

Serving and Supporting
Children and Youth with
Special Health Care Needs
and Their Families in Maryland



FAMILIES REPORT ON
THE STATE OF THE STATE

BY

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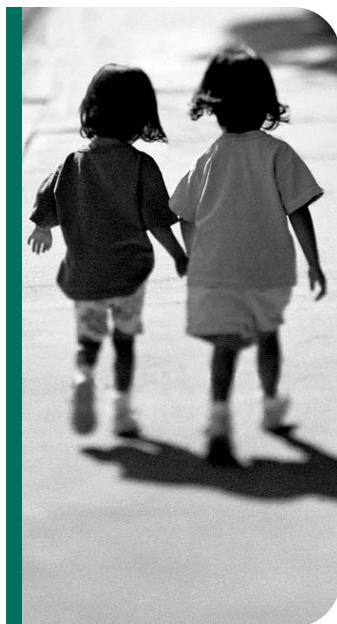
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ABOUT THIS REPORT



This report was developed by the Maryland Family Access Initiative. The Maryland Family Access Initiative is a collaborative project between the Parents' Place of Maryland (PPMD) and the Georgetown University Center for Child and Human Development funded by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, US Department of Health and Human Services. The Maryland Family Access Initiative was created to provide appropriate, consumer-friendly information to families of children with special health care needs, educate primary care providers on the needs of these children and the resources available for them, and inform managed care organizations (MCOs) and state agency personnel about their needs.

This State of the State report highlights what families and providers 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 are from four key sources:

- **National Survey of Children with Special Health Care Needs 2001;**
- **Data on requests for assistance to Parents' Place of Maryland in 2004-2005;**
- **Focus group interviews with families and providers throughout Maryland in 2004-2005; and**
- **2006 on-line survey conducted by PPMD sponsored and funded by the Maryland Department of Health and Mental Health, Office of Genetics and Children with Special Health Care Needs Survey of families with CYSHCN in Maryland in 2006.**

All of these sources paint a consistent picture of the challenges families face. See Appendix A for specifics about these methodologies.

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 and includes 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 and families and advocates is spelled out.

WHO ARE CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS?



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.

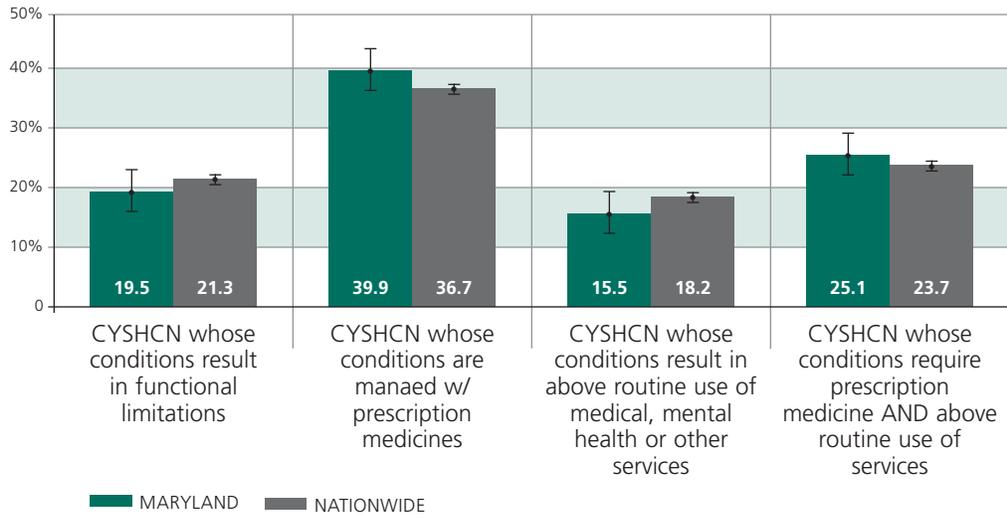
Based on the National Survey of Children with Special Health Care Needs sponsored by MCHB and conducted in 2000-2001 it is estimated that 15.2% of all children in Maryland ages 0 through 17 meet this criterion. This translates into 209,000 children with special health care needs. Maryland has a significantly higher percentage of CYSHCN than the national average of 12.8%. 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 criteria due to a medical, behavioral or other health condition that has lasted or is expected to last for at least 12 months:

1. Limited or prevented in ability to function
2. Prescription medication need/use
3. Need for specialized therapies (OT, PT, Speech)
4. Above routine use of medical care, mental health or other health services
5. Counseling or treatment for on-going emotional, behavioral or developmental problem

Table 1 reflects the percentages of children in Maryland who were included in the definition based on functional limitations, increased use of prescription medications, increased use of services or both of the latter two. (Child and Adolescent Health Measurement Initiative, 2005)

TABLE 1. PERCENT OF CYSHCN (AGES 0-17) QUALIFYING ON SPECIFIC TYPES OF SPECIAL HEALTH NEEDS CRITERIA

Nationwide vs. Maryland



Child and Adolescent Health Measurement Initiative (2005a).

