Autism Commission Meeting Minutes

September 27, 2018 – 2:00 p.m.–4:00 p.m.

One Ashburton Place, Boston, MA

Present: Secretary Marylou Sudders, Carolyn Kain, Rep. Christine Barber, Emma Schlitzer for 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, Matt Regan for Sen. Richard Ross, Michele Brait, Joan Rafferty (DPH), Catherine Canada, Assistant Commissioner (DCF), Glenn Gabbard (DHE), Vinny Strully, Jennifer Halisey for Laura Conrad (MassHealth), Dania Jekel, Dan Burke and Rocio Calvo.

**Welcome - Review and Approval of Meeting Minutes from May 10, 2018**

Commissioner Jane Ryder called the meeting to order and welcomed the Autism Commission members. She introduced new members to the Autism Commission; Elizabeth Morse, Deputy Commissioner of DDS, Matt Regan attending for Senator Richard Ross, and Katherine Canada, Assistant Commissioner for DCF. Secretary Sudders also welcomed members of the Autism Commission and asked for a motion to approve the minutes from the meeting on May 10, 2018. The minutes were reviewed and approved unanimously.

**Presentation by Co-Chairs of the Recommendations from the Autism Commission’s Subcommittees**

There are six (6) subcommittees for the Autism Commission and the co-chairs have worked with the subcommittee members to develop up to three (3) recommendations for consideration by the commission members. These recommendations, if agreed to by the commission members, will move forward in the Autism Commission’s 2018 annual report.

**Birth – Fourteen Years Old Subcommittee**

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***

* The members of the subcommittee met and saw a brief demonstration on the new IEP that is being developed
* The group made early recommendations and gave feedback on the needs specific to ASD - there will be a report on the new IEP in November
* The subcommittee will review the report and make further recommendations on the new IEP

1. ***Addressing the shortage of ABA providers across the state***

* Workforce Development is also working on this issue
* This subcommittee will explore school based ABA and the lack of a required license from DESE – this subcommittee will examine this issue to see if this is a barrier for individuals not wanting to get into this field but instead work in a school where there is no license required
* There is a question of it being helpful to have a DESE license to get paid more by school districts
* Joan Rafferty updated the subcommittee on the waitlist for ABA services - this topic will be discussed further and may or may not develop into a recommendation based off of findings
* There are complexities with insurance companies that make it more difficult for providers to bill and the lack of ABA providers is a large issue across the state
* Ms. Kain has met with the DOI to discuss this issue. She said that DOI reports that they require credentialing but that if there were any companies that were taking an unreasonable amount of time to accomplish that process after licensure has been obtained they could take a look at that issue.

1. ***Identify ways to decrease wait times for evaluations and early diagnosis, and promoting existing resources for health care professionals***.

* This is in process and Joan Rafferty from DPH provided the subcommittee with information on wait times
* The subcommittee will review the information from DPH and follow up with next steps

**14-22+ Years Old/Employment Subcommittee**

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*.**

* The subcommittee feels that looking at the retention data will assist with understanding the supports needed for employment

1. ***Additional and ongoing trainings 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 with the proper supports***.

* This is a critical issue and it was noted that the supports and the training needs to be meaningful
* Training has been identified as an overall need and will require different types of training
* The Federation for Children with Special Needs agreed to assist this subcommittee with training for pre-employment skills. The subcommittee will help to create a survey for providers to get a better understanding of the training needs
* This committee has a long term goal of developing a library of trainings
* Members from the Housing Subcommittee did a training for MassHousing managers and have been invited to do another training in the winter
* Training for joint providers (MRC, DDS) to leverage expertise

1. ***ESE and DDS will identify best practices for educational and family supports for transitioned aged youth with ASD, including those who are behaviorally challenging and those who have co-occurring diagnoses through; Expanding the ESE/DDS residential prevention program; Developing specialized curriculums to address the need for comprehensive sexual education; strengthening linkages among state agencies and their community partners; and Exploring the possibility of a “checklist” for the transition planning process to ensure the unique transition needs of the student are addressed***.

