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## Better Outcomes, Lower Costs: Palliative Care Program Reduces Stress, Costs of Care for Children With Life-Threatening Conditions

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*“Partners for  
Children  
improved  
quality of life  
for the child  
and family.”*

**SUMMARY:** This policy brief examines the Partners for Children (PFC) program—California’s public pediatric community-based palliative care benefit to children living with life-threatening conditions and their families. Preliminary analysis of administrative and survey data indicates that participation in the PFC program improves quality of life for the child and family. In addition, participation in the program resulted in a one-third reduction in the average number of days spent in the hospital. Shifting care from a

hospital setting to in-home community-based care resulted in cost savings of \$1,677 per child per month on average—an 11% decrease in spending on a traditionally high-cost population. As the three-year pilot program draws to an end, policymakers are considering the advisability of extending the program beyond the 11 counties that now participate. This policy brief provides recommendations that policymakers, families and advocates should consider to ensure sustainability and successful expansion of the program.

California is one of the few states to offer a public community-based pediatric palliative care benefit to children living with life-threatening conditions and their families that is available earlier than the last six months of life. Through the Partners for Children (PFC) program, eligible children receive in-home coordinated family-centered care including pain and symptom management, access to a 24/7 nurse line, family education, respite care, expressive therapies and family counseling.

Currently, the number of children living with a life-threatening condition and receiving treatment in community settings is estimated at half a million a year nationally.<sup>1,2</sup>

### What Is Pediatric Palliative Care?

Pediatric palliative care seeks to relieve symptoms associated with a serious medical condition or its treatment and to enhance the quality of life for children and their families, addressing their unique psychological, social and spiritual needs.

Source: The Institute of Medicine (IOM)<sup>3</sup>

### California’s Response to the Need for Pediatric Palliative Care

California was one of the first states to respond to the need for comprehensive pediatric palliative care. The Nick Snow Children’s

### Counties Participating in the Partners for Children (PFC) Program\*

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

\* Due to a lack of providers, Alameda and Fresno counties are currently not serving clients.

Hospice and Palliative Care Act of 2006 (bill number AB 1745) required the California State Department of Health Care Services (DHCS) to develop a pediatric palliative care benefit for children eligible for Medicaid alongside curative care and regardless of the child's life expectancy. Approved as a three-year pilot program in 2008, PFC was implemented in January 2010.<sup>4</sup>

The objective of the program is to improve the quality of life for the child or teen participant and his or her family through the provision of supportive home-based services and to minimize costly hospital stays.

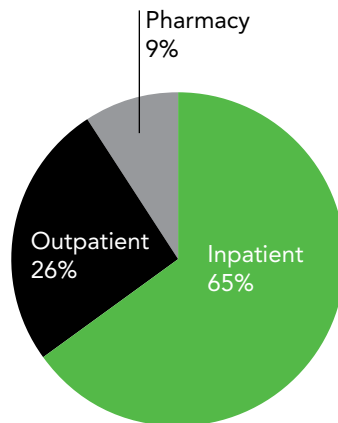
As of March 2012, there are 123 participants in the program from seven counties, ranging in age from less than 1 to 20 years old. Sixty-nine percent of the children are male, 71% are Hispanic/Latino, 12% are non-Latino Caucasian and the remaining 17% are from other ethnic or racial backgrounds. About half report speaking Spanish at home. The eligible life-threatening conditions of the participants include neurologic (29%), cancer (20%), pulmonary (16%), neuromuscular (10%), gastrointestinal (6%), cardiac (4%) and others that meet medical eligibility (15%). There are 45 children on wait lists in different counties, the majority of whom are unable to participate due to the lack of participating care agencies in the area or the lack of space at the currently participating care agencies.

The program was considered highly innovative given that before the enactment of the Patient Protection and Affordable Care Act (ACA) in 2010, children with life-limiting health conditions under Medicaid were eligible for a hospice benefit only in the last six months of their life. Additionally, to receive the benefit, families had to end all curative treatment for the child's life-limiting condition, a choice many found difficult to make.

