Autism Commission Birth to Fourteen Years Old

Subcommittee Meeting

April 7, 2023 10:00am - 11:00 am

Via Zoom

Present on zoom: Co-chairs Russell Johnston and Michele Brait, Emily White, Shari Krauss, Beth Jerskey, Jen Chebator, Mary Haswell, Larissa Mendez Penate, Moses NDuati, Erin Sherman, Dianne Lescinskas and Carolyn Kain.

Dr. Russell Johnston called the meeting to order and welcomed all members of the Birth to Fourteen Years Old subcommittee and introduced new members present to the group. The meeting norms were reviewed. The subcommittee members present unanimously voted to approve the December meeting minutes.

DPH Presentation

DPH gave a presentation related to a 3-year grant to address delays and barriers to ASD evaluations and service delivery. The focus of the first year of the grant is exploration through qualitative interviews. The second-year focus will be to develop a work plan and the third-year focus will be putting the plan into action. Data received to date was shared.

* Typically, appointments book six months out
* There has been a 500% increase in ASD diagnosis from 2003-2021
* The number of conditions under the ASD umbrella has grown
* Diagnostic tools have also increased
* Common barriers to health care overall also apply to those with ASD
* CDC numbers indicate 22% increase in ASD prevalence since 2018 (1 in 36)
* Focusing on academic medical centers only is not scalable, as it can be too far for some to travel to for an appointment
* The growing treatment numbers impact the diagnostic capability
* Fewer providers are accepting insurance, moving to private pay
* Behavioral specialization is not as desirable as alternative conditions for new medical professionals, partly related to pay conditions
* The traditional capacity is not able to meet demands
* Special Ed enrollment for ASD was 4,876 in 2033 and 24, 640 in 2021
* The current number of professionals that can diagnose ASD in the state is 1,616

Innovations to help resolve these barriers include:

-Increasing efficient of the existing system with secondary screenings and family navigators

-Expanding pathways to diagnosis, by earlier diagnosis, through PCP for non-complex cases

* + Addressing the impact of reimbursement/insurance restrictions
  + Addressing school system capacity and treatment capacity overall
  + Addressing Mass Health coverage/ reimbursement issues
  + Could MassHealth allow NP to make diagnosis, or partnership with PCPs?
  + Some insurance complained refuse services based on diagnostic tools used, discussion around policy change to remove some of the restrictions and barriers
  + Consider obtaining data from families, schools regarding barriers

DESE NEW IEP UPDATE

Dr. Johnston gave an update on the new IEP project, which he described as vision centered from the beginning.

-If ASD is selected under the disability category, 7 ASD related questions will be displayed

* + Questions related to use of AAC devices is not a requirement under the laws but will be recommended to address
  + The Acceptance page has been adjusted to allow more space for the parent to describe when a partial acceptance of the IEP is checked off, what they are looking for, or what is missing
  + The strength-based focus of the new document hopefully brings students to their meetings
  + Workshops for districts to become more familiar with the document and aware of the changes will help districts to become more comfortable with it
  + There will be a follow up with our subcommittee related to the roll out plan
  + there will be videos made to help support the families, so they know what to expect and for teachers to understand and implement the IEP

With no further topics to discuss, the meeting adjorned 11:02 am.