Section 2 | OVERVIEW + TRANSITION

As of January 1, 2019, California’s Pediatric Palliative Care (PPC) waiver and the Partners for Children pediatric palliative care program have been discontinued. The California Department of Health Care Services (DHCS) is committed to delivering pediatric palliative care services under Medi-Cal fee-for-service and managed care plans. This section of the resource guide provides an overview of the PPC waiver and Partners for Children, and the transition plan being implemented by DHCS under Senate Bill 1004 and EPSDT (Early and Periodic Screening, Diagnosis, and Treatment).

Background on the Pediatric Palliative Care Waiver/Partners for Children

Pediatric palliative care (PPC), provided concurrently with life-prolonging or curative treatment, enhances patient care and quality of life, with measurable improvements to the physical and emotional well-being of children and their families. The American Academy of Pediatrics recommends that PPC, as defined by the Institute of Medicine (IOM), begin upon the diagnosis of a child’s life-threatening condition, and continue for the duration of the disease and alongside curative care or life-saving treatment, and that it be included in both public and private insurance plans.¹

California was one of the first states to respond to the need for comprehensive pediatric palliative care. The Nick Snow Children’s Hospice and Palliative Care Act of 2006 (Assembly Bill 1745) required the California Department of Health Care Services (DHCS) to submit a Medicaid (or Medi-Cal as it’s referred to in California) Home and Community-Based Services (HCBS) waiver that would enable eligible children and their families to receive in-home palliative care services during the course of the child’s illness, while concurrently pursuing curative treatment for the child’s life-limiting or life-threatening medical condition.

The waiver was first approved as a pilot project in December 2008, and established the Partners for Children (PFC) Program within the Service of Care Division (SCD) of DHCS. The first children to participate in PFC were enrolled in March 2009. The waiver was based on the principle that if curative treatment is provided along with palliative care irrespective of life-expectancy projections, there can be an effective continuum of care throughout the course of the participant’s medical condition. Under the waiver, children had access to an array of home-based palliative care services, including intensive care coordination, pain and symptom management, expressive therapies (i.e. massage, art, music, and child-life), and family counseling, without electing to receive hospice care. Services were provided by licensed hospice and home health agencies.

PPCW/PFC Eligibility

To qualify for the PPC waiver, children had to be younger than 21 years, have full-scope Medi-Cal, and have a qualifying life-limiting condition. In addition, children had to meet the Level of Care determination, which required that a referring physician assert that in the absence of waiver services the child’s condition and stage of progression put them at risk of being hospitalized for at least 30 nonconsecutive days in the coming year. However, children enrolled in the PPC waiver program were not required to meet hospice eligibility life-expectancy requirements. Notably, the eligibility criteria for the PPC waiver were broader than those for the federal concurrent care benefit, which requires that children have a life-expectancy prognosis of likely less than six months to live should the disease follow its normal course.

Outcomes

The PPC services offered under the waiver proved to be beneficial for children throughout the progression of their condition, with even greater efficacy for children with less severe disease progression. These results further demonstrate the benefits of introducing PPC services earlier on in the continuum of care.² PPC services such as
enhanced family-provider communication and coordination of social and community supports were independently shown to improve the family experience. In addition, the PPC waiver services demonstrated success in reducing caregivers’ stress and worry related to their child’s care, in building the confidence of the caregiver in their ability to provide care in the home, and in reducing children’s pain as observed by their caregiver. Notably, two independent studies conducted by the UCLA Center for Health Policy Research authenticated high levels of family and staff satisfaction with the PPC waiver program among diverse families and children and a wide range of service providers.

The PPC waiver program also demonstrated notable reductions in days spent in the hospital, expenditures per enrollee, and improvements in families’ quality of life. The provision of caring, supportive services for children in their homes offered families relief and alternatives to 911 calls, emergency department (ED) visits, and unnecessary hospitalizations while reducing lengths of stay, which consequently resulted in substantial cost avoidance. A 2015 study demonstrated:

- A nearly 50% reduction in the average number of inpatient days per month, from 4.2 to 2.3.
- A significant drop in average hospital length of stay from 16.7 days to 6.5 days (more than a 60% reduction).
- A strong trend in reducing 30-day readmission rates, from 45% of readmissions to 37%.
- Net savings – after deducting program costs – of $3,331 per enrollee per month.

Transition of PPC Services to Medi-Cal Benefit

In March 2017, new Conflict of Interest (COI) guidelines from the Centers for Medicaid and Medicare (CMS) prohibited any agency responsible for care coordination and case management from also providing direct care services. These new requirements proved to be too restrictive to allow home-based providers to continue providing PPC under the waiver. With funding from the California Health Care Foundation (CHCF), the Coalition for Compassionate Care of California (CCCC) convened stakeholder groups to brainstorm solutions to the challenges posed by the new Conflict of Interest guidelines. Despite the recommendations that stemmed from the stakeholder meetings, CMS declined to modify the guidelines, and in 2018, DHCS, in communication with CCCC and other stakeholders, made the decision to not pursue renewal of the PPC waiver and to work with providers to deliver comparable PPC services to children and their families under Medi-Cal.

SB 1004/EPSDT

California Senate Bill 1004 (SB 1004), implemented on January 1, 2018, required DHCS to establish a framework for Medi-Cal beneficiaries of all ages to receive palliative care services. The initial All Plan Letter (APL) developed to support implementation of SB 1004 under Medi-Cal Managed Care was initially adult-centric, but on December 7, 2018, the APL was amended to include eligibility requirements and language specific to children. It went into effect on January 1, 2019, and requires the provision of home-based palliative care services to eligible pediatric patients whether they are enrolled with a managed care plan or are under Medi-Cal fee-for-service.

DHCS revised and published APL 18-020: Palliative Care and NL 16-1218: Palliative Care Options for CCS Eligible Children to guide plans and providers through the transition and ensure that California children and their families continue to have access to critical home-based PPC services.

For more information on services covered by SB 1004, please see the FAQ section in this resource guide, or refer directly to APL 18-020 published by DHCS.