

Intervention Subcommittee
AL Autism Task Force
2nd Meeting
8-27-07

In attendance:

Tim Ferguson, Chair
Kerry Mataya
Jennifer Muller, Recorder
Dr. Hanes Swingle
Angela Collier
Joe Carter
Eileen Mueller
Heather French
Melody Crane
Rep. Cam Ward
Tracey Battaglia, Clerk
Dr. Robert Simpson
Candy Knickerbocker
Carol Gill Kral
Amanda Bellmeyer
Bob Babcock

Welcome and Introductions: Tim Ferguson, Chair called the meeting to order at 10:04, EM has a 4 year old grandchild with autism, KM is with Autism Asperger Syndrome Consulting Group in Birmingham, Angela Collier works with AASCG in Huntsville, JC- is the VP of adult services at Glenwood, TF has an 11 year old son with AS, Melody Crane and Dr. Heather French are from The Riley Center in Huntsville, Dr. Simpson is the Director of the Auburn Autism Center, Amanda Bellmeyer is a BCBA from Mobile, HS is a Developmental Pediatrician from USA in Mobile, Carol Gill Kral is the aunt of an individual with AS and the sister of Candy Knickerbocker. Bob Babcock is a professor of Psychology at Auburn.

TF: The folders provided are for us to use to track the work being done by the committee. We will add info to these books as we get more information.

Review and approval of minutes: 1 correction, USA in Mobile has the diagnostic going now-2 days a week-they are operational at this time.

Motion to approve the minutes was made by Joe Carter, 2nd Robert Simpson. TF minutes from the last meeting were accepted with the changes noted above.

Review of progress to date: TF: This is the 2nd meeting of this committee, we have 2 distinct missions-come up with recs for EI and the other to come up with recs for older individuals even up to adulthood. He has compiled the info provided to date and then he has also provided info from PA (good with EI) and IL. This helps give us a guideline of what we are trying to come up with. We are still gathering info regarding what is out there in the state and we quickly need to come up with recommendations.

There is still info to gather-Auburn is in the forefront (Simpson will send his information). CW-working on a series of meetings around the different parts of the state for ease of access. A brief tour is being scheduled at Auburn, members of the task force and legislators in that area will go on a tour. Planning on an October meeting in Spanish Fort. We will also work on one for Huntsville as well. TF: due to the nature of the group and the diverse issues we need to discuss, he would like to discuss the option of dividing the work of this subcommittee into 2 groups. He has spoken to Cam this morning about this and he wanted to get the group's feedback. He would recommend 2 vice chairmen to be appointed-on EI side-Hanes Swingle and KM on the adult side. He believes that we can make more progress this way. KM and HS agreed to take these roles. TF to recap for late arrival we will split the group into 2 areas. TF would like the subgroups to meet in locations that are convenient for the larger group. KM wanted to see how many people are interested in what group. CK wanted to know the age split-KM said 18+. CW there is an education committee that is having meetings but none at this time have been held formally. They will handle the school aged group. They will meet this Wednesday after the other 2 meetings. CW-our committee is different, we have the bookends in this committee. A survey of interest was taken with the following results: EM-Early Int., AC-really split, will sit on both, KM young adult, JC adulthood, CK both, CW both, TF both, BB both, MC and HF early intervention, most experience in EI but done research in both (the 2 others from Mobile and RS have split interests. HW EI. KM planning for programming purposes do you have any recommendations? CW he would have Vice Chairs set agenda items for those involved in the areas put those on the main agenda and have a 2 part agenda. The entire committee will be looking at both of the sides and you don't have to attend so many meetings. This will make it logistically easier. We decided that we will not have working meetings outside of the subcommittee meeting but will work on the issues outside of the subcommittee and bring the work back to this group as a whole when talking about the recommendations that would be put forth.

CK she realizes what we are doing and feels that we need to keep in mind that the school system is supposed to be doing this now. She thinks we need to look at this as well. CW Systems of Care is doing this outside of Education and Education is also going to be looking at this. TF-to clarify at the first meeting we needed to keep out of each others areas so that we could look at these issues within the committees that we have determined. CW at the task force meeting this week we will be hearing from MH and Dept. of Ed and Rehab-what is going on and what is not. KM asked if CK was serving on Education. This was kept separate for a reason. CW said that public education is huge and we need to have that as a separate committee. TF asked HS to comment on his thoughts on what EI can do to help. HS- young children have plascity of the brain. Ex.

