



E-NEWS

Released in conjunction with
the National Hospice and Palliative Care Organization

ChiPPS Pediatric Palliative Care Newsletter Issue #33; November, 2013

Produced by the ChiPPS E-Newsletter Work Group

- Donna Armstrong, MSW, CSW, Instructor, College of Social Work, University of Kentucky, Lexington, KY
- Connie Bergh, MSH, RN, CHPPN, Manager, Community PedsCare, Community Hospice of Northeast Florida, Jacksonville, FL
- Charles A. Corr, PhD, Member, Board of Directors, Suncoast Hospice Institute, Pinellas County, FL; Senior Editor
- Ann Fitzsimons, BS, MBA, Executive Director, here4U, Inc., Farmington Hills, MI
- Maureen Horgan, LICSW, ACHP-SW, Executive Director, Gentiva Hospice, Seattle, WA; Co-Chair
- Nathan Ionascu, MD, Bioethics Consultant, Westchester End-of-Life Coalition, Westchester County, NY
- Randy Johnson, MDiv, Chaplain, Pikesville Hospital, Pikesville, KY
- Kelly Cronin Komatz, MD, MPH, FAAP, FAAHPM, Clinical Medical Director, Community PedsCare Program, Medical Director, Pain and Palliative Care, Wolfson Children's Hospital and Wolfson Center for the Medically Complex Child at University of Florida, Jacksonville, FL
- Suzanne Toce, MD, retired neonatologist, Gunderson Lutheran Health System, La Crosse, WI
- Christy Torkildson, RN, PHN, MSN, PhDc, Chief Academic Officer, Unitek College, Fremont, CA; Co-Chair

Issue Topic: **The Affordable Care Act & Concurrent Care for Children: A Sampler**

Welcome to the thirty-third issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of a dozen articles that explore the subject of concurrent care for children, adolescents, and family members, along with examples of how concurrent care is being implemented in various regions of the United States. Our primary goals in this issue are to explain what concurrent care means for children, adolescents, and family members who are coping with life-threatening or life-limiting conditions, to illustrate advantages of this type of care especially in the face of end-of-life issues, and to address practical problems facing providers and others in its implementation. We hope that the articles in this issue and the comments they make about these newly developing opportunities for care will encourage greater recognition of the issues involved and of the care needed in these circumstances.

This newsletter is produced by ChiPPS (the Children's Project on Palliative/Hospice Services), a program



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



of the National Hospice and Palliative Care Organization and, in particular, by NHPCO's E-newsletter Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-newsletter Workgroup, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at christytork@gmail.com or Maureen at horgan.maureen@gmail.com.



Issue #33: The Affordable Care Act & Concurrent Care for Children: A Sampler

(Click on the "bookmark" tab on the left-hand side of the PDF document for links to the following articles.)

Life Line

p. 6

Scott Newport

Once again, our "resident" poet offers a poetic reflection, this time focusing on a parent's grief.

Pediatric Concurrent Care

p. 7

Judi Lund Person, MPH, and Gwynn Sullivan, MSN

Judi and Gwynn describe how the Patient Protection and Affordable Care Act (ACA) changed possibilities of care for pediatric palliative/hospice patients. They explain that while significant barriers remain, there are strategic opportunities for pediatric palliative and hospice care providers. Above all, they report that NHPCO encourages the formation of statewide pediatric palliative and hospice care advocacy coalitions/groups to work together toward improving care for children with life-limiting or life-threatening conditions and they note some helpful resources that are available from NHPCO to support these efforts.

Achieving Medicaid-Reimbursed Pediatric Palliative Care and Hospice

p. 10

Susan Kreutz Rogers, MS, BSN, RN, CHPN, and Karen Smith Thiel, JD, PhD

Susan and Karen explain how the District of Columbia Pediatric Palliative Care Collaborative and NHPCO worked together to develop about a "Concurrent Care for Children Implementation Toolkit" that provides detailed information on the options available to states to implement Section 2302 of the ACA and/or the expansion of pediatric palliative care services to children with life-limiting or life-threatening conditions. They stress the value of a coordinated, collaborative effort among children's advocates, family members, hospitals, hospice providers, and public agencies in this work.

The State of Care for Children in California

p. 14

Christy Torkildson, RN, MSN, PHN, PhDc

Christy reports that to date over 300 children have been served in California under section 2302 of the ACA. These results have been achieved under the leadership of the Children's Hospice and Palliative Care Organization in the state, California Children's Services, and many providers throughout the state. While recognizing these achievements, Christy notes areas in which there is more work to be done to meet the needs of all who are involved in this developing mode of care.

Florida's Implementation of Concurrent Care

p. 16

Stacy F Orloff Ed. D., LCSW, ACHP-SW

Stacy explains that although the state of Florida was one of the leaders in efforts to overturn the ACA, in fact prior to the passage of that legislation Florida had provided similar care to children and their families through a Medicaid waiver program. The program, Partners in Care: Together for Kids (PIC:TFK), was implemented in Florida in 2004 to provide opportunities for seriously-ill children and their families to receive palliative care while continuing to receive curative care for their life-limiting illnesses or conditions. As a result, over 500 children and their families are currently receiving care through PIC: TFK and thousands have received care since the program began. In addition, Florida has established a task force that is committed to resolving all issues that would affect successful implementation of concurrent care under the ACA.

Concurrent Care: An Illinois Perspective

p. 18

Kim Downing, RN, JD

Kim relates how an educational conference sponsored by the Greater Illinois Pediatric Palliative care Coalition in September, 2012, for hospice providers, state agencies, and policy makers helped overcome apprehensions relating to fiscal responsibilities, admission procedures, and billing logistics involved in implementing concurrent care in the state. Her article notes the great need for upfront education in order to rise above concerns from non-hospice providers and residual hesitations from some hospice providers.



She also reports that while Illinois signed into law during July, 2010, a Pediatric Palliative Care Act providing a pilot program with many good features similar to concurrent care, the program is currently unfunded because of budget cuts and collaborative efforts to develop an infrastructure for this project have ceased. Until work on this project is resumed, GIPPCC and dedicated clinicians are left to move forward with one concurrent case at a time.

Developing a Statewide Pediatric Palliative Care Coalition: The Story in Kansas **p. 20**

Kathleen G. Davis, PhD

Kathy explains that Kansas is a state with a relatively modest overall population that is largely concentrated in three metropolitan areas all in the eastern portion of the state. It did not have a pediatric palliative/hospice care coalition when the ACA was signed. She then provides a detailed description of efforts undertaken over a 15-month period to create such a coalition that could identify challenges and barriers to improved pediatric palliative/hospice care implementation in the state.

Benefits and Challenges of Concurrent Care for Pediatric Palliative/Hospice from Hospice's Point of View **p. 26**

Anne Wiedemann, MD, and Barbara Zimmaro, RN, MSN, CRNP, CHPN, HTP

Anne and Barbara argue on behalf of the benefits that the ACA offers to hospice programs while recognizing challenges involved in these new care opportunities. An extended case example illustrates the complexities of concurrent care and the article concludes with six recommendations to enhance the wellbeing of children and families.

Concurrent Care: Unraveling the Requirement to Improve Access to Care and Quality of Life **p. 30**

Diane Parker, RN, MSN, NE-BC, CHPN, CHPPN

Diane argues that the ACA provides new possibilities for child-centered and family-focused options in care. A lengthy case example demonstrates that, although concurrent care brings with it many challenges and complexities, "it far outweighs the old options."

Concurrent Care in Maryland **p. 32**

Susan M. Huff, RN, MSN

Sue describes the developing collaboration between hospice programs and pediatric services in Maryland, along with the emergence of a statewide alliance. She offers two successful examples of care being provided and two broad challenges that remain.

Concurrent Care for Children in Georgia: A Hopeful Update **p. 34**

Jennifer Hale, MSN, BS, RN, CHPN

Jennifer relates that when the Georgia Hospice and Palliative Care Organization first approached the state Department of Human Services, the latter was undergoing a major reorganization of its own. Rather than give up, a loose coalition of organizations and dedicated individuals sought to address issues associated with concurrent care. That effort flagged until late 2012 when new energies led to a successful workshop in spring 2013 and demonstrated the "power of perseverance" to provide desperately-needed care.

Concurrent Care in New Jersey **p. 36**

Mary Ann West, RN, MSN

Mary Ann explains that, contrary to expectations, the ACA did not provide The Butterflies Program with increased numbers of referrals or significant new challenges for most children beyond what the program had previously experienced in providing pediatric hospice care. However, in three case examples we see how end-of-life care was clearly enhanced under the provisions of concurrent care.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



Pediatric Concurrent Care Provision of the Affordable Care Act 2010

p. 37

Debra F. Fox, MS, FNP-BC, CHPN, CHPPN

Debra reports that her hospice and palliative care program has been designated by New York State as a pilot program to assess the feasibility and outcomes of the concurrent care model for terminally-ill children. She describes the potential benefits of concurrent care as "the beginning of a whole new chapter in hospice and palliative care," while also acknowledging some challenges that must be overcome, such as working in close collaboration with primary care physicians and specialists who have been with these children throughout their illnesses.

Reader's Corner

p. 39

Christy Torkildson, RN, MSN, PHN, PhDc

This contribution describes a journal article published in 2011 that offers a policy analysis of the pros and cons of health care reform and concurrent care for terminally-ill children.

Items of Interest

p. 40

ChiPPS customarily shares items that may be of interest to our readers.



LIFE LINE

By Scott Newport

scottandpenni@hotmail.com

Sailing with grief
Is like dragging
An anchor

Occasionally her
Weight holds me
In one position
Both hooks
Wedged into
A shale ledge

Other times her
Grip slips
Leaving a puff
Of grey, silt
In the shape
Of an unfamiliar cloud

In deeper, off-shore water
I drift aimlessly
Amongst the dark,
Blue ocean's current-
Grief just
Hangs like an unresponsive
Red and white Yo-yo

I've thought about
Cutting her away

At times
But the fear of landing
In a foreign land
Isolates my lonely intent

At night, while under
The midnight stars
I wonder about
Cutting grief from
My life

In my thoughts I
See her lying limp on
The ocean floor
Waiting till the
Next wandering fisherman
Snags onto her

I can imagine her
Being wrenched aboard
And the sailor
Discovering the loss
Of his line

The fishermen's bobber
Floating away
And the grief starting
All over again



PEDIATRIC CONCURRENT CARE

Judi Lund Person, MPH

Vice President, Compliance and Regulatory Leadership
National Hospice and Palliative Care Organization
JLundPerson@nhpco.org

Gwynn Sullivan, MSN

Director, Access
National Hospice and Palliative Care Organization
gsullivan@nhpco.org

How the Affordable Care Act (ACA) Changes Care for Pediatric Palliative Care Patients

For many years, healthcare professionals and families with children living with life-limiting or life-threatening conditions had few options for Medicaid coverage when children were very seriously ill. Parents in all but a few states were faced with forgoing curative treatments for their children to be eligible for hospice services. Or conversely, they were not eligible for beneficial interdisciplinary hospice services while getting curative treatment.

The Patient Protection and Affordable Care Act (ACA) changed that situation. It requires all state Medicaid programs to pay for both curative and hospice services for children under age 21 who qualify. On March 23, 2010, President Obama signed ACA into law enacting a new provision, Section 2302, termed the "Concurrent Care for Children" Requirement (CCCR).

