



DISTRICT OF COLUMBIA
PEDIATRIC PALLIATIVE
CARE COLLABORATION

National Hospice and Palliative Care
Organization



Concurrent Care for Children Implementation Toolkit

Section 2302 of the Patient Protection and Affordable Care Act



In loving memory of Carlos F. Gomez, MD, PhD

Table of Contents

Introduction	1
Who should use this Toolkit?	1
About the Concurrent Care for Children Requirement (CCCR)	3
What the CCCR is	3
What the CCCR is not	3
CMS Guidance	4
CMS Answers Questions about state-level issues regarding implementation	6
State Impact	8
Guidance for Pediatric Healthcare Professionals and Hospice Providers	9
CMS Answers Questions Specific to Pediatric Healthcare Professionals and Hospice Providers	10
Implementation of the CCCR	14
Options Beyond the CCCR	15
Washington EPSDT SPA Example	16
1915(b) Waiver Example: Florida's Program For All-Inclusive Care for Children	17
1915(c) PPC Waiver Examples	18
1915(c) Waivers for Medically Fragile Children	19
Crafting your State's Options	20
Build a Coalition	21
Become Familiar with the Current Eligibility and Scope of Services	21
Gather Data on Children and Services Needed	23
Understand the Interests and Preferences of the State Medicaid Agency	24
Learn from Other States	25
Develop a Proposed Program Design	25

Provide Program Cost Information	26
Determine the Appropriate Medicaid Option — SPA or Waiver?	29
Considerations in States Where Hospice Services are Included in a Managed Care Option (MCO) Program	29
Build Support and Advocate for Preferred Option(s)	30
Conclusion	34
Acknowledgments	35
Carlos F. Gomez, MD, PhD	36
Appendices:	
Appendix 1: Section 2302 SSA - Concurrent Care for Children	
Appendix 4: SPA and Waiver Options to Enhance Concurrent Care Programs	
Appendix 5: Medicaid Mandatory and Optional Services	
Appendix 6: Medicaid Mandatory and Major Optional Eligibility Groups	
Appendix 7: Medicaid Waiver Comparison of Major Features	
Appendix 7: Medicaid Waiver Comparison of Major Features (<i>cont.</i>)	
Appendix 8: Resources for State-Level Advocacy	
Appendix 9: Resources for Parents	
Appendix 10: Glossary	
Appendix 11	

Disclaimer: Please understand that 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/or the appropriate agencies before implementing or changing any processes or decisions.

Introduction

For many years, healthcare professionals and families with children living with life-limiting or life-threatening conditions (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 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 (PPACA) changed that situation, and now requires the state Medicaid program to pay for both curative/life prolonging treatment and hospice services for children under age 21 who qualify. On March 23, 2010, President Obama signed PPACA into law enacting a new provision, Section 2302, termed the “Concurrent Care for Children” Requirement (CCCR). (See Appendix 1)

The District of Columbia Pediatric Palliative Care Collaborative (DCPPCC) and the National Hospice and Palliative Care Organization (NHPCO) are pleased to provide this Concurrent Care for Children Requirement: Implementation Toolkit, which details information on the options available to states that are implementing 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/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.

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 with LL/LTC and their families.
- **Parents who have children with LL/LTC** (or children in need of hospice or palliative care services) who need basic information and resources to advocate for their child's care.

Please note that this Toolkit deals only with services that are 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 that might be 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 that are available, nor does it provide palliative care or other supportive services to children with LL/LTC 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 that states have options available 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 federal government. If a state wants to provide more expansive services and eligibility, there are two basic mechanisms for implementing those programs and services. These mechanisms are through:

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

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

Overall, we encourage the formation of statewide pediatric palliative and hospice care advocacy coalitions/groups to work together towards improved options for children with LL/LTC. This includes providing increased services for children who would not qualify under the PPACA 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.

About the Concurrent Care for Children Requirement (CCCR)

What the CCCR is

Section 2302 of the PPACA amended the federal Social Security Act, Section 1905(o)(1) and 2110(a)(23), as detailed in Appendix 1. 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 made for, services that are related to the treatment of the child's condition, for which 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 new provision, termed Section 2302: "Concurrent Care for Children" Requirement (CCCR), went into effect upon the enactment of the PPACA, on March 23, 2010. In its simplest form, implementation of this provision could be accomplished by the state Medicaid agency eliminating any provider claims that deny or pend concurrent curative/life prolonging 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.***

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 (PPC) 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).

Prior to enactment of Section 2302 of the PPACA, some states used either a Medicaid SPA or waiver authority to provide supplemental services to children and replaced the “terminal illness within six months” provision with a requirement that children have a life-limiting condition. States also were able to provide both curative/life prolonging treatment and hospice services using either a Medicaid SPA or waiver.

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

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 PPACA in the form of a State Medicaid Director (SMD) letter (SMD # 10-018).² (See Appendix 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 that:

- The new provisions do not change the criteria for receiving hospice services (including the requirement that a physician certify that the eligible person is within the last 6 months of life, should the disease or condition follow its normal course);
- Prior to the changes, curative/life prolonging 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 believes that the new provisions are “... vitally important for children and their families seeking a blended package of curative/life prolonging and palliative services”;

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.

- 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 that the new 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 curative/life prolonging services even after the election of the hospice benefit;
- At some point in the future, CMS will release 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.

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 be required to submit the SPA within a short timeframe.

Since CMS has stated that 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 that 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 that 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 that states would have specific guidance in addition to the SMD Letter regarding implementation. CMS has been very responsive to specific implementation questions about this provision from NHPCO. 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 PPACA 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.

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 PPACA, the state is now required to pay for both curative/life prolonging treatment and hospice services provided to eligible children. The details of EPSDT are as follows:

Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Requirements

EPSDT is a Medicaid benefit that must be made available to every Medicaid-eligible child under the age of 21. EPSDT includes all of the following components:³

Early	Identifying problems early, starting at birth
Periodic	Checking children's health at periodic, age-appropriate intervals
Screening	Doing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
Diagnosis	Performing diagnostic tests to follow up when a risk is identified
Treatment	Treating the problems found

CMS requires that states provide all medically necessary diagnostic and treatment services within the federal definition of Medicaid medical assistance, regardless of whether or not such services are otherwise covered under the state Medicaid plan for adults ages 21 and older. States vary in how they interpret and enforce EPSDT requirements. EPSDT is, in fact, one of the most heavily litigated areas of Medicaid law, with advocates seeking an ever-increasing array of services through the EPSDT benefit.

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/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.

3. EPSDT Program Background. Department of Health and Human Services, Health Resources and Services Administration webpage. Accessed 02/04/2011 at: <http://www.hrsa.gov/epsdt/overview.htm>

As noted by CMS in the SMD letter, utilization of the hospice benefit is expected to increase for children, since parents will no longer have to forgo curative/life prolonging treatment if they voluntarily elect hospice services for their child. Increased utilization most often means increased cost to the state. 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.

Options and detailed descriptions 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.

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 that CMS has answered below are a strong indication that 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.

CMS Answers Questions Specific to Pediatric Healthcare Professionals and Hospice Providers

In February 2011, CMS answered the following questions that were 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.*

