

State Initiatives *in* End-of-Life Care

Issue 16, September 2002

Focus: Pediatric Issues — Part II

Creating a New Policy Framework for Pediatric Palliative Care



Susie Fitzhugh

Brittney (13) talks to her doctor, Donna Smith, while her guardian, Dawn, looks on. Brittney has cystic fibrosis. Children like Brittney who have life-limiting conditions are best served by professionals like Smith who are trained to provide good pediatric palliative care that honors patient and family goals and preferences and includes pain and symptom management, nonharmful curative treatment, and supportive services. Experts call for policy to support this care.

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Addressing Gaps in Policy and Research

Every day in America, about 400,000 children are living with conditions that are likely to cause their deaths before they reach adulthood. These life-limiting conditions include cancers, damage resulting from accidents, other diseases, and congenital problems. Such children may live for a few hours or for many years, and they experience a wide range of physical and cognitive impairments. Every year in America, about 25,000 of these children die. Few of them get adequate palliative care to manage their symptoms, coordinate their care, help them make medical decisions, and support them and their families through the most traumatic journey of their lives.

It would be difficult to overestimate the impact that these lives and deaths have on families and on society. Experts report that broken families, emotional dysfunction, and lost jobs commonly result. The good news is that innovative practices in medical decisionmaking, care, and professional education are making the experience

better for some children. Issue 15 of this series explored the ways Medicaid and private insurance reimbursement policies could be improved to ensure that children with life-limiting conditions get the care they need. The programs and practices profiled in this brief demonstrate that there is an increasing commitment to serve

children with life-limiting conditions. Yet without a new policy framework, good end-of-life care will continue to be available to only a lucky few. Policy needs to ensure that such care is not just available to children who have access to groundbreaking providers and institutions.

Many of these innovations could be adopted more widely to improve pediatric end-of-life care through changes in Medicaid regulations, regulatory bodies like JCAHO, and state licensing boards for medical care. Other areas, such as medical decisionmaking for children, need further study. Experts argue that while nothing can diminish the tragedy of a child's death, palliative care can ensure that the child is comfortable and the family is supported through the process. ■

Remembering a Pioneer...

This issue of *State Initiatives* is dedicated to the memory of William G. Bartholome, MD, pediatrician and ethicist.

Many Americans became familiar with Bill when he shared the last chapter of his life in Bill Moyers's documentary, *On Our Own Terms*. This was not the first time Bill had been in the national limelight. Years before, while a pediatric resident at Johns Hopkins University, Bill became a central figure in the first nationally publicized Baby Doe case when he went public with the fact that the parents of a newborn with Down's Syndrome had refused a simple procedure that would have allowed the baby to thrive and decided instead that the baby should not be fed.

The ensuing legal case challenged the way society thinks about its duties and obliga-

tions to imperiled newborns, and set the course for the rest of Bill's life. He became a nationally known advocate for the rights of all children to receive competent and compassionate care and to be involved in treatment decisionmaking to the full extent of their capacity, especially children who were terminally ill. He did so as a member of the Ethics Committee of the American Academy of Pediatrics, a member of the board of directors of Midwest Bioethics Center, and as a clinical ethicist.

In a 1995 *Bioethics Forum* article titled "Hearing Children's Voices," Bill wrote, "Are we willing to assist children to participate to the extent of their capacity in making decisions about their health? For me, to do anything less is to fail to respect them for the persons they are in the process of becoming and to fail to live



up to the ethical demands of being parents of and professionals for children." This issue of *State Initiatives* challenges legislators, hospital administrators, regulators, and other policymakers to contemplate America's obligations to our ill and dying children and their families and to consider how they can improve the last chapters for children whose life-book is too short.

Supporting Children’s Rights to Participate in Health Care Decisions

The Patient Self-Determination Act of 1991 asserted that adult patients should understand their health care and make decisions about it. Implementing the act for children has required that the medical profession reconsider both children’s rights and their capacity to make decisions. Two key documents have contributed to this still emerging field: the American Academy of Pediatrics (AAP) statement on “Informed Consent, Parental Permission, and Assent” and Midwest Bioethics Center’s “Health Care Treatment Decisionmaking Guidelines for Minors,” both published in 1995.

