



# Breaking the Link between Special Health Care Needs and Financial Hardship

Second edition

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 (MCHB), 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” (McPherson et al., 1998).

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**The Catalyst Center at the Center for Advancing Health Policy and Practice at Boston University School of Public Health is the national center for health insurance and financing for children and youth with special health care needs.**

## ABOUT THE CATALYST CENTER

The Catalyst Center is a national center that works to advance the federal Maternal and Child Health Bureau (MCHB) outcome measure that “families of children and youth with special health care needs (CYSHCN) will have adequate private and/or public insurance to pay for the services they need.”

Since 2005, the Catalyst Center has been researching and disseminating state-level financing strategies aimed at increasing health insurance coverage for CYSHCN and reducing financial hardship and medical debt for their families.

The goals of the Catalyst Center are to promote universal, continuous, and affordable coverage for all CYSHCN.

Our staff:

- Provides technical assistance and applied research support to state Title V programs and their partners, policy makers, family leaders, researchers, and other stakeholders to maximize access to health insurance
- Engages federal, state, and community stakeholders and partners in ensuring that health care delivery and financing efforts address the needs of CYSHCN
- Supports efforts to improve coordination between Title V, Medicaid, and the Children’s Health Insurance Program (CHIP), especially related to care coordination, Early, and Periodic Screening, Diagnostic and Treatment (EPSDT), enrollment, and quality improvement



- Identifies and supports policy and program initiatives at the state and federal level to reduce inequities in health insurance coverage and other health care financing among underserved CYSHCN, including Black and Latino children, low-income children, children living in immigrant families, and those in which English is not the primary language
- Monitors, analyzes, and reports on emerging federal and state trends, legislation, regulations and other relevant policy proposals related to health insurance and other health care financing
- Identifies and supports innovative financing strategies to improve reimbursement for services used by CYSHCN
- Promotes strategies and policies to finance additional services, which generally are not covered by private and/or public insurance

- Monitors progress in achieving the health insurance core outcome and documents the National Center's impact on improving access to adequate health insurance

**Note:** The Catalyst Center works primarily at the system and policy levels, which means we collaborate with Title V leaders, other government, national and state partners, including researchers and other agencies, to promote strategies for improving the health care system. Families in need of individualized support around health insurance and financing of care for their CYSHCN can find a list of organizations, by state, that provide direct services and assistance to families on the [Information for Families](#) page of the Catalyst Center website at <http://cahpp.org/projects/the-catalyst-center/info/>

**Anyone caring for a child or youth with special health care needs (CYSHCN) understands how stressful it can be. The Catalyst Center has updated *Breaking the Link* to revisit the impact that health care financing and coverage gaps have on the lives of real families and highlight innovative policy solutions that can improve the system of care for CYSHCN.**

## NEW IN THIS ISSUE OF BREAKING THE LINK

**Anyone caring for a child or youth with special health care needs (CYSHCN) understands how stressful it can be.**

The daily demands of raising a child or youth with a special health care need, chronic illness, or disability are significant. Parents, other family members, and caregivers may schedule and drive to multiple physician and therapy appointments, prepare a child for procedures and hospitalizations, negotiate with health insurers and appeal decisions, complete endless amounts of paperwork, communicate with school personnel, advocate for additional services, and perform countless other activities that are all part of caring for a CYSHCN. These responsibilities often affect the physical and emotional health of parents, caregivers, and other family members (Kuo et al., 2011). In addition to these responsibilities, many families also bear

significant financial responsibility for out-of-pocket costs associated with health care and related services for their CYSHCN, even if their children are insured. Inadequate or underinsurance, which refers to coverage that does not cover all the necessary medical and related health services that a child needs, does not allow access to needed health care providers, and/or that has substantial out-of-pocket costs, can affect a family's financial health, putting the entire family at risk of financial hardship, medical debt, and poverty (Bachman & Comeau, 2010).

In 2009, the Catalyst Center created *Breaking the Link Between Special Health Care Needs and Financial Hardship* to highlight the financial hardship families experience in caring for CYSHCN. The publication illustrated three pathways that lead to financial hardship for families even when their children have

health insurance: **higher health care costs, higher routine expenses, and loss of employment income.**

The following year, the Patient Protection and Affordable Care Act (ACA) was passed. This national health care reform legislation created new provisions for health insurance, expanded coverage options available to those who previously could not afford them, and included new protections for individuals with pre-existing conditions, including CYSHCN (The Henry J. Kaiser Family Foundation, 2012).

**Despite the positive impact on the problem of uninsurance, the ACA did not fully address the issue of inadequate or underinsurance.**

Even with the consumer protection provisions and coverage expansions included in the ACA, families whose children require significant health care and related services due to special health care needs, chronic illness, or disability continued to be at risk for financial hardship due to both the costs associated with the services they need and limits on benefits, even though the overwhelming majority of them had coverage (Feldman et al., 2015).

The Catalyst Center has updated *Breaking the Link* to revisit the impact that health care financing and coverage gaps have on the lives of real families. This edition features the stories of three families who continue to incur higher health care costs, higher routine expenses, and the loss of employment income. We have coupled each family's story with descriptions of innovative policy solutions that some states use to cover more children, pay for additional services, close benefit gaps, and build the capacity of the system of care for CYSHCN. These promising practices can serve as models in meeting the challenges of the current and evolving health insurance and health care financing landscape.

We hope Title V Maternal and Child Health (MCH) programs, Medicaid programs, advocates, families, and payers at both the state and national levels will use this resource to support conversations with policymakers to improve their understanding about the health care coverage and financing needs of CYSHCN.

*Three pathways lead to financial hardship for families, despite health insurance:*

- *Higher health care costs*
- *Higher routine expenses*
- *Loss of employment income*



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

**Some families have to make hard choices to ensure adequate care for their children and youth with special health care needs. Many families experience severe financial hardship and incur medical debt, which can place their children at high risk for adverse health outcomes.**

Health insurance coverage is crucial for CYSHCN who, like all children, need access to primary care, but who may also require diagnostic testing, mental and behavioral health services, specialty care, prescription medications, special medical foods, therapies, durable medical equipment, and other health-related services that may not be covered adequately by their health insurance (Kogan et al., 2005; Kogan et al., 2010; Feldman et al., 2015). Access to these services is essential for diagnosing health problems, preventing the worsening of physical or mental health, and maximizing a child's potential to learn, play, and develop alongside his or her peers (HRSA/MCHB, 2016). These services are also essential to a child's successful transition to adulthood (Bloom et al., 2012).

Just because a CYSHCN has health insurance does not necessarily mean the insurance is adequate. Having health insurance is only part of the story when it comes to ensuring CYSHCN have access to comprehensive benefits,

specialty providers, and that the out-of-pocket costs associated with their care do not create a financial hardship for their families.

Access to health care is usually dependent on having a way to pay for it. Most children with special health care needs have typically had access to health care coverage; in 2009/10, before the passage of the ACA, 90.7% of CYSHCN were consistently insured (National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10). For those CYSHCN who were uninsured, or had difficulty remaining consistently insured, provisions under the ACA prohibited denials of, or limits on, coverage for individuals with pre-existing conditions and eliminated annual and lifetime caps for the dollar amount of services a health plan would provide. Other provisions also guaranteed that health insurers could no longer refuse to issue or renew a health insurance policy based on an individual's health status or high utilization of services (Robert Wood Johnson Foundation, 2011).

Even though most CYSHCN were insured before the passage of the ACA, 34% of families reported their child's

insurance was inadequate (National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10). Notably, racial and ethnic minority children had disproportionately higher rates of both uninsurance and underinsurance, as indicated in the table on the next page (National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10).

**Even with the early protections afforded by provisions of the ACA,** 29.2% of families whose CYSHCN had health insurance continue to report their insurance was inadequate (National Survey of Children's Health. NSCH 2011/12). More recent investigations confirm inadequate health insurance remains a problem for families of CYSHCN (Goudie et al., 2014; Thomson et al., 2016).

Inadequate insurance occurs when a family's health care plan does not cover enough of their health care expenditures and the family is left with high out-of-pocket costs (National Survey of Children's Health. NSCH 2011/12; Bachman & Comeau, 2010). Many health plans have established out-of-pocket maximum or catastrophic limits that families pay. However, premium costs, services provided by out-of-network providers, or benefits that a health plan does not cover do not count

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

	White, Non-Hispanic	Black, Non-Hispanic	Hispanic
Consistently insured	92.7%	90.1%	84.1%
Currently insured, insurance is inadequate	33.0%	35.9%	37.9%

Historically, CYSHCN are insured at higher rates than children in general. However, 34% of families of CYSHCN report their child's insurance is inadequate. Racial and ethnic minority CYSHCN had disproportionately higher rates of both uninsurance and underinsurance.

