Children's Hospice and Palliative Care Coalition

CHILDREN'S HOSPICE
AND PALLIATIVE CARE COALITION

# PILOT ASSESSMENT AND CAPACITY EVALUATION

Report to the California HealthCare Foundation

**October 2010**

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## About this Report

This report represents a major milestone in Children's Hospice and Palliative Care Coalition's efforts to implement California's new Medi-Cal Pediatric Palliative Care Benefit in the state's 13 designated pilot counties. Conducted to fill a crucial knowledge vacuum, PACE identifies a contingent of home health and hospice programs that continue to provide pediatric services in their communities despite the crippling recession. PACE also gauges the potential for additional health care resources to extend their services to children.

## Children's Hospice and Palliative Care Coalition

Since 2001, Children's Hospice and Palliative Care Coalition (CHPCC) has been advocating on behalf of vulnerable populations at the state and local level. In pursuit of its core mission—to tackle the health disparity in end-of-life care for children—it exemplifies the belief that coalitions are the necessary vehicle for achieving health care reform. As a coalition, CHPCC brings together a diverse base of stakeholders, including parents, health care providers, policymakers, and social advocates, to rectify moral lapses in the existing health care system. The agency leverages the strengths offered by its collaborative framework to pursue and implement cost-effective strategies that ensure a higher quality of care for children suffering from life-threatening conditions and their families.

Through its work, CHPCC, in collaboration with California Children's Services (CCS), has spearheaded the development of pilot programs that are impacting communities throughout California and that potentially serve as a national model for recent federal health care reform both in terms of delivery and payment systems.

In the Patient Protection and Affordable Care Act of 2009, there is a provision that children who are enrolled in either Medicaid or CHIP be allowed to receive hospice and palliative care services without foregoing curative treatment related to a terminal illness. This new federal policy has state Medicaid programs across the country struggling to define services and formulate interim guidelines for implementation. The eligible prognostic requirements administered under this provision are more restrictive than those detailed in California's new law. However, the concept of concurrent care is reflected in both policies and California's pilot programs are poised to exemplify an actionable model of health care reform.

## Acknowledgements

Children's Hospice and Palliative Care Coalition would like to extend their deepest appreciation to the Department of Health Care Services and California Children's Services for their continued partnership, and to all of the providers who participated in PACE. The agency also would like to thank the California Hospice and Palliative Care Association and the California Association for Health Services at Home for their support in disseminating the PACE questionnaire to their memberships. Additionally, CHPCC extends its appreciation to Betty Ferrell, Ph.D., FAAN City of Hope Professor, Nursing Research and Education, for her assistance in the development of the PACE survey content; to Trisha Rorabaugh, Rorabaugh Design Studio, for creation of the electronic survey and database; and Lisa Simonson Maiuro, MSPH, PhD, Researcher, Health Management Associates, for her assistance with PACE evaluation processes.

## The California HealthCare Foundation

PACE was underwritten in its entirety by the California HealthCare Foundation. The California HealthCare Foundation is an independent philanthropy committed to improving healthcare delivery and financing in California. By promoting innovations in care and broader access to information, the Foundation's goal is to ensure that all Californians get the care they need, when they need it, at a price they can afford.

## Background

In 2008, California's Department of Health Care Services (DHCS), responding to the Nick Snow Act and subsequent passage of a federal pediatric hospice waiver, designated 13 pilot counties across the state as implementation sites for the new Medi-Cal Pediatric Palliative Care Benefit. The Benefit provides eligible children with access to an innovative care system that waives hospice eligibility requirements and allows them to pursue curative and life-prolonging therapies concurrently with the benefits of hospice and palliative care to alleviate their pain and suffering.

The three-year implementation trajectory, which officially launched in October 2009, assembled a diverse geographic roster of communities able to foster a new model of community-based palliative care for children living with chronic, complex, and potentially terminal medical conditions. The first group of counties, Santa Cruz, Monterey, and San Diego have been enrolling children under the Benefit since March of 2010 when DHCS disseminated guidelines and enrollment materials. Additional counties originally selected for the two-year implementation queue were: Los Angeles, Orange, Fresno, Santa Clara, San Francisco, Sonoma, Marin, Alameda, Humboldt, and Sacramento.

All of the counties initially demonstrated the commitment and capacity necessary to meet DHCS standards for enrollment in the pilot program prior to its launch; yet the state's widespread economic plunge, budget deficits, fiscal considerations such as low reimbursement rates, and lack of pediatric knowledge among providers, have sorely impacted the initiation and enrollment process.

Administrative concerns at the state and county level, such as the highly restrictive medical eligibility criteria, subsequent conservative interpretation of those requirements on the part of California Children's Services (CCS), and cumbersome admission documentation also have hindered the program's capacity to serve vulnerable children. As one CCS nurse liaison administering the Benefit shared, "I think the barrier is the medical criteria. For instance, our cancer kids are perfect for this type of program but eligibility requirements say that they have to have failed conventional protocols. All kids with cystic fibrosis would be good candidates because they have a difficult life and a shortened lifespan; however, the criteria dictate that they have to be 'end stage'. The list goes on. If it were up to me, I would add neurological problems like cerebral palsy, anomalies, etcetera, cancer kids on chemo or after chemo, and all types of muscular dystrophy and spinal muscular atrophy. I would also re-write the central nervous system injury category and add an 'other' category to the list."

## Project Scope

This report examines capacity, trends, and metrics for all 13 of the pilot counties whether currently engaged in the program or flagged as pending by the state. Statistical tables reflect results collected through 486 provider surveys; the majority of which were completed by home health and hospice agencies. Results provide a new perspective into the waning pediatric health care community and highlight opportunities to expand provider pediatric palliative care knowledge.

Personal interviews conducted with active pilot site providers give voice to the institutional values that govern them along with the culture and leadership that supports them in maintaining service provision despite economic challenges. Through PACE, CHPCC has identified a baseline of current and potential pediatric providers and their collaborating partners. The agency also has developed a system for engaging adult-focused hospice and home health providers who demonstrate interest in expanding services to children in each of the pilot counties.

