

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
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TABLE OF CONTENTS

	Page
Executive Summary	4
Introduction	7
Target Population / Data Sources	8
<i>Use of Proxy Groups</i>	8
General Maryland Characteristics.....	10
Prevalence and Incidence of ASD and other DD among Maryland Children	13
Autism Spectrum Disorder.....	13
Other Developmental Disabilities.....	13
Prevalence of Autism, Developmental Delay and Intellectual Disability Among Maryland Special Education Students	14
Demographic and Other Characteristics of ASD and other DD Child Populations	19
Race/ethnicity and Age.....	19
Socioeconomic Status.....	20
Experience with Challenging Behaviors.....	22
Unmet Needs for Medical Care.....	23
Unmet Needs for Family Support Services.....	26
Maryland Center for Developmental Disabilities Needs Assessment	28
Maryland Commission on Autism	31
Core Outcomes/Key Components for an Effective System of Care	34
Family and Professional Partnerships and Satisfaction with Care and Services.....	34
<i>Family and Professional Partnerships</i>	35
<i>Satisfaction with Care and Need for and Adequacy of Services</i>	36
Medical Home.....	40
<i>Usual Source of Care</i>	41
<i>Care Coordination and Impact on Families</i>	41
Adequate Insurance and Financing.....	44
<i>Uninsurance among Maryland Children</i>	45
<i>Uninsurance among Maryland Children with ASD and other SHCN</i>	49
<i>Adequacy of Insurance Coverage</i>	50
Developmental Screening.....	53
Easy-to-Use Community-Based Services.....	56
<i>Difficulty “Navigating the System”</i>	57
<i>Transportation</i>	58
<i>Uneven Distribution of and Shortages of Needed Providers</i>	59
Youth Transition to Adulthood.....	61
Gaps in Knowledge	63

Interim Conclusions.....	64
Next Steps – Final Needs Assessment Activities and Statewide Planning.....	64
2011 Stakeholders Priorities Poll.....	65
2012 Strategic Planning Meetings.....	67
Final Conclusions.....	70
Glossary of Acronyms	72

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 priority 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 Assessment¹ 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 report².

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 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.

¹ 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>

² <http://www.census.gov/did/www/sahie>

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 report³ 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.

³ 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.

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.⁴

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 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.)

⁴ Maryland Commission on Autism (2011). *Interim Report on Activities, Findings and Recommendations*. Available at http://dhmh.maryland.gov/autism/pdf/2011/Autism_Report.pdf

Figure 1. Maryland Counties and Regions



From 2000 to 2010, the state's poverty rate increased from 7.4% to 9.7%⁵. 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.⁶

⁵ 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/saie/index.html>

⁶ 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)

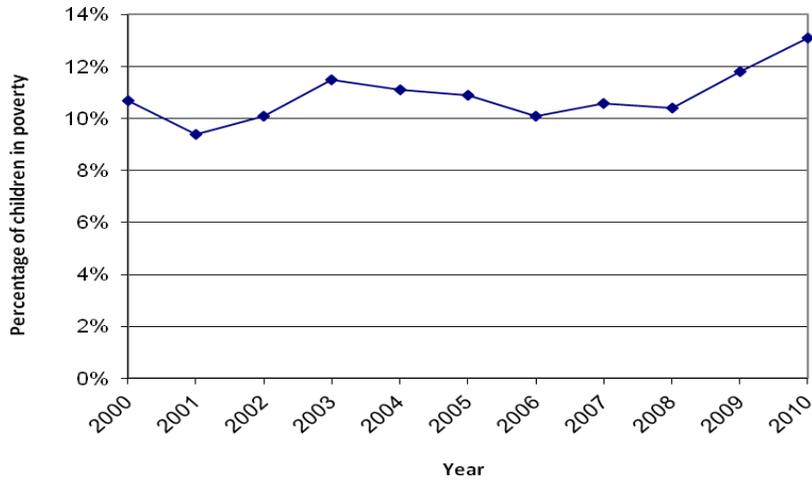
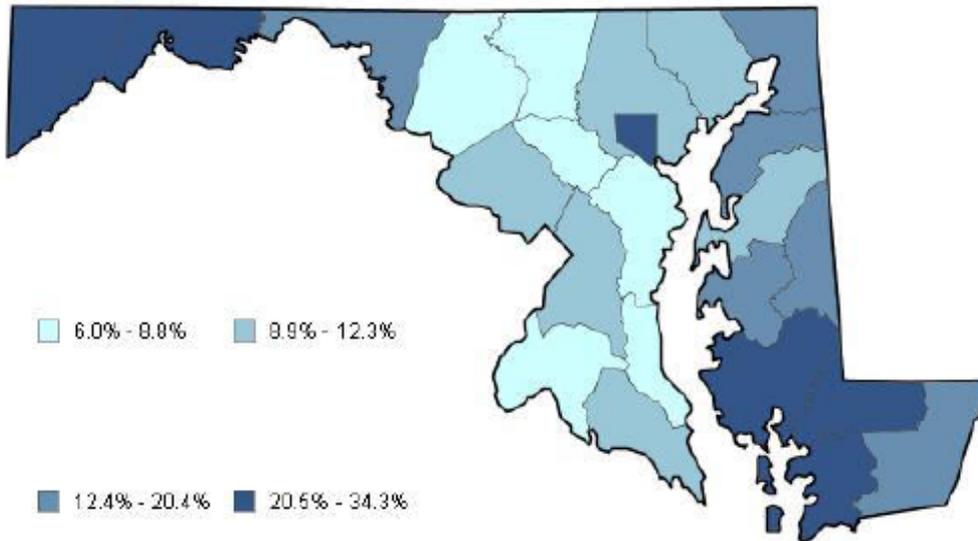


Figure 3. Maryland Child Poverty Rates 2010 (Source: Advocates for Children and Youth KIDS COUNT Data Center)



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.⁷

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%

⁷ 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.

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.)⁸ 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.⁹

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 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, 2004¹⁰ 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 to 21 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,

⁸ 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).

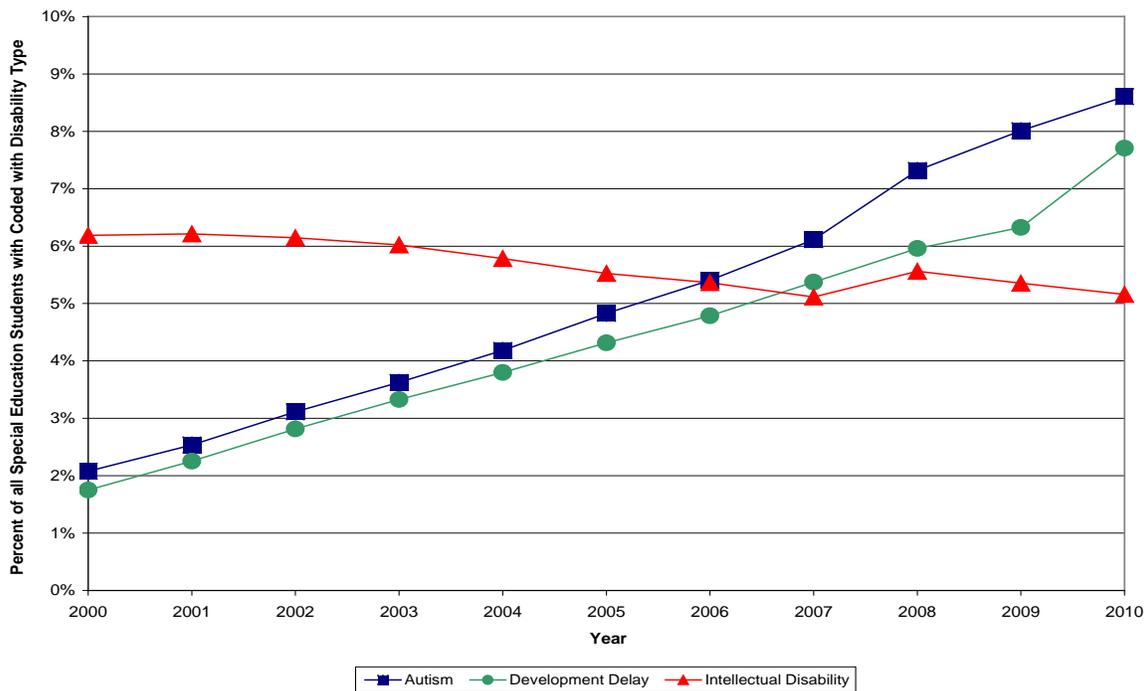
⁹ Lee, Li-Ching (2010) *A review of update prevalence of autism spectrum disorders*. Presented at the Maryland Autism Commission meeting, January 12, 2010. Accessed on 4/18/11 at http://dhmh.maryland.gov/autism/pdf/2010/ASD_prevalence_MD_Autism_Commission_1-12-2010.pdf.

