



Concurrent Care for Children Requirement: Implementation Toolkit

Table of Contents

1. Introduction	1	6. Crafting your State's Options	14
2. About the Concurrent Care for Children Requirement (CCCR)	3	Build a Coalition	14
What the CCCR is	3	Become Familiar with the Current Eligibility and Scope of Services	15
What the CCCR is not	3	Gather Data on Children and Services Needed	16
CMS Guidance	4	Understand the Interests and Preferences of the State Medicaid Agency	16
CMS Answers Questions about State-level issues regarding implementation	5	Learn from Other States	17
3. State Impact	7	Develop a Proposed Program Design	17
4. Guidance for Pediatric Healthcare Professionals and Hospice Providers	8	Provide Program Cost Information	17
Implementation of the CCCR	10	Determine the Appropriate Medicaid Option – SPA or Waiver?	19
5. Options Beyond the CCCR	11	Build Support and Advocate for Preferred Option(s)	20
Washington EPSDT SPA Example	11	7. Conclusion	22
1915(b) Waiver Example: Florida's Program for All-Inclusive Care for Children	12	8. Acknowledgements	23
1915(c) pediatric palliative care Waiver Examples	13		
1915(c) Waivers for Medically Fragile Children	13		

Disclaimer: These materials are intended to serve as general advice only. Anyone using this toolkit is responsible for ensuring that programs and services be provided in compliance with all applicable federal and state laws and regulations and should consult with counsel and the appropriate agencies before implementing or changing any processes or decisions.

1. Introduction

For many years, healthcare professionals and families with children living with serious illness had few options for Medicaid coverage when children were very seriously ill. Parents in all but a few states were faced with forgoing disease directed treatments for their children to be eligible for hospice services. Or conversely, they were not eligible for beneficial interdisciplinary hospice services while getting disease directed treatment. The Patient Protection and Affordable Care Act (ACA) changed this situation and requires state Medicaid programs to pay for both disease directed treatment and hospice services for children under age 21 who qualify. On March 23, 2010, ACA was signed into law enacting a new provision, Section 2302, termed the "Concurrent Care for Children" Requirement (CCCR).

The National Hospice and Palliative Care Organization (NHPCO) Pediatric Advisory Council are pleased to provide this *Concurrent Care for Children Requirement: Implementation Toolkit*, which details information on the options available to states regarding Section 2302 or are considering expansion of pediatric palliative care services to children living with life-limiting or life-threatening conditions.

Specifically, this Toolkit can be used as a guide to:

- Understand the impact of the CCCR on state Medicaid programs;
- Consider the different Medicaid state plan amendment and waiver options available to states;
- Review examples 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 living with serious illness through a comprehensive array of services.

Who should use this Toolkit?

- **Hospice and palliative care providers** seeking an overview of changes made to federal Medicaid law in 2010, as a part of healthcare reform, so they can provide quality care for eligible children and their families.
- **State hospice organizations, coalitions and other advocacy groups** interested in learning mechanisms to collaborate with their respective state Medicaid offices and advocate for children living with serious illness and their families.
- **Parents who have children living with serious illness** (or children in need of hospice or palliative care services) who need basic information and resources to advocate for their child's care.

Note: This toolkit deals only with services paid for by state Medicaid programs for children who are eligible to be enrolled in Medicaid or Children's Health Insurance Program (CHIP). This Toolkit does not address programs and services available through private insurance programs or private pay.

While the CCCR is a positive step forward in obtaining better care for children at the end of life, it does not expand the types of services available, nor does it provide palliative care or other supportive services to children living with serious illness whose prognosis falls outside the last six months of life (should the disease or condition follow its normal course).

Despite this limitation, it is helpful to know states have options available to permit them to provide services more expansive than basic hospice services and to forgo the requirement of eligibility 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 federal government. If a state wants to provide more expansive services and eligibility, there are two basic mechanisms for implementing those programs and services.

Note: An administrative rule change may be necessary in addition to a waiver or SPA depending on each state's requirements.

These mechanisms are through:

- Amendments to a state's Medicaid state plan (State Plan Amendment or SPA)
- The use of Medicaid waivers

Overall, we encourage the formation of statewide pediatric palliative and hospice care advocacy coalitions to work together towards improved options for children living with serious illness. This includes directing state to provide increased services for children who would not qualify under the ACA provision and expanding the array of services for them.

The information and resources provided in the "*Options Beyond the CCCR*" and "*Crafting your State's Options*" sections of the Toolkit can assist you in these efforts.

2. About the Concurrent Care for Children Requirement (CCCR)

What the CCCR is

Section 2302 of the ACA amended the Federal Social Security Act, Section 1905(o)(1) and 2110(a)(23). The new provision states 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 made for, services related to the treatment of the child's condition even though, a diagnosis of terminal illness has been made.¹ This provision affects children who are eligible for Medicaid or the Children's Health Insurance Program (CHIP).

This provision, termed Section 2302: "Concurrent Care for Children" Requirement (CCCR), went into effect upon the enactment of the ACA, on March 23, 2010. In its simplest form, implementation of this provision can be accomplished by the state Medicaid agency eliminating any provider claims denying or pending concurrent disease directed and hospice claims (usually through processing edit codes). States are also required to submit a Medicaid state plan amendment when CMS releases a template for this submission. *However, states are required to comply with these requirements in advance of amending their state plans.*

Note: For more information on Concurrent Care for Children guidelines for your specific state, please visit your state Department of Health website. Additionally, a useful tool to view and compare state-by-state guidelines is presented by the University of Tennessee, Knoxville: [State Concurrent Care | Pediatric End-of-Life Care Research \(utk.edu\)](http://StateConcurrentCare.PediatricEnd-of-LifeCareResearch.utk.edu)

What the CCCR is not

While Section 2302 addresses what has been a significant barrier to enrollment of children into hospice care, a state's amendment of its Medicaid state plan to comply with Section 2302 does not remove the major remaining barriers to providing a more expansive pediatric palliative care (pediatric palliative care) program, which are:

- Physicians must still certify a 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.

