Breaking the Link
between Special Health Care Needs and Financial Hardship

CATALYST
CENTER

IMPROVING FINANCING OF CARE
for Children & Youth
WITH SPECIAL HEALTH CARE NEEDS

Children and Youth with Special Health Care Needs | As defined by the federal Maternal and Child Health Bureau, and endorsed by the American Academy of Pediatrics, children and youth with special health care needs (CYSHCN) are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.

HAVING HEALTH INSURANCE IS ONLY PART OF THE STORY...

As the following pages illustrate, families need a range of financing solutions to finally break the link between their children's special health care needs and financial hardship. They need comprehensive health insurance, family supports, and a broad investment in public health.

Anyone engaged in the daily care of children and youth with special health care needs (CYSHCN) is well aware of the strains that inadequate health insurance coverage and limited public programs place on families. Others, particularly policymakers who decide how public dollars are spent and how private health services are structured and regulated, may not be as aware of significant gaps in the health care financing system that require urgent attention.[1]

National leadership for improving the health and well-being of children and families is provided by the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, U.S. Department of Health and Human Services, which has responsibility for implementing Title V of the Social Security Act. Children and youth with special health care needs are one of the Bureau's areas of special focus.

The public health policy community is of course complex and made up of many important stakeholders, including legislators, state and federal agencies such as Departments of Public Health and Medicaid, state Commissioners of Insurance, and many other groups, including family leadership organizations. Among these, the Title V program is the only public health entity with a specific federal mandate to serve CYSHCN.

The Catalyst Center, housed at the Boston University School of Public Health, was established in 2005 through a cooperative agreement with MCHB to improve financing of care for CYSHCN. The Catalyst Center has spent the last four years researching and disseminating state-level financing strategies aimed at reducing financial strain on families.

As comprehensive health care reform appears again on our national agenda, we welcome the opportunity to bring some of these state-based reforms to the attention of policymakers. Many of these financing strategies and programs are summarized in this report, and are described in more detail in the Catalyst Center's online *State-at-a-Glance Chartbook on Coverage and Financing for Children and Youth with Special Health Care Needs,* http://www.catalystctr.org.

Health insurance coverage is essential for CYSHCN who may need access to diagnostic testing, primary care, specialty care, prescription drugs, therapies, mental health services, durable medical equipment and other health-related services. Access to these services is critical for detecting health problems, preventing the deterioration of physical or mental health, and maximizing a child's potential to learn, play and develop with his or her peers.[2] They are also essential to a child's eventual transition to a successful adulthood.

The good news is that the percentage of uninsured CYSHCN dropped from over 11.6% to 5.2% between 2001 and 2006. This was mostly due to expansion (from 30% to 36%) of public benefits through Medicaid and the State Children's Health Insurance Program (SCHIP), which was established under the Balanced Budget Act of 1997.[3,4] These programs provide a critical foundation of health insurance coverage for children with special health care needs; and if we can decrease the percentage of uninsured CYSHCN by 6.4% over a period of five years, is there a reason we cannot reduce the percentage another 5.2% to 0?

Nearly one in five American families is caring for at least one child with special health care needs.

According to the *National Survey of Children with Special Health Care Needs*, nearly one in five American families is caring for at least one child with special health care needs. In 2005-06, 8.8% of these children were reported to have had no insurance at some point during the last twelve-month period. This is over 900,000 children who by definition "[require] health and related services of a type or amount beyond that required by children generally," but who likely went without care at all during that period, or received care at full out-of-pocket cost to their families. Within this group of uninsured children there are significant racial and ethnic disparities; over 15% of all Hispanic children with special health care needs report a lack of health insurance in the past year, as compared to 11% for non-Hispanic black children and 7% for non-Hispanic white children.[4]

Medicaid buy-in programs,[5] SCHIP legislation changes, and premium assistance programs are some of the policy changes that could help ensure coverage for all CYSHCN.

The causes of financial hardship for families of CYSHCN are complex and often intertwined. Some relate directly to a lack of health insurance, while others result from underinsurance—the gaps in coverage that result when a public or private insurance policy doesn't cover all of the services that are medically necessary for a child. Over half of all CYSHCN (60.3%) receive their health insurance through the private sector alone,[6] and restrictions on the amount or scope of health benefits in those private health plans result in unmet need for about 30% of these children, according to parents.[4]

Although the percentage of uninsured CYSHCN has declined, just over one third of families still report that their child with a special need has inadequate health insurance coverage. These families most commonly report that the costs that are not covered by their health plan are unreasonable (28%), or that their health plan does not offer the benefits or services their child needs (12.2%). Inadequate insurance coverage is reported most often among the lowest income families, families with private insurance coverage, and families whose child's condition is most likely to affect his or her functional abilities.[4] Research also documents significant state variation in underinsurance.[7]

Furthermore, one fifth of all families (20%) report spending over $1,000 per year on out-of-pocket costs for their child's special health care needs. That translates into more than 1.7 million families nationwide who spent a *minimum* of 1.7 billion dollars out of pocket. A subset of those families, 8.8% of all families of children with special health care needs, spent over $5,000 in one year's time.[8]

For a wealthy family, an expenditure of $1,000 or even $5,000 may not be that hard to absorb. Since out-of-pocket expenses may or may not result in real hardship for a given family depending on that family's income and its other expenses, the *National Survey of Children with Special Health Care Needs* also asks whether respondent families experienced financial problems related to a child's health condition. Nearly one in five families (18%) report that they have.

The most telling finding of the *National Survey of Children with Special Health Care Needs* related to family finances, however, concerns the impact on family income rather than expenditures. Nearly one quarter of the national sample of families (24%), extrapolated to be almost 2.5 million families nationwide, report at least one adult family member has cut back on work or quit work entirely to provide care for their child with a special health care need.

These data reveal patterns of hardship that are complex. They reflect characteristics of children, families and the system itself. What that means for policymakers and others concerned with the well-being of children and families is that preconceptions about who is likely to experience hardship may be misleading. Families living in varied circumstances, with children who have a range of different conditions, encounter significant financial challenges.

