# Why Medicaid Matters

## The Front Line Perspectives of People with Chronic Conditions

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Prepared
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National Health Council

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Alpha-One Foundation
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WHERE THE HEALTH COMMUNITY MEETS
NATIONAL HEALTH COUNCIL

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# Overview

Debate is now swirling around the future of Medicaid. The President has proposed major changes in the program; the Congress is considering various proposals to reduce federal Medicaid spending; the National Governors Association and the National Conference of State Legislators have issued recommendations for reform; several states, including Florida, Georgia, South Carolina, and Vermont, are considering sweeping Medicaid “waiver” proposals to change the basic design of their programs; and the Secretary of the U.S. Department of Health and Human Services has assembled a Medicaid Commission charged with coming up with short and long term recommendations for restructuring Medicaid. Two basic elements of the program – its benefit guarantee and limits on the amount that people can be charged to enroll in Medicaid and to use health care services – have been a focus of these proposals.

These debates often occur far from the realities of the people with the most vital stake in their outcome – those who rely on Medicaid to help them control and live with chronic medical conditions. Yet their experiences shed considerable light on these complex and sometimes contentious issues. To help bring their perspectives to this debate, the National Health Council and the Center for Children and Families at Georgetown University’s Health Policy Institute, in collaboration with Council member organizations, including the Alpha-One Foundation, the Asthma and Allergy Foundation of America, the Epilepsy Foundation, and the National Mental Health Association, conducted a series of interviews with individuals who are insured by Medicaid to chronicle their experiences. Their perspectives are uniquely theirs, but as shown by the statements prepared by the medical directors and advisors to these organizations, their experiences are not unique.

This report begins with a review of how Medicaid works for people with chronic conditions largely because of current federal benefits and cost sharing standards. The second part looks at some of the consequences to people and their health that could result from the changes under consideration at the federal and state levels. The experiences shared here and the circumstances faced by others with similar medical conditions starkly illustrate why the federal standards governing benefits and cost sharing are so fundamental to Medicaid’s basic mission. Unraveling those standards could undermine the program’s ability to accomplish its mission. Lives will be lost or irreparably altered if some of the changes under consideration are adopted, and, rather than save money, these changes may lead to increased costs for Medicaid, for individuals and families, and for the health care system more broadly.

# Medicaid Works For People With Chronic Conditions

Medicaid provides a relatively comprehensive package of benefits to most adult beneficiaries and limits the amount that they can be charged for using services. Federal benefits and cost sharing standards are even stronger for children. The key elements of program include:

- **Federal guidelines and state options combine to provide relatively comprehensive Medicaid benefits for most adults.** Federal standards establish a list of services that states must cover, including hospital care, physician and specialty care, lab and x-ray services. Other services may be covered at state option (with federal financing); states generally cannot pick and choose among groups who will be offered an optional service. Some benefit limits are permitted for adults (for example, a state may limit the number of prescription drugs it will cover for adults).
- **Under "EPSDT," children enrolled in Medicaid are guaranteed a comprehensive array of medical services.** The federal benefit standard for children in Medicaid is much stronger than the standard for adults. Known as Early and Periodic Screening Diagnostic and Treatment ("EPSDT"), it assures that the scope of coverage for children will be consistent with each child's particular medical needs. In other words, all medical services a child needs must be covered.
- **Federal rules limit the amount low-income people can be charged for enrolling in Medicaid and using covered services.** Federal standards assure affordability in a number of ways. In general, states may not charge people a fee to enroll in Medicaid. Once enrolled, adult beneficiaries generally can be charged copayments, but not more than a nominal amount in recognition of the extremely low incomes of nearly all Medicaid beneficiaries. Some services and some groups of people are exempt from cost sharing, including children and pregnant women.

## The View From the Frontline

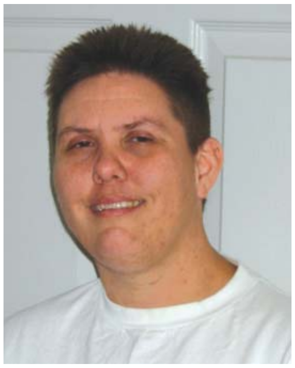
Medicaid standards are not abstract principles to the people who rely on the program. They give the program its integrity and provide the assurance that their coverage will be affordable and sufficiently comprehensive so that they will be able to receive the care they need. This assurance is essential for people with chronic conditions.

*Renee Hall Freeman* is the mother of three children, the youngest of whom is 12-year-old ***Kevin Hall.*** Kevin has suffered from severe allergic asthma for most of his life. Their family lives in Columbus, Ohio, where Kevin attends school and (now) plays basketball. Kevin is covered both by Renee's job-based insurance and by Medicaid.

