impulsively.	1	0
2. Has trouble following directions.	1	0
3. Is restless.	1	0
4. Has a problem with spelling.	1	0
5. Shows poor judgment.	1	0
6. Is easily distracted.	1	0
7. Has temper tantrums.	1	0
8. Has strong mood swings.	1	0
9. Is hyperactive.	1	0
10. Has a problem with money	1	0
11. Seems unaware of the consequences of your actions.	1	0
12. Has a problem with maths.	1	0
13. Interrupts a lot during conversation.	1	0
14. Is agitated.	1	0
15. Is very forgetful of everyday things.	1	0
16. Talks a lot but says little.	1	0
17. Has a poor memory.	1	0
18. Has a problem with reading.	1	0
19. Is easily victimized.	1	0
20. Has trouble completing tasks.	1	0
21. Has a poor attention span.	1	0
22. Has few friends.	1	0
23. Is easily manipulated.	1	0
24. Is disorganized.	1	0
25. Has trouble staying on topic.	1	0
26. Has poor social skills.	1	0

Score on behavioural items _____ (Maximum 26)

0-9=low risk

10 or more=moderate to high risk

Part 2
Historical Information

The second set of questions is about your history.

Directions: Please answer the following questions to the best of your ability. There are no right or wrong answers. I will begin asking you the second set of questions now.

27. Were you adopted?	Yes	No	Do Not Know	
28. How many times have you been in foster care?	Never	1-2 times	3 or more	Do not know
30. Have you had problems with school from an early age?	Yes	No	Do Not Know	
31. How many times have you been in mental health treatment?	Never	1-2 times	3 or more	Do not know

Score on historical items _____ (Maximum 6)

Scoring :

- 0-1=low risk
-
- 2 or more= moderate to high risk

Part 3
Maternal Indicators

The final set of questions is about your mother's use of alcohol when you were young and during the time she was pregnant with you.

Directions: Please answer the questions to the best of your ability. There are no right or wrong answers, just do the best you can. I will begin asking you the last set of questions now.

32. Did your mother drink alcohol when you were young? **Yes** **No** **Do Not Know**
(if answer is 'no' or 'do not know' go to question 35)

33. If yes: how often did your mother drink?

<input type="checkbox"/> Once monthly or less	<input type="checkbox"/> Do Not Know
<input type="checkbox"/> 2-4 times per month	<input type="checkbox"/> Not Applicable
<input type="checkbox"/> At least 2 times per week (<i>high risk</i>)	

34. How many drinks of alcohol did she usually have on a typical drinking occasion?

One standard drink is defined as:

- 12 oz (341 ml, standard bottle) of regular beer
- 5 oz (142 ml, regular size wine glass) of table wine,
- 3 oz (85 ml) of fortified wine (sherry, port, vermouth),
- 1.5 oz (43 ml, single shot) of spirits (whiskey, rum, gin)

- | | |
|--|---|
| <input type="checkbox"/> One to three | <input type="checkbox"/> Do Not Know |
| <input type="checkbox"/> Four or more (<i>high risk</i>) | <input type="checkbox"/> Not Applicable |

("At least twice a week" and/or "four or more drinks" = high risk)

35. Did your mother drink alcohol when she was pregnant with you? Yes No Do not know
 (If no or do not know, go to 37)

36 Who told you about your mother’s drinking during pregnancy?

<input type="checkbox"/> Mother <input type="checkbox"/> Other Relatives <input type="checkbox"/> Friends <input type="checkbox"/> Foster/adopted parent	<input type="checkbox"/> Health Professional <input type="checkbox"/> Elder <input type="checkbox"/> Other: _____
---	---

37. Did your mother use any other drugs during pregnancy?

<input type="checkbox"/> Tobacco <input type="checkbox"/> Prescription – from a doctor <input type="checkbox"/> Prescription – used without a doctor’s order Which drugs did she use? _____	<input type="checkbox"/> Illegal drugs (eg. marijuhana, hashish, cocaine, heroin) <input type="checkbox"/> Do not know <input type="checkbox"/> Did not use
---	---

That is the end of the questions. Thank you for answering.

That is the end of the questions. Thank you for answering.

NOTE TO INTERVIEWER: Please provide any other details discussed during the interview regarding the participant’s behaviour, family history or mother’s use of alcohol.

REFERRAL FOR FOLLOW UP ASSESSMENT

Need Behavioural, Historical and one Maternal criteria:

- Behavioural Items** Score of 10 or more (*required*)
- Historical Items** Score of 2 or more (*required*)
- One or both of the following required:*
- Maternal Items** Response of “At least twice a week” during childhood
And/Or
- Maternal Items** Response of “four or more drinks per occasion” during childhood

Offender Final Assessment

- Risk of Fetal Alcohol Spectrum Disorder** (follow up required)
- No risk of Fetal Alcohol Spectrum Disorder**

Appendix IV: Brief Jail Mental Health Screen

Source: <https://www.prainc.com/?product=brief-jail-mental-health-screen>

BRIEF JAIL MENTAL HEALTH SCREEN

Section 1

Name: _____ <small>First MI Last</small>	Detainee #: _____	Date: ___/___/_____	Time: _____ AM PM
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Section 2

Questions	No	Yes	General Comments
1. Do you <i>currently</i> believe that someone can control your mind by putting thoughts into your head or taking thoughts out of your head?			
2. Do you <i>currently</i> feel that other people know your thoughts and can read your mind?			
3. Have you <i>currently</i> lost or gained as much as two pounds a week for several weeks without even trying?			
4. Have you or your family or friends noticed that you are <i>currently</i> much more active than you usually are?			
5. Do you <i>currently</i> feel like you have to talk or move more slowly than you usually do?			
6. Have there <i>currently</i> been a few weeks when you felt like you were useless or sinful?			
7. Are you <i>currently</i> taking any medication prescribed for you by a physician for any emotional or mental health problems?			
8. Have you <i>ever</i> been in a hospital for emotional or mental health problems?			

Section 3 (Optional)

Officer's Comments/Impressions (check all that apply):

Language barrier
 Under the influence of drugs/alcohol
 Non-cooperative
 Difficulty understanding questions
 Other, specify: _____

Referral Instructions: This detainee should be referred for further mental health evaluation if he/she answered:

- YES to item 7; OR
- YES to item 8; OR
- YES to at least 2 of items 1 through 6; OR
- If you feel it is necessary for any other reason

Not Referred
 Referred on ___/___/_____ to _____
 Person completing screen _____

INSTRUCTIONS ON REVERSE

Fetal Alcohol Spectrum Disorders and the Alaska Educational System

Executive Summary Component 3

Fetal alcohol spectrum disorders (FASDs) is an umbrella term used to describe the range or spectrum of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects can include physical, mental, behavioral, and/or learning disabilities; the effects are life-long. These disabilities are expressed as attention problems, memory deficits, executive functioning impairments, neurocognitive delays and impairments, motor delays, and inconsistent social skills.

This report is part of an endeavor to develop data, information, and recommendations for improving systems of care for individuals experiencing fetal alcohol spectrum disorders (FASDs), and to identify strategic opportunities for the prevention of FASDs in Alaska. In this report, we focus on the experience of FASDs within Alaska's educational system. Other reports in the larger endeavor addressed FASDs systems of care and involvement and FASDs and the criminal justice system. This report was guided and informed by an advisory group of seven individuals with lived experience with FASDs, including an individual with FASDs as well as parents of children with FASDs.

There is no method to accurately assess the number, incidence and prevalence of students with FASDs in Alaska's educational system. FASDs are not a specific disability type within Alaska state statute nor are FASDs documented within the Alaska Department of Education and Early Development's data system for special education. The common approaches used to calculate prevalence/incidence of FASDs (passive surveillance, clinical-based studies, active case ascertainment) are difficult and costly to implement in the educational setting.

Two focus groups with a total of 10 participants were held with individuals with lived experience of FASDs in the educational system. Most of the participants were mothers to children with FASDs, with the exception of one male participant who experiences FASD. Participants had experiences in all stages of public education (Infant Learning Programs through post-secondary education) and had described educational experiences of their children who experience FASDs in small village settings, rural hub

communities and urban centers. Participants provided rich, detailed descriptions of their experiences with the school system, including supports that were or were not helpful, and described how their children who experience FASDs currently interact with, and move out of, the education system in Alaska. Participants discussed standard transition periods and also highlighted critical social-emotional developmental periods. Parent experiences with the educational system, student transition points, noted resources, and gaps in service were similar regardless of urban/rural location. The negative effect of turnover of educators, staff and administrators was noted in all settings. Parents noted school district variability in the assessment and type of support offered to their child. Perseverance of students in the educational system, ongoing advocacy of parents with educational staff who were aware of the needs of students with disabilities led to positive outcomes in the education of students with FASDs.

A survey of Alaskan educators from across the state described FASD-related knowledge, attitudes, training needs, challenges and opportunities in educating students with known or suspected FASDs. Educators largely agreed that FASDs negatively affect many aspects of an individual's life. Educators still lack familiarity with many of the organizations, programs, and websites that may address FASDs. There is a need for more collaboration outside of IEP and/or 504 meetings. Educators noted needs in communication both with families and among staff and desired one place to go to with clear resources and information related to FASDs. Educators reported being relatively unaware of the resources available as students transition out of the education system. Educators mentioned participating in training that was useful when working with students with FASDs: Positive Behavior Supports, Non-Violent Crisis Intervention, and Applied Behavior Analysis. Of these, educators were most satisfied with the Positive Behavior Supports training. Most schools offer FASD prevention activities in the form of health classes.

Introduction

Purpose

This report is part of an endeavor to develop data, information, and recommendations for improving systems of care for individuals experiencing fetal alcohol spectrum disorders (FASDs), and to identify strategic opportunities for the prevention of FASDs in Alaska. Specifically, this report is focused on the experience of FASDs within Alaska's educational system. Other reports in the larger endeavor addressed FASD systems of care and involvement and FASDs and the criminal justice system. This report was

guided and informed by an advisory group of seven individuals with lived experience with FASDs, including an individual with FASD as well as parents of children with FASDs. We also sought feedback from professional stakeholders, including individuals who staff key roles in health and education in state government and individuals who have been leaders in FASD advocacy in Alaska.

Background

Fetal alcohol spectrum disorders (FASDs) is an umbrella term used to describe the range or spectrum of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects can include physical, mental, behavioral, and/or learning disabilities; the effects are life-long. Each person who is affected by prenatal alcohol exposure is affected differently, so it's important to look at the individual, not the term. FASD is not a term intended to be used as a clinical diagnosis. Clinical diagnoses can include fetal alcohol syndrome (FAS), alcohol related neurodevelopmental disorder (ARND), neurobehavioral disorder (ND), atypical fetal alcohol syndrome (AFAS), and static encephalopathy. The clinical diagnosis given may be dependent on the diagnostic process used. In Alaska, the process that is most widely used and recommended is the University of Washington 4-digit code system (Astley, 2013).

Individuals with FASDs may have physical disabilities and differences that are visible as well as invisible developmental delays and neurodevelopmental disorders. These disabilities are expressed as attention problems, memory deficits, executive functioning impairments, neurocognitive delays and impairments, motor delays, and inconsistent social skills. Some disabilities associated with FASDs may not be noticed in infancy and toddlerhood; however, as a child grows older and expectations increase, the differences due to FASDs can become more apparent. Unaddressed core deficits, weaknesses, and vulnerabilities related to FASDs and childhood trauma during infancy, childhood and adolescence can lead to the development of secondary disabilities. Secondary disabilities are disabilities an individual is not born with, but which arises out of the interaction between the person's primary disabilities and their life experiences. Secondary disabilities include disruption of school experience, criminal activity, and mental health problems.

Individuals with FASDs are often supported by a variety of specialists throughout the individual's lifespan to assist with primary and secondary diagnoses and issues related to FASD (see Table 9. FASDs experiences across the lifespan).

Table 9. FASDs experiences across the lifespan

Life stage	Education Setting	Common FASDs related issues
Infant and Toddler (0-2 years)	Early care and education	Sensory and regulatory problems, fine motor issues, and problems with physical health.
Preschool (3-5 years)	Pre-K	Fine and gross motor delays, failure to comply, and loss of previously learned material. Disabilities that were present in infancy/toddlerhood might also continue or increase. Conditions often suspected at this age as a result of behaviors can include attention-deficit/hyperactivity disorder (ADHD), conduct disorder, and oppositional defiant disorder.
Elementary ages (5-12 years)	Grades K-6	Attention/cognition, and visual-spatial and social skills problems.
Middle and High School (12-19 years)	Grades 7-12	Cognitive, behavioral, and functioning problems associated with FASDs during elementary years continue. The onset of puberty, increased difficulty with social understanding, and other cognitive difficulties may cause new or ongoing mental health problems such as mood disorders, substance abuse, and social problems. Difficulty with abstract thinking.
Early adulthood	Transitioning out of the school system	Continuation of cognitive, behavioral, functioning problems; abstract thinking and mental health issues from adolescence; benefit from case management and ongoing support
<p>note: Sensory = to do with the senses: touch, taste, sight, smell, hearing; Regulatory problems= poor sleep cycles, irritability, stress reactivity, early attention skills; Fine motor skills = being able to make small, controlled movements, for example, picking up and writing with a pencil; Gross motor skills = walking/running smoothly, jumping, climbing; swimming; Attention problems = difficulty sitting in class, problems with focus, poor impulse control, difficulty learning, attention disorders, and often problems with sleep; Visual-spatial abilities = perceiving and judging visual information, understanding spatial relationships, using mental imagery, symbol recognition, and storing visual images in short- and long-term memory, math skills; Social skills = difficulties understanding social boundaries, reading social cues, and relating to peers; mood disorder = depression and/or anxiety; Social understanding = difficulty developing personal or social boundaries, poor self-esteem, impulsivity, poor judgement. Abstract thinking = the ability to use concepts to make and generalize meaning such as time or money.</p>		

Given the spectrum of how FASD presents for each individual, it is difficult to create and recommend interventions in the community and educational system to support individuals with FASDs across their lifespan. Individuals with FASDs are most commonly treated with processes and interventions developed for other disabilities. This report describes the context of Alaska's educational system with attention to FASDs related policy. New information is provided regarding the lived experience of students with FASDs and their families, gathered through focus group discussions and surveys of

Alaskan educators. Finally, systematic reviews of literature and policies were conducted to summarize educational interventions, instructional practice, in addition to describing considerations on estimating the number, incidence and prevalence of students with FASDs in Alaska's educational system. The report concludes with a description of policies impacting the education of students with FASDs and policy recommendations.

Mapping Alaska's Educational Systems

The Alaska education system is broadly divided into three major components: 1) early care and learning, 2) primary/elementary education and 3) secondary education. A wide range of teacher certifications (e.g., initial, professional, special services) and endorsements (e.g., early childhood, special education, reading) are offered through the State of Alaska's Department of Education and Early Development (DEED; see DEED, n.d. for a complete list).

Article VII, Section 1 of the Alaska Constitution directs the legislature to establish a school system open to all children in the state. In its entirety, the section reads: "The legislature shall by general law establish and maintain a system of public schools open to all children of the State, and may provide for other public educational institutions. Schools and institutions so established shall be free from sectarian control. No money shall be paid from public funds for the direct benefit of any religious or other private educational institution." DEED is the State's education agency. Alaska Statute designates the State Board of Education and Early Development as the head of the DEED and the Commissioner of Education and Early Development as the chief executive officer of DEED (AS 44.27.010). At the local level, Alaska's 53 school districts are each governed by a locally elected School Board. Thirty-three of the districts are city or borough entities, while twenty regional educational attendance area districts serve students in rural and remote settlements outside the cities and boroughs of the state. There are about 10,000 full-time equivalent certified personnel at Alaska's public schools who serve 130,394 students (enrollment as of October 1, 2020).

The Alaska Early Childhood Coordinating Council (AECCC), is a 25-member entity that serves as the state's advisory body for early childhood education grants and planning activities that require a designated advisory, reporting, or consulting body. These include the Child Care & Development Block Grant; Maternal, Infant, & Early Childhood Home Visiting Program; and the Early Childhood Comprehensive Systems project. The Alaska System for Early Education Development, or SEED, is a statewide professional development system for early childhood and school-age professionals. Alaska SEED

works to improve overall professionalism and advocates for fair compensation in the field. Alaska SEED is housed and managed by thread Alaska.

The **early care and learning component** includes a variety of approved, licensed, or otherwise regulated providers. It includes federally funded Early Head Start/Head Start and other privately funded preschool programs such as center-based, before and after school programs, and learning and care opportunities in a private home or in the child's own home. Additionally, public preschool is available in many school districts but is not universally available. While Alaska does not have statewide **kindergarten** transition policies many programs and districts support transition activities. The minimum kindergarten entrance age is five years old on or before September 1. Kindergarten entrance assessment is required; districts must submit to DEED an Alaska Developmental Profile (ADP) for each student entering kindergarten or first grade with indicators of the student's physical and cognitive development, social-emotional health, cognition and general knowledge, language, and literacy. For more on educators' use of the ADP see Harvey and Ohle (2018) and Ohle and Harvey (2017). Following Kindergarten students move through the public school system unless families choose private or home-school options. School choice options (e.g., Charter, optional, alternative) vary by school district with notable differences between urban and rural.

Policy related to public education of student with disabilities

Individuals with disabilities age 0 to 21 years have the right to a Free Appropriate Public Education (FAPE) as specified under the federal law Individuals with Disability Education Act (IDEA, 2004). Part C of IDEA provides guidelines for states to follow in providing services to families with infants and toddlers (birth to three years old) that have disabilities. Part B of the law gives minimum requirements for special education services to children 3 to 21 years of age. In Alaska, Part C and Part B special education services governed by IDEA are administered by different departments. Part C services fall under the Department of Health and Social Services (DHSS), Early Intervention/Infant Learning Program (EI/ILP). Part B services fall under the Department of Education and Early Development (DEED), with Preschool Special Education services (Part B Section 619) under the DEED's Early Learning Program. IDEA mandates, through what is known as **Child Find**, that all states must have policies and procedures in effect to identify, locate, and evaluate children with disabilities ages birth - 21 in order to provide appropriate services. This mandate is carried out through the EI/ILP program for infants and toddlers, and through school districts for children age 3 to 21.

The State of Alaska defines 14 disability categories, which the child must meet criteria for at least one category, or a combination of categories, to be eligible for special

education: autism, deafness, deaf-blindness, emotional disturbance, hearing impairment, specific learning disability, cognitive impairment, multiple disabilities, orthopedic impairment, other health impairment, early childhood developmental delay, speech or language impairment, traumatic brain injury, or visual impairment. FASDs are not mentioned in IDEA Part B legislation or regulations. In 2016, FASDs were added to the Other Health Impairment special education eligibility category list of medical conditions, making Alaska the first state in the country to name FASD in education regulation (4 AAC 52.130 – Criteria for determination of eligibility). The definitions of the Alaska state disabilities categories are included in the Guidance for Special Education Personnel handbook (DEED, 2020). The presence of a disability alone is not sufficient to establish the need for special education services. The disability must result in an educational deficit that requires specially designed instruction.

Eligibility for Part C is determined through an evaluation/assessment by the local Alaska Early Intervention/Infant Learning Program (EI/ILP). Any infant or toddler with a diagnosed or suspected developmental delay has a right to a free screening and evaluation to determine their eligibility for enrollment in EI/ILP. Children, from birth to 3 years old, who meet one of the following criteria, are eligible: (1) developmental delay of 50% or greater in one or more areas of development, (2) disabling condition with a high probability of resulting in a 50% or greater developmental delay, or (3) child's development appears atypical and a multi-disciplinary team determines that the child is likely to have a severe developmental delay. For those who are eligible and with parental consent, an Individualized Family Service Plan (IFSP) is developed. The goal of EI/ILP is to make sure that families have easy access to a coordinated, community-based service system in order to help their children develop to the best of their ability. The program is designed to include a wide range of family-centered services, resources and supports; and is provided in everyday routines, activities and places relevant to families' lives.

Eligibility for Part B is also determined through an evaluation/assessment by the local school district. Part B requires, with parental consent, school districts to evaluate whether a student has a disability and whether that disability impedes the student's ability to progress in the general education settings of their school. Through the referral and evaluation/assessment process, the school-based team reviews existing data, determines the child's present level of academic achievement and functional behavior, and gathers additional assessment information related to area(s) of concern. The evaluation/assessment is documented on the **Evaluation Summary Eligibility Report (ESER)** to help determine if a child has a disability, based on the State of Alaska's 14 disability categories, and is eligible for special education services. If eligible, a team including the family and school professionals creates an **Individualized Education Program (IEP)**. IDEA requires that a continuum of special education (SPED)

placements is available, which includes support in the general education classroom supervised by special education or related services personnel, direct service by SPED personnel in the general classroom, pull-out from the general education classroom with service from SPED personnel, self-contained special education classrooms, special schools, home or hospital instruction or instruction in an institution.

The IEP must address all of the child's special education and related services based on need, not the disability. In addition to special education services, the IEP team may determine a need for related services which may include speech therapy, occupational therapy, physical therapy, counseling, specialized nursing services, audiology services and transportation. Part B requires a re-evaluation to occur at least once every three years (or more often if there are changes that affect the child, or if a parent or teacher requests it) to determine if the child continues to be eligible for special education. During high school, the IEP team begins planning for a student's post-school outcomes. A statement of transition needs must be included in the IEP for every student by their 16th birthday or before with the intention that the IEP team is focused on post-school outcomes and the student's course of study.

Section 504 of the Federal Rehabilitation Act of 1973 is a **federal anti-discrimination law** that protects persons with disabilities of all ages. Section 504 ensures that students with disabilities have equal access to their educational programs and requires a school district to provide a FAPE to each qualified student with a disability who is in the school district's jurisdiction, regardless of the nature or severity of the disability. A student may qualify for a **504 Plan** if they have a physical or mental impairment that substantially limits one or more major life activities (e.g., communication, walking, learning, standing, working, thinking). Section 504 does not require that the child's educational performance be adversely affected. Therefore, a child may qualify for a 504 Plan, but may not qualify for an IEP.

Students with FASD who are assessed and offered either special education services (with an IEP) or a 504 plan are provided classroom modifications and associated services. However, some students with FASDs are not assessed or are assessed and determined to not meet the criteria for services. FASDs are considered an invisible disability, and many students with FASDs do not receive school based supports and services. Additionally, there are reports of difficulty accessing all needed supports and services in school districts in rural areas and where staff are unable to be recruited and retained regardless if an IEP or 504 plan includes the services.

As students navigate through middle and high school, transition planning occurs. The Workforce Investment Opportunity Act (WIOA) requires State Vocational Rehabilitation agencies to set aside a minimum of 15% of their Federal dollars to provide pre-

employment transition services to students with disabilities and states must submit a 4-year workforce plan to the US Department of Labor. Alaska submitted an original plan in 2016 and a required 2-year revision was submitted in April of 2018. The vision for Alaska is that “all Alaskans, including individuals with disabilities, the underserved, Alaska Natives, dislocated workers, and others who experience significant barriers to employment, will have access to the career education, training, and support services needed to prepare for and participate in high-demand occupations that pay family-sustaining wages.” In Alaska, the Division of Vocational Rehabilitation (DVR) provides Pre-Employment Transition Services (**Pre-ETS**) to students with disabilities ages 16 to 21 years old who are eligible or potentially eligible for DVR services. Pre-ETS requires coordination between the schools districts and DVR to provide the following required activities: 1) job exploration counseling, 2) work-based learning opportunities, 3) counseling and postsecondary educational opportunities, 4) workplace readiness training, and 5) instruction in self-advocacy.

According to the National Center for Education Statistics (n.d.), 13.7% (n = 19,473) of Alaska students receive special education services under IDEA, which is slightly above the national average of 13%. Of those receiving special education services, more than 2% (n = 2,473) are infants, toddlers, or preschoolers eligible for IDEA in the category Early Childhood Developmental Delay (does not include those birth to five years in other eligibility categories as the eligibility data was not disaggregated by age). In AY19, 1.88% (n = 190) of infants birth to one year in Alaska received Part C services as compared to the national average of 1.24% (DHSS, 2019). Furthermore, in FY19, Alaska EI/ILP data showed that for all three federally required Office of Special Education Program (OSEP) Early Childhood Outcomes, none of the target goals for Indicators A (Positive social-emotional skills), B (Acquisition and use of knowledge and skills), or C (Use of appropriate behaviors to meet needs) were met. At the time of exit, only 50% (target 65%) of infants and toddlers receiving Part C services demonstrated positive rate of growth for emotional and social skills at the time of exit, less than 44% (target 59%) showed age expectations for emotional and social skills, 55% (target 75%) had a positive rate of growth in using appropriate behaviors, and 40% (target 56%) showed age expectations for using appropriate behaviors (DHSS, 2019).

School based interventions

FASDs present differently for each individual student, as such, there is no single classroom intervention, strategy, or environmental accommodation that will work for all students with FASDs. Individual assessment and interventions are needed given the spectrum of how FASDs present within an individual and the frequent development of secondary disabilities due to inadequate supports and services in infancy/childhood. Students with FASDs have brain differences that may require adaptations in curriculum,

environment, and the structure of their school day for them to be successful. Changes in school environment and content often overwhelm students with FASDs by requiring them to demonstrate a mastery of skills that FASDs often impair. Students often present their disabilities through behaviors that suggest they are students with emotional issues rather than students with brain differences due to prenatal exposure to alcohol.

Very little research has been conducted with children who have FASDs and even less research has been done with children who have FASDs in the educational setting. Several **adaptive interventions** have been shown to be effective for children with FASDs. Some of these behavioral interventions include: Project Bruin Buddies – social skills training to improve peer friendships for children with FASDs; the Georgia Math Interactive Learning Experience (MILE) Program – adapted materials and tutoring methods to improve math knowledge and skills; the Alert program® – educational curriculum to improve behavior regulation and executive functioning; and parent therapy program – parent training to improve parent effectiveness and reduce clinically significant behavior problems in school-aged children with FASDs. These interventions are community-based (e.g. take place outside of school and take place after school hours, and do not involve educators), not school-based interventions.

Most Alaska-based organizations and groups supporting students with disabilities focus their reports and efforts in early childhood. There is a gap in efforts noted in statewide reports related to elementary and secondary students, particularly those with FASDs. Observations and reports from educators and families indicate that students with FASDs may be faring well in earlier elementary grades, but, as school curriculum and social interactions become more complex, students with FASDs often have more difficulties.

Staffing Issues

Throughout the lifespan, individuals with FASDs are best supported by teams of support providers. In childhood and adolescence, the team of support providers includes educators, paraprofessional instructional team members and parents. School districts may employ service providers who supply specialized services to students with special needs. Examples include:

- Speech Language Pathologists (SLP) who design intervention strategies for training students in communication and teach other staff members how to incorporate communication strategies into daily routines and activities
- Physical Therapists (PT) who evaluate and treat students who have dysfunction of the joints, muscles and central nervous system
- Occupational Therapists (OT) who provide expertise with assessment and activities of daily living, assist in adapting the environment to meet sensory needs

- School Psychologists who consult on behavior management and help families understand the needs of their child and support positive family interactions
- Nurses who serve as a liaison between school staff and medical staff on physical needs of the student and provide medical screening for vision and hearing loss and
- Social Workers who serve as an advocate for the child and family, and facilitate community services that the student may be served by or the family may wish to access.
- Board Certified Behavior Analyst (BCBA) who may conduct functional behavior assessments and support behavior intervention planning and implementation
- Registered Behavior Technician (RBT) who support the implementation of behavior plans in the classroom

Unfortunately, on a statewide basis, school districts report difficulty recruiting and retaining support providers. Rural school districts are understaffed in all positions and have more difficulty recruiting and retaining staff due to low wages compared to local cost of living, housing shortages, isolation, and reported burnout. Students with FASDs are best served by individuals they trust and the lack of long term staff impacts the relationship building and therapeutic alliances between students with FASDs and the educational professionals who support them.

Review of Statutes, Regulations, and Policies

Policy is key to initiating systems change to benefit individuals with FASDs and their experience with education. Both in Alaska as well as federally, there are few FASDs policies that directly relate to education. However, there are several policies that, although tangential, may impact FASDs in education. Furthermore, the overall picture of policies provides a helpful lens through which one could make policy recommendations. The following policy section includes: 1) a timeline of relevant Alaska-based reports, 2) a review of federal legislation related to FASDs and education, 3) a review of state legislation related to FASDs and education, and 4) a summary of policies outside of the education system related to FASDs.

Timeline of Relevant Alaska-Based Reports

Over the past couple of decades numerous Alaska-based organizations, groups, or individuals have documented policies, reports, comprehensive plans, or strategic goals to address FASD and related needs in the state. However, from this policy scan it is unclear how these reports and recommendations are strategically implemented, integrated, monitored, and evaluated. Table 10 provides a brief timeline and overview of

these reports and acknowledges that this is not an exhaustive list. Many initiatives and organizational practices have been in place since the 1970s as noted in the Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022.

