

State Advisory Council on Quality Care at the End of Life



Required Under HB 797

Study of Health Care Services for Children with Life-Threatening Conditions



January 31, 2008

Table of Contents

1. Introduction.....	1
2. The Needs of Children and their Families.....	3
3. Summarizing the Situation in Maryland.....	12
4. Efforts to Establish Model Programs in Other States.....	15
5. Policy Options.....	26
Challenges and Opportunities to Improve Pediatric Palliative Care in Maryland	
Appendix A	29
Children’s Hospice International Program for All Inclusive Care for	
Children and Their Families®: State Summary Appendix B	48

1. Introduction

In 2007, the General Assembly passed House Bill 797 (Chapter 81), “Study of Health Care Services for Children with Life-Threatening Conditions.” The bill requires the State Advisory Council on Quality Care at the End of Life (Advisory Council) and the Maryland Health Care Commission (MHCC) to “jointly study the current services and potential care delivery alternatives available for the care of children with life-threatening medical conditions.”

This report has been created pursuant to House Bill 797. Following this introduction, Section 2 characterizes the needs of children who have life-limiting conditions and how an optimal care delivery system would respond to those needs. Section 3 describes the situation in Maryland. Section 4 considers projects in other states to implement a robust model of pediatric palliative care. Finally, Section 5 sets out the main policy options to promote positive change and encourages prompt voluntary efforts to reduce shortfalls in care.

DEFINITION OF TERMS:

Child is a person up to the age of 19 years.

Comfort care is another term for palliative care.

End-of-life care is care that focuses on preparing for an anticipated death and managing the end stage of a fatal medical condition.

Family refers to the persons who provide physical, psychological, spiritual, and social support to a child.

Hospice is a philosophy, program, or site of care that provides, arranges, coordinates, and advises on a wide range of medical and supportive services for dying patients and those close to them. The goal of hospice care is to enable patients nearing the end of life to live as fully and comfortably as possible by providing pain and symptom control, as well as physical, psychological, emotional and spiritual support services.

Infant is a child less than 1 year of age.

Life-threatening condition is one that (1) carries a substantial probability of death in childhood, and (2) is perceived as potentially having a fatal outcome.

Neonate is a child from birth through 4 weeks of age.

Palliative care is a philosophy of care that aims to provide comprehensive care for patients and their families through the living, dying, and grieving processes. Palliative treatment focuses on relieving the physical and emotional distress produced by a life-threatening medical condition or its treatment. It also emphasizes the emotional, spiritual, and practical needs of patients and those close to them. Palliative care may benefit anyone with a life-threatening condition, not just those

patients who are nearing the end of life. Although palliative treatment does not itself focus on cure, it may be provided concurrently with curative or life-prolonging treatment.¹

Plan of care is the overall approach to the assessment, management, and evaluation of a patient's care. A plan of care is designed to address the expectations and needs that the child and family consider priorities.

Quality of life is well being as defined by each individual. Quality of life often encompasses various domains such as physical health, mental health, social and role functioning, sense of well being, freedom from bodily pain and other physical distress, and overall sense of general health.

Respite care allows an ill child's usual caretakers to take time off and tend to their own needs or the needs of other family members while alternate providers care for the child. Respite care may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility, or hospice.

¹ American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care. Palliative Care for Children. *Pediatrics*. 2000;106:351-357

2. The Needs of Children and their Families

Each year in the United States, approximately 55,000 children die and another 500,000 cope with life-threatening conditions.² The number of childhood deaths each year is small in comparison to the number of overall deaths per year (approximately 2.4 million in the United States),³ but their collective impact is extraordinary. The death of a child stands out as a particular tragedy: it is a painful, sorrowful loss for parents, siblings, health care providers, close friends and others. Indeed, “the loss of a child is one of the most stressful events possible.”⁴

In 2005, 74,880 individuals were born in the State of Maryland; it is estimated that 973 of them will die before they reach the age of 20.⁵ According to national statistics, nearly half of all childhood deaths occur during infancy.⁶ Indeed, of the 986 Maryland children who died in 2005, 545 (55%) were less than one year old, and 394 (45%) were less than one *month* old.⁷ In the same year, children between the ages of 1 and 14 accounted for 18% of child deaths, while adolescents between the ages of 15-19 accounted for 27% of total childhood deaths.⁸

In Maryland, the leading causes of infant death are disorders related to short gestation and low birth weight, congenital anomalies,⁹ and sudden infant death syndrome.¹⁰ Among children ages 1 to 14, the leading causes of death are accidents (intentional and non-intentional) and cancer.¹¹ The leading causes of death for adolescents between the ages of 15 and 19 are homicide, accidents, suicide, and cancer.¹² Events that result in sudden death preclude the need or opportunity for palliative care.

² Himmelstein, BP, Hilden, JM, Boldt, AM, Weissman, D. Pediatric Palliative Care. *N Engl J Med*. 2004;350:1752-1762.

³ Miniño AM, Heron M, Smith BL, Kochanek KD. Deaths: Final data for 2004. Health E-Stats. Released November 24, 2006.

⁴ Himmelstein, BP, Hilden, JM, Boldt, AM, Weissman, D. Pediatric Palliative Care. *N Engl J Med*. 2004;350:1752-1762.

⁵ Maryland Department of Health & Mental Hygiene Vital Statistics Administration webpage, at <http://www.vsa.state.md.us/doc/05annual.pdf> (last visited August 30, 2007).

⁶ Field M, Behrman RE, eds., for the Institute of Medicine Committee on Palliative Care and End-of-Life Care for Children and Their Families. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: National Academies Press; 2003.

⁷ Maryland Department of Health & Mental Hygiene Vital Statistics Administration webpage, at <http://www.vsa.state.md.us/doc/05annual.pdf> (last visited August 30, 2007).

⁸ *Id.*

⁹ Congenital anomalies are malformations, chromosomal abnormalities, or diseases existing at birth.

¹⁰ *Id.*

¹¹ *Id.*

¹² *Id.*

DIFFERENCES BETWEEN SERIOUS ILLNESS AND DEATH IN CHILDREN AND ADULTS:

Children are developing

Children and adolescents are in a process of physical, emotional, cognitive, and spiritual development. They have unique needs that are constantly changing, and they often lack the verbal skills to identify or communicate their needs, feelings, and wishes.

Children are not able to advocate for themselves

Pediatric patients are not legally competent and must rely on parents or other adult guardians to make medical decisions on their behalf. In addition to being primary decision makers, parents and other family members are usually the key providers of physical and emotional support for their child. As substitute decision makers, parents are charged with making decisions in their child's best interest, but as parents, they may need to feel that they have done everything possible to save their child. In the face of these often conflicting roles, parents must make extremely difficult decisions about their child's care.

Causes of death in children are substantially different from causes of death in adults

The leading causes of death among Maryland adults are heart disease, cancer, stroke, chronic lower respiratory disease, and diabetes mellitus.¹³ Only one of those, cancer, is among the leading causes of death in Maryland children;¹⁴ this underscores the fact that causes of death in children are substantially different from causes of death in adults. Indeed, many life-threatening conditions that affect children are rare and *only* affect children.¹⁵ Examples of such conditions include disorders related to short gestation and low birth weight, sudden infant death syndrome, and congenital malformations.

Disease trajectories are unpredictable

Several factors contribute to the difficulty of determining prognosis and predicting or identifying the end stage of illness in children. Children experience unique symptoms which are not well understood. They experience and express pain differently than adults, and even children with the same initial diagnosis can differ considerably in their experience of disease-related symptoms.¹⁶ Indeed, for different children, the same diagnosis and initial prognosis can be followed by different pathways that end in death for some and extended survival or cure for others. However,

¹³ *Id.*

¹⁴ *Id.*

¹⁵ Himmelstein, BP, Hilden, JM, Boldt, AM, Weissman, D. Pediatric Palliative Care. *N Engl J Med.* 2004;350:1752-1762.

¹⁶ Field M, Behrman RE, eds., for the Institute of Medicine Committee on Palliative Care and End-of-Life Care for Children and Their Families. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families.* Washington, DC: National Academies Press; 2003.

those children who will eventually die and those who will survive often cannot be predictably distinguished at the time of diagnosis, during initial treatment, or even after initial treatments have failed.¹⁷

For those conditions that affect both children and adults, the same condition will often follow a different course in children and adults.¹⁸ Moreover, children are generally more resilient to disease than adults;¹⁹ this adds to the difficulty of determining prognosis, as many life-threatening conditions run unpredictable courses of relapses and remissions in children.²⁰

Loved ones experience profound grief

The grief associated with a child's death is different from the grief of losing an adult, and it tends to have devastating and long-term impacts on parents, siblings, providers, and the community. In particular, bereaved parents are at an exceptionally high risk for complicated grief reactions.²¹

GUIDING PRINCIPLES FOR THE CARE OF CHILDREN WITH LIFE-THREATENING ILLNESS:

Historically, patient management has focused on curing illness and prolonging life. Palliative care, which seeks to treat symptoms and relieve pain, has been viewed as a separate treatment model which becomes relevant, if ever, after efforts at curative care.

Viewing palliative care as an alternative rather than a complement to curative treatment is a misconception that is reinforced by existing reimbursement systems. Following the lead of the Medicare program, most insurance plans have a hospice benefit. The Maryland Insurance Code, in § 15-809, requires certain policies to "offer benefits for hospice care services." Patients qualify for the benefit, however, only if they agree to forgo curative treatment and accept only palliative care. Moreover, patients must be deemed by a physician to have a life expectancy of six months or fewer if the disease runs its normal course. These limitations were adopted by Medicare to control program costs²² and are used by insurance plans in designing and pricing an appropriate product. However, existing reimbursement systems preserve the division of curative and palliative services that has long hindered optimal patient care, especially for patients whose dying trajectory cannot be confidently predicted.

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ *Id.*

²¹ Himmelstein, BP, Hilden, JM, Boldt, AM, Weissman, D. Pediatric Palliative Care. *N Engl J Med.* 2004;350:1752-1762.

²² Field M, Cassel CK, eds, for the Institute of Medicine Committee on Care at the End of Life. *Approaching Death: Improving Care at the End of Life.* Washington, DC: National Academies Press; 1997.

In recent years, recognition of low hospice use among older adults, low percentages nationally of adults dying at home, despite a commonly expressed preference to do so, and the small number of hospitals offering palliative care programs has spurred substantial research into end-of-life care for adults. Studies have gauged the quality and effect of palliative care services and have revealed suboptimal end-of-life care for adults.²³ The result has been increased attention to hospice and palliative care across the United States, and the development of a range of programs to reform and improve palliative care for adults.

Pediatric palliative care has been slower to emerge than its adult counterpart. This is due in part to the far smaller number of children who die in the United States as compared to adults. In addition, the decreased attention to pediatric hospice and palliative care may be attributable to the tendency to model such care after adults. However, while several problems in palliative and end-of-life care are common to adults and children (e.g., inadequate management of pain and problems with continuity of care), other issues are unique to pediatrics and may justify a separate focus on pediatric palliative care.

Trajectories of disease

Life-threatening conditions in children follow several common trajectories. We will describe the similarities and differences among these.

The first category includes *conditions that result in sudden or imminent death*. Events that result in sudden death preclude the need or opportunity for palliative care.

Many of the leading causes of infant death fall into this category, including prematurity, low birth weight, congenital malformation, and sudden infant death syndrome. This category also includes accidents, homicide, and suicide, which are among the leading causes of death among older children and adolescents. In these situations, death is inevitable, and the focus of care will be exclusively palliative. Most of these children will die in intensive care units; thus, an optimal care strategy will make hospice services available in neonatal and pediatric intensive care units.

The second category of life-threatening conditions includes *severe, non-progressive disabilities that cause affected children to be highly vulnerable to health complications*. Conditions in this category include extreme prematurity, severe cerebral palsy with recurrent infection or difficult-to-control symptoms, severe neurologic conditions resulting from infection or disease, hypoxic or anoxic brain injury²⁴, and severe brain malformations such as holoprosencephaly²⁵. Children living with these conditions may live for several years without

²³ Field M, Cassel CK, eds, for the Institute of Medicine Committee on Care at the End of Life. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academies Press; 1997.