¹⁰ Maryland Autism Commission 01/12/2010 Meeting Minutes. Available at <http://dhmh.maryland.gov/autism/pdf/2010/Jan2010.pdf>

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 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)

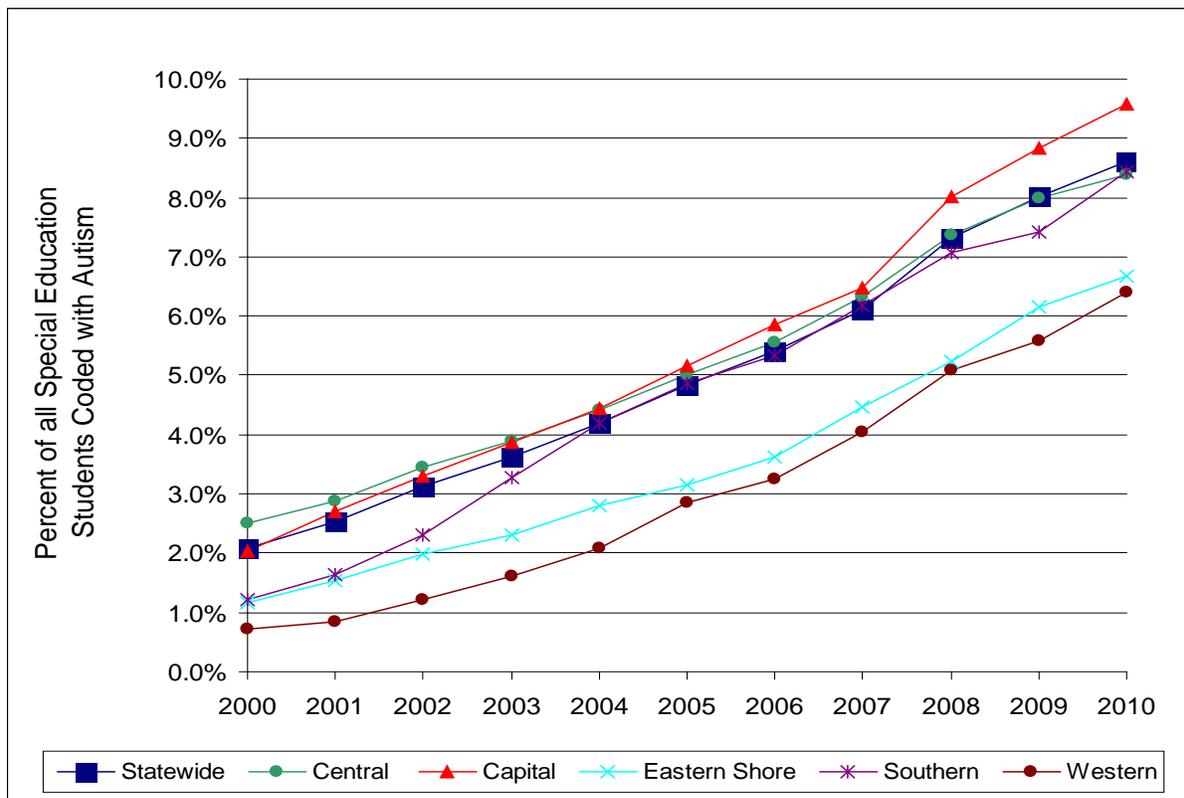


An examination of the MSDE data also reveals a growing trend of children in the developmental delay category. Of the 110,925 students receiving special education services in 2000, 1,943 (1.8%) were categorized as having a developmental delay. By 2010, the number of students receiving special education 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)

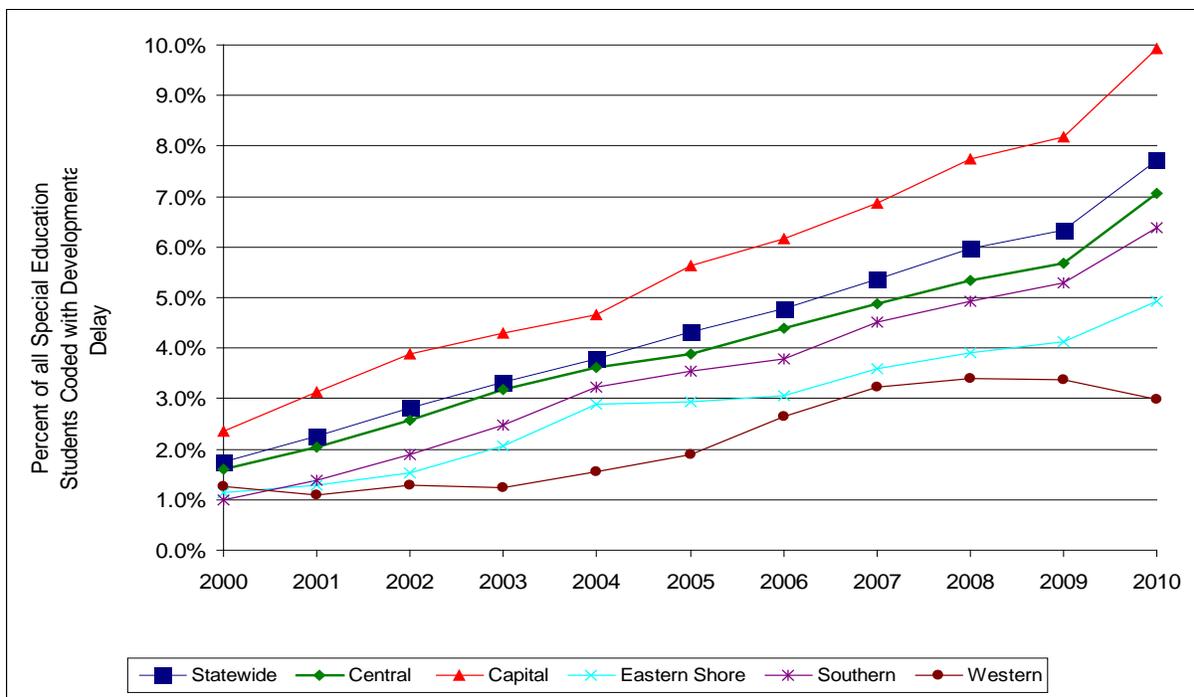


Figure 7. Maryland Rates of Special Education Students Ages 3 to 21 Years Coded with Intellectual Disability by Region, 2000 to 2010 (Source: Maryland State Department of Education, Special Education Data)

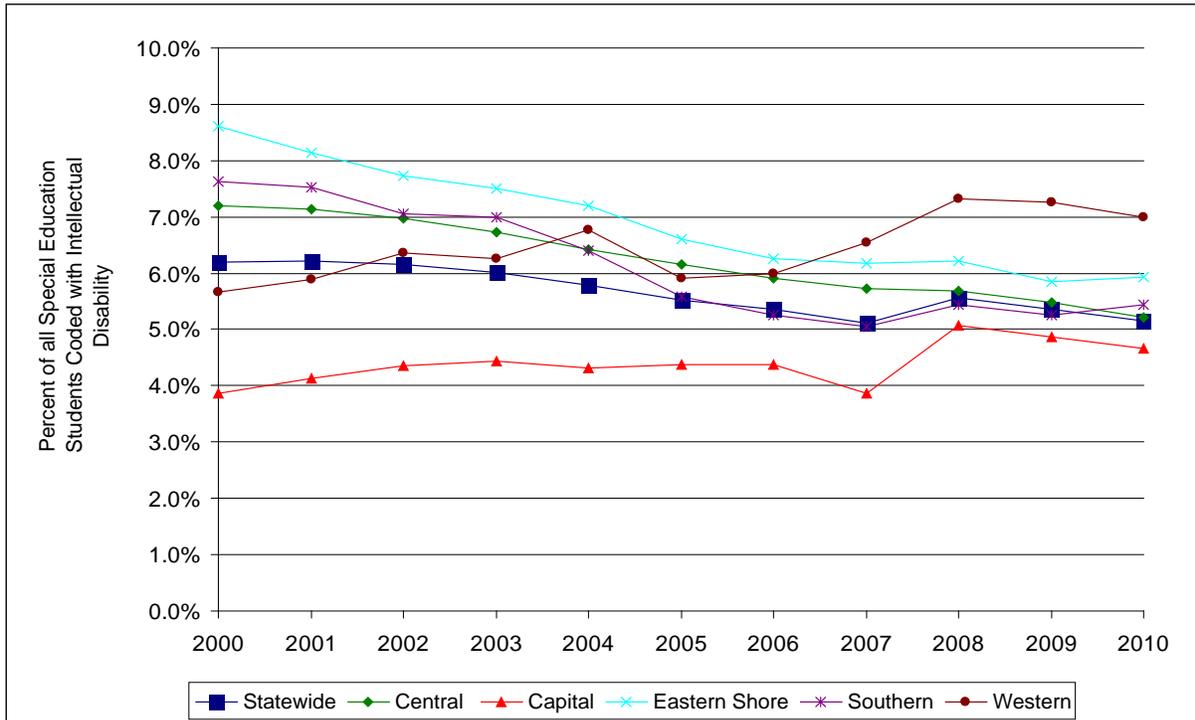


Figure 7 displays Maryland rates of special education students ages 3 to 21 years coded with intellectual disability by region from 2000 to 2010 which shows some variation in rates throughout the state. Statewide, there was an overall decline in children coded with intellectual delay during this 10 year 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.

