Autism Commission Meeting Minutes

December 10, 2018 – 2:00 p.m.–4:00 p.m.

One Ashburton Place, Boston, MA

Present: Secretary Marylou Sudders, Carolyn Kain, Rep. Kimberly Ferguson, Janet George (DDS), Christine Hubbard, Patricia Gentile (NSCC), Kathy Sanders (DMH), Russell Johnston (ESE), Jane Ryder (DDS), Toni Wolf (MRC), Ann Neumeyer, Amy Weinstock, Elizabeth Morse(DDS), Judith Ursitti, Sacha Stadhard (EOLWD), Julia Landau, Michele Brait, Chris Supple, Joan Rafferty (DPH), Katherine Canada, (DCF), Glenn Gabbard (DHE), Bronia Clifton (DHCD), Vinny Strully, Laura Conrad (MassHealth), Dania Jekel, Dan Burke and Rocio Calvo.

**Welcome - Review and Approval of Meeting Minutes from September 27, 2018**

Secretary Sudders called the meeting to order and welcomed the Autism Commission members to the meeting. Secretary Sudders then called for a motion to approve the minutes from the meeting on September 27, 2018. Amy Weinstock motioned to approve the minutes and Rocio Calvo seconded the motion with all members approving unanimously.

**Review of Draft 2018 annual report of the Autism Commission, with the Draft Unapproved Recommendations of the Commission’s Subcommittees**

Ms. Kain has worked with the subcommittee members and the respective state agencies to update the recommendations that were presented at the last Autism Commission meeting. There is more recent data from MRC and DDS that was added and is bolded within the document. A number of the recommendations have been completed, including the establishment of ABLE accounts and the Autism Endorsement by ESE, which was expanded to general educators. There is additional ongoing work that is taking place and is reflected in the report. Ms. Kain was able to work with state agencies to come up with cost estimates for the recommendations related to the respective state agencies.

**Review of recommendations and comments**

1. *Collaborate with the Department of Elementary and Secondary Education (ESE) on its development of their new IEP to address issues that relate to students with ASD*
* ESE reports that there is no estimated cost for this work as ESE is in the process of updating its IEP system
* The Birth – 14 year old subcommittee participated in a presentation on the new IEP and there is another presentation that will happen this week. The subcommittee will continue to work with ESE to come up with recommendations to ensure the ASD focus will be infused in the development of the new IEP. The subcommittee will put forth their recommendations in the upcoming months.
* Ms. Landau commented that cultural, linguistic and race needs should be addressed in the new IEP.
1. *MRC, DDS and their respective employment providers will commit to strengthening their data collection processes to include retention data of one year for all individuals they serve with ASD*.
* DDS does not anticipate any increased cost for this. DDS will leverage existing data systems
* Individuals struggle with maintaining employment – the subcommittee wants to look at data on individuals obtaining and maintaining employment
* MRC and DDS are both capable of collecting this data
* Ms. Landau commented that she would like the data that will be collected to be broken down by race and culture and to also include broken down data by race/culture in the annual report when giving updates on numbers of individuals served by state agencies
* Ms. Kain commented that in her organizational memo from March 2018, she included that all subcommittee Chairs were to address the cultural and linguistic barriers in their respective work.
1. *Additional and ongoing trainings, (with specialized consideration for any cultural, linguistic, and/or socio-economic needs) for MRC, DDS and their providers to support adult individuals with ASD, including those who present with more challenging behaviors, to enable these individuals to work and be in their community*.
* DDS is currently developing 3 trainings to address the needs for children, adolescents and adults. These trainings will be a basic introduction to ASD and will be available to providers, employers and state workers
* The goal is to create a library of trainings and build off of the basic trainings
* The subcommittee has created sub-groups that and are working with the Federation on a survey to Pre ETS providers and find out if they are seeing any challenges serving ASD individuals – based off of the response from the providers, the subcommittee will create a training to address the need
* Commissioner Ryder commented that DDS is working with the subcommittees and will update the commission on further trainings that will be developed
* Commissioner Wolf commented that MRC will be collaborating with DDS on developing trainings
* Ms. Calvo asked if there was a way to keep track of what trainings providers are accessing and in what languages. Secretary Sudders asked if the BC School of Social Work could be helpful with this type of data collection. Ms. Calvo agreed to provide this type of support.
1. *ESE and DDS will identify best practices for educational and family supports (with specialized consideration for any cultural, linguistic, and/or socio-economic needs) for transitioned aged youth with autism, including those who are behaviorally challenging and those who have co-occurring diagnoses through:*
2. *Expanding the ESE/DDS residential prevention program*.
* DDS gave an estimate of the cost for an additional 100 students – $14k per student – approximately $1.4 million total (the number 100 was provided as an example)
1. *Developing specialized curriculums to address the need for comprehensive sexual education*
* Ms. Canada suggested doing outreach to existing residential schools who have already developed a curriculum - some schools have also developed a curriculum for non-verbal students – Ms. Canada and Mr. Strully will share information that they have with Ms. Kain
* There has been professional development offered across the state with an identified curriculum through Elevatus
* It was asked that this curriculum could also address gender identity
* Mr. Johnston discussed DESE updating its educational standards and it relates to this topic. Any curriculum that will be produced will address gender and race issues and will infuse the needs of ASD.