Table 10. Timeline of Relevant Alaska-Based Reports

Date	Report Name	Author(s)	Overview and Connection to FASD
July 2010	Alaska Birth Defects Monitor Volume III, Issue 2	Alaska Birth Defects Registry	Description of the decline in birth prevalence of FAS in Alaska, the Arctic FASD Regional Training Center, parent navigation support from Stone Soup Group
January 2018	Alaska Fetal Alcohol Spectrum Disorders (FASD) Strategic Plan 2017-2022	Governor's Council on Disabilities and Special Education & Partnerships	Identifies six priority areas with goals and objectives: Primary Prevention, Screening and Diagnosis, Early Childhood and Education, System Transformation and Navigation for Youth and Adults, Workforce Development, and Community Outreach and Engagement
July 2019	Strengthening the System: Alaska's Comprehensive Integrated Mental Health Program Plan 2020-2024	Department of Health and Social Services & Alaska Mental Health Trust Authority Partnerships	Provides a guide for resource allocation decisions in the development of services, workforce, and facilities to meet needs of Trust beneficiaries.
December 2019	A Needs Assessment of Alaska's Mixed-Delivery System of Early Childhood Care and Education	McDowell Group for the Association of Alaska School Boards	Statewide needs assessment is intended to inform understanding and improvement of the Alaska early care and education system, with particular attention to low-income, disadvantaged, and rural children. Provides context for IDEA part B and C.
June 2020	Alaska Early Childhood Environmental Scan & Baseline Report on the Condition of Young Children	All Alaska Pediatric Partnership	Comprehensive description of current status of young children in Alaska and the infrastructure in place to coordinate, monitor and improve the policies and services that exist for young children and families.
July 2020	Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations	McDowell Group	Reports data from Alaska's FASD diagnostic team databases; provides policy literature review; presents FASD Data Scoreboard

Federal Legislation Related to FASDs and the Educational System

There are several federal laws that govern the policies and educational practices related to individuals with disabilities in educational settings:

- *Individuals with Disabilities Education Act (IDEA)* enacted in 1975 and reauthorized in 2004 (see section above “Mapping Alaska’s Education System”)
- *Every Student Succeeds Act (ESSA)* enacted in 1965, reauthorized in 2001 and replaces the *No Child Left Behind Act (NCLB)* of 2001. ESSA requires that all students, including those with disabilities, have access to a well-rounded education that will help prepare them to succeed in college and careers. Title IV of ESSA is aligned with Part B of IDEA, the authorization of coordination of services across agencies involved in supporting the transition of students with disabilities to postsecondary education settings.
- *Rehabilitation Act* enacted in 1973 Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive Federal financial assistance from the U.S. Department of Education.
- *Americans with Disabilities Act (ADA)*, enacted in 1990, is an equal opportunity law for people with disabilities. The ADA is modeled after Section 504 of the *Rehabilitation Act of 1973* and the Civil Rights Act of 1964, the latter which prohibits discrimination on the basis of race, color, religion, sex, or national origin.
- *Workforce Investment Opportunity Act (WIOA)* signed into law in 2014 superseded the *Workforce Investment Act of 1998* and amends the *Adult Education and Family Literacy Act*, the *Wagner-Peyser Act*, and the *Rehabilitation Act of 1973*. The WIOA aims to more efficiently and effectively meet the employment and labor market needs of Americans, and specifically aims to increase access to vocational services and competitive integrated employment for Americans with disabilities. Related to education, the WIOA requires State Vocational Rehabilitation agencies to set aside a minimum of 15% of their Federal dollars to provide pre-employment transition services to students with disabilities.

As noted earlier, the Individuals with Disabilities Education Act (IDEA) provides free appropriate public education to all eligible children with disabilities to ensure the provision of special education and related services. Part C of IDEA provides guidelines for states to follow in providing services to families with infants and toddlers (birth to three years old) that have disabilities. Part B of the law gives minimum requirements for special education services to children 3 – 21 years of age. Refer back to Mapping Alaska’s Educational Systems section for more details on IDEA. Since Part C (EI/ILP)

services are administered under DHSS while Part B 619 (Preschool Special Education) services are administered under the DEED, there are data disconnects and communication gaps as students transition between the agencies administering the programs. In some cases, data is reported differently about the same programs. This is relevant to consider given the importance of continuity of systems of care and data tracking.

IDEA and Student Discipline

Given the evidence that children with FASDs experience a range of behavioral support needs and many subsequently experience disciplinary actions, a brief review of policies relating to behavioral supports and discipline procedures in federal and state policies are reviewed here.

The federal regulations for IDEA require the use of evidence-based practices (EBPs) for behavioral interventions and supports, and reference the use of Functional Behavior Assessments (FBAs) in connection with long term changes of placement (i.e., out of school suspensions). However, IDEA federal regulations do not provide requirements for how to implement these supports, what they must include, nor specify the requirement for conducting a FBA (4 ACC 07.010-07.900). For many states, including Alaska, there is nothing in state statute that requires conducting a FBA and offering a Behavior Intervention Plan (BIP) to address behavioral challenges or in response to discipline (even though deemed as an EBP), but rather the state regulations say to follow IDEA (E. Fraczek, personal communication, April 21, 2021). Furthermore, the Alaska Department of Education and Early Development (DEED) Special Education Handbook (DEED, 2020) confirms that there are no state regulations specific to the FBA process and provides guidance that schools shall “provide services, conduct an FBA & offer a BIP, as appropriate” (DEED, 2020, p. 93).

Under the IDEA §300.530(e) (2004) school teams must conduct a manifestation determination review to determine whether or not the child’s behavior that led to the disciplinary infraction is linked to his or her disability. A manifestation determination must occur within 10 days of any decision to change the child’s placement because of a violation of a code of student conduct. Again, even with a manifestation determination and despite strong professional recommendations (Collins & Zirkle, 2017), neither IDEA nor Alaska’s state regulations require a FBA/BIP (DEED, 2020).

In a comprehensive review of all states’ special education laws for FBAs and BIPs, Zirkle (2011) revealed that “...only 31 out of 50 states have statutory or regulatory provisions for FBAs and/or BIPs that exceed the requirements of IDEA and that most of the provisions are relatively limited in terms of scope and strength” (p. 267). In a follow

up study, Zirkle (2017) noted an increase from 31 to 35 states with provisions, but concluded, “the overall extent of the state law FBA/BIP provisions remain rather scant, particularly with regard to who must conduct FBAs and BIPs and the how, or procedural specifications, for FBAs” (see Section Discussion). Alaska is one of the states in which there is an absence of provisions. As one example of a provision exceeding IDEA, Utah has a state regulation which defines the features of a FBA (Section 1.E.19...) and specifically states, “[W]hen making decisions on behavior interventions, the IEP Team must refer to the USBE Technical Assistance (TA) manual that outlines the Least Restrictive Behavior Interventions (LRBI) for information on research-based intervention procedures” (UT III.1b(5)(a)). For a comprehensive review of FBA/BIP legal requirements and professional recommendations see Collins and Zirkle (2017).

State Policies Related to FASDs and Education

The most notable Alaska state policies addressing FASD in education are the Administrative Code under IDEA; the Criteria for Determination of Eligibility (ACC 52.130), which stipulates that those with FASD may qualify for special education under the title of “other health impairments”; and the Binkley Law (Statute 14.20.680), which requires alcohol or drug related training for educators. The Administrative Code adds FASDs to the list of possible health impairments which may impact a child’s success in an educational program; however it does not stipulate that any child with FASDs qualifies for special education or related services. Under IDEA, children must not only meet criteria for eligibility but also require special facilities, equipment, or methods to make the child's educational program effective.

The Binkley law was developed to ensure that Alaska educators understand the needs of individuals affected by prenatal exposure to alcohol. Due to the Binkley law, DEED offers an online training called “Prenatal Alcohol and Drug Related Disabilities.” Per state statute, the training must include an overview of the medical and psychological characteristics of drug and alcohol-related disabilities, highlight associated learning needs, and utilize the best available technology. The training is one of four trainings that are mandatory for teacher certification. There are no other required trainings related to FASDs for staff in the educational system apart from the training required in the Binkley law.

State and Federal Policies Related to FASDs Outside of Education

A number of notable policies related to FASDs outside of the education system exist and are briefly noted here as they intersect with the education system. Alaska has enacted several laws and policies regarding FASDs including:

- AS 47.20.290 which recognizes Fetal Alcohol Syndrome as a disability,
- AS 12.55.155 which allows mitigation in sentencing for those with FASDs in court
- AS 47.17.024 which requires healthcare workers involved in the delivery or care of a child who they expect was prenatally exposed to make a report to the Department of Health and Social Services (<http://www.akleg.gov/basis/statutes.asp#12.55.155>), and
- 7 AAC 50.820 and 3 AAC 304.465 which focus on training for both residential psychiatric treatment centers as well as alcohol servers (<http://www.akleg.gov/basis/aac.asp#7.50.820>; <http://www.akleg.gov/basis/aac.asp#3.304.465>).

At the federal level the “Advancing FASD Research, Prevention, and Services Act” is currently being reviewed. If passed, it would address multiple aspects of FASDs through policy, research, and services (NOFAS, n.d.).

Estimating Incidence and Prevalence of FASDs in the Alaska Educational System

The process of generating accurate estimates of incidence and prevalence of FASDs is fraught with complicating factors including the lack of standard agreement on how best to diagnose FASDs and inconsistency among the outcomes from research studies (Brown, Bland, Jonsson, & Greeshaw, 2019). Despite these barriers, there is no argument that FASDs continue to be a global health problem, and not just in educational systems but in sub-populations of children (e.g., children in care, children in correctional facilities, children receiving special education, children receiving specialized clinical services, and Indigenous populations) where prevalence is significantly higher compared to the general population (Popova et al., 2019). Thus, the need for ongoing assessments of FASD prevalence cannot be overstated. What follows is a brief discussion of the most common approaches in research to estimating the prevalence of

FASDs followed by information on the application of various approaches specific to Alaska.

Review of approaches for estimating incidence and prevalence of FASDs in educational systems

The term incidence commonly refers to the number of new cases of a medical condition that occur over a specified time period while prevalence refers to all new and existing cases. The number of studies within the literature that refer to the incidence of FASDs pales in comparison to the number of studies involving prevalence, at least in part because it is difficult to determine when new cases of FASD arise. May and Gossage (2001) argued that since FASDs can exist in a fetus up to seven months prior to birth with frequent spontaneous abortions among women who abuse alcohol, the prevalence of FASDs may actually be higher during some months of pregnancy than the number of cases recorded at birth. Thus, there is no point of time reference for when FASD should be considered a new case, and the conventional use of the term incidence as it applies to other areas of epidemiology, such as infectious diseases, does not apply in the context of FASDs. Since FASDs generally persist throughout the lifespan, May and Gossage used the term prevalence to describe the existence of FASDs among all age groups with no need for the term incidence in the traditional sense. Prevalence is therefore the predominant term used in the literature.

As described by May et al. (2009), the three most common approaches to the epidemiological study of FASDs are 1) Passive surveillance, 2) Clinic-based studies, and 3) Active case ascertainment methods. See Table 11 for a brief description of each approach along with some of their advantages and disadvantages.

Table 11. Common approaches to epidemiological study of FASDs

Approach	Advantages	Disadvantages
Passive surveillance - Use of existing record collections	- Use of pre-existing data - Inexpensive - Relatively easy to implement	- Lack of rigor/consistency of diagnoses - Affected by variation in quality of data sources
Clinic-based - Rigorous methodology with controls	- Opportunity to gather maternal history data - Opportunity to study large number of pregnancies with various levels of alcohol exposure - Greater control and rigor in measuring variables	- Self-selection biases - Difficult to get a representative sample - FASDs are not accurately diagnosed at birth

<p>Active case ascertainment</p> <ul style="list-style-type: none"> - Find and assess children who may experience FASDs 	<ul style="list-style-type: none"> - Involves children of appropriate ages for accurate diagnosis - Likely to uncover children with FASDs and mothers at high risk of abusing alcohol - Tendency to eliminate selection biases (if there is cooperation among various community constituencies) 	<ul style="list-style-type: none"> - Labor intensive, time consuming, costly - Cooperation required among many non-researchers (community, political, health, and education officials, parents, etc.)
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In general, estimates of prevalence rates based on passive surveillance studies tend to be lower than the prevalence rates from clinic-based studies, which in turn are often less than the estimated rates based on active case ascertainment studies (May et al., 2009). Furthermore, none of the approaches are easily implemented in an educational setting. Even the comparatively least costly and easiest approach, passive surveillance, often involves a significant amount of work since access to some types of records may not be readily available (e.g., medical records). On the other end of the spectrum, active case ascertainment methods, despite being the most costly and labor intensive approach, can still provide inaccurate estimates of prevalence if there is differential access to the various populations within the community. It is also important to note that the vast majority of FASD prevalence studies, regardless of the approach used, represent a snapshot of a specific point in time or they are based on aggregated data over a time span as opposed to ongoing surveillance involving prevalence estimates updated on a regular basis.

Application of various approaches/models to Alaska

Tracking the prevalence of FAS is more common than that of FASDs since the former is a more specific diagnosis and a subset of the latter. Egeland et al. (1998) conducted one of the earliest extensive studies of FAS prevalence in Alaska using a passive surveillance approach involving 16 data sources spanning the years 1977-1992. The CDC's Fetal Alcohol Syndrome Surveillance Network (FASSNet) used a similar multiple source passive surveillance approach to determine the FAS prevalence rate in four states including Alaska from 1995-1997 (CDC, 2002). More recent estimates for the years 2007-2017 come from the Alaska Birth Defects Registry (ABDR) which collects and reports on FAS prevalence (State of Alaska DHSS, 2021). Results are broken down by three-year moving averages, seven regions of the state, and various demographic variables.

Tracking the prevalence of FASDs is far more difficult compared to FAS. For example, it is not possible to calculate the prevalence of FASDs based on data from the ABDR due

to the lack of standardized diagnostic criteria for the entire spectrum of disorders. Furthermore, there are no prevalence studies within the literature specific to an Alaska educational setting. However, during an interview, Clayton Holland--Assistant Superintendent of Instruction for the Kenai Peninsula Borough School District (KPBSD)--described a brute force method for determining the number of students who experience FASDs within the district (personal communication, March 31, 2021). District staff reviewed the eligibility and associated medical record reports of students within the "Other Health Impairments" category for special education services to count those with an FASD diagnosis. The estimated time to complete the review process was less than two weeks. As reported by the McDowell Group (2020) in a previous interview, approximately 80 out of 400 students had an FASD designation. Other districts could use the 20% prevalence proportion within the "Other Health Impairments" classification to estimate the number of students who experience FASDs in their own districts, but the identification of FASDs may be higher in KPBSD due to the presence of an FASD clinic in the area, not to mention the large disparities (size, demography, etc.) that exist among Alaska's 54 school districts. Furthermore, an estimate based on the process described above would likely be conservative due to a lack of routine screening protocols and FASD awareness training among all educators, together with limited access to assessments. Also, there are likely special education service eligibility categories, in addition to Other Health Impairments, that include students who experience FASDs (e.g., Emotional Disturbance, Cognitive Impairment, Specific Learning Disability).

Another option for estimating the prevalence of FASDs in Alaska would be to extrapolate from the results of research studies conducted elsewhere. For example, one of the most commonly cited studies within the literature was conducted by May et al. (2018) using active case ascertainment methods involving four communities in the Rocky Mountain, Midwestern, Southeastern, and Pacific Southwestern regions of the United States. Despite the relatively diverse settings in the study, there are nevertheless substantial demographic and regional differences between Alaska and the represented communities that would render the extrapolated results highly questionable. A study by Popova, Lange, Burd, Nam, and Rehm (2016) used extrapolation to estimate prevalence in areas of Canada that had incomplete data based on data from other geographic regions. Even if reliable and accurate FASD prevalence estimates existed for some portions of Alaska, because the state is so diverse, it would be difficult to extrapolate results to many extraordinarily unique areas.

All approaches to estimate the prevalence of FASDs are difficult to implement in an educational setting for multiple reasons, including the challenges associated with gaining access to records associated with children and obtaining consent from parents/guardians to conduct diagnostic measurements/tests. Providing the most

accurate estimate would likely involve conducting an extensive active case ascertainment in numerous diverse areas around the state. However, as previously mentioned, such an endeavor would be costly, time-consuming, and only provide a snapshot in time. It is not a feasible approach for ongoing surveillance.

Instead of tracking the prevalence of FASDs directly, there may eventually exist the option of monitoring data from surrogate sources. For example, in Washington State, data from the Pregnancy Risk Assessment Monitoring System (PRAMS) showed a significant decrease in the prevalence of maternal alcohol use during pregnancy that coincided with a significant decrease in the prevalence of FAS (Astley, 2004). Of course, additional research is needed because the prevalence of FAS does not necessarily mirror the prevalence of FASDs. Since drinking behavior is also monitored by the Behavioral Risk Factor Surveillance System (BRFSS), future research may involve the development of a statistical predictive model of FASD prevalence based on data readily available from surveillance systems such as PRAMS and BRFSS. Though for much of Alaska, data from nationwide surveillance systems may not be conducive for analyses at the local level due to insufficient sample sizes in sparsely populated areas.

Literature Review

For the past three decades FASDs prevention and intervention programs have targeted students in the Alaska educational system. However, it is unclear what kind of information is available in literature about what educators and educational systems do in support of students with FASDs, and what kind of problems and needs they have in supporting students with FASDs. For these reasons, a scoping review was conducted in order to systematically map the research done in this area, as well as to identify any existing gaps in knowledge, recommendations for educational practice, suggestions for education policy and areas of future research. This scoping review was undertaken to identify the context, the range and variety of existing school-based interventions for students with FASDs, in addition to educator strategies and needs.

Scoping Review Methodology

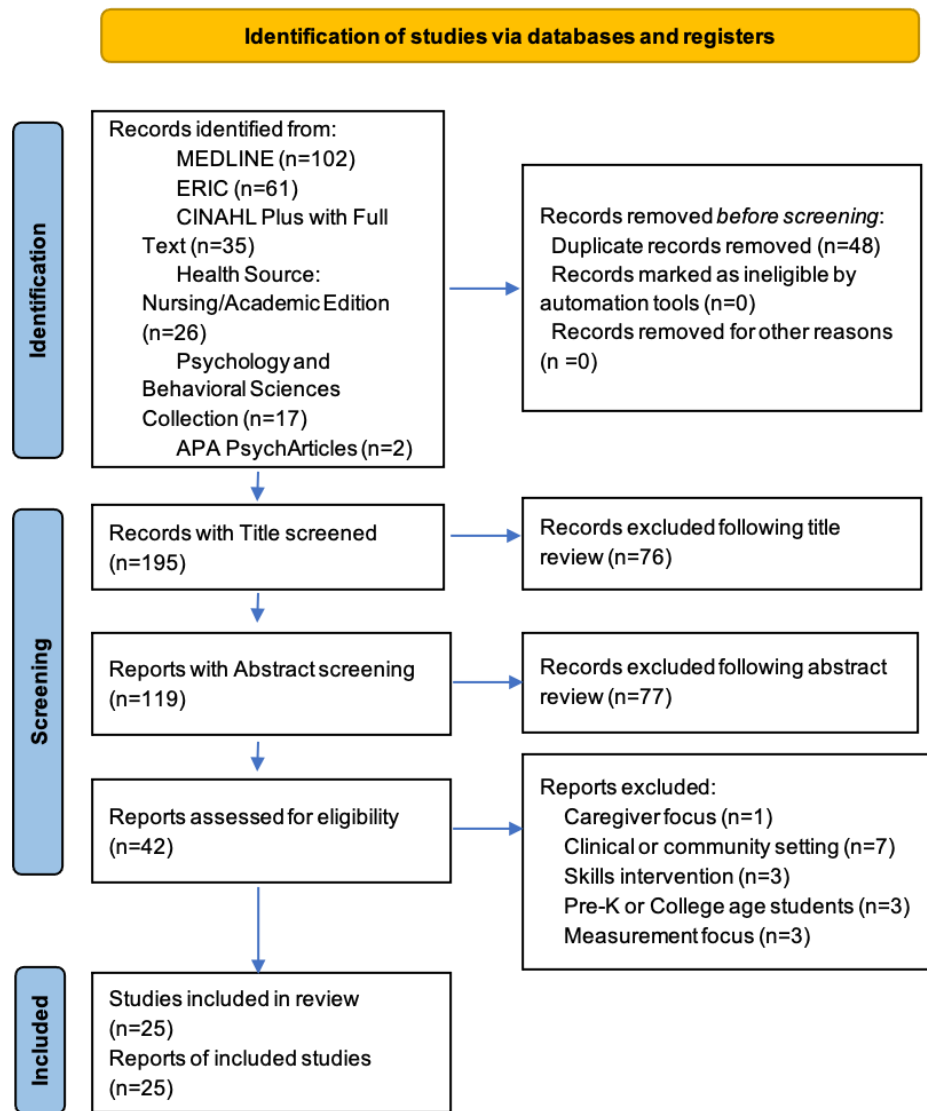
Scoping reviews are aimed at summarizing the scope, content, and specific research available on a given topic, with the aim of orienting practitioners, policy makers, and researchers to current gaps in knowledge and practice (Levac et al., 2010). The five-stage methodological framework described by Arksey and O'Malley (2005) was used as it is currently recognized as best practice for scoping reviews (Colquhoun et al., 2014).

The five stages are: 1) identifying the research question; 2) identifying relevant studies; 3) study selection; 4) charting the data; and 5) collating, summarizing and reporting the results. The findings are crucial for educators and education administrators to design and implement intervention programs for students with FASDs and to develop research directions that enrich evidence-based practice in education.

Our protocol was drafted using the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMAP), which was revised by the research team (VYH, DJ, HH, PB). Ethics approval was not required for this scoping review. To be included in the scoping review, papers needed to be focused in the educational system, pertaining to students with FASDs. Peer reviewed journal papers were included if they were: published between the period of 2000–2020, written in English, involved human participants and described an intervention supporting students with FASDs in the educational setting. Quantitative, qualitative, mixed-method studies and literature reviews were included in order to consider different stages of intervention development. Figure 5 provides the PRISMA-ScR flow chart which summarizes the selection of peer-reviewed articles.

The database search took place in February 2021. Electronic searches of the following databases were conducted: Academic Search Premier, ERIC, CINAHL with full text, Health Source: Nursing/Academic Edition, Psychology and Behavioral Sciences Collection and APA PsychArticles. The search strategies were drafted by the project lead (VYH) and further refined through team discussion. Electronic database searches were conducted using a set of defined subject keywords as follows: (fetal alcohol spectrum disorder or fetal alcohol syndrome or fasd or fas) AND intervention OR (fetal alcohol spectrum disorder or fetal alcohol syndrome or fasd or fas) AND education.

Figure 5. PRISMA-ScR flow chart



A customized data extraction instrument was developed to explore the scope of the available literature and to compare study design, subjects, location, methods, results, study limitations and implications for educational practice, policy and future research.

Studies were grouped the studies by the types of intervention, literature review, qualitative description of phenomenon, and educational practice then summarized the type of settings, populations, and study designs for each group, along with the measures used and broad findings.

Scoping Review Results

Ryan and Ferguson (2006) noted that there has been nearly no systematic research on the needs of students with FASDs or on the best educational strategies. Further, Blackburn, Carpenter and Egerton (2010) reported that systematic training for teachers to educate young people on the consequences of maternal alcohol consumption were also not present in the literature. Broadly speaking, across the existing literature on FASDs in the educational system there is a recognition that students who experience FASDs are prevalent in the educational system at a rate higher than reported in the literature and few evidenced-based interventions and educational strategies are taught to educators. The atypical learning processes and disruptive behaviors of students with FASDs are often outside of the expertise of teachers who find themselves “pedagogically bereft” (Carpenter, 2011).

With few FASDs specific intervention options in existence, educators and parents attempt to adapt strategies and frameworks intended for students with other disabilities. Adaptations are focused on the awareness that developmentally appropriate practices are needed to support each student with FASDs’ social, emotional, physical and cognitive development needs. A team approach to support students with FASDs in all grade levels was described as a best practice as was integration of students with FASDs into general classroom settings whenever possible.

In addition to classroom and curricula accommodations, the literature reviewed noted a need for enhanced ecological consciousness within the school system, where there is a leadership and system recognition that the diversity of students with FASDs should be embraced rather than excluded or folded within a general special education framework. Finally, many of the papers described the need for close relationships between parents of students with FASDs and the school team with a recognition of the advocacy role of parents in accessing resources for students within the school setting.

The following section describes specific findings per article grouping. The 25 articles identified in the scoping review fell into four categories: reviews of the literature, qualitative studies, intervention studies, and descriptions of educational strategies for students with FASDs (referred to as education engagement). Seven of the identified articles assessed education-based interventions directed at students with FASDs. Two articles described systematic reviews of the literature related to education and FASDs.

Six of the identified articles were qualitative studies that described the lived experiences of parents (biological, foster, or adoptive), early interventionists, teachers, and young adults living with FASD. Finally, ten articles described the educational engagement of students living with FASD. The majority of articles in all categories were focused on tertiary prevention, with only one (Boulter, 2007) focused on a primary prevention intervention. Although the scoping review was not limited to literature from North America, only two articles (Blackburn, 2010; Carpenter, 2011) were from outside the United States or Canada.

Reviews of the Literature

Of the 25 articles examined, two were reviews of the literature. The first review (Peadon et al., 2009) examined 12 different studies, while the second built upon the first and included a total of 32 studies (Reid et al., 2015). Both reviews systematically summarized the results of their respective studies by including each of the FASD interventions tested as well as an analysis of how well each study was conducted. Although there were relatively few interventions specifically geared towards individuals with FASD who were attending school, some were noted as having an effect and potential application in either education or learning skills.

Overall, of these interventions, only a small number showed real, noteworthy improvements. Furthermore, in general they seemed to approach the teaching of students with FASDs by focusing on very specific skills rather than a holistic manner. For example, Peadon et al., 2009 found that Cognitive Control Therapy improved personal behavior scores; and unnamed language, literacy interventions, and math interventions were linked to phonological awareness, improvements in literacy, and increases in math knowledge respectively. Furthermore there seems to be potential in using virtual reality games as a teaching method, although the game was used to teach safety and there were mixed results at follow up (Peadon et al., 2009). In the next review, aside from the overlapping studies mentioned above, interventions including the ALERT® program, The Computerised Progressive Attention Program, and activities from the pay attention training protocol focusing on self-regulation and attentional control showed positive gains, although with limited follow up. When addressing specific skills the MILE program showed some promise in improving math skills and behavior. Additionally, a group-rehearsal training improved digit span scores, and the cover, copy, and compare spelling procedure increased the amount of correct words spelt. From the teaching strategy standpoint, one study showed that training in the classroom environment led to fewer school problems and improvements in adaptive skills (Reid et al., 2015).

Based on the articles summarized, the authors of the literature reviews made the following recommendations in regard to both educational practice as well as future research. Perhaps due to the specific nature of the interventions, Peadon et al. (2009) recommended that interventions should remain focused on the problems most prevalent among those with FASD, with the stipulation that more quality research on interventions should be conducted. However, Reid et al. (2015) noted that interventions targeting multiple aspects of FASD would be helpful. Adding to their practical recommendations, they also made recommendations for future research, most notably, focused on providing a comprehensive framework, examining the interaction between the individual and their environment, and measuring intervention effects with different tools.

Intervention Studies

Unfortunately, only seven articles were identified that focused on specific education related FASD interventions. Of the seven articles in this category, only one (Boulter, 2007) could be considered a primary prevention intervention, while the others were geared towards tertiary prevention. The studies were a combination of individual case studies and case-control designs with sample sizes ranging from one to 642. The ages ranged from four to 19, although only two studies focused entirely on students aged 10 and under (Kully-Martens et al., 2018; Wiskow et al., 2018). The individuals participating in the interventions, sans the preventative intervention, either had a previous diagnosis of FAS, FAE, or FASD. It should be noted that not all of these were able to be confirmed with testing and there was limited specificity as to how the diagnoses were originally made.

As noted by Peadon et al. (2009) and Reid et al. (2015), the majority of tertiary intervention studies reviewed were rather specific, focusing on education or behavior strategies to target: spelling, reading, writing, and self-esteem through a tutoring program (Johnson & Lapadat, 2000); attention, behavior, working memory, and academic fluency through the Caribbean Quest Game (Kerns et al., 2017); disruptive behavior through the Good Behavior Game (Wiskow et al., 2018); and math skills and cognitive deficits through a modified version of the MILE (Kully-Martens et al., 2018). One of the other tertiary interventions looked at how an entire education center impacted those with FASD compared to other students (Flannigan et al., 2017), while another took a more holistic approach and looked at how a specific type of coaching could be used to impact overall metacognitive strategy use (Makela et al., 2019). The one study that examined primary prevention used a presentation and pre- and post-tests to see if overall knowledge of the effects of alcohol consumption during pregnancy improved (Boulter, 2007).

