Autism Commission Meeting Minutes

March 6, 2017

10:00 a.m. – 12:00 p.m.

1 Ashburton Place, Boston, MA

Present: Undersecretary Alice Moore, Carolyn Kain, Rep. Christine Barber, Daniel Burke, Rep. Kimberly Ferguson, Todd Garvin, Janet George, Ayana Gonzalez, Commissioner Elin Howe, Christine Hubbard, Dania Jekel, Patricia Jennings, Patricia Gentile, Jessica Katon for Sen. Richard Ross, Sen. Barbara L’Italien, Julia Landau, Carolyn Langer, Susan Loring, Kathy Sanders, Teri Williams Valentine for Russell Johnston, Patricia Marshall, Jane Ryder, Chris Supple, Judith Ursitti, Amy Weinstock, Cathy Boyle, Rocio Calvo, Joan Rafferty for Ron Benham, Julia O’Rourke for Ann Neumeyer, Dianne Lescinskas and Kathleen Stern.

Undersecretary Alice Moore called the meeting to order at 10:05 a.m. and welcomed the Commission members. She asked Commissioner Howe to update the group on the Turning 22 funding that the Governor put forth in his budget, and that this will be the first time it will be fully funded to meet the increasing needs of the turning 22 population. Commissioner Howe highlighted that there are 927 individuals in this year’s graduating class and that next year’s class will be fully funded under the Governor’s proposed budget. Commissioner Howe said this was very exciting news for DDS and that it is the result of significant support from the administration and the collective work of stakeholder. Dr. Carolyn Langer gave an update on the progress in implementing a new process for obtaining Augmentative and Alternative Communication devices (ACC) tablets. Dr. Langer emphasized that getting this accomplished was a priority for the administration. Effective March 1, 2017, the new process will be implemented and this new benefit will be available to individuals with ASD under the age of 21. There is additional information on the MassHealth website.

**Autism Commission Website**

Carolyn Kain provided the Commission with a preview of the Autism Commission’s revised website, she said this was a first draft of the site and welcomed feedback from the Commission. Ms. Kain said that she felt it was important that if parents were seeking information on-line and came to the Autism Commission’s website that they would find helpful information and resources on a variety of issues in addition to the reports, meeting schedule and minutes of the Commission. Comments were as follows:

* Dania Jekel requested that all puzzle pieces be removed
* Senator L’Italien commented on the role of Executive Director and said that the statute required the Executive Director to go out and present to groups about the Commission.
* Senator L’Italien wanted to Highlight the 2013 Autism Commission Report on the website
* Dania Jekel commented about “What is Autism” – and that it needed to highlight the strength of individuals with autism
* Sue Loring commented that the new version of the website is more user friendly
* Ms. Kain said they would send out a link for the site for Commission Members to further review and send their comments to her office

The minutes from the Autism Commission meeting in December were reviewed and approved unanimously with the exception of three individuals abstaining from the vote because they did not attend the December meeting.

**Update from CEDAC regarding the Home Loan Modification Program**

Susan Gilman gave an update about the state funded loan program that will help to make homes more accessible and may include modifications such as:

* Sensory spaces
* Fencing
* Specific drains
* Plexi-glass windows

More information was provided on the Home Loan Modification Program (HLMP) handout.

**Updates from the Autism Commission Sub-committees Chairs**

The Chair of each sub-committee gave an update on the work of their respective subcommittees;

***Birth-3*** Joan Rafferty from DPH presenting for Ron Benham, Chair

1. Early Identification/Early Diagnosis/Early Treatment
2. Increase knowledge of Pediatricians and Families of Early Signs through expanded use of Mass Act Early website and materials
3. Expand outreach on Turning Three process for Families

* Working on a brochure for families to inform them about the turning three process, when they transition from Early Intervention to the public school system
* MA Act Early campaign is rolling out cable shows and they will be filmed in 7 different languages that include; English, Spanish, Hasian Creole, Portuguese, Chinese, Vietnamese and Arabic. The program is 25 minutes long and the focus is on early screening and screening more often.

Carolyn reported to the Commission that she has met with DPH and Early Intervention to discuss the importance of early detection. Her office is working on a brochure for Turning Three that they would like to be disseminated in multiple forums and languages for parents and caregivers.

