

PROPOSED MINUTES –JULY 13, 2010
MARYLAND COMMISSION ON AUTISM

The Maryland Commission on Autism convened its third meeting on Tuesday, July 13, 2010. The meeting was held at the Western Maryland Hospital Center in Hagerstown, Maryland. The meeting began at 9:30 am.

Commission members in attendance included: Renata Henry; Dr. Carol Ann Heath-Baglin; Dorinda Adams; Cristine A. Ceely; Lisa Crabtree, Ph.D.; George Failla; David A. Geier; Scott D. Hagaman, M.D.; Carol Ann Heath-Baglin, Ed.D.; Katherine Klausmeier; Rebecca Landa, Ph.D.; Rachel Beth London; Wendell H. McKay, M.D.; H. Angela Mezzomo; Karen S. Montgomery; Debra A. Perry; Kirill Reznik; Carol Samuels-Botts, M.D.; Marjorie Shulbank; Thelma Thompson, Ph.D.; Careen Wallace; Zosia Zaks (on-line)

Commission members who were absent: Denise P. Cedrone; Edward A. Feinberg, Ph.D.; Fred Whiton, Jr.

Welcome

Department of Health and Mental Hygiene (DHMH) Deputy Secretary Renata Henry led the Commission members in making their introductions. After introductions, Secretary Henry requested that the Commission members review and approve the minutes from the April 20, 2010 meeting. Secretary Henry then led the group in a review of the day's agenda, noting the presentations that would be heard, review of the subgroup structure, and the addition of a stakeholder Listening Panel to the agenda. Dr. Henry thanked the individuals who are staffing the subgroups for their time and leadership.

Listening Panel

Deputy Secretary Henry introduced the participants for the Listening Panel, comprised of key stakeholders in the Western Maryland Autism community. Our distinguished guests included Cynthia Hill, a parent; Linda Werner, an Autism Waiver service coordinator; Pamela Pencola, Director of Special Education for Frederick County Public Schools; Laretta Williams, an adult with Autism Spectrum Disorder (ASD); Larry Lipsitz, Intensive Behavior Management Program for The ARC of Washington County; and Phyllis Landry, Adult Service Provider for The ARC of Washington County.

Cynthia Hill is the mother of two sons, one of whom is on the Autism Spectrum. Ms. Hill stressed the importance of intensive early intervention services and autism waiver services in her son Luke's life; citing dramatic improvements in his behavior and socialization as a result of receiving these services. She discussed the impact that Luke's Autism has had on her family and her marriage. Ms. Hill acknowledged the intensity of her son's needs and the strain that her family experiences in trying to meet his needs. Ms. Hill discussed the nature of Luke's Autism, indicating that he developed typically until he reached 20 months of age, at which time he experienced significant regression

and began exhibiting a host of behavioral concerns, most notably, aggression. Ms. Hill reported that her son has done extensive damage to the family's property and their home. A primary concern of the family's is keeping Luke safe in their home. Ms. Hill went on to discuss her feelings of sadness about having a child with whom she struggled to connect, commenting that she feels as though objects are of more interest and importance to him than his relationships with family members.

Ms. Hill reported that her family would encounter difficulty accessing behavioral interventions and supports for her son without the support of the Autism Waiver. As a result of her son's enrollment in the Autism Waiver, environmental adaptations have been made to her family's home to ensure his safety. As a result of her son's participation in intensive individualized support services, Ms. Hill has seen a noticeable improvement in her son's receptive skills. Ms. Hill shared that her son's school has worked synergistically with his home program, augmenting his success and development.

Ms. Hill indicated that her "Wish List" for youth with ASD and their families would include access to Autism Waiver services to improve socialization and behavior and promote the acquisition of needed life skills. Acknowledging the body of research to support the efficacy of early, intensive intervention, she suggested that a period of intensive support be provided as soon as a child is identified, and that these services be systematically phased down to ensure that each child has a healthy transition (without an abrupt interruption of services). Ms. Hill shared that while her son still faces many challenges, he does not require the same level of service that he did upon diagnosis of ASD. Ms. Hill spoke to the difficulties of securing and retaining intensive individualized support services technicians, as the majority of these personnel are of college age, with great flexibility in the summer time and scheduling challenges during the school year. Her wish list included efforts to strengthen and retain the workforce that is available to provide this vital service.