The American Academy of Pediatrics recommends that pediatric palliative care, as defined by the Institute of Medicine (IOM), begin upon the diagnosis of a child's life-threatening condition, and continue for the

#### Exhibit 1

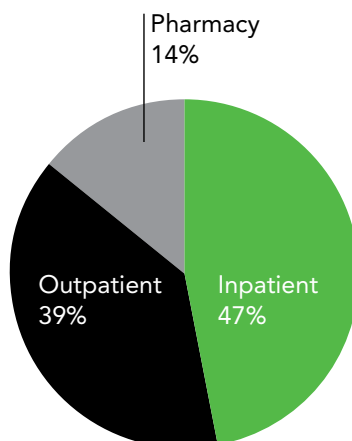
### Per Enrollee Per Month Medical Expenditures Before Enrollment in the PFC Program by Type of Service



Source: UCLA Center for Health Policy Research preliminary analysis based on MIS/DSS claims, MEDS and CMS Net data from 2009 until September 2011.

#### Exhibit 2

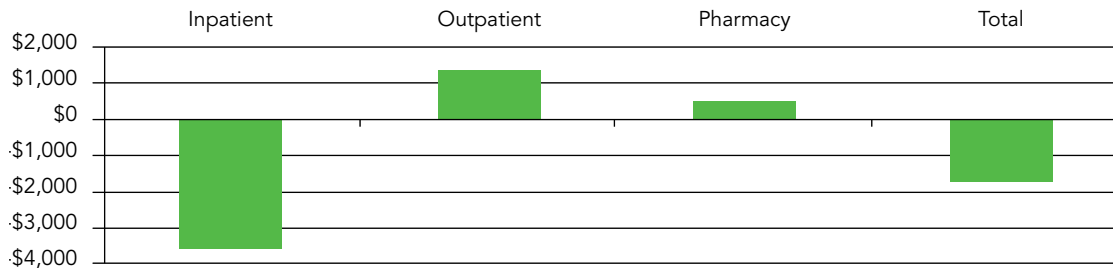
### Per Enrollee Per Month Medical Expenditures During Enrollment in the PFC Program by Type of Service



Source: UCLA Center for Health Policy Research preliminary analysis based on MIS/DSS claims, MEDS and CMS Net data from 2009 until September 2011.

## Change in Per Enrollee Per Month Cost in U.S. Dollars From Pre- to Post-Enrollment in the PFC Program by Type of Service

Exhibit 3



Source: UCLA Center for Health Policy Research preliminary analysis based on MIS/DSS claims, MEDS and CMS Net data from 2009 until September 2011.

duration of the disease and alongside curative care or life-saving treatment.<sup>5</sup> Additionally, the IOM recommends that such care be included in both public and private insurance plans.<sup>3</sup>

With the passage of the ACA, including the new Concurrent Care for Children Requirement (CCCR Section 2302), state Medicaid programs were required to provide hospice care alongside curative treatment for qualifying children. However, the eligibility requirement that a child has at most six months to live was not changed. In contrast, the PFC program provides access to comprehensive in-home palliative care services as early as at the time of diagnosis and throughout the course of the disease.

### Assessing the PFC Program: Preliminary Findings

#### • *One-Third Reduction in Hospital Days*

One of the PFC program's goals is to minimize hospitalization through the use of community-based care. Based on preliminary data, there was a 32% reduction in the average number of days spent in the hospital per member per month from 4.0 to 2.8.<sup>6</sup>

Before participation in the program, the majority of the medical expenditures (65%) occurred in the inpatient hospital setting, with a smaller proportion in the community: 26% in outpatient settings (e.g., doctors' offices, clinics) accompanied by 9% in pharmaceutical costs (Exhibit 1). After enrollment, only about half of

the expenditures (47%) occurred in the inpatient setting with a larger share in community settings: 39% in outpatient settings (including added PFC services such as expressive therapy sessions and care coordination) and 14% in pharmaceutical costs (Exhibit 2).<sup>7</sup>

#### • *11% Reduction in Spending*

The average total medical expenditures per enrollee per month after enrollment (\$13,976) were \$1,677 lower than expenditures before program participation (\$15,653)—an 11% reduction in average costs. For the first 18 months of the program operation from January 2010 to September 2011, these cost savings amounted to nearly \$1 million.