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



ACCESS TO NEEDED SERVICES

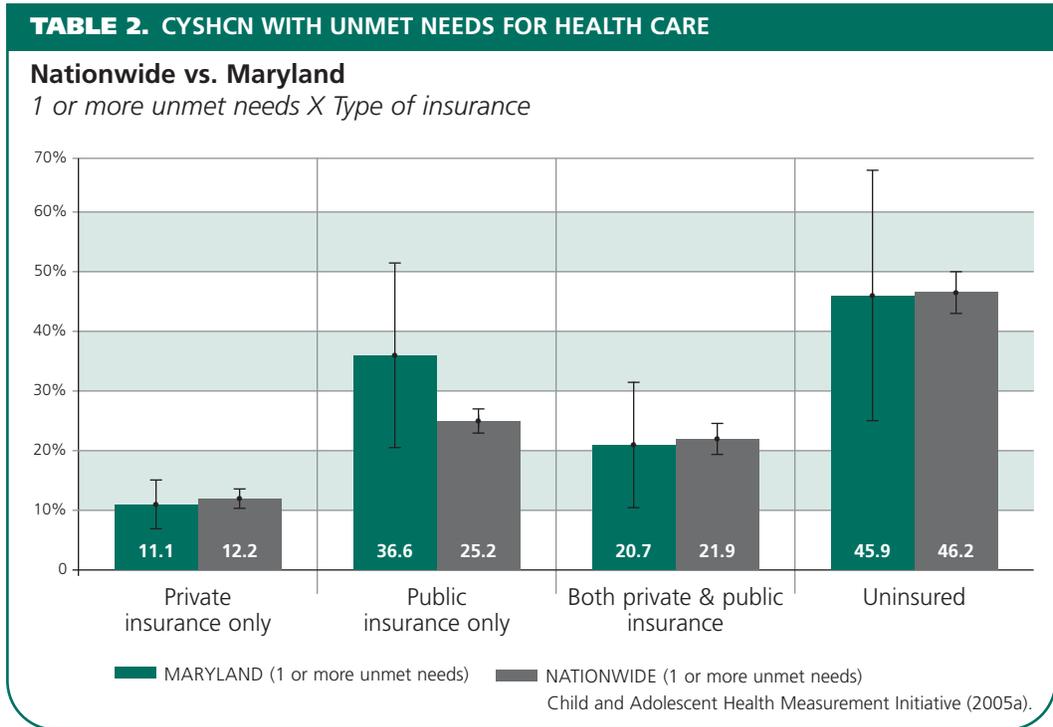
Access to services is a key concern for families of children and youth with special health care needs in Maryland. It is reflected in all of the data sources.

On the 2001 National Survey of Children with Special Health care needs 17.7% of Maryland children with special health care needs had families who reported that their child had one or more unmet need for specific health care services. The more severe the child's condition as rated by their parent, the more likely that there were unmet needs. Nearly half (45.5%) of children with severe conditions were facing unmet needs for health care services. These unmet needs are not equitably distributed for Maryland families. Those with public insurance and with no insurance are significantly more likely to face unmet needs than those with private insurance. Table 2 presents a comparison of Maryland to the nation as a whole.

In addition to needs for health services for their children, 15.6% of children in Maryland had parents who reported that they had unmet needs for family support services including respite care, mental health services and genetic counseling.

Of the 1,664 phone calls to PPMD for assistance during 2004-2005, 34.2% related to access issues. Specific concerns included: 1) no needed specialists in their area (9.8%); 2) no access to appropriate providers who had the expertise needed to treat their children's conditions (9.1%); 3) difficulty getting referrals through their health plan to get needed services (8.3%) and 4) difficulty accessing non-medical services such as respite care or durable medical equipment (7%).

Problems accessing needed services were the most frequently noted issues in focus groups of families and providers. Specific concerns related to lack of providers in the area, providers taking no new patients, provider networks for their health plans that did not include appropriate or available providers,



difficulty or long waits in getting appointments, distance to services and related transportation issues, and limits on referrals and reimbursement of services by health plans.

What Restricts Access for Maryland Families

While there are a number of factors that impact individual families, qualitative analysis of the focus group data, confirmed by the other quantitative data sources, indicate several common themes.

- Uneven geographical distribution of providers**—Almost 16% of 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 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 snowy, mountainous roads. In addition, Medicaid managed care plans are not evenly distributed throughout the state limiting choice and access to specialty care in parts of the state.

Families and providers suggested that having specialty services provided on an outreach basis in rural areas would be boon to families. In parts of the state, however, such efforts have been complicated by the fact that only one managed care plan covers that area. The

I laugh because the joke at my house is we subscribe to the Interstate 68 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

The availability of services is limited by managed care. The fact is that doctors who specialize in these kinds of issues cluster in metropolitan areas—they don't come to rural America. • PARENT, WESTERN MARYLAND

I can't get an appointment before 1 in the afternoon, because it's going to take me all day just to get to the appointment. ...Managed care plans calculate distance as the crow flies. Trying to find a local provider they ask you what your zip code is... They say it is so and so many miles, but don't know it will take me all day. They wanted to send me to Woodbridge. • PARENT, SOUTHERN MARYLAND

provider network does not include many specialists needed by children and youth in that area. Another provider network agreed to travel to the area and provide services. They worked out an agreement to be paid by the managed care organization in that area. Unfortunately, the hospital at which those specialists had admitting privileges was not included in the agreement, so that when children needed hospitalization, they could not be followed by the physicians who saw them on a regular, outpatient basis.

- **Lack of mental health providers to serve children and youth**—Approximately half of calls for assistance to PPMD came from families with children with behavioral and mental health problems. A consistent theme from the focus groups with families and providers was the dearth of mental health providers for children and youth.