Linda Werner, an Autism Waiver Service Coordinator for the ARC of Frederick County, opened her remarks by stating that "nothing works comprehensively to address the needs of the person with ASD from birth to death." Ms. Werner shared information about her role in serving individuals on the Autism Spectrum and their families through the Autism Waiver. Ms. Werner spoke to the numerous barriers and gaps in service delivery that youth with ASD and their families encounter. She shared with the Commission that upon re-certification of the Autism Waiver, Adult Life Planning Services (ALPS) became available to youth and their families. She cited concern that there are currently no Autism Waiver service providers to provide this service. With the increasing number of youth with ASD approaching transition age, this must be addressed. Ms. Werner indicated that there are also shortages of therapeutic integration and environmental adaptation providers, whose services are in equally high demand. Ms. Werner indicated that the difficulties in accessing and utilizing providers of needed Autism Waiver services may be related to the way the regulations for these services are written in the Code of Maryland (COMAR).

Ms. Werner reported that for a variety of reasons, many families don't utilize each of the services that are available to their children through the Autism Waiver. Ms. Werner suggested a potential strategy for sharing resources amongst Autism Waiver participants, in which families that do not access all of the services (Therapeutic Integration, for example) would be able to transfer their child's allotted hours for a specific service to other children with ASD. This would allow for increased participation in the Autism Waiver. Ms. Werner shared that families that are not utilizing all of their child's allotted service hours feel guilty that the hours aren't transferrable to other children.

Ms. Werner's "wish list" included a seamless service delivery system in which individuals receive tiered services as soon as they are diagnosed with ASD, and continuously throughout their lifespan. Ms. Werner noted that there are many children and youth with ASD that do not qualify for the Autism Waiver (e.g., youth with Aspergers Syndrome) and that a tiered delivery system would strive to meet their needs as well as those children who are moderately to severely impacted by ASD.

Pam Pencola, Director of Special Education for Frederick County Public Schools, thanked the Commission for welcoming her to share the public education perspective on the impact of ASD. Ms. Pencola shared that during her tenure as Director of Special Education, there has been greater acceptance of ASD. Ms. Pencola reported that children with ASD are being identified earlier, and that there are a variety of services and evidence-based practices available in the public school system to address these children's' educational needs. Ms. Pencola reported that there are currently 500 children with ASD in Frederick County and that the vast majority of these students are included in general education with their typically developing peers. Ms. Pencola indicated that Frederick County Public Schools has allocated significant resources and staff time to providing school personnel with training and technical assistance on ASD. She commented that her school system has benefitted from innovative online consultation and training strategies, which have allowed them to access a Board Certified Behavior Analyst consultant, which has been critical to addressing the timely provision of supports for students with ASD.

Ms. Pencola spoke to the importance of strong programming for transition aged youth with ASD. Transition-aged Frederick County Public Schools students with ASD get vocational training and job placements. They are taught to utilize public transportation. There are opportunities for parents to participate in training on transition. Ms. Pencola shared that the Frederick County Public School system is fortunate to have coordination through the ARC of the "Success" program. This program is designed for certificate bound students aged 18-21. The students attend school for half of their day, and are engaged in supported employment for the second half of their day. Ms. Pencola shared that programming like this has had positive outcomes for youth and their families, but that the school system is still challenged to meet the needs of this rapidly growing population. Ms. Pencola indicated that in order to improve outcomes for youth with ASD, there must be ongoing collaboration and open communication between private service providers and school-based personnel. Ms. Pencola's "wish list" included greater collaboration between the aforementioned parties, more aggressive programming, and

more evidence-based resources for teaching reading comprehension with this population of students. In addition, Ms. Pencola suggested that institutions of higher education require general education majors to complete additional coursework in the area of special education, as their knowledge of disabilities is critical to their success in educating students with special needs.

Loretta Williams, a 30-year-old adult with ASD, described her experiences about her own transition to adulthood. Ms. Williams, employed as a housekeeper, lives in a group home setting. She shared her dreams of getting married and raising a family. She spoke of her desire to be more autonomous in her activities of daily living; stating that while she enjoys the activities that she engages in with her outreach worker from the ARC, she would like to use public transportation, go shopping, and take walks independently. Ms. Williams indicated that she currently has supervision when engaging in each of these activities. Ms. Williams described the supports that she has found most helpful, commenting that she preferred for support staff to visit her regularly, rather than providing constant 1:1 supervision.