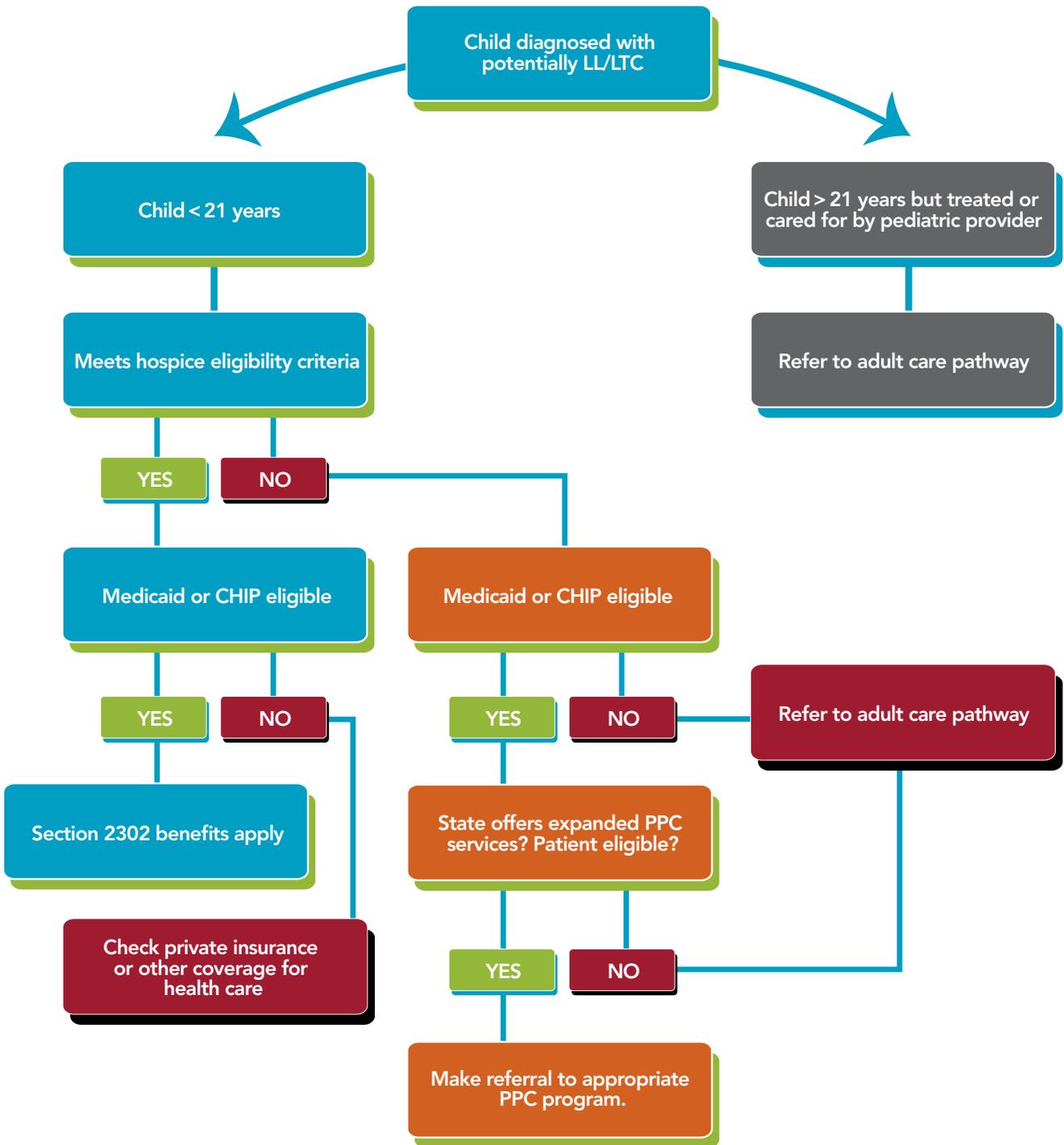
CMS Response: As CMS stated in our State Medicaid Letter (SMD # 10-018), dated September 9, 2010, this provision was effective upon enactment of the Affordable Care Act on March 23, 2010. Therefore, under Medicaid, including CHIP programs operating as Medicaid expansions, we expect States will

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 process” (or algorithm) for PPC and hospice providers re: the CCCR is outlined on the next page 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 a SPA is all that will be required, in addition to whatever administrative and legislative processes your state must use to make changes to the state plan.

If your state already has a PPC 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.

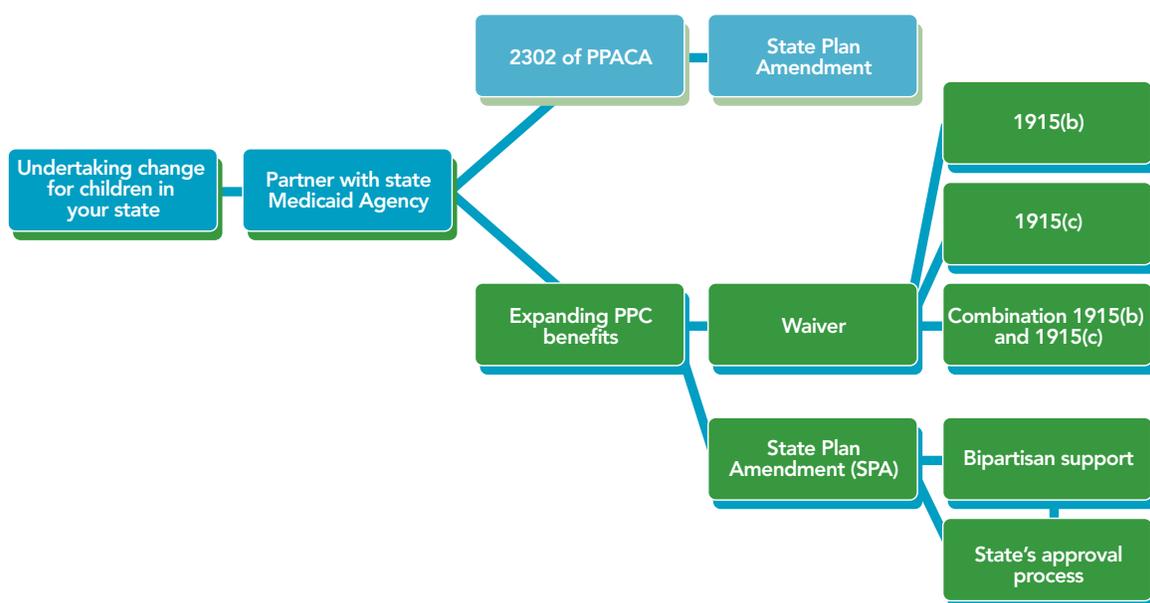
Options Beyond the CCCR

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 with LL/LTC 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.

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 PPC programs: through an SPA or through a waiver. The mechanism that is most appropriate for your state depends on the types of changes being proposed.

The figure below details the options the state has for implementing Section 2302, as well as options for an expanded PPC benefit. For a complete overview of the SPA and waiver options, see Appendix 4.

Figure 1: State Options for Implementation of 2302 and Expanded PPC Benefits



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

Washington EPSDT SPA Example

The State of Washington provides PPC under the authority of EPSDT using an SPA, providing additional services and expanding eligibility to include life-limiting conditions. The SPA states specifically that hospice care “also includes PPC 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 PPC benefit consists of up to six PPC 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 PPC-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 at: <http://www.cms.gov/MedicaidGenInfo/StatePlan/list.asp>.

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

Florida operates a PPC 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 PPCPPC 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 CMS Network.

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 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.

1915(c) PPC Waiver Examples

California, Colorado and North Dakota each operate PPC 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 PPACA, CMS approved concurrent care for the children enrolled in these 1915(c) waivers.

Table 1: 1915(c) PPC Waiver Services Examples

California Waiver Services	Colorado Waiver Services	North Dakota Waiver Services
Care coordination	Expressive therapies	Case Management
Home respite care	Client/Family/Caregiver Respite Care	Home Health Aide
Expressive Therapy	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 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.

Crafting your State's Options

The Appendices (4-7) provide the options and mechanisms that are required by CMS to implement the CCCR, to implement changes to the Medicaid eligibility criteria, and/or 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 that are required prior to submitting a SPA or a waiver.

The options that are 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 PPC 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 PPC 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; and
- **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.

Build a Coalition

You and your organization may have a good general idea of the types of changes that 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 that there are most likely other individuals or groups that have 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, that 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.

For more information on coalition-building in your community/state, an important resource is "*Partnering for Children: Pediatric Outreach Guide*" (located at www.nhpco.org/pediatrics).

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 that are 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, at the following link: <http://www.cms.gov/MedicaidGenInfo/StatePlan/list.asp>.

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 that describes these limitations. For example, Washington state's Medicaid state plan includes its statement of PPC coverage in Attachment 3.1-A to its state plan on page 59. (See http://hrsa.dshs.wa.gov/medicaidsp/Attachment%203%20-%20Scvs%20Gen%20Provision/SP_Att_3_Services_General_Provisions.pdf)

You will note that the format of the State Plan is a checklist template that 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 at: <http://www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp>.
- 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) and find the link for providers at: <https://www.forwardhealth.wi.gov/WIPortal/Default.aspx>.

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/or 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 fragile

Specific state information is always preferable to estimates. However, while you are collecting data, you can calculate rough estimates of these rates using the information contained in NHPCO's recent report on PPC (Friebert S. *NHPCO's Facts and Figures: Pediatric Palliative and Hospice Care in America*. National Hospice and Palliative Care Organization, April 2009). Incidence rates for conditions that are appropriate for palliative care services can also be calculated from ICD-9 data in your state, using consensus-derived PPC referral criteria (available at www.capc.org/tools-for-palliative-care-programs/clinical-tools/consult-triggers/pediatric-palliative-care-referral-criteria.pdf). Other references that may be helpful include:

- Katherine H. Burns, Patrick H. Casey, Robert E. Lyle, T. Mac Bird, Jill J. Fussell and James M. Robbins, "Increasing Prevalence of Medically Complex Children in US Hospitals," *Pediatrics* 2010, 126, 638-646.
- Tamara D. Simon, Jay Berry, Chris Feudtner, Bryan L. Stone, Xiaoming Sheng, Susan L. Bratton, J. Michael Dean and Rajendu Srivastava, "Children With Complex Chronic Conditions in Inpatient Hospital Settings in the United States," *Pediatrics* 2010, 126;647-655.

