

# **MARYLAND FAMILIES REPORT ON THE STATE OF THE STATE**

## **For Children and Youth with Special Health Care Needs**



**2018**

**the  
parents' place  
of Maryland**



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# **MARYLAND FAMILIES REPORT ON THE STATE OF THE STATE**

## **For Children and Youth with Special Health Care Needs**

### **INTRODUCTION**

We would like to welcome you to the 2018 Maryland State of the State report for children and youth with special health care needs and their families who love and support them. This is their story. This report highlights the struggles, challenges, and sacrifices that families make every day for their children. The State of the State report also clearly highlights action steps that need to be taken to improve outcomes for some of our most vulnerable citizens. This report gives rise to their collective voices and their needs.

The Parents' Place of Maryland (PPMD) is the statewide special education and health information center. Our mission is to empower families as advocates and partners in improving education and health outcomes for their children with disabilities and special health care needs. There are so many people who made this report possible. The families who took the time to answer our surveys and participate in focus groups, the PPMD staff, our partner Maryland Department of Health (MDH) Office for Genetics and Children with Special Health Care Needs (OGPSHCN), the Johns Hopkins School of Public Health, Sally Chan, Ph.D. for her stellar data analysis, and last but definitely not least, one of our founding members and long term leader, Josie Thomas. Her dedication, hard work, and passion are an inspiration to us all.

### **ABOUT THIS REPORT**

The State of the State report highlights what families are telling us about the issues and challenges faced by families of children and youth with special health care needs in the state of Maryland. The data presented is from five key sources:

- ◆ National Survey of Children's Health (NSCH) 2016;
- ◆ 2014 and 2017 surveys conducted by PPMD in partnership with MDH OGPSHCN;
- ◆ 2016-17 PPMD data collected from parents' calls for assistance;
- ◆ Focus group interviews with families throughout Maryland in 2017 regarding care coordination.

All of these sources paint a consistent picture of the challenges families face.

The report focuses on four areas identified through these processes that are of greatest importance to Maryland families raising children and youth with special health care needs. These four areas include:

- ◆ lack of access to needed services and supports;
- ◆ adequacy of health insurance (private and public insurance);
- ◆ fragmentation of the system of services and supports; and
- ◆ the burdens—financial and other—that the first three issues place on families.

The report is based on quantitative and qualitative data that illustrates the daily reality for Maryland families in their own words. In addition, a Call to Action for Marylanders—policy makers, employers, state and local service and support agencies, health and related services providers, families, and advocates—is spelled out.

Respectfully for your consideration,



Rene Averitt-Sanzone  
Executive Director

# EXECUTIVE SUMMARY: CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)

**C**hildren with special health care needs (CYSHCN) are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.\*

**250,000  
MARYLAND  
CHILDREN**



*Maryland CYSHCN would fill 5,545 school buses.  
Those buses would span the Bay Bridge 9 times!*

**5,545**

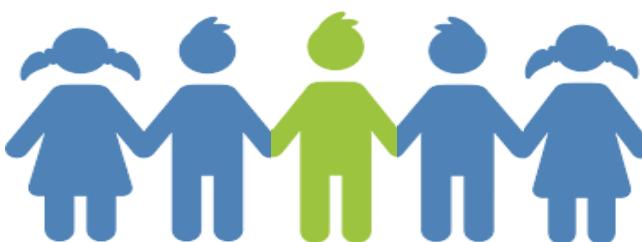


**9 X**

**PREVALENCE**

**19%**

NEARLY ONE IN FIVE  
MD CHILDREN



*4.9% HAVE TWO OR MORE CYSHCN!*

**23%**

NEARLY ONE IN FOUR  
MD HOUSEHOLDS

**65%**

NEARLY ONE IN SEVEN  
MD CYSHCN

**ENCOUNTER ONE OR MORE ADVERSE  
CHILDHOOD EXPERIENCE (ACE)**

*ABUSE, NEGLECT, OR HOUSEHOLD DYSFUNCTION*

\* As defined by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, US Department of Health and Human Services. Based on child's needs for services and supports, not on diagnosis.

# EXECUTIVE SUMMARY: GAPS IN SERVICE AND IMPACT ON FAMILIES OF MARYLAND CYSHCN



## CARE COORDINATION

- 49%** needed help finding services
- 60%** had difficulty getting help
- 32%** did NOT receive needed help



## SPECIALTY CARE ACCESS

- 32%** of CYSHCN needed specialty health treatment but did NOT receive it
- 73%** drive 25+ miles to specialty care
- 28%** drive 100+ miles to specialty care

GAPS



## FINANCIAL

- 30%** CYSHCN lack adequate health insurance
- 52%** paid \$500+ out of pocket medical expenses per year



## CARE COORDINATION

- 92%** of CYSHCN (age 12-17 years) do NOT receive care in a well-functioning system
- 64%** of CYSHCN (age 0-11 years) do NOT receive care in a well-functioning system



## SPECIALTY CARE ACCESS

- 82%** with inadequate insurance report CYSHCN did NOT see a specialist in the last year
- 31%** report a delay in their own or a family member's care due to their CYSHCN



## FINANCIAL

- 51%** family members cut hours, stopped working, or avoided changing jobs
- 21%** had problems paying medical bills

IMPACT



## **EXECUTIVE SUMMARY: A CALL TO ACTION ON BEHALF OF MARYLAND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)**

**ACTION 1.** Implement provision that allows families of children and youth with special health care needs to buy into Medicaid for their CYSHCN with its often broader array of covered services and lack of co-pays and co-insurance costs to families. Other states have developed such programs. The Catalyst Center can provide information about such buy-in programs.

**ACTION 2.** Continue to address the lack of pediatric mental health providers and their distribution across the state.

**ACTION 3.** Implement workforce training as well as family education and supports on trauma-informed care to effectively address the impact of Adverse Childhood Experiences (ACEs) on Maryland children.

**ACTION 4.** Individual families can no longer be forced to spend inordinate amounts of time dealing with a fragmented system of services and supports. Maryland should implement state and local efforts that bring together key stakeholders to create easy to use and coordinated services and supports. While there may often be multiple care coordinators, families are not experiencing coordinated care.

**ACTION 5.** Implement an approach that addresses the out of pocket costs that families sustain. This might include solutions to wrap extra coverage around existing private health coverage. In addition, institute a state catastrophic relief program, modeled on such programs in New Jersey, Massachusetts, and Michigan. These programs use special funds, trusts or endowments to provide funds to families who have spent amounts above a defined percentage of income related to care of children and youth with special health care needs.



**ACTION 6.** Adopt an approach in which state health agencies work with the private sector to create an infrastructure to address geographically based access problems and workforce shortages. Approaches may include coordinating traveling clinics, use of telemedicine technologies, etc. The coordination of financing such approaches should also be part of the solutions identified.

**ACTION 7.** Continue to support and expand support for programs that help families navigate the complex and fragmented systems such as the Family to Family Health Information Center at The Parents' Place of Maryland (PPMD), Pathfinders for Autism, Maryland Coalition of Families, Kinera Foundation, and other such family-run organizations.

**ACTION 8.** Adopt a universal application form for service and support programs that impact children and youth with special health care needs. The Anne Arundel County Birth to Five program has instituted such an initiative that should be Implemented statewide.

