

Autism Commission Meeting Minutes  
September 12, 2017  
2:00 p.m. –4:00 p.m.  
1 Ashburton Place, Boston, MA

Present: Secretary Marylou Sudders, Carolyn Kain, Rep. Christine Barber, Daniel Burke, Rep. Kimberly Ferguson, Linda Spears, Todd Garvin, Janet George, Ayana Gonzalez, Paola Ferrer, Christine Hubbard, Dania Jekel, Patricia Gentile, Jessica Katon, Julia Landau, Carolyn Langer, Susan Loring, Kathy Sanders, Russell Johnston, Vinnie Strully, Patricia Marshall, Jane Ryder, Chris Supple, Judith Ursitti, Amy Weinstock, Cathy Boyle, Rocio Calvo, Joan Rafferty, Ann Neumeier, and Teresa Touhey Schirmer.

**Meeting Minutes Approval**

Secretary Sudders called the meeting to order at 2:05 p.m. and welcomed the Commission members. Secretary Sudders asked if there was a motion to approve the minutes from the meeting on May 31<sup>st</sup>, 2017. Pat Gentile made a motion to approve the minutes, the motion was seconded by Vinnie Strully and passed unanimously with three members, Chris Hubbard, Dan Burke and Cathy Boyle, abstaining from the vote because they did not attend the May 31<sup>st</sup> meeting.

Secretary Sudders thanked the Commission members for their work to date. She then asked Ms. Kain to present the next item on the agenda.

**Center Based ABA Programs**

Ms. Kain presented a summary of ABA center-based programs. She reported that it is a newer program model that has been emerging and expanding. These programs are providing ABA therapy and BCBA supervision at their facilities and they may or may not also be providing OT, Speech and social skills. The issue for discussion by the Commission involves the oversight of these programs. Center Based Programs are not currently regulated by the Department of Public Health (DPH) or Early Education and Care (EEC). Ms. Kain stated that parents are choosing these sites due to the potential benefits of longer hours, increased socialization, and opportunities for generalization. The hours of services varies depending on the number of hours authorized by the individual's private or public insurer. Some children may receive 4 hours a week, and other may receive up to 40 hours per week with older children accessing services after-school and on the weekends.

Ms. Kain and Ms. Weinstock met with DPH, the Division of Insurance, EEC, and Mass Health to discuss the issue of oversight and safety of these centers. MassHealth has a policy that limits the use of center-based programs. While insurers are authorizing the hours of service they are not overseeing the facilities themselves for health and safety issues. Unlike home services where parents are present, at center-based programs parents are dropping off their children for services and not remaining on-site.

**Open discussion on Center Based Programs (CBP):**

- Cathy Boyle stated that there may be some overlap with CBP and school particularly for after-school hours, where older children are accessing these services during after-school hours

- Russell Johnston said that some school districts may be using CBPs to provide compensatory hours beyond the school day
- Some members said they believe that the majority of the CBP providers also provide home services. Carolyn Kain said they don't have a list of all the current center-based ABA programs and some of them also provide home services because they are large organizations that have been doing ABA services for years.
- Judith Ursitti said providers should be at the table for these discussions.
- Judith Ursitti commented that some people may have out of state insurance that they are using to pay for services.
- Vinnie Strully said there is a market for these programs and they will continue to grow but that health and safety needed to be addressed.
- Most people are in favor of having the service being offered to families to accommodate their many needs and fill voids of services needed, so while the model may be helpful the issue of oversight is a concern.
- Vinnie Strully said that we should get ahead of this before something happens that will then force the state to regulate the centers.
- Summer programs are also emerging in these CBPs and they are also functioning as afterschool programs
- The CBPs are not licensed by EEC but some are attached to afterschool programs that may be licensed by EEC for that purpose.
- Most states do have CBP – we should look at quality providers in other states, Judith Ursitti said that she does not believe there is regulation for this service in other states but Massachusetts could be a leader on this
- Joan Rafferty said that these centers are providing segregated services which goes against the work being done by early intervention to provide services in integrated settings with peer models
- Carolyn Kain commented that the quality of services is a concern (staff training) – we don't know what they are telling families in terms of staff credentials and training. There is no standard for direct ABA providers like there is for BCBA's and some direct ABA providers have a bachelor's degree while other may have no college degree.
- Vinnie Strully said there are many safety concerns and big issues to consider i.e. how do they handle restraints, basic building codes, Cori/Sori of employees, operational skills, ratio of staff to children. He said that programs that are regulated like approved special education schools and EI providers are being held to standards that don't exist for these CBPs.
- Clear guidelines should be put in place – too many CBPs are growing too quickly
- Most of the individuals working in these centers are credentialed but the program itself is not licensed.
- Families need more – children have a 6 hour school day or 24/7 residential care but nothing in between – this fits what some families are seeking for additional hours of treatment beyond the school day

