

DEVELOPMENT OF AN EVIDENCE-BASED POLICY HANDBOOK UTILIZING A HUB
AND SPOKE PRACTICE MODEL: A QUALITY IMPROVEMENT DNP PROJECT

Submitted by

Leah M. Coffman, MSN, FNP-BC

School of Nursing

Presented to the Faculty

of the University of Alaska Anchorage (UAA)

in Partial Fulfillment of the Requirements

for the Degree of

DOCTOR OF NURSING PRACTICE

Anchorage, Alaska

October 15, 2024

Doctoral Committee:

Chair, Professor: Sharyl Toscano, PhD

Committee Member, Assistant Professor: Morgan Brissette, DNP

Committee Member, Assistant Professor: Jonathan Beatty, Lt Col, USAF, NC, DNP

Abstract

Diagnosing a child with a fetal alcohol spectrum disorder in the State of Alaska requires a team-based approach. The current model is a hub model where providers refer to one of a few certified 4-Digit Code method teams in the geographically vast State of Alaska. Telehealth has been suggested as a viable alternative to in-person hub evaluations for fetal alcohol spectrum disorders (FASDs). The State of Alaska FASD program and the Alaska Mental Health Trust Fund's goals of moving towards a telehealth program for FASD evaluation, diagnosis, and management (WICHE-BHP, 2021). This Doctor of Nursing Practice (DNP) project sought to improve the current model. After critical review and evaluation of the literature, the Hub and Spoke model was selected. The policy handbook was evaluated by experts in the field and revised. Using the Model for Improvement (2013), a policy handbook was developed incorporating the Hub and Spoke model and specific requirements and recommendations specific to Alaska. The new model is called the FASD telehealth Hub and Spoke practice model.

Keywords: Telehealth, fetal alcohol spectrum disorder (FASD), fetal alcohol syndrome, 4-Digit Code method, interdisciplinary, policy handbook, Hub and Spoke

Table of Contents

| | Page |
|------------------------------------|------|
| Title Page | 1 |
| Abstract | 2 |
| Table of Contents | 3 |
| List of Figures | 9 |
| List of Tables | 10 |
| List of Appendices | 11 |
| Nomenclature | 12 |
| Chapter 1: Overview of the Problem | 13 |
| Background | 13 |
| Prevalence of the Disease | 13 |
| Outcomes | 14 |
| Economic Burden | 15 |
| FASD Teams and the 4-Digit Code | 17 |
| FASD Teams | 19 |
| 4-Digit Code Training | 20 |
| Funding | 21 |
| Clinical Significance | 21 |
| Current Clinical Problem | 22 |
| Telehealth Models | 22 |
| Aim | 25 |
| Conclusion | 26 |

| | |
|-------------------------------------|----|
| Question Guiding | 26 |
| PICO | 26 |
| Chapter 2: Review of the Literature | 27 |
| Methodology | 27 |
| Strategies | 27 |
| Critical Appraisal | 28 |
| Evaluation | 29 |
| Synthesis | 29 |
| FASD and Telehealth | 30 |
| FASD and Prevalence | 30 |
| Limitations | 31 |
| Conclusion | 31 |
| Chapter 3: Organizational Framework | 33 |
| Framework Description | 33 |
| Question One | 34 |
| Question Two | 34 |
| Question Three | 34 |
| Framework Application | 37 |
| Aim | 37 |
| Measures | 37 |
| Change | 38 |
| PDSA | 38 |
| Question Guiding | 38 |

| | |
|---------------------------------------|----|
| Conclusion | 39 |
| Chapter 4: Design and Methods | 40 |
| Initial Project Design | 40 |
| Hub and Spoke Method | 41 |
| Measures | 42 |
| Institutional Review Board | 43 |
| Data Collection | 44 |
| Confidentiality | 45 |
| Risks and Benefits | 45 |
| Evidence-Based Practice Change Design | 46 |
| Leadership | 47 |
| Team Members | 47 |
| Methodology and Resources | 47 |
| Data Collection | 48 |
| Sustainability | 48 |
| Challenges of Collaboration | 49 |
| Plan for Project Evaluation | 49 |
| Post-Intervention Plans | 49 |
| Conclusion | 50 |
| Chapter 5: Implementation | 51 |
| Introduction | 51 |
| IRB Submissions | 51 |
| AAIRB | 53 |

| | |
|----------------------------------|----|
| Discussion | 55 |
| Change in Project | 56 |
| Subject Matter Experts | 56 |
| Policy Handbook | 58 |
| Expert Review Data | 58 |
| Conclusion | 59 |
| Chapter 6: Outcomes | 60 |
| Introduction | 60 |
| Policy Handbook Questions | 60 |
| Outcomes | 61 |
| Round 1 | 61 |
| Round 2 | 63 |
| External Reviewer Two | 65 |
| External Reviewer One | 66 |
| Discussion | 67 |
| Strengths and Limitations | 68 |
| Change in Project AIM and Design | 69 |
| Implications for Future Research | 70 |
| Conclusion | 70 |
| Chapter 7: DNP Essentials | 71 |
| Introduction | 71 |
| DNP Essentials | 71 |
| DNP Essential I | 71 |

| | |
|---|----|
| DNP Essential II | 71 |
| DNP Essential III | 72 |
| DNP Essential IV | 72 |
| DNP Essential V | 73 |
| DNP Essential VI | 74 |
| DNP Essential VII | 76 |
| DNP Essential VIII | 76 |
| Conclusion | 77 |
| Chapter 8: Summary | 78 |
| Introduction | 78 |
| Challenges | 78 |
| Ongoing Literature Review | 79 |
| Discussion | 80 |
| Updated Literature Review | 81 |
| Discussion | 82 |
| Key Points and Project Goals | 82 |
| Methods | 83 |
| Implementation and Resources | 83 |
| Significance of Results | 84 |
| Implications for Future Projects | 84 |
| Boyer's Model of Scholarship | 84 |
| Self-Reflection and Summary of Learning | 86 |
| Conclusion | 87 |

References

88

Appendices

95

List of Figures

| | Page |
|---------------------------------|------|
| Figure 1. Model for Improvement | 35 |
| Figure 2. PDSA Cycles | 36 |

List of Tables

| | Page |
|---|------|
| Table 1. Hub Team Services in the Hub and Spoke Method | 41 |
| Table 2. Common Themes from Subjective Responses, External Reviewer 3 | 63 |

List of Appendices

| | Page |
|--|------|
| Appendix A. Evidence Table 1 | 95 |
| Appendix B. Synthesis Table | 98 |
| Appendix C. UAA IRB Modifications Needed Letter | 99 |
| Appendix D. Alaska Area IRB October 2022 Letter | 100 |
| Appendix E. Alaska Area IRB Incomplete Submission Letter November 2022 | 101 |
| Appendix F. Alaska Area IRB Incomplete Submission Letter December 2022 | 102 |
| Appendix G. Alaska Area IRB Revisions Required Letter January 2023 | 103 |
| Appendix H. Alaska Area IRB Withdraw Letter February 2023 | 104 |
| Appendix I. UAA IRB Not-HSR Letter February 2023 | 105 |
| Appendix J. Evidence Table 2 | 106 |
| Appendix K: Policy Handbook | 110 |

Nomenclature

| | |
|-----------|--|
| AACN | American Association of Colleges of Nursing |
| CDC | Centers for Disease Control |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| DHSS | Department of Health and Human Services Alaska |
| EBP | Evidence-based practice |
| FAE | Fetal alcohol effects |
| FAS | Fetal alcohol syndrome |
| FAS DPN | University of Washington Diagnostic & Prevention Network Clinic |
| FASD | Fetal alcohol spectrum disorder |
| FASD | Ptarmigan Connections FASD team |
| HHS | Health and Human Services |
| HRSA | Health Resources and Services Administration |
| IEP | Interprofessional education plan |
| IRB | Institutional Review Board |
| MFI | Model for Improvement |
| ND/AE | Neurodevelopmental/alcohol exposed |
| NIH | National Institutes of Health |
| PDSA | Plan-Do-Study-Act |
| PFAS | Partial fetal alcohol syndrome |
| QI | Quality Improvement |
| SE/AE | Static encephalopathy/alcohol exposed |
| SEARHC | SouthEast Alaska Regional Health Consortium Sitka |
| US | United States |
| WICHE-BHP | Western Interstate Commission for Higher Education Behavioral Health Program |

Chapter One: Overview of the Problem

Fetal alcohol spectrum disorder is a term that describes a set of observed and experienced manifestations of a neurocognitive disease (Cook et al., 2016). These manifestations can present themselves as physical, behavioral, cerebral, and/or maladaptive impairments (Cook et al., 2016). The prevalence of fetal alcohol spectrum disorder (FASD) is estimated to be 11-50 cases per 1000 children. This rate is even higher in Alaska, with 65 cases per 1000 children (Alaska FASD Strategic Plan Working Group, 2021; May et al., 2018). Prevalence, though, is felt to be higher than actual diagnoses, as there are certain barriers surrounding the diagnosis of FASDs (Popova et al., 2016).

Barriers to diagnosing FASDs include but are not limited to, the lack of FASD teams available to evaluate symptomatic patients (Goh et al., 2008). An FASD team consists of clinicians who are specially trained in FASD diagnosis, in which the official diagnosis is dependent upon each team member's input (Astley, 2013). An insufficient number of FASD teams results in less opportunity for evaluation.

Background

Prevalence of the Disease. The current prevalence of FASD is difficult to determine. Former estimations of the disorder were 10 cases per 1000 children. In the present climate, this statistic is felt to be inaccurately low (Centers for Disease Control [CDC], 2022). A recent study found a prevalence of 50 cases per 1000 children (31-98.5) in four communities in the U.S. (May et al., 2018). These communities include the following: (1) a Midwest location with a population of 172,000, (2) a Rocky Mountain site with a population of 60,000, (3) a Southeast site with a

population of 206,000, and (4) a Pacific Southwest site with a population of 1.4 million (May et al., 2018). The FASD rate found within the May et al. (2018) study is regarded as more accurate than previous measurements; however, the general applicability of such findings to other U.S. communities is unknown.

Fetal alcohol syndrome (FAS) is one of four diagnoses under the FASD umbrella (Astley, 2004). The four diagnoses that fall under the FASD umbrella are ranked in order of severity: (1) fetal alcohol syndrome, (2) partial fetal alcohol syndrome (PFAS), (3) static encephalopathy/alcohol-exposed (SE/AE), and (4) neurobehavioral disorder/alcohol-exposed (ND/AE) (Astley, 2004). In Alaska, fetal alcohol syndrome makes up 10% of all FASD diagnoses. The other diagnoses that fall under the FASD umbrella account for the remaining 90%, affecting about 65 per 1000 children (Department of Health and Human Services Alaska [DHSS], 2021). The rate of official diagnosis of an FASD disorder is 1 in 600 of affected children (DHSS, 2021). The number of those affected and diagnosed is severely mismatched.

Outcomes. Fetal alcohol spectrum diagnoses stipulate a disability for a patient. Once a child is diagnosed with this disability, they qualify for a higher level of therapeutic services for the entirety of their life. These services may include: physical, occupational, and/or speech therapies, as well as school individualized educational plans (IEP), and increased medical care (Hendricks et al., 2021). Therapy and early intervention have been shown to improve outcomes in children with FASD (Davis et al., 2011; Ordenewitz et al., 2021; Reid et al., 2015). Children with FASD may display behavioral difficulties that manifest within the home and at school (Jirikowiz et al., 2008; Maya-Enero et al., 2021; Tsang et al., 2016). These behavioral difficulties increase stress for both the child and parent, and create poor adult outcomes (Tsang et al., 2016).

The exact impact of FASD on family structures has been studied. Phillips et al. (2022) measured the impacts of having a child or sibling with FASD, using the child-health-related functioning scale (Children Measure of Function [MOF]) and family impact scale (Impact on Family [IOF] Scale). Moderate (60%) or high (34%) impact was found in these family structures (Phillips et al., 2022). Between siblings and caregivers, almost half reported moderate, severe, or major issues in one subscale on the MOF (Phillips et al., 2022).

Similar studies mimic these findings (Bobbitt et al., 2016). There are challenges when parenting a child with FASD (Sanders and Buck, 2010). Parents report the need for strict home routines and structure, along with support services as children with FASD grow into adulthood (Dow, 2019).

Economic Burden. The financial constraints of caring for a child with FASD can be difficult to estimate (Greenmeyer et al., 2018; Popova et al., 2011). Greenmeyer et al. (2018) estimates a cost of \$23,000 annually for children and \$24,000 for adults. The cost of residential care is greater for children and healthcare is more costly for adults (Greenmeyer et al., 2018). These total costs do not include the \$7,200 required for the special education of children with FASD. Costs for FASD exceed that of autism (\$23,000 vs. \$17,000). This comparison demonstrates the economic burden an FASD diagnosis can carry throughout one's lifetime. Greenmeyer et al. (2018) estimates the total annual cost of caring for all with FASD in the United States (U.S.) to be between \$1.29 billion to \$10.1 billion.

A systematic review of the literature was conducted by Popova et al. (2011) to determine cost estimates, including medical treatment, work-related productivity losses, special education,

and home health or residential care (2016). It should be noted that this cost estimate does not include child welfare or law enforcement/incarceration. The total lifetime cost estimate for FAS was \$596,000 per birth in 1980, with years of care ranging from ages 0-to 65. This number was adjusted to \$2 million to align with the inflation values of 2002. If adjusted once more for the inflation in modern times, this number would be much greater in 2022. A search in PubMed, Ovid, Cumulative Index Nursing, and Allied Health did not yield more recent systematic reviews.

The Alaska Mental Health Trust Authority partnered with the McDowell Group (2018) to determine the economic burden of FASD specific to Alaska. In 2018, they estimated the cost of taking care of an FASD child, youth, or adult to be \$21,079 per person, up to age 53 (McDowell Group, 2018). This figure amounts to a total cost of \$1 billion per year for FASD care in Alaska. The cost of special education services for children with FASD is estimated to be \$3.9 million per year (McDowell Group, 2018).

The McDowell Group (2018) reports separate costs related to homelessness, special education, medical care, foster care, and correctional facility care. Those diagnosed with FASD, in contrast to those without an FASD diagnosis, are at greater risk in needing access to these resources. The Alaska Screening Tool (AST) screens for substance abuse, mental illness, traumatic brain injury, and FASD. All health grantee providers are required to use this screening tool as a part of the Alaska Division of Behavioral Health (McDowell Group, 2018). Using the Alaska Screening Tool (AST), costs can be further broken down. Among those who screened positive for FASD on the AST, the following findings were reported:

- 11% were homeless, costing \$4.7 million in services
- 3% were living in a shelter, costing \$183,960 in services
- 6% were in foster care, costing \$1.5 million in services
- 3% were in a correctional facility, costing \$1,796,927 in services

(McDowell Group, 2018)

While the costs related to the care of individuals with FASD are high, consideration must be made given that FASD is also an underdiagnosed disease (Dow, 2019).

FASD Teams and the 4-Digit Code. An FASD can be diagnosed by either a single clinician or through a team-based approach (CDC, 2022). In Alaska, state services require a team-based approach for FASD evaluation and utilize a method that is referred to as the 4-Digit Code (Astley, 2013; Health and Social Services, n.d.; Hemingway et al., 2023). There are other validated methods that exist to diagnose FASD in the United States and the rest of the world; however, the 4-Digit Code method was agreed upon by the Alaska Division of Public Health to be the only acceptable method for evaluation (Cook et al., 2016; Hoyme et al., 1996; Stratton et al., 1996; Western Interstate Commission for Higher Education Behavioral Health Program [WICHE-BHP], 2021).

The 4-Digit Code diagnostic method was created by the multidisciplinary team at the University of Washington Diagnostic and Prevention Network Clinic (FAS DPN) through a rigorous process of research and experience with patients affected by FASD (Astley, 2013; Hemingway, 2024). The 4-Digit Code was the product of reimagination, developing upon what

had already been published and defined in the field of FASD evaluation and establishing a quantitative method that didn't exist prior (Astley & Clarren, 1999).

The method was first utilized in each of the seven FAS DPN clinics across Washington state (Astley, 2013; Hemingway et al., 2023). Each clinic comprised a multidisciplinary team of experts: a physician, a psychologist, a speech-language pathologist, and an occupational therapist. Each core team had access to community resources, such as social services and the like. The method was then tested for accuracy and power. Inter- and intra-rater reliability was high (100%, $\chi = 1.0$, $P = 0.000$). The t-test was employed, and the ANOVA was found to be statistically significant (85%) (Astley, 2013). After rigorous testing, the 4-Digit Code was instituted as a standardized method to accurately diagnose an FASD (Astley, 2013).

The four digits of the 4-Digit Code represent features of an FASD: (1) growth deficiency, (2) FAS facial phenotype, (3) brain dysfunction, and (4) intrauterine alcohol exposure (Hemingway, 2024). Each component is rated by the appropriate specialty. For example, growth deficiency is measured from in-utero (growth on the day of birth) to the current date, if records exist. Facial phenotype is measured by the facial analysis program, and a score is given. Brain dysfunction is measured through an assessment by all four clinical specialties through a battery of medical, language, and neuropsychology tests. The findings are consolidated, and the team assigns the final 4-Digit Code. If applicable, the comprehensive findings will relate to the final FASD diagnoses. There are 256 possible codes, and each code falls into 1 of 22 clinical diagnostic categories. Each code level relates to the severity of the disease, with 4444 being the highest code, equating to a fetal alcohol syndrome diagnosis (Astley, 2004).

The 4-Digit Code diagnostic method provides high inter-rater/intra-rater reliability, facial analysis with high sensitivity and specificity to fetal alcohol syndrome, and accurately predicts central nervous system dysfunction (Astley, 2013). The State of Alaska FASD agreement requires an FASD diagnosis to be made by a team trained in the 4-Digit Code method (McDowell Group, 2021). A team approach provides higher accuracy in the final diagnosis (4-Digit Diagnostic Code) and is the recommended method by the State of Alaska (Astley, 2024; McDowell Group, 2021). However, few FASD teams exist in Alaska, thus contributing to missed diagnoses (Health and Social Services, n.d.).

Given Alaska's distinctive geography, the vast distances within the state give rise to isolation between clinicians, posing a barrier to 4-Digit Code team training. (S. Astley Hemingway, personal communication, March 10, 2022). In the past, team training occurred by sending specially trained clinicians to each remote location, which would often require unique modes of transportation (S. Astley Hemingway, personal communication, March 10, 2022). Using planes to access remote areas can cost anywhere between \$600-1000 per ticket. This cost excludes lodging, food, and lost work revenue (Alaska Airlines, 2022). Utilizing telehealth as a method for team training in the future may provide a solution for overcoming this financial roadblock.

FASD Teams. One of the barriers to diagnosing FASDs in Alaska is that there are few FASD teams that exist (DHSS, 2021). In 2006, there was a loss in funding from the Alaska Medicaid waiver, and teams began to dissipate (WICHE-BHP, 2021). At one point, there were as many as 17 FASD teams in Alaska. As of today, this number has dwindled down to three

(WICHE-BHP, 2021). According to Dr. Susan Astley Hemingway, it can be difficult to train and maintain a team, and many collapse due to a lack of adequate team support (Personal communication, September 16, 2021). Historically, support has been essential to the successful maintenance of an FASD team. Support often comes from the team coordinator, who provides leadership and sustains the team's momentum (Susan (Astley) Hemingway, personal communication, March 10, 2022).

Team training can be completed via a live one-day session at the University of Washington (UW) FAS DPN clinic or through a 20-hour online course over the span of four weeks (FAS Diagnostic & Prevention Network Training, n.d.). Clinicians must be trained and certified on the FAS DPN program called the 4-Digit Code, per the State of Alaska provider agreement under the Alaska Department of Health and Social Services (Astley, 2004; WICHE-BHP, 2021).

4-Digit Code Training. Training, both in-person and online, is not time-consuming. However, it is best that a novice team shadow or receive support from an experienced team to fully understand the diagnostic process and ensure the validity of their findings (Susan (Astley) Hemingway, personal communication, September 16, 2021). For this very reason, the UW FAS DPN clinic offers shadowing experiences for novice FASD teams using the 4-Digit Code method. Novice teams are also supported through in-person visits from Dr. Astley Hemingway and members of her team (Susan (Astley) Hemingway, personal communication, September 16, 2021). Dr. Hemingway travels to new teams for the purpose of validating patient evaluations and

providing support. Given the emergence of video conferencing technology, training can be done via telehealth with clinician shadowing evaluations and/or video conferencing.

Funding. The State of Alaska funnels funding to support FASD diagnoses through FASD teams (DHSS, 2021). There are currently three operational teams in the state (Health and Social Services, n.d.). The teams are in Fairbanks, Wasilla, and Soldotna. These teams provide all the state's diagnostic evaluations of FASD (Health and Social Services, n.d.). The limited number of FASD teams impacts families through extensive wait times for crucial appointments, as well as an increased financial burden associated with added travel, coupled with an overall lifetime increase in expenses as they navigate the services required for their child's extra needs (Health and Social Services, n.d.). The longer a child with FASD is left without intervention, the poorer their outcomes (Petrenko & Alto, 2017).

Clinical Significance

Patients with FASD symptoms need prompt medical and therapeutic intervention during critical periods of growth and development (Petrenko & Alto, 2017). A child's developmental progress and trajectory can be improved with adequate therapeutic support, as long as it is made available soon after identifying one of the umbrella FASD diagnoses (Reid et al., 2015).

Therapeutic support is gained with dedicated monies from the State of Alaska Mental Health Trust Authority. Receiving an FASD diagnosis at an earlier age, along with the presence of a stable home environment, has been shown to decrease adverse life outcomes (defined as incarceration, disrupted school, drug/alcohol abuse, and inappropriate sexual behaviors) by 2- to 4-fold (Streissguth et al., 2004).

Improved patient outcomes occur alongside adequate access to care (Healthy People 2030, n.d.). Significant outcomes that are measured include physiologic, cognitive, and behavioral. Rural residents often encounter increased barriers in the area of “access to care,” and all of Alaska is considered rural by federal reimbursement allocations (Rural Health Research Center, 2021; Rural Health Information Hub [RHIH], 2021). Sufficient access to care is vital for rural residents to receive essential healthcare services (RHIH, 2021). Adequate access to healthcare improves screening, diagnosis, and treatment of disease (RHIH, 2021).

Current Clinical Problem

Since few FASD teams exist in Alaska, there is a drive from state stakeholders to widen the impact of community-based FASD-specific diagnostic teams through an integrated approach (WICHE-BHP, 2021). This integrated approach allows for diagnostic services to either be in person or through telehealth and can vary throughout a single evaluation to best suit the needs of the patient and their family (Whittingham & Coons-Harding, 2021; WICHE-BHP, 2021).

Telehealth Models. Telehealth models have been piloted in other locations, but mainly in Canada, where rurality plays a role in access to care similar to Alaska, especially for those affected by FASD (Whittingham & Coons-Harding, 2021). To date, only three studies have published their findings on the utilization of a telehealth FASD diagnostic program, with all three studies occurring in rural Canada (Benoit et al., 2002; Ens et al., 2010; Hanlon-Dearman et al., 2014; Whittingham & Coons-Harding, 2021). These qualitative studies based out of Manitoba, Canada described the general satisfaction of stakeholders regarding the use of telehealth in FASD evaluations (Whittingham & Coons-Harding, 2021).

Ens et al. (2010) evaluated an FASD telehealth program based in several Manitoban communities. These northern, remote communities utilized telehealth services for FASD evaluations. Telehealth services were evaluated for areas of improvement. Semi-structured interviews were conducted with 26 professionals who utilized the telehealth service. The findings revealed certain themes related to areas of improvement, along with the strengths of the telehealth program. These findings suggested that telehealth had a positive impact on access to care and allowed for barriers to be addressed for further expansion of the FASD telehealth program (Ens et al., 2010).

