Autism Commission Meeting Minutes

September 26, 2019 – 2:00 p.m.–4:00 p.m.

One Ashburton Place, Boston, MA

Present: Secretary Marylou Sudders (EHS), Carolyn Kain, Jane Ryder (DDS), Elizabeth Morse (DDS), Christine Barber (HOU), Samantha L. Aigner-Treworgy (EEC), Ann Reale (EOE), Sacha Stadhard (EOL), Christine Hubbard, Kathy Sanders (DMH), Amanda Green for Russell Johnston (ESE), Toni Wolf (MRC), Amy Weinstock, Elizabeth Morse(DDS), Bronia Clifton (DHCD), Theresa Touhey Schirmer, Julia Landau, Michele Brait, Joan Butterfield (DPH), Katherine Canada (DCF), Kathryn Downes (ELD), Todd Garvin, Dania Jekel, Vinnie Strully, Laura Conrad (MassHealth), Judith Ursitti, and Dan Burke.

**Welcome - Review and Approval of Meeting Minutes from May 30th, 2019**

Secretary Sudders called the meeting to order and welcomed the Autism Commission members. There are new members to the Autism Commission and introductions were made and new members were welcomed. She asked the commission members for a motion to approve the minutes from the meeting in May. The minutes were approved with Sam Aigner-Treworgy, Todd Garvin and Ann Reale abstaining from the vote.

Secretary Sudders asked the new Commissioner of Early Education and Care to introduce herself to the commission members. Commissioner Samantha L. Aigner-Treworgy shared, with the commission members, her background in education. One of her goals is to make it as easy as possible for families to access services and help them navigate the system. She would like to get a deeper understanding of state issues and visit programs across the state. Ms. Weinstock brought up concerns regarding Center Based Programs and lack of regulations. Ms. Kain and Ms. Weinstock met with EEC in the past about CBP and it is an important issue that needs to be addressed. The Commissioner is aware of Center Based Programs and the issues surrounding it and it is also on her radar.

**DDS Budget Updates, Commissioner Ryder**

Commissioner Ryder updated the commission members on the DDS FY20 budget:

*Highlights*

* Level funded T22 at $25 million – approximately 1200 individuals in the T22 class, and estimated 319 are ASD only and 192 are ASD and I/DD
* DDS/DESE program – $4 million increase that will support an additional 300 students – the goal is to do more outreach in urban areas across the state
* Increase in Family Support - an additional $5.1million which will help families keep their loved ones in their home
* Children’s Autism funded at $7.4 million - $450,000 increase
* Adult Autism funded at $30.7 million, a $12.6 million increase
  + 2,194 individuals are eligible for ASD services and supports in 2019
  + Area offices coordinating with eligible individuals to provide community day/employment support, individual support, transportation and family support and a broad category of services and assistance to families
* DDS is now a $2 billion agency

*Discussion*

* Matching needs to what the department has traditionally offered at DDS – the department is getting feedback from service coordinators. Some individuals do not want services, they feel they are not ready
* Many ASD only individuals are pursuing college and employment – DDS is providing support to navigate different environments
* DDS does not have data on the number of ASD individuals across the state; they started collecting this data in 2014 and will continue on an ongoing basis
* MassHealth reported that they spent $93 million on ABA services for FY19 – Early Intervention spent $14 million

Several Commission members expressed their appreciation for these increases in funding for the ASD community.

**Review of Updates and Recommendations from Subcommittees**

Birth –Fourteen

Michele Brait, co-chair for the Birth to Fourteen Subcommittee updated the commission members on their recommendations:

1. The Birth to 14 Subcommittee will collaborate with the Department of Elementary and Secondary Education (“DESE”) on its development of their new electronic IEP (Massachusetts IEP Improvement Plan) to address issues that relate to students with autism spectrum disorder.