Section 2302 states that a child who is eligible for and receives hospice care must also have all other services provided, or have payment made for, services that are related to the treatment of the child's condition. *[The full text of Section 2302 is included in the Patient Protection and Affordable Care Act, Subtitle D, Improvements to Medicaid Services. Public Law No. 111-148, as amended in Section 1905 of the Social Security Act.]* This provision affects children who are eligible for Medicaid or the Children's Health Insurance Program (CHIP). In its simplest form, implementation of this provision could be accomplished by the state Medicaid agency eliminating any provider claims that deny or delay concurrent curative care and hospice claims.

Significant Barriers Remain

While Section 2302 addresses what has been a significant barrier to enrollment of children into hospice care, this new requirement in section 2302 does not remove the major remaining barriers to providing a more expansive pediatric palliative care program, which are:

- Physicians must still certify that that child is within the last six months of life, if the disease runs its normal course.
- Children who qualify for this benefit remain limited to the existing array of Medicaid hospice services and other existing Medicaid services covered by a state. However, a child may be simultaneously enrolled in other programs that provide supplemental services such as home and community-based service (HCBS) waivers.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



While Section 2302 is a positive step forward in obtaining better care for children at the end of life, it does not expand the types of services that are available, nor does it provide palliative care or other supportive services to children with life-limiting or life-threatening conditions whose prognosis falls outside the last six months of life should the disease or condition follow its normal course.

Strategic Opportunities for Hospice and Palliative Care Providers

As states implement concurrent care for children, it is clear that hospices have an opportunity to develop specific pediatric expertise to care for children needing hospice care, and when allowed in the state, pediatric palliative care. However, the number of pediatric patients that need care is fairly small; as a result not every hospice in a particular community needs to have pediatric expertise. There may be opportunities for hospices to work together to provide pediatric care, or for referrals of pediatric patients to be directed to a smaller number of providers so that professionals with pediatric expertise can provide high quality care.

Conclusion

NHPCO encourages the formation of statewide pediatric palliative and hospice care advocacy coalitions/groups to work together toward improved options for children with life-limiting or life-threatening conditions. This includes providing increased services for children who would not qualify under the ACA provision and expanding the array of services for them.

It is important to remember that the implementation of Section 2302 of ACA, Concurrent Care for Children, is **required and mandated by CMS**. It is not optional. At the same time, Medicaid has been hit hard with budget issues and many new demands on staff time and resources. Requests for new benefits and services come at a time when states are strapped for money and are looking for any and all ways to trim services being offered.

NHPCO strongly encourages you to work together with other key stakeholders in your state with one voice. By understanding and being sensitive to the stress and strain in the state's Medicaid agency and the state budget, and through a collaborative and committed strategic approach, you have a true opportunity to make positive changes for children in your state.

Of all the key strategic approaches identified in the Toolkit for leveraging Section 2302, collaboration is the key! With collaboration, individuals, groups, and providers can have a unified voice, work to identify champions, and become strong advocates for your state's children. This is the way to succeed in securing the care and resources the families of these children desperately need. The ultimate goal is to assure that your state's most fragile children have the quality care they deserve.

Resources from NHPCO

Pediatric hospice and palliative care resources available at www.nhpc.org/pediatrics:

- *Pediatric Concurrent Care - Continuum Briefing*
- *Concurrent Care for Children Implementation Toolkit: Section 2302 of the Patient Protection and Affordable Care Act*
 - Questions and Answers on Concurrent Care for Children from CMS (February 2011 & May 2011)
- NHPCO's 14th Clinical Team Conference and Pediatric Intensive, Concurrent Session: *The Concurrent Care Requirement for Children with Life-threatening Illness - Successful Strategies for Implementation*. (PowerPoint)
- *NHPCO's Pediatric Palliative Care Online Training Series*



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



-
- *NHPCO's Facts and Figures on Pediatric Palliative Care and Hospice*
 - *NHPCO's Standards of Practice for Pediatric Palliative Care and Hospice*

Additional legislative advocacy materials and resources can be found at Hospice Action Network - www.hospiceactionnetwork.org.



ACHIEVING MEDICAID-REIMBURSED PEDIATRIC PALLIATIVE CARE AND HOSPICE

Susan Kreutz Rogers, MS, BSN, RN, CHPN

former Executive Director

District of Columbia Pediatric Palliative Care Collaboration

susan.k.rogers@verizon.net

Karen Smith Thiel, JD, PhD

Partner, Patton Boggs, LLP

kthiel@pattonboggs.com

On March 23, 2010, the Patient Protection and Affordable Care Act (ACA) was signed into law by President Barack Obama. Together with the Health Care and Education Reconciliation Act, it represents the most significant government expansion and regulatory overhaul of the country's healthcare system since the passage of Medicare and Medicaid almost 50 years ago. The ACA aims to increase the quality, affordability, and incidence of health insurance coverage for Americans and reduce the costs of health care for individuals, the federal government, and the states. Of special significance to children with life-threatening medical conditions and their families, ACA also included Section 2302, the "Concurrent Care for Children" Requirement (CCCR), which permits children enrolled in hospice care not to forego curative care.

Inclusion of CCCR in ACA paved the way for child advocates to work with the states to develop a Medicaid benefit for pediatric palliative care and hospice (PPCH) that could be provided in the child's home with medical and social supports for the child and family caregivers. In-home services are not only less costly than inpatient services, but often family members want their children to receive hospice services at home. To this end, the District of Columbia Pediatric Palliative Care Collaboration (DCPPCC) and the National Hospice and Palliative Care Organization (NHPCO) collaborated to bring about a toolkit, "Concurrent Care for Children: Implementation Toolkit" which provides detailed information on the options available to states to implement Section 2302 and/or the expansion of pediatric palliative care services to children with life-limiting (LL) or life-threatening conditions (LTC). The Toolkit provides a guide to:

- Understand the impact of the CCCR on state Medicaid programs;
- Consider the different Medicaid State Plan Amendment (SPA) and waiver options;
- Review a sample of existing comprehensive hospice and palliative care programs for children in states that have implemented such programs; and
- Learn how to develop a coordinated, collaborative state-wide approach for advocating for children with LL/LTC through a comprehensive array of services.

What is the CCCR and How Does it Impact the State Medicaid Programs?

For many years, healthcare professionals and families with children living with LL/LTC had few options for Medicaid coverage when children were very seriously ill. Parents in all but a few states were faced with forgoing curative/life prolonging treatments in order for their child(ren) to be eligible for hospice services. Or conversely, they were not eligible for beneficial interdisciplinary hospice services while getting curative treatment. Section 2302 of PPACA changed that situation, and now requires that every state and the District of Columbia's Medicaid program pay for both curative/life prolonging treatment and hospice services for children under age 21 who qualify. The District of Columbia's use of the SPA process to provide such care is described below.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



Existing Comprehensive Hospice and Palliative Care Programs for Children

The Toolkit also provides examples of states that have implemented the CCCR through other methods, including the Medicaid waiver process. Appendices 4-7 in the Toolkit, describe the mechanisms required by CMS to implement the CCCR, to implement changes to the Medicaid eligibility criteria, and/or to expand the scope of Medicaid services. They also discuss the circumstances in which a specific option is used, although individual states may have additional administrative, regulatory, statutory, or budgetary steps that are required prior to submitting either a Medicaid waiver or SPA.

Developing a Coordinated, Collaborative State-wide Approach for Advocating for Children

Achieving a change in Medicaid reimbursement for pediatric palliative and hospice care requires the development of a coordinated, collaborative effort among children's advocates, family members, hospitals, hospice providers, and public agencies. The Toolkit recommends that advocates:

- Build a coalition by identifying a group of individuals and organizations in your state such as disease-based groups, parent advocacy networks, and medical home providers, among others, to build a coalition of support for an expanded PPCH benefit for the state's children;
- Become familiar with the eligibility and scope of services currently in effect in your state;
- Gather data on the number of children affected, including, if possible, a differentiation between the number of children who would qualify for hospice services and those who would qualify for an expanded PPCH benefit;
- Understand the interest and preferences of the state Medicaid agency;
- Learn from other states;
- Develop a proposed program design and begin to articulate the types of changes for which you would like to advocate;
- Provide program cost information, as available;
- Determine the appropriate Medicaid option—SPA or waiver—to implement PPCH services;
- Build support and advocate for preferred option(s).

Regardless of your plan of action, the first and most appropriate steps include networking with others in your state to create a constituency that is strong in numbers and advocacy, and to begin conversations with your state Medicaid office early.

District of Columbia State Plan Amendment for PPCH Services

Applying all of the recommendations of the Toolkit, the DCPCC worked very closely with the District of Columbia's Department of Health Care Finance (DCDHCF) to establish a PPCH Medicaid benefit for children with LL/LTCs. After a series of efforts to advocate for a waiver, the DCDHC informed the DCPCC that a SPA approach would be the preferred option. CMS regulations had made the SPA process easier to negotiate and DCDHCF clearly was supportive of a Medicaid reimbursement for PPCA services. Over the course of the next year, DCPCC, NHPCO, and national pediatric hospice experts assisted the DCDHCF in its preparation for submitting the PPCH Medicaid SPA to CMS, including the certification and election processes, the nature of the interdisciplinary team, and the type and scope of services to be provided.

On June 11, 2012, the DCDHCF submitted its SPA to CMS to provide Medicaid reimbursement for PPCH services, consistent with ACA's section 2302. CMS reviewed the SPA and approved it effective August 1, 2012. DCDHCF then began to develop a Proposed Rule to add a new Section 940 to Chapter 9 of Title 29 of the District of Columbia's Municipal Regulations (DCMR).



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



Significantly, the Proposed Rule defined pediatric palliative and hospice care in the same manner used by DCPCC and the larger pediatric hospice advocacy community as "...an organized program for delivering care to children with life threatening conditions...that focuses on enhancing quality of life for the child and family, minimizing suffering, optimizing functions, and providing opportunities for personal growth." The Proposed Rule was issued on March 1, 2013 with a sixty-day comment period. Due to the widespread support for the benefit among District of Columbia-area hospitals and hospice providers, the DCPCC, NHPCO, and parents of children needing PPCH services, there were no comments to the Proposed Rule. The Final Rule was published on August 2, 2013, and the PPCH Medicaid benefit in the District of Columbia became effective that day.

Children under the age of 21 who are eligible for Medicaid and certified as terminally ill are eligible for the program. The hospice medical director or the physician member of a hospice's interdisciplinary team, and the child's attending physician, specialty care, or primary care physician must certify that the child's life expectancy is six months or less. Certification is for an initial 90-day period followed by a second 90-day period and any subsequent period of 60 days (or one or more 30-day extended election periods) provided there is written certification from the hospice's medical director or the child's attending physician, specialty care, or primary care physician. The election statement must be filed with the participating hospice provider.

An election to receive PPCH does not constitute a waiver of the child's rights to receive concurrent treatment services. A parent or legally authorized guardian must file the PPCH election statement for a child under the age of 18, but children age 18 through age 20 may file the election statement on their own or through a legally authorized representative. The PPCH election may be revoked by filing a revocation statement which does not preclude the child from re-electing PPCH services at a later date.