There are not enough child psychiatrists out there at all. I lived in Essex and had to go to Columbia, Maryland to find one. That is about 50 minutes ride from where I lived, it was crazy. And then I couldn't find a therapist, I had a hard time finding a therapist in the same location he was in. Then you have to make the appointments the same day, I can't keep going 2-3 times a week.

- **Lack of dental services for children and youth with special health care needs**—In addition to the generalized issues of access to dental care for children, particularly those on Medicaid, families and providers report lack of dental services by providers trained and willing to deal with the behavioral issues of children with developmental disabilities. Children with these disabilities often need specialized approaches, sedation or even general anesthesia to tolerate dental procedures. Parents repeatedly gave examples of extreme difficulty finding such services and large out-of-pocket expenses when they could locate them.

When our son was 4 or 5, he had to have dental work. Only way was to have him anesthetized so we had to go to the hospital. We got a \$4-5,000 bill. My insurance would not pay because it was a dental benefit, not a hospital benefit. • PARENT, PRINCE GEORGE'S COUNTY

We went through about five different dentists in the county, not being able to get services from them. And so now we go to Baltimore to get dental services. • PARENT, PRINCE GEORGE'S COUNTY

An issue for the special health care needs is how many providers can and are willing to do these kids. Many of them need exams under anesthesia, etc. Kernan has a very good special needs dental clinic...but now they're basically closed to new patients. And it is one of the few places in the state that will see them. • PEDIATRICIAN

My son had a tooth that was bad. It took us months, months and months to finally get him in at Kernan Hospital in Baltimore and get preauthorization—in his case not only dental, but also medical. Medical preauthorization because he has to be put under. Here is this little autistic kid and he is not going to sit there and just open his mouth. The day before we were scheduled, they said they didn't have preauthorization. It took 3 more weeks. He had 3 abscessed teeth they pulled and 5 crowns. This kid had been in agony. • PARENT, SOUTHERN MARYLAND

- **Insurance related issues**—Four issues were cited repeatedly in focus groups.
 - First, families on Medicaid frequently report that they cannot find providers willing to take their insurance. A secondary problem is that some providers who will take Medicaid, will only give those patients less desirable appointment times that interfere with school and work hours.
 - Second, some children are in need of care by “super specialists”—there may only be one such provider in the state and that provider is not part of the provider networks for all health plans. For children to receive services of a super specialist it may take extensive negotiations with the health plan and the provider and large out of pocket expenses for the families. In some cases, there were reports that negotiations took so long that children did not get timely care and the conditions could no longer be addressed.
 - Third, families reported that provider networks for their health plans either did not include the specialist they needed or those specialists on the plan had no openings for new patients. This necessitated foregoing services or paying large out-of-pocket costs.
 - Fourth, families had difficulty getting referrals for specialty, diagnostic and mental health services from health plans. In the 2006 PPMD survey of families in Maryland with CYSCHN, over a quarter (26.12%) reported having somewhat to extreme difficulty getting a referral for needed services.

Three quarters of them are saying, well we only keep a couple of appointments open for MA patients there during the morning. So my son is out of school quite a bit because the prime, you know, appointments are going to those that are paying full freight.... • PARENT, PRINCE GEORGE'S COUNTY

When they knows it's MA, they take forever to get appt—they tell me “There's no openings.” I'll bet they'd take him if it wasn't MA. • PARENT, PRINCE GEORGE'S COUNTY

ADEQUACY OF HEALTH INSURANCE

Based on findings from the National Survey of Children's Health in 2003, children in Maryland are significantly more likely to be insured (95.6%) and to be insured continuously over the past year (91.5%) than the national average (Child and Adolescent Health Measurement Initiative, 2005b). 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 National Survey of Children with Special Health Care Needs, between 22 to 47% of children in Maryland had parents who reported that their child's insurance coverage was not adequate depending on the severity of the child's condition. The more severe the child's problems, the more likely parents were to cite inadequate insurance. (Child and Adolescent Health Measurement Initiative, 2005a)

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

- **Access to needed care is problematic**—As already noted, families found insurance coverage inadequate in many instances, because of limited coverage of needed services, limited provider networks and problems using their insurance with some providers limited access.

In addition, a series of other issues emerged. Families struggle with the complexity of their health plans' administration and policies. Thirty percent of calls for support to PPMD in 2004-2005 related to health plan administration issues ranging from lack of information about the plan and how to use it, to not understanding the benefits, and denials and appeal procedures.

On the PPMD survey of families with children with special health care needs in 2006, nearly a third of families responding (30.7%) indicated that they understood the process for getting authorizations or referrals from their health plan only "somewhat to not at all." When asked how well they understood their health plan's appeals process when services/claims were denied, 45% indicated that they did so only "a little bit or not at all."

The most discussed issues in the state-wide focus groups were complex rules, coordination of benefits, "crazy policies" and denial of services. Families and providers discussed the complex and often-changing rules, having to know the "right words or language" to get approvals, long and difficult processes to get approvals or referrals and large investments of time and energy to get needed, covered services through the plan in a way that met the child's special health care needs.