*Kevin has had allergic asthma since he was four years old. His asthma is triggered by so many things– ragweed, dust mites, trees, leaves, pollen, cats,* *dogs, feathers, and many foods. We did everything we could limit his exposure to irritants that could trigger an attack, but no matter what we did, his asthma kept getting worse. At times his lung capacity was only 60 percent the equivalent of breathing through only one nostril. He was thin and so weak – he would try to ride his bike to the park across the street but needed help coming home, from just across the street. Until recently, he missed an average of 70 days of school each year.*

Ultimately, for Kevin, a new treatment made the difference.

In 2004, Kevin's pulmonologist prescribed a new therapy that would treat an underlying cause of Kevin's asthma. Medicaid covered Kevin's breakthrough treatment; he receives injections twice a month. It has literally given Kevin back his life. His lung function is now 98 percent. Last spring, Kevin did not miss a day of school, his weight is up to 125 pounds, and now he can ride his bike and play with friends just like other boys his age. His dreams of becoming a doctor, an expert on weather–and a basketball player–are suddenly all within his reach.



***Sheryle Stafford*****,** 33, lives in Concord, California, and works as a volunteer at the California Association of Social Rehabilitation Agencies. She was diagnosed with bipolar disorder and also contends with a range of other physical health conditions. Medicaid has filled in for the large gaps in her Medicare coverage.

*I was in my mid-20s when I was diagnosed with bipolar disorder. About eight years ago, I was so impaired that I started receiving Medicare on the basis of disability. Even though I was on Medicare, I was not receiving adequate mental health services. Medicare's coverage of its inpatient psychiatry benefit has a lifetime limit of 190 days and only pays for 50 percent of outpatient mental health services. As my condition worsened, I ended up relying on California's community mental health program. In 2002, I needed inpatient hospitalization. Because of the unavailability of services in Sacramento where I was living, I was sent to a non-profit hospital in Berkeley that finally helped me get Medi-Cal (California's Medicaid program)—and the extensive mental health treatment I needed.*

*Karen and Bill Haughey* and their daughter ***Brandie*** and son Nicholas live in Seminole, Florida. Adopted in 1999, *Brandie* has extensive medical and developmental problems. Her speech, gait, small and large motor skills are impaired, and she weighs only 55 pounds. EPSDT assures that Brandie can receive coverage for all her complex medical needs and developmental disabilities.

Brandie *is our beautiful 10-year old daughter. We both work full time (Karen as a nurse and Bill as a musician), and we have private health insurance, but*

*Brandie's extensive medical needs are such that even as a two-income family we could not afford to give her the care she needs without the comprehensive coverage she receives through Medicaid.*

*Brandie has a genetic condition, Neurofibromatosis I (NF), a disease in which tumors and lesions can grow anywhere in the body. Lesions have developed in Brandie's brain, on her optic nerve, and on her spinal cord. About half of the people with NF, including Brandie, have learning disabilities. Brandie was also born with Fetal Alcohol Syndrome and suffers additional developmental delays as a result. At age three, she spoke with the garbled speech of a one-year old.*

*Before the adoption, when Brandie was in foster care, she was left unattended near a swimming pool. She nearly drowned and was intubated for 36 hours. She was then diagnosed with absence epilepsy and fine and gross motor skill deficiencies believed by the neurologist to be a result of the trauma.*

*One of the most challenging aspects of Brandie's medical care has been her epilepsy. Since 1999, we have been working with the pediatric neurologists at All Children's Hospital in St. Petersburg, Florida, to find the right combination of drugs. After years of trying different drugs, we found the combination that was able to give our daughter a nearly seizure free life – Lamictal and Depakote.*

***Kimberly*** is from North Carolina, where she lives with her husband and three children. She suffers from a rare genetic disorder, called Antitrypsin Deficiency (Alpha-1). This progressive and fatal lung disease strikes about 400,000 people nationwide.

> ***Medicaid is particularly important for me because of the high cost of the prescription drugs I take.***

*I was diagnosed with Alpha-1 in 1999. At the time, I was uninsured, and no one was able to identify the cause of a severe pain in my right side. Ultimately, I was referred to Chapel Hill, North Carolina, where I received a liver biopsy which led to my Alpha-1 diagnosis.*

*Medicaid is particularly important for me because of the high cost of the prescription drugs I take. I manage my illness with protein replacement therapy derived from the blood of normal donors. It treats the emphysema associated with Alpha-1. I receive this expensive intravenous therapy weekly to maintain my lung function. I am still significantly impaired and my activities are limited. My kids have to do much of the housework. Even light cleaning stirs up dust that makes my breathing difficult. I also have to wear a face mask when going outside when it is particularly dry out, when it is windy, or during flu season.*

## Greg Barkley, MD
## Professional Advisory Committee Chair, Epilepsy Foundation

Epilepsy, sometimes called a seizure disorder, is a chronic medical condition produced by temporary changes in the electrical function of the brain, causing recurrent seizures which affect awareness, movement, or sensation. Seizures are caused by a combination of genetic and environmental factors. A seizure may range from a brief staring episode to a sudden drop attack, to a massive, prolonged life-threatening convulsion.

