Autism Commission Meeting Minutes

April 12, 2016

10:00 a.m. – 12:00 p.m.

50 Milk Street, 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 10:03 a.m. and welcomed Commission members.

Minute Approval

Secretary Sudders asked for a motion to approve the minutes from the February 25, 2016 Commission Meeting. The motion was seconded and passed unanimously.

Executive Director Introduction

Secretary Sudders formally introduced the first Executive Director of the Autism Commission, Carolyn Kain. She thanked the nominating committee for their process and expressed that Carolyn’s addition will accelerate the work of the Commission. The Secretary stated that she hopes all Commission members will have an opportunity to meet with Carolyn individually.

Carolyn Kain stated that she is looking forward to getting started and is hoping to build upon the tremendous amount of work that has already been done. She said that her first order of business will be the annual report. She is looking at what has been accomplished so far as well as the age groups, and would like to implement the recommendations already made and build upon them.

Ms. Kain added that on a personal note, she is the parent of a child with a disability and feels she can bring a unique perspective to the Commission as she understands that in regards to age groups, needs and access change over time. Ms. Kain is looking forward to the work and asked for the Commission members’ patience and assistance as she settles into the role.

Secretary Sudders stated that going forward, work will be done through committees, and Ms. Kain will reach out to determine chairs of those committees. Chairs will be members of the larger Commission, but members of the committees do not necessarily need to be.

Secretary Sudders acknowledged that it was a significant day in the Commonwealth – the 10th anniversary of Healthcare coverage under Chapter 58. Lack of coverage decreased to 3.5% and there has been a significant decrease in avoidable deaths, particularly in the African-American and Latino communities.

Massachusetts Rehabilitation Commission Presentation

Kasper Goshgarian presented on the Massachusetts Rehabilitation Commission (MRC).

Regarding the profile of those served by MRC, Secretary Sudders asked how the agency accounts for individuals with ASD and if they are included in the 2.3% who have developmental disabilities. Mr. Goshgarian responded that he believes they should be included in the developmental disability category but will follow up on that. Commissioner Elin Howe added that in the next year, the Department of Developmental Disabilities expects to double the number of individuals they work with through MRC.

Ms. Kain stated that there are a high percentage of psychiatric disabilities and asked if anyone falls under that category in addition to having ASD. Mr. Goshgarian replied that there are those with dual diagnoses, and the ASD is first with the psychiatric diagnosis being second.

Todd Garvin asked that within the demographic are consumers, have any communities been identified as underserved. Mr. Goshgarian replied that there are.

Senator Barbara L’Italien stated that her son could be within the statistic of 4.9% of successful employment outcomes, but believes the standard should be better than 90 days. At that 90 day mark, her son had a job and was considered a success, but then that company closed and he is now unemployed – the statistic is skewed because it is only counting for those 90 days. Mr Goshgarian replied that there are many consumers who receive ongoing support, and that many lose their job or need another training opportunity and come back. It is not just a one-shot opportunity.

Cynthia Orellana asked if there have been any efforts to reach out to the underserved populations. Mr. Goshgarian replied that they have sent out a survey and do plan to reach out to those populations. Ms. Orellana asked if there was any sense of the numbers. Mr. Goshgarian was not sure of specific numbers, but stated that the population included minorities and language barriers, though MRC now has a more language-proficient staff.

Ms. Kain stated that MRC has representatives in high schools, but asked how that helps with reaching the underserved. She asked if there is a connection between agencies. Mr. Goshgarian replied that the counseling staff has approximately 240 people, each of whom must spend 7.5 hours per week at the high schools working with special education staff. He added that MRC does make a concerted effort to outreach and identify the underserved.

Mr. Goshgarian stated that the real challenge is with the older community and with providers.

Cathy Boyle stated that she would like to know more about what the Transitional Advisory Committee (TAC) does. Mr. Goshgarian replied that the TAC responds to complex cases that come to the attention of EHS that often need services from more than one agency. He added that there are not very many of these cases and believes that the TAC receives 8-10 referrals per year.

Regarding percentage of consumers with Autism serviced by district, Janet George stated that the DDS data of what’s happening and what’s going to happen are different than MRC’s. Mr. Goshgarian said that MRC has noticed the number of people served with ASD has gone up, but was unsure if that is tied with a definition change.

Senator L’Italien asked if financial eligibility will be discussed in this presentation. She stated that even with a defined disability, many individuals are still subject to their parent’s financial eligibility, though that isn’t the case with DDS. She added that it restrains who qualifies and is able to get into the program.

Mr. Goshgarian stated that if someone is on SSI or SSDI, they are presumed eligible. If not on social security and living with their parents, they are dependent on their parents’ income for eligibility.

Secretary Sudders stated that this is an unintended consequence for parents. She added that if it were a nephew instead of a son, the “parent” wouldn’t be considered as income. The Secretary asked Mr. Goshgarian to go back to Senator L’Italien’s point with Commissioner Osborne and take a look at the rules around this.

