

## **Draft Minutes of Autism Technical Advisory Group - November 14, 2012**

### **I. Meeting Start and Introductions**

The first meeting of the Autism Technical Advisory Group, created by HB 1055 and SB 744 of 2012, convened at 2:20 p.m. at the Maryland Department of Transportation Headquarters in Hanover, Maryland.

The meeting began with introductions. The chair of the workgroup, Dr. Czinn, introduced himself and the members. Dr. Diana Fertsch and Dr. Paul Lipkin attended in person and Dr. Rebecca Landa and Dr. Valentine attended the meeting by conference call. Staff members Dr. Deborah Badawi, Marie Grant, and Russ Montgomery also attended. Dr. Czinn also invited members of the audience to introduce themselves.

### **II. Overview of Workgroup Charge**

Marie Grant from the Department of Health and Mental Hygiene, summarized the workgroup charge. The workgroup was created by HB 1055 and SB 744 of 2012. This legislation charged the Department of Health and Mental Hygiene, in consultation with the Maryland Insurance Commissioner, to establish a technical advisory group on the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders.

The group must develop recommendations for the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders. When making a recommendation, the technical advisory group must consider whether the recommendation is 1) objective; 2) clinically valid; 3) compatible with established principles of health care; and 4) flexible enough to allow deviations from norms when justified on a case by case basis.

In its work, the group must obtain input from the public, including input from parents of children with autism and autism spectrum disorders and insurers subject to the habilitative services insurance mandate.

Based on the recommendations of the group, the Insurance Commissioner must adopt regulations on or before November 1, 2013, relating to the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders for purposes of the habilitative services mandate. Ms. Grant noted that the Insurance Commissioner requests that the technical advisory group provide recommendations on or before April 15, 2013, in order to meet the deadline for regulations.

### **III. Presentation from the Maryland Insurance Administration**

Next, Tinna Damaso Quigley from the Maryland Insurance Administration (MIA) gave a presentation to the technical advisory group on the other workgroup relating to habilitative services created by HB 1055 and SB 744, as well as the MIA's enforcement of the habilitative services insurance mandate.

**a. Workgroup convened by MIA on habilitative services**

Ms. Quigley first gave an overview of the habilitative services workgroup convened by MIA pursuant to HB 1055 and SB 742 of 2012.

The workgroup must determine:

- Whether children who are entitled to and would benefit from habilitative services under health insurance policies are actually receiving them;
- If the children are not receiving the habilitative services, the reasons why;
- Any actions needed to promote optimum use of the habilitative services to maximize outcomes for children and reduce long-term costs to the education and health care systems; and
- The costs and benefits associated with expanding habilitative services coverage to individuals under the age of 26 years.

Since June, the workgroup has met 5 times at the MIA. All meetings have been open to the public. The workgroup also has its own web page.

The workgroup must submit an interim report to the House Health and Government Operations Committee and the Senate Finance Committee, as well as a final report that is due November 1, 2013.

Ms. Quigley provided an overview of the membership of the workgroup – the workgroup includes a number of different types of providers, as well as representatives from other state agencies.

Preliminary observations of the workgroup include:

- A need for education of individuals and providers; and
- A need for coordination between education and medical system.

MIA staff were able to pull insurance complaints for the workgroup to examine, but have found very few related to habilitative services.

The workgroup has also expressed the need for more data. The workgroup currently is developing surveys for insurance carriers, providers, parents, and educators.

The next meeting of the workgroup is December 19, and will likely be focused on further developing the surveys of stakeholders.

In short, Ms. Quigley noted that the workgroup is well on its way to fulfill its statutory mission.

#### **b. MIA's Current Enforcement of Habilitative Services Mandate**

Next, Ms. Quigley provided an overview of MIA's enforcement of the habilitative services insurance mandate. This enforcement is provided in two ways – through contract review and through complaint investigation.

Contract review is one way the MIA enforces the mandate. MIA reviews every contract for regulated health plans before they are approved for sale. If the contracts don't contain coverage for habilitative services, the MIA will not allow the plans to sell in Maryland.

The second way MIA enforces the mandate is through complaint investigations. The appeals and grievances unit investigates medical necessity complaints, while the life and health unit handles other types of complaints (such as what the deductible due is).