**ACTION 9.** Expand the implementation of the Medical Home approach for pediatrics to improve care and coordination for CYSHCN.

**ACTION 10.** Maryland employers should learn about and implement policies and approaches that support families of children and youth with special health care needs to remain employed and productive and gain a greater understanding of how decisions in purchasing coverage may impact employees who have a child with special health care needs.

**PLUS ONE.** Continue to provide resources to a statewide consortium of stakeholders to assess the system of services and supports and work toward collaborative solutions that address issues of access, insurance, medical home, and coordination of care for CYSHCN. The Maryland Community of Care Consortium (COC) for CYSHCN has worked successfully and been sustained since 2008.

# CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS IN MARYLAND

As defined by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, US Department of Health and Human Services: *Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.* This definition includes children with chronic illnesses, behavioral and mental health disorders, developmental disabilities and physical and sensory disabilities. It is not based on diagnosis, but instead on their needs for services and supports.

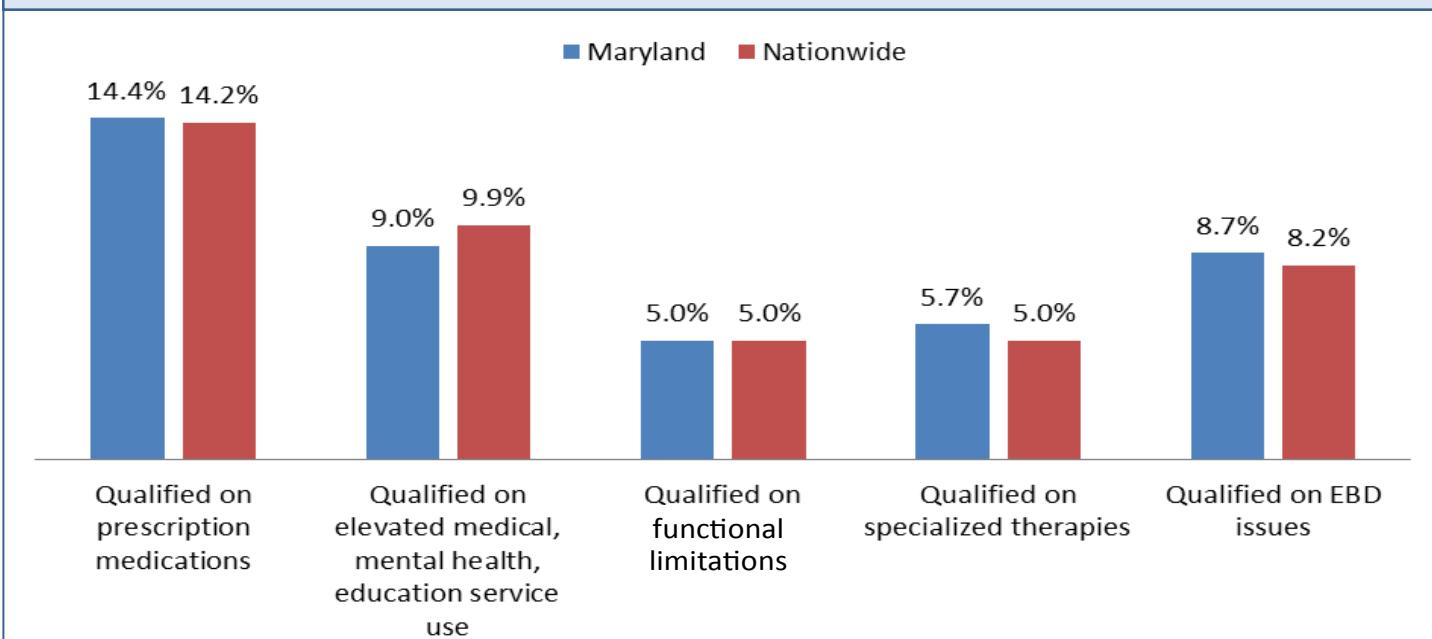
The 2016 National Survey of Children's Health (NSCH) conducted by the Data Resource Center for Child and Adolescent Health (DRC)<sup>1</sup> estimates that 18.6% of all children in Maryland ages 0 through 17 meet this criterion. This translates into 250,000 children with special health care needs. Maryland has a slightly lower percentage of CYSHCN than the national average of 19.4%.

On this survey, children were classified as having a special health care need if their parent reported that they met one or more of the following screener criteria due to a medical, behavioral or other health condition that has lasted or is expected to last for at least 12 months:

1. Use or need of prescription medication;
2. Above average use or need of medical, mental health or educational services;
3. Functional limitations compared with others of the same age;
4. Use or need of specialized therapies (e.g., OT, PT, speech);
5. Treatment or counseling for emotional, behavioral, or developmental (EBD) problems.

The percentages of children in Maryland who were included in the definition based on functional limitations, increased use of or need for services, and those with ongoing emotional, behavioral or developmental (EBD) issues are reflected in Chart 1.

**Chart 1: Percentage of CYSHCN (ages 0-17) qualifying on specific types of special health needs  
Maryland vs. Nationwide<sup>2</sup>**



<sup>1</sup>The DRC is a project of the Child and Adolescent Health Measurement Initiative (CAHMI) supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). <http://childhealthdata.org/>

<sup>2</sup>Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. 2016 National Survey of Children's Health (NSCH) data query. Retrieved 01/19/2018 from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org).

## HEALTH STATUS OF CYSHCN IN MARYLAND: ADVERSE CHILDHOOD EXPERIENCES (ACES)

In the 2016 NSCH, 83.4% of families of Maryland CYSHCN reported excellent to very good health as compared to the national average of 69.8%, while 16.6% of MD CYSHCN reported good, poor, or fair health as compared to the national average of 30.2%. MD has a higher percentage of CYSHCN in better health than the national average, especially those CYSHCN with more complex health needs. 90.4% of MD CYSHCN with less complex health needs reported excellent to very good health as compared to the national average of 82.1% while 80.4% of MD CYSHCN with more complex health needs reported excellent to very good health as compared to the national average of 64.3%

However, Maryland children seemingly face more traumatic events than the national average and their families seem less equipped to deal with their negative effects.<sup>3</sup> Adverse childhood experiences (ACEs) are stressful or traumatic events in a child's life and are strongly related to the development and prevalence of a wide range of health problems throughout a person's lifespan. Maryland CYSHCN reported more adverse childhood experiences (64.8%) than those of Maryland typical children (41.2%) or the national average of CYSHCN (62.6%). In addition, 73.6% of MD CYSHCN with emotional, behavioral, or developmental difficulties experienced one or more adverse childhood experiences (Table 1).

In addition, data from the 2016 NSCH shows that when compared to typically developing peers, children ages 3 to 5 with developmental delays were 7.5 times more likely to be suspended or expelled,



while the odds for children with autism increase to 10 times. Children with behavioral problems were 43 times more likely to be suspended or expelled.