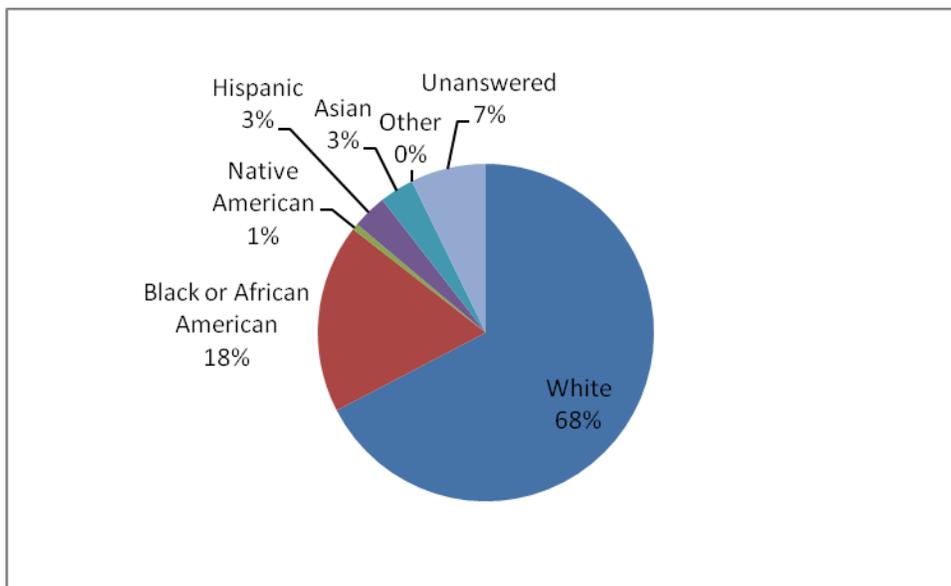
24% of families with CYSHCN with ASD who responded to the 2010 Maryland Parent Survey report that their child has had problems with anger/conflict management; 23% report problems with depression; and 22% report problems with bullying.

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)

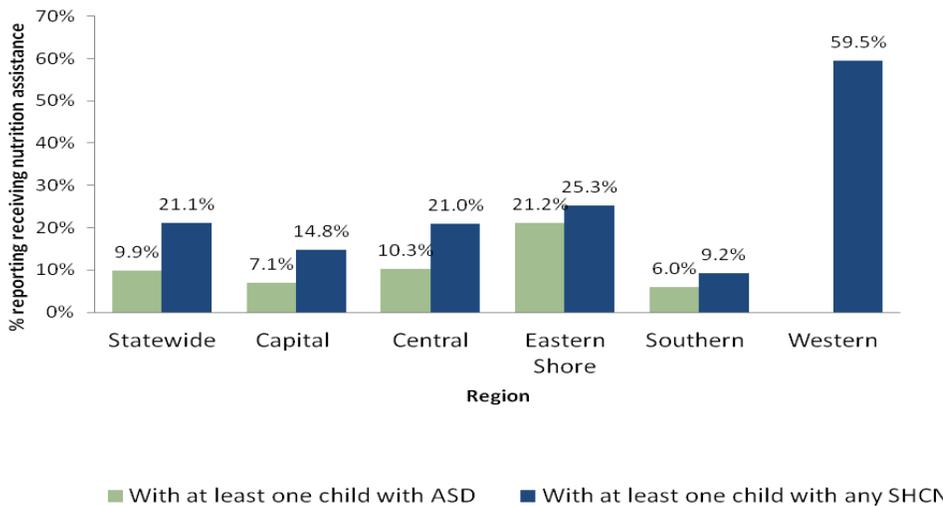
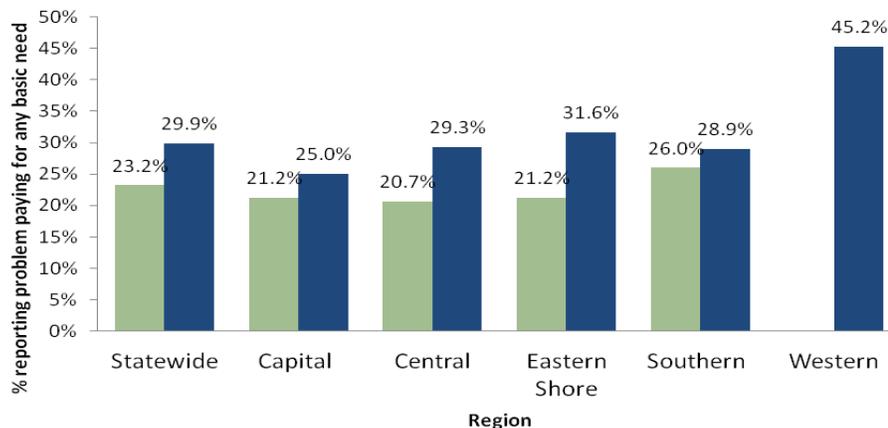


Figure 10. Difficulty Paying for Basic Needs among Families of Children with ASD and Families of Children with any SHCN (Source: 2010 Maryland Parent Survey)



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 Maryland¹¹ 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)

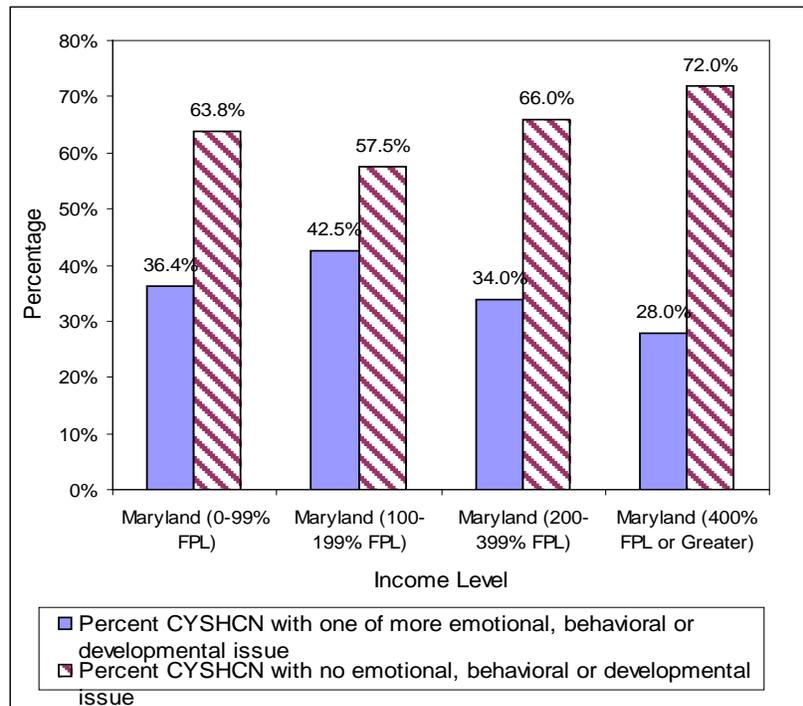


Figure 11 shows the percentage of CYSHCN in Maryland who have one or more E/B/D issue (this category is being used as a proxy for developmental disabilities) and those without an issue in different family income brackets. CYSHCN with one or more E/B/D issue are more likely to live in poor families. Taking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

¹¹ 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.