The AAP guidelines hinge on the idea that children have a growing capacity to participate in decisions that impact their living and dying. Insisting that one person cannot give informed consent for another, even when they are parent and child, the AAP provides important decisionmaking terms: “Only patients who have appropriate decisional capacity and legal empowerment can give their informed consent to medical care. In all other situations, parents or other surrogates provide informed permission for diagnosis of children with the assent of the child wherever appropriate.” (The AAP’s statement can be found at www.aap.org/policy/00662.html.)

Midwest Bioethics Center convened experts, parents, and children to create guidelines to address minors’ rights to self-determination in medical decisions. The guidelines identify three categories of decisional capacity for minors: minors who don’t have the capacity to participate in decisionmaking in a meaningful way (infants, toddlers, and most preschoolers); minors who have a developing capacity to participate in decisionmaking (elementary school age children); and

minors who have the capacity to make most health care decisions (mature minors, emancipated minors, and most young adults in high school). The guidelines analyze each of these three categories, describing the ethical roles, rights, obligations, and responsibilities of the patient, parents, providers, and institutions. They also suggest strategies for resolving conflict and for determining the decisional capacity of minors. (To order the guidelines, call 1 (816) 842-7110 or e-mail partners@midbio.org.)

Some medical professionals believe that minors can and should participate in decisions about their treatment (including DNR orders) as they are developmentally able. In many cases, while providers are not legally obliged to involve minors in making medical decisions about themselves, they are also not prohibited from doing so. Yet this does not help children whose parents exclude them from the process. “Children—especially those who have been ill for a long time—can be advanced in their decisional capacity,” says Sarah Friebert, MD, director, Regional Pediatric Palliative Care Service, Children’s Hospital Medical Center of Akron. “One of our biggest difficulties is when a parent isn’t able to acknowledge that a child needs to participate in making decisions. We try to empower children to advocate for their own choices, with providers as well as with parents, but this is not legally supported.” The lack of legal frameworks for children’s involvement in decisionmaking means that children have vastly different experiences, depending on their parents’ approach, the institution they are in, and the medical professionals they are working with.

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Promises to Keep

Excerpts from the Child-Friendly Patients’ Rights Documents at Children’s Mercy Hospital and Clinics, Kansas City, Missouri

We will listen to you.

You and your parents are a part of our medical team. We want you to help us decide the best ways to take care of you.

We will talk with you about your plan of care before you are treated, while you are treated, and after you are treated.

It is okay to tell us what you want or do not want, if you are afraid, angry, lonely, or sad. It is okay to laugh and to cry.

We will tell you:

- who we are
- what we do at the hospital
- why we have entered your room
- why you are here
- what the medical team thinks will help you
- how things may feel to you

We will explain all these things in ways you can understand.

We will be as gentle as possible when we have to touch you. We will keep your body covered up as much as we can.

You may read your chart. Please ask us how you may do this.

If we ask you to be part of an experiment or research, you can say yes or no.

Supporting Children's Rights to Participate in Health Care Decisions

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Experts believe that children have better outcomes when they participate in medical decisions. "The more these children can be given a sense of control over the impact of the disease on their lives, the better they respond to treatment and the more successful they are with the often daunting task of adjusting to the demands of the illness and of growing up with a chronic illness," writes William G. Bartholome, MD, in "Hearing Children's Voices."

Groundbreaking programs, including those at Children's Mercy Hospital (Kansas City) and SSM Cardinal Glennon Hospital (St. Louis), are forging new institutional policies and practice standards that shape the ways children and families experience treatment options, their futures, and their deaths. Experts say the field needs to research and develop tools to assess the capacity of children to participate in decisions about their care and to measure children's quality of life.

Communicating with Children about Their Rights as Patients

A team at Children's Mercy Hospital in Kansas City, led by the chaplaincy staff, has developed two child-friendly documents that inform children of their rights and impact the care that children receive at that institution. Because young children may not understand the word "rights," the documents focus on the hospital's promises to patients and the patients' responsibilities.

According to Dane Sommer, MDiv, director, Chaplaincy Services, the documents not only inform children about their rights and responsibilities as patients, they also shape daily practices and attitudes among patients, parents, and staff. The rights document initially met resistance from some staff, particularly because it

states that children have the right to see their medical records, a time-consuming promise, since staff may have to help children understand the records. Both documents are posted at child's eye-level in the hospital and are available in outpatient areas. To read them, visit www.childrens-mercy.org/welcome/rights.asp.