**Source:** National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10.

toward these plan maximums, leaving families of CYSHCN to pay these costs out of pocket.

Across the United States, even middle-class families raising CYSHCN are experiencing material hardship (Thomson et al., 2016; Parish et al., 2008). To put this in perspective, in 2017 the family out-of-pocket maximum for a family of four with Health Insurance Marketplace coverage earning 399% of the federal poverty level, or about \$97,000 per year (Office of the Assistant Secretary for Planning and Evaluation, 2016), will increase from \$13,700 in 2016 to \$14,300, almost 15% of household income (HealthCare.gov, 2016). In addition, families incur higher routine expenses when they modify vehicles to accommodate wheel chairs, and accrue costly gas and parking expenses because they need to drive their children to multiple appointments. And, family members continue to cut back on work or leave the workforce to care for their CYSHCN, resulting in loss of employment income (LeRigne, 2012).

As noted above, under specific provisions of the ACA health insurers can no longer impose annual or lifetime limits on the dollar amount of services they provide. But, plans can still limit the amount,

scope, and duration of benefits such as rehabilitative services that are crucial to many CYSHCN. And, in an effort to control costs, many employers are offering high deductible health plans, which also contribute to financial hardship, or narrow provider networks, which do not always include the specialized hospitals and providers CYSHCN require (Bartrum et al., 2013). These plans leave families to bear the burden of the full cost of any additional services their children continue to need. This may mean that a family has to make difficult choices between paying for groceries, rent, or other living expenses in order to afford needed health care services or forgoing these services and compromising the health outcomes of their CYSHCN (Thomson et al., 2016). In addition, the essential health benefits required of some types of plans did not ultimately address underinsurance for CYSHCN, due to their higher-than-average need for specialized services and the broad flexibility granted to states in determining what is “essential” (Fry-Bowers, 2015).

Other factors that contribute to benefit gaps include state-to-state and plan-to-plan differences. For example, depending on the state and type of health plan, specially modified foods and formulas, critical to the development of children

with certain metabolic disorders may not be a covered benefit. Medical foods, which families often pay for out-of-pocket are expensive and an additional source of financial burden (Berry et al., 2013; Therrell et al., 2014; Wilson et al., 2016). Medical devices and supplies, including over-the-counter medications or diapers for older children, may also not be covered benefits.

In addition to inadequate coverage, coverage gaps are another pathway to financial hardship for families raising CYSHCN. Children and youth with special health care needs may experience periods of uninsurance if parents or caregivers lack access to affordable coverage through their employer, if they have insurance coverage through their employer and lose their job, or if they change jobs and there is a waiting period before the family can enroll in the new employer-sponsored private coverage. The ACA did not prohibit waiting periods, but it did reduce them; as of 2016, waiting periods cannot exceed 90 days. However, the average waiting period is still almost two months, which could create significant financial hardship for a family with a CYSHCN (2016 Employer Health Benefits Survey, 2016) whose child cannot go two

months without services and who would be responsible for the out-of-pocket costs associated with needed care during this time.

Finally, new barriers arose from unforeseen consequences related to the implementation of the ACA. The “family glitch” is a barrier to coverage (Brooks, 2014). The “glitch” occurs because regulations governing the ACA considered employer-sponsored health insurance to be both affordable and adequate if the employee’s share of the premium for self-only coverage was less than 9.66% of household income (HealthCare.gov, 2016) and the plan paid at least 60% of medical costs (HealthCare.gov, 2016). However, premiums are higher for family coverage, so calculating what is affordable based on the cost of individual coverage may cause undue financial hardship. Alternatively, families caught in the “glitch” could purchase Marketplace health plans, but they would not be eligible for subsidies to reduce the cost as, technically, they had access to affordable, adequate employer-sponsored insurance. As a result, CYSHCN impacted by the family glitch remained at risk for uninsurance or financial hardship.

*Inadequate health insurance remains a problem for children and youth with special health care needs.*

Some families have to make hard choices and difficult sacrifices to ensure adequate care for their CYSHCN. Other families, whose earnings are just above the income eligibility thresholds for Medicaid or CHIP may suffer dramatically because they earn “too much” to qualify for certain public benefit programs. However, in reality they do not make enough to pay the out-of-pocket costs incurred in caring for their CYSHCN (Parish et al., 2008; Feldman et al., 2015). Many families experience severe financial hardship and incur medical debt, which can place their children at high risk for adverse health outcomes. These negative outcomes could be avoided with the implementation of financing strategies aimed at covering more services and reducing families’ out-of-pocket expenses.

As noted above, some provisions of the ACA, such as the family glitch and out-of-pocket maximums, perpetuated the problem of inadequate insurance and financial hardship for families with CYSHCN. But other provisions of the ACA strategically improved health insurance and access to care for CYSHCN. Racial and ethnic minority children experienced coverage gains (Schwartz et al., 2016). And, individuals with pre-existing conditions, including children with special health care needs, disabilities, and chronic illnesses had increased access to needed health services because they could no longer be denied coverage; were not at risk for maxing out any insurance they did have because they exceeded an annual or lifetime benefit cap; and could remain on their parent’s insurance to age 26 to help bridge any coverage gaps during the transition to adult life.

In the pages that follow, we explore policy initiatives that can help ensure adequate and affordable coverage that provides a comprehensive array of health care and related services and family supports. As federal and state health care reform continues to evolve, these strategies may be useful to policymakers as they critically analyze the capacity of the private and public health infrastructure to support both the medical and financial health of CYSHCN and their families.

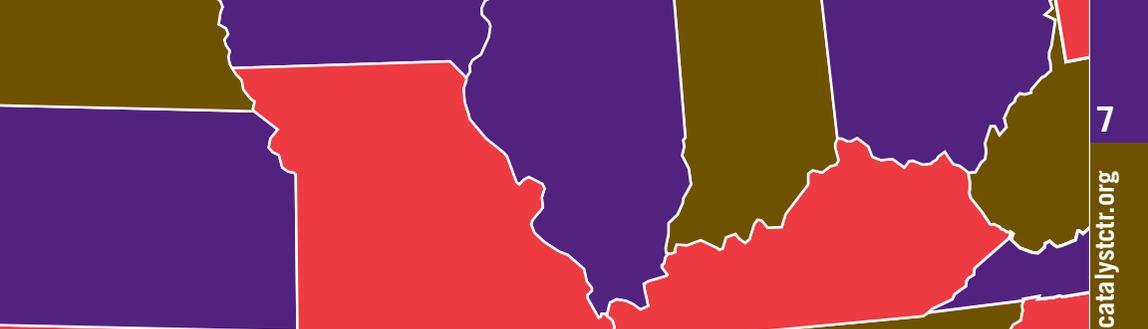
**Inadequate insurance, high health care costs, and benefit gaps may mean that a family has to make difficult choices between paying for living expenses or forgoing services and compromising the health outcomes of their CYSHCN.**

## A CALL TO ACTION FOR STATES

**We encourage Title V leaders, Medicaid programs, state and national health policy leaders, and family advocates to use this issue of *Breaking the Link* to spread the word and raise awareness about the continued financial hardship endured by many families raising children and youth with special health care needs.**

### **Breaking the Link between Special Health Care Needs in Children and Youth and Financial Hardship**

States have options to help families meet the challenges of inadequate health insurance. For example, some states have successfully adopted Medicaid buy-in programs, which allow families whose income is too high to qualify for Medicaid to supplement their existing private insurance by purchasing Medicaid coverage. In other states, relief funds for families of children with catastrophic health care expenses provide flexible funding to help pay for expenses that are not typically covered by health insurance, but that are directly related to a child's complex health needs. Examples include vehicle or housing modifications or costly nutritional supplements that are necessary to treat rare disorders. Finally, some state agencies and family leader organizations provide care coordination and benefits counseling that help families maximize both private and public benefits and reduce out-of-pocket expenses. And partnerships with navigator and consumer assistance programs help ensure families from diverse backgrounds receive culturally and linguistically appropriate information about their health insurance options.



For too long, we have seen these strategies and other innovations implemented successfully on a limited scale or for a limited time. Because only small numbers of families benefit, these are missed opportunities for improving child health and reducing family financial hardship across the country.

## THE CATALYST CENTER CAN HELP

Today, underinsurance remains a critical problem for families raising CYSHCN and often results in family financial hardship and medical debt.