²⁴ Hypoxic or anoxic brain damage results from lack of oxygen in the brain.

²⁵ Holoprosencephaly is a condition caused by failure of the forebrain to divide into hemispheres. It is characterized by facial malformations and defects in brain structure and function; such defects may cause seizures or mental retardation.

substantial suffering; on the other hand, they may incur unexpected and sometimes life-threatening medical crises as a consequence of their extreme vulnerability to health complications. Thus, it is difficult to predict the trajectories of disease for many of these conditions. An optimal plan of care will provide palliative and curative care services simultaneously, allowing the emphasis of care to shift in response to the needs of the child. In the absence of crises, care will focus on helping the child and his or her family to maintain their quality of life. If and when a crisis arises, the focus will shift to emphasize life-prolonging care or deciding to focus on palliative and end-of-life care.

The next category of life-threatening conditions includes *complex, chronic conditions characterized by slowly deteriorating health and periodic, potentially fatal medical crises*. Examples include AIDS, cystic fibrosis, muscular dystrophy, chronic or severe respiratory failure, severe epidermolysis bullosa,²⁶ and certain cases of renal failure²⁷. Conditions in this category are characterized by a gradual deterioration in health that may be interrupted by potentially fatal medical crises. Similar to the previous category, an optimal plan of care will combine elements of palliative care with those of curative care and allow the balance between the two to shift in response to the needs of the child and family .

Another category includes *conditions for which curative treatment is possible but may fail*. The life-threatening conditions in this category include cancer, some congenital malformations, and complex and severe congenital or acquired heart disease. Treatment for such conditions is initially likely to emphasize cure, but the goals of care may become predominantly palliative if initial or subsequent treatments fail. Given the unpredictability of disease trajectories, however, the uncanny resilience of children, and the difficulty of losing a child, many parents are likely to resist such a shift and will instead pursue aggressive treatment until the end. For this reason, an optimal model of care will take into account the medical and psychological difficulty, often present in other illness trajectories but especially intense in this circumstance, of accepting a child's grim prognosis. In this way, children and their families may benefit from comprehensive palliative care services without having to forgo curative treatment in exchange for such care.

The final category includes those *conditions in which treatment is exclusively palliative after diagnosis*, because interventions aimed at cure are either not appropriate or not available. Examples of these conditions are metabolic disorders, some brain tumors that are uniformly fatal, chromosomal abnormalities such as trisomy 13²⁸ and trisomy 18,²⁹ and severe forms of

²⁶ Epidermolysis Bullosa (EB) is a genetic disease characterized by extremely fragile skin and recurrent blister formation. Death from EB may occur as a result of blistering of the lining of the respiratory, digestive and genitourinary systems.

²⁷ Renal failure is included in this category of life-threatening conditions when dialysis, transplantation, or both are neither available nor indicated.

²⁸ Trisomy 13, also known as Patau syndrome, is the condition of having three copies of chromosome 13. It is characterized by mental retardation, cardiac problems, and multiple deformities. Approximately 82% of those born with trisomy.

osteogenesis imperfecta.³⁰ Death is the predicted outcome for children with these conditions, but the length of time preceding death may vary according to the severity of the condition. Regardless, care in these cases will be exclusively palliative and will focus on relieving distress, helping the child and family to maintain their quality of life, and, ultimately, preparing the patient and family for death. An optimal model of care will make such services available in the home and will provide them from the time of diagnosis, without regard to the length of time for which the child is expected to survive.

ASSESSMENT OF TRADITIONAL CARE MODEL:

The traditional model of care delivery, which sharply differentiates between curative efforts and palliation after these efforts cease, may be effective for situations in which the outcome is predictable and the disease trajectory is constant. In such cases, children may benefit from care that is exclusively curative followed by care that is exclusively palliative, because there is little uncertainty as to when the child's death is nearing; at that point, a switch to hospice care is clearly appropriate. In other words, the traditional model of care works well for children whose trajectory of illness closely resembles that of an adult cancer patient. This comes as no surprise, since that is the very population for which hospice care was originally intended.

However, the traditional model of care may create a barrier to care, especially for children. First, to the extent that disease trajectories are unpredictable, children and their families may be deprived of palliative care services, as physicians simply are unable to offer a confident prognosis. The traditional switch from curative to palliative care is not likely to be an effective strategy, because the point at which the child is nearing the end of life is unclear. These cases may be marked by periods of stability and acute crises. When a crisis occurs, it is hard to predict whether it is indicative of an abrupt or gradual decline that will lead to death. If one must wait until certainty about the timing of death, it is often too late to take advantage of the beneficial support and services offered by hospice and palliative care.

Second, in cases where death tends to result from a medical crisis, even if the fact of the child's impending death is recognized, there may be only a brief period of time between that recognition and the child's death; thus, the child and family will have very little, if any, opportunity to benefit from palliative services. Finally, given the particular difficulty of losing a child, parents are likely to advocate for aggressive care until very end, even when faced with the inevitable death of their child. This, too, contributes to a delay in the timely provision of palliative care, as parents are not willing to give up curative care for young children to take advantage of hospice services as long as the hope for a cure persists.

²⁹ Trisomy 18, also known as Edwards Syndrome, is a genetic disorder caused by the presence of an extra copy of chromosome 18. It is characterized by low birth weight, a small and abnormally shaped head, low-set ears, heart defects, and other organ malformations. Fifty percent of infants born with trisomy 18 will not survive past two months of age, and 90-95% will not survive past one year of age.

³⁰ Osteogenesis imperfecta (OI), also known as Brittle Bone Disease, is characterized by physical deformity and bones that are exceptionally prone to fracture. Children with certain forms of OI may live for many years despite severe disability.

KEY ELEMENTS OF AN OPTIMAL MODEL OF CARE:

Several research studies support the concept of integrating curative and palliative care.³¹ This approach will allow the child and family to benefit from palliative services throughout the course of the child's treatment, and not just when the child is very near death. It will also enable parents to continue to seek cure for their children without compromising their child's well-being by depriving him or her of essential palliative care. This model of care recognizes the role of the hospital in providing end-of-life care for children. While most adult hospice care is provided in the home, the majority of infants and children die in hospitals.³² Indeed, recent data from Johns Hopkins Children's Hospital in Baltimore indicates that in 2006, 84% of pediatric deaths from illness occurred in the hospital and 16% occurred in the home. Thus, palliative care services should be available in the hospital setting, integrated with curative, disease-focused treatments.³³

From the literature the following elements of an optimal model of care can be drawn:

1. Child- and family-centered care

Parents and families play a central role in the lives of seriously ill and dying children. Parents are often the medical decision-makers, as well as the primary sources of a child's physical and emotional support. Thus, an optimal model of care should recognize that the provision of care for children involves a partnership between the child, family, and health care professionals.

An optimal model of care should maximize family involvement in decision making and care planning in the ways and to the degree that each family finds comfortable, given wide variation in personal, cultural, and spiritual values, beliefs, and practices. It should inform children with life-threatening illnesses and involve them in decisions regarding their care and care planning as fully as possible, given their developmental abilities and desires.

2. Effective pain and symptom management

Health care providers should aim to minimize the child's discomfort, suffering, or pain with the timely provision of palliative measures. The child's plan of care should include a plan for effective pain and symptom management, and care providers should be knowledgeable in recognizing pain and assessing symptoms, as well as adjusting and evaluating symptom management strategies. All members of the care team should be involved in observing, evaluating, and documenting symptom management interventions and their effectiveness.

³¹ American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care. Palliative Care for Children. *Pediatrics* 2000;106:351-357.

³² Himmelstein, BP, Hilden, JM, Boldt, AM, Weissman, D. Pediatric Palliative Care. *N Engl J Med*. 2004;350:1752-1762.

³³ Carter, BS, Howenstein M, Gilmer MJ et al. Circumstances Surrounding the Deaths of Hospitalized Children: Opportunities for Pediatric Palliative Care. *Pediatrics* 2004;114:e361-e366.

3. Concurrent palliative and curative treatment

Access to palliative care services should be available from the time a child is diagnosed with a life-threatening condition. Integrated care should continue to be provided throughout the course of illness. An integrated model of care eliminates the need to predict nearness of death, and allows children who survive as well as children who die to benefit from palliative care services. In addition, it permits parents who wish to continue pursuing aggressive curative treatment for their child to do so without sacrificing the benefits of palliative care.

4. Effective communication

Effective pediatric palliative care depends on the ability of the palliative care team to communicate with the child and family. Health care providers should speak with the child and family on a regular basis about issues related to the child's condition and status, and the well-being of the child and family. Providers should be sensitive to the family's needs and reactions, exercising compassion in their comments and actions. Health care providers should be familiar with the normal emotional and spiritual development of children so that they can provide children with developmentally appropriate information regarding their condition. Care providers should invite children to contribute to the decision-making process to the fullest extent possible, given the child's level of understanding and desire to be involved.

5. Emotional and spiritual support

Caregivers should aim to promote the coping skills, positive adjustment, and quality of life of the child and family. They should be able to recognize and address the fears and worries of the child and family, but also strive to ensure that the child and family have opportunities for personal growth, happiness, and celebration. Caregivers should help the child and family access appropriate spiritual or religious resources.

6. Accessible and practical care

Pediatric palliative care should be accessible to children and their families in a setting of their choice that is appropriate to their disease trajectory, level of physical and cognitive development, and resources. Providers should facilitate the resolution of the family's practical needs, such as the need for respite care, through coordination with the community. To that end, the child's care plan should identify the community and other resources available to address those needs related to activities of daily living and caregiver support.

7. Continuity of care

Children with life-threatening conditions have a variety of needs that require a collaborative and cooperative effort from multidisciplinary care providers. Health care providers should meet on a regular basis, first to develop a comprehensive plan of care and subsequently to review and update goals of treatment. There should be a designated care coordinator who facilitates continuity of care across settings and ensures that the care provided is consistent with the goals of the child and family. In addition, protocols should be in place to promote the timely flow of information among caregivers.

8. Loss, grief, and bereavement care

An optimal system of care should provide loss, grief, and bereavement care to the child and family before, during, and after death. Family members may experience a range of grief responses, and some may benefit from referrals for counseling and appropriate treatment. Care providers should focus on identifying the family's strengths; mobilizing personal, family, social and community resources; and providing emotional, practical, social and spiritual support.

3. Summarizing the Situation in Maryland

The information presented in this section is derived from a 2004 report of the Maryland Pediatric Palliative Care Summit, involving more than 40 participants from a wide range of stakeholders³⁴; follow-up discussions with several Summit participants; reports from other sources relevant to the situation in Maryland; interviews with experts; a survey conducted by the Hospice and Palliative Care Network of Maryland; and meetings with parents in a support group, case managers and other nurses at Johns Hopkins and University of Maryland Hospitals, Maryland Medicaid officials, and representatives of major health insurers.³⁵

The overall assessment is that, although excellent care is frequently delivered, there is no comprehensive system of care that reflects the optimal model described in Section 2. Instead, clinicians and family members may find themselves striving to meet children's needs in the face of shortages of key resources, payment mechanisms ill-suited to the problem, and other barriers.

The only full-scale pediatric palliative care program at a Maryland hospital is the Harriet Lane Compassionate Care Program at the Johns Hopkins Children's Center.³⁶ Program staff consulted with other health care professionals at Hopkins to identify children who might benefit from palliative care and to deliver appropriate services, including to parents and other family members. The program has noted certain "triggers" that can help identify these patients:

- Does this patient have a disease that will limit his/her life span?
- Would you be surprised if this patient died in the next 6-12 months?
- Has the frequency of hospitalizations increased during the past 6-12 months?
- Has there been a major clinical event (e.g. relapse, need for transplant) related to this patient's condition?

³⁴ Rushton, CH, Reder E, Hall B, and Hutton N. Challenges and Opportunities to Improve Pediatric Palliative Care in Maryland. October 14, 2004. This report is reproduced in Appendix A.

³⁵ Specific data from the survey are not included, given the low response rate.