There are so many hoops that they make you jump through that after a while it almost feels like that they are putting up the hoops so you won't jump through them, so you'll finally just throw up your hands and go—forget it. • PARENT, WESTERN MARYLAND

And it's like the insurance companies don't know our children, don't see them, don't live with them, don't know anything about them but dictate where we can take our children and who will provide them with care solely based on nickels and dimes. • PARENT, WESTERN MARYLAND

We needed a new nebulizer immediately. It took 1 month to get the machine and we had to go to the doctor for treatments. • PARENT, PRINCE GEORGE'S COUNTY

My child is catheterized. With our previous insurance, every month UPS showed up at our door with a box of catheters. But when we changed insurance, they were like OK, you can't get it any longer, so we had to go from using a catheter once to reusing catheters. We have been blessed that she hasn't had any urinary tract infections so far. I kept calling the referral line or whatever, telling my story over and over. I was like I need to speak to a supervisor. Long story short, we still don't get them. I found that it was considered durable medical equipment. So are her braces and she needs them to walk, and her wheelchair. • PARENT, SOUTHERN MARYLAND

Parents frequently used the term “crazy policies” for health care plan decisions that seemed to serve neither the child nor the fiscal interests of the plan. In some cases, denial of a service led to the need for far more expensive care. Both families and providers shared frustration with constant changes in provider networks and in health plan policies.

The 12 hospitalizations my son has had in 20 months cost the insurance company about \$200,000. If I had \$200,000 to take care of my son, I would have purchased home care and I could have provided that care for 5-10 years. It would have been cheaper, longer with better outcomes. • PARENT, BALTIMORE CITY

I called the insurance company... the insurance company assured me that the surgeons at a particular hospital did (take the insurance). So I refer the kid to that hospital. He goes over there. He gets there and the surgeon calls me, the office calls me and says, “We don't take this insurance any more.” • PEDIATRICIAN

- **High out of pocket costs**—A key issue related to families rating of adequacy of their insurance was out-of-pocket costs for their children's services. Based on the National Survey of Children with Special Health Care Needs, 23.6% 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 23.8% 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 PPMD survey in 2006 of Maryland families with children with special health care needs found that approximately 42% spent \$1,000 or more out of pocket for medical expenses for those children. 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, as would be expected. What was surprising was the finding that 18% of respondents whose children were only on public insurance had out of pocket expenses of over \$1,000. Table 3 presents the types of out of pocket expenses reported.

TABLE 3. TYPE OF OUT OF POCKET EXPENSES X TYPE OF INSURANCE

		Private Ins n=140	Public Ins n=57	Private & Public Ins n=32	Total n=229
Copays	COUNT	119	14	25	158
	%	85.00	24.56	78.13	69.00
Deductibles	COUNT	82	3	16	101
	%	58.57	5.26	50.00	44.10
Medications	COUNT	101	22	17	140
	%	72.14	38.60	53.13	61.14
Equipment	COUNT	37	17	9	63
	%	26.43	29.82	28.13	27.51
Mental Health Services	COUNT	48	16	8	72
	%	34.29	28.07	25.00	31.44
Services Not Covered	COUNT	59	14	19	92
	%	42.14	24.56	59.38	40.17
Other	COUNT	41	17	9	67
	%	29.29	29.82	28.13	29.26

*Total percentages may exceed 100 due to multiple responses

Data Source: 2006 PPMD Survey

- Poor coverage for durable medical equipment**—For families whose children utilize durable medical equipment such as wheel chairs, braces, orthotics and even special glasses, numerous 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 and policies related to durable medical equipment were often based on adult needs, not the special needs of young and growing children.

I have a patient who has a diaphragmatic pacer that keeps him alive basically. It's what makes him breathe. And they have these antennae that go on his chest. And every six months or so I have to get it reauthorized. And finally, I just write, "Without these he'll die". • PEDIATRICIAN

I have to pay out of pocket—Medicaid will only pay for a wheelchair every 5 years, but she's growing and needs a new chair every 2 years. Our last chair cost \$8,000 and standers are \$2,000. Medicaid doesn't deem it necessary. • PARENT, PRINCE GEORGE'S COUNTY

I needed glasses for my child. He's very small and grabs and breaks them. Medicaid only pays for 2 pairs a year. Sometimes I can't afford new glasses. They cost much more than \$100. • PARENT, PRINCE GEORGE'S COUNTY

- Frequent changes in coverage**—Since over three quarters of children in Maryland are insured privately, the impact of changes by employers to their health coverage has an impact on families. For families of children with special health care needs, the impact can be significant, when needed specialists in one plan are no longer in the provider network of the new plan and hard won relationships with providers who understand the

very specialized needs of their children are lost with each change. A recurring theme from families in the focus groups across the state was the impact of having to change health plans.

We have insurance through my husband's job and it keeps changing every year—something different. Of course it's not ever getting better—only reducing what you do get. It makes it very difficult to stick with it. I'd like to see union contracts stay the same for at least two years so you don't have to keep reinventing and relearning. • PARENT, WESTERN MARYLAND

I been with my employer now for 10 years—right after my daughter's diagnosis my employer drops the insurance plan—the one they drop has one mental health panel and switch her to a different plan with a different mental health group. It didn't effect us so much for the medical care but the mental health care was a nightmare—transitioning her from a therapist we had an excellent relationship with who was not on the new provider group. It took her a year to get certified by that time my daughter was in Social Services custody. Her psychiatrist didn't take the new insurance so we had to switch to a different psychiatrist in the practice that did take it so it was like starting from square one again. • PARENT, BALTIMORE CITY

- **Coordination of benefits impacts access to care**—Two categories of families noted difficulty with coordination of benefits for their children. First, when parents were divorced, insurance companies apply a rule that the policy of the parent whose birthday occurs first during the year will be primary coverage. This can then assign the child or youth with special health care needs to a policy with lesser coverage, or in some instances to a policy of a parent who lives out of the state and whose health plan has no provider networks in Maryland. A second group of families struggle with the complexity of coordinating private and public coverage when their children participate in one of the Medicaid waiver programs in Maryland. In these instances families struggle with conflicts over which health plan will cover a service, which will be primary and which providers will accept.

