

EXECUTIVE SUMMARY

PEDIATRIC PALLIATIVE AND HOSPICE CARE TASK FORCE
DEPARTMENT OF PUBLIC WELFARE, COMMONWEALTH OF PENNSYLVANIA
November 2008

PEDIATRIC PALLIATIVE AND HOSPICE CARE **TASK FORCE**

EXECUTIVE SUMMARY

“It was once said that the moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, and the handicapped.”

~ Hubert H. Humphrey

For as long as doctors have diagnosed children with life-limiting illnesses and life-threatening conditions, the healthcare and human services delivery system has had a difficult time providing these children and their families with a satisfactory array of palliative and hospice care information, services, and support. Parents need these options to properly ameliorate their child’s pain and offer opportunities to enhance their child’s quality of life in the time they have left. From the time of a child’s diagnosis, throughout their care and during the final weeks of their lives, parents and guardians struggle with making very difficult medical decisions regarding their child’s medical care, navigating multiple systems and bureaucracies, and financing their child’s expensive healthcare needs. At the same time, they are trying to emotionally and psychologically cope with the tough realities of loving and caring for a child with a life-limiting illness or life-threatening condition.

In recognition of the need for a thorough examination of the availability and administration of pediatric palliative and hospice care options in Pennsylvania, Estelle B. Richman, Secretary of Pennsylvania’s Department of Public Welfare, established the Pediatric Palliative and Hospice Care (PPHC) Task Force. The PPHC Task Force, which is comprised of more than 190 applicants from throughout Pennsylvania, is a volunteer “think-tank” of parents, siblings, family members, caregivers, doctors, nurses, hospice workers, social workers, therapists, administrators, lawyers, educators, and researchers. The goal of the PPHC Task Force is to identify challenges and systemic gaps children and their families encounter when attempting to access palliative and hospice care services in Pennsylvania, while simultaneously developing recommendations that will resolve any identified challenges. The PPHC Task Force’s findings

and recommendations are respectfully presented in this Final Report in an effort to improve and enhance Pennsylvania's healthcare and human services delivery system's provision of comprehensive information, services, and programs that support the administration of pediatric palliative and hospice care services.

The PPHC Task Force held its Kick-off Meeting on Saturday, January 12, 2008, in Harrisburg, Pennsylvania. In the morning, the entire membership was introduced to and heard speeches from their respective PPHC Task Force Process Leaders, including Secretary Estelle B. Richman, Founder and Executive Chairperson of the PPHC Task Force; Uma Ramaswamy, Executive Director of the PPHC Task Force; and the five Co-Chairperson Advisors of the PPHC Task Force: Chris Feudtner, Bereaved Sibling and Director of Research and Attending Physician for The Children's Hospital of Philadelphia's Pediatric Advanced Care Team (PACT); Gail Inderwies, Bereaved Sibling and President and Founding Executive Director of Keystone Hospice, Wyndmoor; Kathryn Lawson, Bereaved Parent and Vice President and Co-Founder of LIAM's Foundation for Pediatric Palliative Care; Carol May, Manager of the Children's Hospital of Pittsburgh's Supportive Care Program; and Meghan Murphy, Bereaved Parent, Co-Founder of the Pittsburgh Pediatric Palliative Care Coalition, and Social Worker at the Children's Home of Pittsburgh.

In the afternoon, the Task Force membership was divided into 12 topic-specific Subcommittees, which focused on important subsections of the various healthcare and human services delivery system that need to be addressed with respect to the provision of proper pediatric palliative and hospice care, including:

- Patient and Family Issues
- Pain and Symptom Management
- Hospital Care
- Hospice Care
- In-Home Care
- Care In Alternate Residences/Facilities
- Systemic Financing and Funding
- Education, Training, and Certification of Professionals
- Medical Ethics
- Research
- Community Resources and Systems Enhancements
- Quality of Life Enhancement Areas

Each Subcommittee was charged with brainstorming ideas relevant to their topic-specific area that ultimately laid the foundation for their members writing a Subcommittee Chapter for this Final Report.

For 10 months following the Kick-off Meeting of the PPHC Task Force, each Subcommittee met regularly via intra-state teleconference to discuss, deliberate, debate, develop, and write the material included in their respective Subcommittee Chapter. As a result of this structured analytical process, each Subcommittee Chapter addresses the following three core areas of service delivery systems analysis, as it relates to each Subcommittee's respective topic:

1. The current state of pediatric palliative and hospice care provision throughout Pennsylvania through the collective personal and professional experiences of the Membership of the PPHC Task Force;
2. The major themes and challenges associated with accessing and providing pediatric palliative and hospice care services throughout Pennsylvania; and
3. The ideal solutions and recommendations that address any challenges to accessing and providing comprehensive pediatric palliative and hospice care throughout Pennsylvania.

Information from all 12 of the Subcommittee Chapters contributed to the major content and writing of the Executive Summary of the PPHC Task Force's Final Report. The Executive Summary serves as a synopsis that recounts the overarching and recurring challenges to and recommendations for improving and enhancing access to and provision of pediatric palliative and hospice care in the current healthcare and human services delivery system in Pennsylvania.

