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## Fetal Alcohol Spectrum Disorder Telehealth Feasibility Study

Prepared for

### **The Alaska Mental Health Trust Authority**

June 2021



Western Interstate Commission  
for Higher Education  
Behavioral Health Program

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Key informant interviews

Focus groups

Providing data and other information

Sharing your perspectives

And keeping us on track.

# Executive Summary

## INTRODUCTION

Alaska's Fetal Alcohol Spectrum Disorder (FASD) system began over 20 years ago when, in the late 1990's and early 2000's, Alaska received over \$25 million dollars as a result of a federal earmark administered by the Substance Abuse and Mental Health Services Administration (SAMHSA). Soon after, Alaska adopted a Medicaid FASD waiver to provide access for individuals and families served by a broad array of medical, behavioral health and developmental/intellectual disabilities services. The system included seventeen (17) community-based FASD Diagnostic Teams strategically located in all parts of the state. As a result of its vision, robust services, governmental funding and support, Alaska grew to become a leader in the FASD field both nationally and internationally.

Approximately 15 years ago the landscape began to change when the Medicaid Waiver ended, and funding began to shrink. One consequence of the loss of funding was the slow erosion of active community-based Diagnostic Teams, which gradually dwindled from 17 Teams to just four (4) today. As a result, large swaths of the state now have no access to local evaluation and diagnostic services. Despite the systemic challenges, Alaska's FASD stakeholders, advocates, and leaders, remain committed to preventing FASD, to finding solutions that can increase access to services, and to improving the lives of Alaskans impacted by FASD. In fact, there is growing interest among stakeholders in a new approach that might help address service gaps and system needs in Alaska: telehealth. By definition, telehealth (sometimes referred to as tele-medicine and tele-practice) is:

*"The distribution of health-related services and information via electronic information and telecommunication technologies. It allows long-distance patient and clinician contact, care, advice, reminders, education, intervention, monitoring, and remote admissions. Telemedicine is sometimes used as a synonym or is used in a more limited sense to describe remote clinical services, such as diagnosis and monitoring. When rural settings, lack of transport, a lack of mobility, decreased funding, or a lack of staff restrict access to care, telehealth may bridge the gap. It may also be used for provider distance-learning; meetings, supervision, and presentations between practitioners; online information and health data management and healthcare system integration. Telehealth could include two clinicians discussing a case over video conference; a robotic surgery occurring through remote access; physical therapy done via digital monitoring instruments, live feed and application combinations; tests being forwarded between facilities for interpretation by a higher specialist; home monitoring through continuous sending of patient health data; client to practitioner online conference; or even videophone interpretation during a consult." [Wikipedia]*

## STUDY FOCUS AND GOALS

With growing interest in telehealth applications, and in recognizing the need to rebuild FASD prevention and diagnostic services for the thousands of Alaskans impacted by FASD, The Alaska Mental Health Trust Authority (The Trust) retained the Western Interstate Commission for Higher Education/Behavioral Health Program (WICHE/BHP) to conduct the "Fetal Alcohol

Spectrum Disorder Telehealth Feasibility Study”. The study focused on four goals relevant to rebuilding capacity of FASD services for Alaskans:

1. Recommend an optimal and financially sustainable **model for the use of telehealth/telemedicine technology** (synchronous and asynchronous) to support a continuum of FASD **screening and diagnosis** in Alaska.
2. Develop recommendations to **support a continuum** of FASD screening and diagnosis model in Alaska.
3. Recommend a **model for a standalone multidisciplinary** FASD community-based diagnostic team as well as a **model for integrating the function** with a neurodevelopmental clinic model -- including the reach and sustainability of each model.
4. Recommend a **model for using telehealth/telemedicine technology** (e.g., ECHO model etc.) for FASD related **continuing education** for providers, and for **community education/prevention** activities.

## VALUES AND GUIDING PRINCIPLES

During the course of the study, WICHE/BHP discovered an important thread of values and principles shared by stakeholders, leaders, experts and model programs alike. Those six values and principles underscore the theme of this report and corresponding recommendations.

- **ACCESS:** Having a diagnosis and getting connected to support can change the trajectory of one’s life. Increasing access to diagnostic and support services is of paramount importance.
- **LOCAL OWNERSHIP:** Regardless of the model Alaska adopts, local ownership and involvement is key to increasing access and connecting with people in their homes and communities.
- **POINT OF CARE/FAMILY AND PERSON-CENTERED:** The ‘point of care’ is the child and their family or the adult seeking services. Efforts to open access and improve quality should be informed by the perspective of the ‘point of care’. Embedding navigators and peer services can steer a system toward a robust person-centered model.
- **CONSISTENCY:** Consistency in screening and diagnostic protocol is essential -- especially as children, youth, and adults age, move, and/or transition to (or between) education, child welfare, juvenile and criminal justice, developmental, behavioral health and vocational, etc. systems. Consistency can increase access and prevent people from ‘falling through the cracks”.
- **EVIDENCE-BASED AND PROMISING PRACTICES:** Evidence-based Practices and Programs (EBPs) are research-based, have been proven to work and, therefore, are more likely to produce desired outcomes. They should be included and promoted in the system of care. For example, Screening Brief Intervention and Referral to Treatment (SBIRT) is an evidence-base screening and early intervention tool that quickly identifies the severity of substance use and identifies the appropriate level of treatment.
- **LEADERSHIP:** Underlying these principles is the invaluable asset of leadership. Trusted and collaborative leadership can create momentum, increase resources, and advance

services.

## RECOMMENDATIONS

In context of the history and current landscape of FASD services in Alaska, the goals of this study, the values and principles shared by stakeholders, and our research findings, we submit the following recommendations to The Alaska Mental Health Trust Authority:

### **1. Incorporate Telehealth Technology into FASD Diagnostic/Support Services**

The COVID 19 pandemic fundamentally resulted in a shift in thinking about telehealth – from being an outlier to being an accepted and, for some patients and providers, a preferred method of receiving and delivering healthcare. Families/clients have experienced real benefits of telehealth services, including ease of access, decreased travel and transportation expenses, decreased absences from school and work, and alleviation of stress related to child and family care. Providers also save time in travel, report a decrease in missed appointments, and are able to serve clients beyond their normal geographic service boundaries. Given the potential to improve access as well as the benefits to families/clients and providers, we believe telehealth (coupled with in-person service) should be a priority strategy worth serious consideration.

Alaska is a leader in using telehealth/telemedicine technology. In preparing this report, we assume telehealth will be one vehicle for implementing the recommendations that follow. Further, recognizing current bandwidth limitations as well as difficulty in conducting certain specialized evaluations, we minimally recommend the use of a hybrid model (i.e., combination of in-person and telehealth) initially, with greater adoption of the telehealth/telemedicine technology over time.

### **2. Streamline Evaluation and Diagnosis**

To open access and save resources, Alaska should consider streamlining diagnostic and evaluation services by implementing a "tiered evaluation and diagnostic system" similar to that used by model sites, as well as Alaska's "traveling" neurodevelopmental clinics that are currently focused on evaluating for and diagnosing Autism. For example: Tier 1 - Unambiguous Diagnosis - Evaluation conducted by a pediatrician, family doctor, nurse practitioner, etc.; Tier 2 - Questionable or Uncertain Diagnosis - Evaluation conducted by a Developmental Behavioral Pediatrician and/or Neurodevelopmental Psychologist; Tier 3 - Complex or Complicated Diagnostic Picture - Evaluation conducted by the multi-disciplinary team, i.e., pediatrician, psychologist, Occupational Therapist (OT), Physical Therapist (PT), Speech and Language Pathologist (SLP), etc.

### **3. Undertake Universal Screening**

We recommend promotion of both universal screening for alcohol exposed pregnancies as well as for FASD in both primary care and behavioral health settings. Identifying and/or developing the screening tool should be a priority. And although there are currently no evidence-based screening tools for FASD, there are evidence-based screening tools for alcohol use -- for example, the SBIRT screening tool. Further, screening should occur at all locations where children who are suspected of having FASD come into contact with healthcare, behavioral health, and developmental/intellectual systems as well as the education, juvenile

justice, child welfare and social services. For example, all school nurses should be trained to screen for FASD.

#### **4. Open Access with Options in Diagnostic Clinics**

Given the challenges of accessing diagnostic services, it makes programmatic and financial sense to support both the integrated neurodevelopmental clinics and community-based diagnostic clinics. Integrated clinics offer a range of diagnostic specialties for children and adults, as well as the multi-disciplinary “gold standard” diagnostic model. The community-based clinics, which also offer the “gold standard” but specifically focus on FASD, should remain as a vital part of the system, and continue to offer patients and families the option to receive diagnostic services in their community and close to home. Finally, when the integrated traveling clinics are in operation again, we strongly recommend the inclusion of FASD diagnostic services as a third option for families and adults.

#### **5. Implement Standardized and Consistent Diagnostic Policies and Protocols**

Screening and diagnostic policies and protocols are inconsistent from one diagnostic team and clinic to the next in Alaska. As a result, the system is fragmented, uncoordinated and confusing - especially for families. Standardized application of screening and diagnostic protocols would result in consistency among providers and across systems where children and adults may be identified (i.e., education, child welfare, juvenile and criminal justice, and vocational systems). Having a designated single point of entry is one strategy to alleviate inconsistencies, help people avoid “falling through the cracks”, secure relevant system use data, and support access to diagnostic services.

#### **6. Invest in Capacity Building**

Investing in building workforce knowledge and capacity for systems that serve individuals with FASD will ultimately result in increased access and improved services for children, their families, and adults with FASD. This includes developing or growing the workforce through partnerships with educational institutions, conducting training in evidence-based practices, and connecting with outside expertise in prevention, screening, diagnostics, and systems. Options for professional development, including an FASD “community of practice” where practitioners can learn from one another and feel supported, combined with ECHO cohort and training opportunities, will further build FASD service capacity, knowledge, skills, and competencies.

#### **7. Parent/Family Navigation and Care Coordination**

Services should include care coordination and parent/family navigation functions -- ideally prior to the evaluation, throughout the evaluation, and post evaluation, regardless of diagnosis. Children, parents, and families need an ally throughout the entire process, as well as assistance accessing services once they are delineated and recommended.

#### **8. Link Funding to Work/Service Performed vs. Confirmed Diagnosis**

We recommend the State of Alaska approves and implements the "pending" State Diagnostic Teams provider agreement in the short term. A longer-term approach would move the payment system from a reimbursement model that rewards "finding a diagnosis" to one that reimburses providers/practitioners adequately for the work they perform. It also should consider (perhaps through a demonstration project) moving from a fee for service (FFS) payment/reimbursement mechanism to an encounter, case or bundled rate based on the cost

to do the work.

### **9. Support Advocacy and Peer Support**

"Self-Advocates" are people with FASD who seek improved access to services for themselves and/or their families to better meet their needs. They may also advocate for changes in the system (i.e., System Advocates) to better serve people overall who are impacted by FASD. Although Alaska has an excellent track record of including consumers, clients, and patients in all aspects of the work, it should be intentional about including people with FASD whenever possible, demonstrating commitment to the "Nothing about us without us" philosophy. Adults with FASD should have opportunities to connect to peers for support and guidance throughout their lives.

### **10. Create a Formal Mechanism for Data Collection, Analytics, Reporting and Sharing**

Collecting data regarding screenings, referral numbers, completed assessments, diagnoses, and the costs of assessments has been a significant challenge of this project from as many providers as possible. We recommend Alaska create a formal mechanism for data collection that is updated regularly and analyzed at least annually. Currently only clinics that are part of the Provider Agreement submit data through AKAIMS; to accurately capture information on the entire system, as many providers as possible should submit data to the new system. The data collected should include details about the number of referrals, referral source, completed assessments, and diagnoses. Access to data is instrumental to building a viable case for increased funding and system improvements, especially for advocates, policy makers and providers who require needs-based data (i.e., requests for services overwhelming available resources) to effectively advocate with elected officials and decision-makers.

### **11. Institute Shared Leadership**

Trusted and collaborative leadership singularly focused on Alaska's FASD services, and the system of care can refuel and stimulate momentum for system advancement and growth. A community-based organization that partners with government but is independent of government -- an organization with expertise in FASD that is dedicated to working with individuals with FASD and their families and committed to improving systems of care -- would ideally serve in this capacity. Based on our interviews with key informants and review of models, the Alaska Center for FASD could fulfill this important leadership role.

In addition, the National Organization for Fetal Alcohol Syndrome (NOFAS) is a nonprofit advocacy, prevention, and education organization with affiliates across the United States, Canada, Australia, and the United Kingdom. As the leading FASD advocacy organization, NOFAS works on the national level to increase support for FASD prevention and services. Currently, there are two NOFAS affiliates in Alaska: the Alaska Center for FASD and Frontier Community Services. We encourage Alaska to continue its affiliation and involvement with this valuable advocacy resource.



