

**Family/ Peer Support Workgroup - MINUTES**  
**Alaska FASD Partnership**  
**December 7, 2011- 1:30-3:00 pm**

**I. Introductions**

Jeanne Gerhardt-Cyrus, Jen Wagaman, Hersh Wallace (DVR-Anchorage), Paul Cornils (AYFN), Jill Burke (Anchorage), Trish Smith (VOA-Anchorage), Gen Moreau (HOPE), Robyn Priest (APSC), Amy Hansen (ABADA, Wasilla), Deb Evensen (Homer), Gloria Stuart (Homer), Kee Warner (Whitecrow Village), Sean O'Brien (DVR-Juneau), Melody Price-Yonts (SEARHC, Sitka), Teri Tibbett (Advisory Board on Alcohol and Drug Abuse/Alaska Mental Health Board, Juneau).

**II. Request for assistance with Minutes/Agenda:** Teri will continue to do minutes and help w/agenda.

**III. Whitecrow Village**

Kee Warner ([www.whitecrowvillage.org](http://www.whitecrowvillage.org)), Deb Evensen ([www.fasalaska.com](http://www.fasalaska.com)) offered an overview of Whitecrow Village family camps in British Columbia. Deb said Whitecrow Village is one of the only programs she's seen where people with disabilities are treated equally as people without disabilities. A really strong program. Kee introduced herself. White Crow village started because she wanted a place for her 5 kids to go to camp. They had the acreage in a remote area, so they started a 3.5 week camp for kids with FASD. They invited kids from all over, targeting people who were feeling desperate because no one else would take their kids. From the first day, the youth met friends and found that the problems that usually got them in trouble were not coming at the camp. Now, many years later, WV is fully staffed, with only 2 people without FASD; everyone else is affected by FASD, 14-16 staff. At first they just served kids. Now serve kids and adults. Adult camps do morning exercises and teaching, afternoons. They bring in families, adults, professionals and kids together to learn together – modeling successful techniques and practices. Everyone lives, eats, plays, learns together. Professionals see successful interventions. Parents see their kids be successful. WV is a peer-run program, where people with FASD are in charge of the programs and activities. Kee described it as a culture of respectful relationships, interdependence and giving as much control as possible to participants. Nutrition is important (6 meals a day, lots of protein (no processed foods or sugar) and snacks throughout the day helps with emotional self-control. Deb confirmed that nutrition for brains prenatally exposed to alcohol is important and supported in research. WV's goal is to give people the principals for success and let them develop individually. They put a lot of focus on people's strengths, putting people in the right place with the right beliefs – including success. Strategies are different for every person. What primary function of the brain is working and not working? What are their strengths? What is their learning style? What part do I play in this, what do I need to know to help this person? The emotional tone of the location is low-key. Important to create a place that is calm. Jill (who took her kids to WV last summer) said there is an initial settling-in time. There is a schedule they can anticipate, but freedom to work within that schedule. Jeanne asked about curriculum. Kee said they do have a curriculum for the staff and a 4-day intensive training. WV staff will travel with the curriculum and offer to share it with others. Two objectives are an educator and EA? Model. WV doesn't work as a train the trainer model. Trish asked how they evaluate their program. Kee said they have evaluation pieces from participants and keep track of comments people make, and they collect anecdotes. Kee also talked about developing relationships and being respectful of each other, and the importance of having the right people involved. Sometimes there are people with great skills, but they don't fit in, and it doesn't work. Important to project a calm energy. Jeanne asked about where we could start developing a "Whitecrow Alaska." Kee suggested they take their trainings on the road and can do a 4-day training in Alaska. She said they charge \$400 per participant for 4-day workshops, with a minimum of 25 people (total \$10,000). Ideal to have it be an actual camp and they come in and work at the camp with everyone else. It's an intense training, so they

like to do it over two weekends because of how intense it is. If they do it in a camp setting, then the costs are in addition to the training fee. Also that the cost of their LIFE Session (the camp now named Live-In FASD Education) if they bring it to Alaska would be about \$30,000 plus facility fees. Jeanne talked about a facility near Kiana and Selawik. Trish said the Alaska camp that Volunteers of America put on last year cost \$32,000. **ACTION: Jeanne suggested a subcommittee to discuss bringing Whitecrow to Alaska. Jenn Wagoner, Trish, Jill Burke, Jeanne all volunteered.**

**Topics for the Whitecrow Alaska subcommittee meeting:**

- a. How feasible is it to replicate or at least approach a similar program here?
- b. What resources might be available for funding?
- c. Is there any technical assistance available to guide our way?
- d. Since we need to start small, what would you recommend would be our first step?
- c. Send representatives and families to attend Whitecrow Village Life Session

**IV. Alaska Peer Support Consortium**

Robyn Priest from the Alaska Peer Support Consortium talked about increasing participation in the consortium. Offering support to small groups and agencies who are doing peer support. They are starting groups around the state to begin connecting with other groups. There's a big push to go statewide – mostly focused on mental health and addiction issues. Also, connecting organizations to other organizations. Inviting individual memberships as well are welcome. Working on Peer Support 101 to help people understand what is peer support and how to bill for peer support. Recently released an RFP for peer ??, also looking at doing a training in April. Trying to set up a section where people come and talk about their personal stories. They are very interested in linking the consortium with the Partnership, and would like to see service providers link clients with peer support specialists, also hospitals link clients with peer support specialists. It's a less-costly way to go because people who have a peer support specialist working with them do better. Trish works with Wellness courts and sees clients needing support and this would be great. Robyn said they are working on specific training for people working in justice field. Kee suggested they use peer support, go to: [www.youtube.com](http://www.youtube.com) and search for "Whitecrow Village Lifeskills Project" – videos about their strategies for money management, how to be a dad, saying no, who I am, and who cares. She noted it was the process of putting the videos together that was the most valuable part (not just the product).

**ACTION: Investigate AK FASD Partnership joining the Alaska Peer Support Consortium; ask Robyn to add the Partnership to the consortium's website.**

**V. Youth Component**

Jeanne suggested the workgroup needs a youth component. Paul volunteered to be chair, Trish, Robyn, Jeanne and Teri would like to be on it. Teri suggested expanding the youth component to the entire Partnership.

**VI. NEXT MEETING:**

The group discussed a regular meeting time. Jeanne will send out the announcement when that is. The topics for discussion at the next meeting, in addition to updates about FASD camp should include:

**Lifelong Case Management:**

1. Quality Assurance in the services; make sure services are appropriate and good
2. Technical assistance in how to do "active" case management
3. 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.
  - a. Establish requirements:

- i. Need Follow-Up AND follow-through
- ii. Must be trained in FASD (FASD into Action)(RTC)
- iii. Must trust and respect the individual and family and LISTEN to them
- iv. Person-Centered Planning
- v. ACCOUNTABILITY
- b. Explore curriculum for primary care providers:
  - i. Sufficient training (FASD into Action) for anyone who is doing direct care
  - ii. Coordinate with Arctic FASD RTC has this covered. Insuring that everybody has FASD training and support.
  - iii. Fidelity related appropriate services.

**Mentoring:**

- a. Need for all people impacted, not just SED
- b. Need lifelong services

**Advocacy:**

- a. Schools: PTI Training
- b. Legal: Disability Law, Alaska Legal Services, Kelly
- c. Parenting: Supported Parenting; Assisted Living for families
- d. Family:
- e. Financial: