Addressing the Needs of Individuals with Autism Spectrum Disorders in Maryland

RECOMMENDATIONS FOR A STATEWIDE SYSTEM OF CARE IN RESPONSE TO HG § 13-2806(2)

MARYLAND COMMISSION ON AUTISM
SEPTEMBER 2012

MARYLAND
Commission
on Autism

September 30, 2012

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

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

RE: HG § 13-2806(2) and SB 963, Ch. 337\HB 503, Ch. 338 of the Acts of 2009 – Addressing the Needs of Individuals with Autism Spectrum Disorders in Maryland

Dear President Miller and Speaker Busch:

On behalf of the Maryland Commission on Autism, it is our privilege to submit the Commission's report to you for your consideration and support. The report is the culmination of a three-year process of evaluation, study, findings, and recommendations.

This report contains twelve recommendations that represent hours of work from the members of the Commission to ensure that many viewpoints were heard and considered on behalf of individuals living on the autism spectrum and their families. The members of the Commission should be commended for their significant work. The members represented a wide range of areas and philosophies of the Autism Spectrum Disorders (ASD) community. This comprehensive member representation produced a report that presents a range of recommendations aimed at filling gaps, meeting unmet needs, and developing a foundation for a comprehensive system of services and supports.

The Commission realizes that the recommendations will require legislative support, funding commitment, and both short and long term implementation strategies to achieve the desired outcomes. This report provides an opportunity for Maryland to have a renewed focus on ASD and address a lifelong condition that now impacts one in eight-eight children born in Maryland. We look forward to your support and thank you for recognizing the importance of this issue.

Sincerely,

Renata Henry

Renata J. Henry
Former Deputy Secretary, DHMH
Chairperson

Marcella E. Franczkowski

Marcella E. Franczkowski, M.S.
Assistant State Superintendent, MSDE
Vice-Chairperson

Enclosure

c: The Honorable Martin O'Malley

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The Maryland Commission on Autism wants to recognize members who formerly served and contributed to the work of the Commission.

Carol Ann Heath-Baglin, former Assistant State Superintendent, MSDE
Ellen Kuhn, former Assistant Attorney General, Office of the Attorney General
Thelma Thompson, Retired President, UMES

The Commission on Autism also expresses their appreciation to the parents and other individuals who regularly attended meetings and actively contributed to the content of this report.

DISCLAIMER AND NON-ENDORSEMENT STATEMENT

The Maryland Commission on Autism (Commission) report sets forth the collective recommendations and positions of its members and does not necessarily reflect the individual position of any member and/or the organization the individual represents.

The Commission has taken all reasonable measures to ensure that material contained in this report is valid. However, the Commission gives no warranty for the accuracy or the completeness of the material and the user should check for confirmation with the originating or authorising faculty, department, or other body.

Additionally, neither the Office of the Governor, individuals serving on the Commission, the Department of Health and Mental Hygiene, the Department of Disabilities, the Maryland State Department of Education, the Department of Human Resources, nor the Attorney General warrant or represent the accuracy, completeness, or the scientific validity of any information contained therein.

Finally, the Commission's references to specific organizations, programs, research institutions, events, commercial products, processes, or services do not constitute or imply endorsement or favoring by the Department of Health and Mental Hygiene, Department of Disabilities, the Maryland State Department of Education, the Department of Human Resources, the Office of the Governor, or individuals serving on the Maryland Commission on Autism.

A note on language used in this report:

There are two types of language used to refer to people throughout this document: **person-first language,** and **identity-first language.** People who prefer one type of language often find the other type to be offensive. The Commission has decided to use both types of language in this document out of respect for the difference of opinions.

Person-First Language

Generally, when speaking about people with disabilities, it is standard etiquette to refer to the person first and the disability second. For example, one would say, “a person with autism,” instead of “an autistic person.” Person-first language is often preferred by non-disabled parents, professionals, and many people with a variety of disabilities. Proponents of person-first language believe it to be the most respectful because it emphasizes an individual’s humanity rather than the disability. They believe this translates into putting an individual before their disability.

Identity-First Language

The Autistic Self-Advocacy Community, in general, prefers Identity-First Language. For example, one would say, “an Autistic person,” instead of “a person with autism.” Identity-First Language is often preferred by Autistic people, other disability groups such as the Blind and the Deaf Communities, and a growing number of non-disabled parents and professionals. Proponents of identity-first language believe it to be the most respectful because it acknowledges that disability is an inseparable and important part of a person’s identity, rather than an appendage the person *has*. They believe this leads toward acceptance and affirmation of disabled people and decreases stigma.

Autism and Autism Spectrum Disorder

By editorial decision, the terms “autism” and “autism spectrum disorder” are used interchangeably in this report as an umbrella term that includes the current DSM-IV diagnoses of Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger Disorder.

EXECUTIVE SUMMARY

Maryland Commission on Autism

On October 1, 2009, Governor Martin O'Malley appointed the Maryland Commission on Autism. This was in response to Senate Bill 963, Chapter 337/House Bill 503, Chapter 338 of the Acts of 2009 establishing the 26-member Commission and defining its work. The members of the Commission consist of a broad representation of Maryland citizens, representing both urban and rural communities, who are concerned with the health and quality of life for individuals with autism spectrum disorders (ASD) and are from diverse backgrounds that include adults with ASD, parents, legislators, state agency representatives, non-profit organizations, health care providers, disability organizations, labor, and insurers.

The Maryland Commission on Autism was established by Health-General §13-2801 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."

Specifically the General Assembly charged the commission to:

- Evaluate ways to promote ASD awareness
- Review the findings of any summit or conference regarding ASD
- Determine the need for the creation of services in designated areas of the state
- Develop recommendations for expanding services in conjunction with hospitals
- Develop recommendations to address the transition of children aging out of the autism waiver
- Develop a recommendation for enlisting universities and colleges in workforce development
- Evaluate programs that exist in other states to determine benefit to individuals in Maryland
- Develop recommendations for facilitating the coordination of research opportunities

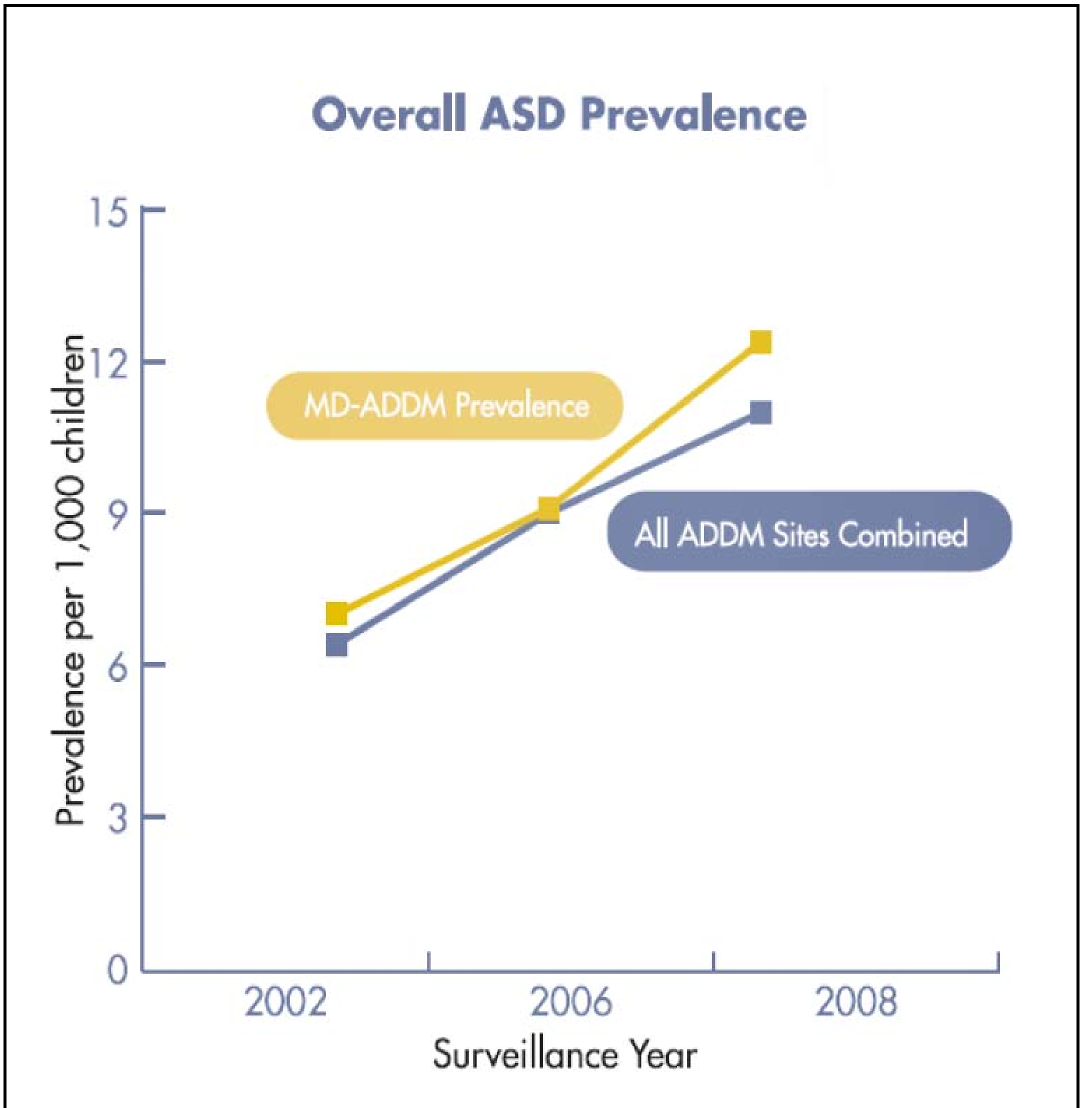
The result of the Commission's work is a plan with recommendations that will:

- Guide the Governor, the General Assembly, and relevant State agencies in the development of a coordinated community system of care for individuals on the autism spectrum
- Clarify the array of necessary services and supports that will enable individuals with autism to function to their potential across the life span
- Provide a vehicle to support the system of care infrastructure

ASD in Maryland

The latest figures from the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring Report (ADDM), reaffirm that autism is a critical health issue. Nationally, the prevalence of ASDs among children increased by 78%, from 6.6 per 1000 children in 2002 to 11.3 per 1000 children in 2008. In Maryland, the overall estimated prevalence of ASDs is 11.3 per 1000 or one in eighty-eight. This translates into an impact on the lives of thousands of Maryland children, adults, families, and state agencies and systems.

Chart 1: Overall ASD Prevalence in Maryland Compared to All ADDM Sites, 2002 - 2008



MD-ADDM also collected data for the 2000 and 2004 surveillance years. See the earlier ADDM Network reports for this information. The data shown are based on the surveillance area covered at all three time points.

With prevalence continuing to increase, the demand for access to services, education and training, community awareness, and improved research is considerable and indicates the need for a comprehensive, coordinated and systemic approach to the above issues.

Commission Work

As mandated, the Commission undertook its work through a number of methods. Nine workgroups were established to tap into a variety of professional and stakeholder perspectives in the areas of: Health and Medical Services, Transitioning Youth, Adult Services, Funding and Resources, Research Partnerships, Evidence-based practices, Workforce Development, Data, and Early Intervention and Awareness. The Office of Genetics and People with Special Health Care Needs was added as an ad-hoc workgroup based on their receipt of a CDC Planning Grant targeted to children with autism and other developmental disabilities.

The Commission held quarterly public meetings from November 2009 to September 2012. Four of these meetings were designated as Regional Listening Sessions and held in the Eastern Shore, Western, Southern, and Central Maryland areas to hear directly from families, adults with autism, service providers, special educators, autism waiver coordinators, doctors, and other community members regarding their perspectives and experiences with existing services, access to and availability of services, and gaps in services. Additional public meetings of the Commission included presentations from special experts to inform and educate the commissioners on related ASD topics.

The Commission also held two one-day retreats in April of 2011 and 2012 to review findings, summarize outcomes, and draft recommendations. In developing the recommendations for this report, the Commission members and workgroup participants spent many hours gathering information from individuals on the spectrum, families, state agencies, key stakeholders, and health professionals. Each workgroup put forth recommendations for potential inclusion in the final report. Where recommendations were similar or overlapping, the recommendations were combined. The recommendations were then voted on and approved by a majority of the Commission members.

The recommendations are focused on individuals with autism spectrum disorders. However, the Commission recognizes that many of the recommendations are applicable to individuals with disabilities other than autism. As the plan is implemented it will be imperative to ensure that the system of care is not developed in a silo, but is agile and efficient in meeting the needs of individuals with other disabilities.

The Commission also recognizes that this report is being submitted during a period of financial uncertainty for the State, but also in a time of great promise with Maryland’s implementation of health reform. The Commission strongly endorses the creation of an Autism Coordinating Council, (Recommendation #1), to ensure that the plan and the implementation process is coordinated across state agencies and communities.

RECOMMENDATIONS

The Commission's recommendations are listed below. A detailed description of each recommendation is contained in the full report. The Commission did not prioritize the recommendations.

1. Create the Governor's Autism Coordinating Council to facilitate implementation of the Autism Commission's recommendations through Executive Order

2. Improve the process of gathering, linking, and sharing information on autism spectrum disorders in Maryland.

3. Maximize the Centers for Medicaid and Medicare Services Home and Community Based waiver opportunities for children and adults in Maryland.

4. Initiate additional mandates for insurance coverage for diagnosis and treatment of autism spectrum disorders to include coverage for habilitative, medical, and behavioral treatment services for adults as well as children.

5. Partner with agencies and organizations serving individuals with ASD and their families to establish Regional Collaborative Hubs as central points for assistance in accessing ASD services, information, and resources.

6. Ensure that all interventions provided to autistic individuals should be safe and consistent with evidence-based practices, practice-based evidence, and/or promising practices.

7. Continue to expand the existing infrastructure for improving developmental screening in all Maryland health care practices using the American Academy of Pediatrics guidelines.

8. Develop and implement a Customized Employment model demonstration project for autistic adults.

9. Create a statewide awareness and outreach plan to increase the awareness and understanding of autism.

10. Provide access to educational opportunities that promote awareness, understanding, and acceptance in addressing the issues of individuals with ASD across the lifespan.

11. Develop consistent operational processes for partnerships and collaborations between ASD researchers, relevant state agencies, and individuals on the spectrum to ensure access to settings, information, participants and service providers.

12. Establish a statewide, universal education and training system using a tiered approach that is available to all public and private providers in Maryland serving individuals on the autism spectrum across the lifespan.

MARYLAND COMMISSION ON AUTISM
FINAL REPORT

Background on Autism Spectrum Disorder

Autism is a group of developmental brain disorders, collectively called autism spectrum disorder (ASD). The term "spectrum" refers to the wide range of symptoms, skills, and levels of impairment, or disability, that individuals with ASD can have. Some individuals are mildly impaired by their symptoms but others are severely disabled. The difficulties usually present in social interaction, verbal, and non-verbal communication and restricted and repetitive patterns of behavior. Symptoms typically are apparent before age 3 and can result in disability throughout the lifespan. The presentation of ASDs are heterogeneous and can have environmental, genetic, and behavioral manifestations. Some individuals with ASD also have a range of co-morbid medical conditions including but not limited to motor and sensory impairments, seizures, metabolic and immunological abnormalities, sleep problems, and GI symptoms. The term ASD includes the current DSM-IV diagnoses of Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger Disorder.

Data on the prevalence of ASDs among children are available from The Centers for Disease Control's Autism and Developmental Disabilities Monitoring Network (ADDM). The ADDM estimates national ASD prevalence based on the number of cases among 8-year-old children in 14 study sites across the nation, including central Maryland. Findings indicate ASDs increased nationwide by 78% from 2002 to 2008 and that the average prevalence, which was 1 in 150 children in 2002, is now over 1% or 1 in 88 children as of 2008 among 8-year-olds, with boys being about 5.2 times more likely to have an ASD than girls. The estimated prevalence of ASDs in Maryland is slightly higher, at 12.4 per 1,000 children, or 1.24%. This varies by sex and race/ethnicity: boys in Maryland are 6.5 times more likely than girls to be diagnosed with an ASD and white, non-Hispanic children have a higher prevalence at 9.3 per 1,000 than black, non-Hispanic children at 7.9 per 1,000 and Hispanic children at 6.3 per 1,000. There is currently no method of accurately assessing how many adults in Maryland have ASDs.

Unfortunately, diagnostic and service disparities exist among poor and minority children with ASD, who are diagnosed later and enter the mental health system later as well[1]. Racial and ethnic minorities may have restricted access to care or experience cultural differences in ASD symptom awareness[2]. 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[3] .

The services a child receives is impacted by where the child received the ASD diagnosis[4]. One study examining service use among adolescents with mental health problems found school

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[1] Mandell, Listerud, Levy, and Pinto-Martin 2002

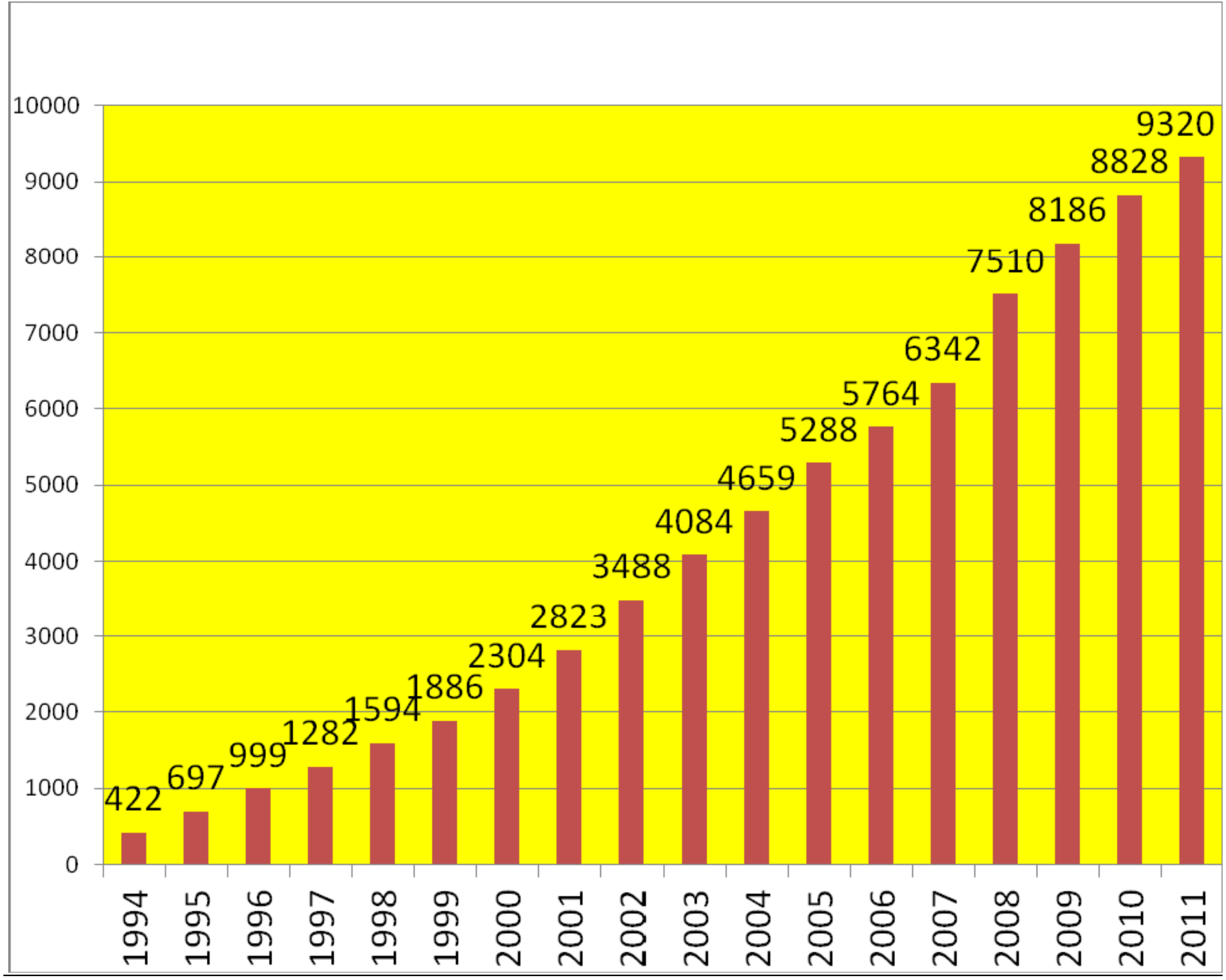
[2] Liptak, et al., 2008; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007

[3] Mandell, Novak, & Zubritsky, 2005

[4] Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2001

systems play a crucial role as the point of entry for mental health services[5]. 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 over 9,000 students on the autism spectrum last year.

Chart 2: Number of Students in Maryland Identified with Autism Code In Educational System*



- This data does not include children birth to three who receive early intervention services, children coded developmentally delayed, children with another special education code, children with Section 504 plans, or children with autism placed in private schools by their parents.

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[5] Farmer, Burns, Phillips, Angold, & Costello, 2003

An article published in the JAMA-Pediatrics and Adolescent Medicine in April 2007 by Michael Ganz, MS, Ph.D., described the societal cost of medical and nonmedical treatment and support for people with autism. Although autism is often viewed as a childhood disorder, the costs continue well into adulthood and throughout the lifespan. The literature review conducted by Dr. Ganz and chronicled in his 2007 article showed that the total annual societal per capita cost of treating and caring for a person with autism in the United States is estimated to be $3.2 million and about $35 billion for an entire birth cohort. The distribution of the cost varies over the lifespan. Understanding the cost variations helps planners, policy makers, and families to make current and future financial decisions.

This complicated picture of ASDs 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 Activities of the Commission

On October 1, 2009, Governor Martin O'Malley appointed the membership of the Maryland Commission on Autism. This was in response to Senate Bill 963 establishing the 26 member Commission and defining the Commission’s work. The members of the Commission consisted of a broad representation of Maryland citizens, both urban and rural, who are concerned with the health and quality of life for individuals with autism spectrum disorders and are from diverse backgrounds that include adults with ASD, parents, legislators, state agency representatives, non-profit organizations, health care providers, disability organizations, labor, and insurers.

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 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."

Vision

An accessible, comprehensive, coordinated system of services and supports are available to families and individuals in Maryland for prevention, early intervention and treatment of autism spectrum disorders to enable them to live full and productive lives.

Mission

To engage in a process of fact finding, data gathering, evaluation, assessment , and analysis of information to determine the adequacy of existing resources and services in Maryland for individuals on the autism spectrum.

Guiding Principles

- Principles of self-determination will be incorporated in all aspects of the recommendations.
- Services should be available to support individuals throughout the lifespan.
- Consumer and family participation and information sharing is required in the development of the Commission's recommendations.
- Stakeholders from all levels will be engaged in the information gathering process.

Autism Summit

In July 2009, a one-day Summit sponsored by the Maryland House of Delegates, the State Department of Education, and the Department of Health and Mental Hygiene, in collaboration with the Milbank Memorial Fund, was convened to discuss the growing prevalence of autism in Maryland and the resulting impact on Maryland families and state agencies. Representatives from State agencies, legislators, and other key policy makers heard perspectives from key community stakeholders; summaries of services and resources from Maryland state agencies; and presentations from the states of Pennsylvania and Missouri on how they are addressing the challenges of autism.

One of the specific outcomes from the Summit was a participant-generated list of opportunities and challenges to guide the Autism Commission's work in the subsequent two years. Many of the identified opportunities and challenges were incorporated into the goals and recommendations of the Commission.
The Summit agenda and list of challenges and opportunities are found in Appendix A.

As mandated, the Commission undertook its work through a number of methods. Nine workgroups were established to tap into a variety of professional and stakeholder perspectives in the following areas: Health and Medical Services, Transitioning Youth, Adult Services, Funding and Resources, Research Partnerships, Evidence-based practices, Workforce Development, Data, and Early Intervention and Awareness. The Office of Genetics and People with Special Health Care Needs was added as an ad-hoc workgroup based on their receipt of a CDC Planning Grant targeted to children with Autism.
More details regarding the workgroups, the participants, and the recommendations are listed in Appendices B through J.

The Commission held quarterly public meetings from November 2009 to September 2012. Four of these meetings were designated as Regional Listening Sessions and held in the Eastern Shore, Western, Southern, and Central Maryland areas. Additional public meetings of the Commission included presentations from special experts to inform and educate the commissioners on related ASD topics.

The Commission also held two one-day retreats in April of 2011 and 2012 to review findings, summarize outcomes, and draft recommendations. In developing the recommendations for this report, the commission members and workgroup participants spent many hours gathering information from individuals on the spectrum, families, state agencies, key stakeholders, and health professionals.

Regional Listening Sessions

The Regional Listening Sessions were held to hear directly from families, adults with autism, service providers, special educators, autism waiver coordinators, doctors, and other community members regarding their perspectives and experiences with existing services, access to and availability of services, and gaps in services. While specific concerns were voiced at each session, there were common themes that cut across all of the regions:

- Access
  - Barriers include geography, finances, transportation, language and cultural factors
  - Shortages in available personnel to deliver the services
- Quality
  - Lack of measures of quality, consistent application of standards of care, benchmarks of excellence
- Collaboration and Partnership
  - Need to improve public-private partnerships
  - Need better communication and collaboration among professionals, self-advocates, and families
- Training and professional development
  - Training needs to be kept current as new evidence becomes clear and substantiated
  - Improved link between research and practice to ensure quality in all dimensions of services
  - Need for evidence-based training that is practical and applicable for day-to-day operations
- Funding
  - Improved funding for all system components
  - Access to ABA and other therapies through insurance
  - Better assessment of budget needs for all system components
- Transition
  - The lack of services, housing, and employment for youth transitioning to the adult system

Despite the concerns, the Commission did consistently hear that when early intervention services were able to be accessed, the MSDE Infants and Toddlers program services were good and the experiences were positive.

A needs assessment conducted by the Office for Genetics and People with Special Health Care Needs and the Parents' Place of Maryland with funding support from a federal grant[6] reinforced what was expressed at the listening sessions. With prevalence continuing to increase, the

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[6] 2011 State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities; Health Resources and Services Administration.

demand for access to services, education and training, community awareness, and improved research is considerable and indicates the need for a comprehensive, coordinated, and systemic approach to the above issues.
A summary of the Regional Listening Sessions can be found in Appendix K and the Needs Assessment can be found in Appendix L.

Current Resources

Federal agencies provide funding to the states for research, policy development, and direct services. State funding is aligned with the federal resources to maximize services to support children and adults with autism and their families. Below is a list of federal and state supported services available in Maryland.

Early Intervention and Special Education Services provided under the Individuals with Disabilities Education Act (IDEA) Part C (birth to age 3) and Part B (ages 3-21) -The Maryland State Department of Education (MSDE), Division of Special Education/Early Intervention Services is the lead agency for the Maryland Infants and Toddlers Program and is also the state education agency responsible for ensuring a free, appropriate public education for all eligible children with disabilities from birth to 21. Approximately 115,000 children a year benefit from an array of specially designed services, as determined by an Individualized Family Service Plan (IFSP) or an Individualized Education Program (IEP). Services could include assistive technology, audiology, special education/instruction, occupational, physical and speech therapy, as well as other therapies and services. In Maryland, all of the services provided under an IFSP or an IEP are at no cost to the family, but are at significant cost to local jurisdictions and the State, in addition to the federal funds Maryland receives under the IDEA.

Infants and Toddlers – Administered by the Maryland State Department of Education (MSDE) and operated by local school systems, this program provides services for families of children birth through 36 months of age who have, or may have, developmental disabilities, delays, or special health needs. If the assessment indicates that a child is eligible for services, an Individualized Family Service Plan will be developed defining the services necessary to meeting the child's and family's needs. Services could include: assistive technology, audiology, developmental monitoring, educational instruction, individual/family counseling, nursing, occupational therapy, physical therapy, service coordination, speech therapy, and social work.

Autism Waiver – Administered by the Maryland State Department of Education (MSDE) and funded by Medical Assistance (Medicaid) and State funds, this Home and Community Based Services waiver allows eligible children with ASD to receive specific waiver services to support them in their homes and communities. Children are eligible based on their diagnosis and based on the child's income and resources. Allowable services include respite care, environmental accessibility adaptations, family training, service coordination, adult life planning, residential habilitation, individual support services, and therapeutic integration.

Division of Rehabilitative Services (DORS) – Operated by MSDE, DORS provides personalized support and employment services. Individuals may be eligible if they have a physical or mental disability that impacts their ability to get or keep a job or live independently.

Transitioning Youth – The Developmental Disabilities Administration (DDA) within the Department of Health and Mental Hygiene currently administers the Governor's Transitioning Youth Initiative to fund supported employment and other day services for eligible students from their 21st birthday, or upon exiting school following their 21st birthday, for one full year.

Community Pathways – The Developmental Disabilities Administration (DDA) administers the Home and Community Based Services Community Pathways waiver. This program is funded by Medicaid and State funds. Individuals are eligible based on their diagnosis of a developmental disability and income. The funds can be used to support community-based services such as employment or vocational supports, behavioral supports, respite, assistive technology, environmental modifications or residential in the person's home or community.

New Directions – This is a Home and Community Based Services self-directed waiver administered by DDA and funded by Medicaid and State funds. People in the New Directions Waiver can manage their own services which are funded through a community agency called a fiscal intermediary. New Directions provides the opportunity for people to self-direct their services and supports in their own home or their family home. The person, with the assistance of a Support Broker and a Fiscal Management Services provider, directs the planning, budgeting, management, and payment of services and supports. The person is required to have a Support Broker and a Fiscal Management Services provider. Most, but not all, services are available for self-direction.

Autism Training Plan - The DDA has entered into a partnership with the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute to assist community providers in better serving people with autism. The training will assist in addressing some of the concerns raised by the Autism Commission's findings about provider capacity and will enhance providers' skills in supporting people with autism.

DDA has allocated $300,000 in Fiscal Year 2013 towards this effort. Topic areas to be covered in the training include:

- Autism 101
- Positive Behavior Support
- Communication Skills
- Employment strategies for people with autism
- Assistive Technology
- Social skills and relationship building
- Sensory differences in people with autism
- Environmental assessment and adaptation

Office for Genetics and People with Special Health Care Needs – Under authority from Title V of the federal Social Security Act, this office in Maryland's Prevention and Health Promotion Administration (PHPA) works to build infrastructure to improve systems of care for children and youth with special health care needs, including those with ASD, throughout the state. In partnership with The Parents' Place of Maryland, this office has a two year grant funded by the federal Health Resources and Services Administration to develop a statewide plan to improve the system of health care and related services for Maryland children and youth with ASD and other developmental disabilities. Once the plan is completed, Maryland will be eligible to apply for a federal implementation grant for funding to enact the plan.

Findings: What We Know

- In spite of an array of federal, state, and local resources in Maryland, there remain multiple barriers.
- Prevalence continues to increase, resulting in strain on services.
- Access to services is difficult. Barriers include geographic, financial, and cultural factors.
  - Effective services are not equitably distributed in all areas of the state. There are particular regional disparities in access to needed primary and specialty care, including speech, occupational, and behavioral therapies in Western Maryland, Southern Maryland, and the Eastern Shore.
  - It is estimated that each person with autism accrues approximately $3 million in costs over a lifetime. Families often incur large debts related to medical and educational services not covered through public programs or medical and dental insurance; or reduced/lost income when one parent leaves the workforce to care for child/children. According to the 2010 Maryland Parent Survey, 30.6% of families of children with an ASD spend between $1000 - $5000 per year on out-of-pocket medical expenses for their child, and 41% of families of children with an ASD report that a family member had to reduce the hours they work or had to stop working due to their child's condition. The cost to society of ASD is currently estimated to be $35-90 billion annually.
- Information about services is lacking.
- System of care is fragmented
  - Transitioning from the education system where most services are required, to the developmental disabilities and vocational systems are difficult to understand and manage
  - This fragmentation impedes access to services, especially for youth transitioning to adulthood, or during other periods of transition.
- There is a shortage of trained providers to deliver evidence-based practices in our long-term care systems, mental health/disability, medicine, and child and adult services

Research is disconnected from families and communities and often not disseminated to individuals, families, and providers.

Autism System of Care

As a result of input from the Regional Listening Sessions, workgroup findings, public testimony, and presentations to the Commission from autism experts, the Commission developed a conceptual model of five system components linking communities and systems of care. The model is the foundation for the Commission's recommendations and the basis of the comprehensive plan. Each component can be thought of as a goal with a concrete outcome and short- and long-term objectives/action steps.

Screening, diagnosis, and referral: This includes physicians, early interventionists, special educators, clinicians, self-advocates, and other diagnosticians utilizing effective techniques/tools to identify and refer children, youth, and adults for services. There is a need to increase the quantity and quality of diagnosticians, as well as the ability to link them to a collaborative system of services and supports for referrals.

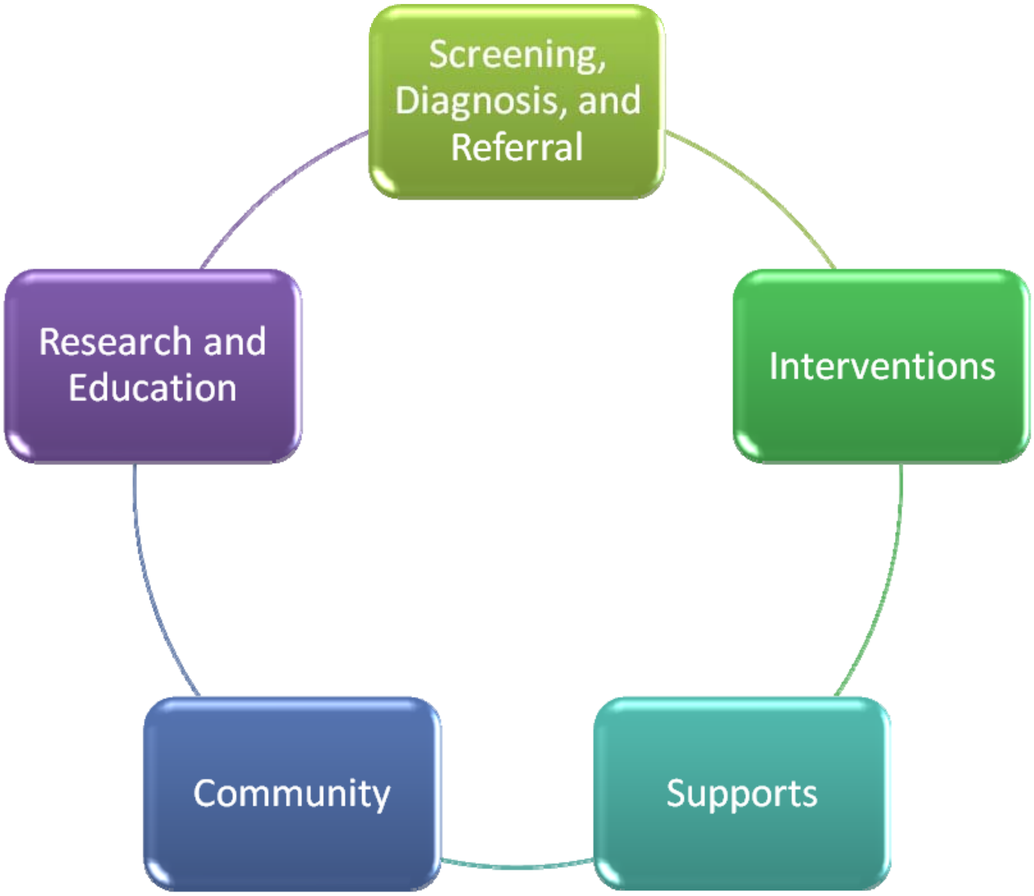
Interventions: This includes clinicians, schools, providers, agencies, self-advocates, and families collaborating to implement evidence-based interventions. Interventions should include a broad array of medical, behavioral, psychological, and social models.

Supports: This includes community based, professional, and informal supports to ensure the success of interventions

Community: This includes communities that understand and support families, children, and adults in their efforts to integrate into the broader community, including childcare, schools, communities of faith, workplaces, stores, and other public accommodations. This component relates to the contexts within which the other components are being utilized.

Research and Education: This includes universities, research, and education personnel collaborating with families, self-advocates, schools, clinicians, and state agencies to understand what works, improve systems, disseminate information, and build workforce capacity and skills.

Linking Systems of Care and Communities Through Identification, Intervention, Supports and Research



Infrastructure: Activities to ensure the viability of the system of care to include data sharing, collection, and analysis; adequate workforce capacity; access to services; and interagency collaboration and coordination.

Recommendations

As the Commission conducted its work, it became clear that Maryland could serve its citizens with autism better; from improving access to care for children in the rural areas of the State to developing a system of sharing information about resources to support adults in the community. The workgroups identified problems and developed recommendations. Some recommendations overlapped and therefore were combined for efficiency. The Commission as a whole reviewed the recommendations multiple times, while some individual members provided input on content and structure.

The Commission realizes that the recommendations will require legislative support, funding commitments, and both short- and long-term implementation strategies to achieve the desired outcomes. This report provides an opportunity for Maryland to have a renewed focus on ASD and address a lifelong condition that now impacts 1 in 88 children born in Maryland. We look forward to your support and thank you for recognizing the importance of this issue.

Recommendations are presented in the following categories:

Policy and System Coordination

- Activities to ensure the viability of the system of care. This includes the development of policies on data collection, analysis, and data sharing; the development of a vehicle for interagency collaboration and coordination; and, oversight for implementation of the Autism Commission recommendations.

Services

- Screening, diagnosis, and referral
- Evidence based interventions
- Supports

Community

- Autism literacy
- Awareness campaigns

Research and Education

- Research collaboration and communication
- Research partnerships with communities
- Workforce capacity

Recommendations with Summaries

Policy and System Coordination

The system of care requires an infrastructure to ensure the viability of the system. Activities include data sharing, collection, and analysis; ongoing interagency collaboration, communication, and coordination; cross system planning; adequate financing; and, policy development among public sector, private sector, individuals with ASD, families, and other stakeholders.

Recommendation #1: Through Executive Order, create the Governor's Autism Coordinating Council to facilitate the implementation of the Autism Commission's recommendations.

Problem Statement: Current autism-related resources and services are offered in siloed, fragmented systems creating variation in policy, financing, and service delivery decisions.

The purpose of the Coordinating Council would be to ensure the development of an implementation plan that puts into operation the Commission's recommendations and maintains the Administration's focus on autism. The Coordinating Council would further develop and strengthen partnerships and continued collaboration between state agencies, academic institutions, and private and community organizations to ensure consistency in policy, financing, and service delivery; work to eliminate barriers to resources; and provide a forum for the work on regional collaborative hubs. Coordination, collaboration, and communication among and between state agencies, academia, and private providers are necessary to implement a statewide plan for an integrated system of care.