Figure 12. Severity of Condition among CYSHCN with E/B/D Issues in Maryland
 (Source: 2005-06 NS-CSHCN)¹²

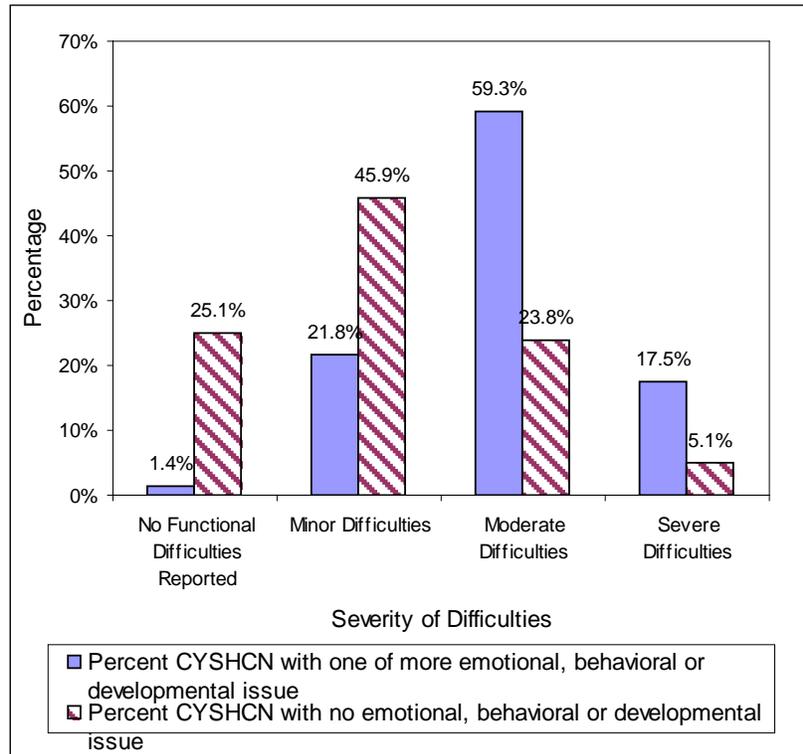


Figure 12 shows the parent-rated severity of difficulties caused by their child’s health problems. Families of CYSHCN with one or more E/B/D issue are more likely to rate the child’s condition as moderate (59.3%) or severe (17.5%) than are families of CYSHCN without E/B/D issues (23.8% moderate and 5.1%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

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.)

¹² This question is asked differently in the 2009-10 NS-CSHCN. Therefore, data from the 2005-06 NS-CSHCN is used.

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%).

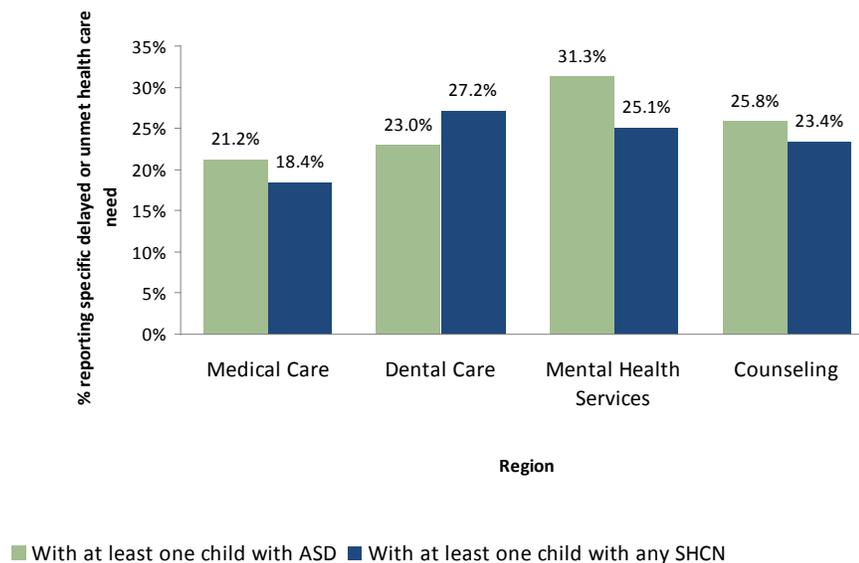
Data from the 2011 Survey of Pathways to Diagnosis and Services indicate that, nationally, 9 out of 10 school-aged CSHCN children with ASD use one or more healthcare services/therapies to meet their developmental needs. Just over one half of school aged CSHCN with ASD use three or more of the eight services 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.¹³

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).

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

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.

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)

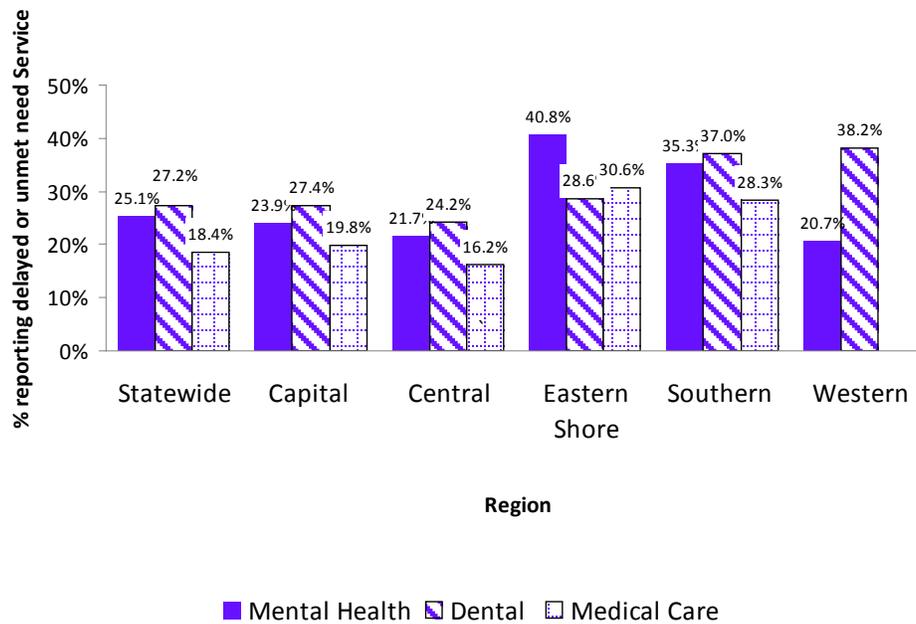


Figure 14 shows regional differences in types of delayed care or unmet needs for health care services among families of children with any SHCN¹⁴. The Eastern Shore, Southern Maryland, and Western Maryland have higher rates of unmet needs across types of services than do the Central or Capital regions 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' 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,

¹⁴ 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.

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)

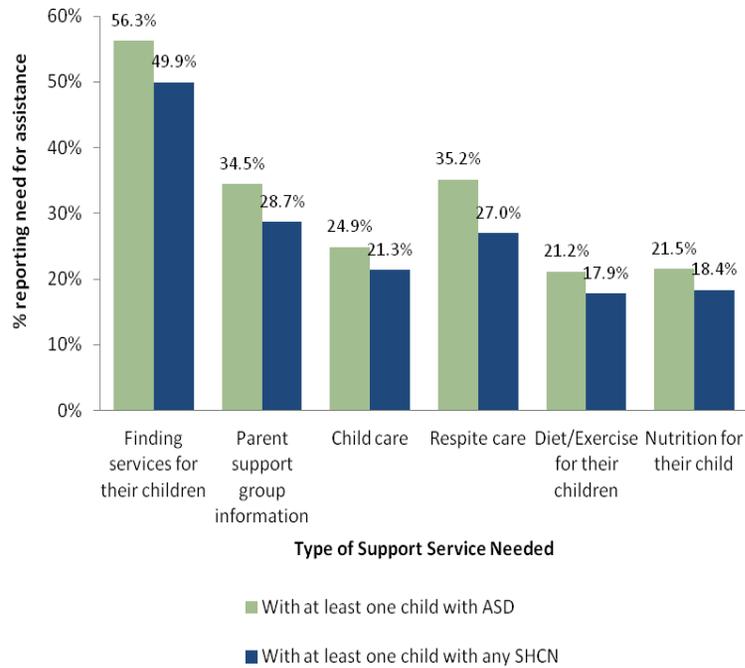
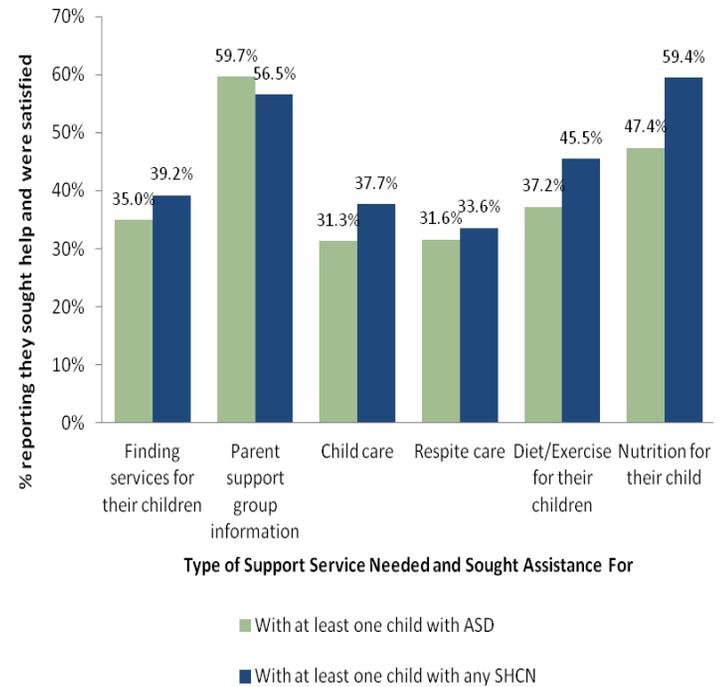