* ESE/DDS program is very successful at preventing residential placement – the program served 570 individuals and 85% are ASD – there is a 90% success rate. Any expansion of this program would require additional funding from DESE.
* The allocation varies for each individual – some individuals are able to access other benefits, and not use all of their allocation, and this allows DDS to serve more individuals with the monies reverted back to the program by families.
* The allocation is based off of an initial evaluation and there is also a semi-annual evaluation – this allows DDS to look at the progress of the individual and if money is not being used they can adjust the budget mid-year
* Families are informed of this program through their DDS coordinator and from parents – DDS does a blanket outreach
* It was reported that families believe it is more difficult to get a residential placement when their young adult turns 22 if they have not been involved in the ESE/DDS program – day students involved in residential prevention program have a more difficult time getting residential placement at 22 – they may not be prioritized.
* Turning 22 was fully funded but it was said that is a “safety valve” but not a solution
* The lack of a modified sex education curriculum was discussed – it is an important topic
* DDS has a trainer that focuses on this issue for adults
* NPR did a series on this topic and it is said that individuals with disabilities are 7 x more likely to be abused
* Students need education and need to be better prepared when they exit the school system on health relationships and boundaries
* Glenn Gabbard discussed the MAICEI program and a convening that took place over the summer on this topic and healthy relationships. They were addressing a need for education and will continue to explore additional ways to inform on this topic

**Adult Subcommittee**

1. ***Families of 20-30 year old individuals with ASD (no ID) who self-isolate need assistance and consultation services to help their adult family members engage in their communities. DDS in collaboration with DMH develop and implement a family consultation initiative to address that need. DDS and DMH will report annually to the Autism Commission on the implementation of this initiative.***

* This is more than a training and will address the different types of needs
* The initial step is a consultation to better understand the need and will then give access to specialized expertise
* Chris Hubbard commented that Chris Supple thinks this could be a housing issue as well and could cut across other subcommittees
* Ms. Kain reported that there is a pilot program that was approved to address this issue and DDS and DMH are collaborating on this with strategies for families. This program was designed after hearing from families of the newly eligible

1. ***The Adult Subcommittee will work with the 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 EOES 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.***

* This recommendation will start with gathering information on individuals with ASD and aging
* The subcommittee will enter into a dialogue with EOEA
* Ms. Kain has already contacted EOEA and asked that they come and do a presentation for the Adult subcommittee on their network of services.
* Many aging adults may not have a formal ASD diagnosis and may not understand services they may be eligible for from different state agencies.
* The subcommittee would also like to learn more about their caregivers who are also aging and may need additional supports for their adult children with ASD.

1. ***DDS, in conjunction with DMH and Mass Health develop and establish specialty ASD adult services that are designed and staffed to meet the needs of adults with ASD who present with sever 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***.

* This recommendation was in the 2013 report.
* There is an emphasis on specialty services being needed for adults with high acuity and sever challenging behaviors that require additional supports beyond the traditional day programs offered by DDS, DMH and MassHealth.
* The clinical support services necessary to service these individuals effectively increase the cost for service for this segment of the ASD population.

**Health Care Subcommittee**

1. ***Extend MassHealth coverage of medically necessary treatments for persons over the age of 21 who are diagnosed with ASD 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.***

* This is an overarching recommendation and is broadly written
* There was a suggestion to pilot this with the ESE/DDS Program individuals as they age out so services are not immediately ended
* Ms. Weinstock reported that they get many calls from families asking for this service to help keep their young adults at home and not moved to residential
* This recommendation is carried over from the 2013 report

1. ***Expand training on ASD and appropriate strategies for assisting individuals with ASD for health care providers, including hospital emergency room personnel and residents.***

* Emergency rooms are an area of stress for many families
* There are great models across the state
* The training should be expanded and standardized for all

1. ***Expand Mental Health emergency and treatment services to specifically address the needs of children and adults on the spectrum.***

* This work is ongoing across the state
* There was a discussion on the lack adult doctors when aging out of a pediatricians care
* Secretary Sudders discussed the Massachusetts Medical Society and said that she would be willing to make an introduction for the subcommittee to start a conversation regarding the need for more doctors to treat individuals with ASD as they move from pediatricians to the adult world of medical care.
* Dan Burke discussed that there are also many individuals with medically complex needs– we need to include these individuals in the conversation

**Housing Subcommittee**

1. ***Develop design guidelines that will meet the needs of individuals with ASD to obtain and sustain tenancy in supportive affordable state funded housing unites 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.***

* Currently working with DHCD on this recommendation
* Working off of the Rolland Guidelines –i.e. soundproofing, corner units – these adjustments will allow individuals to be more successful in their home
* This effort is not to develop new guidelines but to review the current guidelines and make recommended additional adjustments to meet the needs of individuals with ASD
* It is about obtaining and maintaining tenancy at existing developments and new developments.

