

Systems of Care
Meeting #4
October 11, 2007

Meeting called to order shortly after 10:00 by Lee Yount.

In attendance: Debbie F, Kim Hill, Alice Widgeon, Tuwanna McGee, Jennifer Sellers, Beverly Marson, Mike Weeks, Rep. Ward, two other individuals were in attendance in the general audience for the majority of the meeting (names were not obtained).

Handouts: Minutes provided from Meeting #3 (September, 13, 2007), Governing Magazine Article October 2007, People Magazine Article October 1, 2007.

Framework

I. Discussion around Informal Systems of Care.

The **family and/or child are in the center**. Concentric circles around the person are outside of them. Alice says if you think about this from a lifespan you need to think of things that are supports you need: **Medical/Health, Educational**, (if you are looking at Early Screening and/or Diagnosis that should happen before educational), **Community/Social** Network (Family). Alice says if you are going to make recommendations regarding insurance parity you need to have that under medical and mental health. We talk about the importance of having quality of life and purpose. We need to consider vocational services and work. Mike says with the blind they have helped people get into business. We want to consider mental health and make sure people feel connected to the community. Towards the end of your life you need someone to care for you. **Retirement/Senior Services**. If you think of a child as part of a local community you think of community: church, community programs, etc.

The question is asked if there is anything this group can do to increase their ability to participate in the community. Jennifer Sellers suggests that we need to increase awareness. Beverly Marson suggests respite care. Mike asks if there is anywhere that you can take these children for daycare? Lee says not for autism. Lee suggests that the ARC has a grant that will give families a small allocation that is for them to use for respite. Some churches provide respite.

Cam says it would be a good idea to talk about the Office of Faith Based Initiatives. We discussed respite needs for those that are older.

Mike/Cam says that there is a state person that is responsible for Faith Based Initiatives.

In our recommendations we can recommend that we need to 1) increase awareness (down to the local level), 2) look at opportunities to partner with Faith Based Initiatives, 3) breaks from constant care, 4) educating people on what is available (we can produce this as a group and share it), 5) finding a way to engage the business community, 6) create

some type of incentive that engages a normal peer group, 7) educating people at daycare programs on the needs of children with ASD.

Mike asks if we have tried to get the business community involved.

Beverly says another idea she has as far as sources of support are college students. They need part time work and places to live. That is a great source for people to learn about disabilities. She suggests some type of work study or benefit program that would pair these people with persons with autism.

Debbie talks about using Nursing Students with these individuals. Mike asks about the YMCA and having them involved. Counseling, Social Work, etc are also suggested.

Cam says Workforce Development can be helpful to us; Jefferson State does have a number of individuals that are attending. Lee wants to start a 2 year training program. Alice says Mental Health used to do this.

II. State Agencies

Where do they fit within our circles? Does Medicaid fit under Medical-yes and in funding and education? State Department of Education is Education. Social/Emotional-EI, DMH, DYS, DHR.

*We had a brief discussion about the importance of educating police; Lee says that Community Service Officers in Metro areas are well trained in dealing with Mental Health issues. Mike suggests APOT and Allen Benefield, he would be knowledgeable and potentially helpful to us.

Kim says that all First Responders need this type of training. Mike says that the exposure in the academy will be helpful. Beverly says that regional centers are important. Lee wonders if we couldn't start some type of autism speaker's bureau. We need to come up with parent volunteers that can do this type of training for us for free. Tuwanna says they are doing a lot of training and are trying to get into JPOs. Cam says that ½ of the battle is that the information is out there and they key is getting it to people and groups. The structure is important; we need a process of delivering this information. Cam wishes we had a State Clearing House. Mike says they have a police chief convention and we could tap into these types of groups.

We have multiple state agencies that affect these individuals. We don't have good coordination of these state agencies. Cam says we don't want to put it under 1 agency. He thinks a good idea would be to create some type of advisory board made up of all of these agencies. That person would be responsive to these agencies.

