

## Medicaid and its Role for Children and Youth with Special Health Care Needs (CYSHCN): A Family Perspective

By Liz Arjun, Cathy Hope, Jocelyn Guyer, and Joan Alker

### Introduction

**The nation's children have much at stake in the current debate at the federal and state level over the role Medicaid should play in deficit reduction efforts, but none more so than children and youth with special health care needs (CYSHCN).** Children and youth with special health care needs are more likely to be covered by Medicaid than other children. They are more likely to require Medicaid's comprehensive benefit and cost-sharing protections because of their relatively extensive health care needs. Overall Medicaid is the largest single payer of health care services for CYSHCN.<sup>1</sup>

Many CYSHCN live with serious conditions such as autism, cerebral palsy, complex genetic disorders, and epilepsy. Other CYSHCN have chronic health conditions, such as asthma and diabetes.<sup>2</sup> Across the spectrum of severity, Medicaid is vital, providing them with the care and supports they need to maintain and improve their health, stay in school, learn, and thrive. Medicaid's comprehensive benefits and cost-sharing protections also provide a measure of economic stability to the families of CYSHCN. In some instances, the care and supports that Medicaid offers can be what allows children to be cared for at home and in their community, rather than in a hospital or nursing home.

To explore what is at stake for CYSHCN in the current debate about Medicaid, this issue brief provides data on the number of CYSHCN enrolled in Medicaid and outlines how they qualify for coverage. It presents findings from interviews with families of CYSHCN about Medicaid's role in their lives conducted by the

Georgetown University Health Policy Institute Center for Children and Families and case studies collected by Family Voices.<sup>3</sup> The issue brief concludes with a discussion of policy implications and recommendations.



Laura and her brother

"Medicaid is really important to me and other kids. My parents have health insurance for our family from their jobs but it is not enough to cover the cost and needs that come with mitochondrial disease that my brother and I both have. Without Medicaid, my family would have declared bankruptcy years ago. I wouldn't have my scooter to get around and I wouldn't be able to live such a productive, independent life. I have big plans for my future and Medicaid is helping me achieve those dreams."

-Laura Rodgers,  
11-year old from Lebanon, Indiana

### Illinois Family Makes Personal Sacrifices to Meet Son's Health Needs

A family in Illinois is sending their oldest son off to college this year. It should be a joyful time— he was accepted into his first choice college and he's a very responsible young man— yet they worry. Despite the fact they work hard and earn a good living, the family has only been able to save enough to cover one year of college as they have been paying the equivalent of a college tuition each year to cover medical and autism therapy bills for their younger son for the past several years. They have taken out a second mortgage and short-changed their retirement fund in order to pay the bills. The family would be far worse off if they had not been able to enroll their youngest son in a home and community based waiver through Illinois' All Kids program. Seizures caused their younger son to lose the ability to walk last year and, at 130 pounds, it is impossible for his mother to care for him in their home without the help of home health care aides. Potential cuts to Medicaid at the national and state level threaten to reduce the amount of help the family receives. They have already made great personal sacrifices to care for their son and have nowhere else to turn if Medicaid cuts are passed onto them.

### Medicaid's Role for Children with Special Health Care Needs: A Review of the Data

The most recent data indicate that of the 74 million children in the United States, approximately 14 percent (10.2 million children) meet the criteria of having a special health care need.<sup>4</sup> Thirty-six percent or 3.6 million of these children rely on Medicaid or CHIP for all or part of their health care coverage.<sup>5</sup> In most instances, Medicaid is the sole source of coverage for these children, but it also often plays the role of serving as a “backup” or “supplemental” source of coverage for those with private insurance. Notably, the majority of CYSHCN have private insurance, but 33 percent of their families report their child's coverage is inadequate in meeting their needs.<sup>6</sup> For these families, Medicaid can help fill coverage gaps and make the private coverage more affordable.

### Routes to Medicaid for Children and Youth with Special Health Care Needs

For families with CYSHCN, securing insurance for their children's health care needs is essential, and they often will sacrifice other top family priorities if they must to do so (See the Illinois family story above).<sup>7</sup> This may help to explain why the rate of children and youth with special health care needs who lack coverage is lower than that of children in the general population.<sup>8</sup> Currently, more than nine in ten CYSHCN (91.2 percent) have health insurance,<sup>9</sup> although as noted above, it is often not fully adequate to address their needs. Of the CYSHCN with coverage, more than one in three (35.5 percent) are enrolled in public coverage,<sup>10</sup> sometimes as their primary source of insurance and sometimes as a secondary source of coverage. For these children, there are many different

routes to obtaining Medicaid coverage:

