

Autism Commission - Adult Sub-Committee
500 Harrison Avenue
November 21, 2016 – 1:00pm – 3:00m

Present at the meeting were Janet George, Kathy Sanders, Todd Garvin, Dania Jekel, Mark Dumas, Maria Stefano, Nancy Marticio, Cynthia Berkowitz, Carolyn Kain, Dianne Lescinskas and Kathy Stern.
Accessing the meeting remotely: Sue Loring, Gail Gillespie, Casey Seaman, Sandy Honig, and Tara Callahan

Janet George 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 teleconferencing. Remote access was approved unanimously. Minutes from October were reviewed and approved unanimously.

Janet said they wanted to focus the meeting on gaps in the service system and access points. She said that examples of non-emergent access are through the family support centers and the autism support centers.

Kathy Sanders said the idea is for us to look at the issue on how to access care and where potential problems may exist so that we can fix them.

There was a discussion about the Autism support centers and the fact that some do not receive information on the newly eligible. The issue of obtaining consent from individuals and families to share their contact information with the Autism Support Centers. There is also an issue with people in homeless shelters, we do not have any information on who the people are that may have ASD and need services.

Cynthia Berkowitz asked if the autism support centers offer milieus for people with ASD to get together. Sue Loring responded that the autism support centers she leads offers support groups for parents, a once a month social activity, a cooking group, games and snacks in the Milford area and relationship groups through a grant but that transportation is a challenge. Janet George mentioned the contractual responsibilities of the autism support centers and those include the adult population.

AANE is also an access point for adults.

The urgent setting was discussed where people go into a setting to achieve stability and return to their previous level of functioning.

How do we begin to connect with the homeless shelters, workers at the shelters are not trained to identify ASD and many individuals have not received a diagnosis. Individuals in shelter lack basic health care. There is a need for training for shelter personnel. Casey Seaman mentioned that there is an adhoc group in Plymouth trying to address some of these issues. Dania Jekel said there needs to be healthcare

available to the homeless. DTA in Framingham has been going into some of the homeless shelters to try and assist people.

Kathy Sanders said that the DMH clubhouses are not programs but they are an access point, and that the people working in those clubhouses need to know more about ASD.

MGH has done training in the medical setting about ASD. Cynthia Berkowitz commented that there needs to be a much broader understanding across healthcare professionals about ASD and in the school systems so that when mental health issues arise they can be addressed and that these can look very different in people with ASD.

The next issue discussed was the substance abuse providers and the fact that this is getting a lot of attention and resources and this is also an access point for individuals with ASD into the human service agency arena.

The issue of ED Boarding was brought up. Many individual with ASD have been boarding in emergency rooms. The state issued an RFI about what needs to be developed to address mental illness, behavior, mental illness + IDD, acute presentations, medical issues + mental illness and ASD + mental illness. A variety of presentations are coming into the hospital emergency rooms. Cynthia said that stay longer than 5 days tend to be adolescents. There is nowhere for these kids to go presently and ASD requires a separate unit with expertise about ASD.

Janet George remarked that the physical layout of these facilities is not appropriate or therapeutic for these individuals. There are not a large number of outpatient units.

Domestic violence shelters also do not have access because of the confidentiality with information.

Nancy Marticio said that what they are seeing in her program is that the age range of 18-27 is very difficult time for families to manage these individuals on their own, and they are in need of assistance. These adolescents and young adults need to build relationships with peers and the opportunity for this to happen is rare. Dania commented that it needs to occur in a class type setting like when they were going to school. Carolyn said that these issues can and should have been dealt with while they were in school, which has a structured and predictable environment and a built in peer group. Kathy Sanders said that the transition age youth keep coming up again and again and that while they have many competent abilities their ASD has a huge impact on their post school life.

Cynthia Berkowitz also mentioned that we can't address access for individuals who are without a diagnosis. Janet George said that in recent reports they have reviewed at DDS they don't include how they arrived at a diagnosis. Mark Dumas talked about the need for diagnostic criteria.

Janet George stated that you see diagnosis for children because that provides them greater access to service through special education. They were working with DMH to create better access to psychiatric services through the fellowships. Janet also talked about the current doctoral programs at BU, BC,

Northeastern, UMass Lowell, and Clark as potentials for expanding access to psychiatric services. Kathy Sanders said that DMH funds training programs.

The group then talked about the need for short and long term recommendations and that this would be a topic for discussion at the next meeting.

There being no further business at this time the meeting was adjourned. The next meeting will be Monday, December 19th, 1-3pm at 500 Harrison Ave.