*Update: This work is on-going.*

* *Our subcommittee comprised a list of recommendations specific to the needs of Students with Autism Spectrum Disorders and sent them to DESE in June. They were discussed with the DESE Dept. Office of Special Education Planning and Policy, and they concluded that our recommendations aligned with established goals for the IEP Improvement Project. Many of the suggestions we made had already been incorporated. Documents to be updated include the IEP itself, A Special Education Guide, A process guide for writing the IEP, an annotated agenda for parents, and a Parent Guide to Special Education.*
* *We will continue to keep this an ongoing recommendation for the upcoming year, as the IEP project is still in process. DESE will continue to keep the Autism Commission advised about the progress of the project.*

The first priority was **to improve recruitment and retention strategies of BCBA’s and related behavior therapists in public education Settings**. *This work is on-going.*

* *Update: Our subcommittee created 2 surveys for input; one went to BCBAs and one to District Special Education Directors, which were distributed in June. 250 responses were received. Our subcommittee began a review of the surveys at our July meeting and will be analyzing them further to determine next steps, possibly a quick resource guide for district leaders about helpful recruiting and retention practices. This will be an ongoing priority (but no formal recommendation at this time) for the subcommittee with further work to be done.*

The second priority was **to reduce wait times for evaluation and diagnosis of ASD.** *This work is on-going.*

* *Update: Our subcommittee was informed about current available information gathered by DPH Early Intervention regarding wait times state-wide for evaluation and diagnosis, as well as updates on some pilot programs that are currently in place and expanding. The subcommittee would like to know more about the rate of delay in diagnosis and treatment broken down by demographics to address the issue of under-served populations and racial disparity within the system to assist us on this ongoing priority.*
* The sub-committee would like to make a new recommendation to the Autism Commission to develop solutions so that data can be collected and reported on regarding the age of diagnosis broken down by race.

**New Recommendations to the Autism Commission from the Birth - Fourteen Subcommittee**

* **Access to Augmentative/Alternative Communication Devices for Children with ASD**

The sub-committee would like to make a recommendation to the Autism Commission to request that MassHealth provide data about children who have received dedicated and non-dedicated AAC devices, broken down by race and language spoken in the home.

* **Inclusion for Students with ASD**

The sub-committee would like to make a recommendation to the Autism Commission to request that DESE provide data broken down by race, language spoken in the home and level of inclusion (full/partial/substantially separate) for students with ASD.

* **Children with ASD in DCF Care**

The sub-committee would like to make a recommendation to the Autism Commission that trainings be developed for DCF staff about ASD.

* The subcommittee has 2 members (DDS) that work with clients of DCF and will work on a training for all DCF workers
* Ms. Kain had previously done a webinar for DCF employees

*Discussion*

Ms. Jekel asked questions on the underserved population, particularly Spanish speaking and being under diagnosed and labeled as “behavior” issues in school - how to address this issue. She also said that some with ASD profile are not getting diagnosed until 2nd – 4th grade and has concerns. Ms. Kain responded that there was a presentation at the last Autism Commission meeting and cultural responsive videos from the 1,2,3 Grow Project has been developed and widely distributed addressing cultural barriers. The materials have been developed in multiple languages and are based off of the CDC materials. The Executive Office of Education is also looking at this issue and developmental milestones, as part of a federal grant.

14-22+/Employment Subcommittee

Commissioner Toni Wolf and Judith Ursitti, co-chairs of the 14-22+/Employment Subcommittee addressed the commissioner members on their updates of their recommendations:

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 autism spectrum disorder (ASD).

* *Update: Ongoing. In FY19 MRC referred 994 consumers with ASD**to its Pre-ETS vendors.  In terms of race and ethnicity these 994 are broken down as 842 white, 92 African-American, 9 Native American, 37 Asian/Pacific Islander, and 65 Hispanic ethnicity.  During FY19, 336 individuals achieved successful employment outcomes during FY19, and 93.1% of individuals retained employment after placement to successful employment outcomes.*
* *DDs reported that the number of individuals working in individual integrated jobs increased from 2,187 in 2017 to 2,309 in April 2018. The number of individuals currently employed who were employed for 10 of the last 12 months was 86%. DDS data does not currently differentiate by type of disability.*

*2.* Additional and on-going 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 with the proper supports.