#### Eligibility Based on Being Part of a Low-Income Family.

If a family meets a state's Medicaid income eligibility requirements, they can enroll their child through the Medicaid “poverty level” categories, regardless of whether the child has a disability or special health care need. Under the poverty level eligibility categories, all states, at a minimum, must offer Medicaid for children ages zero to five whose family income is up to 133 percent of the federal poverty level (FPL) (equal to about \$29,000 for a family of four) and children ages six through 18 in families with income up to 100 percent of the FPL (approximately \$22,000 for a family of four). States also have the option to expand Medicaid to children above these minimum thresholds, and all states have opted to do so through Medicaid or the Children's Health Insurance Program (CHIP).<sup>11</sup> In fact, 25 states and the District of Columbia provide coverage to families with income at least up to 250 percent of the FPL. See table 1 at the end for a list of states and their maximum eligibility levels for children's coverage.

#### Eligibility Based on Receipt of Supplemental Security Income (SSI).

A second pathway to Medicaid for children and youth with special health care needs is through Supplemental Security Income (SSI), a federally administered program that provides cash assistance to those with long-term disabilities. In most states, receiving SSI automatically confers Medicaid eligibility.<sup>12</sup> Approximately 1.2 million children are enrolled in Medicaid because of their SSI status.<sup>13</sup> To qualify for SSI a child's family must have income below roughly 75 percent of the FPL and the child must:

- Have a medically determinable physical or mental impairment(s) which results in marked and severe functional limitations (i.e., impacted in two or more areas of ability to learn); and
- Have a condition(s) that has lasted or is expected to last for a continuous period of at least 12 months or expected to result in death; or
- Be blind.

There are some CYSHCN whose family income is higher but who are able to obtain Medicaid coverage through SSI because the level of care that they need can only be provided in an institutional or hospital-based setting. Since these children are living outside the home, their parents' income is not counted when evaluating their eligibility for SSI and related Medicaid coverage. Historically, this policy created a bind for families torn between wanting to care for a disabled child at home, but whose only access to Medicaid coverage was through institutionalization. Later in the brief, we discuss the ways that Medicaid has evolved to better serve CYSHCN in such situations, including initiatives to provide care in a home or community-based setting, and what more needs to be done.

**Eligibility as “Medically Needy.”** A third way that children and youth with special health care needs are able to obtain Medicaid coverage is through the “medically needy” option. It allows states to extend Medicaid coverage to people, including children, who may have income that is too high to qualify for Medicaid, but whose medical expenses are significant enough to bring their income below a state's eligibility threshold. For example, a child undergoing chemotherapy for cancer treatment or receiving an organ transplant would quickly accrue medical bills that bring the family's income below a state's Medicaid

eligibility level. States can also charge families premiums that would bring the family income to below the Medicaid eligibility level. Data suggest that in 2010, approximately 800,000 children were covered under this option.<sup>14</sup>

### How Does Medicaid Serve Children and Youth with Special Health Care Needs?

To fully understand the role of Medicaid in the lives of children and youth with special health care needs, it is important to consider the range of ways Medicaid serves them. In general, CYSHCN require more health services and have significantly higher expenses, making Medicaid and its benefit and cost-sharing protections even more important to them than other children. For example, one study found that CYSHCN spend seven times as many days in hospitals as other children; receive five times as many prescription drugs; and see health care providers (physicians and non-physicians) far more frequently. Overall, their health care expenditures are more than three times the average for other children.<sup>15</sup>

**As a Primary Source of Health Coverage.** Close to eight in ten children and youth with special health care needs who are enrolled in Medicaid and CHIP—some 2.9 million children—rely on these programs as their primary source of health care coverage.<sup>16</sup> These children typically enroll in Medicaid because they lack access to affordable employer-based insurance and cannot secure an individual insurance market policy<sup>17</sup> or because the private coverage available to them does not cover critically important services and supports. For these CYSHCN, Medicaid and/or CHIP are their only source of health insurance, and it provides them with a payment source for everything from primary and preventive care to hospitalizations, therapies or other specialized services.

### EPSDT – Providing CYSHCN With the Services They Need to Maintain Health and Thrive

A key component of what sets Medicaid apart from private health insurance for children is its Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit. EPSDT provides children enrolled in Medicaid with preventive care services, including well child visits and immunizations, as well as medically necessary early interventions before conditions worsen and are more costly to treat.

EPSDT has proven to be a vital pathway through which children and youth with special health care needs obtain essential services, such as durable medical equipment and rehabilitative and habilitative services like physical, speech and occupational therapy. Many of these services are not provided by or are insufficiently covered by private insurance.<sup>18</sup> EPSDT is the definitive standard of well-child and preventive care recommended by The American Academy of Pediatrics.

