

**Alaska FASD Partnership
Family/Peer Support Workgroup - MINUTES
January 19-20, 2011**

January 19

Present: *Jeanne Gerhardt-Cyrus, Laurie Rorem, Larry Rorem, Robyn Priest, Teri Tibbett*

Opened the meeting with discussion about the recommendations and actions decided at the December summit; goal of the workgroup is to identify first steps; and identify what actions members of the workgroup can take on. Jeanne noted that many of the recommendations decided with this workgroup were rolled into the Adult Services Workgroup, so look at that list for recommendations related to adult services.

Discussion on SHORT TERM GOAL: Work with Alaska Peer Support Consortium (AKPSC)

Robyn Priest offered an overview of the AKPSC: The Consortium includes individuals and peer-run organizations, formerly only mental health, but recently expanded to include all Alaska Mental Health Trust (Trust) beneficiary groups (people with mental health issues, substance abuse, Alzheimer's and related dementia, developmental disabilities); Consortium is currently working with the Trust on workforce development issues to develop peer worker credentialing, asking what are the core issues that parent navigators would need training in for working with people in the beneficiary groups; also works with parent navigation and family members; AK Peer Support Consortium conference is April 11-12; the next Consortium meeting is April 9-10. Robyn encourages members of the AK FASD Partnership to join the Consortium (there are parameters), she will send out brochure that explains how to join and what are the parameters.

The workgroup reviewed the list of goals from the summit:

- Join AKPSC (so FASD has a voice at the Peer Support meetings and planning)
 - Ask members on workgroup to join (see AKPSC brochure)
 - Ask members on workgroup to recruit others to join (see AKPSC brochure)
 - Invite members of the Partnership to join (Teri will do this)
- Attend AKPSC meetings (in person/by phone)
 - Invite members to attend meetings
 - Meetings happen in Anchorage and by teleconference. Next meeting is April 9-10 in Anchorage – AKPSC will pay for travel for members to attend.
 - Attend AKPSC Conference
- Work with AKPSC to develop credentialing for Peers/Parent Navigators

General Discussion:

Rorem's: They are the parents and grandparents of children/grandchildren with FASD. Trouble navigating the system, identifying the issues early, facing the reality of the disability, when the problem appears to be fixed they child/person is dropped from the system, parents of younger kids need to be educated about the realities of the disability so they will be able to advocate throughout the child's life and work on accommodations throughout their lives.

Jeanne: Wants to put energy into the case management/care coordination piece. Not just those who qualify for DBH and/or DD services.

Teri: Gave an update on the funding that passed last session for access to services for people diagnosed with FASD, four diagnostic clinics are working with DHSS to develop provider agreements that will allow case managers to get paid for helping families and individuals navigate systems, understand the disability, learn interventions, etc. The department is writing up the agreements now and will soon go out into the communities of Sitka, Bethel, Juneau and Kenai. Also noted that some people with FASD are being served in the DD service system, others are being served in the BH service system, but many are not being served by either. There is a need to identify who are NOT being served, what are their needs, and what steps are necessary to reach this group.

Jeanne & Rorem's: Many do not qualify for DD services because IQ is too high, so they "fail miserably" and eventually develop behavioral difficulties. Lots of kids with FASD don't show signs of difficulty in Pre-K and Early Childhood – not until transition points, e.g. intermediate grades, Middle School and High School.

Intermediate grades (4th-6th grades) is when children are developmentally moving into conceptual learning, kids with FASD have difficulty "catching on" because of their processing difficulties; they're accused of being inattentive, off-task, etc. resulting in frustration and failure, rather than recognizing their brain differences and need for accommodations; they often end up on the 'crime and punishment cycle' and get disciplined out rather than being helped. Higher functioning kids often develop the attitude "it's better to be bad than stupid" and so behaviors become an issue; it's important to ask what can be done in the child's environment to help solve the problem.

In Middle School, children continue to struggle with processing difficulties, exacerbated by expanded choices and opportunities – because processing everything at once is difficult; also social issues develop: interactions with peers, inappropriate social behaviors, chastised for being different, etc. In High school there is more falling behind because previous needs haven't been met, dealing with lack of skills, low self esteem, and often turning to self-medicating to cope with what's not working in their world.

All through school many high-functioning youth with FASD look normal and have high IQs and so are judged by the adults around them as normal, being high functioning "is the worse curse," because they are perceived as acting intentionally, not trying, etc. It's not that they can't learn the information, they can with accommodations. They fail in areas like getting assignments turned in on time, processing lists of tasks, etc. because they need added supports to help with those skills. Young adults leaving school are developmentally still a kid in many ways, and struggle with not being prepared for the outside world like their peers of the same age. Many, if not most need supports past 18 years of age.

Jeanne: Expanding eligibility is important and necessary because kids who present well don't get identified or diagnosed, but are still in need of services. Need case management for kids with FASD, case managers who can intervene early and offer support and training for the families in an ongoing way, with regular check ins and face to face meetings. Need Peer Support Consortium for this – to help with families navigating the systems and provide ongoing support.

