



Partners for Children (PFC) Pediatric Palliative Care Waiver Renewal

Kick-off Meeting
August 31, 2016



Welcome, Introductions, and Purpose of Today's Meeting



Topics to be Discussed Today

- Overview of the Waiver Renewal Process and Technical Workgroup
- Overview of Current PFC Program
- Possible Changes to PFC Waiver
- Public Comment
- Wrap-up and Next Steps



Overview of the PFC Waiver Renewal Process

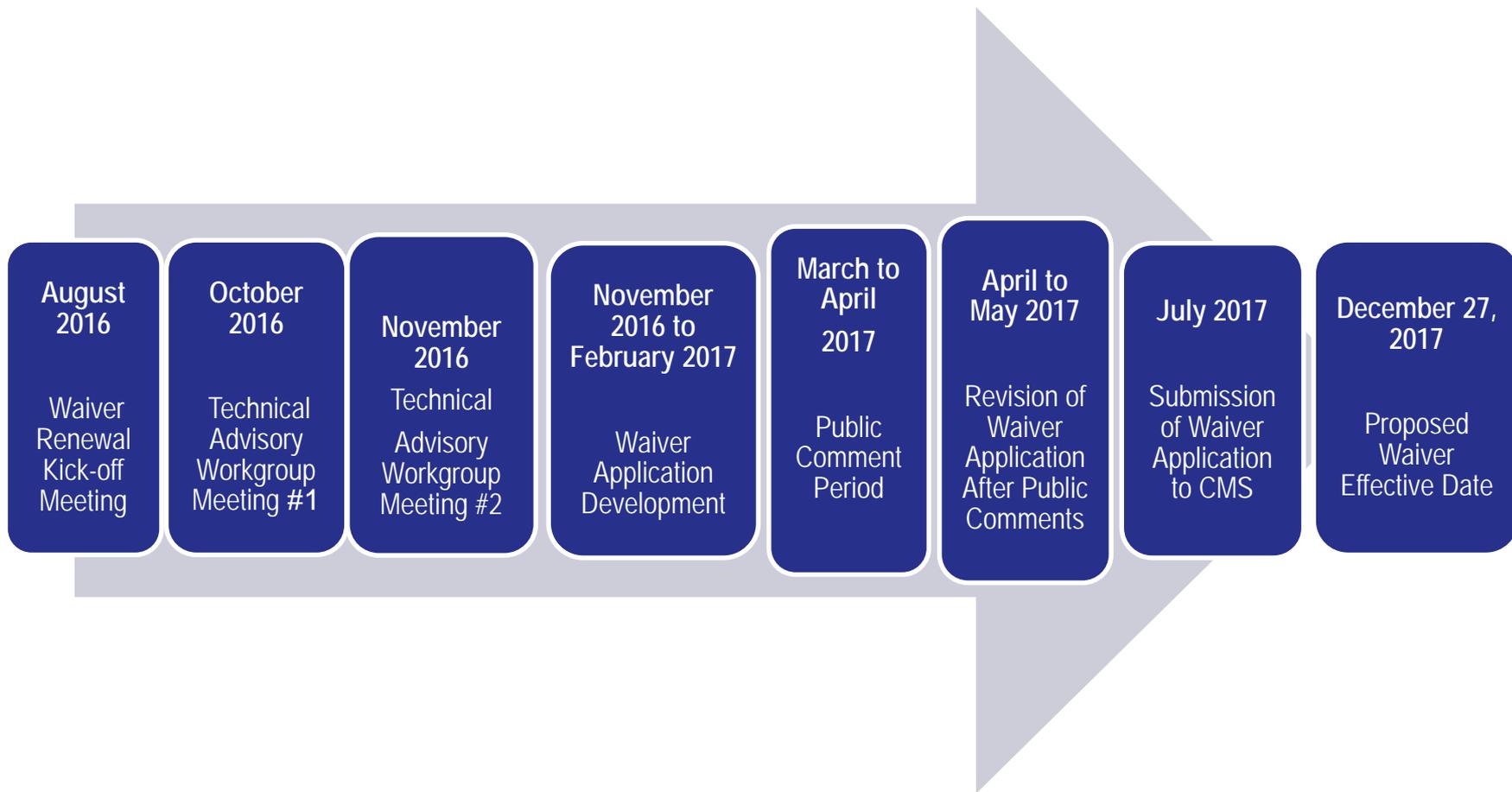


PFC Waiver Renewal Process

- Renewal Timeline
- Renewal Website
- Kick-off Meeting with Stakeholders
- Technical Expert Workgroup
- Waiver Application Development
- Public Comment
- Revise Application after Public Comment
- Submit Waiver Application to CMS



