Autism Committee

Data Sub-Committee Minutes

February 22, 2017 11:00am-1:00pm

500 Harrison Ave, Boston, MA

In attendance: Jane Ryder, Carolyn Kain, Julia O’Rourke, Dianne Lescinskas, Christine Hubbard, Deidre Donaldson, Ashley Montgomery, Elaine Gabovitch, and Dan Burke

Remote access: Emily Lauer and Carly Sebastian

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.

Jane Ryder, the Chair of this sub-committee, called the meeting to order and minutes from last meeting were reviewed and approved.

Carolyn started the meeting by discussing the process and timeline of making recommendations for the Autism Commission. She passed out data from DESE and Mass Health (see attached) that captures the number of individuals with Autism from the respected organizations. It is not a clean data set but it is what is available to us currently. The question was asked about the purpose of the data – to inform the needs of individuals with ASD. The number of individuals is only one piece of the puzzle, a question we should ask is how the data does inform us of the unmet needs and that would depend on the impact of ASD on the individual. Carolyn stated that data collection has been an issue with the state in general and when we are looking at these data sets it is clear that DESE has touched the individual the longest. DESE felt the data was reliable and goes back to 2003 – we should look at these numbers, especially the older individuals. She pointed out the percent increase in individuals with ASD from 2003 to 2015 – the numbers are large and show the dramatic increase. Carolyn also said that she requested data from MRC but there could be an overlap. Mass Health’s data is from 2012.

DDS had not tracked individuals until recently (2014- newly eligible) and the number is over 1000. There are also 350 individuals where no funding is available and there is an effort to reallocate funding to those individuals – currently 30-40 have received funding through reallocation.

Carolyn discussed her recent meeting with Early Intervention, DESE and Bureau of Transition. The purpose of this meeting was to discuss the SASID tracking number that DESE uses for students and if that number could begin as a tracking system starting in EI and then to adult services. Jane also responded that DDS collects a lot of data and they can go back and look at the data with a different lens.

Carolyn discussed the Master Data Management System, a data collection system that the state is going to start using. Phase 1 is finished and they are not far along in the process of getting the system up and running. This is something that we can consider to use for our data collection purpose. Carolyn has set up a meeting with Accenture, the agency that will be running the MDMS and she will discuss Phase 2 of this process. DESE has also expressed interest in being involved. It was said that Accenture has experience in this area and they had done some work in San Diego but it is a long process. Jane said it would be great if they were interested in using autism as a pilot case.

It was mentioned that we should work to shape this process with Accenture and use our current information to inform the process. Currently, the agencies work as silos with data collection. If Accenture can help the agencies work together it would be great progress. Elaine agreed and said that autism as a test case makes sense since it encompasses healthcare, early identification, mental health etc.

Emily said that the DESE data is still secondary data – the purpose of their identification is so an individual can receive services. You are talking about a diagnostic field as part of the IEP but it may not capture the actual diagnosis of autism. Carly agreed and stated that mental health always comes with multiple diagnoses – it is an important conversation and the diagnosis can change. Christine said that one way to capture more information would be in a transition worksheet with a question that could say “Do you meet criteria for AFC care”? Use it as a collection point to inform as they are exiting the education system and moving to adult services.

Julie discussed assessments that are given to students in school settings. If we could have all schools use the same assessment, like Vineland which spans from age 2-90 years old, we could collect information that could lead to more concise diagnosis. This is a common test. Elaine agreed and said that Vineland can map out function level to better understand the level of need.

Jane asked if the DESE data that was collected included the students that are educated substantially separate. Carolyn said that she is not sure but she will find out and that it could significantly change the data.

Elaine discussed a study being done at Children’s Hospital that addresses health needs and is looking at a cluster of co-morbid disabilities – it is emerging research and they will be able to pull data from the study. She will send the link to Carolyn to share with the sub-committee.

Elaine referenced her report where access to medical care had the greatest needs. Julie responded that care coordination is an important issue for families. They need better services but also the right kind of services. Maybe we can think of suggesting that care coordination that would be covered by insurance. This would assist us in data collection as well.

Elaine said the report echoed that comment, care coordination is growing but it is not reimbursed with insurance and is usually funded by a grant. Care Coordination helps families tremendously and it is a lifeline for them. It would also be helpful for the specialists that are serving this population. Also, taking care of a loved one with ASD is a burden on the family – this is another data point that should be considered. As we go through these data points, we need to prioritize by short, medium and long term. Care Coordination is vital.

Carolyn brought up All Payers Claims Data Base – she has reached out to them regarding their data but was unsuccessful. Julie responded that they have data by diagnosis and it is coded – she and Amy W. will reach out to All Payers Claims Data Base to try and get that data.

Carolyn moved the conversation forward and asked if there were any specific issues that have been discussed by this sub-committee that are ready for a recommendation.

Discussions on recommendations included:

1. Master Data Management System and piloting autism.

\*Accenture could build the infrastructure to help with agency information sharing.

1. Vineland Assessment for ages 3-22 for all school districts (use as a 3 year re-evaluation to capture level of need).
2. Insurance Reimbursement for Care Coordination (it is not data specific but needs to be addressed).

After some discussion, it was decided that the sub-committee would move forward with two recommendations for the March 6th Commission meeting. Master Data Management System to pilot autism and Vineland Assessment to become the standard test for public schools.

A doodle poll will go out to the sub-committee to set the next meeting date.

With no further business to discuss, the meeting was adjourned at 1:05pm.