BACKGROUND AND DEFINITIONS

BACKGROUND

We wish that this report did not need to be written. It would be wonderful to live in a world where every child who falls ill or suffers an injury can be returned to full health; that tragedy never befalls children and their families; and that no child ever dies. However, despite remarkable advances and therapeutic marvels, we are duty-bound to acknowledge the unavoidable truths that medical interventions and care cannot cure many children living with a wide variety of life-limiting illnesses and life-threatening conditions. Ultimately, some of our children are going to die. Ideally, care and services delivered to children with life-limiting illnesses/life-threatening conditions would always be effective at reducing their suffering; would be timely and well-coordinated; would be respectful of parents' right to know the truth about the probability of their child's death; and that families would be made aware of the availability of pediatric palliative and hospice care services. However, the medical care provided to children with life-limiting illnesses/life-threatening conditions is often less than ideal.

Clearly, there are no straightforward solutions regarding how to vanquish these and other challenges regarding the access, quality, and financing of pediatric care for dying children and their families. However, the members of Pennsylvania's Pediatric Palliative and Hospice Care Task Force were compelled to explore the difficulties of changing entrenched aspects of our healthcare and human services delivery system, while simultaneously remaining absolutely committed to improving and enhancing the quality of pediatric palliative and hospice care services within the next five to seven years. The crux of the challenges for pediatric palliative and hospice care lies in confronting the truth regarding children dying, however unwelcome, and moving forward with hope and determination. The membership of the Pediatric Palliative and Hospice Care Task Force has written this Final Report in this same spirit of courageous honesty in the hopes of improving the availability of and access to high-quality pediatric palliative and hospice care services throughout Pennsylvania.

Admittedly, talking about death and the dying process is not easy. These two topics are always sad and scary to address, even when we are speaking about them in reference to adults.

However, the difficulty of addressing death and the dying process are heightened when we speak about the subject of dying children. And yet we must resist the temptation to turn away.

Whether we are professionals, parents, administrators, advocates, or all of the above, we all have the responsibility to protect the health and welfare of children, especially the most vulnerable ones. Clearly, society has an obligation to provide proper care for children who are dying and those who can have their pain and suffering assuaged, along with having their quality of life enhanced, if they are receiving proper palliative and hospice care.

Each year in the United States, an estimated 53,000 infants, children, and adolescents die. Many of these deaths follow protracted bouts with chronic illnesses or conditions, including cancer or life-limiting congenital defects. In many of these situations, access to high-quality pediatric palliative or hospice care services could make a marked difference in the lives these children hope to lead before they die. When we take a look at Pennsylvania, it is estimated that just over 2,000 pediatric deaths occur every year. Many of these deaths happen during infancy, due to either premature birth, a complication from a hazardous birth process, or severe congenital malformations. Other children die because of traumas or sudden, unexpected illnesses. Around a quarter of all of these children's deaths are attributable to a wide variety and range of complex chronic conditions, including malignancies (e.g., leukemia, etc.), rare neuro-degenerative diseases, metabolic disorders, genetic syndromes, cardiac conditions, and other maladies.

While the priorities of pediatric healthcare are primarily focused on preventing illness whenever possible, and secondly curing diseases that afflict children, it must be acknowledged that prevention and cure are not always possibilities in aiding children. There are many instances where the main goals of delivering great pediatric healthcare become providing comfort to the child; maintaining as high a quality of life for as long as possible; minimizing pain and difficult symptoms; and maximizing the opportunities for the child to simply be a child - *to play, learn, love, and be loved*. Often, efforts to provide such care, that is to say palliative and hospice care, have succeeded to a remarkable degree. In the case of Cystic Fibrosis (CF), the life expectancy of persons with CF has increased by more than 20 years over the past three decades due to improvements in care, though a cure has eluded the medical community. It has been the case that pediatric palliative and hospice care have helped to assuage the pain and symptoms associated with CF for many of its young patients.

This report addresses the urgent and unmet needs of those infants, children, and adolescents who, despite efforts to cure them or extend their lifespan, have illnesses and conditions that threaten their life and cause death. We will present evidence that these patients and their families need more timely and secure access to high-quality pediatric palliative and hospice care, and offer concrete recommendations about how to do so.

DEFINITIONS

For our audience's convenience and general information, we will be defining some terms widely used in our Final Report and throughout the pediatric palliative and hospice care world. First, let us define **palliative care**, a phrase that was coined by a Canadian cancer physician, Dr. Balfour Mount, in the early 1970s. While many people incorrectly associate palliative care with stopping all medical treatments and procedures and "giving-up" on patients, nothing could be further from the truth. Pediatric palliative care represents an unwavering commitment to all aspects of care for children who are confronting life-limiting illnesses and life-threatening conditions. Palliative care and Palliative Care Teams have slowly, and incompletely, become incorporated into hospital care in the United States for adults, and to a much lesser degree for children.

