

Systems of Care

Meeting #3

September 13, 2007

Meeting was convened shortly after 10:00am.

- I. **Introductions**- In attendance: Mary Lawrence, Legislative Fiscal Office, Janie Peterson, Alabama Medicaid, Monica Abron, Alabama Medicaid, Marilyn Chappelle, AL Medicaid, Abbie Felder, AL Dept. of Ed, Dan Roth, ALSDE, Mike Weeks, AHIP, Lonnie Williams, ADAP, Kim Hill, ADRS/EI, Commissioner Shivers, ADRS, Jennifer Sellers, Auburn University Autism Center, Marijo Lathaem, Office of Children's Services (DMP), Debbie Flournoy, Medicaid, Beverly Marson, parent, Lee Yount, Glenwood-Chairman, Jennifer Muller, Autism Society of AL-Secretary.
- II. **Approval of Minutes**-Lee asked for an approval of the minutes from August 22, 2007. This will be moved to the end of the meeting to allow for review, copies were not available until this morning.
- III. Special Guests

Commissioner Shivers-Their department works with children from Birth to Retirement. At birth (EI) -at least 25% delay in one of the developmental domains, VR works with children with IEPs in school and kids have IPEs to help transition kids to work, they also have a homebound program. He indicates that they need more help with Early Intervention specifically as it relates to children with autism. With EI ending at 3 and a lot of kids don't get diagnosed until 2.5 many children with autism may not receive the EI services, after 3 we rely on school systems to provide the support that is needed.

Early diagnosis has a cost factor. The earlier the diagnosis can be made the less severe the impact on the child.

CRS does not recognize autism as a diagnosis that they can work with but they have changed their philosophy and they start asking questions to the family (intake) regarding hearing, seizure disorder, speech disorders, etc. and other diagnoses that are covered by their program. What they do is only a piece of the pie. That is the reason we have so many people here. We want to make things better for the families who have children diagnosed with autism.

VR starts at 16 in the school system and works with the areas identified on the IEPs. They develop an IPforE and they already have a link. So, when they exit school they already have a link with VR. There is a capacity issue here. There are over 130 school systems and a number of high schools within those and they have about 154 VR counselors at any given time. They have about 1

VR person per school. 78% of their funding is Federal. They have been advocating to put more monies in rehab to help the capacity issue. They are Title IV of the rehab act. They are working with 68 projects now where the school systems pay ½ of job coach and they pay the other ½. They are helping them transition from school to work and it has been successful but they need more of those projects. He looks at it from the top and what Kim is doing in EI and making accommodations early on so they have overcome many of the problems before high school. It is important to concentrate on how early we begin. Ed Richardson once said that it is critical that we get education for kids at 4 years old and it is so critical that he would be willing to cut out 12th grad to be able to begin education at 4. They started seeing an increase of autism cases in 2002 and they have been trying to train their counselors and staff to training so they would have a better influence with their knowledge.

Kim mentions that Medicaid is the lead agency on the ABCD grant and they have 4 pilot sites that are working with pediatricians to do developmental screening. That is very positive and they are pleased to be recognized for this 15 month grant.

They open it up to the group for questions:

BM asks how they train to actually work with people who have autism?
Commissioner Shivers: They have been involved in the autism conference for several years and getting experts to come there and hear those that have scientific knowledge. Kim Hill says that thru the Autism Society they had Marshall Univ in and every year they have sessions on autism. She adds that the state is divided into 7 councils and they typically have speakers on that at the regional events. DMH/MR had a grant and they trained people in North AL. They have a variety of trainings.

BM asks about best practices? Commissioner says he thinks they have a large gap there, they try to individualize services and the needs are so broad. He thinks what is most important is learning the needs of the individual regardless of their autism. BM says as we are developing needs she suspects that we will see training as a big need. Kim says they have also had some specific training and they have a contract with DMH/MR that can help when they have a family that has more specific need.

Jennifer Sellers adds that she knows from past experience and research that on average the 68 job coaches are typically working with people going for the AOD. Shivers says that that is correct. Jennifer Sellers says that many people with AS are going with a standard diploma. It seems like that is a huge area of need for this population. Dan says he would agree and adds: like Steve says there is a capacity issue. Job coaching has been targeted to the AOD first but they could work with others as well. Shivers would hope that in working with

the Special Ed Coordinator they could be available to help with those that have AS also.

