



SHARED RESPONSIBILITIES

Tools for Improving Quality of Care for
Children with Special Health Care Needs

101 Tremont Street
Suite 812
Boston, MA 02108

www.neserve.org

Best Practices

Children's Hospital and Regional Medical Center Seattle, Washington

Pediatric Palliative Care Project

demonstrated that health care providers could successfully partner with insurance companies to improve the quality of care and life for children who suffer from life abbreviating illnesses. Each year, 53,000 children in the U.S. die from trauma, lethal congenital conditions, extreme pre-maturity, hereditary disorders, and acquired illnesses. A number of factors commonly conspire to prevent chronically ill and dying children from receiving the high-quality care they deserve: society is reluctant to admit that children suffer from life abbreviating illnesses, medical education focuses on curing children of illness not addressing the challenges of living with illness, and insurance benefits are designed to maximize curative care. Families are often required to give up hope and curative care coverage in order to access hospice care supports and services.

The *Pediatric Palliative Care Project*, a three-year demonstration study funded by the Robert Wood Johnson Foundation in 1998, created a partnership between Children's Hospital and Regional Medical Center, and Regence Blue Shield and Primera Blue Cross insurance companies. The project allowed flexibility in offering children a hospice care benefit by permitting families to continue with curative care, thereby removing previous barriers built into benefit administration policies.

The study demonstrated that palliative care not only improved the quality of care but also helped control health care costs. With the study complete, the insurance plan has continued the program for children and is now exploring developing a Palliative Care Option for adults with life-threatening illnesses.

For further information contact:

John M. Neff, MD
Center for Children with Special Needs
Children's Hospital and Regional Medical Center
Seattle, WA 98105
(206) 528-5275
jneff@chmc.org