Massachusetts Autism Commission

Adult Subcommittee

October 27, 2022

Via Zoom

**Participants**

Christine Hubbard, Kathy Sanders, Carolyn Kain, Dianne Lescinskas, Josh Greenberg, Rita Gardner, AJ Cullen, Danielle Sheehan, Maria Stefano, Karen Seck, Janet Barbieri, Carol Gracia, Chris Pelltier and Beth Zwick

**Meeting Minutes** – Dianne Lescinskas

**Approval of Meeting Minutes from September 7, 22022**

The meeting minutes from September 7th were reviewed and Mr. Greenberg made a motion to approve the minutes . After hearing no discussion or opposition, the meeting minutes were approved unanimously.

Chris Pelltier is a new member of the Adult Subcommittee representing DDS, he is the Director of Adult Autism.

**Update from DDS on various initiatives**

Ms. George was unable to make the meeting today to provide updates regarding the work being done by DDS. Others in attendance, representing DDS, were able to give updates.

* ARPA funds – in process/interviewing for statewide managers – wrap around service, intensive in-home therapies to keep people stable
* Creation of five different group home models throughout the state
* Expanded and enhanced respite models
* There is work being done on the RFR and it should be going out early in the new year
* There was a presentation done by MassHealth and the new Road Map for Behavioral Health – there is an overlap with this model and the ARPA DDS initiatives – DDS and DMH are working collaboratively – referrals will come from DDS and DMH
* They are being mindful of where programs are located and prioritizing near clinical expertise in the area
* DDS is working on initiatives of getting more of the workforce engaged – looking for creative ways of retention and recruitment
* ADDP website – released an RFR (using ARPA funds) looking at ways to build career ladder for pipeline purposes – focused on MassHealth enrolled providers and creative avenues to increase workforce
* The federal government has increased the date to use ARPA funds to March 31, 2025
* College Navigation – there are open slots – it requires more qualified staff but the payrate is higher
* 110 million of loan repayment for Behavior Health – applications will be ready in a few months – up to 300k in repayment for some – based on loan debt – includes social work and nursing level in behavioral health
* DMH – line item at 20 million for loan repayment/tuition reimbursement

**Review of Recommendations to the Autism Commission**

Recommendation #1

*Status of Services for Adults with Autism Receiving Day and Employment Services Prior to the Pandemic*

* The co-chairs are reaching out to MRC on this recommendation
* Data isn’t available by diagnosis or level of services
* Explore where the data is available
* MassHealth – the data is through “claims” and it could be remote or in person and there is no diagnosis attached, not a full picture of race as it is not a requirement to get that information. MH is trying to get better demographic information now
* There is a 90 day “claims” lag so the data will not reflect a live picture – MH has explored provider surveys but have not been successful in getting providers to report back on the surveys
* The number of drops in DayHab has not grown – it has stayed consistent during the pandemic – there is a lack of new additions, and they are not seeing the 22 year old individuals
* MassHealth does not collect waitlist data – providers are required to keep that data but it is not reported to MH - they do not know the current capacity status
* Could MH give data on individuals that require 1:1 support?
* The subcommittee would like to have a conversation with DESE on transition/compensatory services (pandemic) as they continue to look for data
* DESE has a 10 million grant for individuals transitioning during the pandemic to address the needs
* DayHabs – 20 closures since the pandemic

Recommendation #2

*Barriers to Medicare*

* Ms. Zwick spoke with Amy Weinstock from the Autism Insurance Resource Center about this recommendation – she has a group doing research on this issue. Medicare doesn’t just decline; the request doesn’t go anywhere since there is no code and they are not used to these types of claims
* Many individuals have MassHealth as a secondary insurance but without a denial from the insurance company, they cannot get the secondary insurance to pick it up
* This is a good example of issues on aging – it is difficult to predict when and individual ages and things that come up as barriers
* It will be helpful to give Ms. Weinstock support on this issue and invite her and others that are doing the research to one of the meetings of the Adult Subcommittee

Recommendation #3

*Identifying the Prevalence of Autism among Older Adults/Promoting Increased Future Planning Among Parents of Autistic* *Adults*

* The first step is asking if data collection is possible – do we know if SSI collects specific disability data
* Two different issues here, first is figuring out the prevalence and second is future planning
* The problem is already known to DDS – a parent dies and doesn’t plan – the individual then needs housing and may not be formally diagnosed – lack of documentation is a challenge
* Resources are developed for families but how to get these resources to other families/caregivers who do not know about it.
* The ARC is working with senior centers in Lexington – we could invite them to speak to us – also, invite Elder Affairs

A question was asked about language used in the recommendations. In several places in the document, it refers to an individual as autistics and in other places it refers to individuals as autistic. Some individuals prefer one over the other and there are many strong opinions on this as well. There is a research paper, Autism and Adulthood and there was a survey regarding terminology – the preferred term and non-preferred terminology. This subcommittee decided it was best to use both words in this document.

Ms. Kain will add a footnote in the Annual Report recognizing that individuals use different language to describe themselves.

**Next Meeting**

Ms. Gracia will send out a doodle poll for the week of December 5th.

With no further business to discuss, the meeting was adjourned.