***3-14 Year Olds*** Carolyn Kain, Chair

1. Increase capacity of Children’s Waiver Program
2. Explore with DESE the addition of interpretation and translation services to its Coordinated program Review process and Regional meetings with school districts
3. Increase educator knowledge and use of augmentative and alternative communication devices

Carolyn Kain summarized each of the issues and then asked if there were any comments or questions.

Senator L’Italien said that she has proposed legislation that will increase the Children’s Waiver by 50 slots, and that this was an area for the individuals who are on the Commission but not working at any of the state agencies to advocate for this increase to be included in the budget for next year.

***14-22/Employment*** Carolyn Kain, Chair

1. Autism Commission recommends added resources to meet the needs for services of newly eligible adults with autism and adequate resources for FY18, including for individuals with ASD and ID
2. Increase the capacity of the Inclusive Concurrent Enrollment Initiative (ICEI) program to allow more individuals with ASD to participate

Julia Landau asked for an update on the number of newly eligible adults from DDS. Commissioner Howe gave an update on the number of individuals who have been deemed eligible and that DDS was working to allocate any unused funding to additional individuals.

* It was noted that DDS is using utilization of services to address some of the issues of funding and services
* Sen. L’Italien said that she is requesting an additional $2million this line item in the budget and Sen. L’Italien said that she is also asking for the MAICEI budget to be brought up to $2million, and this was another area for the individuals who are on the Commission but not working at any of the state agencies to advocate for this increase to be included in the budget for next year.

***22+Employment***

1. Develop outreach materials to inform individuals with ASD about services that they may be eligible for from state agencies
2. Work with Shelter Alliance and DMH to identify and assist individuals with ASD with referrals and accessing services

* Carolyn gave an update on her recent meeting with the Shelter Alliance
* There is work around developing outreach information for adult individuals that may not have been diagnosed or who may not have been eligible for state services when they were younger and connecting them with state agencies and services they may be eligible for
* Transportation was discussed as a barrier to community life and employment
* Dan Burke raised the issue of employment and SSI – Carolyn Kain talked about the fact that MRC has benefit counselors to help individuals understand this issue and that being employed does not automatically disqualify you from SSI services. Ms. Kain said there are benefits to being employed that go beyond wages.
* Cathy Boyle said that there is training for shelter workers that was done in the UK, she also recommended looking at the AQ10 to help train shelter workers.
* Dania Jekel said that women, men and children are in shelters and all three need to be addressed. Ms. Kain agreed that this issue also involved families with children with ASD.
* Sen. L’Italien discussed a bill around federal funding (7%) to be set aside for people with disabilities – we should look at this bill and see if this is being implemented

***Adults*** Janet George and Kathy Sanders, Co-Chairs

1. Develop a robust continuum of care; inpatient, crisis and outpatient/community
2. Develop a robust system of family supports for adults
3. Develop and Enhance Supports to Counter Social Isolation

* This sub-committee has honed in on health care in relation to adults with ASD
* Reviewed the Emergency Department Information form and card that was created and will be piloted in a hospital
* Mass. General training for all workers in the hospital – looking at the results of this training
* ED boarding was discussed and the effort put forth by all agencies involved to work on this issue
* DMH is looking at specialized units for children with ASD
* Increase outpatient services and community based options
* Transportation and gaps were discussed – especially in Western part of the state
* ACO’s and MassHealth – to address the many issues on healthcare and ASD
* It was noted that some of the issues being discussed were an overlap for Workforce Development

Under Secretary Alice Moore asked that MassHealth present at the next Autism Commission meeting to update the members around MassHealth and ACO’s.