Parents take these rights to heart, Sommer says, and expect the hospital to keep its promises. He recalls a 15-year-old girl who had leukemia, experienced a year of remission after treatment, and then relapsed. In the hospital, her doctor told her that she could either go home with hospice care or receive experimental chemotherapy. She quickly chose to participate in the research protocol. After the doctor left the room, the girl's parents asked her what she had heard, and it became clear that she thought her choices were between dying and being cured. The parents called the doctors back to explain more carefully that she was probably going to die soon and that she could go home and be kept comfortable or spend what would likely be her last three months of life getting chemo. The young patient was devastated by the news. The staff called Sommer,

and he sat with the girl and her mother for several hours, talking through their feelings. Because this patient and family understood the options, they were able to make an informed choice about how she would spend her remaining time.

"You truly have to take time to educate people and allow them to make a real decision," says Sommer. Patients must understand four key aspects of any procedure: what the procedure is, its risks and benefits, alternatives to it, and their right to say no. A commitment to informing child patients about their rights can profoundly challenge providers, says Sommer, in terms of emotional difficulty, time, cost, and potential conflict with parents and other medical professionals. The physicians, chaplains, counselors, play therapists, and other staff at Children's Mercy share the responsibility for keeping these promises.

According to Joanne Hilden, MD, chair, Department of Pediatric Hematology/Oncology, The Children's Hospital at The Cleveland Clinic, the risk of this work to providers is real: "The challenge to providers is to find time to communicate with children and families when

Using Oregon's POLST Form with Minors

Do-not-resuscitate orders (DNRs) raise social, cultural, and developmental considerations when they are used for children. While most American adults have the legal right to DNR orders, only 26 states allow parents to sign DNRs for their children, and schools may not respect a DNR when a child is in their care. Experts call for research and guidelines in pursuing further rights to DNR for minors.

Seven years after implementing the Physician's Orders for Life-Sustaining Treatment (POLST) form for adults, physicians in Oregon began exploring how the form could be used for children who are expected to die soon. The POLST form was originally developed to allow ill adults to express their preferences for life-sustaining treatment across settings, whether they are at home, in the hospital, in an ambulance, in long-term care, or in a hospice (see *State Initiatives in End-of-Life Care*, Issue 3, for a full description of POLST and its development and a sample form for adult use).

the federal payment system does not support this work by adequately reimbursing for the time spent. Good-hearted people can burn out as a result of this lack of support.”

Advance Care Planning for Children and Families

At SSM Cardinal Glennon Hospital (St. Louis), the FOOTPRINTS™ program offers children with life-limiting conditions coordinated, comprehensive care and the opportunity to participate in planning their care. When a child starts the program, a “continuity physician” is identified to synthesize and represent medical viewpoints for the family and to coordinate care in the network of community providers that can support the child and family physically, emotionally, and spiritually.

The program facilitates a care planning conference, attended by family, the continuity physician, and any other caregivers. Children are always welcome at their care planning conferences; if they are old enough to participate in the decisionmaking process, they are encouraged to come. At the end of the conference, the parents and continuity physician sign the advance care sheet, which documents



Susie Fitzhugh

Children with life-limiting conditions need comprehensive, fully coordinated care that respects the treatment decisionmaking rights of children and families.

the child’s and family’s preferences, goals, and values, including whether they want resuscitation treatment if the child’s heart and breathing stop.

After the meeting, the program staff informs all community agencies that may interact with the child, including home health agencies, hospice, EMS, and police. They verify that the agencies will honor the plan; if the agency refuses, the staff negotiates a plan with everyone involved or finds another provider. For example, in the area that the program serves, responders to a 911 call are required to resuscitate a patient whose heart and breathing have stopped. For patients with DNR

orders, the program arranges for parents to call another number when they need an ambulance to transport their child, ensuring that the child doesn’t die on artificial life support in an ICU after being resuscitated against family wishes.

