

Adult Services Meeting #1

July 1, 2008

Meeting held at Triumph, Inc., Birmingham

Meeting called to order at 10:03

In attendance:

Brooke Stephens, Ex. Director of Triumph Services

Mike Martin, Community Service Director Region 4 for DMH/MR and also a parent of a soon to be 19 year old.

Tim Ferguson, Parent of a 12 year old son with AS, wife is on the Board of ASA, served on Task Force last year.

Jennifer Muller, Executive Director of Autism Society of AL.

Lory Hemby, Region 5 Certification Person for MH/MR, has been very interested in the services persons with autism received.

Joe Carter, VP of Adult Services and Chairman of Committee, started serving adults in 1987-now they have 60 adults that they support on a day to day basis.

Shirley King, Alabama A and M

Leigh Belcher, therapist that works for Triumph

Cathrine DeCola, has a 23 year old nephew with ASD

Melanie Bush, Chief Evaluator at Easter Seals in Montgomery

We will meet at different providers' sites so that we can learn about their services for adults on the spectrum as we go.

Brooke spoke about her work at Glenwood and then about her personal connection to autism. She worked at Civitan Center's Lifelong Coordination Clinic. When it closed, there were 16 individuals that needed services. This past August, she and Isabelle Porter started Triumph with those 16 individuals (life coaching, supported employment, weekly social outings). Soon they recognized that most of those individuals had deep seated issues that needed to be addressed and they hired 2 licensed therapists. They changed their structure in May to be a non-profit.

Brooke passed out a handout that showed that of the 35 they serve 20 have ASD diagnosis. 19 of their 20 receive supported employment. 4 are currently being assessed for employment, she is actively seeking employment for 5, 65% are receiving individual therapy. She feels that they are unique because everything they do they do in the community; all supports that they provide are in that persons environment and they are not agency based. They try to provide true wrap-around services, and 2 times a month they staff cases and talk about client concerns.

Joe asked about the 20 people on the spectrum, if they were HFA/AS? Brooke says yes; 3 are pretty impaired by their diagnosis and have great needs. Tim asked about the 12 people engaged in social events and if they have developed friendships...yes, but in baby steps. They facilitate getting people together. They have an informal interest inventory to identify people who have similar interests. Leigh says that almost all of them comes to the therapists and ask for help to find friends. Catherine asks about getting typical peers to interact with them on social outings; Brooke says no right now but that is a goal. They

would like to have mentors. Catherine says her nephew learns better from those that are typical and her nephew listens to people his own age better than to older individuals.

Charge to the committee/time frame-this is the 2nd year for the AATF and their charge is what do we do about the needs that were found and what is the financial impact of that and how do we address that? Recommendations should be completed by the first of February. Legislation has been passed to create the Interagency Coordinating Autism Council.

Joe asked for a back up for Jennifer Muller as scribe. Mike agreed to take notes when Jennifer is not able to attend.

National Association Residential Providers Adults with Autism (NARPAA), Joe indicated these are the groups that are recognized as providing residential services for adults. The Needs Assessment indicated that we need more residential options. Joe suggested that we look at this list and ask about the services that they have in their states. We agreed that we can split up the list and identify questions that we would like to ask. Tim offered that he could go to Houston and Dallas in particular. Mike Martin will contact Autism Services Center and Judevine. Catherine DeCola can do the Maryland program in August or September (Joe is pretty familiar with the Rockville MD program). Joe says their County has some of the best resources in the country. Jennifer will do South Carolina. Joe asked if Leigh would contact AdvoServ. Brooke will research Bittersweet Farms and Ardmore. Jennifer will do the Groden Network. Joe will do Benhaven and the Higashi School. Tim indicated that face to face interviews will probably yield more information. Catherine could also visit Randolph in November. Leigh will do Rusty's Morning Star Ranch and Lory will do Eden Family Services and Chapel Haven, Inc. Joe asked Shirley to research Homestead and Mission Hills.

Catherine spoke about a speaker who spoke in Gulf Shores on providing residential services in the community. She will look that person up and let us know who it was. Joe asked if there are other states that are doing innovative systems. He indicated that Pennsylvania just passed an adult autism waiver. Lory indicated that she felt that while they were getting school services and there should be some push for services during the adolescent years. Tim indicated that while housing is critical, there is a crucial need for services to those that are higher functioning. There are many kids that need these niche services that can't afford them and don't have access to them. Kids who are high functioning can get off the state money if they have coaching. Brooke says that community based services are not that expensive in comparison to facility based services. The biggest factor is that there are people that aren't eligible for services because of their IQ scores.

Joe recapped for the member who joined us late. He indicated we wanted to look at PA, OH, Indiana. We will look at Pennsylvania first.

Project Grow, Adult Residential in Massachusetts.

What questions do we want to ask them? Joe provided a draft, models to recommend for our state what works and what doesn't? Joe asked if Melanie could find out more about the Pennsylvania Autism Waiver.

Catherine asked if we needed to ask about eligibility requirements. Mike asked about the length of waiting periods for services, and how does their waiting list work? We need to add that question. We should also ask what doesn't work. Joe also asked if we should ask about autism specific certification program. Also we need to ask about the certification requirements in general for programs and what accreditation they have. Mike asked if we should ask them about their method/approach. Catherine suggested we ask them about follow up. If the answer for #7 is not indefinite, then ask what type of follow up/service time is allowed. Also ask how you address crisis situations.

Mike also talked about us asking about case management and what is provided and by whom. Catherine asked if we can ask about how much they spend per person.

The subcommittee decided these were the questions that would be posed to the programs of interest:

What services are available to adults with autism in your program?

What is the size of your program?

What are the eligibility requirements to access services?

How are services funded?

Do you support individuals with "high functioning" autism or Asperger's Syndrome who do not have mental retardation?

Do you provide both facility and community based services?

What is the average length of service time? If time limited, how is follow-up done?

What services are available to adults with autism in your State? Are there other providers?

How are services funded in your State?

What is the length of time for access to services/ waiting list process?

Do you work with State agencies like DMH, Voc Rehab and others?

What are their roles in providing services to adults with autism?

How is case management handled?

What are your program certification/accreditation requirements?

Is there a State contact for access to services in your State? Who is it?

Tim and Catherine talked about the importance of our mission and the fact that we need to be more successful this year than last. Catherine talked about the importance of parents knowing their rights and their options. Joe spoke about Lory bringing up the transition issues. We need to define what we need in our state. The plan needs implementation and implementation needs money. Mike says we need to present something that is tangible. Departments are apprehensive because they only have the money that they are allotted. We need to have grassroots support of our efforts and use the contacts we have (families, extended families, etc.).

We decided on August 5th, 2008 to have our next meeting and will ask Judy Barclay/Full Life Ahead and/or Kerry Mataya to host our meeting at 10:00am. We also discussed alternating our meeting times so we can accommodate the needs of consumers and families who may want to attend.

Meeting adjourned at 11:32.