**As Secondary Coverage to Fill the Gaps.** For some 700,000 children and youth with special health care needs, private coverage is simply inadequate and Medicaid fills the gaps. For example, because private insurance typically is designed to address acute health problems rather than chronic illness and disability, it often places limits on services important to children and youth with special health care needs, such as habilitative therapies (speech, physical and occupational), durable medical equipment and mental health care.<sup>19</sup> Medicaid is able to play this role because of its strong child-specific benefit, known as “EPS-DT”, which requires children be provided with all care that is medically necessary to improve and maintain their health.

As a secondary source of coverage, Medicaid also assists families with the cost-sharing required by their private insurance. Over time, the cost of the co-payments, co-insurance charges and deductibles associated with caring for a child with special health care needs adds up and could be financially debilitating to a family. For example, one recent analysis found that for an otherwise healthy child with asthma, the family’s employer-sponsored insurance would cover most of the care but the family could still expect to pay \$2,020 out-of-pocket. For a child with more severe health care needs such as cerebral palsy, the study found that not only would the child’s medical needs not be met, but that the child would exceed the coverage limits under the plan and that the family could expect to pay more than \$9,000 out-of-pocket.<sup>20</sup> However, if a family is able to secure Medicaid as a secondary source of insurance, the care the child needed would be covered and the family would be protected against excessive out-of-pocket spending by Medicaid cost-sharing rules.



Emma camping with her family

**“I cannot imagine going one single moment through Emma’s life without Medicaid as her secondary insurance. At times, her medical and pharmaceutical bills could easily put our family of six on the street. It’s hard enough to raise a family in this day and age, but imagine what it’s like to live with children affected by life-long special healthcare needs.”**

*-Natalie Woolridge, Camden, Arkansas, Mother of daughter born with spina bifida*

**Allowing Children and Youth with Special Health Care Needs to Live at Home.** For many years, automatic access to Medicaid coverage as the result of institutional placement served as a powerful reason why many families felt they had no choice but to institutionalize their children. (As noted earlier, children who receive care in institutional settings, such as nursing homes, qualify for SSI-related Medicaid because their family’s income is not counted since they are receiving

care outside of their homes.) Despite the gains outlined below, even today, many parents are faced with the agonizing decision to institutionalize or relinquish custody of their disabled child, not because they believe it is in their child’s best interest, but because it is the only way they can access the depth and breadth of care and services available through Medicaid (See the Burge family’s story on page seven). This problem is particularly acute for families of children with behavioral or mental health issues; a 2003 report by the United States Government Accountability Office noted that approximately 13,000 children per year were being voluntarily placed by their parents in the child welfare or juvenile justice

system in order to obtain access to behavioral or mental health services available through Medicaid.<sup>21</sup>

In recent years, there has been a movement toward providing more care for CYSHCN in their home environment as opposed to institutional settings. There is growing evidence that children, even those with complex health care needs, are best raised at home, as members of their families and communities. The increasing inclusion of children and people with disabilities in schools, workplaces and the community in general, along with advances in the accessibility of medical technology for use in the home have contributed to this trend. Notably, this trend has resulted not only in better health outcomes, but more cost-effective care, because care provided at home is typically a fraction of that in hospitals, nursing homes or other congregate care settings.<sup>22</sup>

## Medicaid is Lifeline for Florida Family

Mothers often worry about whether or not their children will successfully make the transition to adulthood but that concern is magnified for parents of children with special health needs. Will they be able to live independently? Will they find work? Will they get adequate health care coverage?

Lynn and her 20-year old son, Kevin, live in suburban Florida where she works for Easter Seals assisting other families with children with special health care needs. Kevin was diagnosed with Williams Syndrome. He also has a heart condition and is on the autism spectrum. Lynn was a strong advocate for her son throughout his childhood and he is doing very well today as a result of the services (including applied behavioral analysis, speech, physical and occupational therapies) he was able to get through a Medicaid Home and Community Based Service waiver. He was one of the first in Florida to get on the program.

In fact, he is doing so well, Lynn is optimistic about him obtaining employment in their community. Many other children are not as fortunate; there are more than 21,000 children on the waiting list. Florida is now cutting funding for its Medicaid HCBS waiver and Lynn is very concerned about what the cuts will mean for her family. The amount of support her son receives for personal care has been cut significantly and Lynn is trying to figure out how to fill in the gaps. She's considering cutting back her hours to spend more time at home helping her son but she can barely make ends meet on her current salary. Home care is physically demanding work and as she gets older, she's worried that she will be unable to manage. And those aren't the least of her worries. Medicaid has been a lifeline for her family and now it is in the cross-hairs of state and national budget cutters.



Kevin on stage with his music therapist at his percussion group debut.



Lynn and her son, Kevin, with his music therapist.