# Fetal Alcohol Spectrum Disorder

## Telehealth Feasibility Study

### Introduction and Methodology

In March 2021, the Alaska Mental Health Trust Authority (The Trust) retained the Western Interstate Commission for Higher Education/Behavioral Health Program (WICHE/BHP) to conduct “The Fetal Alcohol Spectrum Disorder Telehealth Feasibility Study”. Per The Trust’s direction, the study had four (4) primary goals relevant to advancing FASD services in Alaska:

1. Develop recommendations to **support a continuum** of FASD screening and diagnosis model in Alaska;
2. Recommend a **model for a standalone multidisciplinary** FASD community-based diagnostic team as well as a **model for integrating the function** with a neurodevelopmental clinic model -- including the reach and sustainability of each model;
3. Recommend an optimal and financially sustainable **model for the use of telehealth/telemedicine technology** (synchronous and asynchronous) to support a continuum of FASD **screening and diagnosis** in Alaska; and
4. Recommend a **model for using telehealth/telemedicine technology** (e.g., ECHO model etc.) for FASD related **continuing education** for providers, and for **community education/prevention** activities.

**Methodologies:** In conducting the study, the WICHE/BHP Team used the following methodologies (as requested by The Trust), to accomplish the study’s goals:

- Reviewed and summarized the **current models** of prenatal alcohol screening and FASD screening and diagnosis services in Alaska;
- Explored **models used in other rural states and Canada**;
- Identified and analyzed **relevant research, materials, and available reports**;
- Examined costs, cost-**benefits, reach and sustainability** of the standalone multidisciplinary FASD **community-based** diagnostic team model versus **integrating** the function within a **neurodevelopmental clinic** model;
- Sought **available financial information** to conduct a feasibility analysis to **determine the costs and a sustainable financial structure**;
- Researched **telehealth models and methods** to support technology-based model for diagnostic and support services as well as workforce development; and
- Interviewed **32 key informants** who represented 26 government, provider, healthcare, advocacy, and higher education organizations.

Among the Key Informants were members of the **Alaska FASD Study Advisory Group** -- a group of professionals and advocates identified by The Trust who contributed their knowledge,

wisdom, experience and insights regarding the operation and challenges of FASD services in Alaska. The members included:

- ✓ **Hope Finkelstein** – Program (Prevention) Coordinator/FASD Program Manager, *Office of Substance Misuse and Addiction Prevention, Alaska Department of Health and Social Services*
- ✓ **Meghan Clark** - Associate Director Training and Technical Assistance, Alaska Primary Care Association; previous, Director ECHO, *Center for Human Development, College of Health, University of Alaska Anchorage (UAA)*.
- ✓ **Jenn Wagaman** - Coordinator/FASD Diagnostic Team, *Alaska Center for Children and Adults, Fetal Alcohol Community Evaluation & Services (FACES)*
- ✓ **Cody Chipp, PhD** - Behavioral Health Director, *Alaska Native Tribal Health Consortium (ANTHC)*
- ✓ **Jean Gerhard-Cyrus** - Trainer and Advocate
- ✓ **Marilyn Pierce-Bulger** - CEO, *Alaska Center for FASD, Anchorage*
- ✓ **Lanny Mommsen** - Research Analyst, *Governor’s Council on Special Education and Disabilities*
- ✓ **Sherrell Holtshouser** - Nurse Consultant II, *Maternal and Child Health Division of Public Health, Alaska Department of Health and Social Services*

In addition to Advisory Group members the following stakeholders were interviewed:

- ✓ **Diane Casto** - Director, *Council on Domestic Violence and Sexual Assault*
- ✓ **Michael Jeffery** - *Superior Court Judge (Retired)*
- ✓ **Matt Hirschfeld** - Medical Director, *Maternal and Child Health, Alaska Native Medical Center*
- ✓ **Kelly Farwell** (and the entire **Ptarmigan Connections Team** - Ellen Kelsey, Abbie Parris, Erika Stannard, Elowyn Smith) - Team Coordinator
- ✓ **Ann Applebee** - Clinic Coordinator, *ANTHC/SCF Neurodevelopmental Clinic*
- ✓ **Erin Johnson** - Psychologist, *ANTHC/SCF Neurodevelopmental Clinic*
- ✓ **Tamara Russell, PsyD** - Psychologist, *Providence Neurodevelopmental Clinic*
- ✓ **Chuck Lester** - Clinical Director, *Hope Community Resources*
- ✓ **Teri Tibbett** - Advocacy Coordinator, *Alaska Mental Health Board/Advisory Board on Alcohol and Drug Abuse*
- ✓ **Maureen Harwood** - Health Program Manager II, State of Alaska, *Infant Learning Program, Division of Senior and Disability Services, Alaska Department of Health and Social Services*

Additionally, WICHE team members remotely attended the April 30, 2021, meeting of the **Governor’s Council FASD Work Group** and interviewed other key informants recommended by the Project Advisory Group, including:

- ✓ **Tami Eller** – Assoc. Director of Community Programs, *Alaska Child and Family*
- ✓ **Mary Middleton** - Executive Director, *Stone Soup Group*
- ✓ **Cindy Roleff** - Telehealth Program Development Director, *ANTHC*
- ✓ **Gina Schumaker** - *Self-Advocate*, Anchorage

WICHE Team members also researched model programs and interviewed model program leaders from outside Alaska, including:

- ✓ **Susan Ellsworth** - Affiliate Manager, *National Organization on FAS*
- ✓ **Edward Riley, PhD** - Distinguished Research Professor, *Center for Behavioral Teratology, San Diego State University*
- ✓ **Sara Messelt**, Executive Director; **Julia Conkel-Ziebell**, Neuropsychologist; **Kendra Gludd**, Training and Program Manager - *Proof Alliance MN* (Formerly Minnesota Organization for FASD)
- ✓ **Kee Warner**, Founder, *Whitecrow Village*, British Columbia, Canada

Finally, as reflected in the body and footnotes of this report, WICHE identified, reviewed, and analyzed relevant research, materials, and available reports.

## [Alaska’s Current Models of Screening and Diagnosis](#)

### **PRENATAL SCREENING IN ALASKA**

Within the Alaska Department of Health and Social Services, the Division of Public Health’s Maternal Health/Perinatal Program coordinates FASD prenatal screening and prevention activities. A portion of a staff member’s time (<.5FTE) is allocated to FASD prenatal prevention. Under her guidance, in 2019 the Maternal Health/Perinatal Program rolled out the Division’s first FASD screening and prevention tool: “4P’s Plus”. Further, she worked closely with the developer, Ira Chasnoff MD, to customize a culturally appropriate version of the tool now in use in Alaska.

The “4P’s Plus” is a validated screening methodology that identifies pregnant women at risk for alcohol, tobacco, and illicit drug use. At the initial prenatal visit, the five-question screening tool quickly identifies obstetrical patients in need of in-depth assessment or follow-up monitoring. Once completed, it is used for follow-up screening throughout the pregnancy.

Acknowledging the critical need and impact of prenatal screening, the Office of Substance Misuse and Addiction Prevention through the Substance-Exposed Newborns Initiative (via SAMSHA funding) paid the “4P’s” Screening and Prevention Tool license use fee of \$1.00 per woman screened. In 2020, 5,000 women were screened early in their pregnancy (and in some cases, near their delivery date), for a total of \$5,000 to the Division’s budget.

The “4 P’s Plus” is being used at the 27 Alaska Community Health and Federally Qualified Community Health Centers. However, it is not yet being utilized more broadly by women’s health providers in Alaska. According to the Division of Public Health, this is a challenge given 40% of women in Alaska do not get regular healthcare; that is, pregnancy and prenatal care may be the one time they seek/receive medical care. Further, seven percent (7%) of Alaskan

women use midwives for their prenatal care and birth services. Therefore, given the reliance on obstetrical and midwife services, it makes strategic sense to train and encourage women’s healthcare providers to use the 4P’s for every healthcare visit as a prevention priority.

## ALASKA’S FASD DIAGNOSTIC STRUCTURE AND MODELS

There are three clinic models or structures for FASD diagnostic services in Alaska: 1) Community-based, standalone FASD-specific Diagnostic Teams; 2) Integrated Neurodevelopmental Diagnostic Clinics; and 3) Traveling Integrated Diagnostic Clinics.

1. Community-based, Standalone FASD-specific Diagnostic Teams have Provider Agreements with the State Office of Substance Abuse and Addiction Prevention.
2. Standing Integrated Neurodevelopmental Diagnostic Clinics are operated by and at Providence Health Services and Alaska Native Tribal Health Consortium/South Central Foundation (ANTHC/SCF) medical facilities. They also offer (or soon plan to offer in Providence’s case) traveling integrated diagnostic clinics.
3. Traveling Integrated Diagnostic Clinics operated by the Center for Human Development and funded by the State Office of Women’s, Children’s, and Family Health, are primarily for autism diagnostic services; currently, they screen and refer children with FASD indicators to diagnostic services.

**Integrated Clinics:** “Integrated clinics” are clinics in which FASD diagnostic services are included as part of diagnostic services conducted at neurodevelopmental clinics, such as those operated by ANTHC/SCF, Providence, and other model sites in the country. Integrated clinics have specialization and expertise in FASD as well as a range of other disorders and disabilities. This results in children and adults getting screened and, when indicated, assessed for a range of developmental, neuropsychological, sensory processing, etc. disorders – including FASD.

**Community-based, “Stand-alone” Clinics/Diagnostic Teams:** The Alaska Department of Health and Social Services contracts, via “provider agreements”, with community agencies to provide FASD screening and diagnostic services. The Department employs one, .5FTE, staff member who is responsible for overseeing and supporting FASD prevention work as well as the Diagnostic Team network. Currently, the State has agreements with four (4) organizations; however, as of this report, one of the four (Nome/ Norton Sound Healthcare Corporation) has temporarily halted diagnostic services. Additionally, a second Team, Kenai, has reduced capacity for diagnostic services due to the loss of a long-time FASD “champion” who is no longer able to help manage and coordinate the clinics.

Community-based diagnostic clinics are located, as the name applies, in communities across the state. In comparison to integrated clinics that are supported by healthcare agencies, community-based clinics are supported by local behavioral health or developmental disability providers who serve defined regions and/or communities and villages. Like their counterparts in integrated clinics, the Diagnostic Teams are comprised of multi-disciplinary professionals including (but not limited to) medical providers, psychologists, neuropsychologists, speech/language pathologists and occupational therapists. However, the community-based Diagnostic Teams focus on assessing for FASD and not, necessarily, on other disorders or disabilities.

In 2005 there were 17 operating community-based diagnostic clinics. Today there are four.

**Traveling Integrated Diagnostic Clinics.** The Traveling Integrated Diagnostic Clinics are presently operated by the University of Alaska’s Center for Human Development. Funded by the State Office of Women’s, Children’s, and Family Health, the Traveling Clinics specialize in autism diagnostic services but also screen for FASD. When children present with FASD indicators, they are referred to other FASD diagnostic providers, as well as family support services.

## **DIAGNOSTIC PROTOCOL AND PRACTICES IN ALASKA**

In terms of protocols and practices, there are three areas of uniformity and consistency in Alaska’s FASD diagnostic services:

1. **Eligibility:** Children, youth, and adults experiencing physical, mental, learning, and behavioral disabilities potentially related to prenatal alcohol exposure to alcohol are eligible clients.
2. **Model:** Diagnostic Teams uniformly use the University of Washington FASD 4-digit Code model.
3. **Multi-disciplinary:** Assessments are conducted by multi-disciplinary teams that typically include medical providers, psychologists and/or neuropsychologists, speech/language pathologists and occupational therapists.

Children, youth, and adults experiencing physical, mental, learning, and behavioral disabilities potentially related to prenatal alcohol exposure are eligible to be evaluated by the Neurodevelopmental Clinics and Community-based Diagnostic Teams. The University of Washington FASD 4-digit Code model is the validated diagnostic tool used by Alaska’s Diagnostic Teams and Clinics. Widely accepted and used by diagnosticians in the U.S. and Canada, the Code measures or evaluates on a 1-4 scale (with 1 being the least and 4 being the most) Growth, Facial Features, Brain, and Alcohol history. <sup>1</sup>

In terms of the diagnostic practice, FASD assessments in Alaska (as well as in model sites in other states and Canada) are conducted by multi-disciplinary teams, which typically include (but are not limited to) medical providers, psychologists, neuropsychologists, speech/language pathologists and occupational therapists. The teams evaluate for domains of impairment commonly seen in individuals with prenatal alcohol exposure (PAE): executive function, adaptive/social skills, language/social communication, academic achievement, memory/learning, motor/sensory, behavior/attention, cognition, mental health/psychiatric (including consideration of trauma history), development and functional observations from caregivers. Relevant records, reports and data from other sources may also be reviewed by

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<sup>1</sup> In addition to the FASD 4 -Digit Code, Alaska’s community-based Diagnostic Teams are testing a new technology in FAS screening: the Morpheus Q I-Phone app. Developed by the University of Washington’s FAS Prevention and Diagnostic Network, the MorpheusQ uses computerized analysis of a digital facial photograph that is then reviewed and analyzed by UW FASD experts who use widely accepted and replicated diagnostic criteria of FASD sentinel facial features to measure and examine facial features. The smartphone app is intentionally designed to be an easy-to-use, affordable, and effective screening tool for physicians and health professionals with limited expertise or knowledge of FASD. Although somewhat controversial, it is an exciting example of technology-based advancements in diagnostic services.

team members and included in the evaluation. Key informants referred to the multi-disciplinary model of diagnostic services as “the gold standard”.

