

PROPOSED MINUTES –JANUARY 12, 2010
MARYLAND COMMISSION ON AUTISM

The Maryland Commission on Autism convened its second meeting on Tuesday, January 12, 2010. The meeting was held at the Anne Arundel Community College, Arnold, Maryland. The meeting began at 9:40 am.

Commission members in attendance included: Dorinda Adams, Denise Cedrone, Dr. Lisa Crabtree, Kelli Cummings, Dr. Edward Feinberg, David Geier, Dr. Scott Hagaman, Renata Henry, Eric Backes for Senator Klausmeier, Ellen Kuhn, Dr. Rebecca Landa, Rachel London, Dr. Wendell McKay, Angela Mezzomo, Delegate Karen Montgomery, Debra Perry, Delegate Kirill Reznik, Dr. Carol Samuel-Botts, Marjorie Shulbank for Dr. Heath, Dr. Thelma Thompson, Careen Wallace, Fred Whiton Jr. and Zosia Zaks

Commission Members who were absent: Christine Ceely

Welcome

Deputy Secretary Renata Henry made opening remarks and welcomed the Commission members to the meeting. The Commission members were asked to introduce themselves. After introductions, Secretary Henry requested that the Commission members review and approve the minutes from the November 10, 2009 meeting. Secretary Henry then led the group in a review of the day's agenda, noting the presentation that would be heard, the need to come to consensus on subgroup structure, and the addition of stakeholder Listening Panels to our future meetings.

Follow-Up Items

Deputy Secretary Henry shared that there are 2 vacancies on the Autism Commission for an adult on the Autism Spectrum and for a parent of an individual with Autism Spectrum Disorder (ASD). Deputy Secretary Henry reported that Linda Carter Ferrier, parent and advocate, is no longer able to serve as a member of the Commission. The Commission members were asked to forward recommendations for potential appointees to Valerie Roddy of DHMH for referral to the Governor's Appointments Office.

Deputy Secretary Henry asked Marjorie Shulbank, Family Support Specialist, Maryland State Department of Education, and (MSDE) Division of Special Education/Early Intervention Services, to provide a follow-up to a request for data that was made at the November 10 meeting. Ms. Shulbank reviewed MSDE's special education data on students coded 14 (Autism), providing a snapshot of the number of students with ASD as was reported on Oct. 30, 2009. There are currently 7,510 children identified as having an ASD and receiving special education services in Maryland. In configuring next year's child count data, Ms. Shulbank confirmed that the number of children coded 14 (Autism) and receiving services will be at least 500 students higher. Ms. Shulbank clarified that the

code for Developmental Delay (DD) can be used to identify and serve children up until they reach age 9, and that the data presented today is only inclusive of children identified as having ASD and receiving Individualized Education Program (IEP) services under the code 14 (Autism). Of the 7510 children identified, 919 are in non-pub special education facilities.

Ms. Shulbank explained that there are 900 slots on the Medicaid Home and Community Based Autism Waiver Program (“the Autism Waiver”) and that the waiver is at full capacity. Ms. Shulbank shared that there are over 3,200 children on the Autism Waiver Registry. The last child to be found eligible and enrolled in the Autism Waiver Program was placed on the Registry on May 15, 2004.

Ms. Shulbank answered the Commission members’ questions about MSDE’s data collection procedures and the agency’s ability to populate the data differently. Inquiries were made about the number of students who would qualify for special education and related services under Code 14 (Autism) but are instead referred to IEP teams under different codes (for example: “Other Health Impaired” or “Multiply Handicapped”) and the number of children coded 14 that have 1:1 aides to support them in the classroom. Another area of interest is the number of students with Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), Asperger Syndrome, or High Functioning Autism that receives services under Section 504 of the Civil Rights Act. MSDE is unable to quantify the data for these requests.

Ed Feinberg described the efforts of the local school systems to select the most appropriate disability code for each child referred to special education, and spoke to the struggles that IEP teams often encounter in this process. He explained that in order to ascertain the data that the group is requesting, we would have to review the minutes from every child’s IEP team meeting, which is not feasible. Mr. Feinberg commented that the Maryland Infants and Toddlers Program is reporting an increase in the number of children identified as DD that are able to attend kindergarten with minimal supports, due to the efficacy of the State’s early intervention services.

The Commission membership expressed interest in learning more about the data collection procedures used by Maryland’s State agencies to monitor outcomes for individuals with ASD from birth to transition to adulthood. The group discussed the need for a fiscal note to describe the funding and resources that are allocated for serving this population each year.

Deputy Secretary Henry referred the Commission members to DHMH-Mental Hygiene Administration (MHA) and Developmental Disability Administration (DDA) data on the number of consumers w/ASD in each jurisdiction throughout the state. MHA funded services for 390 individuals in Fiscal Year 2009 and 1,476 individuals were receiving DDA funded services as of 1/11/09.