Across America, a substantial proportion of middle-class families raising CYSHCN are experiencing material hardship.[9] Some families have to make hard spending choices and difficult sacrifices to ensure adequate care for their children. Other families, who do not have the resources even to consider these choices, experience severe financial hardship and medical debt while their children are placed at high risk for adverse outcomes that do not need to happen.

Research conducted by the Catalyst Center and others on the extent of financial hardship for families of CYSHCN reveals several important findings:

Financial hardship is common among all families of children and youth with special health care needs — regardless of income.

Financial hardship is not linked only to the most severe cases of disability, the most complex medical needs, nor the most significant medical expenses.

Families are linked to financial hardship through three interconnected pathways: higher health care costs, higher routine expenses, and the loss of employment income.

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A CALL TO ACTION

Breaking the link between special health care needs and financial hardship

The Catalyst Center has prepared this publication as a resource for policymakers, and to support conversations among advocates, families, payers and Title V programs at both the state and national levels. In addition to providing data on the scope of the problem, ***Breaking the Link*** illustrates the impact that coverage and financing gaps have on the lives of real families, while simultaneously describing policy solutions that are in place in some states and can offer promising practices and models to others.

For too long, we have seen innovations like those described in these pages piloted, demonstrated, and implemented successfully, but with only small numbers of families benefiting. Recognition of the prevalence and depth of family hardship should be a spur to growing these effective and necessary interventions to scale across the nation.

Some states have successfully adopted Medicaid buy-in programs, for example, that allow families to enhance their existing private insurance by purchasing supplemental Medicaid coverage even though their income exceeds normal eligibility limits. Some have established mandated benefits to expand coverage for critical services such as early intervention, autism services or surgical procedures to correct cleft palate. In some states, relief funds for families of children with catastrophic health care expenses provide flexible financing to help families pay for special vehicle or housing adaptations, or for costly nutritional supplements that are necessary to treat rare disorders. Some states have established specialized medical day care or respite services for medically fragile children. And some state agencies are investing in care coordination and benefits counseling services that assist families in maximizing both public and private benefits to reduce out-of-pocket expenses.

Consideration of new options must be part of state and national health reform activities. We invite Title V leaders, state and national health policy leaders, and family advocates to use ***Breaking the Link*** to increase visibility and awareness of the levels of financial hardship endured by families caring for children and youth with special health care needs. Help spread the word that current public investments are not sufficient, that two-thirds of children with significant chronic health conditions or disability—while covered by private insurance—face underinsurance resulting in critical barriers to care and experience threats to family financial security. Begin the process of exploring policy and program options that could be solutions in your state. As a start, you might create a collection of family stories like those in this booklet to help illustrate the gaps in your own state's system of financing care.

The Catalyst Center can be a resource to you as you move forward to identify possible solutions. Visit our website, **www.catalystctr.org**, to review the data on your state in the ***State-at-Glance Chartbook***, and to seek examples of how other states have paid for specific services. The Catalyst Center staff is also available for technical assistance or to consult with your state on how to estimate costs for implementing the Family Opportunity Act's Medicaid Buy-In option, how to create and fund a Catastrophic Illness and Relief program, or how to launch your own storytelling campaign. This is indeed a call to action.

Please join us.

THE FAMILY EXPERIENCE

In order to think about effective strategies for breaking the link between special health care needs and financial hardship, it is first necessary to understand the real problems facing families.

In the following pages you will meet:

AMY AND TIM WILSON
who sometimes buy less food and skip a car payment in order to pay for the electricity that runs their son Hunter's life support equipment.

RYLIN AND DAVID RODGERS
who were told they were doing too well to qualify for services from their state's Title V program, and were thousands of dollars in medical debt by the time they found out that wasn't true.

PAMELA OGUAGHA
a single mom who makes just a few dollars too much for her teenage daughter to qualify for SSI and Medicaid.

These families, like others caring for children with special health care needs, are "linked" to financial hardship because they have higher out-of-pocket health care costs, higher household and family expenses, and reduced employment income. Most programs designed to assist families with the financial burden of care consider gross income in their eligibility requirements, but not what a family is actually living on after out-of-pocket expenses.

These factors can bring families to financial hardship whether they were low-, middle- or even high-income before raising children with special needs. The impact of financial hardship depends partly on which state a family calls home. And the burden on families goes beyond dollars and cents.

EXPLORING THE LINKS

Consider the three primary ways that a child's special health care needs may bring financial hardship to families.

1. HIGHER HEALTH CARE COSTS

can include over-the-counter or prescription medications, procedures or medical treatments recommended by physicians, adaptive equipment like orthotics or special cushions used to prevent pressure sores for wheelchair users, or wipes for older children who are incontinent due to cognitive and/or physical conditions. These are the sorts of expenses that many people—including some policymakers and the general public—assume are covered by insurance or government programs, but often are not.

> *"Neither insurance nor Title V would cover the muscle biopsy needed to get a diagnosis. We thought it would be about $20,000, and we couldn't afford that for both of them. So what we did was, we picked a child. Just one of them was diagnosed officially. The difficulty was that he had very serious complications. And it ended up being closer to $100,000."*
>
> Rylin Rodgers, whose two children both have the same degenerative mitochondrial disease

Families are 'linked' to financial hardship because they have higher health care costs, higher 'routine' expenses and the loss of employment income.

Out-of-pocket costs also include health services such as physical therapy, mental health counseling and durable medical equipment, for which most private insurance policies have built-in coverage limits. Those coverage limits may allow adequate care for a child with an acute injury or illness, but they generally are not designed with chronic illnesses or ongoing disabilities in mind. Families are left to pay the difference.

> *"One day Hunter's g-tube came out, and the balloon that holds it in had burst. I had to tape it to his stomach so his stoma wouldn't close. The supply company told me I would have to pay $200 for a replacement, because Medicaid only allows for one g-tube every fiscal year. I had to borrow money from my mom so my child could eat."*
>
> Amy Wilson, Hunter's mother

Families can also get caught in the middle when a child's health insurer is in dispute with the school system over the responsibility of paying for needed services. In such cases there can be lengthy bureaucratic wrangling over whether a particular service is medically or educationally necessary, and families may end up paying out-of-pocket for the services their child needs immediately.