## COMPARISON OF INTEGRATED CLINICS VS DIAGNOSTIC COMMUNITY TEAMS

As of May 2021, the total number of organizations that operate diagnostic clinics in Alaska is six (6) -- four (4) are community-based organizations that operate “stand alone” clinics; two (2) are healthcare organizations that operate integrated clinics:

### COMMUNITY-BASED DIAGNOSTIC TEAMS <sup>2</sup>

<b>Agency</b>	<b>Location</b>	<b>Serving</b>
× <b>Frontier Community Services</b>	Soldotna	The Kenai Peninsula
× <b>Alaska Center for Children and Adults, Fetal Alcohol Community Evaluation &amp; Services (FACES)</b>	Fairbanks	Interior Alaska
× <b>Norton Sound Health Corporation, Behavioral Health Services</b>	Nome	Nome and surrounding villages
× <b>Ptarmigan Connections</b>	Wasilla	Mat-Su Burrough; serving other parts of the state as needed (Sitka)

### INTEGRATED CLINICS

<b>Agency</b>	<b>Location</b>	<b>Serving</b>
× <b>Southcentral Foundation/Alaska Native Medical Center, Child and Family Developmental Services, FASD Diagnostic Clinic</b>	Anchorage	Statewide, Alaska Native people
× <b>Providence Health and Services, Center for Children with Special Needs</b>	Anchorage	Anchorage and (when traveling clinics renew) statewide

### **Benefits and Challenges of Integrated Clinic vs Community-based Teams**

An objective of this study was to compare the benefits and costs of integrated clinics to stand-alone clinics. As described in the Cost Benefit Analysis of this report, we were able to secure limited data regarding operating costs for both the integrated and stand-alone clinics. However, in our interviews with Key Informants we found consistent perspectives and opinions regarding the benefits and challenges of each model (see Table 1 on following page).

<sup>2</sup> Notably, at this time there is no active community-based Diagnostic Team in Anchorage.

Table 1. Benefits and Challenges of Integrated Clinic vs Community-based Teams

	INTEGRATED DX CLINIC	COMMUNITY-BASED DX TEAMS
<b>BENEFITS</b>	<ul style="list-style-type: none"> <li>★ <b>Multidisciplinary teams with expertise on FASD and other disabilities, etc.</b></li> <li>★ By being inclusive, helps <b>relieve stigma or discrimination</b> associated with seeking FASD diagnosis and services.</li> <li>★ FASD <b>requires a neuro-developmental assessment</b>; it may mask as autism or other neuro-developmental issues and vice versa.</li> <li>★ Assessment can be <b>completed in one day vs. series of appointments.</b></li> <li>★ Families have <b>one point of care</b>, can avoid being “shuffled from here to there”, and don’t have to choose which clinic they need: FASD, Autism, or ...</li> <li>★ Regardless if FASD, Autism or other neurodevelopmental challenge, the <b>treatment, individualized learning plan (ILP), and behavior interventions are similar.</b></li> <li>★ Reports, records, assessment findings are shared under <b>one electronic health record system</b>, easing access for healthcare providers, parents/caregivers, clients, etc.</li> <li>★ Have a bevy of <b>resources to support and sustain diagnostic services</b>, e.g., administrative, technology, facility, financial, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>★ <b>Multidisciplinary teams with expertise in FASD.</b></li> <li>★ Located <b>close to home, saving the expense and stress of travel, lost work time, and family/childcare.</b></li> <li>★ <b>Providers/Teams are familiar with the community, local resources, and the culture.</b></li> </ul>
<b>CHALLENGES</b>	<ul style="list-style-type: none"> <li>○ <b>Located in Anchorage.</b></li> <li>○ For those who must travel to clinic:</li> <li>○ <b>Travel costs</b>, arranging <b>transportation</b>, arranging <b>child/family care</b> while away, taking <b>time off</b> work, traveling to <b>unfamiliar</b> places can be burdensome and stressful.</li> <li>○ <b>Children with FASD may have an especially difficult time with the travel and unfamiliar surroundings.</b></li> </ul>	<ul style="list-style-type: none"> <li>○ <b>Sustainability</b> is a challenge; subject to <b>fluctuations in organizational support, funding and dedicated “FASD champions”.</b></li> <li>○ As stand-alone, <b>families/ individuals may avoid diagnostic services due to stigma</b> associated with prenatal alcohol use and FASD.</li> <li>○ <b>Community may lack consistent access to diagnostic experts/allied professionals --</b> resulting in <b>long wait times</b> for families, individuals.</li> <li>○ Diagnostic <b>sessions may occur over multiple appointments</b> due to challenge of coordinating/ scheduling multiple DX Team members.</li> <li>○ <b>Reports, records, assessment findings, may be stored on multiple electronic and paper systems</b>, making it difficult for providers, parents/ caregivers, clients to access easily.</li> </ul>

## Distribution of Screening and Diagnosis in Alaska

### CURRENT DISTRIBUTION OF DIAGNOSTIC SERVICES

The Trust had asked the WICHE/BHP to analyze current distribution of screenings across Alaska to include factors such as populations in need of screening and unmet needs. Unfortunately, due to the absence of a comprehensive data collection system in Alaska, we were unable to provide current distribution data for this report. Given the absence of these data, assessing Alaska's populations in need and unmet needs also posed a challenge. However, we were able to pull data from national and state sources, including the 2020 McDowell Group report, to offer summaries and projections.

### POPULATIONS IN NEED

Evaluating the prevalence of FASD in Alaska is not feasible with currently collected data. It is likely there are many people with FASD who have not (and will not be) diagnosed with FASD than those appearing in the Alaska FASD Diagnostic Data. Current data to project the prevalence of FASD in Alaska is difficult to gather. Complicating the matter further, there are no national or international standards used for determining prevalence of FASD<sup>3</sup>. However, assuming Alaska's birth rate of roughly 10,000 children per year<sup>4</sup> and a rate of FASD of 6.5%<sup>5</sup> in a state with a total population of 731,545<sup>6</sup>, approximately 47,550 of Alaskans have FASD. Notably, the average number of assessments performed between 2017 and 2019 was only 135. Given the projected prevalence of FASD compared to the number of assessments conducted, we can surmise that thousands of Alaska's children, youth and adults are not diagnosed or served.

### UNMET NEEDS

As with estimating prevalence, there is no standard for estimating unmet needs associated with FASD. This results from the lack of data on prevalence, the stigma associated with identifying as someone who used alcohol while pregnant, limited newborn screening tests, unawareness, or lack of ability to recognize FASD, unreported diagnoses, overlooked or misdiagnosis of less severe cases, and the lack of a universal definition for FASD at the national and international levels. However, as stated above, there are likely thousands of Alaskans with FASD who have not been assessed or referred for treatment. In addition to unmet needs, it is important to note that many Alaskans live in communities where few if any local services or resources to support children and families after a diagnosis are available.

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<sup>3</sup> Details of the challenges in estimating FASD prevalence, as well as the different methods available for doing so, can be found in the report, "Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations", July 2020, McDowell Group.

<sup>4</sup> <https://www.cdc.gov/nchs/fastats/state-and-territorial-data.htm>

<sup>5</sup> *The Economic Costs of Alcohol Misuse in Alaska, 2019 Update completed in January 2020*. McDowell Group <https://alaskamentalhealthtrust.org/wp-content/uploads/2020/06/1949-AMHTA-Alcohol-Misuse-Report-Final-Revised-June-12.2020.pdf>

<sup>6</sup> <https://www.census.gov/quickfacts/AK>



## Cost and Cost Benefit Analysis

Due to limitations (as previously described), we were unable to conduct a cost-benefit analysis of the FASD stand-alone community-based diagnostic team model versus integrating the function with a neurodevelopmental clinic model. In order to conduct this type of analysis, we recommend that Alaska undertake a comprehensive time study to fully understand the costs associated with FASD assessment. The time study should include:

- Billable rates for specialists;
- Hourly rates for specialists and administrative staff (when applicable);
- Reimbursement rates from all funding sources;
- Time spent by specialists conducting assessments, writing reports, meeting with team members;
- Time all staff spend meeting with and supporting families; and
- The cost to families to travel to assessment sites.

Although we were not able to conduct the cost and cost-benefit analysis, we were able to gather relevant reimbursement information and data. Throughout our key informant interviews and cost-specific conversations, we consistently heard that reimbursement rates, from all funding sources, fall below the billable rates for specialists across the team. Currently there is no central repository for data related to FASD assessments and costs associated with those assessments. Given that reimbursement rates vary by source (Medicaid, Private Insurance, Indian Health Services, and self-pay) it is important to know the actual cost of each assessment to enable clinics to deliver this service effectively and efficiently. More than one key informant described FASD assessments as a “loss leader” and a service that they lose money providing. If these assessments cannot be delivered in a way that allows clinics to at least break even, it will be impossible to expand those services.

Additionally, data on the costs of standalone multidisciplinary FASD community-based diagnostic teams and integrated neurodevelopmental clinics was unavailable. However, based on our interviews, we understand that clinics delivering more than just FASD assessments are able to distribute some of the costs across more programs, allowing them to be more sustainable and to lose less money per assessment than standalone clinics -- though we were unable to identify data to support this statement.

The complicated matter of assessing cost is exacerbated by the variation in the type of insurance individuals use to cover FASD assessments (for example, one clinic reported a combination of Medicaid, Private Insurance, Indian Health Services, and Self-pay clients (see Table 2 on next page). Therefore, we recommend the time study described above be conducted to assess costs of operating both the community-based diagnostic teams and the integrated neurodevelopmental clinics.

Table 2. Type of Insurance Covering FASD Assessment

<u>Type of Insurance</u>	<u>Percent of Clients Covered</u>
Medicaid	49%
Private Insurance	27%
Indian Health Services only	23%
Self-Pay	1%

Despite not being able to fully analyze the cost-benefit for community-based diagnostic teams or integrated clinics, we were able to gather limited, more general cost information. *The Economic Costs of Alcohol Misuse in Alaska 2019 Update*, completed by the McDowell Group in January 2020<sup>7</sup>, states that the total estimated cost for conducting 139 FASD assessments in 2018 was \$879,731, which results in a cost of \$6,329 per assessment. In contrast, one clinic we interviewed stated they bill Medicaid a daily rate of \$808 for a 2-day assessment, resulting in a total of \$1,616 per assessment. The discrepancy between the actual cost of delivering services and reimbursement rates appears consistent across specialties (see Table 3 on next page). Across most clinics, key informants described Medicaid’s rate as covering roughly 25% of the cost of conducting assessments. For example, an Occupational Therapist (OT) in one clinic reports a flat-rate fee of \$340 for each FASD assessment, yet they reported Medicaid reimburses them at approximately \$117 -- that same clinic reported a reimbursement from Private Insurance of approximately \$182 for the same services. This pattern holds true for Speech and Language Pathologists (SLP) where that same clinic reported a flat rate fee of \$450 per FASD assessment, with a reimbursement by Medicaid of \$270 and a reimbursement of \$425 by Private Insurance. Neuropsychologist rates, as reported to the team, range from \$750-\$6,000 depending on what services are performed, yet Medicaid reportedly reimburses at \$350 for those specialists. In 2005 the Department of Health and Social Services, Office of FAS had a cost study conducted which found that providers could expect to be reimbursed by Medicaid for no more than \$1,075.93<sup>8</sup> which is slightly less than the \$1,616 per assessment reported by one of the clinics in 2021, indicating that while the cost of conducting assessments may have risen, the reimbursement rate by Medicaid has only risen \$540.07 in the 16 years since the first cost study was conducted. Despite considerable effort to obtain data on current Medicaid reimbursement rates by specialist, we were unable to obtain those data, this may be due to the DHSS website being hacked in May 2021.

The variation between fees and reimbursement rates contributes greatly to the difficulty in determining the cost-benefit analysis of different operational models. Without a detailed analysis of costs by specialist, it will not be possible to determine the best operational model to optimize funding.

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<sup>7</sup> <https://alaskamentalthrust.org/wp-content/uploads/2020/06/1949-AMHTA-Alcohol-Misuse-Report-Final-Revised-June-12.2020.pdf>

<sup>8</sup> FAS Evaluation, Cost of the FASD Diagnostic Process in Alaska (Revised for Individual Team Distribution), February 2005, Behavioral Health Research and Services, University of Alaska Anchorage.

Table 3. Specialist Fees and Reimbursement Rates by Funding Source

<b>Occupational Therapy</b>	
<i>Flat-Rate Fee</i>	\$340
<b>Reimbursement Source</b>	<b>Rate</b>
Medicaid	\$117
Private Insurance	\$182
<b>Speech and Language Pathology</b>	
<i>Flat-Rate Fee</i>	\$450
<b>Reimbursement Source</b>	<b>Rate</b>
Medicaid	\$270
Private Insurance	\$425

Given that reimbursement rates fall below the cost of conducting assessments, additional sources of funding will be required for clinics until those reimbursement rates are increased. This additional funding has been obtained by Proof Alliance in Minnesota from a combination of State General Fund dollars, foundation and government grants and donations.

The need for care coordinators or family navigators was discussed by many key informants, yet Medicaid and Private Insurance do not cover those services to help the family collect all the necessary paperwork, understand the diagnosis once completed, and get connected to services deemed necessary in the assessment. Additional funding to cover those services would help families use the information gained through the assessment process more effectively and help their children access the resources they need.

