

Sept. 11, 2008
Full Task Force Meeting
Huntsville, AL

The meeting was called to order at 12:25 by Rep. Cam Ward, Task Force Chairman. He thanked the Premier School and Applied Behavioral Concepts for the tour that was given earlier in the day, he also thanked 801 Franklin and Jenny Morris for their hospitality. He spoke of the friend in the Montgomery Department of Mental Health and Legislative Advocate Mac McCutcheon from Huntsville.

Joe Carter, VP of Adult Services at Glenwood, Inc. is the Chairman of the Adult Subcommittee and was asked to speak on their progress to date. He indicated that they are experiencing good turn out at their meetings, they have a very active subcommittee . To date they have had 2 meetings. They are looking at 1) Residential options for individuals with ASD (noting that these are not all out of home placements, but also thinking of in home/companion and respite care type services). A big issue is eligibility.

They are also discussing case management and they are examining a group of organizations that belong to a group called NARPA (there are 28 of them). They want to come up with a plan that can be implemented. It is important that the options presented allow consumer choice, are integrated in the community and have a lifespan focus.

Jim Wrye, Communication Director for the AEA is the Chairman of the Intervention 6-21 group. Jim thanked the people from Huntsville for their involvement with the task force. He referred to the Needs Assessment that was completed and spoke about the Regional Center concept and the need to base/affiliate them with Universities. He spoke to the group about the research his subcommittee had done on the Florida model. Currently they have 11 regional centers and they are based in Universities, they have responsibility for a geographic region and have education, working with teachers, developing resources, advocacy, working with families and case management as focuses.

Rep. Ward spoke briefly about the Systems of Care subcommittee, led by Jennifer Sellers, in her absence. They are working on coordinating agencies to create an Interagency Autism Council, that council will oversee a State Autism Coordinator and the group is currently working to write a job description for that position. The goal is to work this person into a Cabinet Level post. The idea of a hub and spoke method was used to describe the regional center concept in relation to the Interagency Autism Coordinating Council and this State Autism Coordinator.

Jennifer Muller reported for the following subcommittees in the absence of their Chairmen. Diagnosis and Screening, Hanes Swingle; Intervention 0-5, Elizabeth Griffith; Healthcare/Medical, Bama Hager and Jennifer Sellers, Systems of Care.

Diagnosis and Screening Chairman Hanes Swingle

-the group has been discussing the impact that will be felt by Autism Centers once more screening is taking place; there has also been discussion about the number of children that may test false positive and be referred for unnecessary testing....2 solutions have been offered –training EI personnel to do level II screening and have screening clinics within the regional centers that are being proposed.

-The Vice Chair of Pediatrics from USA spoke to the group about the barriers to getting autism instruction into the medical school curriculum. There was also a presentation of the ABCD screening project that has been coordinated under Alice Widgeon and others.

-the next meeting is scheduled for Sept. 17, 3 guests will be presenting to the group- Dr.Karen Dahle on the differences between eligibility for services in school and a medical diagnosis, 2) Betsy Prince will review eligibility for EI services and 3) Angie Barber will discuss the CSBS (a screening instrument that is being discussed for use in primary care physician offices

-they are also interested in the development of an awareness campaign and in the services that should be offered in our regional center model.

Intervention 0-5 Chairman Elizabeth Griffith

Their next meeting is scheduled for next week.

They are focusing their work on 3 domains: 1) The Family, 2) The Child and 3) The Community/Setting.

In the Family domain they are concerned about a family's access to diagnosis and their first services.

-A parent to parent network has been discussed as well as a formal case management system that would provide not only empowerment to caregivers but also education

As far as the child is concerned the group is discussing the need for truly individualized services that are developmentally appropriate and target social and play skills so as to lay a foundation for the other interventions that will follow.

The group has discussed the community/setting which includes service providers, place of service provision and integration into the larger community. There is a need for individuals from DoE, PreK and Head Start as well as others that interface with these young children to participate in this subcommittee, if you know anyone –please ask them if they would consider joining this group. *Conference calls can be arranged.

Healthcare Update Chairman Bama Hager

-They are discussing the inclusion of services for the diagnosis of ASD in both public and private insurance.

-They have discussed the need have private insurance providers provide for more OT and SLP sessions in a given year.

-The group has discussed the need to provide incentives for physicians who provide ASD screening.

-They have also discussed the need to remove age limits for ASD related services.

-They feel there is a need for a comprehensive Autism/Asperger Syndrome awareness campaign.

-It is their goal to first recommend what they feel is needed for families regardless of financial limits. They are working from a view point of best practices....

Systems of Care Chairman Jennifer Sellers

This group has been working diligently to create the job description for the State Autism Coordinator.

In addition, the group has been revisited the Regional Center concept and has been trying to work out the details (what will be done within the centers, how will they be organized, etc.)

Another important issue that is being discussed by this group is quality control. With more and more individuals being diagnosed we have a high demand for services-what type of credentialing is needed to work with these children and adults.

The next meeting is Sept. 23 and a guest speaker from a National Accrediting body, referred to as CARF, will speak to the group. As with any of our Task Force meetings, this one is also open to the public.

Public Comments/Questions were then taken from the floor:

- 1) Is a state coordinator going to be funded? Yes, State Autism Council is being appointed now
- 2) 2 areas of hope; Cam Ward's leadership and Alabama Hospital Association (people working together without conflict)
- 3) Rep. Ward and his wife Julie are being honored at the Easter Seals Convention in Orlando, Fl.
- 4) Is Easter Seals working with the task force? Yes
- 5) Dr. Pipa Absten is a Pediatrician from UAB that has clinic in Huntsville-she accepts Medicaid, they do the MChat.
- 6) 13 year old son is in special ed, what is being done to educate the medical community? Medical education is being recommended for training
- 7) Cheryl Smith from UCP described their programs and let the group know that respite money is now available
- 8) Is the task force addressing teacher education? Yes
- 9) What can families do to get more insurance coverage? Contact their employers
- 10) Training is a huge issue, teachers don't have professional leave days they can take, Making Connections is a free conference sponsored by ASA and the Whitesburg Baptist Church and will be Oct 24 and 25.
- 11) www.nea.org/Specail
Ed Booklet The Puzzle of Autism 800-229-4200
- 12) What are agencies doing with VR? AL Community Colleges do workforce development, working with ADRS
- 13) A question to Cam –what did you do? ABA, OT, SLP, time at home “socialized her”
- 14) 52 year old with AS, what are you doing for us-looking at the issues across the lifespan and looking to address the issue of eligibility for services without the MR
- 15) Where do you go to get info on adult services, contact ASA and they will put you in touch with ADRS and/or Department of Mental Health/Mental Retardation
- 16) Huntsville Hospital therapist-autism is an excluded condition for CRS
- 17) Can families buy into a special plan? Can we gradually increase therapy over time?
- 18) Going out of state for medical appointments because there aren't people here
- 19) Mandated insurance coverage-are we going to do that?
- 20) Families are facing huge financial burdens caring for their children
- 21) ABA is not covered by insurance
- 22) Insurance coverage should be a priority.

Meeting was adjourned.