## Geographic Considerations

Distribution of pilot counties in Southern, Central, and Northern California represent a diverse ethnic sampling of the state's multi-cultural population. Regions vary considerably in population size; therefore, aggregate data reporting is skewed. The Southern California Region in particular reflected the highest per-capita percentile of respondents for the study in keeping with the tri-county area's overall census.

In order to represent the penetration in each county accurately, PACE captured the overlapping service areas of providers. It was anticipated that each unique facility participating in the survey would serve multiple counties.

In addition to population scope, the density of low-income inhabitants also is a factor considered in PACE. Eligibility for the Benefit requires children to be enrolled in the state's public insurance program as full-scope Medi-Cal.

## CCS Concentration in Pilot Counties

According to 2009 data from California's Department of Health Care Services, the number of Medi-Cal beneficiaries under 21 years of age in the pilot counties totals 2,319,598. Approximately 3% of these users are CCS children. Prior to the launch of the Benefit in 2008, Dr. Marian Dalsey, former Chief, Children's Medical Services Branch, California Department of Health Care Services, estimated that 10% of the CCS population statewide were children afflicted with life-threatening conditions that could benefit from the services offered under the new concurrent care model. Of this 10%, more than 7,000 CCS Medi-Cal children reside in the pilot counties. While not all of these children will be enrolled in the program due to current eligibility requirements and program capacity, a significant portion of this population are potential candidates. The majority of these children do not meet the current hospice eligibility criteria of having likely six months or less to live.

| Rank | County | Medi-Cal Population | CCS Service Users | LTC Children In Pilot Counties |
|---|---|---|---|---|
| 1 | Los Angeles | 1,202,220 | 36,067 | 3,607 |
| 2 | Orange | 213,034 | 6,391 | 640 |
| 3 | San Diego | 204,415 | 6,132 | 613 |
| 4 | Fresno | 167,613 | 5,028 | 503 |
| 5 | Sacramento | 155,890 | 4,677 | 468 |
| 6 | Santa Clara | 114,593 | 3,438 | 344 |
| 7 | Alameda | 107,581 | 3,227 | 322 |
| 8 | Monterey | 46,961 | 1,409 | 141 |
| 9 | San Francisco | 39,372 | 1,181 | 118 |
| 10 | Sonoma | 27,152 | 815 | 82 |
| 11 | Santa Cruz | 20,582 | 617 | 62 |
| 12 | Humboldt | 11,593 | 348 | 35 |
| 13 | Marin | 8,592 | 258 | 26 |

**Table 1:1**

[1] *Overview for Medi-Cal Beneficiaries by Demographics, April 2009, Research and Analytical Studies Section, California Dept of Health Care Services.*

[2] *Assessing the California Children's Services Program, August 2009, California HealthCare Foundation Issue Brief.*

## Key Findings

In each of the counties surveyed, CHPCC was able to gather important data regarding the availability and capacity of providers currently offering pediatric services, and those serving adult populations that are potentially able and/or willing to consider expanding their service provision to children. Statistical data was collected and segmented based upon whether a provider is a licensed hospice, home health agency, holds dual hospice/home health licensing, or is a supportive provider of another type that may be able to offer waiver services as a collaborative partner. Figure 1:1 to the right illustrates the PACE respondent composition.

**What type of provider are you?**

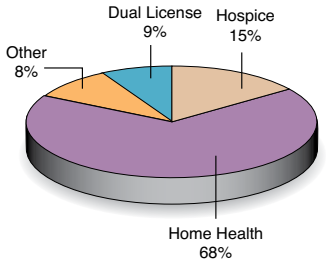



**Figure 1:1**

| RANK | COUNTY | TOTAL NUMBER OF PROVIDERS (PACE) |
|---|---|---|
| 1 | Los Angeles | 268 |
| 2 | Orange | 141 |
| 3 | San Diego | 51 |
| 4 | San Francisco | 42 |
| 5 | Santa Clara | 37 |
| 6 | Alameda | 34 |
| 7 | Marin | 24 |
| 8 | Sacramento | 20 |
| 9 | Sonoma | 15 |
| 10 | Humboldt | 13 |
| 11 | Santa Cruz | 10 |
| 12 | Fresno | 10 |
| 13 | Monterey | 8 |

**Table 1:2**

There were a total of 1,126 for-profit, and not-for-profit facilities originally identified for the PACE project. Forty-three percent, or 486 total surveys were effectively completed. The remaining 57% were non-responsive for the following reasons:

- unable to make contact within the brief time period of the study,
- out of business,
- refused to participate,
- satellite offices located in other counties,
- contact information not available, or
- parent company outside California.

Many of the organizations surveyed through PACE extend their service delivery beyond their county of residence into adjacent territories. For example, numerous facilities serving Los Angeles County also provide care in Orange County. Table 1:2 to the left illustrates the total number of organizations interviewed through PACE that are providing services in each of the pilot counties.

**Do you provide palliative and/or hospice services for children?**

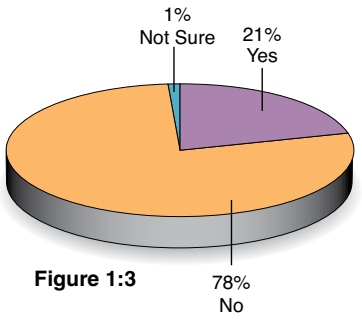



**Figure 1:3**

PACE results affirm CHPCC's earlier belief that children suffering from chronic, serious medical conditions are often marginalized in the health care system. Only 21% of providers who responded to the survey are currently serving the pediatric patients in pilot counties as shown in figure 1:3.

PACE allowed CHPCC to identify and connect with more than 60 previously unidentified facilities that expressed substantial interest in augmenting services for children. Research also shed new light on the pulse of pediatric hospice and palliative care in the state and presented CHPCC with various challenges that must be addressed.

The following key findings are categorized based on two specific survey tracks: providers who currently are serving children and those who are not. Results are divided between these two unique provider populations.