PPCH services may be provided by a hospital, a hospice that is enrolled in the Medicare program, or a home health agency enrolled in the Medicare program that meets the requirements for the District of Columbia's Health-Care and Community Residence Facility, Hospice and Home-Care Licensure Act. All PPCH services must be provided in accordance with a written plan of care that is developed by the pediatric interdisciplinary team consisting, at a minimum, of a hospice medical director or pediatrician, a nurse or pediatric nurse practitioner, a licensed social worker, a counselor, a child life specialist, and a spiritual care provider. The following services qualify as covered PPCH services with some limitations on levels of care-related per diem reimbursement:

- Physician services;
- Pediatric nursing services (provided by a registered nurse who is certified by the National Board of Pediatric Nurse Practitioners or the Pediatric Nursing Certification Board);
- Child life specialist services, consisting of play and psychological therapies to facilitate coping and adjustment of the child and to establish a therapeutic relationship with the child and family members that helps the family's involvement in the child's care;
- Counseling services (pastoral, spiritual, bereavement, as necessary)
- Nutrition counseling;
- Homemaker services, home health aide services, and personal care aide services;
- Medical social services provided by a licensed social worker;
- Durable medical equipment and supplies;
- Pharmacology and pharmacy services for pain control and symptom management;
- Physical, occupational, and speech therapy services;
- Expressive therapies, if necessary;
- Massage therapy, if necessary; and
- Respite care for the child's family or other persons caring for the child at home.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



Medicaid-enrolled providers who are treating children enrolled in PPCH who are receiving concurrent curative treatment will be reimbursed by the DCDHCF under the authority of the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services benefit.

Conclusion

Both the Medicaid waiver process and the SPA process are vehicles to achieve Medicaid reimbursement for PPCH for children with LL or LTCs, but the process requires advocacy, analysis, cooperation, and steadfastness among child advocates and public agencies. Ultimately the range of services available to children and their families, as demonstrated by the recent DCDHCF-approved Medicaid SPA and Final Rule, will assure that children receive the PPCH services they need while not foregoing curative treatments.

Notes:

Election statements must identify the PPCH provider that will provide care to the child, acknowledgements that the child or their representative has been given a full explanation of the palliative rather than curative nature of PPCH services and that the child or child's representative understands that a PPCH election is a waiver of Medicaid services from another hospice provider or from a provider that duplicates PPCH services, the effective date of the election and the signature of the child (if age 18 or older) or the child's representative.

PPCH providers are reimbursed on a per diem basis for one of four levels of care: routine home care; continuous home care (to maintain the child in his or her home during a brief period of crisis lasting 72 hours or less); general inpatient care for pain control or acute or chronic symptom management provided in either an approved freestanding hospice or hospital; and inpatient respite care or short-term care to relieve family members caring for the child at home when the child does not meet the requirements for either continuous care or general patient care. Rates for each of these levels of care will be set by CMS's Hospice Wage Index guidelines and posted on the DCDHCF website at www.dc-medicaid.gov.

Links:

Concurrent Care for Children Implementation Toolkit Requirements:
http://www.nhpco.org/sites/default/files/public/ChiPPS/CCCR_Toolkit.pdf

DC Concurrent Care for Children SPA: contact Susan K. Rogers, MS, BSN, RN, CHPN at susan.k.rogers@verizon.net to obtain the DC SPA pages:

DC Concurrent Care for Children Rule Section 940, go to Chapter 9 of Title 20 of the DC Municipal Regulations:
http://regs.cqstatetrack.com/info/get_highlighted_text?action_id=507200&text_hits=&text_id=509049&type=action_text



THE STATE OF CARE FOR CHILDREN IN CALIFORNIA

Christy Torkildson, RN, MSN, PHN, PhDc

Co-Chair and Co-Editor; ChiPPs e-Newsletter
Doctoral Student ABD, UCSF School of Nursing
Departments of Family Nursing and Social Behavioral Sciences
Chief Academic Officer, Unitek College
christytork@gmail.com

There are some very good articles in this issue and I hope the lessons learned and shared will help with the work in your individual geographical area, region, state, and nation. Much has changed over the past three years in the landscape of services for medically fragile children. The Affordable Care Act (ACA), section 2302 allows for concurrent care for children—meaning children who are currently receiving life-prolonging, life-sustaining, or curative therapies can now also receive expert hospice services at the same time. Children must still meet the requirements for hospice in their state. For most that still means a 6-month prognosis; however for most, they do not have to forego or make a decision to limit services or treatments as they had to in the past. As you will note in several of the articles in this issue, implementation has not been without its challenges but overall the news is quite positive.

Unfortunately, this progress does not extend to integrating the principles of palliative care into the care of all medically fragile children and still does not address one of the primary barriers to hospice for children—the 6-month prognosis. Nor does this apply to all children who would benefit by this model of care but is specific to children who are funded by Medicaid or MediCal as it is known in California. Medically fragile children are being defined as children with complex chronic or acute medical conditions as well as children with life-threatening or life-limiting conditions for this article. California was the third state to implement a pediatric palliative care home and community-based Medicaid waiver to provide pediatric palliative care services to medically fragile children. California is also one of the first states to implement concurrent care. This article will review the state of this care for children in California.

Concurrent care became a reality in California almost three years ago. Similar to many other states the initial challenges were with billing. Providers worked with the state while processes were figured out and enrolling children into concurrent care was put on hold while these systems were created and implemented. The leading advocate organization helping to facilitate and coordinate these efforts, working with both state and providers, was the Children's Hospice and Palliative Care Organization, Executive Director and Co-Founder Devon Dabbs. Leading the effort for the state was Dr. Jill Abramson. Many of the guidelines and processes developed can be found on the California Children's Services website.

To date over 300 children have been served under the ACA section 2302 in California. The state has worked diligently to fix any barriers to the provision of services, working with providers to streamline processes and maintain open lines of communication. Services provided are traditional hospice services: nursing care coordination, pain and symptom management, social work, and spiritual support, as well as any services deemed palliative in nature. However, one treatment not covered under concurrent care is palliative chemotherapy. Services considered curative or necessary "to maintain the status of the child" fall outside of the hospice scope of care. The consistent requirement for any services under MediCal (Medicaid) is no duplication of services meaning that if a child is receiving a service from one provider another cannot provide the same service. A significant challenge for concurrent care has been hospitalizations. The state has provided no specific direction on this issue, but the majority of statewide providers have agreed that if a child is hospitalized for 2 weeks, they are discharged from hospice; in hospitalizations less than 2 weeks, they stay on service. Expressive therapies, which are a covered service under the palliative care waiver, are an unreimbursed service for the hospice agency under



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



concurrent care, and as such are generally not offered as a concurrent care service. Providers report, however, that these services (art, massage, music, etc.) when offered have turned out to be a major benefit to children and families and are one of the most highly rated in satisfaction surveys. As one provider stated, "I have always felt that the expressive therapies were, well, ho hum, **but** they have been so positive, especially music therapy. I was not a believer, but we have had impressive results with expressive therapies; I'm a believer now!"

Although concurrent care is a Medicaid provision, providers report that private insurers are starting to also approve concurrent care. Please note this is on an individual case-by-case basis and is not only dependent on the child, but also on the circumstances or situation and the third party payor. The principle barrier to services for children in the state of California is the limited number of community-based providers willing to care for children. The dearth of providers is also one of the primary challenges facing the "Partners for Children" home and community-based waiver for pediatric palliative care services. Unfortunately, the Partners for Children waiver is struggling, due to a shortage of qualified pediatric providers and limited reimbursement rates. The state has responded to these concerns and several changes have been made and implemented recently including a monthly administrative fee and changes to the billing/payment system for greater efficiency. These steps have paved the way for greater sustainability on the part of providers, thus impacting both retention and recruitment. The waiver was initially approved for 3 years as a demonstration home and community-based 1915c waiver. The evaluation required for the renewal demonstrated the exceedingly positive outcomes for children and families participating in the waiver, as well as demonstrated savings in avoided hospitalizations and length of stay. The waiver was renewed for a full 5 years earlier this year and is no longer considered a demonstration project in California. The waiver is still limited to specific geographical counties and participants must meet the medical need and eligibility criteria. To date, approximately 200 children have been served by the waiver with approximately 85 on service. As one provider stated, "concurrent care is great but it does not meet the needs of the majority of the children as the waiver could."

Although the landscape of care for children is improving much more change is needed to streamline services, increase reimbursement rates, and decrease barriers to services. Most importantly, providers are needed to care for children in the home and community.

This article is an excerpt from the dissertation work of the author. Special thanks to Devon Dabbs, Executive Director and Co-Founder of the California Children's Hospice and Palliative Care Coalition.



FLORIDA'S IMPLEMENTATION OF CONCURRENT CARE

Stacy F. Orloff, Ed. D., LCSW, ACHP-SW

Vice President, Palliative Care and Community Programs
Suncoast Hospice
Clearwater, Florida

Stacyorloff@thehospice.org

The state of Florida has been a leader in providing care to seriously-ill children seeking curative care and their families. Prior to passage of the Affordable Care Act, Florida provided similar care to children and their families through a Medicaid waiver program. In 2004 the state of Florida implemented a Medicaid waiver program, Partners in Care: Together for Kids (PIC: TFK), that provided opportunity for seriously-ill children and their families to receive palliative care while continuing to receive curative care for their life-limiting illness or condition. Florida is the first state in the country to do this. The goal of PIC: TFK is to ensure that all eligible children in the state of Florida have access to specific palliative care services while continuing to receive curative care.

Eligibility is based on accessing Medicaid as the healthcare payer and a physician attestation that the child has a life-limiting illness/condition and is not expected to live to age 21. A child and family could potentially be a recipient of services for years. What is remarkable about this program is that Medicaid reimburses hospices for palliative care provided to family members, even when the identified patient (the ill child) is not present for the care.

This innovative model allows qualified hospice providers to provide interdisciplinary palliative care to the entire family unit, including parents and siblings, and be reimbursed for this care. PIC: TFK services include: individual, family, and group counseling, nursing and personal attendant care, physician pain and symptom management consultation, volunteer support, and respite.

Over 500 children and their families are currently receiving care through PIC: TFK. Thousands have received care since the program began in 2004.

Florida was one of the lead states who filed suit against the federal government to overturn implementation of the Affordable Care Act. Until the final Supreme Court hearing that ultimately ruled in favor of the ACA, Florida hospices and the Agency for Health Care Administration (Medicaid) were not able to begin concurrent care. The positive outcome during this time is that the Partners in Care: Together for Kids program continued providing concurrent palliative care to many of the same children who would qualify for concurrent care; thus ensuring access to care for many children and their families.

During the time the legal process was unfolding, Florida Hospices and Palliative Care Association and the Agency for Health Care Administration (Medicaid) were working closely together, discussing early implementation questions and processes so that the state would be able to implement quickly when the legal issues were resolved. The PIC: TFK state steering committee kept concurrent care as a standing agenda item. The state also maintained an active presence on the pediatric policy calls facilitated by the National Hospice and Palliative Care Organization.

Florida is now following a detailed and deliberate process in implementing concurrent care. We wanted to ensure there would be very few impediments to the program, particularly in paying all providers. A state task force was created, with the goal to develop a seamless implementation process within 4 months. Members of the task force include representatives from Medicaid and the state hospice association. It was important that task force members had the authority to make decisions and positively impact implementation.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



Task force members were committed to resolving all issues that would affect successful implementation. We reviewed case studies, considered which Medicaid handbooks would need to be revised, identified non-hospice covered services a child might receive, and began discussions about the educational and informational sessions needed to inform all stakeholders. The task force developed a working project plan. This project plan has been instrumental in helping members stay focused on outstanding action steps and deadlines. We also believe this process has helped us to ensure we've not "left out" any important provider.