Medicaid has a significant impact on people with epilepsy in the United States. Estimates show that 18% (450,000) of the more than 2.7 million people with epilepsy rely on Medicaid. Approximately 9 million Americans develop epilepsy by age 75, with nearly 200,000 new cases of seizures manifest each year; moreover, approximately 30 million Americans will experience a seizure in their lifetime.

There is good news in the treatment of epilepsy. In recent years, treatment advances have led to the treatment goal of "no seizures, no side effects" to be achievable by the majority of people with epilepsy who receive appropriate medical care. At the same time, the treatment of epilepsy is complex, individualized, and in some cases, costly. Recently, many private and some public payers have sought to establish closed formularies in which insurers do not cover all FDA-approved pharmaceuticals. Closed formularies are inappropriate when applied to the treatment of epilepsy. "Fail first" or step therapy policies in which individuals must try and fail on a lower cost drug before they can obtain a specific drug prescribed by their physicians are also not appropriate for epilepsy because seizures are inherently risky, potentially damaging to the brain, and can lead to life-threatening situations.

Maintaining seizure control with minimal side effects requires careful evaluation and monitoring by the physician and patient.

Antiseizure drugs are taken for years, and therapy decisions must be looked at in terms of their long term side effects, as well as the age and sex of the individual, as these variables affect which products are best. It is important to note that no one or two products currently available to treat seizures will be successful for all people with epilepsy. Some of the available medications are effective for treating only specific types of epilepsy, and even in cases where drugs are available to treat the specific type of epilepsy, individual responses to therapy can vary dramatically. Perhaps most significantly for epilepsy treatment, safety, drug interactions, and long-term side effects are as important as efficacy for proper treatment, and must be included in any evaluation of the appropriateness of a particular drug for a particular individual. In 25% of individuals with epilepsy, seizures resist control and are intractable.

Many individuals with epilepsy need access to newer, more expensive anti-convulsants. Fifty percent of children who have seizures have been diagnosed with genetic epilepsy, and many of these children do better on the new antiseizure medications. Recent studies also provide evidence that epilepsy is controlled with fewer side-effects, by the new, often still brand name, anti-convulsants than the older drugs.

While state Medicaid programs sometimes have attempted to limit access to epilepsy medications in ways that are harmful, there are core protections in Medicaid that must be preserved. Although Medicaid permits states to operate preferred drug lists (PDLs), states must still make available all FDA-approved drugs when they are medically necessary. This is an essential protection that must be maintained. SCHIP programs and commercial insurance plans which sometimes have benefit limitations and operate closed formularies may fail to effectively meet the needs of people with epilepsy.

## A Frontline Perspective on the Implications of Proposed Changes in Federal Medicaid Standards

Prompted by rising costs, and, in some instances, by an ideological interest in scaling back publicly-financed health care coverage to rely more heavily on the private market, policymakers at the state and federal levels are considering a number of different types of changes to Medicaid's benefit and cost sharing standards. Key themes and proposals that have emerged in the recent debate over how to change Medicaid are considered below.

### ● Proposal: Providing "Basic" Coverage

The National Governors Association (NGA) and some individual states (in the context of waivers[1]) are pressing for a weakening of federal benefit standards that would allow a more "basic" set of benefits for many Medicaid beneficiaries. Although the details vary depending on the proposal, these "basic" benefit packages could exclude many of the services currently covered by Medicaid. For example, Utah has secured a waiver that allows it to provide a Medicaid benefit to selected adults that covers primary care, but does not cover specialty care, mental health services, durable medical equipment, or even inpatient hospital care.[2]

### The View From the Frontline

A "stripped down" benefit package would fall far short in providing Kevin Hall with the extensive care he has needed as a result of his allergic asthma condition.

#### Renee Hall Freeman

*Because Kevin's asthma is so severe – and for a long time out of control, Kevin has needed a great deal of medical care and different kinds of services. He was on multiple medications. At one point he was taking 13 drugs a day, and we were in the doctor's office and in the emergency room several times a month. During one nine-month period, Kevin needed special injections to help him rebuild his immune system, which had been virtually destroyed by the steroids he was taking for his asthma. For a while, he needed a home health aide, and, at another time, a daily check-in with a visiting nurse to give him his medications and check his lung capacity to see if he could manage going to school.*

Reducing Medicaid's benefit package to a "basic" set of services could similarly threaten Sheryle Stafford's ability to continue to live independently.

