

Improving Home Hospice and Palliative Care Policies

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Children with serious illness make up <10% of the US population yet account for at least 50% of hospital resources for all children.¹ While most of these children and their families would rather not be hospitalized or at the doctor's office, addressing the children's physical, emotional, and practical needs within the home can be challenging. Parents report struggling to ensure their children are comfortable and receiving needed treatments while addressing the emotional and practical needs of the entire family.² Professional home-based care (HBC) services can be helpful, yet until recently, few options for this support existed. Home nursing care has been restricted to technology-dependent children and provides a limited range of services. Traditionally, home hospice, focusing on symptom management and psychosocial support, is only available at advanced disease stages if parents agree to forgo disease-directed treatment of their children. With these constraints, only a fraction of children with serious illness received HBC and typically do so only late in the disease course.³

Fortunately, recent federal and state policies have expanded options for HBC for children with serious illness. The 2010 Patient Protection and Affordable Care Act's Concurrent Care for Children provision allows children <21 years old with Medicaid and/or in the Children's Health Insurance Program to receive disease-directed treatment along with hospice care, although life-expectancy guidelines of <6 months still apply.⁴ Tricare (for military families) and some commercial insurers have also covered concurrent hospice care for children. In addition, several states have created options to provide home-based palliative care to children earlier in the disease course, mainly through Medicaid waivers and State Plan agreements.⁴

California has been an innovator of pediatric HBC services for this population by implementing the federal concurrent care provision in 2011 and creating an HBC program through a Medicaid waiver and the 2006 Nick Snow Hospice and Palliative Care Act.⁵ This state policy created Partners for Children, providing home-based palliative care for publicly insured children with serious illness regardless of prognosis. The policy was implemented in 2009 in 5 counties and later expanded to

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6 more, and services included nursing visits, respite, psychosocial support, and expressive therapies such as art and massage.⁶ The Partners for Children program did not include direct care from physicians and was not available for children living outside eligible counties. Limited evidence suggests that these federal and state policies together have increased use of HBC for children with serious illness and may improve patient and family outcomes along with lowering health care costs.^{6,7}

Despite the benefits of expanded HBC services, having separate federal and state policies has had unintended consequences in California for both families and providers. Below, we review some of these concerns. Although focused on the California experience, we believe the lessons learned can inform efforts in other states to fully implement federally mandated concurrent hospice care and to create broader home-based palliative care policies. In addition, our review of challenges in HBC programs can inform innovative community-based care efforts for adults (eg, Medicare Care Choice Models).⁵ The challenges of coexisting federal and state policies are seen at 3 levels: child and/or family, referring provider, and HBC provider.

1. Child and/or family factors: For seriously ill children, their health status and goals of care directly influence which HBC program (hospice or palliative care) is the best fit for a specific family at a given time. Although adult serious illnesses follow a predictable disease trajectory, most childhood illnesses do not, so predicting a 6-month prognosis (as required for hospice) is difficult.³ A child may have periods of relative stability alternating with periods of decline, and so the program

chosen initially may not have the best set of services for the family over time. In addition, even when a poor short-term prognosis is clear, families often choose to continue intensive medical interventions and so may be disappointed with hospice's slower response times and more limited diagnostic and treatment options.³ Because families' hopes and needs are ever changing, clear communication is required to ensure that families get care that is aligned with their goals at any given moment.

2. Referring provider factors: Although hospital-based pediatric palliative care providers are familiar with both HBC programs, they see only a fraction of patients who could benefit from this care. The majority of children with serious illness are cared for exclusively by primary care or subspecialty clinicians. These potential referring providers may lack a detailed understanding of the specific enrollment criteria and services of the federal and state HBC options, which is needed to ensure that the right patients are referred to the right programs and that families understand the possible benefits and drawbacks of the program before enrollment.
3. HBC provider factors: Because most hospice agencies rarely care for children, staff overseeing pediatric admissions or caring for families may be unaware of the enrollment criteria or details of concurrent care policies. Subsequently, home-based palliative care providers (who may work for home nursing or hospice agencies) may not have sufficient pediatric experience to provide high-quality care.³ Frequent staff turnover among hospice and palliative care

agencies also complicates the situation, requiring ongoing staff education and relationship building with referring providers. As a consequence, the lack of pediatric experience among HBC staff with pediatric patients may contribute to confusion about enrolling children in a federal or state program.