Figure 16. Reported Satisfaction with Assistance for Specific Types of Needed Family Support Services among Families of Children with ASD and Families of Children with any SHCN in Maryland (Source: 2010 Maryland Parent Survey)



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
<p style="text-align: center;">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)</p>	<ul style="list-style-type: none"> -Infants and Toddlers Program (early intervention) -Collaborative Transitioning Program -Improved communication among agencies -Supportive advocacy groups (i.e. Chesapeake Voyagers; Family Navigators, Shore Power) 	<ul style="list-style-type: none"> -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
<p style="text-align: center;">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.)</p>	<ul style="list-style-type: none"> -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 	<ul style="list-style-type: none"> -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.

Region (location and participant details)	Strengths	Weaknesses
	-Creative use of funding and fostering community collaborations	
<p>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.)</p>	-Transportation (portions of the region have access to Metro Access - PG County)	<p>- Unreliable Transportation (increasing safety concerns, lack of training of Metro Access staff, unreliable transportation, increasing cost)</p> <p>-Lack of dental and mental health care and services</p> <p>-Lack of respite care</p>
	<p>-Infants and Toddlers (significant improvement due to community collaboration over the last 10 years)</p> <p>-Transition Fairs</p>	
<p>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, 12% were individuals with disabilities and 4% were members of the general public)</p>	<p>-Transportation exists</p> <p>-Collaborative Transition Program</p> <p>Advocacy groups (CSACs, others)</p> <p>-Families are experienced and well-informed about DD system</p> <p>-Improvements in collaboration and communication have led to communities of practice working well together.</p>	<p>-Lack of reliable and affordable transportation</p> <p>-Information for families need to be consistent and reliable</p> <p>-Limited funds</p> <p>-DD system is complex and intimidating and discouraging for people with DD to apply for services and supports</p> <p>-Lack of mental health services, particularly for individuals with dual diagnoses</p> <p>-Need for more respite care.</p>

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 PPM. 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.

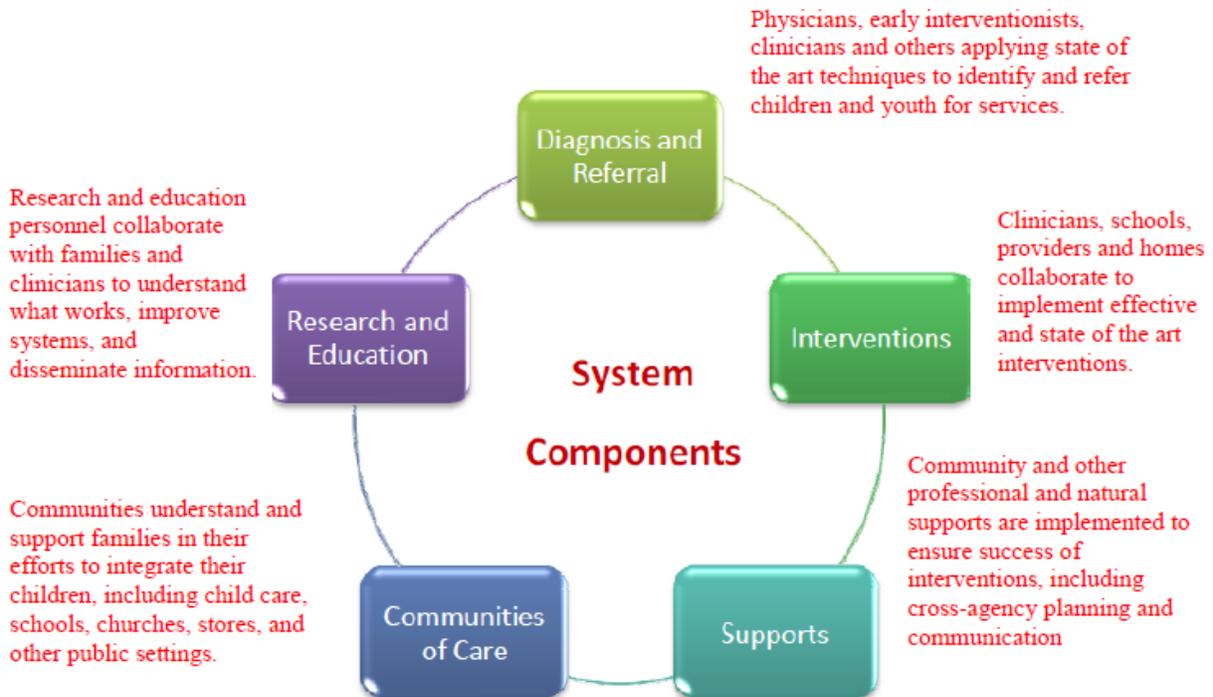
The Maryland Commission on Autism identified five cross-cutting themes for improving services for individuals with ASD – Access; Quality; Communication, collaborations and partnerships; Training, professional development and dissemination; and Funding.

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 Maryland¹⁵. 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 Family/Professional Partnerships and Medical Home; “Supports” and “Communities of Care”

¹⁵ 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.

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)



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 37 nd 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.¹⁶

Satisfaction with Care and Adequacy of Services among Families with ASD

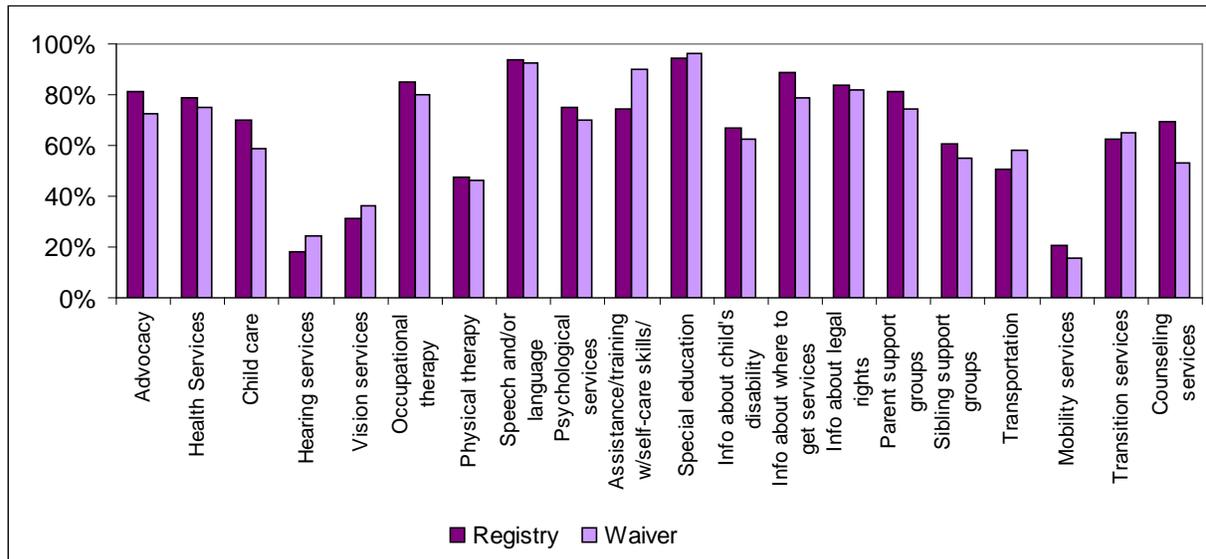
In terms of satisfaction with the services provided, the 2010 Maryland Parent Survey found that 47.2% of parents of CYSHCN are very satisfied with their child's medical care (41.9% among parents of children with ASD), and almost 40% are somewhat satisfied (45% among parents of children with ASD). This 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

¹⁶ 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

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.