The Catalyst Center can be a resource to you. We can work with you to identify innovations, such as a Family Opportunity Act Medicaid Buy-In program that can be implemented in your state. We can provide information about strategies to reduce health insurance inequities, explain the implications of legislation and policies for CYSHCN, and provide data to help you make a case for improving coverage and financing of care for CYSHCN in your state.

We invite you to visit our online State-at-a-Glance Chartbook on Coverage and Financing of Care for Children and Youth with Special Health Care Needs (<http://chartbook.cahpp.org/>) to learn about the health care financing landscape in your state. Our staff is readily available to provide technical assistance and consultation about the successful strategies to cover more services and reduce family financial hardship highlighted in this publication, and ways to implement these strategies in your state. We look forward to hearing from you.

Contact us through our website at <http://catalystctr.org> or via email at [cyshcn@bu.edu](mailto:cyshcn@bu.edu)



# 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 problems facing families.**

In the first edition of *Breaking the Link*, we highlighted three family stories that were representative of the experience of many families raising CYSHCN. For this edition, we revisited the Rodgers family to learn about how their financial lives have evolved. We also met two new families who graciously welcomed us into their lives and shared details about their children and the challenges they face in ensuring their children have access to all needed health care services.

These families thanked us for “giving them a voice,” but it is the Catalyst Center team who thanks them for sharing valuable information that has the potential to educate policy makers

and change the way health care is financed for children and youth with special health care needs.

We extend our admiration, respect, and heartfelt appreciation to the Rodgers, Cerrato-Bondi, and Hatlen families.

# EXPLORING THE LINKS



## Consider the three primary ways that the structure of our health care system brings financial hardship to families of CYSHCN:

- Higher health care costs
- Higher routine expenses
- Loss of employment income

## Learn more in the first edition of *Breaking the Link*

([http://cahpp.org/wp-content/uploads/2015/04/Catalyst\\_Center\\_Breaking\\_The\\_Link.pdf](http://cahpp.org/wp-content/uploads/2015/04/Catalyst_Center_Breaking_The_Link.pdf))

Research conducted by the Catalyst Center and others on the extent of financial hardship for families of CYSHCN revealed 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, or 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, although even one of these pathways can result in a financial burden that can dramatically affect a family's financial status.

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

**DEBT**



## The Rodgers Family Revisited

### What Adequate and Affordable Health Care Coverage Means to Them

*Key provisions under the ACA changed the Rodgers family's life. David and Rylin could switch jobs without fear of losing their insurance coverage, Rylin could return to full-time employment, and in short, economic stability became attainable for them once again. Importantly, Matthew and Laura could choose future careers based on their aptitude and interests, and not be limited by insurance choices or by being "forced poor" in order to stay eligible for Medicaid as adults with disabilities.*

Things like a simple dinner out or cable television became unthinkable luxuries as bills for necessities sometimes went unpaid. They existed under the shadow of deep concern for the future, wondering how Matthew and Laura would successfully transition to productive adulthood when life-saving treatment was potentially outside of their reach.

### PATHWAYS TO FINANCIAL HARDSHIP

The dramatic impact of underinsurance was financially devastating to the Rodgers family for many years. The Catalyst Center has identified three primary pathways to financial hardship for families raising children with special health care needs; the Rodgers family experienced all three:

**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. For example, 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 had considered changing careers to something more lucrative, but he stayed in teaching because of the medical insurance.

Rylin and David Rodgers live in Indiana with their two teenagers, Matthew and Laura. Both Matthew and Laura have a complex neuromuscular condition called Mitochondrial Disease which impacts their health in multiple ways. Every parent expects their life will change with the arrival of a new baby, but the Rodgers' never anticipated how much their financial lives would be impacted. When the Rodgers family was first interviewed by the Catalyst Center team in 2009, they talked about their

utter shock at how quickly the expenses mounted once special health care needs entered the picture.

Rylin and David were in good financial standing when they welcomed their first child, Matthew, into the world. Both teachers, they had a comfortable combined annual salary, owned their own home, and had zero consumer debt. 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.” 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 said in 2009, “but no one offered, either. I think we looked ‘too good’ to need help.”

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

Required by their health insurance to pay 20% of all health care costs out of pocket, the couple took out three mortgages on their home. They 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 assumed that a family like ours, because we had two college-educated parents, would have the resources they needed to take care of their family’s medical conditions,” recalled 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 that we’d

been income-eligible the whole time for Children’s Special Health Care Services (Indiana’s Title V program).”

With both children finally enrolled in Children’s Special Health Care Services, the program helped the Rodgers pay for Matthew and Laura’s medical care for several years. However, when David received a pay raise that pushed the family’s income over 250% of the federal poverty level, they exceeded the program’s income criteria, and were no longer eligible. By trimming their grocery budget to \$40 a week for the family of four, buying second-hand clothes, and forgoing non-essentials, the Rodgers were able to pay \$500 a month for the nutritional supplements that Rylin says are the only recommended treatment for Matthew and Laura’s condition. Neither Medicaid – which Matthew and Laura subsequently enrolled in after ten years on a waiting list for a special waiver program – nor the family’s private insurance covered any part of that cost.

The Rodgers had to make other difficult choices and adjustments, too. When they couldn’t afford the muscle biopsies required to diagnose Matthew and Laura’s condition, which were not covered by

## BREAKING THE LINK

Provisions of the ACA helped ensure individuals with pre-existing conditions have universal and continuous coverage. It prohibited private insurance companies from denying or limiting coverage to individuals with pre-existing conditions. Insurers must issue and renew policies, regardless of an individual’s

health status, age, or gender. Parents may also keep their children under age 26 on their health plans.

Provisions of the ACA helped ensure adequate coverage. Insurers can no longer impose annual or lifetime caps on the total dollar amount of health care they will provide.

insurance, they chose to have just one child officially diagnosed. When wheelchair maintenance grew to thousands of dollars a year, they got Matthew and Laura scooters instead. And while four different subspecialists wanted to see Laura every month, she typically went only every three months. “I tried to balance appropriate medical care with reality,” recalled Rylin.

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

After the ACA was upheld by the Supreme Court in 2012, Rylin reflected on what this legislation meant for her family and other families raising children with special health care needs. From birth, both Matthew and Laura have required extensive medical care, which was so costly that the family quickly hit the annual and lifetime caps imposed by their health insurance. Before the passage of the ACA, Matthew and Laura had quickly joined the ranks of Americans whose pre-existing conditions made them uninsurable, locking the Rodgers’ young family into a world of limited choices, financial hardship, and ongoing stress.

For example, fearing a gap in insurance coverage, neither parent could change jobs. They experienced financial hardship because once the annual and lifetime health insurance caps were met, they paid the tremendous cost of their children’s medical services out-of-pocket. Things like a simple dinner out or cable television became unthinkable luxuries as bills for necessities – including their own medical bills – sometimes went unpaid. They survived, but just barely, and continuously were

**“We were shocked by how many people advised us to divorce so we could get Medicaid.”**

forced to make painful choices about treatment priorities. They existed under the shadow of deep concern for the future, both for themselves and their children, wondering how Matthew and Laura would successfully transition to productive adulthood when life-saving treatment was potentially outside of their reach.

Amidst the darkness of a national financial crisis, a ray of hope appeared for the Rodgers family. When the ACA was passed in March 2010, Rylin read every word; she is nothing if not fully aware that knowledge is power and that knowing exactly what the ACA held would allow her to support her family and others in accessing its protections.

Debate over the ACA did not end with its passage. On June 28, 2012, the US Supreme Court upheld the constitutionality of the ACA. The Rodgers family understood the enormity of this decision for themselves and for other families raising children with special health care needs. When the “upheld” tweet came over her phone, Rylin turned to her son and said, “You have a future.”

As of September 23, 2010, Matthew and Laura became permanently uninsurable throughout their lives despite their pre-existing conditions. Rylin was able to take a full-time position and enrolled her children in private coverage, something that would have been impossible pre-ACA. Provisions under the ACA also prohibited annual

and lifetime limits on the dollar amount of services health plans provide, so Matthew and Laura no longer worry about hitting these caps. Under the family's new insurance they are able to access ongoing and continuous coverage as an entitlement provision of the ACA.

Key consumer protection provisions under the ACA changed the reality of the Rodgers family's life. David and Rylin could switch jobs without fear of losing their insurance coverage, Rylin could return to full-time employment, and in short, economic stability became attainable for them once again. Importantly, Matthew and Laura could choose future careers based on their aptitude and interests, and not be limited by insurance choices or by being "forced poor" in order to stay eligible for Medicaid as adults with disabilities.