Resilience is a composite measure on the 2016 NSCH based on responses to the following 4 survey items: "When your family faces problems, how often are you likely to do each of the following?" (a) Talk together about what to do, (b) Work together to solve our problems, (c) Know we have strengths to draw on, and (d) Stay hopeful even in difficult times. In order to meet the family flourishing composite measure, the family should meet all or most of the time for all items. Only 65.9% of MD CYSHCN families met this resilience measure as compared to 81.2% of MD typical children or the national average for CYSHCN (70.4%). Only 63.3% of MD families with CYSHCN with more complex health needs met this measure as opposed to 72.2% of MD families with CYSHCN with less complex health needs and only 59.4% of MD families with CYSHCN who have emotional, behavioral, or developmental issues (EBD) met this measure.

**Table 1. Adverse Childhood Experiences: Maryland CYSHCN compared to all Maryland children**  
(Source: 2016 NSCH)

	1 ACE	2 or more ACES	Total
All Maryland children	25.6%	15.6%	41.2%
Maryland CYSHCN	28.4%	36.4%	64.8%
Maryland CYSHCN with emotional, behavioral, or developmental issues	25.6%	48.0%	73.6%

<sup>3</sup> <http://www.baltimoresun.com/health/bs-hs-adverse-childhood-experiences-20171018-story.html>

# WHAT MARYLAND FAMILIES ARE SAYING ABOUT THE STATE OF SERVICES AND SUPPORTS FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

## ACCESS TO NEEDED SERVICES

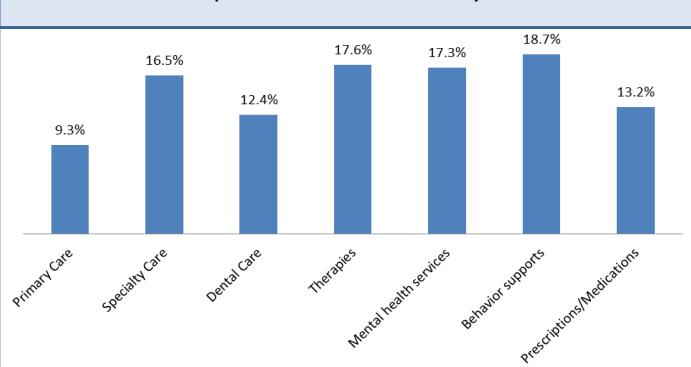
**Access to services is a key concern for families of children and youth with special health care needs in Maryland. It is reflected in focus groups conducted statewide, parent calls to PPMD, and in all of the other data sources.**

In the 2016 National Survey of Children's Health, 63.6% of Maryland children with special health care needs (ages 0-11 years) had families who reported that their child does not receive care in a well-functioning system. For Maryland children with special health care needs ages 12-17, 91.9% had families who reported that their child does not receive care in a well-functioning system. The measures for children ages 12-17 include the ones listed below and also include preparation for transition to adult health care services.

A well-functioning system for children ages 0-11 years includes the following measures:

1. family feels like they are a partner in their child's care;
2. child has a medical home;
3. child had a preventive medical and dental visit;
4. child has adequate insurance; and
5. child has no unmet need or barriers to services.

**Chart 2. Needed Care for CYSHCN Delayed or Not Received in the Past 12 months**  
*(Source: 2017 MDPS)*



For both of these age groups, the more severe the child's condition as rated by their parent, the more likely that there were unmet needs. For children with emotional, behavioral or developmental issues (EBD), about 53% had families who reported that they had a problem obtaining mental health treatment or counseling for their child. About 27% of families of children with more complex needs reported that they had problems getting the specialty care their child needed.

These unmet needs are not equitably distributed for Maryland families. For children both with or without special health care needs, those with private insurance (26.6%) are more likely to face unmet needs than those with public insurance (16.1%).<sup>4</sup>

The 2017 Maryland Parent Survey (MDPS) asked parents if certain health care related services for CYSHCN were delayed or not received in the past 12 months. Respondents identified therapies, mental health services, and behavioral supports as the most frequently delayed or not received services (Chart 2).

In addition, almost one third of families reported a delay in their own health care or a family member's care due to the child's special needs (31%).

The 2017 MDPS asked parents about any behavioral needs during the last 12 months. Slightly more than six in ten parents (61%) reported anxiety problems in their children during the past year. Other frequently reported behavioral issues included anger/conflict management, depression, and an increase in problem behaviors. For each behavior cited, parents sought help between 67-96% of the time; yet the majority of parents reported accessing the help they needed was either somewhat or very difficult. The chart above identifies each reported behavioral issue and the difficulty in getting help (Table 2).

<sup>4</sup> Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. 2016 National Survey of Children's Health (NSCH) data query. Retrieved 01/25/2018 from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org).

**Table 2. Unmet Needs Based on Child Behavioral Health Issue**  
*(Source: 2017 MDPS)*

BEHAVIORAL HEALTH ISSUE	% REPORTING DIFFICULTY IN GETTING HELP
Anxiety	60.6%
Suicidal Thoughts/Behaviors	44.7%
Increase in Problem Behaviors	51.2%
Depression	50.5%
Anger/Conflict Management	50.4%
Bullying	40.4%
Drug/Alcohol Abuse	35.7%

In addition to needs for health services for their children, Maryland parents of CYSHCN reported that they had unmet needs for family support services. In the 2017 MDPS, the most frequently cited needs for family support services were: assistance finding

*We had to stop doing certain therapies for my daughter because we just couldn't afford it anymore. She was making good progress but insurance wasn't covering it so we had to drop some treatments that she really needed.*

*~ Parent, Central Maryland*

services for the child (49.3%); information about family support (30.8%); respite care (20%); assistive technology for the child (21.7%); and other unspecified need (26.9%). Other needs identified by parents included finding therapies, child care, psychiatrists and other mental health providers or services, ABA therapies, camps, and general financial assistance for middle income parents. In most cases, parents



*While I had funding for in home aide services, it took me 2 to 3 years to get reliable, consistent care givers.*

*~ Parent, Central Maryland*

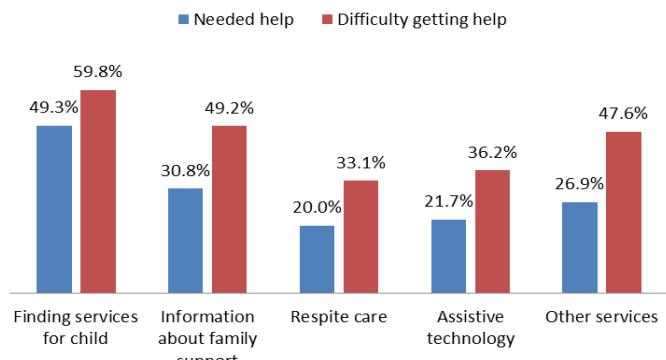
sought help from someone in getting this need or service but many found this help difficult to obtain.

Problems accessing needed services were the most frequently noted issues in focus groups of families conducted during 2017. Specific concerns related to lack of providers in the area, provider networks for their health plans that did not include appropriate or available providers, difficulty or long waits in getting appointments, and distance to services, specialists, and related transportation issues.

Families also noted difficulty accessing respite care, child care, and recreational opportunities for their children with special health care needs.

Families are frustrated in their efforts to get services. On the 2016 NSCH, about one quarter (24.5%) of parents reported that they were frustrated in their effort to get services for their child. For children who had more complex needs such as emotional, behavioral, or developmental issues, 37.3% of parents reported they were frustrated in their effort to get services (Chart 3).

