



STATE OF MARYLAND

DHMH

Maryland Department of Health and Mental Hygiene

201 W. Preston Street • Baltimore, Maryland 21201

Martin O'Malley, Governor – Anthony G. Brown, Lt. Governor – Joshua M. Sharfstein, M.D., Secretary

August 23, 2011

The Honorable Martin O'Malley  
Governor  
State of Maryland  
Annapolis, MD 21401-1991

The Honorable Thomas V. Mike Miller, Jr.  
President of the Senate  
H-107 State House  
Annapolis, MD 21401-1991

The Honorable Michael E. Busch  
Speaker of the House  
H-101 State House  
Annapolis, MD 21401-1991

RE: Health - General Article § 13-2806(1) - 2011 Preliminary Legislative Report on  
The Maryland Commission on Autism

Dear Governor O'Malley, President Miller and Speaker Busch:

Pursuant to Health - General Article, Section 13-2806(1), the Department of Health and Mental Hygiene and the Maryland State Department of Education submit this report on the preliminary findings and recommendations of the Maryland Commission on Autism. The Commission is mandated to advise and make recommendations to the governor, General Assembly, and relevant State agencies regarding matters concerning services for individuals with Autism Spectrum Disorders at all State levels, including health care, education, and other adult and adolescent services. The Commission is also charged with developing a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with Autism Spectrum Disorders; and to evaluate ways to promote Autism Spectrum Disorder Awareness.

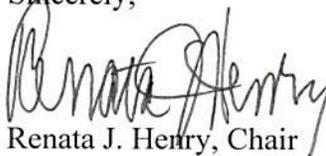
This report synthesizes the work of the Commission and its activities since its inception in October 2009 in a concise subset of findings and recommendations. The report also describes the focus of the Commission's work over the next year and half. Although this report includes comments and quotes as examples, it is not a comprehensive representation of the efforts put into the work of the Commission or a reflection of individual Commission member's opinions or recommendations.



The Honorable Martin O'Malley  
The Honorable Thomas V. Mike Miller, Jr.  
The Honorable Michael E. Busch  
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I hope this information is useful. If you have questions regarding this report, please contact Ms. Jill Porter, Assistant Director of the Office of Governmental Affairs, at (410) 767-6509.

Sincerely,

A handwritten signature in black ink, appearing to read "Renata J. Henry". The signature is fluid and cursive, with the first name being the most prominent.

Renata J. Henry, Chair  
Deputy Secretary for Behavioral Health and Disabilities  
Maryland Department of Health and Mental Hygiene

Enclosure

cc: Joshua M. Sharfstein, M.D.  
Members of the Maryland Commission on Autism  
Marcella Franczkowski, Assistant State Superintendent, MSDE  
Jill Porter  
Ms. Sarah Albert, MSAR #7883

*Maryland Commission on Autism*

**INTERIM REPORT ON ACTIVITIES, FINDINGS  
AND RECOMMENDATIONS**

**August 15, 2011**



## Executive Summary

As many as 50,000 Marylanders may have a form of autism. From the time autism was officially recognized in 1943 and until the 1970's, it was considered fairly rare. By the 1980's, the estimated prevalence doubled and jumped to a ten-fold increase in the 1990's. Current studies have consistently found the prevalence to be increasing, with the most recent U.S. estimate at 9.0 individuals per 1,000, or roughly 1 in 110.

Autism Spectrum Disorder (ASD) is a term frequently used by physicians, researchers, and the media to encompass a number of diagnoses including Autistic Disorder (AD), Asperger's Syndrome, and Pervasive Developmental Disorders – Not Otherwise Specified (PDD-NOS). While the severity of symptoms and the expression of characteristics vary from individual to individual, the common characteristics include challenges or marked deficits in communication, restricted or unusual interests, difficulty with social relationships, and inflexibility. Regardless of the specific diagnosis, the impact of an autism spectrum disorder is pervasive, affecting most if not all major life activities.