#### Sheryle Stafford

*Over the years, there have been periods where I needed inpatient hospitalization, and I have also required extensive outpatient services. Currently, I am in a partial hospitalization program. This means I spend days in the hospital, working on core, chronic issues that contribute to my condition, but I go home at night. Medicaid has allowed me to get the care I need while still being able to stay in my home.*

## National Mental Health Association

Mental illness is the leading cause of disability and premature death in this country. Contrary to popular perceptions, however, mental health treatment is effective. Appropriate, timely and adequate intervention is critical to helping individuals recover from serious mental illness. Medicaid plays a central role in making resources available to meet the therapy, prescription drug, and other needs of children and adults with mental illness. Benefit packages modeled after commercial insurance are inadequate for people with serious mental illness.

Schizophrenia is successfully treated 60% of the time, depression is successfully treated more than 80% of the time. These success rates surpass those of other medical conditions, such as heart disease which has a 45-50% treatment success rate. Despite the efficacy of mental health care, two-thirds of American adults and one-third of children who need mental health treatment do not receive it. Access to appropriate mental health services is even lower – and the quality of care poorer–for ethnic and racial minorities. Financing barriers and stigma, as well as the lack of culturally competent community-based services contribute to this dilemma. *For many, Medicaid is the only means to achieve access to services.*

Medicaid is a vital support to Americans who live in or near poverty and suffer from mental illness. The program provides more than fifty percent of state and local mental health funding. Nearly a quarter of all Medicaid spending on children ages 6-14 years old pays for mental health services. Medicaid services of greatest relevance to mental health care include physician services, Early and Periodic Screening, Diagnosis and Treatment services (EPSDT); and general hospital services (all of which are mandated), and such optional services as clinic services, rehabilitation services, targeted case management, services of other health professionals (such as psychologists), prescription drugs, and inpatient services in psychiatric hospitals.

Importantly, many of the services and benefits that Medicaid covers enable individuals to remain in their homes and communities instead of being placed in expensive institutions. Medicaid was a major factor in the rapid deinstitutionalization of mental health consumers in the 1960's and 1970's and has led to increased use of community-based services.

Almost all states now use the rehabilitation option in Medicaid to offer psychiatric rehabilitation and most offer targeted case management as well providing an array of services that enable even individuals with serious mental illnesses to remain in their communities instead of expensive, restrictive institutions. The Department of Health and Human Services has described the coverage of rehabilitative services as the most important Medicaid option for working age adults with serious mental illnesses, providing a comprehensive array of community-based services that may include individual and group outpatient clinic services, crisis services, family psychosocial education, peer support, life skills training and support, medication education and management, community residential services and supports, and supported employment. Research has demonstrated that individuals who receive psychiatric rehabilitation services experience significantly shorter hospitalization, improved social functioning, and greater satisfaction and fulfillment in employment, and are more likely to return to school or work as productive members of society.

Because of Medicaid's unique role and critical success, making Medicaid more like SCHIP or private insurance is a recipe for making it less effective at meeting the needs of people with mental illness.

As described by Stanley Mrozowski, Director of the Children's Bureau for Pennsylvania's Office of Mental Health and Substance Abuse Service, in the area of mental health "comprehensive" versus "basic" comes down to more than how many outpatient visits are covered.

*"When you consider the extensive mental health needs of so many of our low-income children, Pennsylvania's CHIP program (Pennsylvania's State Children's Health Insurance Program) is what I would consider "very basic." I say that not because there are very harsh limits on the number of outpatient clinic visits or inpatient days that are covered, but because the range of services covered under CHIP is quite narrow and considerably less child- and family-centered.*

*For example, Pennsylvania's Medicaid program covers family-based mental health services where trained, culturally competent staff goes into a child's home and provide highly individualized treatment in the child's environment. Through this approach, we can identify issues and work with the family in a way that could never be done in an outpatient clinic setting. Family-based services allow us to develop natural supports for the child, involving relatives, ministers, coaches, or other key adults in that child's life. Medicaid also covers case management services so that children with intense, complicated needs receive individualized and coordinated care. These types of Medicaid-covered services often help children succeed in school and avoid costly residential treatment.*

*CHIP's approach is much narrower. CHIP works for some children, but is woefully inadequate for the vast majority of Pennsylvania children with Medicaid who have mental health problems."*

## • Proposal: Scale Back Medicaid's Guarantee Of Comprehensive Coverage For Children

Congress currently is considering a proposal to eliminate the EPSDT benefit for some children and replace it with a standard similar to that used in commercial plans or the State Children's Health Insurance Program ("SCHIP"), a smaller, companion program to Medicaid.[3] Under these types of standards, states could elect not to cover certain types of medical care for a child, or they could place limits on a medical service that are unrelated to the child's needs. Under federal SCHIP standards, for example, some state SCHIP programs limit the amount of vision, dental, and mental health care, and speech and physical therapy that are provided to children.