Finally, even the "ordinary" costs of health care may be elevated. A co-payment of $20 per physician visit, quite typical for privately insured families, may not be a burden for a family whose child goes to the doctor once or twice a year. But a family whose child has five or six doctor visits a month, not uncommon with some conditions, may need to spend over $100 a month for co-payments.

2. HIGHER ROUTINE EXPENSES include things that all families pay for such as housing, utilities, food, clothing and child care, that often cost more for families caring for children with special health care needs.

Additional housing costs may be related to necessary home modifications for wheelchair ramps or remodeling a bathroom to make it accessible. The cost of utilities such as heating or cooling can be exorbitant for the family of a child whose body can not regulate temperature, or who uses electricity around the clock to keep life-saving equipment in operation. Families living in rural or remote areas may incur high phone bills to stay in touch with medical specialists. Children with inborn errors of metabolism may require special diets or costly dietary supplements. Specialized day care, after school care or summer camps may also be required.

"I am a single parent. Taylor has autism. This means that she needs to have care all year. Even though she is high functioning and semi-independent, Taylor still needs to have things to do to keep her busy – I cannot leave her home alone. Camp is number one in the summer with before and after care, and the most expensive. After that it's before and after school care during the school year."

Pamela Oguagha, Taylor's mother

3. LOSS OF EMPLOYMENT INCOME is perhaps the most common pathway to financial hardship for parents of children with special health care needs, at all income levels. A child's need for frequent medical visits is one impediment to employment reported by many parents. The unpredictability of some chronic conditions adds to the challenge. Children with sickle cell disease, for example, may experience acute episodes calling for multiple doctor visits interspersed with periods of relative health. Conditions that keep children out of school or day care for prolonged periods also pose challenges.

This link is not limited to families of children with bouts of what is typically thought of as "illness." Children with conditions ranging from congenital heart defects to cerebral palsy may require multiple surgeries with post-operative periods at home, making prolonged absences from work almost inevitable and career advancement difficult for parents. Even conditions that do not require ongoing medical intervention can interfere with employment. Parents of children with mental health or behavioral conditions may be frequently interrupted at work to take a child who is acting out or troubled home from school. Again, this may make consistent employment impossible, or may be a barrier to well-paid employment or advancement.

The result? Parents cut back hours, take less responsible jobs or leave work entirely because of the demands of a child's care. Of course, these challenges do not affect all parents equally. Parents with less flexible jobs or less autonomy on the job are more affected than those with greater freedom.

"I have given up some really good jobs or just didn't apply. I've left some places for lower skilled work so that I could be available for Taylor. What I've decided to do is when I go for a job, I check out the benefit package and that clearly dictates where I work. Benefits are more important than salary."

Pamela Oguagha

STATE TO STATE DIFFERENCES

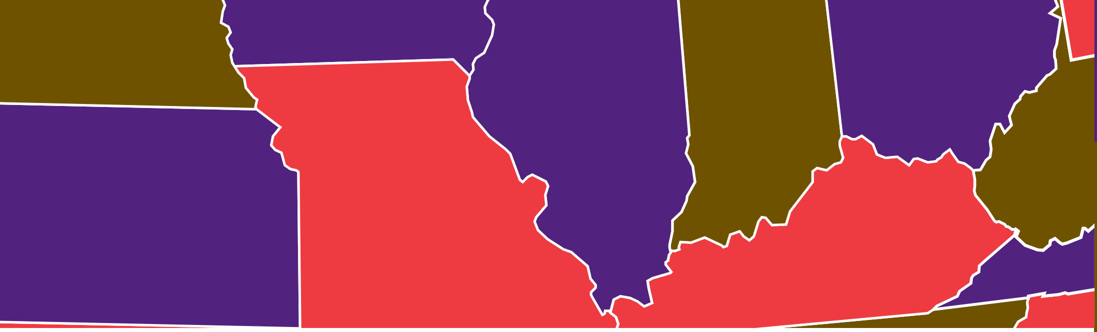
Two nearly identical families—with the same number of children and adults, whose children are the same ages and have identical special health care needs, and whose household incomes are equal—may experience very different levels of financial burden if they live in two different states. While many programs that serve children and families are based on federal legislation, there is enormous variability across states in the way those programs are implemented.

Medicaid and the Title V Children with Special Health Care Needs programs both reveal this variability across states. Income limits placed on Medicaid eligibility, for example, may simply meet the federal requirement, or go beyond it to make more families eligible. Twenty-six U.S. states and territories have implemented the TEFRA State Plan Option, also known as the Katie Beckett waiver, which disregards family income as a qualification for Medicaid altogether for children with the most severe disabilities. Some states have expanded access even further by implementing Medicaid buy-in programs, which allow families to purchase Medicaid benefits even if they are over-income, as long as they meet other eligibility criteria.

Suppose our two identical families have health insurance through their employers, but it doesn't cover all the services their children need. They earn too much money to qualify for Medicaid. If one of them lives in a state with a buy-in program, that family may be able to purchase Medicaid benefits specifically to supplement their current insurance. The other family, living in another state without access to a buy-in program, will be left with much higher out-of-pocket costs, and almost certainly a higher degree of financial hardship.

MORE THAN HEALTH INSURANCE

In addition to financial hardship, there is a real administrative burden on parents when traditional public and private financing sources do not meet their children's needs. In the best case scenario, families are able to cobble together funding from a variety of other sources, including charitable foundations, secular and faith-based non-profit organizations, and so on. There are many good community programs available, but they often have narrow eligibility criteria



and are difficult for families to access. This administrative burden—often accompanied by significant emotional stress—leaves parents less available to be just loving parents instead of unofficial care coordinators.

Having adequate health insurance is only part of the story. As the following pages illustrate, a range of supports are needed—specialized medical day care, care coordination, benefits counseling, respite services, to name a few—requiring a broad investment in public health systems to finally break the link between special health care needs among children and financial hardship for their families.

The Catalyst Center gratefully acknowledges the vitally important contribution made by the families of children with special health care needs who generously answered our initial survey on financial hardship and took the time to talk with us in greater detail about their children and their experiences. Three of those families are featured in this publication, but we learned valuable information from everyone involved. We offer them all our heartfelt thanks, and respectful admiration.