*“Overall, nothing is working now that comprehensively addresses the needs of people with autism across the lifespan.”*  
Parent Participant

## History and Goals of the Commission

The Maryland Commission on Autism was created when Governor Martin O'Malley signed Senate Bill 963 (Chapter 337)/House Bill 503 (Chapter 338) on May 7, 2009. The Commission is charged with envisioning a comprehensive and integrated approach to service systems and supports for persons on the spectrum and their families at all state levels.

The Commission held its first meeting in November 2009 and since then, has held seven meetings. Four of the meetings were designated as “listening sessions” and held in four different parts of the state – western, central, southern and eastern. These sessions included a panel of speakers and public comment which provided the Commission with insight into regional issues.

## Preliminary Findings

Five themes evolved as the Commission heard from parents, special education specialists, waiver coordinators, adult services providers and adults with autism and through the work of the seven workgroups. They were: access, quality, communication, training and funding.

### Access

Issues included geographic access as well as affordability, transportation, language interpreters, cultural sensitivity and others. Specific issues related to access included information, funding,

distribution of services and supports, more collaboration and an integrated approach to a system of services and supports.

### Quality

This includes measures of quality of professional services, benchmarks of excellence, evaluation, and consistent application of standards. Some of the comments indicated that access to more services and supports would be meaningless if there is no focus on quality.

### Communication

Discussions focused on improving private-public partnerships, better communication and improved collaboration among professionals and with families.

### Training

Concerns raised included ensuring that pre-service and in-service content and processes are linked and based on evidence based practices. This included the need for professional development to ensure that staff is familiar with best practices and training for indirect service providers such as police, fire and emergency medical services personnel to improve their awareness of ASD and acquire the skills to interact with people with ASD.

### Funding

Issues ranged from funding for research to services and supports, especially in a more integrated manner with families, consumers and self advocates aware of and guiding these efforts. While some efforts require more funding, it was also recognized that some savings could be realized with shared resources and greater collaboration and integration of the system.

## **Next Steps**

The themes that emerged helped the Commission to envision what a comprehensive system of services and supports would include. Parts of a comprehensive and integrated system would include Diagnosis and Referral, Interventions, Supports, Communities of Care and Research and Education. These parts would be interconnected and would enable an individual with ASD to live full and meaningful lives.

The Commission will continue to conduct most of its work within the seven workgroups established during its first year of operation. Its work will move from the initial needs and resource assessment to the development of a comprehensive plan for a system of services and supports for persons with autism across their lifespan.

## **Autism Commission Membership**

**Renata Henry**, Chair, *Deputy Secretary for Behavioral Health and Disabilities, DHMH*  
**Carol Ann Heath**, Co-Chair, *Assistant State Superintendent, MSDE*  
**Dorinda Adams**, *Program Manager, Office of Adult Services, DHR*  
**Kim Cammarata**, *Assistant Attorney General, Consumer Protection Division*  
**Denise Cedrone**, *Frederick County Public Schools*  
**Cristine Ceely**, *Physical Therapist, Montgomery County Public Schools*  
**Lisa Crabtree, Ph.D.**, *Occupational Therapist, Assistant Professor, Towson University*  
**Kelli Cummings**, *Director of Community Living Policy, Department of Disabilities*  
**Ed Feinberg, Ph.D.**, *Anne Arundel County Public Schools*  
**Scott Hagaman, M.D.**, *Medical Director for the Linwood Center*  
**Cynthia M. Hill**, *Parent*  
**Katherine Klausmeier**, *Maryland Senate*  
**Rebecca Landa, Ph.D.**, *Kennedy Krieger Institute, Associate Professor Psychiatry, JHU*  
**Rachel London**, *Director of Children and Family Policy, Maryland DD Council*  
**Wendell McKay, M.D.**, *Pediatrician*  
**H. Angela Mezzomo**, *Maryland Speech Language Hearing Association*  
**Katie Miller**, *Autistic Self-Advocate*  
**Karen S. Montgomery**, *CSAAC*  
**Debra Perry**, *President, AFT Healthcare Maryland*  
**Kirill Reznik**, *Maryland House of Delegates*  
**Carol Samuels Botts, M.D.**, *Kaiser Permanente*  
**Marjorie Shulbank**, *Education Program Supervisor, Division of Special Education/Early Intervention Services, MSDE*  
**Careen Wallace**, *Parent*  
**Fred Whiton, Jr.**, *Parent*  
**Zosia Zaks**, *Autistic Self-Advocate*