Phyllis Landry, a service provider with expertise in behavioral intervention with adults, described the concerns faced by the families of transitioning youth with ASD. She described The ARC's Community Supported Living Arrangement, in which adults with disabilities have 1:1 staff supervision for 24 hours per day. She reported that her client base consists of families from all over the State who are willing to travel a great distance to access services to address behavioral concerns among transitioning adults. She indicated that The ARC employs psychology associates and behavioral consultants who live on-site in residential facilities for adults with behavioral issues, to ensure an immediate response to behavioral concerns as they arise. Ms. Landry described The ARC's efforts to include adults with ASD in structured groups and tailor interventions to meet each of their individual needs. She emphasized the importance of learning about what motivates adults with Autism, and what their interests are, in order to make determinations about the type of work and community needs they may have. Ms. Landry commented that a priority of the Commission should be to increase the capacity of the Western region to support families impacted by ASD.

Larry Lipsitz spoke briefly about his role in supporting Loretta Williams. He reported that she became engaged in intensive supports when her father became ill and could not provide her care. Mr. Lipsitz assisted Ms. Williams in securing and maintaining employment in the food service industry and in her current position. Mr. Lipsitz emphasized the importance of intensive behavior management programming and respite care for individuals with ASD and their families.

Overview of Autism Waiver

Marjorie Shulbank, Family Support Specialist for the Maryland State Department of Education, Division of Special Education/Early Intervention Services, provided the Commissioners with a history of Medicaid waiver programs and a comprehensive overview of Maryland's Home and Community Based Autism Waiver Program. Ms.

Shulbank's presentation included information about the oversight and administration of Maryland's Autism Waiver, the process for placing a child on the Autism Waiver Registry, the process for enrolling a child in the Autism Waiver, the technical eligibility criteria for participation in the Autism Waiver, the specific services and supports provided through the Autism Waiver, and the funding mechanisms for maintaining the program. Ms. Shulbank shared that there are 900 slots for the Autism Waiver, and that the program has been at capacity for the last 6 years.

Karla Saval, Interagency Specialist for the Maryland State Department of Education, Division of Special Education/Early Intervention Services, and part-time Family Trainer, gave an overview of each of the services provided through the Autism Waiver, with emphasis on the impact of Intensive Individual Support Services, Respite Care, and Family Training. Ms. Saval spoke to the role of these vital services in improving academic, social, communication, behavior, and vocational outcomes for youth with ASD and increasing their community involvement and access to typical peers and preferred activities. Ms. Saval described the inherent challenges of recruiting and retaining a highly qualified workforce to provide Intensive Individual Support Services, Respite Care, and Family Training, as they relate to education, training, compensation, and the lack of benefitted, full-time positions for these professionals.

Public Comments

Tucker, a youth with ASD, shared information about himself with the Autism Commission. He spoke about his experiences in school and at home. He reported that he has an outstanding instructional assistant that works with him at school. He shared that he plays drums in the school band. Tucker indicated that he is gifted in mathematics, earning the role of team captain for a competitive math team. Tucker shared that a hobby he enjoys is making collages.

Bonnie, Tucker's mother, gave testimony about her experience as the parent of an exceptional child. She encouraged MSDE and DHMH to publish "success stories" about the Autism Waiver, to highlight the benefits of this resource to young people across the State. She discussed the effect of pathogens on prenatal development, referencing current environmental and epidemiological research endeavors. Bonnie reported that she feels as though environmental factors, such as exposure to mercury, are implicated in causing ASD. Bonnie indicated that she has had difficulty engaging with her local school system administration to have all of her son's needs met. An area that continues to be a concern for Bonnie and her son is transportation to and from after school activities. Bonnie described concerns about her local school system's lack of follow-up after a recent due process hearing.

Workgroup Reports

Adult Service workgroup- Karen Montgomery reported that this workgroup has developed areas for further study on the resources that are available for adults. Ms. Montgomery indicated that a particular area of interest is addressing the staffing concerns

of adult residential facilities and continuing care communities. This workgroup is working with nursing homes, stakeholders, and CSAAC to examine the service options that are available to individuals with ASD in adulthood. Zosia Zaks is assessing what resources already exist, in order for the group to determine gaps in adult service delivery and availability. The issues of sexuality and relationships have emerged as important topics for this group. They will also research the sex education options that are available for individuals on the spectrum.

