Autism Commission - Adult Sub-Committee

500 Harrison Avenue

October 17, 2016 – 1:00pm – 3:00m

Present at the meeting were Janet George, Carolyn Kain, Dianne Lescinskas, Kathy Sanders, Todd Garvin, Dania Jekel, Mark Dumas, Maria Stefano, Gail Gillespie, Tim Cahill, Cynthia Berkowitz and Kathy Stern.

Accessing the meeting remotely: John Townsend.

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 tele-conferencing. Remote access was approved unanimously. Minutes from June and July were reviewed and approved unanimously.

Janet George, co-chair of this committee welcomed everyone and asked that we all introduce ourselves. She started the meeting by saying she wanted to continue the conversation about what works now for adult services, where are the gaps in service delivery, and how should we proceed at this point. Kathy Sanders talked about the service delivery and the different levels of care that is needed. She suggested we walk through all of the entry points for services. There is a gap in understanding what is available.

Dania talked about homeless shelters and other domestic violence shelters as a point of entry. Another point of entry is the police and court systems. She also mentioned that adults are getting diagnosed while they are incarcerated.

Kathy discussed the court ordered evaluations typically will go to Bridgewater State Hospital or DMH – this is where the diagnosis typically happens. Carolyn asked if we are tracking the evaluations. Kathy discussed the forensic division at DMH – they are collecting the information from the evaluations but there is not a lot of detail in the database. Bridgewater has its own system for tracking information. Janet asked how we know about the homeless population. There is some information from DDS in the Metro region where 2 out of 180 newly eligible were found to be homeless.

Todd asked if someone was to self-refer to DMH – how that would work. Kathy said they should be able to get directed to an entry point to access services. Autism Support Centers were supposed to be the entry point but they are not equipped right now to help with the level of refinement and nuisances to direct them to more specific care. When asked if the ASC track calls and newly eligible, Janet responded that DDS just started to ask them to collect basic data about calls and referrals, not specifically the newly eligible so it is basic data that they are collecting right now – they are collecting this data twice per year. The centers are not currently equipped for that level of data collection. Additionally, individuals and families do not always provide the level of information to identify whether they are part of the newly eligible or whether they have obtained DDS eligibility at the time of the call. Sometimes the call serves to help individuals and families identify that they should apply for DDS eligibility.

Carolyn asked if adults are aware of the Autism Support Centers. Janet said it depends on the support center; historically they were focused on children to age 18 and now they are expanding their focus to adults. Some centers have always had an adult focus as well as serving children and young adults. If the support centers are taking calls and answering questions it may be a way for us to capture the gaps in services. Find out what questions are being asked at the ASC.

Carolyn asked Dania what issues she is hearing at AANE and she responded that it is a lot of mental health questions, finding a psychiatrist for medications, inpatient/outpatient services, and adult children with autism living with their parents, social isolation and many questions about anxiety and how it relates to autism.

Carolyn discussed that the levels of anxiety that some adults are experiencing and how it can be paralyzing to them. The anxiety increases with aging - without a predictable schedule like the one they had when they were in school. Kathy agreed and said that anxiety is not always best treated with just medication; we need to look at other services and therapeutic expertise to meet the individual needs. Carolyn stated that some of the anxiety should be dealt with when kids are in school and starting to transition into adulthood. The districts are not doing a great job with the social and emotional aspects of the individuals while they are still in school. Could we expand upon services that should be happening in the school and have more structured day programs?

Kathy agreed with Carolyn and said that the school system could be an incredible opportunity on how to ultimately prepare the students for life. How are schools dealing with autism and anxiety? So much more needs to be addressed earlier – by the time they get to the adult system, too many have much larger needs.

Janet had brought up that we should not be focused on school aged and that the 14-22 year old sub-committee is addressing those needs. She talked about two prospectives: 1.) Programs – many adults do not want to go into programs – we cannot market them as such. 2.) The inherent value to individualism and person-centeredness.

Tim asked about Asperger’s and mental health – is Mass Health doing most of the coverage or commercial insurance? Dania said it is mostly Mass Health but it is difficult to find a qualified psychiatrist – it is better now than five years ago but there is a lack of expertise in this field.

Kathy said the psychiatric field has not caught up with the numbers. Beacon Insurance was going to set up an area of expertise and attest to providers’ standard of care – Janet said the program is on life support. Kathy said this is the first time this group has brought up insurance but it is crucial to this work.

Kathy asked that we stop and review a list of entry points for identification. The list should include:

1. Crisis/emergency
2. Police
3. Outpatient
4. Homeless
5. Domestic violence shelters
6. Criminal justice system
7. Corrections
8. Detox/rehab system
9. Autism Support Centers
10. Schools (688 process)
11. State Agencies
12. Internet

The discussion focused on a public health awareness/education around where you turn for help. Kathy said they are developing a public health announcement on depression and suicide.

Kathy informed the group about MCPAP, Massachusetts Child Psychiatric Access Program. It is a web based program that can direct you to services. They just developed one for moms to deal with postpartum depression. Janet asked if there would be a willingness to expand and develop an MCPAP for Autism. People need to have one place where they can access information and be directed to services. Exceptional Lives also have a helpful web based model and it is user friendly. The state has the “Index” but most people felt like it was not user friendly for individuals.

Kathy discussed the lack of workforce development in the psychiatric field. Over the last 20 years they have not kept up with the growing need of doctors in this field. Janet asked about the role of nurse practitioners and are they able to prescribe to this population.

Dania wanted to review her recommendations for this committee to consider.

1. Single entry referral for newly eligible
2. Massachusetts Autism website (to get all your information)
3. Case manager to work on an individual basis for adults
4. Inpatient/outpatient mental health that is autism friendly
5. Crisis intervention
6. Service options/non-program based – community and living based
7. Family support
8. Physician and Psychiatric training
9. Education and awareness for staff

Janet said we have 23 crisis teams that cover the commonwealth and many are contracted by private insurance. If you can build it so that everyone has to go through the crisis teams, a lot of the school issues could be solved. If the crisis teams had better training on autism we would have better outcomes. Insurance companies would be interested in the cost savings it would provide.

Todd asked how we would direct people to the information that they need around ASD and services– can we direct people right to a site. Janet mentioned we could use Mass. Options (211 system) – they can direct people to a site and they advertise in places like the MBTA.

Dania talked about a website at AANE that they call “Give us a shout”. It allows the user to ask questions and then filters the questions out so the appropriate person can answer in a friendly manner.

Janet mentioned the workforce group and Employee Assistance Programs – could they direct questions to the “new information site”. We need to have a multifaceted way to get information to people. Dania also suggested using the Autism Support Centers as a local resource.

Todd asked if we could send out an evite for the next meeting which was scheduled for November 21st at 1:00pm-3:00pm at 500 Harrison Avenue. Janet said she would have someone from her office send out the minutes and evite for the next meeting.

There was no further business and meeting was adjourned.