



## Respite Care at The Children's Institute

**For many families of children with special needs, the demands are seemingly endless. No appointment, no project, no undertaking can be carried out without planning for the medically specialized care their child needs. And respite – an interval of rest – is essential for families to care for their children with special needs and their siblings as well as themselves.**

Until The Children's Institute created the Respite Care Program, families with children with special needs had few – if any – viable resources for short-term, temporary assistance in this region.

The Hospital at The Children's Institute has provided respite services on an as-available basis. When contacted by a family in need, The Children's Institute would accept a respite care referral based on available beds and the type of services needed by the family. But The Children's Institute's ability to serve these families was limited, not by its desire to help, but by the limited bed capacity on the inpatient unit.

By creating the Respite Care Program, The Children's Institute provides families of medically fragile children an option for highly trained specialists to provide care during periods of conflicting family demands. In fact, The Children's Institute serves as a trusted partner in the care of their special child.

In its introductory phase, the Respite Care Program at The Children's Institute is available for as many as eight children at a time. The capacity of the program will expand over four years to serve a maximum of 18 children at one time. Families of children with cerebral palsy, brain injuries, ventilator dependence, spinal cord injuries, seizure disorders, Prader-Willi Syndrome, cancer and developmental delays turn to The Children's Institute for respite care. The Children's Institute provides the special support their children require for their often-complex medical needs and for toileting, eating and communicating needs in an around-the-clock respite program.

More than providing medical services and bedrooms, The Children's Institute ensures that children in respite enjoy their time away from home. A multi-sensory room is available for socialization and entertainment, and Austin's Playroom is filled with games, toys, a television and most importantly, other children. For those who are interested, religious services are held in The Children's Institute's chapel. Child-friendly music featuring camp-style songs replace traditional hymns, and our chaplain engages children and families in child-friendly, interactive services.

The Respite Care Program— one more way The Children's Institute is creating new solutions to age-old challenges for children with special needs and their families.



The  
**Children's Institute**  
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### FACTS ABOUT RESPITE CARE

- Respite has been shown to improve family functioning, improve satisfaction with life, enhance the capacity to cope with stress, and improve attitudes toward the family member with a disability (Cohen and Warren, 1985).
- In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and his parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities (Ableson, A.G., 1999).
- There was a statistically significant reduction in somatic complaints in a study of primary caregivers of children with chronic illnesses, and a decrease in the number of hospitalization days required by children, as a direct result of respite care (Sherman, B.R., 1995).
- A Massachusetts social services program designed to provide cost-effective family-centered respite for children with complex medical needs found that for families participating for more than one year, the number of hospitalizations decreased by 75 percent, physician visits decreased by 64 percent and antibiotic use decreased by 71 percent (Mausner, S., 1995).
- An evaluation of the Iowa Respite Child Care Project for families parenting a child with developmental disabilities found that when the families use respite care, there is a statistically significant decrease in foster care placement (Cowen, Perle Slavik, 1996).
- Without adequate family support, it is estimated that children with disabilities are 3.76 times more likely to be victims of neglect, 3.79 times more likely to be physically abused and 3.88 times more likely to experience emotional abuse than children without disabilities (Sullivan & Knutson, 2000).