Prior to enactment of Section 2302 of the ACA, some states used either a Medicaid State Plan Amendment (SPA) or waiver authority to provide supplemental services to children and replaced the "terminal illness within six months" provision with a requirement a children have a life-limiting condition.

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).

States also were able to provide both disease directed treatment and hospice services using either a Medicaid waiver or Medicaid SPA.

States may wish to use the opportunity presented by the CCCR to include supplemental services and a change in eligibility for these services in their SPA, permitting children with a life-limiting condition to access the more comprehensive benefit. Alternately, a state may wish to use waiver authority to implement these enhancements.

CMS Guidance

The Centers for Medicare and Medicaid Services (CMS) is the federal agency responsible for oversight of Medicare and Medicaid services and issues guidance to states on the implementation of Medicaid services. On September 9, 2010, CMS released guidance to states about the implementation of Section 2302 of the ACA in the form of a State Medicaid Director (SMD) letter (SMD # 10-018).² This letter re-states the changes made by the CCCR, to "... remove the prohibition of receiving curative/life prolonging treatment upon the election of the hospice benefit by or on behalf of a Medicaid or Children's Health Insurance Program (CHIP) eligible child." The letter notes:

- The provisions do not change the criteria for receiving hospice services (including the requirement a physician certify the eligible person is within the last six months of life, should the disease or condition follow its normal course);
- Prior to the changes, disease directed treatment usually ceased with the election of the hospice benefit;
- This provision "requires States to make hospice services available to children eligible for Medicaid and children eligible for Medicaid-expansion CHIP programs without forgoing any other service to which the child is entitled under Medicaid for treatment of the terminal condition. These services and supports may include pain and symptom management and family counseling provided by specially trained hospice staff." CMS stated the provisions are "... vitally important for children and their families seeking a blended package of curative/life prolonging and palliative services;"
- CMS reiterates a state's obligation to provide Medicaid hospice services to children even if the state does not include hospice services for adults: "Hospice is a 1905(a) service, and would therefore need to be provided to individuals from birth through age 20 when medically necessary, regardless of whether hospice is offered to individuals over age 21";
- CMS anticipates the provisions will increase utilization of hospice services;
- The provisions were effective on March 23, 2010;
- CMS expects states to continue to provide and pay for disease-directed/life prolonging services even after the election of the hospice benefit;
- CMS released a template, called a state plan preprint, for state Medicaid agencies to use for submission of a SPA to reflect this change in requirements;
- States may proactively amend their state plan prior to release of the preprint, but are not required to; and
- CMS expects states to provide services consistent with this new provision upon enactment of the federal law on March 23, 2010, even before an SPA preprint is provided to state Medicaid agencies.

² A copy of SMD #10-018, as well as the link to the CMS site for State Medicaid Director letters, is included as Appendix 2.

When CMS implements changes to the Medicaid program, such as the CCCR, it provides a “pre-print” checklist that States can use to submit their SPAs. *Submission of a SPA is a State’s formal indication to CMS of its intention to implement a change in Medicaid eligibility and benefits.* When the preprint is issued, the State may very well be required to submit the SPA within a short timeframe.

Since CMS has stated implementation of this change requires a SPA, the state is required to submit the SPA to CMS for approval. The State Medicaid agency will be in charge of the process for submission. While the Federal requirement for implementing the CCCR is fairly straightforward from a Federal perspective, each State has its own processes it must follow to implement programmatic change. In some States, statutory or regulatory changes may be required, budget action may be needed if the change has a fiscal impact, and some changes require State agencies make programmatic changes or changes in information technology systems, provider billing systems, or other administrative procedures.

CMS Answers Questions about State-level issues regarding implementation

In February 2011, NHPCO asked CMS for clarification on Section 2302 so States would have specific guidance in addition to the SMD Letter regarding implementation. CMS was responsive to specific implementation questions about this provision. CMS’s direct responses to NHPCO questions are in **bold** below the question. The complete text of all Questions & Answers (from CMS) is located in Appendix 3.

Below are several answers that may be helpful to states beginning the implementation process.

1. **Does a state have to have a Medicaid hospice benefit to offer concurrent care for children through Medicaid or CHIP? And if a state eliminates its hospice benefit, does that mean that it no longer has to offer concurrent care for children because there is no Medicaid Hospice benefit?**

CMS Response: Eliminating the hospice benefit is really only possible for adults. Hospice is a 1905(a) service and would therefore need to be provided to individuals from birth through age 20 when medically necessary, regardless of whether hospice is offered to individuals over age 21. States **MUST** comply with 2302, whether or not they offer hospice to adults.

2. **If we look at 2302 in its simplest form it states, “to make hospice services available without forgoing any other services for which the child is eligible.” Our state interpreted this to mean remove all edits in the systems, but we are still responsible for everything that the state will cover under the Hospice Benefit. But Early and Periodic Screening Diagnosis and Treatment (EPSDT) and aggressive treatment and “other things” can be provided. So, the “other things” is where it gets sticky.**

CMS Response: This is similar to other questions we’ve received. A good first step in implementing 2302 is to remove system edits that prohibited payment of curative treatment on top of hospice care. Hopefully there are also conversations happening between the State Medicaid Agency and the provider community to make sure everyone is aware of this provision and what it means.

Many hospices had been hoping that 2302 meant relief from some of the services they had had responsibility to provide, especially more expensive treatment options. But that’s not how CMS is interpreting this provision. If a service is appropriate under the hospice benefit, it remains the responsibility of the hospice to provide it. We’ve had some tough conversations with hospices calling about specific medications that are very expensive, hoping that CMS would deem the medication “curative,” and therefore not their responsibility to provide. This creates a very uncomfortable position

for CMS to be in. What's curative for one child could be palliative for another. We've instead reinforced the parameters of what's palliative – pain and symptom relief of the terminal condition. If a service fits that characteristic, it's part of the hospice benefit.

3. Do all states have to pay for concurrent care for children with Medicaid? What is the interface with the state's Medicaid hospice benefit?