In addition the Coordinating Council would ensure collaboration and address barriers such as the confusion as to which state agency or groups are responsible for particular aspects of autism treatment and services, and the confusion regarding autism as a mental health, medical, behavioral, neurological, or educational issue.

Recommendation #2: Improve the process of gathering, linking, and sharing information on autism spectrum disorders in Maryland.

Problem Statement: The incidence and distribution of cases of autism spectrum disorder in Maryland are unknown. Current laws often make it difficult to share data and information between agencies for planning purposes.

As the estimates of the incidence of autism continue to increase, information and data on the number and location of individuals impacted is vital to inform the decision-making process.

Policy development, prevalence studies, cost estimates, research, program development, and workforce needs, all rely on accurate data and information. There are multiple sources where this information is likely to already exist and multiple strategies to gather the information. Regardless of the specific strategies used to gather information on autism spectrum disorders, it is essential that Maryland develops the capacity to review the autism information currently available and, further, to improve gathering information on the number and distribution of cases of autism spectrum disorder within Maryland.

Numerous public, private, and non-profit agencies, institutions and organizations within Maryland collect a wide variety of ASD-related data. The existence of so many disparate groups collecting, analyzing, and disseminating this data makes coordination difficult to achieve, which limits the availability and usefulness of the data produced. Creation of data linkages between datasets of all entities that collect data on individuals with autism would ensure that data meets the needs of internal and external end-users including individuals with ASD and families.

Shared data would also allow the system to develop data sets to measure accountability and outcomes of programs and services for the purposes of planning, financing, and developing services.

Funding for this recommendation will be required, but represents an investment in individuals with autism spectrum disorders and their families.

Recommendation #3: Maximize the Centers for Medicaid and Medicare Services Home and Community Based waiver opportunities for children and adults in Maryland.

Problem Statement: There are currently more than 3,700 children on the Autism Waiver registry. Further, no current support waiver exists for adults with autism.

The current children's waiver could be expanded if additional state funds were made available. The State of Maryland has CMS approval to expand the number of slots by 100 per year. The Commission believes the State should maximize the waiver to serve more children.

The average age of a child beginning services in the current autism waiver is between 11-15 years, well past the time of maximum impact of early intervention services. Research has shown that intensive behavioral, speech, occupational, and other therapies when delivered consistently and initiated as early as 18 months of age are key to optimal outcomes. There are emerging efforts to assess other strategies and therapies.

The adult service system is not prepared nor funded adequately to effectively provide the level of support services to youth transitioning to the adult system. The current adult waivers require that the individual meet an institutional level of care to be eligible. Many adults on the spectrum do not meet this requirement, but are in need of behavior supports, community training, and personal care assistance that could be provided by a 1915i State Plan Amendment.

Recommendation #4: Initiate additional mandates for insurance coverage for diagnosis and treatment of autism spectrum disorders to include coverage for habilitative, medical, and behavioral treatment services for adults as well as children.

Problem Statement: The average cost of providing services and supports over the lifetime of an individual with autism is estimated to be 3.2 million dollars, creating significant financial hardship for families and individuals with ASD.

Medical expenses for children with autism are six times as high as those for children without the disorder. Behavioral therapy, often delivered one-on-one, can cost as much as $60,000 per year. Coverage for other effective therapies such as speech or occupational therapy, often varies by insurer. With the increased prevalence of ASD, there are many children and families who need services, but cannot afford them. Research has shown that early screening, diagnosis, and treatment as early as possible significantly improve a child's chances for optimizing outcomes and maximizing quality of life. Early intervention can also result in long-term cost savings for both families and the State of Maryland.

In a recent policy change, the U.S. Office of Personnel Management said that it has determined there is enough evidence on the effectiveness of ABA therapy to have ABA included in plans provided to federal workers starting in 2013.

Coverage must also be provided for adults with autism to ensure access for medically necessary services including mental health services.

Mandatory coverage ensures that more of Maryland's children and adults with autism can receive the necessary services as early and timely as possible. This would not affect continued funding for children provided by local education agencies.

Recommendation #5: *Partner with agencies and organizations serving individuals with ASD and their families to establish Regional Collaborative Hubs as central points for assistance in accessing ASD services, information, and resources.*

Problem Statement: Comprehensive information on ASD resources is difficult for families and individuals to access.

Improving the network of access to ASD services, information, and resources was a theme that was universally echoed at each of the regional listening sessions, Autism Commission meetings, and in multiple workgroups. This was especially true for those aging out of special education services or the Autism Waiver and transitioning to adulthood, and for those families whose children never receive Waiver services. For many, the search to replace those necessary services and supports lost with the ending of special education and/or Waiver eligibility and services under the IDEA is perplexing and frustrating. Families report they often have difficulty finding the information to help them in this quest.

The need for a repository of evidence-based interventions, research findings, and one-stop accessible information on where to access health services, housing, social, employment, and education options for adults is crucial. For example, the hub will include information on housing, residential supports for successful community living, funding options for various housing models, a forum for families and adults seeking housing or offering housing to connect with one another, and design information for including behavior and sensory supports in housing structures. These needs are not limited to people with ASD and their families; people with other disabilities and special health care needs and their families experience the same issues with access to services, information, and resources regardless of disability type or diagnosis.

Various state programs and organizations serve people with disabilities and special health care needs, including ASD, and would be interested in partnering together to establish regional hubs throughout the state to provide individuals and families with an assisted point of entry to needed services, information, and resources. The Regional Hub's interaction with individuals and families would be dynamic and bi-directional, expand the ability of existing resources, and would provide assistance and information to individuals and families on how to access local:

- Primary health care
- Specialty health care (such as oral health, mental health)
- Related services (such as occupational, speech/language, physical, and behavioral therapies, and assistive technology)
- Early intervention and education services
- Health insurance and financial assistance to cover needed health services
- Family support services (including childcare, respite care, transportation, parent mentoring, etc.)
- Housing
- Employment
- Peer support and social activities
- Maintaining a current compendium of ASD research information
- Self-advocacy and linkages to disability rights organizations

It is critical that these Regional Hubs have sustainable sources of funding.

Services and Supports

Evidence based services targeted to persons with ASD - ranging from screening, diagnosis, interventions, and supports

Recommendation #6: *All interventions provided to autistic individuals should be safe and consistent with evidence-based practices, practice based evidence, or promising practices.*

Problem Statement: In the face of an insufficient range of evidence-based interventions to address all treatment needs it is critical to support continued development of new and innovative treatments.

In order to make informed decisions about treatment and service options, individuals with ASD, their families, educators, clinicians, and service providers should use the following as guidelines as essential elements as they plan, implement, and measure the impact of interventions:

- a comprehensive assessment of the individual's interests, choices, skills, needs, and challenges;
- intensive, early intervention;
- a set of treatment goals and objectives that address the core challenges of ASD;
- a focus on the development of social/emotional competence;
- a focus on the mastery of self advocacy and functional life skills;
- strategies must be person-centered, family informed, and culturally competent; and
- support, resources, and planning for post-secondary transition and entry into the adult service system.

Recommendation #7: *Continue to expand the existing infrastructure for improving developmental screening in all Maryland health care practices using the American Academy of Pediatrics guidelines.*

Problem Statement: Many children with Autism Spectrum Disorders are still not diagnosed until after 3 years of age.

The vast majority of children ultimately diagnosed with ASDs have parent or caregiver concerns noted before the 3rd birthday. The American Academy of Pediatrics recommends developmental screening at regular intervals, with autism specific screening at 18 months of age. Early intervention provides the best opportunity for children to reach their fullest potential, and the earlier it can begin the better. Valuable time in all areas of learning is lost when diagnosis is delayed. Many programs serving young children provide some type of developmental screening and currently there are several parallel efforts underway to improve training in developmental screening for primary care clinicians, including family practitioners, to support the implementation of this screening in their practices. These efforts have focused on central

Maryland and need to be expanded to all areas of the state. In addition, plans are being developed to train childcare providers to do developmental screening as well.

Partnerships between health care practices, service providers, and families, are critical to ensure access to interventions post diagnosis.

Recommendation #8: *Develop and implement a Customized Employment model demonstration project for autistic adults*

Problem Statement: Adults with ASD are under-represented in the workforce. At least two out of every three adults with autism are unemployed or underemployed.

Customized employment, though designed to work with any disability, is an employment support model that is uniquely poised to address some of the most complex issues and challenges posed by autism, and it is the model currently backed by federal policy and research. Through a process of enhanced individual discovery and planning, the Customized Employment model capitalizes on the special interests, talents, and skills of adults on the autism spectrum to meet the needs of both employers, and employees, resulting in meaningful contributions to workplaces and communities. Customized Employment is also capable of addressing the employment services needs of adults across the wide spectrum of autism, maximizing efficiency in service delivery by allowing varying levels of support based on actual needs.

By capitalizing on the specialized interests and skills common in adults with autism, Customized Employment can better match the needs of both employees and employers and can create business incentives by meeting specific business needs**.** The model will provide a source point for employers to locate relevant information about autism, address concerns about job readiness, and demonstrate how accommodations are both legally mandated and can maximize employee performance. It will also include information on practical and legal concerns, especially pertaining to the Americans with Disabilities Act (ADA). Employers could access this information as either part of the hub (resources mentioned in recommendation #5) or as an aspect of the Customized Employment Demonstration Project.

Additional information on Customized Employment is found in Appendix C.

Community

It is critical that communities understand and support individuals with ASD and their families in their efforts to integrate into their communities, including, but not limited to, childcare, schools, communities of faith, business settings, and other public spaces. The general public's understanding of how autism affects communities will lead to greater inclusion and increased quality of life.

Recommendation #9: *Create a statewide awareness and outreach plan to increase the awareness and understanding of autism.*

Problem Statement: The increasing prevalence and impact of autism on individuals, families, and communities is not well understood.

An outreach and awareness effort will improve early screening, early evaluation, and early intervention; decrease stigma; and expand options. Increased public awareness will improve integration of individuals into the community.

Recommendation #10: *Provide access to educational opportunities that promote awareness, understanding, and acceptance in addressing the issues of individuals with ASD across the lifespan*.

Problem Statement: Limited awareness and understanding of ASD often results in an inappropriate response to individuals with ASD.

Target groups for education and training include, but are not limited to, personnel in housing shelters, first responders, emergency rooms, law enforcement, criminal justice, courts, medical clinics, employment agencies, child care centers, community recreation programs, senior centers, and emergency preparedness programs.

Workshops, online resources, written materials, and frequent training sessions scheduled throughout the state should be supported through grants and systems of continuing education requirements. Inclusion of autistic self-advocates in development of training sessions is critical.

Research and Education

The increasing prevalence of autism creates an imperative to understand the development and causes of autism, the interventions that work, and if possible how to preempt/prevent the challenges and disabilities of ASD.

Researchers, families, self-advocates, consumers, and communities must collaborate to quickly and efficiently develop much needed services and supports and create a dissemination mechanism to get evidence based services and practices into provider communities.

Recommendation # 11: *Develop consistent operational processes for partnerships and collaborations between ASD researchers, relevant state agencies, and individuals on the spectrum to ensure access to settings, information, participants, and service providers.*

Problem Statement: Lack of public information around autism and benefits of research for children, adults, and the larger community.

It is critical to include individuals on the autism spectrum in establishing research protocols, reviewing research objectives, and protecting the interests of self-advocates, other individuals with ASD, and their families in the research process. The research goals chosen, the language used to recruit participants, and the research experience from the vantage point of the participant are all necessary components of good research outcomes and ensure that autistic people and their families are full partners at every stage of the research process.

Recommendation #12: *Establish a statewide, universal education and training system using a tiered approach that is available to all public and private providers in Maryland serving individuals on the autism spectrum across the lifespan*

Problem Statement: Inequities across the state related to training and education of educators and service providers across the lifespan result in inadequate services and high staff turnover.

The statewide, universal education and training system would require a tiered approach addressing the education and training needs of direct care workers, supervisors, administrators, educators, and community providers, including physicians, dentists, mental health care providers, and therapists.

Create access to a series of online tutorials and face-to-face workshop sessions that will expand the knowledge of health and service providers about the relevant issues in the behavioral, social, and medical management of autism across the lifespan.

Cost of the education and training would be linked to the individual with ASD and support staff associated with that individual would be provided with autism related education and training. Online modules would be made available for access at any time by any person within the Community of Care for an individual on the autism spectrum. Using one curriculum that can be modified and adapted to the unique needs of individual service providers creates a uniform level of education across the state, thereby increasing equity.

Support and develop university and community college curricula, community continuing education, and training programs that prepare a workforce to address the needs of individuals on the autism spectrum across the lifespan.

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Appendix A

SUMMARY OF OPPORTUNITIES AND CHALLENGES
JULY 9- 10, 2009 AUTISM SUMMIT
GUIDANCE FOR THE COMMISSION

Opportunities

- Coordinated system of care working across silos
- Stakeholder engagement
- State actions to incentivize self funding of care through tax savings mechanisms
- Examine payment to providers so there is no penalty for progress
- Expand new Directions Waiver Program
- Information and data sharing for decision making: policy, program, and funding
- Utilize previous work done in Maryland, Pennsylvania, and Missouri and other states
- Identify opportunities for change in Federal requirements (CMS)
- Innovation in use of funding sources/shared/braiding (state, federal, local)
- Integrated managed care organization (MCO) for physical, behavioral health, and community services
- Bring to scale existing successful projects
- Inventory the workforce need/gaps
- Analysis of training available and training needed
- Interagency sharing of resources and information by: age, program, funding source, agency
- Family involvement and participation in training, opportunities, and information sharing

Challenges

- Evidence –based diagnosis
- Workforce development
- Coordination
- Funding to expand programs and services
- Transitioning youth (18-21). Maintaining the gains achieved. Not losing services because of progress and improvement
- Lack of standards /protocols for services and supports. Particularly for adults with ASD
- Integrate community supports (physical and behavioral health, treatment)
- Disparities in training and knowledge into practice (EBP)
- Building capacity. Project areas of need for services (OT, SLP, etc)
- Forensic and justice system interaction. Registry of individuals with ASD?
- Autism viewed only as a mental health diagnosis
- Means testing for eligibility. Payment for services
- Ability to access good information
- Sustainable employment for individuals with ASD
- Securing assistive technology
- What are we willing to trade for improved services
- Reaching isolated communities
- Reliance on non-public special education. Are there opportunities for inclusion?

Appendix B

Maryland Commission on Autism
Early Intervention and Awareness Recommendations
(Act Early)

Christopher Smith, Maryland Center for Developmental Disabilities, and Rebecca Landa, Kennedy Krieger Institute, Chairs

Members: Anna Maria Wilms Floet, Cecilia Leger, Charlene Iannone-Campbell, Charles Baugh, Debbie Badawi, Deepa Menon, Diane Bonnani, Eric Levey, Gloria Valentine (Wicks), Jessica Henkin, Kelly Sheperd, Linda Zang, Marcella Frankowski, Marjorie Shulbank, Mirian Greenleaf-Miller, Paul Lipkin, Ramsay Mihavetz, Scott Krugman, Sharon Leyden, Tom Stengel, Tracy King, Valerie Smirlock

Recommendations:

1. Encourage consistent screening in health care practices using Academy of American Pediatrics recommendations in all clinical practices in Maryland.

2. Empower parents to screen their own children using an evidence-based video guided system so that parents are empowered in helping to determine best outcomes for their children.

3. Make available navigator training for child care, faith-based community, and neighborhood organizations to recognize signs of early communication delay and ASD.

4. Develop stronger and efficient systems of communication between health care providers and electronic information systems. Encourage health care providers to create and maintain an electronic record of status and plans for each referred child.

5. Establish partnerships across the early child care, early intervention, and health care system

Appendix C

Maryland Commission on Autism
Adult Services Recommendations

April 10, 2012

Zosia Zaks and Karen Montgomery, Chairs

Members: Andrea Kolp, Beth Benevides-Hill, Brian Mund, Brian Rubin, Careen Wallace, Chiquita Crawford, Dide Cimen, Ellen Fiefarek, Ian Paregol, Janet Livingston, Jocelyn Walls, Karen Kaye-Beall, Katie Miller, Linda Pearl, Marjorie Shulbank, Mary Beth Collins, Reda Sheinberg, Ryan Shannahan, Sue Howarth, Therese Erdman, Janet Furman, Brenda Isennock, Polly Huston, Kelli Cummings, Sally Stanfield, Lisa Crabtree, Rhonda Greenhaw

1.) Recommendation for Employment Supports

Problem Statement:

At least two out of every three adults with autism are unemployed. Of those adults on the autism spectrum who have a job, the overwhelming majority is working part-time or is under-employed. Maryland adults with autism face significant barriers to employment.

Recommendation:

The Adult Services Work Group recommends that the State of Maryland (1) design and deploy a Demonstration Project of a Customized Employment model for autistic adults and (2) create a Support and Information System for potential employers and employees.

Explanation:

Customized Employment is the research-backed employment support model recommended by the federal Department of Labor Office of Disability and Employment Policy. Please see the attached Employment Recommendation document for full details.

2.) Recommendation for Housing and Residential Supports

Problem Statement:
Adults on the autism spectrum, their families, and autism professionals consistently report lacking access to comprehensive housing and residential supports information. The emergency shelter system lacks information on autism. Individuals on the autism spectrum may lack access to the in-home supports needed to live independently in the community.

Recommendation:
The Adult Services Work Group recommends that the State of Maryland (1) develop an easily accessible One-Stop clearinghouse where constituents can locate materials on a broad range of housing-related subjects and (2) train and prepare the emergency shelters to respond effectively to autistic adults and their families and (3) explore and develop funding sources for in-home supports when an individual is not eligible for supports from current systems.

Explanation:
By providing constituents with centralized and accessible housing and residential supports information and resources, Maryland will maximize the opportunity for adults on the autism spectrum to live independently in and contribute to their local communities.

Employment Supports Recommendation for Maryland
Adult Services Work Group of the Maryland Commission on Autism

At least two out of every three young adults with autism are unemployed, and of those who have a job, the overwhelming majority is working part-time. Because Maryland adults with autism face significant barriers to employment, the Adult Services Work Group recommends that the State of Maryland create:

1. Demonstration Project of a Customized Employment model for autistic adults,
2. Support and Information System for potential employers and employees.

What is Customized Employment?

The United States Department of Labor defines Customized Employment as “a flexible process designed to personalize the employment relationship between a job candidate and an employer in a way that meets the needs of both. It is based on an individualized match between the strengths, conditions, and interests of a job candidate and the identified business needs of an employer. Customized Employment utilizes an individualized approach to employment planning and job development – one person at a time . . . one employer at a time.”

Briefly, Customized Employment:

- Is a proven employment strategy which emphasizes sustainability of employment in addition to placement by focusing on creating employment situations that meet the needs of both the employer and the job-seeker.
- Is a flexible process that considers the needs of both the employee and the employer.
- Matches employees to jobs where natural supports are more easily integrated into the employment scenario and external supports can be phased out more quickly.
- Promotes competitive employment in the community.

Why Does Maryland Need a Customized Employment Model For Adults on the Autism Spectrum?

Customized Employment, though designed to work with any disability, is uniquely poised to address some of the most complex issues and challenges posed by autism. It is also capable of addressing the employment services needs of adults across the wide spectrum of autism, maximizing efficiency in service delivery by allowing varying levels of support based on actual needs.

By capitalizing on the specialized interests and behaviors common in adults with autism, Customized Employment can better match the needs of both employees and employers

- Customized Employment can create business incentives by meeting specific business needs. The job developer performs an exploration of the local business community. What business needs are not being met efficiently? Where is productivity lagging? What business needs are being ignored or underserved?
- During the initial phase of the process, known as the Discovery Phase, a Customized Employment team develops a profile of the autistic adult that provides the detailed data needed to make successful employment plans. Data from the Discovery Phase allows the autistic adult to be matched with and placed into jobs where his or her skills, talents, and interests are economic assets. This method not only targets more realistic business needs but can also eliminate traditional job-seeking methods that require complex social skills.
- Traditional vocational assessments may miss social skills challenges common on the autism spectrum, may not test for issues unique to autism such as sensory issues that can impede or enhance employment, and may underestimate or overestimate an autistic adult's adaptive skills – all crucial areas for successful job placement that are in addition to, but as important as, any task training issues.
- Customized Employment may use job carving, job sharing, flexible schedules, self-employment, and resource ownership to maximize work success, particularly in cases where self-regulation, communication, and social differences pose barriers to traditional employment scenarios.

Research on the Customized Employment Model

The Office of Disability Employment Policy (ODEP) at the United States Department of Labor has been researching Customized Employment programs for about a decade in many states including Washington, Illinois, Ohio, Mississippi, New York, Louisiana, Missouri, Alaska, and Washington D.C., among others. In Maryland, some features of Customized Employment have been used by various projects and agencies such as the Montgomery County Customized Employment Public Intern Project, Transcen, and Itineris. For additional statistics and data, please see the website of the federal Department of Labor, Office of Disability Employment and Policy, or the resources listed below.

Maryland Customized Employment Demonstration Project Details

We recommend that the state create a three-year Demonstration Project to develop, implement, and test a Customized Employment model for adults with autism. The Demonstration Project should have several sites, in different counties. Although the Demonstration Project will be designed to address the urgent employment situation in the adult autism community, the project will be structured flexibly so that the model can be expanded to serve other disability communities.

The Demonstration Project should be coordinated by one or more agencies or organizations with experience in the following three key areas: serving autistic adults, providing Customized Employment, and coordinating funding. We suggest agencies such as Itineris or Transcen or other agencies with similar strong qualifications.

Issues such as eligibility for the services offered through the Demonstration Project, markers for client success, and funding and training for provision of the services would be worked out jointly amongst the selected Provider(s) and a task force of stake holders.

Data should be collected on effectiveness of the Customized Employment Model and delivery variables. Interested universities could provide research and data collection support.

Development of a Support and Information System

To provide a single location of vital materials and resources for both employers and employees, we recommend the development of a Support and Information System.

Employers need a single source point where they can locate basic autism information. This Support and Information system will address concerns about employee job-readiness; will demonstrate how employers can utilize accommodations to maximize employee performance; and will include information on practical and legal concerns.

A hotline will provide an ombudsman for special questions, resolutions of unique issues, and possibly even on-site consulting. The hotline system could be housed in and supported by an already existing department such as the Autism and Behavioral Health Services office of the Maryland Department of Health and Mental Hygiene.

A workforce conference is currently being planned for the Greater Baltimore metropolitan area, by leading autism community advocates, which will target key personnel influential to the employment process for adults on the autism spectrum. This effort is likely to develop a hub of supports for potential employers, and by extension, the autistic adults they may hire. Pathfinders for Autism has been recommended as the location for this hub of support. The Adult Services Work Group suggests that the State partner with this initiative as part of developing the Support and Information System described in this section.

Resources and References

Websites

Department of Labor, Office of Disability Employment and Policy (ODEP)
Customized Employment Fact Sheet
http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/what/index.htm

National Center on Workforce and Disability (NCWD)
Customized Employment Fact Sheet Series
http://www.onestops.info/i.php?i=1

National Center on Workforce and Disability (NCWD)
Customized Employment Innovation: Findings from the Field
http://www.onestops.info/website.php?page=ce_index

United States Department of Labor
The Case for Customized Employment
http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/case/index.htm

United States Department of Labor
List of Customized Employment Demonstration Projects by State
http://www.dol.gov/odep/categories/workforce/CustomizedEmployment/response/projects.htm

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Statistics on Employment and Autistic Adults

Autism Society of America: Facts and Statistics.
Available at http://www.autism-society.org/about-autism/facts-and-statistics.html

Shattuck, P., Narendorf, S. C., Cooper, B, Sterzing, P. R., Wagner, M., Taylor, J. L. (2012). Postsecondary Education and Employment Among Youth with an Autism Spectrum Disorder. *Pediatrics*, 129 (6), 1042-1049.

Tanner, L. (2012) Autism Study: 1 In 3 Young Adults With Autism Have Few Job Prospects Years After High School Graduation. Huffington Post. Available online at: http://www.huffingtonpost.com/2012/05/14/autism-study-career-prospects_n_1513682.html

Taylor, J. L., McPheeters, M. L., Sathe, N. A., Dove, D., Veenstra-VanderWeele, J., & Warren, Z. (2012). A Systematic Review of Vocational Interventions for Young Adults with Autism Spectrum Disorders. *Pediatrics*, 130 (35), 531-538.

Appendix D

Maryland Commission on Autism

Data Workgroup Recommendations

Date: April 10, 2012

Workgroup Name: Data Workgroup

Chair Name: Li-Ching Lee

Members: Meredith Pyle, Paul Law, Rhonda Greenhaw, Susan Bradley, Peter DeFries, Marjorie Shulbank, Sally Slade, Tricia Roddy, Valerie Roddy

Recommendations:

(1) Recommendation: Create data linkages between datasets of all state agencies, institutions, academic universities, and service providers that collect data on individuals with autism in Maryland.

Problem Statement:
Numerous public, private, and non-profit agencies, institutions and organizations within Maryland collect a wide variety of autism spectrum disorder (ASD)-related data. The existence of so many disparate groups collecting, analyzing, and disseminating these data makes coordination difficult to achieve, which limits the availability and usefulness of the data produced. A solution is needed to ensure that data collected or produced by all relevant Maryland groups meet the needs of internal and external end users. The linked database can potential serve as a foundation for developing Autism Registry that is addressed in Recommendation #2.

Additional explanation:
Necessary partnerships would involve agencies, institutions and organizations who regularly collect data about individuals with autism in Maryland. In addition, resources for expertise in developing linkage processes, building the linkage platform(s), and ongoing maintenance of the linked dataset(s), including IT support, staffers who monitor the process and make things happen. Potential barriers are the inconsistency in ASD definitions, service eligibility criteria, and the types of collected data (e.g. for service, educational, or research purposes).

2) **Recommendation**: Convene a group to consider the creation of an autism registry for the state of Maryland which would collect demographic information such as date of birth, race/ethnicity, and gender; contact information such as name and address so that potential services can be offered; diagnosis information; and diagnostician's information and information on the person submitting the registration form. Questions to be answered by the group include 1) have other states' autism registries been successful in connecting children and adults with autism to needed services?; 2) have other states' autism registries been successful in estimating the

prevalence of autism?; 3) would Maryland benefit from an autism registry?; and 4) if Maryland would benefit from an autism registry, should it be mandatory or voluntary?

Problem Statement:
Maryland currently has no systematic way to connect children and adults with autism to needed services in their communities and no way to ascertain how many Marylanders have autism. Various agencies and organizations within the state do track data on the number of individuals with autism that they serve, however the criteria for diagnosis varies among agencies and institutions and there is little or no data sharing among them. Knowing the number of Maryland residents with autism will better enable the state to understand the extent of autism in the state, allow the state to conduct thorough and complete epidemiologic surveillance of autism, enable the state to analyze needs, and help plan for and provide services to children, adults and families affected by autism. Other states including West Virginia, New Hampshire and New Jersey have used mandatory autism registries to address these issues.

Additional explanation:
Potential barriers to this recommendation include a lack of participation among relevant partners (member organizations), and a lack of available staff time among potential representatives of member organizations.

Legislation may not be required to convene a workgroup to consider a registry if the necessary partners (including but not limited to individuals with autism and their families, the Department of Health and Mental Hygiene, the State Department of Education, the Kennedy Krieger Institute including the Interactive Autism Network, Pathfinders for Autism, local autism society of America chapters, Maryland ARCs, and healthcare professionals and healthcare professional organizations in the state) were willing to voluntarily participate. Legislation may be advisable to provide guidelines and structure for the group if the above does not seem feasible.

Clear roles and responsibilities would have to be defined at the outset of the project. Funding to cover meeting costs and a project coordinator to schedule meetings, prepare agendas and minutes, and coordinate a final report/recommendation of the group may be advisable to ensure success.

What part of the Commission’s legislation does this recommendation address?
The recommendation to establish a group to consider the creation of an autism registry addresses the broader recommendation category of policy and system coordination.

(3) Recommendation: Establishment of an “Autism Data Collaborative” in Maryland which would (1) facilitate access to comprehensive autism data; (2) coordinate and prepare responses to autism data requests that involve multiple agencies, organizations, and/or institutions; (3) promote optimal approaches to data collection, analysis and reporting as it relates to autism in Maryland; and (4) support the development and interpretation of uniform measures of access and quality for needed services for people with autism in Maryland.

Problem Statement:

Numerous public, private, and non-profit agencies, institutions and organizations within Maryland collect a wide variety of autism spectrum disorder (ASD)-related data. The existence of so many disparate groups collecting, analyzing, and disseminating this data makes coordination difficult to achieve, which limits the availability and usefulness of the data produced. A solution is needed to ensure that data collected or produced by all relevant Maryland groups meet the needs of internal and external end users. In addition, the Commission uncovered a need for measures of quality of professional services, benchmarks of excellence, evaluation, and consistent application of standards as well as a need for collaborative and transparent quality data.

Maryland does not have a mechanism with which to develop solid principles around autism data access and sharing.

Additional explanation:

No legislation would be required to implement this recommendation as participation in the collaborative would be voluntary. Incentives for organizations to participate would include having a central role in the development of measures of quality of professional services, benchmarks of excellence, evaluation, and consistent application of standards in Maryland. To establish the Data Collaborative, a workgroup of interested/pertinent agencies, organizations and institutions could be formed to determine the structure of the collaborative as well as roles and responsibilities for participating members. Resources needed for this preliminary stage include staff time of participating members and meeting space. Additional resources in later stages may include funding for a dedicated staff person or staff people to administer the collaborative.

What part of the Commission's legislation does this recommendation address?

The recommendation to establish an Autism Data Collaborative (1) addresses the broader recommendation categories of policy and system coordination and research and education; and (2) addresses the system of care components of research and education and infrastructure.

Appendix E

Maryland Commission on Autism
Evidence-Based Practice Workgroup Recommendations

Scott Hagaman, Chair

Members: Scott Hagaman (Chair), Angela Mezzomo, Ed Feinberg, Rachel London, Careen Wallace, Lauren Kenworthy, Karla Saval

Recommendations:

Problem Statement:

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disability, with implications for an array of social, communicative, educational, sensory, behavioral, and medical difficulties. The number of individuals identified as having an ASD has dramatically increased in the last 20 years (Centers for Disease Control and Prevention, 2011).

People with ASD are receiving a variety of services and supports in a number of settings across our State, based on their individual strengths, needs, and challenges. Family members of individuals with ASD and the caregivers, educators and health care professionals who serve them are in constant pursuit of information about how to best meet the unique needs of these individuals. Many youth and adults with ASD themselves are engaged in efforts to advocate for the resources and service options they need to maximize their quality of life.

Through the guidance offered in these recommendations, consumers will be able to understand the strengths and challenges associated with individual intervention strategies and make informed decisions about treatment and service options for individuals with ASD and their families. While there are a number of multidisciplinary intervention practices that yield consistent, reliable outcomes in the treatment of ASD, there are a myriad of interventions whose efficacy has not been proven through rigorous evaluation (but have otherwise been adopted through current trends in practice or model programs), and there are also those intervention strategies which have been proven ineffective or harmful to individuals with ASD. With the understanding that research conditions can be manipulated to yield desirable outcomes, the Evidence-Based Practice Workgroup does not intend for these recommendations to imply endorsement or recommendation of any specific interventions or treatment methodologies in the remediation of the symptoms of ASD. Stakeholders utilizing these materials should exercise their best judgment with respect to the needs of the individual with ASD, as well as the potential benefits or risks to that individual when selecting, employing, and tailoring interventions.

The EBP Workgroup agrees that:

1. We **will not** endorse specific treatment methodologies to address autism;
2. We **will** review the literature and identify elements of effective service delivery and recommend that treatment teams utilize these guidelines for intervention; and

3. Advocate for the development of an online resource repository, or "hub."

Rather than endorsing **specific intervention strategies or treatment modalities**, the Evidence-Based Practice Workgroup proposes that individuals with ASD, families, educators, clinicians, service providers and support personnel use the following **guidelines** for **planning, implementing, and measuring** the impact of **interventions** for individuals with ASD across the lifespan:

1) Recommendation:

Design comprehensive interventions to address the primary difficulties associated with autism.

Focus on the following domains:

- Self Regulation
- Executive Functioning
- Socialization/Communication
- Biomedical Complications/
- Co-morbid Disorders

Guidelines:

- Teams should consider:
    - The setting in which intervention is being implemented (home, school, community)
        - Do environmental modifications need to be made?
    - Exploring a variety of methods of communication
    - The importance self advocacy skills and empowerment of the individual with ASD
    - Emphasize the development of social/emotional competence
    - Utilization of a methodological approach to instruction
        - Progress monitoring strategies

2) Recommendation:

Intervention and service delivery for individuals with autism must include:

- A comprehensive assessment of skills, needs, and challenges
- Treatment goals/objectives that are clearly (operationally) defined
- Teaching/support strategies that are individualized/tailored to meet the individual's unique needs
- Implementation/service delivery
- Progress monitoring strategies
- Data- driven decision making

Guidelines:

The following are essential elements of effective service delivery for educators and service providers working with individuals with ASD:

- The individual with ASD’s interests, strengths, and choices guide programmatic decision making, making intervention a person-centered process
- There is interdisciplinary involvement in planning for the individual including family, physicians, educators, service providers, etc.
- Goals and objectives focus on mastery of functional life skills
- Data drives decision making
- Consultative services are sought to address barriers
- Assistive Technology is employed, as needed
- Support and pre-planning for Transition
- Continuing education/Professional Development for all staff
- Family Support
- Early identification and Intensive Early Intervention to paramount; these help ensure the best outcomes

3) Recommendation:

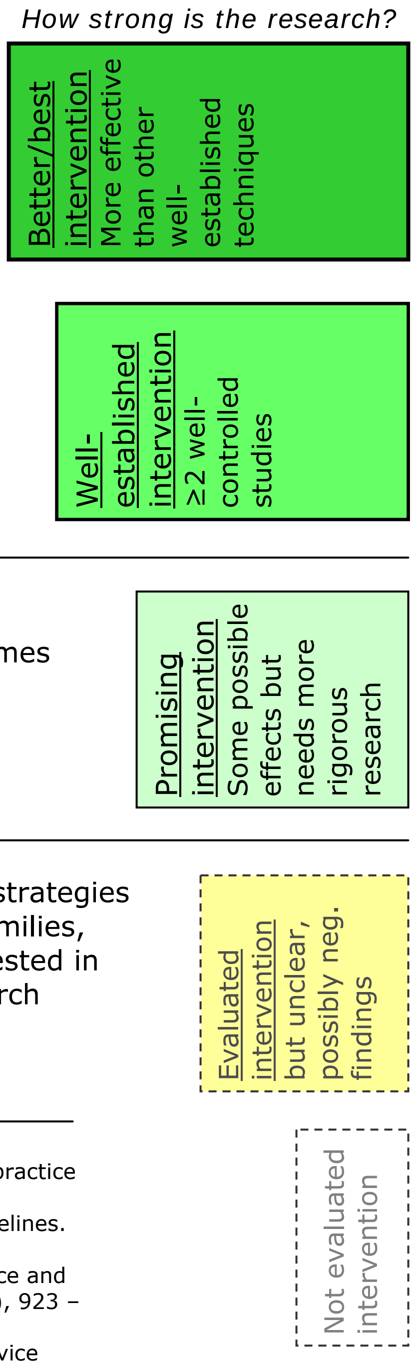
Develop an online repository for state and national resources on ASD.

- Link to the following sources:
    - Pathfinders for Autism
    - AutismConnect
    - Association for Science and Autism Treatment
    - National Research Council
    - National Autism Center
    - Interagency Autism Coordinating Committee

The EBP Workgroup would also like to recommend that stakeholders refer to the National Standards Project, a report from the National Autism Center, for information about the evidence base for specific interventions and treatment methodologies to address ASD.

Evidence-Based Practice, Promising Practice, & Practice-Based Evidence: What's the difference?

The purpose of this document is to educate providers, policymakers, and others interested in effective interventions about three categories of available interventions. Understanding the ways in which interventions differ could influence the selection and adoption of a new intervention. These categories are evidence-based practice (EBP), promising practice, and practice-based evidence (PBE).



Evidence-based practice (EBP) refers to the integration of the best available research with clinical expertise in the context of youth and family characteristics, culture, and preferences. In other words, the effectiveness of an EBP to help children and families reach desirable outcomes is measured by three vital components:

1) Extent of scientific support of the intervention's effects, particularly from at least two rigorously designed studies;
2) Clinical opinion, observation, and consensus among recognized experts (for the target population);
3) Degree of fit with the needs, context, culture, and values of families, communities, and neighborhoods.

Promising practice refers to interventions that have *some* research evidence to indicate that they produce positive outcomes for children and adolescents. Promising practices require additional supporting research evidence to be considered evidence-based practices.

Practice-based evidence (PBE) refers to interventions and strategies that are accepted as effective by the local community (e.g., families, youth, providers, administrators). Therefore, PBE have been tested in the "real world"; however, they typically lack supporting research evidence.

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The Maryland Child & Adolescent Innovations Institute
The Maryland Child & Adolescent Mental Health Institute
University of Maryland, Baltimore, School of Medicine
Phone: (410) 706-0961; Email: innovations@psych.umaryland.edu

Appendix F

Maryland Commission on Autism
Funding and Resources Workgroup Recommendations

Members: **Delegate Kirill Reznik, Chair,** Kimberly Camarata, Renata Henry, Rachel London, Senator Kathy Klausmeier, Ian Peregol, Jill Spector, Stuart Spielman, Careen Wallace, Fred Whiton,

1.) Recommendation to Expand Autism Waiver Slots:

Problem Statement:

There are currently 3,700 children on the waiting list for waiver services. The average age of a child beginning services is between 11-15 years, well past the time of maximum impact of early intervention services. Research has shown that intensive behavioral therapy is most effective when delivered consistently and initiated as early as 18 months of age.

Recommendation:

Expand the current Autism Waiver to the maximum slots approved by the Center for Medicare and Medicaid Services (CMS). Funding for the Maryland state match should be included in the operating budget for Maryland State Department of Education.

2.) Recommendation to Re-design the Autism Waiver:

Problem Statement:

Too often the amount/dosage of services is not fully utilized by families. The waiver is constructed so any unused hours of service cannot be distributed to another person on the waiting list.