³⁶ The Pediatric Chronic Illness Program at Mt. Washington Pediatric Hospital, while not explicitly a palliative care program, does serve children with potentially life-threatening illnesses, such as chronic lung disease, and offers a multi-disciplinary team approach seeking to stabilize children medically, "maximize their developmental skills and meet their emotional needs." <http://www.mwph.org/inpatient/pchroni.htm> (last accessed September 29, 2007). We also note that the District of Columbia's Children's National Medical Center, which serves many Maryland children, has a Family Services Program offering many elements of palliative care. <http://www.dccchildrens.com/dccchildrens/forparents/subservices/child.aspx> (last accessed September 29, 2007).

- Does the patient have symptoms that have changed the frequency of clinic visits?
- Has there been a change or deterioration in the patient's response to treatment, pain intensity, energy, functional status, respiratory function, mental status or quality of life?
- Has the patient/family voiced concerns about the treatment plan? Is there conflict among the family or the health care team about the goals of care?

Other Maryland acute care hospitals have palliative care services, but they focus on adult patients and likely lack expertise about the full range of needs of children and their families. Physicians and nurses in neonatal and pediatric intensive care units often do have an experiential understanding of palliative care needs, but their attention is necessarily concentrated on the technically demanding interventions aimed at sustaining a child's vital functions. In these settings, palliative care is likely to be spotty and inconsistent, not well integrated into an overall care plan.

Some interviewees described the difficulty they faced as parents when they took their child home from the hospital. Hospice is often not an option, either because the local hospice lacks staff expertise in pediatric care or because, for the reasons already explained, the prerequisites to hospice – a prognosis of death within six months and requiring the forgoing of curative efforts – make this choice impossible. Pediatric palliative care is provided by home health agencies, but limited staffing may make this difficult to implement. Some home health nurses are ill-prepared for the care needs of the child or do not desire to work with children, sometimes resulting in preventable trips to the emergency department.

Some interviewees commented that a transition from home health to hospice is often problematic, given limitations on available pediatric hospice services. Although several Maryland hospice programs expressed a willingness to accept children, few have done so on a regular basis given the cost of training and maintaining the service capacity in light of the limited number of children that would be served.³⁷ Hence, maintaining specialized expertise is difficult.

Geographic boundary issues can arise when a child who has received services from a hospice program moves to a county outside that hospice's service area. In addition, given scarcity in pediatric palliative care expertise, even a single staff member's change of employment can have an impact on a hospice program's ability to offer pediatric services. In some cases, inpatient hospice might best serve the needs of a dying child and the child's parents, but inpatient hospice beds are difficult to find, especially for infants.

Sometimes the gap between established services and the needs of dying children is managed through flexibility and kindness. In one family's situation, bringing their child home to die would have created a host of problems, in terms of both the patient's medical management and the needs of a young sibling. Although the local hospice's inpatient facility was neither

³⁷ One exception is Maryland Community Hospice, whose pediatric team serves a small number of children regularly.

designed nor staffed for pediatric patients, the hospice director nevertheless opened a bed for this child. As the parents put it, the hospice “really went out on a limb to help a family in need. Thank goodness for people who look at individual situations and make decisions rather than leaning on policies when there are difficult decisions to be made.”

One key goal is to preserve parents’ time and energy for their child. Parents who are under immense stress should not have to struggle with bureaucratic complications simply to get the care their child needs. Case managers should serve this role, and in many of the interviews that appeared to be the case. However, there have been instances where, for example, obtaining the specialized medical equipment that has worked well for a child may turn into a challenge if a new service provider has a contract with a different equipment supplier. As one child’s parents put it, “The children are the ones who suffer. And it is the children who should be made as comfortable as possible in these situations.”

An important determinant of access to services is reimbursement. For those children whose death is inevitable and close at hand, traditional hospice pays for a range of needed services. For children with disease trajectories that do not fit the traditional hospice model, however, there is no defined method for assuring access to palliative care as such. In general, representatives of both private insurers and Medicaid spoke of efforts to find ways to provide needed services, whether through flexible interpretation of coverage limits or efforts to mobilize community-based resources. Some elements of the spectrum of pediatric palliative care services – for example, interventions for pain and other symptom management – may be reimbursed by private insurers or the Medicaid program routinely. Other elements, especially age-appropriate therapy to address the non-physical aspects of a life-threatening condition and respite care, are less likely to be available or reimbursed. Case management services to help a family cope are often, but not universally, made available.

4. Efforts to Establish Model Programs in Other States

The 2003 Institute of Medicine report *When Children Die* made a number of recommendations related to the many dimensions of care for dying children and their families. These recommendations stressed the need for restructuring hospice benefits and policies to allow the family to be treated as a unit without restrictions that require children to forgo curative treatments, and without restrictions on benefits for related palliative services. The report also stressed the need for greater coordination of care because of the diverse needs of, and sometimes diverse payment sources for, this type of care.

CHI PACC®: A RESPONSE TO THE CALL FOR REFORM

The Children's Hospice International Program for All-Inclusive Care for Children and Their Families (CHI PACC®) was developed by Children's Hospice International (CHI) in coordination with the Centers for Medicare and Medicaid Services (CMS). Unlike the traditional hospice/palliative care models, a CHI PACC® program provides a continuum of care for children and their families from the time that a child is diagnosed with a life-threatening condition, with hope for a cure, through the bereavement process, if cure is not attained.³⁸

The CHI PACC® addresses the Institute of Medicine recommendations by eliminating the requirements that patients decline further curative treatments and have a prognosis of six months or less. Additionally, CHI PACC® places no limits on the number or types of services that may be provided to children and their families. Any combination of traditional medical and non-medical services may be provided depending on the needs of the patient. These typically include pain management, curative treatments when appropriate, environmental modifications, palliative care, and counseling for not only the ill child, but also for siblings and parents. Many hospices employ child-life specialists to assist in maintaining as much normalcy as possible in the lives of children and families. Services can include various therapies such as art, music, physical, and play.

The U.S. Congress appropriated funds for FY 2000-2003 to enable CHI, through the Department of Health and Human Services, to conduct state demonstration model programs of the CHI PACC® model. The demonstration programs were intended to test the viability of a CHI PACC® program for children and families enrolled in state Medicaid plans. Six states were included in the original demonstration: Colorado; Florida; Kentucky; New York; Utah; and Virginia.³⁹ Each state was to receive approximately \$100,000 per year for three years to develop a CHI PACC® model.

The original intent was that states would apply for a CMS 1115 waiver for the program. The CMS 1115 waiver provides a mechanism for states to obtain approval for demonstration projects that test alternate policies designed to better meet the goals of the Medicaid program.

³⁸ From CHI-PACC International Website: www.chionline.org/programs/about.php

³⁹ Although Utah is listed as one of the initial demonstration states, no pediatric hospice initiatives have been identified for this state.

Experience established that the 1115 waiver process is labor intensive, not as effective as intended, and too time consuming.⁴⁰ In May 2004, CMS, concerned about the effect of budget neutrality on the pilot programs, indicated a preference to use 1915(c) (Home and Community Based Services) waivers instead. The work done with the original demonstration funds has identified a variety of means to assess the need for, and if appropriate, to implement a feasible CHI PACC® program.

CHI-PACC STANDARDS OF CARE

1. Comprehensive Care Interdisciplinary Team: Creation of a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical, nursing, psychosocial, or spiritual service needed for the child or family unit.
2. Curative/Palliative Care Simultaneous: Integration of curative care with palliative care and community-based supportive services.
3. Care From Point of Diagnosis with Single Entry into System: Establishment of a system of comprehensive care with one point of entry providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.
4. Ample and Flexible Funding: Redistribution of funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.⁴¹

EXPECTED CLINICAL OUTCOMES

1. Early implementation of palliative care integrated with medical treatments of the life-threatening condition with the goal of addressing quality of life needs and issues through palliative care.
2. Expanded availability of home and community-based services to reduce dependence on institutional care.
3. Enhanced support services to maintain family cohesion, sense of control, satisfaction with care, and informed decision making.

⁴⁰ Email to Meredith Frost of MHCC from Ann Armstrong-Daily of Children's Hospice International, August 29, 2007

⁴¹ CHI-PACC® Standards of Care and Practice Guidelines, Rev. October 2003. Children's Hospice International.

4. Facilitation of transitions from settings of care due to progression of condition.
5. Advance preparation and support of families when end-of-life care becomes imminent.⁴²

EXPECTED FINANCIAL OUTCOMES

The implementation of CHI PACC[®] programs will have a “cost neutral” impact on the total expenditures of public and private payers. This will be achieved by cost-offsetting to fund expanded palliative care services through reducing expenditures in the following ways:

1. Preventing unnecessary emergency room and hospital admissions.
2. Facilitating earlier discharges from hospitals into home care.
3. Performing some treatments and procedures, such as chemotherapy, at home.
4. Supporting families to provide end-of-life care at home rather than the hospital, as appropriate.
5. Providing “hospice in the hospital” when it is appropriate for terminal admission.⁴³

CHI PACC[®] TARGET POPULATION

The effect of CHI PACC[®] is to combine two historically separate target populations. The first population is the traditional hospice patient, a child with a life expectancy of six months or less for whom all curative treatments have been exhausted, or for whom no curative measures exist. In addition to palliative care, CHI PACC[®] allows some expansion of services such as allowing life prolonging treatments, if available, and child life therapies and counseling for the ill child and siblings.

The second population is the child who is diagnosed with congenital or other life threatening illness, but for whom life prolonging treatments are available. This population has not traditionally been eligible for hospice services until the late stages of disease and many do not use hospice services at all. These children may live for many years and their care imposes serious stresses on their families. With CHI PACC[®], children in this category and their families can receive the same type of care management, therapies, and counseling that hospice care provides, in addition to curative and life- prolonging care.

The annual number of children traditionally served in hospice has been very small, totaling in the single digits in Maryland and many other states. With the merging of these two populations as targets for CHI PACC[®] programs, it can be expected that the number of patients served will be greater than can be determined based on historical trends.

⁴² *Id.*

⁴³ *Id.*

CHI PACC® FINANCING

Children from all socioeconomic groups may face life-threatening illness. However, some states, finding it easier to finance CHI PACC® services to children with private insurance than for children whose care is financed through public programs, have been able to piece together needed services either through negotiating more flexibility with payers or finding donated services. This is helpful for families with private insurance coverage, but leaves families dependent on public programs like Medicaid without alternatives. The purpose of the CHI PACC® Medicaid waiver is to make the same services available to children and families enrolled in Medicaid. Most states that have approached the CHI PACC® through private payers also have plans to apply for a Medicaid waiver.

Programs funded privately do not always meet all of the standards of the CHI PACC®. For example, CHI PACC® standards require that the continuum of care provide any services needed by the child or the family; Maine and New York exclude respite care, even though respite care is mentioned repeatedly in the IOM report and by parents as a necessary service to help them renew their energy or even to help catch up on normal household activities. CHI PACC® standards also require that funding be redistributed to meet all the needs of the child and family. The fact that states relying on private payment sources find it necessary to patch together programs to try to meet patients needs is evidence that insurance plans have less flexibility in redistributing the funds to meet these needs.

A 1915(c) CHI PACC® waiver, on the other hand, requires that any needed services be available, which eliminates limitations that have traditionally been placed on reimbursable Medicaid services. Proponents of the CHI PACC® anticipate that private insurers will gradually adopt the more liberal policies related to amount, duration and scope of services, permitting children with private insurance coverage to benefit from the same approach that is enjoyed by Medicaid enrollees.

STATE APPROACHES TO THE CHI PACC® MEDICAID WAIVER

Only two states have applied for and been awarded waiver programs for pediatric Medicaid enrollees. Florida has had a waiver program in operation since July 2005 that includes seven sites. The Florida program was approved under an existing 1915(b) waiver for special needs children. The 1915(b) waiver (Freedom of Choice Waiver) allows states to carve out a delivery system for special care. Florida's existing waiver was modified to include the CHI PACC® program. Colorado's recently approved 1915(c) waiver program will begin operation in January of 2008. The 1915(c) Home and Community-Based Services (HCBS) waiver allows states to provide a variety of medical and non-medical services and is intended to allow states flexibility in creating and implementing community-based alternatives to institutional care for the targeted populations. In addition to meeting the CHI PACC® Standards of Care and Practice Guidelines, the HCBS waivers must meet a test of "cost neutrality", which means that the federal costs to the target population must be no more than what it would have cost Medicaid to serve this same population in an institution. Seriously ill children are more likely to require acute episodes of institutional care because they live longer and can be more difficult for families to

manage at home. Most states hope to meet the cost neutrality requirements by reducing the number of hospitalizations.

