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Summary of Public Comment on the Pediatric Palliative Care (PPC) Waiver Amendment

OVERVIEW

The purpose of the Pediatric Palliative Care (PPC) Waiver is to provide pediatric palliative care services to allow children up to age 20 who have a California Children’s Services (CCS) eligible medical condition with a complex set of needs and their families the benefits of hospice-like services, in addition to state plan services during the course of an illness, even if the child does not have a life expectancy of six months or less. This waiver is authorized under Welfare and Institutions Code §14132.74. The waiver is based on the principle that if curative treatment is provided along with palliative care, there can be an effective continuum of care throughout the course of the medical condition. The objective is to minimize the use of institutions, especially hospitals, and improve the quality of life for the participant and Family Unit (siblings, parent/legal guardian, and others living in the residence).

Services provided through the waiver include:
- Comprehensive care coordination;
- Respite care;
- Family counseling (for members of the Family Unit and other primary caregivers, as applicable);
- Expressive therapies (art, music, massage, child life);
- Family training (including but not limited to: education and instruction on palliative care principles, care needs, treatment regimens, and use of equipment);
- Pain and symptom management; and
- Personal care.

PURPOSE OF SOLICITING FEEDBACK AND PUBLIC COMMENT FROM STAKEHOLDERS

PPC Waiver Home Health and Hospice agencies have expressed concern over their ability to recruit and retain an adequate provider pool. Serving PPC Waiver participants requires specialized training and certification, and there is a significant administrative responsibility of Home Health and Hospice agencies to ensure the necessary conflict of interest safeguards are in place. In order to address these concerns, the State is submitting a Waiver Amendment to implement a supplemental payment to Home Health and Hospice agencies.
During the process of the PPC Waiver amendment, The Department of Health Care Services (DHCS) solicited comments and feedback on the waiver amendment from waiver participants, waiver providers, family members, and advocates. DHCS accepted and read each form of public input by logging every letter, note, email, etc. All public comment received is listed below.

After DHCS published the waiver amendment, DHCS opened a public comment period from April 28, 2017 through June 14, 2017. DHCS dedicated an email box and phone number to receive stakeholder input. DHCS received written comments from one (1) entity:

- 100% of these comments came from a County CCS office

This document lists the comments received during the public comment period that opened on April 28, 2017 and ended June 14, 2017. The public comments are organized by Waiver Appendix. Each section below represents the questions/comments received related to each Appendix.

**APPENDIX A: WAIVER ADMINISTRATION AND OPERATION**

This section lists the comments and feedback received on Appendix A of the Waiver concerning Waiver Administration and Operation.

1. Waiver language: “Specify the Medicaid agency division/unit that has line authority for the operation of the waiver program – Systems of Care Division, Children’s Medical Services, Medical Policy and Consultation Section.”

**Question/Comment:** Does it need an edit/correction to “Long Term Care Division”?

**Response:** The State has notated this comment. This change will be made during the PPC Waiver Renewal.

**APPENDIX C: PARTICIPANT SERVICES**

This section lists the comments and feedback received on Appendix C of the Waiver concerning Participant Services.

1. Waiver language: Provider specifications for pain and symptom management include Hospice Agency Registered Nurse (RN) and Hospice Agency.

**Question/Comment:** What about RN employed or contracted by a home health agency (HHA)?
Response: The State has notated this comment. This change will be made during the PPC Waiver Renewal.

2. Waiver language: The PPC Waiver allows the State to make payment to relatives/legal guardians under specific circumstances and only when the relative/guardian is qualified to furnish services.

Question/Comment: What is the definition of “relatives”?

Response: A person connected by blood, marriage, adoption, or legal guardianship.

Question/Comment: What if the legally responsible individual for the care of the CCS client is the same person as a relative/legal guardian, can the State pay him/her for respite, personal care?

Response: No, State does not allow the parent/legal guardian to provide and get paid for direct Waiver services.

APPENDIX D: PARTICIPANT CENTERED SERVICE PLANNING AND DELIVERY

This section lists the comments and feedback received on Appendix D of the Waiver concerning Participant-Centered Service Planning and Delivery.

1. Waiver language: “Entities and/or individuals that have responsibility for service plan development may provide other direct waiver services to the participant… DHCS has safeguards in place to mitigate and address potential problems that may arise when an individual's HCBS provider also performs service plan development.”

Question/Comment: This seems to conflict with the newly proposed conflict of interest remediation plan.

Response: This is part of the remediation plan. The remainder of the remediation plan is located on pages 23 – 29 of the Waiver application.

2. Waiver language: “State Hearings are coordinated and conducted by the California Department of Social Services.”

Question/Comment: Is it not CA Department of Health Care Services?

