

**MINUTES**  
**Family/Peer Support Workgroup**  
**Alaska FASD Partnership**  
**May 9, 2012**

**Introductions:** Brittany Arey, Jan Wagaman, Maria Chythlook (Kasilof), Laura & Larry Rorem, Cynthia Puhaalsaki, Teri Tibbett, Trish Smith, Jacquie Erickson (AYFN), Angel Gonzales, Jeanne Gerhardt-Cyrus, Melody Price-Yonts, Nan Truitt (Neuropsychologist, travels around the state for different diagnostic teams).

**II. Regroup – Direction of Workgroup**

1. Regular meeting time, 1<sup>st</sup> Wednesday each month, 9:00-10:30am. We're an active workgroup hoping everyone will help the team succeed by taking a part.

**III. Recommendations/Goals from 2010 Partnership Summit:**

1. Recommendation: Expand Family FASD Camps to rural areas. 3-day camps, staff provides training, FASD Into Action training, presenters, planned activities for the kids while the parents learn. Game room, toddler room, crafts, fishing, dog sledding, etc for the kids, while the parents are learning. Sunday family activity.
  - a. Summary of 2012 camps in Mat-Su and Homer (Trish Smith, Volunteers of America). This year took the recommendations provided in last year's evaluations. Provided some advance information so everyone had an idea of what was happening in advance. Provided more culturally-appropriate activities. This year had storytelling from an expert storyteller. National Guard did a presentation about gateway drugs. Family activity in the past was a craft, this year decorated T-shirts with tie dye method. Talked about family patterns on their clothing, so that was a theme for the crafts this year. Has photos of T-shirts. 53 people total in Mat-Su. 24 (8 youth) in Homer. Had families and non-families in the volunteer pool. Used the Elk's lodge, one big room, wasn't as good as having different rooms to separate the group. Having two camps was a little harried to get done by May 1. The value of the camp is everybody is equal, no standout family with the kid who is acting out, all equal, all experiencing the same challenges, all together under the FASD umbrella. Jeanne: helpful for families to realize they're not alone, sharing stories and experiences, everybody has challenges, builds comradery and support. "FASD Camp is the place where I'm not judged for my parenting skills." Everyone is constantly trying to learn and share and talk with other parents, getting ideas from each other. Supportive environment. Acceptance, "my children are normal here," "more understanding here," "more patience shown." Friendships are long-lasting and carry on from year to year. Plans for next year are to have two camps. VOAAK is looking for research or other support to show their grants person the value of the camps (they're questioning if this is the best value for the money it costs). Will do one camp in Mat-Su next year, but will be looking for another community for the second camp. Looking for a local sponsor to help make it happen. Jeanne suggested tying the Youth and FASD Workgroup in the mentoring and planning of camps.
2. Recommendation: Bring Canada's White Crow Village model to Alaska-send Alaskans there. Whitecrow is a model developed in Canada based on peer-run, peer-driven strategies. They

conduct several camps a year and invite families, people with FASD, professionals and others to come and live at the camp for a week and participate in “hands-on” experiences with others to have good experiences, but also to develop skills and strategies for success. The Family/Peer Support workgroup is committed to bringing the model to Alaska. However, the goal is NOT to replace our existing FAScinating Camps, or to blend the models, but to have the Whitecrow Alaska be stand-alone camp with fidelity to the Whitecrow Village Model. Teri and Jill met with Katie Baldwin-Johnson at the Alaska Mental Health Trust Authority to discuss funding options. Katie suggested creating a white paper describing the project idea, background, costs, timelines, resources needed, etc. and presenting it to the Trust, who might be able to help figure out funding and next steps. Teri and Jill developed the proposal (attached) and asked the workgroup to read it over and get back with any comments, additions, suggestions, etc. At the next meeting, the group will solicit help on accomplishing the next steps. Jacquie suggested there are Youth in transition (through the Alaska Youth and Family Network-AYFN) that would be great mentors and would probably like to be involved.

