

MINUTES –APRIL 20, 2010
MARYLAND COMMISSION ON AUTISM

The Maryland Commission on Autism convened its second meeting on Tuesday, April 20, 2010. The meeting was held at the Krystal Q in Talbot County, Maryland. The meeting began at 9:40 am.

Commission members in attendance included: Renata Henry, Dr. Carol Ann Heath-Baglin, Dorinda Adams, Denise Cedrone, Cristine Ceely, Dr. Lisa Crabtree, Kelli Cummings, Dr. Edward Feinberg, David Geier, Senator Kathy Klausmeier, Dr. Rebecca Landa, Rachel London, Dr. Wendell McKay, Angela Mezzomo, Delegate Karen Montgomery, Debra Perry, Delegate Kirill Reznik, Dr. Carol Samuels-Botts, Marjorie Shulbank, Dr. Thelma Thompson, Careen Wallace

Commission Members who were absent: Fred Whiton and Zosia Zaks

Welcome

Secretary John M. Colmers brought opening remarks to the Autism Commission. Secretary Colmers discussed healthcare reform at the national level, and the implications that the current legislation would have for the work of this commission and the wellbeing of citizens with Autism Spectrum Disorder (ASD) in the future. Secretary Colmers encouraged the Commissioners to begin thinking about pilot programs that can be developed and implemented to improve the lives of individuals with ASD in Maryland, a state that has seen a 57% increase in the number of people living with ASD. Secretary Colmers noted that this would be the first meeting in which we were to hear from a listening panel- and commented on the tremendous value in incorporating the insight of families, individuals on the spectrum, educators and service providers in the Commission process. Secretary Colmers reported that April is Autism Awareness month, and read a proclamation from Governor O'Malley.

Deputy Secretary Renata Henry led the Commission members in making their introductions. After introductions, Deputy Secretary Henry requested that the Commission members review and approve the minutes from the January 12, 2010 meeting. Deputy Secretary Henry then led the group in a review of the day's agenda, noting the presentation that would be heard, review of the subgroup structure, and the addition of a stakeholder Listening Panel to the agenda. Deputy Secretary Henry thanked the individuals who are staffing the subgroups for their time and leadership.

Presentation

Dr. Carol Ann Heath, Assistant State Superintendent, Division of Special Education/Early Intervention Services, Maryland State Department of Education,

provided a presentation on the funding mechanisms for special education and early intervention services in the State of Maryland. Dr. Heath provided an overview of the federal, State, and local funding sources that are needed for the provision of these services. The presentation focused on federal funding through the Individuals with Disabilities Education Act (IDEA), variance in local government funding for education, state general funds, and medical assistance.

Dr. Heath explained that local government funds include local, other state, other federal and private funds. Dr. Heath clarified that state general funds include Intergovernmental Transfer dollars, Federal funds include IDEA and supplemental funds, and Medical Assistance includes Health Related Services, Transportation and reimbursement for Service Coordination.

Listening Panel

Deputy Secretary Henry introduced the participants for the Autism Commission's first Listening Panel, comprised of key stakeholders in the Autism community in Maryland. Deputy Secretary Henry introduced our distinguished guests, Brandon Crawford, a youth with Autism; Mr. Bonnell, a parent of a youth with ASD-Talbot County; Maleasa Blackway, the Autism Waiver Service Coordinator for Wicomico County; Trish Esh, an Adult Service Provider for Dove Pointe; and Bonnie Walston, Director of Special Education for Wicomico County.

Mr. Bonnell, a parent speaking on behalf of himself and his wife from Talbot County, spoke first and discussed his family's journey through diagnosis and early intervention for their 2 daughters that are on the spectrum. Mr. Bonnell shared his family's struggle to accept the diagnosis of Autism for both of their daughters. He described how he and his wife learned to navigate the special education system and work collaboratively with the public school system to ensure that their children's needs are met. He emphasized that their family's experience with the public school system in their jurisdiction has been very positive, and that they are pleased with the individualized intervention and education that their children, who present very differently, have received. Mr. Bonnell talked about how his family has struggled to obtain health insurance coverage for the array of services that their children need.

Mr. Bonnell concluded his comments by offering strategies to improve outcomes for individuals and families impacted by Autism. He suggested that the public school system consider implementing year-long education programs for students with ASD in order to prevent regression (which often occurs during extended summer breaks), provide increased support through key early childhood transitions (from the Infants and Toddlers Program to preschool, preschool to school, etc.) and move toward addressing secondary transition at an earlier age.

Ms. Bonnell indicated that her "Wish List" for youth with ASD and their families would include access to a special education liaison to improve knowledge and understanding of the special education process, increased training to pediatricians on screening and referral to medical, mental health, and other treatment options. Ms. Bonnell discussed the need

for expansion of State and local child care advocacy programs to support families with kids with special needs in securing child care so that they can continue to work.

Ms. Trish Esh, Adult Service Provider for Dove Pointe, shared information about her role in serving adults on the spectrum in supportive day and residential programs. She reported that ongoing training and professional development have assisted her in increasing her knowledge about Autism and her insight as a service provider.