As Matthew and Laura are on the threshold of young adulthood, the impact of the ACA is once again critical. They

can stay on Rylin's health insurance until they turn 26, creating a cushion of time to complete higher education and pursue employment that will provide them their own coverage options. The access to private insurance frees them from having to remain in Indiana as a condition of their Medicaid waiver eligibility, leaving Laura free to pursue out-of-state college scholarships. Additionally, the ability to buy coverage as adults through the Health Insurance Marketplace without consideration of their pre-existing conditions will allow Matthew and Laura to consider jobs and career paths regardless of the availability of employer-sponsored insurance.

The ACA is not perfect – there is no law that is – but it has been a life-changing, life-saving step forward for families like the Rodgers.

### Laura and Matthew in 2009





## The Cerrato-Bondi Family

**“You never think it will happen to you...”**

*When Ethan was born, the family immediately added him to their health insurance policy purchased through Colorado’s Health Insurance Marketplace. But when Ethan was older than 30 days, a NICU specialist informed Christine and Matt that their health insurer claimed they failed to enroll their son within the required 30-day period. In the following 6 months, Ethan was disenrolled from the insurance multiple times. In his first 3 months, the cost of his care was almost \$1 million.*

**In Ethan's first 3 months, the cost of his care was almost \$1 million.**

**"You hear this happens to other families but you never think it will happen to you, and then all of a sudden it does and there is no way out."**

Several months before their son Ethan was born, Christine Bondi and her husband Matthew Cerrato moved to Broomfield, Colorado with Christine's three children (ages 13, 8, and 5). Christine gushed that Ethan, now 23 months old, "is such a great little guy!" She went on to share that he was born 6 weeks prematurely with a Sacrococcygeal teratoma (SCT) tumor, a type of tumor that grows on the coccyx (tailbone) of developing fetuses. His had grown both internally and externally, damaging his rectum, urethra, and spine, which has resulted in paraplegia. At four days old, Ethan had a 9-hour-long surgery to remove the tumor and place a stoma, called a colostomy, for voiding fecal matter. Ethan has had even more surgical procedures since.

When Ethan was born, Matt immediately added him to the health insurance policy that he purchased

through Colorado's Health Insurance Marketplace. The family had previous positive experiences with the insurer who issued the policy and felt good about being able to add Ethan to their coverage. Christine thought their \$509 monthly premium "was a bargain compared to other monthly premiums [they] had seen." She went on to share that, "Once we enrolled Ethan in the plan, our experience [with the insurance plan] went south very quickly."

When Ethan was older than 30 days, a NICU specialist informed Christine and Matt that their health insurer claimed they failed to enroll Ethan within the required 30-day period. Christine recalled how panicked they were to learn Ethan was uninsured. Fortunately, Matt had an e-mail from the insurer confirming Ethan had been added to the policy. However, this was not a one-time communication glitch; their insurance problems persisted throughout Ethan's 3-month stay in the NICU and continued even after he was discharged. "In the following 6 months, Ethan was disenrolled from the insurance multiple times. The plan gave a different reason for why it happened every time. It has been a nightmare, and we were still paying the premiums."

In Ethan's first 3 months, the cost of his care was almost \$1 million. After an exhaustive online search for other health insurance options for her son, Christine



## “Secondary to seeing Ethan suffering, the financial part has been very difficult.”

### PATHWAYS TO FINANCIAL HARDSHIP

Had it not been for the wrap-around coverage their son received through the Colorado Medicaid Buy-In Program for children with disabilities, Christine and Matt would have had to file bankruptcy on nearly \$400,000 of medical care. But the Medicaid benefit did not provide universal protection from the three primary pathways to demoralizing financial hardship.

**Higher health care costs:** Maintaining the integrity of Ethan’s colostomy is a matter of life and death. Even with the supplemental coverage provided by the Colorado Medicaid Buy-In program, Medicaid limits on colostomy supplies were insufficient, leaving the family responsible for \$360 per day in out-of-pocket costs until the next month’s supply arrives.

**Higher routine expenses:** The family traded in a fuel efficient car for a van to accommodate Ethan’s wheelchair. Fuel costs are an increasing amount of the family budget, as Christine drives considerable distances for Ethan’s medical appointments, therapies, and in search of discount medical supplies. While Medicaid pays for ankle-foot orthoses (AFOs), Ethan cannot wear them as the cost of shoes that fit over the AFOs is prohibitive.

**Loss of employment income:** Christine has given up her career as she cannot hold down a job without compromising Ethan’s care. She spends the whole day, every day, juggling to make everything fit: Ethan’s medical appointments, OT, feeding therapy, PT, and speech therapy, and endless insurance paperwork.

eventually found the Health First Colorado Buy-In Program for Children with Disabilities, a program that allows families to purchase Medicaid coverage for children with disabilities even if their income is too high to qualify for Medicaid. “For all the time he was in the hospital, no one, including social workers in the hospital, ever told us about the Buy-in Program.” Christine recalls a hospital social worker spoke with them once during Ethan’s 3-month stay, noting, “Once the social worker knew we were well-educated, middle class people she never came back.”

“The Medicaid Buy-in program saved us. Like it literally saved us. Ethan’s private insurance only paid roughly 60% of his three month NICU stay. Had it not been for the Buy-in, we would have had to file bankruptcy on the nearly \$400,000 we owed to the hospital, surgeons, specialists, and therapists.”

Christine acknowledges they are lucky to live in a state that has a Medicaid Buy-in Program option, which picks up copays and pays for benefits that their private insurance did not cover. This includes a \$7,000 wheelchair and a hospital bed that Ethan needs — initially estimated at around \$11,000, but which actually cost more than \$25,000. The buy-in program, however, is not a cure-all. Every day, Ethan uses a tremendous amount of medical supplies including colostomy bags, flanges, and powders. Ethan’s needs exceed the monthly Medicaid allotment for these supplies and the difference is costly. Christine estimates that they go through 10 bags and 10 flanges a day, yet at the time of the interview Medicaid provided only 2 days’ worth. With the doctor’s justification of

To Christine's credit, she learned about the Colorado **Medicaid Buy-In Program** through an internet search. A referral to the Colorado **Family-to-Family Health Information Center** would have helped her learn about this important program sooner, as well as connected her with other services and supports.

Even though Christine's family lives in a state with a Medicaid Buy-in for a child with a disability, Christine struggles to obtain the additional colostomy supplies Ethan needs, in excess of what Medicaid provides because at the time of the interview, the family's Marketplace plan kept dropping Ethan. An **ombudsman** could help resolve the issues with the insurance plan they purchased through the Marketplace so Christine could complete paperwork for the additional colostomy supplies Ethan needs each month. In addition, a **12-month prior approval** for the additional colostomy supplies would not only reduce emotional stress, but also reduce the amount of paperwork and portion of the family budget that is spent on colostomy supplies. Christine provided an update that the family's Marketplace plan has now been cancelled and Ethan's sole source of medical insurance is Medicaid.

medical necessity, Ethan could receive 200 bags and flanges per month from their Marketplace plan, but in a race against the "disenrollment clock," Christine is never able to complete the paperwork before their other insurance plan drops Ethan again. Once she reinstates him, the clock resets and she has to start the process again. Christine calculates that each colostomy bag change, including all associated supplies costs about \$36. Ethan may need 10 changes per day, which translates to \$360 per day in out-of-pocket costs until the family receives the next month of supplies from Medicaid. If the integrity of Ethan's colostomy is not maintained, he is at risk of a major

**Flexible funding** or a **relief fund** would help the family defray the cost of fuel and colostomy-supply-related expenses and allow the family to purchase shoes that Ethan can wear over his ankle-foot orthoses so he can make progress towards walking. It would also free up the family budget so Christine could afford to let her other children participate in activities such as school field trips without having to choose between Ethan's health or rent, car payments, and groceries.

Christine has given up her career as she cannot hold down a job without compromising Ethan's care. She spends the whole day, every day, juggling to make everything fit: Ethan's medical appointments, OT, feeding therapy, PT, and speech therapy. There's endless insurance paperwork and she also needs to be available to her other children. **Specialized medical day-care** would make it possible for Christine to return to the workforce to pursue her career and free up her time to enjoy activities with her children, rather than driving to Ethan's appointments and searching for discount medical supplies.

systemic infection. "It's a matter of life and death that would cause an infection that could kill him. Supplies are the number one priority – we have to purchase these supplies first, before rent, before car payments, before groceries."