JS says another issue that she is dealing with is that there are different answers depending on where you are in the state on when the rehab counselors are supposed to go in. She suggests that it would be helpful to have some expectation as to when the counselors come into the IEP meetings. Lonnie says they have gone to meetings where they did not seem to know that they could invite ADRS to come in. It seems that one of the problems is that they aren't aware of what ADRS can do for their students. There are a lot of times that ADRS and the schools have to negotiate. Dan says you address this need at 16 in the school systems. Abbey says that is a rule and a process. VR should be at the table at that age. Some systems may share a person and they may bypass it. JS adds again that this is with the more severe kids. There seems to be a good relationship between the AOD teachers and the VR. She would like it to be noted that there needs to be more of a collaborative effort.

Lee says we are looking at what systems exist, what is available and what is not, and if you had unlimited resources what would we do. Abbey says it is really a capacity problem. You also have teachers coming and going. We need to wrap around service and see how can provide the services. We have 43% of teachers leaving each year. CS says where they are not involved when they should be there are agencies that are not even thought of. 90% of the time unless parents are involved with the autism society they don't have anything else beside the school. When the school is closed in the summer they don't have programs.

CS says there is a respite conference October 4th and that is something that parents should go to. Mike Weeks asks where the money comes from in the State-ETF. What % of that is state? 28% is State Appropriation. How many people are we talking about? If you use the 1 out of 150 stat to the number of 3-10 year olds you are talking about as many as 8,000. BM says we need to remember that education stops at 21 and then you don't even have that. We all recognize that capacity is a problem. The volume is growing. With better diagnosis at the same time we need to move money down to EI for the Intervention.

JS has more questions-about 2 sessions ago we looked at other states and she looked at Indiana. In Alabama we have the Milestone program that allows people to get paid at different levels. Her understanding is that they are paid for case closures. She asks if they are familiar with other states and how they are paid. CS says what they are doing is working with community non profit organizations. They went to Milstones after looking at a program in Colorado that had made a big difference. Last year their average wage was 6.00+ an hour and they worked with 539 and 359 went to work. If a group puts a lot into the first milestones they don't want to give up. Lee says at Glenwood

they have the most severe kids. They have tried the Milestones program and they didn't have much success because they found that their supports can't really fade. For autism they will need coaches forever and to different degrees. She asks if there are other mechanisms to cover this with a waiver? JS says once you get a diagnosis of autism, when it comes up for eligibility for services you don't have to have an IQ test. Abbey says they can get that. Abbey says that parents don't want the MR label.

Lee thinks that one of the recommendations will be that Alabama prepare a autism specific waiver. BM says her personal experience is even with parents who have less severe kids they will need support. She would like to see a development of adult supports long term. We need to come up with a way that if people get intensive training to support people with behavioral needs they would need to be compensated. Woman from audience asks if this has to be a waiver or could it be worked into the state plan. No, it doesn't... it can be part of the state plan. They can identify a population that they want to serve and the number of people they are planning on serving. But the DRA does give them some flexibility to provide services.

Lee says going back to the job coach-even with the higher functioning end they are job coached within the company but they are paid because you don't know when the situation is going to occur. Dan says he thinks when you talk about things happening in work we need to have them represented in our committees so they see the importance of this workforce. We need the employers here. He and Linda Haines have put together an interagency team to get them all back on the same page and to help them understand. (State Interagency Transition Team). He would like to see that replicated within the local systems. They (ALSDE) are working on redoing their state interagency agreement with Department of Rehab and Education. Business and industry are typically left out when we have these discussions. They know how things work. BCA -he suggests that they might be helpful. What type of person are we wanting to recruit? BM says it is not a person who is trained at a workshop. There needs to be a training program that works with people. He says the Governor is putting money into Workforce Development. He says he did his math and that gives us a rough estimate of 30,000 people. He is involved in T Cup and they are looking for construction people. Lee says they have people working for 8.00 an hour that are extensively trained. They don't have a high attrition rate at Glenwood but that is unusual.