Recommendation:

Re-design the current Autism waiver to maximize the efficiency of available resources and allow flexibility to individualize the services based on need.

Appendix G

Maryland Commission on Autism
Health and Medical Services Workgroup Recommendations

Wendell H. McKay, MD, FAAP, Chair

Members: Carol Samuel-Botts, MD, Kaiser, Deepa Menon, MD, Kennedy Krieger, Mary Mussman, Maryland Medical Assistance, Cynthia Hill, Parent, Deborah Badawi, MD, OGPSHCN, Jane Casper, Office of Oral Health, and Gayle Jordan-Randolph, MD, Mental Hygiene Administration

1.) Recommendation: Create a series of online tutorials that will expand the knowledge of Medical, Dental, Behavioral Health and Service Providers Physical, Dental, and Mental Health providers about the relevant issues/topics in the management of Autism.

Problem Statement: The prevalence of Autism Spectrum Disorders is increasing however studies show that children with Autism Spectrum Disorders are less likely to receive care consistent with the American Academy of Pediatrics medical home model. Care for these children is frequently fragmented, difficult to access and not directed by a single provider in a coordinated fashion. Similar issues exist in the adult population as well. Although Autism Spectrum Disorders are subcategorized as a psychiatric and behavioral disorder, the cause is multifactorial and as such there are a multitude of medical problems associated with the disorder. Often subspecialty care for these medical problems is difficult to access due to a limited number of providers located at limited facilities throughout the State. Despite the American Academy of Pediatrics recommendation to routinely perform developmental screening at all wellness appointments (and there are Autism Spectrum specific screening tools available) many children with Autism Spectrum Disorders are still not diagnosed until 3-1/2 to 5yrs of age even though most had documented concerns about their behavior before the 3rd birthday. Diagnosis in the adult population is even more difficult because of a lack of standardized screening tools along with a void in the knowledge base of adult providers. Studies have reported that many Primary Care physicians report low competency in their ability to care for children and adults with Autism and therefore not surprisingly many parents report dissatisfaction or lack of confidence with their Primary Care Physicians knowledge about Autism Spectrum Disorders. Fortunately studies also report that medical care providers are highly motivated to improve their competency in this area.

<u>Resources needed</u>:
Centralized site
Personnel to organize and create tutorials on topics such as:

- Recommended screening and diagnostic resources already available to them
- Methods of improving the medical home aspect of their offices

- Coding tips on getting the most appropriate compensation for their efforts (applicable to other diagnoses and problems as well)
- Tips from various specialists about handling the more common medical conditions associated with Autism (i.e. gastrointestinal dysfunction, nutritional compromise, sleep disturbance, seizures, ADHD)
- Other module/Tutorial topics include: Dental health, transition issues (school age to high school and high school to adult), Medical transition from pediatrician to adult primary care, Advice on helping parents and other caretakers.

Certification procedure could be included to document proficiency in mastering information/concepts presented.

Barriers
End users need a computer to access the tutorials
Finding experts that have appropriate technology to record a tutorial

Potential Partners
American Academy of Pediatrics
Maryland Department of Disabilities
AUSD
American Dental Association
ASA
Parent Groups
Self-Advocates

2.) Recommendation

Initiate legislative efforts to ensure insurance coverage for diagnosis and treatment of autism spectrum disorders with treatment including habilitative, medical and behavioral health treatment services.

Create an Autism Specific Medical/Dental Newsletter with regular (quarterly) distribution.

Problem Statement:

Currently, the cost of autism diagnosis and treatment is often shifted to the educational system which does not have consistent expertise or resources to meet all of the diagnostic, habilitative, medical and behavioral health needs of children and youth with autism spectrum disorders. This also leaves many adults with autism lacking coverage for diagnosis and treatment. There are 30 states that have passed legislation requiring insurance coverage for autism diagnosis and treatment. This year the Maryland State Legislature rejected mandatory coverage but did pass a Habilitative Services bill stating that the "…the Department of Health and Mental Hygiene, in consultation with the Maryland Insurance Commissioner, shall establish a technical advisory group on the medically necessary and appropriate use of habilitative services to treat autism and autism spectrum disorders."

Additional explanation:

In a 2012 Autism Stakeholder Poll conducted by the Office for Genetics and Children with Special Health Care Needs in Maryland, access to needed therapies and adequate insurance and financing were among the top 3 out of 10 needs identified in most regions and in the top 5 across the state. While the vast majority children in Maryland have insurance, the 2009-2010 National Survey of Children with Special Health Care Needs indicates that only about half of children with behavioral or developmental needs have insurance that is adequate to cover needed services. While we do not have similar statistics for adults, we do know that coverage for adults is more limited, particularly for habilitative and behavioral health services.

<u>Resources Needed:</u>
<u>Legislative advocates</u>
<u>Advocacy group to promote legislation and public support</u>

<u>Barriers:</u>
<u>Funding scarcity</u>
<u>Resistance from insurers</u>

<u>Potential Partners</u>
<u>Pathfinders, MCDD, KKI, DHMH, AAP</u>

3.) Recommendation: Create an Annual or Bi-Annual Conference on Autism. Sponsors might be Autism Speaks or American Society of Autism, or Governor's Office could be asked to sponsor.

Problem Statement:

There is a perceived lack of up-to- date information about diagnosis and treatment of autism all along the age spectrum within the health care provider community.

Additional explanation:

Currently, there is not any ongoing statewide multi-discipline collaboration between researchers, primary care providers, and specialists regarding the care of people with Autism Spectrum Disorders. We propose convening healthcare personnel (including physicians, nurses, dentists, habilitative professionals) researchers, educators, and insurers to discuss evidence-based practices regarding the ongoing physical, dental and mental health care of autistic individuals.

Conference would be publicized to: PCP's, specialists, OT/PT/speech therapists, nurses, educators, and insurers who would like to stay abreast of evidence-based coverage of autism. Offer free CME and CEUs through in-kind contribution of MedChi or other group able to obtain CME credits. Use professional societies, such as Maryland Chapters of American Academy of Pediatrics, American Academy of Family Practice, American Nurses Association etc. to publicize the opportunity.

Consider offering a special “Autism-Certified” credential (Good Housekeeping Seal of Approval) from Autism Speaks or American Society for Autism that providers can list upon completion, such as in Health Plan provider directories. Could also be a basis for a reimbursement incentive from insurers.

Consider requesting that certain medical (AAP, AAFP, ADA, AOTA, APTA, ASHA) societies incentivize attendance.

Resources Needed:
Funding
Facility to host
Entity to derive content and organize educational material

Barriers:
Funding
Single organization needed to take charge and organize/host/evaluate

Potential Partners:
Autism Speaks, Pathfinders, KKI/UMMS/JHU, American OT Association (AOTA), American PT Association (APTA), American Speech-Hearing Association (ASHA)

4.) Recommendation

Encourage caregivers and autistic self-advocates to use an electronic personal health record as a method to provide a continuity record of an individual’s medical, behavioral, and resource history. This Personal Health Record (PHR) would augment the physician’s electronic health record/medical record, and would be maintained by the caregiver or autistic self-advocate. The PHR provides a comprehensive health record that is owned and held by the patient or caregiver. It 'grows' with the person, as new information is added and old information is retained as past history.

Problem Statement: (What problem is the recommendation solving?)

Autistic patients often have extensive medical and psycho/social histories which are not maintained in a concise record. There is a need to organize this information so that it can be appropriately shared with the autistic patient’s primary care provider and various specialists. This PHR would be a resource in the care coordination amongst providers for the lifespan of the patient.

Resources Needed
PHR software created by outside entity
Template of “Autism Specific documentation” that is across the lifespan

Barriers

- Caregivers or autistic self-advocates may lack access to or a comfort level with this type of technology.
- Concerns about the security of personal health information maintained in a portable or web-based PHR, especially in a free PHR service.
- Possibly prohibitive costs associated with the various PHR vendors that offer secure on-line access, portable access, and the automatic update service options offered by select vendors.
- PHR maintained by caregiver would need to be updated frequently to keep record current.
- Availability of software with a specific Autism Spectrum Disorder application.

Potential Partnerships
IT depts of medical institutions (UMMS, KKI, JHU), local software/IT companies

5.) Recommendation:

Create incentives for the training of medical specialists, mental health specialists, dentists, and service providers to help increase access to necessary resources for people with Autism Spectrum Disorders.

Problem Statement:
There is a significant shortage of medical, dental, and mental health specialists that serve people with Autism.

Additional explanation:

Centers of higher education (colleges and professional schools) currently provide limited opportunities for exposure to and training for the care of children and adults with Autism. Such experience could be fostered by the provision of grants that provide for the specific exposure needed for training competent caregivers. Organizations such as Autism Speaks, Pathfinders, and the Autism Society of America could partner with various training institutions and professional societies (American Academy of Pediatrics, American Association of Family Practitioners, American Dental Association, etc.) to guide more trainees towards the field of Autism care.

Resources Needed
Buy in from decision makers in higher education
PR campaign to increase interest in Autism related specialties among trainees

Barriers
No chance for immediate impact
Grant funding probably needed to improve adoption

Potential Partners
AAP, AAFP, ADA,
State University System
Professional Schools (Medical, Dental)/Doctoral programs

Appendix H

Maryland Commission on Autism
Research Partnerships Workgroup Recommendations

Rebecca Landa, Chair
Members: Denise Cedrone, Li-Ching Lee, Marjorie Shulbank, Karla Saval, Christopher Smith, Laura Anthony, Lisa Hovermole

Recommendations:

1.) The Commission should support the development of consistent operational processes that will allow researchers interested in Autism Spectrum Disorders (ASD) to appropriately and efficiently secure state-approved access to Maryland state employees as collaborators, relevant information about Maryland children and service systems, research participants, and settings relevant to the conduct of the research, beginning with establishing such operational processes in MSDE

partnerships, mostly involving MSDE as the public agency. Some such research involves early intervention studies, designed to define efficacious interventions that will be adopted as evidence-based practice. Maryland is fortunate to have prominent and well-respected researchers focused on important ASD-related matters. Supporting collaborations between researchers and public agencies is important for many reasons. For example, such research improves the rate of translation of new findings into practice in our state. In some such studies, children directly benefit from innovative interventions at no cost to the family or the school system. In addition, teachers and parents receive training in some of these studies, providing a permanent and scalable benefit to children, families, and teaching staff that are likely to improve outcomes (with possibly reducing long-term financial expenditures) of children with ASD. Finally, revenue brought into the state of Maryland from the acquisition of research funds benefits all Marylanders.

Research has established that the most effective clinical interventions for people of all ages on the Autism Spectrum occur in the setting where there will be an immediate use and reinforcement for the desired behavior. . A major goal of the Commission should be to increase research being conducted in Maryland aimed at improving the lives of citizens with ASD and their family members. In particular, mechanisms are needed to promote collaboration between state agencies and researchers in private institutions, as well as to promote research within and across state agencies. In order to advance a research agenda in Maryland, research-facilitative mechanisms must be put into place in Maryland. a statewide review process with policies and procedures to clarify and streamline guidelines for access to research subjects in educational settings. Academic researchers will undoubtedly have the approval of their Institutional Review Boards (IRBs) which have been established by the federal government to protect the rights of human subjects but these IRBs will have limited knowledge of MSDE’s policies and particular concerns. To foster the ASD-focused research that meets the objectives described above into intervention studies in authentic settings throughout the state, MSDE must begin to define study (approval processes that would evaluate the risk/benefit of the research and verify how the rights of subjects (ie, families and children) will be protected. This is just one example of the type of processes that need to be established. Thus, we recommend that one Maryland agency be identified to begin the development of such processes. It is suggested that MSDE serve in this capacity. We recommend MSDE because there are numerous existing MSDE-Researcher collaborations currently underway, and thus, there may be existing mechanisms and procedures already in place that could be expanded and refined to establish a prototype set of procedures and policies. . We further suggest that a workgroup be convened within MSDE for such purpose. If MSDE decides to proceed with establishing, for example, a process for reviewing proposed collaborations, it will require specific resources and funding to create and maintain the process, but that cost may be offset by the benefits of the research; for example, access to high quality teacher training needed to conduct the research could result in greater adoption of evidence based practices for the classroom. With funding always being a concern, MSDE may consider having researchers subsidize some of the cost of this process in the indirect portion of their research budget.

2.) Recommendation:

The workgroup supports the establishment of an ongoing body (members to be determined) dedicated to establishing a centralized awareness of existing research, ongoing research needs assessment, analysis of barriers preventing research, and general problem solving to facilitate research.

Problem Statement:

While most public-private ASD research collaborations in Maryland currently focus on early interventions and demographic studies requiring collaborative partnerships with MSDE, future research will expand to explore research questions involving best practice interventions and other types of research for people with ASD throughout the life span. This workgroup cannot now anticipate all the organization needed to support that future research. Building sustainable partnerships is an ongoing process of creating relationships between individuals with ASD, their families, researchers, public resources, private resources, and academic institutions. Such a body would have the tasks of assessing demand, encouraging researchers to develop translatable products, problem solving to remove barriers to research, and shepherding stewarding the production of evidence based practices. The momentum produced by the work of the Autism Commission should be nurtured by this body establishing a foundation from which to consider issues that are evolving but not yet thoroughly vetted.

Additional explanation:

This body would need to meet 1-2 times per year. A listserv could be created to maintain communication between meetings. There has to be some central organizing point to facilitate this.

Appendix I

Maryland Commission on Autism
Transitioning Youth Workgroup Recommendations

Fred Whiton, Jr., Chair

Members: Marcia Anderson, Tom Barkley, Adele W. Connolly, Sarah Edwards, Eric English, Rachel Faulkner, Deborah M. Fisher, Tom Flis, Anne Geddes, Lisa Hovermale, Desmond Kaplan, Sue Murray, Ryan Shannahan, Sequaya Tasker, Albert Zachik

Recommendations:
We respectfully recommend that the Maryland Commission on Autism consider the following:

1) **Implement an electronic Autism Registry.**

Problem Statement: Estimates of the incidence of autism continue to increase without consensus on the reasons for this increase, how to address it, or the cause of autism. The number and distribution of cases of autism spectrum disorder within Maryland is unknown.

Additional explanation: An autism registry, such as used in states including New Hampshire and New Jersey, can provide information on the number, distribution, and severity of cases of autism spectrum disorder within Maryland, and information significant to the epidemiology of autism and additional clues to its cause and treatment. The scope of the problem of autism in Maryland is unknown as are the amount of resources necessary to address this problem.

All workgroup members agreed on the need for the strictest protection of all information in any such registry, including the expectation that this would not take the form of a public database and would likely follow the existing public health registry model in Maryland for the mandatory reporting requirements for infectious diseases and other disabilities, such as HIV infection, so there would be no relinquishment of privacy through close management of the information.

Although some may resist the idea of any registry, we suggest that increasing concern about the growing prevalence of autism spectrum disorders and the consequent need for reliable information in the design and funding of systems of care will prove important to issues of self determination by providing choices to individuals with autism and their families through the greater availability of effective evidence based practices in diagnosis and treatment and that these increasing public health concerns ultimately will require such an information system.

Funding for registry operation will be required, as may legislation to implement the registry. Despite privacy safeguards, resistance to the establishment of a registry is a potential barrier.

This proposal is central to ***13-2805 (B) and (C) (5)*** *of the legislation establishing the Commission.*

2) **Designate a state entity specific to the needs and interests of individuals with autism spectrum disorders, their families, providers, and the public.**

Problem Statement: While information is available through the Maryland State Department of Education concerning the current "Autism Waiver," general information about autism such as prevalence, diagnosis, and treatment and specific information about access to services and treatment options across the lifespan can still be difficult to find and navigate. Furthermore, there will need to be a state entity designated with the responsibility to implement and manage the comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders envisioned in and required by SB 963.

Additional explanation: The workgroup has clarified that this recommendation for a state "entity" dedicated to addressing the needs of individuals, families, providers and public concerned with autism spectrum disorders does not necessarily mean development of any new state department or agency. Rather, the recommendation was intended to suggest that some part of the existing state framework of administration and services be designated as a central focus for the state government's concern with autism. Such an "entity" could be created by identifying an office within a department or agency that which already deals with autism spectrum disorders, thus avoiding creating additional bureaucracy. Nevertheless, additional funding for such an entity may well be required for it to have its full benefit.

This proposal is integral to ***13-2805 (A) and (B)*** *of the legislation establishing the Commission.*

3) **Establish a university-based research and training center or consortium to collect and disseminate data and information on autism; to establish standards for services including identification of evidence-based and promising practices; and to provide comprehensive training opportunities for providers and families, after the models used in other states.**

Problem Statement: Continuation of comprehensive statewide planning for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorders, as envisioned in and required by SB 963, will involve the collaboration of academic and technical experts from a wide range of disciplines to advise the State and to organize and provide a base for the research and training necessary for continuing quality improvement.

Additional explanation: Creation of this research and training center will likely take place within one or more universities and can be promoted by official designation and/or with an RFP, perhaps with startup funding. As the center exists outside State government, legislation would not be required, however the State may continue to invest or contract with the center for specific needs and purposes. Competition between universities for this designation could be a source of conflict, but could also result in a larger consortium of resources for Maryland.

This is central to ***13-2805 (B) (1) - (4) and (7) - (9)*** *of the legislation establishing the Commission.*

4) **Improve the network of access to information on autism spectrum disorders and resources for individuals of all ages with autism spectrum disorder and their families, and especially for those transitioning to adulthood and those aging out of the current Autism Medicaid Waiver.**

Problem Statement: There are many individuals with autism spectrum disorders aging out of the current autism waiver whose families and caregivers are distressed by the imminent ending of essential supports and services. For many, the search for how to replace necessary services and supports lost with the ending of waiver eligibility is perplexing and frustrating. Individuals and families report they often have difficulty finding the information to help them in this quest. Improved access to information is vital to planning for services to individuals leaving the waiver.

The Transition Workgroup developed flow charts and companion documents describing the pathways for transitioning youth that exist under the current autism waiver. These clearly demonstrate just how complex this process is now (Appendix A). This daunting complexity represents additional support for recommendations #5 for service navigators and #6 extending waiver services throughout the lifespan.

Additional explanation: Planning for the future should begin long before leaving the waiver. Information for planning should include both online and offline access to information on state-of-the-art research on autism spectrum disorders and the currently available diagnostic and treatment resources.

Online information should include links (1) to descriptions of the pathways for transitioning youth that exist under the current autism waiver as described in the flow charts and companion documents developed by the Transition Workgroup (see Appendix A) and (2) to a resource map of autism services and providers designating those providing services to those individuals transitioning to adulthood, also developed by the Transition Workgroup (see Appendix B).

These (and any other useful links) should be included on websites such as the Transitioning Youth website (http://www.mdtransition.org), the Maryland Department of Disabilities (DOD) website (http://www.mdod.maryland.gov), and the Early & Periodic Screening & Diagnostic Assessment (EPSDT) website (http://dhmh.state.md.us/epsdt), and others, all of which currently contain important information about autism spectrum disorders and services.

Offline resources are also essential and should include handbooks and brochures on autism spectrum disorder and diagnostic and treatment services in locations such as public libraries, clinics, offices of primary care physicians and pediatricians, Maryland Access Point locations, and the One-Stop Career Centers of the Department of Labor, Licensing and Regulation (DLLR).

Much of the information system needed may already exist. Funding and/or partnerships for establishing and maintaining information databases and brochures will be necessary and these are likely to be the only potential barriers. No legislation should be necessary for this initiative.

This is integral to ***13-2805 (A) (2) and (B) (1) - (5)*** *of the legislation establishing the Commission.*

5) **Implement a system of managers or coordinators who are specifically trained to help individuals and families navigate the autism service system.**

Problem Statement: Even with the best availability of written and online information, most individuals with autism spectrum disorder and their families face many decisions and have many questions in planning for services and choosing providers throughout the lifespan.

Additional explanation: Given the complexity of assessment procedures and service options for a condition with pervasive effects on daily living, personalized guidance can be essential to making the best decisions on care for the present and planning for the future. Understanding the many aspects of healthcare, education, behavioral instruction, and social habilitation can benefit from assistance from an individual familiar with services systems and providers. Such assistance is already available to many individuals with disabilities and their families through the services of case managers in the mental health system and service coordinators from the Developmental Disabilities Administration of the Department of Health and Mental Hygiene.

Training of individuals to provide such case management to individuals with autism spectrum disorders should be a central part of services to them and their families. The current system of service coordinators would be ideal to provide guidance and assistance if it were to be available to all individuals with a diagnosis of autism spectrum disorder without eligibility determination.

Such services require funding. However, assistance given to individuals with autism spectrum disorders and their families to navigate the autism service system should be intermittent rather than continuous, given only when requested, and much, if not most, of this assistance could be made available by telephone contact. No legislation should be necessary for this initiative.

This proposal is integral to ***13-2805 (B) (1)-(4)*** *of the legislation establishing the Commission.*

6) **Expand the services available under the autism waiver to include individuals of all ages.**

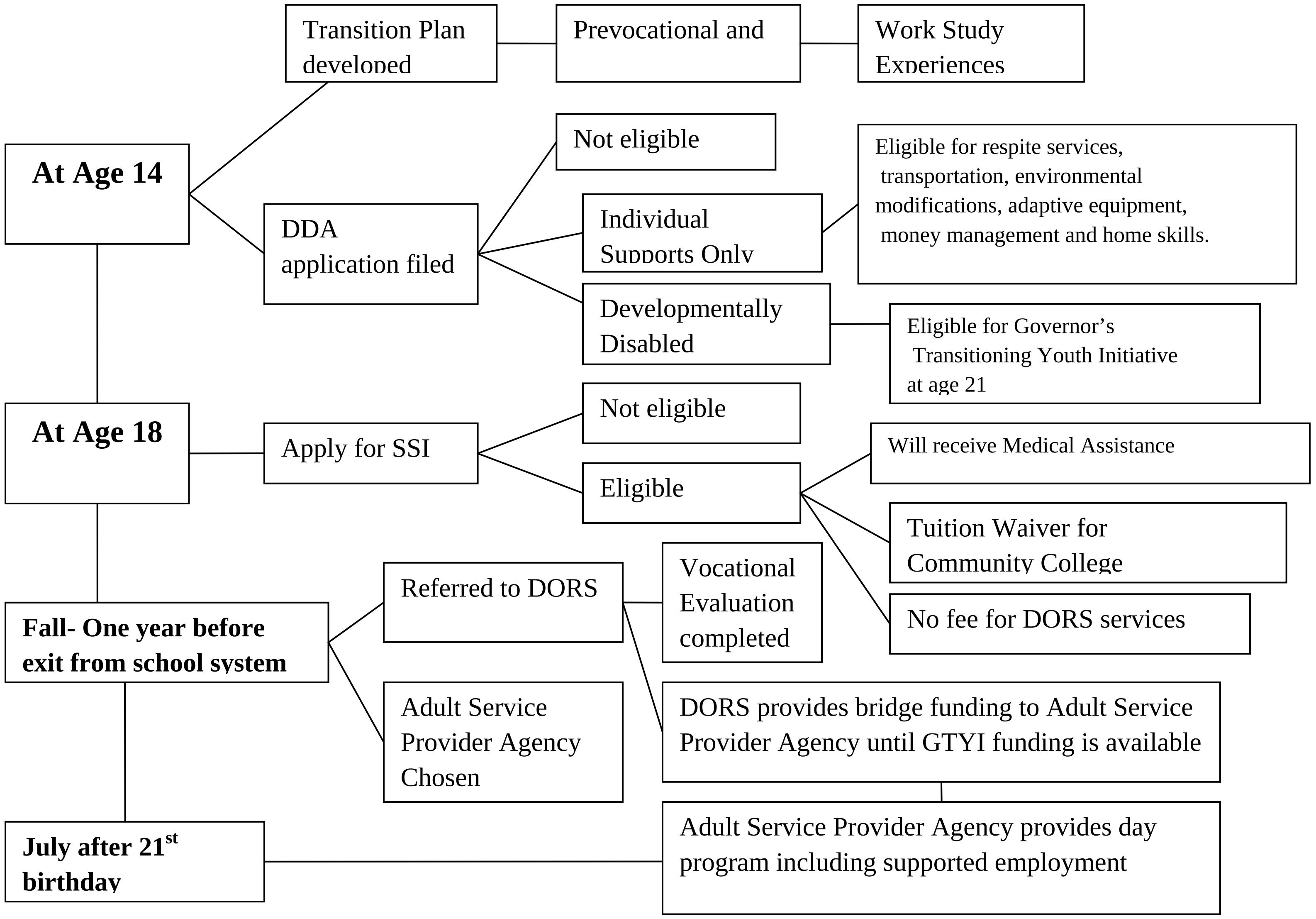
Problem Statement: The need for services and supports does not go away simply because an individual has reached a certain age, completed a course of education, or just withdrawn from school, even though these events frequently mean the end of their autism waiver services.

Additional explanation: This could be accomplished through the addition of an adult autism waiver, such as that of Commonwealth of Pennsylvania, together with provision for a “bridge” for individuals of transition age who have left the public school system at age 16 or 18 under the current autism waiver administered by the Maryland State Department of Education, or through the creation of an autism waiver for individuals of all ages, as in the State of Missouri. This could be a better way to extend autism services throughout the lifespan than transition to the current, fundamentally different system of the Developmental Disabilities Administration.

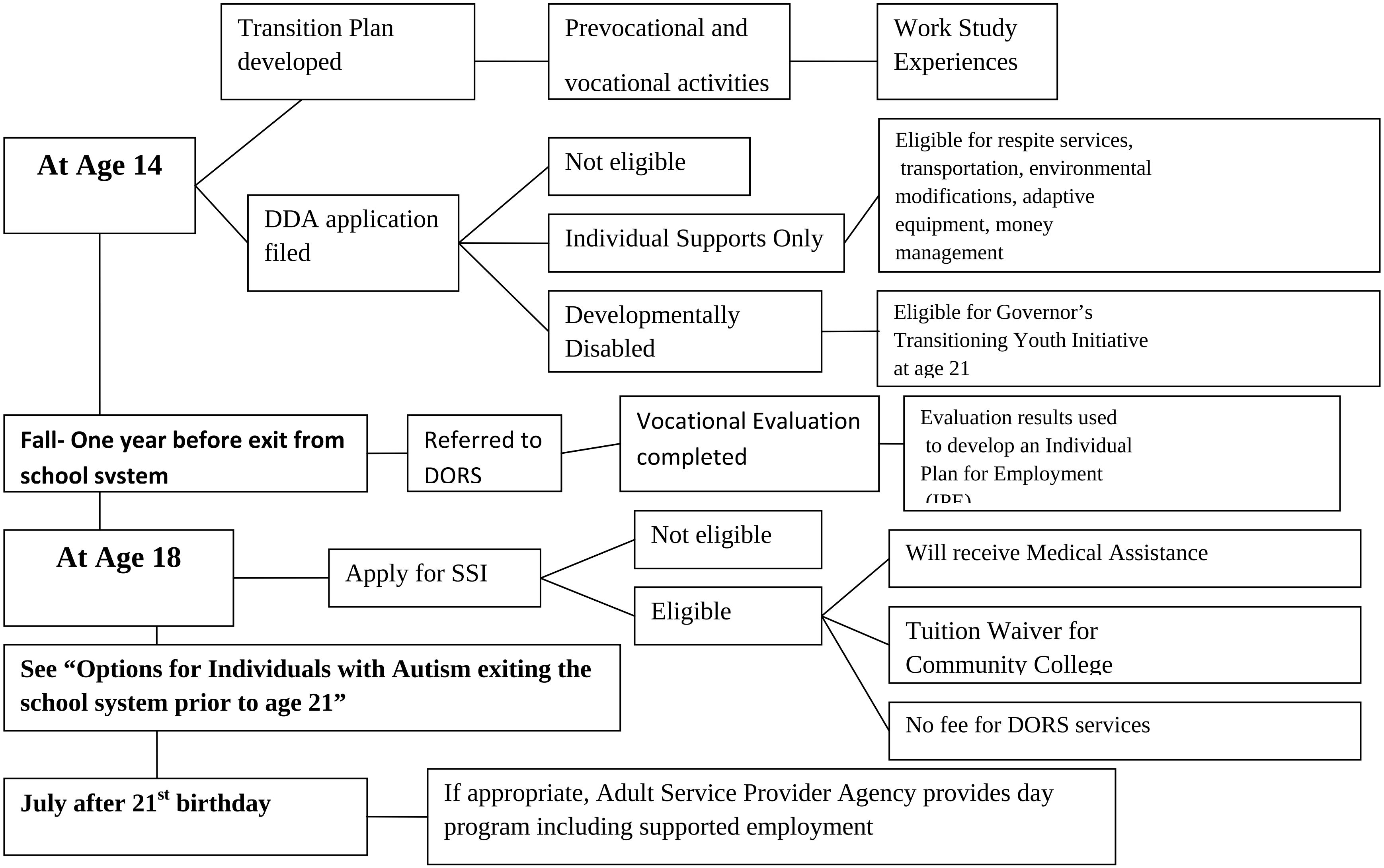
This is likely to be the most ambitious of recommendations and the one which will require the most planning, funding and legislation. Additional individuals will be served through a medical assistance waiver. However, except perhaps in the most debilitating cases of this disorder, a much smaller number of individuals will be served though traditional disability programming.

This proposal is integral to ***13-2805 (B) (5)*** *of the legislation establishing the Commission.*

Current Process for an Individual with Autism who has an IEP and will exit the school system at age 21 with a certificate or diploma



Current Process for an Individual with Autism who has an IEP and will exit the school system prior to the age of 21 with a certificate or diploma (or not)



Options for Individuals with Autism exiting the school system prior to age 21

A. DORS Programs/Services

- a. Community Living Skills Program at the Workforce and Technology Center
    - i. 4 month program which teaches individuals independent living skills.
- b. Career Assessment
    - i. Focused assessments for particular vocation training areas
    - ii. Comprehensive assessments
- c. Pre-vocational Training/Employee Development Services
    - i. 10 week program which focuses on developing positive work related attitudes and behaviors
- d. Academic Services
    - i. Tutoring to support/enhance academic skills necessary for vocational training in a specific area.
- e. Assistive Technology Services
    - i. Assessment to determine if assistive technology is required to be successful in college/on the job
    - ii. Training to use assistive technology
    - iii. Assistive Techno devices provided if individual meets financial criteria.
- f. Pathways Program at the Community Colleges of Baltimore County
    - i. Provides academic/social supports in community college setting for adults with autism.

B. College Campus Based Programs (see flyers further describing each program)

- a. Community Colleges of Baltimore County
    - i. Pathways Program: (see above)
    - ii. Harbour Horizons: (two year non-credit program for adults with autism focusing on job skills and internships in the community culminating in job placement.) This program is run by Single Step/Harbour School and accepts private pay for tuition.
    - iii. Single Step: (specific job training on the community college campus in warehouse management, office technology and childcare.)
- b. Howard Community College
    - i. Project Access: (summer program which prepares individuals with autism and other disabilities for college)
- c. Montgomery Community College
    - i. College Access Program: (serves individuals with language based disabilities)
    - ii. Challenge Program: (serves adults with developmental disabilities)

        iii. Graduate Transition Program: (2 year, noncredit certificate program offering academic classes, job coaching, job development, career exploration and social/recreational activities).
    d. Towson University Center for Adults with Autism: (pragmatic language, social skills, wellness and recreational programs for adults with autism)

C. Employment/Training

   a. DORS programs
   b. Supported Training and Employment Programs (STEP) available in Howard and Baltimore Counties for GTYI eligible individuals exiting school prior to age 21.
   c. St. Luke's House: (support services for Montgomery County residents who have mental health issues.)

D. Volunteer jobs/Internships-sources

   a. Parents/family friends
   b. Nonprofit organizations
   c. Service Coordination
   d. DORS

References:

Pathways for youth transitioning to adulthood under the current autism waiver
Created by: Sue Murray, MANSEF Transition Consultant, Transition Coordinator, Hannah More School, 12039 Reisterstown Road, Reisterstown, MD 21136, 410-526-7631, smurray@hannahmore.org

Resource map of resources for youth transitioning to adulthood, Created by Ryan Shannahan, MSW, RTC Waiver Coordinator, University of Maryland School of Medicine, 737 W Lombard Street, 4th Floor, Baltimore,MD 21201, 410-706-6544, rshannah@psych.umaryland.edu

Appendix J
Maryland Commission on Autism
Workforce Development Workgroup Recommendations

Lisa Crabtree, Chair
Members: Janet DeLany, Jan Miller-Vogel, Carla Nabors, Debra Perry

1) Recommendation:

Establish a statewide, universal education and training system that is available to all public and private providers in Maryland serving individuals on the autism spectrum across the lifespan.

Problem Statement:

One challenge identified by agencies in rural areas of the state, including the Eastern Shore and Western Maryland, was access to training sites. By offering online course modules that are geared towards varying levels of expertise, agencies, families, and schools can provide expert training and education opportunities to those who are supporting individuals on the autism spectrum.

There are inequities across the state, with a variety of agencies providing differing levels of education and training experiences. For example, CSAAC has been providing consistent, regulated hours of training for all of their direct care workers and supervisors, while other agencies have an inconsistent workforce and may only receive mandated DDA training lasting a few hours without additional supports.

Additional explanation:

The statewide, universal education and training system would require a tiered approach addressing the education and training needs of direct care providers, their supervisors, administrators, educators, and community providers and support systems including first responders, criminal justice staff, physicians, counselors and others. Cost of the education and training would be linked to the individual on the spectrum, and any number of individuals linked to that individual would be provided with autism related education and training. Modules would be made available online for access at any time by any person within the Community of Care for an individual on the autism spectrum.

The CDC is developing education and training modules to educate physicians about early identification of ASDs, and the Autistic Global Initiative received a grant from Autism Speaks to develop education modules to educate the workforce addressing the needs of adults with ASD. Both of these modules will be accessible online at no cost, but coordination access to these learning tools, accountability for application of the knowledge in a consistent manner, and consistency.

One organization that is prepared to implement an education and training program is the College of Direct Support (http://directcourseonline.com/directsupport/about/1-888-526-8756). This organization has collaborated with the University of Minnesota over the past 10 years to develop online modules to train and educate service providers working with individuals with developmental disabilities. The cost of
courses may be prohibitive for individual agencies, but could be affordable with a state contract that would provide training for anyone working with an identified individual. Using one curriculum that can be modified and adapted to the unique needs of individual service providers creates a uniform level of education across the state, thereby increasing equity.

2) **Recommendation:**

Support and develop university and community college curricula and community continuing education and training programs that prepare a workforce that understands and is able to address the needs of individuals on the autism spectrum across the lifespan. This includes coursework and educational experiences at the associate, baccalaureate, master's, certificate, and continuing education levels.

Problem Statement:

Currently, in the state of Maryland, there is no comprehensive system to educate and train a workforce that is knowledgeable about working with individuals with ASD across the lifespan. For example, Towson University has developed a Post-Baccalaureate Certificate in Autism Studies and a Master's in Teacher as Leader in Autism to begin to address this need, and Johns Hopkins University offers a Master's in Education with a concentration in autism studies for teachers in the K-12 system. At the baccalaureate level, the Towson University Center for Adults with Autism supports credit-bearing courses in mentor training, and the College of Health Professions is developing a baccalaureate degree in community living for individuals with autism and other developmental disabilities. However, these degree programs that focus on autism studies are centralized and not accessible to everyone in the state. Additionally, there are limited opportunities for continuing education courses or workshops for professionals and direct support service providers who are working with this population across the lifespan.

Additional explanation:

System coordination is necessary to ensure that there is ongoing communication, planning and policy development related to educating the workforce already in place as well as the future workforce. A centralized calendar and database of information related to what courses and continuing education opportunities are available could address this recommendation. Funding through appropriations or grants would support initiatives for course and continuing education program development. Identification and dissemination of opportunities through federal grant monies also would support development of initiatives across the state.

3) Recommendation:

Provide access to educational opportunities that promote awareness and acceptance and develop competency in addressing the issues of individuals with ASD across the lifespan. Particularly important groups for the focus of these educational opportunities include emergency room personnel, first responders, law enforcement and criminal justice employees, child care workers, and community recreation staff.

Problem Statement:

Montgomery County has had training events for first responders, support professionals in agencies, and educators. HCAS has worked to develop programs for law enforcement/first responders, and with the recreation department to educate personnel about autism. However the training sessions in these cases was limited to one county, while other counties had no resources to educate community agency personnel, justice and law enforcement, hospital emergency room employees, and others. A statewide program to educate public employees about the characteristics and needs of individuals with ASD across the lifespan is critical to ensure equity across the state.

Additional explanation:

State resources to address this recommendation include a speaker’s bureau, pamphlets and brochures, information and access to online education and training modules, and scheduled workshops. These activities could be centralized and accessed by county agencies, or statewide by Pathfinders for Autism. A central calendar of training events, and free access to training and education materials would support this initiative.

Appendix K

Regional Listening Sessions

Eastern Shore

PARENT

- Early intervention is important
- Knowledge of special education system
- Understanding of insurance coverage
- Year-long educational services
- Wish List:
    - childcare advocacy program
    - increased support through educational transitions
    - increased training and support to pediatricians on screening and referral to medical, mental health, and other treatment

ADULT SERVICE PROVIDER

- 1:1 support programs support improvement in outcomes for adults with ASD
- more support in transition from school to adult services
- provider training from professionals

ADULT WITH AUTISM

- ongoing need for direct support and coaching to assist with social navigation and maintaining employment
- DORS provided positive support through process of interviewing for and acquiring a job.