Medicaid covers the ankle-foot orthoses (AFOs) Ethan needs on both feet to correct foot drop, but no one covers the shoes that go over AFOs. "The shoes are \$100, which I can't afford. And Ethan has to wear shoes with the AFOs. He doesn't wear the AFOs because I can't afford shoes." Christine has spent considerable time and money at various discount stores trying to find shoes to fit over the AFOs,

even cutting the tongues out to make the shoes fit, but has not found a solution. “Every day Ethan can’t wear the AFOs is another day we can’t work on walking.”

The impact of their out-of-pocket expenses has greatly affected the family’s financial stability. Christine traded in an almost fully paid for, fuel efficient sedan for a van that could accommodate Ethan’s wheelchair. Their previous car payments have now almost doubled to absorb the \$600 monthly van payment. Ironically, there are places that help with paying for van modifications, but the family has to have the van first and no one provides assistance to purchase the van. Gas is also expensive and Christine drives considerable distances to pick up special formula and shop at a medical supply thrift store, where people sell supplies they have not used, to try to gather enough supplies at reduced cost so she can still buy groceries and pay utility bills.

Ethan is eligible for the Medicaid Buy-in Program based on his medical needs, but the family’s income is too high for them to receive assistance from other needs-based programs that could help with food, transportation, and utilities. So even with the Medicaid Buy-in Program, Christine and her family continue to have financial trouble. Christine has given up her career as she cannot hold down a job without compromising Ethan’s care. She spends the whole day, every day, juggling to make everything fit: Ethan’s

**“Had it not been for the [Medicaid] Buy-in, we would have had to file bankruptcy.”**

medical appointments, OT, feeding therapy, PT, and speech therapy. There’s endless insurance paperwork and she also needs to be available to her other children.

Matt works hard and has a good job, but due to the medical and other expenses there were times they could not afford groceries, parking, gas, or babysitters so they could see Ethan when he was still in the hospital. Christine talked about how hard they had worked to be self-sufficient, maintain their cars, and take vacations, and how all that changed when Ethan was born. At one point they had \$12 in a bank account, “...no savings, no credit cards, no nothing to make it through the rest of the month.” They couldn’t afford anything for the other children either, including the \$5 her 8-year-old needed for a school field trip.

“You hear this happens to other families but you never think this will happen to you, and then all of a sudden it does and there is no way out.”

Christine emphasized how the family system as a whole is devastated when something like this happens. They went from being financially stable to being both emotionally and financially destroyed, and 23 months later they are still working to recover.

Everyone in the household is suffering and is traumatized, and there are no therapy benefits for any of them, so the family pays \$360 out of pocket for family therapy. “That’s been one of the hardest things. Medicaid picks up so much of Ethan’s stuff; we are grateful to have access to the [Medicaid Buy-in] program, but there’s still a huge amount of unmet need.”

## The Hatlen Family

**“It’s like going through medical school, law school, and advocacy training in a matter of months.”**

*When Cash was a baby, he had an episode in which he stopped breathing for reasons that are still unknown. The consequences were serious enough that he required a 2-year-long hospitalization. Cash has since been diagnosed with cerebral palsy and needs 24-hour-a-day nursing care.*

**“We started getting bills and garnishments [of wages] that first year. It was a nightmare. [My husband’s] wages continue to be garnished and we are taking a huge hit. In addition to this, we are paying for certain medications out of pocket.”**

Kelly Hatlen, her husband, and their now 4-year-old son Cash live in North Dakota. When Cash was a baby, he had an episode in which he stopped breathing for reasons that are still unknown. His mom and doctors do not know how long Cash was without oxygen, but the consequences were serious enough that he required a 2-year-long hospitalization. Cash has since been diagnosed with cerebral palsy and needs 24-hour-a-day nursing care.

Kelly is devoted to Cash. Caring for him, navigating his insurance coverage, and advocating for him, both in the hospital and at home, is her full-time job. Kelly willingly shares her newfound expertise with others and is also an activist and spokesperson for Native American rights and issues. Kelly, a native person herself, explains that in her culture caring for one’s own family is of critical importance and institutionalization is not an option.

During Cash’s hospitalization, Kelly was connected to Family Voices of North Dakota, the state’s Family-to-Family Health Information Center. The staff helped to guide her through the appeal process when her insurance company tried to drop Cash. They also told her about the Katie Beckett program, a Medicaid state plan option, which would make it possible for her to care for Cash at home. In addition to the challenges she faced navigating the complex systems of medical care and health insurance, as a native family, Kelly faced additional challenges. Kelly

shared that Native Americans generally lack an understanding of private health insurance, as they are primarily only familiar with Indian Health Services (IHS).

“So I can’t imagine families that live their entire life on the reservation and have never had private insurance – I’ve seen it with [Native American] families – they were overwhelmed and gave up a lot of times. Insurance is something that is a big barrier for native people.”

North Dakota Family Voices helped Kelly learn how to work with her private insurance and Medicaid to coordinate Cash’s benefits and cover the round-the-clock care he needs. “They [Family Voices] were amazing in terms of clarifying language and helping me figure out what to do next. As a result, I was able to go back to the reservation and help other native families with the same process.” Kelly continues, “There are a lot of resources that are out there, but when you go through a situation like this, you’re so beat down and so involved with keeping your child alive, your brain is on another planet. Hospitals do not put out information for things like Family Voices. Family Voices giving me support, and connections, and the tools to help my people is amazing because it’s branched out to so much more than just the services they’ve given me. It’s great to see a kid on a reservation get the help he needs and know that you’re a part of that.”

Commenting on what she had to go through to fight for her son, Kelly notes, “It’s not even advocacy, it’s like going through medical school, law school, and advocacy training in a matter of months.”

Kelly also advocated with her private insurance company—actually inviting company representatives to her home to see what the care she provides for her son entails. While home care is less expensive than hospital-based care, it was a struggle to get them to cover home-based services.

Kelly’s husband has a good job that provides employer-sponsored insurance coverage, but the family is still struggling financially because of medical bills resulting from Cash’s extended hospitalization, uncovered medical costs, and costs associated with maintaining multiple households while Cash was hospitalized. In addition to the financial burdens, there is the added stress in dealing with an insurer that frequently denies claims that they should be paying,

“We started getting bills and garnishments [of wages] that first year. And it was a nightmare. [My husband’s] wages continue to be garnished and we are taking a huge hit and in addition to this, we are paying for certain medications out of pocket.”

As a native parent navigating the health care and medical insurance systems, Kelly spoke of the inequities in health care coverage and of the misconceptions of others who think native people receive all their care for free [through Indian Health Services or IHS]. Most assume Cash receives special care, treatment, and services because of her native status.

“... others think we get disability payments for Cash but we don’t get any of that – and also no parking, no gas, no meals – we get none of that.” These daily

**“Insurance is something that is a big barrier for native people.”**

#### PATHWAYS TO FINANCIAL HARDSHIP

Even though the Hatlen family had employer-sponsored health insurance, they incurred huge medical expenses during their son’s 2-year-long hospitalization. Their wages continue to be garnished to repay their medical debt. In addition to experiencing three pathways to financial hardship, the family experiences emotional stress due to the misconceptions about health insurance for Native Americans, assumptions about benefits Cash was receiving, and a lack of understanding about how Native American families prioritize taking care of each other.

**Higher health care costs:** Kelly’s family is still struggling financially because of medical bills resulting from Cash’s extended hospitalization, which has resulted in garnishment of her husband’s wages. They also pay out of pocket for some of their son’s medications.

**Higher routine expenses:** The daily expenses for parking, gas, and meals while Cash was in the hospital also added up. At one point, Kelly’s electricity was shut off for non-payment.

**Loss of Employment Income:** This usually references family members who cut back on work to care for their CYSHCN. For the Hatlen family, the impact on employment is different. The family maintained two households while their son was hospitalized and continues do to so now that Cash is home, as Kelly’s husband is now working out of town to earn additional money.

expenses add up, especially during Cash's two-year hospitalization when they did not receive any supports, services, or benefits to defray those costs. In fact, Kelly's electricity was shut off just prior to Cash's transition home. The financial burden families experience takes a toll, and Kelly's husband is now working out of town to earn additional money, which means he will be away from Kelly and Cash all week.

Kelly says that "...growing up native, you learn to do without. You take care of each other. Money always comes and goes. I can't stress about that." Further, she says, "Natives don't revolve around money; we've never had it so we can't. As long as you have your family and you take care of

each other, money is going to come and go, we're always going to owe someone. White people's worries are different and it does cause marital difference." Kelly describes her culture as having been a natural personal coping mechanism where money is not the main thing—as long as there is family. She says, "I think it is because we experienced so much trauma. We have a higher suicide rate, we were almost killed off by small pox; higher addiction, and auto accident rates."

