Autism Commission Sub-Committee for Children Birth to Three Years Old, Meeting Minutes

June 29, 2016, 3:00pm-5:00pm

500 Harrison Ave, Boston, MA

Ron Benham, the Chair called the meeting to order at 3:10pm and welcomed the members to the first meeting of this Sub-Committee. Carolyn Kain, Executive Director of the Autism Commission stated that the meeting was subject to the Open meeting Law and that the Sub-Committee members present needed to vote to approve the remote participation of some members because of their geographic location. The members present Ron Benham, Rafael Castro Ph.D., Vinnie Strully, Rob Polsinelli, Sarah Richmann Palin, and Carolyn Kain voted unanimously to allow others to participate remotely. Others participating were Dr. Ann Neumeyer and Nancy Lunden.

The meeting began with introductions. Each member of the sub-committee introduced themselves and described their work with children with ASD birth to three years old. Ron Benham stated that the Department of Public Health (DPH) has 18 provider agencies and most of the DPH dollars spent for this population was in covering services for families who have employers who do not cover the benefits because they are not subject to the ARICA law. Ron stated that has done a good job at educating its Early Education providers on the needs of children with autism and identifying the early signs of autism. While some children are referred to E.I. prior to being diagnosed with autism because of a developmental delay, E.I. staff were educated on looking for families who have a history with autism, having bi-lingual staff work with families who confront cultural and linguistic barriers and assisting families who receive a referral from their pediatricians with obtaining an actual diagnosis. Ron also said that DPH has not seen the growth they have been expecting and that raised the question about how many children are being reached.

Ms. Kain said she was concerned that the literature states that the average child is being diagnosed at 2.5 years old and that was concerning given that early intervention services end at age three. Dr. Castro stated that he did not believe that the current literature reflects what they were experiencing in specialty clinics and that in his experience children are being diagnosed earlier and that it is now unlikely to see a child over two years old who has not been diagnosed. In response to Mr. Benham’s comment about the numbers of children being diagnosed, Dr. Castro said that there is also pressure on clinicians to provide a diagnosis of ASD when the actual criteria may not be met because the diagnosis itself provided access to greater services through insurance and with public school systems because the changes in laws. Dr. Castro gave the example of Smith-Magenis syndrome and how children with that diagnosis need intensive services similar to children with ASD but that diagnosis did not provide those children with the same access to services. Ms. Kain stated that while the Omnibus Law did include the Smith-Magenis diagnosis the law did not address the types of services available for those individuals, and that was a void that this sub-committee should explore further.

Dr. Castro mentioned the difficulty in obtaining service providers, and that this is a workforce issue and a problem of industry. In addition to an overall problem with the workforce size to meet the demand, there is also an issue finding providers for non-English speaking families. Ms. Kain mentioned some of the cultural barriers that exist with the Vietnamese community, the Cape Verde community, and with some families in the Spanish community. Ron Benham mentioned that the Federation for Children with Special Needs and Mass Advocates for Children had been working to assist them with language barriers. Nancy Lunden mentioned that parent to parent connections helps. Ms. Kain mentioned at program at Boston Medical Center that connects families of different cultures with another parent of a child with autism of the same culture.

Carolyn Kain mentioned that the Autism Consortium had very helpful information on its website but she heard that they had disbanded. Dr. Neumeyer said that she had been part of the Autism Consortium but that it had lost its funding. She said there were five Boston hospitals that provided patient navigators and they were focused on improving care. She also commented that pediatricians needed to be screening children at 18 and 24 month and they were getting paid to do so under the American Academy of Pediatrics standards. She said that she was glad to hear Dr. Castro’s experience with age of diagnosis but she felt that differed from the work being done by UMass Medical Center.

Nancy Lunden said that in working for the May in their specialty services that the M-Chat screening tool was being used but that parents then required assistance for obtaining a diagnosis. The group discussed the fact that some pediatricians are willing to give an autism diagnosis while others refer their patients for further evaluation, and that this was delaying families getting services especially through their insurance.

The group then discussed the fact that since the passage of ARICA many families are accessing more services through their private insurance, and that even at age three families were continuing to access private insurance and decline services from their public school district because they were not as intensive as what they could access through their insurance. Vinny Strully commented that the insurance companies are likely to deny services once a child becomes eligible for services from their school district.

Mr. Strully commented that the greatest outcome possible was through intensive services at the earliest age possible and that they were seeing great success for these children when they received 27-28 hours of ABA services a week at NECC. He pointed out that by investing more heavily in the provision of these services the data shows that this is where the most benefit from that investment can be realized. Nancy Lunden said that they had been asking doctors not to put that high a number of hours in their reports because it was overwhelming for families. Mr. Strully said that ABA is prescription education and that families needed to know the intensity of the services needed and the possible outcome of that treatment. Dr. Castro agreed and stated that is what the research supports and there was an ethical obligation on doctor’s to include that recommendation. Ms. Lunden said that this left little time in a child’s schedule for other services at this young age when they are still napping and parents felt like they needed to trade off ABA with speech and other services. Mr. Strully said that other services can be done in a consult model, but the research and evidence support the need for more ABA as the best chance to change the child’s trajectory for life.

The sub-committee discussed the need to look at training, funding, quality control issues and workforce issues. The issue of training for DCF workers was specifically brought up by Sarah and Rob who both work with families and they have been dealing with misunderstandings by DCF on how to work with children with ASD and the misguided nature of the responses they get when they contact DCF. Carolyn said she would contact DCF and ask that they assign someone to be part of this sub-committee.

The group talked about dates for their next meeting and there was a consensus that meeting every month was too often and that every other month would be more workable for people’s schedules. Vinny Strully offered to host the group at NECC in Southborough, Dr. Castro offered to host in Newton and Dr. Neumeyer offered to host in Framingham. Mr. Benham said that he would be in touch with proposed dates for the next meeting. There being no further business, upon motion duly made, seconded and approved, the Chair Mr. Benham adjourned the meeting at about 4:45pm.