Hanlon-Dearman et al. (2014) performed a follow-up study to the Ens et al. (2010) study. The authors explored the feasibility, usefulness, and experiences of telehealth and FASD evaluations in rural Canada through a qualitative study and focused on insights from professionals who utilized a telehealth FASD program. Hanlon-Dearman et al. (2014) found that there were barriers to overcome, but overall, users appreciated the benefits of telehealth. This study had unique findings about cultural context as an important factor in explaining “psychometric, therapeutic, and diagnostic data during the assessment process” (Hanlon-Dearman et al., 2014). One of the more pertinent findings of the study was that a central coordinator or hub played a crucial role in creating a standardized system in preparation for telehealth use.

With these three studies, Benoit et al. (2004) gave the most comprehensive description of team management, noting having a central hub team of clinical experts in the field of FASD. The expert team met with the less experienced team members either in person or via video

conference, during pre-and post-assessments of children. The expert team included a developmental pediatrician, developmental fellow, clinic coordinator, nurse clinician, occupational therapist, speech-language pathologist, and geneticist. The less experienced team included a program coordinator, nurse, clinical psychologist, and traditional pediatrician. Each assessment was centered around what worked best for the child/family. Therefore, some assessments were completed entirely in person by the less experienced team, and the findings were reviewed with the expert team. On other occasions, children were assessed solely through video conference by the experienced team, while the less experienced team acted as facilitators in person (Benoit et al., 2004).

There were lessons learned from the Benoit et al. study (2004). The study discovered that telehealth evaluations could be provided for FASD, and telehealth could be used for preliminary data collection. Communication between families and the clinic could be provided via telehealth, including evaluation preparation. It was also found that treatment plans for children and debriefing to families or community professionals could be implemented through telehealth. Finally, the study demonstrated that less experienced team members could be educated on the process of FASD evaluation through telehealth, thus increasing the team's confidence (Benoit et al., 2004). The results of this study were satisfactory in that video-conferencing options were explored; however, an updated study using current technology is needed.

Aim

These three studies had the most influence on the direction of the project: Benoit et al. (2004), Ens et al. (2014), and Hanlon-Dearman et al. (2010). Given this data, a telehealth model here in Alaska was a natural choice.

The project aims to assess provider satisfaction with the addition of a Hub and Spoke practice model. The pilot project will be centered around the Hub and Spoke model, with the central hub being Ptarmigan Connections, which houses a team coordinator and an experienced FASD team, and the spoke will be the satellite team at Southeast Alaska Regional Health Consortium (SEARHC) Sitka. Existing provider services in the hub model do not allow for clinician support. The addition of the spoke will provide support for participating clinicians.

A second aim of this project is to establish the best practice in assisting FASD teams in Alaska through the creation of a policy handbook that may be utilized by local FASD teams. A critical review of the literature will include a review of best practice models. Developing a policy handbook represents a theoretical application of the Hub and Spoke model to explore its potential for providing guidance in the accurate diagnosis of FASD and access to FASD support.

The policy handbook highlights the foundation of the Hub and Spoke FASD evaluation practice model. The handbook provides a foundation of methods that could be utilized in various services where trained providers are scarce, and patient evaluations need to be completed, so long as there exists an able clinic willing to serve as the main source of Hub and Spoke management. Due to the geographical and logistical constraints of rural areas in Alaska, the Hub and Spoke model is a natural solution. The policy handbook guides a hub clinic through the steps

of the referral process, 4-Digit Code evaluation, and dissemination of results of an FASD evaluation.

Conclusion

Question Guiding. PICO (patient, intervention, comparison, and outcome questions present a framework by which to critically analyze and appraise a body of evidence to steer clinical practice (Melnyk & Fineout-Overholt, 2019). The following is an explanation of how the author utilized the PICO question for this clinical problem: The hub clinic (FASD Team at Ptarmigan Connections).

PICO. The PICO question was formed through the derivation of evidence from literature supporting a Hub and Spoke model of care. Within the scope of this project, the literature helped guide the theoretical application of a Hub and Spoke model. For this project, the PICO question was: in FASD evaluation clinical practices using a hub model (SEARHC Sitka); will a telehealth practice model using the Hub and Spoke model, be satisfactory as measured by practice model indicators; when compared to the hub only model? The PICO is described below:

P: FASD evaluation practice

I: Hub and Spoke

C: Hub

O: Practice model indicator

Chapter Two: Review of the Literature

This chapter will review the literature that exists on fetal alcohol spectrum disorders (FASD) in terms of diagnosis, prevalence, interprofessional teams, telehealth use for FASD, and Hub and Spoke model services. Fetal alcohol spectrum disorders (FASDs) have a high prevalence, and significant barriers to diagnosis persist (Popova et al., 2019; Whittingham & Coons-Harding, 2020). In the United States, 86% of FASD diagnoses were missed in a particular population (Chasnoff & King, 2015). One of the reasons missed FASD diagnoses occur is a lack of specialized training, specifically in recognizing the disease's physical and behavioral features (Chasnoff & King, 2015). Training and validation of appraisals can be difficult to obtain, especially for providers living in rural areas (Dr. Hemingway, personal communication, September 16, 2021). A Hub and Spoke model has been developed for FASD telehealth evaluation in rural areas to increase community access to FASD-trained teams (Benoit et al., 2002; Ens et al., 2010; Hanlon-Dearman et al., 2010).

Methodology

A literature search was performed to find evidence of fetal alcohol syndrome (FAS) prevalence and diagnosis; databases were searched using specific terms to match the themes of the pilot project. Search topics included rural healthcare, telehealth, and practice models. The results from initial searches were reduced to find more distinct conclusions. Once relevant studies were identified, they were critically appraised, and themes were distinguished. The findings are discussed in-depth in the excerpts to follow.

Strategies. Several databases were utilized for this literature review, primarily the Cumulative Index for Nursing and Allied Health Literature (CINAHL), as well as PubMed. In CINAHL, search terms included individual use of the term along with combinations of terms: (1)

Fetal Alcohol Syndrome (FAS), (2) multidisciplinary care team, (3) diagnostic error, (4) rural health personnel, (5) telehealth, (6) Hub and Spoke, and (7) team building. The term 'Fetal Alcohol Syndrome' alone yielded 1,442 articles with no limit on publication date. The search was then narrowed down by type, namely articles and publication date (< five years), giving 438 results. This search combined FAS with each of the above terms to find relationships, though few articles were found. Zero articles were found regarding the relationship between Hub and Spoke models of care and FAS. Only one article was found on telehealth and FAS. 'Multidisciplinary care' was included in the search, as this project seeks to draw on personnel from varying positions. One article was found on interprofessional education, yet it was not specific to FAS interdisciplinary teams. After finding minimal studies less than five years old, the search was broadened to include those 20 years older or less, and the yield increased to 3.

The types of FAS studies vary greatly since the broad topic of FAS lends itself to describing many types of articles. Topics of discussion include biomarkers for FAS, symptoms, diagnosis, and post-diagnosis care, including therapies. Other studies focus on the prenatal risks of alcohol use, specific population risks based on ethnicities, and more. Once search terms were narrowed through different combinations, few studies specific to FAS were found, especially regarding implementing a rurally located team.

The studies found are reliable as their findings are relevant to most parts of the project, focusing on aspects such as FAS, telehealth, multidisciplinary teams, and hub-and-spoke methods in FAS. The data was evaluated for applicability within the project context.

Critical Appraisal

The data were critically analyzed using the Johns Hopkins evidence-based practice model (Dang et al., 2022). The critical evaluation of data is an essential step in the process of project

development (Dang et al., 2022). The literature are described in *Appendices A & B*. The evaluation and discussion of the critical appraisal process includes: evaluation, synthesis, and limitations.

Evaluation. Overall, there is a scarcity of literature discussing the formation of a rural team specifically for the purposes of FASD diagnosis, with the use of a spoke method. Benoit et al. (2002) described the use of telehealth for diagnosis and the nature of team meetings for portions of the evaluation; however, the study only focused on individual telehealth exams (Benoit et al., 2002). There was some discussion in the literature on FAS diagnoses, a high rate of missed diagnoses, and a lack of standardized training across the world for those completing the evaluations (Popova et al., 2019). Another study, which examined interprofessional or multidisciplinary teams and the value of a lead clinician, was also appraised (Walker, 2021). This study demonstrated the value of a clinician serving as the center of a team. This clinician would bring the evaluation together and create a line of steady communication that keeps the evaluation's momentum (Walker, 2021). This study also supported the use of a Hub and Spoke -type method, in which a central person acts as the hub to keep the spoke team moving along through an evaluation (Walker, 2021).

Synthesis. Several themes were identified in all the studies that focused on FAS (Grubb et al., 2020; Popova et al., 2019; Whittingham & Coons-Harding, 2021). A discrepancy was noted in how to diagnose a child with FAS world-wide (Grubb et al., 2020). This lack of a standardized approach makes the initial diagnosis difficult (Grubb et al., 2020). In addition, few teams were making FAS diagnoses in rural locations, especially those utilizing telehealth technologies and/or Hub and Spoke models (Whittingham & Coons-Harding, 2021). See *Appendix B, Synthesis Table*.

FASD and Telehealth. The project design mimics a similar design used in Manitoba for FAS evaluation using the hub method (WICHE-BHP, 2021). The Manitoba group used a central team coordinator to facilitate satellite clinic diagnostic services. Each satellite clinic may have its own clinicians; if not possible, telehealth or a traveling team is utilized. Satellite clinics have a sub-coordinator that falls under the central coordinator. The key to their success falls mainly on the considerable use of a coordinator to maintain the momentum of the diagnostic process.

A theme emerged in the literature review: access to care in rural locations. Few studies exist in the United States; however, Canadian agencies have put forward research on this subject (Benoit et al., 2002; WICHE-BHP, 2021). Canadian healthcare teams have approached FASD diagnoses with the use of telehealth to increase access to care. While there weren't many studies reported, the few that existed provided examples of how to pilot an FASD project in a rural location (Benoit et al., 2002; Ens et al., 2010; Hanlon-Dearmaan, 2014).

Three examples were identified within the FASD Alaska study, with the strongest coming from Manitoba, Canada, which has similar geographical and healthcare-related challenges as Alaska. In this report, Manitoba used a similar style of evaluation, using a central clinic method with outlying clinics reporting to them (WICHE-BHP, 2021). This method demonstrated an effective means of evaluation for both clinicians and families (WICHE-BHP, 2021). Replication of this method seems logical, given the lack of standardized benchmarks.

FASD and Prevalence. The study with the strongest evidence (Level I) was executed by Popova et al. (2019). The authors approached FASD prevalence from a worldwide lens, seeking literature that would present themes within subpopulations, via a systematic literature review and meta-analysis of quantitative studies from November 1973-December 2018 (Popova et al., 2019). The data of subpopulations was gathered to observe trends in FASD prevalence. Critical

appraisal was utilized for each of the studies (n = 69), which encompassed data from 17 countries: Australia (n = 5), Brazil (n = 2), Canada (n = 15), Chile (n = 4), eastern Europe (Moldova, Romania and Ukraine; n = 1), Germany (n = 1), Israel (n = 1), Lithuania (n = 1), the Netherlands (n = 1), Poland (n = 1), Russia (n = 9), South Korea (n = 1), Spain (n = 1), Sweden (n = 1) and the United States (n = 25). Subpopulations were defined as children in foster care, incarcerated individuals, aborigine peoples, special populations, and special education populations. The estimated prevalence was found to be 10-40 times that of the regular population (Popova et al., 2019).

Addressing FASD and prevention in these subpopulations is an important approach to providing adequate support for diagnostic evaluations (Popova et al., 2019). This meta-analysis supports the focused interventions for at-risk subpopulations, as prevalence rates can be much higher (Popova et al., 2019).

Limitations

The literature review had limitations. Future literature searches could add more depth, especially with the inclusion of hub-and-spoke models of care in rural populations; other facets of exploration include a handbook policy within FASD team evaluations. Other limitations to the studies addressed included a low number of Level I-III Evidence, given that most of the studies were descriptive.

Conclusion

In summary, the literature review demonstrated a paucity of literature specific to the Hub and Spoke model project; however, the project's components are adequately studied. Although the studies were mostly descriptive, they provided clear guidance on essential elements for FASD diagnoses within the context of a rural location using a hub method. During the duration

of this project, new research was published. A summary and critical review of that literature is included in Chapter 8.

Chapter 3: Organizational Framework

Quality improvement (QI) aims to improve healthcare through purposeful, systematic actions (Health Resources and Services Administration [HRSA], 2011). These improvements must be measurable, which is a key factor in a project led by a QI framework (HRSA, 2011). Health care organization practices contain two parts: (1) what is done and (2) how it is done. QI seeks to improve one or both aspects with superior strength in both (HRSA, 2011).

The current provider model is a hub practice model. The evidence supports implementation of a Hub and Spoke model in rural areas similar to Alaska. Through the provision of additional support for hub team providers, this scholarly project seeks to evaluate the quality of a Hub and Spoke model policy handbook. A hub model is currently in place at Ptarmigan Pediatrics. During this project, a Hub and Spoke policy handbook will be written to explain the new model. The policy handbook will be evaluated by external reviewers for quality, and QI concepts will be applied to each step of the change model. Quality improvement provides a systematic foundation for this project, as it seeks to improve the process of FASD evaluations in rural Alaska through the initial implementation of a policy handbook to guide the hub team.

Framework Description

Within the context of quality improvement in healthcare, the most frequently utilized framework is the Model for Improvement (MFI) (Agency for Healthcare Research and Quality [AHRQ], 2013). This quality improvement model uses a two-part system to make changes. In part one, questions are asked to create a plan. Model for Improvement part one begins with the following questions, as quoted from the Agency for Healthcare Research and Quality Practice Facilitation handbook (Knox & Brach, 2013, p. 31): “(1) What are we trying to accomplish? (2) How will we know that a change is an improvement? and (3) What changes can we make that

will result in improvement?” The second half of the model uses Plan-Do-Study-Act (PDSA) cycles to make small changes to systems as the plan is executed (Knox & Brach, 2013). Teams then use the PDSA cycle to test changes within a system, testing for effectiveness until the desired outcome is achieved (Knox & Brach, 2013).

Question 1. The first question, ‘What are we trying to accomplish?’ refers to the project’s aim (Associates in Process Movement [APM], 2013). The aim is significant as it must be specific, measurable, and focus on key issues. Key issues define the *why* behind a project, such as *why, for whom, and how good*. The aim also defines a timeline for the project in which to be completed (APM, 2013).

Question 2. The next question, ‘How will we know that a change is an improvement?’ looks at *measures* to determine how a goal has been met (APM, 2013). Outcomes must be measurable, and the project leader must know where they want the project to go. An assessment must be made: if the goal is achieved and changes are administered, do these changes affect any other parts of the whole, whether the effects be negative or positive? The process measures must be examined to understand if the researcher is making progress toward the desired outcome (APM, 2013).

Question 3. Change is the next focus of MFI: ‘What changes can we make that will result in improvement?’ (APM, 2013). Change concepts must be undertaken to improve the system. This includes looking at excess resources, workflows, environments, errors, and what is produced (APM, 2013). Changes occur on account of improvement, given that the applied changes are correct and necessary.

The second part of the MFI uses the PDSA cycle. The key theme of the PDSA cycle is that changes are made as the QI project team progresses. Systematic processes drive the discipline to cycle and test improvements continuously. See *Figure 1*.

Model for Improvement

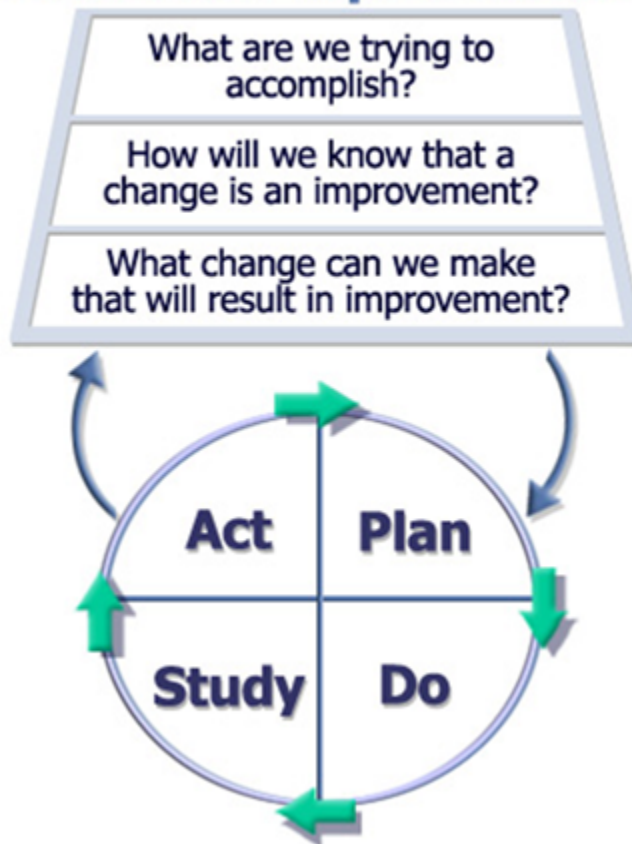


Figure 1. Model for Improvement. Provost, Nolan, Moen, Langley, Nolan, & Norman (2024)

This QI project will apply each step of the PDSA. The framework will look at the following steps: 1) Plan-FASD Project, 2) Do-Create a policy handbook, 3) Study-evaluate the policy handbook for content by external reviewers with subject expertise, 4) Act-improve the policy handbook as recommended by reviewers, 5) Repeat steps 1-4 to improve the product.

Figure 2 depicts the PDSA in motion.



Figure 2. PDSA Cycle. EMSC (n.d.)

Framework Application

Aim. This project aims to establish a telehealth model of care like that described by Benoit et al. (2004). The Hub and Spoke model has the potential to increase access to care for affected children living in rural Alaska, as evidence has shown other telehealth models have been successful in similar rural settings (Whittingham & Coons-Harding, 2021).

In 2017, the Alaska State Council on Disabilities (Governor's Council on Disabilities and Special Education [GCDSE]) began to devote funding and energy to primary, secondary, and tertiary prevention of FASD, which is now known as the Alaska Fetal Alcohol Spectrum Disorders Strategic Plan 2017-2022 (McDowell Group, 2020). Within this plan, its objectives and strategies are aimed toward improving the identification, support, and quality of life for those affected by FASD (McDowell, Group, 2020). Given these priorities, this pilot project aims to provide additional support with the implementation of the Hub and Spoke model, illustrating strategies for the improved identification of FASD.

Measures. Practice model success indicators on quality applicability of policy handbook, will be examined by external reviewers using their expertise to guide their review. Each of the reviewers will be experts in the field of FASD who are practicing within a multidisciplinary model. For example, one external reviewer is a psychologist who has created and led an FASD team and diagnosed children with an FASD. This perspective helps to identify gaps in the policy handbook that a typical psychologist couldn't identify, such as process problems or inaccuracy with the team-based process. This psychologist is aware of the business piece of the FASD team, such as abiding by the provider agreement (State of Alaska) and reimbursement, which are both important pieces of a functional team. These niche nuances make formulation of a team difficult. A second reviewer is with the field of specialty of the second reviewer- creator and

epidemiologist of the 4-Digit Code method, who still continues to study diagnosis of FASD through a multi-disciplinary approach. This reviewer can measure the effectiveness of the policy handbook through the lens of the 4-Digit Code along with team specialty contributions. The third reviewer is a team coordinator who has assisted in the team-based approach, leading a team (Fairbanks) to diagnose many children with FASD and understands both the 4-Digit Code method and rigor of the team-based approach.

Change. This project is focused on the theoretical application of an evidence-based model. The policy handbook will provide the foundation for change. The policy handbook, if adopted, will establish one of the first steps of change for an FASD team-based approach, as a clinic moves from a hub to a Hub and Spoke model of care. Due to the nature of QI, it is expected that further positive changes will occur throughout the development of this project.

PDSA Cycles. Plans will be evaluated and modified accordingly to improve the projected outcomes. A plan will be made for each step of the process. It is important to develop a policy handbook that serves as a guide to support FASD team members. The policy handbook will be constructed to follow evidence-based models of care that have demonstrated success in other rural settings.

Question Guiding. In Chapter 2, this author employed a PICO (population, intervention, comparison, outcome, and time) question by which to critically analyze and appraise a body of evidence to steer clinical practice (Melnyk & Fineout-Overholt, 2019). The PICO question was formed through the derivation of evidence from literature on the hub versus Hub and Spoke model.

Conclusion

The Model for Improvement using the PDSA cycle is a useful tool implemented by many healthcare sectors (APM, 2013). Clinical frameworks in nursing should be used as the underpinnings for a project, creating borders and limitations to the project's extent (Bonnell & Smith, 2013). Implementing evidence-based practice requires careful adherence to a framework. The Model for Improvement will provide this scholarly project an EBP Evidence-Based Practice framework to successfully guide the QI process (or changes), to establish a policy handbook for a new model of care similar to that described by Benoit et al. (2004)

Chapter 4: Design and Methods

Telehealth has broadened the horizons of healthcare in rural areas. The State of Alaska FASD Division studied FASD services specific to telehealth to identify ways to increase rural evaluations (WICHE-BHP, 2021). This study gathered data on methods of FASD diagnostics, noting that “dwindling teams” were a problem in Alaska (WICHE-BHP, 2021). Three methods for diagnostic services were gleaned from this study: (1) community-based diagnostic teams, (2) standing integrated teams that evaluate FASD and other developmental issues, and (3) integrated traveling diagnostic teams. The authors recommended a shift from more community-based diagnostic teams to focusing efforts on the expansion of integrated diagnostic clinics with varying telehealth and in-person services. This scholarly project addresses this need and recommendation by presenting additional support to providers regarding the Hub and Spoke care model delivered via telehealth.

Initial Project Design

The following information in this section reflects the initial project design and indicates where it was revised after Institutional Review Board barriers prevented implementation. Revisions are indicated throughout Chapter 4 and further reviewed in Chapter 5. This method retains initial design and method, noting revisions where applicable.

The project design mimics a similar design used in Manitoba, Canada, for FASD evaluation using the hub method (WICHE-BHP, 2021). The Manitoba group uses a central team coordinator who facilitates diagnostic services at satellite clinics. Each satellite clinic may have its own set of clinicians, and if not, telehealth or a traveling team is utilized. Satellite clinics have a sub-coordinator that falls under the central coordinator. The key to their success is mainly their considerable use of a coordinator to maintain the momentum of the diagnostic process.

Hub and Spoke Method. The project seeks to use the Manitoba method with some modifications. The addition of a second team, or spoke, allows for a change in the current practice model. The current practice model is a brick-and-mortar clinic in which the FASD team sees patients face to face. The caveat of this method is that the team must be properly trained in the state-mandated (by contract) 4-Digit Code. However, not every team has the resources for maintenance and sustainability. By adding a Hub and Spoke model, the spoke team can still see the patient face to face while having access to a supportive team (hub) that can maintain the state contractual guidelines through regular training and continual expert evaluations. Using the Hub and Spoke model allows the spoke team to perform evaluations within rural areas while receiving support from the hub team. The hub team will provide the following services, as shown in *Table 1*.