- With ARICA and the Omnibus Law coverage for ABA services, some schools are no longer providing ABA services after-school or on the weekends as they did in the past, schools are directing parents to their insurers for these services.

### Questions

1. What are we trying to regulate
2. We need a better understanding of who we are talking about and to the extent that these centers exist
3. Pursue which areas of CBP that need to be regulated
4. Look at existing laws and regulations and where this could fit in – dive deeper
5. Get the providers involved
6. Is it the responsibility of the payer to look at the quality of services
7. Do we look to only regulate the safety of the sites
8. Look at other models in other states

Secretary Sudders asked for several commission members to work with Ms. Kain and Ms. Weinstock on this issue. Ms. Kain will follow up with the members and form a working group to address Center Based ABA Programs. She also asked that if members have any information on CBPs that they contact Ms. Kain. She said there are 2 areas of focus; 1) What aspect of regulation is needed for these types of businesses and; 2) Should the focus be limited to the health and safety issues rather than the quality of ABA services of these programs. Secretary Sudders said that she meets with major insurance companies in Massachusetts and will raise this issue and get their feedback.

Ms. Ursitti stated that it could be difficult for some of these programs to operate with regulations but Massachusetts could take lead on his issue. Secretary Sudders asked if Ms. Ursitti could put together a map that indicates which states have insurance laws that cover ABA, and which ones have Medicaid coverage for ABA services and where things are starting to change. Ms. Ursitti responded that she would put together the map.

### **Housing Sub-Committee Survey**

Ms. Kain gave an overview of the survey that was prepared for by Technical Assistance Collaborative (TAC). The “Autism Omnibus Law” requires the Massachusetts Autism Commission to “conduct a statewide housing survey to determine the current status of affordable supportive housing stock for adults with autism spectrum disorder and make recommendations in regard thereto”. The survey included telephone interviews with providers, an electronic survey of the Autism Service Coordinators, and 4 focus groups with self-advocates and family members.

Dan Burke, the chair of the Housing Sub-Committee, shared that the goal of this report is to determine the current status of the affordable supporting housing stock and as we move forward with this work, the housing subcommittee will use the survey to develop recommendations and a plan of action to address the affordable supportive housing needs of individuals with ASD who will become adults in the coming decades. The sub-committee will also look at additional information including the Think Tank

recommendations that were prepared by Cathy Boyle. Mr. Burke reviewed the survey and the scope of the work that was done by TAC. He acknowledged that the report uses the term “supportive housing” because there needs to be support services put in place for many of the individuals that will access affordable housing. There are all different levels of support discussed in the report. Mr. Burke also acknowledged that without the data (number of people with ASD) it is difficult to come up with accurate numbers given that in the past this was not captured in data collection, but TAC did estimate in their report that at a minimum there are 15,200 people with ASD that may need supportive housing of some type. Mr. Burke said that it was discussed and that there was concern if the number was too high numbers that may impact progress on the issue as some people may be scared away. Data is still a point of discussion. Ms. Kain said the Housing Committee’s charged with conducting the survey to determine what is currently available for affordable and supportive housing and the report reflects a culmination of fact gathering by TAC. The report will also assist families in learning what is currently out there and educate them on their options.