There are two main avenues that Medicaid supports home and community-based care for CYSHCN—for both children are required to meet an ‘institutional level of care’ standard in order to be eligible. The first is through the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), often referred to as the “Katie Beckett” option after the child (now a young adult) whose mother successfully advocated for authorization of the original waiver program. The second is through Home and Community-based Service (HCBS) waiver programs.

**TEFRA** (or, the “Katie Beckett” option) allows states to provide regular Medicaid coverage to children un-

der the age of 19 with severe disabilities that would usually be delivered in an institutional setting. It does so by disregarding the family's income when considering the child's eligibility for Medicaid. Currently, 18 states (including DC) have elected the TEFRA option.<sup>23</sup> See the map at the end for states that have taken the TEFRA option.

Since the availability and scope of institutional level of care differs among states, the number of children served also varies widely. Unlike Home and Community-based Service waivers (discussed below), there are no waiting lists or enrollment caps for the program and it serves as an entitlement for all children who

### Utah Family Would Face Financial Ruin without Medicaid

Monica of Salt Lake City, Utah had a nagging feeling that something was wrong with her infant but her pediatrician kept reassuring her that she was developing fine. Then, at seven months, the diagnosis came— microcephaly and cerebellar hypoplasia. Now, at age five, Katelyn has some delays, doesn't walk or talk, but she is making progress toward those milestones. Monica had to cut back on work to provide care for Katelyn. She is fortunate to have private health insurance for herself and her daughter. However, the cost-sharing for the special therapies that Katelyn needs have exceeded her ability to pay and at times she has struggled with hundreds of dollars of unpaid health care bills.

Luckily, Monica was able to enroll Katelyn in Medicaid through Utah's Medically Needy program, because the amount she would be spending for cost-sharing would bring her income be-



low the level to qualify for Medicaid. In addition to help with cost-sharing, Medicaid also fills in where private insurance doesn't do the job.

Without Medicaid as a source of coverage or as a supplement to make coverage more affordable, many families like Monica and Katelyn would face financial ruin.

are determined eligible. Unfortunately, there are no solid data on the number of CYSHCN who are enrolled in Medicaid as a result of the TEFRA option.

**Home and Community-based Service Waivers.** The second pathway to home-based coverage for CYSHCN who are eligible for institutional level care is through a Home and Community-based Service (HCBS) waiver program. Similar to the TEFRA state option, HCBS waiver programs allow states to disregard parental income when determining eligibility for Medicaid, so that the child is able to receive benefits while remaining at home. There are a few key differences between the TEFRA state plan option and a HCBS waiver program.

First, HCBS waivers often provide services not available through regular Medicaid. For example, a HCBS waiver can cover personal care (e.g., assistance eating or bathing) or home modifications (e.g., building a ramp for a wheelchair), whereas the TEFRA state option is more limited to the medical services that the child would receive under regular Medicaid. Second, HCBS waivers include a "cost neutrality" requirement: the state must prove to the federal government that it will not cost more to provide home and community-based services than institutional care. As a result, there is a finite amount of money attached

to every HCBS waiver and so states can and often do have limited slots and long waiting lists. Approximately 48 states operate some form of a HCBS waiver program, often serving both children and adults with specific diagnoses.<sup>24</sup> Close to 140,000 CYSHCN are covered by Medicaid through a HCBS waiver, a number that does not reflect the tens of thousands of additional children who are on waiting lists across the country.<sup>25</sup>

**1915(i) State Option.** A third option available to states to offer more care in home and community-based settings is the section 1915(i) state option, which is named after the section of the Social Security Act that created it. The 1915(i) option, originally included in the Deficit Reduction Act of 2005, allowed states to offer the services available under HCBS waivers through a simple state plan option. There were a number of limitations in the original 1915(i) option that kept states from adopting it. Fortunately, many improvements were made to the option in the Affordable Care Act that may result in more states taking it up. Using this approach rather than a HCBS waiver is considered preferable because it does not include caps and waiting lists. It also gives states more flexibility to develop their programs to target the needs of specific populations.

## What Families Say

Recently, Georgetown University in conjunction with Family Voices had the opportunity to interview approximately twenty families of children and youth with special health care needs identified through Family Voices. These families were asked about a number of issues, including: what type of insurance coverage they had, how satisfied they were with their coverage, and what they hoped health care reform might mean for their family. A number of common themes emerged in these and other interviews conducted by Family Voices that underscore the critical role of Medicaid and emphasize that now is the time to strengthen the program, rather than move backwards by cutting federal funding.