***Data*** Jane Ryder, Chair

1. Collaborate with EOHHS and Master Data Management System initiative to determine the possibility of developing an autism pilot project.
2. Propose that DESE include the Vineland Adaptive Behavior Scales as a required assessment for special education initial and three-year re-evaluations

* DDS has extensive data on the 1000+ newly eligible and will continue to collect this data
* DESE data goes back to 2003
* MassHealth data from 2012
* Looking at DPH data from Early Intervention as well as MRC data (some overlaps with DESE) The data has been shared with the sub-committee
* Review of the Vineland Assessment and that it looks at daily living skills, social skills, communication and can look at current level of function to help guide with planning for individuals. Ms. Kain said that the Vineland had been proposed for discussion with DESE because it provides information on level of functioning for 5 domains. Ms. Kain said some individuals with ASD may be at the 95th percentile and others could be at the 5th percentile and that it was important for planning purposes to understand each person’s level of need.
* Janet George noted that to get reliable data from Vineland schools need to be trained and supervised to use it – requires a well trained workforce.
* Ms. Kain noted that DDS uses this assessment currently and it could create better consistency as individuals transfer from one agency to another.
* The sub-committee would work closely with DESE around training
* Ms. Kain said that the Master Data Management System is in its very early stages of development but the goal was that it would allow state agencies to collect and share data, and that we know many individuals with ASD access multiple agencies at the same time and it would be helpful to be able to share information.

Julia Landau said that given they were almost out of time in today’s meeting, they should turn to the issue of process regarding recommendations, given the Commission meets quarterly and that the next meeting would not be until after the budget process was done. Ms. Kain said that in response to requests at the December Commission meeting she had requested each Chair of the respective subcommittees to present 1-3 recommendations on the work they had been doing to date and that this was being provided for informational purposes today. Ms. Kain said that the statute called for an annual report and that while they had not gotten to the process memo she prepared for today she had proposed an interim report to be filed this year, since she was appointed after March 1st last year, and that report was proposed for the Commission in June. Ms. Kain said that the statute does not provide a mechanism for recommendations outside of the annual report of the Commission.

Undersecretary Moore stated that the Commission’s role is advisory in nature and not one of advocacy. Ms. Moore said that the Commission is comprised of representative of the Legislature, state agencies, and a number of different advocacy groups who each play different roles beyond the Commission but their role on the Commission itself was its stated mission of identifying the unmet needs of individuals with ASD. Ms. Moore stated that as Senator L’Italien had highlighted a number of times earlier in the meeting that it was up to individual advocates and advocacy groups to advocate for any particular issue they or their groups supported. She said that there is a specific and distinct budgetary process with the Governor and the Legislature and it was not the role of the Commission or any state agency to be advocating for any budgetary related issues. Undersecretary Moore said this was raised at the previous meeting and there had been more discussion on the issue including with Ms. Landau and that she was happy to continue the discussion but she was not in the position to support any motion for budget related matters.

Ms. Landau said that they needed to be able to inform the Legislature about the Commission’s position and that it needed to occur today in order to be used during the budget process. Representative Ferguson said that Ms. Landau was correct regarding the timing of the information and that taking a vote today would occur before the budget process that will take place over the next few months.

Ms. Landau made a motion. Ms. Kain asked her to restate the motion for the minutes, and Cathy Boyle made a friendly amendment to the motion which Ms. Landau accepted, which read;

“The Commission votes to increase the capacity of and resources for the children’s waiver, the ICEI, and newly eligible adults”

Members were asked for a raise of hands to record the vote, which was recorded by Ms. Kain.

Those voting YEA were; Patricia Jennings, Dan Burke, Amy Weinstock, Dania Jekel, Susan Loring, Todd Garvin, Rep. Christine Barber, Chris Hubbard, Cathy Boyle, Rep. Kimberly Ferguson, Chris Supple, Judith Ursitti, Julia Landau, Sen. Barbara L’Italien, and Jessica Katon.

Those voting NO were; Undersecretary Moore, Patricia Gentile, Patricia Marshall, Janet George, Jane Ryder, Elin Howe, Carolyn Langer, Ayana Gonzalez

Two abstentions were: Rocio Calvo and Terry Williams Valentine

Ms. Kain read the results of 15 YEA, 8 NO, and 2 abstentions, the motion carried.

Undersecretary Moore noted the time, and that the remaining business would be addressed at the next Commission meeting in June. Ms. Kain asked that the members send her any comments on the proposed process and by-laws before the next meeting.

Upon receiving a motion duly made, seconded and approved. Undersecretary Moore adjourned the meeting at 12:15 p.m.