**Chart 3: Need for family support services and difficulty obtaining help**  
(Source: 2017 MDPS)



## **What Restricts Access to Needed services for Maryland Children with Special Health Care Needs?**

**While there are a number of factors that impact individual families, analysis of the data indicate several common themes.**

### **UNEVEN GEOGRAPHICAL DISTRIBUTION OF PROVIDERS**

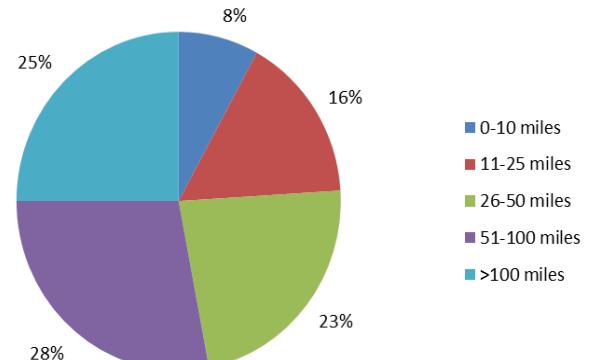
Almost 16% of parent calls to PPMD from rural areas addressed the issue of no appropriate pediatric specialist in their area compared with 4% of calls from urban areas. In Western Maryland, a full one-third of parent calls related to having no specialist in the area. Families are traveling to metropolitan areas in Central Maryland and to West Virginia for services. During winter months, families describe attending routine health care appointments as harrowing experiences in driving on snowy, mountainous roads.

The impact of the lack of providers is that Maryland CYSHCN may not be getting needed medical services and visits. As reported in the 2016 NSCH, 9.1% of MD CYSHCN had no preventative medical visits during the last 12 months and 10.3% of MD CYSHCN with more complex health needs had no preventative medical visits during the same time period.

According to the 2017 MDPS, almost two-thirds (65.9%) of parents reported that they took their child to see a specialist (such as a cardiologist, neurologist, or others who specialize in one area of health care) in the past 12 months. More than half (53%) reported at least one round trip specialist visit to be over 50 miles; and 25% traveled more than 100 miles round trip. The distance traveled to see a specialist during the last 12 months is shown in Chart 4.

In addition, parents reported on the distance traveled to obtain therapy services outside of school or child care. 63.8% of respondents to the survey have a child who receives physical therapy, occupational therapy, speech language therapy, or behavioral services outside of school or child care. Over 1/3

**Chart 4: Farthest round trip distance traveled to see a specialist  
(Source: 2017 MDPS)**



(about 36%) drove over 25 miles to access behavior services and mental health counseling; 7% drove more than 100 miles to access those services. About 76% drove over 25 miles to access unspecified other therapy services for their child, with 25% of these parents driving over 100 miles.

*I have to go to two different hospitals for both of my kids. I am going in both directions—to Baltimore and DC. I try to make their medical appointments at both places during the same time frame, so we don't have to make several trips down there. We end up staying for several nights and we have to pay 1,000 dollars to stay in a hotel.*

*~ Parent, Western Maryland*



## LACK OF HEALTH PROVIDERS TO SERVE CHILDREN AND YOUTH

More than half of parent calls for assistance to PPMD came from families of children with behavioral and mental health problems. A consistent theme from the focus groups with families was the dearth of mental health providers for children and youth. Data from the 2017 MDPS, aside from multiple specialists, mental health specialists such as psychologists and psychiatrists were the most frequent specialists seen (37%). The 2016 NSCH data shows that 31.9% of MD CYSHCN with a mental/behavioral condition needed treatment but did not receive it. For children ages 6-11 years old, 48.2% of families responded that it was a problem to get the mental health treatment or counseling that this child need-

*A lot of the psychologists, OTs, and speech therapists don't participate in our health plan. And it's really hard to find pediatric specific providers.  
That's a big gap for us.*

*~ Parent, Eastern Shore*

ed. For children ages 12-17 years old, 37.6% also found it to be a problem to obtain those services for their child.<sup>5</sup>

## PROBLEMATIC ACCESS TO CARE FROM SPECIALISTS

Four issues related to access to specialists were cited repeatedly in parent calls, focus groups, and survey data.

- ◆ Families reported problems getting needed specialist care. In the 2016 NSCH, 28% of CYSHCN received or needed specialist care but had problems getting it and 40% of children with emotional, behavioral, or developmental (EBD) issues had problems getting needed specialist care.
- ◆ Families also reported long wait times for specialist appointments, especially for diagnostics or mental health services.
- ◆ For families who reported their health insurance was not adequate, 82% said their child did not see a specialist in the last 12 months.
- ◆ While most families reported they were able to get referrals when needed for their child, about 11% reported they had problems getting referrals when needed.

## UNEVEN IMPLEMENTATION OF A MEDICAL HOME MODEL OF CARE

*"All children should receive care within a "medical home;" that is, comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families."*<sup>6</sup>

The American Academy of Pediatrics developed the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to every child and adolescent. 2016 NSCH data indicate that only half (50.8%) of the care MD CYSHCN received meets the medical home criteria. While this percentage is higher than the national average for CYSHCN, this metric was 8.6% lower when compared with the care typical children in Maryland receive that meets the medical home criteria (59.4%). For children with EBD, only 41.3% of the care received meets the medical home criteria.

<sup>5</sup> Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. 2016 National Survey of Children's Health (NSCH) data query. Retrieved 01/18/2018 from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org).

<sup>6</sup> Ibid

## ADEQUACY OF HEALTH INSURANCE

Based on findings from the 2016 National Survey of Children's Health, children with special health care needs in Maryland are significantly more likely to be insured (98.6%) and to be insured continuously over the past year (95.8%) than the previous report in 2007. This extensive coverage is largely due to the changes brought about by the Affordable Care Act (ACA).

For children and youth with special health care needs, however, the issue goes beyond having coverage. With their increased needs for medications and services, the adequacy of the insurance they have is a crucial issue. On the 2016 National Survey of Children's Health, almost 30% of Maryland CYSHCN had parents who reported that their child's insurance coverage was not adequate and depending on the severity of the child's condition, the more likely parents were to cite inadequate insurance as a problem. For example, 33.6% of parents of children

with more complex health needs reported that their child's insurance was not adequate compared to 20.4% for those with less complex health needs. 35% of families whose children have EBD reported that their child's health insurance is not adequate.

*We've already spent \$1800 of our Flex account and it's only mid-March. Our deductible hasn't even been touched. I'm wondering where we're going to find the money to cover medications and co-pays for the rest of the year. It's frustrating and very expensive.*

*~ Parent, Central Maryland*



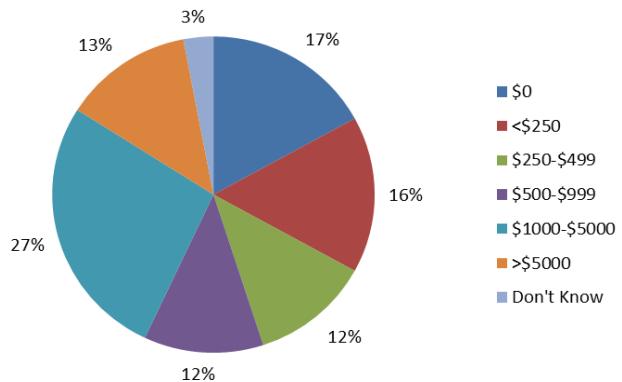
## **Why is health insurance inadequate for some children and youth with special health care needs?**

### **HIGH OUT OF POCKET COSTS**

A key issue related to family's ratings of adequacy of their insurance was out-of-pocket costs for their children's services. Based on the 2016 NSCH, 41.2% of children in Maryland had parents report that they spent \$500 or more out-of-pocket for their child's health care in the past year. Again, severity of the child's special health care needs related to out-of-pocket costs with 26.6% of children whose parent's rated their problems as severe having families that reported spending over \$1,000 out-of-pocket in the past year.