We were trying to get an evaluation and we had Tri-Care and they said they don't take Tri-Care. That's fine. I have cash and I will pay, but silly me, I broke down that he has a Medicaid waiver. You can't self-pay if you have the Medicaid waiver. I was denied medical care that I wanted to buy for cash because they wouldn't see my child. They wouldn't accept my cash, because he had a Medicaid waiver. • PARENT, SOUTHERN MARYLAND

FRAGMENTATION OF THE SYSTEM

In family and provider focus groups, the issue of the lack of coordination of services and supports for children and youth with special health care needs was a frequent theme. In 2004-2005, almost 22% 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 National Survey of Children with Special Health Care Needs. Overall, 29.4% of children had parents who reported that services and supports were not organized in a way that was easy to use. Children with family incomes of 0-99% of federal poverty level had even more parents who were having difficulty using the system (54.9%). An even higher percentage (68.7%) of parents with children rated as having the most severe conditions and the highest needs reported that the system was not easy to use.

Families and providers 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. There were concerns that there is no reimbursement to health care providers for care coordination who need to support families in dealing with the fragmented system. At the same time, families and providers 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.

My Cystic Fibrosis patients...they all go to one hospital for Cystic Fibrosis, but they all go to different institutions for other parts of their medical care, and it becomes a nightmare for them. • PEDIATRICIAN

We do find that the doctors will not give my kids tetanus shots (they have to go to the Health Department) because ...it's such an expensive shot and because Medicaid doesn't even come anywhere near covering their cost. • PARENT, PRINCE GEORGE'S COUNTY

If there could be some kind of general generic training for the local hospital and emergency room for an autistic kid. To have him wait 7 hours in the waiting room—they have no clue what to do with him. • PARENT, SOUTHERN MARYLAND

If a child is in Infants and Toddlers and in REM and in Foster care and has autism, they could end up with four different case managers, but none of them talk to each other. • PEDIATRICIAN

IMPACT ON MARYLAND FAMILIES

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 their children. Families report 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 parents having to give up employment, again impacting the financial status of the entire family.

They have no way of getting their children where they really need to be to get the services that need to be rendered...And that's horrific. We don't have things like respite care. If you have a situation where your child needs to go to Kennedy Krieger and is going to be there overnight for testing or something like that, and you're a single parent and you don't have resources at home, who is going to be there for your other kids? • PARENT, WESTERN MARYLAND

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

- **Time spent on arranging and coordinating care**—On the National Survey of Children with Special Health Care Needs, children with special health care needs in Maryland had parents who reported spending the following time on arranging or coordination their care:
 - 32.8% spend 1 to 4 hours a week;
 - 9.5% spend 5 or more hours a week;

Slightly over 10 percent of parents of children rated as having severe conditions spent more than 11 hours a week arranging and coordinating care and 11.7 %parents of children rated most severe spent that amount of time. In addition, 11.5% reported spending more than 5 hours a week providing health care to their children at home.

My son is 10 years old and has no idea how to chew. It took me 2 years to get him accepted at Kennedy-Krieger to get him from pureed to ground foods. My insurance said it would not pay for inpatient treatment, because it could be done on an outpatient basis. I would have to drive him to Kennedy-Krieger every Monday-Friday from 8:30 to 5:00 for 8 weeks and you must stay with your child. Being a single mom with no other means of support and a disabled mother who lives with me and counts on me to do everything, I couldn't do that, so I appealed—if I do this we are going to be homeless and I am going to lose my child. I appealed on a second level and was denied. I appealed on a third level and was denied. When I got to the state insurance commission level...I was so overwhelmed and frustrated with everything. I didn't proceed...I just didn't have the energy anymore. • PARENT, SOUTHERN MARYLAND

I spend about 8 hours a week at least, just dealing with, on the phone, trying to get coverage for things that are supposed to be covered. • PARENT, SOUTHERN MARYLAND

- **Financial impact on the family**— As already noted, families experience high out of pocket costs for services and supports. 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. One or more parent may have to give up employment or change employment to be able to have the time to care for their child.

On the National Survey of Children with Special Health Care Needs, 16.3% of children with special health care needs in Maryland had parents who reported that the family experienced financial difficulties due to the health needs of that child. When the child's condition was severe (37.2%) or in the most severe category (25.9) even more reported financial difficulties.

Parents responding to the PPMD survey in 2006, who on average rated the severity of their children's special health care needs as 6.75 on a scale of 1 (mildest) to 10 (most severe), also reported significant financial impacts. Of those responding, 50% with private insurance, 67.4% of those whose children had public insurance and 80% of those whose children had both types of insurance reported that their child's needs had caused financial difficulties for the families. Depending on the type of insurance they had, between 52.5% and 66% needed additional income to cover expenses related to their child's special health care needs.

The financial impact was not only on expenses, but also on income. Because of the time needed to provide, arrange or coordinate care, many parents had to alter their employment status.