Cost savings were driven by reductions in the volume of inpatient care, in which post-enrollment expenditures were \$3,571 lower than before enrollment—a 35% reduction in hospital stay costs. However, these cost savings were partially offset by increases in expenditures on services outside the hospital, most notably a 34% increase (\$1,398) in outpatient costs and a 35% increase (\$495) in outpatient pharmaceutical costs (Exhibit 3).<sup>8</sup>

Despite the offset, the overall cost savings suggest that the PFC program appears to be reducing expensive inpatient care and replacing it with less expensive community-based and outpatient care.

*“There was a one-third reduction in hospital days per child.”*

## How the Partners for Children Program Works

The PFC program provides the following services: (1) care coordination of services across settings bringing together PFC, Medi-Cal, and other medical and community services to ensure that all of the child's and family's needs are addressed; (2) expressive therapies including art, music, play and massage for the child; (3) family education, providing instruction to families regarding the care of the child and operation of medical equipment; (4) respite care both in and out of the home to provide needed rest for the primary caregivers; (5) family counseling and bereavement counseling after the death of a child, if needed; and (6) pain and symptom management. In addition, the hospice and home health agencies offer 24/7 on-call nursing support providing advice on urgent care questions.

In order to be enrolled in the PFC program, children and young adults up to 20 years old must meet certain financial and medical criteria, and must reside in one of the 11 counties participating in the program.<sup>9</sup>

The program is built on collaboration among DHCS' Children's Medical Services, California Children's Services (CCS) program at the state and county levels, special care centers where children receive curative treatment, and local licensed private home health agencies, hospices or contracted agencies that have voluntarily decided to participate in the program. To start the process, children can be referred by a physician or another health care provider, self refer or be identified by a California Children's Services Nurse Liaison (CCSNL). The county CCSNL serves as the liaison among all state, local and private agencies involved in the child's care. Each child and his or her family are assigned a care coordinator and a multidisciplinary team of providers at the contracted care agency. The care coordinator, in collaboration with the child and family, completes a comprehensive Family-Centered Action Plan (F-CAP) highlighting their needs and desires and updates this plan bimonthly.

*“PFC families felt more confident in their ability to care for their child.”*

- ***Families' Quality of Life***

Caregiving for a child with a life-threatening illness can have a devastating effect on the well-being and confidence of parents and other primary caregivers. A survey of 33 families enrolled in the PFC program was conducted at the time of enrollment (baseline)—before receipt of services—and after about six months of enrollment (follow up).

The survey indicated a decrease in reported frequency of having difficulty sleeping; feeling nervous or tense; and feeling worried. Families also reported an increase in the frequency of feeling confident in their ability to care for their child (Exhibit 4).

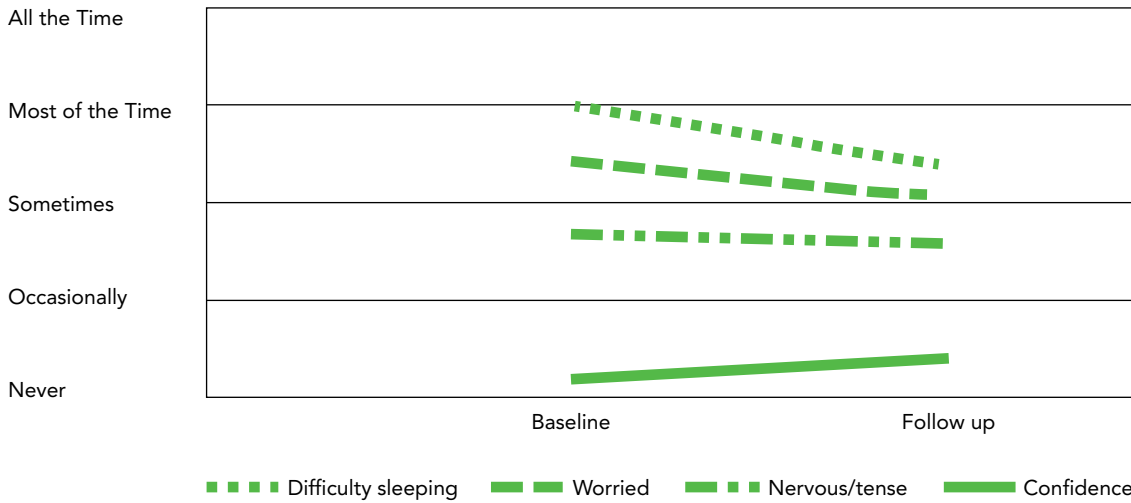
Notably, all surveyed families reported that care coordination, family education and the 24/7 nurse line were helpful in reducing stress and worry and in increasing confidence in managing their child's condition. Massage therapy for the affected children was noted by all families as helpful in reducing stress, and child life therapy was reported by all families as helpful in reducing worry.

