

Family Support Subcommittee  
Wednesday, August 8, 2007

In Attendance: Matt Remick, Chairman, Doug McCallum, Tom Holmes, Alice Widgeon for Mike Martin, Ted Stansill, Carol Wright, Candy Knickerbocker, Paula Pace, Amanda Bellmyer, Mike Martin and Jennifer Muller.

Opening remarks were given by Chairman Remick (Executive Director, Mitchell's Place) after introductions concluded. He informed the group of the task at hand. He suggested that the subcommittee should examine the issues across the lifespan, evaluate what is in existence and determine what should be put in place to supplement current services. At this time the groups goals are broad and a direction will be determined from our initial meetings.

A question was raised by Mr. McCallum (parent and Board Member of the Riley Center) as to the subcommittee's exact charge.

Jennifer Muller (Director of the Autism Society of Alabama) indicated that the group was to evaluate family support issues to inform the full task force of the needs so that recommendations could be made to the legislature, governor, public agencies, etc in the report that would be the end product of the Alabama Autism Task Force. The recommendations are to be brought to the entire task force in December. Jennifer also indicated that a Needs Assessment would be completed in conjunction with this project but project proposals had just been turned in to the AL Council for Developmental Disabilities yesterday. This group will have the opportunity, as will all groups, to pose research questions that need answered in order to have recommendations accompanied by data.

Paula Pace (grandmother) stated that there were several different ways to look at family support.

Chairman Remick echoed Ms. Pace and illustrated that you can look at family support from the very beginning with the identification of children on the spectrum, you then consider the supports needed as children are in the school system, you can think about a families ability to afford services, and then you also have to think about the transition to adulthood. Currently we have several organizations that are serving children under 18 but not nearly as many that are working on transition services and trying to link persons with adult systems of care. We should consider those that are in the age range of 18-23 that are academically/intellectually capable of attending college but due to social deficits are not currently in this type of setting. Another group to think about is the siblings, as the parents age the siblings are often expected to be caretakers of the individual with autism. Think about respite care, what is available, how can we make families aware of what is available, etc.

Paula Pace-pointed out that she was only aware of services due to her experience as a teacher prior to being a grandparent of a child with autism, she also pointed out that there is no standardization of services thru LEA's in the state.

Tom Holmes (Executive Director of The ARC of Alabama and parent) indicated that this is true across the board, services are highly variable depending on the area. Tom indicated he was aware of meetings being held by the State Dept. of Education to inform their staff of the more specific needs of certain groups.

Chairman Remick-comment on pros and cons of inclusion

Tom Holmes-the point being that individual families should have choice in the types of services their loved ones are receiving wherever they are.

Alice Widgeon (Department of Mental Health/Mental Retardation, Early Intervention) brought up the idea of teaching to the future and looking ahead at what the students will be needing and making their experiences meaningful.

Chairman Remick-indicated that there were 2 areas of IEP's that concerned him-the process of getting a good one in place and subsequently making sure that it was being implemented.

Doug McCallum (Board Member, The Riley Center and parent) pointed out that there was a good model in the Army that helps families with advocacy by having someone attend meetings along with them.

Jennifer Muller asked if we should look at what existing groups are doing that have this type of thing as part of their responsibility (Parents as Partners in Education) and find out what they do exactly and the magnitude and effectiveness of their program and think about what we could do to have some our need met by enhancing what they are already funded to do. We could also look at ADAP and consider their role in helping families to advocate and know their rights.

Carol Wright (Vice President of the Autism Society of North Alabama and parent) said there is a huge need to advocate for kids that is bigger than individual advocacy.

The group agreed that we need to 1) identify children with autism early, 2) make sure that all of those children receive high quality services and 3) put services in place for those that are older and may not have received the type of high quality services we know are effective.

Tom Holmes addressed how the ARC advises parents to be informed of their rights and how to advocate for services that are needed. He pointed out that this is even more difficult in rural areas that may not have as many resources.