Response: The California Department of Social Services is the designated State department responsible for the overall administration of the hearing process and the conduct of each hearing.
3. Waiver language: “The California Children’s Services Nurse Liaison (CCSNL) and other county staff participate in monthly teleconferences with the state PPC team.”

   Question/Comment: So far, participating Counties had had meeting with the State every 2 months. Our last meeting was in 10/2016.

   Response: The State has notated this comment. The State will resume regular meetings with the County CCS offices as soon as possible.

4. Waiver language: “As an added layer of oversight, one-hundred percent of PPCW care plans are reviewed by the State PPCW team.”

   Question/Comment: With increasing number of enrolled cases over time, would State assign more staff to handle this task? CCSNLs continue to send completed F-CAPs up to the State but have not heard any comment or feedback for some time.

   Response: The State continues to review F-CAPs that are submitted to the PPC Waiver email inbox.

5. Waiver language: Supplemental care coordination is listed as a direct waiver service.

   Question/Comment: Is it NOT in the category of “care coordination”?

   Response: Supplemental care coordination is both a direct waiver service and a component of the care coordination service.

6. Waiver language: “For Counties with multiple willing and qualified PPCW providers, the case management and direct services functions will be separated as follows:”

   Question/Comment: Can families allow to choose the same agency to provide both care coordination and direct services?

   Response: Under the conflict of interest remediation plan, families will have to choose a separate agency to provide both care coordination and direct services.

APPENDIX I: FINANCIAL ACCOUNTABILITY

This section lists the comments and feedback received on Appendix I of the Waiver concerning Financial Accountability.

   1. Waiver language: “Yes. The State makes supplemental or enhanced payments for waiver services.”
Question/Comment: During the course of LA County’s PPC Waiver experience (since 10/2011), we have had two (2) agencies drop from the program. They were both relatively small agencies and had difficulty keeping staff, especially RN care coordinators and expressive therapists which led to difficulty keeping and building their caseloads. The first provider never had a caseload of more than 3-4 participants at any point. The second provider never had a caseload of more than 10 participants at a time. The conflict of interest remediation plan put an extra burden on small agencies. A proposed payment structure based on the number of clients/month would likely benefit small agencies. In theory, there is a minimally fixed cost to comply with all program rules and maintain staff (including training, education, recruitment, etc.). Small agencies that do not have the infrastructure in place come to the program at a significant disadvantage. If they fail to build a large enough caseload in the short period required to pay for these minimal fixed costs, they are guaranteed to fail.

Also, there continues to be poor PPC Waiver access for eligible clients/families in certain geographic/cultural/linguistic areas, even larger agencies are not able or not willing to cover these areas.

In my humble opinion, in order to grow the program, we need not just large providers, but providers of all sizes, and the opportunity for providers of any size to grow and thrive.

With additional incentives, perhaps providers could be enticed to serve in underserved areas. Therefore, I propose a hybrid payment structure:

1. A fixed amount payment/month to any agency with a caseload up to X clients, to comply with rules and maintain staff. X is the number determined by the State to cover the minimal fixed cost.

2. A per client/month-based payment for number of cases exceeding X clients.

3. Additional payments to compensate for additional travel/interpreter expense in underserved areas, based on the number of clients in affected areas per month.

Palliative care is a relatively new field. It is teaching and establishing best practices for various group of patients along the way. There is much data to be collected/analyzed/learned/educated/shared in the pediatric palliative care arena, yet there are not enough qualified providers and no consistent/able entity to review/analyze relevant information from our clients to learn, improve, and share knowledge. Large agencies with analytic and educational arms might be able to
accomplish such, but it is a sure struggle for smaller ones. State/Counties themselves are far from able to fill the void.

In addition, the LA County CCS PPC team observed differences among agencies in regards to providers, quality of services, reporting, and care plan development (Family Centered Action Plan or F-CAP), reflecting various experiences/expertise of staff, and the breadths and abilities of administrative support within each agency, and among agencies.

To ensure that any Waiver client served by any State approved Waiver agency receive equitable services; and staff (professional and administrative) from any Waiver agency receives equitable support, training, feedback, and participation in improvement activities; I propose that the State identify an impartial entity (this could be the State itself) to collect/analyze/educate/share PPC data to both counties and agencies in an ongoing process. If this entity is not the State, the State may contract with an academic institution or a non-profit organization. This entity could also be tasked to do outreach and recruit professionals and/or agencies on behalf of the whole program. Some percentage of the proposed payment or totally separate payment in addition to this proposed sum could be dedicated to this entity.

Response: The State has notated this comment.

CONCLUSION

DHCS appreciates the comments and feedback it received regarding the PPC Waiver amendment and the proposed changes. This summary of the public comment represents all public comments received on the PPC Waiver amendment and the state’s responses.