Autism Commission Sub-Committee on Adults with ASD Meeting Minutes

June 28, 2016, 3:00pm-5:00pm

500 Harrison Ave, Boston, MA

Janet George of DDS and Dr. Kathy Sanders of DMH, as the Chairs of this Sub-Committee, called the meeting to order at about 3:10pm and welcomed the members to the first meeting of this Sub-Committee on Adults with Autism spectrum disorder. Ms. Kain, the 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; Ms. George, Dr. Sanders, Tod Garvin, Dania Jekel, Sue Loring, Mike Moloney, Lea Hill, Mark Dumas, Maria Stefano, David Tobin, Gail Gillespie, Sandy Honig, Tim Cahill, Lisa Saba, and Nancy Marticio voted unanimously to allow remote participation. The other members participating were Rita Gardner, Deb Johnson, Casey Seaman, John Townsend, and Dana Roszkiewicz.

The meeting began each member introducing themselves and briefly describing their work with adults with autism spectrum disorder. Ms. George explained that there were other sub-committees who would be addressing the issues of Housing and Employment, and this sub-committee would be focused on other issues related to Adults with ASD. The group reviewed the 2013 recommendations of the Special Commission, and Ms. George highlighted the ones that she belies are appropriate for this sub-committee to address in its work. Ms. George suggested that the sub-committee organize its work by coming up with some common themes for the traditionally eligible and newly eligible individuals with ASD, and that they also identify unique needs of some of the population. Ms. George commented about the work between DDS and DMH to address the mental health needs of individuals with ASD.

Sue Loring commented that there needs to be more training for the medical community and stated that there are on-going challenges finding a psychiatrist for individuals with ASD. Other service provider members commented that it has been their experience that most people that are being “boarded” in emergency rooms and hospitals are people with ASD. There was further discussion about the collaboration between DDS and DMH to address the mental health needs of individuals with ASD. Core common elements were identified as needs (positive behavior supports, sensory needs and communication needs) and that these needs were consistently being seen with many of the newly eligible individuals.

In response to the issue of more training for healthcare professionals Dr. Sanders described the current effort to establish 2 fellowships one at UMass Medical in Worcester and one at Mass General Hospital to increase expertise on ASD. Dr. Sanders also mentioned that they are looking to add Boston Medical Center in the future. The discussion then expanded to discuss the need for training for the health care delivery field, for when individuals for to the emergency room and helping hospital workers to understand the needs of individuals with ASD. DDS has supported the ALEC program which has trained police officers and EMTs on ASD and its impact on individuals so that the response to ASD persons in crisis would not be further escalated.

Dania Jekel mentioned that AANE database has over 32,000 people with ASD, the average age is close to 50 years old and that supports are needed for these people who did not qualify for DDS and may not qualify under the functional impairment criteria. AANE’s database is not just for Massachusetts but highlights the number of older people with ASD who have not been connected to any state agency. Todd Garvin commented that it is difficult for an adult to obtain a diagnosis. Todd said that for those self-diagnosed or with informed diagnosis that occurred in adulthood it is challenging to meet the requirements of health providers and insurers, and many people are unable to navigate the healthcare system to obtain a diagnosis.

Janet George commented that some older people have been entering the system for services and that many of them are living with their families. She also stated that for others they have no family support because they are estranged from their families for various reasons.

Dania Jekel mentioned that Beth Israel and the Lurie Center at MGH are two medical institutions that are doing adult diagnoses for ASD. Sue Loring commented that it is harder for people living in Western Mass. Since there is less access there and many individuals do not have transportation. Dr. Sanders stated that DMH was trying to expand its reach in western Mass by making their personnel more mobile and traveling to individuals.

Casey Seaman said that efforts are already staring with healthcare literature and identifying what’s available and what are best practices, she mentioned that BID Plymouth is doing good work on this. The group discussed the need to examine if there is any training for medical providers on how to work with individuals with ASD, and how to we let medical providers know when an individual is connected with DDS. Sue Loring mentioned that she trained over 1,000 nurses last year and there is a desire in the medical community for more information on how to work with ASD patients.

The discussion than turned to the issue of Higher Education and the need for supports for students with ASD in College or at Community College. Developing a toolkit for those entities was proposed. One member stated that ULowell is doing a good job at supporting students with ASD and that they have created social clubs as one way for students to make social connections. It was questioned if there was any support available from the state’s Office of Disability or Higher Ed.

Gail Gillespie talked about the challenges that DDS was experiencing trying to get individuals to engage in services. Dania Jekel mentioned that for many who want to access services they are without transportation and that DDS needed to consider funding for Uber and Lyft as they were much more cost effective options for transportation for many people.

Another issue raised was ADDP trainings and doing a survey of staff on what types of trainings they would like to see offered. Mike Moloney mentioned that there have been many trainings for provider agencies of which there are 50+ and that if other agencies were not taking advantage of all the trainings available that may be a reflection of their unwillingness to expand the types of services that they offer. Sue Loring said training needed to be expanded to direct providers so that staff working directly with these individuals understand their needs. Dania Jekel said that training needs to be on-going in order for it to be effective.

Janet George talked about the voices of families and how that has brought about a change in values and culture in terms of what they want to see as services. She said they need to look at retooling their existing resources to meet the needs of the newer population, working with the resource centers to try new things and looking at the autism resource centers and family support centers to see what types of services were available to address the various types of services that were being requested. Sandy Honig and Deb Johnson talked about the need for more web based social opportunities. Sue Loring said we needed to identify where the gaps are in services, there are services for children and adults but what services do not exist that are needed.

Janet George asked the group to provide their reactions to the “draft” charge that had been provided and send her comments. Janet then proposed that there be a presentation on what is currently out there for services to get the landscape of where we are, she said there are 50 shared providers with DMH but there is not the same penetration across the state by DMH.

Dania Jekel asked about the individuals with ASD who would not be found eligible for services. Carolyn Kain said that they would consider the needs of all people with ASD and try to provide supports to as many people as possible and they needed to be creative in identifying and then trying to support the needs of people who were not eligible for DDS or DMH services.

Todd Garvin aid that he believes the “soft skills” support is what many adults need; executive functioning skills, mentoring, navigation skills. Janet George described DDS’ two recent RFRs for coaching services.

Janet George stated that she would discuss with Dr. Sanders (who had departed early to participate in a conference call), which dates at the end of July worked for them and she would be in touch with the sub-committee. Janet said she would include instructions for access to DDS at 500 Harrison Ave and the sign in requirements in her email.

There being no further business, upon motion duly made, seconded and approved, Co-Chair Janet George adjourned the meeting at about 4:55pm.