

## **Autism Commission, Birth to Fourteen Years Old Subcommittee Meeting**

John W. McCormack State Office Building  
One Ashburton Place  
Boston, MA 02108

Thursday, May 10, 2018, 12:00 p.m. to 1:45 p.m.

Members present: Russell Johnston, Michele Brait, Carolyn Kain, Dianne Lescinskas, Vinny Strully, Joan Rafferty, Shari King, and Alexis Glikman

Members participating via telephone: Ann Neumeyer, Alan Jacobson, Beth Jerskey, Michele Poulin, Kristy Murphy, Sarah Richman, Rob Polsinelli, and Sue McCarthy

Kristin Castner attended in person as a guest of subcommittee co-chair Russell Johnston.

Russell Johnston called the meeting to order and welcomed all members of the newly formed Birth to Fourteen Years Old Subcommittee. This subcommittee is a new group made up of members of the former Birth to Age Three Subcommittee and of the former Age Three to Fourteen Subcommittee. Dr. Johnston noted that this meeting, like all Autism Commission subcommittee meetings, would be subject to Massachusetts' Open Meeting Law, and, as such, the present members of the new subcommittee would need to vote to allow non-present members to participate via telephone. Subcommittee members physically present at the meeting voted unanimously to allow such remote participation.

The meeting minutes from the March 27, 2018 meeting were duly reviewed by all meeting participants and approved.

Dr. Johnston then reviewed the meeting norms sent to all members of the subcommittee as part of the meeting agenda. He noted that these norms will be in place for this and all future meetings of the group.

### Reviewing Past Accomplishments

Dr. Johnston reviewed and distributed printed copies of the *Resource Guide for Individuals and Families of Individuals with Autism Spectrum Disorder (ASD) - 3-14 Years of Age*, a publication produced by the Autism Commission's Age Three to Fourteen Subcommittee last year. Ms. Lescinskas commented that this publication was similar in format to the *Turning Three* brochure and the *Resource Guide for Transition Aged Youth*. Ms. Kain indicated the plan was for this new brochure to be posted on the Autism Commission website, translated into five languages, and distributed to school districts.

Ms. King suggested that contact information for MassPAC be added as a resource in the new brochure. Ms. Lescinskas stated it may be possible to also add instructions for parents to check with school systems for information on Special Education Parent Advisory Councils (SEPACs) in their districts, and that the Federation for Children with Special Needs has a helpful hyperlink to this kind of information on their website. Ms. Poulin suggested there be a hyperlink added on the website posting of the Birth to Age Three brochure so that parents and administrators could also easily access the Age 14-22 brochure, and Ms. Lescinskas advised language could be added to the website in that regard.

Ms. Kain mentioned this new *Resource Guide for Individuals and Families of Individuals with Autism Spectrum Disorder (ASD)* had been previously reviewed and discussed by the members of the former Age Three to Fourteen Subcommittee, but not

by other subcommittee members present, and suggested there be an opportunity for all meeting participants to offer additional feedback. No additional feedback was offered, and the full Birth to Fourteen Subcommittee voted to approve the brochure. Ms. Kain added that a limited number of brochures would be printed to send to Autism Support Centers across the state.

#### Review of Recommendations for the Subcommittee

Dr. Johnston and the subcommittee members reviewed a list of suggested possible priorities for Autism Commission subcommittees submitted by Autism Commission Member Julia Landau in a document dated December 17, 2017. The subcommittee then compared the suggestions on this list with those on a numbered list of possible priorities submitted by Age Three to Fourteen Subcommittee members following the last subcommittee meeting. Both documents had been distributed electronically as review documents to the subcommittee group in preparation for the current meeting.