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 PPC 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 that is unique to that state.

In general, Medicaid agencies are likely to favor:

- Programs that require the least amount of state staff effort to develop, implement and provide oversight;
- Programs that do not increase spending or that offer viable and demonstrable cost-savings or cost avoidance;
- Programs that have been demonstrated to be effective – that are evidence-based and supported by the medical and constituent communities; and
- Programs that are 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 likely be easier to secure the state's agreement to proceed with a comprehensive benefit for children with limited life expectancy. See the section below on "Provide Program Cost Information" for more details on identifying cost savings.

Learn from Other States

This Toolkit provides examples of implementation strategies for Section 2302 and PPC initiatives that have been proposed and implemented in other states. Resource materials from state initiatives are available online at www.nhpco.org/pediatrics. There are a variety of examples for states to use and copy in the "Policy Section" of the webpage. 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 that state advocacy groups can proceed with the implementation of comprehensive PPC in their state, using these models as examples.

Develop a Proposed Program Design

Once you become familiar with the PPC and hospice programs and benefit 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 program or benefit features. The components identified below may be some focus areas in 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
 - Use Pediatric Referral Criteria form (www.capc.org)
 - May consider using ACT criteria (www.act.org.uk)
 - Note references on #/% of children with complex, chronic conditions or medical fragility (See Appendix 11)
- 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 that children and their families need, to be provided the best array of supports.
- 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 that forgoing curative/life prolonging 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 that 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 that would be required to pay for the changes.

Costs can begin to be calculated by identifying or estimating the likely 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, that 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 that are 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, etc. 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 that 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 at: <http://aspe.hhs.gov/health/fmap.htm>.

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 very 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 carved out). No matter whether the program is incorporated into the MCO contract or carved out, implementation of a PPC 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 likely 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); and
- Execute the amended contracts.

If the state has an existing 1115 waiver that requires amendment (such as Arizona), the state may be very reluctant to do this because such an amendment will likely be complicated

and/or 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 that share your vision.** While you may have developed a coalition of individuals to help craft your option, it is important that your advocacy approach be as broad-based and inclusive as possible. Issues that appear 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:
 - b. American Academy of Pediatrics, state chapter
 - c. State hospice organization
 - d. Childrens’ hospitals
 - e. Hospice and palliative care providers

Efforts to improve the quality of care and quality of life for children with LL/LTC and their families, is an issue that should garner widespread support. It is important to reach out to families that have 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 had fully developed your proposal, share your ideas and your vision, and invite participation from as many groups and individuals as appropriate.

2. **Be very 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 that provides 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 possible compromises to your proposed option.** For instance, if there is concern that statewide implementation of your proposal would be too costly, could you support a pilot project that tests 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 that 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 possible opposition.** It important that 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 in 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. **Know that 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. Don't 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 with LL/LTC. 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 supports.

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 that an informational hearing be held on the topic of PPC 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 that, although this is certainly their role, some legislators don't 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 that affect children and their families. Make sure that you reach out in a bi-partisan 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 (www.hospiceactionnetwork.org).

Conclusion

With all the information provided, it is important to remember that 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 that 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 that your state's most fragile children have the quality care they deserve.

Acknowledgments

The District of Columbia Pediatric Palliative Care Collaborative and National Hospice and Palliative Care Organization gratefully acknowledge the following for the development of this Toolkit:

- 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
- Health Management Associates
- NHPCO's Pediatric Palliative Care State Leaders Policy Networking Group

We dedicate this Toolkit in loving memory of Carlos F. Gomez, MD, PhD.

Carlos F. Gomez, MD, PhD



Carlos F. Gomez, MD, PhD

Carlos Felipe Gomez was born in Havana, Cuba and came to the United States with his family as a very young boy. He received an exclusively Catholic education from primary school through high school. He entered the University of Virginia as an undergraduate in 1976 and emerged in 1991 with a doctorate in medicine. Prior to finishing his primary medical education at the University of Virginia he had received a Ph.D. from the University of Chicago, School of Public Policy.

Carlos' post-graduate training led him to specialization in areas of medical ethics, especially end-of-life care, and in hospice and palliative care. While serving as an associate professor of medicine at the University of Virginia, he developed a palliative care curriculum and teaching service for medical students and became the medical director of the Center for Hospice and Palliative Care at the University of Virginia. He was profiled in the Bill Moyers documentary "On Our Own Terms: Moyers on Dying." In 2002 he received the Humanism in Medicine Award.

After several years at the University of Virginia, he moved to Washington DC area to devote himself to hospice work and in time to palliative care for pediatric patients.

Carlos and professional colleague Susan Rogers had a shared vision for comprehensive and compassionate care for palliative care for children with life-threatening illness. This vision became the District of Columbia Pediatric Palliative Care Collaboration (DCPPCC). While working with the DCPPCC Carlos concentrated on much more than the administrative and teaching dimensions of the shared vision. He provided care for children and the families throughout the Washington, D.C. area, devoting endless hours providing home-based care and support for children and their families.

Carlos' academic and professional accomplishments during his medical career are both extensive and impressive. They reveal a man with an extraordinary intellect, a profound grasp of the science of medicine, and the unique ability to bring this knowledge and experience to play in the lives of patients young and old. Carlos' ability to communicate the critical importance of integrating contemporary medical science and respect for human dignity, especially in the provision of end-of-life care, made him an exceptional spokesperson. When national media called on him to comment on profoundly important issues, which they frequently did, he was able to present the core scientific and ethical issues in a clear and

understandable manner demonstrating his genuine compassion for humankind.

His friends and colleagues often remarked at Carlos' brilliant diagnostic abilities. He would often see what others did not, offering a medical "way out" of a troubling situation but even more, providing the comfort and hope that is equally important to the suffering patient.

In the later years of his career Carlos concentrated on searching for new and more effective ways of helping people with life-threatening conditions. He deeply believed that his work, which was his passion, was crucial to assisting people who were facing not the end but a moment of transition. He devoted himself to sharing with other medical professionals his commitment to learn more about palliative care for the patient, and compassionate, supportive care for the families and loved ones. Carlos assumed the responsibility to bring care and support in an area that brings extraordinary emotional and psychological challenge: palliative care for children. His commitment was not only to the children whom he cared for but also children he never knew and children not yet born.

Carlos untimely passage from this life did not end his mission. Since his passing we have come to learn just how far-reaching an effect his work had on those who heal and those who seek healing. His death is by far overshadowed by his life. His memorial is not carved in a piece of lifeless stone but in the lives of the many whom he helped either directly or indirectly. More importantly, his legacy lives on in those who may never know who Carlos Gomez was, but whose lives have more hope and more peace because of him.

Appendices:

Appendix 1: Section 2302 SSA - Concurrent Care for Children

Section 2302 of the Affordable Care Act (ACA), titled “Concurrent Care for Children”, amended sections 1905(o)(1) and 2210(a)(23) of the Social Security Act. The complete Social Security Act can be found at www.ssa.gov/OP_Home/ssact/ssact-toc.htm. Below are sections 1905(o)(1) and 2210(a)(23), with the portions amended by the ACA, highlighted.

Section 1905, (o)(1), of the Social Security Act

- a. Subject to subparagraphs (B) and (C), the term “hospice care” means the care described in section 1861(dd)(1) furnished by a hospice program (as defined in section 1861(dd)(2)) to a terminally ill individual who has voluntarily elected (in accordance with paragraph (2)) to have payment made for hospice care instead of having payment made for certain benefits described in section 1812(d)(2)(A) and for which payment may otherwise be made under title XVIII and intermediate care facility services under the plan. For purposes of such election, hospice care may be provided to an individual while such individual is a resident of a skilled nursing facility or intermediate care facility, but the only payment made under the State plan shall be for the hospice care.
- b. For purposes of this title, with respect to the definition of hospice program under section 1861(dd)(2), the Secretary may allow an agency or organization to make the assurance under subparagraph (A)(iii) of such section without taking into account any individual who is afflicted with acquired immune deficiency syndrome (AIDS).
- c. 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 treatment of the child’s condition for which a diagnosis of terminal illness has been made.

Section 2110, (a)(23), of the Social Security Act

Hospice care. (concurrent, in the case of an individual who is a child, with care related to the treatment of the child’s condition with respect to which a diagnosis of a terminal illness has been made.