After only one face-to-face meeting and two conference calls, the task force was comfortable authorizing a pilot project, limiting implementation to 8 hospices across the state. We are carefully monitoring billing and payments to all vendors to ensure there are not any payment problems. We have one key person at our Medicaid state office who has agreed to be the point person for this level of review. We have been successful to date. Educational programs are currently being developed for statewide dissemination. The concurrent care task force will have one final conference call in October. At that time, we anticipate moving forward with a statewide implementation plan. This has been a true partnership between the Agency for Health Care Administration and Florida Hospices and Palliative Care Association.

Final thoughts: (1) although Florida has been late (as compared to many other states) in implementing concurrent care, our PIC:TFK program did provide access to care to many children in our state; (2) We wisely used the time during the federal lawsuit to begin some early planning with all important stakeholders; (3) We believe our detailed implementation process, including developing an ongoing working project plan, is key to our success; and (4) our pilot program has been successful, with all key stakeholders satisfied and eager to move toward statewide implementation.



CONCURRENT CARE: AN ILLINOIS PERSPECTIVE

Kim Downing, RN, JD

Greater Illinois Pediatric Palliative Care Coalition

kdowning@horizonhospice.org

www.GIPPCC.org

Illinois has slowly, yet successfully, begun implementing Concurrent Care. Initially, hospice providers expressed tremendous apprehension regarding utilization of the provision; there was a paralyzing fear from hospices, particularly smaller providers, that a quarrel regarding interpretation of palliative versus curative therapies could leave a hospice program with a significant fiscal responsibility. Additionally, hospices expressed confusion about potential changes in admission procedures and billing logistics.

During September, 2012, the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC), a collaboration of 22 regional hospices, pediatric hospitals, supporting organizations, and individuals, held an education conference regarding Concurrent Care in the state's capitol city, Springfield, Illinois. Invitations were delivered to pediatric hospital and hospice programs statewide, as well as state legislators, legislative staff, and representatives from the Illinois Department of Health Care and Family Services (IL HFS). The goal of the event was to educate Illinois clinicians and policy personnel about Concurrent Care, and to minimize the mystery surrounding the provision. Over 55 clinicians attended the event. Senator Dale Righter, a friend of GIPPCC and a champion for hospice, also participated. Dr. Sarah Friebert spoke about national trends in Concurrent Care implementation and Devon Dabbs addressed successes and challenges in operationalizing the provision in California.

The program was a wonderful learning experience for all in attendance; additionally clinicians and state representatives who were unable to participate requested summary materials from the event. The September 2012 event was effectively a kick off to Concurrent Care implementation in Illinois.

Subsequent to this education event, a Chicago-based hospice with a strong pediatric program admitted the first known Illinois Concurrent Care case. Due to some hesitation about procedure and a lingering fear of being left with considerable, unanticipated costs, GIPPCC and the pediatric coordinator from the hospice program reached out to IL HFS prior to the child's hospice admission to discuss the potential case. IL HFS warmly received the opportunity to dialogue about the provision. The willingness of the state Medicaid office to discuss the potential continued therapies for the child, as well as hospice integration and goals of care, increased the comfort of the hospice in utilizing Concurrent Care for the first time.

GIPPCC, with support from the Illinois Hospice and Palliative Care Organization, clinicians, and IL HFS dialogued about several potential Concurrent Care cases during the end of 2012. On December 21 of that year, IL HFS released an Informational Notice entitled *Concurrent Palliative and Curative Care for Children Receiving the Hospice Benefit*. This notice recognized Concurrent Care as an important provision of the Patient Protection and Affordable Care Act and stated that, for children through the age of 20, the "department will allow access to all curative treatment the patient may wish to obtain." The Department reiterated, "The policy does not change the criteria for electing the hospice benefit."

Following this notice, some confusion remained regarding the procedure for hospitalization of a pediatric patient following admission to hospice. In a subsequent communication, IL HFS clarified, "if the hospice patient is admitted [to the hospital] and the admission is either not related to the terminal illness, or is curative in nature, the hospice is not responsible for payment of the inpatient stay." IL HFS further explained that denial letters from the hospice would be the chosen route for any potential admission that required adjudication. They stated,



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



“Hospitals are required to contact a patient’s hospice provider for a response as to the liability of the hospice for an inpatient admission. If the hospice is not responsible, the hospice must submit a denial letter to the hospital. The hospital then submits the letter with the inpatient claim, and the department will adjudicate the inpatient bill accordingly.”

Those cases that have been successful in Illinois have illustrated the strong need for upfront education regarding the Concurrent Care provision, as well as ongoing dialogue between all providers during the child’s course of care. This often requires non-hospice provider education from the hospice program or GIPPCC, prior to the child’s admission to hospice. IL HFS has supported education, particularly of non-hospice providers, where concern or questions lingered about service provision following hospice admission.

Despite significant progress, there continues to be residual hesitation from some hospice providers about utilizing the provision. Several clinicians have asked for upfront clarification from IL HFS regarding what would be considered a curative treatment; this desire for straightforward answers seeks to eliminate any potential (although possibly elusive) assumption of risk by a providing hospice. Although black and white lines are often comforting when trialing something new, this pre-designation seems nearly impossible since each child and family situation is unique and federal opinion has clearly stated that what is curative in one situation may be palliative in another. GIPPCC will persevere with Concurrent Care education for all individuals and organizations involved in the care of children with advanced illnesses. The coalition will continue fostering dialogue with the state regarding utilization of the Concurrent Care provision with the goal of increased choice of care locations for all children with life limiting illnesses and their families.

Illinois additionally has a legislated Pediatric Palliative Care Act (305 ILCS 60). This statute was signed into law during July 2010. Program development was initiated; clinicians and representatives from IL HFS met multiple times to discuss program design. This program would remove the prognostic requirement for community-based support. The statute instructs for admission to be based upon diagnoses; the details of the eligibility infrastructure, however, require some continued dialogue between clinicians and the state Medicaid office. This programming would include community based care coordination, nursing, social work, and expressive therapies for children with life-limiting illnesses. The statute defines the program as a pilot. The intent, seemingly, is implementation of a smaller-scaled model with the hope of program growth following evaluation of cost and quality improvements. Due to budget cuts, however, this program is currently unfunded and collaborative efforts to develop an infrastructure for this project have ceased. GIPPCC, along with dedicated clinicians, however, hope that work on this project will resume during the upcoming year. But for now, Illinois continues to move steadily forward one Concurrent Care case at a time.



DEVELOPING A STATEWIDE PEDIATRIC PALLIATIVE CARE COALITION: THE STORY IN KANSAS

Kathleen G. Davis, PhD

Assistant Professor

University of Kansas Medical Center

Department of Pediatrics

KDAVIS2@kumc.edu

Introduction

Ensuring that excellent palliative and hospice care is provided to fetuses, infants, children and adolescents ("children" from this point forward) truly does take a village. By 2011, several states were building these villages as they developed state-wide pediatric palliative care coalitions to address topics of common concern in their state. These alliances were organized to provide the opportunity for pediatric palliative care stakeholders to collaborate in the effort to develop consistent access to the best palliative and hospice services to seriously-ill children and their families.

These coalitions were created in states that had large urban and suburban geographic areas, including several large cities. In California, for example, the geographic area and population was extensive enough to require that the original coalition divide into three separate groups, the northern, central and southern collaborative/network, each addressing similar but unique needs in those regions of the state. In addition to California, Pennsylvania, New York, Florida, Maryland, Massachusetts, and several others joined forces within their states to develop pediatric coalitions to provide information, advocacy, education, and training around pediatric services. In addition to working to ensure access to excellent care for children, many coalitions strove to develop standards of care that rivaled the more highly evolved adult services.

These states had an advantage in the existence of well-developed pediatric hospice and palliative care programs throughout the state in the large, metropolitan areas with concentrated pediatric populations. Conversely, rural states have not, as often, ventured into the development of statewide coalitions, perhaps because of the lack of several large metropolitan cities and, thus, the lack of well-developed pediatric hospice and palliative care programs throughout the state. As the population is sparsely spread over the area of a state, the numbers of pediatric patients in need of hospice or palliative care are scarce in any one region and, therefore, challenges exist in identifying resources to respond to a scarce need.

One such state is Kansas.

Kansas Demographics

In order to understand the challenges of developing a statewide pediatric hospice and palliative care coalition in Kansas, it is helpful to first understand some of the demographics of the state. The over 82,000 square miles comprising the state of Kansas makes it the 15th largest state in the U.S., but with a population of almost 2,900,000, Kansas ranks 34th in population¹. Located directly in the center of the country, Kansas is comprised of 105 counties, including 6 urban counties (population of 150 or more persons per square mile), four of which include the greater Kansas City metropolitan area, and 10 semi-urban counties (population of 40.0 – 149.9 persons per square mile). The remaining 79 counties are classified as rural or frontier². Frontier counties are sparsely populated rural areas that are isolated from population centers and services. In addition, the U.S. 2010 Census classifies a metropolitan area as any city which includes 50,000 or more residents³. Employing the U.S. Census definition, Kansas includes 3 metropolitan cities: Kansas City, Wichita, and Topeka, all located on the east side of the state.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



As a result of the sparse population density in most of the state of Kansas, the number of children in need of pediatric palliative or hospice care is small and widely spread out over the state. Kansas death statistics provide the number of annual infant, child, and adolescent deaths, but it is not possible to determine how many of the conditions causing death would have been appropriate for hospice or palliative care. In addition, the statistics include deaths that occur before and during birth, those up to age 24 years of age, and do not delineate between sudden deaths and deaths resulting from a chronic condition. However, the 2010 data from the Kansas Annual Summary of Vital Statistics, the year immediately prior to the initiation of the pediatric coalition efforts in Kansas, provides death statistics for age categories 0 - 1 year, 1 - 4 years, 5 - 14 years, and 15 - 24 years indicating a total of 690 deaths reported in infants, children, adolescents, and young adults ages birth - age 24⁴. The assumption is that at least some of these individuals and families may have benefitted from hospice and palliative care, had it been available for children in the area where the deaths occurred.

Further, pediatric palliative care has a strong history of providing services for children at the time of onset of a serious health condition, regardless of expected prognosis. This model is not often practiced in adult palliative care settings. Children with complex chronic conditions and those who are technology dependent (i.e., feeding tubes, tracheostomies, home ventilators, etc.) constitute the most rapidly growing pediatric palliative and hospice care population. Thus, the actual number of children who need pediatric palliative and, in some cases hospice care, is even larger than those represented in the death statistics of the state. Some children spend several months or even years receiving palliative or hospice care, until death occurs or the child stabilizes or progresses and is determined to not be in need of services any longer.

Feeling the need for a coalition

The director of KU Kids Healing Place (KUKHP), the pediatric palliative care program at the University of Kansas Medical Center, recognized the need for collaboration across the state as the hospital attempted to discharge children home to hospice and palliative care services, only to find that none were available to children in most geographic areas. As a result, children did not receive the palliative care that could improve their quality of life, or the family was forced to choose between the child dying at home without hospice services or staying in the hospital to die, often hours away from the friends, family, support systems, and familiarity of home. Thus, the effort was launched to determine how to ensure access to high quality palliative and hospice services for all children, regardless of whether they live in a metropolitan, suburban, rural, or frontier geographic area.

Paving the way – Year 1

The Community Health Project is an 8-week summer internship course open to students from medicine, nursing, public health, occupational therapy, pharmacy, and other health professions. Students interview and are matched with partner agencies which provide some type of health services. After a student-agency match is made, the student is immersed into the agency to enable the learner to develop a depth of understanding regarding the work, needs, and challenges of the agency. The student and supervisor identify a project that will address an agency challenge or a need and which the student can complete in the 8-week course period.