CMS Response: Yes, States are responsible for covering, and Federal reimbursement is available for, the concurrent provision of curative care and hospice services for Medicaid-eligible children. CMS issued a letter to all State Medicaid Directors (SMD # 10-018) on September 9, 2010, providing guidance on section 2302 of the Affordable Care Act which was effective on March 23, 2010. All Medicaid programs, including CHIP programs operating as Medicaid expansions, are required to continue to provide medically necessary curative services, as well as hospice services for children. We encourage providers to contact their State Medicaid Agencies to discuss an implementation strategy for this provision.

4. Does the state have the opportunity to decide what is considered "related" to the terminal illness?

CMS Response: Yes, the State Medicaid Agency determines the standards or procedures for determining the medical necessity for any Medicaid service. Further, section 2302 of the ACA requires States to remove any limits on the receipt of curative treatment, other than medical necessity, for children also receiving hospice services. We would expect States to have a process to ensure collaboration with the provider community to take each child's case into account in determining whether a service is curative or palliative.

3. State Impact

The provisions of the CCCR do not change the fact that while hospice is an optional benefit under the state Medicaid program for adults, it remains a mandated benefit for children as a part of the services offered under Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements. With passage of the ACA, the State is now required to pay for both disease directed treatment and hospice services provided to eligible children. The details of EPSDT are as follows:

Because the CCCR went into effect on March 23, 2010, CMS is expecting states to have implemented these requirements. However, many states are still in the process of grappling with implementation. As states analyze the impact of the CCCR on the State Medicaid program, state costs and other administrative considerations, there is a perfect opportunity for stakeholders who advocate for hospice and palliative care programs for children and their families to participate in and influence the discussion and outcomes of implementation. State decision makers need to understand the real-world implications of their decisions, and will, more often than not, value the participation and insights of well-organized and informed advocacy organizations and families.

In the SMD letter, CMS expected utilization of the hospice benefit to increase for children, since parents will no longer have to forgo disease directed treatment if they voluntarily elect hospice services for their child. Data on the impact of CCCR on hospice utilization has not been shared. The State Medicaid program is paid for by a combination of Federal funds and State matching funds. Generally speaking, the State must use state general tax funds to match Federal dollars.

With the decline of States' revenues and severe State budget cuts being implemented or considered in many states, programs that cost the state additional funds are sure to be carefully analyzed. States may also be unsure of assumptions to use to estimate the fiscal impact of the CCCR and may use caution before moving forward.

If a State believes the implementation cost of the CCCR to be unaffordable, this may result in discussions about a continuation of the entire hospice benefit. However, elimination of the Medicaid hospice benefit will not affect the implementation of CCCR or coverage of hospice services for children, since these are required whether or not a State includes the Medicaid hospice benefit among its covered services for adults.

Examples for States implementing CCCR can be found in the section entitled "[Crafting Your State's Options](#)" which will provide advocates at the state level with a roadmap for State Medicaid agency discussions.

4. Guidance for Pediatric Healthcare Professionals and Hospice Providers

CMS has provided guidance to pediatric healthcare professionals and hospice providers as states implement the provisions of Section 2302. The questions CMS has answered below are a strong indication the most productive approach in each State is to form a statewide pediatric coalition or advocacy group. Most states have a group of interested professionals and hospice leaders networking together and communicating as a group to the state Medicaid agency. See www.nhpco.org/pediatrics for the most up-to-date list of leaders in your state and ways to contact them to get involved.

In February 2011, CMS answered the following questions specific to pediatric healthcare professionals and hospice providers. CMS's direct responses to NHPCO questions are in **bold** below the question. The complete text of all Questions & Answers (from CMS) is located in Appendix 3.

1. Who would make the decision of where things are billed?

CMS Response: States would continue to pay providers of curative services using the payment methodology approved for those services. States will continue to reimburse hospices for services within the hospice benefit. We would expect States to have a process to ensure collaboration with the provider community to take each child's case into account in determining whether a service is curative or palliative.

2. Do we know what details are left up to the state? Can pediatric healthcare professionals in various states get together to suggest guidelines for state Medicaid agencies to follow?

CMS Response: State Medicaid agencies must make the determinations of whether a particular service for a child meets the State's medical necessity criteria for that service. We encourage and expect States and hospice providers to discuss and agree on a process that would address operational details in implementing section 2302 of the Affordable Care Act. Accordingly, we think that any assistance pediatric healthcare professionals can contribute to that effort would be worthwhile.

3. Does the state have the opportunity to decide what is considered "related" to the terminal illness?

CMS Response: Yes, the State Medicaid Agency determines the standards or procedures for determining the medical necessity for any Medicaid service. Further, Section 2302 of the Affordable Care Act requires States to remove any limits on the receipt of curative treatment, other than medical necessity, for children also receiving hospice services. As above, we would expect States to have a process to ensure collaboration with the provider community to take each child's case into account in determining whether a service is curative or palliative.

4. Are children receiving care under the Hospice benefit also eligible to receive Family Infant Toddler/Early Intervention (FIT/EI) services as well?

CMS Response: Section 2302 of the Affordable Care Act means that States must comply with the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirement to provide any medically necessary 1905(a) service to a child from birth to age 21, even after election of the hospice benefit by or on behalf of a child. Therefore, eligible children receiving care under the Hospice benefit should receive FIT/EI services as well, to the extent these services are medically necessary and are provided pursuant to a service authorized under section 1905(a).

5. The State Medicaid Director Letter seems to imply that the states would have to pay separately under Medicaid for the concurrent services. Is this the case or would hospices have to absorb the cost of curative care under the hospice benefit daily rate? The language in the letter does not specifically state that the states would continue to concurrently pay separately for curative services, just that curative service would not be excluded from the services available to children with life expectancy of 6 months or less.

CMS Response: States would continue to pay providers of curative services using the payment methodology approved for those services. States will continue to reimburse hospices for services within the hospice benefit. We would expect States to have a process to ensure collaboration with the provider community to take each child's case into account in determining whether a service is curative or palliative. Hospices are not responsible for providing or paying for curative treatment.