In each of these intervention studies, improvements were noted, but once again the majority of these were quite specific and only two studies included follow-ups (Boulter, 2007; Kully-Martens, 2018). The metacognitive coaching strategy did show encouraging signs by helping those with FASD. Furthermore, part of the purpose of this study was to test the feasibility of the intervention in schools, which does appear to be a realistic possibility (Makela et al., 2019). Another possibly interesting note is that the model used in a Canadian school model showed that FASD students do use services offered and that these services may be beneficial to those with FASD (Flannigan et al., 2017). Many of the recommendations made consisted of an urge to implement the interventions tested in classrooms, while others focused on teacher understanding and training. Finally, it was recommended that future researchers continue to study these interventions with various tweaks. Johnson & Lapadat, 2000, also recommended the use of longitudinal studies in the future in a variety of contexts, as well as studying FASD with possible comorbidities.

Qualitative Studies

Six studies used qualitative methods (photovoice, interviews, focus groups) to ask open ended questions of participants to explore and allow for first person experience descriptions of teaching and learning among students with FASDs in the educational setting. The articles in this group described data collected between 2009-2011. Two papers included adolescents who had a diagnosis of FAS (Brenna, 2017; Duquette, 2007) and the remaining four articles included educators who work with and parents who support students who have FASDs. Two of the six papers utilized data from the same overarching study but had different aims and analyses of the data source (Job, 2013; Poth, 2014). All but one paper (Koren, 2010) included a thematic analysis of findings. One paper (Pruner, 2020) described FASDs in early intervention, two papers (Benna, 2017; Duquette, 2007) focused on high school students and the remaining three papers (Job, 2013; Koren, 2010; Poth, 2014) described needs in the kindergarten through grade 12 span broadly.

Several key findings and recommendations for educational practice supporting students with FASDs were noted. Educators and caregivers noted that FASDs prevalence in the school setting is underreported and that assessment and diagnosis of children with FASDs are advantageous in students receiving access to special education supports in the school setting (Koren, 2010; Poth, 2014). The development of FASD-informed schools was noted by Brenna, 2017; Job, 2013; and Pruner, 2020 with an importance on staffing early interventionists, teachers, peers and members of the public who understand FASDs.

Relationships emerged as a necessary condition for enhancing communication and collaboration between school personnel and families (Job, 2013, Koren, 2010; Poth, 2014; Pruner, 2020). Students with FASDs have better social interactions in the educational setting and persistence in remaining in the school setting when they have an understanding of their own strengths and difficulties, are part of the team developing their learning targets and career goals (Brenna, 2017; Poth, 2014). Students with FASDs should have the opportunity to interact with peers at school (Duquette, 2007, Poth, 2014). Parental advocacy enhances the quality education for students with FASDs (Duquette, 2007, Poth, 2014) and additional external support in the form of a sponsor, coach, or mentor in addition to parents further enhances quality of education and quality of life for students with FASDs (Brenna, 2017).

The authors of the six qualitative studies suggested areas for future research. The authors note the need for research to amplify how FASDs are described objectively by youth with lived experience. Additionally, students should be asked to share their views longitudinally to better understand how their views change over the course of their educational experiences. Research is needed to understand how to strengthen school/family partnerships, understand how parental advocacy influences the quality of education and what programs and services will best support students with FASDs and their families and how schools should implement such programs and services. Finally, research is needed to determine how to better educate and train early interventionists and school personnel in teaching students with FASDs.

Education Engagement

There were ten articles identified describing educational strategies for teaching students with FASDs. Three of the articles (Harwood, 2002; Millar, 2017; Ryan, 2006) drew findings from specific educational settings and the educators within those settings (e.g. Winnipeg School Division, rural Alaska educators) with the remaining articles summarizing findings from the literature. Two articles were from the United Kingdom (Blackburn, 2010; Carpenter, 2011), one from Canada (Millar, 2017), two from Alaska (Harwood, 2002; Ryan, 2006) and the remainder were not location specific.

The ten papers reviewed offered suggestions for school level and classroom level strategies to support students with FASDs. These were not grade level or developmental stage specific strategies, rather the authors presented frameworks for consideration. We have summarized the salient strategies in the bulleted lists below.

Classroom level strategies to support the learning of students with FASDs:

- Welcoming environment
- Calm learning environment

- Classroom free from clutter
- Focused tasks presented in small steps
- Personal space for the student
- Link visual cues to verbal prompts
- Frequent, short exercise/movement opportunities during the day
- Multisensory learning
- Frequent re-teaching of skills

School level strategies and factors that support positive school experiences for students with FASDs:

- Supportive school administration/executive leadership
- Frequent neurobehavioral assessment with observation of skill development and gaps in natural environment
- Personalized learning based on individual learning characteristics gleaned from assessments and family observations
- Involvement of families and caregivers who provide valuable information on the curriculum and how the child is coping
- Development of shared realistic goals based on the child's individual assessment
- Multidisciplinary teams who regularly support students with FASDs that include physical therapists, occupational therapists, speech language pathologists, psychologists, special education and classroom teachers and paraprofessionals
- Using caregivers, teachers and others as external supports to help with executive functioning
- Implementing strategies to address cognitive, communication, social, emotional and physical developmental delays and preparation for employment among older students
- Supporting relationships with role models and non-parent mentors
- Repeated opportunities to role-play prosocial skills
- Placing appropriate structures (e.g., routines, consistency, supervision, specific work areas and visual aids/instructions) throughout the school environment to help the student know what is expected or decrease visual and auditory stimulation to decrease distractions

Conclusion

Despite the myriad of educational challenges and known importance of early intervention for students with FASDs, there is little published research examining effective classroom strategies for students with FASDs. Across the papers found in our systematic review, authors noted that children with FASDs typically experience significant deficits in executive functioning compared to both children without a disability and children with other disabilities impacting behavior such as ADHD. Children with

deficits in executive functioning struggle with inhibition, impulse control problems, difficulty in planning and organizing and challenges with emotional regulation. These impairments coupled with challenges with sensory processing, motor control, adaptive and academic achievement are difficult to address for classroom educators. Research gaps exist on interventions targeting students in the school environment, specifically interventions that target executive functions at the early childhood, elementary and secondary levels. Additionally, research is needed to better understand and enhance parent support and relationships with the school system staff. Finally, observational and descriptive findings from the field are needed in the literature.

Focus Groups on Lived Experience with FASDs in the Education System

Having a comprehensive understanding of the impact and lived experience for students who experience FASDs and their families is necessary to understand student transition points, noted resources, and gaps in service. Children who experience FASDs may or may not demonstrate the need for K-12 school supports. Some individuals with FASDs may qualify for special education services under a variety of eligibility categories, including but not limited to Emotional Disturbance, Learning Disabilities, Autism, Cognitive Impairment, or Other Health Impaired. It is known that critical shortages in special education teachers and related service personnel exist across the nation and shortages of these professionals are magnified in regions characterized by poverty and rural geography. This is particularly salient in Alaska where access to and turnover of special education teachers and related service providers (including behavioral health providers) is exacerbated by physical geography. As noted in the scoping review (see section “Literature Review” above), the viewpoints of individuals who experience FASDs are absent from the literature. Further, the Alaska Developmental Disabilities (DD) Shared Vision signed into law in 2018 states, “Alaskans share a vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, toward a meaningful life in their home, their job and their community.” Therefore, in alignment with the literature review findings and the DD Shared Vision, the focus groups sought to include both individuals with lived experience of FASDs and caregivers of students with FASDs to share their stories.

Potential focus group participants were 1) parents/guardians of students with lived experience of FASDs, and 2) individuals aged 18 years and over who have lived experience of FASDs and were students in the Alaska educational system. An electronic flyer inviting individuals to participate in the focus group interviews was

distributed using a convenience sample through the project's advisory committee, FASD workgroup listservs, and the CHD Facebook account. The invitation explained the project and participant eligibility and outlined the schedule for focus groups. If people were interested in participating in the focus groups, they were asked to contact a research team member. The research team members gathered information relating to individuals' lived experience with FASDs, Alaska educational experience and accommodation requests; described the focus group process and purpose; and answered any questions participants had about the focus groups. Individuals who met the inclusion criteria were sent the Zoom link for the requested focus group date.

Focus Group Methods

Focus groups were conducted using Zoom as a way to include a combination of rural and urban locations. Focus groups were limited to eight people per group. An incentive was offered for participating in the focus group and participants were given an electronic \$50 gift card to Amazon.com as a thank you for their time.

Prior to beginning the focus group discussion, participants were read a verbal informed consent and provided an opportunity to ask questions. To ensure confidentiality, participants in the Zoom session were renamed and were referred to by their pseudonym. Experienced qualitative researchers served as moderators for the focus groups. Moderators utilized standardized open-ended interviews where the question wording and the sequence of questions were predetermined. The standardized interview format allowed all respondents to answer the same questions and increased comparability of responses. This format also helped to reduce interviewer bias and more than one interviewer was present to conduct the focus group. Four major questions were asked:

1. What were the most important things in education for you/your child and your family?
2. Can you share what educational placements and supports you/your child experienced as they moved up through the school system?
3. Was there ever a time you disagreed with those in the school system on what was appropriate? How did you handle the situation?
4. What helps students who have FASDs have academic success in the educational system?

Focus groups were recorded, only after consent was obtained and participants were renamed, and written notes were also taken for analysis purposes. Focus group recordings were reviewed independently by the contributing researchers and each

noted salient identified themes with supporting quotations. The researchers met multiple times to synthesize themes and subthemes. The analysis was done by hand rather than through use of qualitative software to increase engagement with the data (Charmaz, 2000) and interpretations were made using inductive reasoning (Patton, 2002). All aspects of the focus group portion of the project were approved by the University of Alaska Anchorage Institutional Review Board.

Focus Group Results

Two focus groups were held with a total of 10 participants. All of the participants were mothers to children with FASDs, with the exception of one male student participant who experiences FASD. Participants had experiences in all stages of public education (Infant Learning Programs through post-secondary education) and had described educational experiences of their children who experience FASDs in small village settings, rural hub communities and urban centers. Some of the participants were parents to multiple children with FASDs in various stages of the school system and diagnosis. Half of the focus group participants were currently or previously employed in the Alaska educational system, with three having experience in special education.

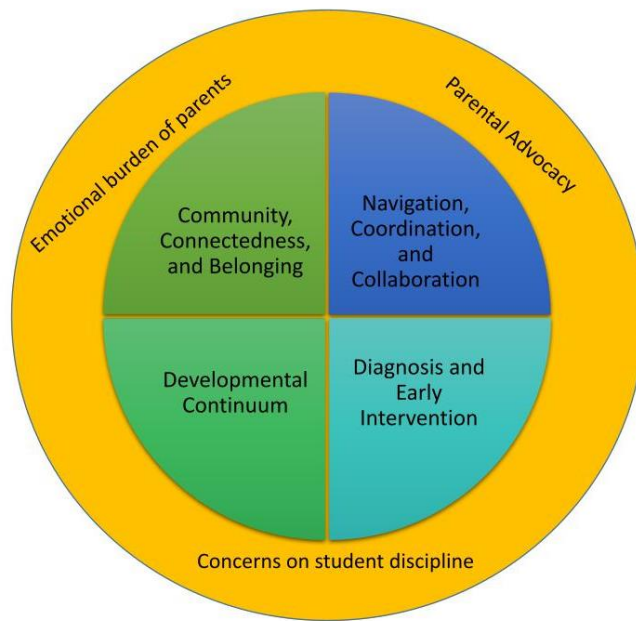
Parent participant responses and stories were consistent within and across the groups. Participants provided rich, detailed descriptions of their experiences with the school system, including supports that were or were not helpful, and described how their children who experience FASDs currently interact with, and move out of, the education system in Alaska. Participants discussed standard transition periods (e.g. entering into the educational system, moving from pre-kindergarten to kindergarten) and also highlighted critical social-emotional developmental periods (e.g self-consciousness grades 3-4 and hormonal changes in 12-14 year olds). The positive attributes of students who experience FASDs were rarely mentioned. This could be due to lack of participation of individuals who experience FASDs in the groups. Perseverance and hopefulness for the future were noted by the student with FASDs who said: *“What you do now determines what happens later. So I mean, if you are trying and all that, and yeah you failed but it’s going to turn around later. What you put in, it’s gonna pay off. Life is like a bicycle ride- every downhill has a price to pay. Everyone loves downhills on their bike but you’re going to have to go uphill.”*

Cross Cutting Themes

Although the groups were small in size, the conversation was robust. Participants frequently endorsed comments made by others in the group as related to their experiences or their student’s experiences with the educational system despite differences in geographic location. Three cross-cutting themes were identified: 1)

Emotional burden of parents, 2) Parental advocacy, and 3) Concerns on student discipline, and four sub-themes: 1) Navigation, Coordination, and Collaboration; 2) Diagnosis and Early Intervention; 3) Developmental continuum; and 4) Community, Connectedness, and Belonging. Cross-cutting themes were present within the sub-themes and sub-themes were often described in concert with one another (Figure 6. Conceptual framework of focus group themes).

Figure 6. Conceptual framework of focus group themes



The cross-cutting theme of **emotional burden of parents** was present throughout the discussion groups. Parents spoke candidly about the emotional toll they felt as they sought to support their child in the educational system. They shared anecdotes about their disappointment with themselves and the systems in understanding and supporting their child in a timely and child focused manner. They commiserated over the effects disciplinary actions had on their child’s relationship to the school system and more so, their entire experience of learning. One parent reflected on the stories being shared in the focus group and said,

I'm really resonating with the pain that parents feel. I lived with that for so many years. I guess that my biggest input for this committee [focus group] is that if the school district is failing these kids so much and families are suffering so much this is a bigger issue than saying we need to do inservicing for our teachers [scoffs and snuffles]. There's a lot of pain here. It's bringing up a lot of old stuff for me.

Another cross-cutting theme was **parental advocacy**. Parents described feeling alone in navigating services and being misunderstood while advocating on behalf of their child. They described years of persevering to access school-based services including IEP or 504 plans to support their child in school. One parent told a story of advocating for several years despite her child having an FAS diagnosis in early childhood:

I've tried since she was in pre-school, knowing what her struggles were going to be, I got her diagnosed at age 4 with fetal alcohol syndrome and then I started my research about it. And realized, like somebody mentioned, finding out early what they have but there is a dearth, it's like a desert. Once you find out, where do you go with that? Because everyone is asking questions but no one really has the answers. So I tried to get her on an IEP, to have those extra supports and I just found barriers. We were in Ketchikan, they said no she didn't need it. We went to Sitka, they said no she didn't need it. I came to Anchorage, and it wasn't until she was 3rd grade and they said you might want to consider a 504. And I said "thank you, I've been trying since she was 4 [years old]" but we got the 504 but really it wasn't until she had a teacher in 6th grade and he had a brother...but this teacher shared that he understood my child.

The final cross-cutting theme was about parental **concerns around disciplinary actions**. Several stories were shared about disciplinary action taken to correct student behavior with little understanding by the student as to what they did wrong. The purpose of the discipline was unclear given the lack of cognitive understanding of the student due to their developmental delay. One parent said, *"It's hard to see kids get treated that way, especially when they have special needs. I think that's what triggered everything after. He has a hard time in school now. He is a junior in high school."* Several parents described suspension as a turning point in their child's willingness to return to school, a decline in the child's view of their self-worth, and loss of tenuous social connection in their community. A parent described her dismay and frustration due to a two week suspension in this story:

When schools have zero tolerance for drugs, I think people in this group are sharing that [zero tolerance] is so detrimental to these kids...all kids with special needs. If they're special needs and can't understand the meaning of a two week consequence [gives example of 9th grade daughter who had smoked weed then came to school]....there was a week that she did a class about drug abuse and then the 2nd week she thought she'd go back to school. And when she couldn't, her routine and anything she found of consistency was gone. She ran away from home that week. Got in trouble, was suicidal,

almost died. And from there, being on the streets, we got her into treatment. But to me, that was a big turning point. And it wasn't that she didn't understand that there was a big consequence but for her, that two week consequence of staying home and being away from her friends at school, she could not cognitively really grasp that. And once you do a traumatic thing like others have said and that seems to set the stage for how they see themselves for the future in education...this zero tolerance thing has been so hurtful for so many special needs kids. Two weeks for a kid who doesn't understand what they did is just so detrimental. If they don't have the cognitive understanding, not just FASD kids but other special needs kids, if they don't have the cognitive understanding, what is the purpose and the point of doing that?

Sub-Themes

The subtheme of **navigation, coordination, and collaboration** emerged across multiple parents' experiences and reflected both challenges and successes. Parents reflected challenges in navigating services, and in particular, decisions around school choice. A number of parents expressed challenges with traditional school experiences and sought out Charter schools, which offered more project-based, arts-based, or inquiry-based learning experiences that they felt were more aligned with their child's needs. However, some parents described this as a "trade-off" as those school placements then lacked the resources to provide individualized special education services and for one family, they were "invited" to leave the school. School-based collaboration and coordination was continuously referenced and included challenges in teachers' understanding of FASDs or making incorrect assumptions; challenges in feeling and being included as a parent on the team; and recurring challenges with discipline policies and procedures, as previously noted. One rural parent described the IEP meeting as a key event requiring advocacy, navigation, coordination and collaboration, as she said:

When we walk into an IEP meeting, those can be nerve racking. It is you the parent and you've got the principal, the teacher, the OT, the PT, the speech and the SPED coordinator and the resource group and they are all on the same page but when they can step back and include you in that process, that really, really helps to a parent or myself realize that you are not giving my child services because these are the things that we are focusing on and let's all work together because that's what's best for the child, especially for the long run- when our student is outside of the school world, the school environment.

Few successes were noted, which included when school teams made individualized adaptations for their child (not necessarily reflected on an IEP) such as allowing for a delayed middle school start, having the school nurse provide a break spot for one child, or having a teacher who "understood" because they too had lived experience.

Numerous parents discussed the weight of having to coordinate services outside of school. Many sought private occupational therapy, speech-language, counseling, and/or academic tutoring services which often were not offered within the school system because their child was not eligible. For example, one parent expressed that although her daughter did not qualify for Speech-Language services, she struggled with social communication and making/maintaining friendships; she felt these services were necessary to help teach her daughter these skills which she was not learning in the school setting. Similarly, multiple parents sought private counseling services for mental health supports, again which they felt were lacking in the school setting. As one parent from a rural community stated, *“I would seek counseling for my children because I felt like we weren’t meeting their needs and they would say they are fine, they are just kids. I was told that the Native community isn’t competitive so your kids are not competitive, more apathetic. This was very upsetting to me.”* Finally, within this sub-theme a few parents discussed the difficulty with navigating dual roles when they worked within the educational system and were also parenting a child and advocating for their needs, as one parent stated, *“I was an Administrator in the Special Ed department...I knew the system and I couldn’t get help for my kid.”*

Diagnosis and early intervention was another recurring sub-theme. Multiple parents expressed the critical role of a medical diagnosis (or lack of) in accessing (or not accessing) school-based and/or community-based services. For those who were not able to obtain a medical diagnosis due to geographic location limitations or absence of family history, this hindered their ability to receive services within the school setting. For one parent, she was told she needed a diagnosis of FAS in order for her child to qualify for OT and PT services. Furthermore, a number of children with FASDs did not meet eligibility criteria and did not demonstrate a need for specialized or related services in early elementary school, often because their academic deficits were not “severe” enough despite experiencing cognitive (e.g., executive function tasks) or social challenges. However, a critical transition point in 3rd grade was experienced by more than one family in which their child’s academic gaps and slower rates of growth became more apparent. For some, this resulted in qualifying for special education services and for others the academic gap was not severe enough, yet cognitive and social challenges persisted. A number of parents reported that eventually their child was eligible for a 504 Plan, which provided some academic support but this typically didn’t occur until middle school and in some cases was not followed. One caregiver expressed, *“Most teachers didn’t care to accommodate, no accountability. Had an experience with a teacher that wasn’t good and sought resources elsewhere. Home schooled, private speech, private counseling. It was all on us, all of it.”*

The **developmental continuum** was the third identified sub-theme, which reflected the idea of recognizing, understanding, and supporting where children are developmentally

across all domains (i.e., cognitive, social, emotional, physical) and adjusting one's expectations across time. For some, this meant their child was performing academically within grade level expectations, yet their social and emotional development were not where teachers expected. This resulted in missed opportunities for teaching those skills and subsequently, disciplinary actions for many because they were "expected" to know how to behave. For one parent, the developmental continuum meant missing critical skills (i.e., alphabet order and sounds) because the focus was on grade level expectations.

One of the biggest successes for our kiddo was actually meeting them at their level. They're so sometimes you see they are hitting them at grade level and I see so much of not meeting them at their level, not seeing where they are. We are going to continue the 6th grade math book but because of COVID, we backed things up and I realized that he did not know, he is 13, and he did not know and still does not know his ABC's in his head. So we were struggling with reading and we realized that he still can't tell you the ABCs in order and he is 13 years old. So how did we miss that? Where did that fall through? Because someone was so busy about making him at grade level that that wasn't even caught. He is in 8th grade so like nine years of schooling.

Another emphasized the importance of individuality, *"All of my children are different academically and social emotionally. We have different goals for our children and different expectations for each one of our children. Teachers need to be able to see them as individuals with individual capabilities and abilities."*

The final sub-theme identified was **community, connectedness, and belonging**. Throughout the focus groups, participants discussed what facilitated and detracted from having social connections within the school setting. Parents described feeling disconnected to their child's schools and their child having poor interpersonal relationships and interactions with most school personnel. As one stated, *"It's not just all about academics. It's about feeling that you belong to an educational community. And she doesn't and will never, like she hates the institution."* Students and families did not feel they belonged and described disconnecting from the school community because they were not welcomed and had different perspectives on student success and goals. A student with FASDs shared, *"One more thing, [it] would be good if teachers were more understanding. [I] wish that teachers would understand the kids more. Kids don't do stuff for no reason. Kids do stuff because they are trying to get to a point."*

Positive connection was described when there was longevity in school personnel. Success in developing and maintaining positive interpersonal relationships with school staff was dependent on teachers who had an understanding of FASDs, were non-judgmental of student behaviors, and had personal experience (e.g. family member with a developmental disability) to draw from. The awareness of educators on the community

and the cultural context of families was noted as a facilitator to building trust, developing a sense of understanding of the family's home context, and developing common goals for their child. One parent described how partnering in their child's education worked best for their family:

[The most important thing in education] is the willingness to work together for a common goal. To really sit down and say okay, are academics the most important? Are social-emotional regulations? Having that open dialogue to where the specific teachers can call me or text me or email me and know that I will respond. That we are working together. That we are utilizing even the same terminology. Like 'use your words and not your body to express your emotions' and utilizing the same calm down techniques and tactics and verbiage. Allowing time for processing. Allowing us [family] to be part of that conversation. Not treating us as though we know less than them or that we are not equal partners in the education and the future of our children.

Conclusion

Parent experiences with the educational system, student transition points, noted resources, and gaps in services were similar regardless of urban/rural location. Turnover of educators, staff and administrators as well as student discipline practices were noted in all settings as detriments to student success. Parents noted school district variability in the assessment and type of supports offered to their child. The positive outcome for students with FASDs that was noted by parents was community integration and creating a system of education where *"our children are as independent as possible by the time they graduate from high school."* Perseverance of students in the educational system, ongoing advocacy of parents with educational staff who were aware of the needs of students with disabilities led to positive outcomes in the education of students with FASDs.

Survey of Educators' knowledge, experience, and perspectives

Educators' knowledge, experience, and perspectives are key to understanding the educational experience and success of students with FASDs in Alaska's educational system. As such, a survey was developed and distributed to Alaska educators to gain better understanding of educator knowledge of FASDs, as well as noted transition

points, resources, and gaps in service for students with known or suspected FASDs. The survey responded to five related research questions:

- 1) What is the FASD-related knowledge, attitudes, and behavior of educators?
- 2) What are the needs of educators and the educational system in supporting individuals experiencing ASD?
- 3) How do individuals experiencing FASDs currently interact with, and move out of, the education system in Alaska, addressing students from preschool through the completion of their secondary education?
- 4) What are the barriers and opportunities for FASD related prevention and educational programming for students from preschool through high school graduation?
- 5) What are current best or promising practices and programming to help students experiencing FASDs address their educational needs?

Online Survey Methods

The 46-item survey was developed by a team of researchers at the Center for Human Development, reviewed by the project's advisory group and based on key themes in the FASD literature. To reduce the burden on respondents, the survey was formatted in Qualtrics using display logic and only a few questions were required. The survey was distributed between March 22, 2021 and April 11, 2021, to educators in Alaska's school system using a single, sharable hyperlink. Participants were recruited through key stakeholders and listservs of educators, counselors, and disabilities advocacy groups. Eligible participants included individuals ages 18 years and older who are educators within the Alaska public school system. Target audiences included special education paraprofessionals, special education teachers, special educators directors, Infant Learning Program Coordinators, Infant Learning Program Developmental Specialists, and counselors; though responses from general educators and other related service personnel were also included.

Consent and eligibility information were provided at the beginning of the survey prior to answering questions. The survey included seven demographic questions on gender, race and ethnicity, primary work location, current position, years of work experience, highest education level and if they had lived experience with FASDs (e.g., as a parent, foster parent, sibling, grandparent). Respondents were asked about their primary work location using the regions from the DHSS ILP map (http://dhss.alaska.gov/dsds/Documents/InfantLearning/pdf/ilp_map.pdf).

A set of five questions on FASD-related knowledge, attitudes, and behavior of educators were included. A set of four questions addressed FASD prevention activities offered at the school, barriers in providing care/services to students/families with

FASDs, resources, connections, or information available to navigate barriers with an open-ended question on areas of support that are needed for students/families with FASDs. A series of questions on gaps in education services for students who have or are suspected to have FASDs by portion of the educational system (e.g. early childhood, pre-kindergarten, elementary, secondary, post-secondary) and a question on awareness about the resources available to individuals who have FASDs after they exit school were asked. A set of open-ended questions on barriers and opportunities for transitioning between stages in the educational system for students with FASDs (e.g. transitioning between 0-3 years to preschool, transitioning between preschool to elementary, transitioning between elementary to secondary, transitioning between secondary to postsecondary) was included. Finally, questions on current best or promising practices and programming to help students experiencing FASD address their educational needs related to training were included.

Results are shown with summary statistics and narrative summaries for open-ended items, as well as tests of significance involving questions for which comparisons were of value. The number of respondents is provided for each analysis. All analyses were performed with SPSS Version 27 (IBM Corp., USA). Survey protocols and questions were reviewed and approved by the University of Alaska Anchorage Institutional Review Board.

Survey Results

Demographics

There were 378 respondents to the survey, of which 345 were included in the analyses. Exclusion criteria consisted of whether or not respondents answered any questions outside of the demographic section. The vast majority of respondents identified as women (86.4%) and were white/caucasian (90.6%). The survey received responses from all over the state, although the majority came from either the Matanuska-Susitna Borough (31.6%) or the Anchorage, Girdwood & Whittier (22.0%) service areas. The remaining 46.4% were divided between the other 14 service areas, with no area contributing to more than 10% of the responses (Appendix F: Figure A 3). Special Education Teacher (31.6%) was the most common profession among the respondents, followed most predominantly by Paraprofessionals (16.4%), Counselors/Psychologists (14.1%), and Aides/Assistants/Support Staff (13.51%) (Appendix F: Figure A 4). The majority of respondents had completed a Graduate or Professional degree (56.5%) (Appendix F: Figure A 7) and on average, respondents had 10.05 years of experience in special education in Alaska, although with a large degree of variance ($SD = 8.26$) (Appendix F: Figure A 6). Approximately eighteen percent of respondents stated that they had lived experience with FASDs, which could include as a parent, foster parent,

sibling, etc. (Appendix F: Figure A 5). Their experience adds immense value to the results of this survey.

What is the related knowledge, attitudes, and behavior of educators?

Respondents displayed general knowledge of FASDs and largely agreed with the fact that FASDs are preventable and that prenatal alcohol exposure (PAE) negatively affects many aspects of an individual's life including motor skills, memory, judgement, ability to plan, ability to reason, and cognition (Appendix F: Figure A 8 Figure A 9). However, on average, respondents demonstrated a general lack of familiarity with organizations, programs, and websites that are involved in the direct or indirect assistance of individuals with FASDs (Appendix F: Figure A 11). Furthermore, although respondents displayed relative confidence on a scale from zero (Not at All confident) to five (Totally confident) in recognizing physical signs ($M = 3.25$, $SD = 1.22$), behavioral signs ($M = 3.27$, $SD = 1.21$), and cognitive signs ($M = 3.27$, $SD = 1.20$), their level of confidence in actually providing programming and supports to children with FASDs was significantly lower ($M = 2.92$, $SD = 1.32$) ($P < .05$) (Appendix F: Figure A 14). In terms of their collaborations with school-based team members to support individuals and families outside of the IEP and/or 504 meeting, 36.3% said they collaborated with each other "Never" or "Rarely", 28.9% said they collaborated "Occasionally", and 34.8% reported that they collaborated "A Moderate Amount" or "A Great Deal", highlighting the potential need for increased communication in the effort to support students with FASDs (Appendix F: Figure A 12).