Items on the two lists were then reviewed item by item for relevance and to eliminate duplications. Going through Ms. Landau's recommendations, it was determined that the first point she raised was more of a clarification issue, and was accepted as such, but not deemed a priority option for this subcommittee. The second point, it was determined, could be identified as being included under item 6 in the Priorities for Voting options list. Ms. Richman and Mr. Polsinelli added that, within the Autism Waiver Program, their experience is that there is access to translators where needed and finding such translators had not been an issue. Ms. King added that, however, finding therapists for non-English speaking families is a challenge, and there is a need for bilingual providers, with families having to wait sometimes 6 months to a year for services due to lack of therapists that speak a specific language.

Points 3, 4, and 5 addressed by Ms. Landau, were determined to be already incorporated into the Priorities for Voting options list, under items 4, 4, and 17 respectively. Regarding point 6 from Ms. Landau, Ms. Kain added that the Coordinated Program Review (CPR) process was addressed at length at a previous Age Three to Fourteen Subcommittee meeting. Dr. Johnston added that option 10 on the list did address some of this concern. It was suggested that point 7 from Ms. Landau should be referred to the Age 14-22 Subcommittee for discussion. Regarding point 8 from Ms. Landau, Dr. Johnston indicated that such information is not reported quarterly by districts. While retrospective data could be provided at years end, the suggestion itself was determined not to be a priority. Point 9 from Ms. Landau was addressed in the Priorities for Voting option list under item number 1.

Ms. Kain noted that there were not any Birth to Age 3-related recommendations outlined in these documents and wondered if anyone wanted to add one. Ms. Rafferty mentioned that resource capacity related to identifying and diagnosing disabilities is a big issue, and that for many families, waiting for diagnosis and services is challenging. Currently, the 1-2-3-Grow program is geared toward reaching out to families of different cultures. Mr. Strully added that funding for early intensive intervention and the shortage of ABA providers in Massachusetts are concerns as well.

Based on this further discussion from this feedback, the subcommittee decided to add an additional option to the Priorities for Voting list to address the issues of decreasing wait time for evaluation and initial diagnosis, and to promote existing resources for medical professionals (option #18).

#### Impact/Effort Matrix and Voting on Priorities

Dr. Johnston explained the priority matrix grid that the subcommittee would collectively fill in before using the resulting chart and a multi-voting process to assist in whittling down the lists of priorities suggestions to three. Each of the options on the list was then

categorized by the subcommittee, according to the likely level of impact the suggested task would have (high or low) and likely level of effort it would take on the part of the subcommittee to accomplish that task (also high or low) . Each option was also discussed and judged as to whether or not it was autism-specific. Option 1 was deemed to be High impact/low effort, options 6, 7 ,8, 12, 17,and 18 were high impact/high effort, options 10 and 11 were low effort/low impact, and 2, 3, 5, 13, 14, 15, and 16 were high effort/low impact. Options 4 and 9 were not placed on the grid, as one was not autism specific, and the other was a funding issue that could not be addressed solely by the Subcommittee.

The subcommittee then began the voting process, using a free online tool, the [polleverywhere.com](http://polleverywhere.com) application. At the same time as other subcommittee members, each member reviewed the newest agreed-upon version of the options list on his or her own and ranked each option in the order of priority he or she deemed appropriate. Data from that vote reduced the number of options to the top 10 options preferred by the group, and members voted again. Combined data from that vote reduced the number of options to the top five preferred options, and members voted again. The data from that final vote determined the top three priorities for the subcommittee to address in the coming fiscal year. The options decided upon by the full subcommittee using this method of multi-voting were:

- Option 18 - to identify ways to decrease wait time for evaluation and early diagnosis and to promote existing resources for Health Care professionals,
- Option 8 - to address the shortage of ABA providers across the state, and
- Option 1 - to provide input into the development of the DESE electronic IEP to ensure inclusion of issues that relate to students with ASD.

#### Final Comments

Dr. Johnston indicated the plan for the next Birth to Age 14 Subcommittee meeting would be to dive into the three specific priorities chosen at this meeting by subcommittee members. The time and date of that meeting is to be determined via a Doodle Poll, which is to be distributed to members in coming weeks.

With no further business to discuss, the meeting was adjourned at 1:45 p.m.