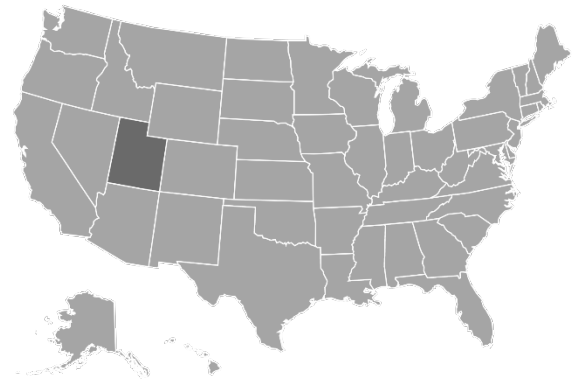

Implementing pediatric concurrent hospice care: Best Practices - Utah

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Key Points

- * Utah demonstrates implementation **innovations** in personnel and administration of pediatric concurrent care.
- * **Pediatric training** plans for hospice staff are integral to Utah's Medicaid pediatric concurrent care. The plans ensure that staff have basic knowledge about caring for children and their families.
- * Utah uses a distinctive hospice **election statement** that ensures children and families understand their rights.



Our research team conducted an extensive review of publicly available, state-level Medicaid documents including manuals, state plan amendments, and letters. We found that between 2010 and 2017 states had taken different approaches to implementing pediatric concurrent hospice care. Our analysis also revealed several state exemplars. Since formally implementing pediatric concurrent care in 2011, Utah's approaches to personnel and administration of concurrent care are innovative.¹

Introduction

The purpose of this policy brief is to highlight the best practices in state-level, implementation of pediatric concurrent hospice care in Utah. Concurrent care offers seriously-ill children under the age of twenty-one and their families the option of continuing their life-prolonging treatment while receiving hospice services.

Personnel

Utah's personnel innovation focuses on staff training. Under Utah Medicaid guidelines,

pediatric hospice providers are responsible for developing a training curriculum for both paid and unpaid staff who provide care to clients under the age of twenty-one. The goal of pediatric-specific training is to provide specialized knowledge about pediatric care that meets the developmental, social and emotional needs unique to children.

Core components of the training curriculum include information on pediatric growth and development, pediatric pain and symptom management, loss, grief and bereavement for pediatric families and the child, and pediatric psycho-social and spiritual care. The curriculum must also include skill development in communications with the family, community and interdisciplinary team, along with coordination of care.

The training curriculum should incorporate pediatric clinical standards such as the National Hospice and Palliative Care Organization's (NHPCO) Standards of Practice for Pediatric Palliative Care. This ensures training is congruent with nationally-recognized practices for pediatric care.

Hospices that seek Medicaid reimbursement for pediatric concurrent hospice care submit their pediatric training curriculum to the state Medicaid office.

Administration

Utah's administration of pediatric concurrent hospice care is another implementation innovation. Utah requires hospices to use a distinctive hospice election statement for pediatric concurrent care patients. The Utah hospice election statement is distinctly different from the election statement for adults. Specifically, it informs pediatric patients and their legal representatives that by electing hospice care they do not forfeit any other benefit they are entitled to through the Medicaid state plan.

Recommendations

As states move to add or improve guidelines specific to Concurrent Care for Children, including information on pediatric training of hospice personnel may ensure that paid and unpaid staff understand the unique aspects of caring for children and their families.

We recommend that these training programs are designed to be flexible and quickly implemented. New staff should receive pediatric training as part of their orientation. Hospice providers may also find it beneficial to host monthly trainings or discussions on how the pediatric population can better be cared for children. Finally, training should be implemented before a child is enrolled in the hospice program. This is especially important for hospices that rarely or never have cared for children.

In addition, the example from Utah highlights the importance of enrollment documentation that distinguishes between standard versus concurrent hospice care. It also suggests that the electronic medical record should include an identifiable notation for concurrent care election.

References

1. Section 2 Hospice Care Provider Manual. [online]. January 2019. [Accessed August 2017]. Available from: [https://medicaid.utah.gov/Documents/manuals/pdfs/Medicaid Provider Manuals/Hospice/Hospice.pdf](https://medicaid.utah.gov/Documents/manuals/pdfs/Medicaid%20Provider%20Manuals/Hospice/Hospice.pdf)

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