Infants with strokes are able to adapt and this is a reason to have 9,18, and 36 months physicians are to screen, at 18months they are to do an autism specific screen-according to the recommendations of the Academy of Pediatrics. EI duplicates services because they continue to screen. He would like to see EI do more services. Kids that come to USA see a host of professionals during an eval and then if they are referred to EI they assess again. EI is now primarily home based and that helps a lot of families. For kids with autism we need intense services. He does not feel that intensive services can be provided in that setting. He likes a combined model. AB was an EI Coordinator and she is now contracting as a service provider. None of their contracts allow for more than 1 hour of in home services. HS has seen children with little stimulation at home, he doesn't think that the one hour a week is worthless but he think they need a different approach. BB says there is very good science on this –Cathy Lord 2001, they recommended that intervention start with 25-40 hours a week both at home and in school settings. HS added that it be year round. BB says it should include the goals of the family. (need to get report from Cathy Lord-ask Bob Babcock to find this source to site in the future). TF said they kept doing a wait and see approach with his son, the pediatrician said he was just a boy and they waited and waited. Not until school setting and they could compare they weren't able to see it before without a comparison group-as parents. If in hindsight they had known and gone in with EI and programs before he had formed his identify we would probably have a different outcome said TF. HS said he had seen 2 kids that had been told by their peds they would refer at 2. How can we change this quickly? He would like to suggest something that happened in FL, 1 hr of CME in HIV and 1 in Domestic Violence. That required every physician in the state to get the knowledge. BB said that in GA they have a similar type program for psychologists. He would like to include this. This would require all physicians to know the screening is recommended at certain dates and it will affect the population in general. AB is concerned because they do wait and see-most people do this-a lot of kids don't start talking until 2. They have the transition meetings at 2.5 and they have another meeting at 3 months out from 3 years. By the time they actually get diagnosed they are in the school system. HS the transition between EI and school needs to be seamless. She doesn't want to hand them off to Education-no, we aren't going to be doing this. AC says a child is being diagnosed now by Sparks and the school systems are doing their entire eval as well. BB says that there are regulations from SDE on how the tests are to be done. Ex. You need to do a Gilliam and if we are already doing an ADOS, if we could intervene with a regulation then you might be able to have a big impact. KM says some systems use the evals and some do not. CGK likes the recommendation of educating the medical community she also suggests that they train the educators. CW thinks this would be a top recommendation that comes out of Education. AC says a group of nurses was just trained on Decatur. CW says this is a good way to do it. CGK wonders who they would have train the educators. They have a choice about how they get the CEU's. CW says the biggest challenges is not wanting to do it but having the opportunity to do it. CW says we need a state mandate that is offered to the teachers and offer them the opportunities. CW says he would like to increase funding to the program within education that has a sit down 1 on 1 with special ed teachers. This would take us down a path that will help us change. KM contracts with a lot of different school systems and she knows how a lot of different schools do things-the problem is they don't have the people to help carry out the

things that she is recommending. KM asked if there was a way to find out what special ed departments are spending their money on? CW says he will let SDE talk about this-he has seen them take units away to help cover expenses. Dr. Morton will talk about this when he speaks to the full task force on Wednesday. HF says an element of the training that gets missed is the training of the administration and the superintendent, etc. BB says their program was in 16 districts last year and many of those were because of settlement agreements. You have to have the support of the systems.