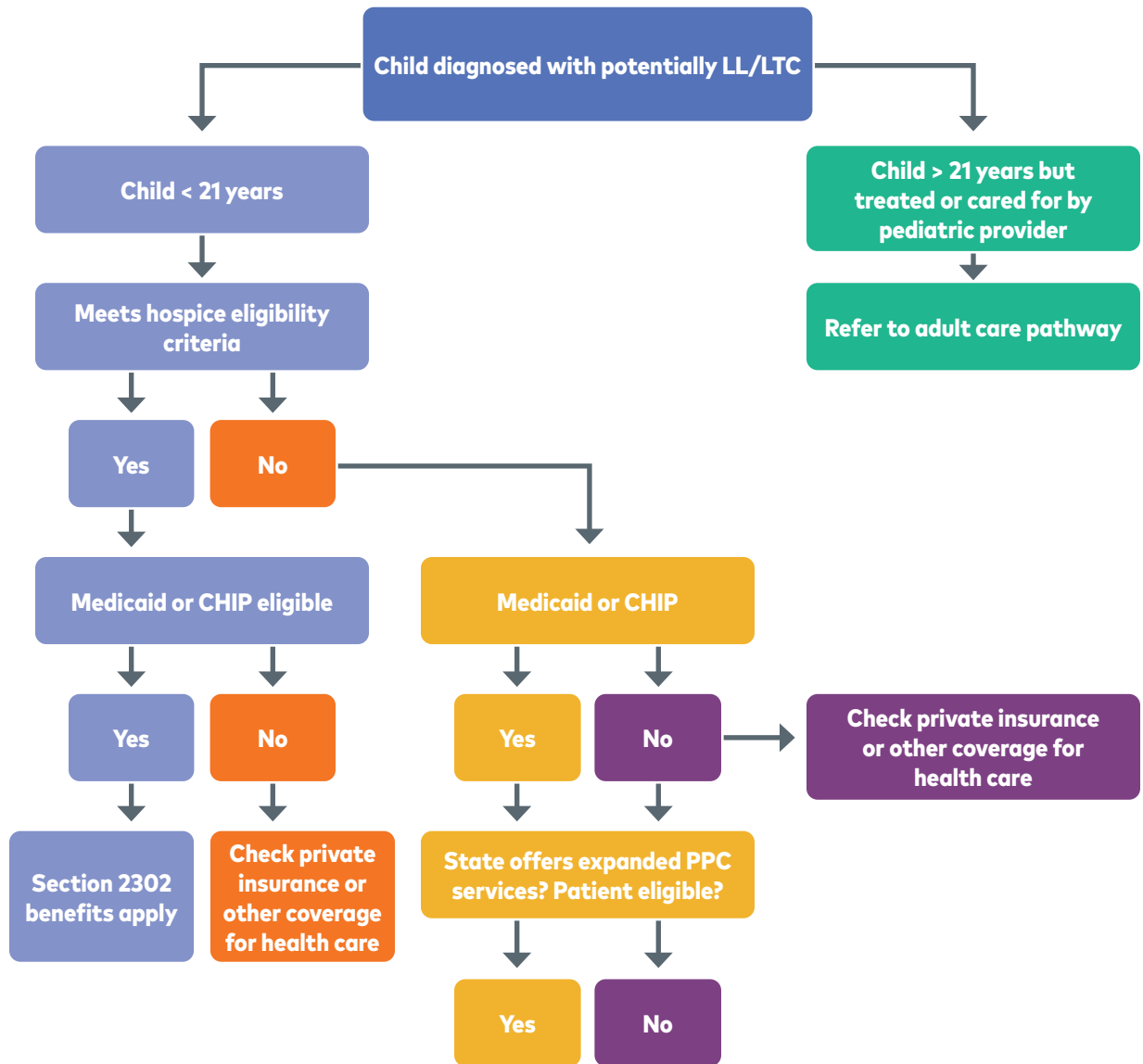
6. Please clarify: the concurrent care can commence immediately, forms will be forthcoming (what and when?), and the dialogue process has just begun. Using the directive that this care is to begin immediately, then, for those of us who have hospice- appropriate children with Medicaid coverage, we should admit these children into hospice care, documenting medical necessity for all care, and move forward.

CMS Response: As CMS stated in our State Medicaid Letter (SMD # 10-018), dated September 9, 2010, this provision was effective upon enactment of the Affordable Care Act on March 23, 2010. Therefore, under Medicaid, including CHIP programs operating as Medicaid expansions, we expect States will continue the provision of medically necessary curative services. States operating stand-alone CHIP programs that offer the optional hospice benefit must now provide it concurrently with medically necessary services.

CMS refers you to your State Medicaid officials responsible for implementing this new provision. We do expect that States will now have processes and systems in place to accept and process claims for children receiving curative treatment after election of the hospice benefit. We emphasize that the ACA statute does not make the hospice financially responsible for any care that it would not have provided previously. States would continue to provide and reimburse for curative care separately from hospice services.

In addition, a decision chart for providers regarding the CCCR is outlined below and may be a helpful resource to distribute among your staff.

Healthcare Professional and Hospice Decision Process: Section 2302 and Pediatric Palliative Care



Implementation of the CCCR

If the focus of your efforts is on the implementation of the CCCR and does not include expanding the eligibility or scope of services currently offered in your state, then most likely only a SPA will be required, in addition to whatever administrative and legislative processes your State must use to amend the State plan.

If your state already has a pediatric palliative care waiver or other type of expanded services, you must also examine the extent to which implementation of the CCCR might affect the children currently being served under these programs.

