How the Wrong Medicaid Reforms Could Devastate Young People with Complex Medical Needs

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Image

Current proposals to simultaneously repeal the Affordable Care Act (ACA) and reform the federal Medicaid program would be devastating to children and young adults with disabilities and complex medical needs. Even if the final ACA replacement plan continues to allow young people to stay on their parents' insurance plans until they turn 26 - which is a benefit largely supported on both sides of the political aisle - the most medically complex among them rely on Medicaid because of the extraordinary level and cost of care needed.

Today, Medicaid covers 10.2 million adults and children with serious illnesses or disabilities whose health needs create significant financial burden for patients and their families. For example:

- Medicaid pays for physical therapy, occupational therapy and speech therapy that children with cerebral palsy and other developmental disabilities may receive through school.
- Medicaid covers private-duty nursing and assistive technology — such as ventilators, feedings tubes and communication devices — that children with disabilities may need to attend school and avoid placement in institutional settings.
- Medicaid frequently fills in coverage gaps for privately insured children with disabilities since over one-third of insured children with disabilities report inadequate coverage.

These individuals and their families have much to lose with the Medicaid reform proposal currently on the table.

The Switch to Medicaid Per Capita Caps

The ACA replacement plan unveiled Monday night in the U.S. House of Representatives recommends converting Medicaid to a "per capita cap" program, which would provide states with a predetermined amount of funding for each Medicaid enrollee. This type of proposal also gives states more flexibility to decide Medicaid eligibility and service options. Far from a new idea, proposals to reform Medicaid in this way go back at least as far as 1981. Supporters have always presented these proposals as a way for the federal government to save billions of dollars and give states more control. Sounds good, so what's the catch?

First, per capita caps endanger funding for medically complex children. Under a Medicaid per capita cap, the federal government will likely determine the limit of reimbursement for each child enrolled in Medicaid based on the average health care cost of a child eligible for Medicaid today. It is reasonable to assume that the reimbursement rate per child will be set fairly low, since children make up 50 percent of the Medicaid population, but only contribute to 20 percent of the program's costs. This may leave insufficient funding for medically complex children whose health care costs are significantly higher than those of other children.

To illustrate, a Medicaid-eligible child costs Pennsylvania $3,561 per year on average. By contrast, a family with a child who has suffered spinal cord injuries may require over $7,000 per month for the mechanical ventilation keeping their child alive. Medicaid per capita caps would not account for the differential health care needs of this family and would shrink both states' overall budget and ability to care for all children regardless of their health care needs.

Loss of EPSDT

Additionally, all children covered by Medicaid are at risk of losing essential health services they are currently guaranteed. Today, to receive federal funds for their Medicaid programs, states must provide insurance coverage and Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services to all children under 21 who qualify for Medicaid based on their health status or family income. EPSDT is a comprehensive set of screenings and preventive services that catch problems early, before they have the chance to escalate. States must also guarantee children have access to all treatment services that Medicaid providers deem medically necessary from these screenings and services.

EPSDT services, which were designed to meet the unique health care needs of children, could be eliminated with major cuts to Medicaid spending through per capita caps. This is because the financial burden of keeping people covered would fall to the states, which would have more flexibility to decide who qualifies for Medicaid and which services to cover. Medicaid coverage would, therefore, be on the negotiating table when states are faced with difficult budgetary decisions. Children with disabilities could lose access to essential services and, in all likelihood, would be left with no affordable insurance options that meet their health care needs. In Pennsylvania alone, over 13,000 people with intellectual disabilities are already waiting to receive Medicaid-funded services.

Impact on therapies children receive in school

For decades, Medicaid has also allocated funding to schools that provide special education and certain medically necessary services to children with disabilities under the Individuals with Disabilities Education Act (IDEA). By reducing federal spending and eliminating the possibility of adjusting funding levels based on changing needs, per capita caps would likely force school districts to compete with hospitals and health care centers for precious Medicaid dollars, and they'd likely take the most significant hit. Schools would be forced to pay for special education programs with funds allocated for general education, potentially reducing the amount of money available to pay for teachers, counselors, nurses and extracurricular programming for all students.

Potential Solutions

One way to decrease the potentially devastating impact that per capita caps will have on children with disabilities is to place children with disabilities and other medically complex conditions into a different category from their healthier peers, essentially creating a "high-risk pool" for Medicaid-eligible children. Alternatively, Medicaid-eligible children with disabilities could be grouped together with adults who also qualify for Medicaid due to disability, which may minimize loss of Medicaid coverage — and the requisite delivery of medical and nursing care services — that frequently occurs when emerging adults with disabilities transition from pediatric to adult health care services.

Lawmakers will confront many difficult decisions in the coming weeks and months, but whether to pursue reforms that will inevitably cut access to care for our most vulnerable populations should not be one of them. As Dr. Ezekiel Emanuel wrote this week in his New York Times op-ed, "this would be even worse than going back to the days before the Affordable Care Act.” Sweeping cuts to a program that nearly half of all U.S. children — and most children with very complex medical conditions — rely upon for the health care they need to survive and thrive is not the answer. We must find thoughtful ways to improve the efficiency and quality of health care in order to achieve the shared goals of bringing down health care costs *and* improving health outcomes for everyone.

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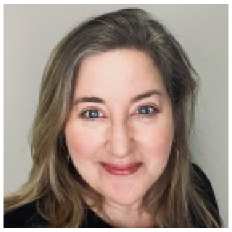

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