Appendix 2: State Medicaid Directors' Letter

The Centers for Medicaid and Medicare Services released a State Medicaid Directors' letter regarding the amendments made by section 2302 of the Affordable Care Act, titled "Concurrent Care for Children". A file containing the letter can be found at www.cms.gov/smdl/downloads/SMD10018.pdf, or the text of the letter is below.

SMD # 10-018

ACA # 8

September 9, 2010

Re: Hospice Care for Children in Medicaid and CHIP

Dear State Health Official:

Dear State Medicaid Director:

This letter is one of a series intended to provide guidance on the implementation of the Affordable Care Act (Pub. L. No. 111-148 as amended by the Healthcare and Education Reconciliation Act of 2010 (Pub. L. No. 111-152)), together known as the Affordable Care Act.

Specifically, this letter provides guidance to States on the implementation of section 2302 of the Affordable Care Act, entitled "Concurrent Care for Children." Section 2302 of the law amends sections 1905(o)(1) and 2110(a)(23) of the Social Security Act to remove the prohibition of receiving curative treatment upon the election of the hospice benefit by or on behalf of a Medicaid or Children's Health Insurance Program (CHIP) eligible child.

Hospice services are covered under the Medicaid and CHIP programs as an optional benefit. However, the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provision requires Medicaid and CHIP programs operating as Medicaid expansions to provide all medically necessary services, including hospice services, to individuals under age 21. In order to qualify for the hospice service in either Medicaid or CHIP, a physician must certify that the eligible person is within the last 6 months of life.

The Affordable Care Act does not change the criteria for receiving hospice services; however, prior to enactment of the new law, curative treatment of the terminal illness ceased upon election of the hospice benefit. This new 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. States with stand-alone CHIP programs continue to have the option to provide hospice services, but if they cover hospice services they must comply with the new requirements under the Affordable Care Act.

We believe implementation of this new provision is vitally important for children and their families seeking a blended package of curative and palliative services. This provision will increase utilization of hospice services since parents and children will no longer be required to forego curative treatment.

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, even after election of the hospice benefit by or on behalf of children receiving services. States operating stand-alone CHIP programs that offer the optional hospice benefit must now provide it concurrently with medically necessary curative services.

Implementation

Medicaid

The Centers for Medicare & Medicaid Services (CMS) is revising the Medicaid State plan hospice preprint page of Attachment 3.1-A and 3.1-B to reflect this new feature of the hospice benefit. Once approved, CMS will release the new preprint page for States' use. States will need to submit the revised preprint page to indicate that hospice is provided to children concurrently with curative treatment. States are not required to submit any needed revisions to their State plan coverage language until the preprint page is made available but are expected, in the interim, to be providing these services consistent with the requirements described in this guidance.

CHIP

As noted above, the Medicaid guidance also applies to CHIP programs operating as a Medicaid expansion. States with separate CHIP programs that currently cover hospice services do not need to submit a State Plan amendment (SPA) to modify this definition, but States are expected to implement these services in compliance with the Affordable Care Act. We are, however, happy to work with States that are interested in submitting SPAs to explicitly modify the definition of hospice services. States with separate CHIP programs that do not currently cover hospice services and would like to extend this benefit to children do need to submit a SPA indicating this intention and confirming that hospice services will be offered concurrently with curative treatment.

We are ready to work with States to provide assistance in implementing this new requirement, and we look forward to our continuing collaboration. If you have any questions, please contact Ms. Barbara Edwards, Director of the Disabled and Elderly Health Programs Group, at 410-786-7089, or at Barbara.Edwards@cms.hhs.gov. If you have any questions on implementing this provision in the CHIP program, please contact Ms. Victoria Wachino, Director of the Family and Children's Health Programs Group, at 410-786-9535, or at Victoria.Wachino@cms.hhs.gov.

Sincerely,

/s/

Cindy Mann

Appendix 3: PPACA Provider Questions and Answers from CMS

Patient Protection and Affordable Care Act (PPACA)
Section 2302: Concurrent Care for Children
PROVIDER QUESTIONS AND ANSWERS FROM CMS
FEBRUARY 8, 2011

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 their hospice benefit, does that mean that they no longer have 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 we state we will cover under the Hospice Benefit. But 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, so I’ll take a crack at answering. 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 ghastly expensive, hoping that CMS

would deem the medication “curative,” and therefore not their responsibility to provide. This is 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. *What about waiver programs, will children still be able to access Home and Community Based Waiver, SCL Waiver or Michelle P Waiver and the Hospice Benefit?*

CMS Response: We’ve also received many questions about how this provision dovetails with waiver programs. The basic rule used to be that a State Plan service must be exhausted prior to using waiver services. The general rule now is that service duplication needs to be avoided, but there is no hard and fast rule about which service needs to be exhausted “first.” Since the waiver respite care is different from State Plan hospice respite care in the use of family members as providers, children could elect hospice under the State Plan AND receive waiver respite care. This is a relatively new policy decision that CMS is working to publicize.

4. *How much can the states tailor the new guidelines for pediatrics? Could they adjust the benefit to better suit pediatrics or is that a federal issue? For example remove the “life expectancy aspect” of the benefit or change it to state “expected to die before adulthood”?*

CMS Response: Section 2302 of the Affordable Care Act does not change eligibility for the hospice benefit, i.e. a physician must certify that the child’s life expectancy is six months or less in order to qualify for hospice services.

5. *Is it up to the states to decide what falls under “curative” therapies? For example a scan to detect disease progression maybe for chemo or just to know the situation, would that be the hospice’s expense or straight Medicare?*

CMS Response: It is CMS’ expectation that States work out a process with hospice providers about how services should be billed. The process should reflect an understanding that each child’s circumstances are unique and that decisions about what is “curative” reflect each child’s unique needs and be based on the State’s medical necessity criteria for the needed service. Ultimately, therefore, determinations of what are “curative” services for a child must be made on a case-by-case basis.

6. *What about blood transfusions, as an example - not really curative but certainly part of a curative therapy regimen for some conditions. These are common end-of-life treatments in some pediatric conditions, but not so common in adult hospice. Who would pay for the transfusions? Hospice or Medicaid?*

CMS Response: In addition to our answer to question 2 above, we think it is also important to bear in mind the particular purpose of the service. In your example, if the purpose of the blood transfusion was a curative treatment for the terminal condition, then the State's Medicaid program would be responsible for the expense. If, on the other hand, it was for pain or symptom control, then the hospice provider absorbs the expense. A review of the physician's orders or the hospice plan of care may assist the hospice provider and the State Medicaid agency in determining the purpose of the service or treatment. Thus, States would reimburse other providers for curative services, but would continue to reimburse hospice providers for hospice services.

7. *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.

8. *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.

9. *How does this work in states with Medicaid waivers at the moment?*

CMS Response: The answer to this question could be different depending on the type of waiver. For 1915(c) Home and Community Based Services waivers offering hospice care in conjunction with curative treatment, the passage of section 2302 does not have a fundamental impact on waiver operation. Services offered through the Medicaid State Plan, which now includes both hospice care and curative treatment, would be accessed prior to accessing waiver services. However, to the extent that services in the waiver include services outside the State Plan, such as respite care, or involve the provision of hospice services outside the life expectancy of six months, those services can be accessed any time.

10. *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.

11. *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. 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.

12. Has there been discussion on how cost neutrality will be calculated with the new requirements?

CMS Response: There is no “cost neutrality” requirement under the State Plan. Section 2302 requires States to reimburse for medically necessary services found at Section 1905(a) of the Social Security Act, even after the hospice benefit is elected by or on behalf of a child.

13. Are children receiving care under the Hospice benefit also eligible to receive 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).

14. The 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.

15. *Moving forward with the application of this new provision of concurrent care for children -- hospice and "curative" focus -- will there be certain parameters placed on current state-provided services e.g. state provided in-home nursing, hospitalizations for hospice-appropriate children? What will need to be included in documentation to substantiate that these services and treatments are "medically necessary." Have there been any guidelines or language given for us to observe?*

CMS Response: Implementation of this new provision for concurrent care for children should be determined at the State level, particularly with regard to determining medical necessity. Whatever standards or procedures the State currently uses to determine medical necessity for any Medicaid service would continue to apply to curative services provided to children who elect the hospice benefit. States should not place any restrictions or limitation on the receipt of curative treatment, other than medical necessity. CMS does not plan to issue any further guidance on this provision, but we are available to provide technical assistance to States on the parameters of this new provision.

