Autism Commission

Employment and 14-22 year old Sub-Committee Meeting

October 25, 2017, 11:00a.m. –1:00p.m.

500 Harrison Avenue

Present: Carolyn Kain, Dianne Lescinskas, Dian Bohannon, Lea Hill, Michael Plansky, Julia Landau, Judith Ursitti, Ilyse Levine, Marisa McCarthy, Gregory Rosen, Michael Stephansky, Jennifer Stewart, Maura Sullivan and Madeline Wenzel

Remote access: Elana Aubrey, Susan Banks, Melissa Guyer, Roberta Lewonis, Ann Guay, Amanda Green, Amy Weinstock and Michelle Brait

Carolyn Kain stated that the meeting was subject to the Open Meeting Law and that the Sub-Committee members present would need to vote to approve the remote participation of some members because of their geographic location, whenever any members were utilizing video and/or tele-conferencing. Remote access was approved unanimously by the members present.

The minutes from the 14-22/Employment and 22+ Employment meeting on July 18th were reviewed and approved unanimously. Ms. Sullivan noticed information in the minutes regarding hospital training and asked to update this sub-committee on additional hospital training and a hearing on this topic. Carolyn said she would leave time during the meeting for Ms. Sullivan to discuss this hearing.

Ms. Kain introduced Greg Rosen; he is a new member of this sub-committee and a self-advocate. Mr. Rosen gave a brief overview of himself and his interest in the work being done by this sub-committee.

**Review and Discussion of Federal Report on Transition Age Youth with ASD**

Ms. Ursitti sent the document to Ms. Kain and asked that this sub-committee review and discuss the findings. The report reflects many of the discussions that have been going on at the sub-committee meetings for transitioned aged youth.

* The report highlights the importance of cross agency work and that is also the Autism Commissions role.
* Health care is discussed in this report
* Ms. Kain referred to page 32 of the report where it discusses a state wide registry – she said that this is not accurately described in the report and it is overstated. She met with folks from UMass about this registry and will reach out again
* Ms. Weinstock was involved with a project to study how data should be collected but it may not happen due to privacy concerns
* Page 78 ©under Supports and Services was reviewed and it looked at other states that also discuss the need for trained service coordinators with specific ASD training as vital. Ms. Ursitti felt that although AANE has done some trainings for MRC vendors it may not address the individuals with more challenging behaviors
* Ms. Kain updated this sub-committee on her ongoing conversations with the Federation for Children with Special Needs and they have agreed to create specific trainings on ASD. This will be funded through a federal grant
* Ms. Ursitti discussed work being done by Autism Speaks in the New York area and their focus on transition to employment and ASD training. There could be an opportunity to do something in Massachusetts
* DDS has heard from providers that they still need the Autism 101 training that had been offered in the past. There is also training from Pennsylvania that was sent to staff. DDS uses different trainers to address different needs.
* Ms. Sullivan discussed the ARC’s Family Conference on Transition and 500+ people are signed up to attend. Three years ago over 50% of the participants enrolled had a family member or was an individual with ASD and this year 90% of those enrolled are either an individual with ASD or is a parent/caregiver of someone with ASD – there will be trainers at the conference and we can ask what types of trainings are needed
* Mr. Plansky asked what questions or concerns do providers have and Ms. Hill responded that most are behavior questions and what to do in the moment. It was discussed that more availability of ABA services after 21 could be helpful – providers are seeing more intense behaviors
* Mr. Rosen commented that the interview process for employment can be overwhelming – ice breakers are helpful
* Ms. Landau asked if moving forward we should develop short/medium/ long term goals for developing training of providers – Ms. Kain responded that first we need to gather information on what currently exist
* One challenge is that so many lose their ABA services at 22 years old – this is part of a federal mandate with MassHealth – could a new waiver work for coverage after 22?
* Ms. Kain would like to take a more basic approach knowing that most do not have a full understanding of ABA – it is about recognizing when to intervene and having a better understanding of ASD – it’s a behavior approach. She agrees that coverage should not be arbitral cut off at age 22 – it makes no sense
* **Two Issues were discussed:**
1. Continue MassHealth after the age of 22
2. Looking at what training is provided for adults and transition aged youth with ASD and what needs to be provided – talk to providers that already work with ASD individuals
* **What are we looking for in a training**:
1. ABA approach
2. Specific trainings to address the spectrum (multiple types of training)
3. Behavior based approach
* Mr. Rosen discussed Life Map Coaching from AANE – could they put together some trainings
* It was asked if there are any ASD specific training requirements across the state – it was said that it is not a requirement on the ASD endorsement for teachers and that there are not any specific trainings that the state is aware of
* Ms. Ursitti commented that through her own personal experience it is up to families to connect with MRC at the high school. It was said that it is a scaling up issue
* Ms. Landau asked if this sub-committee would like to focus on training and an we agree on a structure on to approach this issue
* *We would need a clear goal on the structure and focus on short/medium and long term goals.*
* *The What and Who under training (what types of training and who will be trained)*
* Transition Coordinators at the High School level need more training
* Ms. Kain said maybe it is not a legal entitlement but could be a requirement to become a qualified provider with a state agency
* Ms. Kain discussed the Autism Implementation meetings that she attends and there is a person centered approach by providers and they are creative in responding to the needs

