



## Pediatric Concurrent Care

### Overview

The Mary J. Labyak Institute for Innovation at the National Center for Care at the End of Life is pleased to offer this pediatric-focused Continuum Briefing. It provides:

- Definition of pediatric palliative and/or hospice care;
- An overview of Concurrent Care for Children provision in the Affordable Care Act (ACA);
- Identification of the barriers for pediatric palliative care that are not addressed even with the provision for concurrent care in ACA;
- Key strategic opportunities for hospice and palliative care providers to expand the care continuum for children living with life-limiting or life-threatening conditions and their families.

The goal for all who read this briefing is to work together to assure that each state's most medically fragile children have the quality care they deserve. Individuals, families, professionals and groups can come together, identify champions and develop strategies to overcome barriers to care and continuity of services. The ultimate goal is success in securing the care and resources families desperately need.

### Pediatric Palliative and/or Hospice Care

Pediatric palliative and/or hospice care is both a philosophy and an organized method for delivering competent, compassionate and consistent care to children with chronic, complex and/or life-threatening conditions and their families. This care focuses on enhancing quality of life, minimizing suffering, optimizing function and providing opportunities for personal and spiritual growth. Planned and delivered through the collaborative efforts of an interdisciplinary team with the child, family and caregivers as its center, pediatric palliative and/or hospice care can and should be provided along with concurrent disease-modifying

therapy, when disease-modifying therapy is appropriate, or as the main focus of care, when disease-modifying therapies are no longer effective and comfort measures are of the utmost importance. This care is achieved through a combination of active and compassionate therapies intended to comfort and support the child, as well as family members and other significant people in the child's life.

Effective management of pain and other distressing symptoms, together with psychosocial and spiritual care, are of critical importance beginning at diagnosis and continuing throughout the entire course of a child's life and for their families beyond the child's death. Therapies take a holistic approach, assisting children and families in fulfilling their individual/unique physical, psychological, educational, social and spiritual goals while remaining sensitive to developmental, personal, cultural and religious values, beliefs and practices.

### How pediatric palliative care/ hospice care is different from care for adults

Pediatric palliative or hospice care differs from care delivered to adults in several important ways. First, children with palliative care needs range in age from prenatal to young adult. In fact, some adults over the age of 21 are still considered part of this population because they have conditions monitored by pediatric subspecialists or have developmental and/or physical challenges are better served by pediatricians. Teams must thus be able to care for patients with wide-ranging diagnoses whose understanding of illness and decision making changes significantly throughout the developmental spectrum. There are significant differences between what is effective for adult patients versus pediatric patients on a number of dimensions, including:

- trajectories of illness
- effective pain/symptom management interventions
- clinical models of care delivery,
- funding mechanisms
- research paradigms
- educational initiatives
- communication strategies
- ethical concerns
- staffing ratios and management.

### Mortality Statistics for Infants, Children and Adolescents

#### Infant Deaths

There were 2,436,682 deaths in the United States in 2009, the latest year for which death statistics are available. With 48,073 total deaths, children aged 0-19 years accounted for 1.9% of all deaths in 2009.

Slightly more than half of childhood deaths occur in infancy. Infant mortality in 2009 was

is slightly less than previous years, with 26,531 infants dying; this represents 6.42 infant deaths per 1,000 live births, a figure significantly lower (by 3%) than the 2008 rate of 6.61 per 1000 live births.

Infants of non-Hispanic black mothers are more than twice as likely to die in the first year of life compared to non-Hispanic white and Hispanic infants. Though infancy incorporates the period from death through the first year, most of these children die in the first week of life. Fetal mortality decreased from 2005 (28,534 deaths) to 2009 (26,531).<sup>1</sup>

#### All Infant Deaths (n = 26,531)

1. Congenital malformations **(20.2%)**
2. Short gestation and low birth weight **(16.8%)**
3. Sudden infant death syndrome **(8.4%)**
4. Maternal complications **(6.0%)**
5. Accidents/unintentional injuries **(4.28%)**
6. Complications of placenta, cord and membranes **(3.9%)**

## Deaths among children and adolescents

Beyond infancy, there were 21,542 deaths in children ages 1-19 years in 2009, representing a death rate of 27.2 deaths per 100,000. This number represents a 6.5% decrease from the year 2008. Causes of death in 2009 for children beyond infancy were (in ascending order): accidents, assault, suicide, malignancy, congenital malformations/deformations, heart disease, influenza/ pneumonia and chronic lower respiratory disease.

### All Children Deaths-1-19 Years (n = 21,542 Deaths)

1. Accidents <b>(36.5%)</b>
2. Assault <b>(12.1%)</b>
3. Suicide <b>(8.9%)</b>
4. Malignant neoplasms <b>(8.8%)</b>
5. Congenital malformations, deformations <b>(4.9%)</b>
6. Heart disease <b>(3.2%)</b>
7. Influenza and pneumonia <b>(2.4%)</b>
8. Chronic lower respiratory disease <b>(1.2%)</b>

## How the 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.<sup>1</sup> 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.