### **FEASIBILITY AND SUSTAINABILITY**

Given the lack of data available to assess the cost-benefit of different funding models, it is impossible to assess the feasibility and sustainability of different models. Once a comprehensive time-study is conducted to fully understand the different costs associated with FASD assessment, a proper study into what model is most feasible and sustainable will be possible.

Additionally, as the State gives consideration to expanding the use of telehealth for FASD services, it may be important to assess the costs and reimbursement of services delivered via telehealth in comparison to the costs of in-person service delivery. It’s possible that some overhead costs may be reduced or eliminated by using more telehealth, reducing the need for office space and some fixed costs; however, it’s also possible that expanding the technology needed to effectively deliver telehealth services (giving staff the right equipment, making sure that clients and their families have the proper equipment and can connect to services remotely) could offset those cost-savings and result in no real financial benefit to using telehealth over

meeting with clients in-person.

It will be important as sustainability is assessed to evaluate the reach of broadband and the ability of clients to access services remotely. Further, as explained in the telehealth section of this report, clients who do not have broadband connectivity in their homes might be served at telehealth clinic “hubs” which may or may not be cost effective for the providers/clinics, depending on their infrastructure, service design and resources. It may also be important to investigate the cost to families to travel for assessments or services; those costs may play a big role in determining which models are most feasible.

A study focused specifically on cost will be required to determine the best, most cost effective, feasible, and sustainable model.

## **Models of Service**

During our interviews with key informants, three organizations were identified as providing replicable models of service:

- Proof Alliance Minnesota (formerly Minnesota Organization for FASD);
- Manitoba FASD Network; and
- Whitecrow Village, Canada.

### **PROOF ALLIANCE OF MINNESOTA**

#### **A System Coordination, Collaboration, and Diagnostic Service Model**

Founded 20 years ago by a juvenile justice judge, Proof Alliance (previously known as Minnesota Organization for FAS) is the first affiliate of the National Association on Fetal Alcohol Syndrome (NOFAS). Today, it is a model of collaboration and system coordination. The Alliance’s core programs and services include:

- Advocacy for FAS screening, diagnosis and support, including educating state and political leaders regarding the prevalence and impact of FASD;
- Family support, including education, support groups, and linkage to services;
- Training for families, providers, community health and human service workers, including:
  - Research dissemination;
  - Annual conference for providers, practitioners and families;
  - Training for health clinics, early childhood providers, and home visit programs on screening for FASD;
  - Annual training for foster parents (a new State requirement for foster families);
- Public education campaigns;
- System Capacity building, including:
  - Regranting to support screening and diagnosis in smaller organizations; and

- Coordinating, leading, and convening the Minnesota FASD Consortium, a group of 18 provider agencies who focus on: a) Supporting clinical consistency; b) Increasing accesses to diagnostic services; and c) Provider training and continuing education in Evidence-based Practices, Promising Practices, and Practice-based Evidence.

Proof Alliance has been involved in several collaborative system development initiatives. Currently, they have a new collaboration with Boston Medical Center. Funded by HRSA, the one-year project is focused on:

- 1) developing a standardized screening tool for primary care and pediatric practices; and
- 2) using the ECHO model, teach healthcare professionals (currently, in the Northeast and Midwest) how to use the screening tool.

According to Sara Messelt, Executive Director of Proof Alliance, if the project is successful, the ECHO cohort could include Alaska in the near future.

Diagnostic Services: In 2012, Proof Alliance added a Diagnostic Clinic to its services. Based on the premise that good evaluations and a diagnosis early in life is important for favorable lifelong outcomes, the central goal for Proof Alliance is to “work toward improved access to diagnostic services”. Very similar to Alaska, their years of experience revealed that the “model of always using multi-disciplinary teams is both hard to sustain and impedes access to diagnostic services.” Toward that end, Proof Alliance has streamlined its clinical services from what it referred to as a “dense model” to a “continuum model”. Rather, understanding that not all clients need all the diagnostic services, and not all clinics have all of the professionals or services, a continuum of diagnostic services should be provided based on client need.

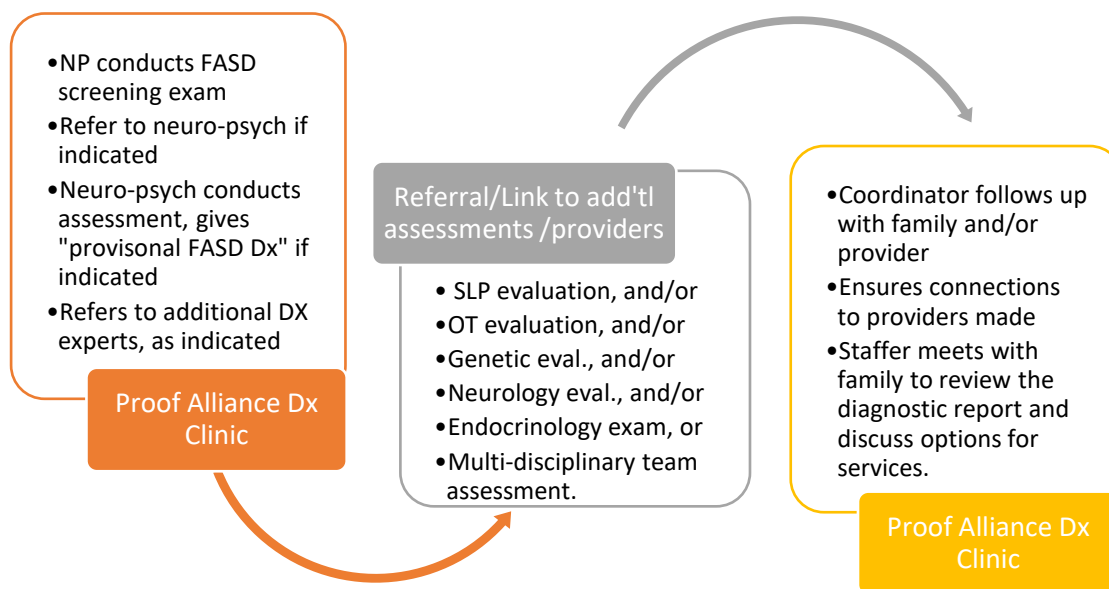


Figure 1. Proof Alliance "triaged" diagnostic services.

Proof Alliance's Diagnostic Clinic is a "conduit to a diagnosis and services" and offers a triage approach to services:

- Child is seen by the Proof Alliance Clinic's Nurse Practitioner (NP);
- If NP exam/assessment indicates FASD, (depending on age) the child receives a neuro-psychological evaluation or a pediatric neuro-psychological evaluation by the Clinic's neuropsychologist;
- If indicated, the Clinic's neuropsychologist gives a "Provisional Diagnosis" and makes a referral for additional diagnostic services as indicated. Additional services may, or may not include a Speech/Language Pathology evaluation, an Occupational Therapy evaluation, a genetic evaluation, a neurology evaluation, an endocrinology examination, and or a multi-disciplinary team assessment;
- Referrals and links to services are made across the state to other clinics and providers (typically within the FASD Diagnostic Consortium) depending on child need, home location, etc. Proof Alliance then follows-up to make sure connections were made between families and providers; and then
- Proof Alliance collects findings, prepares report, and meets with family to review and or coordinate meeting(s) with diagnostic team members and family.

Today, there are 14 FASD diagnostic providers in Minnesota that offer a mix of approaches: some focus on neuro-psych; some on medical, behavioral and/or developmental; others follow the full multi-disciplinary team model. Collectively, the 14 providers conduct 800 – 900 diagnostic evaluations a year. The majority of evaluations are conducted by the University of Minnesota which uses psychology interns to assist with evaluations. In this past year the University conducted 600 – 700 evaluations. Proof Alliance conducted over 100 evaluations.

Telehealth: Like many organizations around the world, the pandemic shut-down required Proof Alliance to use telehealth for diagnostic services – an experience, they stated, "ends up being a silver lining". With the knowledge that mental health and psychology have been using telehealth for years, they have set a goal to use telehealth for their diagnostic services. At this point they use telehealth tools for the initial interview with families whenever possible. To prepare for the interview and appointments, the Clinic Coordinator supports the families with tech support, including conducting a run-through pre-appointment. If needed after the initial interview, families must go to the diagnostic clinic for additional assessments. However, telehealth is offered for feedback sessions and to review assessment results.

Proof Alliance has experienced several benefits by offering telehealth services. For example, the number of missed or "no show" appointments have decreased. In addition, they received an elevated rate increase by the State that continues to this day. Families especially like telehealth; it saves them time as well as travel stress and costs. The Clinic's neuropsychologist finds it beneficial as well; she discovered she can use what she sees in the family's home environment to inform the assessment as well as to formulate treatment and intervention plans. In the future, Proof Alliance's neuropsychologist envisions virtual neuro tests will be a standard option "after a few challenges with remote versus in-person observations, interactions, and test validity gets sorted out."

Telehealth challenges have included:

- The need for a quiet and controlled space (which is not always an option in a home);
- The need for support staff located in tele-clinics/hosting sites to support tele-health sessions, including setting up secure connections between clients and providers;
- A learning curve on how to use equipment and perform the assessment for families and practitioners; and
- Some evaluations and examinations must be done in person.

Despite these challenges, Proof Alliance intends to continue and expand their use of tele-health tools and approaches.

## **MANITOBA FASD NETWORK**

### **A “Hub” Model for FASD Diagnostic Services and Support**

Established in 2009, the Manitoba FASD Network in Canada is a province-wide “pathway” to FASD diagnostic and short-term follow-up services with regional offices throughout Manitoba. The Network’s hub is located at the Rehab Centre for Children at the Specialized Services for Children and Youth (SSCY) Centre in Winnipeg. With the goal of providing FASD assessment, support and education closer to home, its key function is to manage the regional FASD diagnostic locations and coordinators located in five regions. The coordinators support families throughout the assessment process and facilitate local clinics in their regions. They have similar responsibilities to Alaska’s coordinators but have a larger role in family/patient/client support and education. Their responsibilities include:

- Completing initial screening for eligibility after receiving the referral;
- Assisting families/caregivers with completing required forms;
- Providing support and education to families/caregivers while on the wait list;
- Coordinating regional clinics;
- Providing follow-up education, support and planning after diagnosis;
- Hosting and facilitating training and “information series” for parents, caregivers, other family members and professionals<sup>9</sup>; and
- Providing FASD education and presentations to families, professionals and the community.

In addition to managing the coordinators and regional locations, the hub office in Winnipeg provides overall leadership and training for the Network. The Network is overseen by a steering committee comprised of representatives of the each of the key systems: maternal and child health, education, juvenile and criminal justice, child welfare, behavioral health and first nation

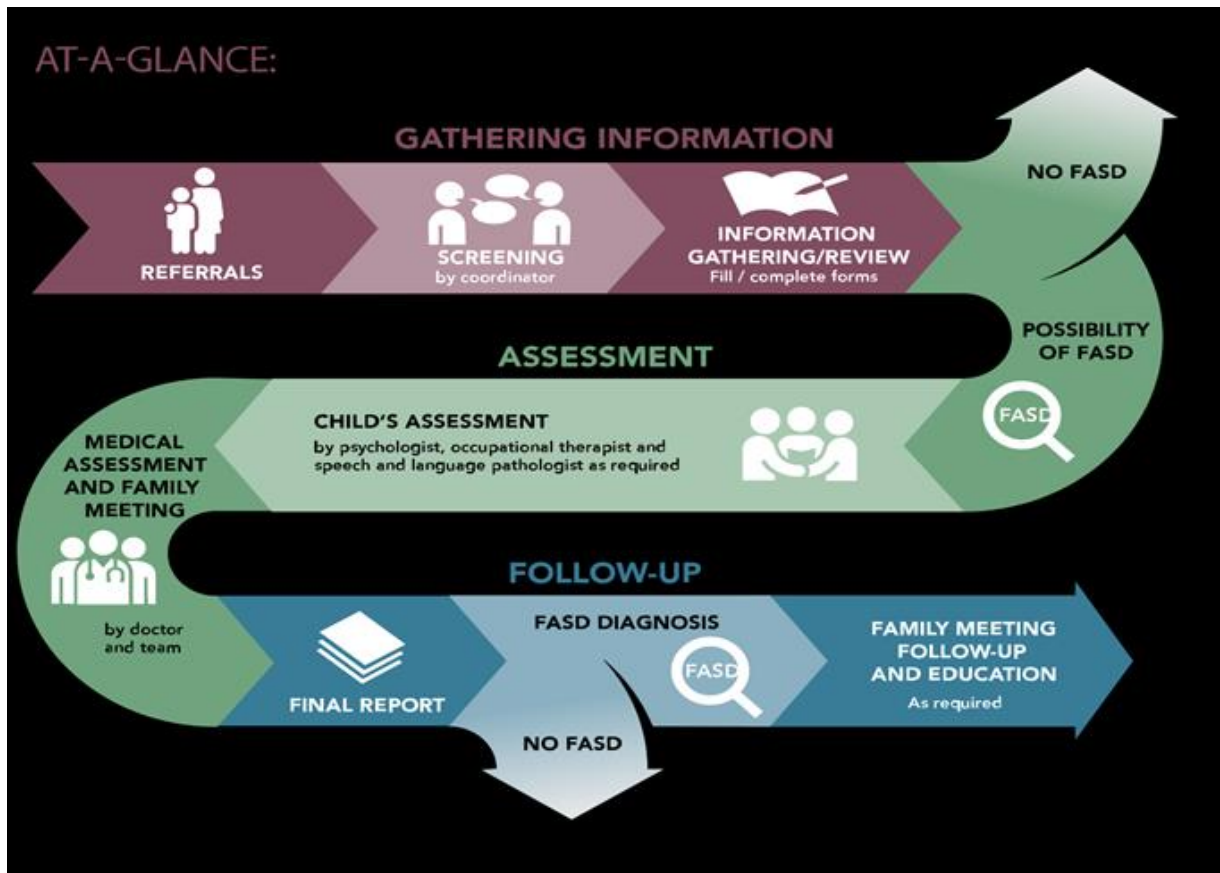
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<sup>9</sup> The Network’s Building Circles of Support”: telehealth FASD education series appears to have been launched during the pandemic. However, it is currently, “temporarily suspended” due to “undisclosed complexities”.

tribal health. It appears to be funded in full with government funds.

