Autism Commission Meeting Minutes

February 25, 2016

2:30 p.m. – 4:30 p.m.

1 Ashburton Place, Boston, MA

The chair, Marylou Sudders, Secretary of the Executive Office of Health and Human Services (EOHHS), called the meeting to order with a quorum at 2:38 p.m. and welcomed Commission members. Commission members introduced themselves. (Secretary Sudders chaired until 3:20 p.m., at which time Undersecretary Moore chaired as her designee until meeting was adjourned).

Minute Approval

Secretary Sudders asked for a motion to approve the minutes from the January 12, 2016 Commission Meeting. The motion was seconded and passed unanimously, with abstentions from Todd Garvin and Cathy Boyle.

Updates

Amy Weinstock announces that the Attorney General’s Office had reached a settlement with Tufts Associated Health Plans, who had been investigated for restricting ABA coverage. The Autism Insurance Resource Center had received an email from a family who had been asking for assistance through MassHealth, but as a result of the settlement they no longer needed those services.

Secretary Sudders provided an update on the Executive Director search, informing the Commission members that she had sent a letter in January to the Governor recommending two candidates, and the Governor’s Chief of Staff had met with the candidates on February 10th. The Governor is scheduled to interview next week, and the hope is to announce the new Executive Director at the March Autism Commission Meeting.

DMH Presentation and Update

Kathy Sanders provided a presentation and update on DMH services and programs (see attached presentation).

Rocio Calvo asked if there was data on the breakdown of the race/ethnicity/socioeconomic status of clients served, and if DMH sees that any population in particular is more difficult to reach. Dr. Sanders replied that they have not pulled that data, but that they are able to access it. The Worcester DPH Office conducted a service needs assessment and found that the immigrant population has very different needs than other populations, and the Mental Health Information System (MHIS) can bring out that info.

Secretary Sudders stated DMH, DDS and MRC do have that data, and that she is charging those organizations with the task of thinking about how to use that data to create common eligibility requirements.

Marty Mittnacht, in reference to the Beacon Centers of Excellence (COE), commented that schools are often serving dual diagnoses through special education, which has many rules and regulations. Ms. Mittnacht asked how DMH through Beacon is serving individuals with dual diagnoses. Dr. Sanders replied that it is through care coordination, not through case management, and that Beacon COE is geared to adults.

Dania Jekel asked the age requirements could be specified, as ages 14-24 is a special time where adult mental health issues become present. In response, Undersecretary Moore, serving as Secretary Sudders’ chair, pointed out that definitions and eligibility can vary between agencies, and is a part of a regulatory review process.

Ms. Weinstock asked if the COE would be run through a third party, and if there are any current centers that will be run as the COE. Dr. Sanders stated that will be specified in the RFR they are about to release, and Janet George informed Ms. Weinstock that the Centers of Excellence aren’t physically present places.

Cathy Boyle asked how Beacon includes the full-range of individuals on the Autism Spectrum, including those who are non-verbal. Dr. Sanders replied that the Beacon COE for Autism and Behavioral Health Needs would not have any exceptions to who they intend to serve within the ASD population, and that the services provided will include crisis services as well as clinicians with ASD experience. Ms. George stated that they are very responsive to input and suggestions.

Ms. Weinstock suggested that the RFRs be submitted to outside people for review and identify any potential disconnects, including members of the Autism Commission. Dr. Sanders said that they have been consulting with others, but that it is a good idea to involve Commission members as they do need a broader understanding.

Ms. Calvo pointed out that certain populations experience healthcare disparities, with ethnic minorities often diagnosed later, mentioning the need to focus on populations systematically left out.

Ms. Boyle stated that there are well defined treatments and cognitive behavioral therapy for those with ASD, but is curious as to who is doing research on treatment for those who are non-verbal. Dr. Sanders replied that people are looking, and that the Laurie Center might be able to look at this. Dr. Ann Neumeyer responded that the Laurie Center does see this as an important need.

Ms. Jekel stated that in regards to outpatient treatment centers or partial hospital centers that are autism friendly, for those who don’t need full hospitalization, are not present in Massachusetts. Ms. Sanders replied that volume drives the ability to develop these programs, and that Massachusetts struggles with specialized services at a high level. Partial hospital centers require certain volume and we do not yet have those numbers. Undersecretary Moore replied that the process considers licensing, and as part of the continuum of care, input will be helpful to consider what community services are needed.

Todd Garvin commented that many adults learn to self-accommodate and often have greater challenges than they appear to. Mr. Garvin asked if there is an assessment designed to capture the full picture for individuals, to which Dr. Sanders replied that they are developing a more refined assessment.

Dan Burke asked that in that assessment have they considered reaching out the Department of Corrections, and Dr. Sanders stated that they would discuss availability for that group.

Dr. Neumeyer thanked the representatives of the Commonwealth for their ED Boarding work, but stated there is confusion about diagnostic criteria. She said it would be helpful to use tests that don’t take hours and that if young children want ABA services, they have to meet eligibility and those tests are difficult to get and not covered by insurance.

Julia Landau asked for more clarification on how the process works for diagnosing families as eligible for both DMH and DDS. Dr. Sanders replied that it is the combination of when the client has Severe and Persistent Mental Illness that is impairing the ASD, and DMH has not created anything new in regard to DMH eligibility.