### Major Themes from Family Interviews:

**Medicaid is a Lifeline for Children and Youth with Special Health Care Needs.** Knowing that Medicaid is there for their children is a lifesaver for many of

the families interviewed. Medicaid is either the sole source of health coverage for their children's often-extensive health care needs, or is a critical supplement to private insurance that allows them to make sure their children receive the services they need to maintain and improve their health, stay in school, learn, and thrive. In some instances, Medicaid is what allows them to keep their children at home with them. For these families, health insurance is essential for their child because their lives depend on it. Some families interviewed are not low-income enough to qualify for Medicaid or CHIP and do not meet the disability criteria for Medicaid; they expressed a willingness to go bankrupt to maintain health coverage for their children. Many families had experience paying for COBRA coverage temporarily after a job loss and a few were currently enrolled in COBRA plans, despite the crippling cost.

**Medicaid "Fills in the Gaps" and Keeps Families from Financial Ruin.** For those families who rely on Medic-

### Home Based Care is Often Best and Cheapest Alternative

Losing a job and your family's only access to affordable health insurance is devastating for anyone but it is even a tougher blow for parents of children with special health care needs. The Burge Family from the Dallas-Ft. Worth area faced just that dilemma. Mary Burge and her husband have one adult child with special health care needs, Tommy, who is fast approaching his 25th birthday. Tommy was born 3 months premature and Mary knew it would be rough from the get go. Tommy was diagnosed with a variety of issues including significant cognitive impairments, visual impairments, cerebral palsy and asthma. Until 2007, the whole family was able to meet its health care needs through private coverage through Tommy's father's employer in Michigan. The recession wreaked havoc, particularly in Michigan, and Tommy's father lost his job and his access to affordable, quality health insurance. The family moved to Texas when Craig found a new job, but it doesn't provide job-based coverage.

The Burge family was able to enroll Tommy in Texas Medicaid because he receives SSI benefits. Like many other states, Texas is transitioning to a managed care model for people with disabilities and there have been some problems that have resulted in Tommy being unable to see a doctor within a reasonable period of time. Mary's strong advocacy skills have helped her navigate the sys-



The Burge Family

tem and Tommy is now scheduled to see a doctor in the next few weeks. Also, having come from Michigan, a state that has long embraced serving children with special health care needs in the community through Medicaid supports, Mary was surprised to see that families in Texas are still faced with the excruciating decision of whether or not to move their children into an institution to ensure they get the services they need when they would prefer to care for them in their own homes with assistance. Home based care costs a fraction of the cost of institutionalized care and is often the best option for the child and family.

aid as a secondary (or even tertiary source of coverage in one instance), many said that they would be bankrupt without Medicaid because of the significant cost-sharing requirements and/or gaps in coverage of critical services in their private insurance. In many cases, because the therapies or services that their children needed were not covered by private insurance, families were paying significant amounts out-of-pocket to cover them. Medicaid either offered some relief from cost sharing or covered specific benefits that were deemed “medically necessary.” In addition to the large out-of-pocket costs families are shouldering, many have to cut back on work hours in order to provide care for their child, furthering financial stress on the family.<sup>26</sup>

**Coordinating Care and Insurance Can Be a Full-Time Job.** Many families that were interviewed have more than one type of health insurance, often private, employer-based coverage combined with Medicaid. In one instance, a family had four plans: a hospital-only policy, a catastrophic plan that covered the children once they hit a specified out-of-pocket spending ceiling, a plan that paid for in-home nursing charges and physician charges, and Medicaid for supports like durable medical equipment. Managing the multiple payers is time-consuming and stressful for families. In addition to managing insurance plans, families must also oversee the actual care itself, often including multiple components such as: participating in and supervising therapy exercises, administering and monitoring medications, and communicating with providers.

**Families Struggle to Find Providers to See their Children.** Families repeatedly report that the biggest problem they face with Medicaid is the lack of providers that accept it—particularly specialists. Families consistently laud Medicaid, but are wary of the possibility of seeking out new providers because finding good ones that take Medicaid can be problematic, particularly for specialty care that CYSHCN require to a higher degree than children without special health care needs. The best source of care for many enrolled in Medicaid are tertiary level children’s hospitals and other major medical institutions. The difficulty in finding providers is particularly acute for parents of adult children with special health care needs. Finding a provider in general to work with their child, let alone one that would accept Medicaid, is extremely challenging.

## Policy Implications

Navigating the intricacies of health insurance coverage is a daunting task for all families. However, for families of children and youth with special health care needs it is often a full-time job. Amidst this complexity, there is one constant that often provides stability and security to these children and their families: Medicaid. In reflecting on the nation’s success in bringing the rate of uninsured children to a historical low and the rate of uninsured children and youth with special health care needs even lower, it seems appropriate to consider steps that can further strengthen Medicaid for CYSHCN and do an even better job of meeting their needs in the future.