PFC Waiver Renewal Timeline





Overview of the Technical Workgroup



Overview of Technical Workgroup

- Purpose
 - Geographically and culturally diverse group of experts from multiple backgrounds to offer guidance on draft proposal on PFC waiver renewal and transition plan
- Suggested Participants
 - Family Members
 - Provider Agencies
 - CCS County Programs
 - Referring Providers
 - Advocates
 - Other Stakeholders



Technical Workgroup

- Committee structure
 - Composed of 15- 20 representatives from various stakeholder groups
- Commitment
 - Two to four meetings/conference calls October and November 2016



Technical Workgroup Statement of Interest

If you are interested in being a member of the PFC Waiver Renewal Technical Workgroup, please complete the PFC Waiver Technical Workgroup Statement of Interest form and send to:

PFCWaiverRenewal@dhcs.ca.gov



Review of Home and Community-Based Services (HCBS) Statewide Transition Plan



HCBS Settings Final Rule

- In 2009, the Center for Medicare & Medicaid Services (CMS) published an advance notice of proposed rulemaking that indicated the federal government's intention to initiate rulemaking on a number of areas within the section 1915(c) program.
- By March 16, 2019 every HCBS program must be in compliance with the final rule and have a CMS approved transition plan.
- This includes residential settings.



PFC Waiver HCBS Current Characteristics

DHCS believes that a community includes a safe and purposeful environment where individuals have:

- Needed support and safety;
- The greatest freedom to live productive connected lives according to their own desires;
- DHCS has the end goal of optimizing autonomy, independence, and consumer choice in mind; and
- PFC Waiver participants already reside in their own home or setting of their choice.



PFC Waiver and Final Rule Requirements

PFC Waiver is in compliance with Final Rule requirements.

- [PFC Waiver Transition Plan Link](#)
- [CA Statewide Transition Plan](#)



Overview of the Current PFC Waiver Program

- Definition of Pediatric Palliative Care
- Program Overview
- Program Staff and Coordination
- Program Eligibility
- Service Areas
- Services
- Forms
- Positive Aspects of PFC Waiver



Pediatric Palliative Care

- Both a philosophy and an organized method for delivering **competent, compassionate, and consistent** care to children with chronic, complex and/or life-threatening conditions, and their families.
- PPC is planned and delivered through the collaborative efforts of an **interdisciplinary team** of MDs, RNs, SWs, and other specialists with the **child and family at the center**.
- PPC is appropriate any time after diagnosis.
- PPC provides an extra layer of support.



Partners for Children (PFC) Overview

- Pediatric Palliative Care Waiver Program
Name is Partners For Children (PFC)
- 1915(c) Home and Community Based Waiver
- Provides Home-Based, Family Centered,
Coordinated Palliative Care to Children with
Life Threatening Conditions



PFC Overview (Cont.)

- Refer (Special Care Center or other)
- Enroll (County CCS)
- Services (Hospice or Home Health Agency)
- Oversight of Each Step by State CCS



Participating Counties

- Alameda
- Fresno
- Los Angeles
- Marin
- Monterey
- Orange
- San Francisco
- Santa Clara
- Santa Cruz
- Sonoma
- Ventura

Counties and Provider Agency Types

County	Provider Agency Type
Sonoma, Marin, San Francisco, Alameda	Hospice Agency
Santa Cruz, Monterey, Santa Clara	Home Health Agency
Fresno	Hospice Agency
Orange	Hospice Agency
Ventura	Home Health Agency
Los Angeles	Hospice Agencies Home Health Agencies



PFC Staff and Coordination

Potential PFC Client

Referring MD/Special Care Center

- Identifies and Refers Client
- PCP or Specialist Approves Care Plan every 6 months

CCS Nurse Liaison

- Enrolls Client
- Connects Client with Agency
- Authorizes Services
- Provides Local Oversight



PFC Staff and Coordination Cont.