AUTISM WAIVER COORDINATOR

- outstanding special education, transition, and recreational resources for families on the eastern shore.
- challenges in locating and accessing services for children outside the school system
- challenges associated with disenrollment from the autism waiver, especially through the teen years
- void in supports for transition-aged youth who are not eligible to access day services and lack in-home support

SPECIAL EDUCATOR

- support system on the eastern shore is “a work in progress”
- need for ongoing professional development
- need more service providers (there is only 1 in Wicomico County)
- families have to travel long distances to seek services
- process of identification, early intervention, and enrollment in support services costs families in time and money
- need collaboration among service providers and the school system
- combined training and professional development opportunities for service providers and school system personnel
- increased opportunities for family training
- restructuring of the autism waiver and increased number of slots
- increased supports, including transportation services
- make training and professional development a priority for all service disciplines
- engage colleges and universities to prepare the workforce
- consider coverage and provision of medical, mental health, and dental services necessary for all individuals with autism, regardless of ability to pay or healthcare coverage

PUBLIC COMMENT

- navigator to help locate providers
- diagnosis is like being in a “black box”
- focus on supports and care for adult children of aging care providers
- services on the shore are limited and travel across the bridge is difficult for families
- need strategies or systems for tracking data on outcomes for people once they exit the school system
- consider utilizing pathfinders for autism as the statewide central repository for autism resources
- dental health and assistive technology for people with ASD throughout the lifespan

Western Maryland

PARENT

- intensive early intervention services and autism waiver services have made a dramatic difference
- lack of providers for behavioral intervention and support
- innovation in the provision of autism waiver services
- strengthen and retain the workforce of vital services

AUTISM WAIVER COORDINATOR

- innovation in the autism waiver to allow sharing resources among participants
- seamless service delivery system
- tiered services from diagnosis throughout the lifespan to allow more capacity

SPECIAL EDUCATOR

- school system has benefitted from innovative online consultation and training strategies
- need strong programming for transition aged youth including vocational training, job placement, and training in the use of public transportation

ADULT WITH AUTISM

- would like to be able to use public transportation, shop, and take walks independently
- desires autonomy in activities of daily living
- prefers regular visits from support staff rather than constant 1:1 supervision

ADULT SERVICE PROVIDER

- important to learn what motivates adults with autism
- need to increase the capacity of the western region to support families impacted by ASD
- intensive behavior management programming and respite care is important for people with ASD and their families

PUBLIC COMMENT

- outstanding instructional assistants make a difference
- MSDE and DHMH should publish success stories to highlight the benefits of the autism waiver to young people statewide
- need to continue environmental and epidemiological studies
- difficulty engaging with local school system administration
- lack of follow up from local school system after due process hearings
- need transportation to and from after school activities

Southern Maryland

PARENT

- need to establish a medical home to meet the unique care needs of individuals with ASD
- early intervention system needs to be parent-driven, focused on parent education, advocacy, and empowerment
- barrier to success is gaps in service availability in region
- difficulty with service coordination and locating service providers who accept Medicaid

ADULT SERVICE PROVIDER

- need to eliminate the divide between children's service system and adult service system
- need to create a seamless lifespan service delivery system
- difficult to find service provider for transition aged youth with severely challenging behavioral and medical needs
- need to develop strategies to share resources

AUTISM WAIVER COORDINATOR

- most significant barrier is "ruralness" of southern Maryland
- very few options available for services
- need for services for transition aged youth moving out of autism waiver
- funding and resources need to be directed to serving teens with severe behavioral and biomedical changes of adolescence
- Wish List:
    - increased funding for autism waiver
    - greater access to services
    - additional services for adults with ASD
    - regional medical satellite centers for evaluation and assessment
    - expanded knowledge of ASD across disciplines

SPECIAL EDUCATOR

- schools comprehensively address the needs of children and youth with ASD
- main barrier is continued perception that there is one type of program or support for all students with ASD
- Wish List:
    - development of a variety of community recreation and social resources
    - adult agencies that are appropriate
    - support higher education and post-secondary employment of young adults with ASD
    - increased funding for community supports
    - therapeutic day programs and non-public special education services

PEDIATRICIAN

- lack of resources to assist families of children with ASD
- need to examine a broad range of triggers and causes of the increase in the number of children with ASD
- teachers need to have higher expectations of children with ASD
- need for more developmental pediatricians to meet demand for developmental screenings
- insurance coverage is needed for evidence-based consultation, evaluation, and behavioral therapies
- need to consider ASD as a neurological disorder rather than psychiatric illness

PUBLIC COMMENT

- difficulty securing needed services and supports due to lengthy process of evaluation and diagnosis
- school systems are tasked beyond capacity
- transportation for school is a challenge: 4-5 hours in transit on school bus daily
- current screening tools often miss kids with ASD
- difficult financial burden to pay for educational advocates and attorneys to get more appropriate educational services
- need more cross training in systems: mental health staff have mental health training and are not prepared for kids with ASD
- need improved communication among agencies and service providers through a data collection system that is HIPAA compliant
- lack of service options for transition aged youth with ASD
- school system is not able or willing to meet the service needs of youth with ASD
- transportation is a significant challenge; especially when attending out of region schools
- long commutes impact the amount of educational services received daily
- need to see results and not just promises
- gap is the knowledge of available services

Central Region

PARENT

- financial strain when paying for interventions out of pocket
- wish list
  - access to the autism waiver
  - improved services for transition aged youth
  - all therapies to be covered by health insurance
  - increase in early intervention
  - more professionals to guide families through vital processes

AUTISM WAIVER COORDINATOR

- need immediate crisis response treatment and inpatient units to stabilize behavior
- limited availability of services
- additional funding should be directed to early intervention systems and the autism waiver to eliminate the wait for services
- wraparound services for kids not currently in the autism waiver could help improve outcomes

ADULT WITH AUTISM (1)

- benefits to early identification and intervention
- challenges in obtaining quality supports
- need for lifespan supports

ADULT WITH ASD (2)

- difficulty being labeled as “autistic”
- current supports available are too restrictive

SPECIAL EDUCATOR

- family support is an integral component of early intervention system
- need for adequate staffing to meet increasing demands
- fiscal challenges in providing transportation
- many children identified never have the opportunity to access autism waiver services

ADULT SERVICE PROVIDER

- need for training and higher education to ensure highly qualified workforce
- need additional providers to serve increasing number of adults with ASD
- funding needs to be allocated toward reimbursement of behavioral support services
- need to increase awareness and education for public servants (police, fire, emergency services)

PUBLIC COMMENT

- cost of private services is prohibitive
- change autism waiver to allow more people to access services
- increase early intervention services and adult services
- need to improve understanding of "free and appropriate education"
- need for periodic evaluation of staff efficacy in replicating evidence-based practices
- challenges in transition planning and lack of adult service options
- difficulties in securing medical care for children with ASD

Appendix L

2012 Comprehensive Needs Assessment of Maryland Children with Autism Spectrum Disorders and other Developmental Disabilities

Prepared by Maryland's Office for Genetics and People with Special Health Care Needs

Maternal and Child Health Bureau

Prevention and Health Promotion Administration

Maryland Department of Health and Mental Hygiene

September 2012

Meredith Pyle, Principal Author

Thanks to the following people and entities for edits, comments, and contributions: Donna Harris, Deborah Badawi, Sally Chan, Stacey Richards and Lynn Midgette (Office for Genetics and People with Special Health Care Needs), Josie Thomas, Kelly Meissner, Mary Baskar and Missy Alexander (The Parents' Place of Maryland), Chris Smith (Maryland Center for Developmental Disabilities), Rebecca Rienzi and Trish Kane (Pathfinders for Autism), Eric Levey (Maryland Chapter, American Academy of Pediatrics), Marjorie Shulbank and Tom Stengel (Maryland State Department of Education), Abila Tazanu and Jan Sullivan (One World Center for Autism), Sue Powell and Lynne Markowitz (Anne Arundel County Public Schools).

Conducted with funding support from a State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities from the Federal Health Resources and Services Administration, Maternal and Child Health Bureau.

TABLE OF CONTENTS

EXECUTIVE SUMMARY

This needs assessment was conducted by Maryland's Office for Genetics and People with Special Health Care Needs (OGPSHCN) and The Parents' Place of Maryland (PPMD) on behalf of Maryland children and youth with special health care needs (CYSHCN) with autism spectrum disorders (ASD) and other developmental disabilities (DD) and their families. PPMD, in partnership with OGPSHCN in the Maryland Department of Health and Mental Hygiene (DHMH) was awarded a federal "State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities" from the federal Maternal and Child Health Bureau; the purpose of this funding is to facilitate development of a statewide plan to improve systems of health care and related services for CYSHCN with ASD and DD.

The prevalence of ASD among children is on the rise in Maryland; 1 per 80 (or 12.4 per 1000) children in Maryland have ASD; this varies by sex and race/ethnicity. Boys are far more likely to have ASD and fewer black and Hispanic children are identified with ASD. Data on the prevalence of DD among Maryland children is not as specific, however 5.2% of all children ages birth to 17 years in Maryland are reported to have at least one emotional, behavioral or developmental issue. Early identification and treatment of ASD and DD is critical if children and families are to have the best outcomes possible. According to the 2007 National Survey of Children's Health, 28% of Maryland children aged 4 months to 5 years are at moderate or high risk for developmental delay, but only 22.3% of families report that their child aged 10 months to 5 years received a standardized screening for developmental or behavior problems. CYSHCN who are in poorer families, are Hispanic or African American, who are not insured or who have public insurance only are less likely to receive early and continuous screening.

There are major gaps in access to needed primary and specialty health care services and as a result, Maryland children and youth with ASD and/or emotional, behavioral or developmental issues have high rates of delayed or unmet needs for health care and related services. Additionally, their families have high rates of delayed or unmet needs for family support services, especially poorer children and families and those in rural regions of the state. Certain Maryland jurisdictions (Baltimore City and many Eastern Shore and Western Maryland counties) and racial/ethnic groups (African American and Hispanic) have disproportionately high rates of child poverty. In the 2010 Maryland Parent Survey, services not covered or inadequately covered by insurance noted most frequently were: therapies (such as speech therapy and behavioral therapies), mental health services, testing and evaluations, and dental care. In the 2011 PPMD Parent Focus Groups, parents of children with ASD and other DD reported their child's private health insurance was not adequate to cover needed medical and therapy expenses. Effective care coordination (which includes help with coordination of care and satisfaction with communication among providers and with schools if needed) is especially important for children with developmental issues; in Maryland, CYSHCN with emotional, behavioral or developmental issues are less likely to have effective care coordination when needed (37%) than are CYSHCN in general (42%).

Delayed and unmet needs for children and youth with ASD and DD are just one example of many difficulties faced by children and families. Caring for CYSHCN has profound logistical, financial and emotional impacts on families. Many families find it necessary to change their work hours or to stop working in order to care for their child; parents frequently turned down higher paying positions or career-advancing promotions because of the need to maintain flexibility in their work schedules in order to care for their children with ASD and other DD. Over half of CYSHCN in Maryland with emotional, behavioral or developmental issues do not have adequate health insurance; 31% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that they spend between $1000 and $5000 per year on out-of-pocket spending for their child's medical care; 21% spend over $5000 per year. Experience with challenging behaviors is common among children with ASD and DD; 24% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that their child has had problems with anger/conflict management; 23% report problems with depression; and 22% report problems with bullying. Only half of Maryland CYSHCN with emotional, behavioral, or developmental issues have services that are community-based and easy-to-use. Families in Western and Southern Maryland and on the Eastern Shore have considerably less access to community-based, easy-to-use services. Youth and young adults with ASD and DD and their families need appropriate supports for the transition from youth to adulthood, yet only 29% of Maryland families of YSHCN aged 12 to 17 with emotional, behavioral, or developmental issues reported that their child received the services necessary to make appropriate transitions to adult health care, work, and independence.

Families, youth, educators, medical and other providers and policymakers need training on how to establish and maintain effective family-professional partnerships in order to have the best possible health, educational and life outcomes for CYSHCN with ASD and DD.

The results of this needs assessment indicate that the highest priority needs to be addressed for CYSHCN with ASD and DD statewide related to health care and related services are:

- Access to therapies such as behavioral, speech/language, occupational, and physical therapies that are necessary in treating ASD and/or DD.
- Adequate health insurance and financing to pay for all needed health and related services for children with ASD and DD, including diagnosis and referral.
- Needed services for children and youth with ASD and DD are community based and are organized so that families can use them easily
- Training for school and child care personnel in how to meet the needs of children and youth with ASD and other DD.
- Youth with ASD and DD receive the services necessary to make transition to all aspects of adult life, including adult health care, work, and independence.

There are important regional differences in priority needs of CYSHCN with ASD and other DD in Maryland; in more rural areas, access to primary and specialty care, mental health services; and developmental screening and diagnostic services are crucial needs. All regions identified training for families and providers as a strategy to address priorities for Maryland CYSHCN with ASD and DD; most regions also identified strategies such as working with service providers to maximize insurance reimbursement, developing integrated service centers, involving health insurers in problem-solving and strategizing, and providing informational hubs for families and providers to facilitate access to information and services.

The following needs assessment further describes the prevalence of ASD and other DD among Maryland CYSHCN; demographic and other important characteristics of this target population; findings from other organizations' needs assessment activities; data and information about the six key characteristics of a system of care for CYSHCN with ASD and DD; and a description and summary of the process used to identify the highest priority needs for the target population.

I. Introduction

The Parents' Place of Maryland (PPMD), in partnership with the Office for Genetics and People with Special Health Care Needs (OGPSHCN) in the Maryland Department of Health and Mental Hygiene (DHMH) was awarded a federal "State Planning Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities" from the federal Maternal and Child Health Bureau. The purpose of this grant is to develop a comprehensive statewide plan for Maryland to improve the system of health care and related services for children and youth who have Autism Spectrum Disorder (ASD) and other Developmental Disabilities (DD). Activities for this grant are being planned and coordinated with current ASD and DD initiatives and partners in the state, including the Maryland Commission on Autism and the Maryland Center for Developmental Disabilities. In order to develop a sensible, effective plan, a comprehensive needs assessment was necessary.

This needs assessment, conducted over the course of one year (September 2011 – September 2012), sought to gather existing data on Maryland's children and youth with autism spectrum disorders and other developmental disabilities, gather additional data and information where needed, and synthesize those data and findings to generate a data-driven list of priorities needs for this target population. This list of priorities was generated, and stakeholders evaluated and ranked the list through several different mechanisms in different venues (online surveys, in-person meetings) until a definitive set of priority needs were identified for the entire state and for each region of the state. These priorities are presented in the last sections of this document, and are the priorities that will be addressed by the statewide plan to improve the systems of health care and related services for CYSHCN with ASD and DD in Maryland.

This needs assessment explores and presents findings on the prevalence of ASD and other DD among Maryland CYSHCN; demographic and other important characteristics of this target population; findings from other organizations' needs assessment activities; data and information about the six key characteristics of a system of care for CYSHCN with ASD and DD; and a description and summary of the process used to identify the highest priority needs for the target population. At the beginning of each section of this document, the reader will find a box with the "Key Findings" for each section.

A. Target Population / Data Sources

Key Findings

The target population for this needs assessment is Maryland children and youth with special health care needs (CYSHCN) with autism spectrum disorders (ASD) or other developmental disabilities (DD).

Many data sources were used for this needs assessment, including national and state datasets and qualitative data. Proxy subgroups were often used when data specific to CYSHCN with ASD or DD were not available. Used in combination, these data sources provide the best available estimate of CYSHCN with ASD and other DD, their characteristics and needs.

Maryland's target population for this needs assessment includes CYSHCN with ASD and other DD. In considering the needs of this population, Maryland's Office for Genetics and People with Special Health Care Needs (OGPSHCN) examined data collected from several sources. Background data for the general population of CYSHCN in Maryland comes from the Title V Maternal and Child Health Block Grant 2010 Needs Assessment[7] and has been updated with the most recent available data whenever possible. Additional quantitative data specific to CYSHCN with ASD and other DD in Maryland was added from several sources, including the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), the 2011 Survey of Pathways to Diagnosis and Services, the 2007 National Survey of Children's Health (NSCH), the 2010 Maryland Parent Survey, and Maryland State Department of Education (MSDE) Special Education program data. Rates of child uninsurance from the Model-based Small Area Health Insurance Estimates (SAHIE) for Counties and States are also included in this report[8].

During the past several years, many Maryland agencies and programs have conducted various needs assessment and data gathering activities with regard to individuals with ASD and other DD throughout the state. A primary aim of *this* needs assessment document is to present information

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[7] Title V Maternal and Child Health Block Grant 2010 MCH Needs Assessment available at https://perfdata.hrsa.gov/mchb/TVISReports/Documents/NeedsAssessments/2011/MD-NeedsAssessment.pdf

[8] http://www.census.gov/did/www/sahie

from all previous relevant assessments in order to facilitate a summary and synthesis of what is known in the state from these various sources, in support of development of a state plan for improved health and related services for children with ASD and DD.

Use of Proxy Groups

Some major data sources, such as the NS-CSHCN, did not disaggregate all data based on specific diagnoses. Throughout this needs assessment data has been disaggregated to represent the population of children in Maryland who are reported to have ASD or other DD whenever possible; however in many cases a proxy subgroup is used.

For example, the NS-CSHCN distinguishes a subgroup of CYSHCN who are reported to have one or more emotional, behavioral, or developmental (E/B/D) issue; this is the subgroup analysis used most often to represent the target population for this needs assessment. While not absolutely limited to CYSHCN with ASD or other DD, this subgroup is the closest proxy for the target population from this rich and statistically representative data set.

Other data sources, such as the 2010 Maryland Parent Survey, allow a sub-analysis of CYSHCN with ASD but are not statistically representative of all CYSHCN in Maryland due to convenience sampling techniques. This data set is also analyzed regionally whenever possible, but one region, Western Maryland, did not have enough responding families who had at least one child with ASD to constitute a subgroup. In regional analyses of that data for families with children with ASD, Western Maryland is not represented as a subgroup. However, families with a CYSHCN with ASD comprise 31.3 % of total respondents (n=294 out of 939 families) to the survey.

However, the recent 2011 Survey of Pathways to Diagnosis and Services conducted as a follow-up to the 2009-10 NS-CSHCN is a nationally representative survey about children with special healthcare needs aged 6 to 17 years old ever diagnosed with ASD , intellectual disability, or developmental delay. Data from this survey is used to supplement information in this needs assessment whenever applicable.

Special Education Census data from the Maryland State Department of Education (MSDE) is included in this report. MSDE tracks the number of students receiving special education services by several characteristics, including disability type. The disability types tracked by MSDE that are relevant to this needs assessment are autism, developmental delay, and intellectual disability.

It is important to note that MSDE codes students by disability type based on the students' primary education-related condition. Accordingly, a student may have a medical diagnosis of autism, but may not have autism as their primary disability type/code according to MSDE, because the student may have a more primary educational need such as blindness – in such cases that student would be coded with blindness, rather than with autism in the MSDE data set. Also, this data does not include children birth to three who receive early intervention services, children with Section 504 plans, or children with autism placed in private schools by their parents. Therefore, the data from MSDE's Special Education Census in this report will reflect many, but not all children with ASD or DD in Maryland.

Data from the Maryland Medicaid Home and Community-Based Services Waiver for Children with Autism (Autism Waiver) is also incorporated from a report summarizing the results of a parent satisfaction survey. The survey, the Maryland Autism Services Survey (MASS; conducted in 2009) and report[9] were commissioned by MSDE in conjunction with Towson University and compares several outcomes for families and their children with ASD, some of whom receive services through the Autism Waiver and some of whom are on the Autism Waiver Registry and so have not yet received services.

Data is also included from the Maryland Commission on Autism, created through legislation in 2009 to envision a comprehensive and integrated approach to service systems and supports for people with ASD and their families.[10]

The Maryland Center for Developmental Disabilities (MCDD) conducted a needs assessment of Maryland's population of individuals with DD during 2011. A discussion of the data gathered as well as preliminary findings are included in this needs assessment.

The Parents Place of Maryland (PPMD) conducted three parent focus groups with parents of children with ASD and other DD in order to illuminate the impact of some of the issues raised by the quantitative data analysis presented in this needs assessment (such as unmet needs, impact on families, etc.) Parents of children in typically under-represented groups such as low income and non-English speakers participated in these focus groups, as did parents from Western and

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[9] Maryland State Department of Education (2009). *Maryland Autism Services Survey Summary of Results.* Prepared for MSDE and Towson University by Karen Goldrich Eskow. Available by request from MSDE.

[10] Maryland Commission on Autism (2011). *Interim Report on Activities, Findings and Recommendations.* Available at http://dhmh.maryland.gov/autism/pdf/2011/Autism_Report.pdf

Southern Maryland. Findings from the focus groups are included where applicable throughout the needs assessment.

Used in combination, these data sources provide the best available estimate of CYSHCN with ASD and other DD, their characteristics and needs.

B. General Maryland State Characteristics

Key Findings

Certain Maryland jurisdictions (Baltimore City and many Eastern Shore and Western Maryland counties) and racial/ethnic groups (African American and Hispanic) have disproportionately high rates of child poverty.

Maryland’s population is estimated at 5,699,478 and is ranked as the 19th largest state population in the nation. Maryland’s population grew by 7.6% from 2000 to 2009, slower than the growth rate for the nation as a whole (9.1%) over the same time period, but ranking 17th in growth rates for states. The state covers 9,774 square miles and is the 5th most densely populated state in the nation, with 595 persons per square mile, yet the state also has rural, less densely populated areas in the southern, western, and eastern shore areas Maryland has 24 counties/county-equivalents divided into five regions (see Figure 1 on next page.)

Figure 1. Maryland Counties and Regions

From 2000 to 2010, the state's poverty rate increased from 7.4% to 9.7%[11]. While the statewide average was well below the national poverty rate of 15.3% in 2010, certain jurisdictions in Maryland have very high poverty rates, well above the national average. The same is true for child poverty rates in Maryland. Maryland's child poverty rate was 13.1% in 2010, up from 10.7% in 2000 (see Figure 2.) Child poverty varies by race/ethnicity and jurisdiction. Figure 3 shows Maryland child poverty rates by jurisdiction. Counties with the *highest* child poverty rates in 2010 include Baltimore City (34.3%; up from 26.2% in 2000); Eastern Shore counties including Somerset (29.3%), Dorchester (25.8%), and Wicomico (23.1%); and rural Western Maryland counties including Garrett (24.4%) and Allegany (23.9%). Counties with the *lowest* child poverty rates in the state are found mostly in the Central (Howard, Anne Arundel, and Carroll counties) and Southern (Charles and Calvert counties) Maryland regions. By race/ethnicity, the highest percentage of children in poverty in the state is among black or African American children, with 17.0% living in poverty in 2008, followed by 13.0% of Hispanic or Latino children.[12]

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[11] Poverty and child poverty rates come from the U.S. Census 2010 Small Area Income and Poverty Estimates, available at http://www.census.gov/did/www/saipe/index.html

[12] 2010 Maryland Title V Needs Assessment.

Figure 2. Maryland Child Poverty Rates, 2000 to 2010, (*Source: U.S. Census 2010 Small Area Income and Poverty Estimates)*

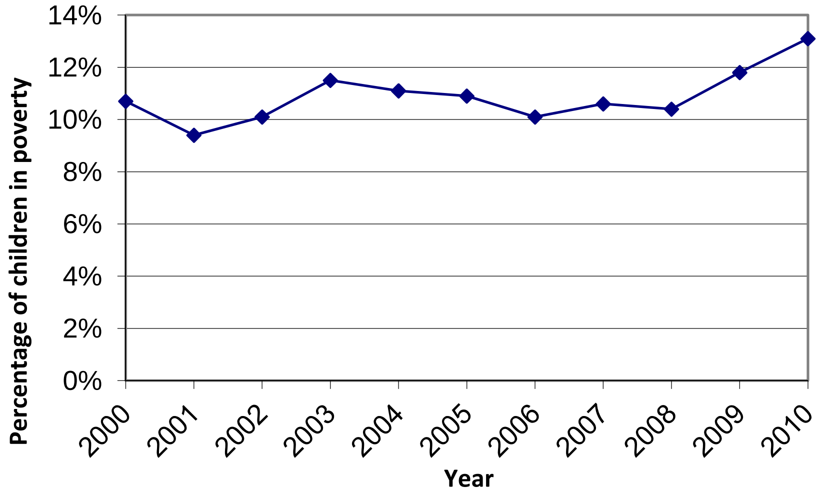
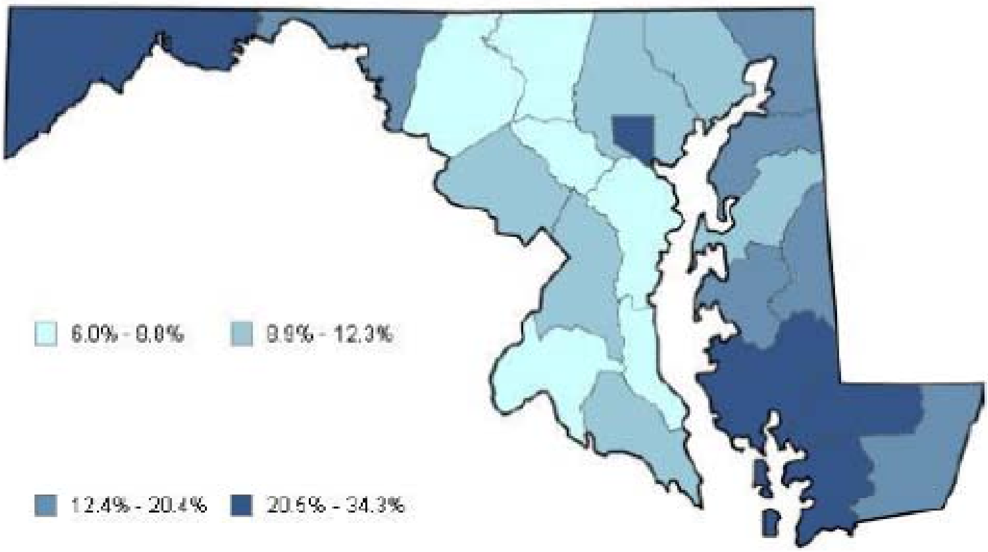


Figure 3. Maryland Child Poverty Rates 2010 *(Source: Advocates for Children and Youth KIDS COUNT Data Center)*



II. Prevalence and Incidence of ASD and other DD among Maryland Children

Key Findings

1 per 80 (or 12.4 per 1000) children in Maryland have ASD; this varies by sex and race/ethnicity. Boys are far more likely to have ASD and fewer black and Hispanic children are identified with ASD.

5.2% of all children ages birth to 17 years in Maryland are reported to have at least one emotional, behavioral or developmental issue.

The number of students in Maryland receiving special education services for ASD has risen sharply over the past decade.

Autism Spectrum Disorder

Data from the 2007 NSCH show that approximately 1% of children aged 2-17 years in the United States currently have ASD, and that boys are four times as likely to have ASD than are girls. Respondents to the 2009-10 NS-CSHCN were asked if their CYSHCN currently has autism or ASD. Respondents with SHCN from Maryland were slightly less likely to respond that their CYSHCN has autism or ASD (7.3%; corresponding to 14,557 children in Maryland in 2010) than respondents nationwide (7.9%). 13.1% of Maryland respondents said their child had a developmental delay, compared to 17.6% nationwide. Respondents were also asked if their CYSHCN currently has an intellectual disability or mental retardation; 2.5% (corresponding to 4,928 children) of respondents in Maryland answered yes compared to 5.8% of respondents nationwide.

National data from the 2011 Survey of Pathways to Diagnosis and Services indicate that the median age when school aged children with special health care needs (CSHCN) and autism disorder (ASD) were first identified as having ASD was 5 years old. Nationally, school age CSHCN identified as having ASD under age 5 were identified most often by generalists and psychologists while those identified over age 5 were identified primarily by psychologists and psychiatrists.[13]

Perhaps the most reliable data on the prevalence of ASD is available from the Center for Disease Control's Autism and Developmental Disabilities Monitoring Network (ADDM[MP1]), which estimated national ASD prevalence based on the number of cases among 8 year-old children in 12 study sites across the nation, including central Maryland. In 2007, ADDM first reported that about 1 in 150 children had an ASD (based on children who were 8 years old in 2002). Then, in 2009, they reported that 1 in 110 children had an ASD (based on children who were 8 years old in 2006). Most recently, ADDM reported that 1 in 88 children had an ASD (based on children who were 8 years old in 2008) meaning that the estimated prevalence of ASDs increased 23% during 2006 to 2008 and 78% during 2002 to 2008 with boys being almost 5 times more likely to be identified as having ASD than girls.

The estimated prevalence in Maryland is slightly higher, at 1 per 80 (or 12.4 per 1000) children and varies by sex and race/ethnicity. Boys in Maryland are 5 times more likely than girls to have ASD, and white, non-Hispanic children have a slightly higher prevalence (12.9 per 1,000) than black, non-Hispanic children (11.7 per 1,000) and Hispanic children (5.9 per 1,000.)[14] The rising prevalence of ASD is due in part to a true increase in ASD symptoms in the population because of increasing environmental and genetic risk factors. Other reasons for the intensifying prevalence include changes in diagnostic criteria over time, increased awareness of ASD in the community, changes in the availability of services, and a recognition that ASD can occur with severe intellectual disabilities, higher intellectual functioning, and other medical and psychiatric disorders.[15]"

Additional data from MSDE's Autism Waiver program (for children diagnosed with ASD and are ages 1 to 21 years with an Individualized Family Service Plan – IFSP – or an Individualized Education Program – IEP – and who meet other eligibility requirements) show that, of the 900 slots available for the program, all were filled. An Autism Waiver Registry was created for

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[13] **NCHS Data Brief No. 97.** *Diagnostic History and Treatment of School-aged Children with Autism Spectrum Disorder and Special Health Care Needs*. 8 pp. (PHS) 2012-1209. May 2012.

[14] Centers for Disease Control and Prevention (CDC). *Prevalence of Autism Spectrum Disorders–Autism and Developmental Disabilities Monitoring Network*, United States, 2008. Morbidity and Mortal Weekly Report (MMWR) 2012; Vol. 61(3).

[15] Lee, Li-Ching (2010) *A review of update prevalence of autism spectrum disorders.* Presented at the Maryland Autism Commission meeting, January 12, 2010. Accessed on 4/18/11 at http://dhmh.maryland.gov/autism/pdf/2010/ASD_prevalence_MD_Autism_Commission_1-12-2010.pdf.

families interested in receiving services; in January 2009, 2,649 families were on the Registry and as of September 2011 there were approximately 3,500 families on the Registry. Families on the Registry may or may not qualify for Waiver services; eligibility is determined for new families as slots become available. The last child found eligible and enrolled in the Autism Waiver program was placed on the Registry on May 15, 2004[16] which highlights the extremely long waiting period families face for those services.

Other Developmental Disabilities

As opposed to autism, it is more difficult to estimate the general prevalence or incidence of children with Developmental Disabilities. The prevalence of all CYSHCN in Maryland aged birth to21 years is 15.7% which corresponds to approximately 211,442 children and youth in 2010 which is higher than the national prevalence of 15.1%. Over one fifth (23.1%) of all Maryland households with children report having one or more CYSHCN. According to the 2009-10 NS-CSHCN, 5.2% of all children ages birth to 17 years in Maryland are reported to have at least one E/B/D issue, compared to 4.8% of all children ages birth to 17 years nationally.

Prevalence of Autism, Developmental Delay and Intellectual Disability among Maryland Special Education Students

The Maryland State Department of Education (MSDE) tracks the number of children ages 3 to 21 years with disabilities by type of disability receiving special education and related services. The disability types tracked by MSDE that are relevant to this needs assessment are autism, developmental delay (currently children can only be served under this category until 7 years of age, when they must receive a more specific diagnosis for continued receipt of special education services), and intellectual disability. It is important to note that these data from MSDE reflect only those children who are coded with autism, developmental delay, or intellectual disability as their primary diagnosis from the school system. There are other children who have ASDs or other DDs but who have multiple conditions and are coded by MSDE under another primary diagnosis. Those children will not be captured by the MSDE data presented here.

Figure 4 shows the Maryland rates of special education students ages 3 to 21 years by selected disability categories from 2000 to 2010. During this period, the number and rate of children coded with autism receiving special education services has risen each year, from 2,304 to 8,828.These numbers represent 2.1 % of the total number of children receiving special education

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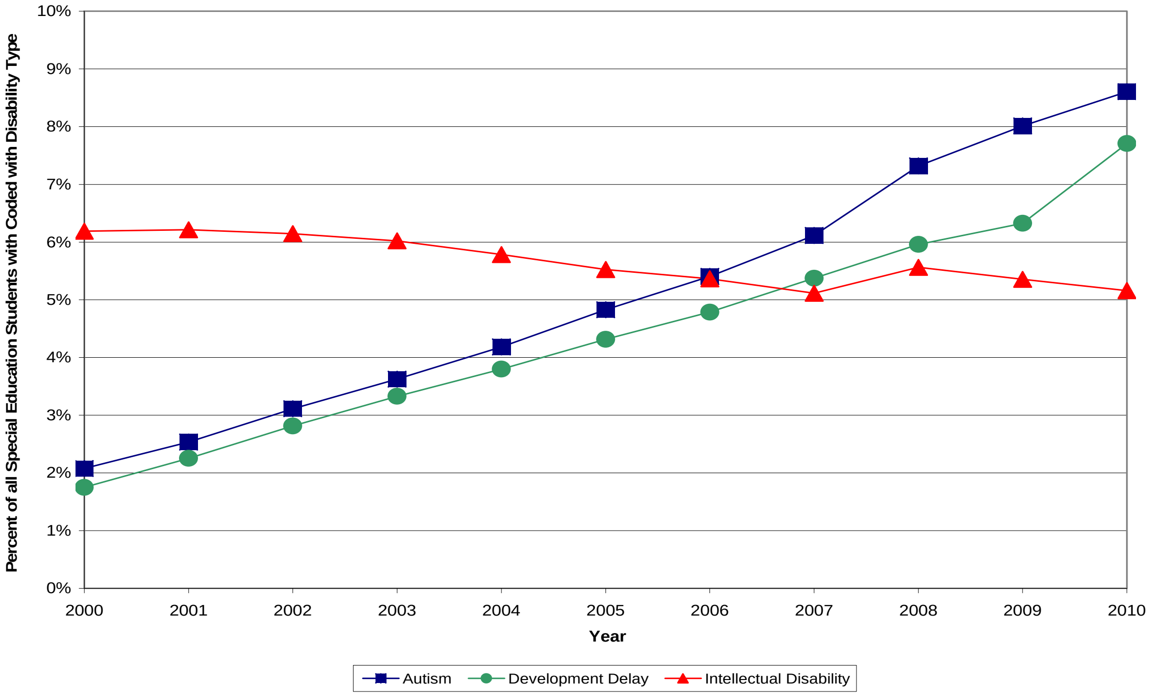
[16] Maryland Autism Commission 01/12/2010 Meeting Minutes. Available at http://dhmh.maryland.gov/autism/pdf/2010/Jan2010.pdf

and related services in 2000 and 8.6% of the total number of children receiving special education and related services in 2010.

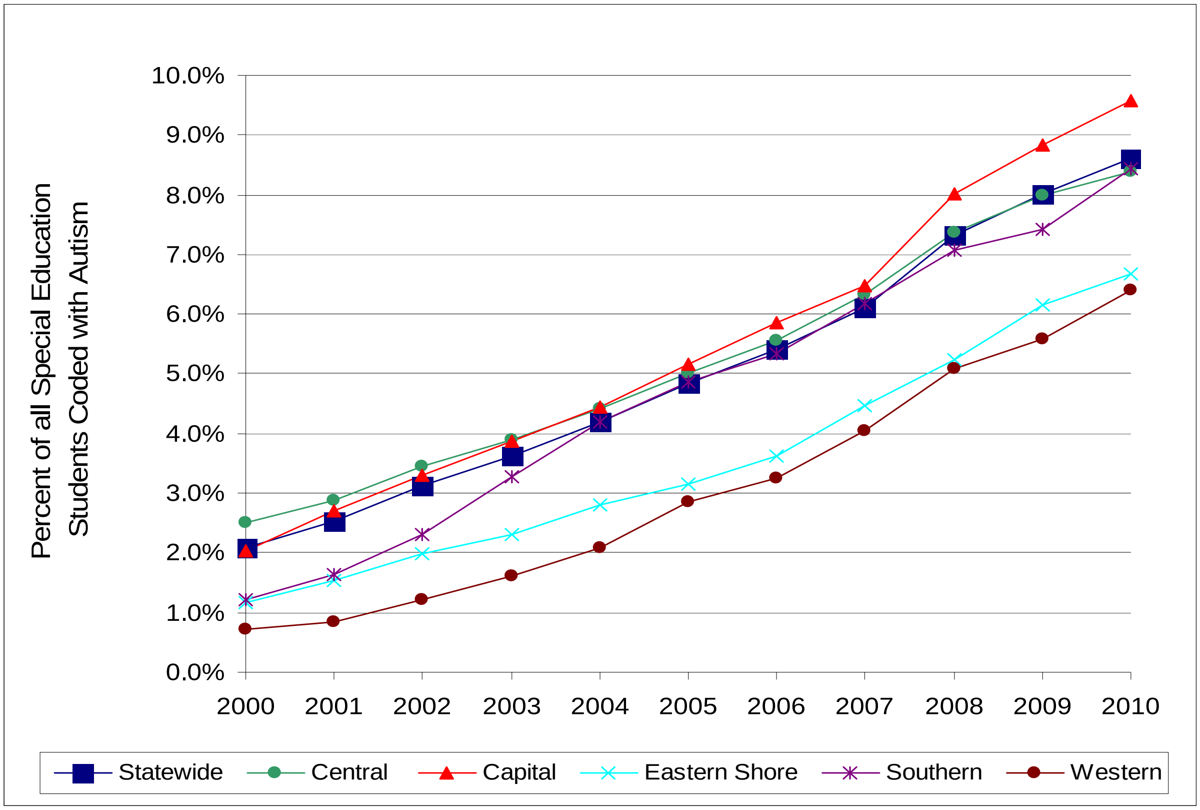
Figure 4. Maryland Rates of Special Education Students Ages 3 to 21 Years by Selected Disability Types, 2000 to 2010 *(Source: Maryland State Department of Education, Special Education Data)*



An examination of the MSDE data also reveals a growing trend of children in the developmental delay category. Of the 110,925 students receiving special education services in 2000, 1,943 (1.8%) were categorized as having a developmental delay. By 2010, the number of students receiving special education and related services decreased to 102,585, yet students in the developmental delay category grew to 6,901 (7.7%). In contrast to both autism and developmental delay, the number and rate of students receiving special education and related services that are categorized as having an intellectual disability has decreased over time. In 2000, 6,894 students (6.2%) were categorized as having an intellectual disability. This designation has since declined. In 2010, there were 5,293 (5.2%) students coded with having an intellectual disability.

As mentioned, the rates of special education students who are coded with autism have increased over a period of ten years. Figure 5 displays the Maryland rates of special education students ages 3 to 21 who are coded with autism, by region, from 2000 to 2010. Statewide, the rate of students with autism has quadrupled, from around 2% (2,304 students) to almost 9% (8,828 students) over this ten year period. In 2010, the state had its highest rate at 8.6 % which corresponds to 8,828 students whom were coded with autism and receiving special education and related services. Similarly, each region displayed their highest rates in 2010. The capital region had the highest percentage of special education students categorized as having autism, which was also slightly above the statewide rate with 3,467 (9.6%) students receiving services.