On the 2001 National Survey of Children with Special Health Care Needs, children with special health care needs in Maryland had families who reported that caring for their children had an impact on employment. Overall 27.4% said they had cut down on work and 47.2% of parents with children whose conditions they rated as severe and 54% of those rated most severe had cut down on work hours. In addition, 12.4% reported stopping work altogether and 26.6% of those with children rated as having severe and 40.2% of those with children rate as having most severe problems had stopped working. Families in Maryland with children rated moderately to very severely involved were more likely than families nationally to report that they had stopped working due to having to deal with their children’s care.

Families who responded to the PPMD 2006 survey also reported impacts on employment. Again, it is important to recognize that these respondents had, on average children with more severe difficulties. Table 4 presents the findings of the PPMD 2006 survey on impact on employment status.

TABLE 4. PERCENTAGE OF FAMILIES REPORTING EVER EXPERIENCING IMPACTS ON EMPLOYMENT X TYPE OF INSURANCE

Impact on Employment	Private Insurance	Public Insurance	Private and Public Insurance
Cut down hours of work	62%	66%	83%
Did not take a promotion or worked in a lesser capacity	59.5%	71.9%	77.4%
Stopped work because of child’s condition	42%	59.7%	53.3%

N = 184

Data Source: PPMD 2006 Survey

That really translates into dollars in terms of your own time and effort, and loss of employment opportunities because you have to do this other full time job that does not pay. • PARENT, CENTRAL MARYLAND

I have a MBA in finance and for me to go and get a job doing what I do what I am trained to do—more likely than not that would be 50-60 hours a week. And to make a commitment to that kind of position—I can’t do that, I can’t and survive.... children with mental health issues tend to require 24hour/7 day a week care, and it’s next to impossible—you have to have one parent up when the other parent is sleeping. • PARENT, BALTIMORE CITY

My husband did switch jobs....so we can get better insurance for us... Now he is traveling from Wheaton to Baltimore everyday for his job, so he can have better insurance. • PARENT, CENTRAL MARYLAND

MARYLAND IS MAKING PROGRESS



In the past five years, there has been some measurable progress made in the four key areas highlighted by this report. Several legislative changes, including mandating hearing aid coverage and the habilitative services coverage in private health plans, have improved health care financing for some families. State regulations passed this year mandated the inclusion of consumers on the Medicaid Advisory Council. Previous legislation (HB 1386) eliminated the need for parents to relinquish custody of their children in order to access services from the state. Maryland is one of seven states awarded a Mental Health Transformation Grant. This grant is charged with revamping the delivery of mental health services in Maryland.

The Department of Health and Mental Hygiene Office (DHMH) of Genetics and Children with Special Healthcare Needs has partnered with the Parents' Place of Maryland on many initiatives that are beginning to bring families into partnership with policymakers. These are changing the landscape for families of children with special healthcare needs. The Maryland Medical Home Leadership Team is comprised of policymakers, state agencies, families, healthcare providers, and more. Together they strive to improve the delivery of medical services to families in Maryland. A Families as Faculty program, matching healthcare students with families for home visits, has begun in Maryland. In partnership with several advocates and families, DHMH published several family friendly brochures on Medical Assistance topics. Advocates and families also pushed to have Maryland apply for the Autism Waiver, which serves over 1,000 families, despite its long wait list.

The Parents' Place of Maryland has been a strong voice for families of children with special healthcare needs for over 15 years, and now is funded as a Family-to-Family Health Information Center (F2FHIC) by the Maternal Child Health Bureau. Previously the F2FHIC was funded by Center for Medicare and Medicaid Services. DHMH continues to fund the work of the F2FHIC at the Parents' Place. PPMD works with DHMH to place a parent in the Medicaid office. The parent has successfully participated in many taskforces and workgroups that change the way services are delivered.

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

A CALL TO ACTION FOR MARYLANDERS



Maryland can do a better job of providing services and supports 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 15 actions for Marylanders follows. For those marked with an *, check the next section to gain more information about the proposed action.

Action 1. Maryland should assure that family voices are heard at every level and that families are full partners in planning, implementing and evaluating services and supports and the systems that coordinate and finance them. State policy makers, program staff, insurers, employers who purchase insurance and make employment policies 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 2. Maryland should implement and 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 and coordination of care. The state of Massachusetts has successfully created and sustained such a consortium.*

Action 3. Maryland should implement the federal Family Opportunity Act's provision that allows families of children and youth with special health care needs to buy into Medicaid with its often broader array of covered services and lack of co-pays and co-insurance costs to families.

Families of children and youth with special health care needs cannot singly address the regional disparities and lack of specific classes of services noted in access to care. There needs to be a state level response.

Action 4. 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. Approaches may include coordinating

traveling clinics, use of telehealth technologies, etc. The coordination of financing such approaches should also be part of the solutions identified.

Action 5. The Maryland Medicaid program should address regional access issues through its contracts to MCO's. The state agency should support a process of statewide planning and interplan coordination. This process could be supported through a task force from the statewide consortium on children and youth with special health care needs.

Action 6. The current Oral Health Coalition in Maryland that is addressing access to dental care for children in Maryland should address the specific access issues of children and youth with special health care needs.

Action 7. Maryland needs to continue to address the lack of pediatric mental health providers and their distribution across the state.

Too many families are burdened with the cost of providing care to their children and youth with special health care needs.

Action 8. Maryland employers providing health care benefits should gain a greater understanding of how decisions in purchasing coverage may impact employees who have a child with special health care needs. Involvement of employees with special health care needs and information from the Family to Family Health Information Center at the Parents' Place of Maryland can inform employers.