“Death is not a medical event; it is a family event,” says director Suzanne Toce, MD. “We enter the world surrounded by those we love; we need to leave the same way. When we work with children who will not survive to adulthood, we need to support the child, family, and providers through death and bereavement. We need policies to support that work.” ■

Physicians in Oregon are now using the POLST form with minors and find that completing the form allows providers and families to have a useful conversation about goals of treatment and preferences. “It enhances coordination and communication,” says Mark J. Merkens, MD, associate professor, Department of Pediatrics, and clinical consultant, Center for Ethics, Oregon Health & Science University. Merkens has used the form himself and has consulted with other providers when they have seen the need for it but were unsure about how to discuss it with the family.

The completed POLST form protects families from even the suspicion of inadequate care for their children when it is clear that resuscitation would not save their lives. However, Susan Tolle, MD, director, Center for Ethics in Health Care, Oregon Health & Science University, argues that Oregon was able to revise the POLST form to include minors only because the state had already established practices for adults and could build on that experience. She cautions against experimenting with POLST-like

policy on children or trying to implement such policy without a well-developed infrastructure: Health care providers, EMS, and the legal community need to know how the form works, to have seen it used with adults, and to be prepared to see it used with children. “Taking the child out into the community to die in the loving arms of parents means that the community has to be ready,” Tolle says. “We don’t want EMS to make a single mistake in understanding and respecting the treatment plans of these dying children.”

Emerging Care Practices That May Hold Promise for the Field

SSM Cardinal Glennon Hospital and Children's Mercy are innovative in the care they offer children as well as in their work on decisionmaking. Several other programs also meet the other unique needs of children who have life-limiting conditions.

Neonatal End-of-Life Care and Compassionate Extubation

In addition to caring for children with life-limiting conditions, the San Diego Hospice Children's Program, recently given the American Hospital Association's Circle of Life Award, runs an Early Intervention program to support parents whose infants are not expected to survive the pregnancy or are born with conditions that will result in early deaths.

In both groups served, the Children's Program offers Compassionate Extubation to support the child and family in a very difficult procedure. Since in these cases extubation—the removal of the tube that allows artificial breathing—is typically followed by the child's death, many families don't want their child to be extubated in the ICU, says Liz Sumner, RN, executive director, Children's Program. They may want it to happen in a warmer, more private setting. Some parents understandably want to hold their newborn child in their home once before they say good-bye. The hospice transfers appropriate medical and hospice staff with the child to the family's home or a care center where family and friends can attend. The process is planned with the families: they can perform any rituals they want and decide whether the child will be held and by whom. In contrast to what typically occurs in an ICU, in this approach, many people can be present to support the family and help them at a critical moment. Parents are offered ways to feel in control of the process. They may get

to hold their child for the first time or to see their child's face unobstructed by medical gear for the first time. The value of this program to families is immeasurable.

A Model for Standardized Communication and Care Coordination

The new Pediatric Advanced Illness Coordinated Care program (PAICC) offers care at The Children's Hospital at The Cleveland Clinic and at the Christus Santa Rosa Children's Hospital (in 2003, two other sites will join). According to Joanne Hilden, MD, director of the Cleveland site, PAICC uses a trained nurse or social worker to facilitate communication between care providers and the patient and family and to coordinate care. These children profoundly need care coordination, says Javier Kane, MD, medical director, Pediatric Palliative Medicine Program at Christus Santa Rosa: "One patient may have a rheumatologist, cardiologist, pulmonologist, gastroenterologist, and surgeon." Hilden believes that placing a care coordinator in the middle of the cancer care program offers "a solution to the fragmentation. And if the child will not survive, the medical discussions with the family will include someone the family knows." ■

A Special Place for Children

Legislating a Dream into Reality

Both state and federal policymakers have helped Amy Kuhner, MDiv, create the possibility of a homelike comfort care center for children with life-limiting conditions: Sunshine House. This organization, now in the process of buying land to build on, will offer care to Connecticut children in a child- and family-centered environment. There, respite care will be available to families and children when they need it, and children can get end-of-life care in a homelike setting when care at home is not feasible.