**Data Profile:** Pediatric providers responding affirmatively to providing hospice and/or palliative care to children:

- Only 102 of 486 respondents, approximately 21% of the agencies surveyed, currently offer pediatric services.
- Of the 102 agencies that serve children, 35% are non-profit and 65% are for-profit organizations.
- The ratio of estimated LTC children served by respondent pediatric providers varies dramatically across the counties as evidenced in Table 1.4 below. With a ratio of 97 children to every palliative and/or hospice care provider in the county, Los Angeles may be considered underserved; however, it is important to note that non-responders may augment the service capacity of each county listed.

| Rank | County | Estimated Number of LTC Children In Pilot Counties | Number of Known Pediatric Providers | Ratio of LTC Children to Pediatric Providers |
|---|---|---|---|---|
| 1 | Los Angeles | 3,607 | 37 | 97:1 |
| 2 | Orange | 640 | 22 | 29:1 |
| 3 | San Diego | 613 | 20 | 31:1 |
| 4 | Fresno | 503 | 14 | 36:1 |
| 5 | Sacramento | 468 | 12 | 39:1 |
| 6 | Santa Clara | 344 | 5 | 69:1 |
| 7 | Alameda | 322 | 7 | 46:1 |
| 8 | Monterey | 141 | 8 | 18:1 |
| 9 | San Francisco | 118 | 8 | 15:1 |
| 10 | Sonoma | 82 | 4 | 21:1 |
| 11 | Santa Cruz | 62 | 4 | 16:1 |
| 12 | Humboldt | 35 | 2 | 18:1 |
| 13 | Marin | 26 | 3 | 9:1 |

**Table 1:4**

- An overwhelming majority, approximately 75% of the agencies that offer pediatric services responded that they are "extremely interested" in increasing the number of children they serve.
- 67% of pediatric service providers not only serve children who are full-scope Medi-Cal but indicate that these children comprise a majority of their pediatric patient census—a significant finding that attests to the impact that the new Benefit will have in the state.
- Data demonstrates a consistent trend across all provider types as to the "culture of collaboration." Roughly 68% of pediatric agencies do collaborate to provide services to children across a broad spectrum of services.
- Services most commonly provided include: registered nursing 90%; care coordination 84%; respite 80%; 24/7 on-call nursing 75%; social work 75%; and, family education 75%. Opportunity to increase access to services under the Benefit exists in the areas of bereavement, child life, and expressive therapies which all ranked 40% or under in terms of current service provision, with the child life specialty reporting a result of only 13%.

- 83% of these pediatric providers stated that they have at least one nurse on staff with three years or more pediatric experience and 51% have a minimum of one social worker on staff with three years or more pediatric experience. It is relevant to note that a qualified applicant for the role of care coordinator under the Benefit requires this minimum level of pediatric expertise in either discipline.

**Data Profile:** Pediatric Providers responding negatively to providing hospice and/or palliative care to children:

- 79% of the organizations surveyed—379 in total—do not offer services to children. Of this number, 75% responded that they were not interested in or were neutral about expanding services to include pediatric populations in their respective communities.

- 25% of the organizations surveyed—93 in total—indicated that they are interested in "expanding" services to children. Of those, 90% are for-profit organizations.

- 71% of respondents cited staff education as a prerequisite to expanding their pediatric service delivery.

- Pediatric protocols and the need for pediatric medical consultants were cited with a high degree of frequency (>65%) as necessary considerations for providers who are interested in expanding services to children.

- The Southern California region indicates an even higher need for pediatric education, protocols and consultation (>75%) across the largest geographic group of providers surveyed.

- Higher levels of reimbursement and support by an agency's board of directors and/or administration were cited by a majority of respondents, suggesting that, at minimum, budget neutrality would be required to expand services to children.

## Reduction of Hospitalizations

The reduction of ER visits, lengthy hospital stays, ambulatory transport and other expensive crisis-driven therapies has proven a key outcome for families enrolled in the Medi-Cal Benefit. Evidentiary results are demonstrated in a random sampling of case studies acquired from the Santa Cruz/Monterey County pilot site.

**CASE STUDY 1** – Nineteen-year-old neurologically devastated male. He lives with a Ventriculoperitoneal (VP) shunt in the brain and is non-communicative. He has a history of respiratory infections. A DNR is in place. Since enrollment in the Benefit, Coastal Kids has received two calls relative to the patient suffering from bouts with fever and rapid breathing. Coastal Kids was able to mitigate the first contact through collaboration with the patient's primary care physician. An appointment was made with a local clinic and the patient was immediately started on intravenous antibiotics. In the second instance, the primary care physician on call was not familiar with the patient. Coastal Kids contacted the emergency room at the local hospital. ER staff requested that the patient be admitted for a chest x-ray. Once there, he was also started on antibiotics and then sent home.

The patient's mother's requested that Coastal Kids do whatever possible to ensure that he is able to remain safely at home where he is "happier." She also commented that hospitalizations are very difficult for him and on the family, particularly his two siblings. Since becoming a participant in the Benefit program in March of 2010, the patient

has been to the ER (at the physician's request) only once and has not been admitted to the hospital. In the year prior to his enrollment, he was taken to the ER on four occasions and was admitted into the hospital on three.

**CASE STUDY 2** – Six-year-old female on ventilator support with a tracheotomy. She is non-communicative. During a routine visit, the Coastal Kids nurse and the patient's mother discussed the possibility that the patient might be suffering from a urinary tract infection. Coastal Kids reported this suspected condition to the patient's primary care physician, who requested that Coastal Kids' staff perform a sterilized catherization, and analyze fluid secretions. The test result was positive and conclusive. On the physician's order, the patient was started on a course of oral antibiotics. She was monitored throughout the 10-day treatment to ensure that the medication was effective. The patient has a history of lengthy hospitalizations resulting from undetected urinary tract infections that spread to her kidneys.

**CASE STUDY 3** – Seventeen-year-old neurologically devastated female. History of skin breakdowns resulting in large bedsores (decubitus pressure ulcers) particularly around her g-tube. She is also susceptible to respiratory infections. Since enrolled in the program, the patient has not had any major skin breakdowns; the weekly nursing visits have enabled staff to spot the symptoms of a pressure ulcer early on, enabling them to administer preventive care and provide immediate treatment to alleviate further systemic trauma. On one visit, the patient demonstrated signs of a respiratory infection. Coastal Kids arranged for a same-day clinic appointment, where she was diagnosed and started on a course of oral antibiotics. Coastal Kids monitored her during the 10-day prescribed treatment. The treatment was effective. Since enrolling onto the program in June of 2010, the patient has not been admitted to the ER or hospital. In the year prior to her enrollment, she was taken to the ER four times and was admitted into the hospital on three occasions.