**\*Ellen Kuhn**, *Assistant AG, Consumer Protection Division*  
**\*Thelma Thompson**, *President, UMES*

**\*Denotes former members**



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## Introduction

Autism Spectrum Disorder (ASD) is a term used to encompass the following diagnoses in the DSM-IV: Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified. The cause of an increase in prevalence is unknown and could be due to increased awareness, genetics, environmental influences, or the ever evolving diagnostic criteria. A rapid increase in the prevalence of autistic disorders is relatively well accepted.<sup>1</sup>

From the time autism was officially recognized in 1943 until the 1970's, it was considered fairly rare. By the 1980's, the estimated prevalence doubled<sup>2</sup> and jumped to a ten-fold increase of 2.0-7.0 individuals per 1,000 in the 1990's<sup>3</sup>. Current studies have consistently found the prevalence to be increasing, with the most recent U.S. estimate at 9.0 individuals per 1,000, or roughly 1 in 110<sup>4</sup>. Unfortunately, diagnostic and service

**"With prevalence on the rise, costs for care and supports increasing, training and awareness lagging, and insufficient coordination, much is needed in a very short period of time."**

disparities exist among poor and minority children with ASD, who are diagnosed later and enter the mental health system later as well<sup>5</sup>. Racial and ethnic minorities may have restricted access to care or experience cultural differences in ASD symptom awareness<sup>6</sup>. One study of quality of care for ASDs in Pennsylvania found that children living in poverty were diagnosed almost a year later than those living above poverty<sup>7</sup>.

The service a child receives is affected by where the child received the ASD diagnosis<sup>8</sup>. One study examining service use among adolescents with mental health problems, found school systems play a crucial role as the point of entry for mental health services<sup>9</sup>. School systems also play a critical role in diagnosis and service delivery for children with ASD. Bhasin and Schendel (2007) report that school diagnoses can account for over half of ASD diagnoses while less than 10% are identified solely by a non-school source. This phenomenon is particularly pronounced in Maryland, where schools served close to 9,000 students on the spectrum last year.

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<sup>1</sup> Fombonne, 2005

<sup>2</sup> Newschaffer et al., 2007

<sup>3</sup> Yeargin-Allsopp et al., 2003; Rice, 2007

<sup>4</sup> Bertrand et al., 2001; Newschaffer et al., 2007; Rice, 2009).

<sup>5</sup> Mandell, Listerud, Levy, and Pinto-Martin 2002

<sup>6</sup> Liptak, et al., 2008; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007

<sup>7</sup> Mandell, Novak, & Zubritsky, 2005

<sup>8</sup> Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001

<sup>9</sup> Farmer, Burns, Phillips, Angold, & Costello, 2003

This complicated picture of ASD's indicates the need for a comprehensive and integrated approach to service systems and supports for people on the spectrum and their families. Addressing physical access, poverty, agency collaboration, and cultural competency issues is critical to developing a successful model. With prevalence on the rise, costs for care and supports increasing, training and awareness lagging, and insufficient coordination, much is needed in a very short period of time.

## History and Goals of the Commission

On October 1, 2009, Governor O'Malley appointed the membership of the Maryland Commission on Autism. This was in response to Senate Bill 963 establishing the Commission and its work.

Generally, the Maryland Commission on Autism was established to "Advise and make recommendations to the Governor, General Assembly, and relevant state agencies regarding matters concerning services for individuals with Autism Spectrum Disorders at all state levels including: health care, education, and other adult and adolescent services." In addition, it was to focus on the development of a "comprehensive statewide plan for an integrated system of training, treatment and services for individuals of all ages with Autism Spectrum Disorders."

"Overall, nothing is working now that comprehensively addresses the needs of people with autism across their lifespan."