There was discussion around adding the cultural and linguistic language to all of the recommendations and Ms. Kain responded that she would like to add the language up front in the report so it is not redundant on every recommendation. Ms. Calvo responded that asking a question about language, on an intake form, the child vs. a parent response is different. You would want to collect data (parent vs. child) separately on an intake and to make sure the language on any intake is consistent with all agencies. Ms. Calvo will send Ms. Kain information on how to appropriately ask a question about language on an intake form.

1. *Strengthening linkages among state agencies and their community partners.*
* This relates to employment of individuals and their providers
* The subcommittee members have been working on a document that has a list of shared providers (MRC, DDS, DMH) – this can be helpful for providers to ensure they are not duplicating services and for families to see who has a shared provider for consistency in services
* Commissioner Wolf discussed MRC starting a provider advisory council and is looking at the linkages
1. *Exploring the possibility of implementing a “checklist” for the special education transition planning process to ensure the unique transition needs of the student are addressed.*
* The checklist is to help families better understand the transition process
* The subcommittee will develop the checklist and it was suggested they partner with the Federation for Children with Special Needs
* Other states provide similar “checklists” for families and there are some schools in MA that do this as well (Brockton Public Schools)
1. *Families of 20-30 year-old individuals with ASD (and no ID) who self-isolate in the family home need assistance and consultation services to help their adult family members to engage in their communities. DDS in collaboration with DMH develop and implement a family consultation initiative to address that need. This initiative would allow families and individuals with ASD, regardless of DDS or DMH eligibility, to have access to specialized expertise and technical assistance to address the needs of this segment of the ASD population. DDS and DMH will report annually to the Autism Commission on the implementation of this initiative.*
* Many of these individuals have graduated with their non-disabled peers and did well academically. They attempted to move on to college or a career and have failed due to lack of social and executive function skills.
* This is a pilot project that is currently underway and the cost has already been approved by DDS and they are using funds from the Turning 22 budget – this will provide information on what works and help to develop strategies for families and providers
* Ms. Landau asked for periodic reporting of data to the autism commission members including how this data relates to the underserved populations.
* Ms. Jekel asked if DDS could report the breakdown of numbers for the newly eligible (race, language) – Commissioner Ryder responded that she will request that information from her Department.
1. *The Adult Subcommittee will work with the Executive Office of Elder Affairs (EOEA) to gather information regarding that agency’s involvement with aging individuals presenting with ASD, and collaborate with EOEA to ascertain if individuals with ASD known to or served by EOEA are aware of other services that may be available to individuals with ASD, and to ensure that EOEA’s network of services are aware of the needs of individuals with ASD and receive training on how to address these needs.*
* EOEA’s office will provide the subcommittee members with information to help better understand their network of services
* Many aging individuals may not have a formal diagnosis or may have never connected with a state agency
* There is no cost associated with this recommendation
1. *DDS, in conjunction with DMH and MassHealth develop and establish specialty ASD adult services that are designed and staffed to meet the needs of adults with ASD who present with severe challenging behaviors, including but not limited to; Day-Habilitation services, Community-Based Day Support services and other types of day services and specialized clinical support services necessary to effectively serve these adult individuals.*
* The costs associated with this recommendation are over and above the residential cost
* There was a question on the number of individuals in day support and the number that require more intensive needs
* Commissioner Ryder was asked if there was a rise in the number of individuals that require more intensive support and what is the percent of increase of those individuals
1. *Extend MassHealth coverage of medically necessary treatments for persons over the age of 21 who are diagnosed with autism spectrum disorder by a licensed physician or a licensed psychologist, said coverage shall include but not limited to, applied behavior analysis supervised by a licensed applied behavior analyst.*
* Currently, under the Autism Omnibus Law, MassHealth covers ABA services up to age 21 There are 45 individuals, between the age of 18-20, that received ABA for FY17 and this includes secondary health insurance coverage. (MassHealth estimates the cost to expand ABA for individuals 21-26 years of age to range from $483,358 on the lower bound up to $4,189,105 on the upper bound.)
* It was noted that most individuals, who are in residential, are not receiving ABA through their MassHealth coverage
1. *Expand training on autism spectrum disorders (ASD) and appropriate strategies for assisting individuals with ASD for health care providers, including hospital emergency room personnel and residents.*
* There is no cost associated with this recommendation – the subcommittee is looking across the state to identify what trainings exist
* Mass General did a hospital wide training and Ms. Kain, along with a few others met with them to gain a better understanding of the training offered