Doug McCallum considered this a crossover issue and pointed out that it is not only advocacy but we need to look what is available, what are the standards for care/education and figure out how to help all parents be familiar with this and make sure that quality services are available throughout the state.

Chairman Remick referred the group to the report by the National Research Council and indicated that the level of service would be dependent on severity of the case, pointing out that services may look very different depending on the child the impact of the autism on that particular child. He suggested that some thought might go into qualifying the level of disability in order to suggest appropriate standards of care.

Carl Wright raised the issue of funding and what could/should be done if the public school isn't the most appropriate setting for a child and the parents want to home school or send the child to a private school. A reference was made to the cost of 40-140K a year for indirect costs associated with ASD. A voucher program could be explored.

Amanda Bellmyer (Behavior Analyst and Board Member of SERFASD) suggested that the money that is dedicated to each child in special ed is very low.

Jennifer Muller suggested that the group should consider raising the standards in the state system rather than think too much at this time about the state giving money to the families to do with as they desire because there would be a big debate over the best way a family could spend that money and what was appropriate and what was not.

Doug McCallum pointed out that we should look at the standards and try to get AL to buy into providing that standard of care that has been suggested by the National Research Council.

Tom Holmes asked if we had gotten into the parity debate on mental illness and the fact that insurance companies should not be discriminating against groups of people.

Candy Knickerbocker (Founder of SERFASD and parent) indicated you can't get life insurance for kids on the spectrum.

Doug McCallum suggested we as a group needed to lock in the standards and really understand them or we won't be able to push forward our recommendations.

Candy Knickerbocker suggested we should think about peer training in our disability awareness training. She also indicated that there are many instances when resolutions to mediation have been drafted but then there is no follow up and nothing changes in the classroom for the child. She said that we needed to have someone inside of the school that would be knowledgeable and kid friendly to help our kids. She also mentioned having a behavior specialist in each school and/or a counselor that was educated to deal with this type of problem.

Mike Martin (DMH/MR, parent) shared with the group that West Virginia has a project out of Marshall University that helps parent's access services. The advocates look at specific needs and help families advocate for the things they need. This would be a case manager/program facilitator, or whatever you would want to call it.

Doug McCallum reminded the group that the needs of persons with autism were diverse and a lot of \$ is coming out for research and things would be changing rapidly so whatever we decided to do/recommend we would want the ability to make additional recommendations as we learn more about best practices, etc.

Chairman Remick indicated we should also remember to think thru the entire lifespan when we are thinking of family support. Needs will change and the resources get fewer and fewer as individuals age.

Candy Knickerbocker reminded the group that there are many who may qualify as having ASD who are older and have not yet been identified as having autism or asperger syndrome. Maybe we ought to think about social skills groups and meeting some of this groups needs. Everyone agreed that there are individuals in this type of situation or that were under employed or not employed that may benefit from some assistance.

Chairman Remick pointed out that as parents age they are less likely to be as active as they might once have been when it comes to advocacy.

Candy Knickerbocker and Chairman Remick discussed the aging population and their need for a variety of service options when it comes to living.

A discussion of the history of the waiver was brought up by Tom Holmes. At this time he believes that Alabama is one of only 2 states who do not have a Department of Developmental Disabilities. The intricate details of waivers were discussed briefly. It was decided that we needed to have a department that has the authority to make changes to the existing structure and then we would need to get the state Medicaid plan to enable a autism specific waiver. Tom also walked us thru the details of state and local match to federal dollars. Tom referred to a report indicating that 12,000 parents over age 65 are caring for a person with a developmental disability. At this time he indicated that we were serving about 6,000 persons in community based services. These numbers would indicate that we are not prepared to serve a large ageing population of individuals with autism.