### The View From the Frontline

The scope of benefits available in commercial insurance plans or some State SCHIP programs are typically ill-suited to a child (like Brandie) with developmental disabilities. Because these types of plans are more oriented toward "treating" an illness or injury, they sometimes limit speech or physical therapy to situations where substantial improvement can be achieved in a relatively short period of time (e.g., 60 days).

### Karen and Bill Haughey

*Brandie attends school in a self-contained setting, having not been able to maintain the pace of the regular classroom. She has had regular and intensive speech, physical and occupational therapy since she was three. (She is now ten.) These sessions will not "cure" her problems, but they have helped her develop her fine motor skills, stabi-*

*lize her gait and improve her speech. She can now print, although it is difficult for her to draw a circle and even harder to use scissors to cut shapes. Just recently, she has learned to color inside the lines, and she is a good reader, although comprehension is difficult for her. Her gross motor skills are such that it is difficult for her to balance. Hopping, jumping and running are not easy, but this summer she started to learn to ride a bicycle. She can pedal a straight line, but not yet turn or stop.*

Commercial insurance and SCHIP programs rarely cover services like over-the-counter drugs and special nutrition supplements that children with special health care needs often require.

### Karen and Bill Haughey

*The medications Brandie takes cause a loss of appetite, and she has been diagnosed with "Failure to Thrive." Brandie only weighs 55 pounds. Her doctor has prescribed three servings of "Boost" a day to help her maintain her weight, but if she doesn't gain more weight soon, she may need a feeding tube.*

Costs for these services can add up quickly. Brandie's nutritional supplements cost $70 a case, and she needs three cases ($210) each month. EPSDT assures that these types of medical assistance will be covered when medically necessary.

## • Proposal: Restrict Comprehensive Coverage To Selected Or "Truly Needy" Groups

A number of the proposals to allow for a more "basic" Medicaid benefit package are accompanied by the notion that comprehensive coverage should be retained for selected groups. For example, the NGA has recommended that EPSDT be retained for some children but not for others.

### The View From the Frontline

It is not clear how states would determine which people would fall into the special protected status. For example, what would happen to a child who originally qualified for Medicaid based on his family's modest income, but who then developed a serious medical condition? How would lines be drawn and who would make those decisions?

### Kimberly

*My access to Medicaid services could be threatened not because policymakers do not want to meet my needs, but because they may not be aware of my needs. I have Alpha-1. It is a rare condition – only about 400,000 individuals are believed to have the most severe form of the disease.*

Given how unfamiliar people are with Alpha-1, it is unlikely that those suffering from this progressive and fatal lung disease would be singled out for special treatment if targeting is permitted. Yet, as Kimberly has explained, Alpha-1 patients' needs are great.

## Robert A. Sandhaus, MD, Ph.D.
## Alpha-1 Foundation

Alpha-1 Antitrypsin Deficiency (Alpha-1) is an underappreciated and underdiagnosed genetic condition that can lead to liver failure in infants and children, as well as pulmonary emphysema and chronic liver disease in adults. When Alpha-1-related emphysema strikes, it often hits individuals in the 30-55 age group, during their prime earning and child rearing years. In addition, a number of other medical conditions are associated with or can be worsened by Alpha-1. While traditionally thought of as a rare condition, in fact, the most severe form of Alpha-1 may affect as many as 400,000 individuals in the US and as many as 20 million Americans may carry at least one abnormal gene for Alpha-1 making this among the world's most common serious genetic conditions.

Fortunately, diagnosis requires only a simple, inexpensive blood test. Unfortunately, the blood test is rarely ordered and it is estimated that over 95% of individuals with Alpha-1 remain undiagnosed. This is especially disheartening because there is specific therapy available. Three commercially available, FDA-approved products are currently used to treat the lung disease of Alpha-1. The annual cost of any of these products is in the range of $100,000 to $150,000. In addition, as with other chronic diseases and especially those whose victims can be struck during childhood or in the prime of their adult lives, comprehensive disease management services can greatly improve the quality of life and health status of individuals with Alpha-1

For Alpha-1 patients with life-threatening liver and lung disease, organ transplantation is often required. Approximately 10% of all lung transplants are performed on individuals with Alpha-1, and Alpha-1 is the second most common diagnosis leading to childhood liver transplantation. Thus, the expenses multiply as the diseases progress.

