

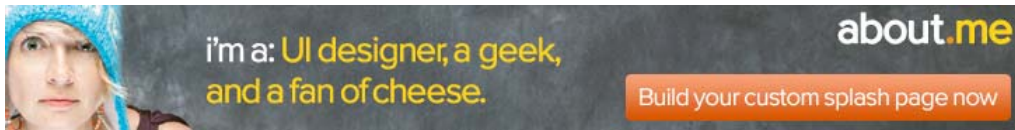
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## Children in the Dawn and Shadows of Life Should Be a Top Priority in Budget Talks

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Our nation's leaders are facing a watershed moment as they try to build a consensus on how to best address the long-term deficit. The path our government takes at this pivotal point in history will define our society. Probably no other group has more at stake in this debate than children and youth with special health care needs. In the words of the late Hubert Humphrey, they are both in the dawn of life and the shadows of life. How these children are treated in the budget debate is a moral test of government.

Children and youth with special health care needs are more likely to be covered by Medicaid than other children. Families raising children with serious conditions such as autism, cancer, cerebral palsy, complex genetic disorders, and epilepsy rely on Medicaid's comprehensive benefit and cost-sharing protections because of their relatively extensive health care needs. Overall, Medicaid is the largest single payer of health care services for these children and many of their families would face financial ruin without its help. Many of these families have private health insurance but need Medicaid to help them meet the costs of caring for their child in their home rather than placing them in more costly institutional care. Others need help paying for expensive life-saving medicine or medical bills that are not covered by their private health insurance plans. Even with Medicaid's help, many of these families make great personal and financial sacrifices in order to care for their children.

Georgetown University Health Policy Institute's Center for Children and Families [partnered](#) with Family Voices to collect case studies of families raising children

with special health care needs to help inform policymakers about what is at stake in the debate over the future of Medicaid. The families [included](#) in our report, released today, were from all across America and working hard to meet the needs of children with a wide variety of medical needs but they were remarkably similar in one respect: they all cherished Medicaid and didn't know what they would do without it. Not only does Medicaid provide their children with the health coverage their lives depend on, but in many instances, it is the backbone of the family's economic security.

The mother of a child born with spina bifida said:

I cannot imagine going one single moment through Emma's life without Medicaid as her secondary insurance. At times her medical and pharmaceutical bills could easily put our family of six on the street. It's hard enough to raise a family in this day and age, but imagine what it's like to live with children affected by life-long special healthcare needs.

The mother of two children with a mitochondrial disorder said her family would be bankrupt without the help of Medicaid. She shared the following story:

When I was pregnant with Matthew, my husband and I felt well-prepared to meet the financial responsibilities of parenthood: we had college educations, owned a home, were blissfully without consumer debt and, via my husband's job as a high school history teacher, had great private insurance. Six months later, as Matthew spent his first Christmas in our local children's hospital, our world was very different.

Our son's complex medical needs were not entirely covered by our health insurance, we had a staggering amount of medical debt, and even when our medical cost swallowed a huge portion of our income we did not qualify for the majority of safety net programs. For several years, our young family struggled to meet our children's needs, often making painful choices about how long we could safely wait for doctors visits, tests, and procedures. We worried about our ability to maintain our housing and often struggled to have enough money for food. For many families like mine, Medicaid is a key partner in meeting those needs.

We are happy to be a family like so many others, spending money in the economy and paying taxes back into the system, as well as volunteering, but none of that could happen without Medicaid. I share my story because it is the story of families all over America, who never expected to need Medicaid and likely didn't understand its role in supporting children with special health care needs until it affected them directly.

The mother of a boy with autism explained that her family has had a hard time saving for her other son's college education because they have spent the equivalent of college tuition on uncovered medical bills for the past several years. She expressed deep concern about the current budget debate saying:

Proposals to cut Medicaid represent survival of the fittest at its worst. By cutting Medicaid, you're telling our children, the disabled, and elderly that they are not valued in our society.

MomsRising has also [collected](#) hundreds of stories from families whose lives have been touched by Medicaid. A nurse who helps care for children with special health care needs told MomsRising that:

Without home care, many of these families would not have the help they need to hold down their job's [or to] help their children to thrive and improve their health.

Many of the families included in our report pointed out that they have made great personal and financial sacrifices in order to care for their children with special health care needs. Most were so financially stretched that they would have nowhere else to turn if Medicaid were unavailable.

Leaders from both sides of the aisle have publicly voiced support for protecting health care coverage for children. Senator Orrin Hatch (R-UT) has said: Parents should not have to decide whether to buy health insurance for their children or put food on the table. President Obama has said: "In a decent society, there are certain obligations that are not subject to tradeoffs or negotiation; health care for our children is one of those obligations." Families of children with special health care needs see Medicaid as a lifeline and are counting on lawmakers to back up those words with action by preserving that lifeline to those who need it the most.

**This blog comes from [MomsRising.org](#) and [CustomFitWorkplace.org](#) and presents innovative ideas to strengthen 21st Century American families through public policy, business practice, and cultural change.**

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