Action 9. 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.*

Individual families can no longer be forced to spend inordinate amounts of time dealing with a highly fragmented system of services and supports. There need to be state and local efforts that bring together key stakeholders to create easy to use and coordinated services and supports. While there are often multiple care coordinators through public programs, families are not experiencing coordinated care.

Action 10. The array of public agencies that impact policies and programs for children and youth with special health care needs should assure that health is integrated into all of their efforts.

Action 11. The state should continue to support and expand support for programs that help families navigate the complex and fragmented systems such as the Local Access Mechanisms established by House Bill 1386, and the Family to Family Health Information Center. In addition, information that is key for the array of children and youth with special health care needs should be available for the emerging 211 call system.*

Action 12. Maryland should adopt a universal application form for service and support programs that impact children and youth with special health care needs. The state of Utah has implemented such a program called Utah Clicks.*

Action 13. Maryland, with strong support for the state chapter of the American Academy of Pediatrics, should implement and expand the work of the Medical Home State Leadership Team that is working to spread the medical home model throughout the state.*

Action 14. A task force from a statewide stakeholder group focusing on the needs of children and youth with special needs should gather information about the array of care coordination models for children and youth with special health care needs and the costs/financing mechanism that support them. The task force should make recommendations for a model that will fit the needs of Maryland and a plan for implementation.

Caring for children and youth with special health care needs can have negative impacts on employment. In some cases, family members have to stop working or reduce hours. The difficulties in providing care and coordinating services then take a toll not only on the individual families, but on the productivity of businesses in Maryland.

Action 15. 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.*

MORE INFORMATION ON SELECTED ACTIONS

ACTION 2

Maryland Consortium for Children with Special Health Care Needs

Contact: Josie Thomas
The Parents' Place of Maryland
801 Cromwell Park Drive, Suite 103
Glen Burnie, MD 21061
V/TDD: 410-768-9100
Fax: 410-768-0830
E-mail: josie@ppmd.org

Massachusetts Consortium for Children with Special Health Care Needs

c/o New England SERVE
101 Tremont Street, Suite 812
Boston, MA 02108
Phone: 617-574-9493
Fax: 617-574-9608
E-mail: info@neserve.org
Webstie: www.neserve.org/maconsortium/mac_about.html

ACTION 9

Models and Financing of Care Coordination, Information About State Catastrophic Relief Funds and State Implementation of the Family Opportunity Act Medicaid Buy-In

The Catalyst Center
Health and Disability Working Group
Boston University School of Public Health
374 Congress Street, Suite 502
Boston, MA 02210
Phone: 617-426-4447, ext. 27
Fax: 617-426-4547
TTY: 617-422-0754
E-mail: mcomeau@bu.edu
Website: www.hdwg.org/catalyst

New Jersey Catastrophic Relief Fund

New Jersey Department of Human Services
Phone: 609-292-0600

Michigan Children with Special Needs Funds

Phone: 517-241-7420

ACTION 11

Information on Family to Family Health Information Centers and Local Access Mechanisms

Kim McKay
The Parents' Place of Maryland
801 Cromwell Park Drive, Suite 103
Glen Burnie, MD 21061
V/TDD: 410-768-9100
Fax: 410-768-0830
E-mail: kim@ppmd.org

Information on Family Needs for Children's Mental Health Services and Local Access Mechanisms

Jane Walker
Maryland Coalition for Children's Mental Health
10632 Little Patuxent Pkwy, Suite 119
Columbia, MD 21044
Phone: 410-730-8267
Toll Free: 1-888-607-3637
Fax: 410-730-8331
E-mail: info@mdcoalition.org, jwalker@mdcoalition.org
Website: www.mdcoalition.org

ACTION 12

Information on Utah Clicks

<https://utahclicks.org/uas/>

Contact for Developers of Utah Clicks

Dynamic Screening Solutions
www.dynamicscreeningsolutions.com/DSS/content
Adrienne Akers, President & CEO
Dynamic Screening Solutions, Inc.
33 N Main, Suite 204
Logan, UT 84321
Phone: 435-770-3796

ACTION 13

Information on Medical Home

The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home.

www.medicalhomeinfo.org

The National Center of Medical Home Initiatives
141 Northwest Point Boulevard
Elk Grove Village, IL 60007
Phone: 847-434-4000
Fax: 847-228-7035
E-mail: medical_home@aap.org

Information on Maryland Medical Home Initiatives

Rachel Hardegree, M.P.H.
Office for Genetics and Children with Special Health Care Needs Maryland Department
of Health and Mental Hygiene
201 W. Preston Street, Room 423A
Baltimore, MD 21201
Phone: 410-767-6731
Fax: 410-333-7956
E-mail: rhardegree@dhmh.state.md.us

ACTION 15

Information for Employers

Children with Special Needs and the Workplace: A Guide for Employers
[www.massgeneral.org/children/professionals/ccahp/empl_benefit_study/pdf/
EmployerGuide.pdf](http://www.massgeneral.org/children/professionals/ccahp/empl_benefit_study/pdf/EmployerGuide.pdf)

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ABOUT THE MARYLAND FAMILY ACCESS INITIATIVE PARTNERS



The Georgetown University Center for Child and Human Development (GUCCHD) was established over four decades ago to improve the quality of life for all children and youth, especially those with, or at risk for, special needs and their families. Located in the nation's capital, this exceptional center both directly serves vulnerable children and their families, as well as influences local, state, national and international programs and policy. The GUCCHD is a designated University Center for Excellence in Developmental Disabilities for the District of Columbia. GUCCHD is a division of the Department of Pediatrics of the Georgetown University Medical Center.