- ***Family and Staff Satisfaction With the PFC Program***

Survey data showed high satisfaction with the program overall and with each of the individual services among both families and providers. When asked to rate the PFC

Change in Stress, Worry and Confidence Levels Before and After PFC Services

Exhibit 4



Source: A survey developed by the UCLA Center for Health Policy Research and administered to families by California Children’s Services Nurse Liaisons at baseline (enrollment) and follow up (six months after enrollment). Based on 33 surveyed families.

program overall on a scale from zero to 10, where 10 indicates excellent care, families and the California Children’s Services Nurse Liaisons (CCSNLs) (the liaisons among all agencies involved in the program) rated the PFC services at close to 10 (average 9.6 and 9.8, respectively).

Home health agency and hospice representatives rated the PFC program lower—at 7.8 on the 10-point scale. However, it should be noted that during the analysis period, only five providers were actively participating in the program and only four of those participated in the survey. It is possible that this rating is affected by what these providers perceive as lower than adequate reimbursement rates for services, an issue that came up in their survey responses as a barrier to provider participation in the PFC program.

Nonetheless, ratings of all individual services were high and 97% of the families reported that they would recommend the

program to a friend or family member in need.

**Conclusion and Recommendations**

Based on preliminary results, there is evidence that the PFC program has reduced costs and improved quality of life. In particular, PFC has had success replacing costly hospital care with less expensive community-based services, a notable accomplishment in this high-needs population.

However, these preliminary results must be interpreted with caution until a full analysis at the end of the three-year program is conducted because of the small number of participants and the wide variability of cost among children. Nonetheless, these promising results indicate that the PFC program is providing cost-effective, beneficial services to a vulnerable group of children and their families. Given existing demand, and demand generated should the program expand beyond the current 11 counties,

*“Nearly all PFC families would recommend the program to a friend or family member.”*



planning to accommodate a larger volume of children and families is needed. In order to ensure the sustainability of the PFC program, policymakers, families and advocates should consider the following recommendations:

*Encourage the participation of hospice and home health agencies.* Availability of providers is key to the PFC program's success. Efforts to retain current providers and recruit new ones should be prioritized. Reimbursement structures, timely reimbursement for services and other potential factors associated with agencies' decisions to participate should be examined. For example, currently Medi-Cal reimburses only for the cost of actual service provision. However, service providers incur additional costs in the form of provider training, billing and other administrative expenses. An additional reimbursement to support the agencies' administrative costs may provide some incentive to participate. Given the potentially significant cost savings of this program, enhancing reimbursement would still be cost effective.

*Continue education efforts across settings regarding pediatric palliative care.* To ensure referral of children living with a life-threatening condition, who will be expected to require significant utilization of health services, concentrated efforts should be made to educate the medical community regarding the fairly new practice of community-based pediatric palliative care and the availability of PFC services in participating counties. Starting care earlier on in the continuum of care will improve quality of life and will likely contribute to lowering the cost of care for the child.

*Develop collaborations and share best practices to simplify referral and enrollment processes.* As the program expands, it is important to build on existing partnerships and develop new ones among the state and county California Children's Services (CCS) programs, specialty care centers, other medical and community

services, and hospice and home health agencies. Along with planning for CCS staffing needs, sharing best practices among the partners will lead to simplified referral protocols across medical settings and enrollment procedures at the county level, and will develop infrastructure for successful expansion.