We would also like to thank:

- The state Title V program staff who participated in a needs assessment that led us to this project;
- The child health advocates who helped disseminate the initial parent survey;
- Our publication review team of family leaders and policy experts for their time and thoughtful feedback;
- Catalyst Center research assistant Kathryn Jantz, MSW for her skillful and compassionate interviewing of the family participants and dedication to this project;
- Catalyst Center research assistant Leticia Manning, MPH for her commitment and hard work;
- Laurie Tellis of New England SERVE for helping to bring the family stories to life in expert written form;
- The design team of MB Jarosik and Rusha Sopariwala from kor group for their creativity, passion and partnership in support of our vision;
- Our project officer, Lynda Honberg, MHSA of the Maternal and Child Health Bureau at the Health Resources and Services Administration, Department of Health and Human Services for her enthusiasm, guidance and support.

COST
OF
LIVING

The Wilson Family

Amy and Tim Wilson describe themselves as "forced poor." Their annual income of $25,000 makes it a constant challenge to support a family of five, but it keeps them eligible for the Medicaid program that covers most of their son Hunter's ongoing medical expenses. "I would be cutting my own throat to go back to work," says Amy.

Amy and Tim Wilson moved their family to Little Rock, Arkansas so their son Hunter, 9, could attend the state's only school for the deaf. An antibody deficiency, however, has since left Hunter unable to attend school at all. A teacher comes to the Wilson home four hours a week.

Amy, an EMT, had to stop working in order to care for Hunter. His frequent hospitalizations and the lack of suitable child care make it impossible for her to maintain employment. "Besides," she says, "if I did go back to work, Hunter would lose his SSI and Medicaid." Tim works two jobs to support the family of five, earning $25,000 a year as an insulation blower by day and a FedEx courier by night.

"We are 'forced poor,'" says Amy, so that the family doesn't have too much income for Hunter to qualify for Medicaid. While the state's TEFRA option would allow the Wilsons to receive Medicaid coverage for Hunter even if their income went up, "you can't apply for TEFRA until you don't have Medicaid anymore, which makes it hard to switch without a gap in your child's coverage."

PATHWAYS TO FINANCIAL HARDSHIP

Higher health care costs: The Wilsons had to pay $200 out-of-pocket for a new G-tube when Hunter's broke. Although G-tubes are covered under Hunter's Medicaid plan, coverage is limited to only one per year.

Higher routine expenses: The family's electric bill is $300 per month, in large part due to the medical equipment that keeps Hunter alive. When Hunter is hospitalized, the family drives his siblings 150 miles to stay with their grandparents, adding significantly to their gas costs.

Loss of employment income: Amy, an EMT, had to leave her job to care for Hunter. His frequent hospitalizations and the lack of specialized medical day care make it impossible for her to go back to work. Tim would turn down a pay raise if it meant the additional income would make Hunter ineligible for his SSI and Medicaid benefits.

BREAKING THE LINK

A **Medicaid buy-in program** like the one that is part of the federal Family Opportunity Act would let Tim accept a pay raise without losing Hunter's public health insurance.

Specialized **medical day-care** might allow Amy to go back to work and bring additional income to the family.

Consumer-directed benefits or a **flexible funding program** would allow the Wilsons to decide how to spend limited resources. They might purchase a new G-tube or hearing aid for Hunter, or use flexible funding to help pay the electric bills rather than getting more suction catheters than they really need.

Because of lung disease, Hunter uses a ventilator much of the time and a wheelchair when he is having trouble breathing. He also needs an intrapulmonary percussive ventilator (IPV), pulse oximeter, feeding pump, suction pump and globulin infusion pump. The family's electric bill is $300 per month, in large part due to Hunter's equipment. Sometimes they skip a car payment to make sure the electric bill is paid.

While glad to have Medicaid benefits for Hunter, the family can be frustrated by its one-size-fits-all regulations. "Medicaid provides thirty suction catheters per month," says Amy. Hunter doesn't need to be suctioned that often. On the other hand, "he can only get one new hearing aid a year. He is supposed to wear them in both ears, but right now he only has one because he lost one, and it's not time yet to get another one." The move to Little Rock meant leaving behind Amy's mother, a primary part of the family's support system. When Hunter is hospitalized, Tim drives the family's other two children 150 miles to stay with their grandparents so he can keep working and Amy can be with Hunter. The gas costs are significant.

Hunter is occasionally able to eat normally, but most of the time he is fed through a G-tube. "We're actually kind of lucky that way," says Amy. What she means is that, when Hunter is in the hospital, the staff will bring him a meal tray, which he won't touch. Because her son is technically able to swallow but prefers to receive nutrients by tube, Amy gets to eat. She says "lucky" without a trace of irony.

"The times when he can't eat, like before surgery, I just go without," she says. "Or I go to the place down the street and give plasma. They give you $40 each time, and I can use that to eat."

DEBT

The Rodgers Family

Rylin and David Rodgers were shocked at how quickly medical debt changed their lives. They had college educations, good jobs with health insurance, and comfortable savings before their children were born. Unaccustomed to asking for help, Rylin once went three days without eating as she sat by her son's hospital bed. "In retrospect I should have asked," she says, "but no one offered, either. I think we looked 'too good' to need help."

Rylin and David Rodgers were in good financial standing when they welcomed their first child, Matthew, into the world. Both teachers, they had a combined yearly income of $60,000, owned their own home, and had zero consumer debt.

PATHWAYS TO FINANCIAL HARDSHIP

Higher health care costs: In just the first year of Matthew's life, the Rodgers were responsible for over $200,000 in out-of-pocket medical costs. They paid for diagnostic tests they expected to cost $20,000, but when Matthew developed serious medical complications the cost rose closer to $100,000.

Higher routine expenses: The Rodgers pay $500 a month for over-the-counter nutritional supplements for Matthew and Laura.

Loss of employment income: Rylin had to quit her teaching job to care for the children, which cut the family's annual income from $60,000 to $30,000. David has considered changing careers to something more lucrative, but he stays in teaching because of the medical insurance.

Six months later, even the ten dollars it cost to park at the hospital where Matthew was having surgery was well beyond the family's budget. "I would get up at 2:00 a.m. to go move the car," remembers Rylin. "There was no parking attendant there at that hour."

In just the first year of Matthew's life, his medical expenses would total over a million dollars.