Another requirement that may be a challenge to states is that there must be no duplication of services provided for enrollees. This is generally not a problem unless a child is receiving skilled nursing care from a home health agency, while simultaneously needing hospice care. In this case, the hospice nurse is the most appropriate person to provide and monitor the palliative medication but is not able to do so because skilled nursing care cannot be duplicated between the two types of providers. Although the hospice nurse can supervise the home health nurse in the administration and monitoring of these drugs, it would be ideal for the nurse that is most experienced with these medications to be able to administer them. It also complicates the process by creating another level of coordination needed among the various providers involved in the child's care.

There is also a prohibition in CMS policy of payment for services rendered after the death of the patient. Therefore, bereavement services under the 1915(c) waiver are permitted to be billed in advance of the patient's death, even though bereavement services are provided during and after the patient's last days of life.

Evaluation of Florida 1915(b) waiver program

The third standard for the CHI PACC[®] program includes a provision for research and evaluation of the program in order to identify and document evidence supporting "the most effective care practices for children." This means that all approved programs agree to participate in any research or evaluation activities to generate new information and innovative practices in the treatment of children diagnosed with life limiting illnesses.

To date, Florida is the only state with experiential data on the CHI PACC[®] waiver program. An evaluation of Florida's program was done by the Institute of Child Health Policy at the University of Florida for the 18-month period between July 2006 and January 2007. The evaluation process included a hospice administrator survey, a parent satisfaction and quality of health care survey, a child quality of health care survey, findings from the state's quality assessment monitoring, and a description of the process used in identifying and comparing children enrolled in Florida's Title V program for Children with Special Health Care Needs.⁴⁴

Enrollment in the Florida program increased 51 percent from 166 to 251 during the 18-month evaluation period; 81 percent were in the mid-stage of their disease process. The top 10 reported diagnoses were: brain injury/development; congenital anomaly/genetic; muscular dystrophy; HIV; cerebral palsy; leukemia; cystic fibrosis; leukodystrophy; cardiovascular disorders; and convulsions. Seventeen percent of Florida hospices participate in the waiver program, compared with 18 percent of hospices nationwide that report an active pediatric

⁴⁴ The full evaluation report is: Institute for Child Health Policy, University of Florida: *Children's Medical Services Network: Partners in Care Together for Kids*. Contract Period 2006-2007.

palliative care program. Staff turnover in the participating programs is low, with no staff turnover of registered or licensed nurses and social workers/therapists in the last year of the evaluation period.

Care coordination is one of the “core elements” of the Florida program with active communication among patients, families, care providers, and the Medicaid program. Children in the program enter the program earlier in the course of their illness and can have a longer lifespan than traditional pediatric hospice populations. This is expected given the goal of integration of curative and palliative care during the course of the child’s illness and several of the hospices commented on the difference between the program participants and other children under hospice care.

The mix of services provided to enrollees varied among the program’s seven sites (see Table 1). While three sites reported that their enrollees received primarily “support counseling” , two other sites provided mostly “in home nursing care “, the two final sites provided primarily “activity therapies.” Two of the sites providing primarily “support counseling” also provided notable percentages of “in home respite care.” Some services were underused, but it was not clear whether the services were simply uncounted because they were provided at other locations outside the CHI PACC® program.

**Table 1: Self-Reported Service Profile by Hospice Sites,
Florida Partners in Care: Together for Kids Program,
August 2005-2006**

	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7
Support counseling	74%	75%	24%	58%	36%	33%	25%
In home nursing care	3%	0%	76%	16%	60%	16%	14%
Activity therapies	0%	6%	*	0%	*	51%	61%
In home respite	22%	19%	0%	7%	*	0%	0%
In patient respite	0%	1%	0%	0%	*	*	0%
In home personal care	0%	0%	0%	19%	4%	*	0%
Pain/symptom consultation	1%	0%	0%	1%	*	0%	0%

*Service not available to PIC:TFK enrollees

NOTE: Hospices in the Florida program are not reimbursed for volunteer or bereavement services, although bereavement services are provided by several of the agencies.

The Institute for Child Health Policy conducted parent and child surveys as part of the evaluation of the Florida program. A number of different tools were used to measure satisfaction, including the Consumer Assessment of Health Plans Survey (CAHPS). The overall response rate was 53 percent. Demographic information, such as age range of parents, marital status, education level, language spoken, gender of the child and head of household are included. Satisfaction variables, such as length of time from invitation to enrollment, length of time from enrollment to

receipt of services, satisfaction with benefits and overall quality of care were measured. Some key findings are listed below.

- About 69 percent of families are very satisfied with the nurse or therapist.
- Eighty-six percent are very satisfied to just satisfied with the program benefits.
- Families' experiences with doctor communication, shared decision-making, getting needed information, care coordination, and having a personal doctor or nurse were all positive.
- Of parents who disenrolled their children from the program for various reasons, one hundred percent were satisfied to very satisfied with the program.

Other state programs

According to the CHI, eighteen states have adopted some form of the CHI PACC[®] model. Several of these states responded to requests for information. Table 2 in Appendix B summarizes some basic characteristics of these programs.

California

California's program was organized and promoted by the Children's Hospice and Palliative Care Coalition. The Coalition has established a broad spectrum of supporters in the state that are committed to providing a scope of services that goes beyond the CHI PACC[®] program in terms of the number of services available, including direct nursing and 24 hour, 7 day per week response. The Coalition is in the process of finalizing their 1915(c) waiver application. (Medicaid waiver applications may be prepared by individuals or groups outside of the state agency as long as the agency is prepared to sign and submit it.) A web-based resource has been established for parents of seriously ill children. The web site (www.partnershipforparents.org) includes guidance and resources for parents whose children are at all stages of their illness, including bereavement. California also has organized privately funded resources for the past three years to meet some of the needs of seriously ill children and their families while preparing their 1915(c) waiver application. If the application process goes smoothly, the program is expected to be operational in the summer of 2008.

Colorado

Colorado has an approved 1915(c) waiver program that will become operational in January 2008. The program will treat children from birth to 18 years of age and follows all characteristics of the CHI PACC[®] program. While preparing their waiver application, Colorado operated a pilot program out of the Hospice of Denver. This program was funded privately and was a modified form of the CHI PACC[®].

District of Columbia

Private entities in the District of Columbia are in the early stages of preparing a Medicaid 1915(c) waiver application for a CHI PACC[®] program. Many details of the DC plan are still in

development at this time, but the effort is led by the District of Columbia Pediatric Palliative Care Collaborative. It is planned that the waiver application will be submitted in early 2008. They are currently collecting data from the District of Columbia Hospital Association, Community Hospices, and Capital Hospice to estimate patient characteristics, costs and volume. A central office that employs a Medical Director and nursing staff will identify potential patients while they are in the hospital. After being assessed and treated in the hospital, patients will receive care at home from a home health palliative care team or from a hospice home care team depending on the needs of the patient and family.

Kentucky

Kentucky's program is privately organized and funded, primarily by the Hospice of the Bluegrass. Although the Hospice of the Bluegrass has been actively lobbying for a CHI PACC® waiver, the plan has been interrupted several times by changes in staff at the Kentucky Medicaid office. The replacements for some of the prior staff have either focused on other priorities or are not as supportive of the CHI PACC® initiative as previous staff. There has also been much discussion on the most appropriate way to acquire funding for a CHI PACC® program. Some in the Medicaid office preferred to use funding through the Early Periodic, Screening, Diagnosis and Treatment program (EPSDT), a program that allows for the provision of many services not usually covered by Medicaid. The thinking was that if children could be enrolled in the EPSDT program, any services that they or their families needed could be funded. This is the same payment plan that was implemented by the State of Washington (see below). Others prefer to seek a 1915 (b) or (c) waiver.

In the meantime, Hospice of the Bluegrass has continued to try to build support for a waiver program among new Medicaid staff, and also to piece together privately and some publicly funded CHI PACC® types of services for the children and families that they serve. They have been very proactive in seeking payment for hospital services from payers, when families wish to pursue curative treatments in addition of hospice services. They are often successful in getting payment from both Medicaid and private insurers. The hospitals have been sympathetic to the needs of these families, and work with the hospice agency to make sure that families get the services they need despite payment issues. They serve children from birth to 21 years of age, but do not have a formalized perinatal program. All services provided under the traditional hospice benefit are provided as needed. About a third of patients are funded from private insurance plans, a third from Medicaid, and the last third receive indigent care. With the provision of indigent care, cost neutrality has been difficult to determine. In the first year the program was offered, only 4 children and their families were served. Since then, the number has increased steadily; in 2006, 76 children and their families were served. It appears to be typical for the number of children served to increase with the implementation of the CHI PACC® due to the previously mentioned merging of two historically separate pediatric populations needing these services.

Maine

The State of Maine has created a program for children and their families, called the Jason Program, which began operation in November 2007. The program will operate as a medical practice with an independent physician, full time nurse and social worker, and part time child life

specialist and spiritual counselor. The program will approach care using a chronic care model along with palliative care. Direct nursing care will be provided by Maine's block care nursing services with the medical practice providing consult services for specific palliative treatments, including medication administration, child life specialists, spiritual counseling, and other services as needed. The program will not provide respite care.

Although the directors of the Maine program, which is a private enterprise, hope to eventually prepare an application for a Medicaid waiver with the support of the state agency, the program as described above will be used to gather supporting evidence for the cost neutrality of a waiver program and information for the application process itself. The initial money for the program was obtained from a Maine Medicaid program grant that was carved out of state-only funds and a gift from a local philanthropist.

Massachusetts

Massachusetts is in year two of a program that functions with non-federally matched funds from the state Medicaid program, and without a waiver. Each year the state hospice association requests a renewal of the funding, which must be approved by the legislature. In the current year, \$800,000 was provided. The funding of the program was possible because of the health care reform activities that Massachusetts initiated in 2006. The program is a hospice program and all care is provided by hospices. This does not mean that families must forgo curative treatments. Families can receive both hospice and curative care because funding for hospice is provided from the funds specifically appropriated for this care, not from the standard Medicaid federal/state funded program.

New York

In New York State, the state hospice association has been the promoter of the CHI PACC®. The program is a pilot program at the Hospice of Buffalo based on the CHI PACC® model and funded from private insurers. It includes all CHI PACC® recommended services except respite care. Currently the age range for pediatric patients served is 0 to 18 years of age; however the age range served under the waiver has not yet been determined. The director of the Hospice of Buffalo estimated that the total costs per family range from \$250,000 to \$300,000. Because of the high cost of the program they have capped the daily census at 30 patients. However, a preliminary analysis of potential cost savings was performed for the New York program in anticipation of an eventual waiver application. The analysis estimated a cost reduction of 15 percent in total medical costs. They estimate cost saving would come from:

- Avoiding terminal hospitalizations (reducing the number of children with life limiting conditions who die in a hospital)
- Avoiding ambulatory sensitive admissions (admissions for conditions such as dehydration, pain management, and pneumonia that can be avoided or treated at home, rather than in a hospital)

- Reducing outlier days for very long stays (through coordinated care and palliative care services in the home)⁴⁵

The estimated savings take into account additional services not typically reimbursed by the Medicaid program.

Virginia

In Virginia, the impact of the CHI PACC[®] is confined to a single institution/agency that has adopted the CHI PACC[®] approach, in this case, the Children's Hospital of Kings Daughters in Norfolk. Children and their families treated at Kings Daughters receive whatever care and support is needed according to individual needs. Services that are not reimbursed through traditional insurance plans are provided by the hospital pro bono. A nurse coordinator manages the program, which treated over 100 children in its first six months of operation. In order to coordinate care between hospice and the Kings Daughters program, the nurse coordinator works with a local hospice to track pediatric hospice patients who are admitted to the hospital. Otherwise, there is little overlap between the patients treated at Kings Daughters and children enrolled in hospice.