More specifically, as expressed by the United Nations' World Health Organization (WHO) [www.who.int/cancer/palliative/en/] and endorsed by the Institute of Medicine (IOM), palliative care:

1. Provides relief from pain and other distressing symptoms;
2. Affirms life and regards dying as a normal process;
3. Intends neither to hasten nor postpone death;
4. Integrates the psychological and spiritual aspects of patient care;
5. Offers a support system to help patients live as actively as possible until death;
6. Offers a support system to help the family cope during the patient's illness and in their own bereavement;
7. Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;

8. Will enhance quality of life, and may also positively influence the course of illness; and
9. Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The term **hospice care** was conceptualized in England during the 1960's through the pioneering efforts of Dame Cicely Saunders, M.D., who went on to establish St. Christopher's Hospice in 1967. Hospice, as a modality, seeks to enhance the quality of life of patients versus prolonging their quantity of years by using a holistic, family-centered approach to care that reduces distress through open and honest communication of prognosis. Ultimately, this allows for more palliation of pain and symptoms in patients. Hospice care uses both palliative and supportive care as a means of accomplishing the goal of enhancing a patient's quality of life. In fulfilling its mission, hospice care provides hope through prognostics disclosure, which gives children and their families the ability to have a meaningful end-of-life period through an honest and supportive means of working through the difficult transition from life to death. In fact, hospice programs have developed palliative care programs that are administratively distinct from hospice services to offer a smoother transition into end-of-life care for their patients, but creating some confusion for people who are not familiar with pediatric palliative and hospice care.

More specifically, as defined by Children's Hospice International® (CHI) [www.chionline.org/resources/definition.php], hospice care for children:

1. Incorporates both a concept for caring and a system of holistic, comprehensive, and interdisciplinary services;
2. Includes the child and family in the decision-making process about services and treatment choices to the fullest degree that is possible and desired;
3. Addresses, in a comprehensive and consistent way, the medical, psychological, social, and spiritual needs and issues of children and families through an individualized plan of care;
4. Ensures continuity and consistency of care in all settings where services are provided;
5. Provides coordinated home care through an interdisciplinary team, coordinated by a qualified physician or registered nurse;

6. Provides medical, psychological, social, and spiritual care as its core services;
7. Makes nursing services available 24 hours a day as needed in any setting in which care is provided. The interdisciplinary service team is provided planned support through educational and professional training programs which enhance skills, and through appropriate individual and group activities, whether formal or informal;
8. Provides medical, psychological, social, and spiritual care as its core services; and
9. Provides attention and care to needs related to loss and grieving for all concerned both prior to and following a death.

Upon introduction, some of the different aspects of palliative and hospice care can be confusing as people are getting acquainted with them. For example, palliative care is too often defined in contrast to curative care. However patients of every age should be receiving palliative care from the time of their diagnosis until the course of their illness runs out, regardless of the outcome, which can either be a cure or death. Both children and adults can simultaneously receive both palliative care focusing on their quality of life and treatments that aim to cure or extend life.

Hospice care, also, is often defined in far too narrow a manner. In the United States, hospice care for adults is mostly funded through a specific Medicare insurance benefit that was established in 1982. This Hospice Medicare Benefit uses certain rules and requirements that determine which patients can apply for and receive hospice and what types of care and services these patients can receive. These rules do have lingering implications for children and adults who do not qualify for the Medicare Hospice Benefit. Even though their care is not funded through the federal Medicare Hospice Benefit, it is often the case that these same requirements and provisions are adopted by state Medicaid programs and by private insurance companies without many, if any, modifications. This includes limitations on expensive treatments outside of the hospice benefit that would allow for more costly and aggressive treatments to be provided.

The 6-month restriction that Medicaid requires a family to elect for children to receive the benefits of hospice can be too limiting. At times, it is difficult to predict if a child will die within the 6-month Hospice Benefit limit. Extensions can be received through proper documentation in these cases. However, there is a point where death is an impending reality or

quite imminent. At that point, hospice care can be elected as a benefit so that children can be made more comfortable as the death process progresses; therapies can be introduced that enable the child to cope with their impending death; and families can begin to receive the counseling and therapies they will need to cope with their child's death through the bereavement process. For this to occur parents and family members need to be properly educated about the option of hospice care well before they need to elect it.

Both pediatric palliative and hospice care, when delivered well and properly administered, turn out to be more about living than dying. Pediatric palliative and hospice care help make children feel comfortable and free from pain so they can continue to participate in the activities they enjoy, from playing and hugging to hanging out with friends or going to school. Both of these types of care help children and their families cope with the daunting stress and physical challenges of severe illness, life-limiting illnesses, and/or life-threatening conditions. It should be noted that both palliative care and hospice care complement each other, especially for the countless patients whose experience with a grave medical condition includes time spent in both the hospital and at home.

For purposes of the Final Report, we should also define the term **pediatric**. With respect to the content of our Report, the term *pediatric* refers to the care of any infant, child, or adolescent patient, and also extends to include young adults who developed their life-limiting illness/life-threatening condition earlier in life or became ill prior to entering adulthood (e.g., as is the case for some young adults who were first diagnosed with cancer during their teenage years). Though pediatric palliative and hospice care is focused on the pediatric patient, it also provides support to the entire family, especially to parents and siblings of the patient. Healthcare providers who work with the pediatric population should be knowledgeable about how infants and children are different from adults, in terms of a child's physiology, how they metabolize drugs, and the palliation of a bewildering array of rare diseases that can afflict children. These professionals should also be skilled at connecting with children; understanding their development; partnering with parents; and, prior to and after the death of a child patient, helping a family through the grieving process (e.g., including mothers, fathers, sisters, brothers, and grandparents).

Finally, we need to consider terms such as **dying, end-of-life, terminal, life-limiting illnesses, and life-threatening conditions**. While many reports on pediatric palliative and hospice care attempt to argue that some of these terms are better than others, we take the view that they all are trying to address the same heart-rending situation. When a child has a medical condition that is quite likely to cause their death in the foreseeable future, and all hopes for a cure are unlikely, the descriptors used to characterize their grave condition are moot. What is of the utmost importance is that families are honestly told about their child's health status, disease prognosis, likely death process, and all of their healthcare options, so they can be in the best position to make the most informed decisions in the best interest of their child and family.