**CASE STUDY 4** – Sixteen-year-old male amputee suffering from osteosarcoma. The loss of his leg was a result of his disease process. He is still undergoing aggressive treatment intended to arrest the spread of his cancer. The patient's family is indigent and has very little in the way of fundamental resources. His father is unemployed and there are two additional siblings in the home. Coastal Kids' care coordinator is working with the family to establish links to community providers such as food banks, social service organizations, and others that can alleviate some of the burden of care and provide practical support, as well as provide for the family's survival. The care coordinator also is working on acquiring a Section 8 housing designation for the family so that they can move into a single-level home; thus enabling the patient greater mobility and independence.

## Pilot Site Metrics

The design phase for the Medi-Cal Pediatric Palliative Care Benefit yielded a functional pilot site blueprint which included: an independent local CCS county office, a community-based hospice or home health agency(s) with pediatric expertise, and a referring children's specialty hospital(s). During the planning stages prior to implementation, all of the counties under consideration demonstrated the leadership, preparedness, and capacity necessary for participation in the program. They met the following criteria:

**County Level**

CCS county office interested in participating in the program and able to fulfill operational requirements including: 1) securing a full time CCS nurse liaison, a position responsible for screening and identifying prospective children, interpreting eligibility criteria, and enrolling children onto the Benefit; 2) understanding of the practical and fiscal benefits of concurrent palliative care; and, 3) willingness to administrate the program at the county level while maintaining cost neutrality, a state and federal requirement. The CCS nurse liaison position is underwritten by a federal/state financial matching program and requires no county contribution at this time.

**Provider Level**

A Medi-Cal certified, licensed hospice and/or home health provider willing to submit an application to DHCS requesting authorization to provide services under the new Benefit and have a proven ability and the capacity to provide pediatric care once approved.

Unfortunately, economic woes caused more than 50% of the early players to withdraw their bid for inclusion. Many were forced to reduce pediatric services dramatically or in some cases, close their doors for good. This funding turmoil left a formidable void in local communities and posed a threat to the success of the pilot projects. Significantly, Humboldt and Sacramento counties temporarily declined participation in the program citing operational and financial barriers.

## Risk-Sharing Partnerships

To mediate this challenge, CHPCC began seeking risk-sharing partnerships among the county health care communities—replacing withdrawal and failure with collaborative opportunity. Early attempts at organizing makeshift pilot sites were met affirmatively. Monterey County was the first to formalize a multi-agency collaboration designed to bundle pediatric services as part of the pilot program. Three unique non-profit organizations joined together to cover the gamut of Benefit services, as well as to offer additional community-based support to needy families.

They are:

- Coastal Kids Home Care, the only pediatric home health agency on the Central Coast;
- Jacob's Heart Children's Cancer Support Services, an organization that provides psychosocial and practical support to children with cancer and their families; and,
- CHPCC's Partnership for Children (PFC), which similarly offers these services to children with complex medical conditions other than cancer. PFC also operates a free transportation service that coordinates and provides frail children and their parents with safe, reliable rides to medical appointments at children's hospitals in the Bay Area.

Figure 2:1 below depicts the service-sharing model.

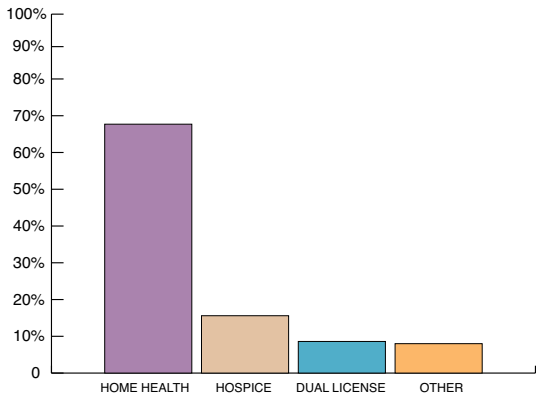

**Figure 2:1**

With the notion of multiplying the successful outcomes of the multi-agency risk-sharing partnership developed for Central Coast children, CHPCC has identified a myriad of providers from throughout the pilot counties who demonstrate a culture of collaboration and who have responded optimistically with regard to expanding services to children. They have stated their interest and offered rationale for what it will take to secure their involvement. Approaching these tentative stakeholders will be a functional activity of CHPCC's educational strategies moving forward.

# Global Statistics

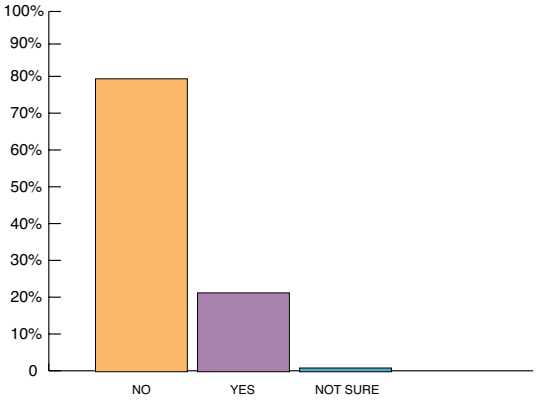
## What type of provider are you?

| | | |
|---|---|---|
| Home Health | 329 | 67.7% |
| Hospice | 76 | 15.6% |
| Dual License | 42 | 8.6% |
| Other | 39 | 8.0% |
| Total Responses | 486 | 100.0% |



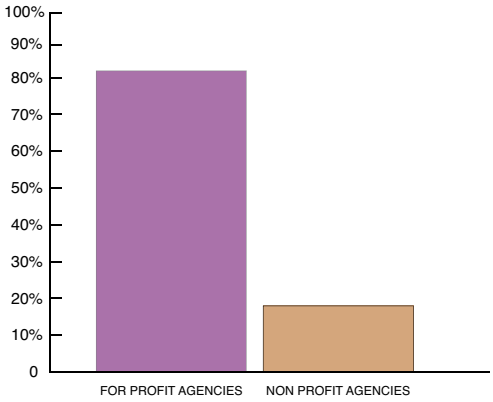

## Do you provide palliative and/or hospice services for children?

| | | |
|---|---|---|
| Yes | 102 | 21.0% |
| No | 379 | 78.0% |
| Not Sure | 5 | 1.0% |
| Total Responses | 486 | 100.0% |