Per this report, we recommend Alaska designate and support a leadership organization that -- similar to the Manitoba FASD Network -- would serve as a collaborative hub for information, referrals, coordination, family support, and training. Organizations and providers across North America have consulted with and visited the Network to assess and replicate its “hub” approach to system access and coordination. The Manitoba FASD Network is an interesting model that we encourage Alaska to investigate further.

**SOURCE: Manitoba FASD Network: “AT-A-GLANCE: Get to Know the Pathway”**



## WHITECROW VILLAGE

### A Model for Self-advocacy

Founded by Kee Warner, Whitecrow Village is a nonprofit organization in British Columbia, Canada “committed to educating communities and professionals about Fetal Alcohol Spectrum Disorders and to improving the lives of those who are affected by this prominent neurodevelopmental disability”. Whitecrow began when Ms. Warner organized a summer camp on Vancouver Island for her two children who have FASD and invited other children near her home to participate in camp activities. Her rationale for starting the camp and working with other children with FASD was to provide respite to families and to give her own children, who had been having difficulty developing peer relationships, a chance to develop friendships. Today, Whitecrow offers:



- Retreat camp-like programs for people of all ages with FASD and for professionals who volunteer or attend camp for an “enlightened experiential education”;
- Training and motivational speaking for national and provincial workshops, conferences, and other events;
- Consulting and mentorship for professionals and local agencies, including schools; and
- Ongoing support and advocacy for families affected by FASD.

All the services offered by Whitecrow Village are primarily provided and supported by volunteers. Ms. Warner is the only paid staff member. Ms. Warner is highly regarded for her leadership in family-focused services for which she believes the key to service provision is working with families and committing to a long-term relationship with those families. Working from a strengths-based perspective is the most helpful to children and families, she says, as many have repeatedly been told their children have deficits that significantly limit what they can do: “Children with FASD need to be valued not just accepted.”

Whitecrow Village is a model for self-advocacy and education. Founded on the principle of empowerment, 90% of its trainers have FASD.

## Telehealth

### **Increasing Capacity via Telehealth**

Telehealth is a mode of service that can increase capacity for screening and diagnostic services, professional and workforce development, family and peer education and support, data collection and reporting. Telephone, videoconferencing, store, and forward email/recordings/ photographs/videos are examples of the tools and technologies that can be used.

Families/clients have experienced real benefits of telehealth services in Alaska, including ease of access, decreased travel and transportation expenses, decreased absences from school and work, and alleviation of stress related to child and family care. Providers also save time in travel, report a decrease in missed appointments, and are able to serve clients beyond their normal geographic service boundaries<sup>10</sup>.

Given the benefits to families/clients and providers, we believe FASD telehealth service options are a strategy in which Alaska should invest. Areas that Alaska’s FASD services can be elevated with telehealth, include:

#### **1. Remote clinical services** via phone and live video for:

- Long-distance patient and provider contact;
- Care planning, intervention and monitoring;
- Advice, reminders and patient/family education and support; and

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<sup>10</sup> According to Stone Soup, the increased use of telehealth during the pandemic helped alleviate long wait lists – especially in Alaska’s more remote communities -- because providers/professionals were no longer region-centric or reliant on local expertise and resources.

- Test forwarding (interpretation by specialists).
2. **Screening and diagnostic** tools, including:
    - Imaging applications; and
    - Long-distance or cross-state expert consultation.
  3. **Professional development**, including:
    - Meetings, supervision, presentations and case reviews;
    - Provider distance-learning; and
    - Communities of Practice engagement and support.
  4. **Client, Family Training and Support**, such as:
    - Family to family and peer to peer online forums; and
    - Seminars and workshops.
  5. **Prevention**, including:
    - Public education/awareness social media campaigns.

**Telehealth Opportunities and Challenges:** Based on our assessment, telehealth can increase access to prevention, screening, diagnostic services, and training. The opportunities and challenges of incorporating telehealth include:

<u>Opportunities</u>	<u>Challenges</u>
<ul style="list-style-type: none"> <li>◆ <b>New practices and approaches for allied professionals</b></li> <li>◆ <b>Remote evaluations and clinics via live video</b></li> <li>◆ <b>Application of new screening and diagnostic tools</b></li> <li>◆ <b>Capacity-building, moving beyond (current) regional/geographic limitations</b></li> <li>◆ <b>“Cross-state” telehealth and “store forward” consultation</b></li> <li>◆ <b>Workforce development and training</b></li> </ul>	<ul style="list-style-type: none"> <li>◆ Telehealth assessment practices and approaches for allied professionals</li> <li>◆ Reliable connectivity</li> <li>◆ Equipment and technology support for families/clients and providers/practitioners</li> <li>◆ Privacy and security considerations</li> <li>◆ Licensing, policy, and regulatory considerations</li> </ul>

◆ [New Practices and Approaches for Allied Professionals](#)

In a teletherapy session, therapists may have minimal control over the environment and, due to camera limitations, a limited ability to physically see and assess the full “picture” of behavioral or physical indicators. Unsure how to adjust their in-person assessment practices to live video teletherapy, Occupational Therapists, Speech /Language Pathologists and Neuropsychologists are, in general, concerned about the viability and accuracy of remote assessments. These concerns (as well as regulatory and reimbursement challenges, as discussed below) have resulted in some resistance to telehealth among allied professionals.

Although there is some resistance, the past year especially has been a boon to live video health consults and services. Professionals – including physicians, neuropsychologists and SLP’s – have incorporated live video into their everyday practice, grown more adept at using video technology, and are experiencing some of the benefits of seeing clients in their natural (i.e., home) versus clinical setting. For example, an FASD-focused neuropsychologist we interviewed described how live video strengthened her assessment process and services:

*“I’m able to see the child and her family in the context of their homes, as opposed to a more sterile or clinical setting ... video conferencing gave me important pieces of information ... valuable insights and environmental considerations that helped me to assess and formulate more realistic and practical interventions to help.”*

With the rapid acceptance and incorporation of telehealth across health disciplines, national associations of allied and other health professions -- including the American Speech Language-Hearing Association, the American Occupational Therapy Association, and the National Academy of Neuropsychology -- are formulating policies and developing telehealth practices, protocols, and standards.

Still, depending on access to equipment, connectivity, the setting, family/client preference, and the complexity of the case and/or assessment, telehealth may be a good option for some clients and providers but not all. Therefore, we recommend Alaska consider a hybrid model of FASD screening and diagnostic services that increasingly incorporates telehealth and maintains in-person service options.

#### ◆ [Live Video Assessments and Tele-clinics](#)

Telehealth video sessions, or “live video”, utilizes computers or smart phones to visually and auditorily connect patients or clients to providers. Live video has been used by behavioral health providers for years. Today, it is increasingly common across most healthcare disciplines.

For both clients/patients and providers/practitioners, an effective telehealth/live video session requires steady and reliable broadband connectivity as well as equipment that supports the web-based applications. While the sessions can occur between the family’s/client’s home and the provider’s office, there are times when the home environment cannot support live video due to connectivity, equipment, privacy and security issues -- as well as practical challenges such as childcare and familial distractions.

When the families’/clients’ homes are not an option, telehealth clinics offer a good option for providing services at a location close to home. Typically, the tele-clinics are connected to a centrally located medical or health center “hub”; the hub offers reliable broadband connectivity, equipment and systems, and IT assistance to support secure connections and sessions that meet legislated health information exchange and privacy laws.

There is a model for a telehealth “hub” system in Alaska: The Alaska Federal Health Care Access Network (AFHCAN) at ANTHC. According to the 2021 Primary Care Needs Assessment<sup>11</sup> conducted by the Alaska Division of Public Health: *“The Alaska Federal Health Care Access Network (AFHCAN) is a telehealth system that encompasses over 200 sites with video-*

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<sup>11</sup> Alaska Division of Public Health, 2021 Primary Care Needs Assessment. [https://alaskapca.org/wp-content/uploads/2021/05/SOA\\_PCO\\_NA\\_20211865-1.pdf](https://alaskapca.org/wp-content/uploads/2021/05/SOA_PCO_NA_20211865-1.pdf)

*teleconferencing clinical care capability. Services are delivered across several specialties. The use of these technologies is constantly being improved to incorporate innovative technologies and practices to expand its application for use in areas of health care need.”*

Indeed, in our interview with Cindy Roleff, ANTHC’s telehealth Program Development Director, we were impressed by the breadth and depth of AFHCAN’s telehealth services and the model of tele-clinics and hubs they have developed. Alaska is fortunate to have this proven model in the state. We strongly recommend the person(s) and/or organization(s) who lead the planning and incorporation of telehealth for FASD services on Alaska meet and collaborate with Ms. Roleff and the telehealth experts at ANTHC and AFHCAN.

#### ◆ Technology Support for Families/Clients and Providers/Practitioners

Some practitioners and providers believe telehealth only works well if the patient or family is in a controlled clinical setting with a “proctor.” Others have found proctors are beneficial for non-clinical settings too. In Manitoba and Alberta, for example, where telehealth is becoming an established practice for diagnostic and support services, proctors assist in a variety of home, community, and clinical settings.

Whether telehealth occurs in the family’s/client’s home or a telehealth clinic, there is often a need for someone (i.e., preferably a proctor) to prepare for and support the session(s). A proctor can help resolve some of the challenges of telehealth and make tele-health session(s) productive, reliable, and supportive – especially when an assessment requires a more in-depth and multi-disciplinary team<sup>12</sup>. Trained in video conferencing equipment and software (and ideally, in diagnostic procedures), the Proctor is key at first establishing and then, as needed, supporting live video consultations and assessments. Similar to the role of Diagnostic Coordinators, but focused expressly on the telehealth aspect of services, Proctors:

- Set-up and test equipment before sessions;
- Secure connections between family/client and the provider(s);
- Train families/clients how to use the systems and what to expect during sessions; and
- Provide technical support and troubleshooting for both the family/client and provider during the consultation/assessment.

Given limited resources and the overlap of a proctor’s role and a coordinator’s role, some providers, including ANTHC, incorporate proctor responsibilities with the duties and responsibilities of the clinic coordinators and/or administrative staff; technical and troubleshooting services are provided by separate and qualified IT staff.

#### ◆ Cross-State Telehealth and Store Forward Consultations

Cross-State telehealth is a term used to describe services provided remotely across state lines. For example, a neuropsychologist in Washington State conducts an assessment via live video

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<sup>12</sup> Connecting People with People: Diagnosing Persons with Fetal Alcohol Spectrum Disorder Using Telehealth Lisa M. Whittingham<sup>1</sup> · Kelly D. Coons-Harding<sup>2,3</sup> Published online 9 July 2020. Journal of Autism and Developmental Disorders (2021) 51:1067–1080 <https://doi.org/10.1007/s10803-020-04607-z> © Springer Science+Business Media, LLC, part of Springer Nature 2020

for a client in Alaska.

Store forward consultations are recordings or records of clients that are forwarded and shared, with the client's permission, to a specialist. The records may include video-taped sessions, photographs (such as facial photographs to measure dysmorphology and/or sentinel physical findings) and/or medical records. For example, a preliminary assessment is conducted and videotaped by a professional in Fairbanks, securely stored and electronically forwarded to a specialist/licensed practitioner located in another community within or outside of the state.

By increasing access to licensed practitioners and specialists, "cross-state" and "store forward" are two common telehealth practices that offer one solution for workforce shortages -- especially for patients and providers who live in remote and rural areas with limited access to licensed practitioners and specialists.

When workforce shortages occur in local communities, wait times and waitlists grow which, for Alaska's diagnostic services, can be months and even years long. For example, pre-COVID, the state's traveling diagnostic clinics (for autism) operated on a rotation schedule which meant that the diagnostic teams moved from one rural community or remote village to another across the span of months. Coupled with limited availability of diagnostic specialists and weather-related travel restrictions, the rotation schedule resulted in some locations/areas (for example, Nome) only having access to diagnostic clinics every one to three years.