Susan Loring commented that many people whose income is too high for eligibility still can’t afford to pay, so they back off.

Cathy Boyle asked what happens if an individual is living with their parents but not reported on their taxes. Mr. Goshgarian stated that they would be considered an emancipated individual and would not rely on their parents’ income for eligibility.

Rita Gardner asked if the transition to work through high school outreach applies to private schools. Mr. Goshgarian stated that the primary focus is with public schools, but that it is an important point for MRC to look at that focus. Ms. Gardner asked about their work with non-verbal students, which Mr. Goshgarian replied he would have to look at and report back.

Ms. Kain asked if the training of staff is focused on training to do job coaching, or to really understand autism, and if MRC is training to take over the LifeMAP work. Mr. Goshgarian stated that LifeMAP is provided through a contract at no cost to the families, and that the focus of the training is to be familiar with family involvement and resources in the community.

Daniel Burke asked about that status of the wait list for those newly eligible. Mr. Goshgarian stated that the wait list is currently about 30 days, during which time contact is made. He added that the waiting list is almost negligible, but there is some.

Secretary Sudders commented that it has been a big priority for the Commissioner and her team to get the wait list down.

Julia Landau asked what capacity MRC has to offer services in different languages. Mr. Goshgarian replied that there is good capacity to offer Spanish services, and that they are getting better with ASL. Secretary Sudders said that there is an MOU in place with MCDHH. Mr. Goshgarian stated that they have done well in certain areas such as Lowell with providing services in different languages. He added that some areas are still difficult, such as French Creole. Ms. Landau asked if there would be a language access plan at some point.

Ms. Orellana asked that if there is any plan to increase outreach in coaching to grow beyond the current 100 consumers. Mr. Goshgarian stated that there is a plan to increase outreach but does not have a projection of numbers.

Secretary Sudders stated that for job-driven training, there is a contract with the Jewish Vocational Services who has replicated a CVS store to train skills in pharmacy tech, cash register, etc. She added that this is a good model for those who may not know what their best match is, and on her recent visit there were several individuals on the spectrum who were training.

Mr. Goshgarian stated that the Office of Federal Contract Compliance Programs has partnered with MRC and together they conducted 6 job fairs over the past 3 years, where employers come and conduct interviews onsite. He added that at the previous day’s fair, 144 interviews were conducted for MRC and Massachusetts Commission for the Blind (MCB) consumers, and previous experience shows that approximately two-thirds of interviewees get hired within 1-2 months.

Ms. Kain asked if there was work readiness training with youth to build resume and interviewing skills. Mr. Goshgarian stated that there is a contract in place for soft-skills.

Ms. Kain asked about the Impactibility Program and if there is any safety awareness training, such as how to speak up and self-advocate in the community. She added that many of these individuals are vulnerable to bullying and victimization. Mr. Goshgarian replied that MRC contracts with the Independent Living Centers, who executes such training.

Ann Neumeyer asked if the summer internships are paid, which Mr. Goshgarian confirmed they are.

Ms. George asked if there is an eligibility requirement for homecare services. Mr. Goshgarian stated that you must be under 60 and be in jeopardy of entering a more restricted environment. He added there is a short waiting list – less than 2 months.

Senator L’Italien’s counsel, Erin Riley, speaking on behalf of the Senator, suggested that MRC advocates be more vocal in their push for additional funding in the budget.

Secretary Sudders stated that to summarize a few points from the meeting, that as systems morph and change, it is an opportunity to think differently about the links to be made. While public schools historically had the greatest connection, MRC should think about a shift. She added that she would like MRC to review Senator L’Italien’s comments about financial eligibility, as well as the connection between MRC and DDS.

Commissioner Howe stated that MRC funds employment services for 90 days, and there are those who have a job but requires additional support past that 90 day mark. She thinks it is important to address this and it is something MRC and DDS are working on together to make sure every individual is supported.

Commissioner Howe stated that the Impactibility Program was funded through a grant that no longer exists, but that it was successful and should be made available again. She also added that there has been a dramatic change for the better between the collaboration of area offices.

M. Goshgarian commented that MRC has similar progress with DMH over the past 2-3 years, holding meetings with both senior staff and on the service provider level so that staff members between agencies know each other.

Commissioner Howe stated that the beauty of collaboration is that individuals can go to one place to seek employment opportunities, instead of agencies competing for those opportunities.

Ms.Kain stated that she would like to meet with MRC and DESE to see how that relationship works and how to improve it. She said that accessing services should be as easy as possible and the agency’s work should be complimented by each other. She asked how people can become more aware of what’s available to them, and how to connect them to those services.

Mr. Goshgarian stated there are Interagency Service Agreements (ISAs) with many agencies, including one with DESE. He commented that DESE only has so much control in the schools, but even in terms of creating guidelines it would be helpful. He added that it is important to find a way for work to be capitalized and not worry about whose dollar is first.

