Autism Commission - Adult Sub-Committee

500 Harrison Avenue

January 30, 2017 – 1:00pm –2:30pm

Present at the meeting were Janet George, Kathy Sanders, Mark Dumas, Maria Stefano, Carolyn Kain, Dianne Lescinskas, Lea Hill, Lisa Saba, Elizabeth Duffy, Rita Gardner, Sandy Honig, Casey Seaman, John Townsend, Nancy Marticio, Cynthia Berkowitz, Gail Gillespie and Dania Jekel.

Accessing the meeting remotely: Dave Tobin, Sue Loring, Susan Fortin and Deb Johnson.

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 November and December were reviewed and approved unanimously.

Janet started the meeting by asking the group to go around the table and introduce themselves. She suggested the group discuss recommendations for the Autism Commission meeting on March 6th and it may include the document that was prepared by Lea and Maria (see attached). She stated we should identify some recommendations and identify service gaps and system changes. This group has discussed the following:

* Homeless Shelters
* Lack of appropriate care in emergency rooms
* Mobile Crisis and ESP – are they responsive
* Expansion of MCPAP

She asked the group if they had thoughts on a focus of recommendation based on what has been discussed in the past 5-6 months. Kathy commented that this is important work and it requires a thoughtful process on the approach. Carolyn said it is up to the committee to decide on short and long term recommendations. 1-3 recommendations are within a doable category for the March 6th meeting.

Kathy said the ED boarding process, where ASD patients are stuck in hospital emergency rooms, has come under great scrutiny and this is an opportunity for us to weigh in. There are 4 groups of individuals that are in the ED.

* Mental illness and substance abuse
* Mental illness and ID
* Mental illness and medicated
* Mental illness and aggressive and violent behavior

These 4 groups stay longer in the system and need specialized units.

Janet asked if there should be a recommendation for in-patient beds for children with ID and mental illness. Kathy said that a continuum of care and a layering of step down to community care with a multidisciplinary approach is needed. The outcome of the ED boarding situation could be a robust network of services and community based continuum of care. We should recommend that this group look at this issue. Janet responded that we would have to frame it to the mission and overall goal of enhanced mental health, education and capacity at the mobile crisis level. If we can support ESP and mobile crisis we can divert from ED boarding. Kathy responded that they are two good recommendations and very specific. Dania asked about out-patient care. She reported that parents are calling them in fear of their older adults with potential for violence in the home. It’s a small but critical need for families. Janet said it is not a small need and we need to figure out how to better support the families.

David asked what is available to families in terms of respite and home support. Heighten the resources at home instead of going to the ER. There was discussion around a mobile respite that would allow for people not to be sent to ED. Dania commented that hospital settings are not the right space and if there could be something in the recommendation about non-traditional types of places – do they exist or do they need to be created. Sue asked if we are tracking people in the ER and do we have data – what happens when they return home to families. Janet said there is a lot of data being collected and the best data is on children.

The following possible recommendations were discussed:

* More specialized in-patient beds
* Increased education in ESP system
* Outpatient treatment available with appropriate expertise – build the capacity of ASD knowledge.

Three areas of service delivery that encompass training and capacity.

It was said there is an overemphasis on medication rather than the behavioral interventions. Carolyn said that this goes to the multidisciplinary approach and psychopharmacology needs to be involved. It was discussed that social isolation causes stress for this population. There should be some thought around expanding the fellowship program.

Janet discussed a recommendation:

* Expand fellowship program (long term)
* MCPAP for ASD (short term)

She said it may require a level of funding and we have not engaged with BMC and Tufts yet regarding the fellowship.

Kathy said expanding the training for psychiatry and psychology is important.

Dania discussed the training that is done at Grand Rounds – it is basic knowledge of ASD. If you could do Grand Rounds at multiple hospitals you can get the information to the medical students. It is just as important as the fellowships. She also discussed that many adults are still not diagnosed or recognized with ASD and ¾’s are women. There aren’t enough medical professionals to do the diagnosis. Awareness and identifying piece needs to get into a recommendation.

There was additional discussion around medication vs. behavior intervention and parent training. There is evidence that when parents are trained to handle behavior the behavior decreases. There is a challenge with adolescent males and aggression at home, some families will choose medication.

Dania said they do many trainings for families and parents are desperate for services and training. Sue also said that there is a lack of help for families and you can’t make adults take medication. It’s an ongoing cycle of ups and downs, no matter how much training you give to the families. Respite is crucial for families and an ongoing constellation of supports. We need more professionals trained and there are only 2 fellowships for a huge state.

Dania said that mobile respite and in-home supports are needed. If professionals are going into the home they will see the behaviors and you could gather observational data.

Two points were made:

* Behavior health – ESP, psychiatry, psychology, for continuum of care
* Supporting families – many adults are still living at home

We should consider education and training for families and mobile respite. Cynthia added that peer mentoring can be helpful – there is an opportunity for social interaction and it helps prevent isolation. DDS funds the PYD mentoring program and BMC Autism Program runs the TEAM mentoring program.

Dania said it all goes back to isolation – no routine and no employment and it creates many issues. There is a big gap with employment and the committees are working on this issue.

Dania discussed two buckets:

* Social isolation of adults can be extreme and needs to be addressed at some point. As people age they become more and more isolated. We have a variation of people that need a variation of opportunities.
* Adult diagnosis – many adults can’t get a diagnosis due to insurance, lack of providers and transportation

Carolyn said we need to get a list of opportunities to prevent social isolation – what can we create. We need to consider transportation. Uber can be too expensive outside of urban areas. Activities can be difficult when the adults have such specific interests. Lea discussed their group activities and some difficulty with attendance. The closed Facebook page is getting good feedback.

Sue said that there are only 4 qualified experts in the state that diagnose adults.

At this point we moved the discussion to the document provided by Lea and Maria – the ED Referral Questionnaire. The document was reviewed and feedback was given.

Suggestions were as follows:

* Add a history of when aggression occurred.
* Eliminate some of the demographic information – too long.
* Pilot this questionnaire before we pose as a recommendation.
* Personalize – like a version of the wallet card from AANE.
* Contact information with psychiatric history.
* One sheet.
* Two versions – one for high functioning and low functioning.

Meeting was adjourned at 2:30pm. The next meeting of the Adult Sub-Committee is on February 27th from 1:00-3:00pm.