As a divinity student at Yale in the 1990s, Amy Kuhner worked both with hospitalized children and with adults in a hospice. She met a hospitalized child who was nearing the end of his life. He and his family felt unsupported in the hospital, and it was difficult for them to watch other pediatric patients get better and go home. But when the child moved to the adult hospice, he was unintentionally isolated by staff and patients who couldn't bear to interact with or even look at a child who was going to die. Even worse, the staff wasn't familiar with technical aspects of health care in which children and adults are very different, like medication dosages, for

Announcing Two New Audio Programs

State Initiatives' newest audio release, *Heart-to-Heart: Improving Care for the Dying through Public Policy: Part III—Children*, offers both a broad view of major barriers hindering good palliative care for children as well as many concrete solutions suggested by the successes of model pediatric programs.

Heart-to-Heart: Part II—Policy Heroes profiles three "policy champions" who are offering exceptional leadership on end-of-life issues.

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Call 1 (800) 989-9455 to order by phone.

example. Kuhner saw the need for a place especially for children: a comfort care center where children and their families would receive excellent care and support.

But vision alone isn't enough to create such a place. State regulations covering hospices and home health care specified facilities that were not designed for children, and licensing procedures for an inpatient pediatric comfort care center didn't exist. In addition, in a climate of increased competition for available funding, existing institutions were concerned that Sunshine House might undermine their own continued work.

That's when Connecticut State Representative Jack Thompson (D-Manchester) got involved. "He is highly respected on both sides of the aisle, as well as among advocates for children's issues, for his dedication and work on behalf of Connecticut's children," says Kuhner. After researching the need for respite and comfort care and studying Kuhner's plans, Thompson helped mobilize other policymakers and worked toward the Connecticut General Assembly establishing Sunshine House legislatively as a pilot children's comfort care center with its own type of licensing. "We don't have anything else like this," says Thompson, "and it seemed like the right thing to do. Families need a facility like this. It's so hard day after day to take care of seriously ill children, and it's a home away from home for children, which makes it a lot easier for them when they come for the last time."

There are at least 20 such institutions in the United Kingdom. In a climate of increasing concern and accommodation for children with life-limiting conditions, America is creating such places, too, with Sunshine House moving toward being built in Connecticut and George Mark Children's House planning to open in 2003 in California.

Thompson continues to support Sunshine House in many ways, keeping the organization in the minds of those who will have an impact on it and helping Kuhner make connections that can facilitate Sunshine House's success. With the help of Congresswoman Rosa DeLauro (D-Conn.), Sunshine House also won federal funding for construction. ■



Connecticut State Representative Jack Thompson (D-Manchester), pictured above with Amy Kuhner, has been a crucial ally in developing successful legislation for Sunshine House, an inpatient comfort care center just for children and their families.

Engaging Professionals

Since children live and die everywhere—not just in big cities that have children's hospitals and pediatric palliative care specialists—experts argue that providers need to know more about palliative care for children, and institutions need incentives to ensure that children are receiving adequate palliative care.

Improving Education and Certification

According to Joanne Hilden, MD, when pediatric oncologists were asked, "How did you learn how to care for dying patients?" the leading answer was "trial and error." She and other experts believe that training, credentialing, and certification should be required for those working with children at the end of their lives—whether specialists in academic hospitals, primary caregivers, or specialists in children's home communities.

According to experts, health care providers need to learn how to imagine a model of care in which comfort care is given to children starting at the moment of diagnosis, even while curative treatment may be pursued. Some programs—like Boston's Pediatric Advanced Care Team (PACT)—actively engage in curriculum development for residents and fellows and work to create a culture of reflection in which providers can learn from their experiences. Experts call for nationwide curricular development to ensure that physicians and others are prepared to meet the needs of children with life-limiting conditions. State licensing boards can ensure that providers have adequate training. "All residents are certified in pediatric resuscitation and CPR," says Suzanne Toce, MD. "What ensures that they get training in pain control, giving bad news, and the other skills that will enable them to work with children who die?"

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Joanne Wolfe, MD, MPH, Dana-Farber Cancer Institute and Children's Hospital, Boston, argues that as part of their education, providers need to confront the difficulty of a child's death for themselves as well as for the child and family. A child's death is very hard to bear witness to, says Wolfe, "and since the culture of caring for children is to extend life as long as possible," children can be subjected to extreme measures that make them uncomfortable and don't lengthen their lives.