The 2017 Maryland Parent Survey found that approximately 52% of families of CYSHCN spent \$500 or more out of pocket for medical expenses for their children in the prior 12 months. Those responding to the survey had, on average, children with more severe special health care needs. Families with private insurance or a combination of private and public insurance were more likely to have higher out of pocket expenses (Chart 5).

**Chart 5: Out of pocket\* expenses for child's medical care in past 12 months**  
(Source: 2017 MDPS)



\*Out of pocket costs in the 2017 MDPS includes: amount paid for all types of health-related needs such as co-payments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, any kind of therapy, or other care or supplies needed. The amount does NOT include health insurance premiums or costs that were reimbursed by insurance or another source.



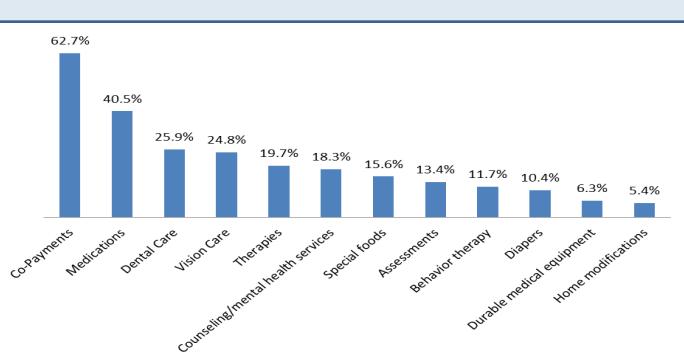


Co-pays (62.7%), medications (40.5%), dental care (25.9%) were the three most frequently cited out of pocket costs for families of CYSHCN. Additional out of pocket expenses for therapies, including behavior therapy, account for more than 31% of costs reported by parents (Chart 6).

### ACCESS TO NEEDED CARE IS PROBLEMATIC

As already noted, families found insurance coverage inadequate in many instances and because of limited provider networks and problems using their insurance with some providers, access was problematic. In the 2016 NSCH, one of the elements of adequacy measured is whether insurance coverage

**Chart 6. Out of pocket expenses by category**  
(Source: 2017 MDPS)



allows the child to see needed providers. For Maryland CYSHCN, families reported that 75.6% of the child's health insurance always allowed the child to see needed providers, while 17.8% reported that the child was usually allowed to see a needed provider and 6.5% reported that the child was only sometimes or never allowed to see the needed provider. For children with more complex needs or with EBD, those always allowed to see the provider the child needed declined to 73.9% for those with more complex needs and 70.6% for those with emotional, behavioral, or developmental issues.

### INADEQUATE COVERAGE FOR DURABLE MEDICAL EQUIPMENT

For families whose children utilize durable medical equipment (DME) such as wheel chairs, braces, orthotics, diapers, and even special glasses, problems with adequacy of coverage were noted. In some cases, health plans simply provided no coverage for needed equipment, other times there were dollar limits that did not match the actual cost of items. Approval processes were difficult and time-consuming. As noted earlier on the 2017 MDPS, 17.7% of families reported out of pocket expenses for DME 10.4% of that on diapers for their child with special health care needs.

*If you take anything from this, please know that the privately insured working class are often penalized and don't have access to certain services. Mental Health services, for instance, only seem to be available for those who can afford to pay out of pocket or those who qualify for Medicaid. I work 3 jobs to support my family and we don't qualify for Medicaid. It feels like my son is being punished because I work hard to pay our bills.*

*~ Parent, 2017 MDPS*

## FRAGMENTATION OF THE SYSTEM

The issue of the lack of coordination of services and supports for children and youth with special health care needs is a frequent theme among families. In 2017, almost 60% of families calling PPMD for support required a referral to a service that they could not identify on their own. This same issue is reflected in response of Maryland parents on the 2016 NSCH. Overall, 76.3% of children had parents who reported that services and supports did not receive care in a well-functioning system. An even higher percentage (81.1%) of parents with children rated as having the most severe conditions and the highest needs reported that the system was not easy to use. Children with family incomes of 100-199% of federal poverty level had even more parents who were having difficulty using the system (83.9%).

Families reported that finding services was difficult, time consuming and the processes and forms were overwhelming. At times, there was lack of coordination within the same institution or agency. For example, in hospitals some departments participated in a health plan and others in the same hospital

*My daughter is involved with so many different systems—Infants and Toddlers, Medicaid, therapies with different providers. At times, she's had multiple case managers, but none of them ever talk to each other. I still end up managing everything because it's so complicated.*

*~ Parent, Central Maryland*

did not. Families were perplexed by this and felt they could not understand how to access covered care. For children with specialized care needs, they might have to go to one hospital for that care, yet be unable to access other aspects of health care at that institution. There were concerns that there is no reimbursement to health care providers for care coordination needed to support families in dealing with the fragmented system. At the same time, families noted that children who were involved with multiple public programs might have more than one care coordinator, yet there was no integration of those services.



## IMPACT ON MARYLAND FAMILIES

### ***How are Maryland families impacted by lack of access to services, inadequate insurance and a fragmented system of services and supports?***

Difficulties with access to care, dealing with insurance coverage and piecing together needed services and supports from a fragmented system takes its toll on Maryland families raising children and youth with special health care needs. The toll is both emotional and financial. Families are frustrated by the difficulty of obtaining services and supports and by the impact the fragmented system has on their ability to parent all of their children. Families reported significant out of pocket costs that can impact the overall financial status of the family. In addition, the time spent dealing with insurance issues, seeking and coordinating care and providing care for their children has resulted in some parents having to reduce or give up employment, again impacting the financial status of the entire family.

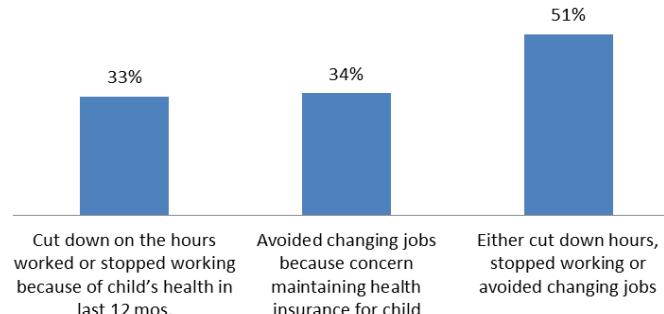
### **FINANCIAL IMPACT ON THE FAMILY**

**Families experience high out of pocket costs for services and supports.** According to the 2016 NSCH, 16.5% of children with special health care needs in Maryland had parents report problems paying medical bills as compared to 5.0% of typical children. Those with more complex health needs reported higher rates of problems paying medical bills than those with less complex health needs (18.0% vs. 13.0%) In addition parents of CYSHCN with emotional, behavioral, or developmental issues reported higher rates of problems paying medical bills (20.6%).