Matthew and his sister Laura both have an unidentified type of mitochondrial disease, a degenerative and terminal illness. Rylin had to quit her job to care for them, which cut the family's income in half. Required by their health insurance to pay 20% of all health care costs out of pocket, the couple took out three mortgages on their house. They have paid for some medical expenses with credit cards, including $400 a week for laboratory tests and $2,000 a month for prescription drugs.

"Most people assume that a family like ours, because we have two college-educated parents, would have the resources they need to take care of their family's medical conditions," says Rylin.

In fact, social workers repeatedly told the family they wouldn't qualify for assistance because their income was too high. "It wasn't until Matthew was two and we were in major medical debt that we learned from another parent we'd been income-eligible the whole time for CSHCS."

CSHCS, or Children's Special Health Care Services, is Indiana's Title V program. Once they enrolled, it helped the Rodgers pay for the children's medical care for several years. When David received a pay raise, however, his income was pushed over 250% of the federal poverty level, and the family was no longer eligible.

By trimming their grocery budget to $40 a week for the family of four, buying second-hand clothes, and foregoing non-essentials, the Rodgers are able to pay $500 a month for the nutritional supplements that Rylin says are the only recommended treatment for the children's condition. Neither Medicaid —which Matthew now receives, after ten years on a waiting list for a special waiver program—nor the family's private insurance covers any part of the cost.

The Rodgers have had to make other difficult choices and adjustments. When they couldn't afford the muscle biopsies required to diagnose the children's condition, which were not covered by insurance, they chose to have just one child diagnosed. When wheelchair maintenance grew to thousands of dollars a year, they got the children scooters instead. And while four different subspecialists want to see Laura every month, she usually goes every three months. "I try to balance appropriate medical care with reality," says Rylin.

One choice they *didn't* make: "We were shocked by how many people advised us to divorce so we could get Medicaid."

BREAKING THE LINK

Well-educated and middle-class, the Rodgers were repeatedly told they wouldn't qualify for public assistance. **Benefits counseling** would have helped them to enroll Matthew in Title V services right away, instead of accruing thousands of dollars in medical debt before learning about the program from another parent when their son was two.

Matthew was on a waiting list for ten years before he could receive Medicaid benefits; Laura is still waiting. A **Medicaid buy-in program** like the one that is part of the Family Opportunity Act would have allowed the family to enroll the children without a waiting list, paying a premium determined by their income.

Some states have passed specific **mandated benefits** that require health insurers to pay for special services like nutritional supplements. If Indiana were one of those states, the Rodgers family would be able to use their private insurance to pay for Matthew and Laura's extra nutritional needs.

FLEX-
IBILITY

The Oguagha Family

With limited means, Pamela Oguagha has been resourceful enough to create a life full of enriching, therapeutic activities for her daughter Taylor, along with educationally and medically needed services. But she finds the process overwhelming. "Because my daughter is high-functioning, less is available."

"About 90% of the time, Taylor is a typical teenager who happens to have autism," says Pamela Oguagha of her 15-year-old daughter. "She knows her way to school, the store, she has her own key. She uses the bus herself."

But Taylor isn't quite typical. In addition to autism, she lives with ADHD, beta thalisema sickle cell disorder, learning disabilities and behavioral challenges. At an age when other girls might start babysitting, Taylor has a constant need for supervised, structured activities.

Divorced from Taylor's father and with an older daughter away at college, Pamela works full-time and has arranged for before and after school care for Taylor. "She has a scholarship through Girl Scouts for sleep away camp, and the choir lets her participate without paying. We pay a portion when we can."

The Oguaghas live in Maryland, which provides the family with up to $3,000 per year in flexible funding known as Rolling Access. "Rolling Access funding is my saving grace," says Pamela, who uses the funds for Taylor's eyeglasses, camp, family support services, and co-payments.

Pamela spends a tremendous amount of time coordinating her daughter's care. "I'm on the phone with someone all the

PATHWAYS TO FINANCIAL HARDSHIP

Higher health care costs: Because there are a limited number of mental health providers with specialized skills to work with young people with autism, Pamela may have to use a provider who is not in her insurer's network, and may have to pay up to $240 per session for her daughter to receive appropriate care.

Higher routine expenses: Fifteen-year-old Taylor requires supervision and structured activities year-round while her mother is working: summer camp is the biggest expense, followed by before and after school care and recreational programs. Pamela has also had to hire legal and educational advocates to secure services for Taylor, and she incurs higher cell phone and commuting costs to coordinate her daughter's care.

Loss of employment income: Over the course of her career Pamela has left jobs, decided not to apply for positions for which she was qualified, taken positions with lower pay and less-skilled work, and reduced or changed her work hours to provide support for Taylor. She is willing to sacrifice higher pay for better benefits.

time, or texting or e-mailing." Her employer is understanding, but it's difficult when she has to arrive to work late or leave early, like when she must take time off to pick up Taylor's prescription—considered a controlled substance—in person at the doctor's office. Last year, in order to make sure Taylor's special education program was meeting her needs, Pamela had to hire advocates to attend Taylor's IEP meetings. She still spends a lot of early mornings at Taylor's school, from which getting to work on time requires a more costly commute.

"I have had to quit work, take a lower-paying job and change my work hours to provide support and parenting for Taylor," Pamela says.

Currently, Taylor is struggling with two recent blows: the death of her grandmother, who provided a significant amount of caregiving and support, and Pamela's own active treatment for breast cancer. Grieving and anxious, this semi-independent young woman has lately needed assistance with even basic tasks. A behavior specialist comes every day to help her get ready for school. Pamela initially paid for that out of pocket, but successfully advocated to get it covered as emergency respite care.

Even with these resources, however, Taylor's need for mental health services continues to be inadequately addressed. Pamela is looking for a suitable provider, but few are trained to treat mental health issues in adolescents with autism. When she does find someone she will have to pay part of the cost, which may be up to $240 per session. In the meantime, Taylor attends a grief support group for teens, for which Pamela negotiated a $10 co-payment instead of the regular $20.

"I make about $5 too much to qualify for SSI for Taylor," Pamela says. "It is so small, it's killing me. The impact has been phenomenal, because if I could get SSI, Taylor could get medical assistance. And whatever that medical assistance didn't cover, my insurance would kick in. So I'm strapped both financially and medically. But that would change our lives."

