Autism Commission Meeting Minutes

May 31, 2017

1:00 p.m. – 3:00 p.m.

500 Harrison Ave, Boston, MA

Present: Undersecretary Alice Moore, Carolyn Kain, Michelle Brait, Vinnie Strully, Todd Garvin, Janet George, Commissioner Elin Howe, Dania Jekel, Patricia Gentile, Carolyn Langer, Kathy Sanders, Teri Williams Valentine for Russell Johnston, Jane Ryder, Chris Supple, Judith Ursitti, Amy Weinstock, Rocio Calvo, Kasper Goshgarian, Ann Neumeyer, Deidre Phillips, Teresa Schirmer, Dianne Lescinskas and Kathleen Stern.

Undersecretary Alice Moore called the meeting to order, when a quorum was present at 1:10 p.m. and welcomed the Commission members.

Undersecretary Moore began the meeting by recognizing DDS Commissioner Elin Howe who will be retiring in July. Undersecretary Moore acknowledged the many contributions made and accomplishments achieved by Commissioner Howe during her ten years as the Commissioner of DDS, and the positive impacts that her work has had on individuals with developmental disabilities and individuals with Autism, Smith-Magenis Syndrome and Prader Willi. Undersecretary Moore thanked Commissioner Howe for her service on behalf of the Secretary Sudders and the entire staff of EOHHS.

Commissioner Howe thanked Undersecretary Moore and the entire Commission for recognizing her, and then gave a brief overview of the progress that has been achieved in serving the Commonwealth’s most vulnerable citizens during her tenure at DDS.

Undersecretary Moore stated the next item on the agenda was the approval of the minutes from the March 6, 2017 meeting. A motion was made to approve the minutes, and duly seconded. The minutes were approved unanimously.

The next item on the agenda was a review of the proposed by-laws. The Executive Director of the Commission Carolyn Kain said that she had drafted the by-laws in response to a request by some of the members for more structure. Ms. Kain said that she had looked at the by-laws for other public bodies and that the draft by-laws presented today had been provided to the Commission at the March meeting. She asked if there was any discussion.

Several members made comments about potential changes to the Autism Omnibus Law;

● Changing the language so that participation by advocacy groups would be less prescriptive

● Looking at stagnated terms of Commission members to ensure continuity

● Having more than one individual with ASD on the Commission

● If the annual report in March was the Commission’s exclusive opportunity to file a report. Ms. Kain said that work is on-going with the subcommittees and that while the statute calls for an annual report collaboration among the state agencies was happening on the issues raised by the subcommittees, and was also on the agenda. Ms. Ursitti stated that she was concerned about the timing of the budget. Undersecretary Moore said that the budget lies in DDS in terms of developing services for individuals with ASD.

Commissioner Howe gave a description of the budget’s development, how it is annualized and that the issue of maintenance of services is a focus. She said that discussions with the Secretary begin in August for the next budget cycle and moves through the fall, and that’s when recommendations should take place.

Undersecretary Moore stated that Ms. Kain is available to all Commission members and that she is the conduit to the Secretary and DDS to ensure the flow of communications. Ms. Kain said that she is in constant communications with the state agencies on moving issues forward and that while the statute acknowledges statutory and regulatory recommendations may be made by the Commission those types of recommendations involve issues such as the one in the Omnibus Law for regulatory changes for the special education teacher endorsement.

Undersecretary Moore redirected the conversation back to the issue of the review of the by-laws, she commented that while the group could certainly look at the statute and possible changes in the future that there was no opportunity to change the statute at this meeting, and that we wanted to discuss the by-laws that had been put forth in March.

Chris Supple made several comments about the proposed by laws. Ms. Kain responded that the issue of the membership of the Commission and the issue of the meetings was taken directly out of the statute. Mr. Supple said the Commission should decide how often it meets and not the Executive Director. Ms. Ursitti said she wanted to meet more frequently. Ms. Kain reiterated that the by-laws restated the law as it was enacted on this issue.

Mr. Supple said he wanted meeting materials with more lead time than at least 48 hours in advance. Ms. Kain said that she was not opposed with providing materials sooner but that the by-laws were drafted similar to other public bodies, and that materials are often times provided by third parties. Undersecretary Moore suggested that they add language that says in practice it would be a week in advance.

Mr. Supple further commented that subcommittees should be appointed by the Commission. Ms. Kain said that all subcommittees were Chaired by a Commission member or herself and that there are over 100 individuals on the 8 subcommittees and included individuals recommended by the Commission.

Undersecretary Moore asked Mr. Supple if he wanted to make a motion. Ms. George said that she had a different perspective on the functioning of the subcommittees and that it would be difficult to have to obtain approval from the Commission on participants. Amy Weinstock suggested the by-laws be tabled and discussed by a smaller group, and that Mr. Supple had the most experience in this area. Vinny Strully said that he did not understand the concerns with the bylaws and suggested that the Commission move on with the other matters on the agenda.