What are the needs of educators and the educational system in supporting individuals experiencing FASD?

Not only do the students with FASDs and their families have needs but the educators supporting them have needs as well. When asked about the barriers educators face in providing support, respondents provided enlightening statements which were summarized into themes. The major themes included family resistance, which in turn impacted receiving a diagnosis; a lack of knowledge, time, training, staff, consistency, and funding; and communication issues and stigma (Appendix F: Figure A 37). In regards to family resistance, one individual stated that,

The family [is] unwilling to participate due to ongoing guilt or misunderstandings of FASDs. Often our parents are the victims of FASDs as well and the "normal" is measured differently in communities with high-incidents of FASDs.

Another said this about the lack of general knowledge or understanding of FASD:

Acknowledgement that they are FASD. Student[s] with FASD have struggles that others don't. They are often treated like [a] student with learning disabilities (SLD) and it is much more complicated than that. So the educators don't understand why they are completely with them today and like a blank page the next. That has been the most frustrating because then they tend to give up and try to push them off on the SPED department all day.

In response to these barriers, educators also provided insights into what resources would be helpful. Consistent comments in response to this question included how helpful it would be to have one place to go where there was clear and succinct information or as one respondent put it, a “clear presentation of what all the resources are and how to access them.” Furthermore, educators advocated for further training and access to local experts (Appendix F: Figure A 38). Continuing to offer prevention activities in schools is one additional way to benefit both educators and families. Based on respondents' answers it would appear that health classes, FASDs awareness activities, and parenting classes are the most common forms of current prevention activities. It is encouraging that of all respondents only 6.6% said there were no prevention activities offered (Appendix F: Figure A 13).

How do individuals experiencing FASD currently interact with, and move out of, the education system in Alaska, addressing students from preschool through the completion of their secondary education?

Respondents to the survey provided valuable information about observed gaps in the education system for those with FASDs and at what stage of the educational experience these gaps are occurring. Compared to the other stages, Secondary Education was selected most often as having gaps. Other trends included the fact that diagnosis and funding were more commonly mentioned as gaps in the early stages whereas mental health supports and transition supports were more commonly noted in the later stages. Lack of staff was a concern noted across all stages of the educational experience (Appendix F: : Figure A 15, Figure A 16, Figure A 17, Figure A 18, Figure A 19, & Figure A 20). However, these results should be interpreted with caution as it is possible that individuals only responded in the age groups where they had the most knowledge, and these results could be a reflection of what age groups respondents work with rather than as a comparison of gaps between the age groups. In addressing transitions out of the school system, respondents were quite unaware of resources to support this transition ($M = 1.59$, $SD = 1.43$ on scale from 0, “Very Unaware” to 5, “Very Aware”), highlighting a critical area in which improvements can be made.

What are the barriers and opportunities for FASDs related prevention and educational programming for students from preschool through high school graduation?

The barriers for students with FASDs and their families are many. To find patterns to these barriers, survey respondents were asked what was particularly difficult as students with FASDs made transitions (e.g. early childhood, pre-kindergarten, elementary, secondary, post-secondary). Common challenges included lack of supports and resources, inherent challenges from FASD symptoms, challenges with the transition itself, and challenges in regards to the diagnosis. Although these themes were present in each of the educational stages, it should be noted that more educators mentioned certain themes during certain stages. For instance, it is apparent that receiving an accurate diagnosis is a particular challenge in early education, whereas when moving from secondary to postsecondary it is the actual transition itself that presents as more of a problem (Appendix F: Figure A 29, Figure A 30, Figure A 31, & Figure A 32). Some particular areas of support that were identified as needs included more community resources and awareness, an increase in training, and a decrease in shame and stigma so parents might be more willing to seek help. To this point one individual stated,

It is a touchy subject? Parents feel shame and blame from others if they admit FASD. If we could eliminate some of that they might get help for their children sooner. We need the message to parents to change and we need to change our hearts and minds so we don't blame and shame them. We educators can be very critical at times.

Although it is easy to focus on these challenges, it is also important to note what is working for these students and families. Across all stages, it was made evident that specific interventions, strategies, and supports were quite helpful. Of these, clarity, consistency and routines, as well as structure and a helpful and supportive staff were mentioned quite often. In the early stages it was noted that when individuals had been assessed and it was determined that they needed special education services, early intervention and receiving an IEP were critical. One educator noted that,

If there is an IEP in place they are immediately placed on a SPED caseload and can receive services both in and out of the [general education] gen. Ed setting as needed. They are supported and monitored as needed.

In later stages parent support groups also seemed to play an important role and several respondents mentioned the importance of going into the post-secondary setting with good relationships already established, and quickly getting in contact with the Division of Vocational Rehabilitation (DVR). Communication was also a major theme, both between families and schools as well as between staff (Appendix F: Figure A 33, Figure

A 34, Figure A 35, & Figure A 36). There is certainly much to improve on and several key barriers for students with FASDs and their families, but it remains important to continually investigate what is going well and how that can be built upon and disseminated to more individuals.

What are current best or promising practices and programming to help students experiencing FASDs address their educational needs?

One piece to ensuring best-practice in programming and interventions for students with FASDs is to train educators. Forty-three percent of respondents said their employer required them to complete FASDs specific training (Appendix F: Figure A 21). However, this number could either be an overestimate or underestimate depending on whether respondents considered the Binkley law training (Alaska Statute 14.20.680) to be employer required. As mentioned in the Review of Statutes, Regulations, and Policies section of this report, the Binkley law requires each teacher, administrator, counselor, and specialist in a school district to be trained on alcohol and drug related disabilities. The DEED online module “Prenatal Alcohol and Drug Related Disabilities” is intended to fulfill the Binkley law training requirement. That being said, when asked which trainings and courses had been completed, of which the DEED trainings were listed as choices, 15.9% of respondents said they had not completed any FASD-related trainings/courses, and in the last year only 31.9% of educators reported receiving specific training on providing programs and supports for students with FASDs (Appendix F: Figure A 22). Besides the DEED trainings, other notable trainings and courses that respondents had completed included 8 Magic Keys (10.3% of respondents), Centers for Disease Control and Prevention (CDC) FASD trainings (9.1%), the University of Alaska Fairbanks Education: Special Education Course (6.3%), the Anchorage School District Academy FASD-focused training (6.0%), and the FASD into Action course from the Stone Soup Group (5.6%) (Appendix F: Figure A 27). Respondents rated the helpfulness of these trainings, and although (Appendix F: Figure A 28), there were not enough responses to run a meaningful test of significance comparing these ratings, it should be noted that they ranged DEED Prenatal Alcohol & Drug Related Disabilities webinar ($M = 3.79$, $SD = 1.03$) to 8 Magic Keys ($M = 4.2$, $SD = 1.16$) (Appendix F: Figure A 28). These ratings were on a scale from zero (“Extremely Unhelpful”) to five (“Extremely Helpful”).

Finally, respondents were asked to report on which specific interventions they have received training. Of those that had received intervention training ($n = 270$), 74.1% had received training in Positive Behavior Supports and Interventions, with the next most common being Applied Behavior Analysis (ABA) (39.6%) and Non-Violent Crisis Intervention (NCI) (38.1%) (Appendix F: Figure A 23). Of those who had received training in Positive Behavior Supports and Interventions, most had received the training as part of a workshop or seminar (74.9%) (Appendix F: Figure A 25). The following

interventions were the least selected with less than five percent of respondents having had received training: Parent-Child Interaction Therapy (PCIT), Facilitating Attuned Interactions (FAN) Training, Parents and Children Together (PACT), Parents Under Pressure (PuP), Math Interactive Learning Experience (MILE), Families Moving Forward (FMF), and Good Buddies (Appendix F: Figure A 23). Of those trainings with a large enough sample ($n > 26$) there was no significant difference in respondent's level of satisfaction (Appendix F: Figure A 26). That being said, it is evident that more training should be required and that the quality of training could be improved.

Conclusion

Overall, the survey responses and data collected were quite insightful. It is apparent that students with FASDs, their families, and the educators involved need more support. Although educators may be aware of these needs, there is a general lack of knowledge and information on what can actually be implemented. There is a lack of familiarity with programs available for those with FASDs. The quality of trainings, as well as the proportion of educators receiving these trainings needs to be addressed. Furthermore, as mentioned in the Literature Review section of this report, there is a lack of effective interventions and strategies for those with FASDs, and of the interventions educators may receive training on, only the MILE, is specifically created for those with FASDs. Finally, while educators stressed the importance of communication, there is much that needs to be done to improve collaboration between education staff as well as between families and educators.

Report Key Findings

The first two key findings (Binkley Law Training and Behavioral Support Training and Needs) are priority recommendations.

Binkley Law Training

Per state statute, the training provided under the Binkley Law must include an overview of the medical and psychological characteristics of drug and alcohol-related disabilities, highlight associated learning needs, and utilize the best available technology. Currently this is implemented through DEED's online training called "Prenatal Alcohol and Drug Related Disabilities." As noted early in this report (see "Survey on FASDs Experience in the Education System"), this training could be improved. The online training could be

reorganized to expand classroom and school level strategies for supporting individuals with FASDs.

Additionally, it is recommended to extend the Binkley law to include early childhood educators and non-teaching certified educational professionals. As noted in the report *A Needs Assessment of Alaska's Mixed-Delivery System of Early Childhood Care and Education*, DEED has created an eLearning module focused on IDEA Part B transitions planning and is working to centralize and systematize transitions training to support districts and DHSS has plans to create a similar training module for IDEA Part C providers on transition planning. It is recommended that the DEED transition planning module and the DHSS transition module be offered to all staff in the educational system with state programmatic requirements for special education team members.

Behavioral Support Training and Needs

Pre-service Level

Given the reported need for increased behavioral supports and training (i.e., from survey and focus group data) along with reviewed literature (i.e., Collins & Zirkle, 2017) it is recommended to examine pre-service special education teacher training, and in particular consider integration or requirement of the existing UAF special education course (EDSE F448/648: FASD Assessment, Diagnosis, and Intervention).

In-Service and School District Level

Given the reported need for increased behavioral supports and training (i.e., from survey and focus group data) along with reviewed literature it is recommended that all school teams include a member with expertise in behavior theory and supports. Although this may be recognized as typical practice (e.g., all school IEP teams include a special educator and a school psychologist at minimum), professionals may have a spectrum of training and experience in conducting and implementing FBAs/BIPs with efficacy. Furthermore, often paraeducators support the implementation of the BIP, who also require training and support.

Policy Level

It is recommended to take a deeper dive into statutes and regulations related to FBAs and BIPs from other states, for example Utah, which has defined required components of FBAs and BIPs in state laws that exceed IDEA requirements. Given that Alaska statute does not include any further regulations beyond minimal IDEA requirements (which as noted earlier does not specify the components of a FBA or BIP nor are they required) and DEED's Special Education Handbook only states that a FBA and BIP may

be completed “as appropriate” (p. 93), it may be relevant to consider the development of a Technical Assistance center (i.e., a living website for evidenced-based practices for behavior supports) modeled after Utah or Washington. This Technical Assistance Center (connected through the state’s Department of Education) can then be referenced in state regulations such as Utah did, “[W]hen making decisions on behavior interventions, the IEP Team must refer to the USBE Technical Assistance (TA) manual that outlines the Least Restrictive Behavior Interventions (LRBI) for information on research-based intervention procedures.”

Were DEED to consider a regulation regarding the use of FBAs, it is recommended to consider following Utah’s model which defines a FBA at section I.E.19: Functional behavior assessment (FBA) to mean a systematic process of identifying problem behaviors and the events that (a) reliably predict occurrence and nonoccurrence of those behaviors, and (b) maintain the behaviors across time. FBA should produce three main results: (1) Hypothesis statements that have: Operational definitions of the problem behavior, descriptions of the antecedent events that reliably predict occurrence and nonoccurrence, and descriptions of the consequent events that maintain the behavior; (2) direct observation data supporting the hypotheses; and (3) a behavior support and intervention plan.

Governance

As noted in the report *Alaska Early Childhood Environmental Scan & Baseline Report on the Condition of Young Children*, there is a lack of clear leadership and authority within Alaska’s early childhood system. Oversight of the IDEA Part C Infant Learning Program occurs through the Governor’s Council on Disabilities and Special Education (GCDSE) while state-funded preschool programs are overseen by the State Board of Education and Early Development. The Alaska Early Childhood Coordinating Council (AECCC) currently provides oversight to five federal grants operated by the state: Child Care and Development Block Grant, Head Start Collaboration Grant, Maternal Infant Early Childhood Home Visiting (MIECHV) Program, Early Childhood Comprehensive Systems (ECCS) Grant, and the Preschool Development Grant (PDG), yet the AECCC does not exist in state statute, nor does it have a line item in the state budget. The recommendation in the *Alaska Early Childhood Environmental Scan & Baseline Report on the Condition of Young Children* report to strengthen the AECCC or equivalent body in statute to provide clarity of roles and responsibilities, enhance communication with agencies serving children in the early childhood system remains salient. The AECCC or equivalent body could then seek to coordinate across agencies including the Alaska Children’s Trust (ACT), the Alaska Mental Health Board (AMHB), the Alaska Mental Health Trust Authority (the Trust), the Alaska Workforce Investment Board (AWIB), the Governor’s Council on Disabilities and Special Education (GCDSE), and the State

Board of Education and Early Development to advocate for FASD related training, policy and development/dissemination of best practices for individuals with FASDs in Alaska's early childhood system.

Transition supports

Although IDEA part B and WIOA support transition services for qualifying students transitioning out of secondary education, there is no state level or district support for the transition from primary/elementary school to secondary education (middle school and high school) for students, including students who qualify for special education. Within elementary aged children with FASDs there are a few notable difficult transition periods including entering kindergarten and within grades 3 and 4, but there are no transition supports or programs targeting these periods in the educational system. Development of state policy to lower the age of the start of transition services noted in federal law could be considered to support early transition service provision. For example, a lower age could support transition between elementary to secondary school.

Data system enhancement

As noted in the report A Needs Assessment of Alaska's Mixed-Delivery ECE System, IDEA Part C services for children under age 3 years are administered under the DHSS while IDEA Part B services for children ages 3 to 21 years are administered under DEED creating data disconnects and communication gaps. The report A Needs Assessment of Alaska's Mixed-Delivery ECE System highlights two exemplar state programs that have successfully navigated data sharing: Maryland's Department of Education and Pennsylvania's Departments of Public Welfare and Education. The report additionally outlines data coordination issues to consider in moving towards an integrated data system. For example, the adoption of a unique identifier across systems requires ongoing investment and legal coordination as the unique identifier system must adhere to local, state, and U.S. privacy laws, including the Family Educational Rights & Privacy Act (FERPA), IDEA, Health Insurance Portability and Accountability Act (HIPAA), and Head Start Program Performance Standards. Data from the Alaska's Automated Information Management System (AKAIMS), a data system that was developed specifically for mental health and substance abuse grantee providers that also housed data from the Alaska's FASD Diagnostic Teams, could also be linked to DEED and DHSS systems to support individuals with FASDs.

Currently, the state must examine the data from DEED and school districts to determine whether significant disproportionality exists on the basis of race or ethnicity for identifying special education needs within a particular impairment; placing children with disabilities in a particular setting; and implementing disciplinary actions, including the

frequency, duration, and type of discipline. The identification and prevention of over- or under-identification, as well as the representation of a child within a specific race or ethnic background for special education services is a national challenge. Districts must maintain data, policies, and procedures pertaining to race, ethnicity, and the disabilities of children in special education. Extracting special education data related to students with FASDs is near impossible since FASDs are not a distinct disability type, for example, it is impossible to determine if there are significant disparities on the basis of race or ethnicity that are occurring for students with FASDs related to the amount, duration, and type of disciplinary actions if students with FASDs are reported in various categories including being lumped into Other Health Impaired. Therefore, it is recommended that FASDs be amended within state statute (4 AAC 52.130 – Criteria for determination of eligibility) and moved from the “other disability” category to a new 15th disability category. This amendment would allow for clear documentation of FASDs in the DEED special education data system and allow for analysis and reporting on the number of students with FASDs in special education as well as review of placement of children with FASDs in a particular setting; and the extent of disciplinary actions.

Recommendations regarding general FASD policy

Federal laws, such as the Indian Healthcare Improvement Act of 1976 and the Indian Self-Determination and Education Assistance Act of 1996 have acknowledged Alaska Native self-determination in healthcare. Alaska Native health organizations have increased screening and assessment in infancy/early childhood for developmental disabilities resulting in a disproportionate number of FASDs noted among the Alaska Native population compared to the general Alaska population, and an increased stigmatization that FAS is predominantly a “Native problem” (Hedwig, 2013). Increased access to neurodevelopmental screening in infancy/early childhood is recommended for all Alaska health systems to identify all infants/children for early intervention services, including IDEA part C services in the educational setting. There are several policy recommendations, although not directly related to education, which could provide increased FASD support, especially among Alaska Native people. These recommendations include increased surveillance in all areas and among all demographics to reduce FASD stigmatization among the Alaska Native population, increased coordination of service providers, focus on in-state care by strengthening services and giving support to policies such as the Bring the Kids Home Initiative, extension of the range of FASD trainings beyond teacher certification, work to increase the representation of Alaska Native people in the foster parenting system, integration of services into all health care settings to widen the range of FASD awareness and further decrease stigma, and work to improve community participation (Hedwig, 2013).

Conclusion

Given the findings of this report, there is much work to be done in Alaska to address the needs of students with FASDs in Alaska's educational system. Within the literature, there is little published research examining effective classroom strategies for students with FASDs, few reported FASD specific interventions, and no reported interventions for the school setting. Focus groups with individuals with lived experiences with FASDs in the educational system indicated low connection to schools and school district variability in the assessment and type of support resulted in poor student outcomes. The survey of Alaskan educators showed that educators were knowledgeable about FASDs but lacked familiarity with resources to support students with FASDs and highlighted the need for more communication with families and support staff to support students with FASDs.

There is no method to accurately assess the number, incidence and prevalence of students with FASDs in Alaska's educational system. FASDs are not a specific disability type within Alaska state statute nor are FASDs documented within the Alaska Department of Education and Early Development's data system for special education. The common approaches used to calculate prevalence/incidence of FASDs (passive surveillance, clinical-based studies, active case ascertainment) are difficult and costly to implement in the educational setting. The FASD strategic plan could consider advocating for the expansion of existing educator trainings on FASDs, adding definition in state statute on FBA and BIP, and enhancing the data system to document and track students with FASDs across state data systems. By working together across health and education systems, improvement in the education and enhanced independent living of Alaskans with FASDs can be achieved.

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Appendix A: Acronyms

Acronym	Definition
ABA	Applied Behavior Analysis
ABDR	Alaska Birth Defects Registry
ACT	Alaska Children's Trust
ADA	Americans with Disabilities Act
ADHD	Attention-Deficit/Hyperactivity Disorder
ADP	Alaska Developmental Profile
AECCC	Alaska Early Childhood Coordinating Council
AFAS	Atypical Fetal Alcohol Syndrome
AKAIMS	Alaska's Automated Information Management System
AMHB	Alaska Mental Health Board
ARND	Alcohol Related Neurodevelopmental Disorder
AS	Alaska Statute
ASD	Autism Spectrum Disorder
AWIB	Alaska Workforce Investment Board
BCABA	Board Certified Assistant Behavior
BCBA	Board Certified Behavior Analyst
BIP	Behavior Intervention Plan
BRFSS	Behavioral Risk Factor Surveillance System
CCT	Cognitive Control Therapy
CDC	Centers for Disease Control and Prevention
CHD	Center for Human Development
DEED	Department of Education and Early Development
DHSS	Department of Health and Social Services
DVR	Division of Vocational Rehabilitation
EBPs	Evidence-Based Practices
EI/ILP	Early Intervention/Infant Learning Program
ESER	Evaluation Summary Eligibility Report
ESSA	Every Student Succeeds Act
FAN	Facilitating Attuned Interaction
FAPE	Free Appropriate Public Education
FAE	Fetal Alcohol Effect
FAS	Fetal Alcohol Syndrome
FASDs	Fetal Alcohol Spectrum Disorders
FASSNet	Fetal Alcohol Syndrome Surveillance Network
FBA	Functional Behavior Assessment
FERPA	Family Educational Rights and Privacy Act
FMF	Families Moving Forward
GCDSE	Governor's Council on Disabilities and Special Education

HIPAA	Health Insurance Portability and Accountability Act
IDEA	Individuals with Disability Education Act
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
IQ	Intelligence Quotient
IQR	Interquartile Range
KPBSD	Kenai Peninsula Borough School District
LRBI	Least Restrictive Behavior Interventions
MILE	Math Interactive Learning Experience
NCI	Non-Violent Crisis Intervention
NCLA	No Child Left Behind Act
NOFAS	National Organization of Fetal Alcohol Syndrome
OSEP	Office of Special Education Program
OT	Occupational Therapist
PACT	Parents and Children Together
PAE	Prenatal Alcohol Exposure
PCIT	Parent-Child Interaction Therapy
PRAMS	Pregnancy Risk Assessment Monitoring System
Pre-ETS	Pre-Employment Transition Services
PRISMAP	Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols
PT	Physical Therapist
PTSD	Post Traumatic Stress Disorder
PuP	Parents Under Pressure
RBT	Registered Behavior Technician
SEED	System for Early Education Development
SERRC	Special Education Resource & Referral Center
SESA	Special Education Service Agency
SLD	Student with Learning Disabilities
SLP	Speech-Language Pathologist
SPED	Special Education
The Trust	Alaska Mental Health Trust Authority
UAF	University of Alaska Fairbanks
WIOA	Workforce Investment Opportunity Act

Appendix B: Reviews of the literature summaries

Table A 1. Reviews of literature summaries

Full Citation	# Studies	Key Findings	Recommendations For Educational Practice	Future Research Recommendations
<p>Peadon, E., Rhys-Jones, B., Bower, C., & Elliott, E. J. (2009). Systematic review of interventions for children with Fetal Alcohol Spectrum Disorders. <i>BMC Pediatrics</i>, 9, 35. https://10.1186/1471-2431-9-35</p>	<p>12</p>	<p>1) Cognitive Control Therapy (CCT) improved personal behavior scores 2) A language and literacy intervention showed improvement on phonological awareness and an early literacy test 3) A math intervention showed improvements in math knowledge 4) Subjects learned some safety skills from virtual reality games</p>	<p>Interventions should be focused on most common clinical & neuropsychological problems</p>	<p>More quality research on interventions</p>
<p>Reid, N., Dawe, S., Shelton, D., Harnett, P., Warner, J., Armstrong, E., LeGros, K., & O'Callaghan, F. (2015). Systematic Review of Fetal Alcohol Spectrum Disorder Interventions Across the Life Span. <i>Alcoholism, Clinical and Experimental Research</i>, 39(12), 2283-2295. https://10.1111/acer.12903</p>	<p>32</p>	<p>1) CCT improved personal behavior scores 2) Interventions focusing on self-regulation and attentional control, including the ALERT® program, The Computerised Progressive Attention Program, and activities from the pay attention training protocol showed positive gains although they had limited follow up. 3) In specific skill interventions the MILE program helped with math skills and behavior, virtual reality games were relatively effective in teaching safety skills, a language and literacy intervention showed improvements on preliteracy, reading, and spelling, group-rehearsal training improved digit span scores, and the cover, copy, and compare spelling procedure increased the number of correctly spelt words. 4) For teachers, professional development focusing on classroom environment improved students adaptive skills and behavior</p>	<p>1) Program developers need to be focused on specific needs of those involved with FASD. 2) Interventions addressed at multiple aspects of PAE may be more beneficial.</p>	<p>1) Explore early intervention with cost effective programs 2) Support adolescents and adults 3) Consider interaction between individual characteristics and the environment 4) Create a unified framework 5) Measure intervention effects with other tools and use standard measures for infants and toddlers 6) Examine whether interventions impact physiology 7) Examine the impact of programs like CFT with adolescents and adults</p>

Appendix C: Intervention study summaries

Table A 2. Intervention study summaries

Full Citation	Study Aims	Sample Description	Intervention	Prevention Level	Outcome Measures	Key Findings	Recommendations
<p>Boulter, L. T. (2007). The effectiveness of peer-led FAS/FAE prevention presentations in middle and high schools. <i>Journal of Alcohol & Drug Education</i>, 51(3), 7-26.</p>	<p>Determine if presentation about FAS would impact middle and high school students' knowledge of FAS and FAE</p>	<p>642 middle and high school students from 6 schools in a southeastern city</p>	<p>Not stated</p>	<p>Primary</p>	<p>1) Knowledge of effects of alcohol consumption during pregnancy: pretest, posttest, and follow up test</p>	<p>1) Slightly older peer led presentations to middle and high school students led to increases in students' overall knowledge and understanding of the effects of alcohol consumption during pregnancy. 2) Increased knowledge held true at the six week post-test. 3) Female students had higher scores than males. 4) There was an age-related increase in scores.</p>	<p>Education: 1) School systems should collaborate with college and community programs to develop engaging health education presentations given by slightly older peers Research: 2) A control group of participants randomly selected, balanced for age and gender should complete the pre and posttest in order to provide a baseline 3) Content and language of presentations should be evaluated for content and language per age/grade level.</p>

Full Citation	Study Aims	Sample Description	Intervention	Prevention Level	Outcome Measures	Key Findings	Recommendations
<p>Flannigan, K., Rebus, M., Mitchell, N., Gear, A., Basisty, B., Couling, K., Whitford, C., Moore, M., Meunier, S., Smale, K., Pei, J., & Rasmussen, C. (2017). Understanding Adverse Experiences and Providing School-Based Supports for Youth Who Are High Risk with and without FASD. <i>International Journal of Special Education</i>, 32(4), 842-857.</p>	<p>1) Characterize adverse life experiences of Youth Who are High Risk with FASD. 2) Explore the services and programs currently employed at Boyle Street Education Center to support students with FASD and examine whether services differ between students with and without FASD 3) Examine the association between service access and school attendance rates, comorbid mental health diagnoses, and legal issues.</p>	<p>90 youth ages 15 - 19; 45 with FASDs, 45 without FASDs or documented PAE</p>	<p>Boyle Street Education Center Services</p>	<p>Tertiary</p>	<p>1) comorbid diagnoses: learning disabilities, substance abuse, ADHD, oppositional defiant disorder, delayed cognition, depression, anxiety, reactive attachment disorder, PTSD, schizophrenia, drug-induced psychosis, personality disorder, other 2) School Services: psychological testing, counseling & health services, alternative classes, youth worker, cultural activities, work related services, incentives & other services</p>	<p>1) No group differences in school attendance 2) Those with FASD and higher rates of mental health comorbidities also had higher rates of service access 3) Service access was not significantly related to criminal record</p>	<p>Research: 1) Study how Boyle Street Education Center services can be used in other schools 2) Research how Boyle Street Education Center services impact student outcomes in a longitudinal study</p>

Full Citation	Study Aims	Sample Description	Intervention	Prevention Level	Outcome Measures	Key Findings	Recommendations
<p>Johnson, C. L., & Lapadat, J. C. (2000). Parallels between Learning Disabilities and Fetal Alcohol Syndrome/Effect: No Need To Reinvent the Wheel. <i>Exceptionality Education Canada</i>, 10(3), 65-81.</p>	<p>1) Examine effectiveness of written language teacher interventions 2) Document the decision making process in one-on-one tutoring 3) Test whether student would improve in the reading skills of decoding, fluency, and comprehension and in the spelling skills of accuracy and automaticity, whether better spelling, proofreading, greater variety, and more context-appropriate vocabulary would lead to greater writing creativity, whether student would be more confident in academics evidenced by more risk taking and greater variety and context-appropriate writing vocabulary</p>	<p>One 14 year old diagnosed with FAE and with learning disabilities</p>	<p>Tutoring program - 3 hours a week for four months</p>	<p>Tertiary</p>	<p>1) Reading, comprehension, readiness, basic skills: Woodcock Ready Mastery Tests - Revised (WRMT-R) 2) Spelling: Wide Range Achievement Test 3 (WRAT 3) 3) Self-esteem: Behavior Assessment Scale for Children (BASC) 4) skills, strengths, behavior, teaching strategies: Qualitative data (observation, interviews, school and medical records)</p>	<p>1) Spelling, reading, and writing improved though with varying practical effect sizes (medium effect sizes on spelling and readiness aspect of reading test and little to practical significance in basic skills, reading comprehension, and total reading aspects of reading test) 2) No self-esteem improvement was shown 3) Similar interventions could be used for FAS/E and Learning Disorders 4) Some helpful strategies included webbing and visual tools</p>	<p>Educational: 1) Teachers should be aware of physiological bases of FAS/E 2) It is important to gain knowledge of language, teaching techniques and resources, how to monitor students, student attributions, and the ability to help students with their strengths and weaknesses Research: 3) Track those with FAS/E in longitudinal studies, in different contexts, and with possible comorbidities</p>

