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The Tangled Web of Pediatric Palliative Care Payment and Policy

By **Holly Vossel** | August 13, 2024

A complex web of state regulations and reimbursement systems can challenge pediatric palliative care access for seriously ill children and their families.

Much of the current state palliative regulations and reimbursement pathways focus on adult patient populations, representing a significant barrier to improved quality and support in the pediatric realm, Cottor said.

“Among the very fundamental differences is that children fall under the Medicaid system, and that’s kind of like trying to fit a square peg in a round hole,” Cottor told Palliative Care News. “Our health care system in the United States is really designed for adult illness care. Children aren’t supposed to die young, but they do, and billing for their services takes understanding a whole different set of regulations. There’s no consistency.”

Challenging reimbursement structures

Billing issues are the most common challenges encountered when shaping pediatric palliative care services, according to Cottor. Medicaid programs vary vastly across different state reimbursement and regulatory structures for pediatric palliative care delivery, he added.

He and his wife Holly Cottor are co-founders of Ryan House in Phoenix, Arizona. Operated in partnership with the Hospice of the Valley, the inpatient facility offers pediatric palliative care, hospice, grief support and respite services. Launched nearly 15 years ago, the facility was in part inspired by the challenges the Cottors experienced navigating care for their seriously ill son, who died at the age of 17.

A large challenge is that much of the available reimbursement is for hospital-based services, with fewer pathways for community- or home-based pediatric palliative care, Cottor said. Current payment structures do not sufficiently support the full scope of interdisciplinary care. Among families’ largest unmet needs is finding pediatric palliative care providers nearby, along with care coordination and caregiver support, he indicated.

Having standardized definitions around these services and clearer quality measures could go a long way toward improving access, he stated.

“There should be a chapter within federal law that really describes pediatric palliative care services and licensing [requirements] instead of playing games at the state levels,” Cottor said. “That clarity allows us to really soup-to-nuts provide the services that should be offered to all families. It’s the regulations and reimbursement systems that are not allowing us to do this easily. If we could crack the federal level, then all 50 states would have clearer guidance and we’d see an explosion of these services.”

Pediatric palliative care providers can focus on building relationships with state Medicaid departments and advocating with legislators for higher rates, Cottor continued. This often involves “getting into the weeds” of state licensing and regulations, he said.

Regulatory questions

Lagging reimbursement and complicated regulations have made it difficult to sustain community-based pediatric palliative care programs, said Dr. Tom McNally, medical director of George Mark Children’s House. The California-based nonprofit operates a pediatric palliative care center in the San Leandro area near San Francisco and offers hospice, palliative, respite and bereavement care.

“Our first question is often about [a patient’s] location and what the laws are there to see what a child can qualify for. It becomes complicated, unwieldy and requires a lot of care coordination and resources to care for

The nation has a small supply of these providers, which ripples effects for families that often travel long distances to receive the care they need, he stated. McNally is also medical director of pediatric palliative care at the University of California San Francisco (UCSF) and co-medical director of By the Bay Health's pediatric hospice program.

Insufficient resources can complicate outcomes and exacerbate the financial and practical burdens on patients and their families, McNally said.

Having federally established standards around pediatric palliative care would help providers operate more robust programs that better support their communities, he added. Standardized eligibility requirements and quality measures are greatly needed, but require careful consideration among policy makers so that they don't unintentionally pose barriers to care, McNally stated.

"It would be much simpler and much more direct if we had national standards in terms of the criteria for children receiving home palliative care," McNally said. "These should be developed with an understanding that they're not going to be able to carve them out of thin air, but recognize palliative as an important part of pediatric care and put resources and financial incentives toward it."



Holly Vossel

Holly Vossel, senior reporter for Hospice News and Palliative Care News, is a word nerd and a hunter of facts with reporting roots sprouting in 2006. She is passionate about writing with an impactful purpose, and developed an interest in health care coverage in 2015. A layered onion of multifaceted traits, her interests include book

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