A Key Step in Advancing Care for America’s Children

By Sarah Friebert, MD, and Susan Huff, RN, MSN

Despite amazing progress in medicine and technology, the unfortunate reality remains that children die. Approximately 53,000 children die each year in the United States and at least 400,000 more live every day with chronic, life-threatening conditions. While these numbers pale in comparison to the number of dying adults, the impact on families and on society is immeasurable.

As noted in “A Call for Change,” the 2001 white paper by the Children’s Project on Palliative/Hospice Services (ChiPPS): “Chronic illness and death can result in devastating consequences for affected children and the people who know and love them, but these consequences are not a foregone conclusion—the harm associated with the death of a child can be lessened by the provision of high-quality palliative and bereavement care.”

Currently, only 10 to 20 percent of dying children receive hospice services (generally for a brief duration), and a similar minority of children with life-threatening conditions receive palliative care support and interventions. Barriers to the provision of this necessary care are numerous and daunting. However, the exponential growth in expertise, programs, resources and educational materials—together with the increasing mandate from patients and families, providers, supporters and healthcare monitoring organizations—means that the time is now for the field of hospice and palliative care to ensure access to its youngest and most vulnerable members.

The Pediatric Services Survey which NHPCO conducted in 2007 reveals that a majority of responding agencies serve pediatric patients, but only a minority has formal pediatric hospice and palliative care programs with specially-trained staff. Many providers indicate willingness to start or expand pediatric services but lack education, tools, resources and performance improvement methods to create and sustain high-quality programming. In response to this need, NHPCO has developed the first national Pediatric Standards—the “Standards of Practice for Pediatric Hospice and Palliative Care Programs.”

These new standards will be available online and free to NHPCO members later this month (www.nhpco.org/pediatrics or www.nhpco.org/quality). This article takes a closer look at their development and how they can help advance the quality and availability of care to children.

continued on next page
Developing the Pediatric Standards

In 2006, NHPCO reorganized the Standards of Practice for Hospice Programs (i.e., the “NHPCO Standards”) around the “10 Components of Quality in Hospice Care,” which serve as the framework for the NHPCO quality initiative, Quality Partners:

1. Patient and Family-Centered Care
2. Ethical Behavior and Consumer Rights
3. Clinical Excellence and Safety
4. Inclusion and Access
5. Organizational Excellence
6. Workforce Excellence
7. Standards
8. Compliance with Laws and Regulations
9. Stewardship and Accountability
10. Performance Measurement

Quality Partners has an overall goal of offering user-friendly tools and resources to help NHPCO members demonstrate clear, measurable outcomes for clinical and non-clinical operations and develop a robust quality assessment/performance improvement (QAPI) program. Organizational attention to these 10 domains will not only improve care for patients and families, but will also enable providers to meet the QAPI requirements outlined in the Hospice Conditions of Participation (Hospice CoPs).

The Pediatric Presence

Recognizing the emergence of pediatric palliative care as a burgeoning discipline and the important differences between adult and pediatric palliative/hospice care, NHPCO asked ChiPPS (see sidebar at right) to develop Pediatric Standards. The ChiPPS Quality work group, with members from the U.S. and Canada, took on the task.

While the Pediatric Standards will be available as a stand-alone document, they were developed as an appendix or “supplement” to the NHPCO Standards (which is now under development to
reflect the new Hospice CoPs). So, the first step was to broaden the language in the NHPCO Standards to include “palliative care,” as more children are cared for through palliative care programs than through hospice. The group then spent the next two years developing the new pediatric-specific standards.

Working on the project was an exciting and groundbreaking opportunity for members of the ChiPPS workgroup. As many providers know, the needs of children and their families do not fit into the typical adult hospice model on many levels. Traditionally, hospice programs have cared for small numbers of children, whose needs easily get lost among the large numbers of adults being served in the community. Organizational implementation of the Pediatric Standards will enable the development of safe, effective, high-quality pediatric programming.

Safety is the first and primary goal when delivering care to children and families. Along with safe care, providers must also strive to improve quality by enhancing effectiveness of team expertise in pediatric care. Applying standards and defining best practice allows pediatric hospice and palliative care teams to achieve two major goals: (1) to identify and support specific medical, psychosocial, spiritual, educational, developmental and emotional needs of children of all ages and their families; and (2) to recognize that improvement of knowledge, skills and increased support is necessary for all caregivers. A third benefit of the Pediatric Standards is to allow unmet needs in care delivery to be identified, thus enabling providers to expand services and develop further partnerships with community providers.