**Medicaid is the most important payer for children and youth with special health care needs, and proposals to cap, block grant, or deeply cut Medicaid would be particularly devastating to them.**

Congress is under enormous pressure to raise the debt ceiling and at the same time address the long-term federal deficit. In the debate, a number of proposals have been put forth to impose a cap on federal Medicaid spending, turn it into a block grant, or otherwise take steps to significantly cut it.<sup>27</sup> Since these policies would shift costs from the federal government onto already-strapped states, it is widely assumed that they would be accompanied by fewer protections for beneficiaries that are of particular importance to children and youth with special health care needs. For example, states may insist upon the flexibility to impose waiting lists, increase costs for families, and cut benefits. These would result in more children in need of vital care and services languishing on waiting lists, limitations on benefits, and other unanticipated changes. The stakes of this debate are high for all children who rely on Medicaid, but the consequences of waiting lists, benefit cuts, and higher cost-sharing will be far more damaging to children and youth with special health care needs. Children and youth with special health care needs are the ones most in need of Medicaid’s cost-sharing protections and strong EPSDT benefit.

**There are smarter, better ways to reduce costs that could also improve the care that children and youth with special health care needs receive.**

Deep cuts, caps, and block grants are not only threats to the stability and security of children and youth

“In a decent society, there are certain obligations that are not subject to trade-offs or negotiation – health care for our children is one of those obligations.”

-President Obama at CHIPRA signing

with special health care needs and their families, but could also undercut the goal of providing them with more cost-effective care.

Within the pediatric community, there is a strong push toward increasing access to medical homes for all children, a model that originated in pediatric practices that wanted to improve the primary care of CYSHCN. If designed correctly, medical homes can provide a setting where CYSHCN can have their intensive needs met in the most cost-effective manner and have better health outcomes. This is because the medical home model emphasizes regular access to primary care and preventive services; care coordination that takes a broad approach to meeting a child’s needs (for example, having a social worker or paraprofessional on staff available to connect families with food or cash assistance or Family-to-Family Health Information Centers); and is “family-centered,” which is to say the family plays a major role in directing the care the child receives. Some studies have indicated that adopting a robust medical home model could not only improve the quality of care that CYSHCN receive, but also potentially lower costs.<sup>28</sup>

**More should be done to promote access to care for children and youth with special health care needs, particularly to specialists.**

Overall, the biggest criticism about Medicaid identified through the family interviews is the difficulty of finding providers who accept Medicaid, particularly specialists. For CYSHCN, this difficulty is acute, because there are fewer providers who are able to meet their needs and those who are, may be overwhelmed with children with intensive needs. The Affordable Care Act does include provisions to increase Medicaid reimbursement for primary care services, which should positively affect access. However, these changes fall short of fully addressing the issue because they do not apply to specialty care and are slated to expire in 2015. Even as Congress debates cuts in Medicaid, the experience of families seeking care for their children and youth with special health care needs indicates that more federal support– not less– is needed to make Medicaid work better for these children and to promote their access to specialty care. For example, Congress could consider extending the enhanced federal support for reimbursement rates to specialty care, and make the increases permanent.

**States have a major role to play in improving coverage and access to care for children and youth with special health care needs.**

Many of the key decisions affecting how children and youth with special health care needs fare in Medicaid are made at the state level. States decide how to deliver care to these children, make reimbursement rate decisions, and set optional eligibility thresholds. Despite facing budget challenges, there are many ways that states can do more to strengthen Medicaid for children and youth with special health care needs.

**Allow more moderate-income families to “buy into” Medicaid if they have a child with a disability.**

Medicaid buy-in programs allow states to offer Medicaid coverage to families at higher income levels.<sup>29</sup> As previously discussed, Medicaid often plays a vital role by “filling in the gaps” when private insurance is insufficient. Despite the fact that health reform will allow millions more Americans to obtain coverage through state-based exchanges, this issue is not likely to abate. The benefits offered through the health care exchanges will be linked to what is covered in a “typical” employer plan and so can be expected to fall short of what many children and youth with special health care needs require.

**Take up options that allow more children and youth with severe disabilities to be served at home or in the community.**

Despite their fiscal problems, states should consider taking up the options available to serve children at home and in the community in light of the evidence that such care can be both higher quality and more cost-effective. Their options include greater use of home and community-based waivers, the TEFRA state option or the 1915(i) option, all of which are discussed in detail above.