MOVING FORWARD

Outstanding palliative and hospice care represents the fulfillment of a promise that should be offered to every patient, young or old, everywhere. As we have learned from numerous parents, family members, nurses, physicians, social workers, child life specialists, art therapists, music therapists, dance and movement therapists, and many others who generously contributed their time and expertise to our Task Force, we have much work to do in order to fulfill this promise to dying children and their families, throughout the Commonwealth of Pennsylvania. At the same time, we heard many stories of how the promise of high-quality pediatric palliative and hospice care, when it was properly delivered, made a world of difference in the lives of these children and their families. The task before us, then, is to clearly understand how and why the current healthcare and human services delivery system is not always delivering on this essential promise, the problems and barriers that confront access to the services these types of care offer, and how to take specific recommended actions that will move us forward toward our goal of providing pediatric palliative and hospice care for every child and family in need.

CORE THEMES AND RECOMMENDATIONS

FIVE OVERARCHING THEMES AND CHALLENGES

The diverse and dedicated membership of Pennsylvania's Pediatric Palliative and Hospice Care Task Force identified many types of problems and barriers that impair the quality of care delivered to children with life-limiting illnesses/life-threatening conditions and their families. Thus, we present on the following pages a summary of the five major overarching themes and challenges that emerged from our careful review of the Task Force Subcommittees' work.

THEME #1: URGENT, UNMET NEEDS

- **The Current Healthcare and Human Services Delivery Systems Do Not Adequately Address the Urgent Yet Unmet Needs of Children with Life-Limiting Illnesses/Life-Threatening Conditions or the Needs of Their Families.**

Many families and healthcare workers participating in the Task Force process agreed that children who are dying experience uncontrolled pain and are plagued by oppressive symptoms (e.g., nausea, loss of appetite or energy, difficulty catching their breath, etc.). Published scientific literature also backs up their claims of inadequate pain and symptom management for dying children. This underscores the need to convert published research into the practical application of current and proven best-practices for improving palliative and hospice care.

Throughout the Task Force process parents lamented about how they would have liked to have learned sooner about the benefits of pediatric palliative and hospice care for their child. In fact, once many of these families had been introduced to the concepts of palliative and hospice care, which typically provide for an enhanced quality of life for the child, they still had to fight to obtain these services for their child. These shared sentiments are red flags, signaling the need for changes both within the healthcare system *and* the community at-large. In fact, almost every member of the Task Force shared their concerns about how the care of dying children is compromised by the daunting complexity of navigating the healthcare and human services delivery systems, the insurance companies, and their respective regulations. Making these systems more user-friendly needs to be a top priority.

Many parents and family members reported that they experienced stifling isolation upon the diagnosis of their child's life-limiting illness/life-threatening condition as well as when they opted to incorporate palliative and hospice care into their child's care. No parent should feel abandoned as they confront life and death decisions regarding the care of their child, but this is precisely what they experienced. Clearly, communication between parents and physicians must be improved regarding their child's health status, disease prognosis, likely death process, and all of their healthcare options, including palliative and hospice care. Healthcare professionals need to learn how to better communicate with and support parents of children with life-limiting illnesses/life-threatening conditions as they make thoughtful and loving decisions on behalf of their child.

And what about the needs of the brothers and sisters of these seriously-ill children? Metaphorically, and too often literally, they are off in the corner, huddled-up by themselves, trying to cope with the overwhelming situation which befell their family. Unintentionally, the needs of siblings of children with life-limiting illnesses/life-threatening conditions are overlooked. The time and attention these Siblings get is a small fraction of what they otherwise would have received, had their brother or sister not developed a life-limiting illness. These siblings need help and gentle guidance in understanding what is occurring with their loved one. Siblings and their parents need to be coached and counseled on how to communicate and interact with each other regarding the seriously-ill child's condition and the possibility of their death.

THEME #2: COORDINATION, COMMUNICATION, AND ACCESS

- **The Current Healthcare System for Children with Life-Limiting Illnesses/Life-Threatening Conditions is Impaired by Poor Coordination, Poor Communication, and Limited Access.**

As previously mentioned, all Task Force members emphatically agreed that the care of children with life-limiting illnesses/life-threatening conditions is currently poorly coordinated. This is a major systems failure. There are no agreed upon standards of practice for the delivery of high-quality pediatric palliative and hospice care services. This lack of standards results in poor consistency and quality of care for children and families. Furthermore, impaired coordination of care occurs at several levels, and has accordingly different problematic

consequences. At the level of interactions between parents and healthcare providers (e.g., physicians), poor communication can result in misinformed or stalled decision-making processes, with the patient suffering as a result. At the level of interactions between different healthcare providers, doctors and nurses at one site-of-care (e.g., the hospital) too often do not communicate a change in the medications or therapies that a child patient is supposed to be receiving to the doctors and nurses at another site-of-care (e.g., the home community). This sort of situation can lead to medical mishaps. At the level of interactions among healthcare providers and insurance companies, poor communication and coordination can result in the failure to deliver necessary services (e.g., therapies, prescriptions, medical equipment) to the patient's home in time.

