

Family/Peer Support Workgroup - MINUTES
AK FASD Partnership
11/23/10

Present: Jean Gerhart-Cyrus (Kiana, parent of six children with an FASD, retired Spec Ed teacher, case manager, parent navigator for Stone Soup Group, FASD 101 and 201 trainer, former coordinator of diagnostic team, has had multiple dealings with Alaska education and correctional systems, husband is Voc Ed for Maniilaq); Tami Eller (Anchorage, works for OCS, does contract work with Stone Soup Group, teaches “FASD into Action” classes, experiences mild FASD, has siblings with FASD, raised foster children with FASD, has attended VOA Family Camps as an employee); Teri Tibbett (Juneau, Advocacy Coordinator with Alaska Mental Health Board, Advisory Board on Alcoholism and Drug Abuse, coordinator of Alaska FASD Partnership, worked with Juneau School District as a para-educator with students who have an FASD); Mary Williard (Anchorage, ANTHC, dentist, parent of children with FASD, former Bethel resident, former member of Bethel Diagnostic Team and did Parent Navigator training).

Current Status of Family and Peer Support

Tami: Urban areas have strong support for families, including offering FAS 101 and FAS 201 training, case management, parent navigation. Rural areas have minimal to no supports. Volunteers of America has offered Family Camps, but funding has been drastically reduced and so fewer people are able to go. Rural areas need more support and services. Monica Leignberger in Bethel has developed an effective support system – find out how to replicate their system. One problem is kids don’t get services until they qualify under either behavioral health or developmental disabilities. What is needed is more early intervention so we can get support for families earlier.

Mary: The diagnostic team in Bethel does a good job, but services are minimal or non-existent after diagnosis. Recommendation to expand local camps and services because traveling is prohibitive. Stone Soup Group used to take proposals for developing local camps/services.

Jean: One gap is support helping families through the process, at home and at school. Family support is synonymous with advocacy. Need help with crisis intervention. Need help accessing services. School district is gun-shy about saying “FASD.” Nothing happens unless parents initiate and do the follow-through, then after many phone calls things get done. Parents reach out when they’re in crisis, but not when they’re not in crisis. There needs to be case management with on-going, regular support, not just crisis management. Need diagnosis so students aren’t just put on a disciplinary cycle. School district personnel dealing with FASD are often limited in how much they can advocate, so recommendation would be to have outside advocates (contractors?) who can step in and not worry about being reprimanded. “No services until you’re in crisis, when you’re in crisis there are no services.” Case managers do not follow the client, they change from agency to agency, and this is inconsistent, confusing and ineffective for the family. Families need ongoing support, monthly meetings, monthly calls, etc. to keep parents in the loop as they don’t often have the where-with-all to call in themselves.

Peer Support vs. Case Management

[no notes available]

Face to Face vs. Distance Delivery

DD system requires face-to-face meetings quarterly. FASD does not have that.

Ages and Stages

[no notes available]

Recommendations:

- Expand funding opportunities to bring more families to camps. There is some data about camps used in the grants process. Ask Trish Smith, Volunteers of America, about data.
- Replicate Bethel's family/peer support system (ask Monica Leinberger)
- Build local networks of support for smaller communities; possibly traveling teams?
- Expand funding for "FASD into Action"
- Expand funding for "Traditional Camps"
- Create a system that offers case management with on-going, regular support, not just crisis management.
- Create a system in which case management services follow the person/family (not agency dependent). Expand case managers to work not only when there is crisis, but on-going help as well.
- Train providers across systems to handle case management, e.g. in schools, in behavioral health, in correctional settings, etc.
- Family support in rural areas that includes quarterly face-to-face with meetings, to debrief, vent, make a plan for the next three months, etc., like they do in the DD system. Being able to come together with other parents and discuss the issues. Suggestion: case manager who works from a distance, but comes to the rural area every three months.
- Expand definitions/waivers to include FASD so they qualify for services.
- Need to expand early intervention programs so we can get support for families earlier. Talk to Kathi Wineman in Juneau about the program she is working on.