Amanda Bellmyer agreed that placement for adults is very challenging and brought up the problems when a family feels that their child needs a residential program for either their own or the families protection because of behavior and the cost associated with this type of placement. She indicated that some families she has worked with have been in this situation and would have rather had the option of receiving supports in their home to maintain the family unit. The things she suggested were: 1) staff in home during waking hours, 2) behavior analysts, 3) persons to train the family. We also have single moms

who are trying to manage these children/adults in their family home at this time with little or no support.

Tom Holmes said that in other states parents are paid through the state Medicaid Waiver to care for their own children. Our state Medicaid agency does not have a provision for this. There is a range of services that are available to families who do have a Medicaid Waiver but we need to make sure that families have freedom of choice and are able to access trained providers. There are lots of providers now that serve these individuals on some level that would be impacted if this type of change was made. Tom reminded the group that once kids reach 18 their Medicaid eligibility is no longer based on their parent's income.

Mike Martin helped the group understand the 4 waivers that currently exist in the state: 1) SAIL thru ADRS, 2) Elderly and Disabled administered thru Department of Public Health, and the MR and Living at Home Waivers administered thru DMH/MR. The main difference between MR and Living at Home is the lack of the residential component of the Living at Home. Mike, as a parent, reminds us that the numbers of individuals affected by this disorder has exploded. We need to keep reminding ourselves that we need to think of these concerns and their impact across the lifespan. He referred to Alice Widgeon and her representation of the 0-3 population, EI does have some contact at an early stage with these kids, there is evidence that intervention at this time of life is highly effective-we need to support the family to ensure their ability to meet the needs of their children. Mike referred to the statistic that 85% of families who have children with autism end in divorce. At this time, if you use the statistic that 70% of children with autism also have MR then many of them in theory would be eligible for the MR waiver but even if they are and do-that is not enough. The specialization of skills required to adequately serve individuals with autism is something that should not be overlooked. This fact should also be a consideration of those working with kids with autism in schools. We need to look out of the box and consider what is appropriate given our level of knowledge in 2007 regarding autism. We need to think about how we can integrate persons with autism into our population as a whole. We should consider looking at what other states are doing specifically PA and Indiana-both of these states have autism specific waivers.

Federal dollars have been allocated in the amount of 100 million dollars but that is relatively little considering the scope of the problem.

Chairman Remick concluded that this group wants to see all persons with autism considered as individuals who are healthy, happy and productive.

Doug McCallum added that he would not discount Biomedical Treatments as part of what is being considered. It is difficult for families to find medical providers in AL.

Mike Martin suggested that case management for these families is essential.

Candy Knickerbocker shared with the group about USA's Autism Clinic. She also shared the overwhelming response she has had from parents wanting to get information and support.

The committee briefly got into the need for respite care, afterschool programs, social skills training. We all agreed that we needed more information about the providers that are currently out there doing all of these things. There are many gaps in services, the largest gaps appear to be in services for older kids and adults.

Chairman Remick recapped for the group:

We need to examine the existing resources, we need to figure out the best way to help families advocate for their children, we need a management system for these families, we should learn more about the waivers, we should consider what can be done to support families to keep them together, how can we enhance respite programs, how can we provide an outlet for parents to talk and get support from one another, we all understand the need for a training and education of all providers when it comes to the specific needs of this population. We should consider the needs of siblings, we need to think about training for peers as these kids are being mainstreamed, we should support the knowledge of teachers in regular ed rooms so they will be prepared for the children with autism, we need to consider biomedical approaches, we need to educate parents so they can make well informed decisions.

Doug McCallum reminded the group that a lot of individuals that will be needing to make decisions regarding our recommendations will not be like this group and will need data and language that can help them see that they can not afford not to follow/make these recommendations.

Chairman Remick scheduled the next meeting for Wednesday, September 5<sup>th</sup> at 1:00 in Birmingham, specifically the conference room at Mitchell's Place.

Meeting minutes will be sent to all in attendance and posted on the Autism Society of Alabama's website. Committee members in attendance will be asked to collect specific information related to the topics discussed in preparation for the next meeting.