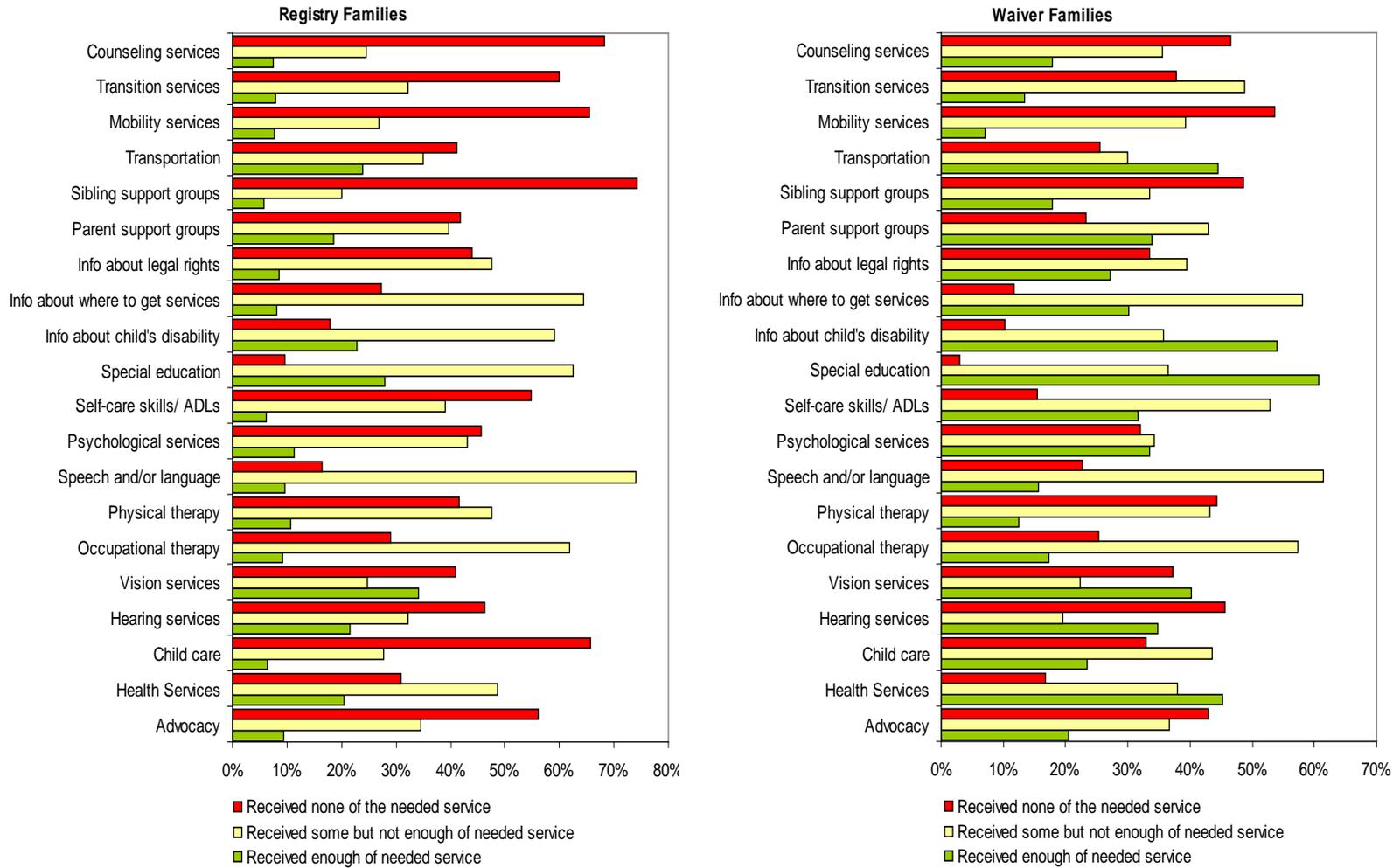
Figure 18. Need for Services among Families on the Autism Registry and Families Receiving Autism Waiver Services (Source: 2009 Maryland Autism Services Survey)



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 28 th 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.¹⁷

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 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.¹⁸

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.)¹⁹ 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

¹⁷ American Academy of Pediatrics.

¹⁸ Hand, L (2011). *Medical home setting lowers out-of-pocket costs*. Medscape, October 17, 2011. Available at <http://www.medscape.com/viewarticle/751586>

¹⁹ 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>.

by name as providing good care coordination, including Children's Medical Group in Western Maryland and Dr. Kerisedes in Calvert County.

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.

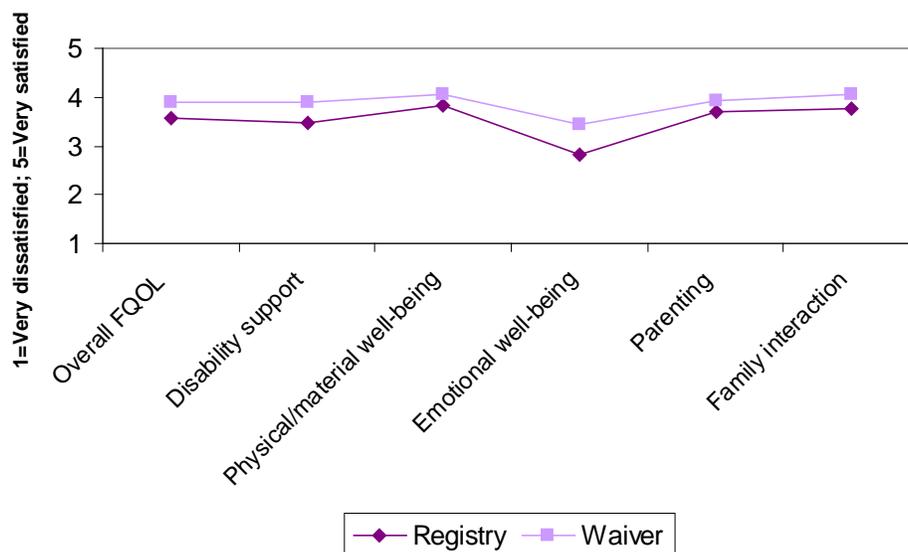
More recent data from the 2010 Maryland Parent Survey support the above finding. Among families of CYSHCN with ASD, a higher percentage (41%) reported that they found it necessary to change their work hours or to stop working in order to care for their child as compared to families of children with any 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.²⁰

²⁰ 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

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.

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 25 th 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%
Related 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.