Washington

Washington State's program, "Pediatric Palliative Care Consulting Services" program serves children from birth to 21 years of age and their families. It is funded under their Medicaid Early Periodic, Screening, Diagnosis and Treatment program (EPSDT). Eligibility for this program is limited to children who are recipients of the state's Categorically Needy Program (CNP) or the State Children's Health Insurance Program (SCHIP). Children must have a life-limiting medical condition that meets several requirements including: the need for coordination with family and providers in multiple settings; have a life limiting condition that impacts cognitive, social, and physical development; a medical condition with which the family cannot cope; goals that are focused on quality of life, comfort, and family stability, among other requirements.

The program is also available to most of Washington State's children and families with private insurance. Washington's program is a partnership among 10 hospice/home health agencies, the Children's Hospital of Seattle, Medicaid, and eight private payers, meaning that the vast majority of children in Washington undergoing treatment for a potentially life limiting illness are pre-qualified.⁴⁶

⁴⁵ Palliative Care for Children with Life Limiting Illness: An Actuarial Evaluation of Costs for a New York State Medicaid Demonstration Project; Milliman USA, Inc.; June 2003.

⁴⁶ Tender Mercies: Creating New Medi-Cal Benefit to Support Children with Life-Threatening Conditions; Butterworth, L., Dabbs, D.; Children's Hospice and Palliative Care Coalition.

SUMMARY AND CONCLUSIONS

To date, only two states have received a Medicaid waiver for the CHI PACC[®] program. Florida received a Medicaid 1915(b) waiver by modifying one for which they already had approval. Their waiver was approved quickly because modification of an existing waiver is simpler than initiating a new waiver application. Florida is the only state, so far, to follow all CHI PACC[®] standards. Colorado was approved for a 1915(c) waiver which will become operational in January 2008. Two states, California and the District of Columbia, are on a “fast track” to acquire a 1915(c) waiver. California’s CHI PACC[®] program will provide more than the minimum standards outlined in CHI PACC[®].

The majority of states that have attempted to address issues of palliative and hospice care for children do not have a CHI PACC[®] waiver, although several are in various stages of developing one. In addition to California and DC, these states include Kentucky and New York. In the meantime, these and other states have managed to piece together programs for children and their families by building support for the CHI PACC[®] philosophy and finding funding for alternative services, or finding providers willing to donate these services. Although these services are available to all children, regardless of payer, the majority served have private insurance. Since funding is patched together for many of the programs in states that do not have a 1915(c) or (b) Medicaid waiver, there are frequently limitations either in the services provided or the number of patients they are able to serve.

The Medicaid agencies in the states contacted are generally supportive of the goals of CHI PACC[®], but the process of preparing and navigating the waiver process has proven daunting for states historically, and some are reluctant to initiate the process again. In general, most states that do not yet have a Medicaid waiver hope that the programs they have been cobbling together now will later provide the data needed to support their waiver applications.

The impetus for most CHI PACC[®] programs is from the private sector. Typically, the state hospice provider association has taken the initiative, but sometimes a single hospice provider has picked up the lead. In other states, such as California and Maine, a group of activists has coalesced to push for this type of program in their states. The programs they have created are a mix of services, payers, and providers, based on what each state has to offer. Sometimes a home health agency is the primary provider because payer rules do not require the family to give up curative treatments for home health care. In other cases, the hospital is the primary provider, funding whatever services they can provide and absorbing the cost of others. In other states, the hospice is the primary provider and works closely with all payers to try to provide services, whether paid or not. In all states without a waiver, it is clear that much effort is expended in trying to create a package of services in a system that provides a variety of challenges for such a program.

5. Policy Options

Seriously ill and dying children and their families require appropriate and compassionate care.

Like hospice care, palliative care recognizes that people of all ages die and that caregivers' attention should be focused on relieving patients' pain and suffering. Furthermore, palliative care considers the patient and family as a unique entity whose members require care both before and after death. Palliative care recognizes the importance of an interdisciplinary team assisting patients and families with the myriad medical, physical, social, psychological, and spiritual needs that arise when a child has a life-threatening illness.⁴⁷

Pediatric palliative care programs are being developed in several states, but with significant variations in eligibility requirements and amount, duration and scope of services. Although the palliative care literature identifies appropriate participants as all children with life-threatening or life-limiting illnesses, some programs place limits on the number and types of eligible children and the range of services offered in order to target their efforts more effectively and control program costs. Some elements of pediatric palliative care are appropriately and routinely covered by private or public health insurance, particularly for a very seriously ill child with a limited life expectancy. Services not traditionally reimbursed as health care may not be dependably available, although they may sometimes be provided through flexible administration of insurance or volunteer or other community programs.

Although staff of the Maryland Health Care Commission (Commission) and State Advisory Council on Quality Care at the End of Life (Advisory Council) have researched the literature and met with health care professionals, insurance plans, and parents to identify unmet needs and funding problems, certain key issues related to eligibility and cost are unresolved. After adjusting for homicides, suicides, and accidental deaths, the number of children who die annually is small. However, larger numbers of children have serious life-threatening conditions that predictably compromise their achieving adulthood. It is therefore difficult to define the eligible population precisely and to quantify the number of eligible children whose needs are not being met by traditional home health and hospice services.

Given this uncertainty, it is likewise difficult to estimate the cost if the General Assembly were to mandate insurance coverage of pediatric palliative care, including non-medical services that do not have a demonstrated cost offset. One of the key tenets of pediatric palliative care is that, unlike hospice, palliative care services do not require that the family forgo active treatment for the child. The likely cost of concurrent active medical treatment makes it difficult to demonstrate a cost offset for the program – one of the justifications for covering the full range of hospice services, medical and non-medical. Although the Medicaid waiver programs discussed in Section 4 are premised on cost offsets, firm data are not yet available.

The inability to bring closure to this issue at present should not compromise the continued pursuit of an appropriate and equitable approach to treatment for these children.

⁴⁷ Himmelstein, BP, Hilden, JM, Boldt, AM, Weissman, D. Pediatric Palliative Care. *N Engl J Med.* 2004; 350:1752-1762.

Although there was some consideration of a mandated benefit approach, and the Advisory Council believes that assured access to the full range of pediatric palliative care services is a desirable public policy goal, the Commission and the Advisory Council agree that a mandate approach should not currently be pursued.

Both the Commission and the Advisory Council support a voluntary, consensus-based pediatric palliative care initiative to address these unresolved issues. Under this approach, the General Assembly would not enact a mandated benefit at this time. Instead, a working group would be convened by the Advisory Council comprising home health agencies, hospice programs, pediatric palliative care service providers, parents, health plans, Maryland Hospital Association, and State officials. The goals would be (i) to reach agreement on appropriate patients and illnesses that should be treated in a palliative care program; (ii) to more clearly define and quantify which services should be included in palliative care and to estimate the demand for those service; (iii) to identify which services and patients meet the usual criteria of medical necessity and which would not be regarded as covered services by health plans; (iv) to identify how, under existing insurance schemes, children with life-threatening conditions, who are not expected to live to adulthood, can gain access to a robust range of medically necessary pediatric palliative care services; and (v) to increase the supply of trained clinicians able to provide these services. The task would *not* be compilation of another report, but instead delineation of concrete steps for development of a pediatric palliative care initiative. Because children facing life-threatening conditions represent only a tiny fraction of an insurer's covered lives, and because insurers can be expected to respond humanely to so distressing a situation, there is reason to expect that insurers would be supportive of this initiative.

Among the commitments that might be part of such an initiative are the following:

1. Hospitals with a neonatal or pediatric intensive care unit would ensure that when appropriate, a clinician with training or experience in pediatric palliative care is available to provide consultations for patients with life-threatening conditions.
2. The major private insurers would seek to ensure that, within existing coverage, the parents of every child with a life-threatening condition who is not expected to live to adulthood, is offered help from a case manager with training or experience in pediatric palliative care. On a case-by-case basis, and as coordinated by the case manager, services normally available only under a hospice benefit would be made available to children with life-threatening conditions without requiring parents to forgo curative efforts or physicians to identify a specific life expectancy.
3. The Maryland Medical Assistance Program would seek to ensure that when appropriate, parents of children with a life-threatening condition, who are not expected to live to adulthood, are offered help from a case manager with training or experience in pediatric palliative care. On a case-by-case basis, and as coordinated by the case manager, services normally available only under a hospice benefit would be made available to children with life-threatening conditions, who are not expected to live to adulthood, without requiring parents to forgo curative efforts or physicians to identify a specific life expectancy if permitted by law and regulation. If funded to do so, the Medical Assistance Program

would staff appropriately to coordinate this effort and contribute to an evaluation of this approach to care delivery.

4. The Maryland Medical Assistance Program would monitor Medicaid waiver programs in other states, particularly Florida and Colorado. If the experience of these programs suggests that improved care for children can be achieved through more effective use of resources, especially by preventing unnecessary re-hospitalization, an appropriate budget-neutral waiver program for Maryland would be pursued.
5. The Maryland Health Care Commission, on a case-by-case basis, would consider requests from licensed hospices to provide pediatric palliative care services beyond the jurisdictional limits of a certificate of need, in the situation where it is documented that existing hospices in the jurisdiction are unable to provide the services needed.
6. A pool of funds, derived from corporate and other private donations and potentially a State grant, would be devoted to cross-training of clinicians. That is, the availability of pediatric palliative care would be increased if clinicians who already provide home health services to children receive training in palliative care and, conversely, hospice professionals already skilled in palliative care for adults receive training in pediatric care. Johns Hopkins Medicine, with its established pediatric care program, the University of Maryland Medical Center, and the Hospice and Palliative Care Network of Maryland might be expected to take the lead in formulating such a training program.
7. To increase access to respite care, a provider of pediatric palliative care would take the lead in developing parent-based respite care cooperatives. This approach, while hardly sufficient in itself to meet the need, might be a useful first step. To achieve it, an appropriate organization would need to train parents or other family members participating in such a cooperative arrangement and provide an organizational framework for the cooperative. In addition, the General Assembly might consider enacting "Good Samaritan" legislation to eliminate fear of liability as a barrier to participation in such an arrangement.

APPENDIX A



Challenges and Opportunities to Improve Pediatric Palliative Care in Maryland

Report of the Maryland Pediatric Palliative Care Summit

October, 14, 2004

Cynda H. Rushton, Elizabeth Reder, Barbara Hall, Nancy Hutton

On Behalf of the participants of the Summit

Executive Summary	32
Background	33
Childhood Deaths in Maryland	36
The Summit	38
<i>The Participants: Involving Parents and Professionals</i>	<i>39</i>
<i>The Program: Learning from Existing Efforts.....</i>	<i>39</i>
Summit Findings	40
Summit Recommendations	42
Next Steps	44
Summit Participants	45
Acknowledgements.....	46
References	47

Executive Summary

Overview

Nearly 1,000 of the more than 40,000 people who die each year in Maryland are children under 18. With each of those deaths, a pediatric palliative care program can offer support to the child and to the family through the dying process and beyond. The purpose of such care is to help children live well, to give them and their families as normal a life as possible and to support families when their child dies.

Description

In fall 2004, more than 40 knowledgeable parents and healthcare professionals attended the Maryland Pediatric Palliative Care Summit to discuss challenges and opportunities for pediatric palliative care in the State. Hosted by the Johns Hopkins Children's Center's Harriet Lane Compassionate Care Program, the summit chronicled the state of pediatric palliative care in Maryland, identified gaps in the clinical care, financing, and policy that affect the care of dying children and their families, and created a model of parent-professional cooperation.

Findings

The summit findings focused around five central themes: denial of death, compassionate communication, continuity of care, public education, overcoming barriers, and current programs and services.

Recommendations

At the summit, the participants agreed upon eight recommendations to improve pediatric palliative care in Maryland:

1. Make palliative care services family-centered.
2. Integrate palliative care with curative care.
3. Educate families, healthcare professionals, and the public.
4. Develop innovative models of care delivery.
5. Improve facilities and space within hospitals to provide palliative and end-of-life-care.
6. Develop pediatric-focused policies and practices.
7. Develop interdisciplinary, state-wide models for the provision of pediatric palliative care from pre-natal through adolescence.
8. Establish resource networks for professionals and parents.