Experts agree that health care providers also need to demonstrate an understanding of facts about pain medications: effective opioid medication is unlikely to lead to respiratory depression or arrest, and dying children are not likely to become addicted to narcotics. "Despite all we know about children and pain—we know that they feel it, that opioids won't cause children to become addicted, that respiratory depression is not a significant risk—there are people whose misperceptions keep them from doing the right thing: providing analgesia for a child in pain," says Gerri Frager, RN, MD, medical director, Pediatric Palliative Care, IWK Health Centre.

Expanding the Reach of JCAHO Standards

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) pain guidelines made institutions accountable for managing patients' pain, say experts, but pediatric patients still experience a great deal of pain and other discomfort that could be controlled. One expert, Jeanne Lewandowski, MD, medical director, Pediatrics, Bon Secours

Healthcare System, suggests that most recent standards, if enforced, may do more to ensure that every patient in an institution, child or adult, is monitored for control of pain and symptoms.

Developing the Field of Pediatric End-of-Life Care

Experts call for further development of the field and for policymakers to support these efforts. In particular, they call for medical professionals to establish clear standards for programs and treatment and to create developmentally appropriate techniques for eliciting the goals and preferences of children. They also ask that payers support this work, so that providers are not asked to do work for which their systems are not reimbursed.

Many professionals working with children who have life-limiting conditions feel the need for an annual pediatric palliative care forum where people can get together for extended conversations. Existing individual programs are regularly contacted for help in developing programs for children. Experts wish these programs could coordinate what they are doing and share their findings in a systematic way. They also argue that while good conversations about pediatric palliative care happen in the national and regional meetings of hospice-oriented groups, those aren't the meetings attended by the pediatricians who will have to refer one or two children a year to palliative care programs. They call for discussion of palliative care to be mainstreamed into the larger field of pediatrics.

Information about the Series

"Pediatric Issues—Part II: Creating a New Policy Framework for Pediatric Palliative Care" is the sixteenth in a series of briefs profiling promising new policies and practices in end-of-life care.

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Last Acts is a coalition of more than 850 national and local organizations dedicated to improving end-of-life care. For more information about the *Last Acts* campaign, contact

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Breaking News

Pediatric Palliative Care Gains New Momentum in Summer 2002

An important report from the Institute of Medicine and several ambitious initiatives were launched recently, offering coherence and support to the field of pediatric palliative care. This special two-page insert briefs *State Initiatives* readers on these new developments.

Institute of Medicine Reports Calls for Change and Research

The recent Institute of Medicine (IOM) report, *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, edited by Marilyn J. Field and Richard E. Behrman, defines what is known about good care for children, explores the extent to which children's needs are being met, and recommends ways to improve palliative, end-of-life, and bereavement care for children with life-threatening conditions and their families. The recommendations are relevant for clinicians, educators of medical professionals, researchers, and policymakers who can help create a better policy environment for needed reforms. This summary will focus on the policy recommendations regarding public funding for pediatric palliative care.

When Children Die offers a detailed account of the current state of pediatric palliative and end-of-life care, explaining barriers that keep many children from getting comprehensive, continuous, and timely services, like inadequate methods for organizing and financing palliative and bereavement care, inadequate scientific and professional knowledge, and a fragmented medical system.

The report also offers a set of principles that guided the committee's work on the project. The principles assert that systems and policies must support providers so that children with life-threatening conditions will receive care that is comprehensive, child- and family-centered, and coordinated. The chapter on financing offers specific guidance on how public and private payers should restructure medical, palliative, and hospice benefits and policies that currently prevent children from getting other services:

Provide Clear Guidance about Coding and Documentation of Covered Services

Restructure Hospice Benefits

- include hospice care in the services required by Congress in Medicaid and other public insurance programs for children and in the services covered for children under private health plans
- eliminate eligibility restrictions related to life expectancy and drop rules that force a choice between curative or palliative care
- protect hospices from some financial losses associated with serving very high cost patients by establishing an outlier payment program (like that adopted by Medicare for inpatient hospital care)

Modify Policies That Restrict Access to Other Palliative Services

- reimburse the time spent by all providers informing and counseling parents (even if the patient isn't present) about the child's diagnosis and prognosis as well as options and plans for care, including end-of-life decisions
- make the expertise of palliative care specialists and hospice personnel more widely available by covering palliative care consultations
- reimburse bereavement services for parents and surviving siblings of children who die
- link coverage and eligibility criteria for palliative inpatient, home health, and professional services to diagnosis (and, for certain services, to severity of illness)

The release of the IOM report was followed by a two-day meeting of pediatric palliative care leaders to seek consensus and develop action steps for improving the care of children with life-threatening conditions and their families. As the National Alliance for Children with Life-Threatening Conditions, the group will continue to work on establishing a coherent national voice that speaks to the needs of children and families. ■

When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families can be ordered or read online at www.nap.edu/catalog/10390.html.

