Massachusetts Autism Commission

Adult Subcommittee

October 3, 2023

Via Zoom

**Participants**

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

**Meeting Minutes** – Dianne Lescinskas

**Guest** – Caitlin Coyle from UMass

**Welcome and Approval of Meeting Minutes from September 5, 2023**

Ms. Hubbard welcomed the members and asked that they introduce themselves to Dr. Coyle. The purpose of this meeting is to discuss the recommendation that was presented to the Autism Commission regarding aging adults and the caregivers – looking for data on where these individuals are located, how to get connected to them prior to an emergency situation (as in the caregiver no longer able to care for the individual) and thinking about services to best support the aging adult.

Ms. Kain made a motion to approve the meeting minutes from September 5th, Ms. Stefano seconded the motion and with no objections, the minutes were approved.

**Presentation from Dr. Coyle**

Dr. Coyle is the Director of a Research Center for Social and Demographic research on Aging. Her work focuses on people aging in community and how the life course shapes the process.

* Community based work – her work on ASD started in 2012 with a small project related to caregivers.
* It was focused more broadly on ID/D and how parents transition care and the family dynamics.
* Policy and practice – disability supports and how do systems talk to each other – barriers in accessing programs related to aging.
* A few years back there was a project specific to AANE and aging with ASD – from that work, issues relating to financial insecurity and how it impacts people to age well – there is isolation, vulnerable to scams and then layer in ASD which contributes to vulnerability.
* Looking at community engagement – thinking of personal care and how do we think of the role of taking care of one self and aging successfully.
* Consider different models of supporting aging individuals.
* Looking at National Core Indicator Data – limitations with doing research with population due to lack of data.

*Comments/questions*

* Issue is that we know individuals with ASD that are aging and cared for by family members that are not connected to agencies, when caregivers are no longer available and they need ongoing support – how do we identify these individuals prior to issues occurring – once we do identify, what resources are needed and what is the cost to advocate for those resources.
* Individuals who are 50+ never had the benefit of special services – because of when IDEA occurred and new ASD laws these services were not available.
* Parents of these individuals will show up at senior centers and ASAP Networks
* One way to identify is thinking about how to equip service providers on recognizing ASD – contract with visiting nurses, home care agencies, ASAP – could be an entry point on training to identify.
* Plans could be in place of aging individuals, but they can change – no one knows the best practice here – also, sometimes the individual does not want a sibling or family member involved in their care.
* For the aging caregiver, plan for outreach strategy – identify where are the places to find these folks – what type of outreach information is needed.

*Next Steps*

* Invite someone from Elder Affairs – we have a member – outreach for next meeting – ask about resources available.
* Data approach is important but getting information out is also important.
* Should we look at data and think about creating information for aging caregivers?
* Possibly explore SSI data
* Think about using rate of prevalence data – this would be rough data but may give you bullet points to discuss.
* 32 ASAPS in MA – Council on Aging helps with connecting to ASAP.
* Look at DDS data on ASD only.
* What is the range of services that we should be developing for ASD aging population?
* Thinking of peer model or navigators to help individuals with access.
* Look at Autism Support Centers
* Could develop materials and train staff for outreach – think about inviting folks from Council on Aging – also inviting MCOA (umbrella agency for ASAP)
* Consider engaging with the authors of The Lost Generation – a book about older autistic adults.
* Thinking about individuals without a formal diagnosis and no paper trail – challenge for eligibility.

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