## Are you a for-profit or a non-profit agency?

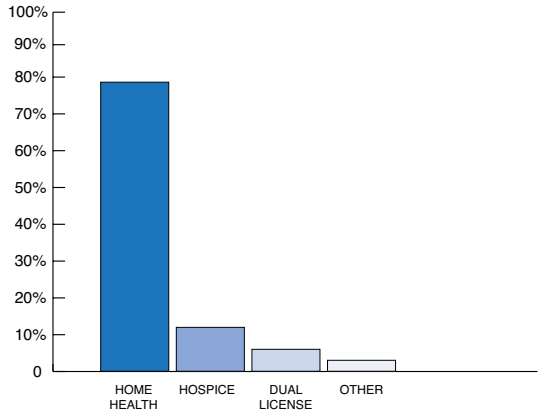
| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Non Profit Agencies | 34 | 20 | 12 | 20 | 86 | 17.7% |
| For Profit Agencies | 295 | 56 | 30 | 19 | 400 | 82.3% |
| Total Responses | 329 | 76 | 42 | 39 | 486 | 100% |



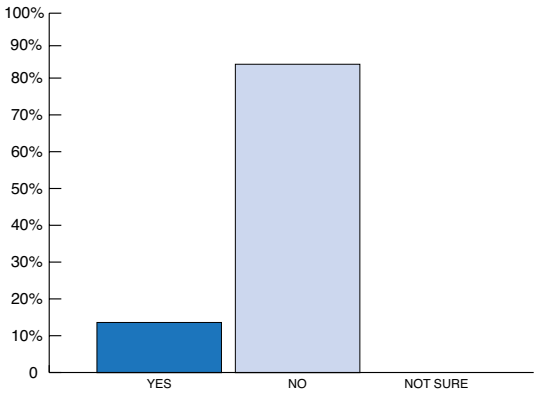
# County Snapshot: Los Angeles

## What type of provider are you?

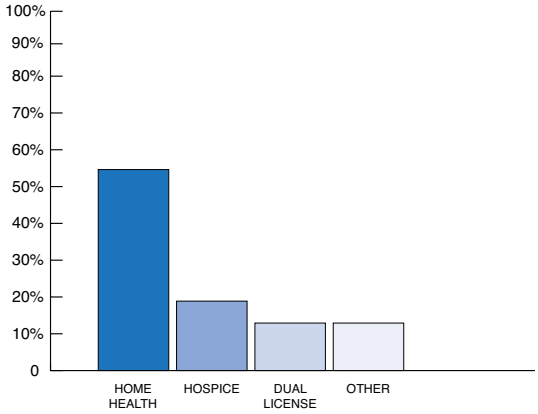
| | | |
|---|---|---|
| Home Health | 212 | 79.1% |
| Hospice | 33 | 12.3% |
| Dual License | 15 | 5.6% |
| Other | 8 | 3.0% |
| Total Responses | 268 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 21 | 7 | 5 | 5 | 38 | 14.2% |
| No | 191 | 25 | `0 | 3 | 229 | 85.4% |
| Not Sure | 0 | 1 | 0 | 0 | 1 | 0.4% |
| Total Responses | 212 | 33 | 15 | 8 | 268 | 100% |

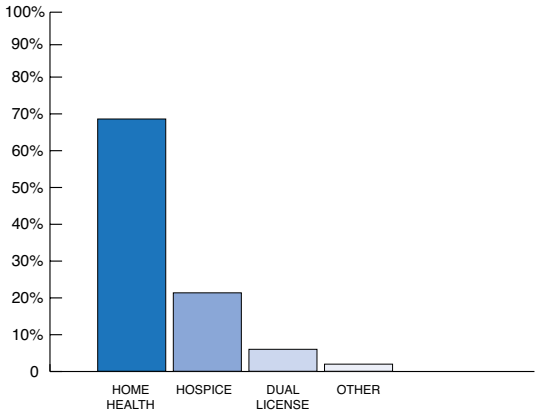
## Which of the following pediatric services does your agency provide?

registered nursing ..... 81.6%
care coordination ..... 84.2%
family counseling ..... 60.5%
bereavement/anticipatory grief support ..... 36.7%
art therapy ..... 15.8%
play therapy ..... 26.3%
respite ..... 76.3%
massage therapy ..... 31.6%
family education ..... 76.3%
24/7 on-call nursing support ..... 73.7%
chaplaincy ..... 31.6%
child life specialists ..... 13.2%
social work ..... 76.3%
other ..... 44.7%

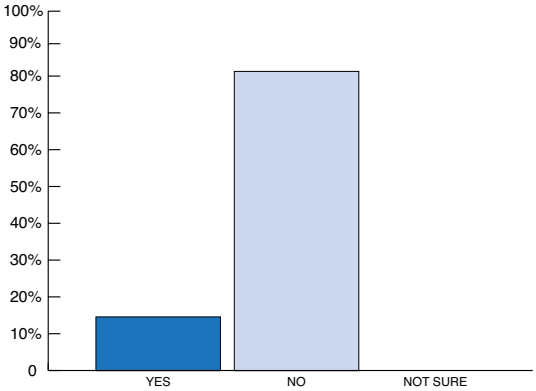
# County Snapshot: Orange County

## What type of provider are you?

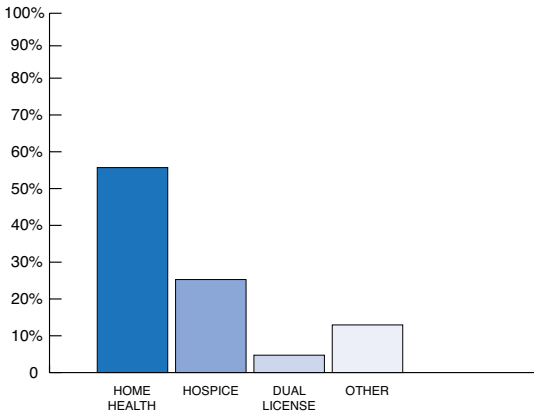
| | | |
|---|---|---|
| Home Health | 98 | 69.5% |
| Hospice | 32 | 22.7% |
| Dual License | 8 | 5.7% |
| Other | 3 | 2.1% |
| Total Responses | 141 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 13 | 6 | 1 | 3 | 23 | 16.3% |
| No | 85 | 26 | 7 | 0 | 118 | 83.7% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0% |
| Total Responses | 98 | 32 | 8 | 3 | 141 | 100% |

