
Pediatric concurrent hospice care: How did states implement?

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Key Points

- * There was significant variation in how states implemented pediatric concurrent care between 2010 and 2017. More than half of states used standard CMS language, while 30% crafted their own implementation guidelines.
- * Among the states with specific implementation language, it was most common for them to note age requirements and least common for clinical guidance.
- * A standardized implementation framework that allows state-level flexibility is needed to ensure high quality pediatric end-of-life care.

Introduction

Prior to the Patient Protection and Affordable Care Act (ACA), over 30,000 families had to make the “terrible choice” to continue curative, life-prolonging therapies or use hospice care for their children with serious illnesses.^{1,2} To improve continuity and quality

of end-of-life care, changes in Medicaid/CHIP regulations under ACA section 2302 enabled pediatric patients to opt for *concurrent care* – the continuation of life-prolonging therapies while enrolled in hospice care.^{3,4} The primary goal of concurrent care is to provide families and pediatric Medicaid patients with life expectancies of six months or less a smoother transition from life-prolonging treatments and therapies to care focused on comfort. All state Medicaid plans are required to pay for both life-prolonging therapies and hospice services for children under the age of 21 upon the signing of the ACA.

Challenges

Pediatric concurrent care has been in effect for 10 years with no formal investigation of how it was implemented at the state level. What we do know is limited. With the passage of the ACA, the Centers for Medicare and Medicaid Services (CMS) issued a series of three letters to state Medicaid Directors notifying them of the change in Medicaid plans.^{3,5} This information consisted of the policy paragraph directly from the ACA document, along with preliminary questions and answers. No regulations were generated or distributed to the states. No deadlines for implementation

were communicated to the state, nor were penalties issued for late or no compliance. Consequently, state-level uptake by the state Medicaid plans varied significantly with some states implementing in 2010, while other implemented as late as 2017.

Our research team conducted an initial evaluation of public documents in each state related to pediatric concurrent care implementation. To standardize data collection, we created a tool to extract information on definitions, payment information, staffing, care coordination, eligibility, and clinical guidance.

Among the 50 states, we identified 35 states using standard information about pediatric concurrent care provided by CMS. These states often offered minimal information on hospice eligibility and age requirements.

In addition, 15 states crafted their own pediatric concurrent care implementation guidelines. These were Alaska, Georgia, Idaho, Indiana, Louisiana, Michigan, Missouri, Montana, Nebraska, New Jersey, New York, Ohio, Texas, Utah, and Washington. Characteristics of those guidelines included the following: 47% definition of life-prolonging therapies, 73% payment information, 13% staffing information, 80% care coordination description, 33% enrollment into concurrent care information, 27% hospice eligibility and concurrent care, 93% age requirements, and 7% clinical guidelines.

State Highlights: UTAH

- * Specific information on training required for hospice staff with concurrent care patients.
- * Distinctive election statements for pediatric concurrent care patients.

State Highlights: MICHIGAN

- * Detailed information on billing/reimbursement between hospice and treatment providers.
- * Staffing requirements for concurrent care that included a pediatric subspecialist.
- * Care coordination outlined including need for collaboration and detailed plan of care.

Recommendation

Although there were distinctive and innovative characteristics of the 15 state implementation guidelines, there was no consistency among states. The policy recommendation based on these findings is for the development of a common, standardized implementation framework that allows state-level flexibility to ensure high quality pediatric end-of-life care.

We encourage national end-of-life groups such as the National Hospice and Palliative Care Organization (NHPCO) or the Center for Advanced Palliative Care (CAPC) to convene appropriate state-level stakeholders from Medicaid offices, hospices, children's hospitals, hospice associations, and pediatric coalitions to initiate conversations about an implementation framework.

This framework should be consistent with current CMS Conditions of Participation (COPs) and other federal regulations (e.g., Ace Kids Act), which may act as barriers or facilitators in the framework development.

Any framework development should also consider how it will be used by providers without pediatric knowledge. As the number of adult hospice-only providers care for children grows, they need to easily understand how to provide concurrent care.

References

1. Murphy SL, Mathews TJ, Martin JA, Minkovitz CS, Strobino DM. Annual Summary of Vital Statistics: 2013-2014. *Pediatr.* 2017;139(6):1-12.
2. Casarett DJ, Fishman JM, Lu HL, et al. The terrible choice: Re-evaluating hospice eligibility criteria for cancer. *J Clin Oncol.* 2009;27:953-9.
3. U.S. Department of Health & Human Services. *Letter to State Medicaid Directors on Hospice Care for Children in Medicaid and CHIP.* 2010: Available at <http://www.scribd.com/doc/37423817/HHS-Letter-to-State-Medicaid-Directors-on-Hospice-Care-for-Children-in-Medicaid-and-CHIP>. Accessed September 20, 2010.
4. Lindley LC. Health care reform and concurrent curative care for terminally ill children: A policy analysis. *J Hosp Palliat Nurs.* 2011;13: 81-8.
5. National Hospice and Palliative Care Organization. 2013 Concurrent Care for Children Implementation Toolkit. Available at https://www.nhpco.org/sites/default/files/public/ChiPPS/CCCR_Toolkit.pdf. Accessed May 1, 2019.

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