*Parent Participant*

## Activities of the Commission to Date

The Commission undertook its work through a number of methods. First, workgroups were established to tap into a variety of professional and consumer perspectives. During the first year of activity, these seven (7) workgroups met 44 times collectively, sharing a total of 74 individuals. More details regarding the workgroups, the number of participants and number of meetings is contained in Table 1 at the end of the report. Second, the Commission traveled to six (6) different locations around the state to offer open meetings, hear public comments, and receive perspectives and recommendations from diverse communities and regions. These regional meetings, the dates, locations, and numbers of public comments are listed in Table 2. Finally, four of the regional meetings included public listening sessions. This information is listed in Table 3. The Commission also held a one-day retreat on April 26, 2011 to review discussions, findings, and recommendations. All Commission meetings are open to the public.

## Preliminary Findings

The findings and recommendations from the workgroups and other Commission activities are extensive and beyond the scope of detailed reporting here. Copies of meeting minutes and workgroup reports can be found at [www.dhmf.maryland.gov/autism/](http://www.dhmf.maryland.gov/autism/). The focus of this report is

to synthesize the work into a brief subset of findings and recommendations that can both inform the legislature of the Commission's work and activities, as well as continue to focus the work of the Commission. Commission staff and other participants worked to analyze the findings and recommendations, to identify themes relevant to continuing the critical work of the Commission. A number of cross cutting themes were identified that were discussed during workgroup and regional meetings. These reoccurring themes led the Commission to identify the components of a comprehensive and integrated system of services and support. Brief descriptions of these themes and system components are described below. While this report includes comments and quotes as examples, it is not intended to be comprehensive in its representation of discussions or comments. It should be noted that this report is not necessarily a reflection of each individual member's personal opinions or recommendations. The Commission will continue to refine its work and its analysis of the needs, solutions, and plans required.

### **Cross Cutting Themes**

1. **Access**: This includes barriers to access including but not limited to geographic financial, transportation, language and cultural differences, and other issues. Many of the comments from workgroups and community participants indicated that if services or supports exist at all, they often exist in drastic shortage to the demand, and often at great distance and cost to individuals and families. A number of issues were mentioned that are related to access including information, funding, distribution of services and supports, and a more collaborative and integrated approach to a system of services and supports. One example follows:

“Jane”, an Autism Waiver Service Coordinator from Southern Maryland, discussed the barriers that families in Southern Maryland are faced with in trying to secure needed services and supports for their children with ASD. Jane indicated that the most significant barrier faced by families is the “ruralness” of the Southern Maryland region. There are 2 primary service providers in the region, and very few options for medical care, related services, respite care, and recreation for children with ASD. Jane indicated that the distance is prohibitive, and that there are no incentives in place to encourage providers to extend their services to Southern Maryland. As a result, families in this region do not have access to timely services. Jane noted that many treatment providers work full-time jobs in addition to their part-time work providing Waiver services. This means that often the most qualified personnel are experiencing “burn out.”

2. **Quality**: This includes measures of quality of professional services, benchmarks of excellence, evaluation, and consistent application of standards. Many of the comments supported the notion that having more services or supports would be meaningless without a focus on quality. While some of this involves issues like training, there were also discussions regarding evidence-based benchmarks for quality in services and supports, collaborative and transparent quality data, and fiscal incentives to engage in quality enhancements. Like all of the system components, quality measures and efforts will require input from consumers, families, and self-advocates to ensure relevance. Access to

standardized and high-quality providers has varied across time, becoming somewhat of a moving target. The comment below illustrates this point.

"Having been a part of the Autism Waiver since its inception, I have observed the growth of the entire Autism Waiver Process. It has been a work in progress that has resulted in continuous refinements of the standards and policies that govern all participants of the waiver. The vigilant overseeing of the process has resulted in better documentation and delivery of services at all levels. We have gone from having no providers to two consistent providers and a list of other providers that are willing to provide services to waiver students in [our county]. We have gone from accepting mediocre services to the "luxury" of dismissing providers because they do not comply with the higher level of standards."

