



# CHILDREN'S HOSPICE INTERNATIONAL®

*Pioneering Children's Hospice and Palliative Care for 26 Years*  
[www.CHIONline.org](http://www.CHIONline.org)

***The ChiPACC Bill, HR 6931, is based on the CHI PACC model of care for children with life-threatening conditions and their families.***

## WHAT IS CHI PACC?

Although hospice and palliative care (comfort-based) programs are generally available to adults, the requirements of these providers severely constrict pediatric access to services. Due to third-party reimbursement and state licensing requirements, hospice and palliative care programs generally must limit their populations to individuals within 6 months of death who have elected to forego curative care. Health care providers managing the care of children with serious medical conditions often cannot state with any level of certainty that a child is within 6 months of death. Families of children with life-threatening conditions should not be required to cease curative care to allow for palliative care. A parent should never have to choose between appropriate care and hope for a cure.

Children's Hospice International (CHI), building upon its 26 years of experience and with technical assistance from experts in pediatric, hospice, and palliative care, and the Centers for Medicare & Medicaid Services (CMS), developed its Program for All-Inclusive Care for Children and their Families (CHI PACC). Unlike traditional hospice and palliative care models, CHI PACC provides a continuum of care for children and their families from the time a child is diagnosed with a life-threatening condition, with hope for a cure, through the bereavement process, if cure is not attained. The core of success for a CHI PACC program is that it:

- Incorporates families as participants and stake-holders in the child's care
- Integrates traditional home care, hospice, and palliative services
- Integrates pediatric acute care with community-based care
- Provides access to hospice and palliative care that addresses symptoms from the beginning of care and integrates palliative care with disease management
- Fills the current gaps in care for the child and family to enable children and their families/caregivers to remain in the community
- Provides a longitudinal view of the child and family/caregivers across the disease trajectory and bereavement follow-up

## WHY CHI PACC?

Children with life-threatening conditions must cope with:

- A wide range of diseases and medical conditions, some of which are not encountered in adults
- An array of distressing physical symptoms such as pain, breathing difficulties, fevers, eating disturbances, bowel and bladder problems, and treatment side effects
- A broad range of psychosocial and spiritual issues such as guilt in burdening the family, fear of abandonment, changes in peer interactions, alienation from the school community, long periods of isolation and uncertainty concerning the future

Families are challenged by:

- Loss of the healthy child and hopes for the future
- Disruption of family routines and roles
- Strain on finances
- Conflicts between values, beliefs, and expectations
- Sense of loss of control over life
- Stresses caused by increasing demands for complex decision making
- Loss of work time and productivity
- Difficulties in balancing care of sick child with continuing nurturing of siblings
- Time pressures that limit ability to sleep, care for children, and maintain a presence in the community
- Conflicting feelings of guilt and self-blame for child's condition

Current systems of pediatric care often:

- Lead to high-cost, crisis-driven access to medical care

- Promote excessive reliance on institutional care that furthers disruption in family life, isolation, loss or reduction of employment, and removal of the child from the community
- Focus primarily on disease treatment rather than symptom control and quality of life
- Rarely take into account the child's voice
- Rarely include family support systems
- Fragment health care through conflicting provider eligibility standards, goals, and reimbursement

The CHI PACC model provides early and continual intervention and care coordination functions to prepare families and health care providers to provide support for the seriously-ill child, as well as respite care to permit parents to continue functioning in the community. The U.S. Congress, through James P. Moran (D VA), appropriated funds for FY 2000, 2001, 2002, and 2003 to enable CHI, through the U.S. Department of Health and Human Services, to conduct a multi-state demonstration model program of the CHI PACC model. The experiences gleaned from this demonstration have aided identification of a variety of means to access the need for, and implement, a viable CHI PACC program. Initially, states were encouraged to apply for an 1115 demonstration waiver from CMS. Based on CHI PACC's promising approach, CMS reinterpreted policy for the 1915 (c) Home and Community Based waiver which meets most of the requirements of a CHI PACC program, and is much easier for states to obtain from CMS.

CHI PACC legislation will provide states with an automatic option for CHI PACC, without having to go through the CMS waiver process.

### **CHI PACC Technical Assistance, Education and Training:**

- CHI and CMS provide technical assistance to interested states and programs
- CHI PACC Implementation Manual and other materials are available
- CHI and CMS continue to hold monthly CHI PACC technical assistance teleconference calls with states and providers who are interested in developing CHI PACC programs
- CHI, with technical assistance from CMS, hosts an annual CHI PACC Technical Assistance Conference

### **What is the scope of services/benefits covered?**

A CHI PACC program can be established by virtually any entity (hospice, home care, children's hospital, etc.) willing to and capable of providing the services outlined below, either through its facility or under arrangement with complementary/ancillary providers. CHI has articulated Standards of Care to guide providers and ensure consistency in services and quality control.

A CHI PACC program provides essential services 24 hours a day, 7 days a week. Program design includes an integrated, coordinated continuum of care involving:

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|------------------------|--|
| • Home care            | • Social and supportive services                         |
| • Outpatient care      | • Acute care   |
| • Community-based care | • Bereavement (anticipatory grief) and follow-up service |
| • Respite care         |  |

An interdisciplinary team involving and coordinating, through care-coordination function(s):

- Pediatric palliative care physician(s)
- Pediatric physician specialists
- Nurses
- Social workers
- Chaplains
- Pediatric therapist specialists (music, art, play, pet, etc ie: child life)
- Home health aids/homemakers
- Volunteers
- Laboratories
- Pharmaceuticals
- Durable medical equipment
- Communication supporters, e.g. non-English language availability and telemedicine
- Medical supplies
- Complementary therapies, e.g. massage, guided imagery, etc.
- "High tech" home care services
- Anything else necessary to sustain presence in the community

The ChiPACC Bill HR 6931, sponsored by Congressman James P. Moran (D VA) and others is based on the CHI PACC Model and provides ChiPACC as a Medicaid state option.