A large percentage of the individuals on therapy are partially or completely disabled by their disease and their earning power has been greatly diminished just as their medical expenses rise. Many of these individuals have very low incomes due to their inability to work. For all these reasons, Medicaid has become an important safety net.

Given the high expenses associated with prescription drug therapy and organ transplantation, few options for coverage exist outside of Medicaid. Commercial insurance plans often have annual or lifetime limits that are quickly exhausted for individuals with Alpha-1. The benefit protections in Medicaid must remain, as this is a hopeful time for persons living with Alpha-1. There are many promising therapies for Alpha-1 in testing, including gene therapy which is already in human trials. Within a few years, the lives of people with Alpha-1 could be greatly improved *if* biomedicine is able to deliver on its promising research and *if* the guarantees of comprehensive Medicaid coverage are protected.

A recent experience is instructive. Last year, Mississippi decided to stop covering 65,000 people and then secured a waiver to maintain coverage for some 17,000 of these individuals. While all of the people who were slated to lose their coverage were disabled, only those who had one of four specified conditions were protected. These were serious conditions, but not necessarily more serious than other conditions not given protected status.[4] Ultimately, the legislature stopped the cut, but the approved waiver illustrates the equity issues that are certain to arise in targeting proposals.

Rather than sorting people by diagnoses or disease (as some proposals have done), the NGA's proposal to change the federal Medicaid benefits standards would provide a greater or lesser set of benefits to people primarily based on their Medicaid "eligibility category." People with chronic illnesses, however, qualify for Medicaid under a number of different eligibility categories (there are many, overlapping eligibility categories). One analysis shows that four out of ten of the children with cancer and one out of four of the children with diabetes who are enrolled in Medicaid could lose their benefit guarantee under the NGA proposal because they are not enrolled in a "protected" category. [5]

It appears that *Kevin Hall* could be one of the children who could lose EPSDT protections under this type of a "targeting" proposal. Despite his extensive medical needs, Kevin qualifies for Medicaid based on an income-based eligibility category not protected by the NGA proposal.

## ● Proposal: Allow Closed Drug Formularies

Another aspect of the NGA proposal is to permit states to adopt closed drug formularies. This would allow states to decide which drugs to cover and potentially to exclude particularly expensive drugs. States now have the authority to assure that only necessary and cost effective drugs are covered, but they cannot simply wall off certain drugs from coverage.

### The View From the Frontline

The Haugheys have already had an experience that shows how their daughter's health might suffer if closed drug formularies were permitted.

### Karen and Bill Haughey

*Just when we were celebrating the most improved EEG since Brandie's adoption, state budget pressures led to some short–sighted restrictions in coverage. The Florida Medicaid program developed a list of drugs it would cover without special approval; the approved drugs included those where the manufacturer was giving the state a discount on price. Without warning, we learned that Lamictal was not on the list. Our doctor's request to keep this drug covered for Brandie (and for many other children treated by*

*All Children's Hospital) was summarily denied. The drug costs $654 a month –we were panicked knowing that this was something we simply could not afford on an ongoing basis. After a nightmarish few days and lots of public attention on the issue, the state finally restored Lamictal to the approved list.*

Preferred drug lists are permitted in Medicaid as a tool to help states ensure that only medically necessary drugs that are the most cost-effective drugs for a particular individual are covered. However, under current rules, if a drug is ultimately determined to be medically necessary, it should be covered. This bottom line coverage guarantee the Haugheys can now rely on would be lost if Medicaid benefit standards were no longer in place.

## • Proposal: Replace Medicaid's Benefit With Personal Accounts Or Vouchers

In the context of waiver proposals, some states policymakers are pursuing even more radical strategies that would essentially eliminate the basic benefit structure in Medicaid. Instead of being assured of a set of defined benefits, people would be given a set amount of funds (a "Private" or "Personal Health Account") to cover their medical expenses. In some cases, they would be allowed to use their accounts to purchase insurance or services in the private market (a voucher-like system). In others cases, these funds would be provided directly to health plans and people would pick the plan (assuming there was a choice of plans) that they believe best meets their needs. The health plans would have broad discretion to decide what they would cover in exchange for the funds provided through Medicaid.

### The View From the Frontline

In general, these proposals assume that people are able to anticipate what health care they will need; identify and compare their available options; and negotiate a good deal on their own behalf. Perhaps most fundamental, is that they put people at risk if the amount of funds allotted to their care falls short of their needs.

Kevin Hall's and Brandie Haughey's experiences suggest that it is often not possible to anticipate health care needs or costs.