Table 1. Hub Team Services in the Hub and Spoke Method

| Team | Services Provided |
|-------------------|---|
| Pre-evaluation | Check in with the spoke team regarding evaluation preparation, to include the FASD software function, how to set up meetings, how to find records (the hub team will not be searching for records), how to book patients per 4-Digit Code recommendations, and how to set up the flow of a patient visit. Services are provided on an as-needed basis only. If a clinician feels confident with their process, they can proceed without assistance from the hub team. |
| During evaluation | Spoke team members will meet with their patients and perform evaluations. Hub team individual members are available for consultation. A hub pediatrician can meet virtually with a spoke pediatrician to go over how to operate the facial analysis program and work through elements of the 4-Digit |

| | |
|-------------------|---|
| | Code. The same services will be provided for therapist-therapist and neuropsychologist-neuropsychologist. |
| Post-evaluation | The hub team neuropsychologist will gather results, format them per the 4-Digit Code standard in a final report, and release it to the spoke team, enabling them to see the final report and use it as a template for future evaluations. |
| Clinician Surveys | The author of the pilot project will assess clinician satisfaction in a qualitative survey administered via video teleconferencing or phone after the evaluation. [ADAPTED] To expert review of the policy handbook without satisfaction survey. |

Measures. This scholarly project aims to assess provider satisfaction with adding a Hub and Spoke practice model. The pilot project will be centered around the telehealth model, with the central hub being Ptarmigan Connections, which houses a team coordinator and an experienced FASD team. The spoke will be the satellite team at SouthEast Alaska Regional Health Consortium (SEARHC) in Sitka. Existing provider services in the current hub model do not allow for clinician support; however, adding the spoke will provide education and support for participating clinicians.

The target population is the spoke FASD team at SEARHC, and the outcome measure will be their satisfaction with a Hub and Spoke practice model using a QI framework. This scholarly project will not involve human subjects nor the patient's private health information. The author will not interact with the patients or families involved in the diagnostic evaluation, as the project focus is on clinician satisfaction with the Hub and Spoke model. The hub team will provide expert advice and team coordination via telehealth. To ensure no inadvertent disclosures

of protected health information, the author of this project will not provide hub or spoke support services to the provider population where satisfaction is being evaluated. There are four other clinicians engaged in these services: two neuropsychologists, an occupational therapist, and a pediatrician. All licensed clinicians provide non-experimental services, as these services are within their scope of practice. **[ADAPTED]** Due to the sensitive nature of FASD evaluations, implementation was not possible. The project evaluation focus shifted to the policy handbook.

Institutional Review Board

The Institutional Review Board (IRB) is a system that protects human rights within research using checks and balances (National Institutes of Health [NIH], 2020). The IRB system is based on findings from the Belmont Report, which encompasses three basic principles of research: (1) respect for persons, (2) beneficence, and (3) justice (Department of Health, Education, and Welfare, 1979). Persons are defined as human subjects in research: living individuals who are being investigated and will serve as the basis of information/data collection (such as biospecimens, interactions, and behaviors) (NIH, 2020). The Office for Human Research Protections (OHRP), under Health and Human Services (2018), provides leadership and legal guidance to determine if research/project activities require IRB panel review and approval. IRB review can range from exempt to a full panel, to ensure the protection and safety of human subjects (HHS, 2018).

The Health and Human Services (HHS) rule 45 CFR 46 states that research activities are exempt from IRB review under certain circumstances (HHS, 2018). Specifically, the rule states: “...the following categories of human subjects research are exempt from this policy:

- Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement)
- survey procedures
- interview procedures
- observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met
 - Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability
 - be damaging to the subjects' financial standing, employability, educational advancement, or reputation,”

(HHS, 2018, Subpart A)

This scholarly project specifically meets the above criteria with its purpose: to assess provider satisfaction with a new practice model. Furthermore, the project does not involve human subjects' data, protected health information, or research activities.

Data Collection. This project will use clinician satisfaction surveys to gain knowledge regarding the experience of rural providers in using a Hub and Spoke practice model compared to the previous hub model of care for FASD evaluation. The clinician satisfaction surveys will be given only to those providers utilizing the Hub and Spoke model of care (n = 3). Results from the survey will be used to collect information about providers' experience. Regarding human subject concerns, the project focuses on clinician satisfaction with the Hub and Spoke process of FASD evaluations rather than on the actual evaluation of pediatric patients. **[ADAPTED:** To the evaluation of the Hub and Spoke model handbook.]

Confidentiality. Several methods will be used to address confidentiality. Per their policy, satisfaction survey responses will be kept confidential through the protected survey platform Qualtrics. Survey responses will remain on the Qualtrics server for 3 years. Collated data, survey response summaries, and comparisons will be shared with the agency for continued quality improvement and may be used in appropriate QI conferences and/or publications.

A determination of non-human subjects for the IRB will be sought through the Alaska Native Tribal Health Consortium (ANTHC) Health Research Review Committee (HRRC). This committee is a board-based group with appointed members; members oversee health research performed at agencies under ANTHC, including SEARHC Sitka (ANTHC, 2022). This committee ensures that research and/or scholarly projects performed in their facilities offer some benefit to the Alaska Native peoples (ANTHC, 2022).

The following documents will be required for IRB submission and review:

1. Non-HSR (human subject research) Self Determination Form- University of Alaska
2. Supporting documents:
 - A. Letters of support- Ptarmigan Connections & SEARHC Sitka
 - B. Legal agreements- Memorandum of Agreement between UAA & Ptarmigan Connections; SEARHC Sitka & Ptarmigan Connections
 - C. Evidence of CITI training of principal project lead (author) & project chair

Risks and Benefits

This QI survey poses minimal risks to providers during the implementation of the Hub and Spoke practice model. However, risks to clinicians may include discomfort with providing honest feedback on their satisfaction of the project. The survey must only be taken once and is

expected to take 10 minutes to complete. To ensure there are no inadvertent disclosures of protected health information, the author of this project will not provide hub or spoke support services to the provider population where satisfaction is being evaluated. There are three other providers engaged in these services within the spoke clinic. All licensed clinicians provide non-experimental services, as these services are within their scope of practice.

The benefits to participation include the contribution of feedback and input for a new service, as well as affecting potential revisions to an existing practice model to reflect the expansion of practice. By collecting satisfaction surveys, the project creates an opportunity for more permanent use of the Hub and Spoke model in future teams.

Evidence-Based Practice Change Design

The pilot project design uses the PDSA model. With this model, the project will undergo multiple trials to assess functionality for both teams, and this will then be altered after each cycle. This scholarly project seeks to assess the possibility of expansion regarding current provider support services offered in rural Alaska for FASD diagnostic evaluation. Using the PDSA model will allow for changes to be made to the new practice model throughout its implementation. The spoke team will have access to diagnostic support and expert advice for any obstacles they may encounter. As part of their practice and within the scope of their license, the spoke team will be able to access a list of services from the hub team related to the FASD diagnostic process. None of the services or practices are experimental in any way.

The hub model is the pre-existing model of care. The Hub and Spoke will be a new practice model that provides the following services: clinician support on FASD diagnostics using the 4-Digit Code, varying levels of support of the analysis software, support on the compilation

of results for the final report (what to place in the report, wording, etc.), and how to disseminate results (Astley, 2024). The focus of this project is not the specific service or care but rather the provider satisfaction with the Hub and Spoke practice model.

Leadership. The hub team must plan the PDSA cycles, deciding what processes must be completed and when. The pilot project manager will work closely with the spoke team coordinator to offer appropriate services for the spoke team. The pilot project manager will not diagnose an FASD condition, view patient records, or be involved in diagnostic evaluation results. The pilot project manager will maintain an open line of communication to provide support services.

Team Members. Team members include those working on the project. Team members include the therapists from both clinics, each with differing roles. The spoke team therapist (occupational therapist) will monitor patient referrals, act as the team coordinator, and complete a portion of the FASD evaluation. The spoke team neuropsychologist and pediatrician will each perform exams and gather results. The pilot project manager will only provide evaluation support; they will not view patient data. Other team members include clinic managers, who will give peripheral support for the project, mainly from a legal and managerial perspective.

Methodology and Resources. The setting will be virtual. Hub team clinicians will receive FASD diagnostic support via distance communication at regularly scheduled intervals. The population surveyed will be the clinicians from SEARHC. They will be surveyed exclusively on their satisfaction with the hub-and-spoke model of care. They will not be asked about any protected or unprotected health information, and children and families will not be studied.

Data Collection. A satisfaction survey will be administered to SEARHC clinicians to gain an understanding of their experience using the Hub and Spoke FASD evaluation practice model. Survey results will be compiled and published in the project's final findings.

Sustainability. Successful implementation of the project will require strong participation from those involved. Provider satisfaction survey results and interpretation is the first step in sustainability, as survey results may yield specific recommendations for continued use, changes, and/or additions to spoke services.

The pilot project will require only equipment, mainly related to computer access (this includes computers). The key groups in this pilot project are each of the teams. The hub team is essential in creating a foundation for the spoke team. The hub team accomplishes this by moving the process along, getting legal documents in place, and giving *guidance* on how to schedule, compile, and analyze results, and disseminate results to families. The pilot project manager will not access the chart or PHI.

The spoke team provides local access to care in a rural location. If additional spoke services were not provided, a novice spoke team would be less successful in completing an FASD evaluation, thus necessitating additional travel for affected families. The spoke team is essential in their collaboration with the hub team, as they evaluate patients in person, document exam findings, and communicate with the hub team. Both teams will be encouraged to engage with each other by maintaining an open line of communication to discuss what is working and what is not. It is essential to understand the clinician's satisfaction with this new practice model to determine if it is worth modeling in another rural location in Alaska. It is critical to distinguish this provider practice model as one that expands access to current practice. It does not make any

changes to care received but may perhaps enhance the quality of services, as the spoke may provide improved access to the hub.

Challenges of Collaboration. Pilot projects can have many challenges. Anticipated challenges include those related to the physical distance between teams. Digital communication can often be cumbersome. In-person collaboration easily facilitates conversations about problems or issues. However, distance can complicate this. Technical aspects can be challenging for teams. Barriers such as slow internet speed or poor connection (especially in rural areas), access to up-to-date computer software, access to the FASD Facial Analysis Software program, and poor computer access can all impede proper evaluation and dissemination. Scheduling can be another issue, as spoke services may include joint visits with patients and families.

Plan for Project Evaluation. Most QI initiatives apply the Donabedian model of “structural, process, and outcome” to evaluate whether the project was effective in achieving its desired results (Agency for Healthcare Quality [AHRQ], 2015). Process measures will be utilized for this project. According to AHRQ (2015), process measures designate what clinicians do to advance health in a particular area. [ADAPTED: Expert review]

Process measures will be assessed using provider satisfaction surveys. Clinician satisfaction will be measured and reported, along with recommendations for continued use, changes, revisions, and/or discontinuation of specific services. The Hub and spoke method will be carried out using the PDSA model.

Post-Intervention Plans. Distance communication technology presents a major opportunity for rural access to healthcare and continuous maintenance for such communities. With the use of distance communication technology, it is viable to maintain professional

relationships, legal agreements, and the Hub and Spoke model, given the support from the state of Alaska and other stakeholders. A post-intervention plan will include a continued Hub and Spoke practice model for FASD evaluations as described in the pilot project, with appropriate method changes as needed between SEARHC and Ptarmigan Connections. Primary stakeholders at the state level will be included in the dissemination of project results in hopes of gaining continued support. The smooth implementation of this project may encourage the administration of additional spokes across Alaska, with Ptarmigan Connections acting as the primary center or hub. **[ADAPTED:** to the development of the policy handbook preparing for the change. The methods described here are necessary to demonstrate application of implementation processes.]

Conclusion

This proposal highlights the foundation of the Hub and Spoke FASD evaluation provider practice model pilot project. The QI project aims to assess provider satisfaction with adding a Hub and Spoke practice model. All licensed clinicians involved in this practice model provide non-experimental services that are within their scope of practice. If successful, spoke services will lead to high provider satisfaction with the additional support services offered by the Hub and Spoke practice model. Though this model change may result in improved accuracy in practice, thus providing benefits to affected families, families are not part of this project and/or data collection associated with this project. **[ADAPTED:** Project stopped at policy development and expert review. These changes are further described in Chapter 5.]

Chapter 5: Implementation

Introduction. The Doctorate of Nursing Practice (DNP) project requires integration of careful appraisal of evidence while considering the spirit of inquiry (Melnyk & Fineout-Overholt, 2022). Scholarly inquiry is required to meet DNP role standards, and implementation of a scholarly project combines “scholarship, evidence, and research findings into practice” (Melnyk & Fineout-Overholt, p. 104, 2022).

Implementation of a DNP project requires planning and project management at a higher level to expedite the final product (Melnyk & Fineout-Overholt, 2022). The process specifically in need of improvement was the use of a telehealth model of care, with evaluation of provider satisfaction of the new model in FASD diagnoses. Due to the constraints of Institutional Review Board (IRB) expectations and the sensitive population, the committee decided to shift the project focus. The IRB process spanned nearly a year. Correspondances are described further below and are relevant to DNP scope of practice and DNP projects in general.

IRB Submissions. First, UAA’s IRB’s approval was sought. Many challenges arose during this process. Initially, the project aimed to apply a Hub and Spoke model, assessing provider satisfaction with the telehealth model. A package was submitted by this author to the University of Alaska, Anchorage’s IRB on March 30, 2022, under the Not-Human-Subject Determination regulation to determine if IRB review was necessary, with the following verbiage:

Purpose of the project: This Quality Improvement (QI) project aims to evaluate the implementation of an evidence-based practice model in rural Alaska aimed at the evaluation of symptomatic children with potential of having a Fetal Alcohol

Spectrum Disorder (FASD) in rural Alaska. This practice model change will incorporate a telehealth component in FASD evaluations in Sitka. In Alaska, there are few teams certified in the evaluation and diagnosis of pediatric FASD. This QI project aims at the evaluation of the success of this hub team approach. The hub will provide administrative guidance and support to the spoke team (novice) via telehealth services. Success of the project will be evaluated through surveying the spoke team experience of the implementation of a telehealth service component. The established survey, Telehealth Usability Questionnaire (TUQ), will be utilized....The information that will be disclosed will involve only their opinion of the telehealth service, as noted through the Telehealth Usability Questionnaire. The survey will be administered to adults, of whom consist of: a single licensed neuropsychologist, occupational therapist, & pediatrician; one parent of the child of whom the FASD evaluation is being completed on.

(Leah Coffman, author, April 4, 2022)

A letter returned from the UAA IRB, stating that this project:

Reports the provision of health care services, which means there would be protected health information. The questionnaire [Telehealth Usability Questionnaire] to be used in this project was not submitted, but an article which includes it was instead. We cannot evaluate what will be done in the survey. Based on the information provided it is impossible to determine if this is HSR

(UAA IRB, personal communication, April 14, 2022)

A subsequent revision was made to satisfy the IRB's requests. Revisions were made to the IRB package and proposal document to give more information to explain the proposal and what items were to be completed. A second letter returned, stating that this project was to also seek approval through a different IRB, Alaska Area IRB, that covered clinics affiliated under Alaska Native Health Consortium (ANTHC) and SEARHC. Once the Alaska Area IRB (AAIRB) approved, then UAA's IRB would follow suit:

Any organization which is part of the Indian Health Services / ANTHC (such as SEARHC) requires review by AAIRB if IHS personnel are involved. While this may not be research, it would need to be reviewed and determined as such either through the non research determination board at ANTHC or through SEARHC if they have a comparable board. UAA IRB will accept their determination.

(UAA, personal communication, April 22, 2022)

AAIRB. The IRB package was moved over to the AAIRB, as UAA IRB was requiring both AAIRB and their own IRB approval of this project. The project was submitted as a Research Determination request with a 49-page protocol attached on September 1, 2022. A response was received October 10, 2022, asking for clarification and more items. The author called the AAIRB office, to ensure she understood how they wanted to proceed with the modifications. The AAIRB office staff (former president) were unclear on QI projects, asking questions about rigor and small number of participants. After this conversation with the office staff, author continued to proceed through the process to get the application approved, and felt an increase in the level of review may satisfy their concern for the project. Thus, the project level of IRB approval was increased to a Limited review, and was submitted at that juncture vs. a

Not-Human-Subjects application. The purpose of the QI project was reiterated from this author in the Limited Review Application:

This Quality Improvement (QI) project aims to assess provider satisfaction with the addition of a Hub and Spoke practice model, which provides clinician administrative support to the spoke team. The pilot project will be centered around the Hub and Spoke practice model, with the hub being Ptarmigan Connections, which houses a team coordinator and an experienced FASD team. The spoke will be the team at Southeast Alaska Regional Health Consortium (SEARHC) Sitka. Existing provider services in the hub model do not allow for clinician support. The addition of the spoke will provide education and support for participating clinicians. All activities are within the scope of practice of each licensed clinician and not considered experimental in nature. The QI project lead will not interact with the patients or families involved in the diagnostic evaluation, as the project focus is on clinician satisfaction with the Hub and Spoke practice model. To ensure no inadvertent disclosures of protected health information, the QI project lead will not provide hub or spoke support services to the provider population where satisfaction is being evaluated.

(Leah Coffman, author, December 2, 2022)

This attempt, plus three more were made between the dates of 11/8/2022-01/03/2023, to appease the desire for increased rigor and safety by the AAIRB. The author called the acting director of the AAIRB twice, to discuss what else may be needed to satisfy their concerns. The author felt some incongruence between what the AAIRB was wanting (rigorous research methods) and understanding of QI DNP projects and practice change models. It explained that

QI projects aimed to evaluate willing adult participants on their satisfaction of the new telehealth model. It explained that the State of Alaska FASD office desired to move towards this model (WICHE-BHP, 2021). After eleven months of attempting to gain IRB approval, the following response was sent from the author to the AAIRB:

I would like to thank everyone for the time and effort given in review of my project proposal. Your feedback has been very much appreciated and gave me insight into what is important to consider in a DNP project. Everyone I encountered at AAIRB has been professional and responsive in this learning journey. It is with great consideration that I have decided to change my project and withdrawal my application to the Alaska Area IRB for Limited Review...My project is a clinical doctorate project, thus does not contain the rigor needed for a research project...I am changing my project to a policy handbook for Ptarmigan Connections that will be reviewed by expert content reviewers, on a Hub and Spoke method. SEARHC will not be involved in this project anymore...I have appreciated your feedback and have learned much from this experience. Thank you again.

(Leah Coffman, author, January 18, 2023)

Discussion. The initial project model emphasized the Hub and Spoke process rather than the distinct evaluation of children (a sensitive population, as viewed through the IRB lens). This was met with great concern by the AAIRB. The pursuit of approval was an 11-month process in total, and changes were made to the QI project to meet IRB standards along the way. In the end, the AAIRB seemed to desire a research project in lieu of a QI project. This resulted in the

author's application being withdrawn, as the DNP project's aim was to create practice change and not research data (Melnik & Fineout-Overholt, 2022).

Subsequently, the decision was made to pivot the project toward the development of a policy handbook. Such handbook would describe the steps of a Hub and Spoke model, an approach that could be exercised by the Ptarmigan Connections medical clinic and/or used as an example for other similar types of telehealth evaluation groups (an autism spectrum disorder diagnostic team, others). With these revisions, a Human Subjects Research Self-Determination package was submitted to UAA IRB and received acknowledgement within weeks. The acknowledgement letter from UAA IRB noted that the package had been reviewed and determined the QI project did not meet the definition of Human Subjects Research.

Change in Project. A policy handbook was created based on evidence of similar and successful telehealth models utilized in Manitoba, Canada (Ens et al., 2010; Hanlon-Dearman et al., 2014). The policy handbook focused on a Hub and Spoke model, including processes specific to Ptarmigan Connections and any spoke team in the state of Alaska. The policy handbook informed FASD team members of each step of the process. The handbook contained a user-friendly algorithm, thus mitigating the complexity of the process. Though the policy handbook was tailored to processes specific to Ptarmigan Connections, the same method can be refined for use in other disease evaluations (i.e., autism spectrum disorder).

Subject Matter Experts. The next step was to identify subject matter experts. Experts could have included neuropsychologists, medical doctors/nurse practitioners/physician's assistants, speech/occupational therapists, FASD team coordinators, and epidemiologists. Such experts needed to be directly involved in the process of regular FASD evaluations. Experts should have experience working with the 4-Digit Code, as they must understand the nuances of

evaluating children with said method. Additionally, experts should have been trained in the utilization of the 4-Digit Code (which is a separate certification in terms of professional licenses).

In continuing expert identification, experts should have worked extensively with the 4-Digit Code. Experts should have used the 4-Digit Code to evaluate children in a brick-and-mortar clinic. This would allow them a sense of familiarity with the workflow, as well as an understanding of the specific, required evaluations. In addition, experts should have performed a high volume of the 4-Digit Code evaluations; having experience working through the process numerous times is critical. There are several nuances to the 4-Digit Code, and increased use of the 4-Digit Code increases the validity of findings (Hemingway et al., 2023). From the author's personal experience, multiple applications with real patients were needed to grasp comprehension. A year into using the 4-Digit Code, the author found evaluations to be much easier; the author could note subtle nuances within patients that could affect the final code result. For example, the 4-Digit Code requires use of a computer software program for facial analysis. Various factors affect where a patient may fall within the 4-Digit Code, dependent on each patient's history of alcohol exposure, neuropsychological/speech testing, and physical exam.

Once expert reviewers were considered, a final decision was made based on who would fill these roles best. Two expert reviewers were invited, Dr. Erika Stannard and Dr. Susan Astley Hemingway. Dr. Stannard was valued as being local to Alaska and had substantial experience running the 4-Digit Code team and performing neuropsychological evaluations. She was an Associate Professor in the Clinical Psychology department at Alaska Pacific University. For five years, she served as the director and clinical psychologist on the Ptarmigan Connections FASD

team in Wasilla, Alaska. Dr. Stannard has a doctorate in clinical psychology and worked with a telehealth FASD team in Sitka, Alaska. Dr. Stannard worked with the busiest 4-Digit Code team in Alaska (FASD), helping perform hundreds of FASD evaluations yearly. She had prior experience with quality improvement projects as well.

Dr. Hemingway's extensive experience dates back to 1981, having "conducted laboratory, clinical, and public health research in the field of FASD" (Hemingway, n.d.). She created the 4-Digit Code method through exhaustive research and implementation. Included in her experience was the development of the FAS Facial Photographic Analysis Software, and creation of the Washington State FAS Diagnostic and Prevention Network (FAS DPN) of clinics across the state. Dr. Hemingway would travel to Alaska to perform FASD evaluations (Personal communication, Susan Hemingway, March 12, 2022; Hemingway, n.d.). She was well-versed in the challenges of diagnosing FASD in Alaska, knowledgeable about the demographic, societal, and population barriers. She served as a Professor of Epidemiology, Professor of Pediatrics-School of Medicine, and Director of the FAS DPN clinic in Seattle, Washington (Hemingway, n.d.). The author considered Dr. Hemingway to be the number one clinical expert on the 4-Digit Code, given her expertise.

Policy Handbook. The policy handbook was finalized and given to Dr. Stannard and Dr. Hemingway for review over the course of one month. Given the small number of experts on the subject matter and limited scope, it was concluded that the use of a standardized tool would be challenging and futile. Instead, narrative written feedback was provided from each expert reviewer to this author. This was followed up with an interview.

Expert Review Data

The external review data was gleaned from two questions asked of the expert reviewers:

Question 1:

We are trying to establish a systematic way to perform a Hub and Spoke model using the 4-Digit Code. How does the policy handbook accomplish this? How does it not?

Question 2:

What content improvements could be made to the policy handbook? What improvements can be made to the process the policy handbook describes?

The author met with each expert either via videoconferencing or in person, and the reviewers were given a first read. In adherence to a true PDSA cycle, the policy handbook was revised after the first read and again once more. The results are as follows in the next chapter.

Conclusion

In conclusion, this implementation process included a plan to evaluate provider satisfaction after implementation of the Hub and Spoke model of care. The project was adapted to instead evaluate the plan to implement the Hub and Spoke model using expert review of the policy handbook. The results of their review are described in the following chapter.

Chapter 6 Outcomes

Introduction

The Model for Improvement (MFI) provides a systematic approach to maintaining momentum in evidence-based practice change (Melynk & Fineout-Overholt, 2023). By utilizing rapid cycle tests of change, small changes can be made to processes (Melynk & Fineout-Overholt, 2023). The MFI was adapted to create the policy handbook and obtain expert content review.