**Conclusion**

Today in Washington, lawmakers are considering how to address the nation’s long-term deficit, a task that will involve difficult choices impacting many. As reported in this brief, the stakes of this debate are extraordinarily high for children and youth with special health care needs. Many of the families included in this study pointed out that they had already made great personal sacrifices in order to care for their chil-

dren and youth with special health care needs. Most were so financially stretched that they would have nowhere else to turn if Medicaid were to be cut further. As one mother from Illinois said: “Proposals to cut Medicaid represent survival of the fittest at its worst. By cutting Medicaid, you’re telling our children, the disabled and elderly that you are not valued in our society.” For these families, Medicaid is a “lifeline” and they are counting on lawmakers to maintain that lifeline to those who need it the most.

**Authors: Liz Arjun, Cathy Hope, Jocelyn Guyer, and Joan Alker.**

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**The Georgetown Center for Children and Families (CCF) is an independent, nonpartisan policy and research center whose mission is to expand and improve health coverage for America's children and families. CCF is based at Georgetown University's Health Policy Institute.**

**For additional information, contact (202) 687-0880 or [childhealth@georgetown.edu](mailto:childhealth@georgetown.edu).**

## Endnotes

1. P. Newacheck and S. Kim, “National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs,” *Archives of Pediatrics and Adolescent Medicine*, 159 (January 2005): 10–17.
2. For purposes of these data, the definition of a child with a special health care need comes from the Bureau of Maternal and Child Health and it is those children “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 encompasses a wide array of children ranging from children with more common childhood diseases such as asthma, to children with severe developmental disabilities whose care is a round-the-clock job.
3. Family Voices, Inc., is a national nonprofit organization that aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through its national network, Family Voices provides families with tools to make informed decisions, advocates for improved public and private policies, helps to build partnerships among professionals and families, and serves as a trusted resource on health care.
4. Georgetown Center for Children and Families calculation based on data from the 2005–2006 National Survey of Children with Special Health Care Needs.
5. op. cit. (4)
6. op. cit. (4)
7. op. cit. (4)
8. A. Davidoff, “Insurance for Children with Special Health Care Needs: Patterns of Coverage and Burden on Families to Provide Adequate Insurance” *Pediatrics*, 114, no. 2, (August 2004): 394–403.
9. op. cit. (4)
10. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006* (Rockville, Maryland: U.S. Department of Health and Human Services, 2008). The survey data used to estimate the share of CYSHCN in public coverage cannot accurately distinguish between children enrolled in Medicaid versus CHIP and other public coverage, but administrative data on enrollment indicate that the vast majority is enrolled in Medicaid. While this issue brief does not dwell on the distinction given data limitations, it can be an important one to CYSHCN. CHIP programs do not always offer the same benefit and cost-sharing protections as Medicaid, and cannot cover children who already have primary insurance through another source.
11. There are important differences between Medicaid and CHIP coverage. While CHIP has been a critical component to lowering the rate of uninsured children, federal law prohibits a child from enrolling in CHIP if a child is insured. This differs from Medicaid which can function

as a supplement to private coverage and provide assistance with cost-sharing for children with insurance.

12. SSI recipients are not automatically eligible for Medicaid in every state. In what are known as 209(b) states, there are stricter disability criteria for Medicaid coverage than in the SSI program. The following are 209(b) states: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma and Virginia.
13. Urban Institute for the Kaiser Commission for Medicaid and the Uninsured based on Medicaid Statistical Information System (MSIS) Data Reports, 2003, Centers for Medicare and Medicaid Services, Department of Health and Human Services.
14. Catalyst Center calculation based on data from the Medicaid Statistical Information System (MSIS) Data Mart (2010).
15. op. cit. (1)
16. op. cit. (4)
17. The Affordable Care Act includes a provision barring insurers in the individual market from denying coverage to children with a pre-existing condition, but, in a number of states, insurers have elected to cease offering child-only plans. When broader health reform goes into effect on January 1, 2014, all insurers offering coverage through the new exchanges are required to also offer a child-only plan. Until then, the availability of child-only coverage in any given state depends heavily on whether its policymakers have elected to take measures to ensure child-only products remain available. For example, New Hampshire and Washington require insurers to offer child-only plans as a condition of selling products to adults.
18. M. Kogan, et al., "Association Between Underinsurance and Access to Care Among Children With Special Health Care Needs in the United States," *Pediatrics* 116(5): 1162-1169 (2005)
19. op. cit. (18)
20. J. Alker, et al., "Children and Health Care Reform: Assuring Coverage Meets their Health Care Needs," Kaiser Family Foundation (September 2009).
21. Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services Washington: United States General Accounting Office; 2003.
22. The American Academy of Pediatrics Committee on Child Health Financing, Section on Home Health Care. *Pediatrics* Vol. 118 No. 2 August 1, 2006, pp. 834 -838 (doi: 10.1542/peds.2006-1489)
23. In addition to the 18 states that have elected the TEFRA option under Medicaid, 3 additional states operate TEFRA lookalike programs to serve severely disabled children in the community or at home. These states include Minnesota, New Hampshire and Pennsylvania.
24. The Kaiser Commission on Medicaid and the Uninsured and The University of California at San Francisco's analysis based on The Centers for Medicare & Medicaid Services Form 372, February 2011, Table 5.
25. op. cit. (14)
26. op.cit. (4)
27. "Medicaid, The Budget and Deficit Reduction: Keeping Score of the Threats." Families USA, May 2011 and "Proposed Cap on Federal Spending Would Force Deep Cuts in Medicare, Medicaid, and Social Security," Center on Budget and Policy Priorities, April 2011.
28. C. Homer, et al., "A Review of the Evidence for the Medical Home for Children with Special Health Care Needs," *Pediatrics*, 122(4): 922-937 (2008) and D. Fields, E. Leshen and K. Patel, "Driving Quality Gains and Cost Savings Through Adoption of Medicaid Homes," *Health Affairs*, 29(5) 819-826 (2010).
29. It is important to offer CYSHCN such buy-in opportunities through Medicaid rather than CHIP. CHIP is restricted to uninsured children, but Medicaid can serve as a supplemental source of coverage for a child whose private insurance is inadequate.