In the summer of 2011, the director of KUKHP was paired with two medical students, just completing their first year of medical school, at the University of Kansas Medical Center. Both of the students developed projects that focused on collecting and evaluating data about existing pediatric hospice and palliative programs in the state. The goals in Year 1 were to determine:



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



- Which facilities, home health, and/or hospice agencies are currently caring for seriously-ill children in Kansas?
- What palliative care programs, providers, and/or consult services are available to families across the state?
- What community-based organizations currently provide seriously-ill children and their families emotional, psychosocial, spiritual, practical, and/or financial support?

In Year 1, the students identified and contacted hospice and palliative care organizations in Kansas. Agencies were identified by the Kansas Hospice and Palliative Care Organization's (KHPCO) list of participating agencies and by a Google search. Twenty seven agencies were identified in Year 1, although the researchers would later learn that there were additional agencies that had not been identified. Each agency was contacted first by a telephone call to the executive director, alerting him/her that a survey would be arriving later in the week, identifying if the ED or another individual in the agency would be the appropriate person to receive and respond to the questionnaire, and obtaining the appropriate person's name and email address.

The interns and the pediatric palliative care director created a Vovici survey, containing 10 questions, which was sent to each adult hospice and palliative care program that they had spoken to early in the week. The questionnaire asked what types, if any, of pediatric services were currently being offered by their agency, how often the agency cared for children, if the agency was interested in participating in a pediatric coalition, what type of training pediatric providers possessed, if the agency was interested in web based or televideo training in pediatric hospice and palliative care, and additional related queries.

The questionnaire yielded valuable data. In Year 1, four programs across the state were identified as providing pediatric services. Three of those programs were in metropolitan cities: one in Kansas City, one in Topeka, and one in Wichita. One program had several children on their daily census, and the other two "often" or "usually" had pediatric patients. The remaining program was in a small town with a population of 28,000 which served a wide geographic area. That program reported having pediatric patients "once in a while." There was only one program with dedicated pediatric professionals including two pediatric nurses, one pediatric social worker, a pediatric chaplain, an art therapist, and a child/teen specialist. The other three agencies providing pediatric care identified one employee with pediatric expertise (i.e., three agencies had nurses with some pediatric training; one program had a med-peds trained physician).

Of the 27 agencies queried, 22 wanted to participate in a coalition and 21 were interested in receiving pediatric palliative and hospice training via webinars or interactive televideo. The interns reported a wide range of responses from some agencies who strongly denied an interest in providing pediatric services to those who were reported to "reluctantly" agree, and on to those who exhibited enthusiasm regarding the possibility of providing pediatric care.

No further action was taken on the development of a pediatric coalition until year 2.

Pediatric coalition development – Year 2

The Community Health Project offered the opportunity to participate in the Summer Internship program again in 2012, and two more interns were matched with KUKHP. During Year 2, one intern focused on the continuation of the coalition development project. The director of the KUKHP sent an email to each individual, identified the previous year, who had indicated an interest in a pediatric coalition. This email identified the name and medical student status of the intern who would be contacting them the following week regarding scheduling a conference call. The email asked that the agencies be on the lookout for that communication and outlined the initial coalition meeting format: getting acquainted and identifying first steps for the coalition. Of importance was communicating to potential partners that this was not a



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



coalition with a political agenda but, rather, a partnership of professionals interested in working to improve access to and quality of pediatric palliative and hospice care.

A week later, the intern sent a brief email along with a Doodle Poll, asking agencies to identify their preferred meeting time(s). He followed up with a phone call to agencies that did not respond by email and obtained 100% response from agencies previously interested in participating in a coalition. The first conference call meeting was scheduled for July 16, 2012.

During the preceding year, the KUKHP supervisor had identified a list of all hospice and palliative care providers in Kansas. This list, available on the Kansas Department of Health and Environment website, was used, going forward, to ensure all agencies had been contacted. This document included 44 agencies in 2012. The intern contacted agencies that had not been contacted the previous year to assess their interest in participating. During the rest of the summer, the intern developed a coalition Facebook page, set up an email account, and scheduled monthly meetings for the remainder of the academic year.

The first conference call included 11 agencies representing three of the four quadrants of the state. The fourth quadrant, northwest Kansas, consists of the most rural and frontier regions and this area, due to lack of need, is proving to be a late adopter. The group consisted of the most developed pediatric program to a program that had one pediatric patient four years previously, and found the experience to be "rewarding but devastating." The participant from that agency believed that, with appropriate training in pediatric hospice and palliative care, the agency would be ready to offer pediatric services again. Several agencies acknowledged that they "want to be ready" when children are referred to them and that they perceived that, in the near future, more children would be identified who are in need of services. This perception was described as being a result of the Affordable Care Act's provision 2302, requiring concurrent care for children and the growing sentiment that agencies should provide care to all patients who need care.

The first meeting also included determining a name for the coalition—The Kansas Pediatric Hospice and Palliative Care Coalition (KPHPCC)—and agreement amongst group members on monthly meetings via conference calls. Interactive televideo meetings were discussed, but some agencies did not have ready access to that technology so that was dismissed as an option.

On December 7, 2012, the coalition members traveled to the University of Kansas Medical Center for a day-long retreat and to present Pediatric Grand Rounds on the process of developing a coalition. During the day, the group created a mission and vision statement and developed the foundation for the goals and direction of the coalition. Networking and becoming acquainted were significant goals of the meeting and strong alliances were formed. One small agency, which had not cared for many children in past years, had or were caring for five children since the Concurrent Care provision had passed. This agency had great success in their pediatric endeavors, combined with challenges in helping staff, who had only cared for adults for many years, cope with the challenges the felt in providing pediatric care. This agency had achieved significant gains in figuring out complex billing issues, working through communication challenges with in-home agency nurses, and learning the necessary lingo to speak to the state hospice Medicaid director. The other agencies were very grateful for the agency's willingness to share that information. Similarly, larger, more experienced agencies shared their practices with agencies who had limited pediatric experience, and offered to be a resource via telephone if agencies had any questions about specific care issues with children. The coalition was succeeding already.

The members of the coalition agreed that there was a need to address professional challenges and barriers before they could begin to address the needs of families and the community. Thus, a commitment was made to address the, in some cases, very steep learning curve for members who had no pediatric training and to instill a sense of confidence and enthusiasm for caring for children. The



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



members recognized that the needs were different for different agencies and that the differences should be embraced from the beginning in order to succeed.

During the next conference call, the group determined a preferred format would be to spend the first half of the call on an educational topic, and the second half on coalition business. Some of the topics included: sharing “pearls of wisdom” in pediatric care; interpreter services, including training medical interpreters and unique challenges in small communities where potential interpreters likely know the patient socially; concurrent care overview; etc.

Adding the icing to the cake – Year 3

Once again, in the summer of 2013, the KUKHP partnered with the CHP summer internship program. Another bright, enthusiastic medical student worked on the development of the coalition. The goal in Year 3 was to do another sweep of contacting agencies not previously involved with the KSPHPCC, provide information about the coalition and its goals, and invite the provider to join us. In addition, the survey queried coalition participants regarding their satisfaction, dissatisfaction, or suggestions for improving the coalition's work.

Surprisingly, the KDHE list of hospice agencies in Kansas had grown from 44 in 2012 to 69 in 2013. Each nonparticipating agency was contacted and 12 new agencies joined the coalition; three additional agencies asked to receive email minutes and other information sent by the coalition. Now, every quadrant of the state is covered by agencies participating in the pediatric coalition. When children are discharged from the hospital, it is probable that there will be an agency that is able to provide needed palliative or hospice care.

In September, three members of the coalition presented their experiences in developing a state-wide pediatric palliative care coalition. Some of the audience members were themselves, members of coalitions from other states (Pennsylvania, New York) and shared their successes in larger, more well-developed coalitions. The member from Pennsylvania has contacted the coalition and suggested opportunities to collaborate in research, and learn from one another.

In the spring of 2014, coalition members will have the opportunity to receive Pediatric End-of-Life Nursing Education Consortium (ELNEC) training, at a very low cost, for their staff. The course will be taught by the University of Kansas Medical Center. Training will be available live or via interactive televideo, for those who are unable to travel to Kansas City for training.

Year 3 of the CHP project correlates with the second year of coalition meetings. The second year has been significant for identifying coalition members' needs and connecting coalition members to support one another. It appears that the “glue” has been applied, and coalition members are sticking together.

Conclusion

During a recent conference call, the group determined that the coalition had created “good bones” and was ready to include other stakeholders—parents, legislators, corporate partners, etc. The coalition is currently recruiting members in those categories. In addition, the coalition members developed the following list representing the challenges and barriers to Kansas pediatric palliative and hospice care professionals.

- Significant need for education/training of personnel regarding how to care for children.
- Support for personnel caring for pediatric patients receiving concurrent care. For example, how does a nurse provide hospice to pediatric patients who are still receiving active life-prolonging treatment?



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



-
- Support for personnel grieving deaths of children. The sentiment was that it is more difficult to care for children who are dying than elderly who are dying.
 - Support for personnel on how to care for parents, siblings, friends, and others who care about the dying child.
 - General idea sharing—what is working for agencies who are doing pediatric care?
 - Legislative issues regarding concurrent care and other issues that affect pediatric care.
 - Addressing common challenges and barriers.
 - How to ensure access to palliative and hospice care for all children.

Several key decisions will be on the table for discussion and decision making during the coming year. These decisions may have a significant impact on the success—or failure—of the coalition. The coalition needs to continue to build with a variety of key stakeholder members, and that recruitment is currently occurring. A topic that has not yet been fully discussed is whether or not the coalition should seek to become a not for profit 501(c) 3 agency. Similarly, the group must decide if they want to begin to seek external funding. Another challenge will be determining how to provide education to patients, parents, providers, schools, insurance companies, legislators, community members, and other interested parties. KSPHPCC is at a point where it must be determined if members are content with the current direction of the organization, or if there is the intent to grow and provide more comprehensive service.

The Kansas Pediatric Hospice and Palliative Care Coalition has now been active for 15 months, and has many characteristics similar to a 15-month-old baby. The coalition recognizes its strengths as well as its need to continue to develop. The coalition is taking its first baby steps. It has begun to speak, is making new friends, and it is becoming more skilled at making its needs known. The coalition is not an adult yet, but it is growing and developing quite nicely as a toddler!

References

1. The Department of Commerce, United States Census Bureau, The 2012 Statistical Abstract: State Rankings Accessed 9/12/13 <http://www.census.gov/compendia/statab/rankings.html>
 2. Kansas Department of Health and Environment, Kansas Regional Groupings and Maps, Kansas Peer County Groups. Accessed 9/12/13 <http://kic.kdhe.state.ks.us/kic/OHA/ksmap.html#peer>
 3. U.S. Department of Commerce, United States Census Bureau, State and County Quick Facts. Accessed 9/12/13 <http://quickfacts.census.gov/qfd/states/20000.html>
 4. Kansas Department of Health and Environment, The Kansas Annual Summary of Vital Statistics. Accessed 9/12/13 <http://www.kdheks.gov/hci/annsumm.html>
 5. Kansas Department of Health and Environment, Health Care Provider Directory, Hospices. Accessed 10/14/13 http://www.kdheks.gov/bhfr/fac_list/index.html
-



BENEFITS AND CHALLENGES OF CONCURRENT CARE FOR PEDIATRIC PALLIATIVE/HOSPICE FROM HOSPICE'S POINT OF VIEW

Anne Wiedemann, MD

Pediatric Medical Director

Board Certified in both Family and Hospice and Palliative Medicine

Abington Kind Pediatric Palliative and Hospice Services

AWiedemann@amh.org

Barbara Zimmaro, RN, MSN, CRNP, CHPN, HTP

Nurse Manager

Abington Health Home Care and Hospice Inpatient Unit

Supervisor of Kind Pediatric Hospice Services

Warminster, PA

BZimmaro@amh.org

Introduction

Historically, providing Pediatric Hospice and Palliative Care has been an uphill battle for acceptance and reimbursement. We agonized with parents as they struggled over being forced to choose between extra shifts of care, palliative treatment options, and hospice services. Some states' Medicaid services were more child friendly by having waiver programs supporting shift care and hospice together. Other states did not have such programs and families were forced to choose between hospice and shift care. Hospice providers worked closely with palliative care teams at hospitals to make inroads into pediatric palliative/hospice services for children and families. Parents expressed appreciation for this support when faced with the sad outcome to their child's life.