Quality improvement allows a system to modify practice by allowing changes along the way. The policy handbook was introduced to expand FASD evaluation services statewide. Using the QI method, Model for Improvement, the policy handbook was reviewed by content experts and modified to make meaningful changes. The author wanted to find ways to improve the policy, which be utilized for clinical use and potentially used on a grander scale at the State level. Using a Hub and Spoke model, it was vital to have a finished product that could be clinic-ready for FASD evaluation.

Policy Handbook Questions. The content experts were given the policy handbook and asked to review it over a four-week period. It allowed them to thoroughly review the book's content and collect ideas for improvement, in following the MFI structure (AHRQ, 2013).

The Model for Improvement asks these questions in providing evidence for change (AHRQ, 2013):

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What change can we make that will result in improvement?

The external reviewers were asked the following specific questions about the policy handbook, using the above questions as a guide:

Question 1: We are trying to establish a systematic way to perform a Hub and Spoke model using the 4-Digit Code. How does the policy handbook accomplish an aim toward this goal? How does it not?

Question 2: What content improvements could be made to the policy handbook? What improvements can be made to the process the policy handbook describes?

Outcomes

Round 1. Round one revision was conducted within four weeks of external reviewers receiving a digital copy of the policy handbook. Two external reviewers were sent a copy of the policy handbook on February 15, 2024, requesting to return their recommendations within two weeks. The first of two external reviewers who agreed was the psychologist who created and managed the initial FASD team at Ptarmigan Connections. The second was an epidemiologist from the University of Washington who created the 4-Digit Code method.

The questions explored subjective responses to the proposed questions. Two subject matters emerged from two external reviewers- content improvement for clarity of process and updates to the policy based on the new 4-Digit Code revisions of 2024 (Hemingway, 2024). The policy handbook could have been more effective in relaying the new evaluation process with the Hub and Spoke model; instead, too much of the standard process was described. The psychologist understood both brick-and-mortar and hub-and-spoke processes; however, she recommended the Hub and Spoke method needed to be more apparent in the policy for an outsider to understand. Thus, an "outsider" could be a spoke clinic provider, manager, or

stakeholder like the State of Alaska FASD office. A clearer picture needed to be painted for anyone from any entity to understand.

The flowcharts were confusing and needed more focus on the Hub and Spoke process, making it difficult for the external reviewers to envision the new process. The flow chart described too much of the brick-and-mortar process—a typical FASD evaluation using the 4-Digit Code. Visuals describing the hub-and-spoke process were essential in providing a clear, succinct policy; thus, revision was needed.

It was recommended that the terms "neuropsychologist" and "neuropsychology" be deleted. The psychologist recommended changing the term from neuro- to just psychologist/ogy. It was noted that neuropsychology refers to a psychological evaluation with an added piece for brain damage secondary to a head injury- rather than a brain injury from a teratogen such as alcohol. The two terms were different; in some cases, a neuropsychology evaluation was necessary, but only sometimes. It was felt that a neuropsychology evaluation would exclude some spoke providers. A neuropsychology referral takes longer to get an appointment (one year vs. three months) than a typical psychological evaluation in Alaska (personal communication, Erika Stannard, April 2, 2024). Thus, a psychological evaluation would suffice for the majority of patients (personal communication, Erika Stannard, April 2, 2024).

The policy handbook needed to be revised to reflect new updates on the 4-Digit Code method (Spring 2024), and it was released at the same time this policy handbook was being created (Hemingway, 2024; personal communication, Susan (Astley) Hemingway, February 27, 2024). The reviewer noted that the changes had not been published just yet but would be released within several months (of Round 1).

The flowcharts needed visual improvement:

- 1) The text was too small to read.
- 2) The color contrasts in the flowcharts were too similar.
- 3) Formatting wasn't consistent.

Revisions were made to accommodate recommendations of external reviewers one and two. Revisions discussed in the following sections.

Round 2. External reviewers were given the revised version of the policy handbook on April 30, 2024. At this stage, a third reviewer was found to replace the original one. This person was considered a content expert in FASD services with the Alaska Center for Fetal Alcohol Spectrum Disorders (n.d.). Reviewer three was contacted on May 6, 2024, requesting to return recommendations within two weeks. The revised version had been improved and felt to be more accurate; thus, the revised version was given to reviewer three. This reviewer had many items suggested for revision. Some revision themes emerged, and they are given in a table format for clarity, given the number of subjective responses.

Table 2

Common Themes from Subjective Responses, External Reviewer 3

| Theme: Updates | Theme: Reimbursement/Business/Financial | Theme: Providers |
|---|--|---|
| <ul style="list-style-type: none"> ● New data was released, and usable codes from the authors of the 4-Digit Code method were updated. ● Update 4-Digit Code diagnosis table. | <ul style="list-style-type: none"> ● Clarify who reimburses the hub team for services. ● Clarify who reimburses for travel to the spoke provider. ● Add release of information (ROI) clarification as to who is responsible for who is signing it. For example, if the guardian is from the State of Alaska, they must sign. Clarify whether or not consent | <ul style="list-style-type: none"> ● Clarify provider form disbursement to providers (digital or paper brought in by patients) ● How to ensure the provider form is completed |

| | | |
|--|---|--|
| | <p>by the biological parents is required.</p> <ul style="list-style-type: none"> ● Distinguish between team and clinic/agency. More than one FASD team could be in a community, but an agency must be the home for the final results. ● Clarify the reimbursement process in the flowchart. | <ul style="list-style-type: none"> ● Add hub provider contact information for questions. ● Use of occupational therapy vs. speech therapy for the evaluation. ● Explain how psychology/speech therapy spoke providers communicate their findings to each other. ● Clarify which providers can be utilized as spoke providers. Can a family find their local provider to complete the form? Do they have to be certified in the 4-Digit Code? |
|--|---|--|

External Reviewer Two

The epidemiologist gave feedback about the 4-Digit Code and how it was inaccurately described in the policy handbook. The advice was invaluable, coming from the person who originated the 4-Digit Code. The policy handbook needed revision to reflect the 4-Digit Code and diagnoses surrounding an FASD accurately. Verbiage was to be changed from "clues" to "criteria" to categorize an FASD correctly.

The epidemiologist also recommended updating all references to the 2024 version of the 4-Digit Code. The policy handbook had the previous version, from 2004. This was key to maintaining up-to-date, critically evaluated evidence. The 4-Digit Code has a long-standing history of high validity in evaluating children for FASD (Astley, 2013). It was vital to have a policy handbook reflecting the most current practices in using the 4-Digit Code to provide accuracy and the most up-to-date knowledge of FASDs.

The reviewer focused on a few terminology updates between 2004 and 2024. This included new and/or revised categories, Fetal Alcohol Syndrome (FAS) and Neurodevelopmental Disorder/ Alcohol Exposed (ND/AE). The following specific changes were recommended::

- 1) Diagnostic categories were changed to reflect current categories (Hemingway, 2024, p. viii). Categories A, B, and C in the grid were combined to a single Category A- Fetal Alcohol Syndrome (FAS). Previously, Categories A, B, and C reflected the diagnoses of Fetal Alcohol Syndrome / Alcohol Exposed (FAS/AE), Fetal Alcohol Syndrome / Expsoure Unknown (FAS/EU), and Partial Fetal Alcohol Syndrome (PFAS), based on their rank scores and 4-Digit Code result (i.e. 4333). The grid in the policy handbook needed to reflect this change in terminology. The change reflected a larger problem- that FAS/EU and PFAS were

interpreted as less severe, when in fact, the brain damage was as severe as FAS but lacking growth delay and/or facial features. Thus, lowering the potential for support services and intervention (Hemingway, 2024, p. viii).

- 2) The diagnostic term Neurobehavioral Disorder / Alcohol Exposed (ND/AE) was revised to Neurodevelopmental Disorder / Alcohol Exposed (ND/AE). Per the updated FASD 4-Digit Code Guide and noted authors, neurodevelopmental disorders encompasses the “onset in the developmental period, inducing deficits that produce impairments of functioning” (Hemingway, 2024, p. viii; Morris-Rosendahl & Crocq, 2020). The new terminology reflected fetal embryonic development and the brain damage that occurs in utero (Gibbard et al., 2003).

External Reviewer One

The psychologist gave feedback specific to the process of FASD evaluations at the clinical level. She had created and managed the FASD team at Ptarmigan Connections for many years, so her understanding of the clinic processes was rich. She established the FASD team at Ptarmigan Connections, and her attention to detail of normal clinic processes vs. the Hub and Spoke method was on point.

Obtaining expert opinions from those with varying experience in the FASD evaluation process proved invaluable. Each expert's approach demonstrated their levels of expertise and the unique lens through which they could see. This unique lens allowed for detailed feedback that only that particular expert could give.

Discussion

An effort must be made to increase primary care screening, evaluation, and diagnosis of FASDs through an interdisciplinary, team-based approach that is evidence-based and reproducible (Hemingway et al., 2023). The revised policy handbook could be used as a model for the State of Alaska FASD telehealth program.

The external reviewers were easy to recruit for the project. They had a varied background and were invested in the project. The psychologist had worked extensively with the FASD team at Ptarmigan Connections, thus having good knowledge of in-house procedures, billing, and the provider agreement. She had also practiced psychology in FASDs, diagnosing children using the team-based approach, and her responses in the review were essential.

The epidemiologist had more than 43 years of experience in researching FASD and created the 4-Digit Code over 20 years ago (Astley, n.d.). Her review helped hit points related to the accuracy of the 4-Digit Code method in conjunction with a telehealth model.

The last reviewer proved more challenging to recruit. Initially, a physician who worked on an FASD team in the past was recruited in person, then by email. This provider was too busy to contribute to the project; thus, a third reviewer was sought and found, albeit later in the project, after Round 1 revisions. This person had served as the coordinator on an FASD team in another part of Alaska and on the board for the essential WICHE project, a telehealth study for the State of Alaska FASD office (WICHE-BHP, 2021). She reviewed the policy handbook and provided the bulk of recommendations for revision after Round 2.

The initial review for Round 1 to the final review was four months. This time allowed a thorough review of both rounds of recommendations, and revisions were completed for the third reviewer. Collecting information from experts in the field gave strength to the policy handbook

to provide a policy that was up-to-date, pertinent, and applicable in practice. The first round produced revisions to the 4-Digit Code, figures/tables, and the telehealth process. The second round provided the most revisions and critiques of both the telehealth process and the quality of the policy handbook.

The second round produced more feedback than the first. This was interesting, as the second round was a first read for that expert, thus seeing it through fresh eyes. This reviewer had served on an FASD team in Fairbanks. She also worked with the State of Alaska on the telehealth feasibility study in 2021 (WICHE-BHP, 2021). The third reviewer's viewpoint came from knowledge of the state's goals in moving forward with a telehealth FASD model; thus, this reviewer viewed the policy in light of what may come from the project- a telehealth model.

After reviewing the policy handbook, the third reviewer approached the author of this project about the potential use of the model for the State of Alaska FASD program. This external reviewer noted the formulation of a particular work group on this subject shortly, and hearing about this project was perfect timing. This particular work group would focus on an FASD telehealth model, the proposed next step after the Alaska telehealth feasibility study (WICHE-BHP, 2021). The timing was coincidental. Given the policy handbook and evidence to support a telehealth FASD evaluation model, much of the work had already been laid out for the work group.

Strengths and Limitations. This project had strengths and limitations. The external reviewers had varied backgrounds and experiences. This was a strength, as they each could view the project and policy handbook from their lens of expertise and practice. However, the individual reviews and feedback were each quite different, which was a surprise.

One expert focused on the micro-level workings of the process within the hub team. This individual had worked closely with the owners of the hub clinic as a manager, psychologist, and FASD team lead. This expert could view the telehealth process from start to finish, with billing, the provider legal agreement, medical/psychological items, and the 4-Digit Code- all in mind while critiquing the policy handbook. This feedback was essential. One focused on the meso-level workings of the 4-Digit Code within a telehealth model. This expert created the 4-Digit Code; thus, her perspective was to critique a telehealth model that accurately reflected the 4-Digit Code.

The last reviewer had a meso-level viewpoint, looking at the policy and how it could be applied to the State of Alaska FASD program on a grander scale. This reviewer looked at processes and had questions that the other reviewers did not. Her focus was on a hub (any team in the state) with local spoke providers, and how the hub could use the project's telehealth model.

Change in Project AIM and Design. There were limitations to the project. The original project involved collecting provider satisfaction levels of the active telehealth model. The bigger goal was to perform the telehealth model, with hopes that, if results were satisfactory, it would go on to be used on a grander scale at the State level in the FASD program. Decreasing barriers to FASD care was the goal.

There were barriers to the project. A validated tool could not be found. A search of the literature proved to find no tools created to critique a policy handbook for use in a medical clinic or for a telehealth program. The search was more comprehensive than working with fetal alcohol syndrome or fetal alcohol spectrum disorders, as those terms-limited the scope. The search was expanded for a validated tool assessing the quality of a workplace policy book, manual, and others to include educational materials. No tools were found; therefore, subjective responses

were collected instead. Subjective responses gave way to varied feedback- limited by a lack of QI metrics, such as outcome, process, and balancing measures (McQuillan et al., 2016).

Including metrics of these types would have given the findings more strength and generalizability (McQuillan et al., 2016).

Implications and Future Research. Future implications of this project include continuing to work with telehealth and FASD evaluations. Details of the telehealth process need to be built upon following this FASD project to continue the momentum of telehealth options. More research is needed to determine best practices in telehealth for use in FASD evaluations, barriers to care, and underdiagnosis of FASD. More validated tools need to be established to cover topics such as this.

Conclusion

External reviewers evaluated the policy handbook, and the author made revisions. Utilizing content experts increased the quality of the policy for future use in a telehealth model. Any application of the policy handbook or use of the Hub and Spoke model should include an FASD evaluation using the Hub and Spoke model followed by provider and family satisfaction surveys. The QI method described in Chapter 4 could be employed, using a PDSA model, improving the Hub and Spoke model as subsequent FASD evaluations continue. A Hub and Spoke model could improve barriers to care in many rural communities with limited resources.

Chapter 7: DNP Essentials

Introduction

This project integrated the eight DNP Essentials from The Essentials of Doctoral Education for Advanced Nursing Practice (American Association of Colleges of Nursing [AACN], 2006). Updated Essentials were released halfway through the project, and it was felt the project had been built on the "old" Essentials; thus, they were utilized. They were threaded throughout the framework, literature review, and project implementation.

DNP Essentials

DNP Essential I. Essential I focuses on the scientific underpinnings of nursing found in moral principles, the natural body, psychological principles, diagnostic findings, and organizational principles (AACN, 2006). These underpinnings provide the foundation for the nurse scientist. This author performed a critical review of the literature to determine an evidenced-based telehealth model of care suitable for use in FASD evaluations in Alaska. A similar model to the Hub and Spoke was found and guided the policy handbook creation. The survey of the data was analyzed through grouping of recommendations by external reviewers, from varying professional backgrounds, none of which were nursing.

DNP Essential II. Essential II focuses on systems, sustainable organizational change, and quality improvement, all through the lens of one's leadership position as doctorally prepared nurse (AACN, 2006). This Essential provides a framework for leadership and interprofessional collaboration with other professionals within the healthcare system, using advanced nursing skills (AACN, 2006). Leadership skills provided construction of a DNP project. The process was managed intercollaboratively with professionals from other specialties, to gain understanding of their roles within the processes of an FASD evaluation.

The Model for Improvement provided a framework from which to make change (AHRQ, 2013). This project took some of those concepts of design and leadership and created first, a model of care, then a policy handbook describing this model.

This DNP project focussed on the characteristics of a DNP graduate who can utilize process change, quality improvement science, leadership, and knowledge transfer based on scientific methods to improve processes in the context of telehealth and FASD evaluations (Rivaz et al., 2021).

DNP Essential III. Essential III focuses on utilization of clinical scholarship and analytical methods (AACN, 2006). Advanced nurses: a) recognize deficits in evidence based practice and strive to connect the chasm that exists between old and new knowledge through clinical scholarship, b) utilize knowledge from multiple disciplines through integration, and c) take the knowledge that is gained in clinical scholarship and solve practice problems through quality improvement. This complex understanding of knowledge gap recognition to problem solving is a skill of the DNP nurse.

This author's project did exactly this. The main problem was identified: few FASD teams exist in Alaska, causing costly travel, prolonged waitlists, and delayed diagnostic services. This project applied the QI framework, the Model for Improvement (2013), to identify a plan to improve. The MFI was put to test with cycles of improvement, both related to IRB barriers and improvement of the policy handbook. The outcome was a new model of care to solve the problem (barriers to care).

DNP Essential IV. Essential IV focuses on Information Systems and Technology for the Improvement and Transformation of Health Care (AACN, 2006). The DNP nurse must manage knowledge of information technology (IT) data and systems within the healthcare sector. The

DNP nurse must utilize IT tools to contribute to the body of knowledge and improve patient care.

This author utilized IT tools for use in the project, by creating a policy handbook for a telehealth model. This project used a potential model for telehealth as a tool within the realm of IT systems as a means to overcome a problem (barriers to care) (AACN, 2006). Knowledge of IT systems is essential for the DNP nurse to understand (AACN, 2006). Specific to this project, the author had to have or gain knowledge of decision supports, legal standards in healthcare, and validity of telehealth specific to FASD. Essential IV was met.

DNP Essential V. Essential V focuses on Healthcare Policy for Advocacy in Healthcare (AACN, 2006). The DNP nurse gains skills and knowledge to participate in decision making on varying levels of policy. Whether they are contributing to government, foundational, or standard level policies, the DNP nurse is equipped with skills to promote public and nursing profession activism.

The policy handbook created in this project contributed to a greater body of knowledge of telehealth for use in FASD evaluations. This project provided a model of care that is in support of the stated healthcare goals of the Alaska Mental Health Trust Authority and is anticipated to be the foundation of a new standard of care model in FASDs. The right to good health is a social justice standard and this project contributed to a greater body of knowledge of telehealth for use in FASD evaluations. This FASD telehealth model provides a framework to address issues in equity and social justice for the population affected by an FASD. In order for a state-funded FASD team to diagnose and treat, the state stakeholders must approve of a new health policy that allows for funding of a telehealth FASD model. This project provides a framework in this direction.

DNP Essential VI. Essential VI focuses on Interprofessional Collaboration for Improving Patient and Population Health Outcomes (AACN, 2006). Interprofessional collaboration in Essential VI was the basis of this project.

The development of the project and policy handbook was based heavily on interprofessional collaboration and wouldn't have been possible without use of Essential VI underpinnings. The 4-Digit Code method requires a team-based approach to the diagnosis of FASD; thus was the focus of the project and policy handbook (Astley, 2024).

There were barriers in working with each specialty of provider on the FASD hub team. Initially, this author was unclear what duties were performed by each specialty. To overcome these barriers of comprehension, the author interviewed each sub-specialty provider within the hub team (FASD) to gain understanding of their roles in the 4-Digit Code method. Generally, speech pathologists and psychologists have a battery of exams they can perform for varying complaints; thus, specific tests are performed on the patient when evaluating for FASD. Crossover exists between psychology-speech testing, as some speech results can be informative to the psychologist of a neurological deficit. This is different than the medical provider role, that operates primarily alone until the team results meeting, where interprofessional collaboration is essential in the final diagnosis.

The Team Coordinator (TC) was also interviewed many occasions to determine their complex role in the FASD hub team. One interview revealed that the TC is essential in collecting records and legal documents, researching mom's history including drug/alcohol incarceration/charges, birth and/or prenatal records. The TC schedules appointments for the patient with a complex schedule of events that must take place in certain order from start to finish, and these appointments can last hours. The TC must understand pediatric development

and a child's ability to maintain attention and avoid mental fatigue- keys to accurate speech/neurological testing. The TC is cognizant of testing requirements and understands fatiguability of the patient (and family) when scheduling a battery of tests. Lastly, the TC manages schedules of providers who also work in other capacities of the clinic and are not fully dedicated to the FASD team. Determining the TC role made it apparent to this author of anecdotal reasons many teams folded in the past in Alaska. Without a strong TC, the team would have no momentum to guide this process. These important nuances of the diagnostic process needed to be highlighted in the policy handbook and reflect interprofessional collaboration.

There were other barriers working with other professionals. The expert reviewers each had a foci in which to approach feedback on the policy handbook. The epidemiologist had a clear focus on the 4-Digit Code, while the psychologist was focused on Hub and Spoke method and how it could potentially work in the clinic setting. The third reviewer approached the policy handbook practically, looking at legal requirements from the Provider Agreement. This same reviewer also envisioned use of the policy handbook at the State level, from any hub service. Understanding the feedback and making appropriate changes was difficult at the first revision of the policy handbook, until the statements were categorized by theme. Clarity was found when the second revision was completed on the policy handbook. It was clear from what vantage point each expert reviewer was approaching improvement of the policy handbook and revisions could be made accordingly.

The policy handbook was designed with a foundation of diagnosis through a team-based approach, with expertise in multiple specialties. The role of the DNP nurse is to lead interdisciplinary teams, and this method was incorporated into the Hub and Spoke method.

DNP Essential VII. Essential VII Clinical Prevention and Population Health for Improving the Nation's Health (AACN, 2006). Clinical prevention and improvement in the health of children with FASDs translates to early identification of the disease and targeted intervention services (CDC, 2024).

Clinical prevention and improvement of the disease first had to be addressed with the scope of the problem and impact of FASD, through a critical review of the literature. The review revealed that FASDs are underdiagnosed, both state- and nationwide, and that underdiagnosing was contributed lack of professionals to diagnose the disease. Specific to Alaska, it was found that few FASD teams existed and those few were located far away from patients needing evaluations. This author recognized that it would be difficult to improve population health if the full scope of FASD prevalence was not known.

The impact of FASD needed to be explored to gain understanding of the problem for the project. Critical review revealed financial impacts of FASD, both on the personal level for the patient and on the State level for lifelong care of individuals with the disease. After the data was examined in critical review, it was clear that either prevention or early identification of the disease could have a positive impact to both individual and population health.

Reducing barriers to care could promote population health, thus this project created a basis for a telehealth model to expand care for persons with FASDs. The policy handbook aimed to establish this model, to improve health and meet Essential VII.

DNP Essential VIII. Essential VIII focuses on Advanced Nursing Practice (AACN, 2006). This role is multifaceted and complex. The role of the DNP nurse is to assess health from a patient all the way up to a health system level (AACN, 2006). Design and implementation of interventions must be supported by evidence, both in and outside of nursing practice (AACN,

2006). The design piece was necessary, as the nurse leader had to know the current practice with the team-based approach and then change it based on evidence in the literature. This author served as a DNP nurse in leading a formulation of an interdisciplinary care model that could affect healthcare policy and improve the health of individuals affected by an FASD through access to care. Finally, understanding concepts in relations, health systems organization, financial supports, and legal agreements between the State of Alaska FASD program, Ptarmigan Connections, and a potential spoke clinic was crucial.

Conclusion

Incorporation of all eight of the DNP Essentials is required to attain outcome competencies measured by the American Association of Colleges of Nursing (AACN, 2006). In conclusion, the use of the DNP Essentials aided in operationalizing concepts into applied outcomes.

Chapter 8: Summary

Introduction

There are known barriers to diagnosing FASD, including a lack of available teams certified to diagnose accurately (Goh et al., 2008). There are few FASD teams in Alaska (Department of Health and Human Services Alaska [DHSS], 2021). Studies have validated the use of telehealth to expand FASD evaluation services successfully (Benoit et al., 2002; Ens et al., 2010; Hanlon-Dearman et al., 2014; Whittingham & Coons-Harding, 2021). No telehealth models are in use in Alaska; however, increasing movement toward this goal has been evident (WICHE-BHP, 2021).

Challenges

This project was met with many challenges. The literature review was performed, and it was found that other clinics had utilized a telehealth model for remote access to care for FASD evaluations. It was decided that this was a viable project and worth moving forward with. A plan was made to use a Hub and Spoke method of FASD evaluation, using Ptarmigan Connections as the Hub and a Spoke clinic in remote Alaska. Both clinic teams/management supported the use of the Hub and Spoke method.

