



## **A Call for Change: Key Recommendations**

Many changes are needed in the care of children living with life-threatening conditions. The National Hospice and Palliative Care Organization's Children's International Project on Palliative/Hospice Services recommends a range of improvements to our healthcare system for these children and their families.

### *CLINICAL CARE RECOMMENDATIONS:*

- The sole admission criterion for pediatric palliative care services must be that the child is not predicted to survive to become an adult. Prognosis for short-term survival should not be required, as it is very difficult to predict, interfering with access to palliative care needed to provide appropriate family-centered support from the time of diagnosis of a potentially life-threatening condition.
- Reimbursement patterns must be changed to place value on comprehensive care for children living with life-threatening conditions, including excellent communication and counseling; aggressive pain and symptom management; coordinated, seamless care between settings and healthcare episodes; and grief and bereavement support for the child and family.
- Interdisciplinary care team meetings are critically important to proper management of the illness, associated physical symptoms, psychosocial and spiritual issues.
- Families should have unlimited access to their children, regardless of the care setting.
- Providers who care for children living with and dying from life-threatening conditions encounter losses and may experience stress; provision of support for staff should be a mandatory component of pediatric palliative care services. Reimbursement for services should factor in an allowance for this.
- Hospice or independent grief counselors should be available to consult with or be employed by hospitals. Post-death care for families and medical care providers should be included in programmatic healthcare design and funding.
- Provision of support services to the affected child's teacher, classmates, and schoolmates and members of community organizations who care about the child is a compassionate, reasoned, and cost-efficient response to the critical illness and death of a child.

### *EDUCATION RECOMMENDATIONS:*

- There are currently very few providers of any discipline that are familiar with pediatric palliative care. The need for education is urgent. Thus, financial incentives for training in pediatric palliative care must be made available. Tuition sponsorship and discounted liability coverage or bonuses are options to consider. Institutions that make palliative care a priority should receive tangible assistance.
- Sufficient resources must be allocated for the development and implementation of innovative training programs in palliative care in schools of medicine, nursing, and social work. Minimal standards for program content and competency-based testing must be developed.
- Residency and fellowship programs in pediatrics must incorporate pediatric-specific palliative care information. Continuing education programs and certification will rapidly make urgently needed pediatric palliative care more available and accessible.
- Appropriate faculty expertise, time and resources must be mandated to address pediatric palliative care issues. Health professions schools must commit to the availability of qualified faculty experienced in palliative care and supportive services.
- Training in pediatric palliative care for home care and hospice workers, non-professional caregivers, parent aides, and volunteers must be provided to enable competent care for children living with life-threatening conditions, particularly in the terminal phase.
- Counselors, psychologists, schoolteachers and officials need training to effectively accommodate the needs of terminally ill children as well as their classmates.

### *LEGAL AND ETHICAL RECOMMENDATIONS:*

- Good Samaritan legislation must be enacted to enable parent-to-parent respite cooperatives and referral.
- The concept of pediatric assent should be actively taught and embraced in policy and law. Extending the mature minor doctrine to children with capacity for medical decision-making regardless of age should be supported in state, institutional and reimbursement policies. Tools to assess minors' capacity to participate in decision-making are desperately needed.

- The use of the school as an expensive and inefficient *de facto* respite provider should be revisited.
- Orders to forgo resuscitative efforts (“DNR”) outside of hospitals must be honored in school and other public and non-hospital settings by the emergency medical system.

*RESEARCH RECOMMENDATIONS:*

- Adequate funding for research in pediatric palliative care must be allocated. Only then will children and families be assured that the child is receiving proven therapies. Outcome measures relevant to the child and family must be developed. Continued extrapolations from adult data is unethical; over and over it has been shown that children are not small adults, physically, psychologically, emotionally or otherwise. Research to be applied to children must be derived from children and their families. Research should build on evidence that already exists, be innovative, and fill existing gaps in service.
  - Specific and urgent research issues include the utility of care coordinators to orchestrate the care of the child, the effectiveness of parent education tools to ensure informed consent, the effectiveness of sibling interventions to improve bereavement outcomes, and the safety and effectiveness of treatment and prevention of pain and other symptoms.
  - Tools to assess the quality of and satisfaction with pediatric palliative care must be adapted and tested.
  - The associated costs of palliative care interventions should also be tracked.
- Standards for the provision and reimbursement of pediatric palliative care services need further development and need to be integrated into the larger healthcare system.

(Source: “A Call for Change: Recommendations to Improve the Care of Children Living with Life-Threatening Conditions,” Children's International Project on Palliative/Hospice Services Administrative/Policy Workgroup of the National Hospice and Palliative Care Organization; Alexandria, VA, October 2001.)