### Rene Hall Freeman

For a time, it was like being on a roller coaster, trying to anticipate, keep up with and then adapt to whatever new treatment Kevin might need. At one point, he needed steroids to help with his asthma and then he needed injections to bolster his immune system that had been almost wiped out by the steroids. One month, he might be doing all right and another month we might have to make three trips to the ER. With all our efforts and close monitoring, we weren't controlling the asthma; it was controlling us.

### Karen and Bill Haughey

*Brandie's health and her ability to function in school and socialize with friends have been improving slowly but steadily. And then, just this month, we learned through her most recent MRI that a mass or tumor of some sort has been identified on the left side of T2 of her spinal column. This was not there six months ago when the last MRI was done. Another MRI is scheduled and then we will meet with a neurosurgeon to discuss further options.*

Insurance is intended to spread the risk of unanticipated costs, and insurance coverage programs like Medicaid are designed to assume those risks. Arrangements that shift the risk to individuals and families that the next MRI will bring frightening news create uncertainty and the prospect that needed care will be out of reach.

## ● Proposal: Weaken Federal Standards On Cost Sharing And Premiums

Often citing the need for more "personal responsibility," or the desire to move closer to a private insurance model of coverage, a number of the proposals to change Medicaid would weaken federal rules governing the amount that low-income people can be required to pay to enroll in Medicaid and use health care services. The NGA, for example, has proposed allowing states to impose cost sharing of any amount (no upper limit is specified) when people use medications that are not on a state's "preferred" list. It also would allow states to charge cost sharing and premiums that could consume up to five to7.5 percent of income if a Medicaid beneficiary has income above the poverty line.

### The View From the Frontline

Reliance on private commercial insurance as the model – or in some proposals as the vehicle – for covering people who now rely on Medicaid can leave those with significant health care needs and limited family resources with unaffordable costs. Increasingly, even middle-income families are finding the costs associated with private health plans to be difficult to manage.[6] The hardship is even greater for people living close to the edge financially.

### Sheryle Stafford

*If I were faced with more costs to see providers right now I flat out could not afford it. I can't even afford the gas to get (to the doctor). There is a lot of talk about how beneficiaries must be financially aware of medical costs, but nowhere does it acknowledge that we are the poorest of the poor and often have to forgo medical treatment or other needed services simply because other costs, such as gas or public transportation, become prohibitive.*

The burden of living with a chronic condition or, as Renee Hall Freeman found, the responsibility for caring for someone with a chronic condition can adversely affect earning power.

## Renee Hall Freeman

*As Kevin's asthma worsened, I was getting deeper and deeper into debt. I was paying for my health insurance through my job, and my ex-husband was paying for the children's insurance through his policy. Until one day, he didn't. When I had to start picking up the cost of insurance for the children, my premium jumped from about $20 to close to $300 a month. I could handle that – barely – but Kevin's asthma kept getting worse and worse and I couldn't afford all of the copays. At one point he was taking more than ten medications a day, each with a copayment ranging form $10 to $50 per prescription. And then there was the cost of the doctor appointments and the frequent ER visits.*

*My finances grew worse as Kevin's health deteriorated. He was sick so often, I used up all my sick days and my vacation days and was frequently taking off time from work without pay to be with him. My earnings dropped, but the insurance payments didn't change and the copayments kept mounting. When his doctor told me that Kevin urgently needed nine months of treatments to help him rebuild his immune system, I was at my wits end. My share of the cost for those treatments under my insurance policy was $2,000 a month. And I would be losing more pay because the treatments would make Kevin sick and weak. I needed to take more time off without pay to care for him.*

*I applied for Ohio Medicaid. It helped me keep my son alive and allowed me to hold on to my job. I still pay for the insurance from my job for the children and for me, but Medicaid fills in for all of the care that the insurance doesn't cover and it helps with the copayments and co-insurance for Kevin's care that I simply could not afford.*

## Medicaid's Investments for People with Chronic Illnesses Can Be Cost Effective

Care for those with chronic conditions and disabilities is, on average, quite costly, but often the dollars spent for a costly medical regimen will save many times that amount over time. Budget-driven proposals to reduce benefit coverage and increase patients' share of costs can backfire.