A local IRB (IRB) affiliated with the spoke clinic was contacted. This particular IRB was a gatekeeper and one of the stakeholders for the project. The IRB package was submitted, revised, and resubmitted several times. The project evaluation focused on provider satisfaction on both Hub and Spoke teams before and after using the new practice model. After eleven months of revised applications to the local IRB, it was clear that the IRB desired a research project with adequate rigor. This misaligned with the author's intention of an evidence based QI

project. Instead, a policy handbook was developed for clinics wanting to adopt a Hub and Spoke model.

Ongoing Literature Review. Searching for evidence, then appraising the evidence is a part of scholarly work in the DNP process (Melnik & Fineout-Overholt, 2019). Continual review of the literature guides the spirit of inquiry for the DNP nurse. As the project continued, new evidence was found supporting the project as it evolved.

A new search was performed in PubMed, CINAHL, and Cochrane databases to include the terms IRB, barriers, minority, Alaska Native, American Indian, and community-engaged research. Abstracts were critically reviewed and two intriguing studies were found that related to a similar experience this author had in obtaining IRB approval. The first of these studies by MacLaughlin et al. (2013) desired to catalog IRB barriers and potential solutions in a large-practice-based research network (PBRN) to inform what influences exist for principal investigators' (PI) when it comes to IRB decisions and barriers to determine their receptiveness for future studies. Their pool of participants included 28 principle investigators (PI) (clinical pharmacists) located in 31 family medicine clinics (MacLaughlin et al., 2013). The authors utilized descriptive analysis and Spearman's correlation coefficient to describe PI and IRB characteristics and the PI's willingness to participate in future trials.

Willingness to participate in future research studies was inversely related to the perceived difficulty of obtaining initial IRB approval. Unforeseen challenges included a delay of eleven months in the approval of the initial study. Minority or pregnant patients were not allowed to participate due to perceived risk. Team support was significantly correlated with likelihood to participate in future studies. The study was completed in teaching facilities linked with

institutions, therefore, IRB barriers were anticipated to be even greater in community clinic work (MacLaughlin et al., 2013).

Onokamaiya et al. (2023) performed a scoping review to evaluate IRB barriers. The authors describe and identify barriers and ways to overcome these barriers for community engaged research (CNeR) partners and PIs working with IRBs. Peer-reviewed U.S. articles that reported on CEnR, specified study-related challenges, and lessons learned for working with IRBs were included for review. The authors found that IRBs were difficult to work with in community research projects due to lack of knowledge about CNeR partnerships, and stifling relationships. The duration of the IRB approval process was found to be long and arduous and too systematic for CNeRs when a shortened more supportive approach was needed (Onakomaiya et al., 2023).

Discussion. These two studies highlight negative experiences of working with IRBs. Similar issues were met between the two studies and also related to the issues this author met in seeking her IRB approval through the Alaska Area IRB. This author attempted to modify this project over a eleven month period, to satisfy the requests of the AAIRB. It was felt in the end, that overall, there was a misconception of what a DNP project should entail (not research), and a perceived danger to the population (providers employed at SEARHC Sitka). These barriers ultimately prevented implementation which may have impacted the FASD population in Alaska in a more direct way by improving access to care. The disconnect appears to be a misunderstanding of the scope of Advanced Nursing Practice where the practice change was inappropriately labeled experimental where it is merely implementation of an already existing practice model to a new location with a specific population. None of the aspects of the model were experimental.

Updated Literature Review

At completion of the project, a second literature review was performed in PubMed, CINAHL, and Cochrane databases to include the terms telehealth, fetal alcohol syndrome, fetal alcohol spectrum disorder, and 4-Digit Code. Autism spectrum disorder was added as another avenue to explore telehealth models. Two new studies were found that hadn't been present during the initial review, both published in 2023.

Hemingway et al. (2023) performed a study with multiple aims. It was a study this author had been told directly from Ms. Hemingway was in the works (Personal communication, Susan Astley Hemingway, March 12, 2022). The purpose of the study was to describe two statewide FASD networks, notate graphically the number/types of FASD diagnoses over 2-3 decades, and demonstrate how FASD data affects public health policy and monitor prevention attempts to influence care. Both states who have similar features (geographic challenges) and populations (Alaska Native/American Indian populations). This information was instrumental in demonstrating value in both operability and benefit of Statewide interdisciplinary FASD diagnostic clinical networks who were diagnostically using the 4-Digit Code. Key findings such as adequate legislative support, consolidated data collection, and use of the streamlined 4-Digit Code were alike strengths in Alaska and Washington (Hemingway et al., 2023).

King et al. (2023) piloted a study to explore ways to improve access to pediatric FASD diagnosis and assessment through creation of a virtual model. A secondary purpose was to explore the use of the pilot model through survey of caregiver experiences of the new model. The study found that after reviewing the informational webinar, 91% of caregivers were satisfied with the virtual model for FASD evaluation vs. in-person. A majority (77%) of providers would also recommend virtual options for at least one part of the FASD diagnostic process.

Telemedicine models in autism spectrum disorders (ASD) are paving the way for FASD telehealth/medicine models. Juarez et al. (2019) piloted a telemedicine model in ASD diagnostic evaluations. The authors piloted the telemedicine model for children symptomatic for an ASD; they validated their telemedicine diagnoses with blinded, in-person assessments of the same child. The study had an accuracy validity score of 78.9% (n = 20). All of the children diagnosed with ASD via telemedicine were also confirmed to have ASD by the in-person (Juarez et al., 2019). These findings were supportive of telemedicine use in neurodiagnostic testing for children with developmental concerns, confirmed by one systematic review by La Valle et al. (2022).

Discussion. The 4-Digit Code has been established for over a decade in demonstrating a valid method to diagnose an FASD through a team-based approach (Astley 2004, 2013; Hemingway et al., 2024). Use of the 4-Digit Code allows for use in telehealth and has been studied for feasibility in Alaska (WICHE-BHP, 2021). Neurodevelopmental disorders in pediatrics have been increasingly using telehealth to aid in diagnosis (Juarez et al., 2019; King et al., 2023; La Valle et al., 2022). New data is indicating a movement in the use of telehealth for FASD evaluation and diagnosis.

Key Points and Project Goals

The project's key points were notable, and much was learned in this experience. The literature review was valuable to the author because it helped the hub clinic determine best practices in this new endeavor of telehealth. A new telehealth method was identified from the literature review and then utilized to create the policy. Through the development of the policy handbook, areas of need were identified in clinic processes, forms, and team dynamics. The author identified areas of need within the FASD evaluation process through conversations with

the team lead and coordinator. Through the literature review, much was learned on evidence-based practices of similar telehealth FASD practices.

The goal of this project was to create a policy handbook for implementation of a Hub and Spoke model which may be utilized in a hub clinic. Since completion of the policy handbook, Jennifer Waggaman (expert reviewer), has asked permission to use the policy handbook and literature review. It is proposed that the Hub and Spoke practice model be the basis of a new telehealth program. Details of this FASD telehealth program will be worked on through a State-level task force.

Methods

This QI project used the Model for Improvement (MFI) as the framework to guide implementation (AHRQ, 2013). The project plan was reviewed as a Not-Human Subjects Self Determination package and acknowledged by the UAA IRB-written approval in Appendices.

The policy handbook was written, and external reviewers were sought. These external reviewers had to be experts in the subject matters of FASD evaluations using the 4-Digit Code method. Participation was optional. Four reviewers were contacted by email or in person, and three agreed. External reviewers were given two weeks to review the policy handbook and give feedback in Round 1. The policy handbook was revised and returned to external reviewers in Round 2. The third reviewer came into the project later and thus evaluated the revised policy in Round 2 revisions. Feedback was received and applied to the policy.

Implementation and Resources. The policy handbook was easily reviewed through email, online teleconferencing, and in-person meetings. Implementation began with the creation of the policy, followed by expert review and revision. Feedback was given verbally and by email. Few resources were needed for this project outside of electronics and internet communication.

Significance of Results. The results were found in the creation of a policy handbook that was practice-ready. The experts' findings were invaluable in completing a product for use in practice, in the field of telehealth and FASD evaluations.

The ultimate goal of creating a foundation for telehealth FASD services in Alaska is coming to fruition. This project lays the foundation for further worktoward implementation of the Hub and Spoke model. The FASD program for Alaska is currently putting together a special task force to create a Hub and Spoke-like method and permission to use this author's project was asked and granted (Jennifer Waggman, personal communication, May 27, 2024).

Implications for Future Projects. The implications for future projects are many. It would be beneficial to complete a hub-and-spoke method project to assess provider/family satisfaction. Other implications include the use of a telehealth method of evaluation for other neuropsychological diseases like autism spectrum disorder (ASD) in Alaska, where resources are few in rural areas. Another project could look at pure telehealth FASD evaluations of patients with no in-person exams. Literature supports these evaluations to help measure needs and overcome barriers to rural care (Whittingham & Coons-Harding, 2021).

Boyer's Model of Scholarship

Ernest Boyer challenged the status quo by creating a model of scholarship that was untraditional to research and teaching in 1990 (Houdyshell et al., 2022). Boyer, the former president of the Carnegie Foundation for the Advancement of Teaching, felt that education had been organized in a fashion that isolated disciplines into "little boxes" (Boyer, 2012; Goldberg, 1995). He changed the models of research and scholarship, explaining that education only matters when it can be used in "day-to-day encounters we have with others" (Boyer, 2012; Goldberg, 2012). Boyer's Model of Scholarship had four categories: 1) discovery, 2) integration,

3) application, and 4) teaching (Boyer, 1990). This model reflected flexibility to social context, with the idea that applied knowledge should be used across disciplines, and the sharing of that knowledge should be dynamic (Houdyshell, 2022).

Boyer's Model of Scholarship can be applied to the post-master's DNP project and degree. The effects of a DNP project and adequate doctoral-level preparation can be evidence of scholarship (Marshall et al., 2016). Boyer's model can be applied to the project in many ways. The element of discovery is demonstrated through publication, presentation, and the need for future research (Marshall et al., 2016). Discovery is noted in the use of evidence-based practice, which contributes to human knowledge (Marshall et al., 2016). An example of discovery in this project was new knowledge of telehealth use in FASD evaluations in Alaska, with evidence that this method would be both beneficial and sustainable. This project will likely be disseminated to other areas for use at the state level in their FASD program.

Next in Boyer's model is integration, which is the use of information across disciplines, bringing light to data from a big-picture view (Marshall et al., 2016). This project utilized expert review from multiple disciplines aside from nursing. The basis of the hub-and-spoke model of this project is an interdisciplinary approach to data collection- three disciplines evaluate the patient symptomatic for an FASD and come together for the final diagnosis and plan.

The third component of Boyer's model is the application of knowledge (Marshall et al., 2016). An example of scholarship in application was of collaboration with the DNP project committee, key stakeholders from the community: Ptarmigan Connections clinic owners/management, FASD Hub team, Sitka Spoke team, State of Alaska FASD program managers, and Dr. Susan Astley Hemingway. This project was experiential, coming from a literature review to a final project and likely on to a broadly used method (state level).

The last component of Boyer's model is teaching/learning that is dynamic and ever-improving (Marshall et al., 2016). The teacher is always seeking new knowledge that is valuable and using this knowledge as a teaching vessel for others to implore (Marshall et al., 2016)). Testing this component of a DNP project means evaluating the effectiveness of the project on the critical population. The relation to this piece of Boyer's has a futuristic component, as the ultimate goal is to apply the Hub and Spoke model at the state level- which is currently being sought.

Self-Reflection and Summary of Learning

A Chinese Confucian philosopher once said, "Tell me, and I forget. Teach me, and I remember. Involve me, and I learn" (Kuang, 1988). These words rang true for my experience with the DNP project. Each step of the process brought about change that had to be learned first-hand. I had to work through the steps of the QI process- plan, do, study, act. I understood the QI process by reading about it, talking to my committee members, and performing each step. The DNP project process helped me apply the scientific underpinnings of the DNP Competencies. Evidence of these competencies were threaded throughout the project, providing a framework for advanced knowledge application.

I learned about QI projects and feasibility. I wanted to create a much larger project with potentially more community impact in FASD evaluation. I learned that a project must be feasible and completed in a timely manner. Out of these barriers, I came to a better understanding of QI projects vs. research and how to complete a feasible project.

Managing a DNP project requires leadership skills. These skills were enhanced after practice, from managing integral pieces of the project. I appreciated the varying disciplines that helped me gain anything from data to legal processes to FASD team duties. I learned that

leadership is essential to any project, with the leader providing the momentum. At times, my momentum would slow. I was key in maintaining the momentum to keep the project on task.

This experience helped me realize the importance of good leadership skills.

Conclusion

In summary, my learning was exponential. Understanding the barriers that exist for a particular problem is paramount. The DNP project informs nurses of areas of need. Nurses can make a difference and impact for patients in need. An advanced practice nurse can improve processes that translate into many disciplines and services through the project. The area of FASD evaluations needs to improve, and this project is a step in the right direction.

References

- Agency for Healthcare Quality and Research [AHRQ]. (2015). *Types of healthcare quality measures*. Talking Quality. <https://www.ahrq.gov/talkingquality/measures/types.html>
- Alaska Airlines. (2022). *Book a flight*. https://www.alaskaair.com/?semid=Google%7c%7cSEMBrand%7c%7c&gclid=Cj0KCCQiAmpyRBhC-ARIsABs2EAooxAxW1UvuJmY4WxmK9Fiz4JZkmzimmaCYdCjA_f2P-63zOR6MRgwaAtiMEALw_wcB&gclsrc=aw.ds
- Alaska Center for Fetal Alcohol Spectrum Disorders. (n.d.). *Homepage*. <https://alaskacenterforfasd.org/about-us/community-education-and-outreach/>
- Alaska FASD Strategic Plan Workgroup. (2018). *Strategic plan*. Governor's Council on Disabilities and Special Education. <https://health.alaska.gov/abada/Documents/FASD-Strategic-Plan-FY2017-2022.pdf>
- Alaska FASD Strategic Plan Working Group. (2021, December). *9 Core messages: What everyone should know about prenatal alcohol exposure*. Alaska Governor's Council on Disabilities and Special Education. <https://dhss.alaska.gov/abada/documents/FASDCoreMessages.pdf>
- Alaska Native Tribal Health Consortium [ANTHC]. (2022). *Research services*. <https://www.anthc.org/what-we-do/clinical-and-research-services/research/>
- American Association of Colleges of Nursing. (2006). *The Essentials of Doctoral Education for Advanced Nursing Practice*. Previous Essential Series. <https://www.aacnnursing.org/Portals/42/Publications/DNPEssentials.pdf>
- Astley, S. J. (2004). *Diagnostic guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*. FAS Diagnostic and Prevention Network. University of Washington.
- Astley, S. J. (2013). Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code. *Journal of Population Therapeutics and Clinical Pharmacology*, 20(3), e416-467.
- Benoit, T., Bowes, C., Bowman, N., Cantin, D., Chudley, A., & Crolley, D. (2002). Telemedicine diagnosis for fetal alcohol syndrome- The Manitoba experience. *Pediatrics and Child Health*, 7(3), 147-151.
- Bertrand, J. (2009). Interventions for children with fetal alcohol spectrum disorders (FASDs): Overview of findings for five innovative research projects. *Research in Developmental Disabilities*, 30(5), 986-1006. <https://doi.org/10.1016/j.ridd.2009.02.003>
- Bobbitt, A., Baugh, L. A., Andrew, G. H., Cook, J. L., Greene, C. R., Peif, J. R., & Rasmussen, C. R. (2016). Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder. *Research in Developmental Disabilities*, 55, 100-113.
- Bonnel, W. & Smith, K. V. (2013). *Proposal writing for nursing capstones and clinical projects*. Springer Publishing Company.

- Boyer, E. (1990). *Scholarship reconsidered: Priorities of the professoriate*. Princeton University Press.
- Boyer, E. [Quest for Peace]. (2012, May 23). *Ernest L. Boyer: The Hope for Education- 1984* [Video]. YouTube. <https://www.youtube.com/watch?v=0HNTSbmTsqU>
- Campo, M. D., Beach, D., Wells, A., & Jones, K. L. (2021). Use of telemedicine for the physical examination of children with fetal alcohol spectrum disorders. *Alcoholism: Clinical and Experimental Research*, 45(2), p. 409-417.
- Carnegie, A. (1986). *The autobiography of Andrew Carnegie*. Boston, MA: Northeastern University Press.
- Centers for Disease Control [CDC]. (2018). *Health Insurance Portability and Accountability Act of 1996 [HIPAA]*. Public health law. <https://www.cdc.gov/phlp/publications/topic/hipaa.html>
- Centers for Disease Control and Prevention [CDC]. (2024, May 14). *Treatment of FASDs*. <https://www.cdc.gov/fasd/treatment/index.html#:~:text=There%20is%20no%20cure%20for,walk%2C%20and%20interact%20with%20others>.
- Centers for Disease Control and Prevention [CDC]. (2022, January 6). *Data and statistics*. FASD Homepage. <https://www.cdc.gov/ncbddd/fasd/data.html>
- Chasnoff, I. J., Wells, A. M., & King, L. (2015) Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, 135(2). 264-270.
- Chokroborty-Hoque, A., Alberry, B., & Singh, S.M. (2014). Exploring the complexity of intellectual disability in fetal alcohol spectrum disorders. *Frontiers in Pediatrics*, 26(2). doi: 10.3389/fped.2014.00090.
- Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., Conry, J. L., LeBlanc, N., Looock, C. A., Lutke, J., Mallon, B. F., McFarlane, A. A., Temple, V. K., & Rosales, T. (2016). Fetal Alcohol Spectrum Disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*, 188(3), 191-197. DOI: <https://doi.org/10.1503/cmaj.141593>
- Dang, D., Dearhold, S., Bissett, K., Ascenzi, J. & Whalen, M. (2022). *Johns Hopkins evidence-based practice for nurses and healthcare professionals: Model and guidelines*. 4th ed. Sigma Theta Tau International.
- Davis, K., Desrocher, M., & Moore, T. (2011). Fetal alcohol spectrum disorder: A review of neurodevelopmental findings and intervention. *Journal of Developmental and Physical Disabilities*, 23(2). Doi: 10.1007/s10882-010-9204-2
- Department of Health, Education, and Welfare. (1979). *The Belmont Report*. Ethical Principles and Guidelines for the Protection of Human Subjects of Research, The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

<https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>

Department of Health and Human Services Alaska [DHSS]. (2021, September). *Core messages: What everyone should know about prenatal alcohol exposure*. Alaska FASD Strategic Plan Workgroup 2017-2022.

<http://dhss.alaska.gov/abada/documents/FASDCoreMessages.pdf>

Dow, B. S. (2019). *Quality of life for Alaskan individuals with FASD and their families*. [Doctoral Dissertation, University of Alaska, Fairbanks].

<http://hdl.handle.net/11122/10488>

Emergency Medical Services for Children [EMSC] (n.d.). Quality improvement framework.

<https://emscimprovement.center/collaboratives/quality-improvement-science/model-improvement/>

Ens, C. D., Hanlon-Dearman, A. Millar, M. C., & Longstafe, S. (2010). Using telehealth for assessment for fetal alcohol spectrum disorder: The experience of two Canadian rural and remote communities. *Telemedicine Journal and e-Health*, 16(8), 872-877.

<https://doi.org/10.1089/tmj.2010.0070>.

FAS Diagnostic and Prevention Network. (n.d.). *The 4 diagnoses under the FASD umbrella*.

<https://depts.washington.edu/fasdnp/htmls/fasd-fas.htm>

FAS Diagnostic and Prevention Network Training. (n.d.). *Training opportunities*.

<https://depts.washington.edu/fasdnp/htmls/training.htm>

Gallagher, R. (2020). *Best practices for securing your classroom*. Zoom.

<https://blog.zoom.us/best-practices-for-securing-your-virtual-classroom/>

Gibbard, W. B., Wass, P., & Clarke, M. E. (2003). The neuropsychological implications of prenatal alcohol exposure. *The Journal of the Canadian Child and Adolescent Psychiatry Review*, 12(3), 72-76. <https://www.ncbi.nlm.nih.gov/pmc/journals/788/>

Goh, Y. I., Chudley, A. E., Clarren, A. K., Koren, G., Orrbine, E., Rosales, T., & Rosenbaum, C. (2008). Development of Canadian screening tools for fetal alcohol spectrum disorder. *The Canadian Journal of Clinical Pharmacology*, 15, e344–e366.

Goldberg, M. (1995). *A portrait of Ernest Boyer*. ASCD.

<https://www.ascd.org/el/articles/a-portrait-of-ernest-boyer>

Greenmyer, J. R., Popova, S., Klug, M. G., & Burd, L. (2020). Fetal alcohol spectrum disorder: A systematic review of the cost of and savings from prevention in the United States and Canada. *Addiction*, 115, 409-417. Doi: 10.1111/add.14841

Grubb, M., Golden, A., Withers, A., Vellone, D., Young, K., & McLachlan, K. (2020). Screening approaches for identifying fetal alcohol spectrum disorder in children, adolescents, and adults: A systematic review. *Alcohol Clinical Experimental Research*, 45, 1527–1547. doi: 10.1111/acer.14657.