3. Recommendation: Work with Alaska Peer Support Consortium (AKPSC) to develop an FASD peer specialist network that can be accessed statewide for people who need support, intervention suggestions, access to resources, questions, someone to talk to or strategize with, etc.
  - a. Peer Specialist and Supervisor Training – The AKPSC is in the middle of a rigorous training for Peer Support Specialists; upcoming will be Peer Supervisor Training. Both will be repeated in the future as funds and impetus are available.
  - b. Peer specialist network/clearing house for trained peer specialists – AKPSC is working on developing a web-based clearing house for peer specialists. They have a contractor who will become the Partnership liaison (Alison) who will also work on the clearing house and other web-based information.
  - c. Forensic Peer Support – AKPSC is working on a grant to hire a Forensic Peer Specialist. For info on this topic go to: <http://www.recoveryedge.org/Forensic-Peer-Support.html>
  - d. Rural Peer Support Services – RFP (Request for Proposal) going out soon from the Dept. of Health & Social Services. Funding will be available to agencies or organizations to help develop local or regional networks or services. RFP should be online by June 1.
  - e. How to engage the Partnership with the AKPSC? What and how does information get to organizations? Go to website: [www.akpeersupport.org](http://www.akpeersupport.org). See “[What is Peer Support](#)” Also, see Group Membership Form and Individual Membership Form in order to join.

**IV. FASD Waiver update** (Jeanne Gerhardt-Cyrus). Still bringing on more organizations into the waiver. Oregon training specialist Diane Malbin offered “FASD into Action” in Anchorage in April. Offered info on incorporating treatment plans and screening tool. Jeanne noted that using the screening tool and “FASD into Action” makes the process better for people. 40-50 people in attendance. Maniilaq has hired someone to be a point person on the FASD waiver. The FASD waiver has to go through an agency to get the waiver and it involves a lot of effort. All waivers allow families to access services in the community, rather than be institutionalized – like respite, treatment, case management, mentoring, social skills, supported employment, etc. To use the FASD Waiver the individual has to have both an FASD and SED (severe emotional disturbance). It is a Medicaid Waiver, based on behavior, not income. The idea is to tailor the

services to the needs of the individual so he/she can be successful in the community. It also helps support community providers and workforce development. The Division of Behavioral Health helps manage the logistics.

**V. Mediated Guardianship** (Jeanne Gerhardt-Cyrus). Talked about dealing with adults who appear articulate and capable, but actually aren't capable of managing themselves effectively in society but want to be free from parents and authority. "We want to protect the children that we raised so that they continue to get services." Nan does a lot of work with people going from the protected world of the youth into the unprotected world of adulthood – and notes its a set up for failure when they turn 18. There is a need to educate parents and agencies on how to help with this transition. The Disability Law Center of Alaska (DLCAK) has developed a Guardianship manual. Jeanne noted Guardianship doesn't have to be forever. Turning 18 doesn't change the person's level of maturity, they are still immature and often in need of services. They think they can be independent, but they may not always be able to. Many end up in jail or homeless. Common response from the youth when confronted with Guardianship is resistance. One suggestion is to develop peer support because parents are not respected by the teens. Laura said there isn't anything out there, "we're drowning." It was suggested that parents or guardians apply for Guardianship before the youth turn 18, because it's easier. The goal of the workgroup is to pursue this. First step, contact DLCAK to describe guardianship to the workgroup; also contact ACCESS in Fairbanks. Begin with education of guardianship to this group and find a way to disseminate the info statewide in some public awareness campaign. Also, the group is interested in a good evaluation that looks at an individual's functional aspects to have a good case when you go to court to get guardianship. High IQ can make it look like they're more capable than they are. Functioning level is the key, not intellectual level.

1. See pages 16-18 in this booklet "Guardianship in Alaska: A Guide to Understanding and Petitioning for Guardianship of Adults with Disabilities":  
<http://www.dlcak.org/files/pdf/Publications/GuardianshipinAK.pdf>

**VI. Next Steps/Actions.**

**ACTION: Everyone read the Whitecrow Proposal and send comments to Teri.**

**ACTION: Jeanne will offer a Bring the Kids Home overview at the next meeting.**

**ACTION: Teri will contact Disability Law Center and ACCESS-Alaska to talk about guardianship at next meeting.**

**ACTION: Trish will send FASD Camp photos to Teri for newsletter.**

**ACTION: Need letters of support, research, data to show the value of FASD camps. Send to Trish.**

**VII. Next Meeting:** June 6 at 9:00am