### **LOSS OF EMPLOYMENT INCOME**

Less visible is the financial impact on families of the time spent on providing, coordinating and arranging care for their children and youth with special health care needs. Because of the time needed to provide, arrange or coordinate care, some parents had to alter their employment status which provides an additional financial impact on the family. On the 2017 Maryland Parent Survey, 33% of parents of

**Chart 7: CYSHCN Family Employment**  
(Source: 2017 Maryland Parent Survey)



children with special health care needs said they had cut down on work or stopped working in the last 12 months because of their child's health care; 34% of parents reported that they avoided changing jobs because of concern about their child's health insurance coverage; and a total of 51% reported they either cut hours, stopped working, or avoided changing jobs because of their child's care (Chart 7).

*I am looking for another job because we need more income. But I'm worried that my two kids with really complex medical needs will lose their Medicaid benefits and I won't make enough to be able to pay for their health insurance and all the co-pays and other costs. My husband has had to turn down work contracts because somebody's got to be home to get the kids off the bus.*

*~ Parent, Central Maryland*

*Sometimes we have no food and we're just kind of going through this day to day. I send my son to his therapies and he's making progress steady but slow. It's just really difficult. We make \$9.00 too much to qualify for food stamps.*

*~ Parent, Capital Region*

The financial impact on families of CYSHCN is also reflected in food insufficiency for the family. 4.6% of families of typical Maryland children in the 2016 NSCH report that they sometimes or often could not afford enough to eat. However, 11.9% families of CYSHCN; 13.8% of families of children with more complex health care needs; and 18.9% of families whose children with emotional, behavioral, or developmental needs reported that the family had food insufficiency during the last 12 months. In addition, a large number (39.5%) of Maryland children with special health care needs received

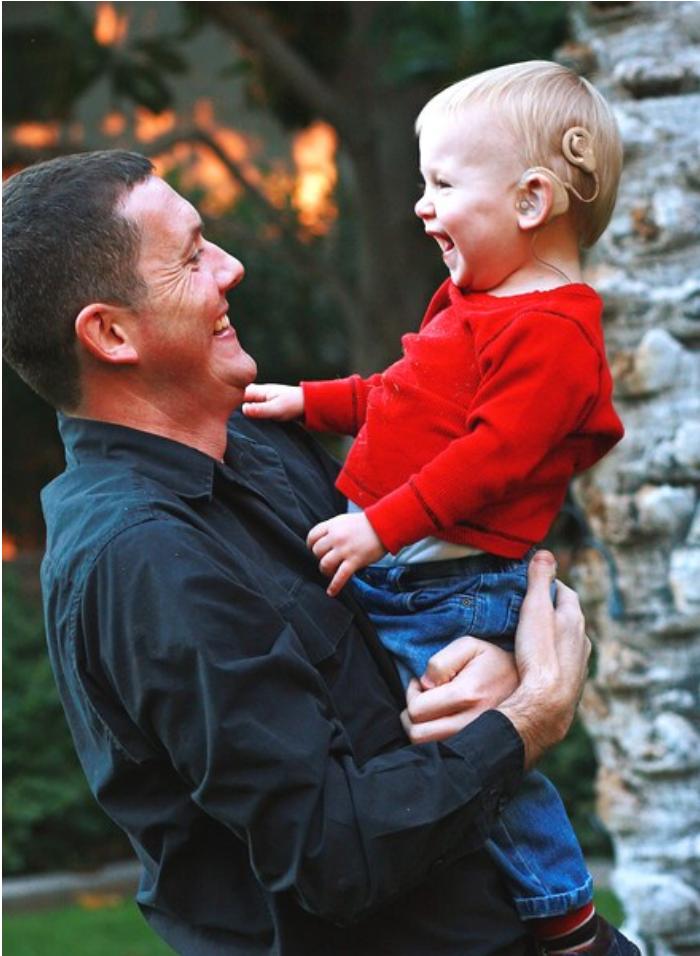
food or cash assistance (between 1 and 4 types of assistance) compared to those without special health care needs (31.5%). 46.5% of families of children with more complex needs and 54.8% families of children with emotional, behavioral, or developmental needs reported they received between 1 and 4 types of food or cash assistance. The types of assistance include WIC, cash assistance from the government, food stamps, and free or reduced cost meals at school.

## TIME AND EFFORT SPENT

### COORDINATING AND ARRANGING CARE

Families reported that finding services was difficult, time consuming and the processes and forms overwhelming. There was lack of coordination within the same institution or agency. For example, in hospitals some departments participated in a health plan and others in the same hospital did not. Both providers and families were perplexed by this and felt they could not understand how to access covered care. For children with specialized care needs, they might have to go to one hospital for that care, yet be unable to access other aspects of health care at that institution. At the same time, families noted that children who were involved with multiple public





programs might have more than one care coordinator, yet there was no integration of those services. In the 2017 Maryland Parents Survey about one in ten families (11%) receive help arranging or coordinating their child's care among the different doctors or services. 37% percent of families could have used extra help arranging or coordinating their child's care; of these families, more than six in ten (61%) never received as much help with care coordination as they wanted.

In the 2016 National Survey, 31.7% of Maryland families of CYSHCN reported they did not receive needed care coordination; 41.1% of families whose children had more complex needs and 44.2% of families whose children had emotional, behavioral, or developmental needs also reported they did not receive needed care coordination.

In addition, parents in the statewide focus groups reported that for more complex children with special health care needs, they found managing all of the appointments a particular challenge. "I do everything myself. I drop lots of balls," one parent said. The primary example here was a medical appointment or procedure (e.g. MRI) that needed to be

repeated cyclically. If all appointments were once a year, it might be easier to remember, but some are every six months, some annually, while others—particularly in the case of certain procedures—might be every three years or more. Parents report that tracking all of the appointments is very challenging.<sup>7</sup>

Parents also noted that they had been dropped by case management when they appeared to be coping well with their child's needs.

Another facet of care coordination that families struggle with is the transition of their youth with special health care needs from pediatric to adult health care. Transition to adult health care is a Title V Maternal and Child Health Bureau Block Grant National Performance Measure. In the 2016 NCSH, 86.6% of families of CYSHCN reported that their child did not receive services necessary for transition to adult health care. On the 2017 MDPS, only 38% of parents reported that their son or daughter with special health care needs had actively worked with a health provider to gain skills to manage his/her health and health care, and only 16% understood the changes in health care that happen at age 18. Much work is needed in Maryland in this area.

*We sorely need case managers who work to minimize the number of visits and driving time and maximize the efficiency of a family's schedule and budget. I spend at least 8 hours a week on the phone trying to coordinate care and get coverage for things that are supposed to be covered. In this age of electronic medical records it seems like communication with and between providers should be more efficient.*

*~ Parent, Southern Maryland*

<sup>7</sup> Child Care Coordination Report: Data Analysis Parent Focus Groups. 2017. The Parent' Place of Maryland

## **IMPACT ON FAMILY WELL-BEING**

In the 2016 NSCH survey families of children with special health care needs reported on the difficulties and challenges they face caring for their child.

