

PROPOSED MINUTES –JANUARY 11, 2011
MARYLAND COMMISSION ON AUTISM

The Maryland Commission on Autism convened its fifth meeting on Tuesday, January 11, 2011. The meeting was held at the Anne Arundel Community College, in Arnold, Maryland. The meeting began at 9:40 am.

Commission members in attendance included: Dorinda Adams, Denise Cedrone, Lisa Crabtree, Kelli Cummings, Ed Feinberg, David Geier, Scott Hagaman, Carol Ann Heath-Baglin, Renata Henry, Cynthia Hill, Katherine Klausmeier, Rebecca Landa, Rachel London, Wendell McKay, Angela Mezzomo, Karen Montgomery, Debra Perry, Carol Samuel-Botts, Marjorie Shulbank, Careen Wallace

Commission Members who were absent: Cristine Ceely, Katie Miller, Kirill Reznik, Thelma Thompson, Fred Whiton, Zosia Zaks

Welcome

Department of Health and Mental Hygiene (DHMH) Deputy Secretary Renata Henry welcomed the Autism Commission members to the meeting and led the Commission members in making their introductions. After introductions, Secretary Henry requested that the Commission members review and approve the minutes from the October 19, 2010 meeting. Secretary Henry then led the group in a review of the day's agenda, noting the listening panel participants, the presentation that would be heard, and report-out by the Autism Commission Workgroups. Dr. Henry thanked the individuals who are staffing the subgroups for their time and leadership.

Presentation

Dr. Thomas Insel, M.D., Director of the National Institute of Mental Health (NIMH) and Chair of the Interagency Autism Coordinating Council (IACC) gave a presentation on the state of Autism Spectrum Disorder (ASD) in our country, and the current research agenda of the IACC. Dr. Insel shared that ASD research is still in its infancy, growing enormously due to coordinated public and private efforts and the President's identification of ASD as a top bioresearch priority. Dr. Insel briefly reviewed the symptoms of ASD and its associated features, and provided an overview of what the research community knows about ASD:

- ASD is a developmental brain disorder in which genetic factors are important,
- that intensive, early behavioral intervention is key to improving skill acquisition, generalization, and overall outcomes,
- the prevalence of ASD is increasing dramatically (at a rate of approximately 13% each year for the past 20 years),
- the increase in ASD is likely driven by environmental factors,
- 80% of the individuals with ASD in this country are under 18 years of age,
- vaccines and geography are not indicated in the causation of ASD,

- ASD should be recognized as a medical diagnosis (rather than as a psychiatric diagnosis), and
- Treatment for ASD should be comprehensive and focused on meeting all areas of need.

Dr. Insel discussed the increase in genetic discoveries related to the occurrence of ASD, and addressed the implications of the following factors, as they relate to having a child with ASD:

- advanced paternal age- the risk for having a child with ASD and other genomal abnormalities increases by six fold for fathers over the age of 40,
- environmental factors- specifically prenatal risk during the beginning of the second trimester of pregnancy, heightened by the use of certain drugs (thalidomide, valproic acid, misoprostol, etc.)
- phenomics- there are various subtypes of ASD which need to be identified, as they may have differing genetic pathways/causes (and thus may respond differently to treatment).

Dr. Insel indicated that there is tremendous interest and growth in the area of microbiomic research. The IACC is optimistic that this field of study will yield more information about the causation of ASD.

The diagnosis of ASD is based on observation and pathophysiology. Dr. Insel shared that researchers are focused on mapping the genome associated with ASD in order to provide biodiagnostic treatment for the core pathology of the disorder. Advancements such as these would allow physicians to personalize treatment (based on ASD phenotype) and eventually employ strategies to prevent ASD.

Dr. Insel stressed that parents and families of individuals with ASD need training to intervene and facilitate their loved one's recovery from the symptoms of ASD. Dr. Insel discussed collaborative ASD research efforts (such as the National Database for Autism Research and the Interactive Autism Network) that provide networks to support and monitor individuals with ASD over time.

Dr. Insel reported that there is no solid evidence base to support the notion that vaccines or geographical location are factors implicated in the causation of ASD. He shared that the IACC plans to directly address its stance on these controversial issues in a report. Dr. Insel's comments on these issues stimulated a great deal of discussion.

