



Children's Hospice International

Children's Program of All-Inclusive, Coordinated Care (ChiPACC)



CHI EXECUTIVE SUMMARY

Statement of Need

- The U.S. Government Accountability Office (GAO) estimates 10 million of the approximately 72 million children in the United States live with a serious chronic condition
- 1.3 million of those children and their families, suffer from life-threatening conditions, they plus the families of the additional 54,000 children that die each year, could benefit from children's hospice and palliative care
- Millions more children and families worldwide are in dire need of this necessary care

To be eligible for hospice and palliative care under current definitions, a child must receive a prognosis of being within 6 months of death, and all treatments must be abandoned. Families should not have to give up fighting for a cure just to get palliative treatment, and should not have to wait until their last 6 months of life to receive comfort care and counseling for themselves and their families.

The Institute of Medicine report *When Children Die* (2003) indicates that children with life-threatening conditions fail to receive competent, compassionate, consistent care that meets physical, emotional, and spiritual needs. The report further states that the integration of effective palliative care from the time of diagnosis will improve care for children who survive as well as children who die, and will greatly help their families.

Meeting the Need – Children's Hospice International

Government Initiatives



Mattie J.T. Stepanek

Federal Government (ChiPACC Bill HR 722): The U.S. Congress is currently considering the Children's Program of All-inclusive, Coordinated Care (ChiPACC Bill HR 722, known as the "Mattie and Melinda Bill"), which will make the program a Medicaid state option.



Melinda Lawrence

State Governments: In June 2005 Florida was the first state -- followed by Colorado, California, and New York in 2009 -- to be granted a waiver by the Centers for Medicare and Medicaid Services (CMS) to implement a model of care that was created by Children's Hospice International (CHI) to help children with life-threatening conditions under Medicaid. The ChiPACC Bill would allow states to select a state plan option vs. going through the waiver process.

Family Assistance and Clinical Support

To date CHI has helped thousands of families receive the care they deserve through referrals and counseling. CHI has provided a seminal work on children's hospice care -- *Hospice Care for Children*, Oxford University Press, 3rd Edition, edited by CHI Founder Ann Armstrong-Dailey and Sarah Zarbock, with a forward by Nobel Prize winner Archbishop Desmond Tutu.

International Leadership

CHI 18 th World Congress Singapore September 2007	CHI 19 th World Congress San Francisco November 2008	CHI 20 th World Congress Cape Town, South Africa September 2009	CHI 21 st World Congress Washington, DC October 2010
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CHI World Congresses bring together experts and caregivers from around the world.

For more information
www.chionline.org