Update: Ongoing. *List of trainings provided in 2019*

* *The 14-22/Employment Subcommittee developed survey questions for MRC’s Pre-Employment Transition Services vendors, which were sent to providers on September 18, 2019, for the development of a training webinar facilitated by the Federation of Children with Special Needs and Boston Medical Center on November 14, 2019.*
* *DDS’s Autism 101 training was reviewed and updated edited by members of the Subcommittee. It is now under view by DDS. Once finalized, it will be presented in a webinar format and available to DDS employees on the DDS training platform.*
* *MRC has had a number of trainings for its employees with a focus on ASD which were facilitated by AANE. In addition, they hosted a 2 day event that focused on executive functioning – these trainings were for MRC employers. It was noted that AANE does not serve the I/DD population and that it is important to have a training that would include ASD with I/DD. According to the CDC, 31% of those diagnosed with autism spectrum disorder have a significant intellectual disability.*

3.DESE 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;

Update: Partially Achieve and Ongoing.

* 1. ***Achieved.****Expanding the DESE/DDS residential prevention program. Additional funding has been provided to expand this program in FY20 from $6.5 mil to $10.5 mil.*
  2. *Ongoing. Developing specialized curriculums to address the need for comprehensive sexual education. We will continue to collect data and work closely with DESE. Individuals with disabilities are 7 xs more likely to be abused.*
  3. *Ongoing .Strengthening linkages among state agencies (including DDS, MRC, DMH, DCF and DESE) and their community partners in order to coordinate and compliment services provided. – looking at a stronger MOU to coordinate trainings. MRC has a strong relationship with DMH*
  4. *Ongoing. 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. This subcommittee has developed a transition brochure that includes a checklist.*

**(New Recommendation)**DESE will continue to assist the 14-22/Employment Subcommittee in determining the numbers of ASD students with IEPs calling for an extended school day. The 14-22/Employment Subcommittee will review any available data on extended school day services for individuals with ASD, access to after-school programs by individuals with ASD, and the number of school aged individuals with ASD accessing other out of school time services (DDS/DESE program).   *The subcommittee will consider whether recommendations should be made regarding the potential role of extended day opportunities after-school and on the weekends in providing options in lieu of residential placements when appropriate and in preparing transition-age youth diagnosed with ASD for life in the workplace and community after their school eligibility ends at 22. The 14-22/Employment Subcommittee will evaluate ways to provide information to parents, self-advocates, and school districts related to the rights to extended day programming.*

*Discussion*

* The subcommittee is looking at what is considered school and what is not school (extracurricular)
* Goal is for individuals to have a robust social and community life
* This is usually a “team” decision at an IEP meeting
* Some parents may not understand that their student has a right to attend after school programming
* Discussion on collecting data around how many students are accessing extended school day. It would be a process to add it to the SIMS program
* There is currently a bill in legislation looking at data collection at DESE
* Discussion on DESE reaching out to schools regarding best practices of inclusion in after school.
* Most of these individuals are served by the different state agencies and this is a lower level intervention that could help fill the gaps between home and residential and possibly prevent residential placement.

Adult Subcommittee

Co-chairs, Kathy Sanders and Christine Hubbard updated the commission members on the work of the adult subcommittee:

1. Families of 20 to 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.

*Update: This work is on-going. DDS and DMH conducted a pilot program from January 2019-June 2019, 8 individuals (5 males and 3 females) with ASD who were self-isolating at home, each individual received up to 10 hours a week of services, meetings were held every 2 weeks with providers and in consultation with DMH. Seven (7) individuals consistently engaged throughout this pilot program. One provider had 117 hours of direct service for 4 individuals which included the two hours of service for one individual who did not participate after the initial meeting, meaning 115 hours of direct service. Provider B had 501.75 hours of direct service. There were a total number of 324 in-person meetings with individuals and coaches spanning six months between January and June 2019. Thirty-three .six % (33.6%) of the meetings included a family member in the meeting with the individual. Typical meetings lasted 2 -3 hours. The individuals made both small and larger gains dues to the impact of the pre- coaching service many of which are not easily quantified but clearly qualitatively real. These include:*