Full Citation	Study Aims	Sample Description	Intervention	Prevention Level	Outcome Measures	Key Findings	Recommendations
<p>Kerns, K. A., Macoun, S., MacSween, J., Pei, J., & Hutchison, M. (2017). Attention and working memory training: A feasibility study in children with neurodevelopmental disorders. <i>Applied Neuropsychology Child</i>, 6(2), 120-137. https://10.1080/21622965.2015.1109513</p>	<p>1) Examine whether a game and training approach was effective with children with neurodevelopmental disorders 2) Examine whether attention and working memory deficits could be improved by the intervention 3) See if it would be possible to train educational assistants to deliver the intervention within a school setting 4) Show that the methods were effective and provide an estimate of effect sizes</p>	<p>17 middle class children ages 6 - 13 with neurodevelopmental disorders (10 with FASD, 7 with ASD) who qualified for special education services in two local school districts, and who had been identified as having problems with aspects of attention and concentration.</p>	<p>Caribbean Quest (CQ) Game - half hour sessions, 2-3 times a week, 10-12 weeks with educational assistant (EA) support</p>	<p>Tertiary</p>	<p>1) Everyday problem behaviors and attentional skills: Behavior Rating Inventory of Executive Function (BRIEF), Conners' Rating Scale - Short Version, Third Edition (CRS-3) 2) Emotional and Behavioral strengths: Behavioral and Emotional Rating Scale, Second Edition (BERS-2) 3) Utility and feasibility of training: qualitative data through interviews with EAs 4) Distractibility, divided attention, attention shifting/flexibility: Test of Attentional Performance for Children (KiTAP) 5) Working Memory: Digit and Spatial Span tasks from Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV) - Integrated, Counting Recall and Listening Recall tasks from Working Memory Test Battery for Children (WMTB-C) 6) Academic Fluency: AIMSWEB curriculum-based measure of oral reading fluency</p>	<p>1) CQ intervention led to improvements of attention, working memory, and academic fluency 2) Subjects showed behavioral, academic, social, and emotional changes that could be applied to academics as reported by EAs 3) The CQ intervention would be possible within a school setting or remotely and could be delivered by EAs trained online</p>	<p>Research: Use a modified CQ game by lowering amount of trials to progress in working memory tasks and by adding "game targeting cognitive set-shifting processes"</p>

Full Citation	Study Aims	Sample Descripti on	Interve ntion	Preven tion Level	Outcome Measures	Key Findings	Recommendations
<p>Kully-Martens, K., Pei, J., Kable, J., Coles, C. D., Andrew, G., & Rasmussen, C. (2018). Mathematics intervention for children with fetal alcohol spectrum disorder: A replication and extension of the math interactive learning experience (MILE) program. Research in Developmental Disabilities, 78, 55-65. https://10.1016/j.ridd.2018.04.018</p>	<p>1) Examine the effectiveness of a math intervention on math performance and cognitive deficits 2) Do those who engage in modified intervention improve in math performance compared to those receiving a different intervention both post-intervention and six months later 3) Does the MILE intervention impact other cognitive abilities post-intervention and six months later 4) Are there any subject characteristics that impact outcomes?</p>	<p>28 Children ages 4 - 10 with PAE and FASD - 15 MILE intervention, 13 behavioral comparison</p>	<p>Modified math interactive learning experience (MILE)</p>	<p>Tertiary</p>	<p>1) Age, grade, placement history, current living situation, caregiver factors: demographic questionnaire 2) Math: Key Math 3 Diagnostic Assessment - Candian Edition (KeyMath 3 DA) 3) Executive Functioning: Auditory Attention/Response Set subtest from NEPSY-II 4) Working Memory: Working Memory Test Battery for Children (WMTB-C) 5) Visuospatial Functioning: Block Construction subtest from NEPSY-II, Rey Complex Figure Test (RCFT) 6) Intelligence: Wide Range Intelligence Test (WRIT)</p>	<p>1) Those participating in the MILE intervention showed significant mathematical improvements immediately and 6 months later 2) None of the results comparing other cognitive outcomes between the two interventions were significant 3) Those who engaged in the MILE intervention and who improved most drastically in math were older, had lower verbal and full-scale IQ, and were PAE but not diagnosed with FAS. 4) Those who engaged in the contrast intervention and who improved most drastically in math had higher IQ 5) Gender and SES did not relate to outcomes</p>	<p>Research: 1) Manipulate length of treatment to see which treatment is best for short and long term gains 2) Examine those who have multiple neurodevelopmental challenges 3) Compare MILE to other math interventions</p>

Full Citation	Study Aims	Sample Description	Intervention	Prevention Level	Outcome Measures	Key Findings	Recommendations
<p>Makela, M. L., Pei, J. R., Kerns, K. A., MacSween, J. V., Kapasi, A., & Rasmussen, C. (2019). Teaching Children with Fetal Alcohol Spectrum Disorder to Use Metacognitive Strategies. <i>Journal of Special Education</i>, 53(2), 119-128.</p>	<p>Hypotheses: Children with FASD would use metacognitive strategies, need less prompting, and become better at spontaneously using metacognitive strategies by engaging in strategy instruction and coaching</p>	<p>7 Children and adolescents ages 8 - 16 with FASD from a local schools</p>	<p>1) Strategy Coaching 2) Cognitive Carnival (60-90 min per week/12 weeks)</p>	<p>Tertiary</p>	<p>1) strategies used: metacognitive strategy checklist (taught, prompted, spontaneous, mastered)</p>	<p>1) children with FASD increased in spontaneously used metacognitive strategies and decreased in prompted metacognitive strategies 2) Children with FASD are able to think metacognitively in order to help themselves succeed 3) Metacognitive training seems to be a valid and accessible intervention in helping those with FASD succeed in school and other areas</p>	<p>Educational: 1) Use metacognitive strategies in classrooms (a non computerized version might be more accessible) 2) Help students use working memory strategies throughout the day Research: 1) See how effective metacognitive approach is in a classroom 2) Examine the carnival's game's and metacognitive training's effectiveness on their own</p>

Full Citation	Study Aims	Sample Description	Intervention	Prevention Level	Outcome Measures	Key Findings	Recommendations
<p>Wiskow, K. M., Ruiz-Olivares, R., Matter, A. L., & Donaldson, J. M. (2018). Evaluation of the Good Behavior Game with a child with fetal alcohol syndrome in a small-group context. <i>Behavioral Interventions</i>, 33(2), 150-159. https://10.1002/bin.1515</p>	<p>1) Examine efficacy of Good Behavior Game on reducing disruptive behavior in a child with FAS 2) Compare behavior to peers 3) Examine whether choice vs surprise rewards has an impact on disruptive behavior</p>	<p>A student with FAS and 3 peers ages 4 - 7</p>	<p>Good Behavior Game: 1-4 times per day / M-F/ 3 week program</p>	<p>Tertiary</p>	<p>1) disruptive behavior (talking without permission, out of seat behavior, inappropriate contact with objects): Data collectors 2) corrective feedback (therapist telling participant to stop the disruptive behavior or reminding the participant of the behavior expectations: Data collectors 3) Praise (positive statements about appropriate behavior: Data Collectors</p>	<p>1) There was less disruptive behavior when the Good Behavior Game was played 2) FAS student had similar levels of disruptive behavior compared to peer team member 3) No difference in disruptive behavior between choice and surprise reward</p>	<p>Educational: 1) Allow a choice of reward when possible 2) Teachers and researchers should continue to explore and use the Good Behavior Game Research: 3) Examine if using highly preferred items has any impact on disruptive behavior 4) Examine if using a token system with a variety of reward options has an impact 5) Replication in general education classrooms (with students with disabilities) and special education classrooms</p>

Appendix D: Qualitative paper summaries

Table A 3. Qualitative paper summaries

Full Citation	Study aims	Location (state/province/territory, country) (Date of data collection)	Data Collection Methods	Sample description	Age range/educational level of students	Key Findings	Themes	Recommendations for educational practice	Future research recommendation
Brenna, B., Burles, M., Holtslander, L., & Bocking, S. (2017). A School Curriculum for Fetal Alcohol Spectrum Disorder: Advice from a Young Adult with FASD. <i>International Journal of Inclusive Education</i> , 21(2), 218-229.	To describe what it is like to live with FASDs during young adulthood by exploring subjective experiences through qualitative Photovoice research and Schwab's four curriculum commonplaces as a framework for discussion: learner, teacher, milieu, and resources.	Saskatchewan, Canada (2011)	Single case study using Photovoice with interviews	1 Young male with ADHD and FAS diagnosis; adoptive parents	21 years old; High school graduate	Self-understanding of strengths and difficulties; external student support in addition to parents; bridging programs to careers are needed. Important to have teachers, peers and member of the public who understand FASDs.	Four themes: need to balance external support with desire for independence; self-awareness of his own strengths and challenges; attitude and adaptation strategies for navigating life with FASDs; advice for others with FASDs.	A facilitated peer sponsor model. More classroom resources showing diversity and variability in lives. Earlier in the educational experience there should be a greater focus on strengths based career possibilities.	Longitudinally studies on transition to young adulthood; descriptions of FASDs by youth with lived experience.

Full Citation	Study aims	Location (state/province/territory, country) (Date of data collection)	Data Collection Methods	Sample description	Age range/educational level of students	Key Findings	Themes	Recommendations for educational practice	Future research recommendation
<p>Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2007). Secondary School Experiences of Individuals with Foetal Alcohol Spectrum Disorder: Perspectives of Parents and Their Children. <i>International Journal of Inclusive Education</i>, 11(5-6), 571-591.</p>	<p>To explore conditions contributing to educational persistence of adolescents with FASDs who are still in high school or who have recently graduated.</p>	<p>Canada & USA (no date noted)</p>	<p>phenomenology with open-ended questionnaires and in-depth interviews</p>	<p>8 Adolescents who had a diagnosis of FASDs and to attend a high school or have recently graduated and 16 parents of an adolescent or young adult with FASD who was either still in high school or had recently graduated.</p>	<p>Adolescents 15-20; high school or recent graduate</p>	<p>Tinto's student integration model only partially explained the persistence of students. Two conditions that contribute to persistence were the opportunity to interact with peers at school and unwavering parental support.</p>	<p>Three themes: background characteristics and attributes affecting the level of goal commitment; level of academic integration; and level of social integration into the institution that determine whether or not a student will graduate.</p>	<p>Additional teacher education on FASD and other disabilities in adolescence is needed. Positive relationships between teachers and parents are needed to support high school students in school persistence.</p>	<p>Research on strengthening school/family partnerships and how parental advocacy that influences the quality of education, which in turn may result in important differences in the educational outcomes of their children are warranted.</p>

Full Citation	Study aims	Location (state/province/territory, country) (Date of data collection)	Data Collection Methods	Sample description	Age range/educational level of students	Key Findings	Themes	Recommendations for educational practice	Future research recommendation
<p>Job, J. M., Poth, C. A., Pei, J., Caissie, B., Brandell, D., & Macnab, J. (2013). Toward Better Collaboration in the Education of Students with Fetal Alcohol Spectrum Disorders: Integrating the Voices of Teachers, Administrators, Caregivers, and Allied Professionals. <i>Qualitative Research in Education</i>, 2(1), 38-64.</p>	<p>Describe the successes and challenges in stakeholder communication and collaboration within and across roles in an effort to better understand how to build and maintain positive working relationships in the education of students with FASDs.</p>	<p>No location noted (March 2009-May 2010)</p>	<p>11 focus groups and 3 individual interviews</p>	<p>60 (31 teachers, 7 administrators, 16 allied professionals, 6 caregivers)</p>	<p>age range for affected children with whom the participants worked was 3 to 18 years; grades K-12</p>	<p>The fostering of relationships is necessary for enhancing communication and collaboration between school personnel and families. The emphasis for improved FASDs awareness and understanding allows for more accurate perceptions and greater preparation of school personnel working with students with FASDs.</p>	<p>Three themes: fostering relationships, reframing practices, and accessing supports.</p>	<p>Educators should be provided resources and training to build foundational knowledge and skill, which can be used to provide appropriate programming for students with FASDs and engage collaboratively with families.</p>	<p>Research is needed to determine what constitutes effective collaboration between educators and parents; how to better educate and train school personnel in teaching students with FASDs; and to learn what programs and services will best support students with FASDs?</p>

Full Citation	Study aims	Location (state/province/territory, country) (Date of data collection)	Data Collection Methods	Sample description	Age range/educational level of students	Key Findings	Themes	Recommendations for educational practice	Future research recommendation
<p>Koren, G. I., Fantus, E., & Nulman, I. (2010). Managing fetal alcohol spectrum disorder in the public school system: a needs assessment pilot. The Canadian Journal of Clinical Pharmacology = Journal Canadien De Pharmacologie Clinique, 17(1), e79-e89.</p>	<p>Explore needs of schools and educators in supporting those with FASD and describe what is currently possible to help those with FASD in the school setting</p>	<p>Toronto, Canada (2009)</p>	<p>semi-structured interviews</p>	<p>12 (2 principals, 2 vice principals, 2 materials and resource teachers, 2 school board psychologists, 2 primary grade teachers, 1 kindergarten teacher and 1 special education teacher in a multiple exceptionalities class)</p>	<p>Ages not stated; grades K-8</p>	<p>FASD was underreported at all schools. Medical conditions rarely determined educational practices. Educators in elementary and middle schools desire more education on FASD.</p>	<p>none noted</p>	<p>Learning disability designation is helpful in gaining needed support for students with FASD; conduct a comprehensive academic assessment to help educators understand the needs of students with FASD.</p>	<p>Research how FASD stigma is related to underreporting in schools.</p>

Full Citation	Study aims	Location (state/province/territory, country) (Date of data collection)	Data Collection Methods	Sample description	Age range/educational level of students	Key Findings	Themes	Recommendations for educational practice	Future research recommendation
<p>Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward Intentional, Reflective, and Assimilative Classroom Practices with Students with FASD. <i>Teacher Educator</i>, 49(4), 247-264.</p>	<p>This study documented the experiences of teachers, administrators, caregivers, and allied professionals and influence of different systems in the education of students with FASD and then identified influential teaching strategies for meeting the learning and developmental needs of students with FASD.</p>	<p>No location noted (March 2009-May 2010)</p>	<p>11 focus groups and 3 individual interviews</p>	<p>60 participants (31 teachers, 7 administrators, 16 allied professionals, 6 caregivers)</p>	<p>Ages not stated, grades K-12</p>	<p>Positive outcomes are achieved through classroom strategies that gain an understanding of the whole student, respond appropriately to the dynamic influences on the student's complex environments.</p>	<p>Three themes: understanding the whole student, responding within dynamic environments, and optimizing student centered programming.</p>	<p>Foster an inclusive school atmosphere that welcomes students and caregivers structured learning environment with consistent leadership, rules, routines, and consequences for behavior</p>	<p>Further research is recommended to replicate this study across populations for greater generalization and understanding of how an approach characterized by intentionality, reflection, and assimilation could enhance classroom practices beyond the FASD population for additional complex student populations.</p>

Full Citation	Study aims	Location (state/province/territory, country) (Date of data collection)	Data Collection Methods	Sample description	Age range/educational level of students	Key Findings	Themes	Recommendations for educational practice	Future research recommendation
<p>Pruner, M., Jirikowic, T., Yorkston, K. M., & Olson, H. C. (2020). The best possible start: A qualitative study on the experiences of parents of young children with or at risk for fetal alcohol spectrum disorders. <i>Research in Developmental Disabilities</i>, 97, 103558. https://doi.org/10.1016/j.ridd.2019.103558</p>	<p>This study identified characteristics of early intervention practice that are both supportive and challenging for parents and sought to use findings to define training and competency needs for early intervention providers working with children with FASDs.</p>	<p>Seattle, WA, USA (2017)</p>	<p>phenomenology with focus groups</p>	<p>25 biological or adoptive parents of children with or at high risk for FASD</p>	<p>0-3 years/early learning settings</p>	<p>When parents talked about their child's cognitive, physical, communication or adaptive development, they all discussed how early intervention was meeting those needs. Early intervention programs did not meet children's social-emotional development needs.</p>	<p>3 themes: child needs; parent needs and priorities; and early intervention capacity.</p>	<p>Providers are encouraged to be truthful about the future needs of the child, provide anticipatory guidance for future life course struggles, and connect the parents with support for their own social-emotional well-being.</p>	<p>Research on the perspectives of early intervention providers who support infants and toddlers with FASD and their families is needed.</p>

Appendix E: Educational strategy summaries

Table A 4. Educational strategy summaries

Full Citation	Study aims	Key Findings	School Level Strategies	Classroom Level Strategies	Recommendations for educational practice
Blackburn, C., Carpenter, B., & Egerton, J. O. (2010). Shaping the future for children with foetal alcohol spectrum disorders. <i>Support for Learning</i> , 25(3), 139-145. https://10.1111/j.1467-9604.2010.01452.x	This article illustrates the educational implications of FASDs and the implications for the educational workforce	The paper summarized the prevalence of FASD in the UK, physical characteristics of FASD, the implications of FASD for child development, the learning profile of children with FASD, and the curriculum for children with FASD.	Repeated assessment to accurately capture evolving strengths and weaknesses to support intervention planning; offer transition between primary and secondary schools to ensure strategies and services continue disrupted and communication continues between teams at the different school levels	Build upon the students positive personality characteristics, strengths and talents and manage the learning environment to allow these to thrive; provide consistency, structure, repetition, sensory regulation, and hands on approach to learning.	Educators need to take into account the students strengths and difficulties and develop personalized learning, the current style and structure of most classrooms is not conducive for students with FASD.
Carpenter, B. (2011). Pedagogically Bereft! Improving Learning Outcomes for Children with Foetal Alcohol Spectrum Disorders. <i>British Journal of Special Education</i> , 38(1), 37-43.	This article describes the challenges for today's educators on teaching children with FASDs	The paper summarized key research related to FASD in education. Challenges in the classroom learning environment presented by the students are described along with major teaching responses. Teacher interventions to mediate the learning environment for managing students with FASD are described.	Blend the learning styles of students with FASD into inclusive classroom settings- include a focused exercise into curriculum, social stories to address the child's lack of environmental awareness, visual presentation of tasks and over-learning routines, give the child concrete experiences of time, number, space, money, etc.	Engagement of students with FASDs improve when the physical structure (lighting, removing clutter), deployment of staffing, visually based resources, groupings of children and teaching styles are reconsidered to meet the needs of students with FASDs.	Educators are encouraged to determine the learning needs of the child before them, question the responsivity in the curriculum and alter teaching strategies that will touch the child with FASD at his or her point of learning need.

Full Citation	Study aims	Key Findings	School Level Strategies	Classroom Level Strategies	Recommendations for educational practice
<p>Green, J. H. (2007). Fetal Alcohol Spectrum Disorders: understanding the effects of prenatal alcohol exposure and supporting students. <i>The Journal of School Health</i>, 77(3), 103-108. https://10.1111/j.1746-1561.2007.00178.x</p>	<p>This article describes characteristics of FASD and summarizes interventions that may be helpful in schools</p>	<p>Effective interventions must consider the interplay between behavioral symptoms and the neuropsychological effects of prenatal alcohol exposure. In designing interventions, children with FASD need opportunities to learn and build skills that will help them regulate their emotions and behaviors as well as environmental modifications that increase the likelihood of adaptive behaviors.</p>	<p>Collaboration between providers, schools, and family in developing individualized interventions. Behavior should be viewed in the context of symptoms.</p>	<p>Intervention plans should draw on literature from Positive Behavior Support programming, cognitive behavioral therapy, and interventions for behavior disorders like ADHD. Effective interventions should involve environmental factors, positive feedback, and learning opportunities and should aim for behavioral and neurocognitive effects.</p>	<p>The team of professionals and caregivers who support a student with FASD can identify a limited number of target behaviors and provide frequent monitoring and reinforcement for appropriate behavior.</p>
<p>Harwood, M., & Kleinfeld, J. S. (2002). Up Front, in Hope: The Value of Early Intervention for Children with Fetal Alcohol Syndrome. <i>Young Children</i>, 57(4), 86-90.</p>	<p>This article provides a description of FASDs related behavior and early educator supports for infants, toddlers, and preschool aged children with FASDs</p>	<p>A common problem for children with prenatal alcohol exposure is consistently performing skills they have been taught.</p>	<p>Offer support at the earliest stages of development. Provide an introduction to FASDs information as a process to parents.</p>	<p>Teach how to play in repeated short demonstrations to allow the child to use toys in a purposeful manner.</p>	<p>Frequent reteaching of skills is needed. Safety tasks should be reviewed, modeled, and practiced daily. Caregivers need to reteach, repeat, and redirect without demeaning or devaluing students who experience FASDs.</p>

Full Citation	Study aims	Key Findings	School Level Strategies	Classroom Level Strategies	Recommendations for educational practice
<p>Kalberg, W. O., & Buckley, D. (2006). Educational planning for children with fetal alcohol syndrome. <i>Annali Dell'Istituto Superiore Di Sanita</i>, 42(1), 58-66.</p>	<p>This article examines the results of neurobehavioral research and how it can benefit school assessments, interventions, planning, and support</p>	<p>Executive functioning deficits in alcohol-exposed children have been found to closely correlate with reported behavioral issues in these children. Understanding the executive functioning deficits in an individual provides a clearer understanding of the issues that interfere with learning and behavior in the classroom, home and community.</p>	<p>Use of neurobehavioral testing to better determine the individual learning profile of children with FASD. Observational assessments should occur in the student's natural environment.</p>	<p>Children with FAS have the most difficulty shifting their attention and encoding new information. Supporting transition points and repeating new information with instructions that are supported by visual reinforcements is helpful.</p>	<p>Create individual learning profile for each child; use of neurobehavioral testing; school team should work with family; carry out a detailed assessment of child's functional abilities; develop individualized interventions based off individual learning profile; systematic and structured teaching must be used</p>
<p>Millar, J. A., Thompson, J., Schwab, D., Hanlon-Dearman, A., Goodman, D., Koren, G., & Masotti, P. (2017). Educating Students with FASD: Linking Policy, Research and Practice. <i>Journal of Research in Special Educational Needs</i>, 17(1), 3-17.</p>	<p>This paper is a summary of the 16-year history of Winnipeg School Division's development of its FASD program of services with a description of best strategies and lessons learned from the educators who have served students with FASD.</p>	<p>The system developed by Winnipeg School Division has led to positive FASD outcomes including success in school, better social skills, increased self-esteem, better understanding of themselves, acceptance of their diagnoses.</p>	<p>Paradigm shift to develop FASD inclusive classrooms and curriculum; students may stay with the same teacher longer; providing resources and up to date technology; comprehensive assessment; flexibility in procedures and rules; additional programming to develop life skills; time periods before and after school.</p>	<p>Innovative teaching approaches based upon an assessment of how the specific child's brain works; Learn to use and adapt tools and technology to support the way FASD brains work; traditional classroom rules may need to be adapted and other activities/procedures done differently.</p>	<p>Specialized FASD classrooms comprised of eight students, one teacher and two educational assistants; all staff have had specialized FASD professional development training. FASD lead teachers serve as peer mentors and train additional teachers to grow the FASD classroom model.</p>

Full Citation	Study aims	Key Findings	School Level Strategies	Classroom Level Strategies	Recommendations for educational practice
<p>Petrenko, C. L. M., & Alto, M. E. (2017). Interventions in fetal alcohol spectrum disorders: An international perspective. <i>European Journal of Medical Genetics</i>, 60(1), 79-91. https://10.1016/j.ejmg.2016.10.005</p>	<p>This article summarizes existing FASD interventions that have empirical support and outlines cultural barriers pertaining to FASDs that may impede the implementation process</p>	<p>Interventions in the parent education and training domain focus on the caregiver-child relationship, psychoeducation, positive behavior support, and/or mentoring and accessing community resources and occur outside the school setting but may impact education of students.</p>	<p>Revise systems to include FASD; disseminate evidence-based interventions; integrate programs into existing systems</p>	<p>Include stakeholders; consider the role of culture when implementing interventions</p>	<p>Researchers need to collaborate with local stakeholders and use cultural liaisons to help bridge the gap between research and practice when implementing interventions.</p>
<p>Ryan, S. M. (2006). Instructional Tips: Supporting the Educational Needs of Students with Fetal Alcohol Spectrum Disorders. <i>TEACHING Exceptional Children Plus</i>, 3(2)</p>	<p>This article highlights instructional tips from 25 teachers and observations in their classrooms over the course of 4 years in rural Alaska say are helpful when teaching students with FASD</p>	<p>A set of instructional tips are provided: Think Person/Child First; Build a Relationship with the Student's Family; Develop Partnerships and Build Collaboration Between Families, Schools, and Community Agencies, and Implement Wrap-Around Services; Develop Social Skills; Provide a Structured Environment; Use Repetition and Consistency; Modify the Classroom Environment and Modify the Curriculum; Make a Referral to Special Education and to an FAS Diagnostic Clinic</p>	<p>Ensuring that there is a strong link between the school, families and agencies that support students with FASDs. Allow for consistency and repetition in all activities.</p>	<p>View the student with FASD as an individual and recognize that each student represents a vast array of abilities and interests. Develop lessons on play and expectations/maintaining boundaries in interpersonal relationships.</p>	<p>Teachers can successfully support the needs of students with FASD through gathering information on the student's strengths, interests, and needs; implementing the recommended practices described as instructional tips; and gathering information on how the student responds to the interventions implemented.</p>

Full Citation	Study aims	Key Findings	School Level Strategies	Classroom Level Strategies	Recommendations for educational practice
<p>Schiltroth, A. (2014). Promoting Success with FASD-Affected Students. <i>BU Journal of Graduate Studies in Education</i>, 6(2), 32-35.</p>	<p>This article describes education practices the support developing learner profiles and individualized learning pathways for FASD-affected students through a team approach and family support</p>	<p>Each child presents his/her own unique set of challenges, involved educators must personalize learning pathways for meaningful education. Developing a relationship with families or caregivers may link educators to background and family insights resulting in accurate, personalized programming.</p>	<p>Well-informed educators meet the needs of these complex children and their families through in-depth planning and advocacy for appropriate services for families and involved caregivers.</p>	<p>Use clear, concise directions and provide immediate consequences. Provide opportunities for positive social interactions, to develop age-appropriate social skills, and promote healthy lifestyle choices to ensure that these students are prepared for adulthood and independent living.</p>	<p>Prepare teachers to handle extreme behaviors, anticipate the need for additional supervision of students who are prone to risk taking/impulsive unsafe behaviors. Educators and parents align to advocate for appropriate services. Provide FASD-related information to parents, foster parents, and other providers.</p>
<p>Watson, S. M. R., & Westby, C. E. (2003). Strategies for Addressing the Executive Function Impairments of Students Prenatally Exposed to Alcohol and Other Drugs. <i>Communication Disorders Quarterly</i>, 24(4), 194-204.</p>	<p>Discuss learning and behavioral characteristics of children prenatally exposed to alcohol and present a framework of strategies for developing executive functioning</p>	<p>A combination of cognitive and behavioral strategies help with academic achievement and social behaviors</p>	<p>School wide programs focused on early intervention; collaboration among professionals; provision of systematic and intensive supports for students and educators</p>	<p>Teachers need to consider strengths, and identify deficit and nature of deficit when choosing interventions</p>	<p>Obtain knowledge, collect info, complete a functional behavioral assessment; educators need knowledge of metacognitive, linguistic, and behavioral interventions</p>

Appendix F: Educational survey result charts

Note: n: represents sample size for that question, Figure 10 & Figure 24 are not mentioned above

Figure A 1. Please specify how you identify yourself (n = 345)