By engaging professionals and practitioners located outside of the community, region or state, live video, store forward and cross-state can effectively and efficiently open access to FASD services beyond geographic and regional limitations and thereby decrease wait times and waitlists.

#### ◆ [Licensing, Policies, and Regulations](#)

During the pandemic shutdown a number of telehealth regulations, standards, rules, requirements and policies were temporarily lifted to allow healthcare providers to quickly implement telehealth services. The lessons learned in the past few months and rapid advances in technology are now forcing state and federal governing bodies, regulatory authorities, health providers and insurance companies to review and update policies, rules, protocols and regulations related to telehealth privacy, security, reimbursement, licensing, and accountability.

Consequently, telehealth regulations, rules, etc. are "a moving target" today. However, understanding policies, regulations and reimbursement requirements will be crucial to the design and success of FASD-specific telehealth service. Two areas especially applicable to reimbursement for remote/telehealth clinics are "originating site" and "out-of-state licensure". According to The National Telehealth Technology Assessment Resource Center (NTTARC):

*"Many of the reimbursement policies that do exist continue to have restrictions and limitations, creating a barrier to utilizing telehealth to deliver services. One of the most common restrictions is a limitation on where the patient is located, referred to as the originating site. While most states have dropped Medicare's rural geographic requirement, many Medicaid programs have limited the type of facility that can serve as an originating site, often excluding a patient's home from eligibility ..."*

As of this report, Alaska is one of the states that has excluded Medicaid reimbursement for telehealth services where the originating site is the patients' homes. However, over half of the

lower 48 states have permanently allowed the home to be an eligible originating site under certain circumstances. Additionally, 27 states and DC explicitly note that their Medicaid program will reimburse telehealth delivered services in a school-based setting.

State licensure is required to allow out-of-state licensed providers to render services via telehealth. That is, *when telehealth is used, it is considered to be rendered at the physical location of the patient, and therefore a provider typically needs to be licensed in the patient's state.* Again, according to the NTTARC:

*“A few states have licenses or telehealth specific exceptions that allow an out-of-state provider to render services via telemedicine in a state where they are not located or allow a clinician to provide services via telehealth in a state if certain conditions are met (such as agreeing that they will not open an office in that state). Still other states have laws that do not specifically address telehealth and/or telemedicine licensing, but make allowances for practicing in contiguous states, or in certain situations where a temporary license might be issued provided the specific state's licensing conditions are met.”*

Licensure compacts ease the way for physicians to apply for and practice telemedicine in member states. According to the National Consortium of Telehealth Resource Centers, they are becoming increasingly common. If this licensure were allowed in Alaska, it would be a great boost for addressing workforce shortage and increasing access, via telehealth, to qualified, out-of-state, FASD diagnostic professionals.

We recommend continuous tracking and advocacy regarding the development and approval of telehealth rules, regulations, and licensure requirements -- especially as they impact the use of (and reimbursement for) live video, cross state services, store forward, and licensure compacts.

#### ◆ [Screening and Diagnostic Tools](#)

Screening for alcohol use during pregnancy, FASD, and developmental delays should occur in a range of settings and systems where women, children, youth, and adults may be seen. Given rapid advances in technology, Alaska can assume telehealth screening and diagnostic tools will be developed and emerge as evidence-based practices that can be used in a range of health care and human service settings. One example currently being tested in Alaska is the MorpheusQ iPhone Screening app being developed by Blue Resonance LLC (Dr. Ganz Chockalingam) and San Diego State University (Dr. Edward Riley) in cooperation with UCSD's Diagnostic Institute for FASD Discovery (with Drs. Ken Lyons Jones and Miguel delCampo).

The MorpheusQ generates highly accurate computerized measurements of facial features which healthcare providers can then upload to a secure HIPAA compliant store forward cloud; once uploaded, the pictures and measurements are analyzed (remotely) by FASD diagnostic experts – including Ken Lyons Jones MD, one of the leading FASD experts in North America. Training on how to use the app can be done via video conference or in-person. Tests conducted by USD and USCD have conclusively shown the Morpheus is an easy to use and accurate screening tool for FAS.

Despite the technology, ease of use, and accuracy, some of the key informants we interviewed expressed doubt about its ability to effectively screen for FASD, especially for people who do not have facial features associated with FAS -- which ostensibly is 95% of the people Alaska's Diagnostic Teams and Clinics assess. According to Dr. Riley, there is no statistically significant

difference between the Morpheus Q and the FAS 4-digit code scoring methods commonly used by diagnostic teams. Further, the app has been shown to:

- Accurately measure facial measurement;
- Be usable without significant training;
- Be HIPAA compliant within secure data saving/sharing space;
- Remove some subjectivity by standardizing the scoring components; and
- Calculate the odds of FASD to determine the need for a full assessment.

Screening tools can serve as a “triaging” function by identifying those most likely to have FASD. Given the incredible scientific and technological advancements that are occurring, technology-based tools and applications will continue to evolve and will undoubtedly change diagnostic processes. While not “the answer,” tools like MorpheusQ provide accuracy and efficiency to the diagnostic and screening processes. We encourage Alaska to continue testing new screening and diagnostic tools and technologies.

#### ◆ [Training](#)

Training using telehealth technologies is also becoming a commonplace practice. In addition to email, video conferencing, webcasts, and social networks, new microlearning platforms such as “just-in-time” training apps and interactive learning hubs are just a few examples of tele-training tools that can support individual and group engagement, learning and planning. Additionally, they can be used in combination or in their simplest form (e.g., Zoom) to support both ECHO training cohorts and Communities of Practice.

ECHO (Extension for Community Healthcare Outcomes) is an all-teach-all-learn tele-mentoring model that uses case-based learning. Specialists and experts at a virtual “hub” meet regularly with physicians, nurse practitioners, and other clinicians at “spokes” videoconferencing to support delivery of specialty care services. Also supported via video and telephonic conferencing is the “Community of Practice” model which facilitates engagement of professionals and service providers specific to a field of service (for example FASD coordinators and diagnosticians). In the spirit of collaboration, Community of Practice participants interact and learn from each other by sharing resources, tools, successes and mitigating challenges.

Mobility, flexibility, connecting with others (beyond a building, a community, or an organization), access to experts, and efficiency savings are just a few benefits of training that utilizes telehealth tools and applications. A coordinated approach to telehealth training specific to FASD will build collaboration among providers and capacity in Alaska’s FASD system.

#### ◆ [Telehealth Resources](#)

The National Consortium of Telehealth Resource Centers (NCTRC) is “dedicated to building sustainable telehealth programs and improving health outcomes for rural and underserved communities”. The Consortium is comprised of two national Resources Centers. One of the national centers, the National Telehealth Technology Assessment Resource Center (NTTARC) is located in Anchorage and funded by ANTHC and HRSA.

Within the Consortium are 12 regional Telehealth Resource Centers. The Centers provide planning and technical assistance at *no cost* to qualifying clinics and organizations. Alaska is served by the Northwest Regional Telehealth Resource Center (NRTRC), which also serves

Idaho, Montana, Oregon, Utah, Washington, and Wyoming. However, depending on the specific need, focus, or issue, organizations in Alaska can also receive consultation and guidance from other Resource Centers within the Consortium.

If Alaska intends to adopt telehealth services for FASD, we strongly recommend consulting with The National Telehealth Technology Assessment Resource Center (NTTARC) and the Northwest Regional Telehealth Resource Center to develop a design and plan for including FASD services in Alaska's telehealth systems.

## **General Impressions and Recommendations**

We offer the following general impressions and recommendations to help (re)generate momentum and build sustainable FASD services for Alaska's children, youth, families, and adults:

### **1. *Incorporate Telehealth/Telemedicine Technology into FASD Diagnostic/Support Services***

*The COVID 19 pandemic fundamentally resulted in a shift in thinking about telehealth – from being an outlier to being an accepted and, for some patients and providers, a preferred method of receiving and delivering healthcare. Families/clients have experienced real benefits of telehealth services, including ease of access, decreased travel and transportation expenses, decreased absences from school and work, and alleviation of stress related to child and family care. Providers also save time in travel, report a decrease in missed appointments, and are able to serve clients beyond their normal geographic service boundaries. Given the potential to improve access as well as the benefits to families/clients and providers, we believe telehealth (coupled with in-person service) should be a priority strategy worth serious consideration.*

Telehealth has been in use for many years and is widely used by healthcare providers around the world. Technologies and policies are constantly being improved to incorporate innovative solutions to support its expanding applications and useability.

During the COVID-19 Pandemic shut down, medical providers and patients grew increasingly accustomed to using telehealth tools for healthcare and therapeutic services. Telehealth platforms and healthcare policies quickly changed to support a rapid transition from in-person to telehealth for a wide range of healthcare needs – including diagnostics, follow-up, prescribing, therapies, consultations, and training. Telehealth helped maintain basic levels of healthcare services for people across the country and even increased access to care for people living in rural and remote regions. Live video patient/doctor visits became the norm rather than an outlier, as did behavioral health visits and diagnostic services. For example, the Alaska Traveling Neurodevelopmental Clinics [for autism] conducted all of their activities via telehealth which, according to a key informant and family advocate, worked well for families and practitioners alike. Additionally, because services were no longer region-centric or reliant on local expertise and resources, it helped alleviate long wait lists in rural and remote villages and communities.

Telehealth from a client's/family's home to a provider's locale can work quite well for initial screening, intake, referral, intervention, and support services. However, key informants pointed to the fact that, at this point in time, various applications of telehealth may work well in one environment but not another. For example, the client/family (as well as diagnostic team



members) may be better served when a telehealth evaluation is conducted in a “controlled or proctored” environment, such as a tele-clinic, where disruptions are less likely to occur. Further, some key informants expressed trepidation about using telehealth for assessments. Practitioners hold strong to the long-standing practice of assessing clients/patients in-person and believe it to be necessary for a variety of reasons – including the validity of testing that was “normed” for in-person encounters. Yet, it's important to note there are organizations, practitioners, and teams (in Minnesota, Manitoba and Alberta, for example) who are using telehealth technologies for FASD screening, testing and assessments. Additionally, many assessment tools are being reviewed/modified to align their validity within a telehealth/virtual environment.

Regardless of patient/client and provider trepidations, telehealth is on a trajectory to become a standard practice in healthcare delivery. Recognizing that, we strongly recommend Alaska incorporate telehealth services into its FASD delivery system --- with one caveat: telehealth is not a “one size fits all”; although technologies exist to support diagnostic and support services, some assessments, examinations, and tests require in-person visits. Further, some patients are simply not well served in a telehealth environment. Therefore, Alaska should adopt a hybrid model that supports options for both in-person and telehealth delivered services.

Experienced, trained, and qualified telehealth experts can assist with service design, implementation, reimbursement, policies, licensing, infrastructure, and security. According to the National Telehealth Technology Assessment Resource Center (NTTARC), clinics often underestimate the time it takes to plan and operate telehealth services. The regional Telehealth Technical Assistance Center that serves Alaska at *no cost* to “qualifying clinics and organizations” can provide technical assistance which includes an “Operational and Technological Readiness and Needs Assessment”. The Assessment would help set the stage for start-up success and sustainably by evaluating:

- Leadership support and the clinical providers buy-in;
- Patient populations and demographics to be served, including payor sources and areas of unmet needs;
- Facility/facilities demographics, including, technical and infrastructure needs, existing telehealth equipment already on-site and/or in use, and staff with knowledge and/or previous or current experience in telehealth; and
- Scope of planned use, including services to be provided and how the (coordinating) organization would like to deliver the services.

Following the assessment, NTTARC would provide:

- Assistance with determining what equipment is needed;
- Technical infrastructure planning and assistance; and
- Training on telehealth use and operational elements.

Based on our assessment, telehealth is a feasible strategy for increasing access to prevention, screening, and diagnostic services in Alaska -- especially for rural and remote communities. If access to care is a priority, we recommend Alaska adopt a hybrid model of screening, diagnostic and support services which incorporates both in-person and telehealth options for families, clients, and providers. Additionally, if Alaska intends to adopt telehealth services for FASD, we strongly recommend consulting with The National Telehealth Technology Assessment Resource Center (NTTARC) and the Northwest Regional Telehealth Resource Center to develop a well-

planned design and structure.

## 2. Streamline Evaluation and Diagnosis

*To open access and save resources, Alaska should consider streamlining diagnostic and evaluation services by implementing a "tiered evaluation and diagnostic system" similar to that used by model sites such as Proof Alliance Minnesota, as well as Alaska's "traveling" neurodevelopmental clinics that are currently focused on evaluating for and diagnosing Autism.*

Given our prevalence projections that over 45,000 Alaskans have FASD, the number of assessments conducted annually (135, on average) falls far short of the State's need for FASD diagnostic services. As in many other parts of the country, accessing diagnostic services is a challenge. In fact, we were informed that it is not uncommon for Alaskans to wait months (or, in very remote communities, years), to be served. Further, when Alaska families/individuals undergo a diagnostic assessment, the assessment process is both time consuming (on average, six to eight [6 – 8] hours) and resource intensive for clients/families and providers alike.

To increase access to and resources for diagnostic services, we recommend Alaska add efficiencies by streamlining its diagnostic protocols and system. Moving from requiring a comprehensive multi-disciplinary evaluation to a tiered screening, evaluation and diagnostic process is one strategy to consider.