Kelly says that in her culture, they are supposed to learn from elders, and family is everything. She describes a different sense of peace and laughter in

## BREAKING THE LINK

Now that Cash is home, he receives Medicaid through the state's Katie Beckett waiver, as his family's finances exceed Medicaid and Supplement Security Income (SSI) limits. However, during Cash's 2-year hospitalization, **benefits counseling** would have made Kelly aware of his eligibility for SSI, which in most states includes Medicaid. When a child is hospitalized a full calendar month, and continues to reside in a medical facility, the child is eligible for SSI, regardless of family income and assets. Medicaid, as the secondary payer, would have covered the medical costs that the family's private insurance did not pay. The SSI cash benefit, which would be the institutional rate of \$30 per month, would have helped pay for gas and parking so Cash's parents could visit him.

**Care coordination services** would have helped Kelly access all the benefits and services, such as SSI, and home health care, for which Cash was eligible. They also could have made her aware of energy assistance to avoid having her electricity shut off.

### Addressing inequities:

Kelly identified several issues with which Native Americans struggle. One is

knowledge of health insurance options other than Indian Health Services. In order to ensure Native Americans are aware of Medicaid and CHIP program eligibility for their children, the North Dakota Healthy Steps program contracts with a vendor that specializes in Native American outreach. Good Health TV, one of their outreach initiatives, is a health and wellness network that broadcasts in the Indian Health Services and other tribal clinics across the state. It broadcasts health-related topics specific to Native Americans. The specialized vendor produced two creative video segments to air on the network promoting Medicaid and Healthy Steps. (View their **HealthySteps video** at <https://www.youtube.com/watch?v=zliO-5bY7EM>)

**Health Insurance Navigators** that represent Native people would be able to provide culturally appropriate information about health insurance options other than Indian Health Services.

**Telemedicine** would help reduce travel-related expenses for families and increase access to care, especially in rural parts of the state.

## Caught in the middle: making too much for assistance but too little to make ends meet.

any family, regardless of race, when there is a lot of trauma. “You can’t control it. We’ve experienced so much trauma in the past and today (as Native Americans), that trauma carries on and there’s always that sense of story and laughter.”

Once Cash was home, Medicaid, in fact, was the only benefit he was eligible to receive. Though not well off, Kelly explained their income is too high for any other benefits; they feel caught in the middle as a result; making too much for assistance but too little to make ends meet.

Even so, Kelly focuses on what is important to her. “When I pray about my children I pray that they’re given the ability to cope. If they can cope, they can

get through anything. The ability to cope is something that is so overlooked. I go back to laughter and hanging out with friends and family and that gets us through everything. I’ve been a natural activist because I look white – my family knew people would question me. My grandmas wouldn’t speak English to me, my brothers and sister skirted by, but being white I can walk into a board room and no one would think anything of it. People would say things not realizing I’m native. I know what it’s like to be treated unfairly without cause.”

Moving from her philosophical beliefs, Kelly shared her thoughts on the health care system in North Dakota in general and spoke about the need for mobile services in the rural areas. She noted that she lives in Fargo and while she can afford to physically get to services, many cannot. Telemedicine would help reduce travel-related expenses for families and increase access to care.

### A NOTE ABOUT HEALTH CARE INEQUITIES

The financing strategies that work to close the gaps for families of children and youth with special health care needs (CYSHCN) may need to be tailored to address the unique needs of children from groups that are most impacted by inequities, including Native American, Black, and Latino CYSHCN. Some solutions work universally to reduce uninsurance. For example, in states that implemented the optional adult Medicaid expansion provision of the ACA, the uninsurance rate for Latino children decreased markedly (Schwartz et al., 2016).

However, inequities still exist because many Native American, Black, Latino, and multiracial families experience discrimination, in general and within health care settings specifically (Nesoff et al., 2016; Shavers et al., 2010), and receive poorer quality of care than white

patients (Shavers et al., 2010). Barriers to health services that are shaped by interpersonal, institutional, and structural discrimination require unique solutions. Thinking ahead, it will be important to modify existing strategies and/or identify new ones tailored to ensure equity. It is also important to evaluate strategies to ensure that they alleviate, rather than exacerbate, existing inequities in access to coverage and care for underserved populations.

The Catalyst Center’s *Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities*

(<http://cahpp.org/resources/inequities-tutorial>) provides tools and examples of policies, programs, and partnerships that users can adopt in their states to improve access to coverage and financing of care for the most vulnerable children.

# BREAKING THE LINK

## Strategies for Addressing Family Financial Hardship: Selected Examples from States

Each state Title V/CSHCN program has some flexibility to tailor its services and supports to the population it serves. In addition, state Medicaid and CHIP programs have the flexibility to be creative and experiment with innovative solutions to improve health insurance and financing of care for CYSHCN. From June 2014 to September 2015, Catalyst Center staff conducted a series of structured interviews with 45 Title V Children with Special Health Care Needs (CSHCN) programs, 34 Medicaid programs, and 40 family leaders in the states, District of Columbia, and Puerto Rico. In the course of these interviews, we identified national and state-specific strategies that can be effective policy solutions for closing the gap between what health insurance covers for CYSHCN and the out-of-pocket costs families incur. Our hope is states will learn from each other and adopt some of the best practices, identified below, to help break the link between special health care needs and financial hardship.

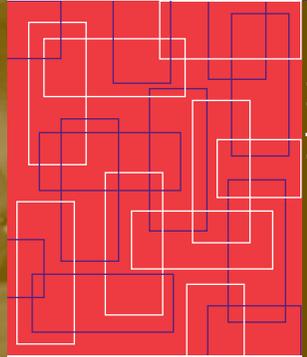
### CONSUMER PROTECTIONS

Section 1201 of the ACA prohibits private health insurers from denying or limiting coverage to individuals with pre-existing conditions. This section also states that new policies must be issued and existing policies must be renewed for anyone who meets the criteria for coverage, regardless of health status, age, or gender. The only exception is in cases of fraud. Insurers can no longer refuse to renew policies for individuals based on health status or high use of health care services. These provisions promote universal and continuous coverage. This is particularly beneficial to individuals with special health care needs, disabilities, and

chronic illness, who can no longer lose coverage or be charged more just because they use a lot of health care services.

### EXTENSION OF COVERAGE FOR ADULT CHILDREN/REMOVAL OF BENEFIT CAPS

Section 1001 of the ACA allows parents with health plans that allow family and/or dependent coverage to extend coverage to their young adult children until they turn 26. This section also removes annual and lifetime benefit caps for the total dollar benefit insurers provide in a given policy year or over the lifetime of an enrolled individual. These provisions promote universal and continuous coverage and help prevent



financial hardship, as families no longer have to worry about a family member with special health care needs, disabilities, or chronic illness losing coverage because they have maxed out their insurance policy and have to pay health care costs out of pocket.

#### **Selected Resource**

The Affordable Care Act: A Side-by-Side Comparison of Major Provisions and their Implications for CYSHCN, The Catalyst Center. <http://cahpp.org/resources/the-affordable-care-act-a-side-by-side-comparison>

#### **HEALTH INSURANCE MARKETPLACES (EXCHANGES)**

The Health Benefits Marketplace or Exchange provision (Section 1311) of the ACA expands health insurance coverage options for individuals whose incomes are too high for Medicaid, and

who do not have access to other health insurance, or whose employer-sponsored health insurance is not affordable or adequate. This provision promotes adequate and affordable coverage by creating a pathway to insurance for individuals with special health care needs, disabilities, and chronic illness, whose income is too high for Medicaid or CHIP and who do not have access to employer-sponsored health insurance.

#### **Selected Resource**

The Affordable Care Act: A Working Guide for MCH Professionals. Module 5: Health Insurance Marketplaces. <http://cahpp.org/wp-content/uploads/2015/04/ACA5-Marketplaces.pdf>

## CONSUMER ASSISTANCE AND OMBUDSMAN PROGRAMS

Section 2719 of the ACA requires health insurance issuers to “implement an effective appeals process for appeals of coverage determinations and claims” and establish Health Insurance Consumer Assistance or Ombudsman Programs (US Government Printing Office, 2010). These programs are responsible for providing culturally and linguistically appropriate information about the internal appeals process and for facilitating connections to health insurance consumer assistance or ombudsman programs that can assist with external appeals. Several provisions of the ACA and the Public Health Services (PHS) Act addressed consumer assistance programs or ombudsman that educate consumers about their rights

and responsibilities, help them file complaints, and assist with appeals for coverage and claims determinations that an insurer denied. These programs must also collect and track data to identify any systemic problems. The District of Columbia (DC) has an ombudsman who deals with all issues related to insurance in the District, including Medicaid. These provisions help families navigate the complexities of choosing, keeping and maximizing adequate and affordable insurance coverage.