**"We have gone from accepting mediocre services to the "luxury" of dismissing providers because they do not comply with the higher level of standards."**

3. Communication, collaboration and partnership: Discussions focused on improving private-public partnerships, better communication, and improved collaboration among professionals, self advocates and families. Some of the workgroup and public comments focused on how agencies and providers could be more collaborative and efficient in their communications. This relates to things like research and evaluation, as well as the other components of the system outlined previously.

"Ms. Smith", a parent, described the diverse needs of individuals with ASD on varying ends of the spectrum. She noted that some youth who are mildly impacted by their autism 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. Smith reported that additional funding should be directed to early intervention systems and the Autism Waiver, to eliminate the wait for access to needed services.

4. Training, professional development, and dissemination: This included topics like ensuring that training content is practical and has day-to-day application and is rooted in evidence-based practices. Some of the discussions in the workgroups and public comments related to how professionals in the field are trained compared to how they should be trained. It was also suggested that these efforts will need to be updated as new evidence becomes clear and substantiated, and that a link between research and practice will be an important part of the state's effort to ensure quality in all dimensions of its service and support systems. Some examples of comments include:

"Ms. Jones" indicated that police, firefighters, 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.

“Ms. Sands” 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.

A service provider indicated, “We need higher education facilities that include a curricular component that gives potential service providers a solid working base for individuals with these intensive and unique needs.”

“We need higher education facilities that include a curricular component that gives potential service providers a solid working base for individuals with these intensive and unique needs.”

*Provider*

Potential service providers could include teachers, occupational therapists, physical therapists, speech language therapists, behavior specialists, etc.

5. **Funding:** This includes improving funding for all system components in an integrated fashion with families, consumers, and self-advocates aware of and guiding these efforts. While it is obvious that some of the efforts outlined may require greater funding than currently exists, it is also recognized that some savings could be realized with shared resources and greater collaboration and integration of the system. The importance of assessing and budgeting for all components of the system was discussed, as under-funding or not funding any part of the system could lead to failures of the system to adequately serve its consumers. In addition, it is critical that the public play an important and informed role in advocating for increased state, federal, and private funding. Some examples of comments include:

“Judy” 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.

“Mandy” reported that her family currently pays out of pocket for her son’s early intervention services, and discussed the financial strain that these programs pose for her family and so many other families like hers. Mandy 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 needs. Mandy indicated that her family can no longer afford to pay for intensive services for [her son]. She discussed the impact that his 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 [her son] to and from his services each day.

## **System Components**

The themes noted previously helped the Commission to visualize the components of a comprehensive system of services and supports for people with ASD across their lifespan. They are: Diagnosis and Referral, Interventions, Supports, Communities of Care, and Research and Education.

1. **Diagnosis and Referral:** This includes physicians, early interventionists, clinicians, self-advocates and others applying state-of-the-art techniques to identify and refer children, youth and adults for services. Many comments referred to the need to increase the quantity and quality of diagnostic professionals, as well as the ability to link these professionals to a comprehensive and collaborative system of services and supports for referrals. As the prevalence and awareness of autism increase, the skills and quality diagnosis and referral to appropriate services and supports becomes more complicated. For instance, one pediatrician noted:

“The diagnosis of ASD is based on observation and pathophysiology.”

*Pediatrician*

“The diagnosis of ASD is based on observation and pathophysiology<sup>10</sup>.” The doctor shared that researchers are focused on mapping the genome associated with ASD, in order to provide bio-diagnostic treatment for the core pathology of the disorder. Advancements such as these would allow physicians to personalize treatment based on ASD phenotype. It was stressed that parents and families of individuals with ASD need training. The doctor 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.

2. **Interventions:** This includes clinicians, schools, service providers, self-advocates, and families collaborating to implement effective and state-of-the-art interventions. Interventions should include a broad array of medical, behavioral, genetic, psychological, and other interventions. Interventions have been described by professionals, parents, families, and self-advocates in a variety of ways, indicating that interventions stretch far beyond medical and psychological ones. For instance, one parent discussed the need to:

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<sup>10</sup> Pathophysiology-the functional changes that accompany a particular syndrome or disease

Develop a model to meet the needs of children and adults with very intensive and complex needs in scattered locations across Maryland. This service model would provide an environment where an individual with severely challenging behavior could receive supports to be educated, recreate, live and/or work safely. The model program would be a resource to community providers as well as a short term or long-term placement for individuals who

