

# Why Medicaid Matters

## The Frontline Perspectives of People with Chronic Conditions

### *Executive Summary*

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#### **Background:**

#### **In the Wake of Katrina, Medicaid Cuts are Still on the Table**

Debate is swirling over the future of Medicaid. Perhaps more than at any time in Medicaid's history, proposals at both the federal and state levels would unravel key federal standards at the core of the program, including the standards that govern which benefits must be offered and the amount of costs that can be imposed on individuals and families with very limited incomes. For the millions of Americans who rely on Medicaid, and particularly for people living with chronic conditions whose perspectives are described in this report, these two standards are central to Medicaid's mission.

Despite widespread calls to abandon federal Medicaid budget cuts in the wake of the extraordinary needs laid bare by the Katrina tragedy, these cuts are still on the table. If policymakers adopt changes that undo key federal benefit and cost sharing standards, the Medicaid coverage available to Katrina survivors could fall far short of their needs. And, as detailed in this report through the words of people with chronic conditions, such changes would also deepen the more hidden, but just as extraordinary crises that children and adults with chronic conditions face each day.

#### **Key Findings**

- **Medicaid's comprehensive benefit package makes vital, life-saving health care services available to people with chronic illnesses.**

The comprehensive scope of benefits provided by Medicaid can literally make the difference between life and death for people with chronic conditions. Kevin Hall, a 12-year-old boy from Ohio, suffers from severe allergic asthma. At times, he has needed as many as 13 medications a day, regular injections to restore his battered immune system, and a visiting nurse to check his lung capacity. Medicaid covered these health care services, and, beginning in 2004, it covered a new treatment that addresses an underlying cause of Kevin's asthma.

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*“Medicaid...has literally given Kevin back his life.”*  
—Renee Hall Freeman,  
Columbus, Ohio

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□ **Proposals to eliminate Medicaid’s comprehensive benefit for children (“EPSDT”) would put children with chronic conditions at risk.**

Some proposals call for eliminating or weakening Medicaid’s comprehensive benefit standard for children known as “EPSDT.” Recommendations from the National Governors Association, for example, would replace EPSDT for some children with a standard like the one that applies in the State Children’s Health Insurance Program (SCHIP). SCHIP benefit standards, however, are typically ill-suited to children, like 10-year-old Brandie Haughey from Florida, who has multiple medical problems and developmental disabilities.

□ **“Targeting” benefits would inevitably leave out some with chronic conditions.**

Proposals to scale back the Medicaid benefits standard often speak about “tailoring” or “targeting” benefits: some people would have access to comprehensive benefits while others would have more limited coverage. These proposals raise many difficult questions. Who would be protected and who would lose coverage? Would someone like Kimberly who suffers from a fatal, but little known genetic condition, Alpha-1 Antitrypsin Deficiency (Alpha-1), be protected? Not if more comprehensive benefits are reserved for more well-known conditions, as was the case in a recently approved Mississippi Medicaid waiver.

□ **Proposals to increase premiums and cost sharing pose a particularly large burden on people with chronic conditions.**

Many proposals under review would impose new costs on beneficiaries. For people with chronic conditions and limited resources, cost sharing obligations that sound modest can add up quickly and prevent people from accessing the care they need. Sheryle Stafford of California, who struggles with bipolar disorder and a range of physical health problems, often “can’t even afford the gas” to get to the doctor.

□ **Proposals to “cash out” the Medicaid benefit standard pose particular risks for people with chronic conditions.**

Some states are considering changes where people would no longer be assured a defined set of benefits. Instead they would be allotted an amount of funds (e.g., through a “personal health account”) to cover their medical care. The idea is to encourage people to plan, manage, and control their health care expenditures, but these approaches, to varying degrees, shift the risk of higher-than-average or unpredicted costs onto patients and their families. Most people, but particularly those with chronic conditions, have difficulty predicting what lies ahead.

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*“Brandie’s health...(has) 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....”*  
– Karen and Bill Haughey, Seminole, Florida

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## **Conclusion**

Out of deep concern for the lives of children and families, and in recognition of the questionable economic wisdom of rolling back core health care coverage, leading health care groups are calling for defense of Medicaid against looming changes that could undermine the program's ability to do its job. These organizations, representing millions of people with chronic conditions, have come together to urge state leaders, the White House and Congress to protect the vital role Medicaid plays in our communities - when national crises like Katrina and September 11<sup>th</sup> hit, and when humbler but equally disastrous economic and health crises strike hardworking American families.