Next Steps

The release of this report, "Challenges and Opportunities to Improve Pediatric Palliative Care in Maryland," documents the summit and identifies the participants' findings and recommendations. These same advocates have since established the Pediatric Palliative Care Coalition of Maryland (PPCCM), which is now refining action steps to accomplish the recommendations and is exploring other opportunities for collaboration and education.

Background

“When Children Die”

In 2003, the Institute of Medicine released its report “When Children Die” and fueled national interest in pediatric palliative care. This came very late in the national agenda, more than a decade after initiatives like “Last Acts” brought death and dying to national prominence. In the years since, a wide range of efforts have defined palliative and end-of-life care, developed models, and created resources for adults facing the dying process.

The focus on children came late for a host of reasons. First of all, denial of death in childhood is strong. Children are not supposed to die. When a child becomes seriously ill, the outcome is often uncertain and the disease trajectory unpredictable. Adults, usually the child’s parents, must determine what is in the child’s best interest in a complicated process that involves deeply held values and beliefs. Finally, the drive to give the child a chance at life can create a cure orientation that sets high thresholds for the burdens of treatment and uses technology close to the time of death.

What Is Pediatric Palliative Care?

What is pediatric palliative care? According to the Institute of Medicine (2003), it supports and comforts children with life-threatening illnesses or injuries. Family-centered, it offers a philosophy of care and an organized model of care that brings all the professions together in an interdisciplinary team to support the child and family.

The purpose of pediatric palliative care is to help children live well, to give them and their families as normal a life as possible. This means offering children and families—especially parents, brothers, sisters, and grandparents—the emotional and spiritual support they need. It means helping families make decisions, by giving them timely and truthful information and by respecting the families’ choices, values, and cultural traditions. Preventing or relieving pain and other physical, emotional, and spiritual distress is fundamental. Based on a model of shared decision-making, children, their parents and health care professionals engage in an evolving process of advance care planning, goal setting, and bereavement support.

Pediatric palliative care works with—not instead of—other treatments. Ideally, it can start as soon as the family knows the child is ill and continue through bereavement. Above all, it does not mean “giving up.” Letting go of our dreams for cure does not mean that we are abandoning caring for the needs of the child and family throughout the disease trajectory. It can help all seriously ill or injured children, not only those who are dying, to live well.

For children who are nearing death, the continuum of palliative care includes end-of-life and hospice care. At this time, the goal is to help each family ease their child’s pain and other symptoms, keep their child calm and comfortable, make decisions about the use of life support, talk about last wishes, and, finally, grieve the death of the child.

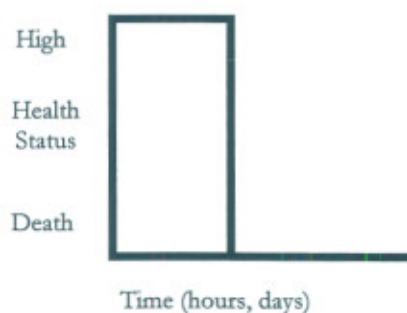
Pediatric palliative care encompasses providing pain and symptom management, psychosocial, spiritual and bereavement support, advance care planning, and coordinated services in the hospital, home and community for children who live with an array of life-threatening conditions. These conditions include but may not be limited to prematurity, genetic syndromes, cancer, AIDS, heart, lung, kidney and neurodegenerative disorders, as well as conditions that arise from traumatic injuries. The continuum of palliative care includes hospital, long term care, home care and hospice. Expanded models of palliative care advocate for integration of palliative and end-of-life services from the time of diagnosis throughout the course of the illness or death, followed by bereavement support (IOM, 2003).

Who Can Benefit?

Who can benefit from pediatric palliative care? Dying children have unique needs. And children do die. Worldwide there are an estimated seven million children and their families who could benefit from hospice services, and even more who could use the support offered by palliative care programs. In the United States, an estimated one million children are very seriously ill. Of the 55,000 children and youth who die annually in the US, one third of them die from life-threatening conditions, while nearly one-fourth succumb to sudden injuries (IOM, 2003). Since most children with life threatening illnesses receive aggressive care until death, the majority of children die in institutions-acute care hospitals, long term care facilities or rehabilitation centers. Of those who die in hospitals, the majority die in critical care units reflecting the aggressive use of life sustaining technologies close to death (IOM, 2003). In contrast to older adults, less than 1% of children needing hospice receive it (Children's Hospice International, 2005).

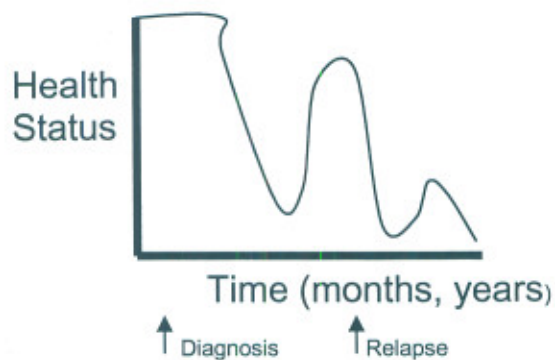
Death in childhood follows several common trajectories. About half occur during infancy, most of them soon after birth, and some later as a result of sudden infant death syndrome. For older children, sudden death results from injuries, intentional and unintentional, which account for about 30% of child deaths. For both of these groups, death occurs suddenly from unexpected causes (Figure 1). For other children, death is expected. It may come from a progressive disease such as cancer with a terminal phase and gradual decline toward death (Figure 2). More frequently, it comes as the child experiences an advanced illness, a slow decline, periodic crises, and then "sudden death" (Figure 3) (Institute of Medicine, 2002).

Figure 1



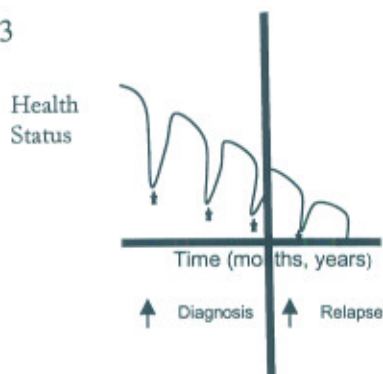
Sudden, unexpected death (IOM, 2002)

Figure 2



Death from potentially curable disease (e.g., brain cancer)
(IOM, 2002)

Figure 3



Death from progressive condition with intermittent crises
(e.g., muscular dystrophy) (IOM, 2002)

Children in the second two groups, who live with chronic, life threatening conditions, pose special challenges in designing models of care. A study done in the state of Washington of deaths of 8893 children and young adults aged 0-24 measured the depth of this problem. One in four, or 25%, had complex chronic conditions. Of infants with these conditions, 84% died in hospital and 50% were mechanically ventilated during terminal admission. For these infants, from 41% to 92% of all days of life were spent in hospital. Of the older children and young adults with complex chronic conditions, 55% died in hospital. Prior to death, their conditions were expected to last at least 12 months (unless death intervened); either several organ systems were involved or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center (Feudtner, DiGiuseppe, Neff, 2003). Clearly, grief is prolonged and has lifelong consequences, for the family and the entire community.

A second study documented the depth of suffering through interviews of 103 parents of children who died of cancer and who were cared for at two hospitals in Boston, where they received aggressive treatment at the end of life. Eighty-nine percent of the parents reported that their child suffered substantially from one to three symptoms during last month of life, most commonly pain, fatigue, or breathing difficulties (dyspnea). Attempts to control these symptoms were largely unsuccessful. Suffering from pain was more likely in children whose parents reported that the physician was not actively involved in providing end-of-life care (Wolfe et al. 2000).

A more recent study evaluated the circumstances surrounding the deaths of 105 hospitalized children at Vanderbilt Children's Hospital underscores the opportunities for palliative care. Most (87%) were in an intensive care setting at the time of death, either pediatric critical care (56%) or neonatal intensive care (31%). Almost 90% of the children received pain medication in the last 72 hours of life, and 55% received additional comfort care measures. Averaging seven days, these final stays offered sufficient time to provide interdisciplinary palliative care. Yet other symptoms, specific interventions, and family support were infrequently documented. For example, healthcare professionals documented discussion of the child's situation with the family in only 23% of the records, a do-no-resuscitate decision in only 42% (Carter et al. 2004).

The findings of these three studies and the situations in the states Washington, Massachusetts, and Tennessee are not atypical. Sadly, as the Institute of Medicine made clear in "When Children Die," they are representative of the situation across the nation and at home in Maryland.

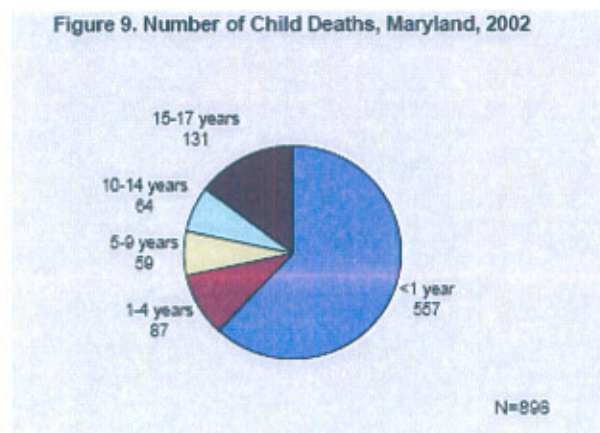
Childhood Deaths in Maryland

The Center for Maternal and Child Health in the Maryland Department of Health and Mental Hygiene published the *Child Death Report* (2003). (Retrieved April 4, 2005, from the <http://www.fha.state.md.us/mch/pdf/ChildDeathReport2003.pdf>.) This analysis of mortality data from the Vital Statistics Administration provides a foundation for assessing the needs of children and families facing life-threatening conditions in Maryland.

Of the almost 44,000 people who die each year in the State of Maryland, fewer than 1000 are children under the age of 18 years. (Maryland Department of Health and Mental Hygiene (2002). *Maryland Vital Statistics Annual Report 2002*. Retrieved April 4, 2005, from the <http://mdpublichealth.org/vsa/doc/02annual.pdf>.) In 2002, 898 children died, 62% of them under one year of age. (Figure 4) Infants under one month of age accounted for 45% of all childhood deaths, infants between 1 month and 1 year accounted for 17%, and older adolescents (ages 15-17 years) made up the next largest age group, accounting for 15% of deaths under age 18 years. This pattern of deaths aggregating in the very youngest and the oldest pediatric age groups indicates that palliative care programs must be designed to care for children at very different levels of physical and cognitive development.

Figure 4: Number of child deaths by age group, Maryland, 2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene



As shown in Table 1, the causes of death in infancy are prematurity and low birth weight, congenital malformations, sudden infant death syndrome, and perinatal complications. Except for SIDS, these deaths occur primarily in hospital nurseries, mandating the need for palliative care services in these facilities. Although cancer is well known as a cause of death in children, it is second to unintentional injury for children age 1-14 years. Among older adolescents (15-17 years), cancer falls to fourth place after unintentional injury, homicide, and suicide. Homicide is the fourth leading cause of death in children age 1-4 years. Therefore palliative care services are needed in pediatric trauma centers, including rapid response bereavement care for the loved ones of critically injured children, including parents who intentionally injure a child, causing his or her death. Of the chronic conditions that cause child death, congenital malformations persist as an important category into the early adolescent years, indicating that many children born with life-limiting conditions live for many years prior to death. Palliative care programs must respond to the long-term needs of children and families for continuous, comprehensive, coordinated care and support.

Table 1: Leading Causes of Death by Age Group, Maryland 2000-2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene

<1 year of age	1-4 years	5-9 years	10-14 years	15-17 years
Low birth weight, short gestation	Unintentional Injury	Unintentional Injury	Unintentional Injury	Unintentional Injury
Congenital malformation	Cancer	Cancer	Cancer	Homicide
Sudden infant death syndrome	Congenital malformation	Heart disease	Homicide and suicide	Suicide
Complication, mother	Homicide	Congenital malformation	Heart disease	Cancer
Complication placenta, cord	Heart disease	Septicemia	Congenital malformation	Heart disease

Pediatric palliative care services must be culturally sensitive and respect the diversity of ethnic, religious and cultural values, beliefs and practices. In 2002, African-Americans infants died at 2.4 times the rate of white infants in Maryland. This ratio remained elevated at 2.0 for older children 1-17 years of age (Table 2). These health disparities must be addressed to reduce the death rate among African-American children. For children whose deaths cannot be prevented, respectful and competent palliative care services must be provided.

