



## IPPC Background and Goals

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### Scope of the Problem

There is growing empirical evidence that the health care system is failing children and families, when they are confronted by a life-threatening illness. Too many children undergo painful procedures and suffer from the symptoms of advancing disease without adequate relief, despite the fact that modern medicine has the means to relieve their pain and improve most symptoms.<sup>1,2</sup> Families of gravely ill children can feel abandoned and overwhelmed, often suffering emotional and sometimes financial consequences for years to come. Social supports to children and families before and after death are woefully inadequate, and health care professionals themselves are often left without emotional support for the difficult work they do.

In their training, physicians and nurses have received virtually no opportunities to practice the skills necessary for communicating effectively with dying children and their families.<sup>3</sup> Practicing health care professionals also lack guidance on how best to manage the conflicting goals and values that can arise in difficult cases.<sup>4</sup> Such conflicts are made all the more challenging by the broad cultural and religious diversity represented in the U.S. population. Moreover, while there is an ongoing national effort to improve palliative care among adult patients, very little has been done so far in the United States on behalf of children and their families.

Clearly, the problem of pediatric palliative care is a multifaceted one that will need to be addressed through multiple reinforcing strategies: medical education, regulatory reform, changes in health care financing, and hospital quality improvement efforts, as well as broad social changes in the ways in which our society views children, families, death and dying. Although it will be essential to address this challenge from all these sectors, the Initiative for Pediatric Palliative Care (IPPC), which is being spearheaded by Education Development Center, Inc. (EDC), is designed to enhance the capacity of children's hospitals, general hospitals with pediatric units, and hospice or home care settings serving children and families to respond to these needs.

### IPPC's Focus

Each year 54,000 children die in the United States. The vast majority of pediatric deaths occur in the hospital setting, most in pediatric intensive care units. The leading cause of death to children over age one is unintentional injury. Other major causes include the complications of prematurity,

death from congenital anomalies, cancer, and intentional injuries.<sup>5</sup> In addition, many more thousands of children live for years with severe life-threatening conditions.<sup>6,7</sup> Thus, the three distinct populations of children who stand to benefit from improvements in palliative care are the following:

- those who are born without an expectation of survival to adulthood but who may live a long time with substantial suffering,
- those who acquire illnesses such as cancer, and
- those who suffer relatively sudden death due to trauma.

In each of these categories, child and family needs differ, yet hospitals have rarely developed mechanisms for responding specifically to those needs.

### **Project Objectives**

The Initiative for Pediatric Palliative Care (IPPC) seeks to enhance the capacity of children's hospitals and related institutions to accomplish the following:

- maximize family involvement in decision making and care planning in the ways and to the degree that each individual family finds comfortable;
- inform and involve children with life-threatening illnesses in decisions about their care and care planning as fully as possible, given their developmental abilities and desires;
- reduce pain and distressful symptoms for children with life-threatening illnesses;
- provide emotional and spiritual support to children and families as they cope with the multiple losses associated with life-threatening conditions;
- facilitate the resolution of families' practical needs, such as the need for respite, through coordination with the community;
- facilitate continuity of care across care settings, both within and outside the hospital;
- offer bereavement support to the child and the family before and after a child's death.

To meet these needs, IPPC will encourage hospitals to do the following:

- develop explicit policies and practices to advance the vision of family-centered, culturally sensitive care for children with life-threatening conditions;
- integrate palliative care with cure-oriented care from the beginning of the diagnosis forward so that it can benefit children who are gravely ill as well as those who are dying imminently;
- develop strategies for enhancing the palliative care clinical competence of staff, including skills in pain and symptom management, communication, and ethical analysis;
- develop specific, routine mechanisms for meeting each of the child and family goals stated above;
- commit to measuring the institution's progress toward these goals through routine, periodic data collection.

## Partners

EDC is carrying out the project in collaboration with:

- National Association of Children's Hospitals and Related Institutions (NACHRI)
- Society of Pediatric Nurses (SPN)
- The New York Academy of Medicine (NYAM)
- The Association of Medical School Pediatric Department Chairs (AMSPDC)

Seven hospitals have developed exemplary quality improvement activities and served as field test sites for the IPC curriculum. These seven are:

- Children's Hospital of Boston/Dana-Farber Cancer Institute (Boston, MA)
- Children's Hospital of Philadelphia (Philadelphia, PA)
- Lucile Packard Children's Hospital at Stanford University Medical Center
- Children's Mercy Hospitals and Clinics (Kansas City, MO)
- Johns Hopkins Children's Center (Baltimore, MD)
- University of California, San Francisco Children's Hospital (San Francisco, CA)
- Vanderbilt University Children's Hospital (Clarksville, TN)

The following institutions have provided or are providing financial support to this large national initiative:

- The Nathan Cummings Foundation of New York City
- Open Society Institute's Project on Death in America
- The Argosy Foundation
- An anonymous family foundation

## Citations

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