Beverly says part of our problem is capacity. She talks about Regional Systems. We talk about having case management to help these families with the system. She thinks that it

is important to have them under one rooftop. If you put this group under DMH/MR then the Education people wouldn't have anything to do with that. The center would be doing training and/or technical assistance. The center would provide the training. Someone there would also do community integration. They would be able to train day care workers and help integrate. Cam asks if you would have multiple centers. Beverly says yes, because you can't have parents driving long distances. Universities could go around and talk to the people at the Centers and talk about.

Tuwanna says the colleges have expertise. Beverly says she can visualize that you could see problems regionally and therefore communicate the need to develop programs.

Beverly says that all Departments would need to put money into this system. If you had Regional Centers, would they all be equal? You would have to look at demographics.

Lee says that what happens with Multi Needs-different state agencies put up money, they meet as a team (SDE, DMH, Medicaid, DHR, DYS, Rehab). Cam asks if you could build on the University Systems that are already doing autism. Bev says they are not going to deliver services. Lee says you could form a board of agencies and legislative reps that would hire 1 person and then link with regional centers.

Cam says the Education Committee is working along on this and has a pretty good consensus that they will be supporting. They are looking to put this into the existing programs.

A council is suggested. Everyone deals with autism but it needs to be present in the State.

Tuwanna speaks on the CARD program they discussed at the Education Committee.

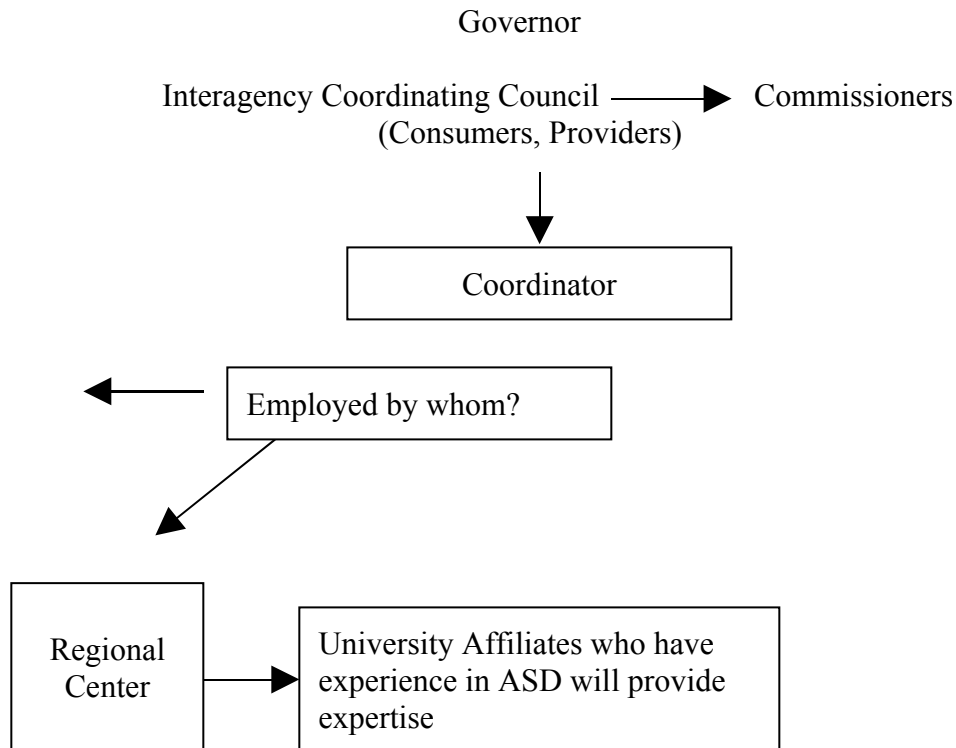
Alice says there is an ICC on Autism at the Federal Level. For EI this System has a lead agency, the Gov appoints an ICC, meets quarterly and has reps from state agencies. 20% of this is comprised of parents; they have a state legislator, someone with state personnel prep, and providers. There are working subcommittees that do the work and then they go with the support of the state agencies that are involved. That is replicated on the district level and they decide how often they meet, they offer trainings throughout the year. There is no money in the committee; EI has to pull it together so they don't duplicate services.