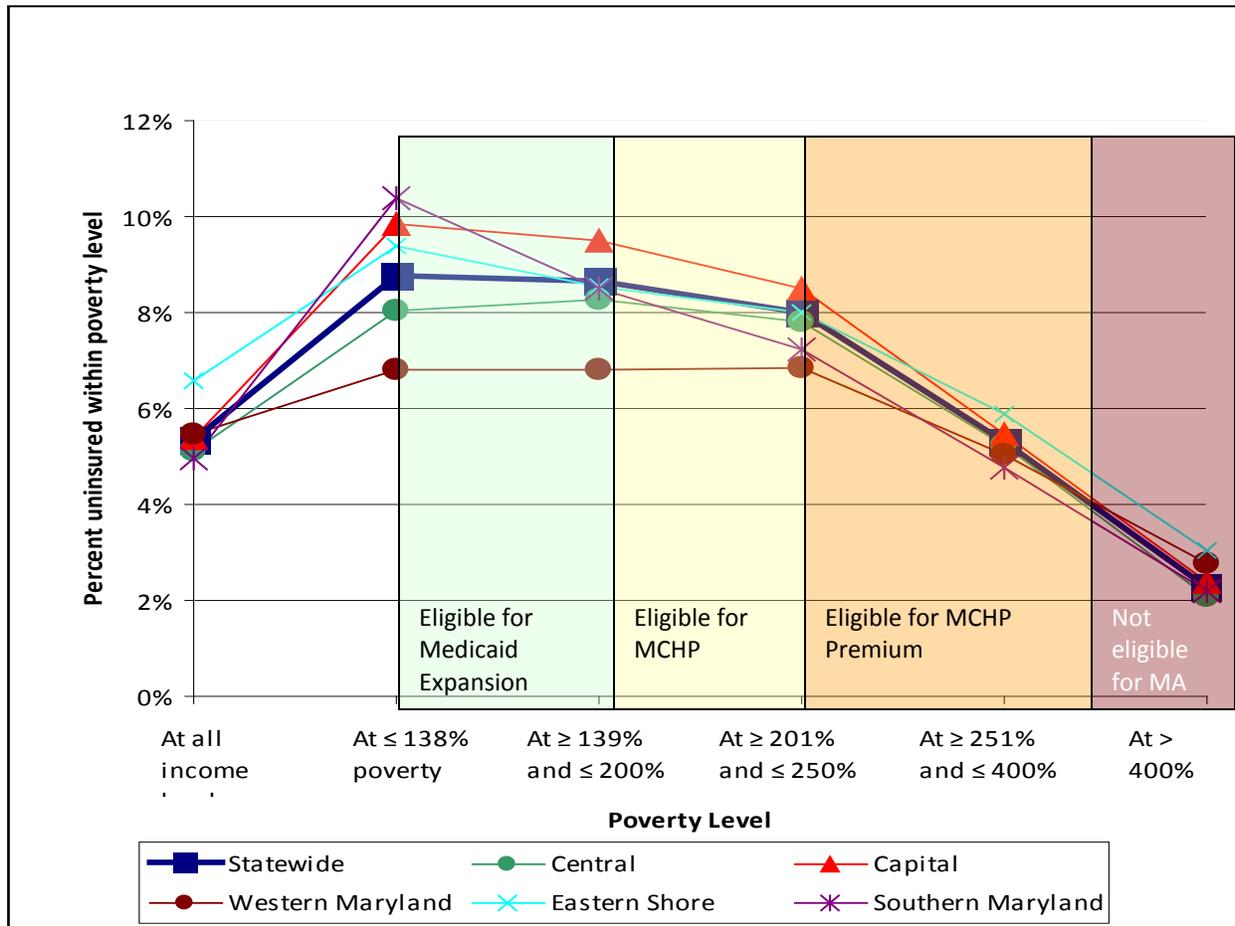
Uninsurance among Maryland Children

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 poverty²¹, allows states to include 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

²¹ U.S. Census Bureau. (2011). *Small Area Health Insurance Estimates*. Available at <http://www.census.gov/did/www/sahie/data/2009/tables.html>

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%).

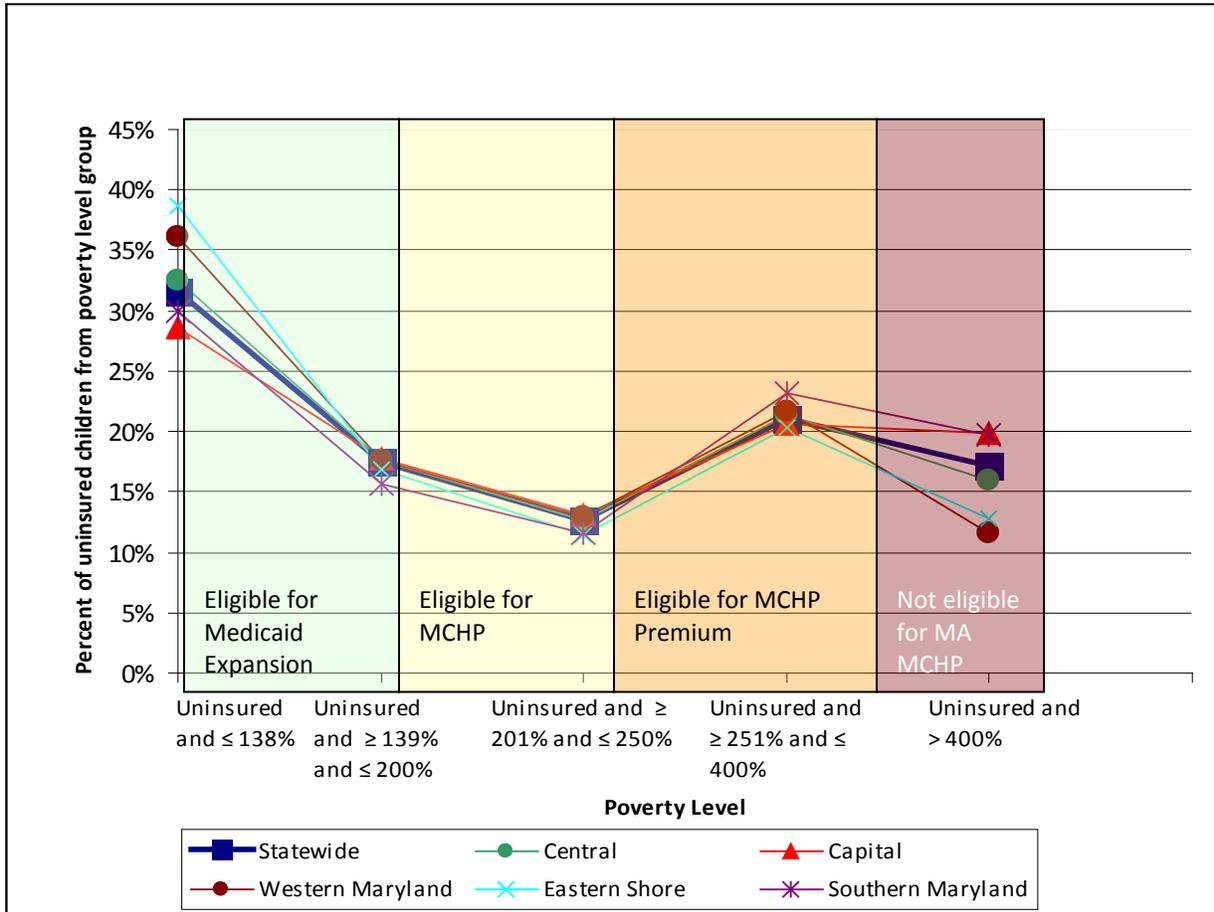
There is some regional variance within the state for children’s uninsurance rates. Southern Maryland has the highest rate of uninsurance among children at or below 138% poverty (10.4%) but drops below the statewide rates among children in different categories of poverty. Uninsured rates in the Capital 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.

As 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%

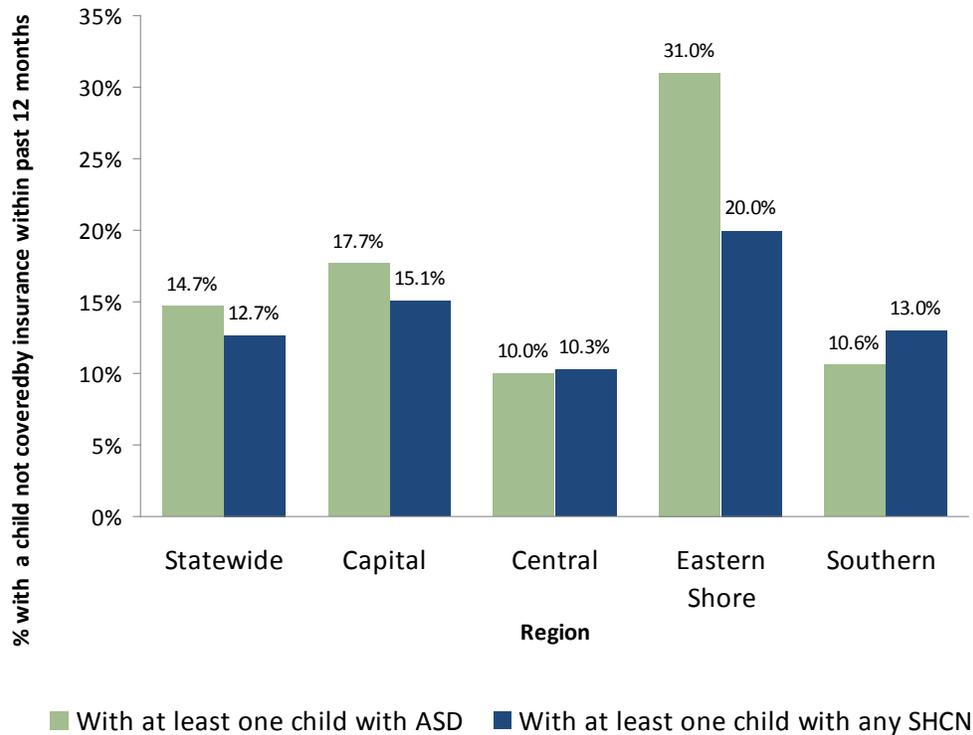
poverty than in the Capital region (28.6%); conversely both the Eastern Shore (12.7%) and Western Maryland (11.6%) have far fewer uninsured children living above 400% poverty compared to Southern Maryland (19.7%) and the Capital Region (19.9%).