16. *The notification sent out indicated that "appropriate forms and language for any revisions to the State Medicaid Plan" will be provided but the provision of this concurrent coverage is to begin immediately. However, in the next paragraph, it states that "This letter should be seen as a 'first step' in the implementation of (this care)... By releasing this transmission to the states, CMS has merely begun a process of dialogue on the provision and will now have more flexibility to field questions from the stakeholders."*

CMS Response: The issued State Medicaid Directors letter represents the universe of guidance CMS intends to release at this time. At the point when the revised pre-print is ready to be released, CMS will issue a subsequent letter. However, given that the effective date of section 2302 was upon enactment of the Affordable Care Act, we expect States and providers to immediately collaborate to determine how to implement this provision.

17. 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 Affordable Care Act 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.

Appendix 4: SPA and Waiver Options to Enhance Concurrent Care Programs

Medicaid State Plan Options

Each state describes its Medicaid program in the Medicaid State Plan. The State Plan specifies how the state administers its Medicaid program, and what the requirements are for eligibility, covered services, providers, reimbursement and oversight. The State Plan is subject to federal requirements including which services and eligibility groups a state must cover (mandatory services and eligibility groups) and those that are optional. Mandatory and optional services are listed in Appendix 1. Mandatory and optional eligibility groups are listed in Appendix 2. Services authorized using the state's Medicaid State Plan are referred to as "state plan services." An important state plan service for children is Early and Periodic Screening, Diagnosis and Treatment (EPSDT).

SPA Option 1: Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

States can provide additional services to children including those with a terminal illness under the authority of the EPSDT provisions, subject to CMS approval. CMS has previously approved not only additional services but the removal of requirements that limit the services to children with a terminal illness and life expectancy of six months or less. For example, Washington State includes expanded PPC services for children who have a life-limiting condition as an EPSDT service. Life-limiting condition is defined as a medical condition in children that most often results in death before adulthood.

Washington EPSDT SPA Example

The State of Washington provides PPC under the authority of EPSDT using an SPA. The SPA states specifically that hospice care "also includes PPC 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 PPC benefit consists of up to six PPC 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; and
 - Visits lasting 20 minutes or less (for example: visits to give injections, drop off supplies, or make appointments for other PPC-related services); and
 - Visits not provided in the client’s home.

Approved SPAs with an approval date of June 1, 2007 or after are now available on the CMS website at: www.cms.gov/MedicaidGenInfo/StatePlan/list.asp.

SPA Option 2: 1915(i) Home and Community-Based Services (HCBS)

The state option to offer HCBS as state plan services became available in 2005 and was amended by the ACA effective April 1, 2010. This option now permits states to make an array of HCBS available to recipients who have functional deficits below the level of institutional care or who would otherwise be eligible for an HCBS waiver.

Section 1915(i) provides an opportunity for a state to develop a specialized package of services for children receiving hospice care in much the same manner as has been implemented under 1915(c) waivers (see below). The 1915(i) option differs from 1915(c) waivers in several important ways. The 1915(i) option permits states to:

- Provide HCBS to persons who have functional deficits but who do not meet institutional level of care as well as persons who meet institutional level of care;
- Provide the same array of HCBS as may be authorized under a Section 1915(c) HCBS waiver;

- Include the higher income group (persons with incomes up to 300 percent of the Supplemental Security Income (SSI, Federal Benefit Rate (FBR ¹), which is equivalent to about 224% of federal poverty level (FPL)) but this only applies to persons who would otherwise be eligible for an HCBS waiver;
- Provide the services on a statewide basis; and
- Not utilize a waiting list (although there is a phase-in provision for new 1915(i) programs).

Therefore, a state can use a 1915(i) SPA in a manner similar to a 1915(c) waiver, but this option is more flexible than a 1915(c) waiver in terms of eligibility (i.e., not limited to children who meet institutional level of care) but less flexible in terms of enrollment (i.e., without the ability to cap enrollment). Consequently, for a state to use this option, the state must be willing to provide the service to all eligible beneficiaries. For a complete description of 1915(i) HCBS requirements see: Improving Access to Home and Community-Based Services. State Medicaid Director Letter 10-013. August 2010.

SPA Process

States amend their state plans by submitting a SPA to CMS.

Most state plan options have an existing template the state may complete requesting authorization for the change to the state plan. When a new state plan option becomes available, like the amended 1915(i) option, states are not required to wait for CMS to issue a template (which may take some time following the effective date of the option). States may instead develop their own document.

The state completes an SPA submission document (template or state-generated document) along with any supplemental information the state believes is needed to explain or justify the request as well as a required cover form (Form HCFA-179). The SPA submission must be authorized by the state's Medicaid agency director. The state submits the SPA to its regional CMS office and requests an effective date, which may not be retroactive. The CMS office documents the date received.

1. In 2010, the FBR is \$674 for a qualified individual and \$1,011 for a qualified couple. The 2011 rate is unchanged from 2010.

CMS has a 90-day timeframe from the date received within which to approve the amendment, disapprove the amendment, or request additional information (RAI).

- If CMS sends an RAI to the state, the state has 90 days to respond to the RAI. If the state does not respond to the RAI by the end of the 90-day period, CMS initiates disapproval of the SPA.
- If CMS does not approve the SPA within 90 days of receipt but also does not issue an RAI, the SPA is deemed approved at the end of the 90-day review period.
- The effective date of the SPA is the date authorized by CMS and generally will be the date requested by the state that was specified in the SPA document.

Medicaid Waiver Options

States seek authorization from CMS to deviate from federal Medicaid requirements through the use of a Medicaid waiver. Different types of Medicaid waivers permit states to “waive” specific federal requirements. Federal requirements for the Medicaid program are contained in Title XIX of the Social Security Act (SSA). Examples of requirements commonly waived using different types of waivers are provided below. Note that only a Section 1115 waiver may be used to waive all of the examples listed:

- **Section 1902(a)(1) State-wideness/Uniformity:** A waiver of this requirement permits a state to operate a program on less than a statewide basis.
- **Section 1902(a)(10)(B) Amount, Duration and Scope/Comparability of Services:** A waiver of this requirement allows a state to provide services to recipients enrolled in the waiver program that are not available to other recipients not enrolled in the waiver program.
- **Section 1902(a)(10)(C)(1) Income and Resource Rules:** A waiver of this requirement allows a state to include higher income individuals who would not otherwise be covered by the waiver program because they do not meet existing “regular” Medicaid eligibility requirements in a specific state.
- **Section 1902(a)(14) Cost-Sharing:** A waiver of this requirement is used to impose cost-sharing requirements that are greater than normally permitted.
- **Section 1902(a)(23) Freedom of Choice:** A waiver of this requirement permits states to limit a recipient’s choice of providers.

- **Section 1902(a)(32) Direct Payment:** A waiver of this requirement allows someone other than the provider of a service to receive Medicaid payment for that services. Often this is a managed care organization (MCO) that then reimburses the provider.

There are three major types of Medicaid program waivers. Each waiver is referred to by the Section of the Social Security Act that authorizes its provisions and by a primary feature of the waiver:

- **Waiver Option 1:** Section 1915(b) waivers: - Most commonly referred to as Freedom of Choice waivers;
- **Waiver Option 2:** Section 1915(c) waivers - Most commonly referred to as Home and Community-Based Services (HCBS) waivers;
- **Waiver Option 3:** Section 1915(b) and 1915(c) combination waivers: - Most commonly used to implement managed long-term care programs that include HCBS waiver services.
- **Waiver Option 4:** Section 1115 waivers: Most commonly referred to for their two primary uses - as Coverage Expansion waivers or Research and Design waivers.

Medicaid Waiver Option One: 1915(b) Waivers

Section 1915(b) waivers, commonly called Freedom of Choice waivers, are used primarily to require Medicaid recipients to enroll in managed care arrangements, limiting their choice of providers. States may also use a 1915(b) waiver to contract with a limited number of providers of a specific service (referred to as selective contracting). Selective contracting is sometimes used for dental services and hospital services.

States may include some or all Medicaid services in a 1915(b) waiver. The most common arrangements are for managed care organizations (MCOs) that provide physical health services; MCOs that provide behavioral health services; and MCOs that provide both physical and behavioral health services.