Senator Barbara L’Italien pointed out that historically it has been hard to get into DMH, asking how broad the need is and if those who had been turned away in the past by DMH had been re-evaluated to see if they would now be eligible for services previously denied. Dr. Sanders replied that the criteria haven’t changed, and they have not gone back to look at previously denied individuals. DMH still works with SPMI, but now works with those who also have ASD, and they are not rejecting for autism.

Senator L’Italien asked if they are accepting those with depressive/anxiety diagnoses. Dr. Sanders stated that individuals with depression and anxiety are not generally eligible for DMH services, but if they meet the criteria of such severe anxiety and impairment (SPMI) then they could accept them. DMH does not provide direct clinical care/outpatient services, but provides day-to-day care and residential services – those that are not covered by insurance.

Ms. Boyle pointed out that there are many levels of care for both outpatient and inpatient regarding mental health hospitalization, and recalled a young man who was released from a mental health hospital but the family had filed a restraining order against him. Everyone was concerned about where he would end up, and he was ultimately placed in the shelter system. Dr. Sanders confirmed that housing is crucial.

Ms. Jekel asked where individuals with paralyzing anxiety and depression are going to go, because with ASD the depression and anxiety presents differently than in those without ASD. Dr. Sanders stated that is what DMH and DDS are working on together.

Ms. Jekel stated she is not looking for residential services. These individuals are so anxious they can’t do daily living, and with ASD it comes and goes and looks different. They may be in their home but need intensive care and support so they can stay in their home. Dr. Sanders replied that they expect that from the healthcare delivery system, and there is a need for autism specific care. Undersecretary Moore stated it is a work in progress, and is positive that DDS and DMH are continuing work.

Ms. Jekel commented that there are many younger men who are frustrated and angry and end up in jail, and that is important to see them get behavioral help from people who understand autism. Dr. Sanders agreed that kind of expertise is needed in Massachusetts

Ms. Mittnacht stated that earlier slides in the presentation were about building expertise, especially among those with dual diagnoses. There is an agreement between DDS and DMH to build capacity among Commonwealth services, not just DMH. At this time, the Commonwealth is underprepared for those with ASD to walk in the door, and we need to grow our general knowledge and grow DDS and DMH services.

Ms. Weinstock pointed out that autism plus mental health presents big challenges and urges DMH to think outside the box of mental health plus autism vs. mental health without autism.

Mr. Garvin asked if, as collaboration between agencies develops, will there be an effort to have voices of autism in the collaboration. Commissioner Elin Howe responded that they will absolutely include those voices as they are not anywhere close to where they need to be, and that the more input they receive the better off they will be.

Christine Hubbard commented that growing services and training, as well as moving forward with data collection would be helpful for both policy development and insurers.

Ms. Jekel pointed out that eating disorders, self-medication, and gender identity issues are also prevalent in this population.

Susan Loring stated that in emergency rooms, thos with ASD often present themselves in the best possible way in an effort to be discharged as quickly as possible. There is a need for the medical profession to understand this. Undersecretary Moore replied that Dr. Sanders and Commissioner Howe are focused on training in all parts of the system.

Senator L’Italien stated that when individuals have no structure, programs, jobs, etc. they are fueled into a downward spiral of anxiety and depression, and so few programs are set up for a good portion of the population, putting those individuals in a unique position. Commissioner Howe replied that there is a discussion of offering services in the model of mental health services to provide daytime programs, and DDS/DMH recognizes that need.

Other Topics

Ms. Mittnacht requested that the Commission reconsider the decision to meet monthly, and proposed bi-monthly meetings instead. Undersecretary Moore asked if Ms. Mittnacht would like to make a motion for bi-monthly meetings, and Ms. Mittnacht so moved. Amy Weinstock commented that, in absence of an Executive Director, a group consensus would be hard, and that she feels it is better for the group to continue meeting on a monthly basis. Senator L’Italien agreed that monthly meetings are best to keep momentum, and that the Commission must still address the two items that they were charged with: housing and employment. Ms. Mittnacht withdrew her motion for bi-monthly meetings and asked to re-visit the topic when an Executive Director is brought in.

Future Topics

Ms. Boyle reiterated that the Commission must address two directives: employment and housing, and that while interested in the agency presentations, feels that continuing presentations may delay these directives. Ms. Boyle asked if there is a game-plan to address these.

Ms. Landau stated that there is a holding pattern while waiting for an Executive Director, and that the last Commission went through this for an entire year. She suggested that at the next meeting they spend time with the Executive Director to discuss the agenda, proposing this conversation be added to the March meeting agenda.

Undersecretary Moore stated that she will check with Secretary Sudders, as they will have to make sure that the Executive Director has cleared the appropriate steps and is ready to begin attending meetings by March.

Ms. Mittnacht added that while the Autism Commission did not formally meet in recent years, many things happened, and that listening to presentations is not necessarily productive, although important. Ms. Mittnacht suggested that if the Commission does not have an Executive Director by the next meeting, that meeting should then be canceled.

Ms. Loring suggested that presentations be scheduled on a single, full day.

Undersecretary Moore, citing a lack of consensus on presentations and future topics, will bring these suggestions 1) process and 2) all-day presentation to Secretary Sudders.

There being no further business, upon motion duly made, seconded and approved, Undersecretary Moore adjourned the meeting at 4:33 p.m.