Massachusetts Autism Commission

Adult Subcommittee

June 26, 2024

*Via Zoom*

**Participants**

Co- Chairs: Christine Hubbard and Kathy Sanders, Dianne Lescinskas, Carolyn Kain, Danielle Sheehan, Cynthia Berkowitz, Beth Zwick, Maria Stefano, Brenda Dater, Michele Brait, AJ Cullen, Carol Gracia, Karen Wylie

**Guests:** Ellen Kilicarsian, Christopher McDougle, Kelly Dakin, Amy Levistan, Julie O’Brien, Ann Giaque

**Meeting Minutes** – Dianne Lescinskas

**Welcome and Approval of Meeting Minutes from May 22**

Ms. Hubbard welcomed the members and asked that they introduce themselves. Ms. Kain made a motion to approve the meeting minutes from the meeting in May and Dr. Sanders seconded the motion and with no objections, the minutes were approved.

**DDS Updates on Aging Caregivers – Ellen Kilicarsian**

This subcommittee has been working on ways to improve outreach to those not connected to the service world including natural supports of family and when a caregiver is gone.

DDS has shared that they use a “needs assessment” for older caregivers and they have an advisory group with 20 parents involved. They meet on a quarterly basis and have proposed a work plan based on the needs assessment – the older caregiver workgroup will actualize the plan.

DDS has also met with Options Program Manager at Elder Affairs to connect with ASAPS. They are looking to collaborate with them at the local level and with individuals not connected to supports and services. They are offering training and support and have met with 7 organizations’ getting to know them and sharing information by providing an overview of DDS and Elder Affairs.

***Next Steps***

Elder Affairs will share their work with service providers from DDS. They do not have the data on number of caregivers in the state but will be rolling out a system network and will capture the age of caregivers.

DDS will continue to train Support Centers on aging caregivers and want to ensure that staff have good skills to answer questions and share resources. They are offering statewide training.

The work is focused on family members living at home.

**Presentation on Aging Well with Autism (Lurie Center For Autism)**

Aging Well with Autism is a Lurie Center initiative supporting individuals with ASD as they transition through adulthood toward the geriatric phase of life.

*Goals*

* Identify/address the most pressing needs and challenge of aging ASD population
* Create comprehensive care model
* Establish partnerships with local, national, and international organizations to add a focus on aging and ASD
* Foster a supportive and inclusive community for individuals with ASD and their families
* Develop a world class research program focusing on unmet needs at the intersection of ASD and aging

We need to prepare now to provide medical and mental health care for elderly autistic patients. Emerging research suggest that autistic adults are at a high risk for an array of physical and mental health conditions including diabetes, heart disease, depression and possibly dementia.

* Developed parent and autistic adult focus groups (4 listening sessions)
* Questions raised on housing, transportation, recreation, financial, legal and healthcare
* Parents feel isolated and alone
* Managing the future is overwhelming
* Concerns beyond the scope of clinical care

Lurie Center can serve families by focusing on 3 core missions: clinical care, education and research.

The themes that emerged from the focus groups included: Communication (person-centered care, professional navigation, letter of intent), Medical (Access to complex adult care, educating health care providers, early screening), Secondary Guardianship (who/when/how, siblings/family, professional guardians)

Lurie Centers current approach to serving patients across the lifespan

* Early diagnosis and intervention
* Childhood 4-11 yrs.
* Adolescence
* Adulthood ages 18+
* School and transition programs
* Guardianship and alternatives
* Increased psychiatric services
* GI and neurological issues

Lurie Center works on preventative care and screening across the lifespan, and they are developing social stories for common medical procedures. Parent support groups for parents and caregivers, they offer life skills and activities for adults without formal programming, workshops and cooking and dining together (virtually).

*Additional Workshops:*

* What you need to know – providing an overview of the important factors for families to address for the future of their aging child
* Guardianship
* Adult Autism Health Resources: CME (HMS and NLMFF)
* Navigating the Health Care System with ASD
* Challenges, Opportunities and Insights’
* ECHO Model for clinician – interactive online seminars with CME to increase ASD expertise of geriatric clinicians

*Research – Longitudinal Data Collection*

* Cohort age 30+ years, starting with Lurie Center patients
* Annual survey
* EMR data
* Subset that will be more deeply phenotype
* Involved autistic adults and their parents for feedback
* Partner with other groups for larger datasets

Looking at cognitive and brain health in adults with Williams Syndrome – assessing brain structure and flow using MRI and neuropsychological data in adults with WS.

Developed a training protocol for neuroimaging studies – videos to view at home with scanner sounds and detailed steps – onsite scanner training sessions. Making neuroimaging more accessible.

**\*\*\*Autism prevalence has increased 317% since 2000**

*Questions/comments*

* How can parents access some of these program – most of the workshops are available online and offered for a nominal fee – if there is a hardship the fee is waived.
* Is there a blueprint for the letter of intent – this is included in the “what you need to know” workshop. The Lurie Center will share templates for families to use.
* Lurie Center does social stories for medical procedures (blood draw/blood pressure) and do some low tech. things for dental visits,
* You could refer individuals to AANE for support of over the age of 50 – they do different activities and most have not grown up with the diagnosis. The Lurie Center could also partner with AANE and use some of their individuals for focus groups. AANE also tracks medical experiences. LifeNet cannot replace a parent but can build out a circle of support.
* The Autism Commission would benefit from this presentation. Moving forward, this subcommittee will work on this topic and look at priorities that coordinate specialty care model and apply that kind of thinking for this specialized group.

With no further business to discuss, a motion was made to end the meeting.