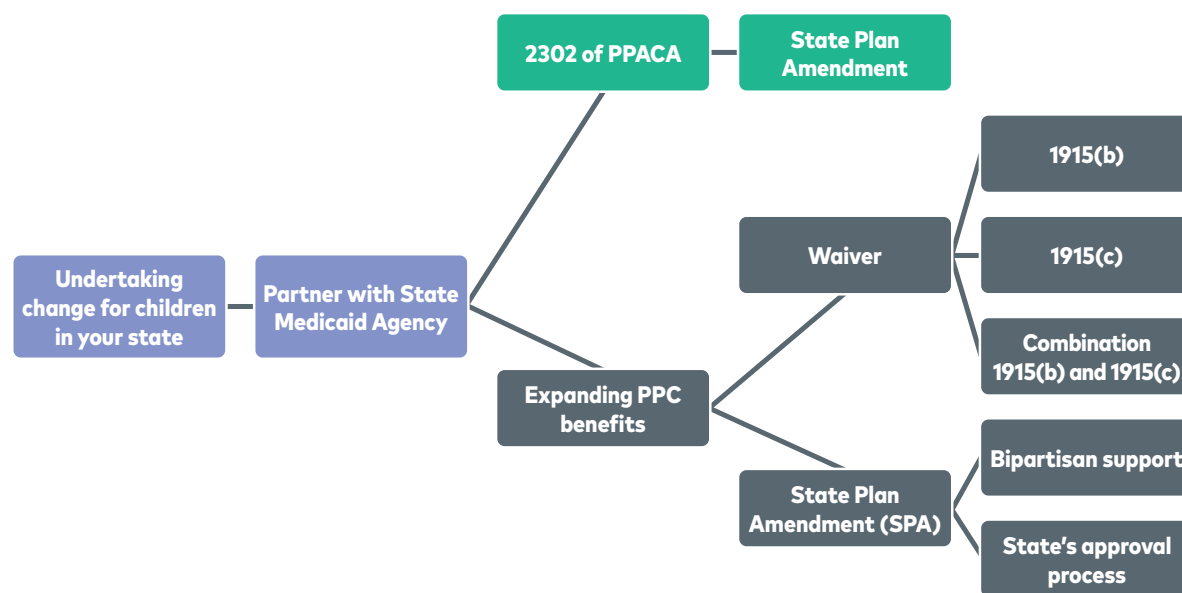
5. Options Beyond the CCCR

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 living with serious illness who **are not eligible** for Medicaid hospice services, but who would 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.

CMS has permitted States to implement alternatives to all of these requirements and limitations using state plan and waiver options, even though there is no specific authority to change the requirements related to medical eligibility for the hospice benefit under either the state plan or through 1915(b) or 1915(c) waivers. CMS flexibility in this area appears to arise from flexibility afforded by the Medicaid EPSDT provisions in law and subsequent legal interpretations. States have two ways to expand eligibility and scope of services for pediatric palliative care programs: through an SPA or through a waiver. The mechanism most appropriate for your State depends on the types of changes being proposed.

The figure below details the options States have for implementing Section 2302, as well as options for an expanded pediatric palliative care benefit. For a complete overview of the SPA and waiver options, see Appendix 4.

Figure 1: State Options for Implementation of 2302 and Expanded pediatric palliative care Benefits



Several states have shared examples of options that have been implemented, provided below:

Washington EPSDT SPA Example

The State of Washington provides pediatric palliative care under the authority of EPSDT using an SPA, providing additional services and expanding eligibility to include life-limiting conditions. The SPA states specifically 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 managed care plans to provide this benefit for eligible children enrolled in the plan. The pediatric palliative care benefit consists of up to six pediatric palliative care 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 SPAs with an approval date of June 1, 2007 or after are now available on the [CMS website](#)

1915(b) Waiver Example: Florida's Program for All-Inclusive Care for Children

Florida operates a pediatric palliative care program (Partners in Care: Together for Kids [PIC:TFK]), under its 1915(b) managed care waiver. The intent of the PIC:TFK 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.

Services covered under the PIC:TFK program include pain and symptom management; counseling; expressive therapies; respite and hospice nursing; and personal care services to children enrolled in the CMS managed care plan.

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 PIC:TFK 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 PACC program on the [Florida Health website](#).

1915(c) pediatric palliative care Waiver Examples

California, 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 even prior to the passage of the ACA, CMS approved concurrent care for the children enrolled in these 1915(c) waivers.

Table 1: 1915(c) pediatric palliative care Waiver Services Examples

California Waiver Services	Colorado Waiver Services	North Dakota Waiver Services
Care coordination		Case Management
Home respite care		Home Health Aide
Expressive therapies		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 palliative care under 1915(c) waivers targeting children who are medically fragile including New York (Care at Home I/II) and North Carolina 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.

6. Crafting your State's Options

Below provides the options and mechanisms required by CMS to implement the CCCR, to implement changes to the Medicaid eligibility criteria, and to expand the scope of services provided and paid for by Medicaid in your state. They also discuss the circumstances in which a specific option is used. Your State may have additional administrative, regulatory, statutory, or budgetary steps required prior to submitting a SPA or a waiver.

The options most appropriate for your State will depend on the nature of the proposed changes. This section will help you to:

- **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 initiatives among others, to build a coalition of support for an expanded pediatric palliative care 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 pediatric palliative care 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** — state plan amendment (SPA) or waiver — to implement those changes.
- **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 strong in numbers and advocacy, and to begin conversations with your state Medicaid office early.

Build a Coalition

You and your organization may have a good general idea of the types of changes you would like to have in place for children and their families. You may already have a core group of dedicated individuals who are willing to invest the time and effort to research the options and how best to implement those options. However, know there are most likely other individuals or groups with an equally vested interest in your efforts and could add benefit to the development of your proposal. Before you start working through all of the issues, options, and processes, consider including as many stakeholders as possible so that your coalition is representative. Keep in mind, too, there may be competing agendas unless all stakeholders are involved and engaged in the process of defining and implementing this expanded benefit. Transparency and ongoing communication will be of the utmost importance throughout the process to ensure success.

Building a coalition can help provide different perspectives and experience, help others to become more fully invested in your efforts up front, and broaden the foundation of support for later advocacy efforts. Make sure that your coalition has membership that will result in bi-partisan support and input from all identified stakeholders, if at all possible.

Become Familiar with the Current Eligibility and Scope of Services

A starting point for any change in programs and services is to understand the related programs and services already in place. Basic steps to identify current eligibility and benefits are:

1. Identify your Medicaid state plan and the relevant portions for hospice care.

Each state's Medicaid program is administered by the State Medicaid agency. Appendix 8 contains a link to the National Association of State Medicaid Directors website. This association maintains a current list of each state's Medicaid director and identifies the state organization responsible for the Medicaid program. Become familiar with your state Medicaid agency's website and its organizational structure.