In a tiered model, the assessment continuum might begin with a review of records coupled with an in-person (or telehealth/live video) neuropsychological or developmental brief assessment; this first tier is a critical first step in the assessment process. Based on the findings, either the evaluation process would end, or the client/patient could/would receive a "provisional" diagnosis and be referred to the diagnostic team. Similar to Proof Alliance Minnesota and Manitoba FASD Network's model, the diagnostic protocol would be based on client indicators (and in some cases, the client's preference) and may include one, two, or all of the diagnostic team members.

In brief, tiered models give options for determining the appropriate levels of service, in this case diagnostic services, based on individual needs and circumstances. For example:

- Tier 1: Unambiguous Diagnosis – Screening/evaluation conducted by a trained healthcare provider, e.g., pediatrician, family doctor, nurse practitioner;
- Tier 2: Questionable or Uncertain Diagnosis - Evaluation conducted by a Developmental Behavioral Pediatrician and Neurodevelopmental Psychologist; and
- Tier 3: Complex or Complicated Diagnostic Picture - Evaluation conducted by a full multi-disciplinary team or a combination of diagnostic team members including a pediatrician, psychologist, Occupational Therapist (OT), Physical Therapist (PT), Speech and Language Pathologist (SLP)

This type of tiered or triage-like system could have a threefold benefit for both people seeking diagnostic services and for providers: 1) opening access to diagnostic services, beginning with screening and preliminary (Tier 2) diagnostic services; 2) connecting Alaskans to education and support earlier in the diagnostic process while they await a full assessment (if needed); and 3) freeing up diagnostic coordinators' and team members' time to serve more clients with a range of services rather than serving fewer (and all) clients with the intensive "gold standard" multi-disciplinary approach.

### **3. Undertake Universal Screening**

*Develop a mechanism to undertake universal screening for alcohol use during pregnancy, FASD, and developmental delays using a variety of screening tools. Screening should occur at all locations where children who are suspected of having FASD come into contact with the healthcare, behavioral health and developmental/intellectual systems as well as the education and criminal justice systems. For example, all school nurses should be trained to screen for FASD.*

We were impressed to learn Alaska's Diagnostic Teams are currently testing the MorpheusQ iPhone screening and diagnostic app and that the 4 P's prenatal screening questionnaire is progressively being used in Alaska's community health centers. Prevention and intervention screening tools for FASD will open access and help prioritize people who should be referred for diagnostic and/or support services.

In our opinion, identifying and adopting screening tools for FASD, alcohol use during pregnancy, and developmental delays that become a standard for healthcare, behavioral health and developmental/intellectual systems, as well as the education and criminal justice systems, should be a priority for Alaska. We encourage Alaska's FASD leaders and experts to look toward FASD screening tools in use and/or being developed and tested by other State's and model providers -- including the tools currently being developed by Proof Alliance Minnesota and Boston Medical Center -- as well as evidence-based screening tools such as the SBIRT.

### **4. Open Access with Options in Diagnostic Clinics and Services**

*Given the challenges of accessing diagnostic services, it makes programmatic and financial sense to support both the integrated neurodevelopmental clinics and community-based diagnostic clinics. Integrated clinics offer a range of diagnostic specialties for children and adults, as well as the multi-disciplinary "gold standard" diagnostic model. The community-based clinics, which also offer the "gold standard" but specifically focus on FASD, should remain as a vital part of the system; they should continue to offer patients and families the option to receive diagnostic services in their community and close to home. Finally, when the integrated traveling clinics are in operation again, we strongly recommend the inclusion of FASD diagnostic services as a third option for families and adults.*

There is concern among stakeholders about whether integrated clinics make sense as the only option for diagnostic services in the state. Informants expressed concern that FASD, with its own unique challenges and impacts, would "get lost" amid other health and support services if integration were to occur. Further, clients and families prefer having access to diagnostic services close to home rather than hours and miles away. The loss of community-based clinics (and consequently dependence on standing integrated clinics) raises additional concerns about weather-related travel barriers, longer wait times, and reliance on services outside of one's village, community, or region. Community-based diagnostic clinics are simply a more accessible option for many families and individuals. And although informants acknowledge that finding and retaining qualified professionals to provide FASD diagnostic services in rural and remote communities has been a challenge, they value and support local providers who know the local resources and limitations. As one Key Informant summarized, "What works in Anchorage won't or may not work in hubs or villages."

Unfortunately, sustaining community-based stand-alone FASD diagnostic clinics has been a significant challenge in Alaska – as evidenced by the decrease in community-based diagnostic teams that has transpired over the years: 17 active teams in the early 2000’s; four (4) teams today. However, by adopting a tiered approach to the diagnostic process and by building telehealth into the service deliver model, the community-based clinics may become more sustainable.

On the other hand, integrated neurodevelopmental clinics appear to have sufficient administrative and professional staff, as well as financial resources, to sustain their clinics.

The Alaska Native Tribal Health Consortium/Southcentral Foundation (ANTHC/SCF) which serves all Alaskan Native peoples (approximately 20% of Alaska’s population), has conducted FASD diagnostic services at its integrated Neurodevelopmental Clinic in Anchorage for years. Further, up until the pandemic hit, ANTHC/SCF operated and its traveling diagnostic clinics across the state. In addition to its state-wide neurodevelopmental and diagnostic services, ANTHC/SCF offers a full range of healthcare services via in-person and, increasingly, telehealth services. As one key informant (not employed by the ANTHC/SCF) explained: “It’s light years ahead of the rest of the healthcare systems and providers in Alaska. Outside of ANTHC/SCF, there is no system for FASD.”

Additionally, Providence Healthcare conducts integrated diagnostic service at its’ Anchorage Neurodevelopmental Clinic. At one point Providence Healthcare also operated integrated traveling diagnostic clinics which included FASD diagnostic services.

In our opinion, integrated clinics, such as ANTHC/SCF’s and Providence Healthcare’s neurodevelopmental diagnostic clinics, are invaluable resources for individuals and families and should be fully supported. They have resources to staff and sustain operations that smaller community organizations often do not while also offering the “gold standard” of the multi-disciplinary team assessments.

A primary focus for FASD services in Alaska should be on access to screening, evaluation and, subsequently, services. Having three models of diagnostic services (i.e., community-based FASD diagnostic clinics, standing integrated neurodevelopmental diagnostic clinics, and traveling integrated diagnostic clinics [that include FASD diagnostic services]) have the potential to open access for thousands of Alaskans. Supporting and funding advances in telehealth, incorporating streamlined (tiered) screening and diagnostic services, and facilitating collaboration between providers, will further help build a robust system -- especially for a state with such diversity and far-reaching corners.

### **5. Implement Standardized and Consistent Diagnostic Policies and Protocols**

*Screening and diagnostic policies and protocols are inconsistent from one diagnostic team and clinic to the next in Alaska. As a result, the system is fragmented, uncoordinated and confusing - especially for families. A single point of entry for information and referrals as well as standardized application of screening and diagnostic protocols would result in consistency among providers and across systems where children and adults may be identified (i.e., education, child welfare, juvenile and criminal justice, and vocational systems).*

FASD is a brain-based disorder with physical, developmental, and behavioral health impacts. Over time, individuals with FASD may, as a result of their FASD-related challenges, have interactions with and/or be served by multiple systems: special education, child welfare, disability, behavioral health, and unfortunately (especially if undiagnosed) the juvenile justice, criminal justice and correctional systems. Unfortunately, services are not integrated and coordinated with medical, educational, behavioral health, and developmental disabilities systems. It is crucial for families and clients, as well as for the providers who serve them, to understand how to access and qualify for FASD services.

There is broad agreement that consistency is an issue in Alaska. According to key informants, the void of a coordinated system causes confusion among families, and providers. “People fall through the cracks” was frequently mentioned. Given that children, families, and individuals frequently cross over and between providers and systems, every effort should be undertaken to integrate the FASD assessment and service delivery system so that it makes sense and is accessible to individuals with FASD and their families – regardless of which system they are served by. A single point of entry for referrals could help alleviate this confusion, provide information, and connect people earlier in life to diagnostic and support services.

Additionally, Alaska should consider a review of provider’s screening and diagnostic procedures and policies and adopt family-focused/client-focused standards or requirements to unify FASD assessment and eligibility practices. For example, per the State Provider’s Agreement, each Diagnostic Team “must have established criteria for priority services and eligibility criteria”. By allowing providers to define their criteria rather than stipulating criteria for eligibility, the State may inadvertently be causing inconsistency and confusion in the system. The state may help alleviate confusion in Alaska’s FASD (multi) system of care by working with providers to define and adopt consistent criteria for priority services and eligibility across systems.

Every effort should be undertaken to integrate Alaska’s FASD service system so that it makes sense to individuals with FASD, their families, and the multiple providers and systems that serve them.

## **6. Invest in Capacity Building**

*Investing in building workforce knowledge and capacity for systems that serve individuals with FASD will ultimately result in increased access and improved services for children, their families, and adults with FASD.*

In addition to streamlining diagnostic services and utilizing telehealth, Alaska can build its FASD system capacity through workforce development. Specific strategies should focus on engaging professionals/practitioners and expanding expertise in the workforce by 1) forming partnerships with educational institutions; 2) conducting training in evidence-based practices; and 3) connecting with outside expertise in prevention, screening, diagnostics, and systems.

Two methods shown to result in new professional alliances and development opportunities include Communities of Practice and ECHO cohort and training programs.

A Community of Practice is an on-line forum where practitioners can learn from one another and feel supported. The Community of Practice model is designed to facilitate engagement of the individuals conducting the assessments and evaluations as well as service providers (for example, FASD diagnostic coordinators and team members), to interact and learn from each other by sharing resources, tools, successes and strategies for mitigating challenges.

This collaborative learning process can enhance consistency across the state while considering and periodically accommodating/addressing the nuances of the various regions. One example of a Community of Practice is the Minnesota FASD Consortium. Hosted by Proof Alliance MN, the Consortium is a group of 18 provider agencies who focus on: a) Supporting clinical consistency; b) Increasing accesses to diagnostic services; and c) Provider training and continuing education in Evidence-based Practices, Promising Practices, and Practice-based Evidence. A strategy to institute a FASD Community of Practice in Alaska might be a collaboration between the state Office of Substance Misuse and Addiction Prevention and the Alaska Center for FASD; together they could replicate the Minnesota model and host the Alaska FASD Consortium. Further, this collaborative learning process can enhance consistency across the state while considering and periodically accommodating and addressing the nuances of services in various regions.

ECHO is an all-teach-all-learn tele-mentoring model that uses case-based learning. Specialists and experts at a “hub” meet regularly with physicians, nurse practitioners, and other clinicians at remote “spokes” to support delivery of specialty care services. Notably, key informants expressed concerns regarding the overuse of the ECHO model in Alaska and are unsure how the ECHO model would work practically with primary care providers who are “already overwhelmed with training opportunities” relevant to a wide range of healthcare practices and issues. As expressed by one informant, “We have too many ECHOs. We’re ECHO’d out.” Yet ECHO is a training strategy that has engaged thousands of professionals on a range of healthcare topics and is used by numerous organizations across the country. Therefore, we believe it is a strategy worth supporting and promoting.

Offering opportunities and choices for providers and practitioners is crucial for increasing knowledge, sharing best practices, and building capacity in the workforce. Toward that end, we recommend Alaska institute a Community of Practice specific to FASD while also promoting and supporting ECHO cohort opportunities in Alaska.

## **7. Parent/Family Navigation and Care Coordination**

*Services should include care coordination and parent/family navigation functions -- ideally prior to the evaluation, throughout the evaluation, and post evaluation, regardless of diagnosis. Children, parents, and families need an ally throughout the entire process, as well as assistance accessing services once they are delineated and recommended.*

Care Coordination: Coordinators are the touchstones for families and clients and are essential to the system as well as operation of diagnostic and family support services. They respond to inquiries and referrals, collect, and disseminates information and reports, support and educate the family/client about the diagnostic process and services, coordinate the assessment and the Team’s schedules, follow up with the family/client and Team post-assessment, prepare reports for the State and, finally, work to link those who have been diagnosed with FASD to services (when available). Across the board, key informants recognized how vital they are to the process and the service. As one informant aptly explained: “No coordinator, no diagnostic team, no assessment.”

Recognizing their crucial role, the Alaska Division of Behavioral Health’s FASD Provider Agreement requires coordinator services for all Diagnostic Teams. Per the Agreement, the State

pays approved community provider agencies \$3,000 for assessment services to help cover the costs of coordination. Importantly, providers are paid \$3,000 for only *each client who receives a diagnosis of FASD*. In addition, the diagnostic teams (MD, NP's, SLP's, OT's, neuropsychologists, etc.) may individually invoice their services to the appropriate payor source (i.e., Medicaid, Medicare, private insurer). The adverse effect of this policy is addressed more fully in recommendations as well as the cost analysis of this report.