The Task Force membership also produced ample evidence that patients' and families' access to important, even vital, services is limited, if not completely lacking, for many Pennsylvanians. For example, many of Pennsylvania's communities do not have hospital palliative care teams; community-based hospice teams, respite for exhausted families, bereavement care for parents and siblings, or complementary and alternative medicine (CAM) therapies (e.g., art therapy for patients and siblings). There is also no coordination of these services for families once they leave the hospital setting with their child. Furthermore, families are at a disadvantage because there is no single point of contact to help them manage and navigate the myriad services their child may need once they are at home.

THEME #3: SKILLS, KNOWLEDGE, AND HABITS OF PRACTICE

- **Pediatric Palliative and Hospice Care Services are Inadequate and Unavailable Due to a Lack of Education and Training for Healthcare Professionals and the Medical Community At Large.**

No one wants the quality of care their child receives to be little more than a roll of the dice. As a larger society, we expect that all healthcare professionals and organizations are constantly educating themselves and improving their practice standards. Unfortunately, this is not the case in the realm of care for dying children. Members of the Task Force confirmed, through their own experiences and through a review of published literature, that the availability of solid educational and training curricula for pediatric palliative and hospice care is limited. The effectiveness of existing curricula has not been thoroughly assessed, addressed, and

adequately implemented as demonstrated by the high levels of system confusion and inconsistencies in care. There are very few developed practice standards or guidelines available to organizations and these, too, have not been assessed to see whether or not they improve the quality of care.

Healthcare organizations tend to have fragmented plans (if any) to improve the knowledge, skills, and practice habits of their healthcare employees who provide services to dying children. Not only are effective educational methods needed to improve the management of pain and other symptoms using a holistic approach, but organizations also need to develop, implement, and evaluate their current practice guidelines.

The Task Force also noted that parents and other family members often have educational needs related to their child's disease progression and their family's ensuing decision-making processes. As time goes on, these needs can turn into deficiencies when they are not adequately addressed, leaving family members less empowered to care for their children. Furthermore, many healthcare professionals do not have the opportunity to benefit from quality educational options, training, or exposure to palliative and hospice care services. This can be especially challenging in the rural areas of Pennsylvania, where access to major medical institutions and innovations can be limited. Therefore, these professionals may be unaware of the full benefits of optimal implementation of pediatric palliative and hospice care for any patients they may encounter.

It should also be noted, that in the instance where clinicians are aware of palliative and hospice care options, some clinicians' personal biases may interfere with them properly sharing this information with families and offering a full array of options, inclusive of palliative and end-of-life measures. This leaves families at a severe disadvantage in being able to consider all of their child's care options. Subsequently, these missing pieces of knowledge could negatively impact a families' access to optimal holistic care considerations for their child.

Many of the recommendations about "best-practices" regarding medical interventions and decision-support are currently not backed-up by evidence-based research. More research is needed to confirm that newer pediatric palliative and hospice care "best-practices" and innovations actually work, make the child more comfortable, and help their parents confront

daunting decisions. This lack of scientific evidence impairs the quality of care that dying children and their families receive. Furthermore, there are no established statewide advocacy groups or clearinghouses that can provide these families with reliable resources and information to assist them in acquiring services and knowledge that will help with their decision-making processes.

Other members of the community (e.g., school nurses and principals) also have educational guidance and medical consultation needs regarding how to best serve children with life-limiting illnesses/life-threatening conditions on an individual basis, that properly trained palliative and hospice care professionals should be able to provide with researched and evidence based practices.

THEME #4: DAUNTING DECISIONS

- **Families Experience Isolation and Tremendous Guilt while Making Challenging and Painful Decisions Throughout Their Child's Course of Care Due to a Lack of Support, Information, and Options.**

Parents of children who are dying from life-limiting illnesses and life-threatening conditions come face-to-face with one of the most extreme worst-case scenarios imaginable - *the death of their child*. Many of our Task Force Families told story after story about the decisions they struggled to make, how helpful it would have been to have all of their child's pertinent medical information presented to them clearly and compassionately from the outset, and how useful it would have been to have support as they struggled to make decisions that were in the best interest of their child. Oftentimes, families shared how they did not receive information about their child's prognosis, the disease progression, their child's life-expectancy, and solid information on palliative and hospice care service options. In the rare instances where families did obtain information on pediatric palliative and hospice care, it was shared with them in a brief, brusque, and/or dismissive manner. Parents did not receive the support they sought, but instead encountered criticism, rejection, or refusal to honor their decisions. These parents did not have any means to appeal or have their child's healthcare providers' decisions actionably adjudicated upon. Instead, they had to struggle to find other physicians or healthcare organizations that would collaborate and partner with them. These experiences left some parents demoralized,

others irate, and all of them keen to see put in place a better means to ensure that decision-making surrounding pediatric palliative and hospice care is more forthright, transparent, skillful, unbiased, well-informed, and ethical.

It must be noted that families may not be introduced to the concepts of pediatric palliative and hospice care until well into a child's disease process. This is sometimes due to a physician's inaccurate/incorrect perception that they will have to stop providing certain medical interventions if they begin introducing palliative care to a child's treatment protocol. Also, some physicians do not understand the benefit of introducing palliative care services earlier in a child's disease process to aid in controlling pain and managing symptoms related to the child's disease progression. Ideally, palliative care would begin at the point of a child's diagnosis and continue throughout the course of the illness. If the disease becomes life-limiting, palliative care services will continue throughout the introduction and delivery of hospice care.