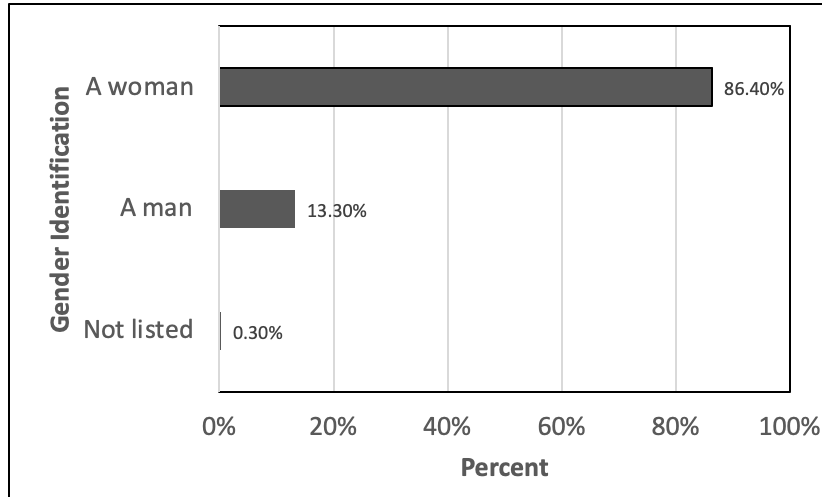


Figure A 2. What is your race and/or ethnicity? (n = 339)

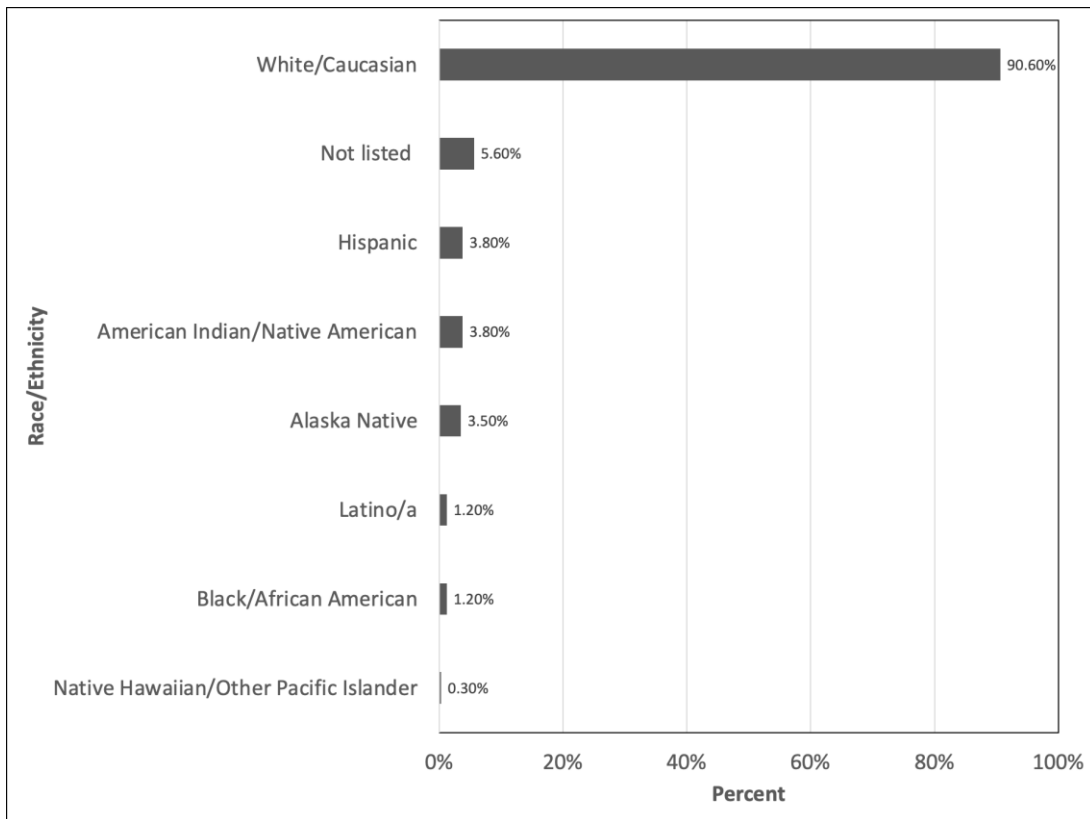


Figure A 3. In which EI/ILP Service Area is your primary work location? (n = 345)

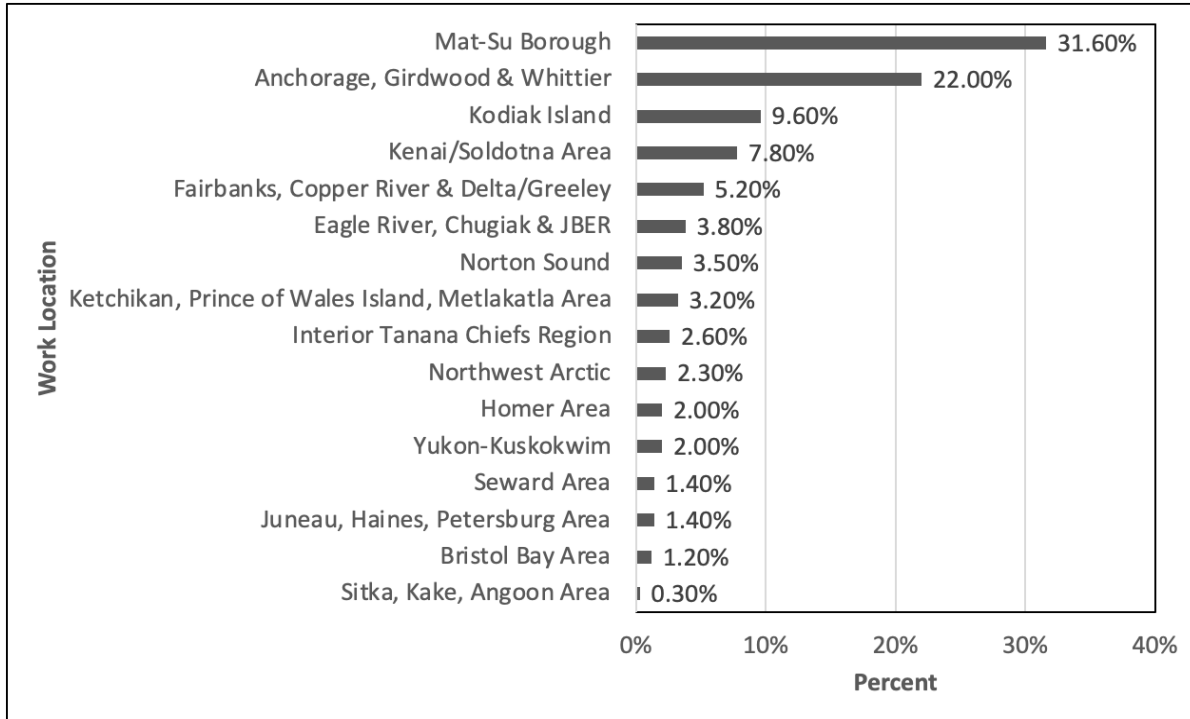


Figure A 4. What is your current position? (n = 348)

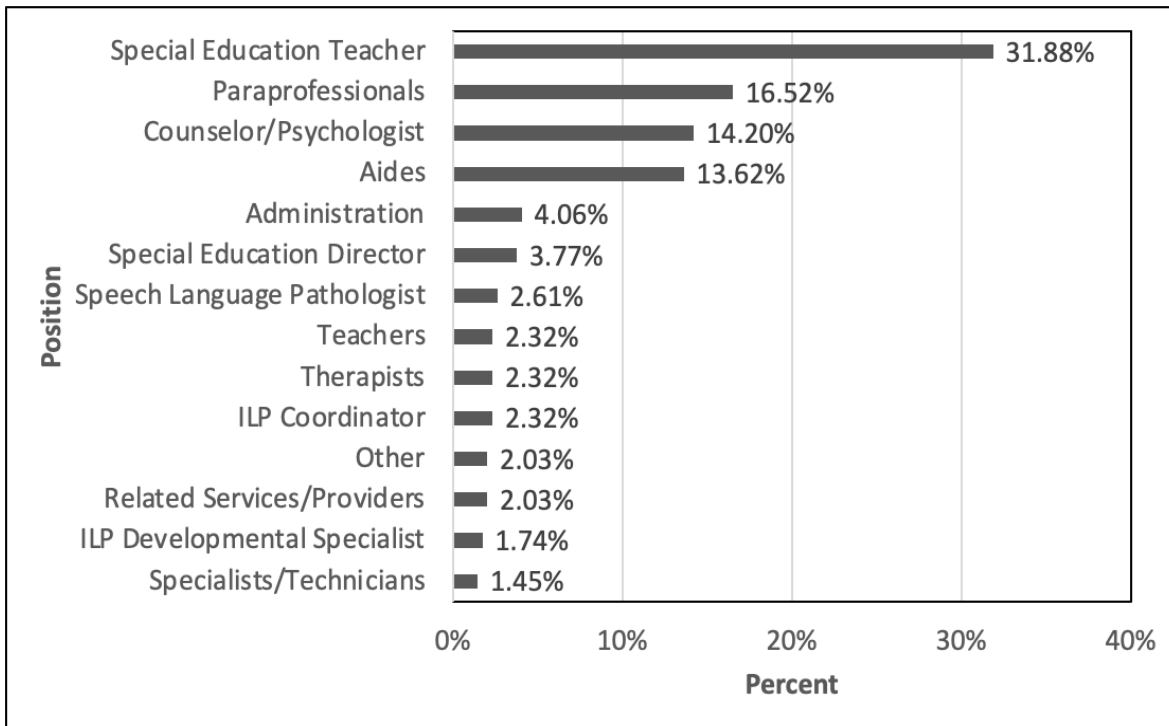
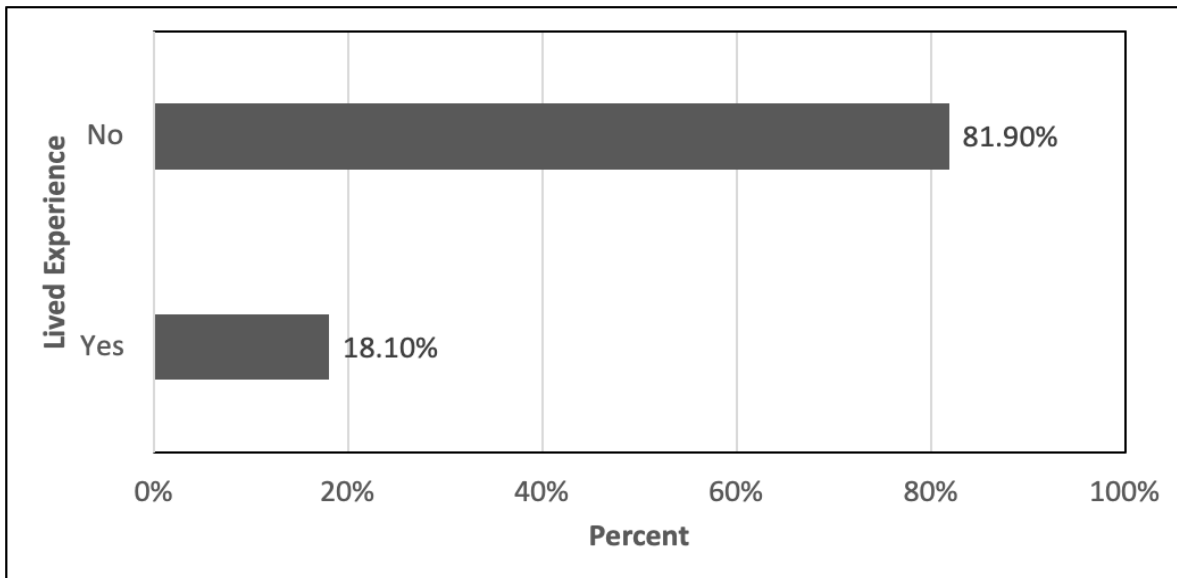


Figure A 5. Do you have lived experience with FASD (e.g., as a parent, foster parent, sibling, grandparent)? (n = 342)



**Figure A 6. How many years of work experience do you have in each of the following?
(247 ≤ n ≤ 304)**

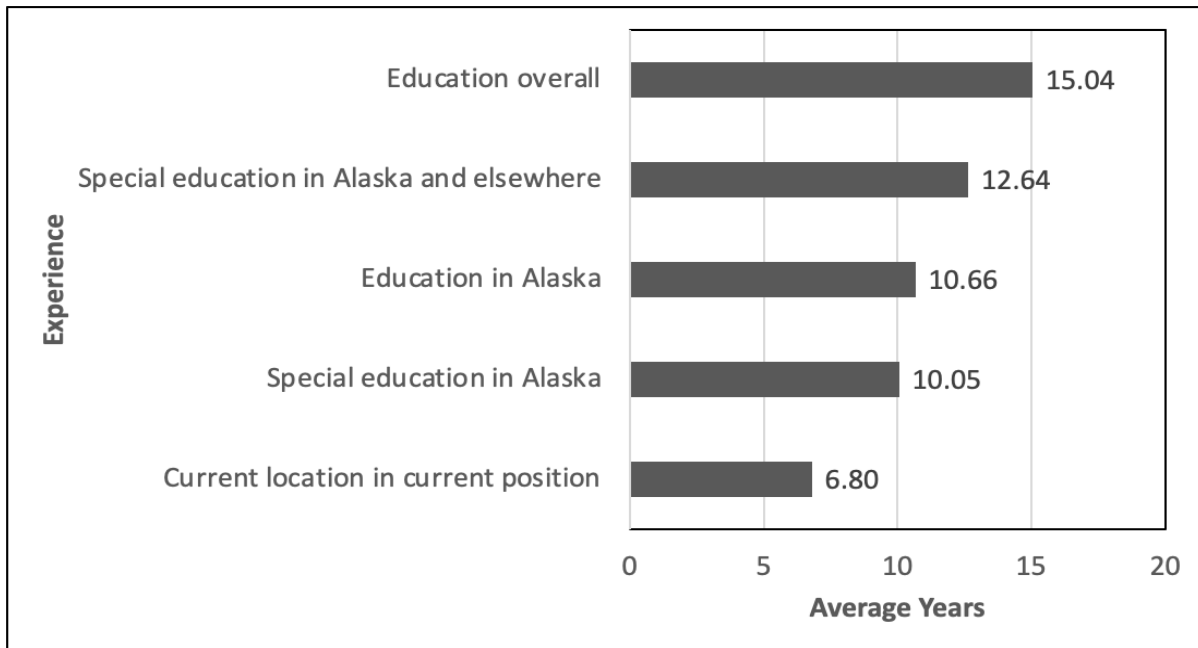


Figure A 7. What is your highest education level? (n = 344)

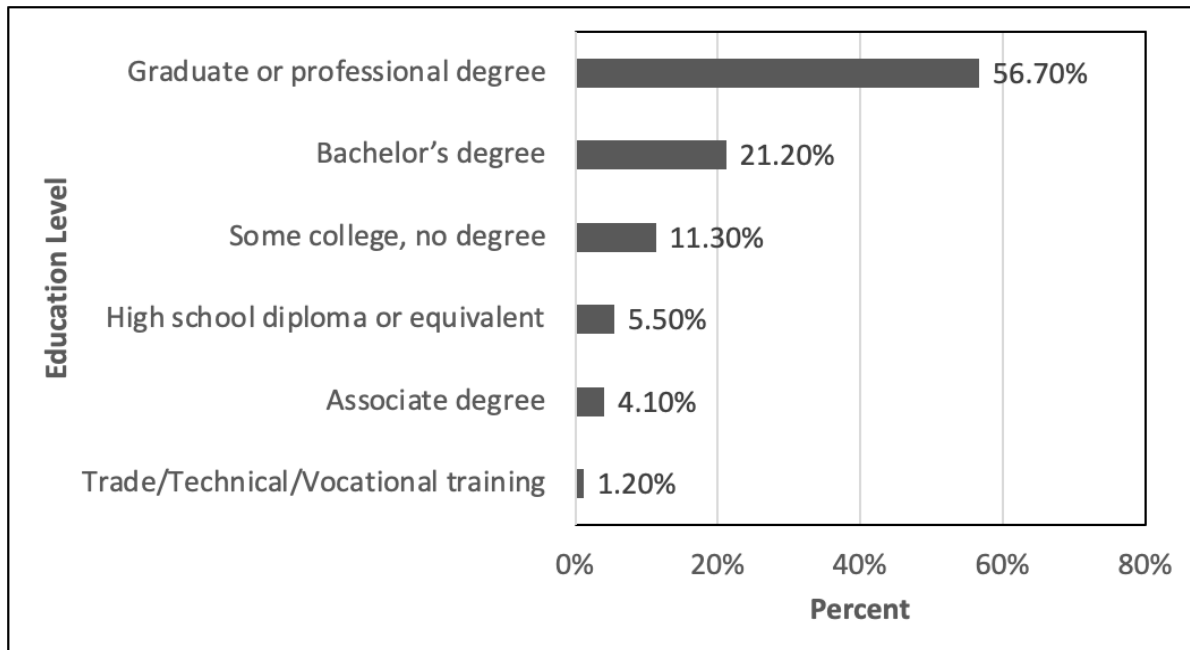


Figure A 8. Please rate your level of agreement with the following statements (n = 298)

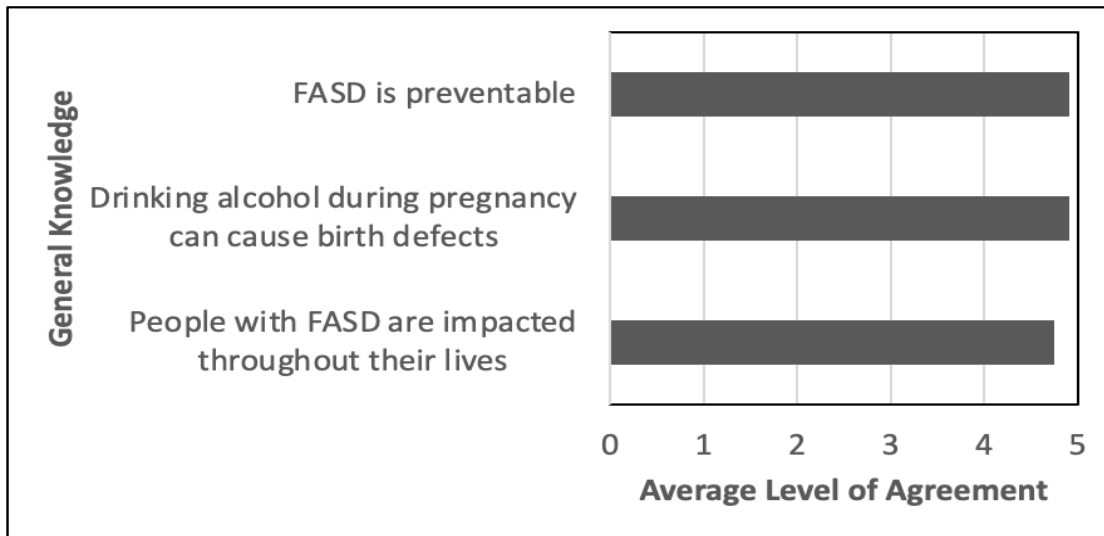


Figure A 9. Please rate your level of agreement with the following statements: Prenatal alcohol exposure can affect a person's... (n = 294)

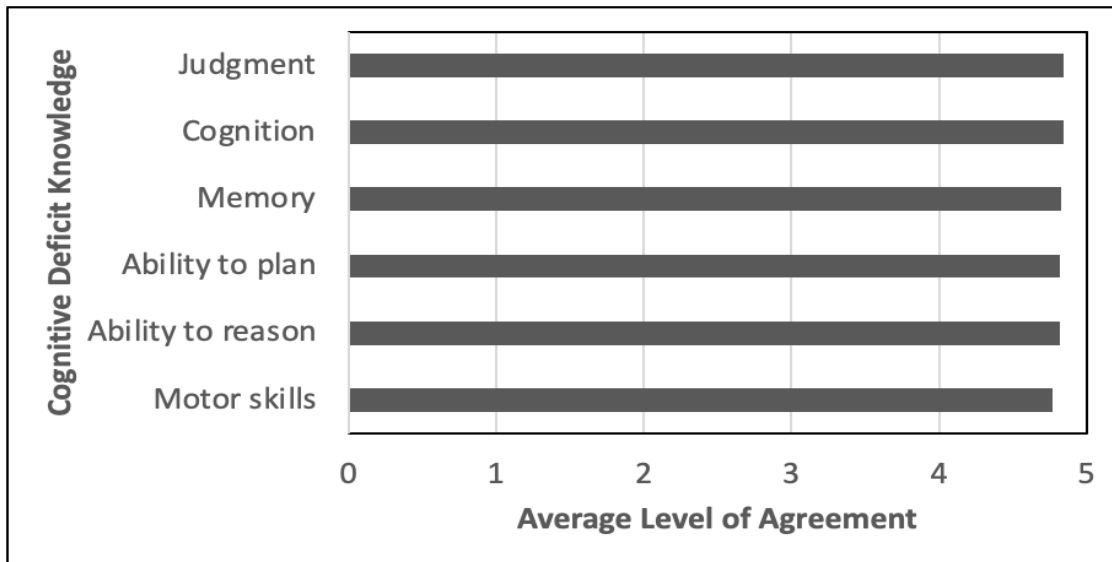


Figure A 10. If a child in your care was known/suspected of having FASD, who do you seek support from? (n = 262)

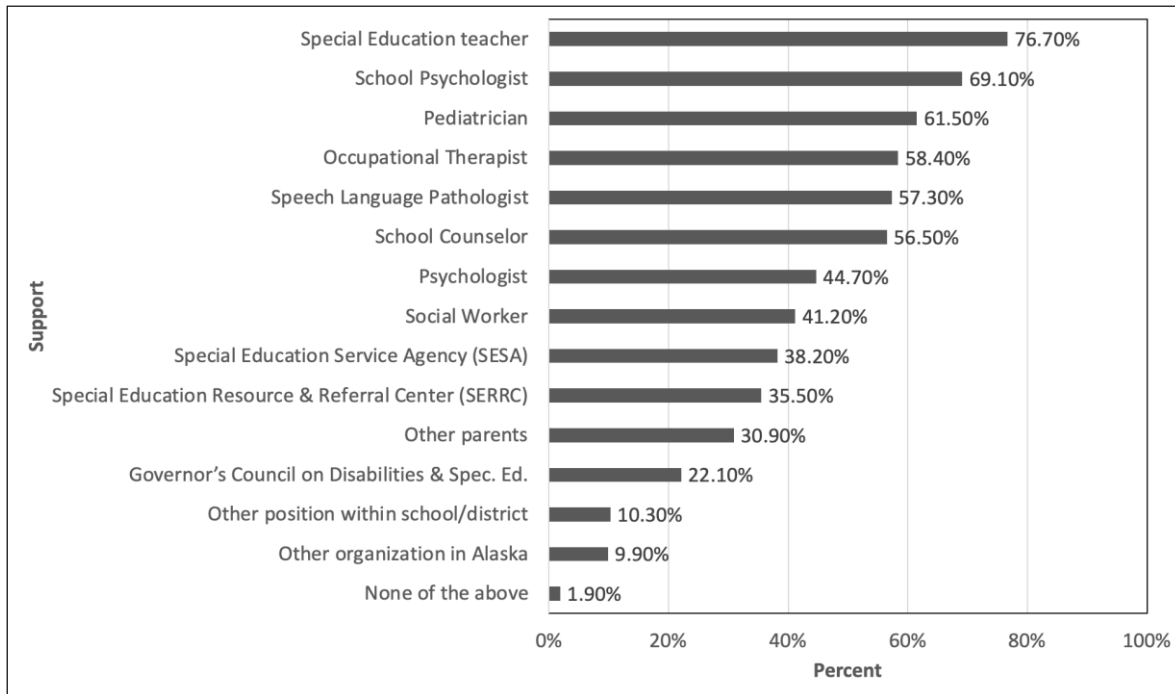


Figure A 11. Please rate your level of familiarity with the following organizations/programs (243 ≤ n ≤ 255)

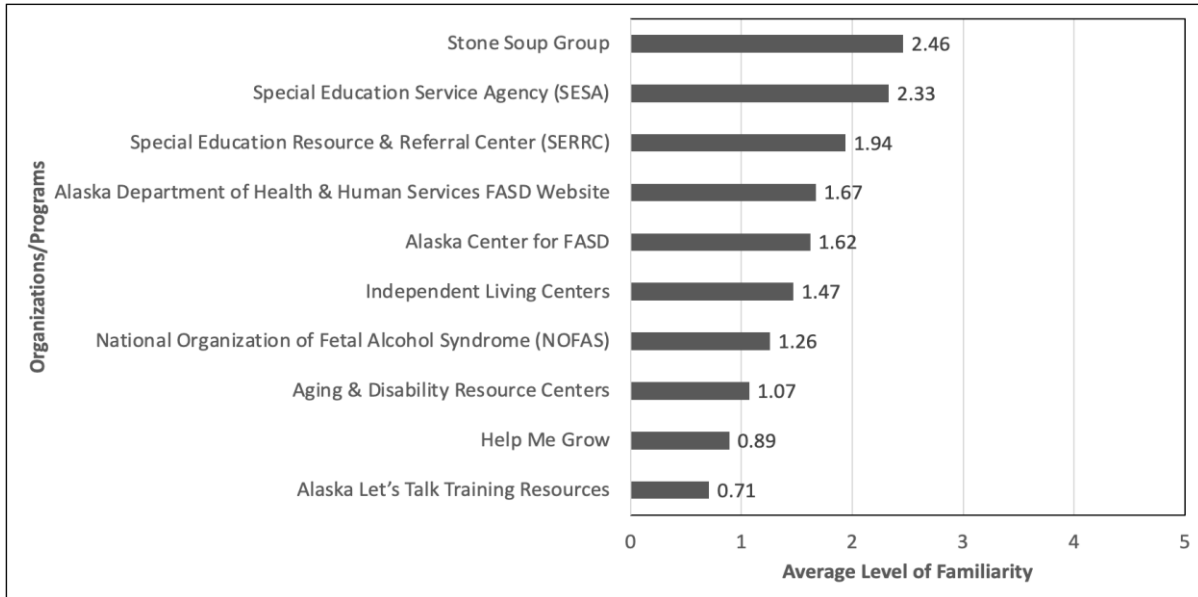


Figure A 12. For those students who have or are suspected to have FASD, how often do you collaborate with school-based team members to support the students and their families (not including IEP and/or 504 plan meetings)? (n = 253)

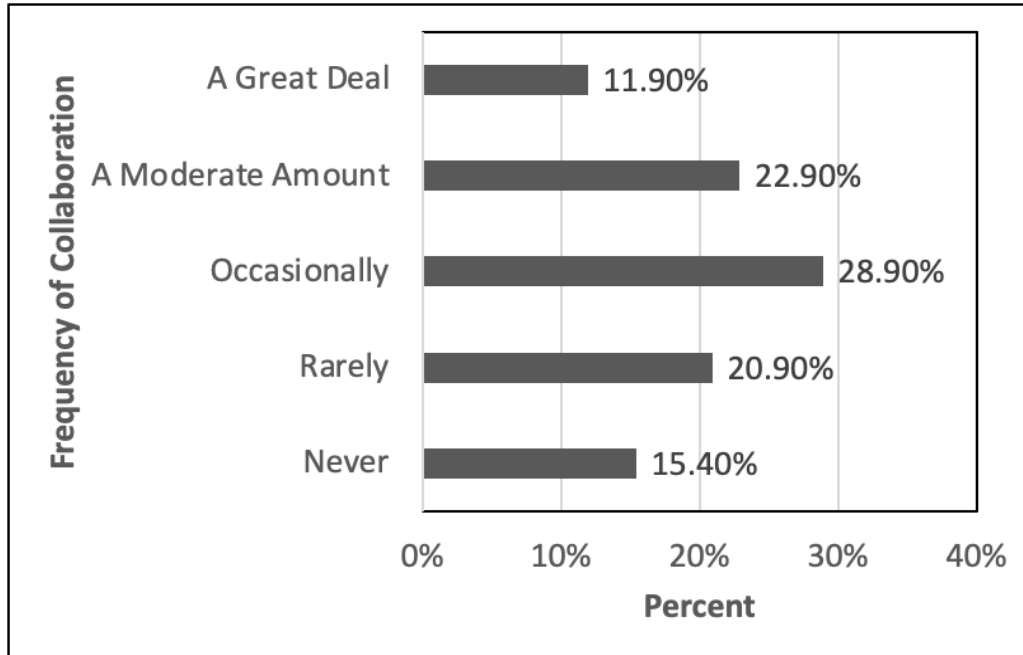


Figure A 13. Does your school or program offer/participate in any of the following FASD prevention activities? (n = 227)