Ms. Esh indicated that 1:1 support programs (previously funded by the DDA) were tremendously successful in improving outcomes for adults with ASD. She reported that there are gaps in the services that are available to individuals with Asperger Syndrome, as they need very different supports than individuals on the spectrum with behavioral concerns (such as self injurious behavior or aggressive behavior toward others). Ms. Esh asked the Commission to develop strategies for augmenting the adult service system, to ensure that the transition from school to community living is as smooth as possible. Ms. Esh elaborated that the sudden transition from intensive support through special education and the school system to very little supports for transition to community living results in a significant disruption in services and supports, making these transitions particularly difficult for youth and families. She encouraged the Commission to consider implementing temporary intensive transition supports to assist in identifying vocational strengths and employment possibilities for youth on the spectrum as they exit the special education system.

Brandon Crawford, a young man with Autism, described his experience growing up with Asperger Syndrome. He explained that at the time of his diagnosis, there were very few resources for individuals with Autism in his community. All of his physicians were on the Western Shore, requiring a lengthy commute to and from their offices.

Brandon discussed his involvement with DORS as an extremely positive experience. He was supported through the job interview process and obtained a job at WalMart, in which he is able to use his strengths. Upon entry into the workforce, Brandon indicated that he felt as though he needed additional ongoing support from DORS in his workplace, citing a need for direct social support and coaching to assist him in navigating socially. Brandon suggested that DORS hire additional personnel to provide more frequent site-visits to adults on the spectrum once they have secured employment, to ensure that the individual receives the supports in the workplace that they need to maintain their employment.

Maleasa Blackway, the Autism Waiver Service Coordinator for Wicomico County, described the school-based and community-based services and supports that have been successful in meeting the needs of individuals with Autism and their families on the Eastern Shore. She cited 'outstanding' special education, transition, and recreational resources for families on the Eastern Shore. Ms. Blackway described the challenges faced by individuals on the spectrum and their families in locating and accessing services for their children outside of the school system.

Upon recertification for the Autism Waiver this past year, three of the children Ms. Blackway serves were found to be 'no longer eligible' for Autism Waiver services. Ms. Blackway discussed the challenges associated with disenrollment from the Waiver, as families are left to navigate the teenage years without the services and supports of the Waiver. Ms. Blackway explained that Transition-aged youth on waiver face a huge void in support; explaining that a few are able to access day services, but lack in-home support, which comes as a shock to families.

In closing, Ms. Blackway appealed to the Commission to make the following considerations: increase the inclusive child care opportunities for children with ASD, enabling their parents to work; develop and implement procedures to re-assess the children who have been removed from Autism Waiver services; pursue an Autism Waiver to provide services to adults with ASD; increase the workforce of available service providers on the Eastern Shore, and provide ongoing training for those already in-service; and conduct research to determine the need for more services in this region of the State.

Ms. Bonnie Walston, the Director of Special Education for Wicomico County, referred to the system of supports for individuals with Autism and their families on the Eastern Shore as "a work in progress," requiring self assessment, continuous improvement, and ongoing collaboration with other agencies to address challenges to the community. Ms. Walston indicated that the Autism Waiver program has been extremely effective in providing support to youth and families impacted by ASD.

Ms. Walston described gaps in knowledge among the provider community and cited the need for ongoing professional development, as well as pre-service training for those seeking employment with early intervention programs and transition planning, specifically.

Ms. Walston reported that there is one approved service provider in Wicomico County, and that more providers are needed in order to accommodate the large number of children that have been identified with ASD. The vast majority of the children in Wicomico County have been on the Autism Waiver Registry for over three years. Their families have to travel long distances to seek services (assessment, assistive technology, augmentative communication, and other supports to functionally and academically participate in education). The process of identification, early intervention, and enrollment in support services costs the family a great deal of time and money.

Ms. Walston spoke to the challenges associated with accessing DDA funds. While there is an expansive list of contractors that are approved to provide environmental adaptations, it takes a great deal of time to get any home modifications approved and completed.

Ms. Walston expressed the need for collaboration among service providers and the school system, citing the stimulus funds as a resource that could fund combined training and professional development opportunities. She cited the need for additional funding for

preschool special education, to include hiring additional behavioral support personnel and provide increased opportunities for family training.

Ms. Walston encouraged the Commission to advocate for re-structuring of the Autism Waiver and an increase in the number of slots. She would like to see increased supports for families on the Shore, including transportation services or reimbursement for transportation to approved Autism Waiver Service Providers. Ms. Walston asked the Commission to make training and professional development for all service disciplines a top priority, as well as engagement with colleges and universities, to ensure that the workforce is adequately prepared to address the needs of individuals with ASD from early childhood (ex. daycare) to adulthood (ex. Transition planning, intensive day programs).

In closing, Ms. Walston suggested that the Commission consider the coverage and provision of medical, Mental Health, and dental services as necessary for all individuals with Autism, regardless of their ability to pay, or their coverage for healthcare services through Medicare or Medicaid, as well as re-evaluating the current reimbursement schedules for non-public tuition assistance, to help keep children with ASD in their community schools and ensure that our rates for reimbursement are competitive.

