

Autism Commission
Adult Sub-Committee Meeting Minutes
March 20, 2017 – 1:00pm –3:00pm
500 Harrison Avenue

Present: Carolyn Kain, Janet George, Kathy Sanders, Mark Dumas, Maria Stefano, Dianne Lescinkas, Dania Jekel, Lea Hill, Lisa Saba, Tim Cahill, Rita Gardner, Cynthia Berkowitz, Beth Zwick, Todd Garvin and Nancy Marticio.

Accessing the meeting remotely: Sue Loring, Deborah Anne Johnson, John Townsend, David Tobin, Lisa Saba, Casey Seaman and Sandra Honig

It was 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 January were reviewed and approved unanimously.

New Sub-Committee Member

Beth Zwick from the Nancy Lurie Foundation introduced herself to the sub-committee and described her work. She also gave out a flyer with information about a golf program for adults with ASD funded by the Nancy Lurie Foundation.

DDS Emergency Room Fact Sheets and Wallet Cards

There was a brief update on emergency fact sheets and wallet cards. They were both reviewed by a few ER doctors and asked if they found it to be useful. They all liked the card and the fact sheet and found it to be a good tool. One request was to list a service coordinator on the sheet because sometimes the person accompanying the individual to the ER is not knowledgeable of the person with ASD. The ER doctors also felt like they had a good working knowledge on ASD.

Dania will take the wallet card to AANE to get feedback on the content and style of the card. Sue Loring will also get feedback from her families. It was noted that the fact sheet is specific to DDS but the wallet card is more generic and can be used by many individuals; even if they are not connect to DDS.

Another suggestion had to do with medication and possibly considering putting in a space to list the medications that the individual is taking.

It was asked that any feedback to either the wallet card or the fact sheet be sent to to Lea and Maria from DDS. We will continue to follow up with this agenda item at our next meeting.

Update from Carolyn Kain on the Autism Commission meeting from March 6th

Ms. Kain gave the members from this sub-committee an overview of the meeting from March 6th.

- Website was reviewed and changes are being made with feedback from commission
- Vote was taken on the increase for the Children's Waiver and the MAICEI program
- The chairs for this sub-committee presented our recommendations (see minutes from last month) and they felt there was positive feedback about their recommendations

It was noted that AANE sees employment as an area of importance and the largest need. Ms. Kain said that employment is an area of focus of the 14-22 year olds subcommittee. Also, the 22+ sub-committee has only met twice and employment is being addressed with this group.

The Autism Website was discussed as a good place to get resources from a variety of sources. It was mentioned that it should be a positive place – a non-stigmatized site with a tone that recognizes strengths and not just challenges. Mental health uses a person centered approach to ensure that all feel welcomed. We should look at other sites and campaigns and create a balanced approach to the website.

Open discussion around other priorities

- Not enough medical providers are willing to take on patients with ASD due to the length and complexity of the visit. The reimbursement rate is not equitable
- Transition from pediatric to adult health care and knowledgeable adult providers
- Access to specialty care – very challenging for people – dentistry is large problem
- Aging and ASD - ARI released a survey today on ASD and aging –Sue Loring will send to Janet George and she will disseminate to the group
- Exercise/nutrition is difficult in the community (eating disorders – more mental health) food sensitivities –restrictive diets.
- Technology could assist with some of the needs around queuing and planning – it is less stigmatizing and noticeable. The Autism Commission's office has met with someone regarding an application that could be helpful in this area
- Using technology to assist in medical appointments
- Specialty care in one location – coordination of care. Lurie Center and Feingold Center are two examples
- DOA – aging agency – AANE has tried to work with them with mixed results
- DDS discussed their support program that could work with the ASD population on executive functioning, cuing, nutrition choices etc. – to help some individuals remain independent as they age
- Subsidized housing – not ideal for ASD with noise and smells (very thin walls) – some who live in this environment wear noise cancelation headphones all day

We will look at these issues and come up with ideas for an approach for new recommendations. We want to get new ideas on the table. Ms. Kain is available to discuss these ideas and also any additional

short term recommendations for this sub-committee. The next Autism Commission meeting is on June 5th and we can look at specifics to present at that meeting.

The next meeting for this sub-committee is scheduled for April 24th.

The meeting was adjourned.

DRAFT