

Spanish Fort, AL
Alabama Autism Task Force
October 9, 2007

In attendance: see sign in sheet.

- I. Meeting called to order at 10:36 by Rep. Ward, this is part of a tour that we have been taking-we are coming out to meet with the people who deal with it on a daily basis. Families and those that are affected understand how complex the problems are.
- II. Approval of Minutes-Without any objection we will stand to have the minutes approved. No objections were noted.
- III. Introductions: Education-Tracy Roberts Baldwin County Board of Education and Jamie Ison, a friend in the Legislature
- IV. Announcements-We will also be having public meetings such as this one in Huntsville and in Birmingham. Facility tours have been conducted at Auburn, and Glenwood.

Comments from Rep. Ward: When we started we realized we would have a long road ahead, everything comes down to resources. We realized the importance of starting down the road. Hopefully before this next legislative session we would have a preliminary set of recommendations that we can present to the legislature. We will extend the life of the task force another year and have more recommendations to follow the next year. We know the statistics; we will all have to work together.

Welcome from the local Legislators-Rep. Randy Davis-It is a pleasure to serve with Cam on this Committee. He is particularly proud of the work being done in Baldwin County and the work being done at Spanish Fort. Hopefully we will be able to report back to the legislature in Montgomery. We would like to recognize Jamie Ison-she is a representative and has served as the leader of the school for the deaf and blind. The Mayor is also here. We are in District 96 today. Tracy Roberts is also here, the principal of Spanish Fort HS is here. Mike McMillan is a City Councilman from Spanish Fort. We are excited to have everyone here and we ask everyone to sign out as they leave.

- V. Subcommittee Reports
 - a. **Healthcare**-Bama Hager (Chair), could not attend but Cam gives her report. They have met twice and will meet again next week. They have looked at Private and Public Insurance. Cam has met privately with BCBS and had very good discussions. He feels that we will become the 19th State that provides expanded coverage. As we move forward we hope to have some announcements. We are also trying to address public insurance regarding coverage. The Medicaid Commissioner will be with

us at the next meeting. We will look at our goals at the next meeting to see how far we can go with this. We need to be creative with our solutions. They plan on having a set of recommendations by December.

- b. **Interventions**-Tim Ferguson (Chair), has a child with autism, he is 11. The Subcommittee has a huge contention of South Alabama representation. We have divided the group into two subgroups. Hanes Swingle, Developmental Ped at USA mentions our discussions that are having regarding early intervention. The key to improved outcomes is early intervention that is not possible without early identification. The AAP recommends an autism specific screening at 18 months. We are looking at how this can be done promptly. We feel that there should be regional training centers. We are also looking at the behavioral needs of these children. We are looking at the intensity of service provided by EI. We are looking at expanding services to children at home and in inclusive center based programs. We have also discussed trying to increase our worker capacity by giving scholarships to students studying the area. We would also like have the legislature recognize parent support groups. The other part of the group is the transition aged children and adults. We are looking to increase opportunities for this population. We will work with VR and the type of jobs our children can do. He is hoping to have concrete ideas.
- c. **Education**-Jim Wrye (Chair)-could not be there but feels that they are making a lot progress. They have been having meetings already to discuss the budgetary issues and the needs of the local school system. He talks about the tour he took recently in Bibb County. He talks about a teacher who wants to do what she needs to do but can't. They are looking at trying to provide autism academies. They want to provide more resources for special education teachers and they can share the information with others. We have also asked for increased funding for special education teachers in the state. We realize we will not get everything. The SBE can tell you right now that the # 1 type of lawsuits they are faced with are those coming from parents of children who have ASD. All of the recommendations are directly related to education and training and trying to get these people the help they need. We need a better awareness campaign. Dr. Joe Morton has been very supportive of this effort. We have a broad based bipartisan support for this effort.
- d. **Systems of Care**-Lee Yount (Chair) it is great to be here and see all those that are interested. She has been working with these issues for the last 26 years and is delighted to see that we are looking forward to major change. We have been working on 3 areas: Looking at existing systems of care, what are we currently doing in the state and then looking at community based organizations and University Based programs that are serving people with autism in Alabama. A survey will be sent. We are also looking at other states and best practices. There are 8 States that have different autism based programs that we are looking at. We will then make recommendations for the systems of care we need. We are most