Care Coordinator at HHA or HA:

- Meets with Family to Develop Family Centered Care Plan (FCAP)
- Coordinates Waiver, State Plan and Community Services
- Meets with Family at least monthly
- Bimonthly Family-Centered Team Meetings with CCS Nurse Liaison (CCSNL)
- Supports client in multiple settings
- FCAP updated every 2 months



PFC Eligibility

- Clients up to 21 years of age
- Live in participating county
- Full-scope, no share-of-cost Medi-Cal
- Life threatening or life limiting CCS eligible condition
- At risk of having at least 30 inpatient days during the subsequent 12 months if the child is not enrolled in the waiver
- Live in home or community based setting
- Not enrolled in other 1915c waiver
- Children who are hospitalized for 30 or more consecutive days are automatically dis-enrolled from the program



Core PFC Services

- Comprehensive care coordination in multiple settings including the home, clinic, hospital, or school
- Providing the extra layer of support - from ensuring child's needs are met at home, to accompanying to a clinic visit, improving communication with providers, or participating in Individual Education Program (IEP) meeting.



Other PFC Services

- Expressive therapies: art, music, play, and massage
- Family palliative care education, including instruction on providing care and operating medical equipment
- Respite care, in and out of the home, to provide needed rest for the primary caregivers
- Family counseling and bereavement counseling
- Pain and symptom management



PFC Forms

- Family Centered Action Plan (Care Plan)
- Level of Care/Medical Eligibility
- Freedom of Choice
- Participant Agreement
- Family Counseling/ Bereavement Log



Summary of Positive Aspects of PFC Waiver

- Referral and Enrollment
- Comprehensive Care Coordination (Core Service)
- Other Services
- Other Issues to Consider:
 - Access
 - Services



Break



Possible Changes to PFC Waiver

- Waiver Services
 - Care Coordination
 - Expressive Therapies
 - Respite Services
 - Pain and Symptom Management
 - Family Training
 - Family and Bereavement Counseling
 - Referral and Enrollment
 - Other



Suggestions to Improve Comprehensive Care Coordination

Issues to Consider:

- Do waiver participants/families have access to the appropriate level of care coordination?
- If not, why not?
- What changes are needed?



Suggestions to Improve Expressive Therapy Services

Expressive Therapies

- Child Life
- Massage
- Art
- Music



Suggestions to Improve Expressive Therapy Services Cont.

Issues to Consider:

- Do waiver participants/families have access to the appropriate level of each type of expressive therapy?
- If not, why not?
- What changes are needed?



Suggestions to Improve Respite Services

Issues to Consider:

- Do waiver participants/families have access to the appropriate level of respite services?
- If not, why not?
- What changes are needed?



Suggestions to Improve RN Services (Pain and Symptom Management and Family Training)

Issues to Consider:

- Do waiver participants/families have access to the appropriate level of pain and symptom management and family training services?
- If not, why not?
- What changes are needed?



Suggestions to Improve Family and Bereavement Counseling

Issues to Consider:

- Do waiver participants/families have access to the appropriate level of family and bereavement counseling?
- If not, why not?
- What changes are needed?



Suggestions to Improve Referral and Enrollment

Issues to Consider:

- Does everyone who would benefit from the current waiver and enrollment process have access?
- If not, why not?
- What changes are needed?



Summary of Possible Changes to PFC Waiver



Questions and Answers





Public Comment





Next Steps

- Technical Workgroup Opportunity
- Waiver Application Development
- Public Comment
- Final Revision of Waiver Application
- Submit Waiver Application to CMS



For Additional Information:

For PFC Waiver Renewal information, please visit:

[**PFC Waiver Renewal Webpage**](#)

Please contact the PFC Waiver Renewal team with questions or suggestions:

[**PFCWaiverRenewal@dhcs.ca.gov**](mailto:PFCWaiverRenewal@dhcs.ca.gov)