Massachusetts Autism Commission

Adult Subcommittee

September 5, 2023

Via Zoom

**Participants**

Co- Chairs: Christine Hubbard and Kathy Sanders, Dianne Lescinskas, Carolyn Kain, Cynthia Berkowitz, Chris Peltier, Maria Stefano, Danielle Sheehan, Josh Greenberg, Harkness Des Neiges, Beth Zwick, Carol Gracia and Janet Barbieri

**Meeting Minutes** – Dianne Lescinskas

**Welcome and Approval of Meeting Minutes from July 25, 2023**

Ms. Kain made a motion to approve the meeting minutes from July 25th, Ms. Hubbard seconded the motion and with no objections, the minutes were approved.

**Discussion of draft recommendations with regard to older autistic adults with aging family caregivers and supporters**

* The recommendation is for this to be included in the AC report – Ms. Hubbard has draft language broken down into 3 parts.
* Do we know how the situation is being handled now with parents/caregivers not in the picture anymore – reach out to support centers to gather information?
* The ARC has been doing work on this issue, we heard from Kerri Mahoney at our last meeting – they are connecting people to services.
* DDS does a breakdown of adults by age but only by 18-21 and 22+ - they do not break down further than this data.
* DDS would like to do outreach to senior service system and do training – need a plan on how to collaborate with the other players.
* There needs to be a connection between EOEA and DDS
* Topic of consensus data came up – could there be a question on how many people are you caring for in your home?
* Dr. Coyle at UMass and others may know how to get census data.
* Currently, these situations are dealt with on an emergency basis – parents don’t know how to connect with government services – the Autism Omnibus Law has existed since 2014 and a lot of individuals pre-dated Chapter 766 – it will be a rolling process of identifying individuals.
* We have a representative from EOEA on this subcommittee and will have them connect with DDS about this issue.
* AANE supports the older community – usually 50+ and they have a new website for this age group – many folks come to AANE without a diagnosis and no records.
* There is a book called Lost Generation – is there a value in reading this and having conversations on the older adult experience.
* We discussed offering training at senior centers, but do we know that senior centers are the place to go?? We need to work with EOEA on this.
* The ASAPS are regional – family caregiver support groups – may be more targeted.
* We have identified a need that has not been the focus previously – look at the prevalence of the need – identify an area where more resources are needed.
* We need a system to address this need – right now being addressed on an individual basis and some end up in the ED.

Dr. Sanders pointed out that we are looking at 2 big issues; Medicare and barriers – there is a white paper developed on this and will soon be rolled out by the Autism Insurance Resource Center – progress in this one – we will have a presentation on this in the future. Second issue is the aging adult and caregivers.

Ms. Kain suggested having one recommendation; *The adult subcommittee, along with DDS, EOEA and other appropriate stakeholders will come up with a proposal of a system of support prior to an individual needing immediate care due to the loss of a caregiver – we will work together to address an identified need an a process will be developed to address the needs of older individuals who cannot live independently and are financially burdened due to the passing of a caregiver*.

* It is about identifying and planning.
* There is no requirement to submit a recommendation, but we could submit a statement saying we have identified an unmet need and will work with DDS, EOEA and other stakeholders.
* Submit a statement as opposed to a recommendation – more appropriate for ongoing work – still want to bring this to the attention of the full commission.
* It was asked if all were ok with moving forward with a statement – communicate the urgency and include ideas and agency support.
* Statement to include: the need, approach to the work, identify supports and how to implement on the go forward.

**Discussion with Caitlyn Coyle, PhD, Director of the Center for Social & Demographic Research on Aging, Gerontology Institute, University of Massachusetts Boston exploring the availability of data about the number of "newly" eligible individuals with autism, particularly the segment of the autism population with aging caregivers on whom they rely for natural supports.**

* Ms. Hubbard has reached out and is in contact with Caitlyn. She will present at a future meeting**.**

**Action Items**

* Submit a statement for the upcoming Autism Commission meeting/report.
* Connect with UMass and accommodate their schedule – plan a meeting in the near future.
* Circulate a new draft.

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