Listening Panel

Deputy Secretary Henry introduced the participants for the Listening Panel, comprised of key stakeholders in the Central Maryland Autism community. Our distinguished guests included Matthew Eberly, an adult with ASD, Sheri Weissman, Autism Waiver service coordinator, Harford and Howard Counties, Mary Tillar, Director of Special Education, Anne Arundel County Public Schools, Ed Feinberg, Director of the Anne Arundel County Infants and Toddlers Program, Robert Harle, an adult with ASD, and Monica McCall, Adult Service Provider, Creative Options.

Matthew Eberly shared about his experience as a young adult with ASD. He noted that he does not like to be labeled as “autistic.” He described his current living situation with his parents as secure and stable. He spoke about his difficulty with executive functioning skills, specifically with reference to challenges with keeping himself organized in his everyday life. He criticized the current supports that exist for young adults on the spectrum, and expressed his opposition to the notion that young people with ASD need strict supervision and monitoring. He indicated that he very much wants assistance from a friend or peer with strengthening his executive functioning skills and support in attending to his daily responsibilities.

Sheri Weissman, Autism Waiver service coordinator, Worcester and Dorchester Counties, discussed the barriers and gaps in service delivery to children and youth with ASD. She stressed that more inpatient units are needed for immediate crisis response treatment, as well as residential services to stabilize behavior when youth with ASD are not able to be safely maintained in their homes. Ms. Weissman spoke to the limited capacity of providers to accommodate children with ASD and reported that families impacted by ASD are in need of additional aftercare services for their children. Ms. Weissman described the diverse needs of individuals with ASD on varying ends of the spectrum. She noted that youth with High Functioning Autism often have mental health needs, and encounter difficulty in finding clinicians that are equipped to support their unique needs, and youth who are moderately impacted by ASD need improved outreach, programming, and educational service options. Ms. Weissman reported that additional funding should be directed to early intervention systems and the Autism Waiver, to eliminate the wait for access to needed services. Ms. Weissman recommended implementing wraparound services for youth that do not currently receive support through the Autism Waiver, to help improve outcomes for this underserved population.

Robert Harle, an adult with High Functioning Autism (HFA), is a student at Towson University, majoring in Psychology. Robert previously attended Anne Arundel County Public Schools (AACPS) and described both positive experiences and challenges he encountered throughout school. Robert spoke to the benefits of early identification and intervention, indicating that he felt as though these services were very helpful to him. Robert commented that his father and his brother also have ASD, and they both had challenges in obtaining quality support services. He reported that as a high school student, he wanted to complete Advanced Placement courses and had difficulty with getting his teachers to adopt new practices and provide the accommodations he needed in order to be successful in such classes. Robert expressed his need for ongoing support services throughout adulthood, citing his desire for a case worker to assist him in developing executive functioning skills, to ensure that he can be successful in living independently.

Marlo Lemon, a parent of 3 young children, discussed her experiences navigating the early intervention system to get services for her youngest child, Matthew, who is impacted by ASD. Marlo explained that Matthew is non-verbal, and discussed some of his needs and challenges, which require occupational therapy, speech therapy, physical therapy, and behavioral therapy. Marlo reported that her family sought early intervention services for Matthew from the Baltimore County Infants and Toddlers Program (ITP) and the Kennedy Krieger Institute Early Achievements Program. Marlo indicated that her family was really pleased with the support services they received through both programs, and that she is thankful for the impact they have

had on Matthew. Marlo reported that her family currently pays out of pocket for Matthew's early intervention services, and discussed the financial strain that these programs pose for her family and so many other families like hers. Marlo provided examples of families taking out second mortgages on their homes or selling their homes and moving in order to pay for the services their children with ASD need. Marlo indicated that her family can no longer afford to pay for intensive services for Matthew. She discussed the impact that Matthew's service schedule has had on her employment, explaining that she had to take leave through the Family Medical Leave Act (FMLA) in order to transport Matthew to and from his services each day. Marlo reported that she is now able to work part time to support her family, in a position with the Baltimore County ITP, where she is able to support families that are experiencing similar challenges. Marlo reported that her son has achieved success with potty training. She commented that communication continues to be a challenge for Matthew, and that she really hopes to hear him speak one day. Marlo discussed the barriers that many families face in meeting the needs of youth with ASD, specifically with reference to accessing services. Her wish list includes: access to the Autism Waiver, improved services for transition aged youth, for all therapies to be covered by health insurance, for an increase in the early intervention workforce, and for more professionals to guide families through vital processes (including the establishment of special needs trusts, applying for Social Security benefits, and services from the Developmental Disabilities Administration) to support their children with ASD.