Table 2: Deaths, 1-17 years, by race, Maryland, 2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene

2002	Deaths (1-17 years)	Death rate
African-American	166	38.0 per 100,000 population
White	155	19.4 per 100,000 population

Most child deaths occur within the state's major metropolitan areas (Table 3). Nearly half occur in the Baltimore Metro region, which includes Baltimore City and Baltimore, Anne Arundel, Carroll, Howard, and Harford Counties. Clearly palliative care services must be available in Central Maryland. Importantly, a significant minority of deaths occur outside metro areas, with equivalent numbers in Northwest, Southern, and Eastern Shore Maryland. This geographic spread demands creative solutions to providing access to comprehensive pediatric palliative care services throughout the state.

Table 3: Maryland Child Deaths by Region, 1998-2002

Source: Child Death Report 2003, Vital Statistics Administration, Department of Health and Mental Hygiene

1998-2002	< 1 year of age	1-17 years	Total
Maryland	2908	1698	4606
Northwest	158	123	281
Baltimore Metro	1350	873	2223
National Capital	1058	462	1520
Southern	146	101	247
Eastern Shore	196	139	335

The Summit

On October 14, 2004, a group of more than 40 parents and professionals gathered at the Johns Hopkins University School of Nursing for the **Maryland Pediatric Palliative Care Summit**, hosted by the Johns Hopkins Children's Center Harriet Lane Compassionate Care Program. The intent of the Summit was to:

- Chronicle what pediatric palliative care programs and services are currently being provided in Maryland.

- Identify the gaps in clinical care, financing, and policy that affect the care of children in need of palliative and end-of-life services.
- Develop recommendations for moving forward to improve the care of children who could benefit from palliative care within Maryland.

The Participants: Involving Parents and Professionals

To succeed in these aims, the Summit brought together representatives who provide care across the care continuum and serve special populations. Professionals attending the meeting represented healthcare professionals from medicine, nursing, social work and chaplaincy, healthcare administration, and other organizations involved in caring for children in need of palliative and end-of-life services. All had been selected by their organizations as knowledgeable about the resources for pediatric palliative care and prepared to discuss the issues that affect clinical areas, financing, or policy. Many were selected as having the influence or authority to propose and act on recommendations within their agency or organization. Participants were invited to contribute information on resources their organizations provide prior to the Summit meeting. Participants and the organizations they represent are listed at the end of this report.

The Summit was unique in that it brought together a wide range of professionals with a small group of parents, each of who had used or was using palliative care services for their child. A key component of pediatric palliative care is a family centered model of care that recognizes the significant role parents play in care for their children. Therefore any recommendations, policies, or outcomes of the Summit would be incomplete without parent involvement. In recognition of this, a parent advocate was involved in creating the agenda for the Summit and the format was designed to facilitate parents and healthcare professionals collaborating on solutions.

In addition to inviting a parent to deliver the keynote, the Summit featured a formal moderated discussion among three healthcare professionals and three parents. Two of the parents had experienced the death of a child, one after a long bout with kidney disease, the other with a rapidly advancing brain tumor. The third parent cares for a child with cystic fibrosis, a life-threatening chronic condition that requires palliative care. The healthcare professionals represented diverse roles and specialties including pediatric oncology, hospice nursing and a bereavement professional. This discussion and other informal interactions provided touchstones and served to validate the group's findings over the course of the Summit. The group quickly coalesced into a collegial atmosphere focused on creative problem-solving and sharing of common concerns and experiences.

The Program: Learning from Existing Efforts

This sharing was enriched by a review of national initiatives in pediatric palliative care, including brief summaries of the recommendation framed by the Institute of Medicine:

- Children should have care that is focused on their needs and the needs of their families
- Health plans should make it easier for children and families to get palliative care
- Healthcare professionals should be trained to give palliative care to children
- Researchers should find out more about what care works best.

Core ideals were identified as central to these recommendations on behalf of dying children and their families. These ideals are:

- Child oriented, family oriented
- Open communication
- Intensive symptom management
- Psychosocial and spiritual support
- Timely access to care
- Flexibility

To help the participants in addressing palliative and end of life issues for Maryland, an overview of initiatives in other states highlighted a number of efforts. The Robert Wood Johnson Foundation has been supporting 22 projects to promote excellence in end of life care, two of them focused on pediatric palliative care. One in the state of Washington is bringing together hospital, health department, insurers, and hospices. The other in Missouri-Illinois involves a regional program, a hospital, and a medical school.

The Children's Hospice International Program for All-Inclusive Care for Children (CHI PACC), part of the Center for Medicare and Medicaid Services, has launched demonstration projects in Colorado, Florida, Kentucky, New York, Virginia, Utah, and New England (including Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, Connecticut). These projects are devising innovative care delivery and financing models to improve the care of children living with life threatening conditions.

The Initiative for Pediatric Palliative Care (IPPC) is a national education, quality improvement and research project led by Education Development Center in Newton, MA. It has designated six IPPC sites, including Children's Hospital and the Dana Farber Cancer Institute in Boston, Children's Mercy Hospital in Kansas City (MO), Children's Hospital of Philadelphia, University of California San Francisco Children's Hospital, Vanderbilt Children's Hospital in Tennessee, and Johns Hopkins Children's Center in Baltimore. These institutions have implemented diverse quality improvement projects and are working with IPPC and other professional organizations to develop curricula for interdisciplinary training.

A representative from Maryland's Attorney General's Office shared recent statewide legislative and policy initiatives that may have impact on the provision of palliative care, with special implications for pediatrics.

Summit Findings

Through the day-long Summit meeting, participants discussed the current state of pediatric palliative care as they identified barriers and formulated recommendations. Five central themes emerged:

Denial of death. Both parents and professionals acknowledged the difficulty in comprehending that some children cannot be cured of their disease and will die. Parents and different members of the healthcare team may arrive at that conclusion at different times creating the potential for conflicts and resistance to efforts to incorporate palliative interventions into the child's care. Accepting the sudden unexpected death of a child at any age is equally difficult. The lifelong consequences to the families of children who die are profound and largely unaddressed beyond the immediate period after death. Comprehensive programs are needed to raise awareness of the challenges these families and their children face and to provide support for them and for the health care professionals providing care.

Compassionate communication between professionals and families. Navigating discussions about diagnosis, treatment, and prognosis can be fraught with confusion and conflict. Parents struggle with accepting the limits of medicine and technology, hoping that their child will beat the often miniscule odds for survival and recovery. Often when cure is no longer possible, professionals may inadvertently convey messages that may be perceived by parents as threats of abandonment. Participants stressed that families need reassurance that their child is being cared for regardless of the outcome, that the professionals are not "giving up" when they speak of palliative care. Care of the child must be family-centered and consistent with the family's belief systems. Professionals cannot assume that their values and the family's are the same; they must be sensitive to the family's needs and reactions, exercising compassion in their comments and actions. Education and continuity of care are both key to improved communication.

Continuity of care from diagnosis, through treatment, and into bereavement. Parents stressed the difficulties posed by changes in the staff caring for their children. In the curative setting, for example, new teams would take over just as the parents had become comfortable with the old one, or staff unfamiliar to the parents would initiate probing conversations. When care transitioned from curative to palliative and the location of care itself changed, problems of continuity intensified. Together parent and professionals at the Summit agreed that a stronger focus on the interdisciplinary nature of the care team could improve continuity and help to bridge the gap between curative and palliative care. Expanding the therapeutic team to include a wider array of professionals and formally introducing parents to the full team early in their child's illness could strengthen continuity and ease decision making. Including clergy, social work, child life and hospice workers in the team, for example, could support the family in choosing whether their child would die at home, in the hospital, or in a hospice.

Education across a broad range of audiences and issues. Participants agreed that healthcare professionals and members of the public need a better understanding of pediatric palliative care and the impact of a child's illness and death on the family. Education is central to changing the attitudes and culture of pediatric palliative care, and to improving communication between families and staff. It is likewise important to community understanding as well, regarding decisions as to whether do not resuscitate orders and hospice placement are, or are not, best for an individual child. The models developed for caring for adults at the end of life are not appropriate for pediatric palliative care and therefore new models will be necessary. Children and their families have special needs, as do the healthcare professionals who care for them. Understanding pediatric palliative care models is critical to addressing these needs and lightening the burdens they impose.

Legal, regulatory, and financial barriers. The burdens borne by dying children and their families are frequently exacerbated by regulatory hurdles and financial difficulties. Some parents must choose between the need to continue work in order to maintain health insurance and the need to be present at the child's side throughout a lengthy illness. Often parents are faced with choosing between the provision of skilled nursing care in the home and comprehensive hospice services. In reality children and families needs would be better served by financing models that allow flexibility in services based on child and family needs. The arbitrary regulatory requirement that death is expected within 6 months, significantly limits access for some children whose death is expected but predicting the exact timing is imprecise.

Current Programs/Initiatives

Based on data supplied by summit participants, there is one pediatric palliative care program in Maryland at the Johns Hopkins Children's Center (JHCC) and a newly formed program in the nearby District of Columbia at Children's National Medical Center. The Harriet Lane Compassionate Care Program, the pediatric palliative care program of the JHCC, was created in 2000 to achieve the best possible quality of life for the child living with a life threatening illness or injury and their family and when death is inevitable, to support the child and family through the dying process and beyond. The program includes clinical support, education, bereavement support, research and advocacy. In addition to this program there are bereavement programs at the University of Maryland Hospital and selected hospice programs that provide care for children. A perinatal bereavement program at Howard County General Hospital provides services to families before and after death. Maryland Community Hospice has the largest pediatric home hospice program in the state with an average census of 2-5 patients/month. Montgomery Hospice has established a pediatric hospice program and Joseph Ritchey Hospice is planning to develop an inpatient pediatric hospice unit. Other hospice programs within the state occasionally provide palliative care and hospice care to children.

Several public and private health care funders were also represented. Maryland Medicaid Program's hospice care program assists family and children with meeting the special needs at the end of life. Children's Medical Services (CMS) serves Maryland's children from birth to 22 years with special health care needs who are either underinsured or who can not meet insurance qualifications can assist in securing resources for children who need palliative care services. Although Carefirst Blue Cross/Blue Shield of Maryland care management program currently only serves adults, there was interest in opportunities to expand to children. Johns Hopkins HealthCare/Priority Partners has no formal palliative care program but has a contract with a hospice agency to provide end of life services for children birth to 18 years.

Participants concluded that there are numerous opportunities for program expansion across the care continuum.

Summit Recommendations

Make pediatric palliative care services family-centered. The cornerstone of pediatric palliative care is the recognition of and respect for the central role parents and families play in

the lives of children. Programs and systems of care should be designed to enhance the collaboration of parents, professionals, and policy makers in creating flexible, integrated programs.

Integrate palliative care with curative care. Both advance care planning using a goal-of-care framework for decision making and enhanced opportunities for developing relationships and effective communication between patient, families and healthcare providers are essential. Integrating palliative care from the time of diagnosis and extinguishing barriers that interfere with implementing comprehensive plans of care are foundational to new models of care delivery.

Provide education for families, healthcare professionals, and the public. Educational initiatives for families and healthcare professionals should be undertaken to communicate an integrated model of care. A standard interdisciplinary curriculum should be disseminated to institutions across the care continuum. Public education should highlight options for caring for children living with life threatening conditions and ways to support families throughout the decision making process. This would include creating new partnerships between communities and health care organizations.

Develop innovative models of care delivery. New models for creating a seamless system of care are needed for children in different disease trajectories. Collaboration should extend across all care settings, from inpatient settings to long term care and on to hospice and home care. New funding models should be created, as in other states, within current structures, bringing state agencies, state Medicaid, private insurers, healthcare institutions, and healthcare professionals together to address legal, regulatory, and policy barriers. Such models should guide the development of pediatric inpatient hospice care and expansion of resources for pain and symptom management across the continuum. In any model, continuity in implementing the plan of care among caregivers and across institutions would enhance the quality of palliative and end-of-life care.

