

## **ATAG Meeting Notes 11-26-12**

### **I. Introduction and Approval of Minutes.**

The second meeting of the Autism Technical Advisory Group started at approximately 2:15 on November 26. Present at the meeting were Dr. Czinn, Dr. Fertsch, and Dr. Lipkin. The members present approved the minutes for the November 14 meeting.

### **II. Presentation from MSDE**

The members then heard a presentation from the Maryland State Department of Education from Ms. June Cohen and Ms. Marjorie Shulbank.

Ms. June Cohen led a discussion on the State's autism waiver. She first discussed the history behind the waiver. She noted that the income determination in the waiver is based on the child's income, not the family's; however, kids can't have resources in their own name to receive services through the waiver. In terms of medical eligibility for the waiver, children must be at risk for institutionalization and must meet a certain level of care. Scoring for medical eligibility is done through a worksheet that is filled out by a school psychologist. Ms. Cohen also noted that services through the waiver are completely separate from services provided in the schools.

Ms. Cohen noted that there is funding only for 900 slots. There are over 3,800 names on the statewide registry (or waiting list). It takes about 5 years for a name to come up on the registry. The cap is based on the amount of state funds available. CMS allows the State to increase by 100 slots per year, if State funds are available to do so. Ms. Cohen also noted that children entering the Waiver this year had been on the list since February of 2005. Last year, only 65 slots opened up. Families tend to stay in Maryland once they are on the waiver. Other reasons for attrition include moving, aging out, a change in diagnosis, and residential placement.

Ms. Cohen also noted that it is difficult to compare services among states, as some states may cover more children but through different means - for example, some states stop at age 8, and some only offer certain services.

Ms. Cohen also noted that at the beginning of the waiver, they had no idea that the demand for receipt of services through the waiver would be so large. Every state has experienced this curve due to the increase of diagnoses.

Ms. Cohen also gave a thorough description of services provided through the waiver. Some services are capped. Services offered include intensive individual support services (capped at 25 hours per week), therapeutic integration (capped at 20 hours per week), and respite services. Review process for residential habilitation. Service coordination is provided on regular basis. The total cost of

services provided through the waiver is \$22 million annually for 900 kids. Ms. Cohen did note that the waiver seems to have decreased strife between families and school systems, although this is hard to document.

Next, Ms. Shulbank gave an overview of services provided through public school systems in Maryland for children with autism. 8.91% of children with disabilities in schools have autism. It is hard to quantify the data on services, and the services that a child receives might depend on the amount of providers in a given school system. However, school systems are getting better at accommodating kids with autism.

Funding for special education for children with autism is provided through state, local, and federal funds. However, services vary widely by county. There may be situations where IEPs send children to non-public schools. Other families may elect to send children to private schools.

Dr. Czinn inquired about ways to demonstrate value of the waiver program. Ms. Cohen noted that Towson University has done consumer satisfaction surveys on quality of life. Researchers have found that families still don't have as high a quality of life, but there is some improvement. There is a difference in employment ratio as well – more parents were able to go back to work.

### **III. Public Testimony (first part)**

Due to timing issues, Ms. Jennifer Polkes gave public testimony earlier than the scheduled portion on the agenda. Ms. Polkes described her experiences with having a challenging autistic child and noted that the treatment methodology that has worked for her child is DIR (Developmental Integrative Relationships) Floor Time. This methodology is a different approach than ABA. It is a similar type of therapy but a different methodology. Ms. Polkes noted that this service has been denied by insurance companies, even though it's provided by Physical Therapists and Occupational Therapists. The financial impact has been very significant – Ms. Polkes said that her family has spent over \$45,000 on services for her child. She requested that the Advisory Group look at this issue, as well as therapies beyond ABA, as the Advisory Group makes its recommendations. Dr. Lipkin noted that this therapy doesn't have a strong evidence base at this time. Ms. Polkes responded that this was true, but studies are available and there will be more coming out.

### **IV. Autism Coverage Laws in Other States**

Next, Ms. Judith Ursitti from Autism Speaks gave an overview of laws regarding coverage of services for children with autism. She noted that Autism Speaks formed about 7 years ago, with a focus on addressing coverage of services for children with autism. At the time – only one state had an insurance mandate (Indiana – passed in 1999).

Ms. Ursitti also described her own personal experience with her son and pediatrician. At age 2, her son was given 1 hour of PT per month, a couple hours of OT per month, as well as a pamphlet on ABA. Ms. Ursitti said that her family had the resources to pay for more services, but many parents do not – she has talked to parents who decided to sell homes to pay for therapy.

Ms. Ursitti worked in Texas for coverage and it became the 3<sup>rd</sup> state to require coverage. The most recent states who have passed laws are New York and Vermont. Autism Speaks is also working to expand mandates in Iowa and Connecticut. Connecticut's mandate only covered speech, OT, and PT originally.

Autism Speaks does not want to ask for things that are not medically indicated. However, they do try to ask for ABA specifically as plans deny it.

States often provide their own definition of “medically necessary” for the purposes of autism mandates. Ms. Ursitti noted that there isn't necessarily a one-sized fits all approach. Autism Speaks is philosophically opposed to dollar caps and age caps, and thinks that costs are far less than opposition indicates.

Ms. Ursitti noted that Massachusetts has strongest autism insurance law in the country, but that the autism waiver there has only 100 to 200 slots.

## **V. Public Comment**

Next on the agenda was the resumption of the public comment period.

The first person to testify was Delegate Ariana Kelly. Delegate Kelly noted that Maryland already has a law, and that legislators wanted to make sure that kids with autism were getting medically necessary services. The law creating this Advisory Group was passed because insurers aren't covering all of the medically necessary services that autistic kids need. Delegate Kelly noted that the bill also created a habilitative services access workgroup that is examining other issues relating to habilitative services.

Regulations will ensure that kids get medically necessary habilitative services. Delegate Kelly stressed the need for help in determining what is on the menu in the State of Maryland. Some kind of specificity is needed – the current law is not protecting the kids.

Next, Rebecca Rienzi from Pathfinders for Autism spoke. Ms. Rienzi noted that Pathfinders is the State's largest nonprofit for autism and acts as a resource to parents. They hear over and over again that families are not getting therapeutic treatments that pediatricians are recommending for their child, and are happy to be at this point with the work of the advisory group.

Next, Ms. Rhonda Greenhaw from the Hassan Center for Adults commented. The Center is a member of ABA. In terms of medical necessity, behavioral situations can have significant impact on medical well-being. Also wanted to address the issue of caps on services. When children with autism have access to effective treatment, they often run into problems (such as when a child is doing well). Dr. Czinn asked who provides coverage for adults with autism. Ms. Greenhaw noted that the work she does was usually cash work. Ms. Shulbank noted that adults with autism often end up receiving medical assistance.

Next, Ms. Annie McLaughlin spoke. She noted that ASAT is a great resource. She also noted that she comes from Washington State where resources are totally different.

## **VI. Conclusion and Next Steps**

There was some discussion among the workgroup members and the public. Dr. Czinn asked whether this issue is a medically necessary issue or a reimbursement issue? Delegate Kelly responded that it is the former. Ms. Tinna Damaso from the Maryland Insurance Administration gave an overview of the regulated market in Maryland vs. the unregulated market (many employers self-insure, which puts them outside the scope of State regulation).

The meeting ended with a note that a comment period would go up on the website, with the next meeting to be in early January.