1. The full text of Section 1905 is included in Appendix 1. Public Law No. 111-148, as amended by the Healthcare and Education Reconciliation Act of 2010 (Public Law No. 111-152).

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.

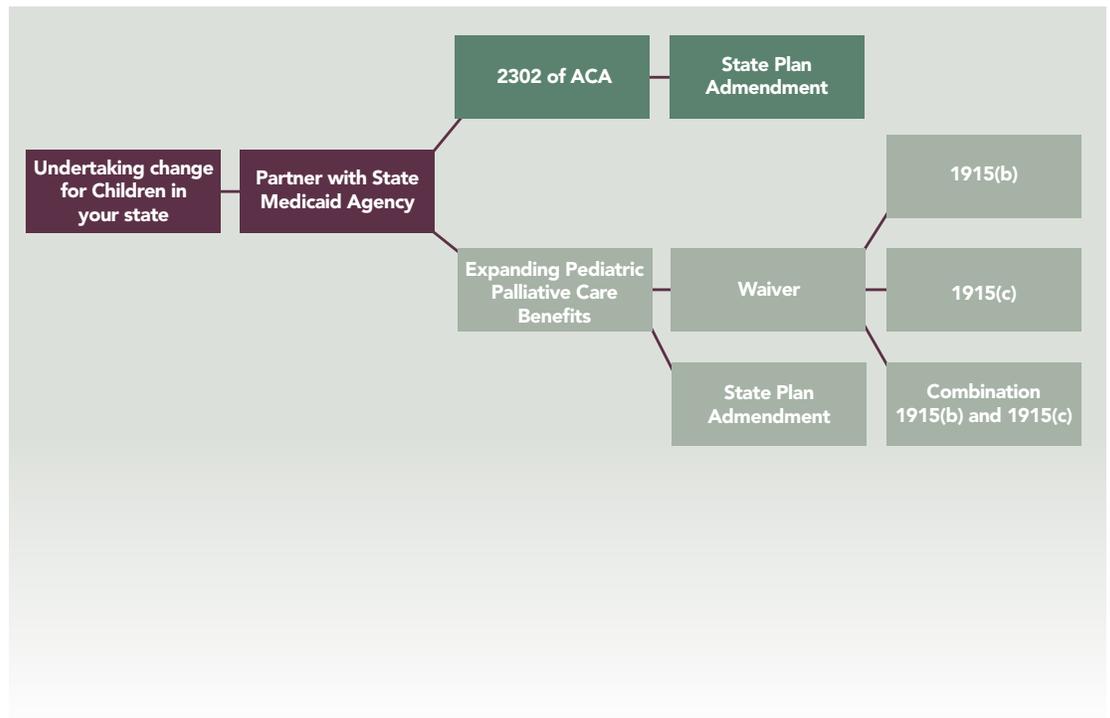
### Options to Address Barriers and Expand Pediatric Palliative Care

There is significant interest in providing children who are eligible for hospice with more expansive programs and services than are currently provided under the hospice benefit. There is also considerable interest in providing more expansive supportive services to children with life-limiting or life-threatening conditions who are not eligible for Medicaid hospice services, but who would greatly benefit from palliative care services earlier in their disease. While states cannot provide fewer services than stipulated by Medicaid, states are certainly free to expand the scope of services paid for by Medicaid, and expand the number of children who might be eligible for those services.

There are options for states that permit them to provide services that are more expansive than basic hospice services and to forgo the requirement that eligibility is limited to children who have a life expectancy of six months or less. These options are available at a state's discretion and must be approved by the Centers for Medicare & Medical Services(CMS). If a state wants to provide more expansive services and eligibility, there are two basic mechanisms for implementing those programs and services:

1. State plan amendment
2. Medicaid waiver.

The figure below details the options states have for implementing Section 2302, as well as options for an expanded pediatric palliative care benefits.



## State Implementation Models

Several states have shared examples of options that have been implemented.