appreciative of State Agencies that have stepped out to serve, DMH/MR has no state mandate to serve, we want a state mandate (we know that people need services (without meeting IQ test to receive services). We want to improve access to services. We need more coordination and collaboration between all systems of care. We have too much isolation. We want to have a group that crosses over. We can't have a great system for care without informed professionals. We want to be able to fill positions and have quality of care and more appropriate systems of care. We don't more funds to do what we are doing; we want funds to do things differently. We want a consumer driven system of care. It is important to be based on what people need and let's create something new that will move the whole system of care forward. We have met 3 times, we meet again next Thursday. We welcome others to join us. Right now we have funded services thru Medicaid. At our last meeting we had several professionals from Medicaid with us, we will be looking at the need to write an autism waiver or look at amending the State Plan. It is great to come up with recommendations but we have to realize that we have to give great consideration to what is prioritized. It may be 5 or 10 years out to fund everything. We have found the agencies want to help but they do not have the funds to do it.

- e. **Family Support**, Matt Remick (Chair) could not attend but gives the following report via Jennifer Muller.

On September 9, 2007 the family systems subcommittee of the Autism Task Force for the State of Alabama held its second meeting.

The family systems subcommittee has narrowed its focus to four distinct areas:

- Parent Knowledge
- Services for High Functioning Persons with Autism and Asperger's
- Development of an office of Developmental Disabilities
- Development of a Case Management System

Parent Knowledge

In this area the focus will be on development and dissemination of information. Specific training sessions will be developed with topics that will include Introduction to Autism, How to Develop a Quality IEP, Toilet Training as well as other specific problems frequently faced by families of children with autism spectrum disorders.

Services for High Functioning Persons with Autism and Asperger's

Further needs in this area will be addressed in the next family systems meeting.

Development of an office of Developmental Disabilities

It is the recommendation of this subcommittee that a system be developed allowing for one agency at the state level to serve those diagnosed with an autism spectrum disorder. This will provide for better continuity of care rather than having a person move through the three different systems that currently exist; Early Intervention, Education, Mental Health and Mental Retardation.

Development of a Case Management System

Once comprehensive services are in place and systems exist to support the persons with autism spectrum disorders, it is being recommended that a case management system be developed. Once diagnosed with an autism spectrum disorder an individual would be assigned a case manager. This case manager will support the individual and family in understanding services available and assist with accessing to these services. Training, salaries, and number of cases for each case manager be determined at a later time.

VI. Community Reports

University of South Alabama-Dr. Dennis Campbell

Used to direct the IFS program for the DD Council, families are at his heart. A few months ago Dr. Swingle gathered people from different departments at USA and they realized that there are lot of things going on. They hope to have an autism center in south Alabama in 2008. In college of Education they train teachers. They train about 85% of teachers in the area. They are taking the lead in the state to have a certification program. They are working with other Universities to do a cross University online program. They are fortunate to have 4 faculty members that have experience in low incidence. They are partnering with Psychology to to a behavioral based program to prepare people to work with behaviors. They are having a session later in the month regarding IEP's. Next week they are sending a proposal to the DD Council in collaboration with the school system to put together a database so that they can track all of the programs that are available. Families will be able to input info about their children and it will search for available programs. They will feed that back to the state. They are working with Dr. Mulvihill and the UAB group in Birmingham and USA polling will be doing a random sample of the state to see what the general population thinks. They will sample 600-800 people. In closing, it is wonderful that we are talking about EI, we are picking them up at about 3, we need specialists training. Schools need the resources. The Task Force might want to look at hiring behavioral analysts. Children need to be actively engaged. Schools need to have inclusive preschool programs so they can learn from peers.