* DDS and DMH, in partnership with BMC, have developed training modules for individuals with co-occuring mental health needs. The training is geared towards adolescents and is offered hospital wide at BMC. It sits on the DDS platform and is available for other medical providers to access
* Ms. Calvo wants to ensure that this is also distributed among the low-income communities - community health centers would benefit from these trainings
* Ms. Jekel commented that this training could work in two ways – it could be used to work with the autistic person on how to talk to a provider in an Emergency Room or hospital setting. Ms. Kain discussed the work that the Adult subcommittee has already made an effort to address that need. They developed emergency room wallet cards for individuals that contain pertinent information about the individual. The information will make it easier for the person if they are unable to express their needs in an emergency room situation
1. *Expand Mental Health emergency and treatment services to specifically address the needs of children and adults on the spectrum.*
* This recommendation is similar to # 9 and the work has started in a broad and comprehensive effort
* This is targeted effort due to the number of ED boarding cases that exist
* The Children’s Mental Health Commission is also looking at this issue
1. *The Housing Subcommittee of the Autism Commission will develop design guidelines that will meet the needs of individuals with ASD to obtain and sustain tenancy in supportive affordable state funded housing units including those that ; 1) currently exist; 2) are being rehabilitated; 3) and any newly developed units. The Housing Subcommittee will work with the appropriate state agencies and other stakeholders to review existing design guidelines and to develop additional guidelines that are necessary to meet the needs of individuals with ASD.*
* The initial environmental scan of the design guidelines could be done with state agency personnel and members of the Housing subcommittee
* Some of the designs are common sense (corner units, soundproofing, drains in bathrooms)
* It is easier to incorporate the designs guidelines with prior to construction vs. existing units
1. *Initiate a statewide outreach and data collection on homeless adults with ASD. The subcommittee will collaborate with stakeholders to identify the number of adults with ASD who may be living in shelters or on the street.*
* The subcommittee would like to get an understanding of the numbers that could be living in shelters or on the street
* There has already been an initial meeting with Pine Street Inn to discuss this issue and talk about any staff training needs
* DMH’s PATH program does not have the capacity to take on this initiative
* There will be contact with Bridge Over Troubled Waters in recognizing that many individuals would most likely not do well in a shelter environment due to the sensory impacts
* Mr. Supple commented that this recommendation could be related to recommendation #5. Some individuals who self-isolate and also have aging parents – when the parents are gone they could move into this category
* Ms. Kain commented also that the language of “aging care givers” could be added to recommendation #6 and she will adjust the language
* Secretary Sudders discussed the opioid crisis and that some families and individuals are now homeless as a direct result and included in this count are older adolescents that have been described as “quirky” or “not fitting in”. Secretary Sudders will send information to Ms. Kain regarding this topic.
1. *The Department of Developmental Services (DDS) will collect data on the number of individuals who have; 1) been admitted to the Emergency Stabilization Unit at Hogan from their group home, and 2) whether that individual returned to their current group home or transferred to another group home. DDS will report this data quarterly to the Housing Subcommittee of the Autism Commission.*
* DDS does not anticipate any additional cost for this report gathering
* They will track individuals with ASD who have been admitted to the Emergency Stabilization Unit at Hogan and if they go back to their group home or to a different group home
1. *The WFD subcommittee will work with the Board of Registration of Allied Mental Health and Human Services Professionals and the Division of Insurance to ensure that the licensure process for BCBAs and credentialing of LABAs by insurers is conducted in an efficient manner to enable LABAs the ability to provide approved services to families of individuals with ASD without unnecessary delay.*
* This is ongoing work and the Board of Registration has committed to addressing this need
* The DOI has been very responsive to this issue and has offered assistance for any insurer not completing the process within a reasonable amount of time
1. *The WFD subcommittee will work with the Executive Office of Labor and Workforce Development and the Office of Immigrants and Refugees to promote employment opportunities at the EOLWD’s Career Centers for direct care workers, and explore with the Department of Higher Education and the 15 MA Community Colleges the possibility of a loan forgiveness program for direct care workers to further support the need to increase the direct care workforce.*
* The subcommittee will work with EOLWD Career Centers on this issue and there is no cost to collaborate with the other state agencies to promote employment opportunities
* The subcommittee will explore loan forgiveness with DHE and the community colleges
* Mr. Burke commented that there is an incredible crisis in the workforce on all levels for direct care workers in Health and Human Services and anything that we can do to support the efforts is positive work

Secretary Sudders thanked the chairs and members of the subcommittee for their work on the recommendations. She also thanked the state agencies for working with the Commission to come up with the estimated cost for the recommendations.

