

**Alaska FASD Partnership  
Diagnosis/Case Management/Parent Navigation Workgroup  
MINUTES - 12/1/10 and 12/2/10**

**Present:** Vicki Tinker, Cheri Scott, Jeri Museth, Mike Baldwin, Teri Tibbett

**Diagnosis in areas without a team**

**Discussion:** Transportation is an issue. People don't have the means to travel to a hub for diagnosis. There are pros and cons regarding itinerant diagnostic teams. Difficult for team to do a thorough job in a short visit. Itinerant teams were the original method in Alaska. Communities with greatest need have no resident team. Itinerant teams and tele-behavioral health could be a solution.

**Recommendations:** Investigate the idea of developing and funding traveling (itinerant) diagnostic teams and using tele-behavioral health system for diagnosis.

**Diagnosis of incarcerated individuals**

**Discussion:** Expressed doubt that Corrections will expand diagnosis capabilities because they have to pay for the services, however, there is a changing culture within the department and the legislature that treatment is cheaper than incarceration, and so officials may support expanding diagnosis and treatment as a way to reduce recidivism, and costs. Corrections staff are receiving needs assessment training and working with Trust and Arctic FASD RTC to gather information on FASD. DJJ is talking about recidivism rates related to Alaska Native youth, but are not moving toward identifying youth with FASD.

**Recommendations:** 1) expand training of Corrections and legal system personnel about FASD, including screening, diagnosis and interventions; 2) develop more accurate diagnosis and support system within the legal system; 3) identify or develop streamlined screening processes that identifies "probable FASD," so judges, attorneys, probation and correction officers, etc. understand the disability and promote appropriate interventions; 4) develop a large scale pilot project using Diane Malbin's screening tool; 5) look into Canadian data that shows 25% of incarcerated individuals have an FASD (in Alaska 25% could mean 1,000-1,250 individuals); 6) educate DJJ about FASD and the need to institute processes that identify youth with FASD.

**Case Management**

**Discussion:** Case management is not available because reimbursement is an issue. Individuals are being diagnosed, but case management is not available. Need more case managers. What is the eligibility criteria? IQ is too high for DD services, but behaviors aren't severe enough to warrant BH services. 90% of individuals being diagnosed do not qualify for DD services because their IQ is above 70. That 90% is underserved. Representatives from DD are part of diagnostic teams (speech, occupational, etc). Need more trained mental health professionals, clinicians, social workers and psychiatrists who can work across the systems to help individuals with behavior and brain-based disorders. Another piece is agency communication and collaboration – building bridges between mental health system and other systems so each is on the same page with the same information and strategies. Possible models are TDM Team Decision Making (used by OCS, an interagency approach in which a team of workers steps in when FASD is identified), and Greater Anchorage Area Child ??? who comes together once a month, and Kenai Peninsula's Children's Team who comes together to discuss common issues. One problem is case manager turnover. Need case managers to work with individuals for a year to integrate individuals with FASD into existing systems. Need FASD interpreters for individuals at all agency levels – courts, education, corrections, employment, etc. Need an entity that trains and sets up a host of case managers/parent navigators.

**Recommendations:** 1) Funding and training for case managers (workforce development); 2) train mental health professionals, case managers, clinicians, social workers and psychiatrists who can work across the systems with individuals with brain-based disorders (workforce development); 3) build bridges between the mental health system and other systems so each is on the same page with the same information and strategies; 4) develop a system in which one case manager works with an individual with FASD across systems “care coordinators”; 5) develop a statewide entity that trains, certifies, and brokers case managers/parent navigators; 6) develop a consensus of what effective case management is related to serving with people with FASD.