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Established in 1990, The Parents' Place of Maryland (PPMD) was created by parents of children and youth with disabilities and special healthcare needs to help other parents and families facing similar challenges. PPMD helps families throughout Maryland, regardless of the nature of their child's disability or the age of their child. The mission of PPMD is to ensure that all children participate as fully as possible in home, school, and community life. Funded by MCHB as the Family to Family Health Information Center and by Office of Special Education Programs, U.S. Department of Education as the Parent Training and Information Center, the Parents' Place of Maryland provides training, information and resources on healthcare and special education issues to families of children with disabilities and special healthcare needs. PPMD is internationally recognized for its work in parent involvement. The Parents' Place workshops, conferences and materials are widely used in Maryland and throughout the United States.

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REFERENCES

Child and Adolescent Health Measurement Initiative. (2005a). National Survey of Children with Special Health Care Needs, Data Resource Center on Child and Adolescent Health website. Retrieved 01/26/06 from www.cshcndata.org

Child and Adolescent Health Measurement Initiative. (2005b). National Survey of Children's Health, Data Resource Center on Child and Adolescent Health website. Retrieved 01/26/06 from www.cshcndata.org

APPENDIX A

METHODOLOGIES

2001 National Survey of Children with Special Health Care Needs

- A national survey conducted by telephone for the first time during 2000-2001
- Telephone numbers are randomly dialed to find households with one or more children under 18 years old
- Trained interviewers ask parents or guardians of children under 18 years old a series of questions to identify all children in the household with special health care needs
- A total of 372,174 children under 18 years old representing 196,888 households nationally screened to identify those with special health care needs
- Approximately 5,500 to 8,500 children in EACH state screened for special health care needs
- A total of 750 children with special health care needs in EACH state selected to be the focus child for the longer, more detailed CSHCN interview
- A total of 38,866 CSHCN interviews collected nationally during 2000-2001, with independent samples taken for all 50 states and the District of Columbia
- The survey is conducted in twelve languages, including English and Spanish
- The National Survey of CSHCN is sponsored by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services
- The National Center for Health Statistics of the Centers for Disease Control and Prevention oversees the sampling and telephone interviews for the National Survey of CSHCN

The Parents' Place of Maryland Calls for Support 2004-2005

Data was collected on demographic and other relevant information for calls received by the Parents' Place of Maryland (PPMD) from February 2004 to December 2005 (N=1,664). The Center received an average of 72 calls per month by 1,338 parents throughout Maryland, who were seeking information or services for their child or children with special healthcare needs (SHCN).

The information collected on the child patient includes his/her age, gender, ethnicity, county of residence, disability, and insurance type, as well as the parent's reason for calling and the service provided by the Parents' Place. Some parents requested services for more than one child per phone call, while others called multiple times regarding one or more children. It is also important to note that many children with special healthcare needs qualify for and obtain multiple types of insurance coverage concurrently. For example, a child with private health care coverage may also qualify for the Maryland state Medicaid program through a waiver granted to special populations. The insurance type identified by parents in this survey specifies which insurance the parent has a problem with or is seeking services about.

Out of all calls made to PPMD by parents of children with SHCN, 61% were Caucasian, 24% African American, 5% Asian, and 4% Hispanic. About 70% were boys and about the same proportion were school-aged children ages 6-18. The most common disabilities reported include autism (30%), emotional disabilities (11%), chronic or neurological disorder (10%), and attention deficit disorder (9%). Nearly half of these children received services through private providers (47%).

State-wide Focus Groups of Families and Providers

MFAI conducted focus groups with families and providers in Maryland to better understand the key issues they were encountering with regard to accessing services for children with special health care needs through their health plans. The focus groups were conducted by region, which included Baltimore city, Central, Southern, and Western Maryland, as well as two sessions from Prince George's county. Each of the 6 regional focus group sessions consisted of on average nine parents of children with various disabilities, ages, races, and insurance types. Focus group participants were recruited by parent educators responsible for locating other parents of children with SHCN within their region of Maryland. Parents who participated in the focus groups are representative of the diversity of children with SHCN in Maryland, with regard to ethnicity, age, disabilities, and type of health coverage. In addition to the six regional parent focus groups, a focus group was conducted with providers, which consisted of nine Maryland pediatricians. This offered unique insight to the challenges they face as providers for children with disabilities. Transcripts were coded using Atlas.ti.5.50 software for key themes by two content experts. A set of themes and families was established and analysis was based on the merged ratings of these experts.

PPMD/DHMH Office of Genetics and Children with Special Health Care Needs Survey

- Conducted survey of families with CSHCN in MD March-May 2006
- Both paper and electronic versions of the survey were made available to families.
- Survey disseminated through PPMD contacts, PPMD website and electronic newsletter, various listservs, disability and support group newsletters and other agency partners.
- Explored variety of issues related to access to health care for CSHCN
- 250 respondents
- Insurance status: 61% private, 25% public, 14% both
- Diagnoses skewed towards children with variety of developmental disabilities and associated health problems

Responding parents were asked to rate their children's special health care needs on a scale of 0 (mildest) to 10 (most severe), In this sample, the overall mean score was 6.25 (SD=2.14). The mean for children with private insurance only was 6.23 (SD=2.19); with public insurance only was 7.86 (SD=1.9) and with both private and public insurance 7.54 (SD=1.4).