Deputy Secretary Henry introduced each of the State agency staff members that will be involved in the process of collecting and reporting data to the Autism Commission (Al

Zachik, Valerie Roddy, Marjorie Shulbank, Karla Saval, Diane Dressler, and Dr. Lisa Hovermole).

Presentations

Dr. Hovermole introduced Li-Ching Lee, Ph.D., ScM, Johns Hopkins School of Public Health, who gave the presentation "*A Review of Updated Prevalence of Autism Spectrum Disorders.*" Dr. Lee's presentation gave a comprehensive overview of ASD, including the criteria from the Diagnostic and Statistical Manual for Mental Disorders- Text Revision, national and State trend data on the prevalence and identification of ASD, and the efforts of the Autism and Developmental Disabilities Monitoring (ADDM) Network to help raise awareness about the magnitude of autism and affect policy through research. Dr. Lee reviewed the findings from the ADDM Network's preliminary national and State ASD surveillance activities.

The ADDM Network released data indicating that an average of 1 in 150 children nationally are affected by ASD, and of all of the research sites, Maryland has the second highest number of children identified as having an ASD, with 9.2 per 1,000. Despite having a large number of children identified with ASD, Maryland early intervention practitioners only documented developmental concerns before age 3 in 70% of children who were later identified as having an ASD. Nationally, the average age of diagnosis is 4 years, 6 months. In Maryland, the average age of diagnosis is 4 years, 10 months. To date, 84.8% of the children identified by the ADDM as having an ASD are receiving special education services. Interestingly, only 75% of these children are coded 14 (Autism) while the remaining children are served under different special education classifications.

Dr. Lee shared that the ADDM has focused on studying national and State data on 8 year olds, when identification of Autism peaks. Nationally, 1% of 8 yr olds (1 in 70 boys, 1 in 315 girls) are identified as having an ASD, reflecting a 57% increase in prevalence for this age group between 2002 and 2006.

Dr. Lee spoke to the methodologies utilized by the ADDM Network to improve the reliability and validity of their research findings, identifying multiple health and education resources, the nature of the behavioral and developmental assessment procedures, and ongoing efforts to maintain fidelity and improve quality control within sites and across all sites involved in the project.

Through surveillance, research, awareness, and collaboration, the ADDM Network is addressing ASD as an urgent public health issue, warranting a coordinated, collaborative response to improve outcomes for children and families.

Organization

Operational Structure

Deputy Secretary Henry discussed the need for the Autism Commission to determine its organizational structure, with a clear vision statement, mission, and identified purpose for moving forward. Deputy Secretary Henry proposed that the Autism Commission form workgroups to address specific areas of need, including:

- Transition Age Youth
- Workforce Development
- Research Partnerships
- Evidence-Based Practices
- Funding and Resources
- Health/Medical Services

Each workgroup is to call on the expertise of subject matter experts in identifying objectives and developing goals. Through the course of the discussion, Autism Commission members aligned themselves with the workgroup(s) related to their respective fields and areas of interest and identified needed resources.

Listening Panels

Deputy Secretary Henry proposed the addition of stakeholder Listening Panels to future Autism Commission meetings. Each Listening Panel would be composed of key stakeholders, such as autism waiver service coordinators, parents, service providers, and individuals with Autism who would respond to a set of questions posed by the Autism Commission membership. As a result of the Listening Panels, the Commission will gain information about the identification of ASD and the availability of supports and services across the State that will be vital in guiding our work. Autism Commission members are asked to submit potential Listening Panel questions to the Commission chairpersons for review.

In order to have enough time to accommodate the addition of workgroup reports and Listening Panels to Autism Commission meetings, Deputy Secretary Henry proposed adjusting our meetings so that they begin at 9:30 a.m. and adjourn at 2 p.m. Autism Commission members expressed interest in utilizing teleconferencing methods (such as “Skype”) so that appointees can participate in Commission meetings remotely if they are unable to travel. Autism Commission members are encouraged to contact the chairpersons if they would like to arrange a carpool to travel to the next meeting.

Public Comment

Careen Wallace indicated that she wanted to submit the following topics for consideration by the Commission workgroups: higher education supports, simplifying access to agencies/services, and services and supports for individuals on the “high functioning” end of the Autism spectrum.

Interested stakeholders in attendance at the meeting stressed the urgent needs of individuals with ASD and their families, encouraging the Commission to make recommendations to the Governor before the end of its 2 year study period.

Stakeholders expressed concerns about the way in which service hours are allocated to the 900 Autism Waiver recipients, and proposed that the number of hours available to each child be reduced in order for the Autism Waiver to accommodate additional youth with ASD and provide support to younger children.

Several citizens asked the Autism Commission to evaluate the State's current use of funding and resources to serve and support individuals with ASD.

Citizens that wish to volunteer to serve the Autism Commission should see Valerie Roddy after the meeting.

The next Autism Commission meeting will be held on April 20, 2010 in Princess Anne. As April is Autism Awareness month; we will make this a special event.

Autism Commission staff will be in touch with each of the workgroup chairpersons to start coordinating the subcommittees.

Adjournment