Undersecretary Moore said that materials could be provided more than 48 hours in advance but that may limit what goes on the agenda. She asked if there was a motion. Mr. Supple moved to leave 48 hours in advance with a week added, seconded by Ms. Ursitti. the motion was approved with Mr. Strully voting NO.

Undersecretary Moore said is there a motion to approve the by-laws as amended. Mr. Strully moved the by-laws be approved, seconded by Ms. Gentile. By-laws were approved with Ms. Ursitti and Ms. Weinstock voting NO.

Executive Director Ms. Kain began her report on updates to the Commission. Ms. Kain began with an update on the state-wide housing survey that is required under the statute. She asked Lisa Sloane from technical Assistance Collaborative to update the Commission. Ms. Sloane gave an overview of TAC and the scope of work for the housing survey that includes three public forums on June 5th, 6th and 7th.

Ms. Calvo asked about reaching families who do not speak English. Ms. Kain said that while the scope of work had been for one forum they expanded it to three forums including one in Roxbury to reach a culturally and linguistically diverse group of families. Ms. George stated that DDS will provide any interpretation services requested. Ms. Kain said she sent the flyer to Boston Public schools and asked them to distribute it to families.

Ms. Sloane discussed the low response numbers for the forums thus far and Undersecretary Moore encouraged all Commission members and the state agencies to disseminate the information as broadly as possible.

Ms. Kain proceeded with updates on Birth to Three including the draft brochure and the Mass Act Early videos in development. She distributed the brochure and several Commission members said they would like to add additional information, and for the Commission to approve the brochure. Ms. Kain said that it was a work in progress and that it was developed in response to the concern that parents do not understand the process for transitioning out of early intervention and into the public school system. Teri Valentine said DESE would be happy to work with Ms. Kain to incorporate their work in this area.

Ms. Calvo asked about the videos by Mass Act Early and specific barriers that she sees in the immigrant communities, Ms. Kain said she would connect Ms. Calvo with Joan Rafferty and Elaine Gabovitch who are leading that project.

Ms. Kain will share the draft brochure electronically with the Commission. She said that a recurring concern at the subcommittees was that families do not understand the processes or how to connect with state agencies and that this was one way of trying to improve access to information for families.

Ms. Kain then proceeded to give an update on the 3-14 year olds subcommittee, its work with DESE on its Coordinated Program Review process and problem resolution process to ensure that school districts are being held accountable for addressing the needs of individuals with ASD. Ms. Kain discussed DESE’s new IEP form under development, a brochure for parents on state agency services, and a webinar that she recorded for DCF workers on the impacts of ASD on young children. Ms. Ursitti asked if the webinar addressed all aspects of ASD. Ms. Kain responded that it included the range of impacts of ASD but it was targeted on DCF workers who work with young children.

Ms. Jekel said that the Commission should vote to require that DCF train all of its workers on all aspects of ASD. Undersecretary Moore said that we should first talk to DCF and find out what they are currently doing. Vinny Strully said that DCF is working to address the needs of individuals with ASD and he has seen improvements especially in the area of children placed for services.

Ms. Calvo also said they wanted to look at high suspension rates for children in underserved communities since children may have ASD that has not been diagnosed and they are being disciplined for behaviors. Ms. Kain said she had requested additional information from DESE on this issue.

Ms. Kain proceeded with an update on 14-22 year olds/employment and the issue of coordination among state agencies on the transition aged youth and pre-employment services available from MRC under W.I.O.A., and accessing services earlier as research and the recent GAO report in May 2017 emphasized.

Ms. Ursitti commented on the RFR by MRC and the comments submitted by MAC.

Ms. Kain said the 22+/employment subcommittee had worked on an informational sheet that was being review by AANE, and that she had met with the Housing and Shelter Alliance and did a training on ASD and they wanted to expand the training on this issue. Ms. Kain said that video recording trainings may be the most efficient way to reach more workers in the shelters.

Ms. Kain discussed the Adult subcommittee and its work, including training videos being done by BMC, emergency room information to assist individuals coming in with ASD, the training that has occurred at MGH and exploring the possibility of expanding MCPAP. Ms. Sanders gave a description of the current MCPAP program. Ms. George and Dr. Sanders gave their impressions of the training at MGH.

Ms. Kain gave a brief update on the data subcommittee and workforce development.

Undersecretary Moore stated that the next meeting would begin with an update of the last two slides, data and workforce development since today’s meeting did not allow sufficient time for those issues.

Undersecretary Moore encouraged the Commission members to reach out to her, the Secretary, and/or Carolyn Kain for ideas on the meetings, to provide feedback and input on how these meetings can be most productive, and to move us forward in a positive direction.

Ms. Kain said that the Commission has 35 members with many different ideas and perspectives and she will continue to include agenda items suggested by members.

Upon receiving a motion duly made, seconded and approved. Undersecretary Moore adjourned the meeting at 3:00 p.m.