- Hanlon-Dearman, A., Edwards, C., Schwab, D., Millar, M. C., & Longstafe, S. (2014). Giving voice: Evaluation of an integrated telehealth community care model by parents/guardians of children diagnosed with fetal alcohol spectrum disorder in Manitoba. *Telehealth and e-Health*. <https://doi.org/10.1089/tmj.2013.0161>.
- Health and Social Services. (n.d.). *FASD diagnostic teams*. State of Alaska. <https://dhss.alaska.gov/osmap/Pages/fasd-team.aspx>
- Health Resources and Services Administration [HRSA]. (2011, April). *Quality improvement*. U. S. Department of Health and Human Services. <https://www.ruralcenter.org/sites/default/files/HRSAQIToolkit.pdf>
- Healthy People 2030. (n.d.). *Increase the proportion of children and adolescents that receive care in a medical home- MICH-19*. Healthy People 2030 Objectives. <https://health.gov/healthypeople/objectives-and-data/browse-objectives/health-care/increase-proportion-children-and-adolescents-who-receive-care-medical-home-mich-19>
- Hemingway, S. J. A. (n.d.). *Susan J. (Astley) Hemingway bio*. University of Washington. <https://depts.washington.edu/fasdnpn/pdfs/astleybio.pdf>
- Hemingway, S. A. (2016). *FAS facial photographic analysis software 2.0*. FAS Diagnostic and Prevention Network. <https://depts.washington.edu/fasdnpn/htmls/face-software.htm>
- Hemingway, S. A. (2024). *FASD 4-Digit diagnostic code*. <https://depts.washington.edu/fasdnpn/htmls/4-digit-code.htm>
- Hemingway, S. J. A., Baldwin, M., & Pierce-Bulger, M. (2023). Washington and Alaska statewide fetal alcohol spectrum disorder diagnostic clinical networks: Comparison of three decades of 4-Digit code diagnostic outcomes and prenatal alcohol exposure histories. *Advances in Pediatric Research*, 10(4). <https://depts.washington.edu/fasdnpn/pdfs/WA-AKdiags2024.pdf>
- Hendricks, G., Malcolm-Smith, S., Adnams, C., Stein, D. J., & Donald, K. M. (2021). Effects of prenatal alcohol exposure on language, speech, and communication outcomes: A review of longitudinal studies. *Acta Neuropsychiatry*, 31(2), 74-83. Doi: [10.1017/neu.2018.28](https://doi.org/10.1017/neu.2018.28)
- Houdyshell, M., Sughrue, J., Carothers, D., & Aydin, H. (2022). Is Boyer's scholarship reconsidered still relevant: A case study of a college-wide professional learning community. *Journal of the Scholarship of Teaching and Learning*, 22(1), 113-137. doi: 10.14434/josotl.v22i1.31185
- Hoyme, H. E., May, P. A., & Kalberg, W. O. (1996). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine Criteria. *Pediatrics*, 115, 39-47.
- Jirikowic, T., Olson, C., & Kartin, D. (2008). Sensory processing, school performance, and adaptive behavior of young school-age children with fetal alcohol spectrum disorders. *Physical & Occupational Therapy in Pediatrics*, 28(2). doi: 10.1080/01942630802031800

- Knox, L. & Brach, C. (2013). *Module 4: Approaches to quality improvement*. The Practice Facilitation Handbook: Training Modules for Facilitators and their Trainers. <https://www.ahrq.gov/sites/default/files/publications/files/practicefacilitationhandbook.pdf>
- Kuang, Z. (1988). *Xunzi: A translation and study of the complete works, Vol. 1, Books 1-6* (J. Knoblock, trans.). Stanford Press. (Original work published ca. 818 A.D.)
- Marshall, B., Evans, B., Hollema, C., Napierkowski, D. (2016). Evaluating post-Master's DNP programs through the Boyer Model lens. *Annals of Nursing Practice*, 3(4), 1056.
- Maya-Enero, S., Ramis-Fernandez, S. M., Aastals-Vizcaino, M., & Garcia-Algar, O. (2021). Neurocognitive and behavioral profile of fetal alcohol spectrum disorder. *Anales de Pediatría*, 95. <https://reader.elsevier.com/reader/sd/pii/S2341287921001344?token=90835D629AD874296F99AC5136CD7CE92960954D7AE5DBC2518AD3770A508A7EB66077EDF1B8EDC04DEAFE91FA99A7F&originRegion=us-east-1&originCreation=20220313165508>
- Mayo Clinic. (2018, January 10). *Fetal alcohol syndrome*. <https://www.mayoclinic.org/diseases-conditions/fetal-alcohol-syndrome/symptoms-causes/syc-20352901>
- McDowell Group. (2020, January). *Summary of the economic costs of fetal alcohol syndrome/fetal alcohol spectrum disorder in Alaska*. The Alaska Mental Health Trust Authority. <https://alaskamentalthtrust.org/wp-content/uploads/2020/06/1949-AMHTA-Drugs-and-Alcohol-FASD-Summary-Report-Final-Revised-6.12.2020.pdf>
- McDowell Group. (2020, July). *Alaska FASD diagnostic team data analysis, policy & prevention recommendations*. Alaska Mental Health Trust Authority. <https://alaskamentalthtrust.org/wp-content/uploads/2021/02/FASD-Diagnostic-Data-Analysis-Policy-Prevention-Recommendations-7.29.20.pdf>
- McQuillan, R. F., Silver, S. A., Harel, Z., Weizman, A., Thomas, A., Bell, C., Chertow, G. M., Chan, C. T., & Nesrallah, G. (2016). How to measure and interpret quality improvement data. *Clinical Journal of the American Society of Nephrology*, 11(5), 908-914.
- Melal, M., McFarlane, A., Sajboi, T. T., & Rajani, H. (2013). Clinical correlates of fetal alcohol spectrum disorder among diagnosed individuals in a rural diagnostic clinic. *Journal of Population Therapeutics and Clinical Pharmacology*, 20(3), p. 250-258.
- Melnyk, B., & Fineout-Overholt, E. (2019). *Evidence-based practice in nursing & healthcare* (4th ed.). Philadelphia, PA: Lippincott, Williams, & Wilkins.
- National Institutes of Health [NIH]. (2020 January). *Human subjects*. Policy & Compliance. <https://grants.nih.gov/policy/humansubjects/research.htm>

- O'Connor, M. J., & Paley, B. (2006). The relationship of prenatal alcohol exposure and the postnatal environment to child depressive symptoms. *Journal of Pediatric Psychology*, *31*(1), 50-64. <https://doi.org/10.1093/jpepsy/jsj021>
- Petrenko, C. L., & Alto, M. E. (2017). Interventions in fetal alcohol spectrum disorders: An international perspective. *European Journal of Medical Genetics*, *60*(1), 79-91. doi: [10.1016/j.ejmg.2016.10.005](https://doi.org/10.1016/j.ejmg.2016.10.005)
- Phillips, N. L., Zimmet, M. D., Phu, A., & Rattan, M. (2022). Impact of fetal alcohol spectrum disorder on families. *Archives of Disease in Childhood*, *107*(8), <http://dx.doi.org/10.1136/archdischild-2021-322703>
- Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: A systematic review and meta-analysis. *Addiction*, *114*, 1150–1172. doi:10.1111/add.14598.
- Provost, L., Nolan, T., Moen, R., Langley, J., Nolan, K., & Norman, C. (2024). *Model for Improvement: Plan-Do-Study-Act chart*. Associates in Process Improvement. <https://www.apweb.org/index.php>
- Reid, N. Dawe, S., Shelton, D., Harnett, P., Warner, J. Armstrong, E., LeGros, K., & O'Callaghan, F. (2015). Systematic review of fetal alcohol spectrum disorder interventions across the lifespan. *Alcoholism*, *39*(12). <https://doi.org/10.1111.acer.12903>
- Rivaz, M., Shokrollahi, P., Setoodegan, E., & Sharif, F. (2021). Exploring the necessity of a doctor of nursing practice program from experts' views: A qualitative study. *BioMed Central Medical Education*, *21*. doi: [10.1186/s12909-021-02758-w](https://doi.org/10.1186/s12909-021-02758-w)
- Rural Health Information Hub. (2021). *Healthcare access in rural communities*. <https://www.ruralhealthinfo.org/topics/healthcare-access>
- Rural Health Research Center [RHRC]. (2021). *Geographic access to healthcare for rural Medicare beneficiaries in five states: An update*. University of Washington. https://familymedicine.uw.edu/rhrc/wp-content/uploads/sites/4/2021/04/RHRC_PBAPR2021_LARSON.pdf
- Sanders, J. L., & Buck, G. (2010). A long journey: Biological and non-biological parents experiences raising children with FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, *17*(2): e308-322.
- Shank, G. D. (2002). *Qualitative research: A personal skills approach*. Upper Saddle River, NJ: Prentice Hall.
- Skorink, J. L. M. (2019). Scholarship of discovery and beyond: Thinking about multiple forms of scholarship and elements of project-based learning to engage undergraduates in publishable research. *Frontiers in Psychology*, *10* (917). doi: [10.3389/fpsyg.2019.00917](https://doi.org/10.3389/fpsyg.2019.00917)

- Streissguth, A.P., Bookstein, F.L., Barr, H.M., Sampson, P.D., O'Malley, K., & Young, J.K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental Behavioral Pediatrics*, 25(4). doi: 10.1097/00004703-200408000-00002
- Tsang, T. W., Lucas, B. R., Olson, H. O., Pinto, R. Z., & Elliott, E. J. (2016). Prenatal alcohol exposure, FASD, and child behavior: A meta-analysis. *Pediatrics*, 137(3). Doi: e20152542
- U.S. Department of Health and Human Services. (2015). *Categories of Research that may be reviewed by the Institutional Review Board (IRB) through an expedited review procedure*. U.S. Food and Drug Administration. <https://www.fda.gov/science-research/clinical-trials-and-human-subject-protection/categories-research-may-be-reviewed-institutional-review-board-irb-through-expedited-review>
- U.S. Department of Health and Human Services. (2021). *45 CFR 46*. Regulations. <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/index.html>
- Walker, L. E. (2021). Interprofessional education in rural clinical learning environments: The role of clinicians. *The Australian Journal of Rural Health*, 29(2), 248-252. doi: 10.1111/ajr.12723.
- Western Interstate Commission for Higher Education Behavioral Health Program [WICHE-BHP]. (2021, June). *Fetal alcohol spectrum disorder telehealth feasibility study*. Alaska Mental Health Trust Authority. <https://alaskamentalhealthtrust.org/wp-content/uploads/2021/06/AK-FASD-Final-Report-6.29.2021.pdf>
- Whittingham, L. M. & Coons-Harding, K. D. (2021). Connecting people with people: Diagnosing persons with fetal alcohol spectrum disorder using telehealth. *Journal of Autism and Developmental Disorders*, 51, 1067–1080. <https://doi.org/10.1007/s10803-020-04607-z>

Appendix A: Evidence Table 1

| APA citations | Purpose of study Sample/setting | Research design/level of evidence Measurement of major variables | Data analysis | Study findings | Appraisal of worth to practice, strengths & limitations, quality |
|--|--|---|--|--|--|
| <p>Walker, L. E. (2021). Interprofessional education in rural clinical learning environments: The role of clinicians. <i>The Australian Journal of Rural Health, 29</i>(2), 248-252 .</p> | <p>Assess the effect of the primary clinician’s role in interprofessional education (IPE) in student education. How are students impacted by IPE.</p> <p>Clinicians from 5 rural health organizations in Tasmania and Victoria, AU from 2015-2019. Clinicians from allied health, midwifery, nursing, and medicine with majority (82%) being female.</p> | <p>Mixed- methods design</p> <p>Level IV evidence</p> <p>DV = likert scale scores for GRIPLS & IEPS</p> | <p>No significant statistical differences were identified by analysis of variance (ANOVA) between the subscales for GRIPLS and IEPS for the years of clinician experience, sex, supervision, or IPE training.</p> <p>Qualitative: IPE activities, enablers that promoted IPE and challenges to provision of IPE. Some clinicians supervised (35%) and debriefed (19%) other professions.</p> | <p>GRIPLS (Quant): desire to understand health from the patient’s perspective received the highest score (M = 4.91, SD = 0.69). 8 items in the teamwork and collaborations skills subscale scored highly. However, scores uneven for function of nurses and therapists is “to mainly to provide support for the doctors (M = 1.97, SD = 0.95).</p> | <p>Limitations: Small numbers of specific specialties (medicine and allied health participants) were too little to find disciplinary differences. The results are very specific therefore not considered generalizable</p> <p>Use of validated tools (GRIPLS & IEPS) were a strength.</p> <p>Worthiness to practice: IPE in rural settings affected by clinician’s attitudes such as flexibility and supportiveness- thus reinforcing importance of attitude in IPE work (across any dyads).</p> |
| <p>Grubb, M., Golden, A., Withers, A., Vellone, D., Young, K., & McLachlan, K. (2020). Screening approaches for identifying fetal alcohol spectrum disorder in children, adolescents, and adults: A systematic review. <i>Alcohol Clinical Experimental Research, 45</i>, 1527–1547.</p> | <p>Sample: Studies Use of peer-reviewed and gray literature from 1990-2020 of FASD screening tools for adults, adolescents, and children.</p> <p>Quality: QUADAS & grade Frameworks only.</p> <p>Systematic review to examine evidence for FASD screening tools.</p> | <p>Systematic review</p> <p>Level I</p> <p>DV = FASD tools, 3 main types of tools emerged from data</p> | <p>Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) utilized for this qualitative review.</p> <p>3392 studies, 45 used in qualitative synthesis to find screening tool characteristics and data</p> | <p>20 unique screening tools, of which came from Canada (49%), United States (27%), South Africa (9%), and other countries (16%).</p> <p>Tools described, including psychometric qualities</p> | <p>Not all existing tools evaluated in study; lack of culturally diverse populations studied; tools not considered for meta-analysis that focused on at risk women for prenatal exposure.</p> <p>QUADAS revealed high risk of bias in selected studies (20).</p> <p>High Level of Evidence</p> <p>Worthiness to practice: Other strong FASD evaluation tools exist, and emerging tools identified</p> |

| | | | | | |
|--|---|--|---|---|--|
| | | | | | (serum biomarkers). Significant to the evaluation process of FASD. |
| Whittingham, L. M. & Coons-Harding, K. D. (2021). Connecting people with people: Diagnosing persons with Fetal Alcohol Spectrum Disorder using telehealth. <i>Journal of Autism and Developmental Disorders</i> , 51, 1067–1080. | Systematic literature review describing studies utilizing telehealth for assessment and diagnosis of FASD and other developmental disorders. Only three studies found to date utilizing telehealth + FASD. Experiences assessed. 3 studies- all set in Manitoba, Canada | Systematic literature review DV = telehealth use in FASD diagnosis, IV = in person FASD diagnosis | Description of outcomes. | Advantages and disadvantages of using telehealth for FASD diagnoses identified: Advantages: decrease in travel costs for families, decrease in costs for clinics and community development; increased participation from support. Disadvantages: technology limitations, coordination of many sites, assessment via video conferencing challenges | Advantages outweigh disadvantages; example of current pilot study in progress of rural FASD formation (central themes identified) All of studies described were in one country (Canada), limited generalizability to other countries. Added to the body of knowledge when there is a paucity of information on FASD and telehealth use. Worthiness: Telehealth feasible in rural locations to accurately evaluate persons with FASD. More studies needed on telehealth + FASD to establish a EBP model. |
| Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: A systematic review and meta-analysis. <i>Addiction</i> , 114, 1150–1172 | Systematic literature review about the economic impact of FASDs. Canada | 69 studies 6177 individuals diagnosed with FASD from 17 countries: Australia (n = 5), Brazil (n = 2), Canada (n = 15), Chile Systematic literature review/meta-analysis DV = prevalence of FASD in subpopulations of children IV = Subpopulations: children in foster care, correctional facilities, special education, specialized clinical and Aboriginal populations. *Aboriginal was not defined | Databases searched: Ovid, MEDLINE, PubMed, EMBASE...13 total Including psychological and sociological databases. 1960-2010. Coders sufficient IRR (>.80), using Fleiss kappa statistics 233 abstracts, reduced to 13, including only those with economic burden + FASD. Studies only found in the USA (10) and Canada (3). | Children in care are more likely to have FAS/FASD diagnosis; children with FASD are 19 times more likely to be incarcerated than typically developing children; Aboriginal ethnicity increases prevalence in most areas of the world; extreme variance exists | Studies compiled from a 40 yr span, and FASD wasn't tracked as much early on (i.e. in the 1980s in American Indian populations); Aboriginal studies in Canada are dated and had methodological issues; varying diagnostic criteria (12 specifically) among countries. Worthiness: FASDs affect cost of illness models in systems. FASD has a significant societal impact. Level I evidence |
| Ens, C. D., Hanlon-Dearman, A., | Evaluate the FASD telehealth program in | N = 26, professionals from | Thematic analysis utilized and | Two themes emerged from interviews: 1) | Low level of Evidence, Level VI. |

| | | | | | |
|---|--|--|--|---|--|
| <p>Millar, M. C., & Longstafe, S. (2010). Using telehealth for assessment for fetal alcohol spectrum disorder: The experience of two Canadian rural and remote communities. <i>Telemedicine Journal and e-Health</i>, 16(8), 872-877.</p> | <p>two rural communities in Canada. Perspectives gathered from team members to help guide future telehealth FASD models of care.</p> <p>N = 26 Professionals from health, education, and social work sampled. Community members sampled if they had dealings with FASD evaluations in the previous 5 years. Majority of participants were female and from education.</p> | <p>telehealth communities and those from the Manitoba FASD Centre team. Professionals from the community were those who had involvement with the FASD telehealth process within the previous 5 years. Qualitative method to evaluate use of telehealth in FASD by two Manitoba communities. Semi-structured interviews Conducted Nominal level variables- demographics of study participants</p> | <p>completed by hand through a method described by Shank (2002).</p> | <p>FASD via telehealth benefits outweigh drawbacks, 2) Dreaming of change, where some elements of the exam needed to be performed differently</p> | <p>Population lacking perspective of patients and families which would add rigor and strength to findings. Population was that of only professionals (medical staff, school personnel, social services staff, & telehealth staff). First study of this type, collecting data on opinions of a telehealth intervention in the setting of FASD evaluation. Worthiness: Supportive evidence to utilize telehealth in a population similar to Alaska. Limitations: low evidence, qualitative with no IRR rating.</p> |
|---|--|--|--|---|--|

Appendix B: Synthesis Table

| Studies | Design | Sample | | Outcome |
|---------|------------------------------|---|-----------------------------------|--|
| A | Mixed Methods | <i>N</i> = 88 Clinician's opinions on interprofessional education | Walker, 2021 | Clinicians can be successful leaders of teams of differing disciplines. |
| B | Systematic Review | <i>N</i> = 45 Tools utilized for FASD diagnosis | Grubb et al., 2020 | Standardized tools aid in the diagnosis of FASD. |
| C | Literature Review | <i>N</i> = 3 Number of studies utilizing telehealth for diagnosis of FASD | Whittingham & Coons-Harding, 2021 | Advantages of telehealth outweigh barriers. |
| D | Systematic Literature Review | <i>N</i> = 6177 Number of individuals diagnosed with FASD from different countries | Popova et al., 2019 | Certain subpopulations of children are at increased risk of having an FASD diagnosis. Increase screening in these areas. |

Adapted from Melnyk & Fineout-Overholt (2021)

Appendix C: UAA IRB Modifications Needed Letter



DATE: April 22, 2022
TO: Leah Coffman
FROM: University of Alaska Anchorage IRB
PROJECT TITLE: [1891148-1] Fetal Alcohol Spectrum Disorder: Evaluating satisfaction of a telehealth program in rural Alaska
SUBMISSION TYPE: New Project
REVIEW TYPE: Administrative Review
ACTION: INFORMATION REQUIRED
DECISION DATE: April 13, 2022
EXPIRATION DATE: April 13, 2022
NEXT REPORT DUE:

Thank you for your submission of New Project materials for this research study. The University of Alaska Anchorage IRB has determined that the following modifications are required in order to secure approval:

Please resubmit a non-HSR determination form which clearly outlines this as evaluation of an existing program.

In this letter, also provide a list of all organizations involved or from where patients would be recruited and/or the data will be derived for evaluation. Any organization which is part of the Indian Health Services / ANTHC (such as SEARHC) requires review by AAIRB if IHS personnel are involved. While this may not be research, it would need to be reviewed and determined as such either through the non-research determination board at ANTHC or through SEARHC if they have a comparable board. UAA IRB will accept their determination.

Additionally, even if this is not research, data use agreements need to be in place to receive any information from a healthcare provider (if data being provided). As an evaluation program, it would be expected that healthcare data would be provided for evaluation. Data use agreements are handled by the Office of Research, not the IRB.

While completing an Exempt or Regular IRB application would be faster as the forms request the information and provide guidance, the faculty advisor requested an exception to be made to use the non-HSR determination form.

If you have any questions, please contact David Parker at 907-786-6590 or uaa_irb_chair@alaska.edu. Please include your project title and reference number in all correspondence with this office.

Appendix D: Alaska Area IRB October 2022 Letter

| | |
|--|---|
| Alaska Area Institutional Review Board | 4315 Diplomacy Drive - IRB Anchorage, AK 99508 |
|--|---|

DATE: October 14, 2022

TO: Leah Coffman, DNP
Principal Investigator
2425 N. Larkspur Hill
Palmar, AK 99845

FROM: Alaska Area Institutional Review Board (IHS IRB #2)

STUDY TITLE: Evaluation of Rural Provider Satisfaction Using a Hub and Spoke Practice Model for Fetal Alcohol Identification and Referral Services

IRB REFERENCE #: 2022-09-041-2

SUBMISSION TYPE: New Project

ACTION: INCOMPLETE SUBMISSION

EFFECTIVE DATE: October 10, 2022

Dear Ms. Coffman:

Thank you for submitting the New Project materials for the above study. The Alaska Area Institutional Review Board (IHS IRB #2) has ACKNOWLEDGED your submission. The Alaska Area IRB (AAIRB) has received the following documents:

- Advertisement - Edited_Email communication to participants_Coffman.docx (UPDATED: 10/10/2022)
- Advertisement - Email communication to participants_Coffman .pdf (UPDATED: 10/10/2022)
- Letter - IRB response 9.21.22 with Comments_Coffman22.pdf (UPDATED: 10/10/2022)
- Proposal - DNP Abbreviated Proposal_Coffman.pdf (UPDATED: 10/10/2022)

HOWEVER, further action on submission 2022-09-041 with IRBNet ID 1957854-2 is required at this time. To be included on the November 2022 AAIRB agenda, please provide the following documents prior to November 1:

1. The 18 page abbreviated protocol added in package 2 does not have a track changes version of the 49 page protocol in package 1 that we have reviewed. Please provide a track changes version and a clean version of the 49 page protocol for our review.
2. Our reviewers have already read the 49 page version and are asking questions to make a determination of whether this is a research project. We must have a track changes version of originally submitted protocol, not a "new" abbreviated protocol.
3. We are missing the digital signature for this package. Please log in to IRBNet, select the current package (2) and then, under Project Administration on the left, you will see "Sign this Package." Please let us know if you have any questions or issues with how to do this.
4. After speaking with you and reviewing the Office for Human Research Protections (OHRP) Decision Charts, it may be best for you to complete our Exempt Research Application in addition to answering each of our questions in our letter dated September 21, 2022.

Appendix E: Alaska Area IRB Incomplete Submission Letter November 2022

| | |
|--|---|
| Alaska Area Institutional Review Board | 4315 Diplomacy Drive - IRB Anchorage, AK 99508 |
|--|---|

DATE: November 8, 2022

TO: Leah Coffman, DNP
Principal Investigator
2425 N. Larkspur Hill
Palmer, AK 99645

FROM: Alaska Area Institutional Review Board (IHS IRB #2)

STUDY TITLE: Evaluation of Rural Provider Satisfaction Using a Hub and Spoke Practice Model for Fetal Alcohol Identification and Referral Services

IRB REFERENCE #: 2022-09-041-2

SUBMISSION TYPE: New Project

ACTION: INCOMPLETE SUBMISSION

EFFECTIVE DATE: November 1, 2022

Dear Ms. Coffman:

Thank you for submitting the New Project materials for the above study. The Alaska Area Institutional Review Board (IHS IRB #2) has ACKNOWLEDGED your submission. The Alaska Area IRB (AAIRB) has received the following documents:

- Advertisement - DNP_IRB_Email communication Clean copy .docm (UPDATED: 10/24/2022)
- Advertisement - DNP_IRB_Email communication track changes .docx (UPDATED: 10/24/2022)
- Application Form - Exempt Limited Review Form_Coffman22.pdf (UPDATED: 10/24/2022)
- Cover Sheet - IRB response@.21.22 with Comments_Coffman22.docx (UPDATED: 10/24/2022)
- Proposal - DNP_AbbreviatedProposal_CoffmanOct22.pdf (UPDATED: 10/25/2022)
- Proposal - DNP_ProposalTrackChanges_CoffmanOct.pdf (UPDATED: 10/25/2022)

HOWEVER, further action on submission 2022-09-041 with IRBNet ID 1957654-2 is required at this time. To be included on the December 2022 AAIRB agenda, please provide the following documents prior to December 1:

1. All revised documents require both a clean and tracked changes versions to be submitted to the IRB for review. Please provide the clean version of "DNP_ProposalTrackChanges_CoffmanOct" to accompany the tracked changes version.
2. We are missing the digital signature for this package. Please log in to IRBNet, select the current package (2) and then under "Project Administration" on the left you will see "Sign this Package." Please let us know if you have any questions with how to do this.
3. The Exempt Research Application is missing the investigator signature and date. Please provide a signed and dated application for the IRB to review.
4. We have unlocked this package so you can provide a complete submission. Please remember to lock IRBNet by selecting "Mark Revisions Complete" when all requested items have been uploaded to begin the review process.