1915(b) waivers include the following requirements and options:

- The program authorized by the waiver may be less than statewide;
- The program must be identified as either a Prepaid Ambulatory Health Plan (which does not include inpatient hospital services) or a Prepaid Inpatient Health

Plan, which includes inpatient hospital services. Different federal requirements apply to each of these arrangements;

- The MCO may choose to offer additional services to recipients who enroll into their health plan. These are services the MCO chooses to offer, rather than services the state identifies that MCOs may provide in addition to required services. Examples of additional services may be dental services or over the counter medications;
- The MCO may choose to offer enrollees alternative services that are more cost-effective if the service can reasonably be expected to achieve a similar outcome and the enrollee agrees to this service. This is referred to as downward substitution;
- The state may include “supplemental services.” (Supplemental services are authorized under Section 1915(b)(3) of the SSA and are services provided to enrollees that are paid for out of cost savings resulting from the use of more cost-effective medical care. The savings must be expended for the benefit of the enrollee and must be services that are not covered under the state plan but that are for allowable medical or health-related care or other services. They are different from additional services because they are services authorized by the state and are included in the cost-effectiveness calculations for the waiver);
- This waiver does not provide for expanded eligibility;
- Payment is typically made on a capitated, pre-paid basis to the MCO (the MCO receives a per member per month (PMPM) amount for each enrollee to cover the cost of all services included in the program);
- The state may not limit enrollment to the program based on a specific number of enrollees or have a waiting list for this type of program, although MCOs may limit enrollment into their health plan based on their provider capacity;
- The state must offer a choice of at least two MCOs or an MCO and another option such as primary care case management (PCCM) to enrollees, except under special circumstances authorized by CMS.

1915(b) waivers are approved for two years and renewed every two years. However, as a result of the ACA and at CMS discretion, waivers that include dual eligibles (patients who are eligible for both Medicare and Medicaid benefits) may be approved and renewed for five-year periods.

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

Florida operates a PPC 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 support 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 CMS Network.

The waiver includes a waiver of state-wideness (operating in limited areas of the state) and uses Section 1915(b)(4) authority to selectively contract 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 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.

Medicaid Waiver Option Two: 1915(c) Waivers

1915(c) or Home and Community-Based Services (HCBS) waivers, are used to provide HCBS such as personal care, respite care and specialized medical equipment, to persons who would otherwise require institutional care. Institutional care is nursing home care, hospital care or care in an Intermediate Care Facility for persons with Mental Retardation (ICFs/MR)² that is covered by Medicaid.³ HCBS waivers generally serve persons at one level of care, although they can serve persons at more than one level of care.

HCBS waivers also include the following features:

- HCBS waivers may be implemented on less than a statewide basis;
- HCBS waivers may include persons with higher incomes, up to 300 percent of the SSI FBR and may also include the medically needy (persons with higher incomes who have very high medical expenses);

2. The Social Security Act and Code of Federal Regulations continue to use the term “mental retardation” although many states now use the term “developmental disabilities (DD)” or “intellectual and developmental disabilities (IDD)”.

3. HCBS waivers cannot be used for groups that would receive non-covered institutional services. For example, a waiver cannot serve persons who would otherwise be residing in an Institution for Mental Diseases (IMD), the cost of which cannot be covered under Medicaid for non-elderly adults.

- The state may limit enrollment to a specified number of persons or slots;
- The state may limit enrollment to persons whose cost of care exceeds a specified amount; and
- The state may include consumer-directed care, but cannot include the option where consumers receive cash to pay for their care.

Colorado operates a 1915(c) waiver that provides services such as expressive therapies and family counseling to children with a life-limiting illness. The waiver, Pediatric Hospice Waiver (HOPEFUL Program), does not require that children have a life expectancy of six months or less. Because it is a 1915(c) waiver, the child must be at risk of hospitalization. The state also limits enrollment to 200 slots, an option not available in most instances for state plan services.

HCBS waivers must be cost-neutral. The cost to serve a person enrolled in the waiver must be no greater than the cost to serve a person in the institutional setting appropriate to the waiver program, on average. The cost calculation includes the cost of all Medicaid services. The calculation is based on the average cost per person – some persons will have higher costs and others lower.

HCBS waivers are submitted electronically to CMS using an electronic application maintained on a portal. Once the application is received, CMS has 90 days to review and approve the waiver, disapprove the waiver or issue a Request for Additional Information (RAI). If the state issues an RAI, the state has 90 days to respond to CMS. CMS sometimes works with states on an informal basis providing comments on the application without issuing a formal RAI in order to keep the review process moving.

HCBS waivers are approved initially for three years and renewed for 5-year periods. However, as a result of the ACA and at CMS discretion, waivers that include dual eligibles (individuals who are eligible for both Medicare and Medicaid) may be approved and renewed for five-year periods.

1915(c) PPC Waiver Examples

California, Colorado and North Dakota each operate PPC 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) PPC Waiver Services Examples

California Waiver Services	Colorado Waiver Services	North Dakota Waiver Services
Care coordination	Expressive therapies	Case Management
Home respite care	Client/Family/Caregiver Respite Care	Home Health Aide
Expressive Therapy	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 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 who are determined physically disabled based on Supplemental Security Income (SSI) criteria, ages birth through 17, and who would otherwise require hospital or nursing home care. The waiver appears to serve 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.

Medicaid Waiver Option Three: Combination Waivers

States may also use 1915(b) waivers combined with 1915(c) waivers (a “combination waiver”) to implement managed long-term care programs that include HCBS waiver services. Combination waivers may include all Medicaid services or just LTC services. The state may choose to limit the HCBS waiver services to a specific number of slots. Therefore, a recipient could be enrolled into the program and be on a waiting list for the HCBS waiver services included in the program.

Table 2: Examples of Combination 1915(b)/(c) Waivers

State	1915(b)/(c)
Texas	STAR+PLUS: Mandated enrollment into MCOs that provide physical health and LTC services, including HCBS waiver services.
Wisconsin	Family Care: Mandated enrollment into MCOs that provide physical health and LTC services, including HCBS waiver services.
Michigan	Michigan Medicaid Managed Specialty Supports and Services Program: Mandated enrollment into MCOs that provide state plan HCBS (such as personal care and home health services), behavioral health services, nursing home services, ICF/MR services and HCBS waiver services.

If the managed care program is voluntary, the state may use the authority under Section 1915(a) combined with Section 1915(c) to implement a program. Florida’s Nursing Home Diversion program is an example of this type of combination program. The Nursing Home Diversion Program voluntarily enrolls dual eligibles into MCOs that provide all Medicaid state plan services (although most physical health and some behavioral health services are received through the Medicare program), nursing home and HCBS waiver services.

Appendix 3 provides a table comparing the major features of Medicaid waivers.

Medicaid Waiver Option 4: 1115 Waivers

Section 1115 waivers may be used to waive most Medicaid requirements in order to test new, innovative program designs. Because of the broad authority available under this waiver, states may use them for very different purposes. There are no PPC programs implemented as 1115 waivers at this time. However, hospice care for adults is included under 1115 waivers in some states (Arizona and Tennessee for example).

Examples illustrate typical uses of the 1115 waiver program.

- Consumer-directed care or “cash and counseling” – prior to the state plan option to permit consumers to receive cash payments for the purchase of HCBS and other services, states needed a Section 1115 Research and Demonstration waiver to implement these programs.
- State Medicaid reform – a number of states have made fundamental changes to their Medicaid program, restructuring how services are provided. Examples include Vermont’s use of this waiver to make the Medicaid agency the MCO that contracts with CMS, and California’s waiver that includes special financing for hospitals and that will soon enroll seniors and persons with disabilities into MCOs.
- Medicaid expansion programs – states use 1115 waivers when they want to cover persons who were previously uninsured and provide them with a different benefit package from the existing Medicaid program. Recent examples include Indiana’s Healthy Indiana Plan (HIP) and Wisconsin’s Badger Care Plus Program.
- Specialty programs – states also may use these waivers for specialty programs like Family Planning and HIV/AIDS waivers.

There is no template for an 1115 waiver and no timelines within which it must be approved by CMS. These waivers must also be budget neutral, and states are limited to a total amount of federal funding for a five-year period for the waiver. These waivers, when approved, include a long list of special terms and conditions imposed by CMS. States may be reluctant to develop 1115 waivers for small programs because of the amount of the associated workload for the state.

1115 waivers are approved for a five-year period. Technically, they cannot be reauthorized, although CMS continues to renew these waivers for three-year periods. As a result of the ACA and at CMS discretion, waivers that include dual eligibles may be approved and renewed for five-year periods.

