

Autism Commission
Sub-Committee for Three Years Old - Fourteen Years Old
Meeting Minutes –December 7, 2016
500 Harrison Avenue

Members present were Carolyn Kain, Dianne Lescinskas, Christina Fitanides and Dr. Beth Jerskey.

Members accessing meeting remotely were, Laura Conrad, Lee Robinson and Janice LeBel.

Carolyn Kain, the Chair, called the meeting to order at 11:05am and welcomed the members to the meeting of this Sub-Committee. Ms. 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. Minutes from last meeting in November were reviewed and approved unanimously.

Carolyn asked that the group look at the priorities that were provided for the meeting and review each one.

1. Mass Health and AAC devices – there is an outside amendment to the budget and she believes that there is movement and will pass. Laura was not present so we were not able to get further updating.
2. Circuit Breaker Statute – Carolyn said that since Julie is not present at the meeting we will wait to further discuss this issue.
3. Autism Endorsement for General Education Teachers – Sarah from DESE is not present to give us an update. We know they are presenting this to their board for approval but are unclear on the timing. Carolyn has some concern with the endorsement – if the teachers have training will district expectations be that teachers to do some of the provider work. Tina stated that the intention is for this to be a well-rounded educational training for the teachers giving them strategies and interventions; giving them a better understanding of who the specialists are and their roles. Carolyn said it could have a diluted effect on who is involved. There are no requirements with the endorsement. Should a recommendation be that the type of service that is needed is connected to the training. Should we look to see how other states are looking at this issue? Tina said that this is a voluntary training and most teachers do not have a full understanding of ASD. This training will give them tools on how to better align services for their students. Can there be some guidelines on who is providing the

services? Carolyn said that the lines can become blurred and we can't count on districts to implement correctly without guidance from DESE. Tina asked if a letter could go out to all superintendents clarifying the role of the endorsement – stating that it should not replace the role of a BCBA.

4. Standard of training for BCBA's – This is a big issue right now and how do we move forward with a recommendation on standards that are feasible. The board is now requiring a master's degree. The RBT training is 40 hours but even if we make that a recommendation it won't be implemented. We will speak to Zac and get his input. Dr. Jerskey talked about Endicott College – they have ABA specific courses and have autism course work. How do they divide up the ABA and basic autism course work?
5. BCBA training and Elms College – Zac from Boston Public Schools will update us regarding this issue- he did not make this meeting.
6. Standard of training for paraprofessionals – The Autism Project (Rhode Island) training is basic but a good start for paraprofessionals. Boston relies on para's to do ABA but each district is different. You cannot do a one size fits all training. Tina also said that you don't want to create a scenario with too much responsibility handed over to the paraprofessionals – it's a fine line. Carolyn has some concerns. The para's need some type of training and it should be foundational training. The type of service they are providing should be connected to the training they receive.

We moved away from the priorities and Sue McCarthy's email, from earlier in the day, was discussed. She discussed BCBA's and the new requirements that are too stringent. The BCBA Board is creating even more requirements to become a licensed BCBA – this is a Workforce Development issue. What is their authority to do this and who is setting the standards? There should be more reasonable requirements. Currently, what is the incentive for people to go into this field? The requirements are the same as becoming a registered nurse but the pay is 30k less than a nurse. This is not sustainable and people in the field are getting burnt out.

7. Discussed with priority #6
8. Insurance rejection on diagnosis using ADOS – it should be more about the providers experience and not just the licensure of the individual. At BMC the nurse practitioners work with ASD patients and have much more experience. Currently, it is taking too long to receive a diagnosis. Dr. Jerskey commented that there is no ADOS certification and diagnosing is based on observation. There is training but it is murky with who is qualified. She also commented that ADOS is considered the gold standard of testing

and they are looking to expand this test for adults. They are currently using it for early markers in the cry of an infant. The pitch and sound are helping with early diagnosis. Laura Conrad, from Mass Health had commented in prior meetings that ADOS is not the standard testing for Mass Health.

9. Families in shelters and lack of services – Carolyn said she will speak to Linn Torto on this issue. There is no one central unit dealing with shelters statewide. Tina asked, what are the issues for families – provision of services or connecting services with families? We need to find out what is available to these families and if there is a social worker helping with the direction of services.
10. Autism Support Centers – Carolyn and Dianne have visited 6 of the 7 support centers.
11. Connecting families to resources – The Autism Commission is working on their website and it will be a resource for families. The Mass. Act Early Campaign had done a PCA in multiple languages – this is something we can explore. The schools are one of the first points of entry into special education and this is where resources should be shared. Lee Robinson said it would be great if information was provided in doctors’ offices because they struggle on how to best give information to the families. There is so much information out there and they want to ensure they are directing the families to the right information. His office is open to being a test site if a resource guide was created for this purpose. He said the biggest hurdle for them is where to send the families for an evaluation. They sometimes spin their wheels because of the insurance hurdles and language barriers. After the evaluations the families are looking for support around school issues and are looking for activities like social skill groups. They know they can send them to AANE and the ASC but sometimes struggle with sending them there not knowing what kind of an experience they will have with these centers. He said they would benefit from knowing more about the ASC and what services are available to the families. Carolyn said that we would provide him with more information about the support centers. Dr. Jerskey commented that at the May Institute they give their families the Autism Speaks link to the First 100 day tool kit, Massachusetts Act Early information and the Autism Consortium link. Dr. Jerskey also said the May Institute has thought about having families of newly diagnosed come to the center for multiple visits so they can discuss the information with the families in small chunks. It was discussed that Basic Rights Workshops are important for families to attend so they are able to advocate.

12. Language barriers - Carolyn had said that we should look at the Federation to see what workshops are being offered and in what languages. Lee asked what languages are available at the ASC and Carolyn responded that it is required under their contract to make the service available in all languages and they will get interpreter services when necessary. All of the ASC are offering information in multiple languages and some have hired Spanish speaking employees.
13. Federal match on language access services and Mass Health – Laura Conrad was not in attendance and we will follow up with her regarding this issue.

Carolyn discussed the upcoming Autism Commission meeting on December 13, 2016 and she said that one of the agenda items is expectations on recommendations. The process will be discussed at the next meeting. She discussed the Commission Report that came out in October and she was not sure if she will be required to submit a report in March. Recommendations regarding funding will also be on the agenda and the sub-committees work thus far will be discussed. Tina commented if the full commission got behind the endorsement for General Education teachers it would hold a lot of weight. Carolyn said that to date the full commission meetings has been focused on presentations but this meeting will be more discussion.

Carolyn discussed the departure of Marcia Mittnacht from DESE. Carolyn commented that she was invited to meet with Russel Johnson to get his feedback on these issues and keep some of these issues on his radar.

The training of medical professionals around ASD was discussed and the need to have all providers trained. A list of trained professionals would be helpful for the Autism Support Centers. Currently, there are only 37 clinicians listed but the majority does not take Mass Health. This is an issue for the Workforce Development subcommittee.

Carolyn will send an email proposing dates for the next meeting in January.

Meeting was adjourned.