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Proposed Medicaid Changes Called ’Devastating for Hardworking Families’

National health organizations representing millions with chronic health conditions call upon Congress to strengthen — not weaken — health coverage for children and families in need

Washington — The devastating impact of proposed Medicaid changes on America's most vulnerable citizens was demonstrated today as families and children living with chronic diseases and/or disabilities testified to the vital role Medicaid plays in their lives. At the event, co-sponsored by the Center for Children and Families at Georgetown University’s Health Policy Institute (CCF) and the National Health Council (NHC), the frontline perspectives of people who rely on Medicaid were shared through personal stories and in a report titled Why Medicaid Matters.

The voices of the children and families who could be hit hardest by proposed Medicaid changes until now have been largely absent from the discussions over reducing and restructuring the program.

Karen and Bill Haughey and their 10-year-old daughter Brandie underscored the need to sustain and strengthen the safety net Medicaid provides. Both parents work full-time and have private health insurance, but Brandie suffers from Neurofibromatosis 1, a genetic condition that causes her to develop lesions on her brain, optical nerve and spinal cord. Even as a two-income family, the Haugheys would not be able to afford Brandie's expensive treatments and prescriptions without the comprehensive assistance she receives through Medicaid. Among the medications Brandie needs to survive is one that costs more than $650 per month.

Ironically, while Hurricane Katrina has made the needs of so many Americans even more apparent, major changes that could undermine Medicaid's ability to carry out its critical mission still are on the table in Washington and states across the country. Many of these proposals would unravel federal Medicaid benefits and cost-sharing rules, making program coverage less comprehensive and affordable.

"In light of the Katrina disaster, many leaders have called for a re-examination of plans to cut the Medicaid program, but others continue to call for major, potentially devastating changes in the basic structure of the program," said Cindy Mann, CCF executive director and co-author of Why Medicaid Matters. "In light of expanding need, we ought to be strengthening Medicaid, rather than weakening it — both for victims of this tragic disaster and for people with chronic health conditions who face their own potentially tragic situations everyday."

"For 53 million Americans, Medicaid means survival — financially and literally," said Myrl Weinberg, president, NHC. "Nearly 70 percent of Medicaid spending actually goes to people who are elderly and/or have serious medical conditions. In addition, many of the adults and children who are not classified as ‘disabled’ under Medicaid still suffer from serious chronic conditions such as asthma and diabetes."

Renee Hall Freeman, an Ohio mother whose son Kevin suffers from severe asthma, was featured at the event. Freeman said, "Medicaid literally gave my son his life back." Proposed cuts to the program, she said, would be disastrous for her family. "Medicaid also 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 co-payments and co-insurance for Kevin's care that I simply could not afford otherwise."
CCF and NHC co-sponsored the event in collaboration with the Alpha-1 Foundation, Epilepsy Foundation and National Mental Health Association (NMHA) to give voice to the tens of thousands of people across the country who would be devastated if not for the assistance they receive from Medicaid. Children and families shared their stories, and CEOs and representatives from these national health organizations spoke about the impact of cuts on those with chronic conditions.

“The stories heard at this event starkly illustrate why the federal standards governing benefits and cost-sharing are fundamental to the basic mission of Medicaid,” said Michael Faenza, NMHA president and chief executive officer. “Weakening these standards — as lawmakers are now proposing — could undermine Medicaid’s ability to provide a safety net for those with chronic medical conditions.”

Mann of CCF agreed. “What will be the cost over the long run, not only to state and federal budgets, but also to Americans’ health and well-being? Lives will be irreparably damaged 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.”

To obtain a copy of the report, visit ccf.georgetown.org or www.nationalhealthcouncil.org/medicaid. For additional information, contact Gina Russo at 202-421-3578, or at mediaiq@comcast.net.

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