Mary Tillar, Director of Special Education, AACPS, and Ed Feinberg, Director of the Anne Arundel County ITP, spoke about what is working with regard to resources and the service capacity of the public school system to address the needs of children and youth with ASD. Ms. Tillar and Dr. Feinberg spoke about the strengths of the birth to five service system in Anne Arundel County, particularly its highly skilled staff, outstanding use of paraprofessionals, flexibility in intervention strategies, its service provision in natural environments, and its outstanding pre-intervention/post-intervention results for children and families. To address the needs of school aged children, Ms. Tillar discussed AACPS' efforts to expand partnerships and programs with State agencies, institutions of higher education, service providers and advocacy groups, focused on providing training and technical assistance for school personnel and supporting families impacted by ASD. Ms. Tillar reported that the AACPS has comprehensive community schools, each offering a continuum of educational options for students with ASD. Ms. Tillar reported that paraeducators have been instrumental in the provision of specialized services to youth with ASD and the promotion of meaningful inclusion for these students. Ms. Tillar indicated that ARRA stimulus funds have helped maximize the use of integrated and augmentative technology for students with ASD.

Dr. Feinberg described family support as an essential component of the early intervention system, discussing its role in helping families become accustomed to the ASD diagnosis, and supporting families in locating and securing needed resources and services. Dr. Feinberg explained that a primary challenge for the Infants and Toddlers Program is acquiring adequate staffing to meet the increasing demand for services. He stressed that paraeducators are critical to improving outcomes for youth with ASD, and that more paraeducators are needed. Dr. Feinberg reported that the ITP pre and post-intervention outcome measures reflect progress, and that more than 50% of the children exiting the ITP are included and receiving community-based services to prepare them for entry into kindergarten.

Dr. Feinberg described several barriers to services for youth with ASD. Dr. Feinberg cited difficulty in providing services to children whose parents work during the day, as well as fiscal challenges in providing transportation children when center-based services are recommended.

Ms. Tillar reported that about 10% of AACPS students are identified with ASD. She commented that a number of students who were on the Autism Waiver registry exited the school system last year, never having the opportunity to access Autism Waiver services. Ms. Tillar discussed the challenges in supporting transitioning youth, specifically with reference to identifying adult service providers, service options, and funding for adult support services. Ms. Tillar stressed that transition planning must begin at age 14 and be focused on facilitating employment or entry into post-secondary education. She noted that parents and transitioning youth need guidance with respect to understanding the difference between entitlement and eligibility as it pertains to access to support services. Ms. Tillar indicated that more resources should be devoted to transition planning and ensuring seamless service delivery for transitioning youth.

Monica McCall, CEO of Creative Options, an adult service provider, spoke about her work in supporting individuals with ASD throughout adulthood. Ms. McCall's organization provides services across the lifespan- serving youth, adults, and senior citizens. Ms. McCall spoke about Creative Options' mission to provide comprehensive, community-based, services and supported living arrangements for adults with ASD. She indicated that a strength of Creative Options is its continuum of diverse support services, equipped to meet the needs of individuals who need limited support as well as those in need of intensive support. Ms. McCall provided case examples, describing the stories of 3 clients currently being served through Creative Options.

- Jake, a 39 year old man with ASD, has been receiving extensive services since the age of 21. He has 2 support staff that are available to assist him around the clock. He receives comprehensive, interdisciplinary care that incorporates feedback from his primary care provider, psychiatrist, speech-language pathologist, and occupational therapist. Through support from a special needs trust fund, Jake had his own home. Jake's neighbors were fearful of him, and he did not speak to them. After years of support and resources from Creative Options, Jake is doing well and engaging positively with his neighbors.
- Shannon, a 21 year old woman with ASD, came to Creative Options from the foster care system at 17 years of age. Creative Options provides Shannon with comprehensive transition services and facilitated her inclusion in a small, supported community living arrangement.
- Paula, a 49 year old woman with ASD, was admitted emergently to Creative Options when her mother passed away. Paula had only ever been in the care of her family and was frightened, combative, and unable to communicate with staff upon her entry into care. With a variety of intensive supports, Paula has become very social and has had success in achieving milestones set forth by her treatment team.