Figure 5. Maryland Rates of Special Education Students Ages 3 to 21 Years Coded as Having Autism by Region, 2000 to 2010 *(Source: Maryland State Department of Education, Special Education Data)*



Among the regions, Western Maryland consistently falls well below the statewide average for students coded as having autism. Western Maryland had the lowest rates within the period of ten years in 2000 with 0.7% (40 students). However, this region has also seen a significant growth in the number of children coded with autism who are receiving special education services over the last ten years. This growth in Autistic students has a significant impact relative to Western Maryland's schools systems in terms of size and capacity. In 2010, the region had its highest rate with 268 students (6.4%). Within Western Maryland, Garrett County had the lowest rate of students (3.3% in 2010) coded with autism of all the counties in the region.

The rates of Maryland students coded with developmental disability ages 3 to 9 years from 2000 to 2010 are displayed in Figure 6. In aggregate, the rates of students with developmental disabilities in general trend up among the five regions despite there being notable regional variation. For example, from 2009 to 2010, Western Maryland was the only region that had a reduced number of students coded with developmental delay with a reported 146 students (3.4%) in 2009 versus 125 students (3.0%) in 2010.

Similar to the data on autism, the Capital Region has the highest rates of students coded with developmental disabilities. The Capital Region consistently has rates above the statewide average from 2000 to 2010. The highest number of students with developmental disabilities receiving special education services in 2010 was 3,596 students (almost 10%) in the region. Within the region, two counties (Montgomery and Prince George's County) had the highest rates (10.8% and 11.4% in 2010) over this 10 year span.

Figure 6. Maryland Rates of Special Education Students Ages 3 to 9 Years Coded with Developmental Delay by Region, 2000 to 2010 *(Source: Maryland State Department of Education, Special Education Data)*

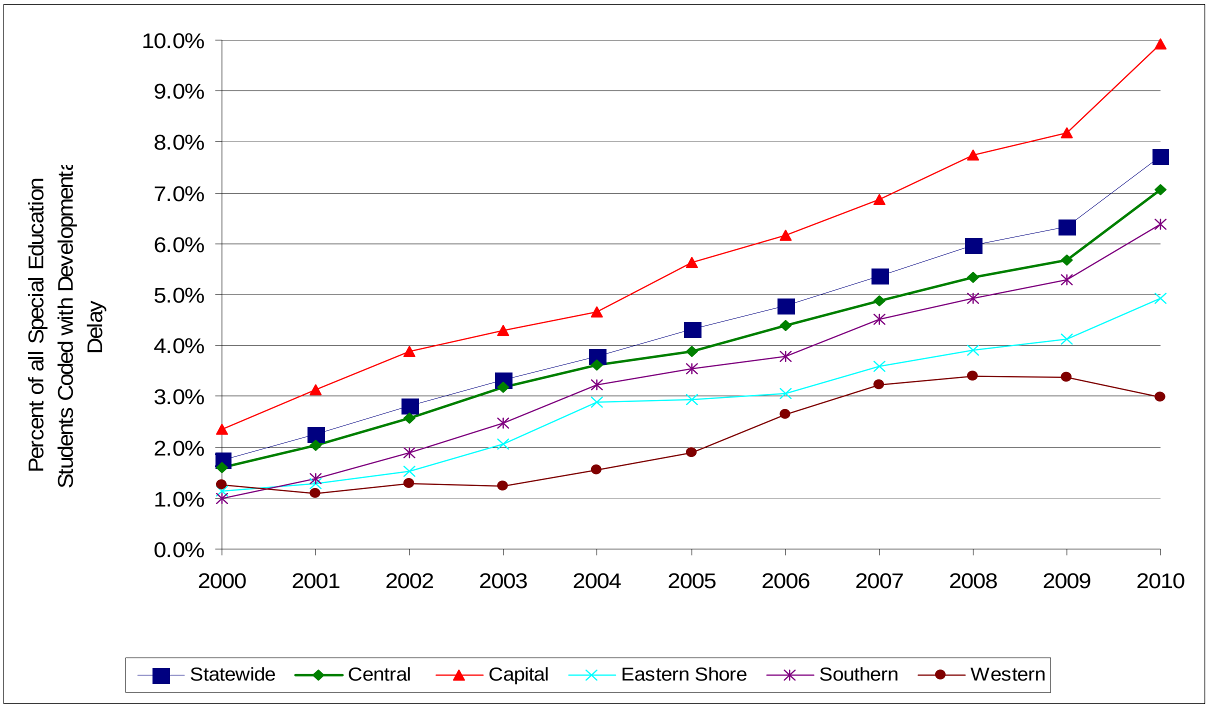


Figure 7. Maryland Rates of Special Education Students Ages 3 to 21 Years Coded with Intellectual Disability by Region, 2000 to 2010 *(Source: Maryland State Department of Education, Special Education Data)*

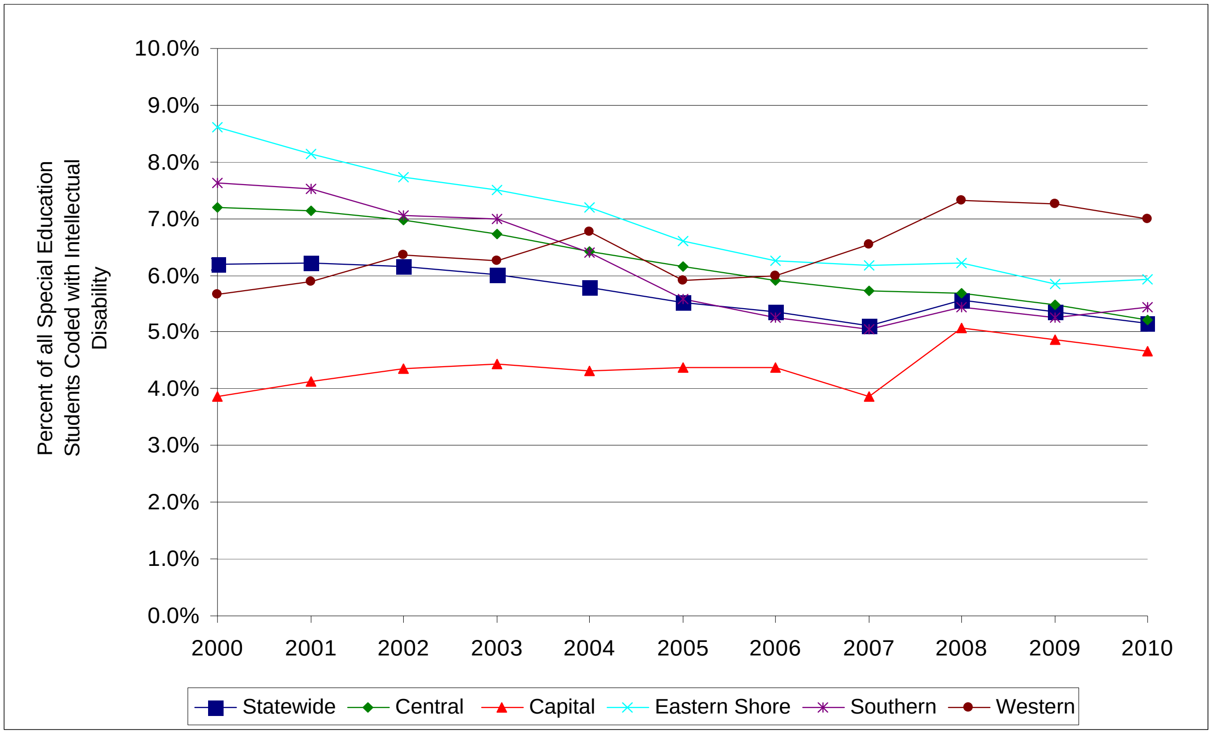


Figure 7 displays Maryland rates of special education students ages 3 to 21 years coded with intellectual disability by region from 2000 to 2010 which shows some variation in rates throughout the state. Statewide, there was an overall decline in children coded with intellectual delay during this 10 year period. The capital region has the fewest number of students coded with intellectual disability while the Eastern Shore had the largest decrease over time. The region had 760 students (8.6%) in 2000 and 450 students (5.9%) in 2010. Within the Eastern Shore, the greatest decrease occurred in Talbot County with 81 students (16.1%) coded with intellectual disability in 2000 declining to 35 students (9.0%) in 2010. Wicomico County had a similar decrease with 227 students (13.3%) in 2000 dropping down to 112 students (6.6%) in 2010.

The highest rate of students coded with an intellectual disability receiving special education and related services was in the Eastern Shore (8.6%) in 2000. However, with the Eastern shore's rates declining consistently over time, in 2007, Western Maryland became the region with the highest rates in special education children coded with an intellectual disability. Garrett and Washington Counties within Western Maryland are driving this increase with rates above 7% from 2008 to 2010.

III. Demographic and Other Characteristics of ASD and other DD Child Populations

Key Findings

30% of families with CYSHCN who responded to the 2010 Maryland Parent Survey report having difficulty paying for basic needs for their families.

CYSHCN in Maryland with one or more emotional, behavioral or developmental issue are more likely to live in poor families.

24% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that their child has had problems with anger/conflict management; 23% report problems with depression; and 22% report problems with bullying.

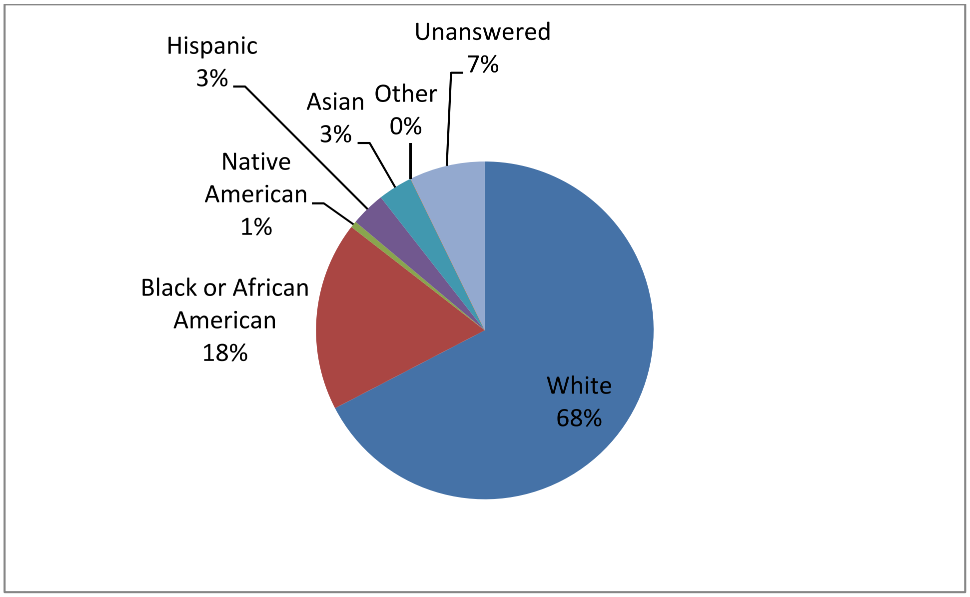
Children with ASD and/or emotional, behavioral or developmental issues have high rates of delayed or unmet needs for health care and related services, including medical care, mental health care, diagnostic services, and needed therapies. Children with ASD on the Eastern Shore and in Western and Southern Maryland have significantly higher rates of unmet needs for primary and specialty medical care than those in the Central or Capital Area regions of Maryland.

Children with ASD and/or emotional, behavioral or developmental issues have high rates of delayed or unmet needs for family support services such as finding services for their children, child care, and respite care.

Race/ethnicity and Age

Figure 8. Race/Ethnicity of Maryland CYSHCN with ASD *(Source: 2010 Maryland Parent Survey)*

By Race/Age



The majority of respondents to the 2010 Maryland Parent Survey reported that their children with ASD are white non-Hispanic (68%); 18% are African American non-Hispanic; 3% of these children are Asian and another 3% are Hispanic (Figure 8.) The majority of children with ASD represented in the survey were between the ages of 6 to 17 years (74.3%); 13.7% were between the ages of birth to 5 years, and 11.9% were ages 18 to 26 years. There were significantly more male children (76.7%) than female children (20.2%) with ASD in the survey sample. It is important to note that this data source cannot be considered to be representative of the target population because the sampling method used for the survey was not randomized. For example, this data set is more representative of white families of children with ASD and higher-income families of children with ASD than of lower-income families.

Socioeconomic Status

As a proxy for socioeconomic status, respondents of the 2010 Maryland Parent Survey were asked whether each of the children in their family received any type of government-sponsored nutritional assistance. Figure 9 shows that within this data set, families of children reported to have ASD (statewide and across regions within the state) are less likely than the families of children with any SHCN to receive family income-related nutrition assistance.

Figure 9. Children with Special Health Care Needs Receiving Public Nutrition Assistance *(Source: 2010 Maryland Parent Survey)*

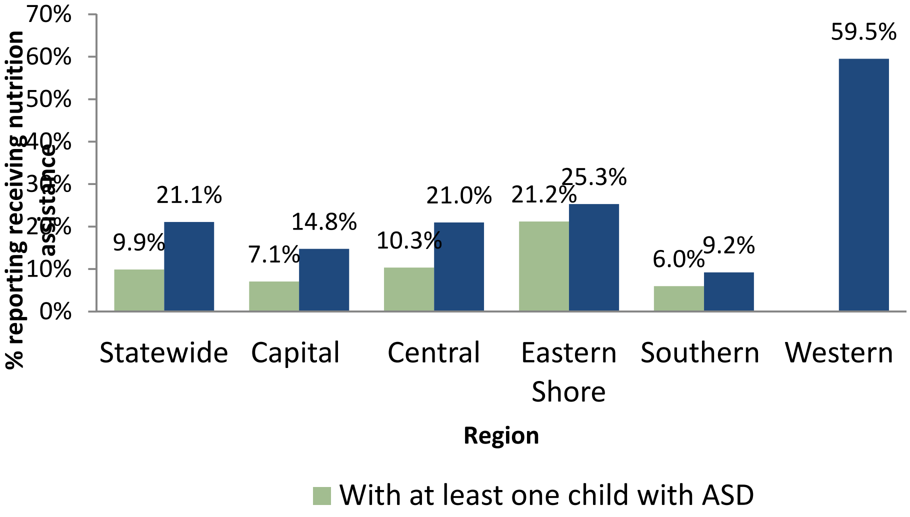
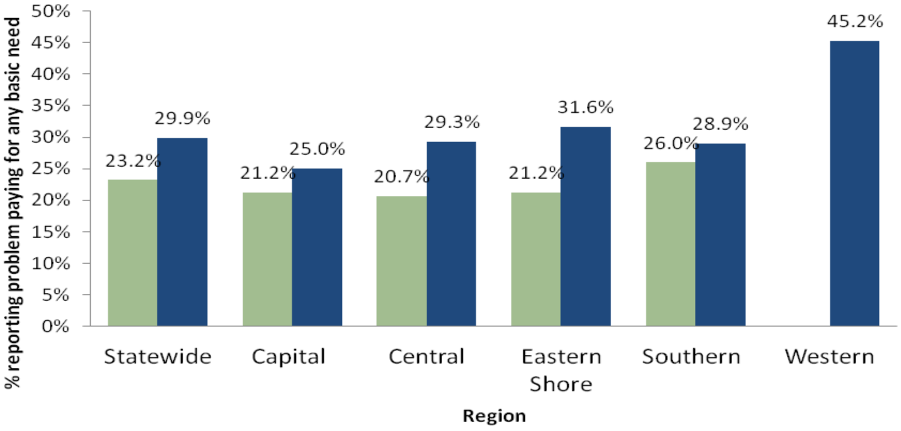


Figure 10. Difficulty Paying for Basic Needs among Families of Children with ASD and Families of Children with any SHCN *(Source: 2010 Maryland Parent Survey)*



The same pattern held true for families' responses as to whether or not they were having trouble paying for basic needs such as food, clothing, utilities, and other household costs – families of children with ASD in the 2010 Maryland Parent Survey were less likely to report having difficulty than families of children with any SHCN. Also, families from Western Maryland[17] and the Eastern Shore were more likely than families from other regions to need nutrition assistance and to have difficulty paying for basic needs (see Figure 10.)

Figure 11. Maryland CYSHCN by Family Income and E/B/D Issues

(*Source: 2009-10 NS-CSHCN*)

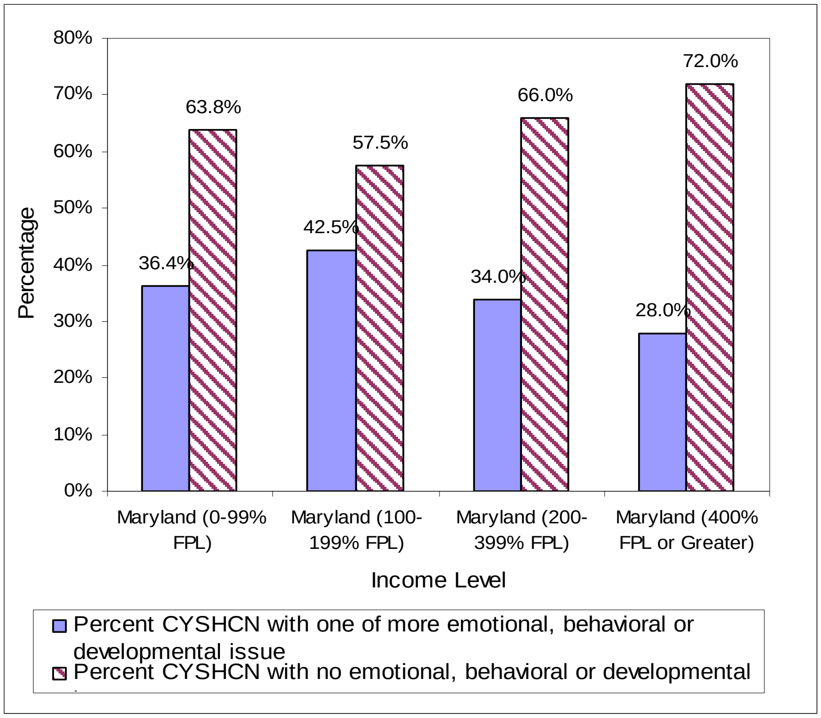


Figure 11 shows the percentage of CYSHCN in Maryland who have one or more E/B/D issue (this category is being used as a proxy for developmental disabilities) and those without an issue in different family income brackets. CYSHCN with one or more E/B/D issue are more likely to live in poor families. Taking into consideration the proxy income data in Figure 9 above, it is

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[17] The sample size of families of children with ASD from Western Maryland was too small to allow subgroup analysis from that region, so Western Maryland is omitted from regional subgroup analyses of families of children with ASD.

likely that there are far more families within lower income brackets with children with ASD in the state than were captured and represented in the 2010 Maryland Parent Survey.

Figure 12. Severity of Condition among CYSHCN with E/B/D Issues in Maryland

(*Source: 2005-06 NS-CSHCN)* [18]

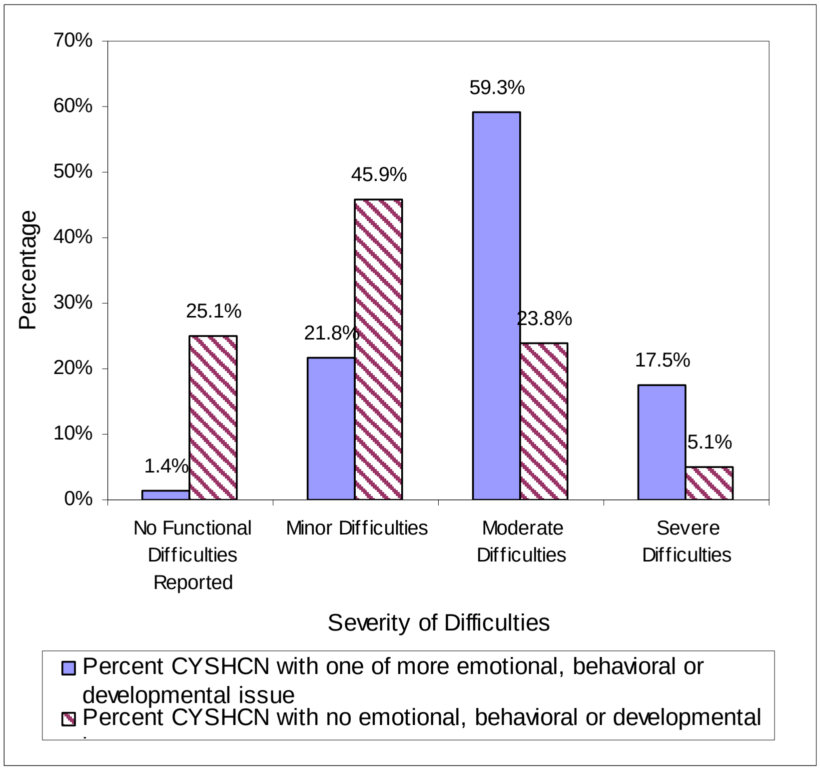

Figure 12 shows the parent-rated severity of difficulties caused by their child's health problems. Families of CYSHCN with one or more E/B/D issue are more likely to rate the child's condition as moderate (59.3%) or severe (17.5%) than are families of CYSHCN without E/B/D issues (23.8% moderate and 5.1% severe.)

According to the 2005-06 NS-CSHCN, in Maryland, CYSHCN with mental retardation or developmental delay are more likely to have functional limitations or a greater need/use of routine services than other CYSHCN. Over 70% of CYSHCN with mental retardation or DD have functional limitations compared to 12.1% of other CYSHCN.

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[18] This question is asked differently in the 2009-10 NS-CSHCN. Therefore, data from the 2005-06 NS-CSHCN is used.

Experience with Challenging Behaviors

The 2010 Maryland Parent Survey asked respondents if their children engaged in or experienced specific challenging behaviors. Among families of children with ASD, almost 24% reported that their child had problems with anger/conflict management, 22.5% reported experience with depression, 21.5% reported problems with bullying, and 14% reported that their child had experience with overweight/obesity (see Table 1.)

Table 1. Experience with Challenging Behaviors among CYSHCN with ASD (*Source: 2010 Maryland Parent Survey*)

	% CYSHCN families with at least one child **with ASD** reporting their child engaging in or experiencing specific behaviors	% CYSHCN families with a child **with any SHCN** reporting their child engaging in or experiencing specific behaviors
Anger/Conflict Management	23.9%	25.4%
Depression	22.5%	22.3%
Bullying	21.5%	22.8%
Peer Pressure	15.4%	17.7%
Overweight/Obesity	14.0%	11.4%

Statewide, there was not much difference between reports of challenging behaviors among families of children with ASD and families of children with any SHCN. When examined regionally, some variation was seen within families of children with ASD, with Southern Maryland and the Eastern Shore regions reporting higher incidences of challenging behaviors than other areas of the state. For example, Southern Maryland (30.0%) and Eastern Shore (33.3%) families were more likely to report issues with anger/conflict management than other regions, while Central Maryland (19.0%) families were far less likely to report issues with that behavior. Southern Maryland families were also far more likely to report issues with depression (34.0%) than the rest of the state, while the Capital Area (17.6%) was less likely to Southern Maryland (28.0%) and Eastern Shore (24.2%) families also reported higher rates of experience with bullying than the statewide rate.

Unmet Needs for Medical Care

According to the 2007 NSCH, CYSHCN are three times more likely than non-CYSHCN to have unmet needs for medical, dental, mental health or other health services. While the majority of CYSHCN received all of the services that they needed, 23% had one or more unmet needs for health services in the past year, and 5.8% had 2 or more unmet needs (an increase from 4.5% in 2001). According to the 2009-10 NS-CSHCN, CYSHCN with one or more E/B/D issue or with mental retardation or DD are significantly more likely to report one or more unmet needs than those without. Families of children with mental retardation or DD are far more likely to have unmet needs for family support services (19.1%) than are families of children without those conditions (1.9%).

Data from the 2011 Survey of Pathways to Diagnosis and Services indicate that, nationally, 9 out of 10 school-aged CSHCN children with ASD use one or more healthcare services/therapies to meet their developmental needs. Just over one half of school aged CSHCN with ASD use three of more of the eight services included in the Pathways survey. Younger CSHCN with ASD are more likely than older CYSHCN with ASD to use any of these eight services.

Social skills training and speech or language therapy are the most common, each used by almost three-fifths of these children. About 40% of school aged CSHCN with ASD use behavioral intervention or modification services to meet developmental needs. Younger CSHCN with ASD are more likely than older CSHCN with ASD to use occupational therapy and speech or language therapy to meet their developmental needs.[1]

Data from the 2010 Maryland Parent Survey shows that statewide, families of children with ASD have high rates of delayed or unmet needs for mental health, medical, dental, and counseling care and are more likely to have unmet needs for certain types of services (mental health, counseling, and medical care) than are families of children with any SHCN (see Figure 13).

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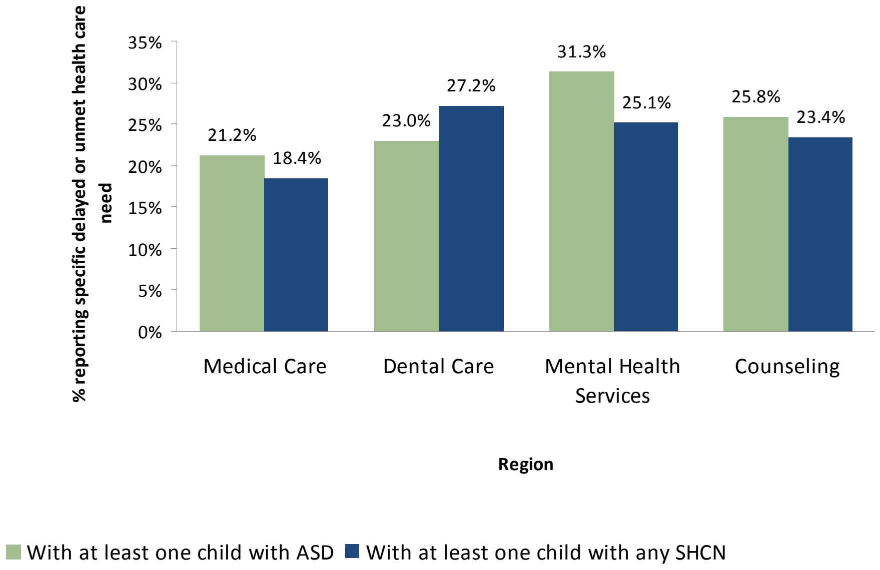
[1] **NCHS Data Brief No. 97.** *Diagnostic History and Treatment of School-aged Children with Autism Spectrum Disorder and Special Health Care Needs*. 8 pp. (PHS) 2012-1209. May 2012.

Figure 13. Unmet Needs (Care Delayed or Not Received) for Specific Services among Families with At Least One Child with Autism and Families with At Least One Child with any Special Health Care Need *(Source: 2010 Maryland Parent Survey)*



The highest reported rates of unmet need for families of children with ASD was for mental health services (31.3%; compared to 25.1% for families of children with any SHCN), followed by counseling (25.8%), dental care (23%) and medical care (21.2%). Services such as occupational, physical, speech, and behavioral therapies were frequently reported as being delayed, often because these services were not adequately covered through the child's health insurance.

"We have given up on therapies – we can't afford to pay out of pocket for those services our daughter needs." Parent Respondent, 2010 Maryland Parent Survey

Figure 14. Unmet Needs (Care Delayed or Not Received) for Mental Health, Dental, and Medical Care Services among Families with At Least One Child with any SHCN, by Region *(Source: 2010 Maryland Parent Survey)*

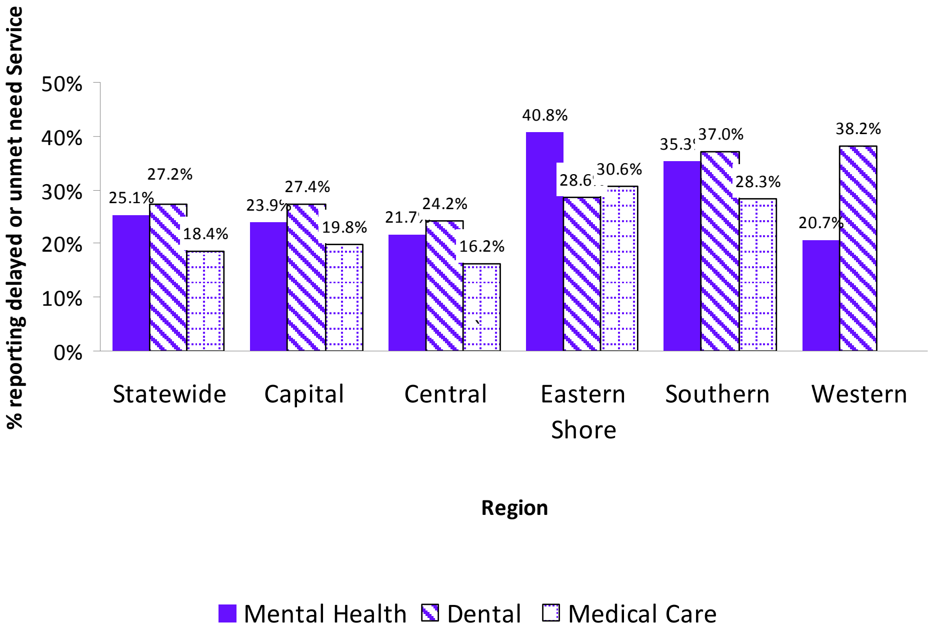


Figure 14 shows regional differences in types of delayed care or unmet needs for health care services among families of children with any SHCN[20]. The Eastern Shore, Southern Maryland, and Western Maryland have higher rates of unmet needs across types of services than do the Central or Capital regions of the state.

PPMD conducted three parent focus groups with parents of children with ASD and other DD in order to illuminate the impact of some of the issues raised by the quantitative data analysis presented in this needs assessment, including insight as to why the above rates of delayed care and unmet needs are so high. A common theme that came up in the focus groups related to medical care for children was that providers (such as developmental pediatricians, mental and behavioral health professionals, and other needed specialists who treat children with ASD and other DD) were not easily accessible either due to geographic barriers (very few are located outside Central or Capital regions) or institutional barriers (the providers did not accept families'

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[20] Cell sizes were too small by type of service to break out by region for families of children with ASD; however regional patterns between families of children with ASD and families of children with any SHCN were similar.

health insurance). Many parents remarked that satellite clinics of needed specialties and local offices for certain providers were previously available in their areas of the state (especially in Southern Maryland and on the Eastern Shore) but have since become unavailable in recent years. Another major contributor to delayed care or unmet needs seems to be the existing Maryland state system of health insurance and financing being system-centered as opposed to being family-centered, meaning that care and services available to children with ASD and other DD (as well as the timeliness of needed care) is more based on the needs of the system (insurers, providers, etc.) as oppose to the needs of children and families resulting in high rates of delayed care or unmet need for children and families. Almost every parent focus group participant recollected multiple stories of their children needing care (such as behavioral therapy, specialty medical care, diagnostic testing, medical equipment, assistive technology) and that care being delayed by as much as two years, if not at all received due to their children's health insurance companies disputing the necessity or coverage of the service or care or due to the only providers available to perform the service non-acceptance of their children's health insurance, or that the service was only partially covered by their insurance. Delays or unmet needs caused by insurance disputes over what is covered and what is not seem to be more common with families whose children had private insurance; delays or unmet needs caused by providers not accepting their insurance seem to be more common with families whose children had public insurance.

"I would say our biggest problem is that the pediatricians in Cumberland and Allegany County are not educated in what an autistic child is… and we [parents] have to do the footwork. But when you find the doctors [you need, they are not in the state]… I had to go to Pittsburgh. Pittsburgh gave me the answers and now …insurance won't let me go back to Pittsburgh, but Maryland doesn't know how to treat her. So you fall into these barriers of, you know, we're the parents, we're trying to fix our child, but we don't have the proper doctors or anything, really, in Allegany County to treat our children with and the parents get frustrated and give up."
(Western Maryland Parent Focus Group, 2011.)

Unmet Needs for Family Support Services

As the parental feedback above illustrates, families experience unmet needs for family support services as well as for needed health care. The 2010 Maryland Parent Survey asked respondents about different types of specific family support services they needed. Figure 15 shows the results of what families said they needed. Figure 16 shows the respondents who needed and sought assistance for those specific services and who were satisfied with the help they received.

Figure 15. Reported Need for Specific Types of Family Support Services among Families of Children with ASD and Families of Children with any SHCN in Maryland (*Source: 2010 Maryland Parent Survey*)

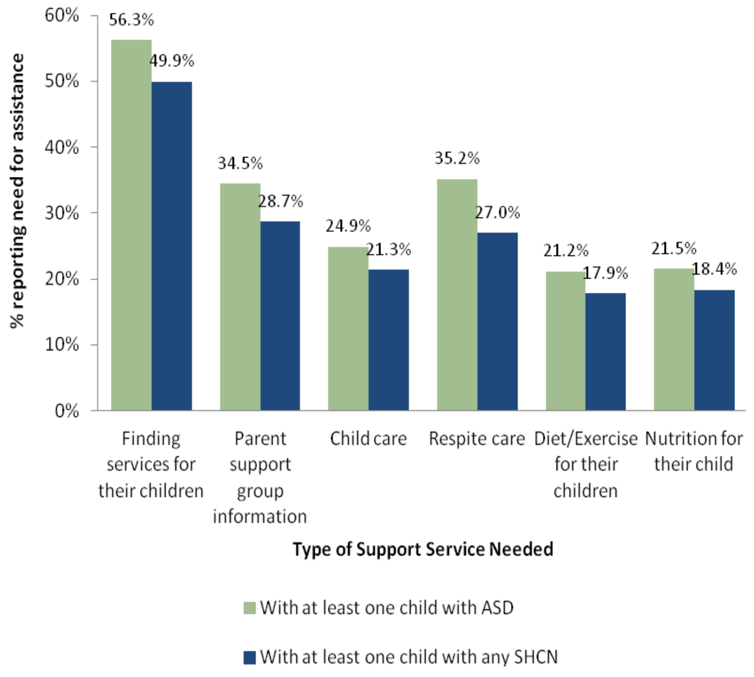
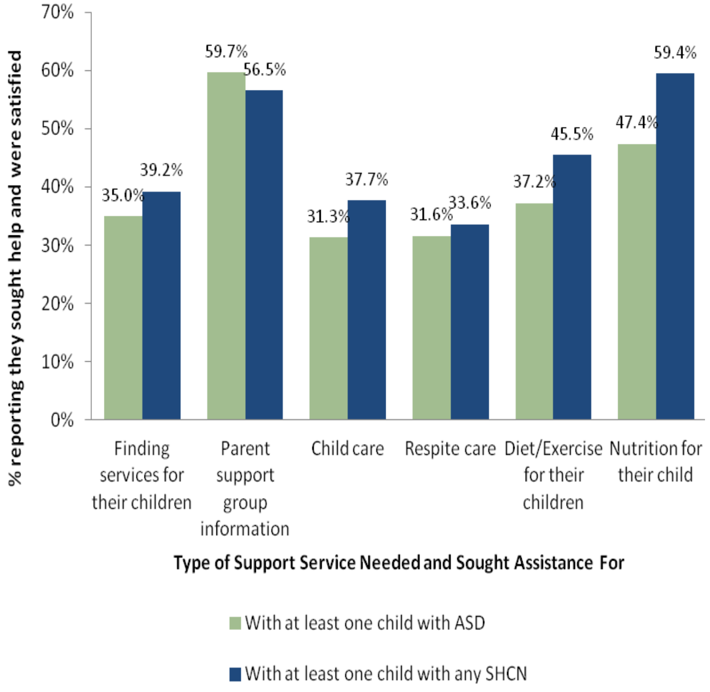


Figure 16. Reported Satisfaction with Assistance for Specific Types of Needed Family Support Services among Families of Children with ASD and Families of Children with any SHCN in Maryland (*Source: 2010 Maryland Parent Survey*)



Families of children with ASD are more likely than families of children with any SHCN to have a need for specific types of family support services. Over half of families of children with ASD reported needing help finding services for their children (56.3%), over one third reported needing respite care (35.2%) and parent support group information (34.5%), and over one-fifth reported needing help with diet/exercise (21.2%) or nutrition (21.5%) for their children. Of those families who needed and sought assistance for these services, families of children with ASD are less likely to be satisfied with the help received, with the exception of parent support group information. Among families of children with ASD, the highest satisfaction rate for services was for nutrition (47.4%) however this was well below the satisfaction rate among families of children with any SHCN (59.4%.) There was a relatively low satisfaction rate among families of children with ASD with assistance finding services for their children (35.0%) though this was the highest need among these families. Other qualitative data sources discussed in this needs assessment reveal that parents of children with ASD have a particularly difficult time finding child care and respite care – this fact is bolstered by Figure 16 which shows that less than a third of families (~31%) whom tried to find child care or respite care were satisfied with the resultant service (compared to 33.6% and 37.7% of families of children with any SHCN).

IV. Maryland Center for Developmental Disabilities Needs Assessment

Key Findings

Stakeholders among and for developmentally disabled individuals in Maryland identified health care, family supports, and home and community supports as the most important issues for developmentally disabled people in Maryland.

There are major gaps in access to needed primary and specialty health care services and a lack of affordable and accessible transportation for people with developmental disabilities in Maryland, as well as inadequate training among professionals working with individuals with DD; and ineffective dissemination of reliable information about needed services.

The Maryland Center for Developmental Disabilities (MCDD) conducted a needs assessment in 2011 of the population of individuals with DD in Maryland as well as an assessment of the current system of care for individuals with DD in Maryland. MCDD conducted 18 community forums across the state as well as a survey with over 200 respondents (including individuals with DD, family members of individuals with DD, service providers, advocates, resource coordinators, and representatives from state agencies) from the DD community.

Quantitative analysis by MCDD of the survey results shows that respondents felt the most important issues for people with DD and their families in Maryland are health care, family supports, and home and community supports. Transition from school to work and transportation issues were also rated as very important. Respondents were also asked to rate how well they felt Maryland was doing in particular areas related to people with DD and their families. Areas respondents identified as the lowest performing included waiting lists for supports and services; housing appropriate for individuals with DD; and transportation. Areas that were ranked as higher performing included family supports and transition from school to work.

Analysis of the 16 community forums highlighted several strengths and weaknesses across the state. Statewide, strengths included the development of a more collaborative transition process in certain areas of the state; opportunities for recreational activities through community collaborations; development of community advocacy groups, and services for infants and young children. Identified weaknesses included major gaps in access to needed primary and specialty health care services; lack of affordable and accessible transportation, inadequate training among professionals working with individuals with DD; and ineffective dissemination of reliable information about services for individuals with DD. There were regional variations in strengths and weaknesses, as well as in what communities saw as priorities in their areas. Table 2 captures the regional strengths and weaknesses identified.