BREAKING THE LINK

Maryland's Rolling Access provides **flexible funding** to families and is working well to help the Oguaghas pay for needed services for Taylor and some family support services.

A **Medicaid buy-in program** like the one that is part of the federal Family Opportunity Act would not only allow Pamela to accept higher-paid employment, but also to purchase Medicaid benefits for Taylor specifically designed to supplement her own insurance.

Care coordination services could help Pamela minimize her absences from work and improve the efficient organization of Taylor's services and benefits, as well as help Taylor and her mother plan for her transition into adult services.


Nemo

The stories generously told by the Wilson, Rodgers, and Oguagha families reveal devastating financial hardships associated with parenting a child or youth with special health care needs.

IMAGINE THE POSSIBILITIES

Financial hardship is not an easy topic for families to discuss in public. Values of self-sufficiency and providing adequate care for one's children are deeply rooted in our society. These families have courageously shared details of their personal lives to illustrate the untenable situations faced by an estimated 2 million families nationwide, and we are deeply grateful to them.

The Catalyst Center has had the privilege of listening to other parents from across the country describe their experiences as they confront medical debt and face financial insecurity. *Breaking the Link* is a product of those conversations. It honors the trust offered by families with a promise to highlight these issues for policy-makers, and to disseminate examples of programs and financing strategies that can offer real solutions.

In some states, collaboration among policymakers, providers, payers and family advocates has helped families break the link between ensuring needed services for their children and finding themselves in financial hardship. Imagine the possibilities if we could build on the innovative strategies they have developed, and spread the word to every state in our nation.

Each state has a unique health insurance and delivery marketplace and a specific context for implementing federal policy. While the state-based Medicaid and Title V Children with Special Health Care Needs programs both have their legislative basis in the federal Social Security Act, they demonstrate much variability at the state level in how policies are implemented and programs designed. The State Children's Health Insurance Program (SCHIP) reveals similar variation across states. State policymakers and other stakeholders influence the structure and operations of these and other federally authorized programs, as well as shape critical state policy on private insurance coverage. As a result, states have had a great deal of room for discretion, creativity and experimentation, and families caring for children and youth with special health care needs experience very different financing and support systems state to state. It is time to spread the experience garnered by individual states through innovation and early adoption of successful program models, and use it to help close insurance and health care financing gaps for families caring for CYSHCN across the nation.

It is clear from the Catalyst Center's research and evidence from tested strategies that effective policy solutions to close these gaps must go beyond basic health insurance. Meaningful reform must encompass universal access to comprehensive coverage, an adequate range and depth of health care benefits for children with chronic illness or disability, and flexible financing for family supports. With these mechanisms in place all three pathways to financial hardship—higher health care costs, higher routine expenses, and loss of employment income—can be circumvented.

As our nation focuses its attention on strategies for reforming the health care system, we call on policymakers to see and acknowledge the realities of medical debt and family financial hardship that place the well-being of American families at risk. Health care reform must include opportunities for families at all income levels to access comprehensive health care benefits that cover the higher levels of health care expenses incurred by CYSHCN.

Health care reform must also include standards that can reduce disparities among families based on race, language, ethnicity, or even where they live. State public health programs and community-based service providers must be challenged to address sources of financial hardship that fall outside the purview of health insurance. These solutions should include adopting flexible financing programs that can assist families with higher routine costs of living and provide supports such as specialized day care that can help families minimize loss of employment income.

The Catalyst Center extends our call to action to a wide range of partners, each of whom can play a critical role in minimizing financial hardship for families of CYSHCN. We urge leaders in state Title V and Medicaid programs, state legislators, family advocates, health policymakers, insurers and employers to come together to imagine an improved system of financing care for CYSHCN. The following range of policy and program solutions have already been demonstrated at the state level. It is time for them to serve as building blocks for both national and state-based efforts. It is time to break the link between special health care needs and financial hardship for families across the country.

BREAKING THE LINK

Strategies for Addressing Family Financial Hardship: Selected Examples from States

BENEFITS COUNSELING

Providing benefits counseling to families is one effective strategy used by states to address underinsurance, maximize benefits and reduce financial hardship. These programs offer assistance to families in navigating the complex world of health insurance, and often provide direct advocacy for families in negotiating benefits either with the state Medicaid program or with private insurance plans. The **Illinois** Title V program has hired former staff of health insurance companies who travel to regional public health offices and work with care coordinators, showing them how to help people maximize their private benefits and advocate with Medicaid to pay for needed services.

In **Vermont**, Title V staff work directly with privately insured families to advocate for coverage of services that are prescribed by a physician or referrals to out-of-network providers that were initially rejected by the insurer. Advocacy and Benefits Counseling (ABC) for Health, a **Wisconsin**-based, nonprofit, public-interest law firm, provides direct benefits counseling services to families having problems with health care coverage, adequacy of benefits or access to services. ABC for Health has developed a model for training culturally competent and family-centered benefits counselors. ***Making the Case for Coverage***, a publication developed in **Massachusetts,** describes health plan decision-making processes and identifies strategies for addressing medical necessity.

Selected Resources

Managed Advocacy: Essential Elements, ABC for Health. http://safetyweb.org/publications/CKSN%20Products/index.asp

The Family-to-Family Health Information Centers (F2F HICs) play a critical role in helping families navigate the system. Continued funding on the federal level is necessary for them to continue this important work. The directory of F2F HICs by state is found at http://www.familyvoices.org/info/ncfpp/grantees.php

Making the Case for Coverage: Tips for Helping Children and Families Get the Benefits They Need from Their Health Plans, New England SERVE and the Massachusetts Consortium for Children with Special Health Care Needs. http://www.neserve.org/neserve/pub_mtcc.htm

CARE COORDINATION

Care coordination is a service that promotes the effective and efficient utilization of resources to assure access to care and services for CYSHCN. Supported by most Title V CYSHCN programs, these services can have a big impact on families, and can help mitigate financial hardship. However, access to care coordination is often limited by the availability of federal or state funds. Several states have expanded the availability of care coordination for CYSHCN by combining state Title V and Medicaid funding, or by blending Title V and private insurance funding.