* *Acquisition of coping skills for anxiety*
* *Increased interest in social activities and positive community interactions*
* *Self-advocacy*
* *Applying for job including resume writing*
* *Increase awareness of public safety*
* *Increase in appropriate social skills including appropriate greetings and engagement in small talk*
* *Barrier was usually anxiety or an untreated or poorly treated condition*
* *Very individualized and very intensive*

1. The Adult Subcommittee will work with the Executive Office of Elder Affairs (EOEA) to

Examine information available regarding that agency’s involvement with aging individuals presenting with ASD, their aging caregivers, and collaborate with EOEA to examine opportunities for local collaboration, including trainings on ASD by the Autism support centers for councils on aging in different regions.

*Update: This work is on-going. A member of the EOEA agency participates on the Adult subcommittee and has provided a presentation on various services provided through EOEA to educate the subcommittee on the types of resources that may be available through EOEA to older individuals with ASD. The Adult subcommittee continues to explore opportunities for collaboration with DDS and other state agencies with EOEA and to establish effective connections for older individuals with ASD and their aging caregivers.*

*Discussion*

* EOEA is now represented on this subcommittee
* Elder Affairs is learning more about ASD and their caregivers
* Ongoing work and thinking about more concrete recommendations

 3. 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 severe challenging behaviors, forensic issues (court involved) 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.

*Update: This work is on-going. The Adult subcommittee is continuing to examine the services currently available to service this population and current unmet needs. Several adult service providers have presented to this subcommittee and DDS has been asked to present on services available through its state programs.* *In the coming weeks, the subcommittee will focus on the potential for increased case management services*

*Discussion*

* Case Management is being discussed at the subcommittee meetings and AANE will present their case management program
* Thinking about ways to help shape services to better fit the population
* DMH had recently put out an RFI looking at the needs for this population – currently looking at the data from the responses and will take the information to the subcommittee and will work with Ms. Kain on this issue.

Housing Subcommittee

Co-chairs, Dan Burke and Bronia Clifton updated the commission members on the Housing subcommittee recommendations:

1. The Housing Subcommittee of the Autism Commission will develop design guidelines that will meet the needs of individuals with autism spectrum disorder (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.

*Update: On-going. The Housing subcommittee reviewed with the DHCD representative on the subcommittee the design specifications on two projects underway on Cape Cod and discussed potential design additions to meet the needs of individuals with autism spectrum disorder.*

*Discussion*

* Looking at residential school settings (discussions with May Center on what works and what needs improvement)
* Adapting DDS group home guidelines for this population

 2. 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. These efforts will include;

* + Explore with the Department of Mental Health (DMH) the possibility of its PATH program case workers being trained on how to recognize the signs of ASD in adults, and during their scheduled visits to shelters collect data on the location and number of adults with ASD that are currently in the Commonwealth’s shelter system.
  + Contact Healthcare for the Homeless to request their assistance in identifying the number of adults with ASD living on the streets, and amending the HUD questionnaire to include questions about disability and ASD diagnosis.
  + Engage with the Inter-Agency Council on Homelessness to provide training on ASD and the states services that adults with ASD may be eligible to receive.
  + Contact the Independent Living Centers to assess the number of adults with ASD utilizing this resource and their housing status.
  + Conduct outreach to the Commonwealth’s Continuum of Care (COC) Programs to collect data on the number of homeless adults with ASD

*Update: On-going. The Subcommittee continues to explore the issues of individuals with autism spectrum disorder who are homeless and are accessing the shelter system on living on the streets. It was not possible for the PATH program through DMH to expand its scope for this issue so that aspect of the recommendation will be removed. The Executive Director of the Autism Commission and the Manager of Program development worked with the Pine Street in to provide training on autism for its outreach workers who may encounter individuals with ASD. Bridge over Trouble Waters has also been contacted about training for its workers interacting with homeless youth who may have ASD.*

*Discussion*

* *We don’t know the numbers or size of the issue yet – we have met with the shelter system and did a presentation*
* *Ms. Kain spoke with someone from the City of Boston regarding their census and identifying what questions to ask on the census – also looking at training the outreach workers*
* *A group from the Housing Subcommittee provided training for property managers at a conference on Cape Cod*
* *Looking at families who have children in homeless shelters*

3. The Department of Developmental Services (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; and 3) length of stay. DDS will report this data quarterly to the Housing Subcommittee of the Autism Commission.

