When Health Reform Resurfaces, Don't Let Special Needs Children Get Lost in the Shuffle

Population Health Sciences

Date Posted:

Nov 03, 2017
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Editor's note: This opinion piece originally appeared on Philly.com's "Health Cents". The views expressed in the piece are Dr. Rubin's own.

While we catch our breath from a year of legislative proposal after legislative proposal aiming to dramatically reshape our health care system, it’s critical that we understand the particular threats those proposals posed to children with special health care needs. During the Capitol Hill debates, many of our politicians said they were committed to “protecting individuals with pre-existing conditions,” yet few of their bills actually did so for children and adolescents. Since we can only expect that these reform efforts will continue, we must work to educate lawmakers and their staff on the unique needs of children when it comes to health care.

In June, I traveled to Washington, D.C., to meet with congressional health policy staff and do just that. There, I presented research on how many lower-income, working families are now relying on public health insurance to insure their children, likely because family coverage either isn’t offered through their employers or is no longer affordable. This migration of the working family to the public insurance market for their children’s health coverage, I explained, provided a worrisome lens through which to view any proposed arbitrary spending cuts to Medicaid – cuts that could endanger far more families than our legislators realize.

While I was there to talk about numbers and trends, what I really wanted to do was tell the story of every child with special health care needs that I’ve seen in my practice over the past 20 years.

One girl in particular keeps dancing through my mind. She was born extremely premature and with lung disease so severe that she required a tracheostomy (an artificial airway inserted into her neck) as an infant. Despite the complexity of her medical needs, she amazed us with her continual progress. She outgrew her need for an artificial airway and, eventually, worked her way through her many physical and developmental issues with the help of several different doctors and specialists. When I last saw her, she was off to college and appeared healthy on the outside – no one would know by looking at her that she still needed numerous doctors.

All too often the health care challenges children face are conflated with how our legislators view the health care needs of adults. There has never been a more important time to shine a light on this fundamental misunderstanding of children's health care in the wake of our lawmakers' expressed desire to significantly alter Medicaid, the single largest insurer for children in this country.

Some might have considered children and adolescents safe under the legislative proposals that sought to protect individuals with pre-existing conditions by maintaining funding for "disabled" individuals covered by Medicaid. Yet, only 3.4 percent of children enrolled in public insurance in 2012 were qualified on the basis of a disability. That number doesn't even come close to protecting the 20 percent of children and adolescents with special health care needs who are insured through Medicaid.

This brings me back to my patient. Is she disabled? Often state laws have such narrow definitions of disability that the government might interpret them to only cover situations commonly associated with "disability," such as individuals in wheelchairs or parents who have had a stroke and are forced to live in nursing homes. An ex-premature infant who has conquered many of her pediatric conditions but still requires significant, regular care might not meet the fixed "disability" definition and, thus, would not get the care she needs. The same could be true for children who had significant congenital heart disease as an infant, leukemia in childhood, or ulcerative colitis that began in high school.

Ultimately, if Congress decides to revisit significant Medicaid cuts with similar proposals to those that we've seen, families who have children with special health care needs – much like the one of my former patient – would be left to negotiate with the government as to whether their sons and daughters could be classified as "disabled." Some states might be willing to alter their definitions in order to cover these children, and others, based on their history, would not.

This issue is not trivial considering that one in five children have a special health care need for which adequate health care is essential for both their immediate well-being and their successful transition to adulthood. We cannot, as a society, afford a system that will leave these children without the care they need to become independent adults.

Some argue that by returning control to the states to implement health care plans, we would remove government from the patient-doctor relationship. As a pediatrician, I am in full support of preventing government interference in my patients' care. But through the proposals we've seen thus far, policymakers have accomplished what they most feared by proposing a scenario in which the government might be the gatekeepers to the care children with special needs receive.

What we need now are proposals that well define the high-quality, essential health care services that all children should receive so families can spend their time not on fighting for coverage or access to those services, but on working with their doctors to keep their children well.

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