For example, **Arizona** blends funding from the Title V program and the Governor's Council on Traumatic Brain Injury and Spinal Cord Injury, using statewide vendors to provide care coordination to these specific populations. **Maine** Medicaid uses EPSDT funding to provide three-tiered care coordination; **Michigan**, **Utah** and **West Virginia** use state funds for CYSHCN to provide the state match to draw down federal Medicaid funds for care coordination for Medicaid-eligible CYSHCN. **New Hampshire's** Partners in Chronic Care program works with the Title V program, Family Voices and private payers such as Anthem Blue Cross Blue Shield, to promote a team approach that includes care coordination and family support. **New Mexico's** Title V program employs 60 social workers throughout the state to provide care coordination for CYSHCN enrolled in either Title V or Medicaid. Title V provides care coordination for all participants including children receiving Medicaid and SCHIP.

Selected Resources

Designing Evaluation Studies of Care Coordination Outcomes for Children and Youth with Special Health Care Needs, The Catalyst Center.
http://www.hdwg.org/catalyst/toolkit

CONSUMER/FAMILY-DIRECTED CARE

Some state Medicaid plans have introduced programs that promote consumer- or family-directed care, with broader latitude for family choice and control. These programs tend to support community-based long-term care. Consumer-directed care models, also called family-directed care models, allow an individual with disabilities or his or her family to decide how limited funds, services, or other resources are used, and to hire or direct personal care staff. A few states have implemented programs that allow families wide-ranging choice in the selection and direction of long-term support services for their CYSHCN. Note: This use of the term "consumer-directed" should not be confused with its use to describe low-cost, high-deductible health plans. **Florida** operates a consumer-directed long-term care waiver that includes children with developmental disabilities. **Massachusetts** covers consumer-directed personal assistance as a state Medicaid plan service, and makes these services available for children with disabilities. **Ohio's** Department of Education created an Autism Scholarship program that allows parents to put together their own education program using state funds to purchase educational and health-related services from private providers. **Virginia** operates a consumer-directed care waiver, primarily for adults with disabilities, but which also includes some children.

FLEXIBLE FUNDING—STATE AGENCIES

States agencies often provide flexible funding to help families cover special expenses associated with raising CYSHCN. States may be more or less restrictive about the amount of money available to a given family per year, and about the kinds of goods and services for which funds can be used. In general, agencies strive to give families relatively wide leeway on the use of flexible funding. Typical uses may include respite services, camp tuition, home or vehicle modifications, replacement parts for durable medical equipment, family support services, and nutritional supplements. Payment may come from publicly or privately administered trusts or other funding sources. **Missouri's** CSHCN/Hope Program covers services often not covered by private payers such as hearing aids, hearing aid batteries, orthodontic care, durable medical equipment, emergency transportation, nutritional supplements, and other therapies. **Tennessee's** Family Support Program, administered through the Division of Mental Retardation Services and operated by local agencies, provides funds for wrap-around services for children who meet developmental disability eligibility criteria. **Maryland's** Developmental Disabilities Administration may provide up to $3,000 per family, per year through Rolling Access funds, which help families receive support quickly without going through a full eligibility process.

FLEXIBLE FUNDING—TRUST AND RELIEF FUNDS

While many Title V programs function as the payer of last resort for CYSHCN who meet clinical and income eligibility guidelines, the funding for these services is limited by the size of the state's Title V funding allocation or state budget. Several states provide flexible funding through trust or relief funds, sometimes called catastrophic relief funds, which expand the availability of this last resort coverage. When established at the state level, catastrophic relief funds are usually administered by independent commissions or Title V programs, and receive funding through a variety of public and private sources. The term "catastrophic" refers not to the condition for which the expense is incurred, but rather, to the impact on a family's finances. State-operated funds to address family financial hardship include **Colorado's** Traumatic Brain Injury Trust Fund; **Georgia's** Brain and Spinal Injury Trust Fund; a fund in **Kansas** that makes use of a special bequest; **Michigan's** Special Needs Fund; and **New Jersey** and **Massachusetts'** Catastrophic Illness in Children Relief Funds.

Selected Resources

Relief Funds: A Safety Net for Children and Youth with Special Health Care Needs, The Catalyst Center. http://www.hdwg.org/catalyst/toolkit

MANDATED BENEFITS FOR SPECIALIZED SERVICES

Mandated benefits are one way to address underinsurance; they require private health insurance carriers to offer specific benefits. State legislatures across the country have passed mandated benefit laws, ensuring that people who are covered by private insurance have access to certain benefits. Often, these are preventive services such as screenings, with the potential to save costs for the system as a whole by catching conditions before they become severe and costly to treat. In some cases, mandated benefits are designed to meet the needs of particular populations at high risk, including CYSHCN. These benefits may be needed by small numbers of children who would be at extreme risk if services or treatment were not provided, such as children with PKU who require special diets to prevent mental retardation or death, or for services that affect larger populations. Examples of benefits deemed essential for public health by some states include mandated coverage for early intervention and developmental services for children age birth to three (**Massachusetts, Rhode Island, Connecticut, New Hampshire, Virginia, Missouri, New Mexico, New York, Indiana**); the use of tele-medicine (**Hawaii**); services for children with autism (**Kentucky, Delaware, Georgia, Iowa, Indiana, Maryland, New Jersey, Pennsylvania**). The mandates have the effect of ensuring that children with either public or private coverage have access to these critical services.

With room for discretion in how they implement federal programs, states have been able to initiate strategies to improve coverage and financing.

An important exemption from state benefit mandates applies to companies that self-insure. Instead of purchasing health insurance coverage for their employees, self-insured companies pay for employees' health care costs directly, usually using a health plan to administer the benefits. Self-insured employers are exempt from all state mandates under the provisions of the federal ERISA (Employee Retirement Income Security Act) law. Many of them choose to follow state laws, but they are not required to do so. It is also important to understand that state-specific statutes determine the parameters of a particular mandated benefit, and that there is variation in what is actually covered from state to state. States may vary in terms of who they make eligible for a given benefit, what it covers, or the dollar amount an insurer may be obliged to pay out for a consumer receiving the benefit. For example, a mandate for mental health parity may mean unrestricted access to mental health services in one state or within one particular health plan, or it may mean that individuals can only receive a certain number of mental health visits or hospital days if those benefits are also restricted for physical health services.