- Lee says from a recommendation standpoint we need to think about recommending a state plan change rather than a waiver.
- Jennifer says her research indicated that from 1991-2006 only 61 persons who applied for VR services were employed. Nearly 300 applied. Jennifer says people that are applying are twice as likely to gain employment if they are not referred by an educational setting. There are tax incentives that are available for large employers. Lee

says that this information should be put into something that can be used as a recommendation.

Abbey Felder-Abbey is no longer the autism specialist for the state and she is now the State Improvement Grant Advisor. This is something they have been trying to do for years. They have had several meetings this week about what they are going to do in Education. They had previously had an autism institute. SE only gets 27% of the money that they were appropriated by law. When you talk about autism it starts with the doctors and the moms. They are asking for more money for professional development. The people they trained from 1999-2003 many of those are still in Alabama in leadership positions. This is the first time we have seen agencies in the same room that work with babies to adults. They are asking for another 2 million for their budget for professional development that will include parents and providers. SIG grant is proposing that they partner with pediatricians in the Reach Out and Read program. They put in the budget a way to provide wrap around services for families to receive respite care, how they can help teachers of severely disabled children. BM asks how many people she thinks they can train? They have broken the state into quadrants they want to have 2 intense trainings in each. You want the teachers to be able to go back and have the tools they need to work with the child that next day. They counted up about 400 people. ADAP asks if that is for teachers or if that is for paraprofessionals? She says both. They would like to have teams of 5 from each school that include a parent.

- IV. Needs Assessment-Beverly Marson-she is going to be the liaison between the Needs Assessment and the Task Force thru an internship. We are going to have family forums across the state. They are also going to have a Needs Assessment Advisory Committee.
- V. Follow up on Assignments
 - a. Ohio-Carl is still in the hospital
 - b. Pennsylvania-Tuwanna is not here today
(Both of these will be carried over)
 - c. Debbie has given Lee lots of information. Debbie doesn't think that people realize what Medicaid does reimburse; she indicates they do reimburse for EI, (to be reimbursed they have to be a contract provider of Rehab. Services). They fund home and community based option for the waiver, psychology services under 21 (must be referred thru EPSDT). With the ABCD academy they will be promoting the use of standardized tools at 9, 18, 24 and 48 months. They hope the 18 month will catch a lot of autism. PT, OT, SLP under 21 and some for adults. EPSDT- case management. Reimburse for special education services in schools. Typically it is the therapy services, some vision and hearing, some speech, some testing. A lot of billing is speech and OT. It has to be on the document that plans care. Kim says in a sense they are somewhat in

competition for the providers. Abbey says they are right now paying for SLP programs thru Universities. They do seem some augmentative communication claims they contract with ADRS and they do cover the devices separate from the waiver. This is a regular state plan program. She has also given Lee the provider list of 310 Boards.

d. Mental Health-see handout. What Makes a System of Care Unique.

Lee's Comments: We have had some good news regarding the possibility of our suggestions being made thru the State Plan change rather than a Waiver.

They would still need to meet financial eligibility requirements. DRA has been proven to be a little easier. They partnered with Senior Services. Both would give you what you wanted. Perhaps our recommendation should be to weigh the difference between the two options. DRA lets you carve out a population and still protect your budget.

Lee passed out the recommendations that the group has submitted. She thinks that we should have a long meeting next time to look at these. Lee serves on Financial Impact and indicates we will need to project costs to accompany our recommendations.

Lee asks for comments on the initial recommendation list:

Comment on 4 and 5-Lonnie says there is no stated effort to include persons with autism and if we are going to do this we should include this group. He thinks that is more important in a commission or coalition.

JS says we had talked last month about the Universities and UA's emphasis, UAB's and AU's. The Center of Excellence is at Sparks. It would be a good starting point to bring these people together. We have all of these separate entities that have expertise but they aren't brought together.

The committee has already been set up, we might need to have a special section on autism. We will have to say how to do it in our recommendations. BM asks would we then have to figure out how to implement them? We need to identify our first steps.

Next meeting: October 11th, Thursday 10-1.

Minutes from last meeting: Motion to approve Debbie F. Approved with the following changes-Indiana had the best how to's not North Carolina.