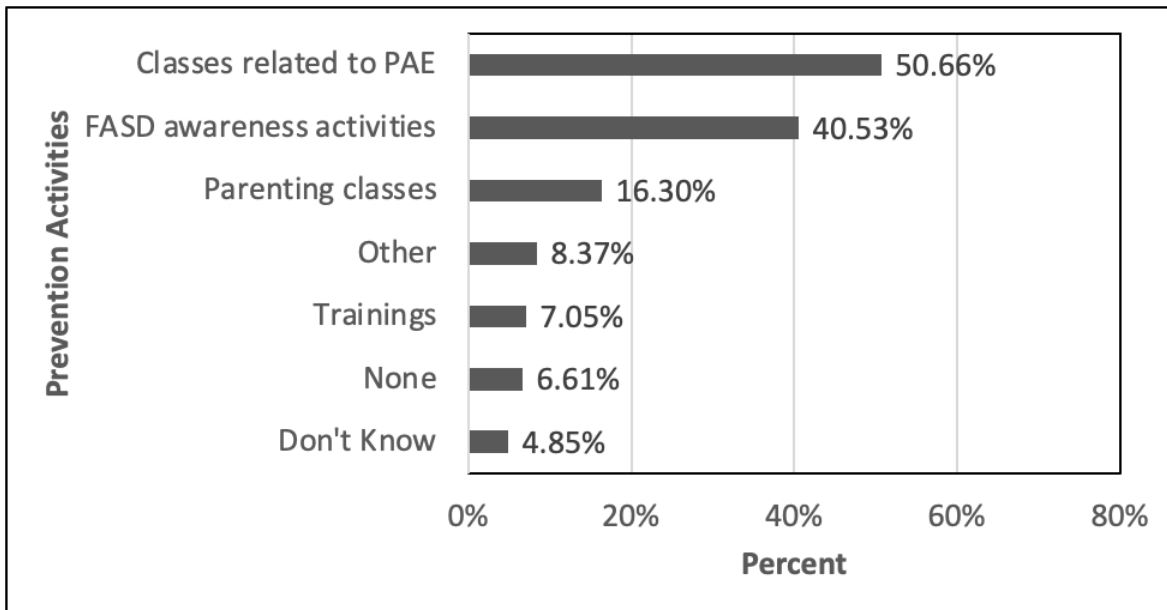


Figure A 14. Please rate your level of confidence in your ability with the following (n = 300)

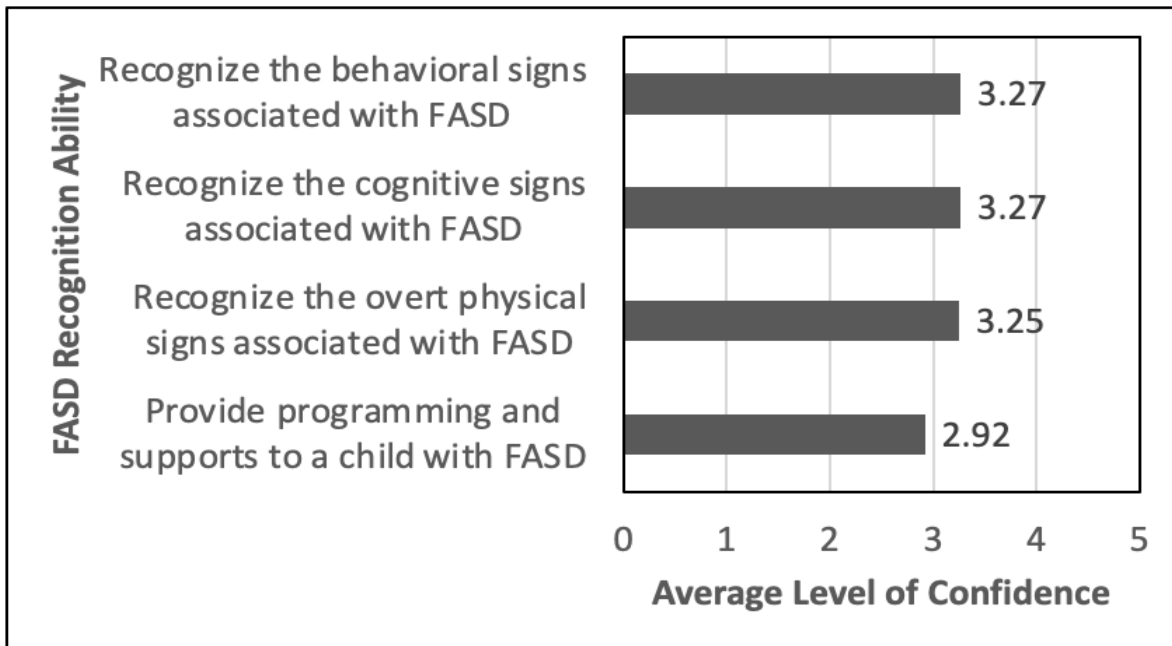


Figure A 15. What do you see as the gaps in education services for students who have or you suspect have FASD? Birth - 3 years old (n = 160)

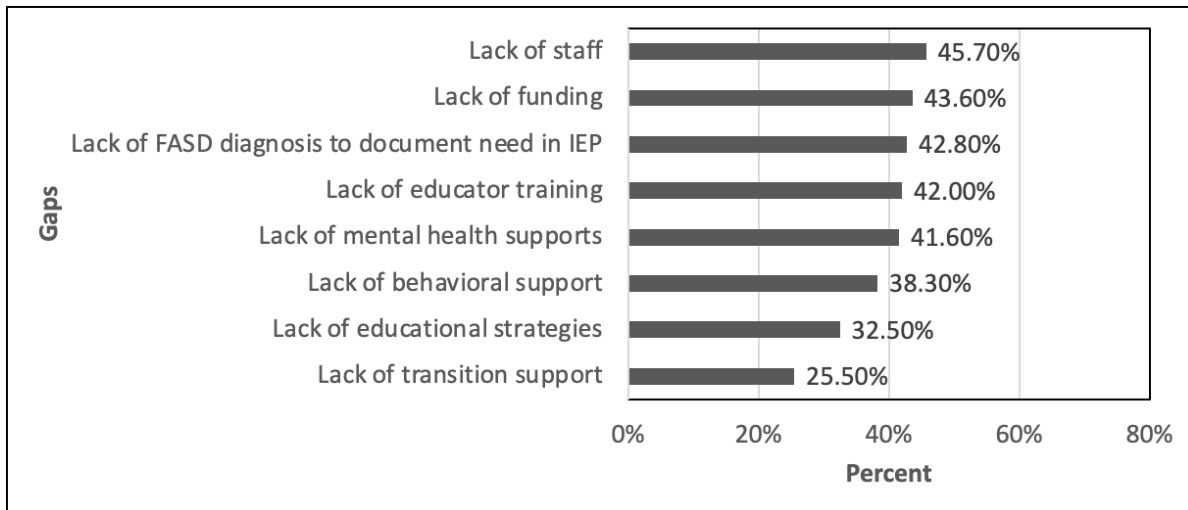


Figure A 16. What do you see as the gaps in education services for students who have or you suspect have FASD? Pre-K (n = 182)

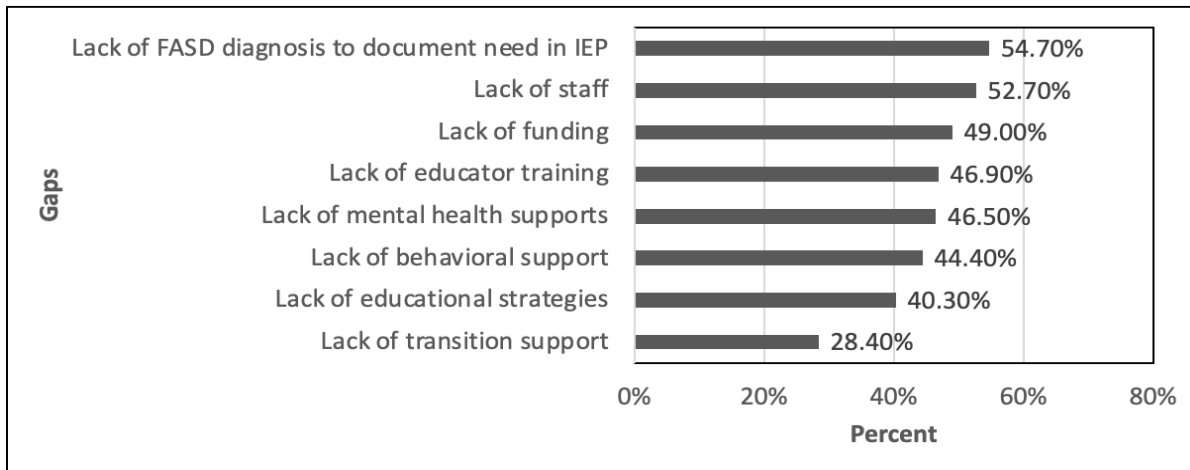


Figure A 17. What do you see as the gaps in education services for students who have or you suspect have FASD? Elementary (n = 200)

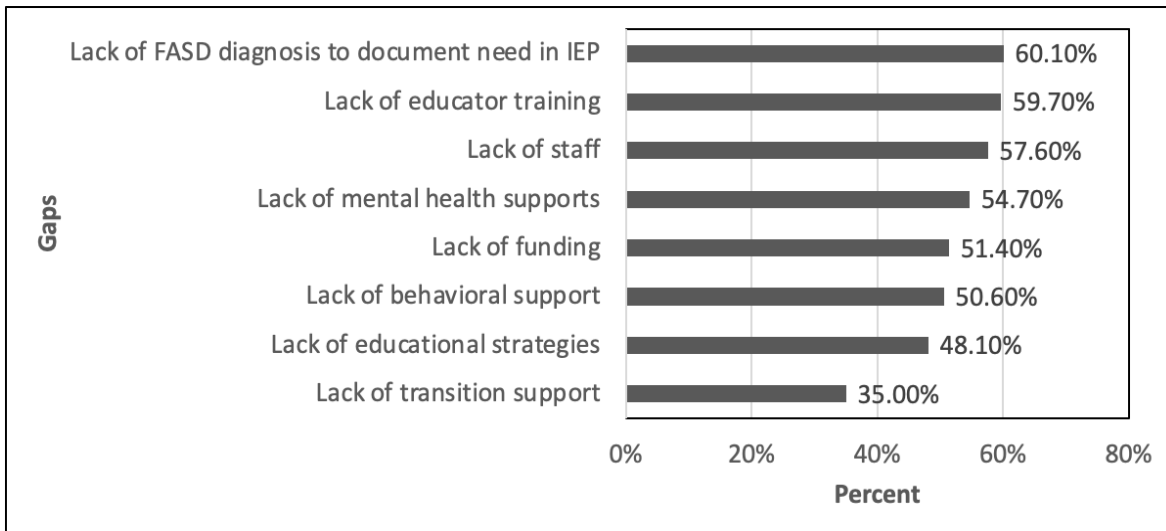


Figure A 18. What do you see as the gaps in education services for students who have or you suspect have FASD? Secondary (n = 194)

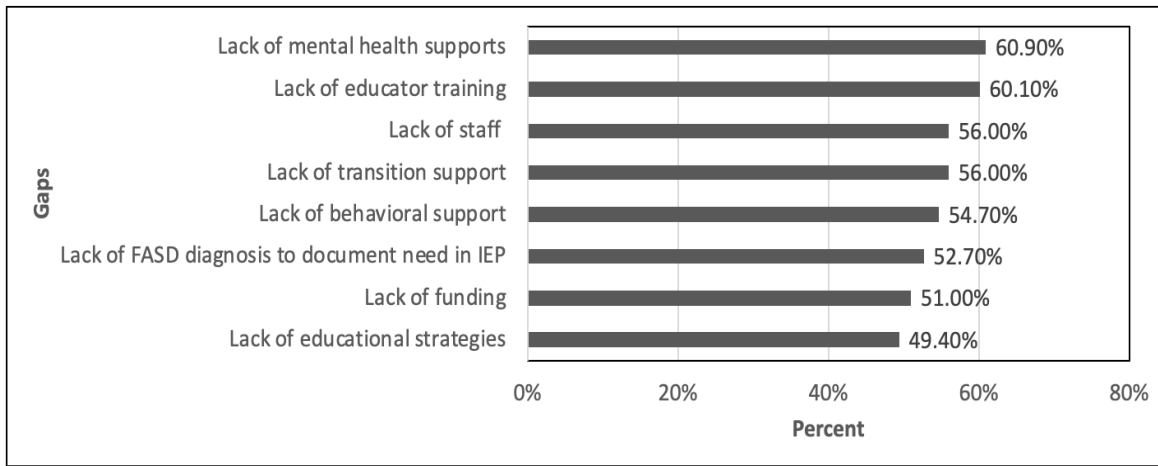


Figure A 19. What do you see as the gaps in education services for students who have or you suspect have FASD? Post-secondary (n = 157)

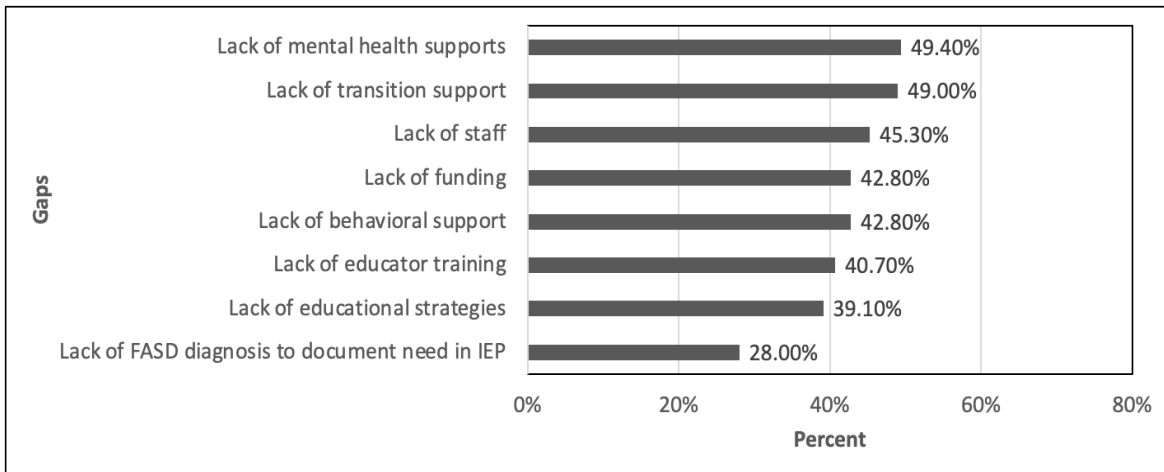


Figure A 20. What do you see as the gaps in education services for students who have or you suspect have FASD? No gaps noted (n = 67)

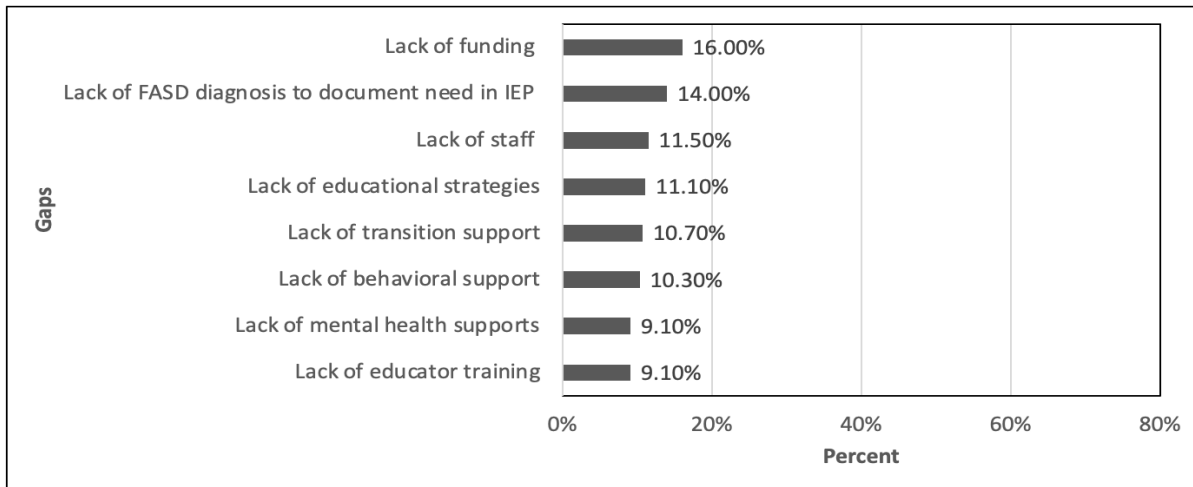


Figure A 21. Does your employer require you to complete FASD focused training? (n = 327)

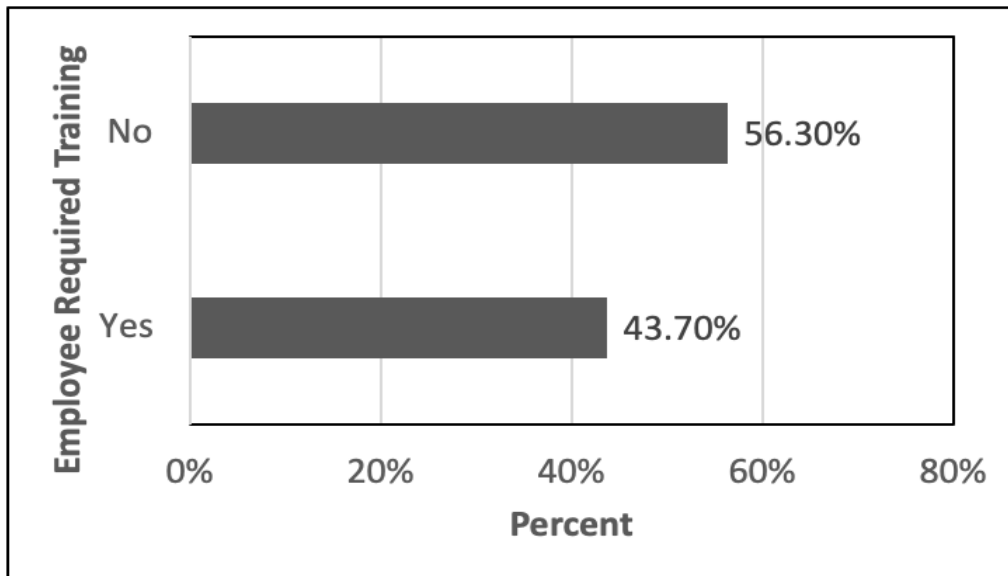


Figure A 22. In the past 12 months, have you received specific training on providing programming and supports for children with FASD? (n = 323)

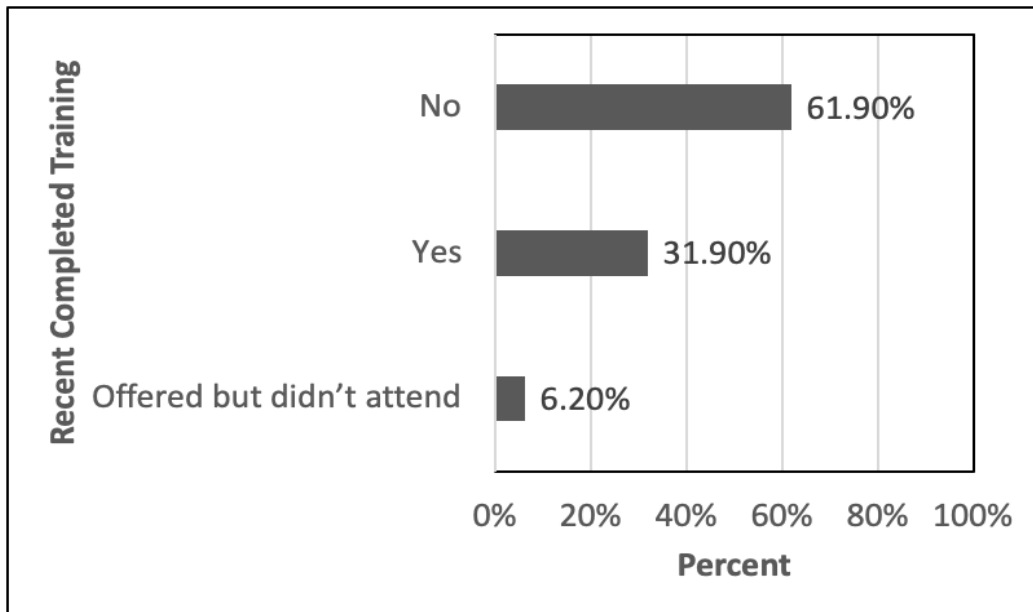


Figure A 23. Which of the following evidence-based interventions to support individuals with FASD have you received training on? (n = 270)

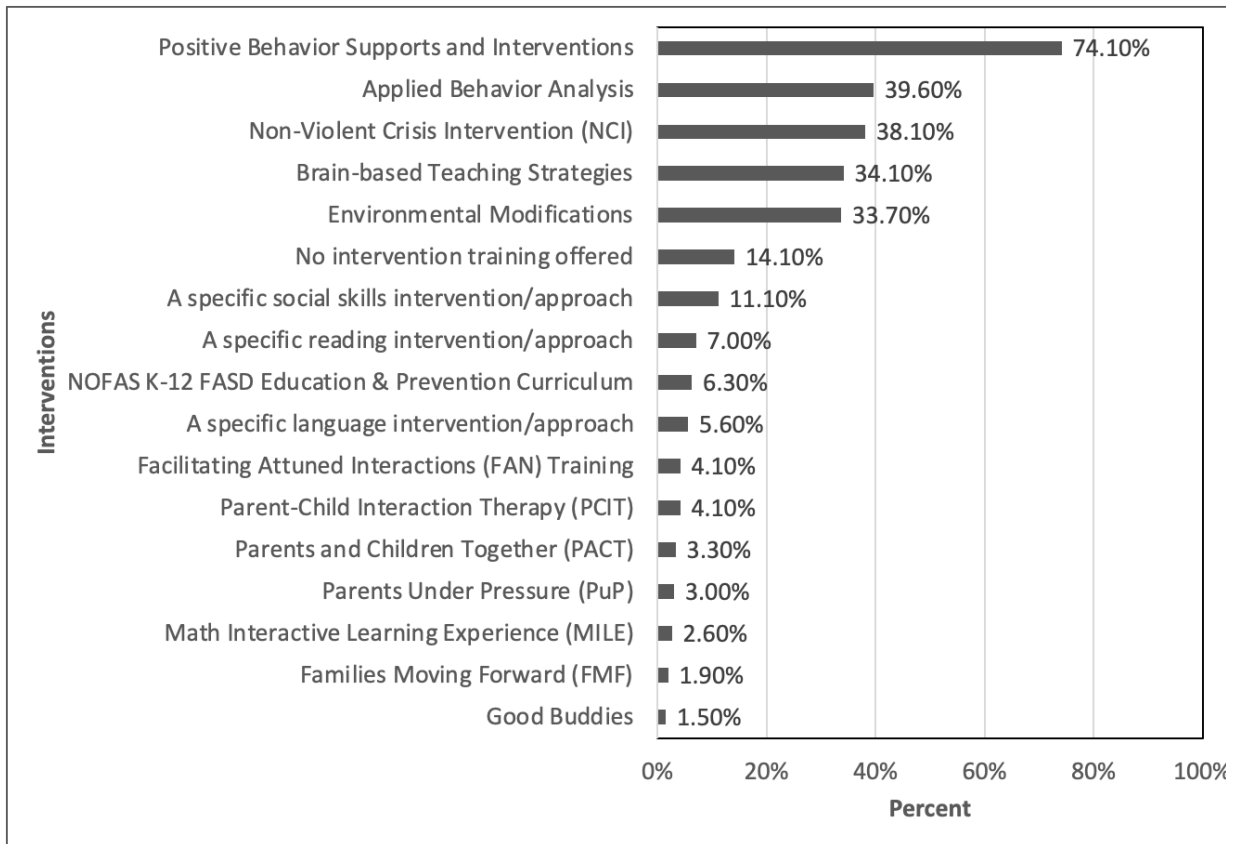


Figure A 24. Having received training in Applied Behavior Analysis, do you hold any of the following credentials? (n = 13)

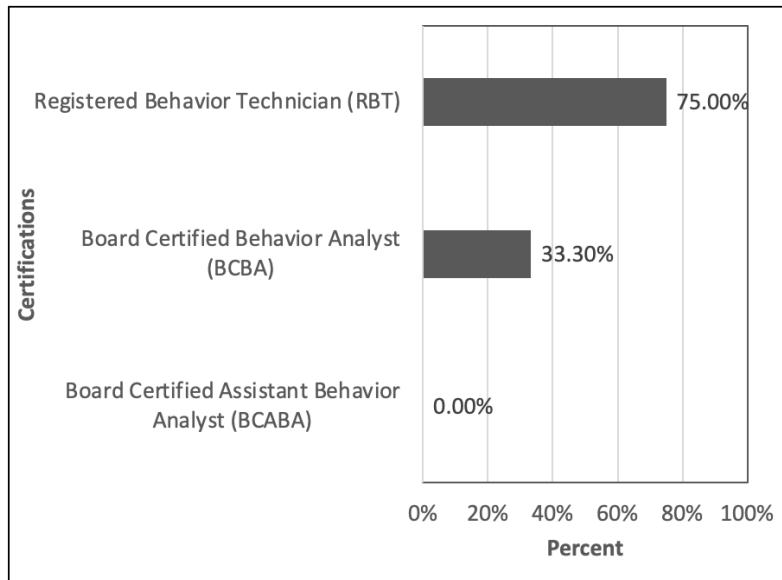


Figure A 25. In what format(s) have you received training in Positive Behavior Supports and Interventions? (n = 187)

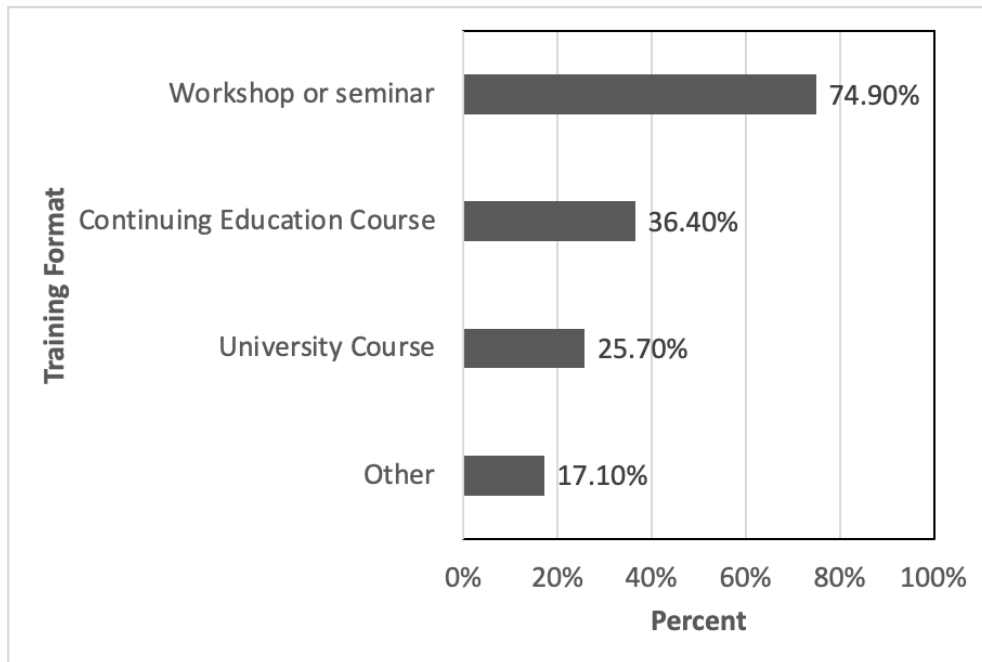


Figure A 26. How satisfied are you with the evidence-based interventions you have received training on? ($2 \leq n \leq 180$)

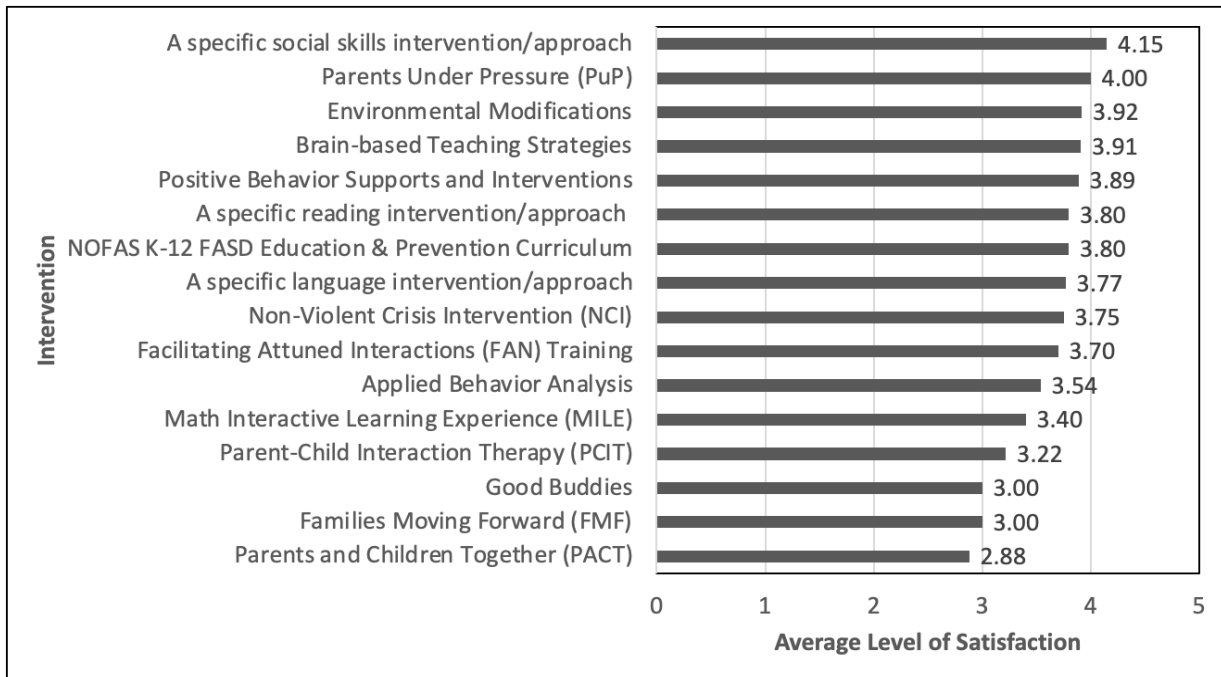


Figure A 27. Which of the following FASD-related trainings/courses have you completed? (n = 252)