Appendix F: Alaska Area IRB Incomplete Submission Letter December 2022

| | |
|--|---|
| Alaska Area Institutional Review Board | 4315 Diplomacy Drive - IRB Anchorage, AK 99508 |
|--|---|

DATE: December 1, 2022

TO: Leah Coffman, DNP
Principal Investigator
2425 N. Larkspur Hill
Palmer, AK 99645

FROM: Alaska Area Institutional Review Board (IHS IRB #2)

STUDY TITLE: Evaluation of Rural Provider Satisfaction Using a Hub and Spoke Practice Model for Fetal Alcohol Identification and Referral Services

IRB REFERENCE #: 2022-09-041-2

SUBMISSION TYPE: New Project

ACTION: INCOMPLETE SUBMISSION

EFFECTIVE DATE: November 28, 2022

Dear Ms. Coffman:

Thank you for submitting the New Project materials for the above study. The Alaska Area Institutional Review Board (IHS IRB #2) has ACKNOWLEDGED your submission. The Alaska Area IRB (AAIRB) has received the following documents:

- Advertisement - DNP_IRB_Email communication Clean copy .docm (UPDATED: 10/24/2022)
- Advertisement - DNP_IRB_Email communication track changes .docx (UPDATED: 10/24/2022)
- Application Form - Exempt Limited Review Form_Coffman22.pdf (UPDATED: 10/24/2022)
- Cover Sheet - IRB_DNP_CoverLetterCoffman112822.docm (UPDATED: 11/28/2022)
- Other - IRBresponse9.21.22 with Comments_Coffman22.docx (UPDATED: 10/24/2022)
- Proposal - DNP_AbbreviatedProposal_CoffmanOct22.pdf (UPDATED: 10/25/2022)
- Proposal - DNP_ProposalTrackChanges_CoffmanOct.pdf (UPDATED: 10/25/2022)

HOWEVER, further action on submission 2022-09-041 with IRBNet ID 1957654-2 is required at this time. To be included on the December 2022 AAIRB agenda, please provide the following documents prior to December 1:

1. IRBNet package 2 is missing the digital signature. Please log in to IRBNet, select the current package (2). Under "Project Administration" on the left you will select "Sign this Package" and follow the prompts.
2. The Exempt Research Application is missing the investigator's signature and date. Please provide a signed and dated application to begin the review process.
3. We have unlocked this package so you can provide a complete submission.
4. Please remember to lock IRBNet by selecting "Mark Revisions Complete" when all requested items have been uploaded to begin the review process.

If you have further questions for the Alaska Area IRB you may contact us at akaalaskaarealrb@anthc.org or call 907-729-3913.

Appendix G: Alaska Area IRB Revisions Required Letter January 2023

| | |
|--|---|
| Alaska Area Institutional Review Board | 4315 Diplomacy Drive - IRB Anchorage, AK 99508 |
|--|---|

DATE: January 3, 2022

TO: Leah Coffman, DNP
Principal Investigator
2425 N. Larkspur Hill
Palmer, AK 99645

FROM: Alaska Area Institutional Review Board (IHS IRB #2)

STUDY TITLE: [1957654-2] Evaluation of Rural Provider Satisfaction Using a Hub and Spoke Practice Model for Fetal Alcohol Identification and Referral Services

IRB REFERENCE #: 2022-09-041-2

SUBMISSION TYPE: New Project

ACTION: IRB REVISIONS REQUIRED

REVIEW TYPE: Review 45 CFR 46

Dear Ms. Coffman:

Thank you for your submission of New Project materials for this study. The Alaska Area Institutional Review Board (I.H.S. #2) has reviewed your submission and has determined that the following REVISIONS are REQUIRED in order to secure approval:

1. The November 28, 2022 response to our review (in our IRB Revisions Required letter dated September 21, 2022) has made it hard for our IRB reviewers to determine whether this is a Quality Improvement (QI) project or a minimal risk Exempt Research project (with Limited Review).
2. It would benefit the project greatly if the Principal Investigator (PI) had access to their academic mentor to help determine whether the intent of this project is to become generalizable knowledge (a requirement for research) or whether this project is a quality assurance project for a program.
3. The small sample size of three eligible participants will mean that the PI will know all participants, and as such cannot fully protect their identifies in the project, while ensuring that participation in the project remains voluntary. Please revise the protocol to include a paragraph informing the IRB how participants will be protected and their participation remains voluntary.
4. With only the possibility of three eligible participants in Southeast Alaska Regional Health Consortium region, tell the IRB how this project could contribute to generalizable knowledge.
5. Furthermore, the IRB is concerned about implied coercion to the three eligible participants that could part in this project to help the student, how will this be addressed. For example, what if all three eligible participants decline to participate, what will the PI do for her project?
6. Please revise the protocol to clarify how the above reviewer comments will be addressed.

To respond to the IRB, add a package to this project with your response to our review. Include a detailed cover letter answering all review items outlined in this IRB Revisions Required/Modifications Required letter to verify that all items has been addressed. All revised documents must include both a tracked changes version and a clean final copy of the relevant documents.

Research activities in accordance with this submission may not begin until this office has received a response to these conditions and issued final approval. This submission has received Exempt Review

Appendix H: Alaska Area IRB WithdrawLetter February 2023

Alaska Area Institutional Review Board

4315 Diplomacy Drive - IRB
Anchorage, AK 99508

DATE: January 24, 2023

TO: Leah Coffman, MSN
Principal Investigator
2425 N. Larkspur Hill
Palmer, AK 99645

FROM: Alaska Area Institutional Review Board (IHS IRB #2)

STUDY TITLE: [2010180-1] Closure of project 2022-09-41. See attached letter.

IRB REFERENCE #: 2022-09-041

SUBMISSION TYPE: Closure/Final Report

ACTION: ACKNOWLEDGED

EFFECTIVE DATE: January 18, 2023

Dear Ms. Coffman:

Thank you for submitting the letter requesting to close the "Evaluation of Rural Provider Satisfaction Using a Hub and Spoke Practice Model for Fetal Alcohol Identification and Referral Services" project. The Alaska Area Institutional Review Board (IHS IRB #2) has ACKNOWLEDGED your submission. No further action on submission 2022-09-041 with IRBNet ID 2010180-1 is required at this time. This project will be included on the February 2023 Alaska Area IRB agenda.

The following items are acknowledged in this submission:

- Cover Sheet - Reply to Alaska Area IRB to Jan 3 Decision.pdf (UPDATED: 01/18/2023)

If you have further questions for the Alaska Area IRB you may contact us at akaAlaskaAreaIRB@anthc.org or call (907) 729-3917.

Sincerely,

Karen M. Morgan
Alaska Area Institutional Review Board
IRB Analyst

Appendix I: UAA IRB Not-HSR Letter February 2023



Office of Research
UNIVERSITY OF ALASKA ANCHORAGE

3211 Providence Drive
Anchorage, Alaska 99508
1.907.786.1099
www.uaa.alaska.edu/research/oric

DATE: February 1, 2023

TO: Leah Coffman, DNP
FROM: University of Alaska Anchorage IRB

PROJECT TITLE: [2013218-1] Evaluation of an Evidenced-Based Policy Handbook on a Hub and Spoke Practice Model: A Quality Improvement Project

SUBMISSION TYPE: New Project

ACTION: ACKNOWLEDGED
DECISION DATE: February 1, 2023
REVIEW TYPE: Administrative Review

Thank you for your submission of documentation that the activities you have described are not Human Subjects Research (HSR). The University of Alaska Anchorage has acknowledged your self-determination that this project does not meet the definition of Human Subjects Research according to federal regulations.

The UAA IRB/ORIC will retain a copy of this correspondence within our records, and the IRB/ORIC may conduct audits of Not-HSR Self-Determinations to evaluate their accuracy. In the event an audit identifies activity that has been miscategorized as Not HSR, the IRB Chair may require that the activities be suspended until standard IRB/ORIC review processes have been completed and the activity judged as exempt or approved.

If you have any questions, please contact the IRB Chair, David Parker, or the UAA IRB Coordinator through IRBNet Project Mail (accessible on the left hand menu within your IRBNet project). The IRB Coordinator is also available at (907) 786-0918 or uaa_urb_coord@alaska.edu. Please include your IRBNet number and Project Title in all correspondence with this office.

Canial Allan, CIP
IRB Coordinator
Office of Research Integrity & Compliance (ORIC)
University of Alaska Anchorage

Appendix J: Evidence Table 2

| APA citation | Purpose of study Sample/setting | Research design/level of evidence Measurement of major variables | Data analysis | Study findings | Appraisal of worth to practice, strengths & limitations, quality |
|---|--|---|---|--|--|
| <p>Hemingway, S. J. A., Baldwin, M., & Pierce-Bulger, M. (2023). Washington and Alaska statewide fetal alcohol spectrum disorder diagnostic clinical networks: Comparison of three decades of 4-Digit code diagnostic outcomes and prenatal alcohol exposure histories. <i>Advances in Pediatric Research</i>, 10(4). https://depts.washington.edu/fasdpn/pdfs/WA-AKdiags2024.pdf</p> | <p>Purpose: To describe two statewide FASD networks, notate graphically the number/types of FASD diagnoses over 2-3 decades, and demonstrate how FASD data affects public health policy and monitor prevention attempts to influence care.</p> <p>Sample: Diagnostic outcomes data from individuals with confirmed prenatal alcohol exposure (PAE) who were evaluated by WA DPN and AK Dept of Health & Social Services from 1991-2023 (n = 2532 1993–2021 (n = 2,532) & 1999-2021 (n = 2469)</p> <p>Setting: AK and WA FASD diagnostic networks</p> | <p>Retrospective descriptive study</p> <p>DV: Washington and Alaska FASD Diagnostic networks, CDC Pregnancy Risk Assessment Monitoring System and CDC Behavioral Risk Factor Surveillance System</p> <p>IV: diagnostic outcomes</p> | <p>Descriptive analyses (proportions)</p> | <p>Obj 1. Establishment and Description of the WA and AK Statewide FASD Diagnostic Clinical Networks:</p> <p>WA: over 3,000 pts diagnosed with prenatal alcohol exposure (PAE); over 100 peer-reviewed publications from FASD DPN data;</p> <p>AK: 3000-4000 pts assessed over 20 yrs, with data reported for only 3000 in that time</p> <p>Obj 2. WA and AK FASD outcomes</p> <p>Socioeconomic differences between both states; distribution of growth, face, CNS abnormalities, and PAE between WA and AK; prevalence of drinking rates between states; distribution by race, age, and year.</p> <p>Obj 3. Tracking successful prevention efforts</p> <p>WA: Successful tools and programs to track prevalence rates established</p> <p>AK: Decline of FASDs in AK Native/AI population by 49%; increase by 64.1% in non-Native children</p> | <p>Limitations: Missing data from up to 1000 pts in AK. 4-Digit Code not utilized in all 50 of U.S., less generalizable.</p> <p>Strength: Evaluation of data over 20-30 yrs in two states Level IV evidence. MODERATE EVIDENCE</p> |

| | | | | | |
|---|--|---|--|--|---|
| <p>King, S., Burns, C., Symes, B., Jessiman, S., Bell, A., & Rajani, H. (2023). Development and evaluation of a virtual model for fetal alcohol spectrum disorder (FASD) assessment and diagnosis in children: A pilot study. <i>Children</i>, 10(2). doi: 10.3390/children10020196</p> | <p>Purpose: Pilot study to explore ways to improve access to pediatric FASD diagnosis and assessment through creation of a virtual model. Secondary purpose was to explore use of the pilot model through survey of caregiver experiences of the new model.</p> <p>Sample/Setting: 1. Four pediatric FASD assessment clinics in Alberta, Canada from June 2020-June 2021 in patients, with assessment of caregivers' through a satisfaction tool. 2. Survey of Providers' of regional FASD clinics (Alberta, Canada)</p> | <p>Research Design/Level of Measurement: Descriptive survey (cross sectional) for both measures (caregiver & provider)</p> <p>1. DV: Caregiver satisfaction IV: FASD virtual model</p> <p>2. DV: Provider satisfaction IV: FASD virtual model post-webinar</p> | <p>Data Analysis: Likert scale data analysis (SPSS)</p> | <p>Study findings: Obj. 1. Caregivers (91%) were satisfied with the virtual model for FASD evaluation vs. in-person. Obj. 2. 77% of providers would recommend virtual options for at least one part of the FASD diagnostic process, after viewing the informative webinar.</p> | <p>Limitations: Non-randomized clinical study; descriptive in nature</p> <p>Strengths: Level VI, WEAK EVIDENCE; however, informative for practice in a similar setting like Alaska</p> |
| <p>Juarez, A. P., Weitlauf, A. S., Nicholson, A., Pasternak, A., Broderick, N., Hine, J., Stainbrook, A., & Warren, Z. (2019). Early identification of ASD through telemedicine: Potential value for underserved populations. <i>Journal of Autism and Developmental Disorders</i>, 48(8). doi: 10.1007/s10803-018-3524-y</p> | <p>Purpose: Evaluation of a telemedicine model for ASD</p> <p>Sample/Setting: 20 children (16 boys, 4 girls) between 20 – 34 months of age and their caregivers</p> <p>Blinded assessments performed of the same child after the in-person exam for comparison</p> <p>Remote assessors (n = 5) were established psychologists with experience in face to face evaluations of children with ASD.</p> | <p>Research Design/Level of Measurement: Quantitative, Descriptive</p> <p>DV: ASD diagnoses</p> <p>IV: Telemedicine assessments</p> | <p>Data analysis: Blinded assessments performed of the same child after the in-person exam for comparison.</p> <p>Mann Whitney U test for diagnostically discrepant children (n = 4).</p> <p>Sensitivity = 78.95%. Specificity not tested due to clinical severity of sample and lack of a non-ASD control group.</p> | <p>Study findings: Telemedicine accuracy validity 78.9% of children evaluated by telemedicine were diagnosed with ASD. The same children (n = 20) were then reevaluated in person by a different psychologist in a blinded study. All of the children diagnosed with ASD via telemedicine were also confirmed to have ASD by the in-person psychologist. First known study of it's kind in diagnosing very young children with ASD looking at feasibility, acceptability, and validity.</p> | <p>Limitations: No control group, Small sample size</p> <p>Strengths: Ultimately, this preliminary feasibility study provided support for the use of telemedicine to accurately identify a significant proportion of young children with ASD who had already been flagged as showing developmental concerns.</p> <p>MODERATE EVIDENCE</p> |
| | | | | | |

| | | | | | |
|--|--|---|--|--|--|
| <p>APA Citation:</p> <p>MacLaughlin, E. J., Ardery, G., Jackson, E. A., Ives, T. J., Young, R. B., Fike, D. S., Carter, B. L., & Keefe, P. E. (2013). Institutional Review Board barriers and solutions encountered in the Collaboration Among Pharmacists and Physicians to Improve Outcomes Now (CAPTION) study: A national, multicenter, practice-based implementation trial. <i>Pharmacotherapy</i>, 33(9). doi: 10.1002/phar.1276</p> | <p>Purpose: To catalog IRB barriers and potential solutions in a large, practice-based research network (PBRN) to inform what influences exist for principal investigators' (PI) when it comes to IRB decisions and barriers- to determine their receptiveness for future studies.</p> <p>Sample/Setting: 31 family medicine clinics with 28 principle investigators (clinical pharmacists) located in 14 states; participants were then stratified to 1 of 3 groups: 9-month physician-pharmacist collaborative model (PPCM) arm (n=216), 24-month PPCM arm (n=216), or control group (n=216) with a distractor asthma group arm.</p> | <p>Research Design/Level of Measurement: Authors of the study created, through content validity, a 15-item Likert type scale survey and distributed them to individual participants (n = 28) from around the country.</p> <p>DV: Satisfaction with IRB experience</p> <p>IV: varying IRB's across the country, including different practices and policies</p> | <p>Data analysis:</p> <p>Descriptive analysis utilized to describe PI and IRB characteristics.</p> <p>Spearman's correlation coefficient was utilized to compare perceived level of difficulty with an IRB, willingness to participate in future CAPTION trials, and time spent from initial to continuing IRB approval in past studies.</p> <p>Mann-Whitney U was utilized to determine whether or not the type of IRB (university vs. hospital based) correlated with time (IRB approval) and willingness to participate in future studies (PI).</p> | <p>Study findings: Willingness to participate in future research studies was inversely related to the perceived difficulty of obtaining initial (rS = -0.599, p = 0.004) and continuing (rS = -0.464, p = 0.034) IRB approval.</p> <p>IRB barriers & solutions described in table format.</p> <p>CAPTION study was delayed 9 months due to IRB barriers, resulting in significant financial implications not planned for.</p> <p>*Minority and pregnancy patients not allowed to participate due to IrB perceived risk when risk was minimal to subjects.</p> <p>Team support was significantly correlated with likelihood to participate in future studies.</p> <p>Study completed in teaching facilities linked with institutions, therefore, IRB barriers anticipated to be even greater in community clinic work and IRBs.</p> | <p>Limitations: Small number enrolled in study (n = 28). External validity questionable due to participants' affiliation with a research institution (research/scholarship in job expectations).</p> <p>Strengths: Participants located across the country from primary care clinics linked to study institutions. Inclusion of underserved and minority populations strengthened validity. STRONG EVIDENCE</p> |
| <p>Article citation:</p> <p>Onakomaiya, D., Pan, J., Roberts, T., Tan, H., Nadkarni, S., Godina, M., Park, J., Fraser, M., Kwon, S. C., Schoenthaler, A., & Islam, N. (2023). Challenges and recommendations to</p> | <p>Purpose: A scoping review to describe and identify barriers and ways to overcome these barriers for community engaged research (CNeR) partners and PIs in working with IRBs. This scoping review aims to identify challenges and recommendations</p> | <p>Research Design/Level of Measurement: 1192 articles initially identified, whittled down to only 15 peer-reviewed articles that met study criteria. A medical librarian performed the review using PRISMA-Scr scoping review</p> | <p>Data analysis:</p> <p>PRISMA-Scr guidelines utilized for two medical librarians to extract data individually, into Covidence</p> | <p>Study findings: IRBs are difficult to work with in community research projects due to lack of knowledge and partnership, stifling relationships. Community board members need to be a part of the IRB to bridge access and understanding of CNeR studies.</p> | <p>Limitations: Scoping review process at risk for inconsistencies between reviewers, Strengths: Study selection from large pool with strict inclusion criteria, followed PRISMA-Scr guidelines to negate inconsistencies,</p> |

| | | | | | |
|--|---|---|--|---|------------------------|
| <p>improve institutional review boards' review of community-engaged research proposals: A scoping review. <i>Journal of Clinical Translational Science</i>, 7(1). doi: 10.1017/cts.2023.516</p> | <p>for CEnR investigators and community partners working with IRBs. Peer-reviewed articles that reported on CEnR, specified study-related challenges, and lessons learned for working with IRBs and conducted in the United States were included for review.</p> <p>Sample/Setting:</p> | <p>guidelines. MEDLINE, PsycInfo, and CINAHL were utilized.</p> <p>DV: Experience with the IRB</p> <p>IV: CNeR (community research)</p> | | <p>Duration of the IRB approval process was long and arduous, too systematic for CNeRs, when a shortened more supportive approach was needed.</p> <p>“Working with multiple IRBs (local, tribal, and national IRBs in addition to academic IRBs).Hurdles around local and tribal policies to obtain IRB approval”</p> <p>Resolution: to create community minded policies to support engagement with community and local stakeholders/IRB/tribal/government.</p> | <p>STRONG EVIDENCE</p> |
|--|---|---|--|---|------------------------|

Appendix K: Policy Handbook



FASD Team: Policy Handbook

Evaluating and diagnosing fetal alcohol spectrum disorders using the 4-Digit Code with a Hub and Spoke Method



The purpose of this employee handbook is to guide and orient those associated with the FASD Team at Ptarmigan Connections. This policy handbook was created to meet needs of those who utilize the 4-Digit Code Method (Astley, 2024). This guide informs users at each step of the process, to provide a user-friendly algorithm in which to carry out this often complex process.

Disclaimer: This policy handbook was created by an FASDx team member, who was also a Doctorate of Nursing Practice candidate at the University of Alaska, Anchorage. This policy handbook was created to meet both degree requirements and improve practice through a quality improvement project. Any information in this policy handbook reflects current practice of an FASDx State of Alaska Team, of which can be changed at any time in the future, as deemed necessary by the Provider Agreement (State of Alaska Mental Health Trust Fund/FASD Office).

Table of Contents

| | |
|--|-----------|
| <i>Section 1 - Introduction</i> | 3 |
| 1.1 Project Statement | 3 |
| 1.2 Purpose of this Handbook | 3 |
| <i>Section 2 – Getting Started with the Hub and Spoke Process</i> | 4 |
| 2.1 Legal Agreements and Standards | 4 |
| 2.2 Referral Process | 4 |
| <i>Section 3 – The 4-Digit Code</i> | 6 |
| 3.1 Code Explained | 7 |
| 3.2 Sample Forms | 7 |
| <i>Section 4 – The Evaluation Process</i> | 7 |
| 4.1 Medical Evaluation | 8 |
| 4.2 Neuropsychology Evaluation | 8 |
| 4.3 Occupational/Speech Therapy Evaluation | 8 |
| <i>Section 5 – Post Evaluation</i> | 8 |
| 5.1 Team Meetings | 8 |
| 5.2 Final Results Report | 9 |
| <i>Section 6 – Patient/Family Support</i> | 10 |
| 6.1 Support | 10 |
| 6.2 Statistics & State Reporting | 11 |
| 6.3 Conclusion | 11 |

Section 1 - Introduction

1.1 Project Statement

Since few FASD teams exist in Alaska, there is a drive from state stakeholders to widen the impact of community-based FASD-specific diagnostic teams through an integrated approach (WICHE-BHP, 2021). This integrated approach allows for diagnostic services to be either in person or through telehealth, and can vary throughout a single evaluation, to best suit the needs of the patient, family, and clinic (WICHE-BHP, 2021). State stakeholders include but are not limited to the following: State of Alaska Department of Health and Social Services, Alaska Mental Health Trust Authority, and the Alaska FASD Partnership.

The aim of this project is to create a Hub and Spoke method policy handbook for use in FASD evaluations and to reapproach a two-team method of FASD evaluation as described by Benoit et al. (2004). This Hub and Spoke method has the potential to increase access to care for those alcohol-exposed children living in rural Alaska.

1.2 Purpose of this Handbook

This policy handbook highlights the foundation of the Hub and Spoke FASD evaluation practice model along with the FASD evaluation process with or without the hub/spoke piece. The handbook provides a foundation of methods that could be utilized in a number of services where trained providers are scarce, patient evaluations need to be completed, and there is an able clinic willing to serve as the main source of Hub and Spoke management. Due to the many geographical and logistical constraints a rural area like Alaska has, the Hub and Spoke method is a natural solution. *The following is a policy handbook which guides a hub clinic through the steps of the referral process, 4-Digit Code evaluation, and dissemination of the final results of an FASD evaluation.*

Section 2 – Getting Started with the Hub and Spoke Process

2.1 Legal Agreements and Standards

Legal agreements must be in place before getting started with the Hub and Spoke process. An up-to-date Provider Agreement (PA) must be signed by all providers at the hub location only. The PA provides a framework by which an FASD team is able to legally give evaluation services, under the guidance of the State of Alaska statewide FASD program. Please review the PA agreement, link provided below. To maintain these standards, a team and clinic must comply with the written standards given in the Provider Agreement. The PA requires standards be met by the involved clinic and providers (FASD team) and is described below:

| Provider Eligibility | Notes |
|--|---|
| State of Alaska IRIS Provider Vendor Number | Listed in signed PA. |
| State of Alaska business license | Must be current. |
| Not Applicable- Alaska Native entities clause | Waiver of immunity from suit for claims arising out of activities of the Provider related to this Agreement using Appendix D; *Ptarmigan Connections does <i>not</i> qualify for this clause. |
| Current list of FASD providers | List name, copy of valid and current licenses and certifications. |
| University of Washington 4-Digit Code training | Provide certificate of proof of training for 4-Digit Code course. |
| Certificates of Insurance | Per PA, see Section IX |
| Licensing/certifications | Necessary licensing and certificates for the service facility. |

*Adapted or quoted from the Provider Agreement Revised 9/2021.