**Table 1: Upper Income Eligibility Level for Children's Coverage**

State	Medicaid, 0-1 Years	Medicaid, 1-5 Years	Medicaid, 6-19 Years	CHIP	Program Type
Alabama	133%	133%	100%	300%	S-CHIP
Alaska	175%	175%	175%		M-CHIP
Arizona	140%	133%	100%	200% (closed)	S-CHIP
Arkansas	200%	200%	200%		M-CHIP
California	200%	133%	100%	250%	COMBO
Colorado	133%	133%	100%	250%	S-CHIP
Connecticut	185%	185%	185%	300%	S-CHIP
Delaware	200%	133%	100%	200%	COMBO
District of Columbia	300%	300%	300%		M-CHIP
Florida	200%	133%	100%	200%	COMBO
Georgia	200%	133%	100%	235%	S-CHIP
Hawaii	300%	300%	300%		M-CHIP
Idaho	133%	133%	133%	185%	COMBO
Illinois	200%	133%	133%	200% (300%)	COMBO
Indiana	200%	150%	150%	250%	COMBO
Iowa	300%	133%	133%	300%	COMBO
Kansas	150%	133%	100%	241%	S-CHIP
Kentucky	185%	150%	150%	200%	COMBO
Louisiana	200%	200%	200%	250%	COMBO
Maine	200%	150%	150%	200%	COMBO
Maryland	300%	300%	300%		M-CHIP
Massachusetts	200%	150%	150%	300%	COMBO
Michigan	185%	150%	150%	200%	COMBO
Minnesota	280%	275%	275%		M-CHIP
Mississippi	185%	133%	100%	200%	S-CHIP
Missouri	185%	150%	150%	300%	COMBO
Montana	133%	133%	133%	250%	COMBO
Nebraska	200%	200%	200%		M-CHIP
Nevada	133%	133%	100%	200%	S-CHIP
New Hampshire	300%	185%	185%	300%	COMBO
New Jersey	200%	133%	133%	350%	COMBO
New Mexico	235%	235%	235%		M-CHIP
New York	200%	133%	100%	400%	S-CHIP
North Carolina	200%	200%	100%	200%	COMBO
North Dakota	133%	133%	100%	160%	COMBO
Ohio	200%	200%	200%		M-CHIP
Oklahoma	185%	185%	185%		M-CHIP
Oregon	133%	133%	100%	300%	S-CHIP
Pennsylvania	185%	133%	100%	300%	S-CHIP
Rhode Island	250%	250%	250%		M-CHIP
South Carolina	200%	200%	200%		M-CHIP

State	Medicaid, 0-1 Years	Medicaid, 1-5 Years	Medicaid, 6-19 Years	CHIP	Program Type
South Dakota	140%	140%	140%	200%	COMBO
Tennessee	185%	133%	100%	250%	COMBO
Texas	185%	133%	100%	200%	S-CHIP
Utah	133%	133%	100%	200%	S-CHIP
Vermont	225%	225%	225%	300%	S-CHIP
Virginia	133%	133%	133%	200%	COMBO
Washington	200%	200%	200%	300%	S-CHIP
West Virginia	150%	133%	100%	250%	S-CHIP
Wisconsin	300%	300%	300%		M-CHIP
Wyoming	133%	133%	100%	200%	S-CHIP

Source: M. Heberlein, et al., "Holding Steady, Looking Ahead," Kaiser Commission on Medicaid and the Uninsured, (January 2011); updated by the Center for Children and Families. Data as of March 1, 2011.