*Update:*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| *Quarter* | *From* | *Discharge* | *To* | *Length of Stay* | *Other* |
| *1/1/18-3/30/18* | 1. *Family home* | *No* |  |  |  |
| *4/1/18-6/30/18* | *1 Residential School*  *------------------------------*  *1 Group Home* | *No*  *Yes* | *New Group Home* | *4 months* |  |
| *7/1/18-9/30/18* | *1 Group Home*  *1 Family Home* | *No*  *Yes* | *Group Home* | *7 months* |  |
| *10/1/18-12/30/18* | *1 Residential School*  *1 Group Home* | *No*  *Yes* | *Returned Same Home* | *9 months* |  |
| *1/1/19/3/30/19* | *1 Group Home* | *No* |  |  |  |
| *4/1/19-630/19* | *1 from Hospital*  *2 Group Homes* | *\**  *No* |  | *1 month* | *Deceased* |
| *7/1/19-9/9/19* | *2 Group Homes* | *No* |  |  |  |
|  |  |  |  |  |  |

*Summary: 13 admitted, 3 discharged, 1 passed away*

*Discussion*

* Hogan has 21 beds – individuals stay for a period of time and then transition back to their home or group residents
* This is a statewide resource located in Danvers – it is a stabilization unit that handle individuals in crisis

Healthcare Subcommittee

Co-chairs, Laura Conrad and Amy Weinstock updated the commission members on the recommendations of the Healthcare Subcommittee:

1. Extend Mass Health 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.

* *Update – This remains a priority recommendation of the Subcommittee. Several pieces of legislation have been filed relating to coverage.*

2.   Expand training on autism spectrum disorders (ASD) and appropriate strategies for assisting individuals with ASD for health care providers focusing on considerations of culture, race, linguistics, gender identity and socio-economic status, including hospital emergency room personnel and residents.

* *Update – This remains a priority recommendation of the Subcommittee. A few hospitals have developed training programs and personnel that are promising models.*

3.   Expand Mental Health emergency and treatment services focusing on considerations of culture, race, linguistics, gender identity and socio-economic status to specifically address the needs of children and adults on the spectrum.

* *Update – This remains a priority recommendation of the Subcommittee. The Children’s Mental Health Campaign has been working on a project to identify a model or models of urgent behavioral health care for the entire population to address this need. The Subcommittee has worked with the Campaign both collectively and as individual members, to incorporate the specific needs of people with ASD and their families into this model.*

*Discussion*

* MassHealth is looking at behavior health and thinking about how to address ASD. They are hosting listening sessions across the state.
* Commissioner Canada thanked Ms. Weinstock for spending time with the DCF area office on training/resources for insurance benefits for families. Ms. Weinstock said the calls coming into the Insurance Resource Center, from DCF, have increased since the training took place.

Laura Conrad is moving off the Autism Commission and she will be replaced by Ipek Demisroy, Chief Accountable Care, Analytics and Systems Office from MassHealth. Members of Autism Commission thanked Ms. Conrad for her work on the commission.

**Subcommittee Co-chairs**

Ms. Kain discussed the role of the Autism Commission subcommittee chairs and asked if any of the new commission members would be interested in co-chairing a subcommittee, as some of the current co-chairs have expressed the desire to step down. The Workforce Development subcommittee is also in need of co-chairs and 14-22/employment subcommittee is also looking for a co-chair. Each subcommittee is chaired by an appointed Autism Commission member and a member from a state agency. She asked members to contact her directly if they are interested in volunteering for this role. Mr. Burke asked if all subcommittees could support the need of the workforce and if they could address this in their work on the subcommittee moving forward.

With no further business to discuss the meeting was adjourned at 3:45 p.m.