The Little Tree-Jerre Brimer, he would like to reiterate what Dennis said, they do school consultation. They see children that aren't being engaged. There are exciting things going on in Mobile. The Learning Tree

is the parent group of the Little Learning Tree. They are a private non profit school. They have residential schools in 3 parts of the State. They have 40 students that have ASD. They partner with Mobile County Schools to provide services to 20 students with autism and 20 that do not. They are in a fully included program. The ACORN project at AU provides hands on training. They provide housing and train parents. This will also be developed in Mobile. They have a school based consultation program that has contracts with 16 systems. In 30 years of work, he has chosen ABA as the best model that they have. It produces outcomes that are measurable. It is not an overnight cure, it is hard work. For those willing to work hard he recommends ABA. They use it primarily for teaching adaptive skills. A common misconception is that it only targets negative behavior. He believes that medical services can help a child but feels that children need this type of program. He refers to a child's chart that indicates on one day he was heavily medicated. People have argued that ABA doesn't fit into school culture. He refers to Robert Kennedy and asks Why Not? ABA has been ruled by federal court to be the most effective programs. He suggests that people who are trained in this manner can be very effective with this group of kids.

Holly Rogers-Director of Little Learning Tree. They are an inclusive preschool program. It is amazing to see the typical children teach the kids with autism. They are year round and 5 day a week. They provide 40 hours of service. 35 hours are in the center and 1 hour is in the home. They only serve kids 3-5. They use ABA all day long. That doesn't mean discrete training all day long. They use incidental training. They have a 1:1 ratio. They have monthly parent meetings, they have weekly clinical meetings to chart progress. It is a preschool program, they have typical program. Mobile County schools have provided a space for them. They are at the old Kate Shepard.

Lee AnnThe in home programming from the Little Tree use competency based training to teach them the principals of ABA. The parents provide the other 9 hours of the in home hours, they provide 1 hour. They have 12 children with autism.

South Alabama Autism Society. Cindy Fulford, has 2 children on the spectrum. Has been involved for over 5 years with ASA. In February she and another mom started the South Alabama Autism Society, to collect monies and raise funds. They are going to collaborate with ASA to manage the efforts in South Alabama. They are going to be offering continuing education in the local area and keep that effort local. They had a workshop recently on Sensory Integration. They will continue to run the support group and increase local awareness.

Rep. Davis, the enrichment program is raising money. This is for Spanish Fort High School

Baldwin County Board of Education-Mike Luce-has 13 autistic children and he is very proud of the students that are engaged with autistic kids each day. They are having success with their program at Spanish Fort. They had the opportunity to get ready for over a year. They don't view special ed as a burden but instead a privilege. They are going to do it to the extent they can. They learned early on that you have to know what they are doing. Scott Parks is a teacher there and he is a huge asset. They have a collective cooperative relationship with the parents. The parents want to help. Their school is good because 8 faculty members support 12 kids, they are supported by neurotypical children as well. He has seen a complexion of a child change with a child in a year. They are very proud of their school.

Mr. Parks-See slides that were provided. The students are a part of what he does in the Project Reach Program. He says the future looks bright. The 10 leaders of project outreach put on a presentation on autism awareness this morning for their students. The club has a tee-shirt that the kids want to be a part of. They are trying to break down barriers. It is a program that serves kids throughout the county. It is a referral based program. They have a preschool class, 2 elementary school classes and high school classes. They had a consultation that required them to change the way the school felt about the students with autism. He recruited students that could help him (football players, cheerleaders, club presidents, etc). They have students that are going to college and need scholarships. They look at the individual needs of the disorder first. The team is trying to make an impact. He thanks The Learning Tree and says that they have learned a lot from Mr. Brimer. He reflects on a Marathon that he ran and the support that he was given by others. We want to remember this for those that have ASD. The students indicated that they would like to start eating lunch with the kids who have autism.