Improve facilities and space within hospitals to provide palliative and end-of-life care. Healthcare institutions are not traditionally designed to meet the special needs of children who are dying. The lack of personal space and of sleeping space in inpatient areas, together with inflexible visiting policies, all undermine the provision of services for dying children and their families. Inpatient beds allocated specifically for palliative and end-of-life care and designated to provide aggressive pain and symptom management could ease the transition to home or other facilities and respite care.

Develop pediatric-focused policies and practices. Doing so could allow the focus to be on the philosophy of care, clarify policies regarding Do Not Resuscitate (DNR) orders, abolish the six month timeframe for expected death for hospice eligibility, and clarify issues regarding access and funding for pediatric hospice care at home. Moreover, specific family-centered palliative care policies and practices would need to be developed and implemented. Maryland's Council on Quality Care at the End of Life is an ideal mechanism to review, evaluate, and recommend policies to the Maryland General Assembly.

Develop an interdisciplinary, state-wide model for the provision of pediatric palliative care across the age continuum (pre-natal through adolescence). Using the model waiver program, state agencies and health care organizations caring for children living with life threatening conditions have an opportunity to develop a system of care and financing that is flexible, and responsive to the unique needs of children and their families.

Establish resource networks for professionals and parents. Develop a variety of resources regarding key aspects of pediatric palliative care including bereavement. A directory of existing resources, programs, and services should be made available online, including educational resources, speakers, healthcare professionals with expertise in pediatric palliative care, and parents offering support to other parents.

Next Steps

The group agreed to continue to come together periodically to advance their agenda to integrate palliative and end of life care throughout Maryland. Participants indicated a wide variety of areas where there was interest in working together in areas such as education, clinical care, collaboration with other institutions and agencies, and addressing policy and regulatory barriers. Baltimore Sun Reporter, Diana Sugg, chronicled the experience of a dying child and his family and explored issues related to pediatric palliative care in a 4-part series “If I Die” in December 2004. The current state of pediatric palliative care in Maryland and nationally was highlighted.

In May of 2005, participants re-convened to refine action steps and explore other opportunities for collaboration and education. At this meeting the participants agreed to establish the Pediatric Palliative Care Coalition of Maryland.

Summit Participants

Stephen C. Buckingham, Hospice Network of Maryland, Millersville
Chantel Barksdale-Streeter, Parent, Baltimore
Colleen Blough, RN, Pediatric Oncology, Johns Hopkins Children's Center, Baltimore
Marc A Blowe, Department of Health and Mental Hygiene, Maryland Medicaid, Baltimore
James Christensen, MD, Vice President of Pediatric Rehabilitation, Director of the Rehabilitation Continuum of Care, Kennedy Krieger Institute, Baltimore
Samuel Colgain, III, Department of Health and Mental Hygiene, Office of Health Services, Medical Assistance Program, Baltimore
Christi Corriveau, MD, Division of Critical Care, Children's National Medical Center, Washington, DC
Beth Diehl-Svrjcek, RN, Johns Hopkins Healthcare, LLC, Baltimore
Deborah L. Dokken, MPA, Family Health Care Advocate, Co-Investigator, The Initiative for Pediatric Palliative Care, Chevy Chase
Jason Fixler, MD, Pediatric Hematology/Oncology, Sinai Hospital, Baltimore
Rosemary Gaidos, LCSW-C, Kennedy Krieger Institute, Baltimore
Reverend David Harness, University of Maryland Hospital for Children, Baltimore
Barbara Hall, RN, Harriet Lane Compassionate Care, Johns Hopkins Children's Center, Baltimore
Nancy Hutton, MD, Harriet Lane Compassionate Care, Johns Hopkins University and Children's Center, Baltimore
Lori Jayne, RN, Pediatric Intensive Care Unit, University of Maryland Medical Center, Baltimore
Beth Koenigsberg, RN, Community Hospice of Maryland, Baltimore
Eileen Lacijan, RN, BSN, MS, Executive Director, Hospice of Queen Anne's, Inc., Queenstown, MD
Debbie Lafond, MS, RNCS, PNP, CPON, Department of Hematology/Oncology, Children's National Medical Center, Washington, DC
Eric Levey, MD, Pediatrician, Kennedy Krieger Institute, Chair, Committee on Disabilities/CSHCN, Maryland Chapter, American Academy of Pediatrics, Baltimore
Judith Mayer Levy, MSW, MA, LCSW-C, Department of Social Work, Kennedy Krieger Institute, Baltimore
Pat Moloney-Harmon, MSN, RN, Women's & Children's Services, Sinai Hospital, Baltimore
Mary Peroutka, RN, Howard County General Hospital, Columbia
Elizabeth A. Keene Reder, MA, Harriet Lane Compassionate Care, Johns Hopkins Children's Center, Baltimore
Melissa Roman, RN, Johns Hopkins Children's Center, Baltimore
Cynda Hylton Rushton, DNSc, RN, FAAN, Johns Hopkins University School of Nursing, Harriet Lane Compassionate Care, Johns Hopkins Children's Center, Baltimore
Jack Schwartz, JD, Maryland Attorney General's Office, Baltimore
Jodi Shaefer, RN, PhD, Healthcare Answers, Baltimore
Caryl Siems, Parent, Cystic Fibrosis Foundation, Baltimore

Melissa Silva, MS, RNCS, PNP, CPON, Department of Hematology/Oncology, Children's National Medical Center, Washington, DC

Reverend Robert E. Steinke, Frederick Memorial Healthcare System, Frederick
Naomi Taffet, LCSW-C, Community Hospice of Maryland, Baltimore
Linda Talley, RN, BSN, MS, Manager Neonatal Intensive Care Unit, Children's National
Medical Center, Washington, DC
Susan Tipsord, Parent, Project Christine, Middletown
Marcus Walker, MD, National Institutes of Health, Pain & Palliative Care, Bethesda
Robert Washington, PhD, MDiv Psychologist & Minister, Chaplain, Montgomery Hospice,
Gaithersburg
Beth Wiczorek, CPNP, Kennedy Krieger Institute, Baltimore
Patricia Williamson RN, BSN, CCM, Department of Health and Mental Hygiene, Office of
Genetics and Children with Special Healthcare Needs, Baltimore

Acknowledgements: The authors thank The Johns Hopkins University School of Nursing for providing space for the meeting, Dr. Karen Spencer for assistance in planning and facilitating the summit, Judith Douglas and Kelly Wilson-Fowler for helping to prepare the report. This summit was supported, in part, by funds from the Initiative for Pediatric Palliative Care (IPPC).

References

Carter, B. S., Howenstein, M., Gilmer, M. J., Throop, P., France, D., & Whitlock, J. A. (2004). Circumstances surrounding the deaths of hospitalized children: Opportunities for pediatric palliative care. *Pediatrics*, 114(3):361-366.

Children's Hospice International (2005). About children's hospice, palliative, and end of life care. Retrieved May 30, 2005 from <http://www.childrepalliativecare.com/resources/about.phtml>.

Maryland Department of Health and Mental Hygiene (2003). *Child Death Report*, Center for Maternal and Child Health, Baltimore, MD.

Institute of Medicine. (2003). When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. In M.J. Field, & R.E. Behrman (Eds.), *Report of the Committee on Palliative and End-of-Life Care for Children and Their Families*. Washington, DC: The National Academies Press.

Feudtner, C., DiGiuseppe, D. L., & Neff, J. M. (2003). Hospital care for children and young adults in the last year of life: A population-based study. *BMC Palliative Care*, 1(1):3. doi:10.1186/1741-7015-1-3
www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=14690540

Wolfe, J., Grier, H. E., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., Emanuel, E. J., & Weeks, J. C. (2000). Symptoms and suffering at the end of life in children with cancer. *N Engl J Med*, 342(5):326-333.

Sugg, D. K., (2004, December). If I die. *Baltimore Sun*. From <http://www.baltimoresun.com/search/dispatcher.front?Query=diana+sugg&target=article>

APPENDIX B

Table 2
Children's Hospice International Program for All Inclusive Care for Children and Their Families®:
States Summary

State	Current Program Description	Waiver Status	Age Range	Other Requirements	Number Served	Services Included in Palliative Care Programs	Payment Sources	Cost Neutrality	Source of Impetus
California	Palliative care program based on CHI PACC® model	In Process	0 - 19 Years	None	150 over 3 years	Currently there are no limitations on the number or types of services provided	Several private insurers but care for many patients is not reimbursed at this time;	Patients served would normally need hospital level care, so cost of \$1600 per day is less than this	Private: coalition
Colorado	Palliative care program based on CHI PACC® model	Approved; Operational 1/2008	0 - 21 Years	Life expectancy of 12 months or less	Average census is 30 - 35 per day; 3 to 4 new admits per month	Pain and symptom management; emotional/psycho/social support; child recreation services; child life services	Pain & symptom management paid by primary insurer; other support services provided pro bono by local hospice	Palliative care program is cost neutral; Waiver program expected to produce cost savings of \$20,000 per year.	Private hospice
District of Columbia	Program Planned: Central Medical Practice with Full-time physician and nursing care	In process; hope to submit January 1, 2008	0 - 19 Years	None at this time	None at this time	Home nursing care; home health palliative care; home hospice care	Private insurance	Are working to establish cost neutrality; working toward decreasing last year of life costs of children who die in a hospital	Private
Florida	CHI PACC® program	Approved; Operational since 7/2005	0 - 21 Years	1) Meet the financial eligibility requirements for Children under 19 years.	January 2007 - 251 children	In home nursing care; in home personal care; pain and symptom control; respite care; art, music, and play therapies;	Florida Medicaid program	Information not provided	Private and Medicaid

State	Current Program Description	Waiver Status	Age Range	Other Requirements	Number Served	Services Included in Palliative Care Programs	Payment Sources	Cost Neutrality	Source of Impetus
				2) Diagnosed with potentially life limiting illness		counseling; bereavement counseling			
Kentucky	Hospice-based program based on the CHI PACC® model	There interest, but probably will not happen for several years.	0 - 21	None	76 children in 2006	Provide traditional hospice services to patient, family, and siblings.	1/3 private insurance; 1/3 Medicaid; 1/3 indigent	Information not available	Private hospice
Maine	Chronic care physicians practice with palliative support	Not at this time	0 – 18 Years; may expand to 0 – 21 Years	None	Target is 100 in 2007; 200 in 2008	All except respite care	Private pay, private insurance, and volunteers	Total cost of the program in 2008 is expected to be \$616,000	Private: organization
Massachusetts	Hospice-based program for children and families	Will apply for waiver after several years of data collection	0 – 19 Years	Must be a resident of Massachusetts; Funding covers only services not already covered by private insurance plans	Average of 10 to 11 children at a time	Only service that has been refused is a camp for well siblings	Grant money from State Medicaid funds	Cost savings are obtained by preventing hospitalization at end of life	Private: State Hospice Organization
New York *	Palliative care program based on CHI PACC® model	Waiver application isn't written yet.	0 - 18 Years	Accept the most serious cases only because of census cap	Capped Daily census of 30	Doesn't include respite care	Three local HMOs, Medicare, Medicaid	Program is not cost neutral at this time; Estimates based on Medicaid costs per child per month anticipate a 15% reduction in costs	Private: State Hospice Organization
Utah									Unknown

State	Current Program Description	Waiver Status	Age Range	Other Requirements	Number Served	Services Included in Palliative Care Programs	Payment Sources	Cost Neutrality	Source of Impetus
Virginia	Facility based coordinated care program at Children's Hospital of Kings Daughters	Not working on waiver application	0 - 19 Years	Must be a patient of the hospital	Over 100 in first six months of program	Currently there are no limitations on the number or types of services provided	Private insurers for services that are reimbursible; other services are provided pro bono by hospital	cost of pro bono services, including salary of nurse coordinator, is absorbed by hospital.	Private: Hospital
Washington	Partnership between Public and Private payers, Children's hospital and hospice providers	No plans for waiver; used EPSCT instead	0 – 21 Years	None	25 – 30 in most recent year	All services are available; hospice decides which are needed.	Medicaid EPSDT; private insurers	Most likely, but data not available	Public and Private