### Renee Hall Freeman

*The new asthma medication that gave Kevin back his life is very expensive. He needs two treatments a month and each costs about $2,000. But Medicaid didn't hesitate about paying; they had been spending thousands of dollars on Kevin's asthma medications, emergency room visits, immune system treatments to address complications flowing from the steroids used to treat the asthma, doctor visits and, occasionally, home nursing care.*

*The investment paid off, not just for Kevin and our family, but for the Medicaid program. Kevin's lung function is now almost 98 percent. He takes only three medications (down from 13) and he has not been in the emergency room in over a year. Before, no matter what we did, we were in the ER as many as three times a month.*

## Asthma and Allergy Foundation of America

Asthma is a disease in which the bronchi and bronchioles of the lungs become blocked or narrowed. While the specific cause of asthma is not known, it is associated with people who have hyperreactive airways—what would be a minor irritant for someone without asthma produces an asthmatic episode in persons with the disease. Symptoms of asthma can include wheezing, tightness in the chest, coughing, and difficulty breathing. Asthma symptoms can be triggered by exposure to certain things in the person's environment, including allergens such as grasses and weeds, animal dander, and mold spores. In fact, allergic asthma is the most common form of asthma, affecting approximately 60 percent of all people with asthma. Inflammation and bronchoconstriction can also be triggered by exposure to a variety of other factors such as tobacco smoke, weather changes, certain medications, illness, and even exercise.

About 20 million Americans currently have a diagnosis of asthma, and while it can be diagnosed at any age, many persons are first diagnosed with asthma in childhood.

There are significant racial and ethnic disparities in the prevalence and treatment of asthma. According to the latest US government data available, in 2003, the asthma prevalence rate in African Americans was 39 percent higher than among whites and African Americans had a rate of asthma attacks 42 percent higher than whites. The asthma prevalence rate in Hispanics depends on subgroup analysis, but some of the highest asthma rates in the nation have been found in Puerto Ricans. In 2002, African Americans were three times more likely than whites to die or be hospitalized for asthma, and five times more likely to seek care at an emergency room.

Asthma is treated with medications including long-term control anti-inflammatory agents, such as corticosteroids and anti-leukotrienes that decrease inflammation in the lungs, and with bronchodilators used for the quick relief of symptoms as needed. Allergen immunotherapy (*i.e. allergy shots*) is a program of injections that reduces allergic sensitization over time. A new treatment for difficult-to-control asthma was approved by the Food and Drug Administration (FDA) in 2003. Known as anti-IgE therapy (for anti-immunoglobulin E), the new drug concentrates on short-circuiting the allergic reaction in the body before it even begins. Anti-IgE therapy stops the allergic reaction before it starts, allowing the patient to avoid allergy symptoms that often trigger an asthma attack or lead to the development of asthma attacks.

According to a 2001 letter from the federal government to State Medicaid Directors, Medicaid covers asthma-related medical services under various categories, including prescription drugs, home health services, physician services, and services by other licensed practitioners. In 2002, asthma was responsible for 1.9 million emergency room visits, 485,000 hospitalizations and 4,300 deaths. Children with asthma in 2003 lost an extra 12.8 million school days and adults missed 24.5 million work days because of the disease. Asthma has been estimated to cost the nation more than $16 billion in 2004 dollars. In recent years, Medicaid programs across the country have been implementing disease management programs and other initiatives to improve the quality of care received by children and adults with asthma.

## Conclusion

Few could disagree that people facing the kinds of challenges described here need robust health care coverage at a cost they can afford.  And yet, so many of the proposals that are now under serious consideration at the federal and state level would deny that coverage to people in these circumstances.

Medicaid standards on benefits and cost sharing are central to the mission of the program.

Eliminating benefits that people need and charging people with little resources and significant medical needs more for the services that are covered will undoubtedly result in short term savings for the Medicaid program, but what will be the cost over the long run, not only to public treasuries but also to people's health and well-being?

As these frontline perspectives show, Medicaid policy prescriptions that miss the mark can have deadly consequences.

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[1] States can seek waivers of certain federal Medicaid rules under Section 1115 of the Social Security Act, which provides the Secretary of HHS with authority to authorize "experimental, pilot, or demonstration project(s) which, in the judgment of the Secretary,(are) likely to assist in promoting the objectives of (the Medicaid statute)." Available online at http://www.cms.hhs.gov/medicaid/1115/default.asp

[2] Kaiser Commission on Medicaid and the Uninsured, *Utah Section 1115 Waiver Fact Sheet*. Available online at http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14329

[3] National Governors Association, *Short Run Medicaid Reform*, August 29, 2005. Available online at http://www.nga.org/Files/pdf/0508MEDICAIDREFORM.PDF

[4] Leighton Ku, *Mississippi's Flawed Medicaid Proposal*, August 11, 2004. Available online at http://www.cbpp.org/8-11-04health.htm

[5] Susan Allen, Allison Croke, *Faces of Medicaid*. Center for Health Care Strategies, November 2000.

[6] Michelle M. Doty, Jennifer N. Edwards, Alyssa L. Holmgren, *Seeing Red: Americans Driven into Debt by Medical Bills*. The Commonwealth Fund Issue Brief, August 2005.

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