Secretary Sudders asked to spend a few minutes discussing the Workforce Innovation and Opportunity Act (WIOA) and its significance.

Mr. Goshgarian stated that it is a federal act that dramatically changes the way states look at workforce. A single state plan must be provided, with many agencies sharing a piece of that plan. It is an attempt to be more collaborative than in the past. The plan must outline who serves whom, how accessible are the 1-stops, who can go to a 1-stop and get a job, and who needs more complex services. He added that they are attempting to come up with a system that best meets everyone needs.

Secretary Sudders added that 15% of the WIOA funding ($42 million) is required to go to serving youth. Mr. Goshgarian specified that this is part of the new recording of time spend in schools by staff.

Ms. Landau asked how MRC works with individuals who are non-verbal, adding she would like to see more information on that. Mr. Goshgarian stated he would bring that information to the next meeting.

Vinnie Strully asked if it was rare for a child with ASD to not need DDS services. Ms. Landau stated that even if an individual is eligible for DDS, they also need to access MRC.

Josh Mendelson stated that there is an emphasis on assisted technology programs. There is a contract with service providers to provide assisted technology in the workplace, and provides many devices which he imagines is inclusive of non-verbal devices. Mr. Mendelson will look further into that and follow up.

Ms. Kain commented that just because an individual is verbal does not necessarily mean they will not benefit from non-verbal devices. She thought it was important to examine if it will be helpful for all individuals, adding that they should be looked at distinctively to determine if augmented communication would help to maintain employment.

Ms. Landau stated that there is a range of non-verbal and limited-verbal individuals.

Ms. Loring stated that augmented communication can supplement an individual, and that most like it.

Dania Jekel stated that there are many innovative programs in the U.S. for ASD, with many in the technological field. She asked if MRC is open to exploring those programs and if MRC considers workshops and not integrated employment. Mr. Goshgarian stated that MRC would give it some thought, but that they have spent years getting away from workshops.

Secretary Sudders said it would be interesting to hear what those models are and suggested Ms. Jekel and Ms. Kain have a conversation and bring that back to the group.

Other Business

Secretary Sudders stated the Education is the next agency to hear from, and that if they present in May, that would complete the “orientation” of these meetings. She stated that at the next meeting, Ms. Kain would have the workgroups organized.

Mr. Burke asked for the status of the IT Bond Bill. Secretary Sudders stated that the funding for this comes from the capital budget, and it is not currently in the budget for this year. She informed the group that Commissioner Howe is exploring alternate ways to address this.

Commissioner Howe stated that DDS is collecting data all the time and it is important for future planning to know who is currently in the door. She added she is happy to share the data with the Commission, and that it will frame how to proceed delivering new services, specifically around social skills, employment, and housing. She also added that they are digging into data on diagnoses.

Commissioner Howe stated that something troublesome to the newly eligible is those who are engaged with the criminal justice system.

Commissioner Howe commented that they are doing their best to break out the population over 22; look at the 18-21population to plan for transition; and look at the general population more closely. When there is autism plus a general disability, they need to work on the people currently in the system to adapt what services are provided to them.

Chris Supple stated that the annual reporting requirements are very detailed, but regarding employment and housing he is unclear how the Commission will gather that data.

Amy Weinstock stated that in the last Commission, they missed the population of DCF children with ASD, and asked if that is being captured now.

Secretary Sudders replied that former Secretary Bigby had creating a MDM, or a portal system to link state agencies, which they have been using to link MassHealth and DTA data to eliminate the SNAP gap. More recently, the MDM is being used to link that with DCF data, and it is incredibly accurate. The Secretary would like to use this to link the DDS piece, but wants to be methodical in doing so.

Ms. George stated that DDS does not know who DCF identifies as ASD that meets DDS eligibility. DDS only knows what they know, not what DCF has.

Ms. Jekel stated that it is not only the children with ASD to be looked at, but also the parents on the spectrum.

Ms. Boyle suggested that when the Commission begins to look at different committees, that there should be a separate committee looking at employment and housing for adults.

Mr. Burke suggested a data collection committee, which Secretary Sudders agreed with.

Ms. Weinstock asked if the Commission would be open to revisiting the structure of populations, and if they could brainstorm alternatives to the age groups.

Ms. Kain stated that the committees could be by age group and that there could be further revisions within that, and that she is open to suggestions. She stated that the subcommittees will allow for a targeted focus, and asked the members to let her know where they would like to participate or if they have any suggestions.

Ms. Kain added that she would suggest that the Commission to return to quarterly meetings, with the subcommittees meeting more often. The subcommittees will be established by the next Commission meeting.

Secretary Sudders asked the group to email suggestions for structure of the subcommittees to Ms. Kain, and they would present it to the group at the next meeting for finalization.

She added that the state budget was to be released the next day, and thanked Mr. Goshgarian for his efforts.

There being no further business, upon motion duly made, seconded and approved, Secretary Sudders adjourned the meeting at 11:45 a.m.