Most Medicaid programs will have a copy of the Medicaid State Plan, as well as any recent SPAs on the state's website. In addition, [CMS has posted all SPAs](#) that have been approved since 2007 on the CMS website.

The description of the State Medicaid hospice benefit will be located in Section 3 of the State Plan, Covered Services. In general, States impose limitations on hospice services, so there will also be an attachment describing these limitations. You will note the format of the State Plan is a checklist template which usually follows the pre-print formats provided by CMS to the States. Depending on the state, there may be additional pages providing details about the specific portion of a state plan.

2. Identify any Medicaid waivers that include hospice or palliative care benefits for children or that serve medically fragile children.

Most states list their Medicaid waivers on their Medicaid agency website. However, other documents or information might be located from the following sources:

- In state law or rule. Some states describe their entire Medicaid program, including coverage and limitations, in administrative rule. Typically, the administrative rule is organized by state agency.
- On the [CMS website Medicaid waiver search page](#)
- In Medicaid coverage handbooks for providers. These might be posted on the Medicaid agency website or on the website for the Medicaid agency's contractor for provider payments. For example, in Wisconsin you will need to locate "[Forward Health](#)," (which is the name of the Wisconsin Medicaid program).

If your state implements all or part of its Medicaid programs through Managed Care Organizations (MCOs) and includes hospice services in its managed care contracts, you will also need to locate the contract. Most states now post the MCO contracts on their websites. If you cannot locate an MCO contract, you can locate a Medicaid managed care plan's website to determine the scope of hospice services coverage, which should be described in the MCOs member and provider handbooks.

3. Understand the developing environment.

If you are not already knowledgeable about the current Medicaid environment and any developments in regard to hospice services, check your State's legislative website for recent Medicaid agency presentations and for any recently filed bills or pending legislation. This is also the chance to reach out to your Medicaid office liaisons to help educate you in a process they know well.

Gather Data on Children and Services Needed

Data Elements: Identify the population to be served by the program in your state, including:

- Number of children under the age of 21
- Number of children with life-limiting, life-threatening, and terminal conditions
- 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
- The number of children who died in a given year, and if known, their Medicaid eligibility status
- If expanding to include palliative care-eligible children, number of children who can be classified as medically complex or fragile³

Where to Look for Data: In most states, the state Department of Health or Center for Health Statistics may have data available, often online. Stakeholders in your state may also have access to data about this patient population.

Partnering for Data Collection: Coalitions could also partner with other organizations in gathering this data. For example, many regional Make-A-Wish Foundation programs have conducted marketing studies to determine the number of children Make-A-Wish should aim to serve each year. Even though Make-A-Wish does not serve children under 2.5 years of age, this data could be really helpful in getting started.

Understand the Interests and Preferences of the State Medicaid Agency

Because a Medicaid comprehensive pediatric palliative care program may only be authorized by CMS and must be submitted to CMS by a state's Medicaid agency, the Medicaid agency is responsible for the ultimate determination of whether and how such a program can be implemented. Each state's legislature and advocacy community may also play pivotal roles in SPA and waiver development. Success is most likely when the program's goals and objectives are aligned with those of the agency. Each State has a process unique to that State.

In general, Medicaid agencies are likely to favor:

- Programs requiring the least amount of state staff effort to develop, implement, and provide oversight;
- Programs that do not increase spending or offer viable and demonstrable cost-savings or cost avoidance;
- Programs demonstrated to be effective – that are evidence-based and supported by the medical and constituent communities; and
- Programs consistent with the direction and priorities of a state's Medicaid program.

State plan options are typically easier to develop than waiver options (having fewer requirements than waiver options) and are typically, but not always, reviewed and approved more quickly by CMS than waivers. States have considerable flexibility under their Medicaid state plan to provide supplemental services to children receiving hospice care. This is in part because States may use the EPSDT benefit for this purpose and because of the new options available under Section 1915(i). However, States may be concerned about the number of recipients and statewide impact associated with most state plan options. If a State wishes to do any of the following, waiver authority will be required:

- Limit the services to a specific number of children (place a cap on the program);
- Implement the program on less than a statewide basis; or
- Limit the number or types of providers who may provide the services.

A State may be willing to implement supplemental services under the State plan if the State believes utilization will not pose an additional expense, or significant additional expense, to the Medicaid program. If cost-savings are anticipated -- and particularly if they can be demonstrated -- it will be easier to secure the State's agreement to proceed with a comprehensive benefit for children with limited life expectancy.

Learn from Other States

This Toolkit provides examples of implementation strategies for Section 2302 and pediatric palliative care initiatives proposed and implemented in other states. There are a variety of examples for States to use. In many instances, 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 this Toolkit to capture key points from these various State initiatives in one place so State advocacy groups can proceed with the implementation of comprehensive pediatric palliative care in their State, using these models as examples.

Develop a Proposed Program Design

Once you become familiar with the pediatric palliative care and hospice programs and benefit offered in your state, you must articulate how you want those programs and benefits to change. These changes can be to any number of program or benefit features. The following sections provide some basic components for which you may want to seek change. The viability of your program design will depend on the demand for the proposed changes, the human cost or consequences of failure to make these changes, the cost of change, the capacity of your state's healthcare delivery system to provide the services, and the political and economic environment.

- Eligibility Criteria
 - Scope of Services
 - Duration of Services
 - Expenditure Cap on Services
- Provider Qualifications
 - Co-pays or Deductibles
 - Measurement of Outcomes

Provide Program Cost Information

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. There will be some information and assumptions that you are in a unique position to provide. You are in a unique position to help advocate for change because:

- You know the types of services children and their families need to be provided with the best array of support.
- You may also have an idea of the numbers of families who would have used hospice or palliative care services, but who were previously prevented from using those benefits for a variety of reasons, usually because they determined forgoing disease directed treatments were not in the best interests of their child.
- You may have parents who could contribute individual stories about the financial and human cost of not having this benefit available for their child.
- You may know the frequency with which those services will need to be provided (utilization).