At the same time, healthcare clinicians spoke about how difficult it can be to figure out how to break bad news to parents; to talk about the alarming possibility that their child might die or the inevitability of death; to introduce the options of pediatric palliative and hospice care to a family; and to balance the hopes of a cure or longer life with the hopes for comfort and dignity. These clinicians, on behalf of themselves and their colleagues, spoke up for the needs of better education and skill building regarding having difficult conversations with families and supporting these families' decision-making processes and decisions. They also asserted the need for evidence-based research that can guide their profession towards better standards of practice.

CHALLENGE #5: DEFICIENT FUNDING AND DIFFICULT FINANCIAL REALITIES

- **Children and Families Do Not Get the Medical Care and Financial Services They Need and Deserve *and* are at High Risk of Becoming Financially Devastated Due to Inadequate Financial Assistance and Poor Funding for Programs and Services.**

The final major challenge consistently cited by the Task Force Subcommittees explores: (1) the deficiencies of funding for direct patient care *and* for program development/enhancement; and (2) the catastrophic financial toll on families of providing proper support for a child with a life-limiting illness/life-threatening condition, while maintaining their family's financial stability.

With respect to the first identified financial challenge, the current reimbursement system is non-existent for pediatric palliative care and extremely limited for pediatric hospice care services. Due to minimal reimbursement levels and funding sources (e.g. grant programs), it is extremely difficult for healthcare providers to offer high-quality palliative and hospice care options for children. In some instances, the money and funds for reimbursement are difficult, cumbersome, or confusing for providers to access. In other instances, the existing pot of funding is simply too little to motivate healthcare organizations to provide or improve pediatric palliative or hospice care services. Additionally, alternative programmatic funding sources are minimal. This subsequently limits a healthcare provider's ability to employ evidence-based practices that would yield the development and/or enhancement of pediatric palliative and hospice care programs throughout Pennsylvania.

With respect to our second financial challenge, the intensive care and services children with life-limiting illnesses/life-threatening conditions require consists of many medical and therapeutic appointments, coupled with long stays in hospitals that may be far away from the family's home. It is often true, due to the child's intense medical needs, that one or both parents may need to leave their job in order to accompany their child to medical appointments and provide them with the type of around-the-clock care they need at home. The loss of any income to these families is devastating and can have a negative financial impact not only on the availability of resources the child with the life-limiting illness/life-threatening condition will require to supplement their healthcare needs, but also on the day-to-day living expenses and needs of other family members living in that household. Throughout the Task Force process members shared that when the added layer of healthcare costs piled onto their family budgets, along with the loss of one or more income streams, families had difficulty affording to pay for a long list of items, including, but not limited to: electricity bills, rent/mortgage payments, utility services, transportation costs, general family insurance premiums, prescriptions, food, and hotel costs (e.g., when visiting their child in a distant hospital).

FIVE CORE RECOMMENDATIONS AND SOLUTIONS

The members of Pennsylvania's Pediatric Palliative and Hospice Care (PPHC) Task Force made numerous recommendations regarding how the Commonwealth of Pennsylvania can improve the quality of pediatric palliative and hospice care services to better meet the urgent and unmet needs of children with life-limiting illnesses/life-threatening conditions and their families. After our Subcommittees developed these many recommendations, we set forth below five core recommendations that we, as a Task Force, believe should be enacted as soon as possible. The Task Force membership believes that the accomplishment of these five core recommendations will set in motion many additional changes, actions, and developments that will improve, immediately and well into the future, the quality of pediatric palliative and hospice care provision throughout Pennsylvania.

RECOMMENDATION #1: ESTABLISH A PERMANENT GOVERNMENT ENTITY

- **Establish a Permanent Bureau or Division Under the Medical Director's Office within the Office of Medical Assistance Programs (OMAP) that is Responsible for Pediatric Palliative and Hospice Care Services.**

Though it is true that our Task Force hopes for a day when all the challenges and barriers enumerated previously have been resolved, we know that such a day of resolution is far away. Therefore, we must plan accordingly and prepare for the long-term implementation of many of the ideas and recommendations imparted in this Report, even as we strategize to make progress quickly in the short-term.

A key element in our plan is the creation of a permanent government entity that can accomplish and oversee the implementation of the recommendations set forth in this Task Force Report. We specifically recommend that Pennsylvania's Department of Public Welfare create a permanent Bureau or Division under the Medical Director's Office within the Office of Medical Assistant Programs (OMAP). This newly established Government Entity will be charged with the following responsibilities:

- A. Fulfilling the recommendations of the PPHC Task Force, as set forth in this report;
- B. Meeting regularly and routinely with Stakeholders and Advocates *and* soliciting and facilitating their input regarding existing or pending projects or programs;
- C. Establishing and overseeing statewide PPHC Regional Centers of Expertise;
- D. Inclusively collaborating with Stakeholders to set standards of pediatric palliative and hospice care, education, training, and quality improvement for hospitals, hospice programs, homecare agencies, and alternate residential and facility settings;
- E. Facilitating healthcare organizations' efforts to improve the quality of pediatric palliative and hospice care;
- F. Establishing clear policy and regulatory guidance regarding existing rules or laws, and if need be assisting with the formulation and enactment of new rules or laws, regarding:
 1. Reimbursement of services;
 2. Funding support for pediatric palliative and hospice care programs; and
 3. Aspects of medical care pertaining to children with life-limiting illnesses/life-threatening conditions; and
- G. Facilitating an *ad hoc* problem-solving advisory unit of professionals who are trained in pediatrics, palliative care, and end-of-life issues. This advisory unit will offer information and advice on clinical, logistical, and ethical issues, for individual children, families, and professionals.