### Selected Resource

The Center for Consumer Information & Insurance Oversight. Consumer Assistance Program. <https://www.cms.gov/ccio/resources/consumer-assistance-grants/>



## ADDITIONAL HELP WITH HEALTH INSURANCE APPEALS

Several Title V/CSHCN programs also assist families with the insurance appeal process. The **Arizona** Title V/CSHCN program provides information, resources, and training for families and the professionals who serve them around effectively maximizing the insurance they have as well as understanding the grievance and appeal processes. In **Washington** State, the Title V/CSHCN program noted that the Office of Insurance Commission has trained volunteers as Statewide Health Insurance Benefit Advisors who help families with appeals. In addition, the **Washington** Autism Alliance and Advocacy organization is a family-led organization with a mission to assist families with accessing health insurance benefits for autism services. The **Nevada** CSHCN program resides within the Division of Public and Behavioral Health, Title V/ MCH program. Funding is sub-granted to diverse community partners to provide assistance to consumers to make connections to health insurance consumer assistance or ombudsman programs. However, the primary provider of funding for this type of assistance is Family TIES, the umbrella organization for family-led programs, including the Family-to-Family Health Information Center. Family TIES has personnel specifically hired to answer the statewide toll-free number that families call for information about applications, insurance disputes, and Medicaid appeals. The **Michigan** Title V/ CSHCN program has parents on staff who, among other things, help families with CSHCN navigate the appeals process.

## NAVIGATORS

Navigators are entities (individuals or organizations) that can help individuals and families find and enroll in health plans such as those offered under

Medicaid or the Children's Health Insurance Program (CHIP). Navigators must be able to provide culturally and linguistically appropriate information in the conduct of outreach and educational activities about the availability of health insurance options and federal subsidies, help facilitate health insurance enrollment in a fair and impartial way, and provide referrals to offices or ombudsmen who can assist with grievances or appeals. Many Title V and Family-to-Family Health Information Centers (F2F) partner with navigators to help them maximize outreach to underserved populations to ensure they knew about their health insurance options. The **South Dakota** Title V/CSHCN program received information from the navigator programs in their local areas and the Great Plains Tribal Health Board so they would know where to refer families for the application assistance they needed. As part of the **Mississippi** Department of Health's Office of Health Disparity Elimination strategy to address insurance inequalities, the MS Department of Health became an ACA Champion for Coverage. As part of that work, they refer families to Navigators or to Certified Application Counselors. As part of the **Oregon** F2F's efforts to expand its cultural and linguistic competence, the F2F has identified navigator programs across the state who represent different communities. This helps staff know the navigator entity that would be the best match for each family that needs assistance with navigating Medicaid, CHIP, and private health insurance plans. For example, they know the navigator programs that work with Somali communities.

## Selected Resources

Recipients of 2016 Navigator Grant Awards. <https://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/Downloads/Navigator-Grantee-Summaries-2016.pdf>

## FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2Fs)

Family-to-Family Health Information Centers (F2Fs) are family run centers that assist families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. F2Fs are a vital one-stop resource that can help families with CYSHCN navigate public and private health benefits and provide connections to other health care services and supports.

Many Title V/CSHCN programs work collaboratively with the F2F in their state to ensure families with CYSHCN have needed information and resources. The Title V/CSHCN programs in **Alaska, Maryland, Minnesota, Missouri, and South Carolina** connect families with their state F2F for information about health insurance options and other resources.

The **Nevada** Title V/MCH program collaborates with, and provides the bulk of funding for, Family TIES (the umbrella organization for family-led programs, including the Family-to-Family Health Information Center) to ensure families have needed information about health insurance options and other resources. Family TIES is a critical partner with the Title V/MCH program on the upcoming Medical Home Portal in **Nevada**, which will provide families with additional information and resources.

The Title V/CSHCN program in **Arizona** works with Raising Special Kids, the state F2F, to provide information and trainings for their staff on numerous topics, including public health and Marketplace plans. The **Iowa** Title V

program has an ongoing relationship with the F2F, which maintains the database of all the family navigators. The **Idaho** Title V/CSHCN and F2F program have a close working relationship, recognizing the F2F is a primary resource for families raising CYSHCN in the state.

In **Kentucky**, the Commission for Children with Special Health Care Needs (Title V/CSHCN program) refers new families to the F2F for help in navigating the complicated issues surrounding health care and making more informed choices by providing support, information, resources and training. The KY F2F also has support parents that are trained to mentor other families of CYSHCN and matches parents with other parents of children that might have the same medical condition or need.

The **Kansas** Title V/CSHCN program utilizes its partnership with the F2F to ensure families receive support around enrollment in private health insurance options.

When **New Hampshire** Medicaid changed from fee-for-service to mandatory managed care, the Title V Special Medical Services (SMS) program developed a plan in partnership with the F2F/NH Family Voices to create a [user-friendly publication](#) that explained the new payment model. Both SMS and NH Family Voices were invited to participate in NH Department of Health and Human Services (DHHS) transition team to ensure that children and adults who were previously exempt from Managed Care due to their

special needs status, understood the change. The NH DHHS transition team included a copy of the publication in the information packet that was sent to the 10,000 individuals with special health needs to support them in choosing a managed care organization.

Many F2Fs work with partners on insurance appeals, connect families with consumer assistance organizations, or provide direct assistance. In **Connecticut**, the F2F provides training and support to help families understand their health coverage and assists families to appeal insurance denials or connects them to organizations that can help them file appeals. The one-on-one counseling that the **New Hampshire** F2F staff provides to families includes helping them assemble the types of documentation they need to appeal insurance decisions. In **Colorado**, the F2F supports and coaches families who are appealing decisions made by Medicaid and chairs a legislature appointed committee reviewing Medicaid provider rates.

F2F staff in **Oregon** is represented on the Medicaid Advisory Committee, a governor appointed position, to learn about the issues families raising CYSHCN are encountering and to have the opportunity to speak up on behalf of families around Medicaid policies. The **Delaware** F2F facilitates a Parents' Forum, a monthly phone call with representatives from Medicaid, the Managed Care Organizations, state



service systems, providers, and parents. It is an opportunity for parents to talk about issues, denials, and other topics. As a result, policies have been changed and services added to the state plan once State Medicaid and providers learn how the existing policies affect families.

#### **Selected Resource**

The Family-to-Family Health Information Centers (F2Fs) play a critical role in helping families and their professional partners navigate the system. The directory of F2Fs is available at <http://www.fv-ncfpp.org/>



## RELIEF FUNDS

Many families with CYSHCN have higher routine expenses for transportation to and from appointments, parking, electricity, and specialized clothing to accommodate mobility devices that health insurance does not cover. To help with the extraordinary expenses that can overwhelm a family's budget, several states have relief funds that reimburse families for the extra expenses associated with having a CYSHCN. The Special Bequest Fund in **Kansas** is a trust that provides financial support for medical equipment, education or other items that can improve health outcomes or function, and quality of life for individuals with special health care needs.

**Massachusetts'** Catastrophic Illness in Children's Relief Fund is a payer of last resort for families who incur excessive financial burdens in caring for a child with special health care needs and disabilities. Families can apply for financial assistance for costs not covered by insurance or other sources of financial support.

The **Michigan** Children with Special Needs Fund is an endowment that helps support some equipment needs for families with children with special needs when there is no other federal, state, or private insurance funding available. The Title V program works directly with vendors and helps pay them for the services and/or equipment they provide for the families.

Eligibility for assistance from **New Jersey's** Catastrophic Illness in Children Relief Fund (CICRF) is determined by the ratio between a family's income and out-of-pocket expenses. To ensure families know about the fund, the New Jersey Title V program has a formal

agreement with the Medicaid Management Units that they will screen for anticipated medical debt. And, while the fund will not pay for insurance premiums, the amount a family pays for premiums does count towards the computation of medical debt and is considered as part of the eligibility determination. The fund will reimburse a family's co-payments for medical services for the child with special health care needs. The NJ CICRF is a reimbursement program. Recognizing that some families cannot afford to layout money up front for the services their children need and wait for reimbursement, the Camden County Board of Freeholders created the CICRF Bridge Loan program. Families residing in Camden County whose children meet the criteria for CICRF can receive a secured "bridge loan" for up to \$5,000. They can use the loan for down payments for expenses such as home modifications or for the purchase or lease of a modified, accessible vehicle for a child who is medically fragile. CICRF recognizes the loan as an eligible expense and reimburses the Camden County Improvement Authority that administers the loan program with the assistance of the Camden County Department of Health & Human Services – Special Child Health Services Unit. These county agencies work closely with NJ CICRF to provide financial assistance in a meaningful way that ensures children with special health care needs receive needed services and protects families from financial hardship.