- You may know the qualifications or credentials of the individuals who are proposed to provide the services.
- If you are proposing to design a scope of services that goes beyond the Medicaid hospice benefit services, you may have a good idea of the number of children and their families whose lives would be significantly improved if those services were available.
- One of the first questions the State legislature or the State Medicaid agency will want to know is how much the proposed change is going to cost the state. At minimum, key State decision makers will need to understand the:
 - Financial impact as it relates to providing the benefits;
 - Net costs to make the administrative changes necessary to implement the change, and any ongoing administrative costs;
 - Likelihood that change might increase utilization of the benefit; and
 - Cost savings that are anticipated as a result of the proposed change.

Since Medicaid is paid for by a combination of Federal and State dollars, key decision makers will want to know the amount of any State funds required to pay for the changes. Costs can begin to be calculated by identifying or estimating the number of children and families who would use the service, the frequency of utilization of services, the cost of the units of services, your state match requirements, and any other costs incurred for conventional treatment if these services were not available. Cost-savings might also be calculated resulting from avoiding or reducing the cost for conventional treatment (especially inpatient treatment) because these services are available.

Here are some factors you may want to consider in preparing cost estimates:

Service Utilization

- The frequency with which certain services will be used is an important factor in determining the cost. Children will certainly need varying levels of care and different services to meet their needs and needs of their families, as specified in their individual plan of care.
- State decision makers can be wary of new services that do not fully articulate the utilization level of services. Concerns about offering a new program or service without fully understanding the demand also lead to concerns about the opportunity for "service creep," thereby resulting in unanticipated costs to the state.
- The reality is, however, the number of children who will use these services is actually a small fraction of a state's healthcare cost, even if eligibility is expanded. Providing realistic estimates of the (likely small) number of beneficiaries can go a long way toward reducing resistance to a new program.

Unit Service Cost

- Since you have identified the services proposed to be provided, you will also need to help State decision makers with obtaining information about the cost of providing such services. You may be able to determine the unit cost of services by working with the State Medicaid agency to obtain existing costs for similar or comparable services, such as for home care nursing, home care supplies, pharmacy costs. Costs from home-based therapy services will need to be obtained from agencies providing those services on a fee-for-service (FFS) basis.

Your State's Medicaid Match Requirements.

- As previously mentioned, the cost of Medicaid benefits is paid for by a combination of Federal and State funds. The percentage of Federal funds CMS will contribute varies from State to State and may change from year to year.
- The amount of the share of cost paid by the federal government is determined based on the federal medical assistance percentage (FMAP) for each state. This percentage is calculated based on a number of factors including the three-year average of state per capita personal income compared to

the national average. The Social Security Act requires the Secretary of Health and Human Services (HHS) to calculate and publish the FMAPs each year. Each state's most current FMAP is available on the HHS, [Assistant Secretary for Planning and Evaluation \(ASPE\)](#) website.

Anticipated Cost Savings

- Although you are proposing to change or add a benefit and there is a cost associated with those changes, it is important to include information about anticipated cost savings as a result of your proposal. For instance, the proposed benefits may provide services that can help prevent unnecessary hospitalizations or re-hospitalizations, or more expensive treatments. It is crucial to include "soft" costs, such as downstream utilization of pharmaceuticals, lost time from work for parents, and overall coping and health of parents and siblings. However, your Medicaid agency will mostly be interested in, and swayed by, actual Medicaid savings and to a lesser extent, by cost-avoidance.

Determine the Appropriate Medicaid Option – SPA or Waiver?

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 Medicaid Agency. However, being aware of the options, their uses and limitations, and the length of time it can take to secure approval from CMS are all important to keep in mind when designing your proposal.

The information in the preceding sections, as well as information contained in the Appendices can be used to identify the appropriate mechanisms or options to implement your program.

Considerations in States Where Hospice Services are Included in a Managed Care Option (MCO) Program

Some Medicaid managed care programs include the hospice benefit. The MCO may provide end-of-life care using its own providers or may contract with a hospice organization to provide hospice services. In these States, a comprehensive hospice and palliative care program could be implemented within the managed care program or removed from the managed care program (hospice could be excluded). No matter whether the program is incorporated into the MCO contract or excluded, implementation of a pediatric palliative care program will require the State to:

- Amend the waiver (to add the new services or to remove existing services)
- Potentially implement an additional waiver if additional services are to be provided as 1915(c) waiver services
- Amend the state plan: Additional services not provided as 1915(c) waiver services will require a SPA to provide these services under the authority of the EPSDT program or Section 1915(i)
- Obtain authorization from CMS for the waiver or SPA
- Calculate new rates for the managed care waiver (if services are added or removed), which will require an update to the actuarial report
- Amend the managed care contract (if services are added or removed)
- Execute the amended contracts

If the State has an existing 1115 waiver requiring amendment (such as Arizona), the State may be very reluctant to do this because such an amendment will be complicated and time consuming. The State may also be reluctant to amend a 1915(b) waiver, unless changes are incorporated into an upcoming waiver amendment required for other reasons or into a waiver renewal.

The MCO will also need to implement changes. It will need to revise its statement of coverage (on the member and provider website and in member and provider materials). MCOs will need to amend their policies and procedures to reflect the addition of enhanced services for children receiving palliative care services or the removal of palliative care from the list of covered services depending on which option is implemented. A contract amendment and revised capitation rates will require review and agreement from the MCO.

Build Support and Advocate for Preferred Option(s)

There is basic information that you will need, and approaches that you will need to take, to build support and advocate for your preferred option(s). These include:

1. **Identify and reach out to other individuals and organizations who share your vision.** While you may have developed a coalition of individuals to help craft your option, it is important your advocacy approach be as broad-based and inclusive as possible. Issues appearing to narrowly benefit one segment of society will more than likely be viewed as self-serving. Some examples of stakeholders who should be "at the table" include:

- American Academy of Pediatrics, state chapter
- State hospice organization
- Childrens' hospitals
- Hospice and palliative care providers

Efforts to improve the quality of care and quality of life for children living with serious illness and their families is an issue that should garner widespread support. It is important to reach out to families with children who would benefit from expanded eligibility or services, providers of services, child and family advocates, respected leaders in the community or state, or anyone who has a role in the provision of services and supports for children and families. Once you have fully developed your proposal, share your ideas and your vision, and invite participation from as many groups and individuals as appropriate.