**"The model program would develop individualized recommendations to support the individual in a community setting, and provide training and technical assistance to the community provider. An individual could return, if unsuccessful, to the model program, re-evaluate support needs and try again."**

are unsafe in current community placements. Specialized services including psychological, psychiatric, neurological and medical services would be available to individuals in the model program. "The model program would develop individualized recommendations to support the individual in a community setting, and provide training and technical assistance to the community provider. An individual could return, if unsuccessful, to the model program, re-evaluate support needs and try again."

Another parent said:

"Our son needed speech, occupational, and behavioral therapy. Our insurance company referred us to the school system for the speech and occupational therapies, but the school system did not have adequate resources to meet the growing demand. Even when our son received Medicaid benefits under the Waiver, participating providers were not readily available, or their schedules were full. There is no way we could have afforded the behavior therapy for our son. Without the behavior therapy, our son would never have made the impressive progress he has demonstrated thus far. Though we were already implementing environmental, nutritional, and dietary changes, the addition of behavior therapy, funded by the Autism Waiver, resulted in noticeable and dramatic improvements. The environmental, nutritional, and dietary changes laid the foundation for our son to be mentally receptive to the behavioral therapy. I do not wish to minimize the educational component as well. The appropriate school placement worked synergistically with his other interventions."

3. **Supports:** This includes implementing community and other professional and natural supports to ensure the success of interventions, including cross-agency planning and communication. Many comments included the need to promote natural and non-professional supports that facilitate the identification, referral, and intervention processes. Agencies, families, self-advocates, and others working to collaboratively plan, develop, implement, and evaluate supports would be helpful, but comments also referred to the need for non-agency related supports and funding. The following example illustrates some of these points.

“Jim” an adult, who is mildly impacted by his autism, is a student at Towson University, majoring in Psychology. Jim previously attended Anne Arundel County Public Schools and described both positive experiences and challenges he encountered throughout school. Jim spoke to the benefits of early identification and intervention, indicating that he felt as though these services were very helpful to him. He 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. Jim expressed his need for ongoing support services throughout adulthood, citing his desire for a caseworker to assist him in developing executive functioning skills, to ensure that he can be successful in living independently.

4. Communities of Care: This includes communities that understand and support individuals with ASD as well as their families in their efforts to integrate themselves or their loved one into the community. All settings including childcare, schools, colleges, civic groups, places

"There [is a] need for increased awareness of ASD in emergency situations; peace officers, judges, or any emergency response system must know what to do upon arrival to an emergency situation."

of worship, and businesses must be considered. “Communities of Care” relates to the contexts within which the other components of the system are realized. It will be critical to keep the public informed and to collaboratively develop, implement, and evaluate systems components with input from these public domains. This is especially important in any public relations and dissemination efforts so that efforts are not solely focused on professional associations and agencies. One provider comment was:

"There [is a] need for increased awareness of ASD in emergency situations; peace officers, judges, or any emergency response system must know what to do upon arrival to an emergency situation. There are too many referrals of people with ASD with forensic and/or legal involvement due an inability to assist them and their families in an emergency situation."

5. Research and Education: This includes research and education personnel who should collaborate with families, self-advocates, and clinicians to understand what works, improve systems, and disseminate information. Some of the comments related to a relative lack of collaboration among researchers, and the lack of a comprehensive clearinghouse or central repository of information related to who is involved in research and evaluation in the area of autism in Maryland. One workgroup noted the following:

- "Barriers between researchers-the lack of forum for researchers in Maryland to be aware of each other’s interests, projects, and opportunities for collaboration,"

- "Barriers between researchers and access to state data-the inconsistently available infrastructure of efficient Institutional Review Boards (IRBs) and research savvy personnel to regulate and facilitate access to state owned data," and
- "Barriers between researchers and potential subjects-lack of a central information point that would allow interested persons with ASD or families of children with ASD to find research to participate in as well as the coordination that would prevent the overburdening of any particular cohort with too many research requests."

