Massachusetts Autism Commission

Adult Subcommittee

September 7, 2022

Via Zoom

**Participants**

Christine Hubbard, Dianne Lescinskas, Karen Seck, Josh Greenberg, Rita Gardner, AJ Cullen, Danielle Sheehan, Cynthia Berkowitz, Maria Stefano, Karen Seck, Michele Brait, Janet Barbieri, Rita Gardner, Carol Gracia and Beth Zwick

**Meeting Minutes** – Dianne Lescinskas

**Approval of Meeting Minutes from July 21, 2022**

The meeting minutes from July 21st were reviewed and Mr. Greenberg made a motion to approve the minutes and Ms. Stefano seconded the motion. There was no discussion or opposition; the meeting minutes were approved unanimously.

**Subcommittee report and recommendations to the Autism Commission**

The co-chairs along with Ms. Zwick have been working on the language of the three recommendations for the Autism Commission meeting. The document opens with a paragraph that describes the recommendations but also recognizes the ongoing work of DDS and DMH. It was noted that it is important for the Autism Commission members to hear of the initiatives and work being done by the state agencies.

*Review of recommendation #1*

**Recommendation**: a. Compile data from appropriate agencies (MassHealth, MRC, DDS) as to how many adults who were receiving day and/or employment services as of 3/1/2020 have not returned to such services as of 3/1/2023 or are not receiving the full complement that they previously received as of 3/1/2023, with particular attention to the impacts on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color. Compile data from DESE and DDS as to the status of day, employment and residential services as of 3/1/2023 for individuals with autism who Turned 22 during the pandemic, with particular attention to the impacts on Black, Latinx, Asian American and Pacific Islander, Native American and other individuals of color. c. With respect to high needs individuals and higher risk settings, examine data to determine the degree to which these individuals are being particularly impacted by the workforce crisis and, working with the appropriate agencies, investigate measures that might be adopted to address the more intensive staffing need that could result in enhanced salaries that would attract for this subset of the workforce. Also include evaluating additional wage differential for residential cases, as well as alternative settings that provide respite or emergency support to individuals and programs during crisis. This would include a specialty behavioral health unit for these individuals.

* Concern for the T22 class – have they been integrated into services or still waiting
* It would be helpful if data revealed geographical reference
* Basic data to see if things are improving
* Those needing more intensive services may be the last to return to services
* Recognizing the workforce crisis – wage deferential – higher wages needed to hire folks to work with individuals with higher needs
* There is a study that just came out of the Boston Foundation that summarizes some of the workforce issues being discussed

[Care Work in Massachusetts: A Call for Racial and Economic Justice for a Neglected Sector | Boston Indicators](https://www.bostonindicators.org/carework)

* Suggestions for edits to the recommendation – focus is on workforce and programs – use simple paragraphs stating the workforce issues and decrease in programs
* Use language of evidence (from the data and the study above) that shows individuals who were disproportionally affected by the pandemic and that is why we seek this data

*Review of recommendation #2*

**Recommendation.** Identify the source(s) of barriers to coverage of ancillary therapies encountered by aging autistics as they transition into Medicare. Take steps to address the barriers, including working with the Executive Office of Elder Affairs (EOEA) to discern how best to communicate with aging autistics transitioning into Medicare regarding how to surmount these barriers.

* Medicare is not familiar with ASD and their needs
* This recommendation is to look at why the barriers exist
* Solutions may only exist at the federal level since it is a federally governed program
* Look at adults not living with ASD (65+) and see if they have the similarities with Medicare struggles – maybe do a comparison
* The Autism Insurance Resource Center is working on this issue, and they believe it could be that providers who serve autistic individuals are not applying to be covered under Medicare
* There are no codes or providers for the type of services that autistic individuals require
* You do not get a denial from Medicare, so it raises the issue of MassHealth not picking up the charge because there was no denial
* This subcommittee should work with the Healthcare subcommittee on this recommendation – Amy Weinstock is the co-chair of the Healthcare subcommittee, and she is already working on this issue at the Autism Insurance Resource Center – they are receiving many calls on this topic
* Suggestions on the language of this recommendation – clarify barriers and clarify what you want done
* Pull in managed care at MassHealth
* There is a catch 22 with this issue, Medicare doesn’t deny services so MassHealth cannot take it but Medicare doesn’t have the specialists to do the service

*Review of recommendation #3*

**Recommendation:**  a. Retain a research group such as the Gerontology Institute at the University of Massachusetts Boston to mine Social Security data to generate prevalence estimates for the number of people with autism currently accessing Social Security in Massachusetts.**b.** Work with the Executive Office of Elder Affairs to offer training to staff at Senior Centers and other agencies who have direct contact with older adults. Train these staff to watch for aging families of adult autistics and seek permission to identify them to DDS, and to be able to refer them to resources to make a plan for when the last parent dies. c. Retain a contractor to roll out a statewide program of future planning workshops for autism families. Various models are available for review. Offer these workshops in partnership with local Senior Centers to identify and bring in as many aging families as possible.

* Difficult to know the numbers on aging adults
* Most identified population are in school and/or aged – with state agency
* When the “last” parent dies, family will scramble to find a placement, but most times need a diagnosis which will prove difficult with an aging adult
* The ARC is working with local agencies and learning about individuals that they didn’t know before
* Autism Support Centers could be used as a source for training by doing workshops – also Family Support Centers have a dedicated person that is knowledgeable on ASD
* The Support Centers could do work with local senior centers to help them identify ASD
* Adult Day Programs would be a good place to do training/workshops
* Suggested changes/edits to the recommendation – instead of saying “retain” use “explore opportunity to engage”
* Instead of saying “older autistics” use “older people with ASD” or “Asperger’s profile” or “individuals previously diagnosed with Asperger’s”
* Build up the content in the introductory paragraph – important to identify this one with a clinical team since there are clinical crossovers
* Start the recommendation with identifying the prevalence of ASD and then future planning
* AANE sees a lot of older adults and they identify as Asperger’s – “Asperger profile” is a good way to move forward with the language
* Currently, there are not a lot of diagnosticians focused on older adults with ASD
* Isolation is a factor for most people aging – especially if they have been undiagnosed and alone/or with an older parent
* AANE reports that when a child is diagnosed the parent will then consider a diagnosis for themselves
* AANE’s LifeNet program was founded on this issue – death of a family member bringing light into a situation of an individual undiagnosed – suggested that in addition to training you could pilot an actual individual going through this event
* There are also a lot of resources for planning for the next stage of life but most times you need to be already plugged into the system
* How to make “estate planning/trusts” accessible to all
* How do other medically complex or disabilities deal with future planning
* ARC of MA has done research on future planning – Family Support Centers have a medically fragile program and maybe have done some work on family trusts
* There are a lot of workshops provided to families regarding trusts - some are presented at Autism Support Centers
* AANE runs an annual benefits conference and finds it is difficult for families to navigate how to access this service – an issue is that once they do access it is difficult staying in compliance and they are at risk of losing benefits

**Action Items**

Ms. Hubbard will work on the changes/edits to the recommendations and will send out to the members by the end of the week. The Autism Commission meeting is on Thursday, September 15th and these recommendations will be presented at the meeting.

A doodle poll will be sent out to the members to establish the next meeting.

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