2. **Be clear about the reason for your proposal:** Why are you proposing these changes? State decision makers will want to know why you believe there to be a problem with keeping things the way they are. You may be able to describe the changes that you want to see implemented, but you also need to explain why these changes are needed. Balance your arguments with factual information, and personal stories that illustrate the need.

It may be helpful to create a one-page fact sheet providing a high-level summary of the proposal. This fact sheet can be used for advocacy efforts and the process of drafting the fact sheet can help provide clarity to your proposal. The fact sheet should include the following elements:

- Problem Statement
- Proposed Solution
- Background on the issue
- Who would be affected by the proposal?
- What would be the cost of implementing the proposal?

3. **Decide, in advance, if there are compromises to your proposed option.** For instance, if there is concern statewide implementation of your proposal would be too costly, could you support a pilot project assessing your changes in certain parts of the state? Are there ways in which changes in eligibility or scope of services could be scaled back or phased in over time? These "hip-pocket" compromises are ones you can propose if it looks like implementation of your full proposal lacks support. Know what

areas on which you are willing to and can compromise. Decide internally when the right time to offer the compromises is for your coalition. There should be broad agreement on this strategy.

4. **Be willing to propose a pilot with a limited number of beneficiaries to make your case and calm fears of service creep.**
5. **Anticipate opposition.** It is important you identify the source of potential opposition, if possible. Could there be opposition based on the public policy or principles behind your proposal, or will opposition be based solely on fears about potential costs? If key decision makers or other stakeholders agree with your proposal, in principle, but are concerned about costs, then you know how best to focus your advocacy efforts. If there are concerns that go beyond the proposal's associated costs, it will be more difficult. Does your proposal make changes regarding who provides care (and therefore who will get paid for the care), or does it exclude certain groups who might also benefit from this care model? Opposition can come from some unlikely sources, or you may not have any opposition to your proposal.
6. **Understand new ideas can take time to take hold.** New ideas can take time to understand and take hold. Many decision makers will have experienced hospice care in the context of services provided to family or friends or may be involved in regulating or paying for hospice care, while others have no personal or professional understanding whatsoever. However, it can take more than one attempt for your proposal to take root and be accepted or supported by decision makers. Do not give up if the education process takes significantly longer than initially anticipated.
7. **Identify key decision makers and focus your advocacy efforts.** It should be clear that building a good, working relationship with your State Medicaid agency is a major key to your success. Identifying the individuals in the State Medicaid agency who work on implementation of the CCCR, the hospice benefit, or children's services is important. Introduce yourself and your organization as advocates for children living with serious illness. Offer your assistance as they work through options for implementation of the CCCR and use the opportunity to explore the extent of their interest in considering other options to expand eligibility, services and support.

State legislators are likely to also be key decision makers – involved in budgetary decisions, oversight of state administrators, and crafting new laws and programs. Usually there are legislative committees that deal with health or Medicaid issues. Identify the members of those committees for initial advocacy efforts. Use this as an opportunity to educate decision makers by inviting them to visit a hospice in their legislative district, meet with family members whose loved ones have benefitted from hospice services, provide them with your fact sheet, information on what other states have done, and the personal and cost effective benefits of hospice and palliative care. It may be appropriate to suggest an informational hearing be held on the topic of pediatric palliative care and hospice programs. This could be an opportunity for legislators to hear from experts about the problems with the current system, what other states have done, and recommendations for change. Keep in mind, although this is certainly their role, some legislators do not hear from their constituents or interest groups unless those groups want something from the legislator. Develop the kind of relationship that results in legislators viewing your group as offering help, rather than always asking for their help.

Offer your assistance and availability to key decision makers as you work through the process of gaining support for your proposal. Building this relationship can result in your group being naturally "invited to the table" for future discussions on issues affecting children and their families. Make sure you reach out in a bipartisan manner. This includes audiences or stakeholders you might not have thought of, so it can be helpful to offer assistance and availability to key decision makers.

Additional legislative advocacy materials and resources can be found in Appendix 8 and online at [NHPCO's Hospice Action Network](#).

7. Conclusion

With all the information provided, it is important to remember the implementation of Section 2302, Concurrent Care for Children Requirement, is required and mandated by CMS - and 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.

We strongly encourage you to work together with others 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, along with 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 come together can have a unified voice, can work to identify champions and strong advocates for your state's children, and can succeed in securing the care and resources their families desperately need. Through it all, the ultimate goal is to assure your state's most fragile children have the quality care they deserve.

8. Acknowledgements

The National Hospice and Palliative Care Organization Pediatric Advisory Council gratefully acknowledge the following for the development of previous versions of this Toolkit:

- District of Columbia Pediatric Palliative Care Collaborative American Academy of Pediatrics Section on Hospice and Palliative Medicine, Policy/Advocacy Workgroup
- District of Columbia Department of Health Care Finance – Linda Elam, Diane Fields, Colleen Sonosky and Roopa Chakkappan
- District of Columbia Cancer Consortium
- Sarah Friebert, MD
- Healthcare Management Associates

This edition of the Concurrent Care for Children Toolkit is based on the work of **Susan K. Rogers, MS, BSN, CHPN, RN**, who authored the Concurrent Care for Children Implementation Toolkit in 2011. Susan K. Rogers was a prolific author, fierce advocate, and health policy expert focused on increasing access to pediatric palliative and hospice care. While the Associate Director of the Institute for Education and Leadership at Capital Hospice in Falls Church, VA, Susan co-founded the District of Columbia Pediatric Palliative Care Collaborative, served on the NHPCO Pediatric Policy Networking Group, and the Hospice and Palliative Care Nurses Association Board of Directors. We dedicate this edition of the concurrent care toolkit to Susan and her pioneering work to achieve greater access to hospice care for all children.



NHPCO

National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org