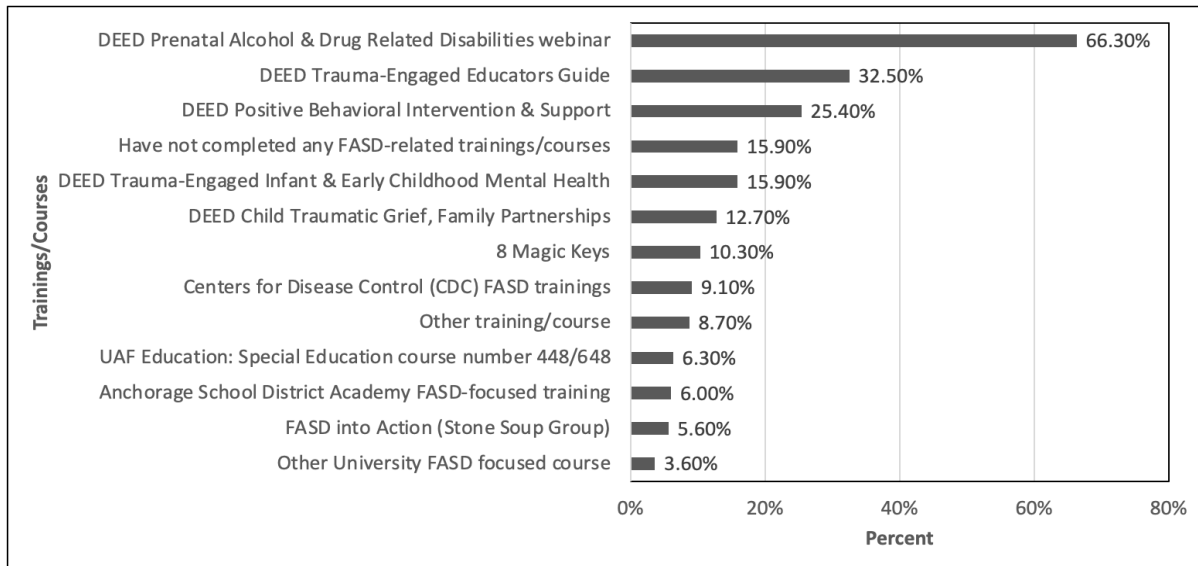


Figure A 28. Of the training(s)/course(s) that you attended, please rate the helpfulness of the training/course (9 ≤ n ≤ 163)

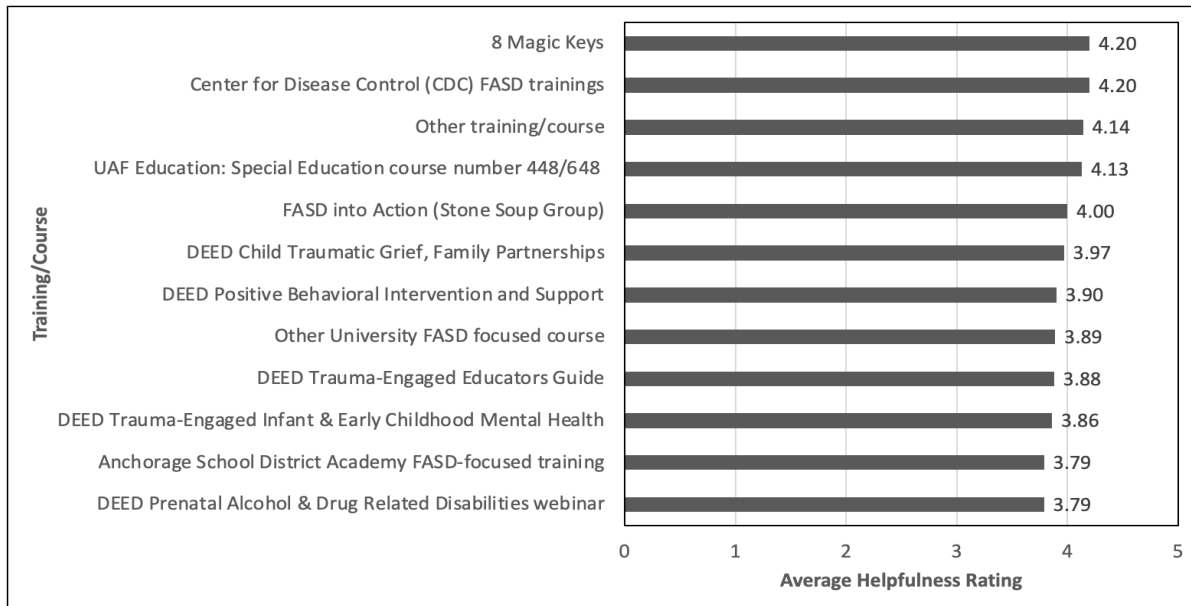


Figure A 29. What are the challenges for students/families who have or you suspect have FASD in transitioning between 0-3 years to preschool? (n = 151)

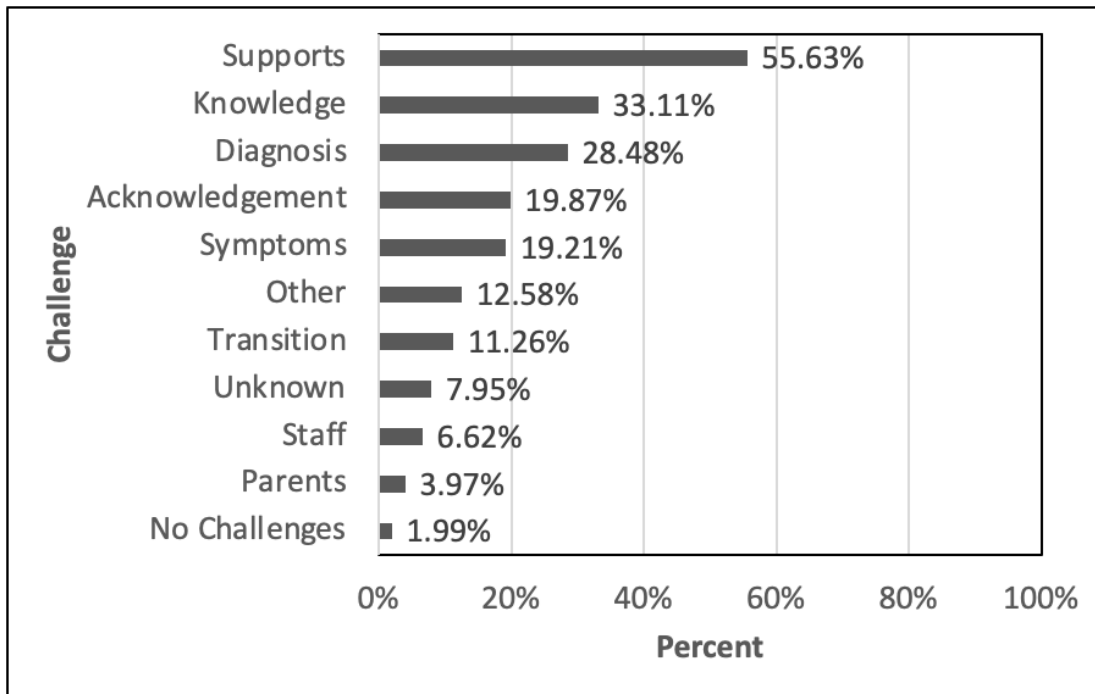


Figure A 30. What are the challenges for students/families who have or you suspect have FASD in transitioning between preschool to elementary? (n = 144)

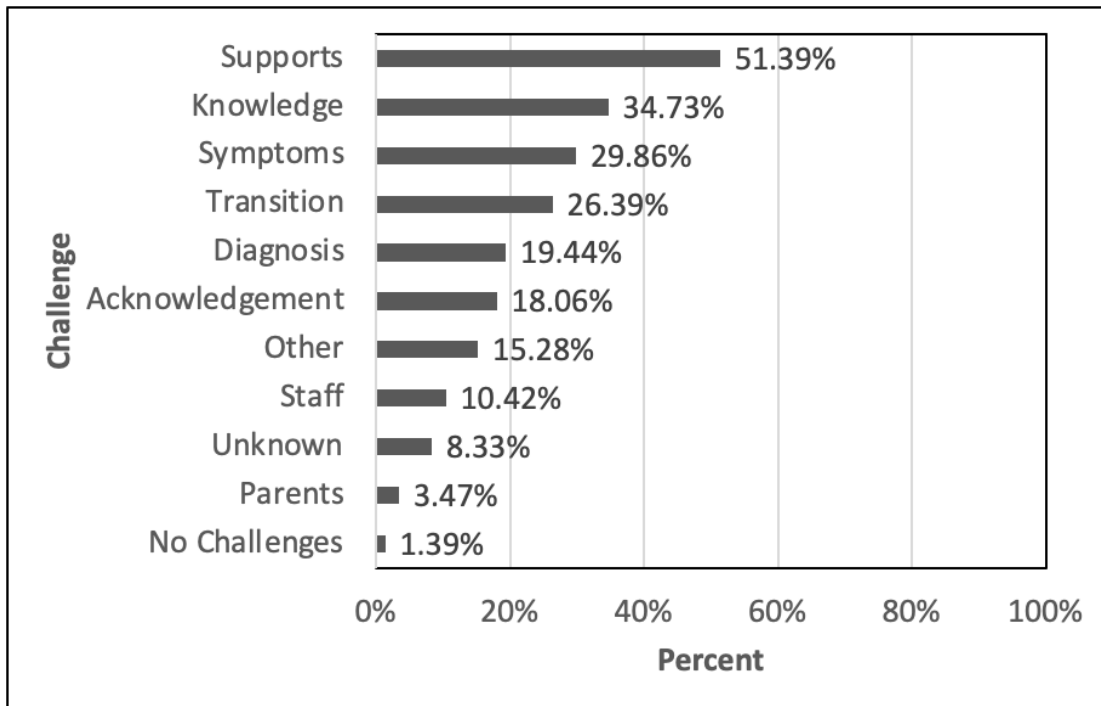


Figure A 31. What are the challenges for students/families who have or you suspect have FASD in transitioning between elementary to secondary? (n ≤ 146)

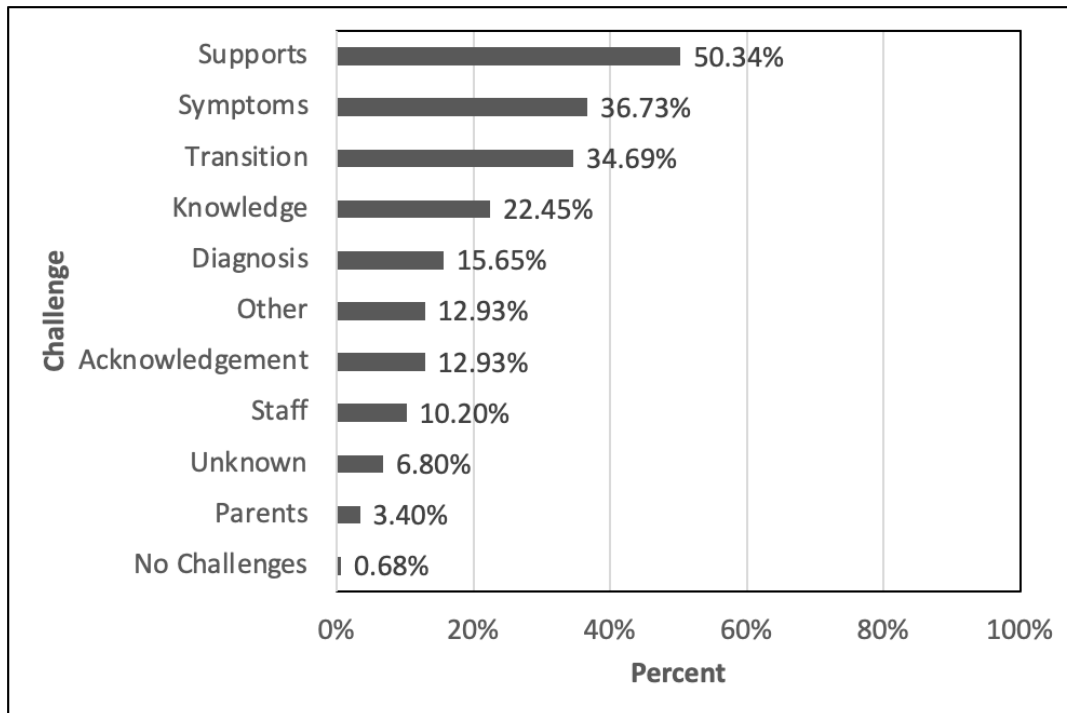


Figure A 32. What are the challenges for students/families who have or you suspect have FASD in transitioning between secondary to post-secondary? (n = 142)

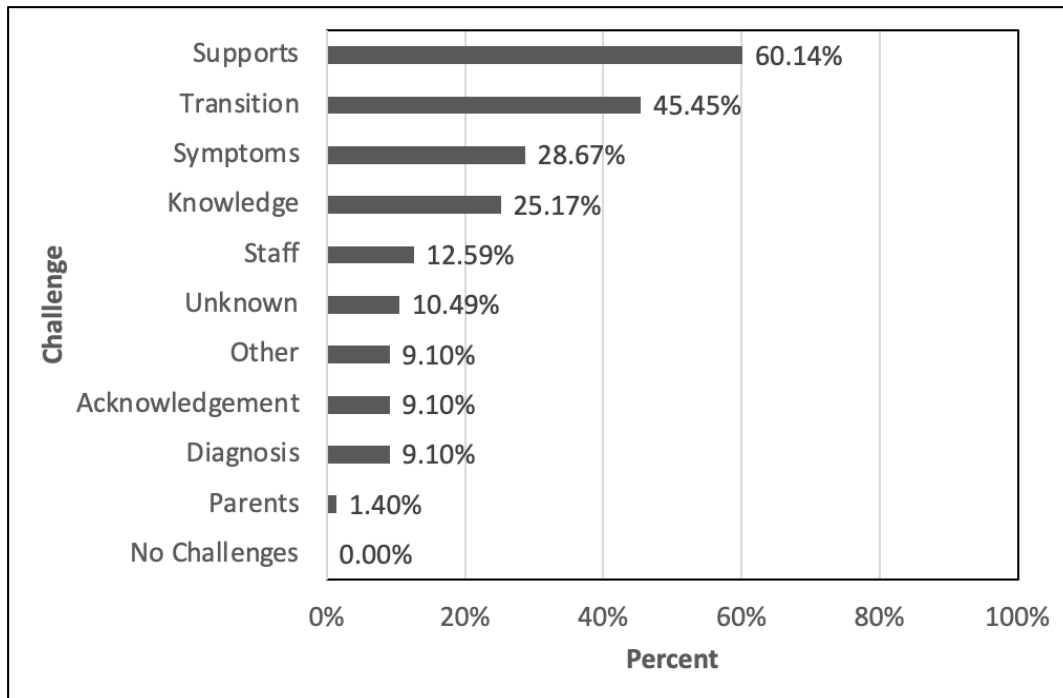


Figure A 33. What has worked well for students/families who have or you suspect have FASD in transitioning between 0-3 years to preschool? (n = 113)

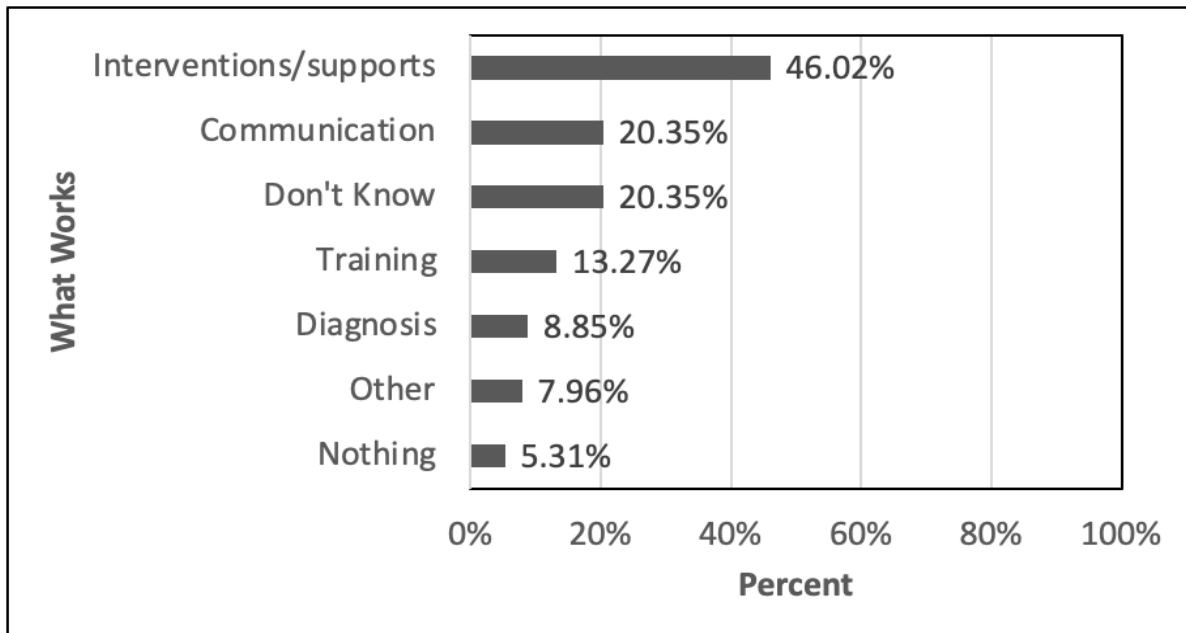


Figure A 34. What has worked well for students/families who have or you suspect have FASD in transitioning between preschool to elementary? (n = 117)

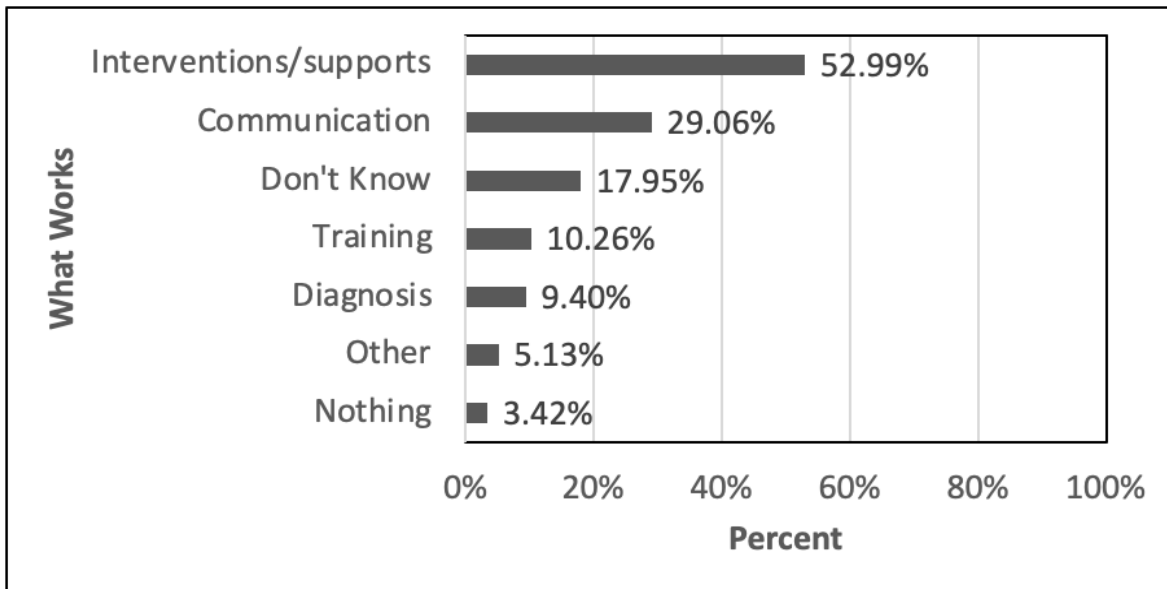


Figure A 35. What has worked well for students/families who have or you suspect have FASD in transitioning between elementary to secondary? (n = 111)

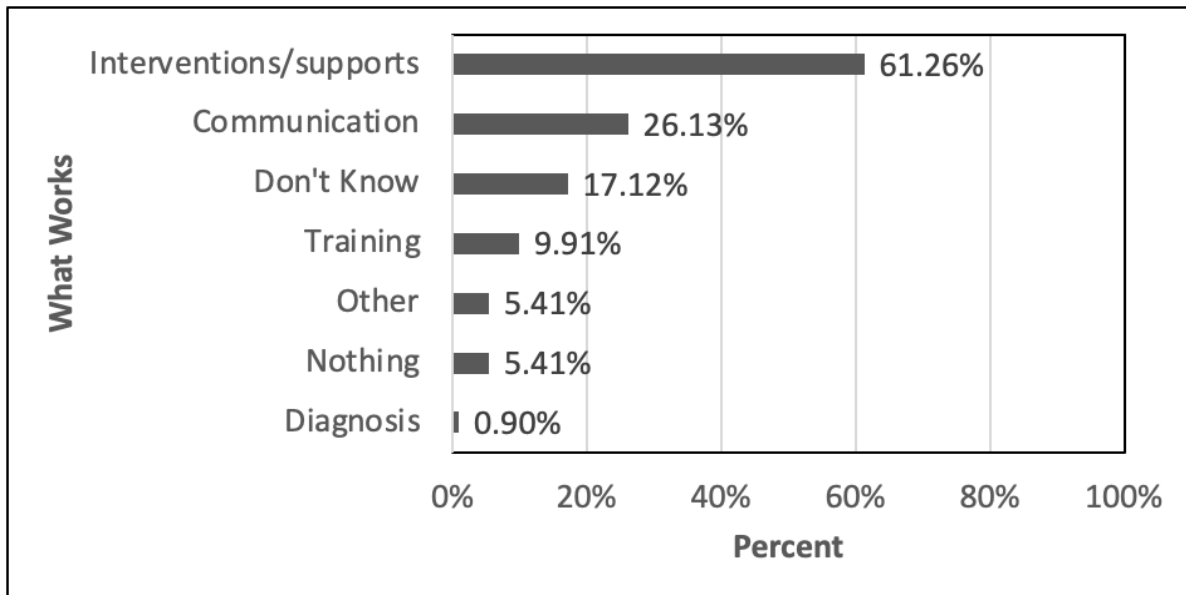


Figure A 36. What has worked well for students/families who have or you suspect have FASD in transitioning between secondary to post-secondary? (n = 108)

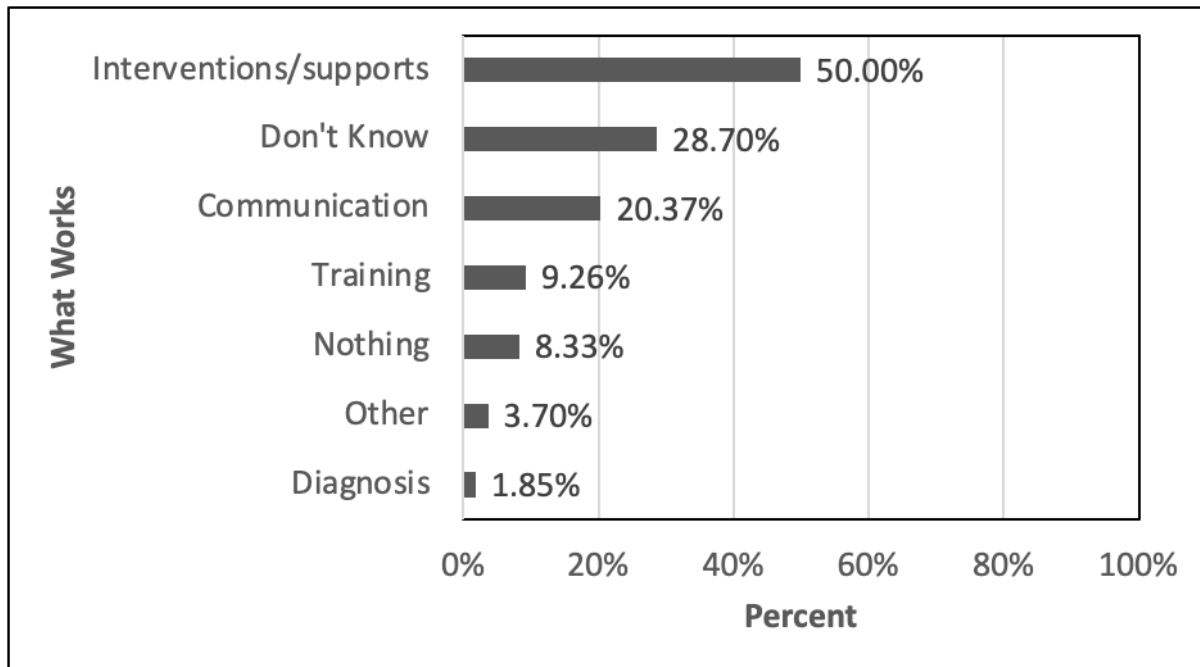


Figure A 37. What barriers do you face in providing care/services to students/families with FASD? (n = 159)

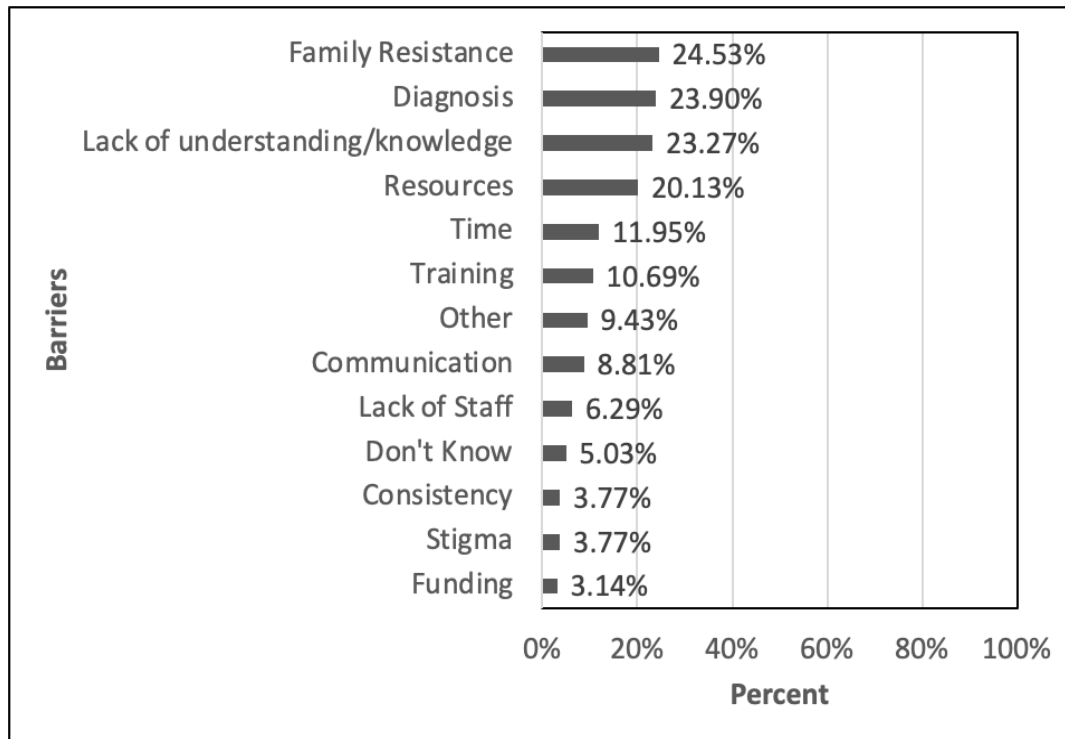


Figure A 38. What resources, connections, or information would help you to navigate barriers and provide the best care/services for students/families with FASD? (n = 135)