### Washington EPSDT SPA

The State of Washington provides pediatric palliative care under the authority of Early Periodic Screening, Diagnosis and Treatment (EPSDT) using a state plan amendment, provides additional services and expanding eligibility to include life-limiting conditions. The state specifies that hospice care “also includes pediatric palliative care services that are provided for approved clients 20 years old and younger who have a life-limiting diagnosis.” The state also requires that managed care plans provide this benefit for eligible children enrolled in the plan. The pediatric palliative care benefit consists of up to six contacts per client per calendar month. A contact may consist of any of the following:

- **One visit with a registered nurse, social worker, or therapist (licensed physical therapist, occupational therapist, or speech/language therapist) with the client in the client’s residence to address**
  - Pain and symptom management;
  - Psychosocial counseling; or
  - Education/training;
- **Two hours or more per month of case management or coordination services to include any combination of the following:**
  - Psychosocial counseling services (includes grief support provided to the client, client’s family member(s), or client’s caregiver prior to the client’s death);
  - Establishing or implementing care conferences;
  - Arranging, planning, coordinating and evaluating community resources to meet the child’s needs;
  - Visits lasting 20 minutes or less (for example visits to give injections, drop off supplies or make appointments for other pediatric palliative care-related services); and
  - Visits not provided in the client’s home.

Note: Approved state plan amendments with an approval date of June 1, 2007 or after are now available on the CMS website at: <http://www.cms.gov/MedicaidGenInfo/StatePlan/list.asp>.

### 1915(b) Waiver: Florida’s Program For All-Inclusive Care for Children

Florida operates a pediatric palliative care program, Partners in Care: Together for Kids, under its 1915(b) managed care waiver. The intent of this model is to provide pediatric palliative care services to children with life-limiting conditions from the time of diagnosis and throughout the treatment phase of their illness. It provides pain and symptom management, counseling, expressive therapies for young children, respite and hospice nursing and personal care services to children enrolled in the program.

The waiver includes a waiver of state-wideness (operating in limited areas of the state) and uses Section 1915(b)(4) authority to contract selectively with Partners in Care: Together for Kids providers who are hospices and who meet specified criteria for the program. The supplemental services are provided under the authority of 1915(b)(3), which means they are funded from savings attributable to the 1915(b) waiver.

More information about Florida’s program is available in the report “Program For All-Inclusive Care For Children – 2009 Partners In Care Annual Evaluation Report (Evaluation Year 3), which may be downloaded at: [http://ahca.myflorida.com/Medicaid/quality\\_management/mrp/contracts/med052/final\\_annual\\_pic\\_report\\_february\\_2009.pdf](http://ahca.myflorida.com/Medicaid/quality_management/mrp/contracts/med052/final_annual_pic_report_february_2009.pdf).

### 1915(c) PPC Waiver Examples

California, Colorado and North Dakota each operate pediatric palliative care programs under a Section 1915(c) waiver. The waivers provide supplemental services to children with a life-limiting condition. The waivers also use a diagnosis of “life-limiting condition” rather than a terminal illness with a life expectancy of six months. Finally, in all three states CMS approved concurrent care for the children enrolled in these 1915(c) waiver, even prior to the passage of the ACA.

**Table 1: 1915(c) PPC Waiver Services Examples**

California Waiver Services	Colorado Waiver Services	North Dakota Waiver Services
Care coordination	Expressive therapy	Case management
Home respite care	Client/Family/Caregiver Respite Care	Home health aide
Expressive therapies	Palliative/Supportive Care services provided concurrently with curative care services	Hospice
Family counseling		Skilled nursing
Family training		Bereavement counseling
Out-of-home respite care		Expressive therapy
		Palliative care

### 1915(c) Waivers for Medically Fragile Children

Some states include pediatric palliative care services under 1915(c) waivers targeting children who are medically fragile. These include New York’s program, Care At Home and North Carolina’s Community Alternatives Program for Children.

As an example, New York’s Care at Home waiver serves children ages birth through 17 years who are determined to be physically disabled based on Supplemental Security Income (SSI) criteria, and who would otherwise require hospital or nursing home care. The waiver serves a broader group of children than those who have a terminal illness or a life-limiting condition. The services covered through the waiver are:

- Case management
- Bereavement services
- Expressive therapies
- Family palliative care education (training)
- Home and vehicle modification
- Massage therapy
- Pain and symptom management
- Respite

Authorized providers include certified home health agencies or hospices.

## Implementation Strategies: Crafting Your State's Options

The Concurrent Care for Children Implementation Toolkit provides readers with the options and mechanisms required to implement changes to the Medicaid eligibility criteria for children, and/or to expand the scope of services provided and paid for by Medicaid in the state. Each state may have additional administrative, regulatory, statutory or budgetary steps that are required prior to implementing a pediatric palliative care program.

The most appropriate options for your state will depend on the nature of the proposed changes. No matter what option/s your state chooses, there are key strategies necessary for implementation in your state that turn affect the care your organization can provide to children and their families in your community.

### 1. Build a coalition

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. Identify a group of individuals and organizations in your state such as disease-based groups, parent advocacy networks and medical home initiatives among others, to build a coalition of support for an expanded pediatric palliative care benefit for the state's children.