Table 2. MCDD Community Forums Summary of Regional Strengths and Weaknesses *(Source: 2011 MCDD Community Forums)*

Region (location and participant details)	**Strengths**	**Weaknesses**
Eastern Shore (Dove Pointe in Salisbury, Maryland and at Chesapeake College in Wye Mills, Maryland. About 73% of attendees were professionals/para-professionals, 12% were family members/caregivers and 15% were adults with disabilities)	-Infants and Toddlers Program (early intervention) -Collaborative Transitioning Program -Improved communication among agencies -Supportive advocacy groups (i.e. Chesapeake Voyagers; Family Navigators, Shore Power)	-Lack of information for Families, especially pertaining to legal assistance for medical consent and special needs trusts; accessible primary and specialty health services; timely information about youth transition. -Public servants (i.e. police, EMTs, judicial system personnel) need to be trained on providing services to people with disabilities -Transportation - lack of which prohibits access to health care including primary and specialty (i.e. mental) care as well as diagnostic services for children. -Difficulty in locating mental health services

Region (location and participant details)	**Strengths**	**Weaknesses**
Western Maryland (Allegany College in Cumberland, Maryland and the Urbana Library in Frederick, Maryland; 74% of attendees were professionals/para-professionals, 18% were family members/caregivers, 6% were adults with disabilities and 2% were members of the general public.)	-Supportive advocacy groups (i.e. Partners for Success/ People First which connects family members/caregivers and consumers to information, opportunities and services) -Service Coordination (supportive entity that is becoming person-centered) -Effective training for behavioral issues (i.e. Intensive Behavior Management Plan - IBMP) -Early Intervention -Improvements linked to training, in-home classes and approaching challenging behaviors in a different way -Creative use of funding and fostering community collaborations	-Transportation -Public Servants need to be trained on providing services to people with disabilities - Late Diagnosis -Difficulty accessing Respite Services (in relation to location and funding) -Health care services sparse; many challenges in accessing health care services (i.e. psychiatry and dental); participants identified distance, insurance regulations and the Board of Nursing regulations as current and prospective barriers to health care services.
Southern Maryland (Bowie Library in Bowie, Maryland and at the Spring Dell Center in La Plata, Maryland; 73% of participants were professionals/para-professionals, 22% were family members/caregivers and 4.7% were adults with disabilities.)	-Transportation (portions of the region have access to Metro Access - PG County) -Infants and Toddlers (significant improvement due to community collaboration over the last 10 years) -Transition Fairs	- Unreliable Transportation (increasing safety concerns, lack of training of Metro Access staff, unreliable transportation, increasing cost) -Lack of dental and mental health care and services -Lack of respite care
Central Maryland (Perry Hall Library in Perry Hall, Maryland and the Meeting House in Columbia, Maryland; 62% of attendees were professionals/para-professionals, 21% were family members/caregivers,	-Transportation exists -Collaborative Transition Program Advocacy groups (CSACs, others)	-Lack of reliable and affordable transportation -Information for families need to be consistent and reliable -Limited funds

Region (location and participant details)	**Strengths**	**Weaknesses**
12% were individuals with disabilities and 4% were members of the general public)	-Families are experienced and well-informed about DD system -Improvements in collaboration and communication have led to communities of practice working well together.	-DD system is complex and intimidating and discouraging for people with DD to apply for services and supports -Lack of mental health services, particularly for individuals with dual diagnoses -Need for more respite care.

Table 3. MCDD Community Forums Regional Top Three Priority Themes *(Source: 2011 MCDD Community Forums)*

Theme	**Eastern**	**Western**	**Central**	**Southern**
1	Knowledge/Education/ Information/Training	Knowledge/Education/ Information/Training	Knowledge/Education/ Information/Training	Knowledge/Education/ Information/Training
2	Transportation	Health Care Services	Transportation	Transitioning
3	Health Care Services	Transportation	Transitioning	Housing

Table 3 shows each region's Top Three priority themes based upon the frequency the theme arose in comments during the community forums. Theme 1 signifies the theme mentioned most often in the region's community forums. The most frequently mentioned theme across regions was knowledge/ education /information/ training among providers and families. This theme was echoed in the parent focus groups conducted by PPMD. Parents frequently encountered pediatricians and other health service providers unfamiliar with ASD and some other DD resulting in delays in diagnoses and needed services for their children. Within regions, the subthemes most often associated with this theme included information (Eastern Shore and Southern Maryland), training (Western Maryland), and information as well as advocacy (Central Maryland). Transportation was also mentioned very frequently in all regions with the exception of Southern Maryland. Health care services were a frequent theme in Western Maryland and the Eastern Shore (a common subtheme there being primary and specialty care). Transitioning was frequently mentioned in Southern and Central Maryland.

V. Maryland Commission on Autism

Key Findings

The Maryland Commission on Autism identified five key components of a system of care for individuals with ASD – Screening, diagnosis and referral; Interventions; Supports; Community; and Research and education.

The Maryland Commission on Autism identified five cross-cutting themes for improving services for individuals with ASD – Access; Quality; Communication, collaborations and partnerships; Training, professional development and dissemination; and Funding.

The Maryland Commission on Autism (MCA), created through legislation passed in Maryland in 2009, 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." During 2010 and early 2011, the MCA conducted four listening sessions across the state to capture regional input from selected stakeholders, including adults with ASD, parents of children with ASD, adult service providers for clients with ASD, special education coordinators, and autism waiver coordinators. One of the sessions also included a pediatrician. During each of the four listening sessions, a representative from each of the stakeholder groups shared prepared answers to a set list of questions from the Commissioners. Public comments were also sought during each meeting of the MCA. The MCA plans on submitting a report to the Governor's Office in October 2012 with a series of recommendations to improve services and supports for people with ASD in Maryland[1]. The MCA stakeholders have summarized their interim findings in five cross-cutting themes as well as in five components of a system of care for individuals with ASD. Their conceptual model of the five system components appears below in Figure 17. The five cross-cutting themes are summarized in Table 4 on the following page. An analysis comparing the MCA's conceptual model in Figure 13 to the six key components of a system of care for CYSHCN (which are discussed in detail in the following section of the needs assessment) was conducted for this needs assessment. Several commonalities were identified as areas for collaboration: "Diagnosis and Referral" can be aligned with early and continuous screening; "Interventions" can be aligned with

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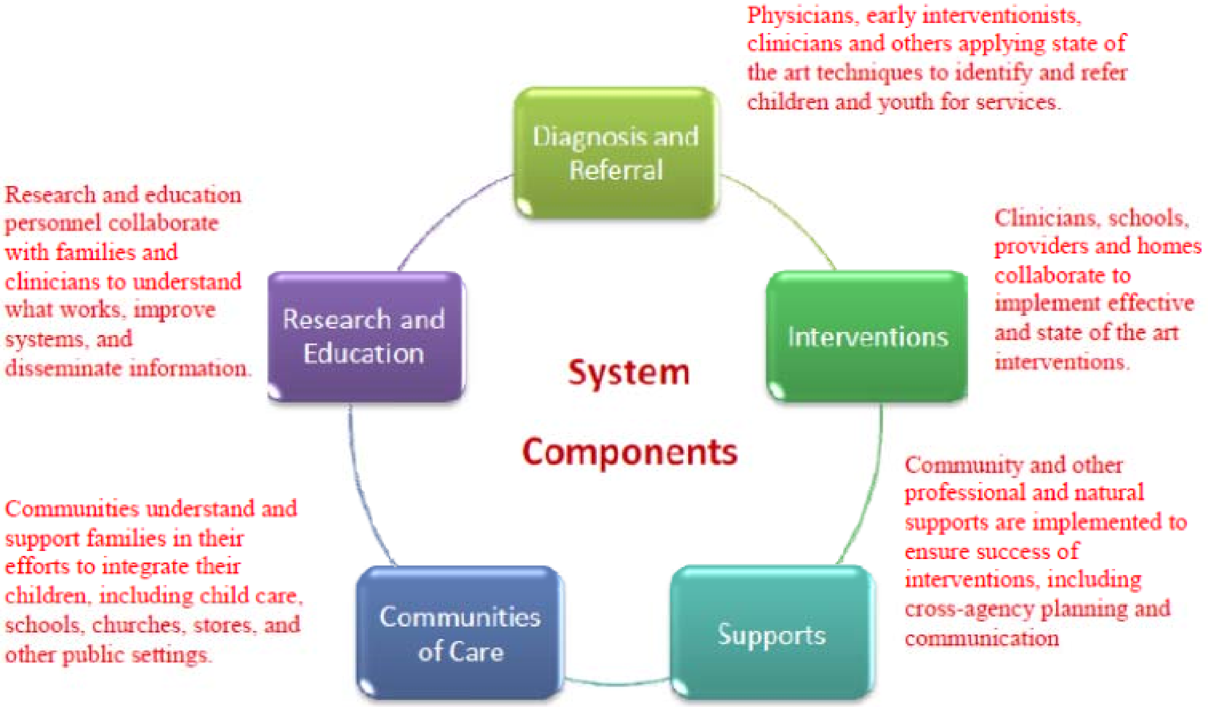
[1] The MCA recommendations differs in scope than the scope of the Planning Grant that this Needs Assessment is supporting: this Planning Grant is to develop a statewide plan to improve systems of *health care* and related services for Maryland *children and youth* with ASD and DD, while the MCA's recommendations will focus on all systems for individuals including adults with ASD (and not other DD.) The project leaders of this Planning Grant have worked in close conjunction with the MCA, and applicable recommendations from the MCA will be incorporated into the statewide plan that results from this Planning Grant.

Family/Professional Partnerships and Medical Home; “Supports” and “Communities of Care” can be aligned with Easy-to-use Community Based Systems; and “Research and Education” can be aligned with Family/Professional Partnerships.

Figure 17. Maryland Commission on Autism’s Conceptual Model Linking Systems of Care and Communities of Care. (Source: *Maryland Commission on Autism Interim Report on Activities, Findings, and Recommendations.* August 2011; pg. 17)



Physicians, early interventionists, clinicians and others applying state of the art techniques to identify and refer children and youth for services.

Clinicians, schools, providers and homes collaborate to implement effective and state of the art interventions.

Community and other professional and natural supports are implemented to ensure success of interventions, including cross-agency planning and communication

Communities understand and support families in their efforts to integrate their children, including child care, schools, churches, stores, and other public settings.

Research and education personnel collaborate with families and clinicians to understand what works, improve systems, and disseminate information.

In examining the summary of themes identified by the MCA (Table 4), the themes and key take-aways can be applied to the CSHCN core outcome framework as well. Funding and cost-savings will require greater and more effective integration of public, non-profit, and private agencies and organizations serving children with ASD and other DD (easy-to-use systems of care) as well as addressing coverage and reimbursement issues with health insurers (adequate insurance and financing). Issues of access and quality relate directly to satisfaction with care and medical home as well as to community-based systems. Socioeconomic, regional and cultural barriers to access to care must be addressed. Communication, collaboration and partnership are cross-cutting to all the core outcomes for CSHCN, as are training, professional development and dissemination.

Table 4. Summary of Five Cross-Cutting Themes from Maryland Commission on Autism.

	Themes				
	Access	**Quality**	**Communication, collaboration and partnership**	**Training, professional development, and dissemination**	**Funding**
Key Findings	Barriers to access include but are not limited to geography, finances, transportation, language, and cultural differences.	Includes measures of quality of professional services, benchmarks of excellence, evaluation, and consistent application of standards.	Need to improve public-private partnerships.	Training efforts will need to be kept current as new evidence becomes clear and substantiated.	Includes improving funding for all system components in an integrated fashion with families, consumers, and self-advocates aware of and guiding these efforts.
	If needed 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.	Having more services or supports will not be effective unless there is a focus on the quality of those services and supports.	Need better communication and collaboration among professionals, self-advocates, and families.	A link between research and practice will be critical to ensure quality in all dimensions of services and support systems.	Some of the recommendations may require more funding than exists in current systems; however a cost-savings is possible with shared resources and greater collaboration and integration of the system.
				Evidence-based training that is practical and applicable for day-to-day operation.	Important to assess and budget for all system components, as inadequate funding for any part of the system may result in system failure for consumers.
					It is critical that the public play an informed role in advocating for increased state, federal, and private funding.

Source: Adapted from *Maryland Commission on Autism Interim Report on Activities, Findings and Recommendations.* Available at http://dhmh.maryland.gov/autism/pdf/2011/Autism_Report.pdf

VI. Core Outcomes

The current national priorities for CYSHCN focus on six core outcome areas (or key system characteristics) identified by the federal Maternal and Child Health Bureau as critical indicators of success in implementing community-based systems of services mandated for all CYSHCN under Title V and Healthy People 2010. The core outcome areas are:

- Families of CYSHCN partner in decision making at all levels and are satisfied with the services they receive;
- CYSHCN receive coordinated ongoing comprehensive care within a medical home;
- Families of CYSHCN have adequate private and/or public insurance to pay for the services they need;
- Children are screened early and continuously for special health care needs;
- Community-based services for CYSHCN are organized so families can use them easily;
- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

This section of the needs assessment focuses on data and information related to Maryland's performance on each of these six core outcomes.

A. Family and Professional Partnerships and Satisfaction with Care and Services

Key Findings

A key component of an effective system of care for CYSHCN with ASD or other DD is strong, effective partnerships between families and the professionals who serve them; Maryland ranks 37th in the nation on family-professional partnerships for CYSHCN.

Many families, providers, and policymakers need training on how to establish and maintain effective family-professional partnerships. Many families across Maryland feel that education professionals in school systems are not adequately trained in appropriate methods for teaching children with ASD and other DD. Many Maryland families, particularly in Western and Southern Maryland and on the Eastern Shore, feel that pediatricians need additional training on screening for and treating children and youth with ASD and DD.

Families of CYSHCN with ASD in Maryland whose children receive services through the Autism Waiver are more likely to report that their child receives adequate services than families whose children are not receiving services through the Autism Waiver; currently there are 900 slots available for Maryland's Autism Waiver program, all are filled. An Autism Waiver Registry was created for families interested in receiving services; in January 2009, 2,649 families were on the Registry and as of September 2011 there were approximately 3,500 families on the Registry waiting for a slot for Waiver services.

A. Family and Professional Partnerships

Table 5. 2009-10 NS-CSHCN Indicators Used to Measure Partnership and Care Satisfaction *(Source: 2009-10 NS-CSHCN)*

Indicator	Nation %	Maryland %
Core Outcome #1: % CYSHCN ages 0-17 whose families are partners in shared decision-making for child's optimal health	**70.3%**	**69.3%** (ranked 37nd in the nation)
Among CYSHCN with E/B/D Issues	61.5%	59.3%
Related Indicator: Child's doctors who usually or always respect parent's treatment choices	**84.4%**	**82.2%**
Among CYSHCN with E/B/D Issues	77.8%	71.8%

A key component of an effective system of care for CYSHCN with ASD or other DD is strong, effective partnerships between families and the professionals who serve them. As Table 5 shows, among CYSHCN generally Maryland fares somewhat poorly on this outcome compared to other states (ranking 37th in the nation.) Among CYSHCN with E/B/D issues, 61.5% (compared to 59.3% nationally) are successfully achieving this outcome. Family-professional partnership and satisfaction with care have traditionally been areas of relative strength for Maryland compared with other states. Maryland ranked 2nd in the nation in the 2001 NS-CSHCN. However, in 2005-

06 Maryland's rank fell to 42nd in the nation, but then rose slightly in 2009-10 to 37th in the nation according to the NS-CSHCN. The reasons for this change are not clear. MSDE's annual State Performance Plan Family Involvement Data also showed a significant drop of approximately 25 percentage points in parent satisfaction between 2008 and 2009. However, according to the 2009-10 NS-CSHCN, a large majority of families in Maryland (82.2%) report that their child's physicians usually or always respected the parent's treatment choices, though this is lower among families of CYSHCN with E/B/D issues (71.8%.)

Maryland has had a strong history of including parents and families in decision-making at all levels. The OGPSHCN supports PPMD with a yearly grant and has maintained a successful partnership that has been a model for promoting family-professional partnerships and family involvement in policymaking at state and local levels. PPMD and OGPSHCN have an ongoing partnership in a number of activities including a variety of workshops held across the state for both parents and professionals aimed at increasing partnership and advocacy skills and effectively accessing health care services for CYSHCN. Additionally, OGPSHCN was instrumental in the award to PPMD of the MCHB D70 grant and have worked together to carry out the activities of this grant through the Maryland Community of Care Consortium for CYSHCN (CoC). The CoC is a working group of diverse stakeholders, including families, providers, advocates, consumers, administrators, and professionals from the public and private service systems. Using the national agenda for CSHCN and core outcomes as a starting point, the CoC works to create systems of care that promote optimal health, functioning, and quality of life for Maryland CSHCN and their families. The CoC meets quarterly and has identified priorities which include building relationships between families and professionals through education and joint training. It is facilitating family-professional partnerships through parent attendance and participation in workshops and trainings for providers centered on early and continuous screening, medical home and a variety of other initiatives. Through the CoC, parent members receive regular updates on state activities for CYSHCN and continuously contribute to shaping state goals and priorities for Title V activities. PPMD leadership has participated closely in all Title V CSHCN planning, reporting, and evaluation including the 2010 Needs Assessment activities.

MSDE also works to partner with parents through their Partners for Success Centers. These centers, established as part of each local school system in Maryland, have as their goal the provision of knowledge and the development of essential skills fundamental to parents and professionals working together as equal partners in the educational decision making process. Specifically, Partners for Success Centers seek to Increase parental involvement in the special education decision making process, provide information and resources about disabilities and community services, assist families in resolving concerns and making informed decisions regarding their child's education, and increase collaborative relationships through information and training. A parent of a child with disability and an educator staffs each Partner for Success Center. Additionally, Maryland is home to an organization, Pathfinders for Autism, whose mission is to improve the lives of individuals with autism and the people who care for them; Pathfinders accomplishes this through a variety of programs and services, all of which are offered free of charge to families and individuals.

According to the 2008 CoC Summit Family-Professional Partnerships Workgroup, Maryland has several strengths around this core outcome. These include a willingness of stakeholders to work together; existing models of partnerships; strong families; and availability of data. Barriers include inadequacies in family and professional supports including training; cultural competency; county and regional variances; and lack of value for family wisdom, experiences, expertise and knowledge; as well as existing partnerships that are not consistently implemented across systems statewide. Inter-related strategies to improve this core outcome include: (1) training along several dimensions for health care providers; (2) developing statewide leadership in addressing county & regional variances; (3) adequate reimbursement for professionals and stipends/honoraria and supports for families; and (4) assisting agencies, organizations, and providers to establish policies and procedures to promote family-professional partnerships.[1]

Satisfaction with Care and Adequacy of Services among Families with ASD

In terms of satisfaction with the services provided, the 2010 Maryland Parent Survey found that 47.2% of parents of CYSHCN are very satisfied with their child’s medical care (41.9% among parents of children with ASD), and almost 40% are somewhat satisfied (45% among parents of children with ASD). This data suggests that parents of children with ASD are less likely to be completely satisfied with their child’s medical care than are parents of children with any SHCN.

The 2009 Maryland Autism Services Survey (MASS) compared outcomes for families receiving services through the Autism Waiver to outcomes for families waiting for services on the Autism Waiver Registry and found that Waiver recipients generally reported lower rates of needs for services and reported much higher rates of service adequacy than did the families waiting on the Registry (not receiving services through the Waiver.) Figure 18 shows the reported need for specific services among responding Waiver families and Registry families and Figure 19 shows the reported adequacy of services received by families.

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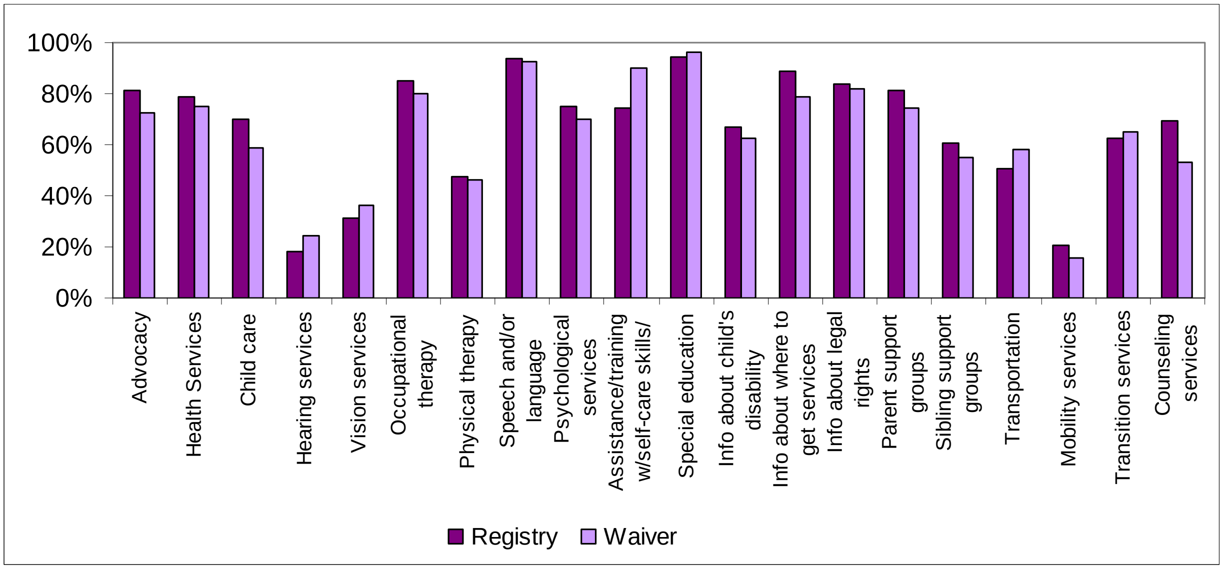
[1] Maryland Community of Care Consortium for CYSHCN (2008). *Family-Professional Partnerships Workgroup Report Out*. Accessed on May 25, 2010 from http://www.marylandcoc.com/uploads/Family_Professional_Partnerships.pdf

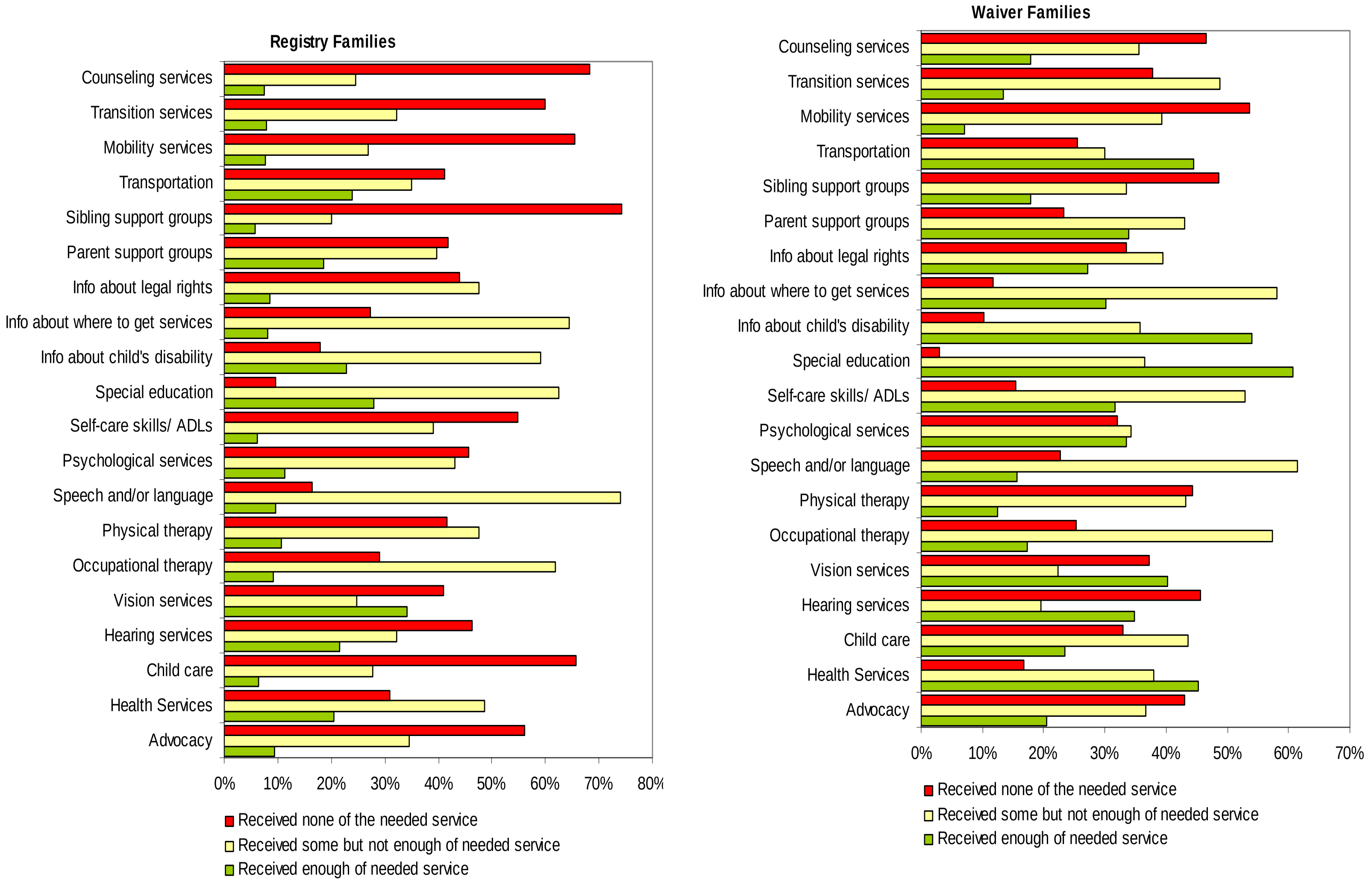
Figure 18. Need for Services among Families on the Autism Registry and Families Receiving Autism Waiver Services *(Source: 2009 Maryland Autism Services Survey)*



Both Registry and Waiver families report high rates of need for services, though Registry families generally reported a higher rate of need in most areas, particularly for counseling (Registry 69.5%, Waiver 52.9%), child care (Registry 70%; Waiver 58.7%), advocacy (Registry 81.4%; Waiver 72.3%), and information about where to get services (Registry 88.5%; Waiver 78.9%). Both groups reported very high rates of need for special education, speech and language services, and occupational therapy. Over three-quarters of Registry and Waiver families reported a need for health services.

Overall, Waiver families report a significantly higher rate of service adequacy (received enough of the needed service) than Registry families (see Figure 19.) Of the services that were needed, there are high rates of *inadequacy* (families receiving *none* of the needed service) among both groups for sibling support groups (Registry 74.2%; Waiver 48.6%), counseling services (Registry 68.2%; Waiver 46.5%), advocacy (Registry 56.2%; Waiver 43%), and mobility services (Registry 65.4%; Waiver 53.6%). Additionally, Registry families noted high rates of inadequacy for child care (65.8%) and self-care skills/activities of daily living services (54.9%); Waiver families noted high rates of inadequacy for hearing services (45.7%) and physical therapy services (44.3%). Waiver families were more likely to indicate that they received *some, but not enough*, of most needed services, while Registry families were more far more likely to indicate that they received none of a needed service.

Figure 19. Adequacy of Services among Families on the Autism Registry and Families Receiving Autism Waiver Services *(Source: 2009 Maryland Autism Services Survey)*



There were several types of services that both Registry and Waiver families reported that they get some, but not enough, of the service – most frequently in both groups was for speech and/or language services (Registry 74%; Waiver 61.4%), followed by information about where to get services (Registry 64.5%; Waiver 58%), and occupational therapy (Registry 61.8%; Waiver 57.4%). Other services for which Registry families reported a high rate of some, but not enough were special education (62.4%) and information about their child's disability (59.1%).

During the 2011 PPMD Parent Focus Groups, parents were asked how well their children's providers understand their child's needs. Responses varied regionally – parents in Southern Maryland expressed a higher satisfaction with medical providers than with education providers. They felt that medical providers typically had a good understanding of children with ASD and other DD's needs "once you find the right doctor." Those same families felt that their children's school professionals "just don't get it" and that teachers do not know how to practically apply an understanding of the special learning and behavioral needs of children with ASD and other DD. Parents in Western Maryland were far less satisfied with medical providers in their area, as there is a consistent feeling that the pediatricians there do not "understand the [autism] spectrum." Additionally, parents feel that there are critically few family supports to help get a child what is needed:

> *"There are no therapies in this town to help our children and there's no respite, there's no funding and the autism waiver, you could put your child on that, but you will have to wait for years on end to get on it. And even if you do get on it, all the therapies and everything, we don't have any of it [therapy providers in the area], so the kids won't receive it… Now, if you want to just have your child get in trouble and get involved with DJS or …or in foster care, you'll get help that way. But a parent who's willing to work and fight for their child and keep them in line, there are no services or help in this area."* (Western Maryland Parent Focus Group, 2011.)

B. Medical Home

Key Findings

A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective; this model has been identified as the best care model for CYSHCN only one quarter of CYSHCN with emotional, behavioral or developmental issues are receiving care in a medical home model.

Effective care coordination (which includes help with coordination of care and satisfaction with communication among providers and with schools if needed) is especially important for children with developmental issues; in Maryland, CYSHCN with emotional, behavioral or developmental issues are less likely to have effective care coordination when needed (37%) than are CYSHCN in general (42%).

Caring for CYSHCN has profound logistical, financial and emotional impacts on families: 41% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that they found it necessary to change their work hours or to stop working in order to care for their child; parents frequently turned down higher paying positions or career-advancing promotions because of the need to maintain flexibility in their work schedules in order to care for their children with ASD and other DD; and families whose children with ASD receive Autism Waiver services have a significantly higher "family quality of life" score than families whose children with ASD are not receiving Autism Waiver services.

Table 6. 2009-10 NS-CSHCN Indicators used to measure Medical Home *(Source: 2009-10 NS-CSHCN)*

Indicator	Nation %	Maryland %
Core Outcome #2: % CSHCN who received coordinated, ongoing, comprehensive care within a medical home	**43.0%**	**44.2%** (ranked 28th in the nation)
Among CYSHCN with E/B/D Issues	28.8%	25.7%
Related Indicator: % CYSHCN whom have usual source(s) for both sick and well care	**89.3%**	**92.0%**
Among CYSHCN with E/B/D Issues	89.0%	95.2%
Related Indicator: % of CYSHCN reported to have effective care coordination which includes help with coordination of care and satisfaction with communication among providers and with schools when needed	**42.3%**	**42.2%**
Among CYSHCN with E/B/D Issues	39.6%	36.9%
Related Indicator: % CYSHCN reported to be receiving care that is family-centered	**64.6%**	**67.1%**
Among CYSHCN with E/B/D Issues	54.7%	50.7%
Related Indicator: % CYSHCN having no problem receiving referrals	**25.8%**	**24.6%**
Among CYSHCN with E/B/D Issues	59.5%	64.9%

A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive, high-quality, cost-effective primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.[2]

While having a medical home is important for all children, CYSHCN and those with ASD or other DD in particular need the type of care embodied by this model. According to the 2009-10 NS-CSHCN, 43% of Maryland CYSHCN are receiving care that meets criteria for a medical

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[2] American Academy of Pediatrics.

home compared with 44.2% nationally. CYSHCN in Maryland with more than one E/B/D issue achieved this outcome at a much lower rate (25.7%) compared to 28.8% nationally (see Table 6).

Parents of CYSHCN who receive care in a medical home setting pay less in out-of-pocket costs according to a study using 2005-06 NS-CSHCN data. Specifically, the care coordination component of the medical home model was most related to the reduction in out-of-pocket costs.[3]

Usual Source of Care

Having a usual source for both sick and well care is a starting point for a medical home. Almost 92% of Maryland CYSHCN are reported to have a usual source of care on the NS-CSHCN, though this was slightly higher (95.2%) among those with E/B/D issues.

In 2010, Maryland had 1.72 pediatricians per 1,000 children (compared to 0.98 nationally), 1,794 family practitioners, and 0.14 child and adolescent psychiatrists per 1,000 children (compared to 0.05 nationally.)[4] We know from various data sources that these providers are not evenly distributed around the state and that not all providers accept all types of insurance or are comfortable treating CYSHCN, creating barriers for families of children with ASD and other DD in accessing primary health care for their children (for further discussion see *Easy to Use Community Based Services* section)

Care Coordination and Impact on Families

Effective care coordination (which includes help with coordination of care and satisfaction with communication among providers and with schools if needed) is especially important for children with developmental issues, as they often require speech, occupational, and physical therapy services in addition to medical care. In Maryland, CYSHCN with E/B/D issues are less likely to have effective care coordination when needed (36.9%) than are CYSHCN in general (42.2%). During the 2011 PPMD Parent Focus Groups, parents were asked how well their children's providers coordinated their child's care. Most parents felt that the onus of coordinating their child's care fell to them, which is extremely challenging. One parent recalled setting up a system in which all of her child's providers can email each other, and that this intercommunication has been very helpful in care coordination. Other parents reported successful care coordination through providers given that their child has a good provider. Parents mentioned several providers by name as providing good care coordination, including Children's Medical Group in Western Maryland and Dr. Kerisedes in Calvert County.

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[3] Hand, L (2011). *Medical home setting lowers out-of-pocket costs*. Medscape, October 17, 2011. Available at http://www.medscape.com/viewarticle/751586

[4] The Catalyst Center. *State at a glance coverage and financing charts, Maryland.* Available at http://www.hdwg.org/catalyst/online-chartbook/bystate/tips=0&sources=0.

Caring for CYSHCN can have a significant impact on families. The needs of CYSHCN vary greatly. For families of children with ASD or other DD, coordinating their child's care can be very time consuming. According to the 2009-10 NS-CSHCN, while the majority of families nationally and in Maryland spend less than one hour per week providing and/or coordinating their child's care, Maryland families with CYSHCN with one or more E/B/D issues (22.6%) spend more time (5 or more hours per week) arranging or coordinating their child's care than Maryland families whose CYSHCN do not have E/B/D issues (17%.) Some families find it necessary for a caregiver to cut back on work hours or stop working in order to be able to meet the multiple demands of caring for a CYSHCN. Among Maryland families with a CYSHCN with one or more E/B/D issue, almost 31.9% had to cut back work hours or stop working altogether, compared to 17.5% of Maryland families whose CYSHCN do not have E/B/D issues. Additionally, 20% of Maryland families with a CYSHCN with one or more E/B/D issue report that they have avoided changing jobs because of concerns about maintaining health insurance for their CYSHCN.

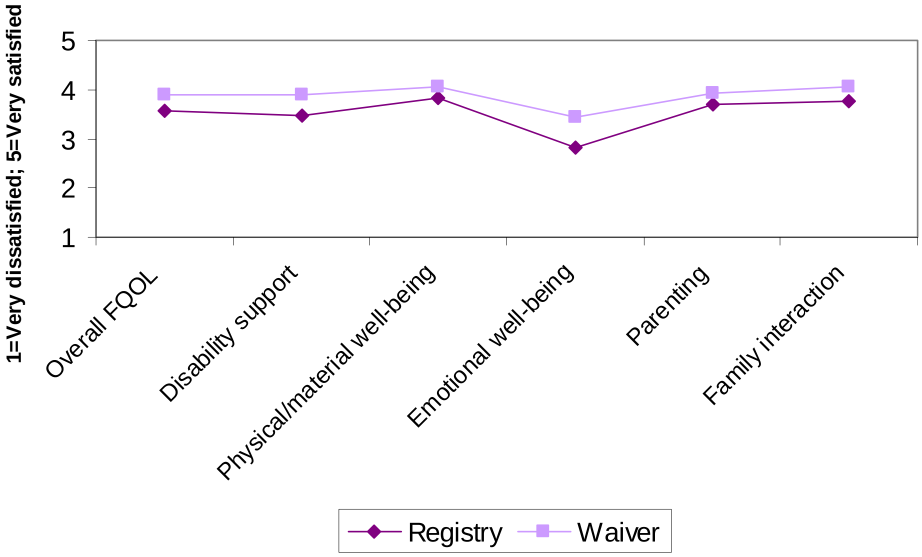
The 2009 Maryland Autism Services Survey (MASS) compared outcomes for families receiving services through the Autism Waiver to outcomes for families waiting for services on the Autism Waiver Registry and found that, among respondents from both Waiver and Registry families, 86% said that the needs of their child with ASD affected their employment status "some" or "a lot." And among Waiver families, parent employment status increased with each year the family received Waiver services, and 38% of Waiver families reported better employment status after receiving Waiver services.

More recent data from the 2010 Maryland Parent Survey support the above finding. Among families of CYSHCN with ASD, a higher percentage (41%) reported that they found it necessary to change their work hours or to stop working in order to care for their child as compared to families of children with any SHCN (38.5%). When analyzed regionally, families of children with ASD in Southern Maryland were found to have reduced their work hours or to have stopped working entirely (47.8%) - far more often than families statewide and in other regions. The 2011 PPMD parent focus groups reveal that Maryland parents frequently turned down higher paying positions or career-advancing promotions because of the need to maintain flexibility in their work schedules in order to care for their children with ASD and other DD. Parents have also quit jobs or changed careers to something less rewarding professionally or financially in order to achieve needed schedule flexibility. Many parents also expressed the paradox of needing to increase their work hours in order to increase earnings to cover medical expenses and insurance copays but not being able to work as much as needed because of the child's care requirements (such as frequent medical appointments, being sent home from school often due to illness and/or behavior, coordinating the child's care, appealing insurance company decisions to not cover needed care and equipment, etc.)

The 2009 MASS reported family quality of life (FQOL) among families on the autism registry and families receiving autism waiver services using a scale of 1 to 5, with "1" being "very dissatisfied" and "5" being "very satisfied." MASS asked the families not only to rate themselves on overall FQOL but also on five subscale quality indicators – disability support, physical/material well-being, emotional well-being, parenting, and family interaction. Figure 20 illustrates the findings.

In terms of overall FQOL, Waiver recipients (3.91) reported significantly higher satisfaction than Registry families (3.56.) Registry families reported significantly lower FQOL satisfaction on all of the five subscales as well, though both groups followed the same subscale pattern with the highest satisfaction rates for the subscales of family interaction (Registry 3.78; Waiver 4.07) and physical/material well-being (Registry 3.82; Waiver 4.06). The lowest subscale ratings for both groups were for emotional well-being (Registry 2.81; Waiver 3.43). This finding for emotional well-being also exhibited the largest gap between Registry families and Waiver families.