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)

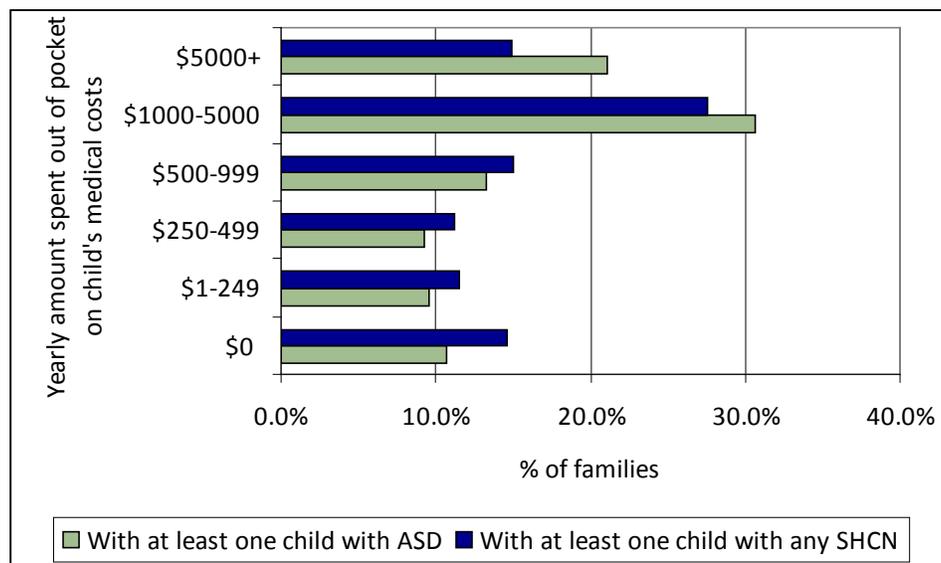
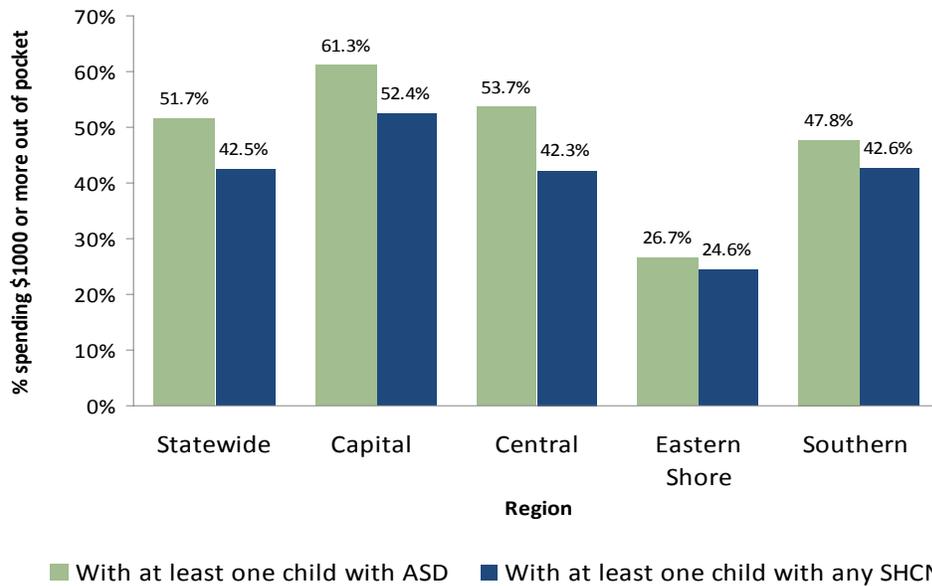


Figure 24 indicates that out-of-pocket spending is greater for families of children with ASD than for families of children with any SHCN. 30.6% of families of children with ASD spend between \$1000 - \$5000 per year compared to 27.6% of families of children with any SHCN, and 21% of

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).²²

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.²³ 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.)

²² Hand, L (2011). *Medical home setting lowers out-of-pocket costs*. Medscape, October 17, 2011. Available at <http://www.medscape.com/viewarticle/751586>

²³ 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.²⁴ 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

²⁴ 2010 Maryland Title V Maternal and Child Health Block Grant Report.

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 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.²⁵

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

²⁵ 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>

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 and 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 29 th 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.²⁶

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 do we 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.”

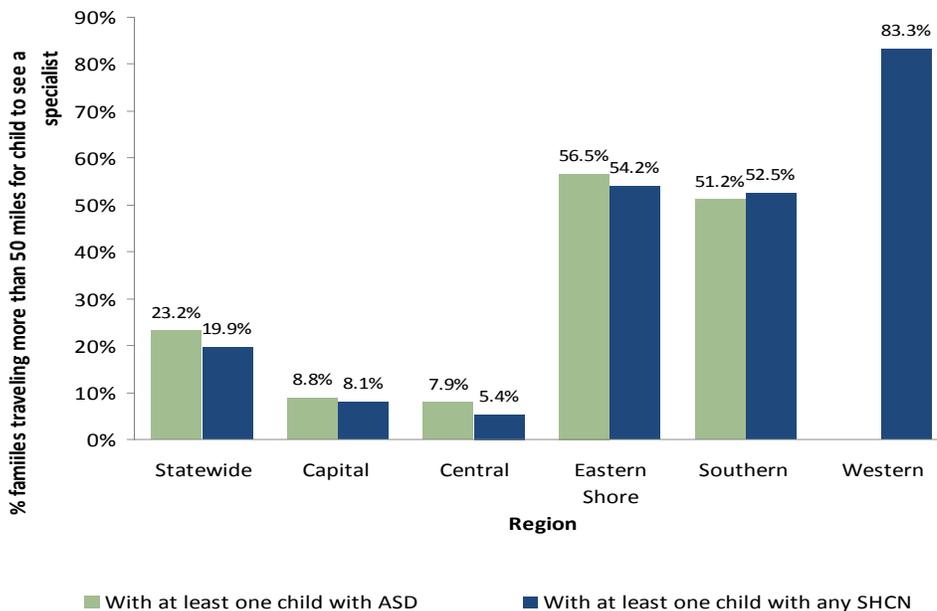
²⁶ Maryland Community of Care Consortium for CYSHCN (2008). *Easy to Use Community-Based Systems Workgroup Report Out*. Accessed on May 25, 2010 from <http://www.marylandcoc.com/Consortium.html>

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.)²⁷

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.

²⁷ 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 Shriners' 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 barriers²⁸.

²⁸ 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.

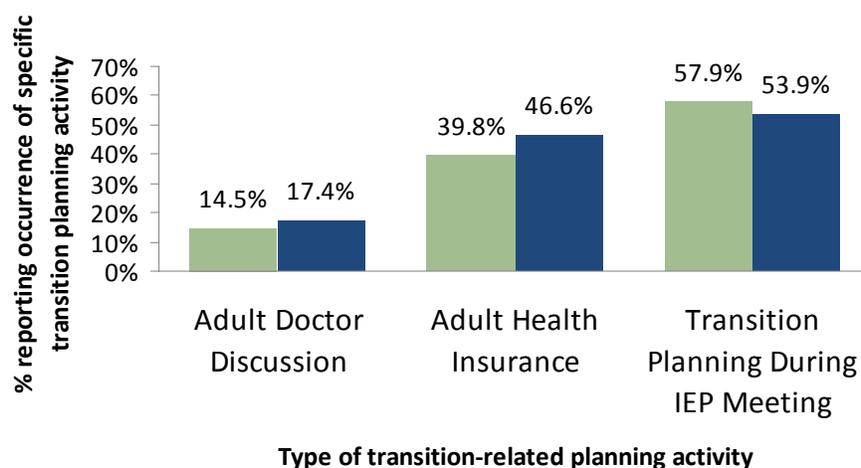
“Everything is so scattered that I feel like I am having to try to figure out what resources might be available for my daughter. Everyone I talk to tells me I have to talk to someone else. Why isn't there one place where I can call and find out what my daughter might be eligible for and help for me to 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 40 th 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)



■ With at least one child with ASD ■ With at least one child with any SHCN

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.

A. 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.

B. 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	Western Maryland	Capital Area	Southern Maryland	Eastern Shore
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	Maryland)				
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