### 2. Become familiar with the eligibility and scope of services currently in effect in your state:

- a. Identify your Medicaid state plan and the relevant portions for hospice care;
- b. Identify any Medicaid waivers that include hospice or palliative care benefits for children or that serve medically fragile children.
- c. Understand the political landscape in your state and what is possible within the Medicaid budget process.

### 3. Gather data on the number of children affected, including:

- a. Number of children under the age of 21
- b. Number of children with life-limiting, life-threatening and/or terminal conditions
- c. Number of children and their families who currently qualify for Medicaid or CHIP or who would be eligible for coverage from either Medicaid or CHIP based on any proposed change to the eligibility criteria
- d. The number of children who died in a given year, and if known, their Medicaid eligibility status
- e. If expanding to include palliative care-eligible children, number of children who can be classified as medically complex or fragile

#### 4. Develop a proposed program design

Once you become familiar with the pediatric palliative care and hospice programs and other benefits that are offered in your state, you must articulate how you want those programs and benefits to change. These changes can be to any number of benefit features:

- Eligibility criteria
- Scope of services
- Duration of services
- Expenditure cap on services
- Provider qualifications
- Co-pays or deductibles
- Measurement of outcomes

#### 5. Provide program cost information as available.

Even if key state decision makers and other stakeholders are generally supportive of the concept, and believe the proposed changes to be good public policy, they will still be concerned about the impact of any costs or cost savings associated with the new program or services. Some factors to be considered in preparing cost estimates:

- Service utilization
- Unit service cost
- Your state's Medicaid match requirements.
- Anticipated cost savings

#### 6. Determine the appropriate Medicaid option

Once you have developed your program design, you can then determine the mechanism best suited to implement your proposed changes. It is not your responsibility to make this determination, but rather the responsibility of the state Medicaid agency. However, being aware of the options described above, their uses and limitations, and the length of time it can take to secure approval are all very important to keep in mind when designing a pediatric palliative care proposal.

#### 7. Build support and advocate for preferred options

There is basic information that you will need, and approaches that you will need to take, to build support for the preferred option(s).

- Identify and reach out to other individuals and organizations that share the vision.
- Be very clear about the reason for the proposal: Why are you proposing these changes?
- Decide, in advance, if there are possible compromises to the proposed option. Be willing to propose a pilot with a limited number of beneficiaries to make the case and calm fears of "service creep."
- Anticipate possible opposition.
- Know that new ideas can take time to take hold.
- Identify key decision makers and focus advocacy efforts on them.

## 8. Learn from Others

NHPCO's Concurrent Care for Children Implementation Toolkit provides specific examples of implementation strategies for Section 2302 and pediatric palliative care initiatives that have been proposed and implemented in other states. Resource materials from state initiatives are available online at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). There are a variety of examples for states to use and copy in the "Policy Section" of the webpage. There is excellent background information on the development of the program, the basis for program approval and the experience to date or evaluation of the program implementation. It is the intent of NHPCO to continue to capture key points from these various state initiatives in one place so that state advocacy groups can proceed with the implementation of comprehensive pediatric palliative care programs in each state.

### **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 strong advocates for your state's children and ultimately succeed in securing the care and resources their families desperately need. The ultimate goal is to assure that your state's most fragile children have the quality care they deserve.

## Resources:

Pediatric resources for professionals, researchers and consumers also available at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics)

*Concurrent Care for Children Implementation Toolkit: Section 2302 of the Patient Protection and Affordable Care Act*

[www.nhpco.org/files/public/chipps/CCCR\\_Toolkit.pdf](http://www.nhpco.org/files/public/chipps/CCCR_Toolkit.pdf)

Hospice Action Network - Additional legislative advocacy materials and resources can be found at [www.hospiceactionnetwork.org](http://www.hospiceactionnetwork.org).

Facts and Figures for Infant, Children and Adolescents – 2009

[pediatrics.aappublications.org/content/early/2012/01/25/peds.2011-3435.full.pdf+html](http://pediatrics.aappublications.org/content/early/2012/01/25/peds.2011-3435.full.pdf+html)

*NHPCO's Pediatric Facts and Figures, 2008.*

[www.nhpco.org/files/public/quality/Pediatric\\_Facts-Figures.pdf](http://www.nhpco.org/files/public/quality/Pediatric_Facts-Figures.pdf)

Kochanek KD, Kirmeyer SE, Martin JA, et al. Annual summary of vital statistics: 2012, *Pediatrics* 2012; 338-348

NHPCO's 13th Clinical Team Conference and Pediatric Intensive, 7L - Pediatrics Concurrent Care: Putting Theory into Practice, MP3 Recording:

[http://www.dcpvidersonline.com/nhpco/index.php?event\\_id=NHPCO110](http://www.dcpvidersonline.com/nhpco/index.php?event_id=NHPCO110)

National Hospice and Palliative Care  
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