Throughout September 2008, the Pediatric Standards were posted on the NHPCO Web site for public comment. The intent of the field review was to give NHPCO members and pediatric hospice/palliative care practitioners the opportunity to review the proposed standards and language, to discuss the document with peers and colleagues, and to provide feedback. After the public comment period, the ChiPPS Quality work group reconvened to incorporate public feedback to strengthen the document. As a result of this process, the Pediatric Standards have evolved to represent a truly democratic and informed pediatric-specific addendum to the adult NHPCO Standards. Hospice and palliative care programs can now use the Pediatric Standards to develop best practices, with the knowledge that the guidelines have been developed, reviewed, and revised by experts in the field of pediatric palliative and hospice care.

Implementing the Standards

The Pediatric Standards do not stand alone, but are designed to supplement the NHPCO Standards and set clinical and organizational precedence for hospice and palliative care programs providing care to infants, children, adolescents, and their families in the home, hospital, and long-term care and respite facilities.

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As with the NHPCO Standards, successful implementation of the Pediatric Standards involves systematic, intentional application of each of the 10 domains outlined, from Patient and Family-Centered Care to Performance Measurement. The first step is to use the standards as an organizational self-assessment tool. This year, the Pediatric Standards will be incorporated into the Quality Partners Self-Assessment System. The system is currently available for use with the existing NHPCO Standards and provides members with a user-friendly means of assessing their organizations and identifying strengths and opportunities for improvement. Programs will have the ability to use the same system and principles for the Pediatric Standards when they are added. (To learn more about the self-assessments, visit www.nhpco.org/quality).

Setting the Bar and Moving Forward

All children with life-threatening conditions deserve excellent pediatric palliative care, either as the primary plan of care or concurrently with life-prolonging therapies. In fact, the sole criterion for entry into a pediatric palliative care or hospice program should be that a child is not expected to survive to adulthood. Delays in the inclusion of palliative care strategies and services are associated with increased physical, emotional and spiritual suffering of children and their families. Families in every area of the country should have access to high-quality pediatric hospice and/or palliative care services, and should have a choice to bring their children home to die when that is the likely outcome. Hospices and palliative care programs are in the best position to provide this crucial care, as they are available in the communities that children call home, and are staffed by interdisciplinary teams capable of alleviating all sources of suffering encountered by children and families facing life-threatening illness.

Creation of excellent, sustainable, robust pediatric services requires each organization to develop a system-wide infrastructure for pediatrics, whether the organization cares for many children or for the occasional child in their service area. Individual organizations will vary in availability of resources to provide safe and effective pediatric palliative care, and may need to partner with programs in the community, regionally or nationally through distance mentoring. Whatever the model, the Pediatric Standards can be used to create a template to prescribe organizational best practice in safe, effective, high-quality care for children and their families facing life-threatening illness.

Sarah Friebert is board certified in pediatrics, pediatric hematology/oncology and hospice/palliative medicine. Currently, she directs the Haslinger Family Pediatric Palliative Care Division at Akron Children’s Hospital in Akron, Ohio and serves as a consulting medical director to NHPCO.

Susan Huff has worked as a practitioner, researcher and educator in pediatric hospice and palliative care for over 25 years. Currently, she is the director of Pediatrics at Home, a Program of Johns Hopkins Medicine in Baltimore Maryland, and also serves as co-chair of ChiPPS, NHPCO’s Children’s Advisory Council on Palliative/Hospice Services.
More information on pediatric hospice and palliative care can be found on the ChiPPS web page of the NHPCO Web site (www.nhpco.org/pediatrics). In addition, the following resources are available for purchase from NHPCO’s Marketplace (www.nhpco.org/marketplace) at member-discounted rates:

- Education and Training Curriculum for Pediatric Palliative Care (Item 820285)
- Compendium of Pediatric Palliative Care (Item 810030)
- Caring for Kids: How to Develop a Home-Based Support Program (Item 820577)
- Family Education Brochures (available in English and Spanish):
  - When Your Child is in Pain (Item 821104)
  - Talking with Your Child about His/Her Illness (Item 821106)
  - Talking to Your Child’s Doctor (Item 821108)
  - When a Child Dies: A Guide for Family and Friends (Item 821110)
  - Helping Children Cope with the Death of a Loved One (Item 820974)