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.***

* We currently do not know the scope of the numbers of individuals with ASD in shelters
* The approach is to look at ways collect data on the ASD population from a variety of resources that engage with the homeless population
* Ms. Kain’s office met with Pine Street Inn for a potential staff training on recognizing ASD and providing information on state agency resources
* Many individuals with ASD may not be in shelters but on the street – shelters can be very over stimulating
* It was noted that this recommendation will be complicated since many individuals may have co-occurring diagnosis, and may not have been diagnosed with ASD.
* The goal is to identify and access existing resources and to being the process of educating other agencies on ASD

1. ***DDS will collect data on the number of individuals who have; 1) been admitted to Hogan from their group home, 2) whether that individual returned to their current group home or transferred to another group home; 3) whether any support services or facility modifications could have prevented the reason for admission. DDS will report this data quarterly to the Housing Subcommittee of the Autism Commission.***

* This is related to individuals with behavioral and complex needs to address what happens in situations when an individual leaves their group home due to behavioral issues. It will eventually help to understand what supports are needed to keep them from leaving their group home
* When individuals leave places like Hogan they go to a stabilizing unit and it is temporary
* DDS will track both ASD and ASD with IDD

**Workforce Development Subcommittee**

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 a time delay and could be addressed quickly
* Insurers are also slow to recognize a license once it is obtained
* Ms. Kain reached out to the Board of Registration and they have lost 3 employees – they are working to address this issue
* Ms. Kain also met with the DOI and discussed the delay and working on a more efficient process

1. ***The WFD subcommittee recommends that DDS, MRC and MassHealth conduct reviews of established pay rates for human service provider agencies to adjust where possible the pay rates for direct service providers to address the need to recruit, retain, and provide career advancement for human service workers.***

* Providers report that the pay rate is difficult to keep credentialed workers – they end up going to school districts for a higher pay rate – there is a mismatch in the market rates
* The Secretary reminded the members that EOHHS has a c.257 rate setting process that exists for this purpose, and that the state is in full compliance with a settlement on this issue. The recommendation as drafted is inaccurate, does not acknowledge the statutory rate setting process and compliance with settlement.
* The WFD subcommittee will revisit this recommendation and make changes to the language.
* The ADDP meets with provider council every quarter
* Dan Burke will reword this recommendation and work in the 257 process
* Mr. Burke discussed this issue as a challenge and we are in major workforce crisis

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.***

* Many Higher Ed. Institutions have certificate programs
* There is a gap in the entry level requirements to becoming a BCBA
* This recommendation is to help move people to be able to work up to the level of credentials
* Ms. Kain had an initial meeting with OIR to discuss the possibility of promoting direct care work with their clients.

**General Comments**

* Ms. Jekel sees employment as a concern and a huge issue. She stated that this is a critical crisis that needs to be addressed. She wants employment to have a larger priority and focus and take center stage.
* Ms. Ursitti discussed AANE has representation on the 14-22/employment subcommittee and they provided feedback on the proposed recommendations. She discussed employment provider training being the foundation to the success of the employment
* MRC had federal level cuts that has effected funding
* Ms. Jekel discussed 1/3 of her staff with ASD and they require coaching – this takes a lot of energy for her staff since they need individual assistance
* There was a question regarding the previous recommendations from the prior annual reports. Ms. Kain responded that the commission is moving on from the 2013 report since this is a new commission, the previous recommendations are five years old, many of those have already been accomplished, and others were not agreed to by the state agencies impacted.
* The Secretary stated that she was clear about this issue at the last commission meeting, and our development of new recommendations to reflect the work that has been done since the previous report and the enactment of the Omnibus Law, current needs, and issues identified through the work of the subcommittees. She noted that if there are specific concerns with any particular previous recommendations from the 2013 report this could be discussed at our next meeting, and that any of those recommendations should be provided to Ms. Kain for the December Commission materials. The Secretary reiterated that we want to focus on the present and current priorities.

**Next Steps**

Secretary Sudders commented that there are potential “price tags” on some of these recommendations. She asked that the subcommittee members discuss this with the relevant state agency that would be involved with individual recommendations, and provide cost estimates associated with any of the recommendations to the next Autism Commission meeting. The state agencies should provide their respective cost estimates to the Executive Director of the Autism Commission for the materials for the next meeting.

The next meeting of the Autism Commission will be on December 10, 2018 at One Ashburton Place from 2:00 p.m. – 4:00 p.m.

With no further business to discuss the meeting was adjourned.