JC refers back to Rebecca Dossett's comment from the last meeting and says you are a child for the first 20 years and an adult for the last 50+. TF asked about the awareness of why someone may be acting different and thinking about law enforcement. BB says ASA has a good packet for this and Dennis Debbaut is the name of the person who wrote the book that came out of this. He wants a general recommendation for ongoing training for law enforcement. CW can expect that it is minimal at best now and adds that this could be done thru the AL Dept. of Public Safety. AC has recently started working with adults and that has made her more aware of the shortcomings of the earlier system. 1 of 9 adults in her groups works and all have a regular diploma. TF says one of the things he thinks the state legislature can help us on is using incentives. There can be things that can be written into the contracts (for the higher functioning people) so that they do some of the repetitive tasks. Sell the idea that Alabama is a great place to work and we have individuals with the needed skill sets that would allow our kids to be good workers. TF says the biggest problem for adults is getting them into the right placement. CW says ADRS has a program designed to do job placement. When Mercedes came in they funded a workplace training center. The problem is that they don't have the money they need. TF with the exposure on showing all of the legislators remind them that the money is going to spent one way or another. CW this is with all mental health issues. CW says MH and Correction are the lowest funded programs always. We need to focus on this when doing awareness activities. KM not sure if this would be possible to do research on why they aren't getting/keeping a job-BB says there is literature that supports this—a huge % of jobs that are lost are due to a lack of social skills. KM says we need to do more on this area. AB says that goes back to what she was saying. They graduate and sit loosing their skills until they can get a placement in an adult program. But they don't teach social skills in schools-AC. AB at 35 you can't put them in a job because they don't have the skills. BB says we have a systemic problem with reimbursement and the community mental health centers-there are functional disincentives from changing waivers. BB says even the reimbursement rates are a problem. A lot of people in day hab centers could be working jobs but for the agency they do better to keep people in the center and pulling down the daily rate. In GA, Charles Hopkins took this on and shifted day hab waivers to supported employment waivers-you can serve more people with less state match. It is hard to serve people with autism in AL because of the MI/MR limitations. BB says Briggs and Associates worked with the closing of Brookrun when it was closed in Georgia. They did a good job with placements. The community based waiver can not be accessed for people that don't have the IQ scores under 70. KM talked about UA's transition program and the fact that they are going to be able to work on behalf of the students without the legal issues that come with guardianship, etc. Linda Murdock at Montevallo has another program but the limitation is that they are only able

to talk to the parents. When discussing people who are graduating from high school-if we could teach them the rules, and let them know that they need to ask for accommodations within a certain period of time. KM student directed IEPs, need to advocate for themselves at an earlier age. AC mentioned that at UAH the counselors that work with her students only allow extended time on tests. We need to look at that. BB says that every University has a disability affairs program that is supported by the University. Every college has a department that does the accommodations. This may be an area that we need to do training in, as well. TF asked of Dr. Simpson how many students might be at Auburn that have autism, he knows they have a lot of accommodations that are available, they will translate into Braille, etc. TF says they have the best college for teaching teachers and it would be good to take those that need a little assistance-simple accommodations can be made for students with autism. TF when heard about what Montevallo was doing using students in education help check up on the students with ASD. That would be a learning experience for the people as well. RS says that as a teacher you can't ask the student what type of disability they have if they have a letter from disability affairs. RS says you can train special educators to be fabulous and then you use inclusion and put these kids in a class with a regular ed teacher who probably has no training on autism at all. The administration is usually less likely to attend workshops, etc. KM says she is doing training that is very specific and feels that can be very helpful, especially if it is targeted to the group in attendance. BB says in addition to the academic stuff—he thinks the Best Buddies program can be helpful to facilitate people with autism and get the regional chapter. He wonders if at our colleges statewide if you use the faculty facilitator of Best Buddies to pair students that need help with social skills. Let them know that the program should be more than for MR-let them know that we are going to include DD. CW asked if we might want to suggest something that mandates these college service centers to do more for the students. Put something uniform into place. KM says it would be helpful for there to be mechanism to help people get jobs right after they finish school. We need to get kids set up to take care of themselves when they finish. CW says with Medicaid services will decrease and by the year 2015 healthcare and Medicaid will consume 70% of state budget. We need to think long term for our solutions. BB says we need to look at moving people from sheltered workshops and into the workforce. It doesn't matter what the agency does right now, we need to look beyond that. Many people are stuck at day hab level where they are supposed to be being trained for jobs and that is not what is happening. CW says it might be time to bring in the 2 year college chancellor because they are over the workforce development program in the state.

AB-what about the lower functioning group and the people that are in need of more support and supervision? CW says DMHMR will talk about this on Wednesday. RS says 4% of persons with autism in AL are employed. He would like us to talk about how to teacher regular ed teachers, and how we can bring the attention of administrators to the fact that kids with autism are in their programs, how we can convince employers of the workforce possible by using the persons with autism, how to educate physicians, and how to get the universities to allocate resources to the put monies into services for students that are being served by disability affairs.

New Business:

We need to come up with recommendations to address these issues, main points have been highlighted. CW says we can add meat to these and come up with solutions at the next meeting. KM would like to have people send in recommendations. HS would like to do the same, have people email him and have virtual meetings between meetings.

Next Meeting:

October 1 at 10:00 in Room 123 of the State House.