- ◆ 37% of parents of CYSHCN and 37.7% of parents of children with EBD issues felt their child was difficult to care for.
- ◆ 17.5% of parents of CYSHCN and 34.7% of parents of children with EBD felt aggravation from parenting.
- ◆ 22.6% of parents of CYSHCN and 32.7% of parents of children with EBD received no emotional help with parenting their child.
- ◆ 37.2% of parents of CYSHCN and 38.2% of parents of children with EBD reported they were NOT coping very well with daily demands of raising children with special health care needs.
- ◆ 29.3% of parents of CYSHCN and 39.2% of parents of children with EBD reported that they sometimes, usually, or always feel angry with their child.

*We're parents. We all want to do everything we can so our children can reach their potential. But none of us signed up to be parents of children with additional needs—it's just so much harder for our kids. So we want to make sure in every way we know how, that our kid has everything they need. And you're a great mom or dad for doing that. That's something we don't do enough for each other, tell each other that.*

*~ Parent, Capital Region*



## MAKING PROGRESS: CELEBRATING SUCCESSES

There are some significant changes for families of children and youth with special health care needs in the past ten years that can be celebrated. Legislative changes—such as the Affordable Care Act, Maryland specific legislative changes such as the habilitative services mandate and autism services coverage in private health plans—have significantly improved health care financing for most families.

- ◆ Significantly more CYSHCN are covered by health insurance. In 2007, about 93% of CYSHCN were covered by either public or private insurance compared to 98.6% in 2017 (2016 NCSH).
- ◆ The burden of obtaining insurance for CYSHCN was substantially lessened due to the elimination of the preexisting conditions clause as well as other robust policies instituted by the Affordable Care Act. About ten percent of respondents in the 2014 Maryland Parent Survey reported problems obtaining health insurance for their child. The majority of MD parents (93%) in the 2017 MDPS indicated no problems obtaining health insurance for their child.
- ◆ In 2007, a recurring theme from families across the state was the impact of having to change health plans due to employer changes. In 2017, if this continues to be a problem it was not noted by families in any of the data sources.

Maryland has improved significantly in dental services for CYSHCN since 2007. Lack of dental services for MD CYSHCN was a theme in the 2007 report but not so in current data sources. The 2016 NSCH reports MD CYSHCN are 3.5% higher than national average in having 1 or more preventative dentist visit in the past year (87.8% vs. 81.6%). However, the survey also reported that a higher percent of MD CYSHCN with less complex health needs were more likely to have 1 or more preventative health dentist per year than the more complex MD CYSHCN (91.4% vs. 86.2%). In the 2017 MDPS, 8.8% of parents reported their child's dental care was delayed in the last 12 months, 3.6% did not receive dental care in the last 12 months. Significant effort from advocates, the State, and the Dental Action Coalition were critical to this statewide improvement.

Maryland has very successfully sponsored a statewide consortium of stakeholders to assess the system of services and supports and work toward collaborative solutions that address issues of access, insurance and coordination of care. The Maryland Community of Care Consortium for CYSHCN has met continuously since 2008 and has spun off into two additional regional consortia in the Eastern Shore and Southern Maryland.

Despite these many advancements in the last 10 years, there is still much work to do.



# A CALL TO ACTION ON BEHALF OF MARYLAND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)

Maryland can do a better job of providing services and support to children and youth with special health care needs and their families. Currently, the burden of finding services, coordinating services and financing those services is too often on the shoulder of families. Finding solutions will require that all Marylanders—families and youth, policymakers, health care providers and institutions, insurers, state and local agencies—work together. A series of 10 (plus one) actions for Marylanders follows.

*In improving care for Children and Youth with Special Health Care Needs (CYSHCN) and their families, Maryland should assure that family voices are heard at every level and that families are full and meaningful partners in planning, implementing and evaluating services and supports and the systems that coordinate and finance them. State policy makers, program staff, insurers, and employers who purchase insurance all need the input of families of children and youth with special health care needs to understand the impact of their decisions and policies.*

**ACTION 1.** Maryland should implement provision that allow families of children and youth with special health care needs to buy into Medicaid for their CYSHCN with its often broader array of covered services and lack of co-pays and co-insurance costs to families. Other states have developed such programs. The Catalyst Center can provide information about such buy-in programs.

**ACTION 2.** Maryland needs to continue to address the lack of pediatric mental health providers and their distribution across the state.



**ACTION 3.** Maryland should implement workforce training, as well as family education and supports on trauma-informed care to effectively address the impact of Adverse Childhood Experiences (ACEs) on Maryland children.

**ACTION 4.** Individual families can no longer be forced to spend inordinate amount of time dealing with a fragmented system of services and supports. Maryland should implement state and local efforts that bring together key stakeholders to create easy to use and coordinated services and supports. While there may often be multiple care coordinators, families are not experiencing coordinated care.

**ACTION 5.** The state of Maryland should implement an approach that addresses the out of pocket costs that families sustain. This might include solutions to wrap extra coverage around existing private health coverage. In addition, Maryland should institute a state catastrophic relief program, modeled on such programs in New Jersey, Massachusetts, and Michigan. These programs use special funds, trusts, or endowments to provide funds to families who have spent amounts above a defined percentage of income related to care of children and youth with special health care needs.

**ACTION 6.** Maryland should adopt an approach in which state health agencies work with the private sector to create an infrastructure to address geographically based access problems and workforce shortages. Approaches may include coordinating traveling clinics, use of telemedicine technologies, etc. The coordination of financing such approaches should also be part of the solutions identified.

**ACTION 7.** The state should continue to support and expand support for programs that help families navigate the complex and fragmented systems such as the Family to Family Health Information Center at The Parents' Place of Maryland (PPMD), Pathfinders for Autism, Maryland Coalition of Families, Kinera Foundation, and other such family-run organizations.

**ACTION 8.** Maryland should adopt a universal application form for service and support programs that impact children and youth with special health care needs. The Anne Arundel County Birth to Five program has instituted such an initiative that should be implemented statewide.

**ACTION 9.** Maryland, with strong support for the state chapter of the American Academy of Pediatrics, should expand the implementation of the Medical Home approach for pediatrics to improve care and coordination for CYSCHCN.

**ACTION 10.** Maryland employers should learn about and implement policies and approaches that support families of children and youth with special health care needs to remain employed and productive and gain a greater understanding of how decisions in purchasing coverage may impact employees who have a child with special health care needs.

**PLUS ONE.** Maryland should continue to provide resources to a statewide consortium of stakeholders to assess the system of services and supports and work toward collaborative solutions that address issues of access, insurance, medical home, and coordination of care for CYSCHCN. The Maryland Community of Care Consortium (COC) for CYSCHCN has worked successfully and been sustained since 2008.