### Selected Resources

Relief Funds: A Safety Net for Children and Youth with Special Health Care Needs, The Catalyst Center.  
<http://cahpp.org/resources/relief-funds-a-safety-net-for-children-and-youth-with-special-health-care-needs/>

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

### **PRIOR APPROVAL/PREAUTHORIZATION**

Public benefits programs and private health plans often require prior approval (also called prior authorization, prior approval or precertification) for health care services, medications, or other medical supplies, even with a written prescription from a qualified health care provider. While prior approval both avoids duplication of services and controls cost, it can be a barrier to timely care and an additional paperwork burden for families. The **Idaho** Title V/ CSHCN program worked with Medicaid to streamline the prior approval process for families needing low-protein foods for children with PKU. They also created a 12-month prior approval for certain services and medications for individuals with Cystic Fibrosis. The **West Virginia** Medicaid program partnered with their Prior Approval Utilization, TPL unit, and Title V/ CSHCN program to develop a standard process for paying for services and supports identified through EPSDT screenings that a child needs that are not traditionally covered by Medicaid. They use this process to cover rare medications or treatments children need as long as it meets EPSDT guidelines, is medically necessary, and was identified through the EPSDT screen.

#### **Selected resources**

Prior Authorization. <https://www.healthcare.gov/glossary/preauthorization/>

### **MEDICAL/THERAPEUTIC DAY CARE**

The **Iowa** Medicaid program includes specific benefits packages that provide private duty nursing in the daycare setting for children who cannot be served in a regular daycare. This specialized daycare program pays for medical benefits provided by credentialed staff who have regular daycare licenses. The **South Carolina** Medically Complex Children Waiver includes a daycare program for medically fragile kids and three therapeutic daycare programs that are paid through state plan services. **Rhode Island** Medicaid does not pay for day care services, but will pay for the medical necessary services a child might require to attend day care.

#### **Selected Resource**

National Center for Education in Maternal and Child Education: Community Services Locator, Georgetown University. <https://www.ncemch.org/knowledge/community.php>

## CARE COORDINATION

Care coordination helps ensure CYSHCN receive all needed services and avoids duplication by promoting effective and efficient utilization of resources.

However, access to care coordination often depends on having a way to pay for it. In **Colorado** the Regional Care Collaborative Organizations (RCCOs) have contractors who pay for care coordination services. And children who require an institutional level of care receive care coordination as part of the state's Katie Beckett waiver services.

In the **District of Columbia**, the Health Services for Children with Special Needs program, an MCO for children who receive SSI, provides care coordination. Medicaid managed care plans in **Florida** are required to maintain written care coordination protocols that include appropriate referral and scheduling assistance for enrollees needing specialty health care or transportation services, including those identified through EPSDT, and for individuals with complex medical needs, including behavioral health needs.

In **Iowa**, Medicaid funds care coordination for Medicaid-enrolled children under the EPSDT benefit. Children with serious emotional disturbance receive care coordination as part of Iowa's Medicaid Health Home. In **New Mexico**, medical social workers provide care coordination in all public health offices. The **Indiana** Title V/ CYSHCN program provides funding to

some clinics and outreach programs that work with CSHCN. They are paid to provide care coordination for families.

The Care Connection for Children (CCC) is one of four Title V programs that serve children and youth with special health care needs in **Virginia**. For the CCC program, Title V partners with health care systems across the state to provide care coordination for children who have a physical condition that has lasted, or is expected to last, a year or more.

The **Alaska** Title V/CSHCN program funds Stone Soup, the Alaska F2F, to provide parent navigation services to help families coordinate care for their CYSHCN. In **Connecticut**, the Title V/ CSHCN program has identified care coordination contractors in each region of the state who provide support at the regional level. They are co-located or work in partnership with pediatric practices in their region.

### Selected Resources

The Care Coordination Conundrum and Children and Youth with Special Health Care Needs, The Catalyst Center.  
<http://cahpp.org/resources/care-coordination-conundrum>

Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems, Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee.  
<http://pediatrics.aappublications.org/content/133/5/e1451>

*Strategies are available to reduce the impact of medical debt on families and to address health-related financial hardship.*



## BENEFITS COUNSELING

Some families struggle to understand how health insurance works and the services it provides. Benefits counseling can help families understand the full range of benefits, in- and out-of-network providers, and additional insurance options, such as Medicaid buy-in programs or Medicaid waivers, which can reduce underinsurance by acting as a secondary payer, and by providing additional benefits that other insurance does not cover.

The **Connecticut** Title V/CSHCN program contracts with an organization that does outreach, enrollment and benefits counseling with families regardless of the type of insurance for which they may be eligible. The **Kentucky** F2F Co-Directors are employed by and housed with the Kentucky Commission for Children with Special Health Care Needs. The Co-Directors are CAC (Certified Application Counselors). They provide information in an impartial manner to everyone who seeks their help. This includes assisting consumers with submitting the eligibility application, clarifying the distinctions among health coverage options including qualified health plans (QHPs), and helping consumers make informed decisions during the health coverage selection process. The F2F Co-Directors also help families with CHIP enrollment or a QHP offered through the Marketplace or Benefind (a web-based assistance and support program for Kentuckians) and explain the types of financial assistance for which a family might qualify. The F2F staff also provides comprehensive information about deductibles, coinsurance and copayments, coverage limitations or exclusions, and if a provider or hospital is in the plan's network.

The **Rhode Island** Title V/CSHCN program contracts with the Rhode Island Parent Information Network (RIPIN - home of the F2F and RI Family Voices) to solve health coverage problems. RIPIN's RIREACH Program (Rhode Island Insurance Resource, Education and Assistance Consumer Helpline) provides easily reachable toll-free phone support by trained advocates who help consumers find and keep insurance, understand and use their coverage, and respond effectively to benefit denials and other administrative headaches.

### Selected Resources

Health Insurance Benefits Advisors: Understanding Responsibilities, Regulations, Restrictions and the Relevance to Implementing the Affordable Care Act, Milken Institute, School of Public Health and Health Services, The George Washington University. [http://publichealth.gwu.edu/pdf/hp/benefits\\_advisors.pdf](http://publichealth.gwu.edu/pdf/hp/benefits_advisors.pdf)

Managed Advocacy: Essential Elements, ABC for Health. [http://www.safetyweb.org/publications/CKSN%20Products/Managed%20Advocacy%20NAT%20\(July2006\).pdf](http://www.safetyweb.org/publications/CKSN%20Products/Managed%20Advocacy%20NAT%20(July2006).pdf)

## TELEMEDICINE

Telemedicine is an important capacity-building service that is of particular benefit in geographic areas where pediatric subspecialty care is unavailable or difficult to access. A growing number of states make extensive use of telemedicine. The **Montana** Medicaid program reimburses for telemedicine to ensure children's timely access to screenings and care. This innovative model was developed by the Fort Peck Tribes in conjunction with several local schools in the remote northeast part of the state. The Tribe has a registered

nurse in several schools. If the school nurse observes a condition that needs more scrutiny, they are supported through contact with nurse practitioners using iPads for Telehealth. Montana Medicaid reimburses for this telehealth visit with the nurse practitioner. This Tribal community has also placed a dental chair in one of the schools staffed by a dental hygienist so children can receive dental cleanings and screening exams. There is also a mental health practitioner at the school. Medicaid pays the tribe for telehealth and direct services for any child who is eligible for Medicaid. An additional bonus to this arrangement is children no longer miss school and parents no longer miss work to travel all day to seek care.

**Mississippi** covers and reimburses for telemedicine services throughout the state, including health centers and for school nurses for children enrolled in Medicaid. This ensures access to care in rural parts of the state, minimizes travel time, and provides care in settings where children are more

comfortable.

**Louisiana** Medicaid requires their Managed Care Organizations' networks to include, among other types of providers, a children's hospital and pediatric specialists that meet certain requirements. If members don't have access to at least one of the specialty providers within 90 miles of their homes, or the provider is not included in the network, the MCO must provide access via other means, such as through telemedicine.

### **Selected Resources**

Telemedicine, Medicaid.gov  
<https://www.medicaid.gov/medicaid/benefits/telemed/index.html>

Realizing the Promise of Telehealth for Children with Special Health Care Needs, Lucile Packard Foundation for Children's Health. <http://www.lpfch.org/publication/realizing-promise-telehealth-children-special-health-care-needs>



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