### **Diagnosis of adults, in general, and what services may be useful/available**

**Discussion:** It’s rare for suspected FASD to have health insurance, and w/o diagnosis there is no Medicaid, getting history on alcohol exposure is a challenge, w/o case manager they don’t make appointments (due to disability of difficulty following what to do), need case manager to help deal with services, lack of resources available, not meeting eligibility criteria for what is available. Adults are not being served as well as children because children are usually better insured and have services available in school, fewer services for adults. Payment for adult services is a challenge. Canada accommodates adults, but their insurance system is different so their system may not work; Joint MOU between US Indian Health Services and Health Services Canada and First Nations related to FASD and did a scan a best and promising practices related to FASD, mostly prevention, but other issues as well.

**Recommendations:** 1) Develop system of peer navigators (friends, family, spouse, pastor); 2) Determine current state of the field, what are the key adult services needed (best practices for diagnostic and intervention services); 3) Research best practices.

### **Review of screening tools available**

**Discussion:** Related to FASCETS tool. Are there other screening tools worth investigating? What is the reliability? Historically, the standard screening tools have not been culturally relevant in rural Alaska. Are there acculturated screening tools? A screening tool used in Washington state takes photos of all children in Foster Care, and does follow-up screening/diagnosis when a child presents with FAS facial features; OCS in Alaska is implementing something similar. Look into incorporating a mixture of screening tools.

**Recommendations:** 1) Research current best practices for accurate screening/assessment tools.

### **Most useful diagnostic report model**

**Discussion:** Alaska Diagnostic clinics use one model for diagnosis, (UW model), but there are other models out there. Alaska’s diverse issues begs to research other models that might fit Alaska’s diverse needs (rural, incarcerated individuals, education, individual teams, regions, clients, etc.) which could be less time-intensive, less costly. Other models: CDC model, Canadian models, Larry Burd/Eugene Hoyme “Institute of Medicine” approach. Be cautious of how many models we recommend. Important to define what is the optimal model for communicating diagnostic teams’ recommendations for intervention and care.

**Recommendations:** 1) Research current best practices for diagnostic tools.

### **Parent Navigation**

**Discussion:** Parent Navigators need to be included in existing systems. Each team varies on how they use their parent navigators – some work as case managers, some do education in the community, etc. Need to clarify PN roles on the diagnostic team.

**Recommendation:** 1) Market what diagnostic clinics are doing and develop awareness campaign that serves to educate people across systems about the role of diagnostic teams and parent navigators. Use

the campaign to recruit diagnostic team members, including parent navigators; 2) Research what are the various roles of Parent Navigators on different teams, possibly organize a forum for PN to come together and share practices and establish standards; 3) Explore Parent Navigation as a reimbursable service.

*Resources:*

- “Promising Practices Scan” produced by the US-Canada Indian Health – Health Canada –First Nations FASD Workgroup about 4-5 years ago. Go to:  
[http://www.ihs.gov/MedicalPrograms/Behavioral/documents/FASDPromisingPracticesfinaldraft\(6\)-jt.pdf](http://www.ihs.gov/MedicalPrograms/Behavioral/documents/FASDPromisingPracticesfinaldraft(6)-jt.pdf)
- Article: “Challenges of Diagnosis in FAS/FASD in the Adult” by Chudley et al. (2007)
- Documents related to the FASCETS Screening Tool: “FASD Neurobehavioral flags for screening,” “FASCETS Conceptual Foundation,” “BC Key Worker & Support Program Summative Evaluation,” “BC Key Worker & Support Program Final Formative Evaluation”

*Additional notes:*

- Teri will gather recommendations for best practices/research/programs and coordinate with Alex at Arctic FASD RTC to augment the list.
- ~~Mike will locate a document MOU between US Indian Health Services and Health Services Canada and First Nations related to FASD and did a scan a best and promising practices, mostly prevention, but other issues as well, and will locate an article out of Manitoba related to adult services (DONE)~~
- Need to consider an FASD awareness/education campaign so agencies who encounter people with FASD know what to look for and what interventions to use.
- Youth are being approved on the FASD waiver, but don’t have case managers to serve them. Why is waiver program not succeeding?
- Jeri is going to Washington DC and serving on a panel related to FASD and will ask about national best practices for diagnosing and serving adults with FASD.