*My employer tries to be flexible, but I've had to reduce hours to better manage my kids care. That translates into actual dollars in terms of my time and effort, as well as loss of productivity for my employer. All because I have to do this other full time job that does not pay.*

*~ Parent, Central Maryland*

## **RESOURCES**

### ***Catalyst Center***

National Center for Health Insurance and Financing  
for Children and Youth with Special Health Care Needs  
Boston University School of Public Health  
617-426-4447  
[www.catalystctr.org](http://www.catalystctr.org)

### ***Children's Mental Health Services***

Maryland Coalition of Families  
10632 Little Patuxent Pkwy, Suite 234  
Columbia, MD 21044  
410-730-8267  
[info@mdcoalition.org](mailto:info@mdcoalition.org)  
[www.mdcoalition.org](http://www.mdcoalition.org)

### ***Medical Home Implementation***

The National Center for Medical Home Implementation (National Center) is a cooperative agreement between the Maternal and Child Health Bureau and the American Academy of Pediatrics. With over 15 years of experience, the National Center is focused on ensuring that all children and youth receive care within, and have access to, a medical home.  
<https://medicalhomeinfo.aap.org/Pages/default.aspx>

### ***The Parents' Place of Maryland***

The Parents' Place of Maryland (PPMD) began in 1990 as a grass-roots effort of families, professionals, and community leaders determined to provide resources, support, and information for parents of children with disabilities and special health care needs. Our philosophy of "families helping families" reflects our commitment to support families from diverse cultures. Today, PPMD serves as Maryland's Parent Training and Information Center and Family-to-Family Health Information Center where we support thousands of Maryland families each year through our programs and services. PPMD also coordinates the Maryland Consortium for Children and Youth with Special Health Care Needs (COC), a diverse stakeholder group dedicated to improving systems of care for CYSHCN.

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Glen Burnie, MD 21061  
410-768-9100  
[rene@ppmd.org](mailto:rene@ppmd.org)  
[www.ppmd.org](http://www.ppmd.org)

## **APPENDIX: Methodologies**

### **2016 National Survey of Children's Health**

The Maternal and Child Health Bureau (MCHB) funds and directs the National Survey of Children's Health (NSCH), and develops survey content in collaboration with the U.S. Census Bureau and a Technical Expert Panel. NSCH was originally conducted three times between 2003 and 2012 and provides data on multiple, intersecting aspects of children's lives. The survey

was conducted using telephone methodology, and was led by the National Center for Health Statistics at the CDC under the direction and sponsorship of the federal MCHB. Prior to 2016, the NSCH and the National Survey of Children with Special Health Care Needs were each conducted three times as interviewer-assisted telephone surveys using random digit dial sampling. In 2016, the two surveys were combined into a single self-administered questionnaire. Due to decline in the number of households with landline telephones, the NSCH now utilizes an address-based sampling method to select participating households, thus all invitations are sent by mail. Participants may choose to complete the survey either online using a secure website or a mailed paper version of the survey. All final data components are verified by the Census Bureau, MCHB and DRC/CAHMI staff prior to public release.  
<http://mchb.hrsa.gov/data/national-surveys/questionnaires-datasets-supporting-documents>

### **2017 and 2014 Maryland Parent Survey**

The surveys were conducted by PPMD and developed in partnership with MDH Office for Genetics and People with Special Health Care Needs (OGPSHCN) and Bloomberg School of Public Health, Johns Hopkins University. Both paper and electronic versions of the survey were made available to families. The surveys were disseminated through PPMD contacts, PPMD website and e-newsletter, listservs, disability and support group newsletters and other agency partners. The surveys explored variety of issues related to access to health care for CYSHCN. Diagnoses skewed towards children with variety of developmental disabilities and associated health problems 839 respondents in 2017 and 1090 respondents in 2014. For more information, contact PPMD at 410-768-9100.

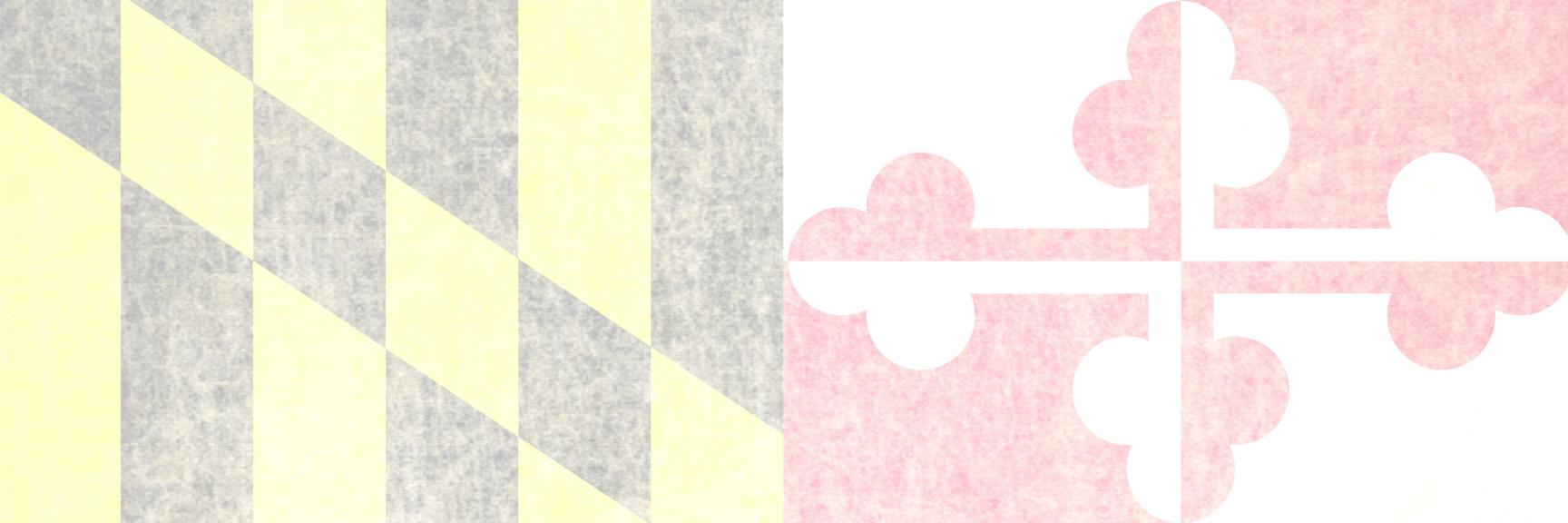
### **The Parents' Place of Maryland Parent Calls 2016-17**

Data was collected on demographic and other relevant information for calls received by PPMD from July 2016 through June 2017 (N=2,266). The Center received an average of 188 calls per month by parents throughout Maryland who were seeking information or services for their child or children with special healthcare needs. The information collected on the child includes age, gender, ethnicity, county of residence, disability, and insurance type, as well as the parent's reason for calling and the service provided by PPMD.

### **2017 State-wide Families Focus Groups on Care Coordination**

PPMD, in partnership with MDH OGPSHCN, conducted focus groups with families in Maryland to better understand the key issues they were encountering with regard to care coordination and accessing services for children with special health care needs. The focus groups were conducted regionally in Central MD, Capital Region of MD, Easter Shore, Southern MD, and Western MD. Each of the 8 regional focus group sessions consisted of on average of seven parents of children with various disabilities, ages, races, and insurance types. Focus group participants were recruited by OGPSHCN, PPMD staff, and a variety of community based partners. Parents who participated in the focus groups are representative of the diversity of CYSHCN in Maryland. Transcripts were coded for key themes by two content experts.





MARYLAND'S SPECIAL EDUCATION  
AND HEALTH INFORMATION CENTER