Selected Resources

Mandated Benefits: Essential to Children and Youth with Special Health Care Needs, The Catalyst Center. http://www.hdwg.org/catalyst/toolkit

A resource on mandated benefits for early intervention from the National Early Childhood Technical Assistance Center: http://www.nectac.org/topics/finance/statelegis.asp

MEDICAID BUY-IN PROGRAMS

Medicaid buy-in programs allow families of children who are over-income for Medicaid to purchase Medicaid benefits, even if they have private insurance coverage. In most cases, the child has to meet disability-related eligibility criteria. Several states have implemented Medicaid buy-in programs for low-income children or children with disabilities. With the recent passage of the Family Opportunity Act, (Public Law No. 109-171), these buy-in programs may serve as models for other states that want to expand coverage or benefits for CYSHCN. Medicaid buy-in programs are particularly important for underinsured CYSHCN, because they allow families to purchase Medicaid benefits specifically to cover services that are not covered or are covered inadequately by employer-sponsored insurance plans. Note that while some states allow families to buy in to SCHIP if a child is uninsured, families cannot buy in to SCHIP to supplement existing private coverage. **Iowa, Illinois, Louisiana, Massachusetts, North Dakota, Pennsylvania,** and **Vermont** allow families to purchase Medicaid benefits for their children, either as full coverage if the child is uninsured or as supplemental coverage if the child has private insurance. Most apply a premium based on a sliding scale, some limit the buy-in option based on disability criteria, and others use income criteria to limit eligibility.

Selected Resources

Reducing Underinsurance for Children and Youth with Special Health Care Needs

Frequently Asked Questions about the Family Opportunity Act's Medicaid Buy-In Option

Methodology for Estimating the Impact of State Implementation of the Family Opportunity Act's Medicaid Buy-in Option

All available from the Catalyst Center at http://www.hdwg.org/catalyst/toolkit

PREMIUM ASSISTANCE

Premium assistance is a health insurance purchasing strategy in which a state uses public funds to pay for a portion of the premium costs of employer-sponsored insurance for eligible populations. States have also infrequently used premium assistance to subsidize individual insurance policies. One state, **Massachusetts,** provides subsidies to small employers who provide coverage to their employees. At last count at least fourteen states are operating premium assistance programs, and many other states are at various points in the planning process.

Many states have expressed interest in pursuing premium assistance because they want to take advantage of the contributions that employers make toward the cost of employee health insurance coverage. These states reason that the savings that will result from leveraging employer contributions can help address tight state budgets and provide a mechanism to cover a greater number of the uninsured population. Some states also place value on using the private sector to provide coverage, rather than expanding public programs.

Selected Resources

This description is taken from the Premium Assistance Toolbox for States, National Academy for State Health Policy, http://www.patoolbox.org/.

Premium Assistance: Issues to Consider, Health Policy Institute, Georgetown University, http://covertheuninsured.org/resources/docs/id184/AlkerCoordination.pdf.

SPECIALIZED MEDICAL DAY CARE, RESPITE AND DAY CAMPS

Providing specialized medical day care, respite care or access to summer programs can allow families to maintain or return to employment and decrease financial hardship. Several states use Medicaid funds to pay for health care services that assist CYSHCN to participate in day care, after-school programs or summer camps. **California's** Pediatric Day Health Care Facilities, developed under Medicaid's EPSDT authority, provide individualized, family-centered services to children who are under 21, who have a medically complex condition that requires skilled nursing and therapeutic intervention for part of the day (less than 24 hours). **Georgia** uses Medicaid funds to pay for health care services that assist CYSHCN to participate in day care. These services are provided through waiver programs that pay for slots in "day care centers for the medically fragile." In **Maryland,** Title V and Medicaid support two medical day care centers serving medically complex infants and young children. These centers provide quality childcare, nursing and developmental services to children whose medical needs are too great to be served in traditional childcare settings.

> *We call on policymakers to see the impact of medical debt on families, and to address health-related financial hardship as part of overall health care reform.*

Through EPSDT, the **Rhode Island** Department of Human services established four CEDARR Family Centers (Comprehensive Evaluation, Diagnosis, Assessment, Referral & Re-Evaluation) to help families navigate the care system. EPSDT authority also enables the **Rhode Island** Medicaid KIDS Connect program to provide payment to childcare centers, after school programs and summer camps to hire an aide to support CYSHCN in inclusive programs. **South Carolina** uses Medicaid funds to pay for health care services that assist CYSHCN to participate in day care. These services are provided through waiver programs that pay for slots in "day care centers for the medically fragile."

TEFRA MEDICAID ELIGIBILITY OPTION FOR CHILDREN

The federal Medicaid program offers a state plan option that allows states to provide Medicaid coverage for certain children under age 19 who have disabling conditions and live at home. This program enables children with complex disabilities to be cared for at home instead of an institution even if family income exceeds state Medicaid eligibility limits. This program is also known as the Katie Beckett waiver. As of December 2008, twenty-eight states have adopted the TEFRA state plan option.

TRANSITION SUPPORTS

CYSHCN who grow to adulthood—as more of them do today than ever before—face a daunting future in terms of employment and financial security when they age out of children's services. According to the U.S. Department of Labor, the unemployment rate for persons with disabilities in 2007 was 79%. However, there are strategies to help. The Ticket to Work and Self-Sufficiency Program of the Social Security Administration is a voluntary program in which qualified SSI recipients can obtain vocational rehabilitation, employment or other support services from an approved provider to help them go to work and achieve employment goals. Another helpful resource is the MCHB-funded national center on transition of youth with special health care needs, known as Healthy and Ready to Work. Healthy and Ready to Work offers resources and supports beyond just employment, including health and wellness, public and private insurance coverage options, youth involvement in decision-making and more. A wealth of information and technical assistance can be found on their website.

Selected Resources

Ticket to Work
http://www.yourtickettowork.com

Healthy and Ready to Work
http://www.hrtw.org

This work was made possible with support from the Maternal & Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, under cooperative agreement #U4IMC04494.

February 2009
Second printing, July 2009

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs

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