Appendix 5: Medicaid Mandatory and Optional Services

Mandatory Medicaid Services

Inpatient hospital services, excluding services for mental diseases

Outpatient hospital services

Federally qualified health center services

Rural health clinic services (if permitted under state law)

Laboratory and x-ray services rendered outside a hospital or clinic

Nursing facility services for beneficiaries age 21 and older

Physician services

Certified pediatric and family nurse practitioner services (when licensed to practice under state law)

Nurse mid-wife services

Medical and surgical services of a dentist

Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services

Family planning services and supplies

Home health services for beneficiaries who are entitled to nursing facility services

Pregnancy-related services as well as postpartum care for 60 days

Optional Medicaid Services

Ambulance services	Non-emergency medical transportation
Certified Registered Nurse Anesthetist services	Nursing facility services for under age 21
Chiropractor services	Therapy services
Clinic services	Speech, hearing and language disorder services
Critical access hospital services	Optometrist services
Dental services	Personal care services
Diagnostic, Screening and Preventive services	Podiatrist services
Emergency hospital services in non-Medicare participating facilities	Prescription drugs
Denture services; Eyeglasses; Hearing Aids	Primary care case management
Hospice care	Private duty nursing services
Inpatient Psychiatric care for under age 21	Program of all-inclusive care for the elderly (PACE)
Institutions for Mental Disease for age 65 +	Prosthetic and Orthotic devices
Intermediate Care Facility services for Developmentally Disabled (Mentally Retarded)	Respiratory care for ventilator dependent beneficiaries
Medical equipment and supplies	Religious non-medical healthcare institution and practitioner services
Medical and remedial care by other licensed practitioners, e.g., psychologists	Targeted case management
1915(i) HCBS	1915(j) Self-directed Personal Assistance Services (cash and counseling)
1915(k) Community First Choice (CFC) Option	

Appendix 6: Medicaid Mandatory and Major Optional Eligibility Groups⁴

Medicaid Mandatory Eligibility Groups

Low-income families with children

Persons receiving Supplemental Security Income (SSI), although a few states have more restrictive requirements than the SSI program

Infants born to Medicaid-eligible pregnant women, birth through age 1, if the mother remains eligible, or would be eligible if she were still pregnant

Children under age 6 and pregnant women whose family income is at or below 133 percent of the Federal Poverty Level (FPL)

Recipients of adoption assistance and foster care under Title IV-E of the Social Security Act;

“Dual eligible” Medicare beneficiaries

Special protected groups – for example individuals who were SSI recipients, who work and lose SSI because of their earned income but who can keep Medicaid up to a specific income level.

Medicaid Optional Eligibility Groups

The Poverty Level group (also known as the Aged and Disabled group, comprised of individuals over age 65 or with a disability who have incomes up to 100 percent of the FPL).

NOTE: The FPL limit varies by state

The Medically Needy group (beneficiaries with higher incomes than in the mandatory coverage groups who also have very high medical expenses)

The TEFRA group (children who need institutional care who may be served in their home for less than the cost of institutional care and whose family income is not counted. Sometimes called the “Katie-Beckett option” after the child whose situation prompted authorization of this coverage group)

Pregnant women with income between 150 and 185 percent of the FPL

Optional, targeted low-income children – income limit determined by each state

Individuals who require hospice care (not otherwise Medicaid eligible – with income up to 300 percent of the SSI benefit rate)

The “special income group” (individuals who receive care in a nursing facility or ICF/MR or alternatively in HCBS Waivers and who are not otherwise Medicaid eligible – with income up to 300 percent of the SSI Federal Benefit Rate)

Medicaid “buy-in” program participants, also known as the Ticket to Work Group

Low-income Breast and Cervical Cancer Program treatment participants

Recipients of state supplementary payments (supplemental to SSI)

4. States have additional options when specifying eligibility groups including the types of amount of income that may be disregarded, resulting in higher FPL limits for certain persons.

Appendix 7: Medicaid Waiver Comparison of Major Features

Federal Authority	Application Requirements	Initial Approval Process	Timeframe for Review and Determination	Features	Budget/Cost Neutrality	Considerations
1915(b)	Complete a web-based CMS-issued pre-print waiver application	CMS Regional and Central Office review process	Up to 2 90-day periods (not counting time taken to answer CMS questions)	Generally used to restrict freedom of choice of provider (for managed care) May provide enhanced benefits to the extent that managed care savings can be used with CMS approval Does not expand eligibility	“Cost effectiveness” test requires state to show that projected PMPM cost will be no greater than would have been incurred under fee-for-service including a projected inflation factor	CMS more flexible in how States target enhanced benefits
	Complete a web-based CMS-issued pre-print waiver application	CMS Regional and Central Office review process	Up to 2 90-day periods (not counting time taken to answer CMS questions)	Provides a wide array of home and community-based services May be operated on less than a statewide basis Can extend Medicaid eligibility to individuals who would be eligible if they resided in an institution	“Cost neutrality” test compares waiver cost to the cost of institutional care at average per person and aggregate cost level (for a specific level of care or separate/combined levels of care)	Can cap enrollment and establish waiting lists
1915(c)	Complete a web-based CMS-issued pre-print waiver application	CMS Regional and Central Office review process	Up to 2 90-day periods (not counting time taken to answer CMS questions)	Provides a wide array of home and community-based services May be operated on less than a statewide basis Can extend Medicaid eligibility to individuals who would be eligible if they resided in an institution	“Cost neutrality” test compares waiver cost to the cost of institutional care at average per person and aggregate cost level (for a specific level of care or separate/combined levels of care)	Can cap enrollment and establish waiting lists

Appendix 7: Medicaid Waiver Comparison of Major Features (cont.)

Federal Authority	Application Requirements	Initial Approval Process	Timeframe for Review and Determination	Features	Budget/Cost Neutrality	Considerations
1115	No set application	CMS Regional and Central office review; other HHS divisions and Office of Management and Budget more involved	No set timeframe; can be lengthy	Can be used to implement major redesign of the Medicaid program in a state Can also be used to test new programs (Research and Demonstration) Can offer additional services Can be used as a vehicle to expand Medicaid eligibility	"Budget neutrality" test compares waiver costs to a negotiated without-waiver baseline and sets a 5-year cap on federal matching funds	Greatest flexibility for redesigning Medicaid including long-term care CMS policy on 1115 waivers after 2014 remains an unknown
1915(i) State plan HCBS	Complete a CMS-issued pre-print State Plan Amendment	CMS Regional and Central Office review process	Up to 2 90-day periods (not counting time taken to answer CMS questions)	Provides a wide array of home and community-based services Can extend Medicaid eligibility to individuals who would be eligible if they were enrolled in a HCBS waiver	Not required	Caps and waiting lists are not permitted and services must be offered statewide

Appendix 8: Resources for State-Level Advocacy

NHPCO's Hospice Action Network has many valuable legislative advocacy materials and resources that can be found at www.hospiceactionnetwork.org.

The National Association of State Medicaid Directors keeps a list of their members on their website at http://hsd.aphsa.org/about/NASMD_Member_List.rtf.

A list of state plan amendments can be found at www.cms.gov/MedicaidGenInfo/StatePlan/list.asp#TopOfPage. This list includes state plan amendments for all states and all provider types approved since July 1, 2007. The list is updated as needed; however, there is often a lag between the approval of state plan amendments and their posting on the website.

As of publication, only Texas has an approved state plan amendment implementing the new concurrent care requirements posted on the CMS website. www.cms.gov/MedicaidGenInfo/StatePlan/itemdetail.asp?filterType=dual,%20keyword&filterValue=hospice&filterByDID=0&sortByDID=1&sortOrder=ascending&itemID=CMS1241097&intNumPerPage=10%20.

Many Medicaid Waivers are available at the link below (not all waivers are posted here.) www.cms.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp

State Pediatric Policy Leaders Roster to network, implement and expand Section 2302 within your state.

Appendix 9: Resources for Parents

Appendix 10: Glossary

Glossary

- **Actuarial report** - As used in the toolkit, Medicaid managed care organizations must submit actuarial reports to the state Medicaid agency to demonstrate their financial solvency or soundness.
- **Authority** - It is important that the source of requirements (authority) for Medicaid (or other programs) eligibility, programs and services are identified and understood. Authority can be provided through federal or state laws or regulations. Some requirements cannot be changed, unless federal law is changed, while other requirements can be changed through state-level actions. Requirements that are at the state's discretion can usually be changed by amending state laws, regulations or rules, and may require CMS approval. Other requirements can be changed by the state requesting a waiver of program requirements from CMS (See Home and Community-Based Services Waiver and Medicaid Waiver below).
- **Centers for Medicare and Medicaid Services (CMS)** - The federal agency responsible for administering the Medicare and Medicaid programs and well as other health and human services-related programs and services. CMS was formerly known as the Health Care Financing Administration or HCFA. For the CMS home page, visit <http://www.cms.gov>.
- **Dual Eligibility** - This term is used to describe individuals who are eligible for both federal Medicare and their state's Medicaid program benefits and services. CMS has provided an overview that describes individuals who are considered to be "dual eligible" at <https://www.cms.gov/DualEligible>.
- **Home and Community-Based Services (HCBS) Waiver** - States may seek to try different approaches for providing programs and services, through the Medicaid program, that help individuals remain in their homes or in the community, rather than receiving care in an institutional setting. These non-institutional settings are known as "home and community-based services" or HCBS. In order for states to be able to provide HCBS, they may need to seek permission from CMS to "waive" Medicaid requirements. The Social Security Act [Section 1915(c)] authorizes multiple waiver and demonstration authorities to allow states flexibility in operating Medicaid programs. Each authority has a distinct purpose, and

distinct requirements. An overview of Medicaid waivers and a listing of current waivers granted to states can be found at http://www.cms.gov/MedicaidStWaivProgDemoPGI/01_Overview.asp.