Lee says that they might want to recommend that a structure be created and not provide the details. Cam says it would be good to go ahead and provide the details. Lee asks if Cam was talking about having a lead agency person. Cam would like to see 1 person that knows the system.

Lee asks about the Department of Children's Affairs? Alice says it is more of a coordinating body and they deal with a number of issues related to children's services.

Beverly says that we need to know that at the end of the day we have some services. Kim likes the idea of regional training centers so that people know how to work with these people.

Cam says that you would also have to have someone coordinate the system.



Services
Case Management
Training
Diagnostic

Alice says that she likes this idea; we have footprints of this already thru the University Programs.

Lee mentions the obstacles: we have regional programs thru the 310 Boards and asks if we need to do this or if we need to have people within the center.

III. Conversation regarding Funding

Lee says they have HFA persons that receive disability. Debbie says we need to consider the income groups we would be talking about and considering State Plan vs. Waiver. Lee says that we need to consider how we can help middle income families. Jennifer says she

knows many families who have given up their children to the state so that they can get services. We need to recognize that all of these groups need services. Beverly asks if it is out of the question to ask for a specific tax. Cam says the only time you see a tax passed is when you are put in a corner.

Lee asks if we could ask State Agencies to put up a nominal amount of money to employ the first person and then you could ask the legislature to start the centers.

Kim says in EI it is not important to know if kids in their system have autism because they serve if they have a 25% delay.

Jennifer Sellers talked about the way a University might be able to put up a person in this type of situation.

Cam says he thinks this model is good.

Lee asks if we support the top of this plan.

Alice says that the top part will help us to maintain legislative continuity. The Clearing House and the separate person- that is a possibility?

Lee asks about the role of a clearing house. Cam clarifies and says that he sees that person as a coordinator. Lee says over the long term she sees that person being the manager of contract management.

Kim asks about EI and the services they are currently providing and how they would fit into the model. Lee indicated that they would continue to do what they are doing.

Lee asks if anyone does not support the top half of the plan?

No one disagreed

Lee asks if anyone doesn't support the bottom half of the plan? (regional concept)

No one disagreed.

-the details could be worked out at with the Interagency Council

Alice says she likes the model and the example of the CARD program.

She also indicates that we need to weave in the Case Management System thru the lifespan. Lee says we need to talk about this next time and we also need to identify the ideal list of services. Lee says that at our next meeting we should have the list of services that are currently in existence and we can use that list to help us direct some of these services.

Cam suggests that we have a conceptual framework when we present this to the group.

Beverly Marson also indicates that we need to look at the funding needs of those that are receiving services. Lee says we can ask the question, if the assessment tools that are being used are the most appropriate (the ICAP and the IRBY). Kim says they also need funding in the early years because they take care of the kids first. This is an example of the politics. We need to capitalize on the momentum we have.

Cam says we are pretty far along. We plan on having another full task force meeting in November. He would like to see our recommendations in December. His intention is that in February we will pass another resolution to extend the life of the task force another year. We will push the recommendations that we have at that time. Our final report will come out a year from January. Lee asks if we will give our committee report in December. Cam says this can be rough but we will need to have a few things that we will push. Cam says we will do our legislative day in April. Our numbers are the biggest strength. Alice says that all that the Financial Impact group needs are our rough numbers. Lee says that Dr. Gary Edwards at UCP contacted her and wanted to participate.

Meeting minutes will be approved at the next meeting as they were just passed out today.

The next meeting will be Wednesday, November 7th at 10:00.

The meeting was adjourned at 12:47.