HB 1055/SB 744 of 2012 changed the law relating to habilitative services, but these changes were really clarifications rather than expansions.

Ms. Quigley reported that the MIA has some complaint statistics, but due to coding of complaints, has not been able to pull complaints relating to "habilitative services" specifically.

Dr. Lipkin asked whether there are legal definitions of "medically necessary." Ms. Quigley responded that a complaint goes to an independent review organization pursuant to a process prescribed in law, who then sends back their review. The decision of the organization is usually upheld by the MIA.

Dr. Steven Czinn asked about the standard for what insurers cover under the mandate. Ms. Quigley noted that the definition provided in law provides that "habilitative services" means "services, including occupational therapy, physical therapy, and speech therapy, for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function." Ms. Quigley said that while this definition includes occupational therapy, physical therapy, and speech therapy, that the MIA does not have information on whether carriers cover additional services. Ms. Quigley said also that when staff at the MIA had been asked about whether independent review organization decisions had dealt with this issue, that the staff did not remember. There is also not information on whether behavioral therapy has been the subject of complaints. One staff member remembers two complaints regarding behavioral therapy that were not found to be medically necessary.

#### **IV. Summary of Evidence Regarding Applied Behavior Analysis**

Next, Dr. Badawi of DHMH, gave an overview of recent evidence regarding applied behavioral analysis (ABA).

Dr. Badawi noted that treatment for autism spectrum disorders (ASDs) can focus on core symptoms and behavioral concerns. It is difficult to make a clear distinction between them as the two overlap.

Treatment types for ASDs include:

- Educational;
- Behavioral; and
- Medical (such as medication, supplements, diets); and
- Allied health (auditory integration, sensory integration)

Educational treatments for children with ASDs are provided in Infants and Toddlers, Child Find and Special Education Systems. Behavioral interventions often part of educational treatments, but target symptoms and quantity have been the question.

To talk truly about behavioral analysis, this is something not used just for autism but for other developmental disabilities as well.

At this point in the presentation, Dr. Landa provided a clarification - ABA is a set of principles – there are other names for specific services. For example, “discrete trial training” is the name of a specific service.

Dr. Badawi noted that early studies done on “discrete trial training” were very positive. However, they were later criticized because the studies weren’t randomized. Currently, discrete trial training is integrated into a comprehensive program.

Dr. Badawi then gave an overview of a few recent large literature reviews regarding ABA.

A 2008 study in Canada that looked at DDT found inconsistent results but better than no treatment or regulation instruction. The review didn’t find whether it was more effective than other autism-specific interventions. Where discrete trials helped, it appeared that higher intensive services were better.

An April 2011 review was conducted by Vanderbilt for the Agency on Healthcare Research and Quality. The study found good results for ABA, but the strength of evidence was low. The conclusion of the review was that there was some support for ABA, but that studies need replication and need to be studied in non-research settings.

In addition, a Rand Report was published in November 2012 issue of *Pediatrics*. This review reviewed studies and rated evidence as high, moderate, low, or insufficient. Within 16 reviews and meta-analyses, there were only 2 randomized trials. The review found moderate evidence found for behavioral intervention resulting in improvement in language, adaptive skills, and IQ, as well as a dose response effect for behavioral interventions on language and adaptive skills. Further, the review found moderate evidence for integrated behavioral and developmental interventions, social skills training for higher functioning children and adolescents, and Picture Exchange Communication System improving communication and social skills.

In short – the review found that behavioral intervention works in treating children with ASDs, but that more study is needed.

In addition, Dr. Badawi reviewed some recent recommendations from different entities. A December 2008 Autism Task Force Report published by MSDE contained significant overlap with the 2007 clinical report published in *Pediatrics*. The Rand Corporation Guidelines for comprehensive intervention recommend that treatment should begin within 60 days of identification, that it be individualized to strengths and needs, and must address family concerns and allow their participation. In addition, the Guidelines recommend that children should receive direct intervention for a minimum of 25 hours per week 12 months per year. Older individuals should also receive direct intervention, but models of service and amount of time are inconclusive.

In summary, Dr. Badawi noted that there is no one treatment plan for ASDs. Individuals require comprehensive interventions that address behavioral needs, core symptoms, and need to be structured to individual's strengths and needs and developmental profile.