- **Federal Medical Assistance Percentage (FMAP)** - The FMAP is the share of state Medicaid benefit costs paid for by the federal government. It is calculated based on a three-year average of state per capita personal income compared to the national average. Each state has its own FMAP. CMS publishes state FMAP each year. It is important to know your state's FMAP in order to estimate the state cost of any proposed change to Medicaid programs or services.
- **Federal Poverty Level (FPL)** - Federal Poverty Level Guidelines are established by the federal Health and Human Services Agency and are used for administrative purposes to determine eligibility for certain federally-funded programs. To find the federal poverty guidelines for each year, visit <http://aspe.hhs.gov/poverty/index.shtml>.
- **Katie Beckett Waiver** - The Katie Beckett provision is a statute—the Tax Equity and Fiscal Responsibility Act (TEFRA) 134—added to Medicaid in 1982. Katie Beckett is the name of the child whose parents petitioned the Federal government for her to receive Medicaid services at home instead of in a hospital, and whose plight led the Reagan Administration to urge Congress to enact the provision. TEFRA 134 gives states the option to cover non-institutionalized children with disabilities. Prior to enactment of this provision, if a child with disabilities lived at home, the parents' income and resources were automatically counted (deemed) as available for medical expenses. However, if the same child was institutionalized for 30 days or more, only the child's own income and resources were counted in the deeming calculation—substantially increasing the likelihood that a child could qualify for Medicaid. This sharp divergence in methods of counting income often forced families to institutionalize their children simply to get them medical care.

TEFRA 134 amended the Medicaid law to give states the option to waive the deeming of parental income and resources for children under 18 years old who were living at home but would otherwise be eligible for Medicaid-funded institutional care. Not counting parental income enables these children to receive Medicaid services at home or in other community settings. Many states use this option, which requires states to determine that (1) the child requires the level of care provided in an institution; (2) it is appropriate to provide care

outside the facility; and (3) the cost of care at home is no more than the cost of institutional care. In states that use this option, parents may choose either institutional or community care for their Medicaid eligible children. (Source: <http://www.hcbs.org/files/54/2668/primer.pdf>)

- **Life-limiting** - No realistic hope of cure; life-limiting conditions are those that are not curable and will end in premature death.
- **Life-threatening** - Cure may be possible; life-threatening conditions are those that carry a substantial potential of death in childhood, although treatment may succeed in curing the condition or substantially prolonging life.
- **Medicaid Hospice Benefit/Services** - A package of services provided for patients with a prognosis of 6 months or less (as certified by two physicians) should the disease follow its normal course) who agree to forgo curative treatment. Modeled on the Medicare benefit, services are paid on a per-diem basis and involve 4 levels of care: routine home care; continuous home care; general inpatient care (symptom management); and inpatient respite care. The benefit covers services provided by an interdisciplinary team (physician, nurse, nursing assistant/home health aide, spiritual counselor, bereavement coordinator, volunteers) as well as durable medical equipment, medications, and supplies related to the terminal diagnosis. While hospice is an optional benefit for adults under federal Medicaid requirements, the 1989 EPSDT amendments stipulate that children must have coverage for hospice services.
- **Medicaid Waiver** - In addition to the Home and Community-Based waivers previously described, state may seek other types of flexibility in how they administer their state Medicaid program. A description of the different types of Medicaid waivers are found in Appendix 4 of this Toolkit. A copy of the most recent state waivers approved by CMS can be found at http://www.cms.gov/MedicaidStWaivProgDemoPGI/01_Overview.asp.
- **Palliative Care Services** - Services designed to prevent, relieve, reduce, or soothe the suffering produced by serious medical conditions or their treatment, provided by an interdisciplinary team of specialists trained to address physical, emotional, spiritual and practical needs of patients and their families. Interdisciplinary teams may be made up of specialists in medicine, nursing, social work, grief and bereavement, spiritual care, expressive therapy, rehabilitation, child life, nutrition, mental health, case management and/or care coordination, body work, education, ethics and research.

- **Pediatric palliative care (PPC)** - An organized system of holistic care that improves the quality of life of children facing life-threatening conditions and their families, through the prevention and relief of suffering produced by a complex, chronic and/or life-threatening medical condition or its treatment. In addition to aggressive symptom control, PPC helps patients with such conditions and their families live as normally as possible by addressing physical/medical, emotional/psychological, social, practical, spiritual, cognitive/developmental, and educational/vocational domains of suffering while providing them with timely and accurate information and support in decision making. PPC is best provided concurrently with curative or life-prolonging care from time of diagnosis.
- **Supplemental Security Income (SSI)** - The Supplemental Security Income is an income supplement program funded by general tax revenues (not Social Security taxes). It is designed for persons who are aged, blind or have disabilities and who have little or no income with cash payments to help meet basic needs. For more information on eligibility for this program, visit <http://www.ssa.gov/ssi>.
- **State Medicaid Agency (Director)** - Each state must have an agency or department that is responsible for the administration of the state Medicaid program, in accordance with federal and state laws. This designated agency is called the “State Medicaid Agency” and the head of that agency is known as the “State Medicaid Agency Director.”
- **State Medicaid Director Letter** - CMS communicates changes, updates, guidance and clarifications in federal requirements for states to administer the state Medicaid program through several mechanisms. One of the more common methods is through the issuance of State Medicaid Director Letters or SMDLs. The link to SMDLs issued by CMS is <http://www.cms.gov/smdl>.
- **State Medicaid Plan** - Each state must have a State Plan that describes the eligibility criteria, and scope of benefits and services for the state’s Medicaid program. This State Plan must be approved by CMS. Most states post a copy of their State Plan on their state Medicaid agency’s website.
- **State Plan Amendment (SPA)** - Any time a state Medicaid agency wants to change the scope of services or benefits, or eligibility criteria for the state Medicaid program it must amend the state plan to reflect those changes. The state Medicaid program must submit proposed SPAs to CMS for approval. A listing of more recent SPAs approved can be found at <http://www.cms.gov/MedicaidGenInfo/StatePlan/list.asp>. Each state’s Medicaid agency may also post SPAs on their website.

- **Terminally Ill** - Terminal illness is defined in federal Medicare hospice regulations as, "Terminally ill means that the individual has a medical prognosis that his or her life expectancy is 6 months or less if the illness runs its normal course." (42 CFR 418.3) This definition is also used by state Medicaid programs. This definition is used to determine if an individual patient is eligible for hospice benefits and services. Some states may have a more flexible definition of terminal illness, if changed by their state plan amendment, waiver and/or state law. The text of this definition and the federal Medicare hospice conditions of participation are found at <http://ecfr.gpoaccess.gov/cgi/t/text/textidx?c=ecfr&sid=f9e5f47021625232afa96271958fb413&rgn=div8&view=text&node=42:3.0.1.1.5.1.3.3&idno=42>.

Appendix 11

References

ACT categories of life-limiting and life-threatening conditions, <http://www.act.org.uk/page.asp?section=164§ionTitle=Categories+and+life-limiting+and+life-threatening+conditions>.

Center to Advance Palliative Care (CAPC), palliative care tools, training & technical assistance for pediatric palliative care, including pediatric referral criteria, <http://www.capc.org>.

Friebert S. NHPCO's Facts and Figures: Pediatric Palliative and Hospice Care in America. National Hospice and Palliative Care Organization, April 2009.

Katherine H. Burns, Patrick H. Casey, Robert E. Lyle, T. Mac Bird, Jill J. Fussell and James M. Robbins, "Increasing Prevalence of Medically Complex Children in US Hospitals," *Pediatrics* 2010, 126, 638-646.

NHPCO Pediatric Palliative Care Online Training Series for health professionals, <http://www.nhpc.org/pediatrics>.

Tamara D. Simon, Jay Berry, Chris Feudtner, Bryan L. Stone, Xiaoming Sheng, Susan L. Bratton, J. Michael Dean and Rajendu Srivastava, "Children With Complex Chronic Conditions in Inpatient Hospital Settings in the United States," *Pediatrics* 2010, 126;647-655.

Concurrent Care for Children | Implementation Toolkit



DISTRICT OF COLUMBIA
PEDIATRIC PALLIATIVE
CARE COLLABORATION

**National Hospice and Palliative Care
Organization**