Many individuals advocated for the concurrent care portion in the new Affordable Care Act so families didn't have to choose. Also, it was anticipated that the disparities from state to state would be resolved. As we move forward in this innovative process, we often find ourselves in a challenging scenario. We would like to share our point of view concerning the act, its benefits, and the challenges that can be overcome to enhance the benefits of the concurrent coverage. We will provide some suggested guidelines that we feel will help in the process.

Summary of Act

Concurrent Care for Children Requirement (CCCR) Section 2302 of the Patient Protection and Affordable Care Act (PPACA) amended the Federal Social Security Act Section 1905(o)(1) and 2110(a)(23). The new provision states that a voluntary election of hospice care for a child cannot constitute a waiver of the child's right to be provided with, or to have payment for, services that are related to the treatment of the child's condition, for which a diagnosis of terminal illness has been made. This provision affects children who are eligible for Medicaid or the Children Health Insurance Program (CHIP).

The goal of this new provision is to allow families to opt for palliative and or hospice care early in the stages of terminal diagnosis while still receiving other treatments and services. Studies have shown that early palliative care involvement helps to manage pain and symptoms while addressing goals of care. It enhances the quality of life and sometimes quantity of life. The parents are supported through decision making and the options available. This consistent relationship with the palliative staff also allows for a gentler and more timely transition to end-of-life care.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



Benefits

The goal of the Concurrent Care for Children Requirement is to make hospice services available to more terminally-ill children. It takes away a parent's need to choose between life-prolonging therapies and comfort-directed therapies and allows them access to more services including nursing care, symptom management, respite, and psychosocial support. Multiple specialists can remain involved in a patient's care, offering varying points of views and options to families. Hospice can focus more on symptom management and goal setting during the course of a patient's treatment, instead of waiting for a family to choose to forego treatment. This will hopefully make hospice utilization a more acceptable option to families who continue to hope for a cure. This also allows a patient's curative teams, who often have strong relationships with their patients and families to remain actively involved in a person's care even as the goals and focuses shift.

Concurrent care will hopefully encourage more hospice providers to start caring for children, as well. It has been estimated that only 14% of hospice programs in the United States have a formally identified pediatric program and that less than 40% of community based hospices provide care for children at all. (5,7). As hospice becomes a more acceptable choice for children and as more physicians are trained in palliative and hospice care, more health care providers will recommend hospice for their patients. This will ultimately lead to increased experience of hospice providers and increased choice for patients and their families. Along with this, hospice no longer has to be revoked each time a person chooses aggressive, cure-oriented measures of care. This simplifies transitions of care and decreases paper work, enticing more hospices to take on the task of pediatric hospice care.

Challenges

Although, the Concurrent Care for Children Requirement (CCRC) makes hospice services available to more children, there are a number of unique challenges in implementing it. A physician still must certify that a patient has a reasonable life expectancy of six months or less. Because of the varying disease trajectories for many life-limiting illnesses in pediatric care, physicians are often hesitant to label a patient as terminal. Approximately 500,000 children are coping with life-threatening terminal illness in the United States annually. Of these, 50,000 die annually. Currently less than 8% of terminally ill children and their families utilize hospice care (NHPCO). This means that even with CCRC most pediatric patients are not getting the full benefit of hospice services.

Usually when hospice becomes involved in a patient's care we become the major caregivers for the patient. Now, there are a number of physicians and healthcare providers involved and often there is little communication between these providers. Health care providers are often unaware of what their colleagues have done and recommended. Parents hear very different versions of their child's prognosis depending on the specialist and may be less likely to accept a terminal diagnosis. There are conflicting goals of care for families, caregivers, and health care providers, which makes decision making more difficult.

Families are happy for the extra services provided by hospice but often continue to pursue treatments that, although may extend life may also cause increased suffering. Hospice is a philosophy of care and with CCRC that philosophy can get lost. It is often hard to focus on end-of-life issues and preparation while pursuing curative treatments.

The Concurrent Care for Children Requirement refers only to state-assisted insurance such as Medicaid and CHIP. It does not provide concurrent care to children with private insurance, despite the fact that the majority of terminally-ill patients are covered by private insurance initially. Also, Medicaid policies are vastly different from state to state, and many states are facing financial difficulties and contemplating cuts to Medicaid, further complicating CCRC and access to hospice.



Our Experience

TC was a newborn with trisomy 18. She spent 3 weeks in the NICU until it was evident that her prognosis was poor and she wouldn't survive much longer. The parents had decided to seek any palliative care that would make their daughter comfortable. The infant was placed on hospice care with the understanding that she could go back to the hospital for any crisis and at time of death. The infant received nasogastric feeds every 3 hours and had oxygen as needed. After being on hospice for 2 weeks, she developed congestion and dyspnea. Her mother took her to the ER and admitted her for 3 days. She was released and continued with hospice care without a break in service. The hospice team and palliative care team worked with the pediatrician to develop a plan of care. The hospice team and palliative care team met with the mother and offered an inpatient hospice for the next time an event occurred. The mother took advantage of this option and brought the child in for symptom management. The baby returned home in 3 days and the mother stated that she was glad for the experience. She decided that she preferred to use the inpatient hospice at time of death. On her subsequent visits to the pediatrician, these goals and options were reviewed and reinforced. The baby died peacefully on the inpatient unit at 4 months of age.

AB was a full term normal vaginal birth. After birth he exhibited some neurological abnormalities and was found to have multiple brain tumors. After consulting with a neuro-oncologist, it was determined there was no treatment for this newborn. Palliative care was consulted and the baby was referred for hospice care. The life expectancy for this baby was several months. Upon admission to hospice the mother informed us that the oncologist would be seeing her baby monthly to determine if and when he could receive treatment for his tumors. The mother's perception was that all she had to do was keep her baby alive long enough to be eligible for treatment. During the monthly meetings with the neuro-oncologist, the mother came away with the perception that her son was getting better. This was not the understanding of the hospice team. The palliative care team also did not have this understanding. The palliative care team approached the neuro-oncologist who remarked that even though there would not be treatment, he felt it was premature to bring in hospice. He also didn't want to destroy the mother's hope and he thought hospice would emphasize death. The baby died at the hospital at less than 3 months of age. The mother chose to go back to the hospital so they could save her son and continue the journey to treatment. The hospice team believed it failed in helping this mother adjust to this tragic end for her child. The mother still believes she failed. She didn't get her child well enough to receive treatment.

Conclusions

These cases show both sides of a complex process and the ways it can go well or have undesirable effects. These cases raise some consistent themes about how you can maintain hope and the understanding of what hospice does or doesn't do. There are many more examples of concurrent care that raises other questions on how to manage, jointly, the care of these children and when to work as a team to transition from concurrent care to end-of-life care as death approaches. There are many contributing factors and it is not all black and white. The prognosis is not always clear during this journey. Is it a crisis that the patient can recover from or is it the final crisis? It is a challenge for all of us to work together on each case and move in the direction of support that meets the child and family needs. This has a better chance of occurring if there is a meaningful, sensitive discussion with all teams involved without destroying the hopes of the child or family.

Suggested Guidelines and Recommendations

There are several guidelines in supporting the concurrent care to enhance the wellbeing of the child and family.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



1. Form a partnership with Palliative Care Teams and Hospice providers for Pediatric Palliative and Hospice Services.
2. Educate healthcare providers from palliative care teams, hospice teams, and specialists who deal with children facing life-threatening terminal illnesses on the provisions of the concurrent care for children outlined in the ACA.
3. Share the current guidelines from the individual State Medicaid Office.
4. Provide formal education of all healthcare providers on palliative care and hospice services.
5. Initiate Palliative Care referrals early in the treatment of children with life-limiting illness.
6. Begin dialogues with each child and family with palliative care to ensure the appropriate selection of children and families that would benefit the most from concurrent care.

Final Thoughts

We are very hopeful that hospices and palliative care teams will work together to develop processes to implement the concurrent care concept. In order to move forward, we need to foster these relationships, educate healthcare providers, and guide the discussion in order to choose the most appropriate children and families. Once we are able to achieve these outcomes, the concurrent care provision will have meaning, effectiveness, and affordability. There is a way to gently guide families through the journey of their child's life-limiting illness if we take advantage of the expertise and skills of the palliative care teams and hospice providers. There are many groups working on this already such as NHPCO, CHIPPS, and the District of Columbia Pediatric Palliative Care Collaboration. It is a work in progress, but we can accomplish a concerted collaboration to make it a reality. Start with the organization in your geographic area that is advancing this care. Check the web for any organizations that are developing programs and initiation of the affordable care act. Together we can provide the best palliative and hospice care for children and families which they so deserve.

Bibliography

1. Health Care Reform and Concurrent Curative Care for Terminally Ill Children: A Policy Analysis. Lindley, LC, J Hosp Palliat Nurs, 2011; Vol 13(2): pp. 81-88.
2. Pediatric Palliative Care. Alexandria, VA: National hospice and Palliative Care Organization, December 2012.
3. Trends in services among pediatric hospice providers during 2002 to 2008. Lindley LC, Am J Hosp Pall Care, 2013 Feb; Vol. 30(1), pp. 68-74.
4. Palliative Care for Infants, Children, Adolescents and Their Families. Himmelstein BP, J Palliat Med, 2006 Feb; Vol. 9(1), pp. 163-81.
5. The need for increased access to pediatric hospice and palliative care. Jones BW, Dimensions of critical care nursing, 2011 Sept-Oct; Vol. 30 (5), pp. 231-5.
6. Lighting the way: improving the way children die in America. Dumner LH, Caring, 2003 May; Vol. 22 (5), pp. 14-8.
7. Himmelstein, BP et al, N. Eng J Med 2004; 350-1752
8. Hoyert DL et al, Pediatrics 2006; 117-168
9. NHPCO National Hospice and Palliative Care Organization. www.nhpc.org
10. CHIPPS Children's Project on Pediatric palliative/Hospice Services. www.Nhpc.org/pediatrics
11. Concurrent Care for Children Implementation Toolkit. District of Columbia Pediatric Palliative Care Collaboration, NHPCO



CONCURRENT CARE: UNRAVELING THE REQUIREMENT TO IMPROVE ACCESS TO CARE AND QUALITY OF LIFE

Diane Parker, RN, MSN, NE-BC, CHPN, CHPPN
Executive Director, Hands of Hope™
Pediatric Division of Hospice Care of South Carolina
diane.parker@handsofhopesc.net

Before Section 2302 of the Affordable Care Act (Concurrent Care) patients, families, and healthcare providers were given very little options for children living with a terminal illness. Essentially, their alternatives were options of hope for a cure or hospice care. The hospice care model as we know it is not child centered or family focused. The patient advocacy work through NHPCO and its members has been a catalyst for many programs and has been instrumental in building our success in meeting the needs of this delicate population. Now there is an option for hospice that is patient centered and family focused. Since March 23, 2010, with the requirement of concurrent care, our hospice has grown from primarily adult with one to two children a year to a dedicated division for pediatric hospice and palliative care that is now considered a best practice. The challenge to most programs though, is to understand the requirements and work collaboratively with multiple providers. The challenge is worth the journey of breaking down those barriers with the rewards of seeing families gain and not lose hope.