For more information about the National Alliance for Children with Life-Threatening Conditions, e-mail nacwltc@thelifeinstitute.org.

Fostering Professional Education and Research

Several initiatives (in addition to those mentioned in this brief) are under development to improve the quality and availability of pediatric palliative care in America.

Last Acts Precepts to Provide Blueprint for Reform

A few days after the release of the IOM report, Last Acts announced the first iteration of a blueprint for reform of pediatric palliative care. *Precepts of Palliative Care for Children/Adolescents and Their Families* establishes five key points that can launch and drive reform: respecting the goals, preferences, and choices of patients and their families; relieving pain and other symptoms, including emotional distress; using multidisciplinary care teams; addressing caregiver concerns like respite care and babysitting; and building systems of support for palliative care through research, innovation, education, and sharing of best practices within the field. Revision of the document continues.

An Initiative to Improve Professional Education and Research

The Initiative for Pediatric Palliative Care (IPPC) is a collaborative effort to improve care of children with life-limiting conditions directly and through research and curricular innovation for medical professionals. IPPC involves several organizations—the Education Development Center (EDC), the National Association of Children’s Hospitals and Related Institutions (NACHRI), the Society of Pediatric Nurses (SPN), and the New York Academy of Medicine (NYAM)—and eight academic children’s hospitals.

Among their achievements so far are a survey of nearly 800 clinicians and other studies that will yield research papers; goals and quality indicators for family-centered pediatric palliative care; the pediatric palliative care institutional self-assessment tool (ISAT), which allows hospitals to evaluate their capacity for providing quality pediatric palliative care; and six curriculum modules that include several videotapes each to teach medical professionals about topics ranging from engaging with children and families to relieving pain and other symptoms and establishing continuity of care. Other programs are also currently working on curricula for professionals.

Funding Research to Inform Care

The National Institute of Nursing Research and the National Institute of Mental Health announced in July that they will address some of the needs for further knowledge identified in the IOM report by underwriting \$2.5 million in grants for new research into pediatric palliative care. They provide examples of potential research questions:

- What are the age-specific end-of-life issues for children ranging from pre-term babies to adolescents?
- How does the age of the parents influence the dying process?

- How can palliative care be integrated with life-prolonging therapies?
- What interventions facilitate communication between health professionals and the extended family?
- What can help a child cope with the visible signs of illness or treatment (hair loss, fatigue, school absence, and so on)?
- How can children be involved in medical decisionmaking through the use of culturally sensitive communication models that are appropriate their cognitive and emotional maturity?

The call for applications provides further details about the types of research that will be funded.

State Initiatives Series Releases Three Pediatric Resources

In September 2002, the *State Initiatives in End-of-Life Care* series released two new policy briefs surveying barriers and innovations in pediatric palliative care, together with an original audio program offering in-depth coverage of the Pediatric Palliative Care Consulting Service at Seattle Children’s Hospital and Regional Medical Center. ■

For More on These Initiatives

Precepts of Palliative Care for Children/Adolescents and Their Families, from Last Acts, is available at www.lastacts.org/files/misc/LastActsPrecepts2.pdf.

The Initiative for Pediatric Palliative Care’s institutional self-assessment tool and pilot versions of their curricular materials can be found at www.ipccweb.org.

The National Institute of Nursing Research’s call for applications is available at grants.nih.gov/grants/guide/rfa-files/RFA-NR-03-003.html.

The two *State Initiatives in End-of-Life Care* briefs are available from Midwest Bioethics Center. E-mail partners@midbio.org or call 1 (816) 842-7110. To get detailed information and hear a sound clip from the new pediatric audio program, visit www.partnershipforcaring.org/statepolicy/audioseries/. Copies of the tape can also be ordered by calling 1 (800) 989-9455.