Autism Committee Data Sub-Committee Minutes

January 31, 2017 10:00am-12:00pm

500 Harrison Ave, Boston, MA

In attendance: Jane Ryder, Janet George, Carolyn Kain, Amy Weinstock, Julia O’Rourke, Emily Lauer, Dianne Lescinskas, Christine Hubbard, Deidre Donaldson, Kathy Phillips, Elaine Gabovitch and Dan Burke

Jane Ryder, Director of the DDS Division of Autism is the Chair of this Sub-Committee. She asked that members introduce themselves stated that the meeting was subject to the Open meeting Law.

Jane called the meeting to order and minutes from last meeting were reviewed and approved.

Elaine and Emily presented their report, *Massachusetts Healthy People 2020 Autism Roadmap Report: Understanding Needs and Measuring Outcomes*. This was a three year effort ($75,000 first 2 years and $51,000 for third year) of needs assessment from a grant that was issued to engage states in autism planning. This is not a state plan but provides suggestions. An Overview of the report was provided by Elaine and Emily. The report was reviewed and discussed.

* Models that exist to assist with data collection – CDC has a prevalence grant and only 14 states participate. The grant cycle is every four years – next cycle is three years from now. Massachusetts may want to consider applying in the next round.
* There are 2 National Data Surveys being brought together as one survey and will be shared. It is a blended survey and MA could look at the questions to use as a model.
* CAHPS – Information System – a home and community based method – questions exist and can be used for this purpose.
* All Payers Claim Database
* APL – Payment Data - a rich resource and there are experts in the state looking at this data
* SASID – student identification at start of public school. Not being used in EI or with other state agencies.

An MOU exists with SASID and Carolyn asked where it stood now. Carolyn discussed an upcoming meeting with DPH, DESE and BTP to gain more information on this topic. Dan asked if the number could carry through to adult services and Emily responded that there could be legal concerns and challenging. Registries and the sharing of information have been controversial and present legal challenges that would need to be addressed.

Carolyn also said that she is meeting with DPH to discuss the need for pediatricians to do early screenings for autism; she said that Mas Act Early has great information available but it is not being used by pediatricians across the state. More needs to be done in remote parts of the state.

Workforce Development was discussed and the need to enlarge and expand service providers across the state. There is also great need for training. Concerns of cultural barriers and linguistic challenges also exist with the current workforce.

Transition, from child to adult healthcare was discussed, and the importance to have trained and competent adults in the medical field working with the transition aged youth. How to motivate doctors to serve adults with autism– is there a possibility of training a family practice to have continuity into the adult years. Are there Medicare incentives?

Elaine discussed Self Advocates and the data around the need for more executive functioning training and building more independence– it is affecting employment, healthcare, and housing. The study found that the least amount of data is around transition – there was no system to measure. There is a great need to assess the youth early, at age 14 and get them in the community with employment.

The last priority that was discussed was the cultural, linguistic and racial disparities – there is a need for interpretation at meetings and everyday school interactions as well as providing material in multiple languages.

Amy said the committee will need to discuss how to best leverage this into an action plan to address the data gaps. Carolyn said that the newest information, from her perspective in this report which had not been discussed by the subcommittees, is the challenge of accessing adult health care. There is not a lot of expertise in the health care system related to ASD and this is an issue of training for primary care physicians and mental health providers. Deidre commented that there is no incentive for doctors – a lot of paperwork and the rates are the same whether or not you are seeing an adult with or without autism. It can be a much longer appointment if an individual has autism and the reimbursement does not change. The payment model should recognize the time and effort required for these appointments. Doctors should be able to bill for a longer appointment.

Elaine asked how we can approach the data and come up with short, medium and long term recommendations in a way to move forward. Carolyn said that after reading the report she had scheduled a meeting to look at using the SASID from early intervention into the adult services world.

Christine Hubbard then asked about two motions she had sent to Carolyn and said that she didn’t know if they were premature but she wanted to have a discussion about them. (See attached). Carolyn commented that she hadn’t received them until after 10:30pm on Friday evening and she wanted a chance to review them and to discuss them with Christine and the group since there was information she wanted to share on the issues raised. Motion #1 – related to a data collection system - Carolyn commented that there is a new initiative with EOHHS for a Master Data Management System and we should inquire if that initiative would also be able to meet our needs since it involves the sharing of data between state agencies. Motion #2 –to endorse a recent bill filed by Senator L’Italien– Carolyn commented under the Omnibus Law that DDS is already required to collect that data (on newly eligible), including those for whom funding is unavailable, and it is being reported to EOHHS.

Christine said she did the motions not knowing if this sub-committee would meet prior to the March 6th Commission meeting and Carolyn proposed that the group meet prior to the Commission’s March 6th. Christine asked about an RFP to take the next steps and look at the gaps like in transition services – have data collection just on this piece. Elaine said that within the report they offer resources and there may be clues on how to approach data collection. Carolyn said that the Master Data Management System (Accenture) may be able to capture this information but she didn’t know whether or not that was true but we could certainly pose specific questions to see if it could meet that need, she also said that the SASID number would be a way of tracking individuals from E.I. through school and beyond. Carolyn said that further inquiry on these issues is appropriate because we don’t want to have competing projects on the gathering and sharing of information between state agencies. Carolyn also mentioned that DESE is in the process of changing its IEP system, and we can request that specific fields be added to a new IEP system that would provide data about individuals with ASD.

Deidre asked if the next time we meet if we could find out the scope of work being done (MDMS) and the funding source – Carolyn said she would inquire about the scope of work and that she believed it was being funded by EOHHS. A comment was made around section 28 of the Omnibus Law, and data collection of adults by DDS – is required. Carolyn said that she hasn’t received the legislation that was filed from Senator L’Italien and is not prepared to comment on her legislation. It was asked if we could invite Sen. L’Italien or her aide to come to the next meeting to discuss the bill identified by Ms. Hubbard and any other legislation related to individuals with ASD. Amy asked if we were going to take a vote and Carolyn responded that she suggested that she get more information first as she had just received the two motions the previous Friday evening after 10:30 p.m.

There was discussion around an ASD registry and concerns with the adult population not wanting to be identified – the biggest concern is that law enforcement could access the registry. Amy said that New Jersey has mandatory reporting and once registered they are referred to support centers. New Jersey also collects an additional $1 for all moving violations and it goes into a fund for autism. Carolyn said that the study by Alixe at UMass highlighted that people do not want to share personally identifiable information. Julia O’Rourke discussed having a data source that is not identifiable – that the information is put into an algorithm and a unique identifier is produced to prevent anyone from knowing the individual’s personal information.

The meeting was adorned at 12:02pm and the next meeting was scheduled for February 22nd at 11:00 a.m.