

# GOVERNOR'S COUNCIL ON DISABILITIES AND SPECIAL EDUCATION

## FASD Workgroup

### LOCATION

Governor's Council Conference Room  
3601 C Street  
Anchorage, Alaska  
Teleconference

### Meeting Date

May 6, 2014  
3:00 p.m.

### Attendees:

Patrick Pillai  
Wendy Barrett  
Travis Hedwig  
Staff: Christie Reinhardt

Barb Chambers  
Chair: Jeanne Gerhardt –Cyrus  
Co-chair- Art Delaune

**CALL TO ORDER – 3:00 p.m.**

**ROLL CALL**

### Welcome from the Chair

Christie started the meeting and Art chaired it, until Jeanne was able to join later in the meeting.

### Old Business

There was a discussion of the April 28-30 Council meeting in Anchorage. It was the first Council meeting where the Workgroup reported to the Council. The priorities were included as part of the DD Committee report. The Council heard learned about the Workgroup's primary focus on FASD informed care (Intervention, Advocacy and Prevention) and the 3 goal areas of

1. Birth through life services (Intervention)
2. Self-Advocacy (Advocacy)
3. Prevention of Secondary Characteristics (Prevention)

There was also a discussion of Duane Mayes, the Director of Senior and Disability Services, message to the Council. It was one of concern by SDS on the growing cost of services and ways the Department is working to keep these costs in check down. One way he mentioned was a crackdown on fraud. His message is important to this group as it lets us know that working to expand eligibility during this time of fiscal concern may be a challenge. Currently the wait list is around 670 and holding steady with about 20 being pulled a month. The target is 50 a month. We also talked about Senator Kelly's war on FASD. His focus is really on prevention. Patrick noted that this "War" with its intense focus on prevention gave an opportunity for advocacy around the need for services.

### New Business

Barb started off the conversation on eligibility by talking about how important it is stress functionality in looking at eligibility, also the level of care requirements. Support through the lifespan is dependent on care providers being able to document the supports the individual may have received at home or the school in order to make the transition. So many with an FASD fall through the cracks without this documentation of their real care and supervision requirements. Without them the documentation turns into criminal records and histories of homelessness and addiction.

Wendy shared a recent example of a young woman with an FASD diagnosis who volunteers at Stone Soup Group, who has been transitioning from child to adult services. She had been living in a group home that continued to house her without payment, as she was homeless. This young woman received some services from a mental health agency. With the help of SSG a DD application was submitted. It was rejected. She then took a risk and discontinued her mental health services. With proper documentation of not only what she needed to be successful, but how poorly she did without supports, the application was resubmitted and she was found eligible. The point was that even with supports of multiple agencies and with professionals documenting her needs it was still very difficult for her to get DD eligibility. It was a gamble. Barb then shared a letter she had received a couple of years ago as a response to her inquiry about why individuals with an average IQ but with documented need in the areas required by the eligibility requirements were being denied. She was encouraged by (Joanne Gibbons?) to have families reapply and that the SDS was trying to correct this staff misunderstanding. It had been brought to their attention that at least 3 of the assessors were using IQ as a gatekeeper. This led to a discussion about the need for training on FASD and clarification (paradigm shift?) for assessors, STAR coordinators and care coordinators, both agency and private. DD agencies need to recognize that individuals with an FASD are part of their clientele and be prepared for that instead of moved off to mental health (there is nothing in the eligibility requirements that say a person with a DD can't also have mental health concerns). FASD seems to be the only DD that the individual has to show they DON'T have mental health issues to qualify.

There was a very good discussion about changing how eligibility is determined and how it may work better with including vulnerability indexes and/or risk factors (ACES). Both a vulnerability score and an ACES score would inform a more comprehensive scoring system that looks at what would happen to an individual without supports. The current DD system for those without a significant cognitive impairment as well as mental health systems require that the individual "tank". This discussion looked at two ways to have an impact on the DD system 1. Education on FASD and reeducation on eligibility requirements for the "gatekeepers"; STAR Coordinators, independent and agency care coordinators and the assessors. 2. The other is a reassessing how the eligibility for DD services in general are determined in Alaska with a greater emphasis on not just current level of documented need, but the use of tools that will predict what will happen to the individual without the supports

Jeanne also mentioned another factor which is that DD applications want IEPs or at least ESERs and without a childhood diagnosis, an individual would not have one of these. It makes official documentation difficult since the state does not really want documentation to come from parents. Without agency involvement or an IEP that just leaves OCS and the criminal system. Travis offered to send the vulnerability and the Aces and Jeanne is going to send DD eligibility criteria and apps just

for us all to have (they are awesome and have already done this) there was a quick check in on upcoming FASD Into Action happening in June. Christie will send out info on those opportunities.

### **Adjournment**

The group adjourned at 4 after agreeing to meet again on Wednesday June 4 at 3:00