Rorem's: Worry that there'll be momentum and change, but die out again, as it has done in the past.

Jeanne: Keep the FASD Partnership alive through the people. Support needs to be ongoing, not end once kids begin functioning because there are always transitions.

FASD needs to access systems, but not be absorbed- there ARE different issues with FASD than other DD/ BH because of the variability of impact depending on biological factors and environment.

January 20

Present: Jeanne Gerhardt-Cyrus, Ric Iannolino, Laurie Rorem, Larry Rorem, Trish Smith, Teri Tibbett

Opened with overview of yesterday's meeting related to working with the Alaska Peer Support Consortium (AKPSC), with the goal being to spread the word about the Consortium and encourage members of the AK FASD Partnership to join. This will help get the topic of FASD on the table in more circles. Trish said a lawyer she works with has been attending trainings and meetings related to FASD and is excited to move forward on it. The discussion then moved to FASD camps.

Discussion on SHORT TERM GOAL: Expand FASD Camps

Trish gave overview of this year's camp in Wasilla Feb 18-21, at Laverne Griffin Recreational Youth Camp, a church camp with heated cabins, lake for ice skating & ice fishing, game room, arts & crafts, nursery, showers & bathrooms, cabins for families, etc. Also, offers respite, education and training opportunities for parents and caregivers.

The workgroup reviewed the list of goals from the summit:

- Locate family surveys and contact info from previous camps – Trish has addresses and telephone numbers of past camp participants that can be used for distributing a survey that inquires about how the camp helped their lives and other outcomes; she will design and send it out and report the results to the Partnership.
- Use camp manual to help rural communities develop local camps (provide stipend SK?). Stone Soup Group has developed a manual and Trish will try to locate it; she will help set up camps however she can; looking at Fairbanks, Southeast; need to identify people to work with Trish to identify partners/funders (e.g. Native corporations, Fish & Wildlife funds a camp in Selawik; also Minto has a Native camp (Howard Luke) that might be used. Ric suggested contacting Ke Warner of Whitecrow Village (in Nanaimo) as a resource, as she runs camps in Canada that educate communities and individuals about FASD, is a model for camps. Trish volunteered to chair subcommittee called "Regional Camp Committee." Goal: to develop regional camps statewide, identify funding and recruit volunteers to help make it happen.
- Expand access for rural families – provide routine language interpreters. Need to have a location and partners/funders (see above). Ric suggested Yup'ik speaker who knows about FASD; hospitals have interpreters.
- Consider rotating location for camp with pre-trained local volunteers. Need location and partners/funders. Or could develop itinerant counselors to go from region to region and partner with local coordinators to put on camps regionally – Northwest, Bethel region, Fairbanks, Southeast.

- Identify funding (options, next grant). Jeanne said we need an FASD grant program so people can access funds for services, camps, respite, training, etc.; there is interest from outside Anchorage to get travel funds for those families to travel; asked Trust for funding; there are funds available for kids who have DD or FASD waiver eligibility; no funding for volunteers or their travel; Trish has a difficult time recruiting volunteers because of no pay; contact Native Corporations for funding; contact Monica Leinberger for funding ideas for specific family from Bethel; GCI has funding (Reggie Joule suggested it); also, contact Donny Olson (Jeanne spoke at rural behavioral health summit and Donny indicated an interest).
- Save current grant funding from state (7/1/11 new grant cycle, RFP – Feb. 2011), through DBH/Diane Casto) (1-how much, 2-how well, 3-is anybody better off?) Need data, evidence Current funding comes through DBH/Diane Casto \$33,000?;Natasha is grant writer who says it's "just an activity" need to show training/education component to make it more "fundable" or call it a "retreat," not camp; call Mike Baldwin to be on the camp committee; ask Diane Casto/Katie Baldwin – do the participants have to qualify as Trust beneficiaries? Need proof of eligibility? Qualifications/eligibility for services?

Proposal: Northwest (Camp Sivuunigbik, between Kiana & Kotzebue), Southeast, Fairbanks, Bethel. 1st step is to get a local coordinator for each region, Friends of Refugees – volunteers to work at camps, AmeriCorps, Jeanne will talk to woman at tribal services at Maniillaq; consider the Ke Warner model of itinerant camps; bring in counselors to the camp beforehand work with local coordinator (cultural understanding, FASD, etc.) to set things up and get on same page; offer 3-day camp for people impacted by FASD, to include activities, food, shelter, respite, educational piece for caregivers, family activity. For eight families, need VOA staff = ? and Local Coordinator.

Discussed the following LONG TERM GOALS:

- **Case Management/Care Coordination (training, proactive, etc.)**
 - Quality Assurance in the services; make sure services are appropriate and good
 - Technical assistance in how to do "active" case management
 - Measurables – what can be documented, families are connected to this many services, how many clients received DD eligibility or are put on a waiver, how are you measuring effectiveness.
- **Explore curriculum for primary care providers**
 - Sufficient training (FASD into Action) for anyone who is doing direct care. Coordinate with Arctic FASD RTC has this covered. Insuring that everybody has FASD training and support. Fidelity related appropriate services.