Funding and Resource workgroup- Delegate Reznick reported that this group will meet monthly through January, with the primary goal of determining the availability of resources and funding for early intervention and therapies for ASD. After the legislation proposing that insurance companies provide coverage for needed Autism services failed to pass during the previous legislative session, this group engaged in a summer study of the issues surrounding this debate. The summer study involved researching and identifying evidence-based Autism therapies, exploring available resources and opportunities for public/private partnerships, and identifying funding sources for services. Rex Cowdry of the Maryland Healthcare Commission will participate in this process.

Rebecca Landa commented that we need to ensure that money is being directed toward research, in order to identify potential causes of Autism. She cited that the Study to Explore Early Development (SEED) and the Early Autism Risk Longitudinal Investigation (EARLI) are 2 federally funded research endeavors that are currently underway to explore the causal factors of ASD.

Workforce Development- Lisa Crabtree reported that the group met twice in June 2010, once by conference call and once in person. This group is focused on pre-service training devoted to developing the workforce to work with individuals with ASD. Discussions have focused on examination of existing workforce development programs, and obstacles to ensuring a well-trained workforce. The group has discussed a three pronged approach; post-secondary training programs, baccalaureate programs for professionals, and graduate programs. They will be working on surveying colleges and universities to determine existing programs and courses and looking at possible delivery methods (on-line, classroom). There will also be some review of Human Services Research Institute (HSRI) and College of Direct Supports (CDS) . Next steps for the group will include examining what neighboring states are doing, listing existing resources and gaps in training, and inviting Bill Tapp from CDS to speak to the group.

Medical workgroup- Wendell McKay reported that this workgroup's primary issues are diagnosis, prioritization of co-morbid diagnoses, and care coordination with families. To date, this group has held one meeting and had one conference call. The group members are in the process of assessing current practice guidelines for diagnosis, conducting a review of current national and local diagnostic practices, compiling a list of the co-morbid conditions that are present for many individuals with ASD, and brainstorming ways to improve care and coordination in our State. This group hopes to improve the exchange of information between families and various professionals, and involve physicians in determinations that are made regarding eligibility for the Autism Waiver. A

topic of interest that has emerged for this group is the issue of Medicaid reimbursement, as physicians who serve children on the model waiver are not reimbursed for their time spent reviewing the child's materials/assessments and coordinating their care.

Scott Hagaman requested that this group address the need for appropriate preventive dental care for individuals with ASD across the lifespan.

Evidence-Based Practices workgroup- Scott Hagaman began his update by acknowledging the expertise of the group members. This group is focused on examining the differences between evidence based practice, best practice, and the current community standard of care. Some of these concepts are clearly defined in law and regulation at the State and national levels; others are far more difficult to define and implement with fidelity. This group will meet with Rosemary King Johnston, Executive Director of the Governor's Office for Children, to learn about Maryland's current initiative to identify the differences between these various stages of practice and research, and how the definition of each pertains to education and funding for services for individuals with ASD and their families.

Research workgroup- Rebecca Landa reported on the four major purposes of this workgroup: connecting researchers; defining and decreasing barriers to research for families; collaborating with State agencies so that information that emerges from research will inform families; and working with researchers as to how to allocate their resources. This group has a particular interest in collaborating with State agency partners to improve our capacity to respond to grant opportunities for major epidemiological studies with increasingly tight timeframes. This group will conduct an inventory of the Autism research that is currently underway in our State and build a collaborative network of researchers and State agencies representatives. This group will explore strategies for researchers to engage with Maryland's Infants and Toddlers Program and Child Find to inform parents and caregivers of relevant research opportunities, as well as methods for reaching out to underserved and minority communities to ensure that they are represented in current studies.

Transitioning Youth workgroup- Marcia Andersen, DHMH MHA, reported that although he is currently out of State, Fred Whiton, the co-chair of this subgroup, has been able to participate in many of the group's activities. The group has met five times and has identified that its primary goal is to create a comprehensive map illustrating the processes and resources for transitioning youth with Autism. The map will provide differing tracks and resources for students that are on a diploma track and for students that are on a certificate track. This group's next meeting was held on September 8, 2010. Staff from the University of Maryland Innovations Institute will assist the group in the resource mapping process.

Review of Future Meeting Dates/Locations

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).