How do you unravel the complicated requirement? It is certainly not simple. It takes commitment, vision, time and passion. We are all equipped with those qualities. The resources that are available from NHPCO and the network of providers with expertise are creating change in the landscape of pediatric hospice and palliative care. Prior to concurrent care our relationship with our state Medicaid office was one directional. That changed after the CMS bulletin September 9th, 2010, and certainly changed after joining the Pediatric Policy State Leaders Group. Having a strong network of providers is crucial to a strategic plan.

Since implementation of concurrent care, we are able to provide children and families more options. Children that are terminally ill, on a medically complex waiver for example, now can have individualized care. Services of the waiver (such as in existence prior to hospice) and the additional support of a comprehensive pediatric hospice team are possible now to help navigate through the overwhelming care continuum. In our experience, concurrent care has been referred to as the case management best practice. It is not a simple process. We must be mindful of the provision of services for every patient. All Medicaid children may be eligible but may not receive concurrent care. It is individual to the patient and requires communication and collaboration among multiple providers. Concurrent care itself is not all inclusive. It is based on the needs of the patient and family and it far outweighs the old options.

Zeta's Story:

Zeta was born March 5, 2010, the third child of Angel and Stevie Brabham of Ulmer, South Carolina. "She had issues with every organ in her body, but never a diagnosis to bring it all together," said Angel. Multiple hospitalizations and

expensive medical equipment created financial worries for the family, especially after Angel quit her job





Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care Organization



as a guidance counselor at Barnwell Primary School to stay home and care for Zeta. They live in a rural part of South Carolina where it is 48 miles to the nearest hospital.

In her first year of life Zeta had more than 60 hospitalizations and emergency room visits. She was ventilator dependent, and both Angel and Stevie had to basically live between the hospital with Zeta and home with her two siblings, that was their normalcy. Year two, the journey was the same with over 30 hospitalizations and emergency room visits until she was admitted to hospice on June 5, 2012, when the transition from hopelessness to hope and peace began. She was receiving services on a medically complex waiver which included some hours of private duty nursing and other therapies. This waiver service continued and we were able to facilitate her interdisciplinary plan of care. Zeta died May 7, 2013, at home, with family where they wanted to be. In her last year of life after we were able to come in and support their needs, she had only two hospitalizations.

The Brabham family



Angel asked to meet with me after Zeta's death so I had the honor of riding along for a bereavement visit with our child life specialist. The moment I arrived at the home I had an overwhelming sense of confirmation even before entering the home. With nothing around but beautiful green pastures I asked myself what would I do if I had been Angel? In a small rural town how could anyone feel comfortable and be at peace with a child that was so fragile? During our time together we were able to reflect on Zeta's purpose and Angel asked to be a voice for others to reshape the perceptions of hospice and share her journey. In a sweet letter thanking me for my visit just days later, Angel said, "this past year under the care of Hands of Hope, our family lived a life full of hope and purposeful memories. The focus was never on death or what Zeta couldn't do, but instead on living and how to make her life the most comfortable and memorable!" Zeta's

legacy is continuing as this precious family has opened up their hearts for support, education, and love for others living with a life-threatening illness. Living with hope.



CONCURRENT CARE IN MARYLAND

Susan M. Huff, RN, MSN
Director of Pediatrics at Home
Johns Hopkins Home Care Group
Baltimore, MD
shuff2@jhmi.edu

Four years ago, there were limited hospice options for children in Maryland. Today, due to collaboration between Gilchrist Hospice and The Johns Hopkins Children's Hospital, pediatric hospice is growing. Children and families have access to several programs throughout the state, including the Eastern Shore. Gilchrist Hospice was the first to step up to the challenge and build a pediatric program. Not far after, Gilchrist was opening Dr. Bob's Place, a pediatric Hospice House in the city of Baltimore. Gilchrist provided the foundation and soon additional hospices committed to care for children and a state alliance was born. The Kids Alliance brings together Gilchrist Kids, Montgomery Kids, Chesapeake Kids, Hospice of Queen Anne's, Coastal Hospice, Dr. Bob's Place, and Pediatrics at Home of Johns Hopkins Medicine.

Until recently, concurrent care was tackled individually by each Hospice. There was no consistency between approvals and no coordination with Medicaid. Two months ago a task force was formed by Alliance Kids to engage the State Medicaid programs. Leading the charge is Holly Herring, Gilchrist Kids Clinical Manager. Our goal is that through coordinated efforts, a process will be implemented to allow consistent application of the law and increase hospice access to children across the state.

Successes:

- A 1 yr. old, referred to hospice during the perinatal period. The baby survived and has been on home hospice since birth. In addition to hospice services, the baby is cared for by a neurologist and orthopedist. She is receiving OT and PT through the State's Infant and Toddler Program at home. The out-patient physician visits and rehab are paid for by Medicaid. Mom has signed a MOLST (Maryland Orders for Life Sustaining Treatment) and does not want any invasive procedures done, but wants to continue these appointments as well as rehab, because they are contributing to the baby's comfort and quality of life.
- An 8 yr. old receives hospice and home health services at the same time, however normally this is seen as duplication of services. The hospice benefit provides nursing, social work, and child life; at the same time the home care billed Medicaid for nursing, TPN infusions, antibiotic infusions, and chemotherapy infusions at home.

Challenges:

- Hospice referral for a 9-year-old ventilator dependent, feed by gastrostomy tube, private duty nurse for 20 hours a day; chest physiotherapy vest, and other Durable Medical Equipment (DME) in the home at the time of referral/admission into hospice. Once the family has elected the hospice benefit who covers the current DME in the home? Who pays for the ventilator the hospice or Medicaid? Does the hospice exchange the DME currently into the home for DME from a contracted provider? Does Medicaid pay for the private duty nursing to continue?

Children without Medicaid MCO oversight can be challenging once bills are sent because of the internal state process of Medicaid Hospice billing. This is one area we are hoping to change. Currently when a claim is submitted, Medicaid "denies" the hospice organization the part of any given 30-day billing period



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



where the child received “concurrent curative care of any kind” (this is part of the state internal computer system). After the denial is received, the hospice provides additional documentation to the State that reflects the nature of the curative medical care needed for the child and a physician’s order for the care (for those overlapping dates of service), and the bill is resubmitted. The billing resubmission then “goes through.” This creates additional work, documentation, and a cash flow delay.



CONCURRENT CARE FOR CHILDREN IN GEORGIA: A HOPEFUL UPDATE

Jennifer Hale, MSN, BS, RN, CHPN
Executive Director, GHPCO
jennifer@ghpco.org

When the Affordable Care Act's section 2302 was implemented in 2010, it was largely viewed as a victory for palliative care and for children seeking curative therapies who needed the supportive help of hospice to deal with broad emotional, social, spiritual, and clinical issues not available from other resources. The reality in Georgia, however, was much different. Politics aside, the Georgia Department of Human Services was itself transitioning per legislative mandate at the state level from a single agency responsible for all public and community health endeavors to a completely new agency with a new title, new charter, and new leadership. The Department of Community Health (DCH) and the Department of Public Health were formed (actually, re-formed as they'd been conjoined back in the nineteen-nineties) into agencies with separate functions focusing on the health and wellness of Georgia's populations. DCH's responsibilities included the administration of the Medicaid benefit across all waiver programs and populations, licensing and regulation of all provider types under state and federal guidelines, and the management of various contracts for billing, surveying, managed care, and so on.

Thus, when the Georgia Hospice and Palliative Care Organization (GHPCO) approached the division representatives at DCH regarding the implementation of the new ACA requirement for concurrent care for children, the effort fell flat on our end. The Department amended the Medicaid Policy Manual to include the exact language from the ACA but provided no mechanism in the reimbursement system for providers to pursue concurrent payment. Neither did the Department offer any kind of support to the hospice and palliative care communities in working through the system's various labyrinthine processes in appealing denials.

While GHPCO's pediatric hospice providers were understandably discouraged by this lack of interest in the issue, they were not dissuaded from all action. A loose collaborative of organizations formed to provide an opportunity for networking and common brainstorming on pertinent topics including clinical expertise, geographic availability (or, rather, lack) of pediatric hospice providers, financial concerns, and access issues. This network was comprised of hospices, Medicaid Managed care providers, various hospitals' employees with interest in pediatric palliative and hospice care, and several other agencies providing long-term support for medically-fragile children. In late 2011, Children's Healthcare of Atlanta (CHOA) implemented a pediatric palliative care team and their clinicians expressed interest in our group but were reserved about their ability to participate due to the fledgling nature of their program.

As happens, without a specific target and with competing demands for time and attention, the pediatric networking initiative eroded to a few very dedicated individuals who remained committed to the idea of a statewide group of pediatric end-of-life care providers with access to resources and clinical expertise. In late 2012, this group convened with members of CHOA's team who were ready then to assume more prominent roles in developing the initiative and a rebirth occurred with the first focus of designing an education and information workshop with a target of the spring of 2013.

A new division representative from DCH was invited to participate in a panel discussion about reimbursement challenges for pediatric hospice and palliative care scheduled to conclude the workshop and she agreed! The workshop was a complete success with over 30 hospices present as well as employees from several hospitals and other DCH employees to round us out. The final panel, featuring the DCH Deputy Division Chief for Medicaid programming, was a robust and thoughtful conversation, culminating in her request to create an advisory group for the purpose of discussing concurrent care cases, issues of reimbursement, and working to streamline provider and payer processes to ensure



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



children in Georgia can take advantage of the ACA provision without either the hospice or the hospital going bankrupt to provide the desperately-needed care. This is a triumphant example of the power of perseverance—even when fighting “City Hall.”



CONCURRENT CARE IN NEW JERSEY

Mary Ann West, RN, MSN
Butterflies Program Coordinator
Valley Home Care/Valley Hospice
Paramus, New Jersey
mwest@valleyhealth.com

The Butterflies Program of Valley Home Care/Valley Hospice provides hospice and palliative care services for children in Bergen and Passaic Counties in New Jersey (there are 21 counties in NJ in total). The Concurrent Care for Children provisions of The Patient Protection and Affordable Care Act have enhanced end-of-life care for several children on The Butterflies Program. There are many children in our community with chronic complex conditions who have a poor overall prognosis and limited life expectancy. Many of these children are receiving home care services which enable their families to manage their care at home over long periods of time.

With the advent of Concurrent Care it was expected by our team that this regulation would lead to many more children with complex chronic conditions being referred for hospice care as their conditions worsened and they approached their end of life. In reality, the number of children referred to The Butterflies Program for hospice care since Concurrent Care came into effect has not increased significantly. Of the 15 children that The Butterflies Program has cared for on Hospice since the advent of Concurrent Care, eleven of these children did not require services beyond what was provided by the hospice program since their care was fully based on the goal of comfort at the end of life and no aggressive life-prolonging or curative interventions were considered while they were home on hospice care.