Shala Walker and Garrett Keeting tell us about their involvement. The club focuses on interactions. 2 years ago they had 5 students this year they had 70 kids that wanted to belong. They had a dance for them, they go to special Olympics with them, etc. She started doing this as part of the girls service club. Many people don't know that autistic kids like the same things they do. They have dinners each month. She asks us to imagine not having a friend; they want to break this barrier. Garrett says that it started with lunch. Most of the participants were in SGA. At first the students seemed shy. They went again. They got other students to sit with them and they decided to start a club. The club was a hit. They go and hang out with the others. He relates a story about the kid who was fascinated by the smoothie machine and the importance of the sensory experiences.

They have seen benefits of tension reduction. They also use tools of sensory integration. He speaks of a school in Pensacola that has a SNOEZELEN, environment that is safe and non threatening. It doesn't demand or expect. The environment allows for the student to replenish. In Pensacola they started small and now they have 4 rooms. This has been found to be very effective for kids with ASD. He would like to pilot this and show that this tension reduction opportunity can be helpful. A choice can be very helpful for these students. As a school they want to increase their training. People are asking the students to get involved. He would like to take these students to other areas in the counties. We need to get past our fear. They are doing that at Spanish Fort.

E. **SERFASD-Candy Knickerbocker**. She thanks the group for the opportunity to speak to this group on behalf of SERFASD. Her son's story is importance. At the age of 3 her son began exhibiting behaviors that looked like hyperactivity. At 4 he was given this diagnosis but she realized that this did not completely fit. Her concerns were ignored. At 10 her son became suicidal because he realized he was different. He was referred and finally received an AS diagnosis. She remained lost as she didn't know anyone else with this disorder. She got on the internet and looked for services. She found a severe lack of services. She was not able to maintain employment because of calls from the schools. She has developed a library. She indicates that she found a group that was operating and calls it a blessing to experience things with a group of parents. She suggests that she has spent a lot of her money to help families and reports that over 300 families are affected in Baldwin County. The stories are very much the same. Many parents in the support group travel extensively for service and pay for services out of their pockets. She has been asked for expanded services, support and training. She says they recognize that problems do not end at age 8. They are enlightened by those that attend their support groups as adults. They struggle in the workplace and in their own families. Their exocentric behaviors are problematic. Her frustration over the lack of services led her to found SERFASD. She began to build a board in 2006. The aim to make connections and build a network of support. They are actively participating in the AL Autism Task Force. Their work prompted USA to develop an autism system and the polling grant that has been awarded. They have written grants to the DD Council but have yet to be funded. They continue to move forward. They hope that we will support legislation that provides more services.

Cam says as a parent himself that is how he got involved. He is not an expert. He is an attorney and a legislature. He and his wife also have searched the internet. He is still learning. He understands the legal process and the legislature. This is a scary experience because we don't have all of the answers.

A grandparent from North Alabama asks to address the group. Lois Rhodes, grandson goes to school in Shelby County. He is 9 years old. They have had 1.5 bad years. They have experienced a lack of training and lack of compassion. She wishes that her kids could move to South Alabama and receive the services we are talking about. They were in Eclipse and that was wonderful. 1st year kindergarten wasn't worth talking about, last year wasn't good. They need a lot of the same rules applying. The change is hard. The students at the high school are great, they just need a lot more help. She is a bit encouraged by what she hears today and hopes it goes statewide.

CAARs(Center for Autism and Related Disorders) in Baldwin County (no name given). She indicates her son is attending the project reach program. She says the parents need help. They had a gap in services because they needed help and testing didn't start until age 3 in the school system. Parents need support, she never thought she would need to talk to legislators, etc. Now she is talking to Roxanne Carpenter as a partner. Her organization want to bring resources to Baldwin County. She wants to help take the stress off of the parents.

Cam thanks everyone that has come today and appreciates the Spanish Fort Community.

Dr. Dagas shares her experience at Mobile Mental Health. Dr. Swingle calls her and the patient is an autistic child, the child is calm, the school says they can't control the child...he has written letters to the school and asked for ABA. So when you talk about doctors adding medication it is because there isn't the partnership that they should have had. The mother that is here with her today has a case manger who helps her.

Rep. Davis thanks the group and Hank Burch and the Land's Facility. The meeting was adjourned at 12:31 by Rep. Ward.