Presentation

Dr. Christopher Smith, Director of the Maryland Center for Developmental Disabilities (MCDD), gave an overview of the Centers for Excellence in Developmental Disability's "Act Early Summit," in Philadelphia, Pennsylvania. The Act Early Summit included leadership from the Centers for Disease Control, federal and State agencies, institutions of higher education, and advocacy organizations. Seven states participated in the Summit, to share about their resources and engage in strategic planning for ongoing improvement.

As a result of our participation in the Summit, the Maryland team learned that there has been a dramatic increase in the number of individuals screened and diagnosed with Autism, and that we currently have a wealth of resources in Central Maryland (with respect to training and technical assistance, available services and providers, universities, research, etc.) and that there are several areas in which our State can improve. The focus of the Maryland team was on comprehensive planning to address multiple life domains (academic, personal, social, and vocational issues) across the lifespan through culturally competent, family and person-centered planning.

The Maryland team identified desired individual, system, and State outcomes. Individual outcomes focused on systematic developmental screening and assessment; decreasing the age at which children are identified, referred and enter into the early intervention system; improved access to evidence-based treatments and services; insurance coverage for Autism services; and awareness of State resources. The system-level outcomes centered around the development of a comprehensive, coordinated, integrated system of care for individuals on the spectrum.

To achieve this, the Maryland team determined that our State needs a solid technology infrastructure, broader geographic outreach, training and technical assistance opportunities, increased access to validated assessment tools, and evaluation procedures for continuous improvement. The Maryland team represented a large group of stakeholders from a variety of disciplines and organizations. The group demonstrated the political will to embark on the new strategic planning upon its return.

Deputy Secretary Henry proposed that the Commission consider naming the Maryland team from the Act Early Summit as an ad-hoc committee to the commission to focus on linking the MCDD to the Commission, identify needed partners, and develop plans and services that families and individuals with ASD need. The Commission moved to accept this proposal.

Public Comments

Hope Bonnell, parent- While the focus on early childhood is critical; we need to focus on establishing supports and care for our children after their parents have gone, such as co-habitation/living arrangements.

Stuart Spielman, parent- The Autism Commission needs to focus on the issues related to the economic security of our youth with ASD. These youth need personal savings, Medicare, SSI, Medicaid, healthcare, and estate planning in place to sustain them. There are growing numbers of people being diagnosed with Autism; we need to ensure that they do not face poverty. Mr. Spielman encouraged the Commission to review the ABLE Act (federal legislation).

Deanna Smith, parent- Individuals with ASD and their families need family navigators to assist them in securing needed services and supports. The services on the Eastern Shore are limited, and travel across the bridge is very difficult for families. More service providers are needed in this region of the State. Ms. Smith emphasized the importance of dental health and assistive technology for persons with ASD throughout the lifespan.

June Nicholas, parent- More data on adult outcomes is needed. From the educational perspective, we can easily track students from birth to 21, but there are no clear strategies or systems for tracking people once they exit the school system. People with ASD need a diverse array of supports in adulthood and targeted assistance in a variety of areas, including legal, mental health, and career services. Ms. Nicholas asked the Commission to consider utilizing Pathfinders for Autism as the Statewide central repository for Autism resources.

Review of Future Meeting Dates/Locations

July 13- Western Maryland

October- Southern Maryland

January- Return to Central Maryland

April 2011 meeting- Dr. Thompson of the UMES has been asked to host an all-day work session at the university. At that time, a facilitator will be contracted to compile all of the data, workgroup reports, and presentations to the Commission and develop a preliminary report (the first report to the legislature is due legislation in June 2011).

Discussion

Karen Montgomery requested that a revised list of the Commissioners and individual workgroup members (to include contact information) be distributed at the July meeting.

Dorinda Adams requested that time for large-group discussion be added to the agenda so that the Commissioners have an opportunity to share information at the conclusion of each meeting. Ms. Adams shared that the National Lifespan Respite Conference will be held in Baltimore this fall, and that at this time, she has not received any proposals for workshops focused on autism. Ms. Adams will forward the information about the upcoming conference to commissioners.

Marjorie Shulbank shared that the Kennedy Krieger Annual Conference will be held October 28-29 at the Sheppard Pratt Conference Center in Baltimore, Maryland.

Rebecca Landa shared that Kennedy Krieger Institute's Center for Autism and Related Disorders (CARD) will be providing training this summer on the development of language and cognition through play. Dr. Landa described the 5 funded research programs that CARD is currently engaged in. These projects include a significant parent training component, which will be written into a manual and serve as an evidence base. A video-guided training is being developed for parents, which will be accessible online, so parents can watch videos of typical children and children with ASD, assess their child's development, and arrive at a risk-score that could be used to identify a variety of developmental concerns.

Workgroups

Each of the individual subgroups gave an informal report on their activities. The workgroups will meet at least once between full-Commission meetings. Formal reporting mechanisms will be determined at the next meeting.

