Autism Committee Data Sub-Committee Minutes

September 27, 2016, 9:30-11:30

500 Harrison Ave, Boston, MA

In attendance: Jane Ryder, Janet George, Carolyn Kain, Amy Weinstock, Deidre, Julia O’Rourke, Emily Lauer, Dianne Lescinskas, Roccio Calvo, Christine Hubbard and Dan Burke

Remote access: Carly Sebastian, Kathy Phillips

Jane Ryder, Director of the DDS Division of Autism is the Chair of this Sub-Committee. She asked that members introduce themselves and described their work at their respective organizations. 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.

Carolyn called the meeting to order and asked for a vote for remote access to the meeting. Minutes from last meeting were reviewed and approved unanimously.

Jane asked to review the charge and goal of the group. The first meeting was a wide range of discussions. Amy Weinstock asked if the work that is being done at the meeting is tied into the Autism Commission charge. Carolyn Kain responded that it is a starting point and that the charge can evolve. People have different thoughts on data as it relates to employment, higher education, and housing. Carolyn had collected data in preparation for this meeting from DPH, Mass Health (their data was from 2012), DESE, MRC and DDS (their numbers are reflective of the newly eligible).

Amy Weinstock commented on the DESE data that was provided. If you look backwards at the numbers, starting in the 12th grade, each year the numbers jump up by almost 20% - raising questions about the data – not a lot of confidence in these numbers. Carolyn mentioned that DESE needs to clarify how they are getting this data; the increase of students with autism grade to grade is notable. Amy also asked if the bump in numbers from 11th -12th coincides with the 688 referral.

Discussion around collecting data at screening (18-24 mo.) in doctor’s office – the positive screen does not necessarily mean you have autism. The DPH data at Early Intervention is more solid. Janet George also reported they are seeing a number of children losing their ASD diagnosis. She reported about 10-15% are medically losing the diagnosis.

Rocio Calvo discussed gathering data from the clinicians at age 6 and up.

Emily Lauer talked about gathering this data from Boston Medical Center from their Clinical Data Warehouse – from the medical claims you can triangulate the medical claims and services. Going to each medical group is not the most efficient way to gather the data but paid medical claims follow the child and can be easily accessed. Rocio commented that not a single data access point is perfect – we should use multiple sources.

Emily had a discussion with folks from All Payers Claim Data Base – they offered to help with data collection. She previewed what they have found in their data collection: a clear need for transition aged students, if the parents do not speak English they are not screening their children, there are not enough providers to translate. She recommends taking a closer look at the data on the non-English speaking group. Emily also talked about a data report that she and others from UMass. Medical are working on -it will be ready to release in October – this report could be helpful to the committee.

Christine Hubbard asked if the information that is gathered from 688 referrals actually give us the needs of the individual. Janet said that DDS only tracks autism 688 referrals – not a large number to date it could be due to the fact that not a lot of them are in special education – they are passing MCAS. Amy Weinstock mentioned that if they are not going through DDS they could be going through MRC. Emily said that the Department of Transitional assistance is a paper based system so it is not a good system for collecting this data – and it would require a lot of work before they could change it.

Rocio discussed the work she is doing around cultural focus groups. 48% of African Americans are suspended in school by the age of 5 (across the U.S.)– How many of these kids are ASD? They are being viewed with behavior issues but many could have Autism. Amy Weinstock proposed looking at the suspension rate across Massachusetts for this population to see how many have been diagnosed with autism.

Deidre Donaldson said that the same issues with data collection exist at the federal level, that there is no perfect system for data collection purposes, but they made a decision to use a consistent methodology. Deidre said I think we can do better at the federal level. Emily discussed the need for ongoing surveillance and the fact that data collection cannot be a onetime effort. Deidre said that we need to also look at how we maintain the resources over time to continue the surveillance. Emily mentioned that we should consider record sampling of electronic health records and determine where is the data strong and where is it weak.

Janet George and Roccio asked what questions we are asking to determine our data collection – how do we want to go about collecting the data? How do we develop a strategy? Possibly go by age groups. Amy said that the 14-22 year old group is crucial for forecasting and projecting for budget purposes, and to put them into buckets based on prioritizations. Emily talked about having strong data for the younger population and as they age up the quality of information starts to wane.

We should look at other states and their data to see how they compare.

Carolyn asked how do school districts report on transition aged kids. In Boston, as a matter of procedure, direct services start to drop as the student enters high school. Carolyn talked about the new IEP system that will be implemented soon and the opportunity exists to include questions that will help us capture data. Carolyn also mentioned that that there is a wide spectrum of needs but the DESE data may not include the higher functioning students who are doing well academically and may not be accessing special education services. If we can address the needs at a much younger age, when it is most impactful, they may not need services for a lifetime. She also expressed the need for a stronger and meaningful program in schools, for the 18-22 year old students that pass MCAS but are not ready to graduate.

Julia recommended that we have a qualitative study – parent stories to summarize what is really going on – the numbers won’t tell the whole story. What does the impact of the disability do to the family as a whole? The data won’t capture this. Julia also talked about collecting data in a way that it did not reveal personal identifiable information.

Janet suggested that we scan the states that resemble Mass. and see where they are and how our numbers compare. Regional Centers in California (Oakland) may have comparable data. Also we should look at the registries in North Carolina and Missouri.

Deidre said that as far as identifying methodologies that prevalence data is what we currently have, we need to look at what information we don’t have and develop a strategy on how we can obtain it. We are trying to determine not just how many individuals have ASD but what are the services needs so that we can make recommendations.

Emily mentioned the citizen’s jury report that will be coming out later this fall and how that includes concerns by individuals about not wanting to be identified as having ASD especially to law enforcement personnel.

Next steps discussed were to compare NJ data to Mass DESE data to see if they have similar prevalence rates. Janet talked about regional centers in Oakland California, Missouri, and North Carolina as having robust surveillance systems. The UMass report is expected around October 12th.

Emily will share the data report prior to our next meeting and we will discuss the results when we meet. The meeting date will be set after we look at the data report. There being no further business, upon motion duly made, seconded and approved, the Chair, Ms. Ryder adjourned the meeting.