#### Discussion and Questions on the TAC Report

- Mr. Supple said that you need to count people first to come up with the housing need and said that we do not want to be lured down a path of a minimum number of 15,200 and asked that we go further to estimate the upper limit and then we would know that the number is somewhere in between the 2 numbers. 15,200 is a good start but it is not getting us where we need to go.
- Ms. Ursitti agreed with Mr. Supple and said that we should have a range.
- Ms. Boyle said that her math tells her the upper number is around 50,000
- Ms. Gonzalez said that while it is important to understand the size of the issue that doesn’t explain what’s needed given that Section 8 already provides has 80,000 units in total. She said that we can begin to work on the issue now based on the current housing options and TAC’s report.
- Mr. Supple commented that Massachusetts does have a lot of affordable housing but almost none are designed for individuals with ASD – at least to his knowledge. Ms. Gonzalez said that actually there are many more units being designed for individuals with ASD than in the past.
- Mr. Supple discussed his work at the BRA and that there were no set asides for disabilities or ASD and the reason for subsidized housing is because people cannot afford housing due to their disability. If we look at the numbers of individuals with ASD in schools currently that will soon be adults the number is high and we will fall short. Ms. Gonzalez said that there are set-asides for DMH and DDS under the FCF program, and the utilization of those units was one of the issues the housing subcommittee can discuss.
- Mr. Garvin asked about what is meant “unmet needs” and if there was any investigation as to why there are unmet needs.
- Ms. Kain addressed the questions of this sub-committee and said that there is no one source of housing that will meet the needs of all individuals with ASD, so we need to figure out a range of options, especially since we have individuals that require a very high level of support and some that require a much lower level of support services, and many requiring moderate levels of

support. Ms. Kain stated that TAC suggested for the housing committee to use this information and brainstorm as a subcommittee on what options are needed, which ones are working for individuals with ASD, and what options should be expanded. Ms. Kain said there is also a need to educate individuals with ASD and families on what currently exists and how they can access it. She said that data is now being collected from DDS (on with the newly eligible with ASD and without ID), and in the future DESE will be able to capture data more specific data with its new IEP system. This will help to inform us as we move forward.

- Ms. Landau asked if this is the final report and Mr. Burke responded that it is the final report for the survey. Ms. Landau also said that looking at the law; the legislation requires us to look at the numbers over the next 30 years. Secretary Sudders responded she considers the statute as a framework for the Commission to do its work, and that the survey provides a baseline of information about affordable supportive housing options.
- Mr. Supple asked if there could be a presentation from DHCD on set asides - Ms. Gonzalez said that she had done a presentation months ago about the housing programs, but that she would be happy to do another presentation. She said that the capital funds used by DMH are used for integrated housing and DDS is doing congregated housing, but it could be used both ways and part of this is matching housing to individuals and making our system work for folks.
- It was mentioned that we should look to other states and models that are being built.
- Ms. Landau asked about the focus groups (survey) and the low numbers that were reflected in some of the groups, as well as, some of the providers who responded to the survey. Mr. Burke responded that this was a survey only and that we already knew some of the information from DDS providers. Ms. Landau asked about how the Commission was focusing on the issue of linguistically diverse communities. The Secretary responded that each subcommittee should be looking at that issue in the course of its work and that each member needed to recognize this was an issue to keep it on their respective meeting agendas.
- Ms. Gonzalez discussed the revamping of the Olmstead Plan and the importance of having autism mentioned by name within the report – and that will help us move this work forward. Ms. Kain is a member of the Olmstead Planning committee
- Ms. Jekel discussed that she sees a lot of people with ASD who are aging and their changing needs as they age – and that those issues needed to be considered in the plan
- Secretary Sudders talked about the Executive Order that was signed by Governor Baker in regards to optimal aging in the Commonwealth. The listening sessions were well attended and in Western, MA in particular there was discussion around family members with ASD and aging. They heard a lot about supports that are needed. Secretary Sudders said she will have the chairs of that committee share their recommendations with the housing sub-committee.

