

Repeal of the Affordable Care Act Will Negatively Impact Children at End of Life

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Unfortunately, hospice care is drastically underutilized by children and adolescents at the end of life.¹ Annually, more than three-fourths of the over 55 000 pediatric deaths take place in a hospital setting without hospice care involvement.² Comprehensive hospice services for children offer an opportunity for family-centered care with prominent symptom management at the end of life. Although the majority of pediatric deaths are due to unintentional injury, it is estimated that nearly 17 000 deaths each year are due to chronic, complex conditions, and the majority of these children are enrolled in Medicaid because of their disability status, severity of disease, or overall functional status.³ Although a small proportion of the pediatric population (an estimated 0.4%–0.7% or 320 000–560 000 in total), children with medical complexity account for 15% to 33% of all pediatric health care spending and nearly 60% to 67% are enrolled in Medicaid.³

Before the Affordable Care Act (ACA), children enrolled in Medicaid and their families had to choose between continuing curative therapies or receiving hospice care services. For many of these children, curative therapies include long-standing regimens necessary for symptom management and optimal quality of life. Forgoing curative therapies to enroll in hospice care was an eligibility requirement that could only be changed by policy action. Recognizing that few families would make the choice to end curative therapies to enroll in hospice care, numerous states led policy initiatives targeted toward expanding palliative and hospice care provision and enrollment for children with life-limiting conditions. Florida was among the first states to publicly finance concurrent curative and hospice care through a 1915 Medicaid waiver program (which allows states to offer benefits to home- and community-based services to promote children remaining in their home and local community).⁴ California enacted concurrent care through The Nick Snow Children's Hospice and Palliative Care Act (Assembly Bill 1745) and later expanded their 1915 Medicaid waivers to incorporate this legislation. In the same year, Massachusetts provided for the funding of a Pediatric Palliative Care Network as a part of the overall state Health Care Reform Act.⁴

Early state legislative initiatives that incorporated concurrent care demonstrated substantial bipartisan support and targeted a pediatric

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population with a specific need for enhanced access to hospice services. The legislative intent for the concurrent curative care policy was threefold: (1) this provision would allow more children with complex, chronic, life-limiting conditions to enroll in hospice care; (2) this provision would enhance patient and family quality of life at the end of life; and (3) earlier enrollment and a longer length of stay in community-based hospice has the potential to offset costly acute care and intensive care hospital admissions near the end of life.⁴ Early state-led actions and advocacy efforts led to a concurrent care provision in the ACA, section 2302, which affected children 21 or younger with a life-limiting illness who were enrolled in the state's Medicaid or Children's Health Insurance Program.⁵ Section 2302 of the ACA went into effect on signing and eliminated challenges in enrollment on the basis of allowing Medicaid hospice reimbursement for both curative and hospice therapies.⁴ Not all states were able to implement the provision directly after signing it into law (Table 1). States actively enacting cost-containment strategies in Medicaid were more likely to implement it early, and states experiencing a budgetary crisis were less likely to implement the provision.⁵ Although the overall economic impact of section 2302 has not yet been evaluated, Lindley⁶ has demonstrated that the concurrent care policy is associated with a longer pediatric hospice length of stay since implementation of the ACA. Although the federal legislation enacted in the ACA only impacted Medicaid reimbursements, the legislative intent was that there would be a spillover effect by which private insurers would match the required benefit.

The current political climate has led to heightened levels of anxiety among families of children with

TABLE 1 State Implementation of ACA, Section 2302

State	Year Implemented
Alabama	2010
Alaska	2013
Arizona	2010
Arkansas	2012
California	2011
Colorado	X
Connecticut	X
Delaware	2011
District of Columbia	2013
Florida	2012
Georgia	2013
Hawaii	2010
Illinois	2012
Idaho	2011
Indiana	2012
Iowa	2011
Kansas	2011
Kentucky	2012
Louisiana	2014
Maine	2010
Maryland	2011
Massachusetts	2010
Michigan	2011
Minnesota	2016
Mississippi	2011
Missouri	2010
Montana	X
Nevada	X
Nebraska	2011
New Hampshire	2014
New Jersey	2011
New Mexico	X
New York	2011
North Dakota	X
North Carolina	2011
Ohio	2011
Oklahoma	2010
Oregon	2011
Pennsylvania	2015
Rhode Island	X
South Carolina	2012
South Dakota	X
Tennessee	2013
Texas	2010
Utah	2012
Vermont	2012
Virginia	2010
Washington	2011
West Virginia	2012
Wisconsin	2010
Wyoming	X

X, implementation not apparent.

complex, chronic, life-limiting conditions whose children and adolescents are enrolled in Medicaid. Almost all states have a pathway ("Katie Beckett" pathway) through which families of children with severe disabilities

and require institutional-level care can access care at home regardless of income.⁷ Most hospice-based services for children with complex, chronic conditions are home and community-based and fall under the Katie Beckett access pathway. The recent House-passed American Health Care Act would establish a cap on federal Medicaid spending.⁷ Furthermore, President Trump's 2018 budget calls for more than \$839 billion dollars taken from the Medicaid budget over the next decade.⁷ Such proposals encourage states to gain flexibility in administering Medicaid programs; however, there are immense concerns that home- and community-based services will be among the first services eliminated in a financially austere environment.

Many clinicians, researchers, advocates, and caregivers of children with life-limiting conditions are concerned that the recent political proposals to transition Medicaid reimbursement to a capitated or fixed block grant structure will vastly destabilize the already limited access to hospice care that currently exists for children with the highest levels of medical complexity. In addition to the overall financing structure, repeal of the ACA would directly eliminate the federal legislation allowing for concurrent curative therapies and hospice services for children at the end of life. If section 2302 of the ACA were repealed, states would not be required to cover the concurrent care provision. States could choose to enact traditional adult hospice guidelines for children on Medicaid, which include forgoing curative therapies to be eligible for enrollment. Finally, if Medicaid budgets are decreased as projected, community care provisions for children with chronic, complex, life-limiting conditions would likely be eliminated in the new Medicaid fiscal climate. Given the projected

policy ramifications targeting the ACA and Medicaid, children who need hospice services at the end of life may not be able to access them.

ABBREVIATION

ACA: Affordable Care Act

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