**General Discussion**

* Ms. Jekel commented that she is still concerned that employment issues are not being addressed by the 14-22/employment subcommittee, as well as not addressed in the report. Ms. Jekel said AANE runs employment therapy groups and they are worried about employment opportunities. The chairs of the subcommittee commented that they are working very hard on employment and have come up with meaningful recommendations. They are looking at the employment support services, as well as where, geographically, services are located to help identify any gaps. They are also working on surveying employment providers to understand their need for training as it relates to ASD and employment, as well as best practices. This is an ongoing priority of this subcommittee.
* It was also stated that on page 5 & 6 of the report it references the “On-going Work” of the commission and employment is included in that work
* Ms. Ursitti commented that AANE has a representative on the 14-22/employment subcommittee and also invited Ms. Jekel to attend a subcommittee meeting to see the work being done
* Mr. Supple commented on Rec. #4, last bullet, as it relates to the transition planning process and a “checklist”. His concern is that teens with ASD do not have a lot of activities afterschool and in the evening. He was looking for data on how many students get more than 6 hours and less than 24 hours of support – is there data on extended day services. Mr. Johnston (ESE) commented that there is no data on the extended school day but there is data on the level of need for students. There is a possibility that it could be captured under the new IEP
* Commissioner Wolf responded that MRC has 3 pilot projects working with Transition Aged Youth on transition and employment and she can collect data on this pilot – there is a high number of ASD individuals in the pilot
* Ms. Kain commented that there are many students in the DDS/DESE program who are accessing services during afterschool hours, the Autism Waiver program also provides wrap around services, and some individuals receive ABA afterschool or on weekends through insurance (private insurers or MassHealth)
* DDS/DESE is in place to avoid residential placement and is success rate in the 90th percentile, additional funds are needed to increase the program.

Ms. Landau asked to have the following language added to the annual report:

*“The Autism Commission has developed new recommendations to highlight in the 2018 report, as outlined below.  The Autism Commission notes that there are many important recommendations included in the 2013 report of the Special Commission Relative to Autism**that remain a priority for the state’s autism community.”*

She is concerned that some of the recommendations from the original report (2013) are not included in the draft report and that some policy makers may think those original recommendations are no longer priorities. Several members of the Commission responded that there is a need to prioritize the recommendations and this new draft report does that.

Secretary Sudders reminded the Commission members of the clear discussion that took place at the September 27, 2018 meeting, which Ms. Landau did not attend, about the current annual report and that it would prioritize current recommendations of this Commission and not continue to include all of the 2013 recommendations, some of which have not moved forward in years. The Secretary noted that there is still information in the current draft annual report that discusses the ongoing work of this Commission since the 2013 report and the Autism Omnibus Law. Ms. Landau asked for a motion to approve her language and Ms. Ursitti seconded the motion. The Secretary asked if there was any discussion on the motion. Several members commented they would not support the language as proposed.

Ms. Landau then amended her proposed language to; *“The Autism Commission has developed new recommendations to highlight in the 2018 report, as outlined below.  The Autism Commission notes that there are recommendations included in the 2013 report of the Special Commission Relative to Autism**that are not included in this report.”*

Representative Ferguson commented that she agreed the revised language met the need of informing the reader that previous recommendations are not included. The Secretary asked if there was any discussion on the revised motion, there being none, the Secretary called for a roll call vote.

Roll Call Votes:

Yes Abstain No

Glenn Gabbard Rocio Calvo Vinny Strully

Toni Wolf Katherine Canada

Dan Burke Russell Johnston

Kimberly Ferguson Elizabeth Morse

Dania Jekel Jane Ryder

Julia Landau Joan Raferty

Ann Neumeyer Kathy Sanders

Chris Supple Laura Conrad

Judith Ursitti Sacha Stadhard

Amy Weinstock Bronia Clifton

Christine Hubbard Secretary Sudders

Michele Brait Janet George

 Patricia Gentile

The amended language proposed by Ms. Landau will be added to the report.

The next Autism Commission meeting will take place on February 6, 2019. With no further business to discuss the meeting was adjourned.