As we have seen in California, more options for HBC across illness trajectories increase the chances that families receive supportive care at home. Yet, the challenges described here show that more work is needed to ensure these HBC programs live up to their full potential. Primary care and subspecialty physicians are the gatekeepers to HBC referrals for children with serious illness. They should endorse and clearly explain the potential value of HBC to families. Local pediatric hospice and palliative care providers, state Medicare services agency Web sites, and state-based palliative care coalitions (see www.nhpc.org/regulatory/state-hospicepalliative-care-organizationsassociations) are good sources of information on the current status of HBC options in a specific community.⁴ Advocates must work in coalitions to lobby for specific guidance from their state Medicaid services agency on implementing concurrent hospice care if needed.⁴ Children with serious illness need HBC programs with broad eligibility criteria and processes ensuring seamless transfer between hospice and palliative care programs as patients' needs and eligibility change. In California, the need for policy advocacy continues because the state recently discontinued the original Partners for Children program and is redesigning a new statewide home-based palliative care program.

In addition to advocacy, the California experience shows that

TABLE 1 Summary of Key Challenges and Potential Educational and Clinical Solutions

Type of Factor	Challenge	Potential Solutions
Child and family	Children with serious illness often have an unpredictable and vacillating disease course. Families lack clear understanding of services provided by different HBC programs.	<ul style="list-style-type: none"> • Clinical decision support tools for determining the most appropriate HBC program at a given level of patient care needs. • Clear explanations by providers to families. Suggested language: “Home-based palliative care is supportive care at home for children with serious illness at any stage of their disease, regardless of life expectancy. Services may be provided by a hospice agency, but this care is different. Your child does not need to change any of the medical services they are getting from other providers while receiving home-based palliative care.” “Home hospice care is for children with life-threatening conditions later in their disease course. Hospice providers can prescribe medications and give other care in the home, helping avoid trips to the emergency department, clinic, or hospital.” • If concurrent hospice care: “Your child may receive hospice care along with disease-directed treatments from his or her usual doctors and nurses.” • If traditional hospice: “Hospice providers can provide care focused on your child’s comfort while discontinuing most disease-directed treatments he or she has received from other doctors and nurses.”
Referring providers	Referring providers have an incomplete understanding of the family’s needs and/or expectations. Referring providers lack awareness of home-based program options and available services.	<ul style="list-style-type: none"> • Communication guidance and assessment tools for referring providers. • Referring providers have detailed contingency planning discussions with families, going through possible scenarios at home and determining the family’s expectations. • Home and primary providers reassess the family’s goals and/or expectations on an ongoing basis, especially when a child’s condition changes. • Education for referring providers on available HBC programs. • Clinical decision support tools for the referring provider team describing program eligibility and services. • Opportunities for HBC agencies and referring providers to develop ongoing relationships. • HBC agencies provide clear expectations of services offered.
HBC providers	Adult-oriented HBC agency staff lack familiarity with pediatric policies and best practices. Families may experience gaps in home services with changes in program appropriateness and eligibility.	<ul style="list-style-type: none"> • Flexible educational opportunities for adult-oriented HBC providers in pediatric best practices and on the different available program options. • Ongoing engagement of pediatric hospice and palliative care providers as consultants to HBC agencies. • Thorough and inclusive care coordination by the HBC agency to ensure needs are met during changes in program enrollment.

ongoing education and clinical innovation is needed to address the concerns described above. Community- and hospital-based pediatric palliative care clinicians can serve as educational resources for referring and adult HBC providers, both locally and through national organizations (eg, the American Academy of Hospice and Palliative Medicine, National Hospice and Palliative Care Organization). Specific targets for educational and clinical solutions are described in Table 1.

Lastly, research can delineate the home-based service needs of children and families and measure the impact of this care. Research can also validate best practices in referral to,

and provision of, HBC. Ultimately, improving access to high-quality HBC allows children with serious illness to have the best quality of life within their communities, for as long as possible.

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ABBREVIATION

HBC: home-based care

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