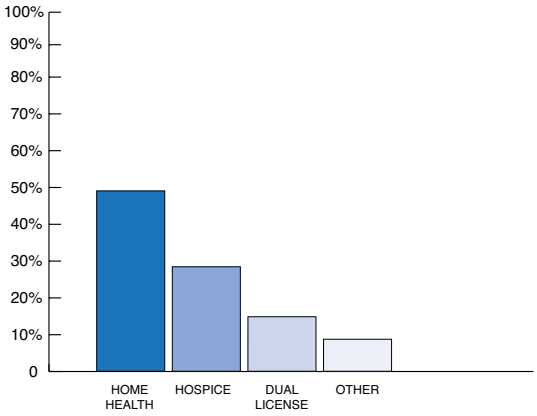
## Which of the following pediatric services does your agency provide?

registered nursing ..... 87%
care coordination ..... 91.3%
family counseling ..... 60.9%
bereavement/anticipatory grief support ..... 47.6%
art therapy ..... 21.7%
play therapy ..... 39.1%
respite ..... 82.6%
massage therapy ..... 26.1%
family education ..... 82.6%
24/7 on-call nursing support ..... 82.6%
chaplaincy ..... 39.1%
child life specialists ..... 30.4%
social work ..... 82.6%
other ..... 43.5%

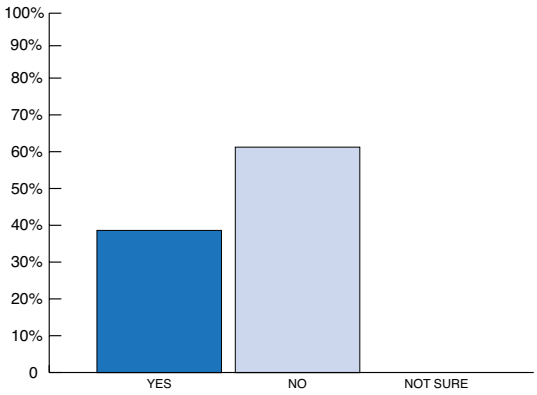
# County Snapshot: San Diego

## What type of provider are you?

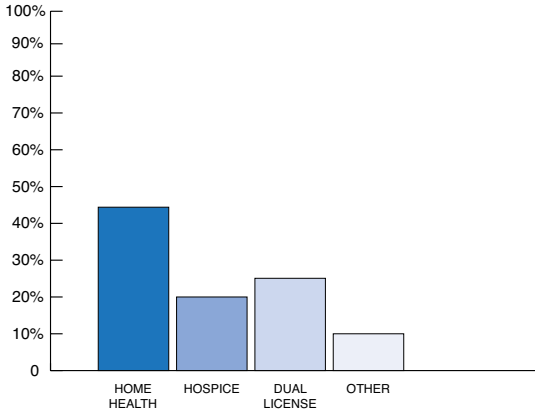
| | | |
|---|---|---|
| Home Health | 25 | 49.0% |
| Hospice | 14 | 27.5% |
| Dual License | 8 | 15.7% |
| Other | 4 | 7.8% |
| Total Responses | 51 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 9 | 4 | 5 | 2 | 20 | 39.2% |
| No | 16 | 10 | 3 | 2 | 31 | 60.8% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0.0% |
| Total Responses | 25 | 14 | 8 | 4 | 51 | 100% |

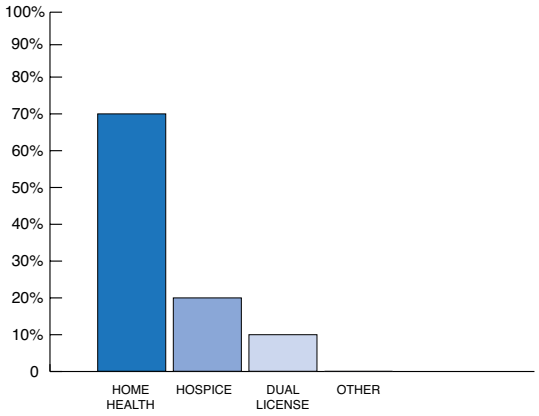
## Which of the following pediatric services does your agency provide?

| | | | |
|---|---|---|---|
| registered nursing | 90.0% | massage therapy | 20.0% |
| care coordination | 80.0% | family education | 75.0% |
| family counseling | 45.0% | 24/7 on-call nursing support | 75.0% |
| bereavement/anticipatory grief support | 40.0% | chaplaincy | 30.0% |
| art therapy | 25.0% | child life specialists | 10.0% |
| play therapy | 30.0% | social work | 75.0% |
| respite | 80.0% | other | 35.0% |

