Autism Commission Meeting Minutes

September 21, 2016

10:00 a.m. – 12:00 p.m.

1 Ashburton Place, Boston, MA

Secretary Marylou Sudders called the meeting to order at 10:03 a.m. and welcomed Commission members. (Secretary Sudders chaired until 11:00 a.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 May 17, 2016 Commission Meeting. The motion was seconded and passed unanimously.

Carolyn Kain introduced the Commission to her new staff member, Dianne Lescinskas. Ms. Kain also informed Commission members that the Commission meetings will go back to recurring quarterly, with the next one scheduled for December 13, 2016. The subcommittees will continue to meet on a monthly basis.

Secretary Sudders thanked the subcommittees for their hard work, and mentioned that she has had the topic of emergency department boarding brought up to her and how the ASD group is particularly affected by this phenomenon. She stated that if the group is interested, she will ask Undersecretary Alice Moore to give a high level presentation on ED Boarding.

New England Center for Children (NECC) Presentation and Update

Vinny Strully, Bill Ahearn, Renee Mansfield, and Amy Geckeler provided an overview of NECC’s programs, its ACE curriculum, and best practices.

Ms. Kain stated that as a consumer, having the information available through the Autism Curriculum Encyclopedia (ACE) system is very helpful, as the data collection and graphing is unprecedented.

Amy Weinstock asked about insurance, and if NECC has any services that are reimbursed. Mr. Strully said there were not any at this time as there are a number of regulatory issues preventing that. Ms. Weinstock stated that California has similar private insurance laws and that there are ways to structure insurance and services that this population could benefit from. Secretary Sudders offered to have a follow-up meeting on this topic.

Cathy Boyle stated that there are not as many individuals benefiting as there could be, providing the example of her son who was at a residential program at 16 benefitted from a good day-school program. He had more functionally than others because he had good educational supports. Mr. Strully stated that NECC has early intensive educational interventions, and that folks lose a lot financially by not having more of than in place.

Dania Jekel stated two concerns:

1. She would be careful using deficit models, and this, to her, is a deficit model. She is concerned about using strengths and changing environments.
2. She would like the Commonwealth to look at programs other than ABA. She wants to consider a variety of models for all ages/levels.

Daniel Burke asked how NECC works toward transitional services. Mr. Strully replied that it is a vast part of the curriculum and begins at a young age, and prep begins around age 18 to develop skills. As a result, they transition into adult programs at DDS very successfully. He stated that he would use anything that will affect these kids, and will tailor anything to individual needs, adding that the Commonwealth shouldn’t waste money on models that haven’t been validated.

Rocio Calvo agreed that we shouldn’t use anything not evidence based. She stated in her experience, it was very difficult to get access to services through early intervention and had to fight for it. Once she was accepted, she started a campaign that everyone needs to offer NECC. Mr. Strully replied that it is a global problem – there is a need for more personnel.

Representative Ferguson asked how many sites are not in the partnership program. Mr. Strully responded that there are over 80 partnership programs across the Commonwealth.

Secretary Sudders offered to host a meeting on the insurance issue raised by Ms. Weinstock to understand better where any issues needed to be addressed.

Department of Housing and Community Development (DHCD) Presentation and Update

Ayana Gonzalez provided an overview of DHCDs programs.

Marty Mittnacht asked how many individuals were served, Ms. Gonzalez explained that this funding is used to build and that support services are provided by DDS or DMH.

Judith Ursitti asked who measures Area Median Income (AMI). Ms. Gonzalez replied it is measured by HUD.

Ms. Boyle stated there is a major problem with what HUD considers AMI. HUD will say rent should be one price in an area, but rates are higher in reality, causing many with Section 8 Vouchers to be unable to rent in their area.

Marty Mittnacht asked how many are served under the Facilities Consolidation Fund (FCF). Ms. Gonzalez was unsure but offered to find out. Ms. Mittnacht asked if the money was used just to build units, which Ms. Gonzalez said it is, and that to utilize those units you must be referred by DDS or DMH.

Ms. Boyle stated that FCF is designed for DDS/DMH, but the other funds are designed for other individuals. She stated that she had a conversation with CEDAC years ago about how it is assumed that all DDS/DMH clients are serviced by FCF, but what about those who aren’t?

Ms. Gonzalez asked how we decide who sets the priority.

Commissioner Elin Howe stated that FCF enabled DDS to meet terms of a rolling settlement agreement and allowed them to close 4 out of 6 facilities. Once the housing is developed, the capacity becomes available to those who may not have been institutionalized. She added that that is on pause now until DDS works with the Commission to determine what kind of housing is really needed.

Julia Landau asked if these funds are all a 30 year loan. Ms. Gonzalez replied that they are, but they are on a deferred payment and after 30 years they can renew for 10 years.

Ms. Landau asked about the structure of the units, and if they’re single homes. Ms. Gonzalez said that they could be apartment buildings or single occupancy or group homes. Commissioner Howe said DDS has all individual homes.

Ms. Boyle asked if the Commission could receive a copy of the National Housing Trust Fund Plan. Ms. Gonzalez said she would send out the link.

Ms. Mittnacht asked how people get access to the various housing units. Ms. Gonzalez stated that it’s all done through applications. For FCF, a referral must be made by DMH or DDS; CBH is through MRC, and HIF is done by walking in to the building and applying. She added that it is much more difficult as an individual and helps to be tied into a state agency.

Ms. Mittnacht stated that schools promote independence; many folks may not choose to do this. She added that it may be counterproductive to what the schools are trying to do.

Ms. Ursitti recalled the MRC presentation and how she was shocked by the low number of referrals they make.

Commissioner Howe stated they support thousands who live on their own in their own apartment, and we shouldn’t think about DHCD being the only option.

Christine Hubbard asked how many loans go to families with ASD. Ms. Gonzalez stated that they don’t track by specific disability, and that the units can’t prioritize one disability over another. She stated that they can use the specific features a unit may offer by prioritizing someone who would benefit from those specific features, such as a wheelchair ramp or soundproof walls.

Ms. Gonzalez also provided the members with information on the home modification program and said that the average loan is $22,500, and that funding is used tomake changes to homes for individuals with disabilities.

Other Business

Undersecretary Moore opened the floor for general discussion regarding the next meeting, noting that ED Boarding was a potential topic, as well as the subcommittee reports. She added that Marty Mittnacht had shared some follow-up information from her presentation, which can be shared here or in the subcommittee. Undersecretary Moore noted that a representative from Labor and Workforce Development will present at the December meeting.

There being no further business, upon motion duly made, seconded and approved, Undersecretary Moore adjourned the meeting at 11:55 a.m.