## Next Steps

The work of the Commission will continue for another year, focusing on moving from the initial needs and resource identification stage to the development of a comprehensive plan for a system of services and supports for persons on the autism spectrum in Maryland. During this next year, it will be important for the Commission and its workgroups to use a model like that in Figure 1 on page 17 to guide its conceptualization of such a system. While it will be tempting to try to fix isolated problems immediately, doing so could jeopardize the ultimate goal of a more comprehensive and integrated system of services and supports. To address the dual goals of focusing on broad systems perspectives while also addressing immediate needs, recommendations have been developed and are listed below.

1. Using the model in Figure 1, workgroups will focus on evaluating specific elements of the model using the five system components and five cross cutting themes represented in the model. For instance, the workgroups will address which barriers to access are present for diagnosis, referral, interventions, and support. Then, the workgroup will address the resources needed to remove or minimize each barrier.
2. Collect initial reports from each workgroup regarding issues and barriers, compile these lists across workgroups, and prepare a comprehensive list of system-related barriers, issues, and needed resources.
3. Distribute this overall list back to the workgroups, who will then prioritize the barriers and resources as part of the overall planning process. This should increase the likelihood of removing the barrier and identifying the needed resources. The workgroups should also ask for ideas regarding how to measure the impact of each new solution or activity.
4. Compile all workgroup rankings and use these rankings to create a master list of activities that can be put into a timeline for statewide action during the coming years.
5. Develop short- and long-term measures of impact for each of the items in the new work plan.
6. Complete final cross-referencing of work accomplished with mandated work of the Commission to ensure that all tasks and areas have been addressed.



***Table 1: Workgroup Information***

<b>Workgroup</b>	<b># Members</b>	<b># Meetings</b>	<b>Workgroup Leader</b>	<b>Workgroup Staff</b>
Adult Service System	16	7	Zosia Zaks, Sen. Karen Montgomery	Colleen Gauruder
Evidence Based Practice	7	10	Dr. Scott Hagaman	Karla Saval
Funding and Resources	12	9	Del. Kirill Reznik	Renata Henry
Health/Medical Services	7	2	Dr. Wendell McKay	Gayle Jordan-Randolph
Research Partnerships	8	2	Dr. Rebecca Landa	Lisa Hovermale
Transition Age Youth	13	10	Fred Whiton	Al Zachik, Marcia Andersen
Workforce Development	11	4	Dr. Thelma Thompson Dr. Lisa Crabtree	Diane Dressler

***Table 2: Regional Meeting Information***

<b>Meeting Date</b>	<b>Location</b>	<b># Public Comments</b>
11/10/2009	Columbia – Howard Co.	12
1/12/2010	Arnold – Anne Arundel Co.	1
4/20/2010*	Easton – Talbot Co.	3
7/13/2010*	Hagerstown – Washington Co.	2
10/19/2010*	La Plata – Charles Co.	4
1/11/2011*	Arnold – Anne Arundel Co.	5

\* indicate listening sessions

***Table 3: Listening Session Information***

<b>Date</b>	<b>Adult w/ ASD</b>	<b>Parent</b>	<b>Adult Service Provider</b>	<b>Special Ed Coordinator</b>	<b>Autism Waiver Coordinator</b>	<b>Pediatrician</b>
4/20/2010	Brandon Crawford	Mr. Bonnell	Trish Esh	Bonnie Walston	Maleasa Blackway	
7/13/2010	Lauretta Williams w/ Larry Lipsitz (staff)	Cynthia Hill	Phyllis Landry	Pamela Pencola	Linda Werner	
10/19/2010		Missy Alexander	Susan Ingram	Melissa Charbonnet	Judith Buckler	Nitya Ramachandran
1/11/2011	Matthew Eberly, Robert Harle	Marlo Lemon	Monica McCall	Mary Tillar, Ed Feinberg	Sheri Weissman	