A second piece of the PA is required to meet PA standards for a licensed agency. See table below for compliance requirements:

| | |
|-------------------------------|--|
| Privacy & Security Procedures | See Appendix C of the PA |
| Fire code, ADA requirements | Meets current fire code and American Disabilities Act standards, and location of program services must provide reasonable and safe access. |
| Licenses | Keep current any and all licenses, certifications and credentials required of the provider agency, staff, and facility to qualify for providing services to DHSS clients through this Agreement and to keep current the necessary documentation on file with DHSS to demonstrate compliance. |
| FASD Network meetings | Provider agrees to participate in monthly |

| | |
|------------------------------------|--|
| | FASD Diagnostic Team Network meetings; other opportunities include specific training and technical assistance. |
| Minimum number of FASD evaluations | A minimum of 12 annual FASD diagnostic evaluations is required to team consistency of process, agency integrity, and commitment to producing a quality, comprehensive evaluation beyond a diagnosis. If these numbers cannot be achieved, the Provider Agreement may terminate at the end of that fiscal year. |

*Adapted and/or quoted from the Provider Agreement Revised 9/2021.

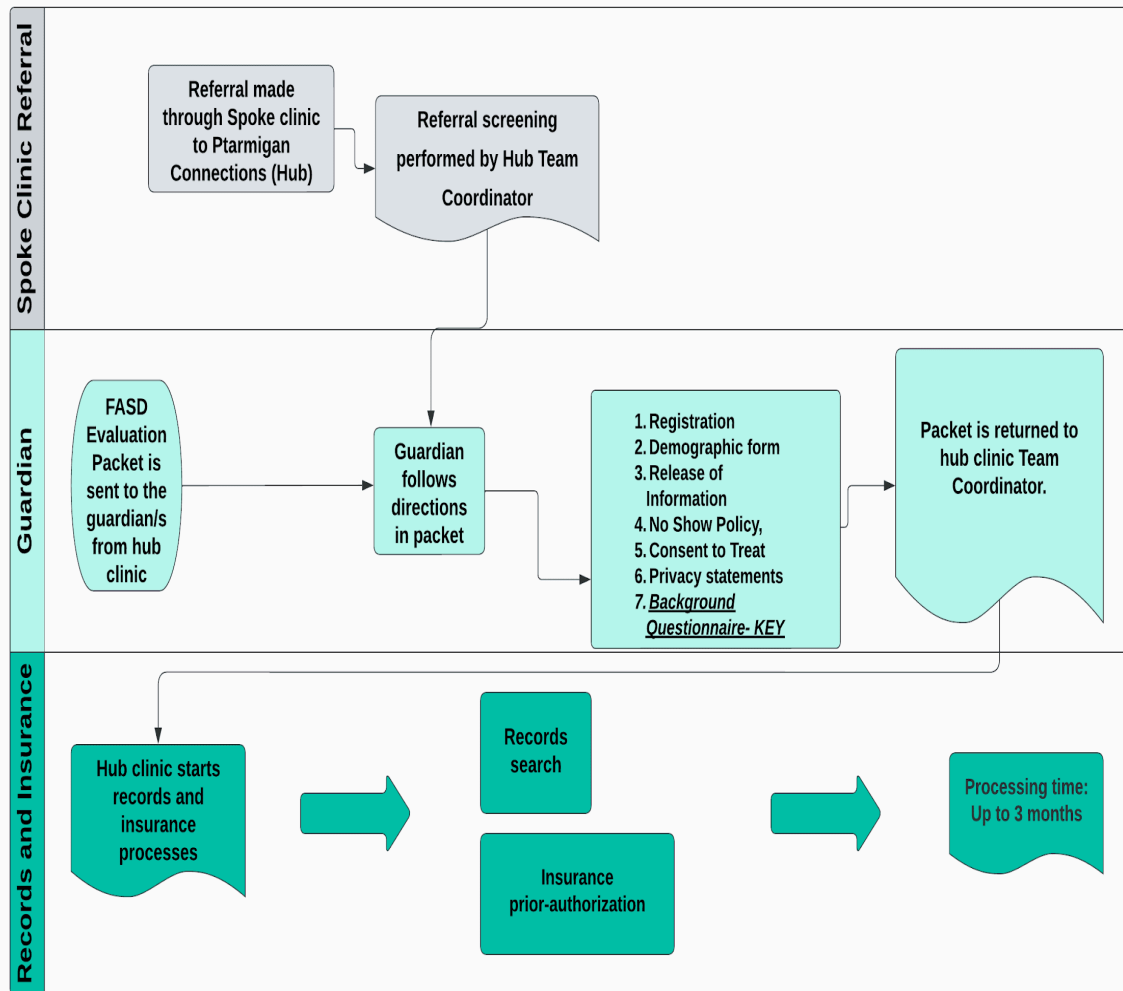
One benefit of the Hub and Spoke method, as only one team is responsible for maintaining the requirements held by the Provider Agreement. The PA must be reviewed and signed every two years per the Alaska State FASD office.

Provider Agreement Link:

<https://aws.state.ak.us/OnlinePublicNotices/Notices/Attachment.aspx?id=129714>

2.2 Referral Process

The referral process begins with the Team Coordinator (TC) role. This role is the foundation of an FASD team and the lifeblood of the evaluation process. With no one coordinating, the momentum of the evaluation process can stall out. The evaluation process starts with the referral. The following is a description of the referral process, as initiated by the TC. The referral process follows these steps, as given in the chart below:



The following information describes the referral process in more detail. A referral is made to the hub clinic Team Coordinator from a primary care provider or other qualifying source. If the child is in custody by a guardian through the Office of Children's Services (OCS), they must also seek a referral through a qualifying source. Other sources include an Alaska Native Corporation or a psychologist. It is ideal for a hub clinic primary care provider to be involved, to maintain a central repository for documentation and continuity of care post evaluation.

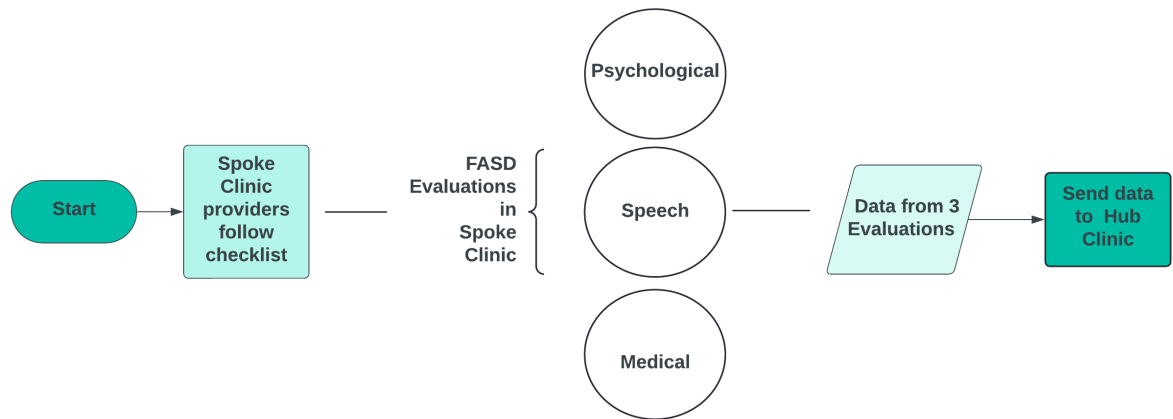
Once a referral is received by fax, email, or hardcopy, a referral screening is performed by the Ptarmigan Connections (PC) Team Coordinator. Included in the referral is supporting documentation. Examples of supporting documentation include a well child check or acute visit with their chief complaints. Insurance verification then occurs, to ensure third-party payment is approved for the evaluation.

The Team Coordinator contacts the legal guardian/s. Legal guardians can include biological parent/s, foster/adoptive parent/s, the Office of Children's Services, and/or Guardian Ad Litem. Contact is made to discuss the referral and reasons for referral if they are not known to the guardian.

An FASD Evaluation Packet is sent to the guardian. *The Background Questionnaire is essential.* On this document, all items must be addressed in terms of previous records. The guardian will check whether or not the child has had any reference to those items. If the child has records related to speech therapy, occupational therapy, school records, or medical records, then the guardian will state yes/no and where those records are housed. If there are no records, then they will state that. Other essential items to find if present are head imaging, inpatient psychiatric care, birth records, weights and heights from birth and on, home care visits, and whether or not the biological mother has alcohol or drug-related legal charges as listed in Alaska State Court View.

1. The guardian will receive (email/mail) the Guardian Letter, which discusses how the FASD evaluation process runs in the clinic.
2. A release of information (ROI) is sent to all parties found on the Background Questionnaire. This request is for records pertaining to the child. This can include therapy notes, a previous neuropsychiatric evaluation, or school testing. Frequent checking in by the Team Coordinator for pending records information is essential in getting necessary documents.
3. Insurance verification should also occur during this juncture while waiting on past records. The child's insurance/s is notified by the Team Coordinator to see if prior authorizations are necessary for an evaluation paid for by a third-party insurer.

*This process can take 1-3 months to complete.



1. Medical evaluation plus psychological testing by Spoke
2. Speech evaluation plus psychological testing by Spoke
3. Data sent to Hub providers. Reviewed.
4. Team Meeting for Hub providers (psychological, medical, and speech therapy) to discuss data and determine final results
5. Final Results Meeting with guardian/s with Hub provider (psychologist) via telehealth appointment.

Section 3 – The 4-Digit Code

3.1 Code Explained

The four digits in the 4-Digit Code reflect the extent of the expression of the four diagnostic clues to a potential fetal alcohol spectrum disorder, and these clues are in the following order: 1) growth deficiency, 2) the fetal alcohol syndrome facial features, 3) central nervous system structural and functional abnormalities, 4) prenatal alcohol exposure (Astley, 2024). Each component is ranked on a 4-point Likert scale, with a 1 reflecting absence of that symptom, and 4 being the strongest presentation of that feature (Astley, 2024).

| 3 Diagnoses under the FASD Umbrella | | Growth | FAS Face | Brain | Exposed |
|-------------------------------------|---|--------|----------|----------|---------|
| 1. FAS | Fetal Alcohol Syndrome | growth | face | severe | yes |
| 2. SE/AE | Static Encephalopathy/Alcohol Exposed | | | severe | yes |
| 3. ND/AE | Neurodevelopmental Disorder/Alcohol Exposed | | | moderate | yes |

(Adapted from Astley, 2024)

3.2 Sample Forms

Spoke provider letters and checklists were created for the purpose of this policy handbook, to give further diagnostic guidance to a spoke clinic. Each form is specialty specific and can be utilized during a patient evaluation by the spoke provider. See Appendices A and B for FASD- Letter and Checklist, adapted from the Diagnostic Guide (Astley, 2004).

Section 4 – The Evaluation Process

The evaluation process consists of separate evaluations from each required specialty. These exams are then brought together in a final report that is available for families, Office of Children’s Services, and any other entity that has legal rights to it (legal guardians/s, Guardian Ad Litem, primary care provider).

Scheduling of Evaluations and Team Meetings

After insurance verification has occurred and all records are received at the Hub Clinic, the guardian can schedule the respective evaluations at their spoke clinic (psychology, speech, and medical) and utilize the FASD Letter/Checklist Forms. The FASD evaluation requires 2-4 separate appointments. It is ideal to combine psychological testing with the other two evaluation days to allow observations from speech testing to be utilized for psychological testing as well, and to reduce the number of appointments for families. Here’s an example of an FASD evaluation schedule:

- a) Medical evaluation plus psychological testing by Spoke
- b) Speech evaluation plus psychological testing by Spoke
- c) Data sent to Hub providers. Reviewed.
- d) Team Meeting for Hub providers (psychological, medical, and speech therapy) to discuss data and determine final results
- e) Final Results Meeting with guardian/s with Hub provider (psychologist or whomever the team lead is) via telehealth appointment.

4.1 Medical Evaluation

The patient will be evaluated by the spoken medical provider in a face-to-face medical exam. The FASD Letter/Checklist Forms will be filled out during this visit. A medical provider can be a physician, nurse practitioner, or physician’s assistant. They do not have to be certified in the 4-Digit Code method to complete this exam/form. The medical

provider will complete a complete medical exam, with a focus on the components required for the 4-Digit Code. These include a thorough history of present illness, review of systems, a head-to-toe assessment including a neuro exam. The focus of the HPI is to assess a general history of the patient along with answering questions related to the 4-Digit Code. The focus of the medical exam is to find abnormalities related to in-utero alcohol exposure, along with unrelated abnormalities. Findings of the exam are written in the chart as a typical chart note, and made available to the hub team via the FASD Letter/Checklist Form that is faxed/emailed back to the hub clinic.

4.2 Psychology Evaluation

The patient will be evaluated by the spoken psychologist in a face-to-face exam. The psychologist will complete a battery of exams according to the 4-Digit Code guidelines. Findings of the exam are written in the chart as a typical chart note, and a FASD Letter/Checklist Form is faxed/emailed to the hub clinic.

4.3 Occupational/Speech Therapy Evaluation

The patient will be evaluated by the spoken occupational or speech therapist in a face-to-face exam in the spoke clinic. This portion of the exam may be completed by either an occupational or speech therapist. The therapist will complete a battery of exams as determined by the 4-Digit Code guideline. Findings of the exam are written in the chart as a typical chart note, and a FASD Letter/Checklist Form is faxed/emailed back to the hub clinic.

Section 5 – Post Evaluation

5.1 Team Meetings

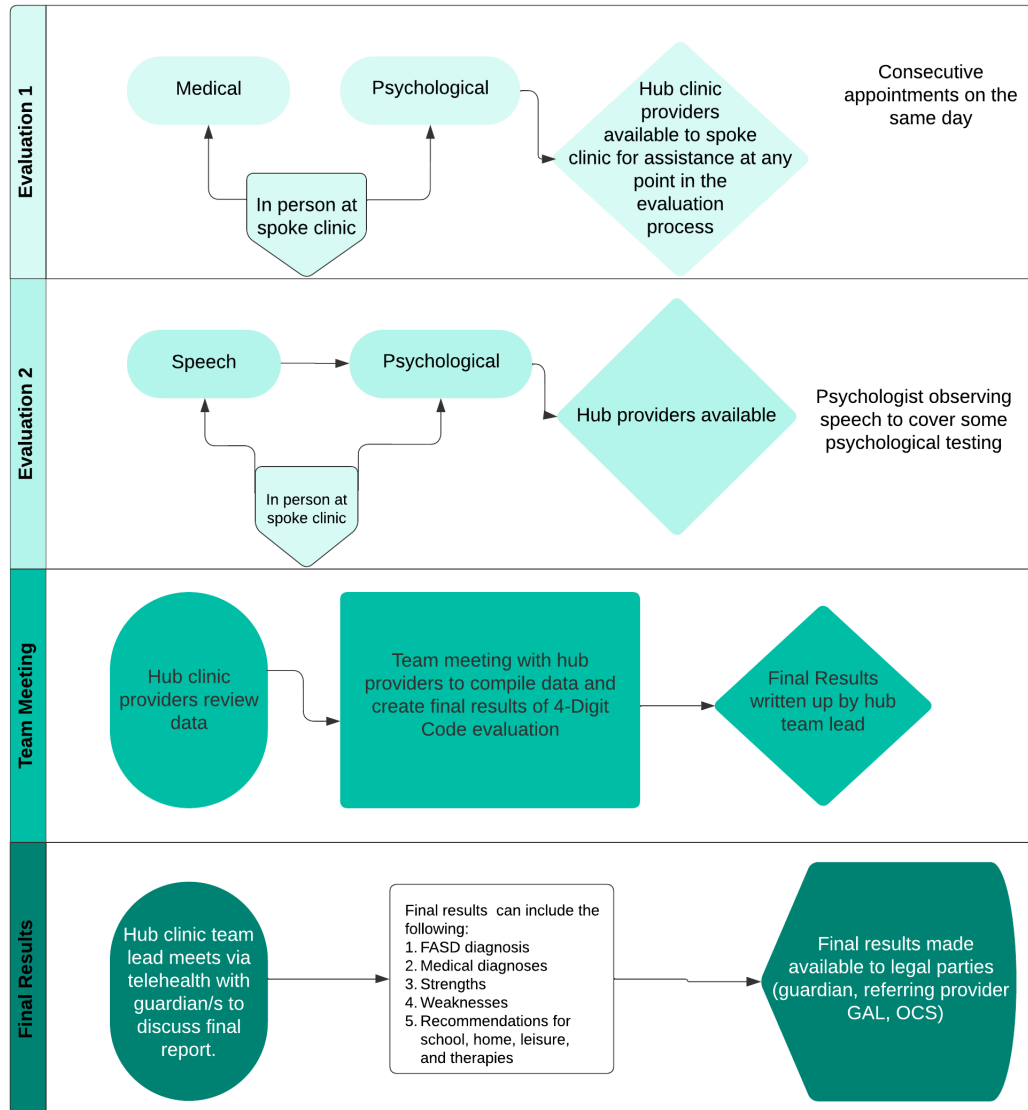
The hub team members will review their respective data (FASD Letter/Checklist and records) and meet to compile the 4-Digit Code into a comprehensive report. The hub team lead will lead this meeting, and create the final report from their findings.

5.2 Final Results Report

Findings from each of the providers' findings will be written in a final report. This summary is a comprehensive report that includes medical history highlights, a thorough description of the actual 4-Digit Code (growth, face, brain, and alcohol exposure) and how the team came to that code, other diagnoses, and a plan of care. A teleconference meeting is scheduled with the patient's family or legal representative. The hub team lead meets with family and reviews the final result report. Questions are answered. The State FASD Family support person also attends the meeting to introduce themselves and give contact information. Family support then provides ongoing support for the patient and/or family from that point on.

A copy of the report will be provided to the family, given proper clearance as necessary by the guardian. If the child is in the care of the Office of Children’s Services (OCS), then proper clearance of the final results will be needed. The referring provider will receive a copy of the report.

Below is a summary of the evaluation process using the Hub and Spoke method and 4-Digit Code:



Section 6 – Patient/Family Support

6.1 Support

One key benefit to this process is the patient and family receive medical, educational, and therapeutic benefits if they receive an FASD diagnosis. These benefits are paid for by the Alaska Mental Health Trust Fund. The family liaison is contracted with the Alaska State FASD Diagnostic Team Network and is tasked with the job of giving families support indefinitely, from the point of diagnosis. Examples of these supports include a monthly dinner for families affected by FASD, a parent support group, personalized care plans, and mini-grants in the amount of \$3500 to pay for any items that may give support. The liaison will also attend care appointments with parents for both home and school supports. Mainly, the liaison will provide essential support and navigation for the family.

6.2 Statistics & State Reporting

Once a final report is generated, statistics are sent to the Alaska Automated Information Management System (AK AIMS). The AK AIMS is an information system that collects state wide data on behavioral health within Alaska. It gives the ability of both primary care and behavioral health data to be combined into one repository for the purpose of improved behavioral data collection. The Team Coordinator sends the following information to the AK AIMS site after each evaluation: creates patient unique profile, 4-Digit code and diagnosis, other diagnoses if applicable.

6.3 Conclusion

Use of this policy handbook will help guide the Hub and Spoke method of diagnostic evaluation in a rural setting. This policy handbook was written with the intent for use with the 4-Digit Code method; however, the Hub and Spoke method could be applied to many other types of evaluations in which specialized, trained personnel is an obstacle. References to follow.



Ptarmigan Connections
3505 E Meridian Park Lp Ste 200
Wasilla, AK 99654
907-357-4400 (office)
907-357-4533 (fax)
ptarmiganconnections.com

***Appendix A
CHECKLIST- MEDICAL**

The following is a checklist to utilize during the medical portion of the FASD evaluation process. Please complete each item as listed as they are required for the most robust evaluation..

Today's Date: _____

Child's Name: _____ Also known as: _____

Birthdate: _____ Age: _____ Gender: _____ Preferred pronouns: _____

Name of School: _____ Primary Teacher(s) Name: _____
Grade: _____ Ethnic background: _____ Tribe: _____

Language(s) spoken in the home _____

Child's Primary Care Provider _____

Child's Other Provider(s): _____

What is the main concern leading to this referral?

MEDICAL HISTORY

What is their pertinent medical history that's relevant for an FASD evaluation? Many items pertain and below is a checklist to help guide you on the important information to gather from your patient and their guardian. Refer to the Background Questionnaire for more detailed information from the guardian. The following is meant to be a checklist of items to include in the medical evaluation in the patient's chart.

Background Questionnaire Reviewed: Yes No

Current Medical diagnoses: _____

Current Mental Health diagnoses: _____

Vision History _____

Dental History _____

Hearing _____

Brain Imaging___
Seizures___
Previous Psychiatric Assessments___
Social History___
 Foster Placement/Guardianship/Adoption___
 Biological Siblings___
 Siblings Living in Household___
 ACES___
Legal Issues___
Family Medical History___
Family Psychiatric History___
Review of Systems___
Strengths___
Developmental History___
Pregnancy History___

—
Alcohol Exposure Prenatally___

Growth
 Prenatal Growth___
 Post-Natal Growth___

Facial Analysis Photos___

Complete Head to Toe Exam___
 Current Head Circumference___
 CNS Exams (Structural/Neurological/Functional)___
 Full Neurological Exam___

Review All Records___



Ptarmigan Connections
 3505 E Meridian Park Lp Ste 200
 Wasilla, AK 99654
 907-357-4400 (office)
 907-357-4533 (fax)
 ptarmiganconnections.com

***Appendix B
 CHECKLIST-SPEECH/NEUROPSYCHOLOGY**

The following is a checklist to utilize during the medical portion of the FASD evaluation process. Please complete each item as listed as they are required for the most robust evaluation.

Today's Date: _____
 Child's Name: _____ Also known as: _____
 Birthdate: _____ Age: _____ Gender: _____ Preferred pronouns: _____
 Name of School: _____ Primary Teacher(s) Name: _____
 _____ Grade: _____ Ethnic background: _____ Tribe: _____

 Language(s) spoken in the home _____

What is the main concern leading to this referral?

SPEECH LANGUAGE HISTORY

What is their pertinent speech language and neuropsychological history that's relevant for an FASD evaluation? Many items pertain and below is a checklist to help guide you on the important information to gather from your patient and their guardian. Refer to the Background Questionnaire for more detailed information from the guardian. The following is meant to be a checklist of items to include in the evaluation in the patient's chart. Refer to the Diagnostic Guide for Fetal Alcohol Spectrum Disorders for the full guideline on utilization of the 4-Digit Code method (Astley, 2004).

Background Questionnaire Reviewed: Yes No
 Current Medical diagnoses _____
 Current Mental Health diagnoses _____
 Hearing _____
 Previous Speech Language Assessments _____
 Social History _____
 Foster Placement/Guardianship/Adoption _____
 Biological Siblings _____

Siblings Living in Household____
ACES____
Legal Issues____
Family Medical History____
Family Psychiatric History____
Review of Systems____
Strengths____
Pregnancy History____

Alcohol Exposure Prenatally____

Psychometric Assessments

Cognition____ Academic Achievement____ Adaptive Behavior/Social Skills____
Neuropsychological____ Motor/Sensory Integration____
Language/Social Communication____ Mental Health/Psychiatric____
Behavior/Attention/Activity Level____ Development____
Number of Affected Domains____

*Clinical Team to Assess Severity of Impairment/Abnormality of CNS
Review All Records____

Astley, S. J. (2004). *Diagnostic guide for Fetal Alcohol Spectrum Disorders: The 4-Digit diagnostic code*. FAS Diagnostic and Prevention Network. University of Washington.

Astley Hemingway, S. J., Jirikowic, T., & Olson, E. M. (2020). What proportion of the brain structural and functional abnormalities observed among children with fetal alcohol spectrum disorder is explained by their prenatal alcohol exposure and their other prenatal and postnatal risks? *Advanced Pediatric Reserves*. Available in the PMC manuscript.

file:///C:/Users/lmcoffman/Downloads/What_proportion_of_the_brain_structural_and_functi.pdf

Benoit, T., Bowes, C., Bowman, N., Cantin, D., Chudley, A., Croll, D. (2002).

Telemedicine diagnosis for fetal alcohol syndrome- The Manitoba experience.

Paediatrics and Child Health, 7(3), 147-151.