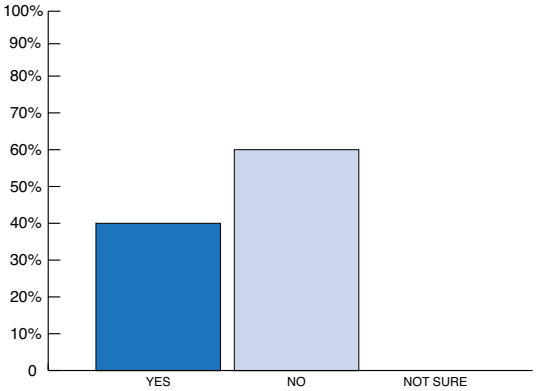
# County Snapshot: Santa Cruz

## What type of provider are you?

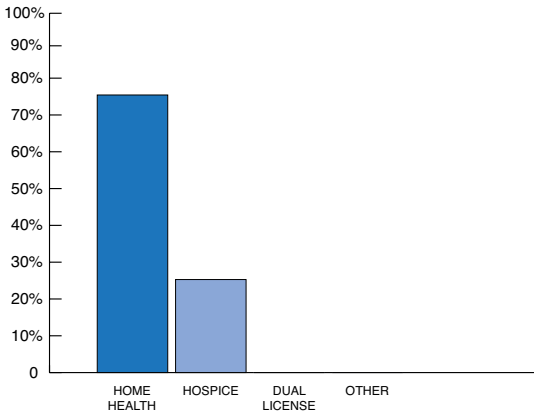
| | | |
|---|---|---|
| Home Health | 7 | 70.0% |
| Hospice | 2 | 20.0% |
| Dual License | 1 | 10.0% |
| Other | 0 | 0.0% |
| Total Responses | 10 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 3 | 1 | 0 | 0 | 4 | 40.0% |
| No | 4 | 1 | 1 | 0 | 6 | 60.0% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0.0% |
| Total Responses | 7 | 2 | 1 | 0 | 10 | 100% |

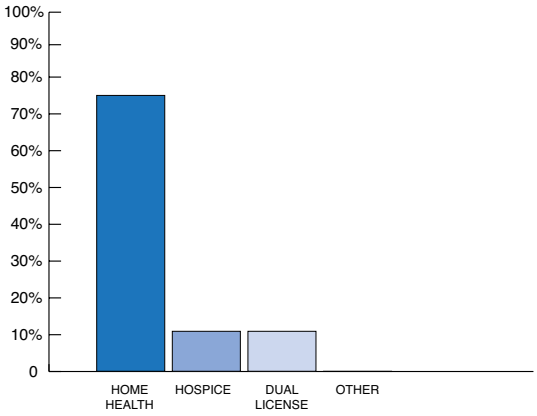
## Which of the following pediatric services does your agency provide?

registered nursing ..... 75.0%
care coordination ..... 75.0%
family counseling ..... 50.0%
bereavement/anticipatory grief support ..... 50.0%
art therapy ..... 25.0%
play therapy ..... 25.0%
respite ..... 50.0%
massage therapy ..... 50.0%
family education ..... 75.0%
24/7 on-call nursing support ..... 75.0%
chaplaincy ..... 50.0%
child life specialists ..... 0.0%
social work ..... 75.0%
other ..... 100.0%

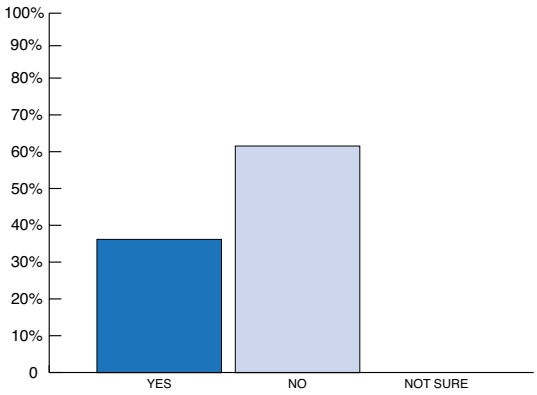
# County Snapshot: Monterey

## What type of provider are you?

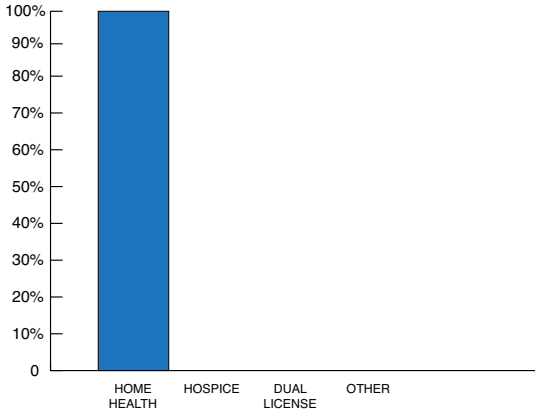
| | | |
|---|---|---|
| Home Health | 6 | 75.0% |
| Hospice | 1 | 12.5% |
| Dual License | 1 | 12.5% |
| Other | 0 | 0.0% |
| Total Responses | 8 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 3 | 0 | 0 | 0 | 3 | 37.5% |
| No | 3 | 1 | 1 | 0 | 5 | 62.5% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0.0% |
| Total Responses | 6 | 1 | 1 | 0 | 8 | 100% |

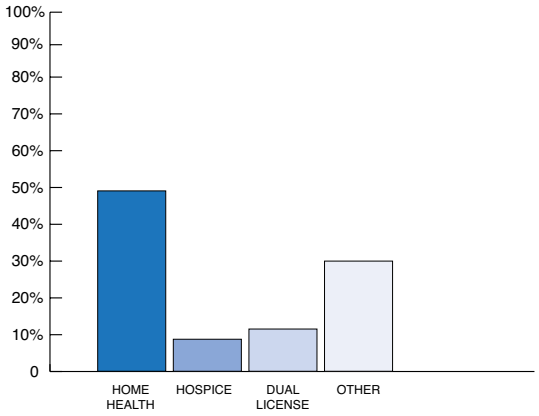
## Which of the following pediatric services does your agency provide?

| | | | |
|---|---|---|---|
| registered nursing | 66.7% | massage therapy | 33.3% |
| care coordination | 66.7% | family education | 66.7% |
| family counseling | 33.3% | 24/7 on-call nursing support | 66.7% |
| bereavement/anticipatory grief support | 33.3% | chaplaincy | 33.3% |
| art therapy | 33.3% | child life specialists | 0.0% |
| play therapy | 33.3% | social work | 67.7% |
| respite | 33.3% | other | 100.0% |