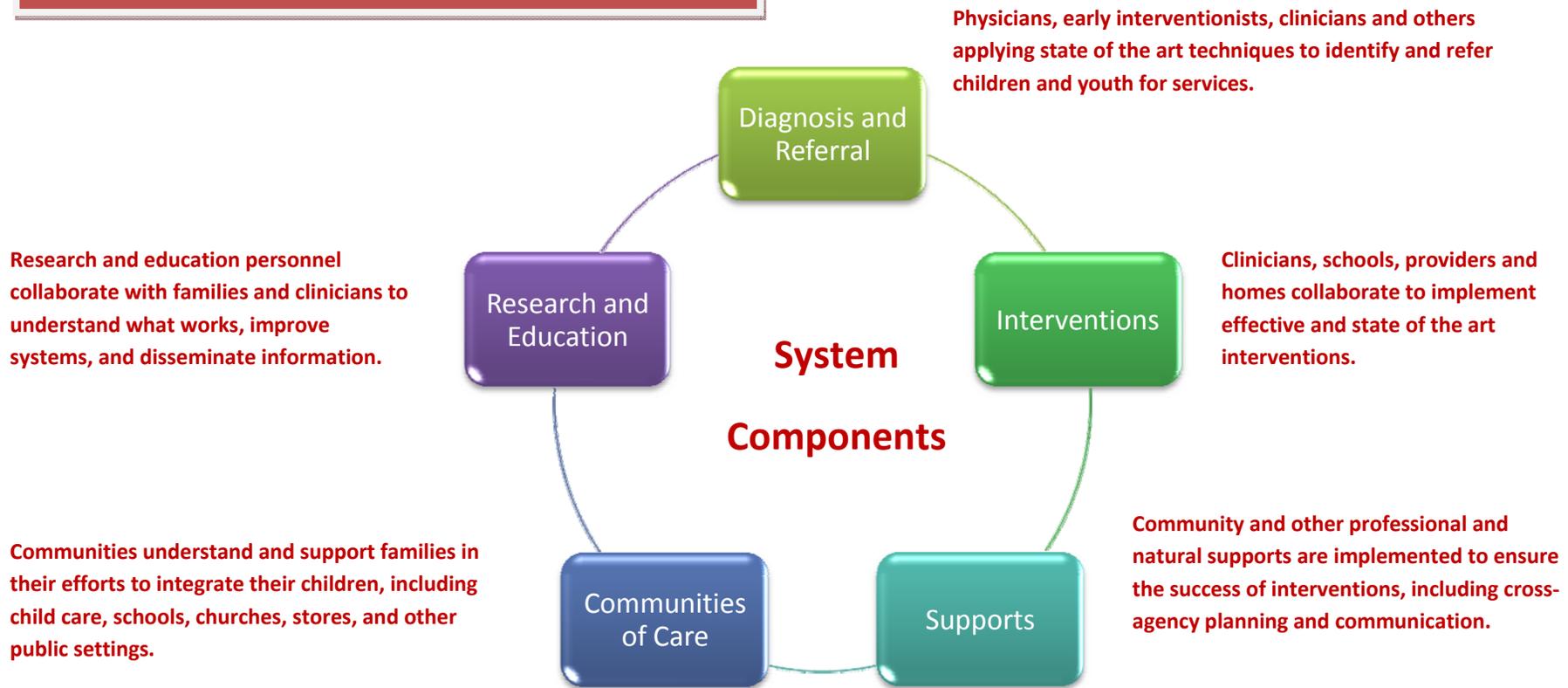


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**Figure 1: Conceptual Model**  
**Linking Systems of Care and Communities of Care**  
**Through Identification, Intervention, Supports, and**  
**Research**



***Cross Cutting Themes: These themes appeared often across the domains listed above.***

**Access:** This included geographic access, as well as things like affordability, transportation, and other issues that facilitated access.

**Quality:** This included measures of quality of professional services, benchmarks of excellence, evaluation, and consistent application of standards.

**Communication, collaboration and partnership:** Discussions focused on improving private-public partnerships, better communication, and improved collaboration among professionals and with families.

**Training and professional development:** This included things like ensuring that pre-service and in-service content and processes are linked and rooted in evidence-based practices.

**Funding:** This included funding for all elements of the system from research to services and supports, especially in an integrated fashion with families aware of and guiding efforts.