Dr. Badawi concluded by noting that the federal Office of Personal Management has found recently that behavioral therapy is an evidence-based therapy. The finding didn't mandate coverage under federal health plans, but did find that it was evidence-based therapy.

## **V. Advisory Group Discussion**

Following Dr. Badawi's presentation, the workgroup entered into discussion about the information that had been presented and the evidence regarding use of ABA for treatment of ASDs.

Dr. Landa noted that the National Professional Development Center on ASDs had standards for evidence-based practice and that there are a nice artillery of evidence-based practices to use. She also noted that in the autism based treatment arena, there are treatments that work, but there's not a single name for the treatments,

which may make it difficult for insurance companies. Providers should better identify what services they are using.

Dr. Lipkin noted that he was impressed with the consistency of the reviews on evidence for ABA as well as the need for hours for therapy to be effective. He then asked about the RAND report, which found a threshold of 25 hours per week – how did they arrive at this conclusion? Dr. Badawi noted that the report referred to several studies and reviews to get to that conclusion. There are also questions on how much of those hours should be direct intervention by therapists as opposed to a provider acting as a “coach” for a parent to implement interventions. Again, the issue that arises is what’s medical versus what’s educational.

Dr. Landa pointed out that one could say that there’s no evidence that educational interventions are efficacious. Dr. Czinn noted that evidence-based medicine is definitely the way to go, but randomized, double-blind studies are very difficult to conduct in pediatrics. These are issues that the advisory group will need to grapple with during its deliberations.

Dr. Lipkin asked about recommendations for frequency of treatment. Dr. Landa replied that an early study was done with direct intervention with kids. In Dr. Landa’s study, 10 hours per week had a great response, but there was also good parent coaching at home as well. However, Dr. Landa noted that parent coaching can vary tremendously from home to home.

Dr. Czinn noted that there was a need of a sense of how to evaluate these therapies. Dr. Landa noted that there have been a lot of studies in the past 5 years, and that she and her staff could try to update the literature review after 2007. The National Professional Development Center on Autism is updating their list of evidence-based therapies, and she will see if there is any information the authors can provide. Dr. Landa also noted that the group could recommend evidence-based practices and require insurers to distinguish between those and non-evidence based. In addition, providers would have to show evidence that children are progressing under treatment. Dr. Czinn replied that this approach seems reasonable, and that the group can take it under advisement as the group moves forward in its work.

Dr. Badawi noted that some states have drafted legislation relating to treatment for autism, and that Autism Speaks could give a summary of the state legislation. Dr. Badawi also noted that the workgroup’s scope is not just limited to ABA, but to all types of habilitative services for children with ASDs. Dr. Czinn noted that he would be happy to obtain some of that information from the community, such as from Autism Speaks.

Dr. Landa described a study that she is conducting right now trying to translate evidence-based behavioral intervention into classroom instruction. She is taking data on what educational interventions are working for children. She noted that the educational system is presuming that children are coming to school with certain

tools that aren't even in their curriculum, and that the school system sees this type of work as medical interventions.

Dr. Lipkin cited the danger of perpetuating silos between the educational and medical world. The reality for children is that they are in a therapeutic environment that looks more like school than like medical treatment. There is a need to be careful about messages for families.

Dr. Czinn noted that the group needs information on what services the schools do provide, and that we will work on getting someone from the schools to give the information to the group. He also noted the need to find out what the school systems' responsibilities are.

Dr. Fertsch noted that there are a lot of differences in what children with ASDs' needs are. She asked whether there are attempts to classify people based on the level of the particular disorder. Dr. Landa responded that the new DSM should allow us to do this. Dr. Lipkin inquired whether there have been any reviews on the evidence for different types of autistic populations. Dr. Badawi responded that the reviews don't really accommodate those types of differences.

Dr. Czinn concluded the meeting by noting that it will be a challenge to do the job, but that it is a good group and that the group is up to the task.

Finally, Dr. Czinn asked whether anyone in the audience would like to briefly comment. A representative of Autism Speaks commented that there was legislation on this topic in 32 states. There shouldn't need to be either/or buckets with educational and medical systems. This has been a newer way of thinking as additional funding has become available through medical systems through insurance mandates.

The next meeting of the workgroup will be on November 26 at 2 p.m. at DHMH (201 W. Preston St., Baltimore, MD), Room L-1.