By contrast, the end-of-life care of three children was clearly enhanced due to the Concurrent Care provisions. One infant whose family was struggling to adjust to a terminal diagnosis chose hospitalization for further testing and treatment of the baby's complex conditions. In this case hospice was able to continue ongoing support to the family in terms of decision-making and emotional/spiritual support during the baby's final days in the hospital under routine level of care while hospital costs were covered by patient's Medicaid. Another patient was able to receive hospice care at home while still continuing aggressive management of his disease including IV infusions of cardiac meds and diuretics as well as private duty nursing care. A third patient was able to keep the home health services of a personal care assistant which was enabling his family to care for him at home prior to hospice referral. One other little girl with private insurance coverage was able to receive additional services that hospice could not provide and this flexibility may have been influenced by the Concurrent Care provisions.

There are still significant gaps in knowledge regarding Concurrent Care provisions among health care professionals providing care for children and also among insurance case managers. This may inhibit timely referrals for hospice care for children with life-threatening conditions. In addition, recognizing when a child with a chronic complex condition is at end of life, and estimating when life expectancy may be under six months, is not only difficult for medical professionals to determine but even more difficult for them to discuss with the parents of these seriously-ill children. If these discussions, along with re-focusing of goals of care to include comfort and quality of life, do not take place, then children will not get the quality end-of-life care they need. Earlier palliative care interventions and reimbursement for these services would significantly help in overcoming some of the barriers to care that currently exist.



PEDIATRIC CONCURRENT CARE: PROVISION OF THE AFFORDABLE CARE ACT 2010

Debra F. Fox, MS, FNP-BC, CHPN, CHPPN
MJHS Hospice and Palliative Care
New York, NY
dfox@mjhs.org

Children are the eyes of the future. Children give us hope and motivate us in remarkable ways. When a child is diagnosed with a life threatening/terminal illness, the best part of my job is working with my colleagues to make a difference in the quality of life a child and his or her family can experience, no matter what.

In 1982, Congress established the Medicare Hospice Benefit. Eligibility was limited to those patients with terminal illnesses and determined to have a life expectancy of six months or less to live, if the disease ran its expected course. Hospice emphasized comfort care and pain control rather than aggressive disease-modifying treatments. The difficulty, however, in accessing comprehensive hospice services when still seeking aggressive disease-modifying therapy is viewed by many as creating an additional emotional roller coaster for the patient, regardless of the age and the family. When the patient is a child, the dynamic can be even more emotional for the parent. To consider not providing whatever disease-focused care is available for a child may generate guilt and leave parents feeling that they have given up hope.

The Affordable Care Act of 2010, Provision 2032, was passed by Congress and directed programs to cover hospice care concurrently with medical treatments aimed at cure or palliative treatment for children who are faced with complex medical conditions. New York State has initiated a pilot program to assess the feasibility and outcomes of the concurrent care model for terminally-ill children. MJHS Hospice and Palliative Care has been designated by New York to provide concurrent care under this pilot initiative.

Prior to the advent of this project, only children whose families had commercial or private payers agreed to both hospice services and "carve out" for the cost of disease-modifying treatments could receive concurrent care. The program typically had to attest to a prognosis of six months or less. Under the pilot concurrent care program supported by New York State, MJHS has admitted children to our hospice program who are receiving a variety of disease-modifying therapies. Accessing this program requires attestation of a prognosis that is one year or less. A medical and administrative evaluation at the time of admission to the program determines which aspects of care will be covered by hospice and which will be covered by Medicaid. Ultimately, this New York State response to the Affordable Care Act, Section 2032 will allow many seriously-ill children the option of concurrent hospice and disease-focused care. Medicaid-eligible children who are battling a life-limiting illness and their parents will have the opportunity to elect to continue treatment of the illness while receiving hospice and palliative care services. The goal is to support comfort and hope during a time when every minute counts.

The roll-out of this new program has revealed some challenges that MJHS and others will need to overcome. One of the most important relates to the attitudes of the treating physicians. Some of the primary care physicians and specialists who have been with these children through their illnesses have expressed difficulty in understanding how this program allows for close collaboration between the hospice program and treating physicians to provide the best coordination and continuity of care for these children. As we have moved forward working with these clinicians, most have come to realize that this collaboration can optimize outcomes and be comforting to the patient and family in knowing that they are receiving the best of both worlds.



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



In this model of concurrent care, close communication among clinicians is essential. The patient can continue to receive whatever disease-modifying therapy is appropriate. Those with cancer, for example, can receive chemotherapy, radiation therapy, as well as transfusions of platelets or blood or both. As this is occurring, our interdisciplinary team offers a wealth of services to support patients and families through their journey. Clinical pain and symptom management is provided from a Nurse Practitioner or Physician. Social workers are experts in searching out various programs and services for patients and their families to provide assistance for a wide variety of needs. We have a unique Creative Arts Therapy program that can provide support to patients and families through the use of art and music, also creating invaluable memories that live on well beyond the passing of the child.

Hospice continues to be responsible for providing treatments that are consistent with those provided under the hospice benefit, regardless of the cost of the treatment. Hospice programs are not expected to cover the costs of disease-modifying treatments. To simplify the administrative process, these are billed separately. MJHS Hospice and Palliative Care, along with our state advocate, the Hospice and Palliative Care Association of New York State (HPCANYS) and the New York State Department of Health have collaborated to develop procedures and safeguards to ensure the proper allocation of resources and proper delivery of services. These are now legally required for all Medicaid and Medicaid expansion programs, including Children's Health Insurance Programs.

When a family is dealing with a child that has been diagnosed with a terminal/life limiting illness, the natural course of everyone's life changes. Parents put their lives on hold, and siblings may get lost in the family's new dynamic. The children who are ill spend much time in clinics, hospitals, chemo units, and elsewhere. They start to wonder, "why me?" Parents of a newborn with a limited amount of time especially need support before, during, and after the birth and passing of their child.

MJHS Hospice and Palliative Care believes that specialist palliative care is essential for the youngest of our patients and families. We are confident that the new concurrent care pilot in New York State will continue to introduce and provide specialized medical, psychosocial, and supportive services to a larger number of sick children, their families, and their clinical caregivers.

Children are the eyes of the future. Managing illness burden and reducing suffering are imperative and doing so will ensure that the memories held by families are less burdened by guilt. Pediatric Concurrent Care is the beginning of a whole new chapter in hospice and palliative care.

References:

www.nhpco.org/files/public/CHiPPS/Children_QA_CMS_Feb2011.pdf

www.healthcare.gov

The Affordable Care Act of 2010, Provision 2032



READERS CORNER

Christy Torkildson, RN, MSN, PHN, PhDc
Co-Chair and Co-Editor; ChiPPs e-Newsletter
Doctoral Student ABD, UCSF School of Nursing
Departments of Family Nursing and Social Behavioral Sciences
Chief Academic Officer, Unitek College
christytork@gmail.com

Lindley, L. C. (2011). Health care reform and concurrent curative care for terminally ill children: A policy analysis. *Journal of Hospice and Palliative Nursing*; 13(2): 81-88. doi: 10.1097/NJH.0b013e318202e308. Retrieved from NIH public access; available in PMC 2012 July 20.

In this article, the author offers a policy analysis of the concurrent care legislation “by examining the intended goals of the policy to improve access to care and enhance quality of end of life care for terminally ill children.” The primary focus of the article was “to conduct a policy analysis of the pros and cons of the federal end of life policy for children.” Please note that this article was initially published in 2011, only one year after the Affordable Care Act (ACA) of 2010 became law on March 23, 2010.

As quoted in the article the specific language of the ACA follows:

A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the care of the child's condition for which a diagnosis of terminal illness has been made.

This article and several others in this issue of our newsletter note that, “the ACA does not modify or amend the hospice eligibility requirement of a 6 month prognosis to live. Children receiving concurrent care must still qualify for hospice admission.” Lindley discusses the pros and cons of: “1) impact on access to care, 2) impact on quality of care and 3) political feasibility.” The article provides an overview of the challenges with federally mandated care to be enforced at the state level. It also highlights the fragility of hospice care for children in this era of fiscal crisis for so many states since hospice is an optional benefit for children in most states in the US.

Many of the shortcomings of concurrent care identified in this article are highlighted in the articles within this issue of our newsletter. The same can be said for the pros. The end result is the continued need for more research, better legislation for all children in all states, and a better-trained professional workforce to care for these children and their families. Although this article is over 2 years old, the foundational information and references make it a worthwhile read.



Items of Interest

In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. SUBJECTS AND CONTRIBUTORS FOR FUTURE ISSUES OF THIS

NEWSLETTER. In the many past issues of this newsletter, we have addressed a wide range of subjects. For upcoming issues, we are thinking about addressing issues related to transitions (in the continuum of care between sites, providers, and modes of care, as well as those involving young adults), logistics around the time of death and memorialization, and a starter kit or "how to" tools for new programs in pediatric palliative/hospice care. If you know of good topics and/or contributors (including yourself) for these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at christytork@gmail.com; Maureen Horgan at horgan.maureen@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

In the meantime, you can visit archived issues of this newsletter at www.nhpco.org/pediatrics. Among them, you will find articles on bereavement, sibling bereavement, self-care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, the role of pediatric palliative and hospice care in creating systems to support children, families, and the community, children are not little adults (i.e., respecting differences in providing pediatric palliative/hospice care), honoring volunteer perspectives, perinatal palliative and hospice care, perspectives of fathers and other males, and differences between pediatric hospice care and pediatric palliative care.

2. READER'S CORNER. Our occasional Reader's Corner column, like the one that appears in this issue, provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative/hospice care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner typically include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles following the model described. Please send all such suggestions to Christy Torkildson at christytork@gmail.com.

3. TWO USEFUL LINKS:

- A policy statement from the American Academy of Pediatrics, Section on Hospice and Palliative Medicine and the Committee on Hospital Care, entitled "Pediatric Palliative Care and Hospice Care: Commitments, Guidelines, and Recommendations," was originally published online in *Pediatrics* on October 28, 2013 (DOI: 10.1542/peds.2013-2731), and is available at: <http://pediatrics.aappublications.org/content/early/2013/10/23/peds.2013-2731>
- An April, 2011, article on "Financing Pediatric Palliative and Hospice Care Programs," is available from the Catalyst Center, Health & Disability Working Group, at the Boston University School of Public Health, and can be retrieved at <http://hdwg.org/catalyst/node/197>



Children's Project on Palliative/Hospice Services

National Hospice and Palliative Care
Organization



4. PEDIATRIC CONTINUUM BRIEFING AVAILABLE. NHPCO's Mary J. Labyak Institute for Innovation is pleased to offer a pediatric-focused continuum briefing, Pediatric Concurrent Care (PDF), available free of charge online.

5. NEW PEDIATRIC CARE MODULE AVAILABLE ON E-ONLINE. The newest module in the 10 module training series on pediatric palliative care is now available on NHPCO's E-Online education portal. Be one of the first to sign up for the latest module in the series that is designed to furnish you with the latest trends in pediatric palliative care provision.

6. CALENDAR OF EVENTS. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, www.NHPCO.org/Pediatrics. *ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.NHPCO.org/Pediatrics.* Please e-mail Christy Torkildson at christytork@gmail.com to have your pediatric palliative care educational offering listed.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to Pediatrics@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, the Solutions Center will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the [ChiPPS Web page](#) for further materials and resources of interest.

NHPCO • 1731 King Street • Alexandria, VA 22314 703/837-1500 • 703/837-1233 (fax) • www.nhpc.org • www.caringinfo.org
--