Ms. McCall discussed the barriers that she encounters in her work as an adult service provider. She stressed the need for training and higher education to ensure a highly qualified workforce and improved service provision for individuals with ASD. Ms. McCall indicated that additional provider agencies and transition services are needed, given the increase in the number of adults

with ASD. She commented that more funding needs to be allocated toward reimbursement for behavioral support services, in order for service providers to pay support service therapists a higher wage. Ms. McCall reported that many people employed as support service therapists aren't adequately compensated and often hold multiple jobs. Ms. McCall indicated that police, firemen, and emergency medical services personnel need training to improve their awareness of ASD and acquire the skills needed to interact with people with ASD and intervene in emergencies.

Public Comment

Bernadette Olean, a parent of a child with ASD, explained that her daughter has been on the Autism Waiver registry for an extended period of time. Ms. Olean reported that her family has had to pay for private services to meet her daughter's needs, which has been very costly. Ms. Olean suggested that the structure of the Autism Waiver be changed, in an effort to serve a greater number of families. Ms. Olean elaborated by commenting that the number of support service hours allocated to each Autism Waiver recipient should be reduced, so more children can be served through the Autism Waiver.

Stacey Daddona explained that she is the parent of a 10 year old with Asperger Syndrome. She reported that her wish list, to improve outcomes for youth with ASD, includes increased early intervention services and adult services through the education system. Ms. Daddona indicated that she is disheartened by the absence of an Autism Commission subgroup on Education, citing the need for improved understanding of what a "free and appropriate public education" means, and that the educational system needs to focus on helping youth with ASD develop functional skills and prepare for independent living. Ms. Daddona expressed her desire for all educators, administrators, and related professionals to receive mandatory training on ASD, with an emphasis on strategies for inclusion and timely service delivery. She spoke to the value of Positive Behavioral Interventions and Supports (PBIS) in identifying behavioral intervention strategies to address the needs of youth with ASD and teaching them appropriate coping strategies. Her final comment was focused on the need for periodic evaluation of staff efficacy in replicating evidence-based practices in their work with students with ASD.

Miriam Machado and Minnie Reeves, parents of youth with ASD, reported that they are residents of Prince George's County and that both of their children with ASD attend school at the Kennedy Krieger Institute. Ms. Machado described her son's difficulty in passing the Maryland High School Assessment (HSA). She reported that she is confident that her son can pass the HSA, with the appropriate supports. Neither parent is satisfied with the notion that their children are assigned to the "certificate" option in school. They believe that their children can achieve a Maryland High School Diploma. Both women described challenges related to transition planning for their children, and voiced their concerns about the lack of available adult service options. Ms. Reeves, a documentarian, is developing a film about her child's experiences in school, in an effort to bring needed attention to the aforementioned issues.

Jane Drum is a parent of a 19 year old son with ASD. Ms. Drum reported that her son is a student at the Chimes School, and that she sits on the school's executive board. Ms. Drum described her son's rigorous early intervention program, which began when he was diagnosed

with ASD at the age of 2. Ms. Drum reported that her family has relocated from one state to another 6 times in an effort to access services for their son with ASD. She indicated that she is pleased with the services and supports that are available to Maryland residents, and thanked Senators Klausmeier and Montgomery for their continued advocacy and efforts to improve autism awareness. Ms. Drum reported that families often experience problems with securing medical care for their children with ASD. She commented that families need additional support in handling emergencies and accessing medical care. Ms. Drum asked the Commission to work on developing recommendations for transition aged youth with ASD, with considerations for youth with ASD that will not go to college.

Discussion

Caren Wallace requested that amendments be made to the minutes for the October 2010 Autism Commission meeting. Ms. Wallace requested that the staff of the Commission provide the Commission members with copies of each of the panel participants' written testimony.