RECOMMENDATION #2: ESTABLISH A STATEWIDE PPHC COALITION

- **Establish a Statewide Pediatric Palliative and Hospice Care Coalition Comprised of Family Members and Professionals, for the Purposes of Advocating for the Needs of Children with Life-Limiting Illnesses/Life-Threatening Conditions and Their Families, Raising Public Awareness, and Disseminating Information.**

As the Subcommittee Chapters of the Final Report detail, children with life-limiting illnesses/life-threatening conditions and their families too often needlessly suffer - *and have done so largely in silence*. A crucial step forward in reducing families' suffering is to end this silence by connecting isolated stakeholders with key decision-makers in order to mutually educate each other and advocate for the improved access to and delivery of high-quality pediatric palliative

and hospice care services. To this end, the Task Force recommends the immediate establishment of a broad-based statewide Pediatric Palliative and Hospice Care Coalition of stakeholders, including family members and healthcare professionals. We encourage this Pediatric Palliative and Hospice Care Coalition to assume the responsibilities of:

- A. Advocating for pediatric patients' and their families' rights to excellent pediatric palliative and hospice care by meeting with various government, healthcare, and community entities, in order to:
 1. Represent the general sentiments, arguments, and positions of patients with life-limiting illnesses/life-threatening conditions and their families;
 2. Provide direct input and feedback to decision-making entities regarding pediatric palliative and hospice care issues;
 3. Actively support policy and legislative changes that improve patients and families access to pediatric palliative and hospice care; and
 4. Inform, support, and defend the very tough decisions families must make for children with life-limiting illnesses/life-threatening conditions.
- B. Collaborating with a newly established Government Entity and any regional pediatric palliative and hospice care programs to create standards of care, provide education and training opportunities, and support high-quality, programmatic improvements for hospitals, hospice programs, homecare agencies, and alternate residential settings.
- C. Collaborating with both the legislative and executive branches of government to accomplish the recommendations set forth in this report.
- D. Assisting with *ad hoc* problem solving for individual patients and families.
- E. Developing accurate and user-friendly information resources (i.e., accessible via the Internet, a toll-free telephone call, or in printed copy) regarding issues ranging from clinical information about specific conditions or diseases, details about treatments and their pros and cons, descriptions of pediatric palliative and hospice care, the practical applicability of medical ethics in common situations, an overview of how health insurance coverage basically works in assisting with issues of benefits management, and community resources for services or equipment.

RECOMMENDATION #3: ESTABLISH PPHC REGIONAL CENTERS OF EXPERTISE

- **Establish a Statewide Network of Pediatric Palliative and Hospice Care Regional Centers of Expertise across Pennsylvania to Provide Leadership in Pediatric Palliative and Hospice Care Regarding Clinical Consultation, Family Advocacy, Education, Professional Development of Clinicians, and Research.**

To rapidly improve the quality of pediatric palliative and hospice care, we should focus not only on fixing problems and remediating weaknesses, but also on building strengths and expanding existing expertise. Throughout the Task Force process, we learned about children's and families' experiences with both suboptimal care and extraordinary care. All of these differing stories raised the question: *How do we further develop and better distribute high-quality pediatric palliative and hospice care skills and services to children and families throughout Pennsylvania?* More specifically, how do we:

- Educate and train medical, nursing, and social work students and junior clinicians in pediatric palliative and hospice care?
- Continue the education and training of established clinicians in the field of pediatric palliative and hospice care?
- Enhance the effectiveness of pediatric palliative and hospice care quality improvement programs in diverse healthcare organizations?
- Promote the conduct of clinical research that is crucial to improving the quality of pediatric palliative and hospice care?
- Enable and ensure that ethically problematic situations are handled with adequate knowledge and support to reach ethically appropriate decisions?
- Accomplish these tasks in a manner that is collaborative and works to build the next generation of leadership?

Many of the Task Force Subcommittees developed the concept of creating Regional Centers of Expertise in response to the questions listed above. Specifically, Subcommittees recommend that the Commonwealth of Pennsylvania create, fund, and sustain a network of Pediatric Palliative and Hospice Care Regional Centers of Expertise, issuing a request for applications that details the expected responsibilities of these Centers, which likely would include:

- A. Promoting significant active partnership and collaboration at any given Center among several regional healthcare organizations serving children with life-limiting illnesses and life-threatening conditions. A potential list

of these organizations would include hospitals, hospice programs, home nursing agencies, alternate residential facilities, and medical daycares.

- B. Developing, though a collaborative process among the Centers:
1. A common document specifying pediatric palliative and hospice care standards of clinical practice that aim, over time, to become best clinical practices;
 2. A standard core pediatric palliative and hospice care curriculum that can be taught to all medical, nursing, and social work students, *and* subsequently evaluating the effectiveness of this curriculum and improving it;
 3. A regional repository for information pertinent to pediatric palliative and hospice care; and
 4. A regional consultative program that would enable:
 - i. Parents, older pediatric patients, or clinicians to obtain information and guidance; and
 - ii. New or established clinical programs to obtain guidance about program development and quality improvement.
- C. Mounting continuing educational programs for all clinicians, by:
1. Expanding access to existing programs such as Training the Trainers or End-of-Life Nursing Education Consortium (ELNEC);
 2. Developing new programs as needed; and
 3. Working with the systems of continuing medical education for physicians, nurses, social workers, and other clinicians.
- D. Conducting program quality improvement evaluations for established practices (e.g., assessment of pain and other symptoms) *and* for new practices and technological innovations (e.g., telemedicine, telehealth, the use of remote monitoring). These quality improvement evaluations should be evaluated through rigorous clinical research, that subsequently circulates its findings broadly.