## Methods

The cost analyses reported in this policy brief are based on medical costs as measured by standard cost accounting systems using MIS/DSS claims, MEDS and CMS Net data from 2009 until September 2011. In order to promote complete claims information, a six-month claims run-out was used. However, unbilled or unpaid claims may be excluded from this analysis, potentially leading to a bias overestimating savings in the program. Analyses are based on 74 children. Due to the preliminary nature of these analyses, the results should be interpreted with caution. To validate these preliminary results, an analysis at the end of the three years' operation of the program should be conducted with a difference-in-differences design using full administrative data. The quality of life and family satisfaction analyses reported in this brief are based on surveys developed by the UCLA Center for Health Policy Research and administered by CCSNLs upon enrollment (baseline) and six months after enrollment (follow up). There were 33 families participating in the follow-up survey. The satisfaction of providers' analyses reported in this brief are based on a provider survey developed by the UCLA Center for Health Policy Research and administered online. There were nine CCSNL respondents and four home health/hospice agency respondents. Responses may be biased due to the nature of voluntary self-reported data.

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“PFC provides cost-effective, beneficial services to a vulnerable group of children.”

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The UCLA Center for Health Policy Research is one of the nation's leading health policy research centers and the premier source of health policy information for California. Established in 1994, the UCLA Center for Health Policy Research is based in the UCLA Fielding School of Public Health and affiliated with the UCLA Luskin School of Public Affairs. The UCLA Center for Health Policy Research improves the public's health by advancing health policy through research, public service, community partnership and education.

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Children's Hospice & Palliative Care Coalition is a nonprofit organization committed to pursuing and implementing cost-effective strategies that ensure a high quality of care for children living with life-threatening conditions. CHPCC represents children, parents, families and health care providers in its collaboration with community leaders, government officials, legislators and social advocates to improve health care systems. Founded in 2001, CHPCC has successfully initiated programs and policies at the state and local levels that address critical gaps in community-based services for children and their families, including California's new Pediatric Palliative Care Benefit.

### Suggested Citation

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### Endnotes

- 1 Elias, ER, Murphy, NA, The Council on Children With Disabilities. Home care of children and youth with complex health care needs and technology dependencies. *Pediatrics* 2012;129(5):996-1005.
- 2 Himelstein, BP, et al. Pediatric palliative care. *New England Journal of Medicine* 2004;350(17):1752-1762.
- 3 Committee on Palliative and End-of-Life Care for Children and Their Families, Board on Health Sciences Policy, Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*. Washington, D.C.: National Academic Press, 2003.
- 4 1915(c) Home & Community-Based Waivers. 2008; [https://www.cms.gov/medicaidstwaitprogdemopgi/05\\_hcbwaivers-section1915\(c\).asp](https://www.cms.gov/medicaidstwaitprogdemopgi/05_hcbwaivers-section1915(c).asp)
- 5 American Academy of Pediatrics, Committee on Bioethics, Committee on Hospital Care. Palliative care for children. *Pediatrics* 2000;106(2):351-357.
- 6 Preliminary analysis is based on administrative data for 74 children participating in the program by September 2011. The post-enrollment period for each child is composed of the time he or she spent enrolled in the program between January 2010 and September 2011. The pre-enrollment period is the 12 months before the child's enrollment.
- 7 For this population, visits to the emergency room represent a very small expenditure: \$4 per member per month (PMPM) before the program, versus \$6 PMPM during PFC. Considering this small number and the very minor change between pre- to post-enrollment, the numbers are not included in the exhibits in the brief.
- 8 In addition, there was a minor (\$2) increase in emergency room costs (not shown).
- 9 Counties were enrolled yearly on a rolling basis from year one to year three (see sidebar for participating counties). Financial eligibility is granted for children with full-scope Medi-Cal coverage. Medical eligibility is decided based on the existence of qualifying California Children's Services (CCS) health condition as well as a set of other more specific medical criteria. The medical eligibility was expanded in 2010 to include children with all CCS eligible life-threatening conditions who are expected to have at least 30 days total per year of hospital service use. Conditions that may qualify a child to receive services include, for example, neoplasm, cardiac, gastrointestinal, neuromuscular, neurological, or pulmonary and other conditions that meet level of care. For more details, please visit the DHCS website at <http://www.dhcs.ca.gov/services/ppc/Pages/default.aspx>



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