

Services for Adults with FASD - MINUTES
Alaska FASD Partnership
February 22, 2013

I. Present

Art Arnold (chair), Wendy Barrett and Suzie Klein (Stone Soup Group), Larry & Laura Rorem (parents, grandparents), Gayle Young (SEARHC), Teri Tibbett (Alaska Mental Health Board/Advisory Board on Alcoholism & Drug Abuse).

II. General Discussion

Trust Beneficiaries. It was reported by Jeff Jessee, CEO of the Alaska Mental Health Trust Authority, that people affected by FASD are Trust beneficiaries. Trust beneficiaries (as defined in Alaska statute) are people with mental illness, alcoholism and/or addiction disorders, developmental/intellectual disabilities, Alzheimer's Disease or related dementia.

DD Eligibility. Teri reported (following this meeting) that efforts are beginning among the Developmental Disability (DD) and Behavioral Health (BH) communities to coordinate efforts to address people with FASD who are "falling through the cracks." While people at one end of the spectrum experience severe enough symptoms to qualify for DD services (paid for by Medicaid) and others at the other end of the spectrum experience severe enough symptoms to qualify for BH services (paid for by Medicaid), there remains a significant percentage of individuals in the middle (diagnosed and un-diagnosed) who do not qualify for Medicaid-eligible DD or BH services. *Note:* A person is eligible for Medicaid if they fall below a certain income (based on the federal poverty guidelines) AND meet certain categorical requirements (parent with dependent children, disabled, etc.). A person is eligible for Medicaid waiver services if they have a disability or disabilities that result in serious functional impairments that would necessitate nursing home/institutional levels of care without community based services and supports. The executive directors of the Governor's Council on Disabilities and Special Education and Alaska Mental Health Board/Advisory Board on Alcoholism and Drug Abuse, are discussing an effort to meet with stakeholders – including the Alaska Mental Health Trust Authority, Division of Behavioral Health, Division of Vocational Rehabilitation, Division of Seniors and Disabilities, Alaska FASD Partnership, as well as providers, individuals, and families affected by FASD – to address the problem and develop solutions.

Public Testimony in Juneau. Several folks provided public comment during the Governor's Council on Disabilities and Special Education and Alaska Mental Health Trust Authority's board meetings in Juneau during the month. Always a reminder to participate in public comment when these types of Boards meet in your community. Let them know what is going on in the service area of your interest.

Scope of the Workgroup. Teri suggested the actions of the workgroup should be what members feel they have expertise and time for. The Partnership set up "workgroups," rather than committees, as a forum for people to roll up their sleeves and be an active participant in the changes that need to happen. Though systems change needs to happen, it's important to tackle systems change in steps – one task at a time, and not wait for the department or legislature to make the systems change. She suggested the workgroup come up with actions each member can take on and work from that standpoint, and that other workgroups have approached their work in this way and have been showing minor accomplishments that are adding up to systems change, little by little. She submitted some of the accomplishments of the other workgroups:

- **FASD & Education Workgroup:** Met with the executive directors of school administrators' association, school boards association, superintendents of the Anchorage and Juneau school districts, and presented before the statewide school board to raise awareness and asking them to address the problems at the school district level. They also worked to create conference kits with educational materials that can be used at education conferences.

- FASD & Legal System Workgroup: Addressed their top priority of establishing FASD as a mitigating factor by working with the legislature, Courts, and Department of Law to come up with the language for a bill, advocate for it directly in Juneau, and educate every legislator about what it meant and why it was important. It passed unanimously and became law last year.
- Family & Peer Support Workgroup: Has been working to expand FASD camps in Alaska, including establishing a relationship with the peer-run Whitecrow Village camps in Canada. Next year we expect to have a Whitecrow camp in Alaska. Successfully advocated for substance abuse treatment for pregnant women and case management for people diagnosed with FASD – all recommendations from the FASD community. This took about a year to develop and accomplish.

III. Ideas for action related to “Expanding services for adults with FASD”

FASD Regional Learning Centers. Gayle Young submitted an idea to the workgroup about regional learning centers and a certificate/training for paraprofessionals. These centers/skills would serve both diagnosed and undiagnosed individuals, teach life skills (cooking, home care, finances & budgeting, driving permit, travel skills, basic first aid, eating out, interviewing for work and work skills, cleaning skills, technology, handling leisure times, parenting, getting along with others, home fix-it skills, etc. Gayle wrote in an email, that was forwarded to workgroup members, that *“The value of this centralize learning center idea is that we could just stop fussing at school districts and also individual teachers who, for various reasons, will not be able to help high school students with transition skills. From my observation, some rural community schools here in Southeast do not even pretend to work on transition skills. The curriculum and the quality of the education could be closely tracked and students would be welcome to join when they themselves are seeing the need for such training. The burden would be on the student to show that they are ‘probable FASD-affected’ and such designation would enable them to gain admittance to a learning center.”*

Mentorship Program. Wendy and Suzie discussed peer mentorship training, programs, grants, and suggested a Mentorship Program. Suzie agreed to write a draft proposal. Teri agreed to work with Suzie on who to present the proposal to, including potential funders and other who can help develop/implement it.

Training. Investigate ways to expand training opportunities for parents. Talk to the Trust Training Cooperative on what they offer. Talk to Disability Law Center of Alaska for their approach to Guardianship. Find a way to spread the word to parents. Talk to Stone Soup Group about strategies. Investigate training all personnel at DVR in methods for working with people with FASD. Investigate this as a division-wide effort. Suzie and Wendy will write a letter to Cheryl Walsh. Look into Train the Trainer, FASD 101 and 201 and ‘FASD Into Action’ as possible training options.

Services/Waiver. Investigate ways to serve people not being served on waivers who are falling through the cracks.

FASD Resources. Discussion followed about resources for individuals and families affected by FASD. Teri noted that while there are still not enough services to cover the intense need, there has been steady improvement in the last 20 years and Alaska actually leads other states in services – including having an Office of FAS and five diagnostic clinics statewide. The state spends approximately \$2 million annually specific to FASD, which includes funding for the diagnostic clinics, \$500,000 for substance abuse treatment for pregnant women, and \$300,000 annually for case management services in four communities.

GOAL #1 Page. Art pointed out at the end of the meeting that he would put together a single page sheet for each member to review and fill out. The goal is to continue to try to acquire the measurable, actions, strategies and interventions necessary to move us forward on GOAL #1. This will be a simple task but one that will allow us to record our individual ideas in a collective manner. We must try to be concise and direct. Good qualities in each one of us.

IV. Next meeting. Monday, March 18, 2013. 9:00-10:00am. Put it on your calendars!