RECOMMENDATION #4: PROGRAM FUNDING AND FAMILY FINANCES

- **Establish, Provide, and Facilitate Funding for Program Development and Maintenance, Direct Patient Care, and Family Support.**

The membership of the Task Force identified two major challenges with the common issue of funding and finances: (1) the deficiencies of funding for direct patient care *and* for program development/enhancement; and (2) the catastrophic financial toll on families of

providing proper support for a child with a life-limiting illness/life-threatening condition, while maintaining their family's financial stability.

With these challenges in mind, we recommend the Commonwealth of Pennsylvania:

- A. Develops additional mechanisms of financial assistance for families that have lost or lowered income streams due to a child's life-limiting illness/life-threatening condition. Such mechanisms may take the form of a Children's Catastrophic Illness Fund, additions to the Family Medical Leave Act programs, and private philanthropic organizations and foundations;
- B. Creates crystal-clear and user-friendly guidance for service providers about how to correctly and optimally bill for pediatric palliative and hospice care services that are rendered;
- C. Evaluates the adequacy of current reimbursement and other funding mechanisms to cover the total costs of pediatric palliative and hospice care programs *and*, in the process, determines whether optimized billing practices are sufficient to cover these costs;
- D. Eliminates the regulatory guidelines and policies prohibiting children with life-limiting illnesses/life-threatening conditions from simultaneously receiving in-home nursing care, palliative care services, and hospice care services. In addition, the Commonwealth should clarify and affirm, through use of newly established regulatory guidance, the appropriateness of children with life-limiting illnesses/life-threatening conditions simultaneously receiving both in-home nursing services and home health services that provide palliative and hospice care;
- E. Rigorously studies the cost implications of increasing access to high-quality pediatric palliative and hospice care services from the perspective of families, healthcare organizations, healthcare payers, and society;
- F. Increases the level of reimbursement of rendered services and establishes performance-based incentives to healthcare organizations that provide pediatric palliative and hospice care services. This will assist in financing any shortfalls of funding due to insufficient reimbursement;
- G. Creates crystal-clear and user-friendly guidance for families and care providers about how to correctly and optimally apply for and receive cash assistance; and
- H. Explores the establishment of grant programs that aim to promote the development of new pediatric palliative and hospice care programs within Pennsylvanian healthcare organizations that currently do not have such programs. The establishment of such programs would work to ensure a safety net of pediatric palliative and hospice care programs across Pennsylvania and to promote the improvement in the quality of existing

programs. Specific attention should be paid to enhancing the capacity and quality of case management and systems navigation offered by these programs.

RECOMMENDATION #5: Range, Depth, and Regional Distribution of Services

- **Improve the Quality and Enhance the Availability of Services Related to Pediatric Palliative and Hospice Care.**

While core elements of pediatric palliative and hospice care programs must provide effective interventions to minimize patients' pain or other forms of suffering, *and* simultaneously empower ethical decision-making, the Commonwealth must promote the development of programs that can address other urgent and unmet needs. Specifically, Pennsylvania should develop mechanisms and funding whereby pediatric palliative and hospice care programs can effectively:

- A. Develop and improve care offered to the siblings of children with life-limiting illnesses/life-threatening conditions. This would include greater access to age-appropriate interventions that would address the challenges of having a seriously-ill sibling and promoting positive adaptations for the entire family;
- B. Address the need for the simultaneous delivery of in-home care nursing, palliative care, and hospice services to children with life-limiting illnesses/life-threatening conditions. In other words, eliminate any system barriers that would not allow for these different services to be offered and accessed simultaneously in a family's home;
- C. Evaluate and improve access to and the quality of grief and bereavement services for all family members;
- D. Develop and expand programs that provide respite and pediatric residential hospice for families of children with life-limiting illnesses/life-threatening conditions. These programs would evaluate the impact of respite upon family function and family members and build evidence regarding the positive impact of respite and pediatric residential hospice;
- E. Develop and improve methods of complex case management for families, both inside and outside of the hospital setting, which includes assistance with families' financial needs and challenges;
- F. Develop and evaluate methods of medical record keeping that are easily accessed and shared between various healthcare organizations;

- G. Expand the access children with life-limiting illnesses/life-threatening conditions have to daycares and schools for educational purposes;
- H. Provide appropriate transportation to children with life-limiting illnesses/life-threatening conditions to and from different medical appointments, therapies, and community activities (e.g., school). Such transportation should also enable children to get to appointments, therapies, and activities that are across county lines, without having to change transportation services/vehicles;
- I. Immediately enable referrals to pediatric palliative care services at the time of a child's diagnosis; and
- J. Establish a system of Coordinated Care Managers and Navigators that can span all levels of care and services needed by children with life-limiting illnesses/life-threatening conditions and their families, both inside and outside of the hospital setting.