Figure 20. Self-reported Family Quality of Life (FQOL) among Families on the Autism Registry and Families Receiving Autism Waiver Services *(Source: 2009 Maryland Autism Services Survey)*



According to the 2008 CoC Summit Medical Home Workgroup, Maryland has several strengths around this core outcome including multiple opportunities based on Maryland's ongoing partnerships and relationships among stakeholders, and strong interest in promoting the medical home model. Barriers exist in the areas of readiness and education of providers, practices and families, care coordination, and aligning compensation with supporting medical home improvement. Care coordination challenges include fragmentation of services, lack of standards, and lack of provider compensation. Strategies that may help to improve medical home outcomes in Maryland include medical home indexing, physician training, family training, parent involvement in physician and resident training, revisiting how case management is implemented, realigning provider compensation to support medical home goals, and creating an ongoing inventory of community resources.[5]

C. Adequate Insurance and Financing

Key Findings

A key component of an effective system of care for CYSHCN with ASD or other DD is adequate public or private health insurance coverage.

92.4% of Maryland families of CYSHCN reported that their child had continuous *public or private health insurance coverage; although most CYSHCN in Maryland have health insurance coverage, that coverage is often* inadequate *to cover all of a child's required health and related services.54% of CYSHCN in Maryland with emotional, behavioral or developmental issues do not have adequate health insurance. In the 2010 Maryland Parent Survey, 65% of respondents with a child with ASD who had private insurance reported that their child's insurance did not pay for all needed services.*

Caring for CYSHCN has profound logistical, financial and emotional impacts on families: 31% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that they spend between $1000 and $5000 per year on out-of-pocket spending for their child's medical care; 21% spend over $5000 per year.

In the 2010 Maryland Parent Survey, services not covered or inadequately covered by insurance noted most frequently were: therapies (such as speech therapy and behavioral therapies), mental health services, testing and evaluations, and dental care. In the 2011 PPMD Parent Focus Groups, parents of children with ASD and other DD reported their child's private health insurance was not adequate to cover needed medical and therapy expenses.

Parents of CYSHCN whose children receive care in a medical home setting pay less in out-of-pocket costs.

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[5] Maryland Community of Care Consortium for CYSHCN (2008). *Medical Home Workgroup Report Out*. Accessed on May 25, 2010 from http://www.marylandcoc.com/uploads/Medical_Home.pdf

Table 7. 2009-10 NS-CSHCN Indicators used to measure Adequate Insurance *(Source: 2009-10 NS-CSHCN)*

Indicator	Nation %	Maryland %
Core Outcome #3: % CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need	**60.6%**	**61.3%** (ranked 25th in the nation)
Among CYSHCN with E/B/D Issues	53.6%	54.4%
Related Indicator: % CYSHCN consistently insured during past 12 months	**90.7%**	**92.4%**
Among CYSHCN with E/B/D Issues	89.2%	92.7%
Relate Indicator: Currently insured CSHCN whose insurance is inadequate	**34.3%**	**34.7%**
Among CYSHCN with E/B/D Issues	40.9%	43.8%
Related Indicator: CSHCN with insurance at the time of the survey	**96.5%**	**96.4%**
Among CYSHCN with E/B/D Issues	96.3%	97.7%

On the 2009-10 NS-CSHCN, 92.4% of Maryland families of CYSHCN reported that their child had continuous public or private health insurance coverage for the year prior to the survey, indicating that the rate of uninsurance (children without health insurance at some point in the year prior to the survey) among CYSHCN in Maryland was approximately 7.6%. Data from the U.S. Census Small Area Health Insurance Estimates (SAHIE) as shown in Table 8 illustrates that statewide, the rate of uninsurance among all Maryland children ages 0 -18 years in 2009 (regardless of special health needs status) was 5.3%, corresponding to ~74,779 children and roughly amounting to the number of babies born in Maryland in a given year. The SAHIE data also provides insurance coverage estimates by county, as well as by poverty level, for all children under 19 years of age. Table 8 and Figure 21 illustrate the rates of uninsurance by poverty level and region.

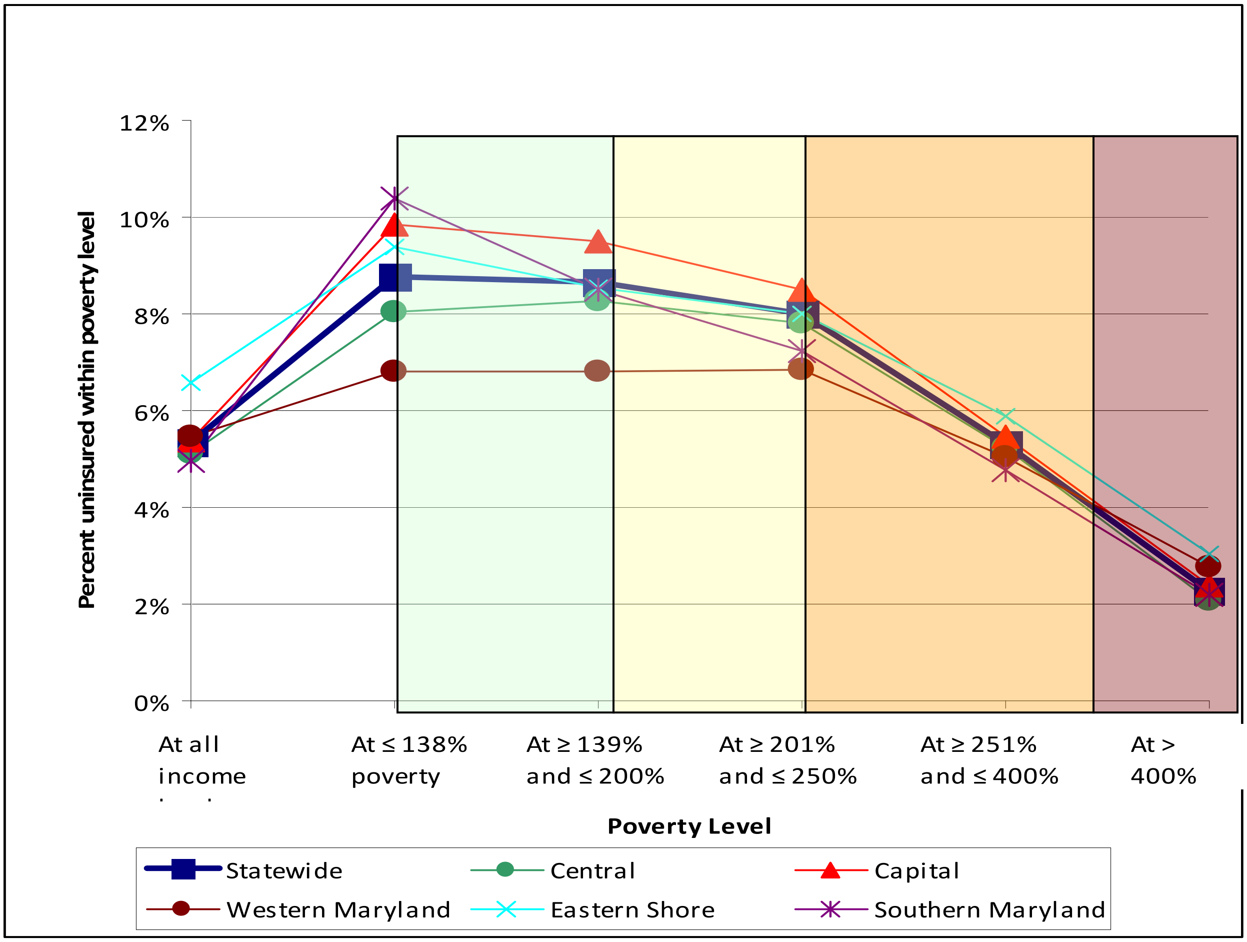
Uninsurance among Maryland Children

Table 8. Uninsurance rates among Maryland children ages 0–18 years by poverty level, 2009 (*Source: 2009 SAHIE*)*

	At all income levels	**At ≤138% poverty**	**At ≥ 139% and ≤ 200% poverty**	**At ≥ 201% and ≤ 250% poverty**	**At ≥ 251% and ≤ 400% poverty**	**At > 400% poverty**
Statewide	5.3%	8.8%	8.7%	8.0%	5.3%	2.3%
Central	5.1%	8.0%	8.3%	7.8%	5.2%	2.1%
Capital	5.4%	9.8%	9.5%	8.5%	5.4%	2.4%
Western Maryland	5.5%	6.8%	6.8%	6.8%	5.0%	2.8%
Eastern Shore	6.6%	9.4%	8.5%	8.0%	5.9%	3.0%
Southern Maryland	4.9%	10.4%	8.5%	7.2%	4.8%	2.2%

**Statistically comparing SAHIE estimates between counties, states, or years is not recommended, as it requires additional correlation coefficients*.

Figure 21. Uninsurance rates among Maryland children ages 0–18 years by poverty level, 2009 (*Source: 2009 SAHIE*)



Although the following analysis and discussion using the SAHIE data is not specific to children with SHCN or those with ASD or other DD in particular, it does shed light on the percentage and amount of vulnerable children without insurance coverage in Maryland. Statewide, among those children living at or below 138% of poverty and between 139% and 200% of poverty, the rate of uninsurance is highest, at about 9%. Maryland Medicaid eligibility for children varies by age group, ranging from 185% FPL for infants, 133% for 1-5 year olds, and 100% FPL for 6-17 year olds. The federal Patient Protection and Affordable Care Act (ACA) expands Medicaid to cover children living in families with incomes up to 138% of poverty[6], allows states to include

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[6] U.S. Census Bureau. (2011). *Small Area Health Insurance Estimates.* Available at http://www.census.gov/did/www/sahie/data/2009/tables.html

children up to 400%, and provides for subsidies through health insurance exchanges up to 400% FPL. The ACA changes have not been implemented yet the Maryland Children's Health Program (MCHP) provides health insurance coverage for children in families living below 200% of poverty. For children living between 251% and 400% poverty, the statewide uninsured rate drops to 5.3%; some of these children's families are eligible for the MCHP Premium in which families can pay a monthly fee to buy into the MCHP. Not surprisingly, the lowest statewide uninsurance rate is among those children living above 400% poverty (2.3%).

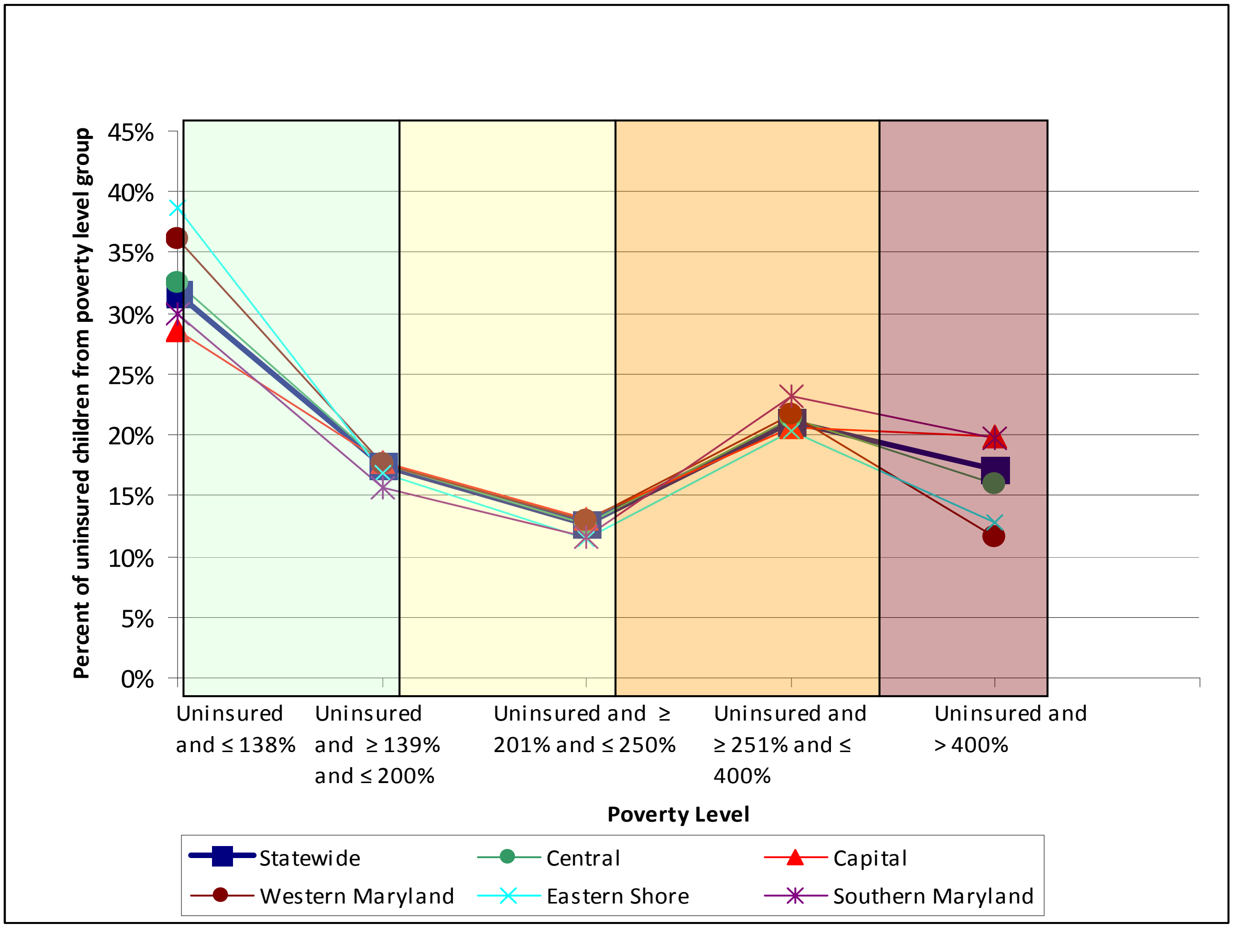
There is some regional variance within the state for children's uninsurance rates. Southern Maryland has the highest rate of uninsurance among children at or below 138% poverty (10.4%) but drops below the statewide rates among children in different categories of poverty. Uninsured rates in the Capital region are consistently roughly equal or higher than the statewide rates in each poverty group. The Eastern Shore leads in the overall uninsurance rate at all income levels (6.6%) surpassing the overall statewide rate at all income levels, as well as in the categories of children at or below 138% poverty and at or above 251% poverty. Western Maryland shows slightly lower rates of child uninsurance as compared with the rest of the state. Within Western Maryland, Garrett County has higher rates of uninsurance as compared to neighboring Allegany or Washington counties.

s previously mentioned, the rate of uninsurance among all Maryland children ages 0 -18 years in 2009 (regardless of special health needs status) was 5.3%, corresponding to almost 75,000 children. Table 9 and Figure 22 show the breakdown by poverty level of this 5.3% of Maryland children without health insurance.

Table 9. Proportion of uninsured Maryland children ages 0-18 years by poverty level, 2009 *(Source: 2009 SAHIE)*

	Uninsured and ≤ 138%	Uninsured and ≥ 139% and ≤ 200%	Uninsured ≥ 201% and ≤ 250%	Uninsured and ≥ 251% and ≤ 400%	Uninsured and > 400%
Statewide	31.6%	17.5%	12.7%	21.1%	17.2%
Central	32.4%	17.7%	12.7%	21.3%	15.9%
Capital	28.6%	17.8%	13.1%	20.6%	19.9%
Western Maryland	36.1%	17.6%	13.0%	21.6%	11.6%
Eastern Shore	38.7%	16.9%	11.4%	20.3%	12.7%
Southern Maryland	29.9%	15.6%	11.6%	23.2%	19.7%

Figure 22. Proportion of uninsured Maryland children ages 0-18 years by poverty level, 2009 *(Source: 2009 SAHIE)*



Statewide, about one third (31.6%; corresponding to 23,600 children) were living at or below 138% poverty. These children and their families will probably be eligible for coverage due to the expected Maryland Medicaid expansion under the ACA. Another 17.5% (13,103 children) of uninsured children statewide live between 139% and 200% of poverty and some would not qualify for the Medicaid expansion based on their age, they would qualify for the Maryland Children's Health Program. Almost 13% (9,505) of uninsured children live between 200% and 250% poverty and do not qualify for MCHP but do qualify for the MCHP premium. Over one fifth (21.1%, or 15,762 children) live between 251% and 400% of poverty (those in this category at or under 300% poverty could qualify for MCHP Premium at a cost to their families).The remaining 17.2% (12,829) of uninsured children in Maryland live above 400% poverty.

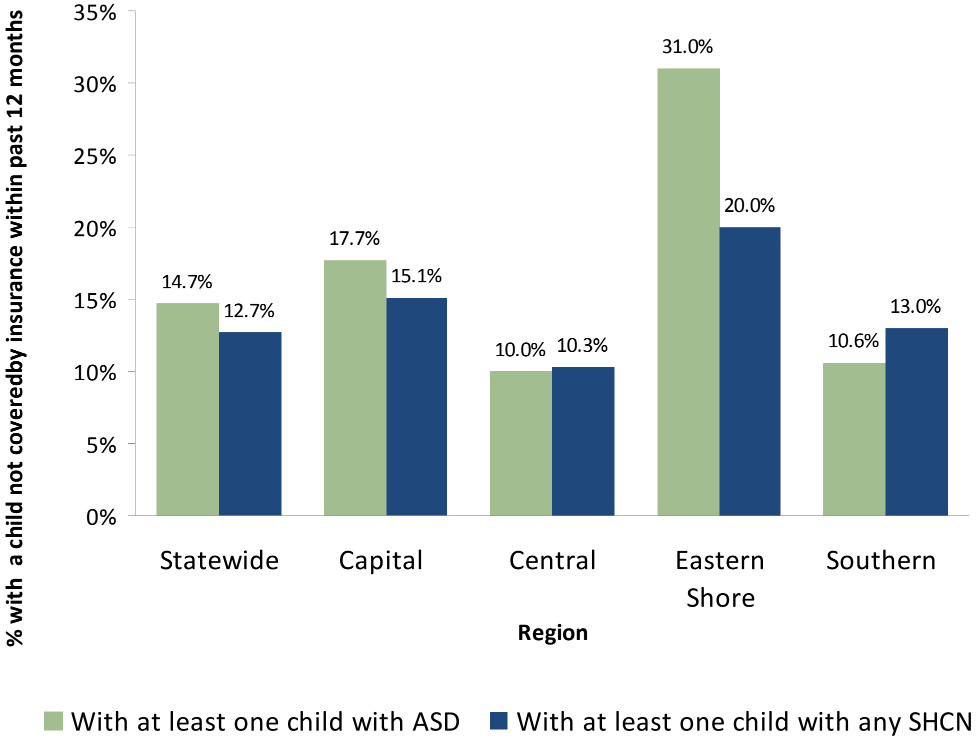
Although all regions in Maryland follow the general statewide pattern of: 1) a greater proportion of uninsured children living at or below 138% poverty, 2) smaller proportions between 139% and 250% of poverty, 3) an increase between 251% and 400%, and 4) a drop off above 400% of poverty, there is variance between regions of the state, especially at the lower and upper extremes. The Eastern Shore and Western Maryland regions have more uninsured children concentrated at higher poverty levels than do the other regions in the state. For example, on the Eastern Shore, a much larger proportion (38.7%) of uninsured children live at or below 138% poverty than in the Capital region (28.6%); conversely both the Eastern Shore (12.7%) and Western Maryland (11.6%) have far fewer uninsured children living above 400% poverty compared to Southern Maryland (19.7%) and the Capital Region (19.9%).

This data begs the question - why are over half of uninsured children in Maryland living at poverty levels at which they would qualify for public health insurance such as Medicaid or MCHP and yet do not have insurance coverage? Possible explanations that may keep some families from enrolling their children in free public health insurance programs include: family resistance (cultural resistance among certain groups such as Mennonite and Amish families); legal barriers among undocumented populations; language barriers among non-English speaking populations; ineffective government outreach to enroll families; cumbersome enrollment procedures; state-to-state mobility; family transience; and the general lack of awareness of eligibility and available programs.

Uninsurance among Maryland Children with ASD and other SHCN

Among respondents to the 2010 Maryland Parent Survey with at least one child with ASD, 14.7% reported that there was a time that their child was uninsured in the year prior to the survey (see Figure 23). This was higher than the rate of uninsurance reported by parents of children with any SHCN (12.7%). Families in the Eastern Shore (31.0% ASD; 20% any SHCN) and Capital Area (17.7% ASD; 15.1% any SHCN) regions were more likely to report uninsurance.

Figure 23. Uninsurance among children with ASD and children with any SHCN by region *(Source: 2010 Maryland Parent Survey)*



Adequacy of Insurance Coverage

Although most CYSHCN in Maryland have health insurance coverage, that coverage is often inadequate to cover all of a child's required health and related services. Table 7 showed National and Maryland specific data on indicators of insurance *adequacy* from the NS-CSHCN. Over one-third of Maryland CYSHCN do not have insurance that is adequate to pay for the services they need; Closer to half of children with E/B/D issues also lack adequate insurance. 21.8% of Maryland CYSHCN with E/B/D issues are restricted from seeing needed providers because of inadequate insurance (compared to 6.8% among all Maryland CYSHCN.) Families of CYSHCN with ASD are less likely to report having adequate insurance. In the 2010 Maryland Parent Survey, 65% of respondents with a child with ASD who had private insurance reported that their child's insurance did not pay for all needed services, compared to 54.7% of families of children with any SHCN with private insurance. Families in the Southern (74.3%) and Capital Area (73.0%) regions were far more likely to report that private insurance does not pay for all needed services than families from other regions.

An issue related to insurance adequacy is out-of-pocket costs. On the 2009-10 NS-CSHCN, 36.6% of Maryland families of CYSHCN with E/B/D issues reported that costs not covered by insurance were never or only sometimes reasonable (compared to 26.7% of all CYSHCN); 31.9% of Maryland families of CYSHCN with E/B/D issues reported spending $1000 or more out-of-pocket in medical expenses for their CYSHCN in the year prior to the survey as compared to 17.5% of CYSHCN Maryland families with such issues. Among families with CYSHCN with E/B/D issues, 31.7% reported that their child's conditions cause financial problems for the family as compared to 11.6% of families of CYSHCN without these issues.

Figure 24. 2010 Out-of-Pocket Costs for Child's Care among Families with At Least One Child with Autism and Families with At Least One Child with any Special Health Care Need *(Source: 2010 Maryland Parent Survey)*

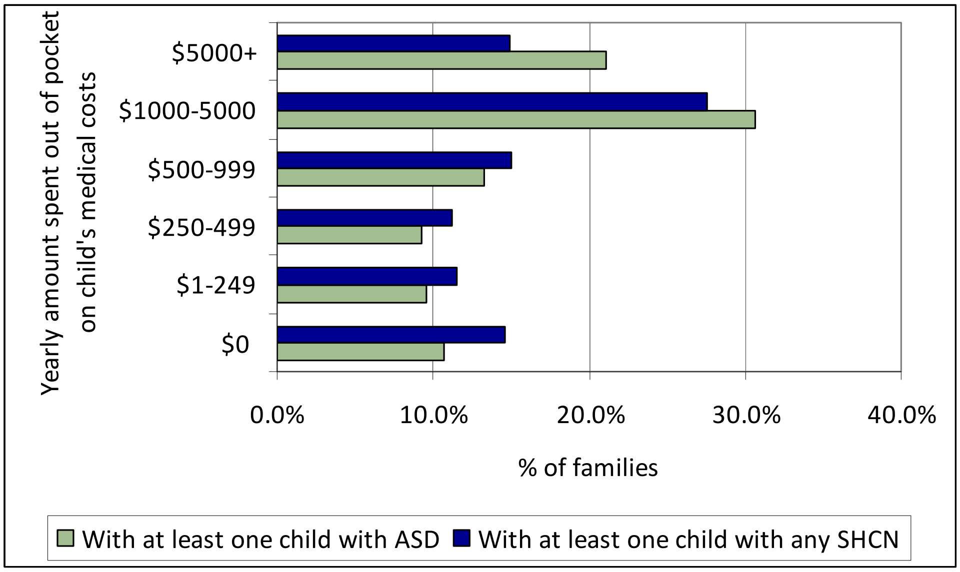
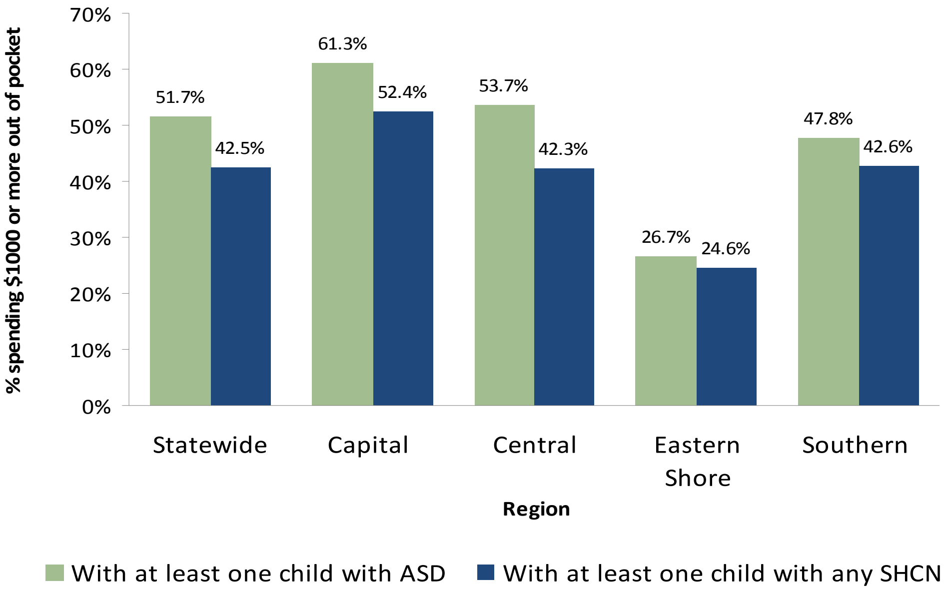


Figure 24 indicates that out-of-pocket spending is greater for families of children with ASD than for families of children with any SHCN. 30.6% of families of children with ASD spend between $1000 - $5000 per year compared to 27.6% of families of children with any SHCN, and 21% of families of children with ASD spend over $5000 yearly compared to 14.9% of families of children with any SHCN.

Figure 25. Families Spending more than $1000 Yearly on Out-of-Pocket Costs for Child's Medical Care Need *(Source: 2010 Maryland Parent Survey)*



There are regional variations among families spending $1000 or more per year for their child's medical costs (see Figure 25). Among families of children with ASD, those in the Capital region are more likely to spend $1000 or over (61.3%) than families in any other region, while those on the Eastern Shore are less likely to spend $1000 or over (26.7%.)

Parents report that insurance packages have gaps in coverage for key services, including mental health, ancillary therapies, home health care, and durable medical equipment. According to the NS-CSHCN, restrictions on the amount or scope of health benefits create unmet needs for about 30.2% of Maryland children with any SHCN and 43.8% of Maryland children with E/B/D issues. In the 2010 Maryland Parent Survey, services not covered or inadequately covered by insurance noted most frequently were: therapies (such as speech therapy and behavioral therapies), mental health services, testing and evaluations, and dental care. In the 2011 PPMD Parent Focus Groups, parents of children with ASD and other DD reported their child's private health insurance was not adequate to cover needed medical and therapy expenses, seriously impacting their families. One parent reported taking a second job to cover over $500 in monthly prescription copays for a child under a PPO health insurance plan; Consequently, the family switched to an HMO plan reducing copays to $85/month, resulting in a lot more of the parents' time subsequently being spent on ensuring the many needed referrals for their child's specialty care, a requirement under the HMO plan. Parents in Southern Maryland reported spending between $6000 and $8000 per year in out-of-pocket expenses on therapies and supplements to improve their child's condition which are not covered by insurance.

Parents of CYSHCN who receive care in a medical home setting pay less in out-of-pocket costs according to a study using national 2005-06 NS-CSHCN data. Additionally, regardless of medical home status, parents of CYSHCN with public health insurance paid less out-of-pocket costs (an average of $317 per year, or 1.8% of their household income without medical home/$215 or 1% of household income with medical home) than did parents of CYSHCN with private health insurance ($1298 per year, or 2.1% of household income without medical home/$1088 per year or 1.6% of household income with medical home).[7]

According to the 2008 CoC Summit Insurance and Financing Workgroup, Maryland has several obstacles to successfully achieving this outcome, including the lack of a comprehensive plan to address how services for CYSHCN are paid for and the inadequate synthesized data to use for problem identification. These impediments are further exacerbated by an uneven geographic distribution of providers, a complex system that is difficult to navigate, and complicated eligibility requirements for services.[8] The CoC is also re-evaluating strategies to address this core outcome in the context of federal health care reform.

As mentioned earlier in the discussion around delayed and unmet medical needs for children with ASD and other DD, the system of health insurance and financing in Maryland is system-centered as opposed to being child- and family-centered which presents major obstacles to getting timely, needed care for children. A parent illustrates how the system prevented her daughter from getting needed surgery because of insurance complications:

“[My daughter] was supposed to have surgery this Monday up in Pittsburgh for adenoids and ear tubes, and they canceled it because they won’t pay for it. They’ll pay for her to go up there for her genetic issues, but they wouldn’t pay for her to get the adenoids and tubes taken out because they didn’t have a Medical Assistance number. And now I took her to [doctor’s name] here in Western Maryland on Monday, who takes our insurance, but is afraid to touch her because of her blood disorder... So where do I go now? [The doctor]’s like ‘they should have just left you up in Pittsburgh. Because I don’t know if I feel comfortable without taking the adenoids out because of the blood condition.’” (Western Maryland Parent, PPMD Parent Focus Group, 2011.)

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[7] Hand, L (2011). *Medical home setting lowers out-of-pocket costs*. Medscape, October 17, 2011. Available at http://www.medscape.com/viewarticle/751586

[8] Maryland Community of Care Consortium for CYSHCN (2008). *Insurance and Financing Workgroup Report Out*. Accessed on May 25, 2010 from http://www.marylandcoc.com/uploads/Insurance.pdf

D. Developmental Screening

Key Findings

A key component of an effective system of care for CYSHCN with ASD or other DD is early and continuous screening for special health care needs.

According to the 2007 National Survey of Children's Health, 28% of Maryland children aged 4 months to 5 years are at moderate or high risk for developmental delay, but only 22.3% of families report that their child aged 10 months to 5 years received a standardized screening for developmental or behavior problems.

CYSHCN who are in families living below 200% FPL, are Hispanic or African American, who are not insured or who have public insurance only, or who have an above routine need/use of services are less likely to receive early and continuous screening.

The 2007 NSCH estimated that almost 28% of Maryland children aged 4 months to 5 years are at moderate or high risk for developmental delay, higher than the nation as a whole (26.4%). However, in terms of screening for developmental and behavioral problems, this survey reports that only 22.3% of families report that their child aged 10 months to 5 years received a standardized screening for developmental or behavior problems. Almost 46% of families of children ages 0-5 years report that they were not asked by their providers if they had concerns about their child's learning, development, or behavior in the past year. Many families who would benefit from Maryland's free early intervention services are being missed. CYSHCN stakeholders in Maryland note that the number of families accessing early intervention services could be increased if pediatricians refer the families to early intervention services themselves after talking to families in the office about possible developmental delays, rather than simply giving families a number to call.

Table 10. 2009-10 NS-CSHCN Indicator used to measure Developmental Screening *(Source: 2009-10 NS-CSHCN)*

Indicator	Nation %	Maryland %
Core Outcome #4: % CYSHCN ages 0-17 who are screened early and continuously for SHCN	**78.6%**	**81.2% (ranked 16th in the nation)**
Among CYSHCN with E/B/D Issues	78.6%	78.7%

According to the NS-CSHCN, 82% of CYSHCN in Maryland are screened early and continuously for SHCN, compared to less than 78.6% nationwide (see Table 10). Maryland is a few percentage points ahead of nationwide developmental screening indicators; however there are disparities among subgroups in the state. CYSHCN who are in families living below 200% FPL, are Hispanic or African American, are not insured or who have public insurance only, or who have an above routine need/use of services are far below the nationwide average. Parents participating in the PPMD focus groups conducted for this needs assessment were asked if they encountered barriers or difficulties in getting their children with ASD or other DD diagnosed; Spanish (non-English) –speaking parents highlighted the lack of available information about ASD and diagnostic services as a major barrier to getting diagnoses. Once a diagnosis is obtained, Spanish-speaking and English-speaking families reported having to “fight” with the school system to get appropriate services for their children through the IEP process. Parents who participated in the focus groups also frequently mentioned that there are disagreements between medical doctors and school systems as to what services, or amounts of services are needed for children:

“…when my son was younger, I used to go to a developmental pediatrician and she wrote a letter saying that she wanted [him] to be seen more often for speech therapy…but… the school can´t provide for more than a limited amount of services… the way doctors see the problem is very different than how the school sees the problem.”

Table 11. Trends in screening, Maryland program data 2005-2010 (*Source: 2010 Maryland Title V Block Grant)*

	2005	2006	2007	2008	2009	2010
% Medicaid enrollees whose age is less than one year who received at least one initial periodic screen (Health Systems Capacity Indicator 2)	85.9	86	87.9	84.1	84.8	85.1
% SCHIP enrollees whose age is less than one year who received at least one initial periodic screen (Health Systems Capacity Indicator 3)	73.3	52.6	83.9	85.3	83.8	82.5

Newborn Screening data from the 2010 Maryland Title V Block Grant (Table 11) shows that Maryland performed well on follow-up for screen-positive newborns; from 2005 through 2010, 100% of screen-positive newborns received timely follow-up to definitive diagnosis and clinical management for conditions mandated by state-sponsored newborn screening programs.[9] Table 11 shows that, for the past five years, over 84% of Medicaid enrollees in Maryland whose age is less than one year received at least one initial periodic screen. In 2008 over 85% of Maryland's Children's Health Insurance Program (MCHIP) enrollees ages one year and under received at least one initial periodic screen; Although this rate decreased slightly to 82.5% in 2010, it still represented an improvement of over 9 percentage points from 2005.

Table 12. 2008 Maryland EPSDT Data (*Source: Maryland EPSDT Program*)

	HealthChoice Managed Care Enrollees	Maryland Average	National Average
% children aged 0-15 months receiving five or more well child visits	77.1-87.3	83.2	70.2
% children between 3-6 years of age receiving one or more well child visits	70-89.9	76.8	65.3
% children between 12-20 years of age receiving one or more well child visits	49.5-76.1	54.7	42

Table 12 shows 2008 data from Maryland's Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. The data suggest that Maryland is performing better than the nation as a whole on several screening indicators. While indicators for some Maryland Managed Care Organization enrollees are below the state average, they are above the national average. For

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[9] 2010 Maryland Title V Maternal and Child Health Block Grant Report.

example, at least 77% of HealthChoice Managed Care enrollees aged 0 to 15 months received 5 or more well child visits, compared to the national average of 70.2%. Staffing and budget issues over the past several years have made quality control measures difficult to maintain in the EPSDT program. However these measures are set to resume in 2012.

Table 13. ADDM Diagnostic Indicators* *(Source: ADDM 2008)*

Median age of earliest ASD diagnosis for:	**Combined 14 ADDM sites**	**Maryland**
Autistic Disorder	4 years 0 months	4 years 11 months
ASD/PDD	4 years 5 months	5 years 7 months
Asperger's Disorder	6 years 3 months	6 years 7 months

**Diagnostic information obtained from evaluation records may not capture the exact age of each child's earliest diagnosis; there is some instability of diagnostic subtypes over time.*

According to the ADDM, Maryland fares poorly against national averages for ASD diagnostic indicators (see Table 13). For example, the average age of earliest documented ASD diagnosis nationally was 4 years 0 months. Maryland's average age of earliest diagnosis was 4 years 11 months in 2006.

The 2008 CoC Summit Early and Continuous Screening Workgroup found that Maryland has several strengths around this core outcome, including effective statewide models of screening for selected conditions and an increasing awareness of the importance of screening, particularly for developmental and mental health issues. Barriers include poor communication and information-sharing among providers, agencies, and families; a need for comprehensive statewide systems involving multiple stakeholders; the need for improved education and professional development of providers; and the need for improved parent/family education and training. Strategies to improve this core outcome in Maryland should focus on increasing the efficiency of existing resources; promoting professional development around screening, referrals, and linkages to services; and promoting education for families about recommended screening practices.[10]

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[10] Maryland Community of Care Consortium for CYSHCN (2008). *Early and Continuous Screening Workgroup Report Out*. Accessed on May 25, 2010 from http://www.marylandcoc.com/uploads/Screening.pdf

During 2010 and 2011, considerable momentum in Maryland around medical homes and developmental screening has spurred greater interest and investment in pilot programs. In particular, a collaborative effort between Johns Hopkins University, OGPSHCN, the Maryland Chapter of the AAP, and PPMD (which provides on-site technical assistance to pediatric practices in effectively implementing developmental screening tools and referral processes) has expanded after several years of success within Baltimore City. Within participating practices, the percent of well-child screens for children ages 5 to 65 months has increased significantly, as have the number of appropriate referrals and enrollment in early intervention services. There are plans to implement this technical assistance at pediatric practices around the state, starting in the Eastern Shore region of the state in 2012 and expanding to Southern and Western Maryland in following years.

E. Easy to Use Community Based Systems

Key Findings

A key component of an effective system of care for CYSHCN with ASD or other DD is that needed services are community-based and are organized so that families can use them easily Maryland ranks 29th in the nation on this indicator.

Only half of Maryland CYSHCN with emotional, behavioral, or developmental issues have services that are community-based and easy-to-use.

Barriers to easy-to-use, community-based services for Maryland families include fragmented service systems which makes navigating the system difficult, significant transportation barriers, a shortage of an uneven distribution of needed service providers, and health insurance coverage gaps.

Families in Western and Southern Maryland and on the Eastern Shore have considerably less access to community-based, easy-to-use services.

"[There are] very little options for knowledgeable mental health services in this county that understand autism spectrum disorders and have therapies available to address their needs." Parent Respondent, 2010 Maryland Parent Survey, when asked open-ended questions about what more was needed for CYSHCN in the state.