Deputy Secretary Henry engaged the Commissioners in a discussion about a retreat during the month of April. The tentative plan for the retreat is to convene at the University of Maryland Eastern Shore campus in Somerset County on the evening of April 25 and for a full day on April 26, 2011. The Autism Commission members present on the evening of April 25 will participate in informal activities focused on teambuilding. The full day meeting on April 26 will be a facilitated work session in which the Autism Commission members develop a preliminary outline for the Commission's interim report to Governor O'Malley.

Workgroup Reports

Evidence-Based Practices (EBP) workgroup- Scott Hagaman reported on the activities of the EBP workgroup. The group has been meeting monthly to develop a framework for input about EBPs that the Commission members would like to see reflected in the final report. Scott commented that he thinks that the Commission members will be pleased with the progress report that the EBP workgroup will provide in April.

Research workgroup- Rebecca Landa discussed the work of the Research workgroup in identifying barriers to the research agenda and developing potential strategies to address these concerns. Dr. Landa identified 3 key issues that will guide this workgroup's ongoing discussion:

- 1.) Many requests for data come through the Maryland State Department of Education (MSDE). There is currently no formal mechanism to review, staff, or support proposals for research projects that are accepted. The Research subgroup would like to start a discussion about this issue.
- 2.) The National Institutes of Health (NIH) is engaged in a variety of translational research endeavors. The Research workgroup feels that outreach needs to be made to jurisdiction leadership to further the translational research agenda in our State.
- 3.) Efforts need to be made to educate the public about ASD research opportunities. The Research workgroup is interested in starting a focus group for families to promote their understanding of the research agenda and their role in advancing it.

Transition Aged Youth (TAY) workgroup- Al Zachik shared about the activities of the TAY workgroup, which is focused on ensuring that TAY and their families are connected to the services, supports, and resources they need for a seamless transition to the adult service system. Dr. Zachik reported that Sue Murray, Transition Counselor for Hannah Moore School has recently become a member of this workgroup. Dr. Zachik indicated that the TAY workgroup is creating a transition flow chart for families, outlining the various steps that families and youth need to follow throughout the transition planning process. The outline will have 2 separate tracks: one for youth that are certificate bound and another for youth that are diploma bound.

Adult Service workgroup- Senator Karen Montgomery discussed the activities of the Adult Services workgroup. She acknowledged the efforts that Kelli Cummings has made to organize the efforts of the workgroup and collaborate with Ryan Shanahan to identify and map all of the resources that are available to adults with ASD. The resource mapping activity will help the workgroup identify gaps in the adult service system and make specific recommendations to improve service provision to adults with ASD. Senator Montgomery reported that the Adult Services workgroup is developing a survey tool for adult service providers and would like the support of DHMH in encouraging all adult service providers to participate and provide feedback.

Medical Services workgroup- Dr. Carol Samuel-Botts provided an update on the activities of the Medical Services workgroup. To date, the workgroup has:

- compiled a list of the commonly co-occurring medical conditions and issues affecting individuals with ASD,
- developed and distributed a survey on screening and evaluation practices to the Maryland Academy of Pediatrics, various departments at Johns Hopkins University, and the University of Maryland, and
- identified tenets of care coordination and family support.

The workgroup is disappointed in the response to the survey thus far and is trying to identify other strategies for collecting data on screening and evaluation.

Funding and Resources workgroup- Deputy Secretary Henry reported that Delegate Reznick will introduce legislation this session focused on requiring health insurers to provide coverage for Applied Behavior Analysis (ABA) services for individuals with ASD. She indicated that the group is examining the costs that would be associated with expanding ITP and Autism Waiver services, in an effort to provide a cost/benefit analysis to support the bill. Deputy Secretary Henry reported that Li Ching Lee is working to identify all of the agencies that have data on individuals with ASD and develop strategies to streamline data collection and data sharing procedures between agencies.

Workforce Development- Lisa Hovernale reported that the Workforce Development workgroup is collaborating with the College of Direct Support, an internet-based caregiver support and training resource, to identify the strengths of this resource and identify principles that should guide training and technical assistance efforts for Maryland's workforce. The Workforce Development workgroup will make targeted recommendations for training first responders and other emergency personnel on the features of ASD and emergency intervention strategies for aiding this population.