Navigators: Linking to and/or providing services post-diagnosis should be a standard practice of organizations contracted to operate Diagnostic Services. According to the National Organization for Fetal Alcohol Syndrome (NOFAS), there are few options for FASD programs and services in Alaska and across the lower 48 states. However, Alaska seemingly has an array of FASD prevention and services operating in behavioral health, medical, public health, developmental/intellectual disability, juvenile and criminal justice, human services, social welfare, and child welfare public agencies and private, as well as nonprofit, organizations. Yet, according to key informants, knowing where services are and how to access those services is difficult -- even for Diagnostic Coordinators. Further, families who have children with FASD receive little if any system navigation or family-to-family support or education.

Parent/Family Navigators play a crucial role in filling service gaps, educating families about systems of care, and connecting them to needed support, direct services, government programs and funding. An interesting note regarding the current FASD Provider Agreement is that the Alaska Division of Behavioral Health does not require community-based diagnostic services to have navigators as team members; however, new drafts of the Provider Agreement stipulate the teams/clinics have a navigation function.

If access to and development of family-focused services is a priority, Alaska should develop and require FASD-specific navigation services for parents and families. Further, the service should include evidence-based practices/programs (EBP's) as well as promising practices. "Good Buddies" and "Families Moving Forward" are two EBPs cited by the National Association for FAS.

Finally, for both community-based and integrated clinics, we recommend Care Coordinators remain a required component of every Diagnostic Clinic or Team service. Research and planning to identify and facilitate collaborative funding mechanisms between state divisions and departments, as well as via philanthropic resources and reimbursement, should be a priority for Alaska's leadership.

#### ***8. Link Funding to Work/Service Performed vs. Confirmed Diagnosis***

*We recommend Alaska approves and implements the "pending" State Diagnostic Teams provider agreement in the short term. A longer-term approach would move the payment system from a reimbursement model that rewards "finding a diagnosis" to one that reimburses providers/practitioners adequately for the work they perform. It also should consider (perhaps through a demonstration project) moving from a fee for service (FFS) payment/reimbursement mechanism to an encounter, case or bundled rate based on the cost to do the work.*

Alaska's provider payments for stand-alone community-based diagnostic services have remained at \$3,000 per completed diagnosis for over 20 years, although an increase from

\$3,000 to \$4,000 has been proposed. Notably, the total 2021 State budget for FASD community-based diagnostic services/clinics was \$525,000.

The fact that community-based providers are paid for only completion of the diagnostic process and not for their evaluation hours has negative implications for diagnostic services. That is, community-based diagnostic clinics may not be paid for the time and resources they have expended to coordinate and prepare for the diagnostic service because one or both of the following scenarios occurs: a) the client or family is a “no show”; or b) the client/family does not complete the full evaluation -- resulting in no payment for the evaluation services.

Given that the coordinating agencies are not paid when the diagnostic process is not completed, the agency may be de-incentivized to expand their diagnostic services.

We recommend changing the provider payment policy from the current fee-for-service to an encounter, case, or bundled rate.

## 9. Support Advocacy and Peer Support

"Self-Advocates" are people with FASD who seek improved access to services for themselves and/or their families to better meet their needs. They may also advocate for changes in the system (i.e., System Advocates) to better serve people overall who are impacted by FASD. Although Alaska has an excellent track record of including consumers, clients, and patients in all aspects of the work, it should be intentional about including people with FASD whenever possible, demonstrating commitment to the "Nothing about us without us" philosophy. Adults with FASD should have opportunities to connect to peers for support and guidance throughout their lives.

During our interviews with key informants, we talked with self-advocates whose stories pointed to seven experiences that positively impacted their lives:

1. Early identification and protective factors;
2. Education about FASD;
3. Access to and choice of services;
4. Counseling for their family;
5. A “trauma infused” approach (versus a “trauma aware” approach);
6. “Being heard” and “invited to the table”; and
7. Peer to peer support.

The importance of peer support cannot be understated for people with FASD. Adults with FASD benefit from being connected to peers for support and guidance throughout their lives. One recent study, the *Lay of the Land Survey #2*, conducted between March and November 2020 by Changemakers<sup>12</sup> found that 85% of the participants agreed that having a peer, with lived experience of FASD would be helpful to them. Additionally, 78% of respondents said that they would like to know more people with FASD. These data support the information gained through our interviews with key informants in supporting the role of peers in FASD work.

Self-advocates are the empowered voice for individuals with FASD and their families. Having experienced firsthand the stigma and challenges associated with FASD, they can effectively



support their peers with insight, understanding and guidance. In addition, they can greatly influence access to care and improvements in systems by educating policy makers, professionals and caregivers.

Coupled with self-advocates, system advocates (which may include collaborative endeavors with peers, family members, caregivers and professionals) can very effectively raise visibility, advance policies, and increase funding. The National Organization for Fetal Alcohol Syndrome (NOFAS) is a nonprofit advocacy, prevention, and education organization with affiliates across the United States, Canada, Australia and the United Kingdom. As the leading international FASD advocacy organization, NOFAS works to increase support for FASD prevention and services. Strategically, it is a respected “voice” that can increase Alaska’s visibility and influence at the national level. Currently, there are two NOFAS affiliates in Alaska: the Alaska Center for FASD and Frontier Community Services.

*“Alaska has been talking about FASD and trying to do something about it for many years ... while other places are fearful about identifying the problem and developing solutions”,* said one of our key informants. Based on our research, we agree! We strongly recommend Alaska build upon its experience and success by ensuring peers are “at the table” and that the collective voice of self-advocates and system advocates are heard at the local, regional state and national level.

## **10. Create a Formal Mechanism for Data Collection, Analytics, Reporting and Sharing**

*Collecting data regarding screenings, referral numbers, completed assessments, diagnoses, and the costs of assessments has been a significant challenge of this project from as many providers as possible. We recommend Alaska create a formal mechanism for data collection that is updated regularly and analyzed at least annually.*

Currently only clinics that are part of the Provider Agreement submit data through AKAIMS; to accurately capture information on the entire system, as many providers as possible should submit data to the new system. The data collected should include details about the number of referrals, referral source, completed assessments, and diagnoses. Access to data is instrumental to building a viable case for increased funding and system improvements, especially for advocates, policy makers and providers who require needs-based data (i.e., requests for services overwhelming available resources) to effectively advocate with elected officials and decision-makers.

We recommend the creation of a central repository for FASD assessment and diagnosis data. Specifically, the system should collect data on:

- the number of teams practicing;
- the number of referrals;
- completed assessments and diagnoses;
- details about the number of referrals and referral source;
- completed assessments;
- wait-list information (how many people are waiting and how long the wait is);
- the time it takes from referral to first appointment;

- time from first appointment to completed diagnosis; and
- the diagnoses.

The central repository for data should be updated regularly and analyzed at least annually for trends.

It may be necessary to expand data collection to teams that are not part of the State's Provider Agreement. Currently, only teams who receive funding from the State are required to submit data, this means that despite everyone's best efforts, there is no complete data set, anywhere, on the full number of FASD assessments and diagnoses conducted in Alaska.

There are several mechanisms that may be effective in storing these data: Health Information Exchange (HIE) or an All Payers Claims Database (APCD), but any method for collecting comprehensive data on the FASD assessment system will be an improvement. Additionally, as teams or hubs are formed and dissolved, it will be important for someone to assess regularly whether there is coverage for the entire state. Without keeping track of those teams regularly, it is easy for teams to stop conducting FASD assessments leaving communities without any resources. Highlighting the need for this new data system, the McDowell Group's, 2020<sup>13</sup> report showed variation in the number of assessments completed annually by each clinic, that is part of the State's Provider Agreement, from 1999 to May 2020. The specific cause for this variation is unknown but understanding the causes may help the system improve consistency.

Knowing that teams are struggling with long wait times due to an increase in referrals or that the team has experienced significant turnover, or the loss of a specialist will help the whole system make improvements that will ultimately help Alaskans. Additionally, without a comprehensive data system, obtaining additional funding to support FASD assessments is made more complicated; funding systems generally require data to determine need when assessing how to distribute funds, having a central repository of data would make it easier for the State to obtain additional funding. It is exceedingly difficult to make a viable case for increased funding and system improvements if advocates, policy makers and providers do not have needs-based data (i.e., requests for services overwhelming available resources).

## 11. Institute Shared Leadership

*Trusted and collaborative leadership singularly focused on Alaska's FASD services, and the system of care can refuel and stimulate momentum for system advancement and growth. A community-based organization that partners with government but is independent of government -- an organization with expertise in FASD that is dedicated to working with individuals with FASD and their families and committed to improving systems of care -- would ideally serve in this capacity. Based on our interviews with key informants and review of models, the Alaska Center for FASD could fulfill this important leadership role.*

A common element of model programs and a theme which ran through interviews with key informants was the need for FASD-focused leadership dedicated to advancing policies, practices

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<sup>13</sup> Alaska FASD Diagnostic Team Data Analysis, Policy & Prevention Recommendations, July 2020. McDowell Group <https://alaskamentalhealthtrust.org/wp-content/uploads/2020/08/FASD-Diagnostic-Data-Analysis-Policy-Prevention-Recommendations-7.29.20.pdf>

and systems. That is, Alaska would benefit from having a trusted “lead” organization or group that has the authority, responsibility and influence to advance FASD services and systems. Working in conjunction with the State Office of FASD in a shared leadership model, the Alaska Center for FASD could serve this important role.

Founded in 2017 by a group of advocates, professionals and family members, the goals of Alaska Center for FASD are to:

- Be a statewide, sustainable resource for credible information and advocacy about Fetal Alcohol Spectrum Disorders (FASD);
- Advocate for systems that better recognize, and support individuals and families affected by FASD across the lifespan;
- Pursue a cultural shift that eliminates stigma and celebrates and supports individuals and families through peer-inclusive community engagement; and
- Support efforts to prevent alcohol exposure during pregnancy.

Working collaboratively with the State Office of FASD, the Center could take on work similar to the model organization cited in this report: Proof Alliance of Minnesota. That is, the Alaska Center for FASD would help generate momentum and advance systemwide improvements by organizing and facilitating stakeholders to collaboratively develop and replicate FASD prevention, screening, and diagnosis services and practices. The Center would:

- Support, advocate for and provide education to families and individuals with FASD;
- Provide Information and Referral services;
- Provide training to practitioners, families and individuals affected by FASD;
- Research and facilitate connections and collaborations with other model organizations and experts;
- Identify, facilitate and/or support quality improvement and capacity building initiatives – including telehealth and Evidence-based Practices/Programs;
- Facilitate consistency and competencies among providers;
- Develop the workforce through relationships with colleges and universities and creating internships and practicums from a range of health, behavioral health and developmental/intellectual disability disciplines;
- Represent Alaska on the national level, including with the National Organization for Fetal Alcohol Syndrome;
- Collaborate with Alaska’s leaders, funders and providers including The Mental Health Trust, the Office of Maternal and Child Health, Stone Soup Group, behavioral health and developmental disability/intellectual disability organizations, providers groups and professional association; and
- Collect data and reporting on system and service use, impact, gaps, needs, etc.

Further, we recommend the creation of a FASD Leadership Council comprised of the State’s influential FASD leaders and experts as well as “decision-making” representatives of systems that serve children, families and adults with FASD. The Council would provide support, guidance and oversight to the Center and the state Office of FASD.

## Final Recommendations

Advocacy is a strategic move toward long-term sustainability. It is key to raising visibility, increasing funding, as well as educating public and elected officials. One opportunity to strategically engage in national advocacy activities is to support the National Organization for Fetal Alcohol Syndrome (NOFAS) priority agenda for 2021: passage of the **Advancing Fetal Alcohol Spectrum Disorders Research, Services, and Prevention Act (FASD ReSPect Act)**,<sup>14</sup>.

The ReSPect Act authorizes:

1. An increase in the current \$11M CDC's budget line item for FASD to \$13M for:
  - expanded FASD prevention;
  - Increases in existing national community-based FASD networks; and
  - expanded diagnostic, treatment intervention and other essential services.
2. A new source of (additional) funding from the Department of Defense of \$5M, for:
  - translational research program on prenatal alcohol exposure and fetal alcohol spectrum disorders at the Uniformed University Services of the Health Sciences.

NOFAS's decision for this priority agenda was based on the facts that:

- The FASD Authorization has expired;
- The Act's language is outdated (i.e., it refers to FAS only);
- There is a lack of public and policymakers understanding of the public health crisis of FASD;
- Federal funding for FASD has declined from \$27M in 1998 to \$12M in 2021; and
- There is no federal agenda on FASD.

Further, as mirrored in Alaska, across the country, children, youth, adults, families, communities, and states are increasingly impacted by the lack of funding for FASD prevention, identification, and intervention, and consistently report:

- There is little to no readily available FASD informed systems of care;
- There are FASD diagnostic and support "deserts";
- There is limited diagnostic capacity;
- Schools are unprepared to support learners with FASD; and
- There are high concentrations of youth and adults with FASD involved in the juvenile justice, criminal justice, and corrections systems.

Importantly, the bi-partisan authors/sponsors of the Act are Senators Lisa Murkowski, Republican, Alaska; Senator Amy Klobuchar, Democrat, Minnesota; Congresswoman Betty McCollum, Democrat, Minnesota; and Congressman Don Young, Republican, Alaska.

We strongly recommend Alaska increase its involvement with NOFAS to have a vocal, visible, and credible presence on this important public health issue.

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<sup>14</sup> Source: NOFAS Policy and Training Center, Monthly Virtual Forum, March 2021