Table 14. 2009-10 NS-CSHCN Indicators used to measure Ease of Use *(Source: 2009-10 NS-CSHCN)*

Indicator	Nation %	Maryland %
Core Outcome #5: % CSHCN whose services are organized in ways that families can use them easily	**65.1%**	**65.1%** (ranked 29th in the nation)
Among CYSHCN with E/B/D Issues	49.7%	51.3%
Related Indicator: Family member(s) avoided changing jobs in order to maintain health insurance for CYSHCN	**17.7%**	**16.9%**
Among CYSHCN with E/B/D Issues	22.4%	20.0%

Ideally, all of the services that a child and family require would be easily available and accessible within that child's community. On the NS-CSHCN, almost 65% of families of CYSHCN reported that services were organized for easy use (see Table 14.) Data from this survey suggest that Maryland has made strides – on the 2001 NS-CSHCN, Maryland ranked 42nd in the nation on successful achievement on this outcome; in the 2005-06 NS-CSHCN, Maryland improved and ranked 26th in the nation but took a step backward in the 2009-10 NS-CSHCH where Maryland ranked 29th in the nation.

The 2008 CoC Summit Ease of Use Workgroup found that Maryland has several strengths around this core outcome including many resources and services for families in Maryland and great potential for infrastructure to improve those services. Barriers to improving systems and ease of use include: redundancy (ex. multiple entities offer case management) and fragmentation (too many specialty areas); lack of acknowledgement of disparities; lack of knowledge of care providers of resources and services available for families; and turf issues among agencies. There are also regional issues that need to be dealt with at the community level. Strategies to overcome these and other barriers include streamlining services and funding and developing structure and strengthening relationships among local agencies for more effective communication and service provision.[11]

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[11] Maryland Community of Care Consortium for CYSHCN (2008). *Easy to Use Community-Based Systems Workgroup Report Out*. Accessed on May 25, 2010 from http://www.marylandcoc.com/Consortium.html

Difficulty "Navigating the System"

A persistent problem for families of CYSHCN is the issue of "navigating the system" or finding out about available services within the community and gaining access to them. In 2007-2008, the Children's Cabinet contracted with The Maryland Child and Adolescent Innovations Institute to conduct listening forums, discussion groups, and surveys in order to provide technical assistance and support for a strategic planning process. Several themes emerged related to the difficulty families have when trying to navigate the system. Stakeholders articulated the need for child-family serving agencies to better share information and communicate with one another more effectively. Family members stressed the need for there to be one agency or place where they can "tell their story" and subsequently receive necessary and appropriate referrals, supports, and services. Also, family members are uncertain of where and how to access services and supports, and observed that the process for applying for services is too lengthy, complicated, and bureaucratic. Finally, stakeholders felt that current resources and community programs could be better utilized and maximized if cross-system collaboration, communication, and coordination were practiced.

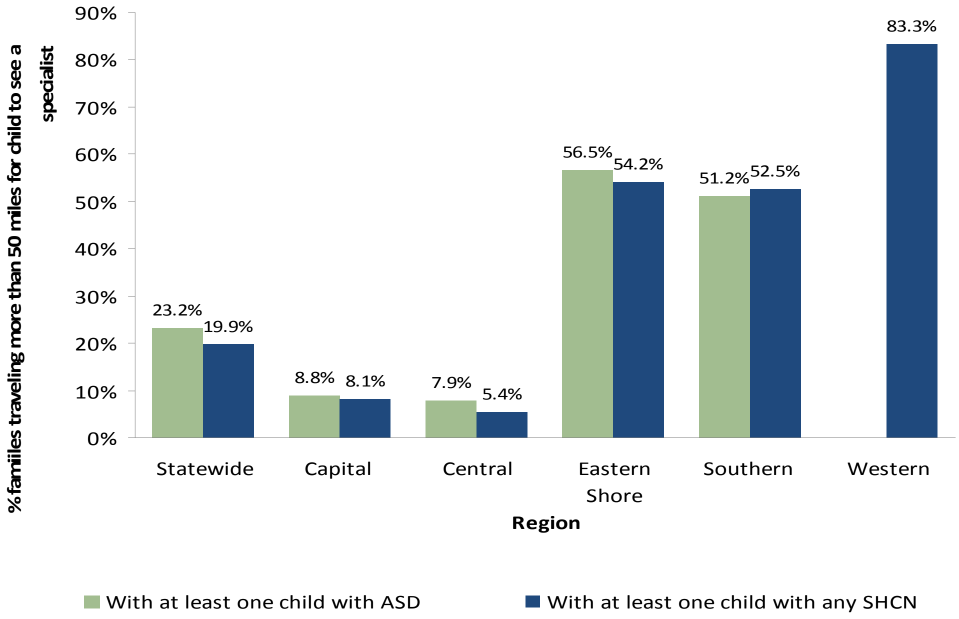
During the 2011 PPMD Parent Focus Groups, parents of children with ASD and other DD articulated the same issues around the difficulty of navigating the system of health care and related services for their children. The following quote from a parent in Western Maryland highlights the sentiments expressed during focus groups when participants were asked what the state could do to help with system navigation: "I would say just having an outlet center that we could go to at any time and be like, look, here's my child. Tell me what she could use, what she can't use, what I can do for her and where we do go… If there's just like here's what will help, here's what won't; here's the sources you can use, here's the numbers, here's the things you need to do."

Transportation

"I laugh because the joke at my house is [that] we subscribe to the Interstate 68 [a highway connecting western Maryland with central Maryland] health insurance plan. If you need specialty care, in all probability you are going to leave Allegany County or you are going to leave western Maryland. So I've just chalked it up to – I'm going to lose a day of work, I'm going to spend anywhere from $50-$100 for gas and a meal and parking and all of that for a 30 minute appointment." Parent, Western Maryland, 2007 Families Report on the State of the State.

Transportation can be a major factor in whether or not families can access care in Maryland. There are several geographic barriers to travel within the state - there is only one bridge connecting the eastern shore counties to the rest of the state, and travel between the far, mountainous western counties and the rest of the state is often difficult due to poor winter weather conditions. According to the 2005-06 NS-CSHCN, 44.5% of Maryland families of CYSHCN who reported having trouble accessing services said it was because the needed services were not available in their area. In the 2010 Maryland Parent Survey, over 11% of respondents with children with any SHCN reported having difficulty paying for transportation. Ten percent of responding families reported that they had unmet healthcare needs due to problems with transportation to appointments. This problem is more acute for families in rural areas of the state. Respondents were asked how far they must travel for specialty care appointments for their child. Figure 26 summarizes these responses.

Figure 26. Distance Traveled for Child's Specialty Care Appointments Among Families with At Least One Child with Autism and Families with At Least One Child with any Special Health Care Need *(Source: 2010 Maryland Parent Survey)*



Statewide and by region, families of children with ASD are slightly more likely to travel over 50 miles for their child's specialty care appointments than families of children with any SHCN. Though a majority (76.8%) of families of children with ASD report traveling 50 miles or less for specialty care, over 23% report having to travel over 50 miles. Regionally, families in Western (83.3% any SHCN) and Southern (51.2% ASD; 52.5% any SHCN) Maryland and the Eastern Shore (56.5% ASD; 54.2% any SHCN) are far, far more likely to have to travel greater distances for specialty care than are families in Capital and Central Maryland. In every data source consulted for this needs assessment, transportation and travel to medical appointments for families from the Southern, Western, and Eastern Shore regions of the state was repeatedly and consistently identified as a major barrier to accessing needed medical, specialty, and therapeutic care for children with ASD and other DD.

Uneven Distribution of and Shortages of Needed Providers

Maryland has shortages of certain types of healthcare providers as well as an uneven geographic distribution of healthcare and related services throughout the state. Health Provider Shortage Areas (HPSAs) are identified and tracked by the federal government. In 2010 Maryland had 43 primary care HPSAs with 375,146 people living in them. Per federal guidelines, it would take 239 providers working full time (40 hours per week) to meet their need for primary care providers (a population to practitioner ratio of 2,000:1.) HPSAs for primary care are concentrated mostly in the mid- and lower- Eastern Shore and Western Maryland regions. There are also similar and significant shortages of mental health and dental care providers in the state. HPSAs for mental health encompass the bulk of the Eastern Shore, Southern Maryland, and Western Maryland regions of the state. HPSAs for dental care are concentrated in the mid- and lower- Eastern Shore, Southern Maryland, and Western Maryland regions. These HPSAs are not specific to pediatric primary or specialty care.

In 2010, Maryland had 1.72 pediatricians per 1,000 children (compared to 0.98 nationally), 1,794 family practitioners, and 0.14 child and adolescent psychiatrists per 1,000 children (compared to 0.05 nationally.)[12]

In 2006, the Maryland Legislature created the Maryland Statewide Commission on the Shortage in the Healthcare Workforce. The Commission found that there are critical shortages in Maryland's current and future supply of 18 types of health care workers through 2014 (commonly needed by children with ASD and other DD) including physicians, pediatric dentists, registered and licensed practical nurses, mental health counselors, physical therapists, occupational therapists, nursing instructors, and pharmacists. Rural and underserved areas were thought to be at increased risk due to these shortages. The diagnosis of autism is made by a developmental specialist. This specialist could be a psychologist, psychiatrist, developmental-behavioral pediatrician, neurodevelopmental pediatrician, or an experienced pediatrician. In Maryland, these specialists are clustered in academic settings in the central region of the state with rare exception. There are approximately five sole diagnosticians outside of central Maryland. In addition, insurance barriers exist for diagnosticians categorized as mental health professionals, since for many private insurance carriers; out of pocket expenses for families are higher for mental health services than for somatic services.

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[12] The Catalyst Center. *State at a glance coverage and financing charts, Maryland.* Available at http://www.hdwg.org/catalyst/online-chartbook/bystate/tips=0&sources=0.

Medically Underserved Areas/Populations (MUA/Ps) are areas or populations designated by HRSA as having too few primary care providers, high infant mortality, high poverty and/or high elderly population. As of June 30, 2010, all but two of Maryland's 24 jurisdictions (e.g. Carroll and Howard counties) had at least one federally designated medically underserved area/population. Maryland currently has 49 federal medically underserved designations, 39 of which are MUAs and 10 of which are MUPs. Concentrated areas of MUA/Ps are found in Baltimore City, on the Eastern Shore and in Western Maryland.

Overall, Maryland is relatively well situated in terms of capacity to provide specialty and subspecialty pediatric medical care for children and families, if those families have access through transportation, time, and health insurance to receive care in the Central and Capital regions of the state. The Mid-Atlantic region has a relatively high population density compared to other areas of the U.S. and the area has a concentration of world class tertiary care facilities. Maryland families primarily access specialty services at the Johns Hopkins Medical Institutions, the Kennedy Krieger Institute, the University of Maryland Medical System, and Children's National Medical Center. OGPSHCN and other agencies within MDHMH provide a partial subsidy to the above institutions to support specialty care clinics, outreach specialty clinics, complex care management clinics, wrap around and enabling services. An obstacle to providing direct specialty care is the lack of availability of appropriate in-state pediatric specialists in the rural, lower population density areas (Southern, Western, and Eastern Shore regions.) Maryland families in those regions sometimes have access to facilities in the surrounding states, such as AI DuPont in Delaware, Georgetown University Hospital, Children's National Medical Center, and Howard University Hospital in Washington, D.C.; West Virginia University in West Virginia; Children's Hospital of Philadelphia, St Christopher's and the Shriner's Hospital for Children in Pennsylvania; and less frequently Inova Fairfax Hospital and the University of Virginia system in Virginia. This out-of-state access is based, among other things, on whether or not these institutions will accept a child's health insurance. Maryland's Department of Health and Mental Hygiene and the Maryland Medical Assistance Program have made efforts to work with these institutions and Medicaid programs in other states; however this does not always ensure access. For example, AI DuPont in Delaware used to have a contract to accept children insured through Maryland Medical Assistance, but this contract was recently not renewed, and families who have come to depend on specialty services there now find themselves without that care due to insurance barriers[13].

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[13] Office for Genetics and Children with Special Health Care Needs. *Meeting Notes for 10/18/2011 Eastern Shore Regional Local Health Department Meetings.* Available upon request from OGPSHCN.

F. Youth Transition to Adulthood

Key Findings

A key component of an effective system of care for CYSHCN with ASD or other DD is that youth with special health care needs receive the services necessary for a successful transition to adult life, including adult health care, work, and independence; Maryland ranks 40th in the nation on this indicator.

Only 29% of Maryland families of YSHCN aged 12 to 17 with emotional, behavioral, or developmental issues reported that their child received the services necessary to make appropriate transitions to adult health care, work, and independence.

During the 2010-2011 MCA (Maryland Commission on Autism) Listening Sessions, youth transition services were consistently identified by participants as being in the category of "what isn't working" in Maryland.

"Everything is so scattered that I feel like I am having to try to figure out what resources might be available for my daughter. Everyone I talk to tells me I have to talk to someone else. Why isn't there one place where I can call and find out what my daughter might be eligible for and help for me to try to get that assistance for her[?] When I called my county office, they told me I had to work with the state as they could not help me find services/assistance for my now adult (18 yr old) daughter who will graduate from high school in June 2010. Please make it easier for us to make sure we are accessing the proper resources and services to help our adult children with special needs (autism) know all possible options, whether Federal, state, or local to help them succeed as best they can in the adult world." -- Parent Respondent, 2010 Maryland Parent Survey when asked open-ended questions about what more was needed for CYSHCN in the state.

According to the 2009-10 NS-CSHCN, 36.8% of Maryland families of YSHCN aged 12 to 17 reported that their child received the services necessary to make appropriate transitions to adult health care, work, and independence (Table 15). Maryland ranked 40th in the nation on this core outcome. Successful achievement of this outcome and related indicators vary – YSHCN with E/B/D and those with mental retardation or DD are less likely than other CYSHCN to make appropriate transitions, have had their doctors discuss eventually seeing providers who treat adults, and have had discussions with doctors about changing health care needs.

Table 15. 2009-10 NS-CSHCN Indicators used to measure Transition *(Source: 2009-10 NS-CSHCN)*

Indicator	Nation %	Maryland %
Core Outcome #6: CYSHCN ages 12-17 who receive the services necessary to make appropriate transitions to adult health care, work and independence	**40.0%**	**36.8%** (ranked 40th in the nation)
Among CYSHCN with E/B/D Issues	28.9%	28.0%
Related Indicator: CYSHCN ages 12-17 whose doctors and other health care providers have discussed shift to adult providers	**13.6%**	**10.6%**
Among CYSHCN with E/B/D Issues	12.8%	5.6%
Related Indicator: CYSHCN ages 12-17 whose doctors and other health care providers have discussed youth's health care needs as he/she becomes an adult	**44.4%**	**45.3%**
Among CYSHCN with E/B/D Issues	40.1%	44.1%

Figure 27. 2010 Maryland Parent Survey Transition Indicators among Families with At Least One Child with Autism and Families with At Least One Child with any Special Health Care Need *(Source: 2010 Maryland Parent Survey)*

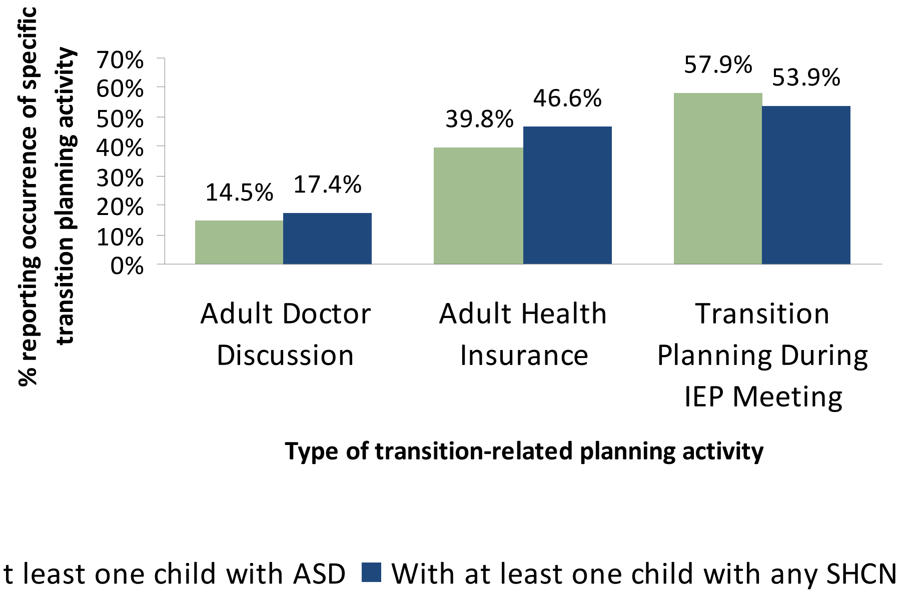

Figure 27 shows more recent data from the 2010 Maryland Parent Survey which indicate that, among respondents who have a YSHCN ages 13 years or older with ASD, 14.5% reported that at least one of their child's health care providers have discussed having their child see a doctor who treats adults (compared to 17.4% of respondents with children with any SHCN); 39.8% have considered how to obtain or keep health insurance coverage for their child as they become an adult (compared to 46.6% with any SHCN); and 57.9% reported having participated in transition planning as part of their child's IEP process (compared to 53.9% with any SHCN). Of those families who did participate in the development of a transition plan for their child, families of children with ASD are slightly more likely to report that the transition plan was specific to their child's needs and preferences (42.2%) than are families of children with any SHCN (39.1%), and are slightly less likely to report that they are satisfied with the transition services provided (26.3%) than are families of children with any SHCN (28.0%).

During the 2010-2011 MCA (Maryland Commission on Autism) Listening Sessions, youth transition services were consistently identified by participants as being in the category of "what isn't working" in Maryland. Participants in Southern Maryland noted the need to eliminate the divide between child and adult service systems for the creation of a seamless lifespan service delivery system; the lack of service options for transition aged youth with ASD; and difficulty in finding providers willing to treat youth and young adults with severely challenging behavioral and medical needs. These concerns were echoed in other Listening Sessions across the state, with other regions (Central and Eastern Shore) adding that there were simply not enough medical and other service providers to treat the increasing number of young adults with ASD, complicated by the lack of training and higher education to ensure a highly qualified workforce. It appears from these Listening Sessions that families of youth with ASD in Western Maryland may face the most difficult challenges as compared to other parts of the state due to an extreme shortage of transition supports in that area. The Commission has a Transition Age Youth Workgroup that has met regularly since the inception of the Commission and has plans to make formal recommendations for improving transition services by July 2012.

In contrast to the MCA findings, youth transition for individuals with DD was identified as a strength in the Central and Eastern Shore regions of the state according to the 2011 MCDD (Maryland Center for Developmental Disabilities) assessment activities (see Table 2). "Collaborative transition programs" were mentioned specifically, which may indicate that in those regions, organizations providing transition services to youth with DD may be collaborating more, which is having a positive effect for youth and families. Despite these positive mentions, Eastern Shore participants noted as a weakness that there was not timely information about youth transition. Transition issues were among the most common themes raised in the Central and Southern region MCDD community forums (see Table 3).

VII. Gaps in Knowledge

Key Findings

There are persistent gaps in knowledge in certain areas, including a clear accounting of the numbers and locations of key resources such as: primary and specialty medical care services for CYSHCN with ASD and other DD, behavioral support services, habilitative services, family support services, and community support services.

Every attempt was made to ensure that this needs assessment of the population of children and youth with ASD and other DD in Maryland was as complete and comprehensive as possible; however resource limitations including constraints on time, funding, and staff will most certainly have resulted in missed information. In addition, there are persistent gaps in knowledge in certain areas, including a clear accounting of the numbers and locations of key resources such as: health services including pediatric primary care providers who treat children with ASD and other DD; adult primary care providers who will treat adults with ASD and other DD; pediatric and adult specialty care providers, and behavioral support services; health related services including occupational, speech/language, and physical therapies; family support services such as respite care providers and child care providers who are willing and equipped to care for children with ASD and other DD, parent support groups, transportation services; community support services including recreation and day habilitation and vocation services. Knowing how many and how accessible these key resources are to families will help public, non-profit, and private organizations caring for individuals with special health needs (including children and youth with ASD and other DD) to appropriately target resources and staff to best serve the health, social, and community needs of children, individuals, and families.

VIII. Interim Conclusions

According to this broad analysis, across data sources and indicators, CYSHCN with ASD or other DDs in Maryland have poorer outcomes on health systems and other indicators than the general population of CYSHCN. This underscores the need to improve service systems for this vulnerable population. This needs assessment identifies significant regional and socioeconomic disparities within Maryland with regards to access to providers and services for CYSHCN with ASD and other DD. The data presented in the preceding sections of this needs assessment was used to generate a data-driven list of priorities needs for this target population. Stakeholders evaluated and ranked the list of generated priorities through several different mechanisms in different venues (online surveys, in-person meetings) until a definitive set of priority needs were identified for the entire state of Maryland and for each region of the state. These priorities are subsequently presented in the following sections of this document and are the priorities that will be addressed by the statewide plan to improve the systems of healthcare and related services for CYSHCN with ASD and DD in Maryland.

IX. Next Steps – Final Needs Assessment Activities and Statewide Planning

The above findings were used to generate a data-driven list of priority needs for Maryland CYSHCN with ASD and other DD. Stakeholders evaluated and ranked the list of priorities through several different mechanisms in different venues (online surveys, in-person meetings etc.) until a definitive set of priority needs were determined for the entire state and for each region of the state. These priorities as well as a description of how the highest priority needs were identified are presented here in the last section of this document, and are the priorities that will be addressed by the statewide plan to improve the systems of healthcare and related services for CYSHCN with ASD and DD in Maryland.

2011 Stakeholder Priorities Poll

Key Findings

High priority needs for Maryland CYSHCN with ASD and DD include access to needed therapies (including speech/language, occupational, physical, and behavioral therapies); youth transition to adulthood; training for school personnel; easy-to-use community-based services; and adequate health insurance and financing.

There are important regional differences in priority needs of CYSHCN with ASD and other DD in Maryland; in more rural areas, access to primary and specialty care, mental health services; and developmental screening and diagnostic services are crucial needs.

OGCSHCN and PPMD conducted an online poll of a diverse group of ASD and DD stakeholders (individuals with interest in and knowledge of Maryland's children and youth with ASD and other DD) to obtain their views about top priorities for this population in Maryland. Dissemination occurred by email to over 200 pre-identified Maryland stakeholders in late 2011. Stakeholders could then email the survey to additional interested parties. Responses were collected from December 1, 2011 to January 10, 2012. Findings from this survey should not be considered statistically representative as sampling was not random.

Respondents were asked to rank their top 5 priority needs (from a list of 22 possible priorities identified through this needs assessment) for Maryland CYSHCN with ASD and DD. There were a total of 351 initial respondents to the survey; of those, 241 respondents completed the survey according to the instructions providing usable responses for the analyses below for a completion rate of 69%. Rankings were then analyzed by region of the state and by stakeholder category. Table 16 below shows the rankings by region of the state. For more detailed analyses of this poll, including a breakdown of rankings by stakeholder category, please see the full report, available at: http://marylandcoc.com/uploads/2011_Maryland_Children_and_Youth_with_ASD_and_DD_Priorities_Poll_Results_Final_03.09.12.pdf.

Table 16 2011 ASD/DD Stakeholder Poll Rankings by Region

(Source: 2011 Maryland Children and Youth with ASD and DD Priorities Poll)

Priority Need	All Regions	Western	Capital	Southern	Central	Eastern Shore
Access to needed therapies	**1** (45.2%)	**1** (50.0%)	**2** (47.9%)	**2** (46.7%)	**1** (43.2%)	**1** (48.0%)
Youth transition to adulthood	**2** (37.3%)	**15** (12.5%)	**1** (56.3%)	**3** (40.0%)	**2** (37.8%)	**4** (32.0%)
Training - school personnel	**3** (35.3%)	**3** (37.5%)	**4** (35.4%)	**1** (50.0%)	**8** (29.7%)	**13** (20.0%)
Community-based easy-to-use services	**4** (32.4%)	**2** (43.8%)	**8** (29.2%)	**4** (33.3%)	**7** (31.1%)	**2** (36.0%)
Adequate health insurance and financing	**5** (29.9%)	**3** (37.5%)	**3** (39.6%)	**15** (16.7%)	**3** (37.8%)	**10** (20.0%)
Family Support and Advocacy	**6** (28.6%)	**10** (25.0%)	**6** (33.3%)	**6** (26.7%)	**6** (32.4%)	**11** (20.0%)
Access to child care and respite care	**7** (28.2%)	**5** (37.5%)	**7** (29.2%)	**13** (18.3%)	**5** (35.1%)	**7** (28.0%)
Recreation and leisure opportunities	**8** (28.2%)	**9** (25.0%)	**5** (35.4%)	**12** (21.7%)	**19** (4.1%)	**18** (12.0%)
Effective local-level cross-sector collaboration	**9** (26.1%)	**18** (6.3%)	**9** (25.0)%	**7** (26.7%)	**4** (36.5%)	**14** (20.0%)
Family training and education	**10** (22.4%)	**7** (31.3%)	**11** (20.8%)	**8** (25.0%)	**10** (20.3%)	**8** (24.0%)
Family/Professional Partnerships	**11** (21.6%)	**10** (25.0%)	**10** (22.9%)	**11** (23.3%)	**13** (14.9%)	**8** (24.0%)
Developmental screening and diagnostic services	**12** (20.7%)	**8** (31.3%)	**14** (14.6%)	**5** (28.3%)	**12** (16.2%)	**5** (28.0%)
Mental health treatment and services	**13** (17.8%)	**6** (31.3%)	**18** (8.3%)	**9** (23.3%)	**15** (13.5%)	**6** (28.0%)
Effective information dissemination	**14** (17.4%)	**18** (6.3%)	**16** (10.4%)	**14** (18.3%)	**11** (18.9%)	**15** (16.0%)
Effective state-level cross-sector collaboration	**15** (17.0%)	**18** (6.3%)	**13** (16.7%)	**18** (11.7%)	**9** (21.6%)	**20** (4.0%)

Access to primary and specialty health care	**16** (16.6%)	**14** (18.8%)	**15** (12.5%)	**10** (23.3%)	**18** (6.8%)	**3** (32.0%)
Training - medical and related services professionals	**17** (15.8%)	**12** (25.0%)	**20** (6.3%)	**16** (15.0%)	**14** (14.9%)	**15** (16.0%)
Medical Home	**18** (14.1%)	**21** (0.0%)	**12** (16.7%)	**20** (10.0%)	**17** (12.2%)	**17** (12.0%)
Access to transportation	**19** (13.3%)	**15** (12.5%)	**19** (8.3%)	**17** (13.3%)	**16** (13.5%)	**12** (20.0%)
Training - other public servants	**20** (10.4%)	**13** (18.8%)	**17** (10.4%)	**19** (11.7%)	**20** (4.1%)	**19** (8.0%)
Other needs	**21** (7.5%)					
Reducing disparities	**22** (5.8%)	**17** (6.3%)	**21** (4.2%)	**21** (6.7%)	**21** (4.1%)	**20** (4.0%)

As shown in Table 16, when results are aggregated to the state level, several top priorities clearly emerge, including access to needed therapies (including speech/language, occupational, physical, and behavioral therapies); youth transition to adulthood; training for school personnel; that services be located in communities and that they be easy to use; and that CYSHCN with ASD or other DD have adequate health insurance and financing to pay for needed services. There are significant differences as to which priorities are ranked highest in each region of the state. In less urban regions of the state, respondents from Southern Maryland, the Eastern Shore and Western Maryland placed a greater emphasis on priority needs such as access to primary and specialty care; mental health services; developmental screening and diagnostic services; and services that are located in communities and are easy to use.

A. 2012 Strategic Planning Meetings

Key Findings

Highest priority needs for CYSHCN with ASD and DD statewide are:

-Access to needed therapies

-Adequate health insurance and financing (including diagnosis and referral)

-Easy-to-use community-based services

-Training for school and child care personnel

-Youth transition to adulthood

There are important regional differences in priority needs of CYSHCN with ASD and other DD in Maryland; in more rural areas, access to primary and specialty care, mental health services; and developmental screening and diagnostic services are crucial needs.

All regions identified training for families and providers as a strategy to address priorities for Maryland CYSHCN with ASD and DD; most regions also identified strategies such as working with service providers to maximize insurance reimbursement, developing integrated service centers, involving health insurers in problem-solving and strategizing, and providing informational hubs for families and providers to facilitate access to information and services.

The above findings from this needs assessment were used (in conjunction with more detailed regional analyses) to develop content for five regional strategic planning meetings throughout the state. Region-specific meetings were held in the spring and summer of 2012 in Southern Maryland, Western Maryland, the Eastern Shore, the Capital Area, and a statewide meeting was held in Central Maryland. At each meeting, between 25 and 80 CYSHCN stakeholders (including parents, local pediatricians, local and state Health Department representatives, local and state special education representatives, community and family service group representatives, support and advocacy group and agency representatives) gathered for a day-long learning and strategic planning session. Group learning and activities led participants to identify the top priorities statewide for children and youth with Autism Spectrum Disorders (ASD) and other Developmental Disabilities and to develop goals and action steps to address those priorities. Participants used data presentations and handouts based on this needs assessment to inform the prioritization and planning process. For more information on the strategic planning process or to see individual meeting summaries as well as data presentations and handouts for each region, please visit http://www.marylandcoc.com/ASD_DD_Planning_Grant.html.

The priorities identified and agreed upon through this needs assessment process, which includes the strategic planning meetings, will be the focus of a statewide plan to improve the systems of health care and related services for CYSHCN with ASD and other DD in Maryland. Table 17 shows the top priorities to be addressed for each Maryland region as well as for the state as a whole. For example, according to the Stakeholder Poll and the statewide strategic planning meeting findings, Central Maryland's priorities are the same as the statewide priorities.

Table 17 Summary of Top 5 Priorities for Maryland Children and Youth with ASD/DD by Region *(X = Priority for Region)*

	Statewide (& Central Maryland)	**Western Maryland**	**Capital Area**	**Southern Maryland**	**Eastern Shore**
Access to needed therapies	X	X (+diagnosis and referral)	X (+diagnosis and referral)	X	X
Adequate insurance and financing	X (+diagnosis and referral)	X	X	X	X
Easy-to-use community-based services	X	X		X	X
Training for school personnel	X (+child care personnel)	X (+child care personnel)	X (+ families and health care professionals)	X (+child care personnel)	
Mental health treatment and services		X		X	X
Access to primary and specialty care				X	X
Youth transition to adulthood	X		X		
Access to child care, before and after school care, and respite care			X		
Family support and advocacy				X	

All regions identified access to needed therapies (including speech/language, occupational, physical, and behavioral therapies) as a top priority. Two regions, Western Maryland and the Capital Area, added diagnosis and referral as a key component of access to therapies. All of the regions also identified adequate insurance and financing as a top priority, with diagnosis and referral being a key component of this priority statewide. Easy-to-use community-based services and training for school and child-care personnel were the priorities identified to be addressed statewide as well as for three regions of the state; additionally mental health services were identified to be addressed by three regions. The statewide plan will incorporate all state-level and region-level priorities presented in Table 17.

Once top priorities were agreed upon, meeting participants strategized as to how to improve service systems in Maryland around these priorities. Table 18 below summarizes the strategies identified; the identified strategies will serve as a starting point in developing a statewide plan to improve the systems of health care and related services for CYSHCN with ASD and other DD in Maryland.

Table 18. Summary of Strategies Identified to Address Priority Needs for Maryland Children and Youth with ASD/DD by Region (*X = Strategy suggested by the region)*

	Statewide (& Central Maryland)	Western Maryland	Capital Area	Southern Maryland	Eastern Shore
Training and provision of educational resources through various methods (for families and providers)	X	X	X	X	X
Educate and assist providers how to maximize reimbursement		X	X	X	X
Integrated Centers for Needed Services	X	X	X	X	
Outreach to health insurers		X	X	X	
Informational Hubs	X	X		X	
Resource Navigator services		X	X		

Child Care Personnel Training	X	X	X		
Offer satellite space to providers or other incentives to attract providers				X	X
Partner with local colleges and universities	X			X	X
Family financial assistance through:			X	X	
Educating families about existing opportunities				*X*	
Changing eligibility requirements from income-based to diagnosis-based			*X*		
Creation of a Catastrophic Relief Fund				*X*	
Telemedicine					X
Specialty Clinics	X				X
Build networks between providers	X		X		
Build networks of families and providers	X		X		
Leverage health care reform to include needed services in Essential Health Benefits	X				
Develop statewide standards and guidance for youth health care transition	X				
Hold a statewide symposium on Youth Health Care Transition	X				

All of the regions identified training for families and providers as a strategy to address priorities for Maryland CYSHCN with ASD and DD, Most of the regions also identified other strategies such as: 1) working with service providers to maximize insurance reimbursement; 2) developing integrated service centers; 3) involving health insurers in problem-solving and strategizing; and 4) providing informational hubs for families and providers to facilitate access to information and services.

X. Final Conclusions

There are major gaps in access to needed primary and specialty health care services and as a result, Maryland children and youth with ASD and/or emotional, behavioral or developmental issues have high rates of delayed or unmet needs for health care and related services. Additionally, their families have high rates of delayed or unmet needs for family support services, especially poorer children and families and those in rural regions of the state. Certain Maryland jurisdictions (Baltimore City and many Eastern Shore and Western Maryland counties) and racial/ethnic groups (African American and Hispanic) have disproportionately high rates of child poverty. In the 2010 Maryland Parent Survey, services not covered or inadequately covered by insurance noted most frequently were: therapies (such as speech therapy and behavioral therapies), mental health services, testing and evaluations, and dental care. In the 2011 PPMD Parent Focus Groups, parents of children with ASD and other DD reported their child’s private health insurance was not adequate to cover needed medical and therapy expenses. Effective care coordination (which includes help with coordination of care and satisfaction with communication among providers and with schools if needed) is especially important for children with developmental issues; in Maryland, CYSHCN with emotional, behavioral or developmental issues are less likely to have effective care coordination when needed (37%) than are CYSHCN in general (42%).

Delayed and unmet needs for children and youth with ASD and DD are just one example of many difficulties faced by children and families. Caring for CYSHCN has profound logistical, financial and emotional impacts on families. Many families find it necessary to change their work hours or to stop working in order to care for their child; parents frequently turned down higher paying positions or career-advancing promotions because of the need to maintain flexibility in their work schedules in order to care for their children with ASD and other DD. Over half of CYSHCN in Maryland with emotional, behavioral or developmental issues do not have adequate health insurance; 31% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that they spend between $1000 and $5000 per year on out-of-pocket spending for their child’s medical care; 21% spend over $5000 per year. Experience with challenging behaviors is common among children with ASD and DD; 24% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that their child has had problems with anger/conflict management; 23% report problems with depression; and

22% report problems with bullying. Only half of Maryland CYSHCN with emotional, behavioral, or developmental issues have services that are community-based and easy-to-use. Families in Western and Southern Maryland and on the Eastern Shore have considerably less access to community-based, easy-to-use services. Youth and young adults with ASD and DD and their families need appropriate supports for the transition from youth to adulthood, yet only 29% of Maryland families of YSHCN aged 12 to 17 with emotional, behavioral, or developmental issues reported that their child received the services necessary to make appropriate transitions to adult health care, work, and independence.

Families, youth, educators, medical and other providers and policymakers need training on how to establish and maintain effective family-professional partnerships in order to have the best possible health, educational and life outcomes for CYSHCN with ASD and DD.

The results of this needs assessment indicate that the highest priority needs to be addressed for CYSHCN with ASD and DD statewide related to health care and related services are:

- Access to therapies such as behavioral, speech/language, occupational, and physical therapies that are necessary in treating ASD and/or DD.
- Adequate health insurance and financing to pay for all needed health and related services for children with ASD and DD, including diagnosis and referral.
- Needed services for children and youth with ASD and DD are community based and are organized so that families can use them easily
- Training for school and child care personnel in how to meet the needs of children and youth with ASD and other DD.
- Youth with ASD and DD receive the services necessary to make transition to all aspects of adult life, including adult health care, work, and independence.

There are important regional differences in priority needs of CYSHCN with ASD and other DD in Maryland; in more rural areas, access to primary and specialty care, mental health services; and developmental screening and diagnostic services are crucial needs. All regions identified training for families and providers as a strategy to address priorities for Maryland CYSHCN with ASD and DD; most regions also identified strategies such as working with service providers to maximize insurance reimbursement, developing integrated service centers, involving health insurers in problem-solving and strategizing, and providing informational hubs for families and providers to facilitate access to information and services.

These needs assessment and strategic planning activities form the basis for development of a comprehensive statewide plan for Maryland to improve the system of health care and related services for children and youth who have ASD and other DD. Project partners including OGPSHCN, PPMD, the Maryland Commission on Autism, the Maryland Center for Developmental Disabilities and others will draft a plan based on the findings from the various needs assessment activities presented here. The draft plan will be disseminated across the state, and regional feedback meetings will be held during the spring and summer of 2013. Stakeholders at these meetings will evaluate and revise the draft plan. Project partners will then finalize the plan and use it to apply for additional funding from the federal Maternal and Child Health Bureau of the Health Resources and Services Administration to implement the plan. Regardless of the outcome of that application, project partners will disseminate the plan widely across the state, promote and support adoption and implementation of plan priorities and strategies, and incorporate plan priorities and strategies into ongoing partner organization goals and activities.

Table 19. Glossary of Acronyms

AAP	American Academy of Pediatrics
ACA	Patient Protection and Affordable Care Act
ADDM	Autism and Developmental Disabilities Monitoring Network
ASD	Autism Spectrum Disorder
COC	Maryland Community of Care Consortium for CYSHCN
CSAC	Community Services for Autistic Adults and Children
CSHCN	Children with Special Health Care Needs
CYSHCN	Children and Youth with Special Health Care Needs
SHCN	Special Health Care Needs
DD	Developmental Disabilities
DJS	Department of Juvenile Services
E/B/D	Emotional, Behavioral, or Developmental
EPSDT	Early Periodic Screening, Diagnosis, and Treatment
FPL	Federal Poverty Level
FQOL	Family Quality of Life
HPSA	Health Provider Shortage Area
HRSA	Health Resources and Services Administration
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
MASS	Maryland Autism Services Survey
MCA	Maryland Commission on Autism
MCDD	Maryland Center for Developmental Disabilities

MCHB	Maternal and Child Health Bureau
MCHIP	Maryland’s Children’s Health Insurance Program
MCHP	Maryland Children’s Health Program
MDHMH	Maryland Department of Health and Mental Hygiene
MSDE	Maryland State Department of Education
MUAs	Medically Underserved Areas
MUPs	Medically Underserved Populations
NSCH	National Survey of Children’s Health
NS-CSHCN	National Survey of Children with Special Health Care Needs
OGPSHCN	Office for Genetics and People with Special Health Care Needs
PPMD	The Parent’s Place of Maryland
SAHIE	Small Area Health Insurance Estimates
SHCN	Special Health Care Needs
YSHCN	Youth with Special Health Care Needs