**It was asked if there was a consensus to move forward with a focus on training and all agreed. It was asked that members of this sub-committee think about different types of training and the structure of the meetings**.

Ms. Sullivan updated the sub-committee on a hearing on ASD and hospital wide training. It was part of the Joint Commission on Public Health and they presented on Operation House Call. They are looking to expand their reach to all medical professionals but it is a funding issue. DPH would develop and oversee a hospital team that would be trained in ASD and there would be a team member available to hospital staff 24/7. This hospital team would also support families and the individual. Currently, the outcomes show a 70% reduced rate of re-admittance. This bill may not pass in one session and there is a lot of interest by medical professionals and it falls in line with the senate’s health care bill on reducing ER visits.

There is still little data on Autism Navigator program at Mass General. Ms. Kain had met with MGH regarding the hospital navigator and it is more of a hospital wide training where they are making areas within the hospital autism friendly. They did not seem interested in sharing their model. Ms. Kain discussed the interagency agreement between DDS and DMH and a new contract with BMC to develop training videos for hospital personal. They would then be shared with other hospitals

**Review of Draft Brochure for Transition Aged Youth**

* The brochure was developed in an effort to compile information for individuals and families and contains multiple state agency links
* The Road Ahead is another source that was mentioned and the Turning 18 Autism Housing pathways
* Ms. Guay asked about technical advisories from DESE and if the schools receive them and use them. Ms. Green responded that they do not keep data on that and they have been working with the Federation on family friendly brochures on transition
* Mr. Plansky commented that the brochure is helpful and he likes a format of a simple “to do” list for families so parents, can minimally, get to resources
* Ms. Ursitti asked if we could develop a check list at some point
* Ms. Weinstock discussed the wealth of information that is under transition and the need to do separate checklists at each age
* Ms. Landau asked if it could be written in plain language for parents and Ms. Weinstock referred us to someone at UMass that could help with the plain language – she will send the contact
* It was asked if the document could provide guidance and give questions for families to ask at their team meetings – Ms. Kain responded that she is not comfortable giving guiding questions – some providers may not give the correct answers
* It was asked if a glossary of terms could be added to the document
* Lea Hill referred to the DDS Resource guide – it has a glossary of terms – it will be send to all sub-committee members (it is on the website)
* Mr. Plansky asked about the newly eligible and if schools were up to date on the information under the Omnibus Law – some may take a diploma at age 18 so the 688 referral should be started at age 16
* Not all will be eligible for 688 but some may
* Some members of the sub-committee discussed that there is still a lot of confusion around the 688 process and they would like more clarity
* This sub-committee was asked to further review the brochure and send their edits/comments to Ms. Lescinskas in the next 2 weeks

The next meeting of this sub-committee is scheduled for November 29th at 11:00a.m. – 1:00p.m. The focus will be on specific ASD training for providers.

With no further business to discuss the meeting was adjourned.