Secretary Sudders thanked the Housing Sub-Committee for their work and said that this is the baseline for our conversation on housing. Mr. Burke informed the commission that the next Housing Sub-Committee meeting will be held on October 11<sup>th</sup>. Mr. Burke also said that the housing sub-committee will draft recommendations for consideration by the Autism Commission.

## **Reconfiguration of Sub-Committees**

Secretary Sudders asked Ms. Kain to present an updated on the configuration of the subcommittees. Ms. Kain stated that in response to feedback from Commission members she met with all of the Chairs of the subcommittees and they all agreed that the Commission should focus on a few priorities. Those priorities will be housing, employment, and adult services.

Ms. Kain said that the Birth-three subcommittee will move to meet quarterly, and that she would update them on the work regarding center-based ABA programs. Ms. Kain also said that Mass Act early is working on a series of videos to educate parents on the early signs of autism and that the videos are culturally and linguistically diverse. Ms. Calvo asked how the videos would address cultural barriers that may prevent some parents from seeking diagnosis and treatment. Joan Rafferty explained the diverse group working on these videos to address those issues, and Ms. Kain offered to reconnect Ms. Calvo with Ms. Rafferty and Ms. Gabovitch about the information being shared in these videos, especially the Spanish speaking population regarding the barriers mentioned by Ms. Calvo.

Ms. Kain said that the 3-14 years of age subcommittee would move from monthly to bi-monthly meetings, that this subcommittee had already reviewed with DESE its Coordinated Review process and its Problem Resolution system and that they would continue to collaborate with DESE as it moves forward with a new IEP system to ensure that certain issues are addressed within that document including better data collection on individuals with ASD.

Ms. Kain reported that the 14-22 years of age/employment would continue to meet monthly but that the number of participants would be reduced to streamline the work of the group, to address on-going absences and to limit the number of participants from state agencies, and that would also occur for other subcommittees as appropriate. Ms. Kain also said that this subcommittee would be re-combined with the 22+ subcommittee.

Ms. Kain reported that the Adult subcommittee would be reconfigured by Janet George and Kathy Sanders to ensure that the necessary clinical expertise was represented to discuss the issues identified by the subcommittee during its work. Ms. Kain said this subcommittee would move from monthly to bi-monthly meetings.

Ms. Kain said that the Commission had just received an update on the work of the housing subcommittee, and they would continue to meet bi-monthly and use the information provided in the TAC survey and other resources including the Housing Think Tank.

Ms. Kain said that she met with the Chairs of the workforce development subcommittee, Pat Gentile and Pat Marshall and they all agreed that the meetings of this subcommittee would be placed on hiatus to enable them to meet with the Executive Office of Labor and Workforce Development on the issues identified by this subcommittee over the last year.

Ms. Hubbard asked about the data subcommittee. Ms. Kain responded that the data subcommittee would be available to assist the housing, employment and adult subcommittees with their respective work, when requested.

Ms. Kain also said that the subcommittees would need to provide any information that they want included in the annual report by the end of October since a draft of that annual report would be provided to the Commission before its next meeting in December.

The next Autism Commission meeting will be held on December 4<sup>th</sup> and a draft report will be ready for review and discussion at that meeting. Ms. Kain said that the Commission meetings for 2018 would be on February 8<sup>th</sup>, May 10<sup>th</sup>, September 12<sup>th</sup> and December 13<sup>th</sup> all from 2:00pm-4:00pm, and she would email the members these dates.

There being no further business, the Secretary asked if there was a motion to adjourn. Ms. Hubbard made a motion to adjourn the meeting and Mr. Burke seconded the motion. The meeting adjourned at about 3:50pm.

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