Autism Commission Data Sub-Committee Meeting Minutes

June 22, 2016, 3:00pm-5:00pm

500 Harrison Ave, Boston, MA

Carolyn Kain, Executive Director of the Autism Commission called the meeting to order at 3:10pm and welcomed the members to the first meeting of this Sub-Committee. 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. There were no members participating remotely at this meeting. Jane Ryder, Director of the DDS Division of Autism is the Chair of this Sub-Committee, other members in attendance were; Dan Burke, Janet George, Roccio Calvo, Christine Hubbard, Julia O’Rourke, Deidre Donaldson, and Kathy Phillips.

The members of the Sub-committee introduced themselves and described the work their work at their respective organizations. Ms. Kain then provided some basic numbers from DPH, DESE, DDS and MRC on individuals with ASD receiving services. The group then discussed that this data would likely not capture all of the individuals with ASD in the Commonwealth and that some of it was duplicative since individuals can access services through more than one state agency. Ms. Kain also mentioned that she asked DESE to provide the information it had presented to the Commission in May 2016 for each grade level from K0-grade 12 for every year from 2003 forward since most individuals with ASD would have received services during their educational career, and this would also provide numbers for individuals who have aged out of school and may no longer be receiving any services from any state agencies.

The group discussed the issue of prevalence information provided by the CDC as a place to start to examine the potential number of individuals with ASD. Deidre Donaldson commented that Rhode Island had instituted a registry. Janet George commented that we were informed by the Secretary of EHHOS that there is no money currently available to create a registry in Massachusetts, and that we needed to look at how data is being collected, and what criteria are being used currently. Rocio Calvo mentioned that prevalence data for specific areas where we know there are high concentrations of families for whom English is a second language could show that the estimates of individuals with ASD are far below other geographic locations and that would show that we are not identifying and reaching many individuals with ASD. This information could help to identify where there are gaps in services and would also impact the future needs for services.

Julia O’Rourke and Deidre Donaldson talked about the fact that the Healthcare industry is currently tracking data but there are also privacy issues with the sharing of data.

Rocio Calvo talked about the collection of data with personally identifiable information and then creating a coding system that makes the information about each individual private. Julia talked about her expertise in working with data as part of her work at the Lurie Center and how she can input data and have it come out with an unidentifiable code so that privacy is protected.

The group then discussed the need to be creative and non-traditional in its approach to data and to keep in mind what they were trying to achieve. They discussed the fact that the medical community has state imposed requirements, including the requirement on pediatricians to screen children for ASD. The transition of individuals into adult services through the 688 process was also discussed but it was acknowledged that in the past to be eligible for DDS services a person needed to have an intellectual disability and that ASD was not tracked in the past but it will be on the go forward for all DDS clients.

The sub-committee presented the various ways that data is currently being collected by health insurers through claims submitted, at the autism clinics in hospitals, that the GIC is the largest insurer in the Commonwealth and they may have access to data on the individuals they provide coverage to including diagnosis, Social Security and MassHealth should also have data on diagnosis as part of their eligibility process. Members felt that the Division of Insurance may be able to assist the sub-committee since they could request information directly from health insurers and that medical data and billing data and the differences should be examined to look at what specific questions and/or fields the DOI should be asking of insurers. Carolyn Kain agreed to connect Julia O’Rourke and Amy Weinstock to discuss the issue of queries with the Division of Insurance. The group then looked at meeting dates, and decided that it would be more beneficial for Amy Weinstock and Julia O’Rourke to connect regarding the issue of what to ask from the Division of Insurance before the group reconvened. There being no further business, upon motion duly made, seconded and approved, the Chairs Ms. Ryder adjourned the meeting at about 4:45pm.