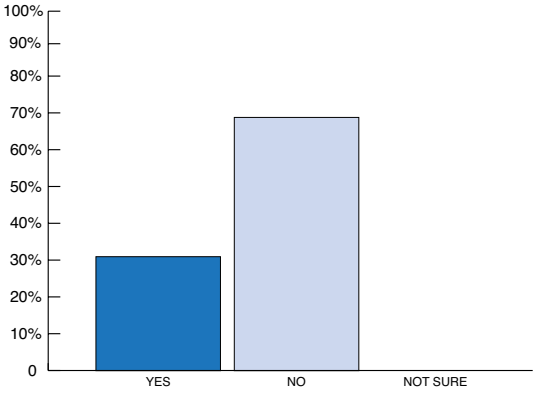
# County Snapshot: Santa Clara

## What type of provider are you?

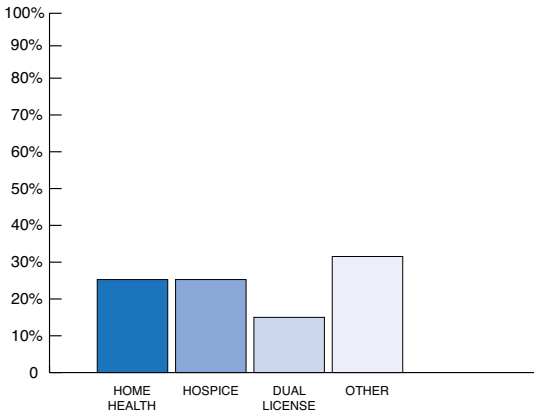
| | | |
|---|---|---|
| Home Health | 18 | 48.6% |
| Hospice | 3 | 8.1% |
| Dual License | 5 | 13.5% |
| Other | 11 | 29.7% |
| Total Responses | 37 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 3 | 3 | 2 | 4 | 12 | 32.4% |
| No | 15 | 0 | 3 | 7 | 25 | 67.6% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0.0% |
| Total Responses | 18 | 3 | 5 | 11 | 37 | 100% |

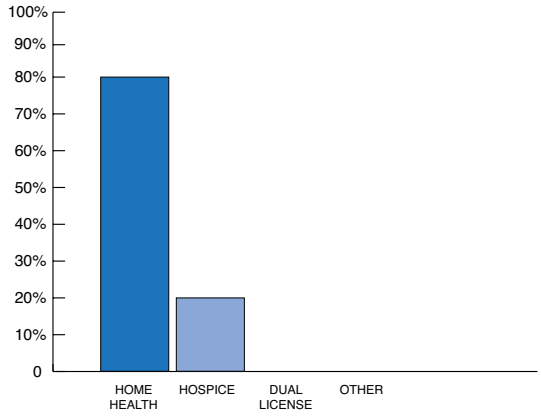
## Which of the following pediatric services does your agency provide?

registered nursing ..... 58.3%
care coordination ..... 56.3%
family counseling ..... 50.0%
bereavement/anticipatory grief support ..... 66.7%
art therapy ..... 41.7%
play therapy ..... 41.7%
respite ..... 41.7%
massage therapy ..... 25.0%
family education ..... 58.3%
24/7 on-call nursing support ..... 58.3%
chaplaincy ..... 50.0%
child life specialists ..... 8.3%
social work ..... 58.3%
other ..... 58.3%

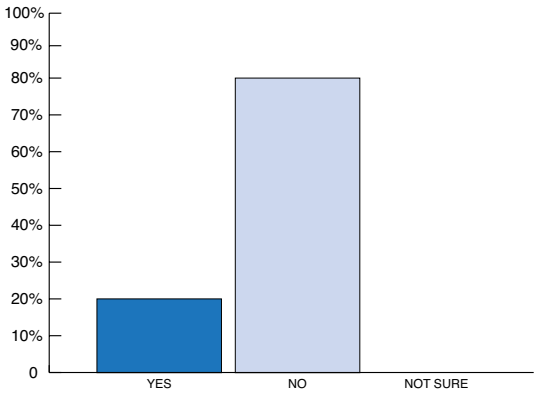
# County Snapshot: Fresno

## What type of provider are you?

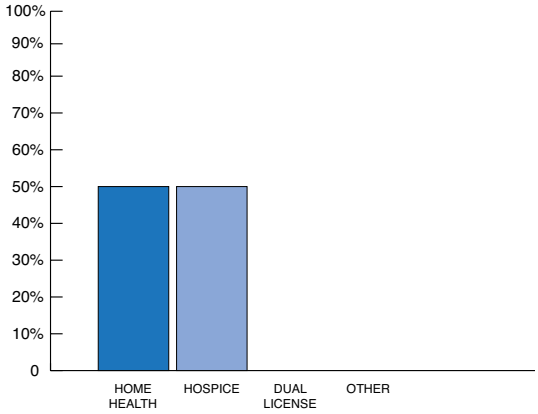
| | | |
|---|---|---|
| Home Health | 8 | 80.0% |
| Hospice | 2 | 20.0% |
| Dual License | 0 | 0.0% |
| Other | 0 | 0.0% |
| Total Responses | 10 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 1 | 1 | 0 | 0 | 2 | 20.0% |
| No | 7 | 1 | 0 | 0 | 8 | 80.0% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0.0% |
| Total Responses | 8 | 2 | 0 | 0 | 10 | 100% |

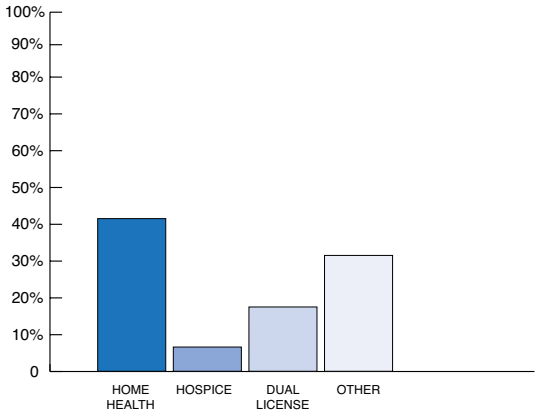
## Which of the following pediatric services does your agency provide?

| | | | |
|---|---|---|---|
| registered nursing | 100.0% | massage therapy | 50.0% |
| care coordination | 100.0% | family education | 100.0% |
| family counseling | 50.0% | 24/7 on-call nursing support | 100.0% |
| bereavement/anticipatory grief support | 50.0% | chaplaincy | 50.0% |
| art therapy | 0.0% | child life specialists | 0.0% |
| play therapy | 0.0% | social work | 100.0% |
| respite | 50.0% | other | 50.0% |

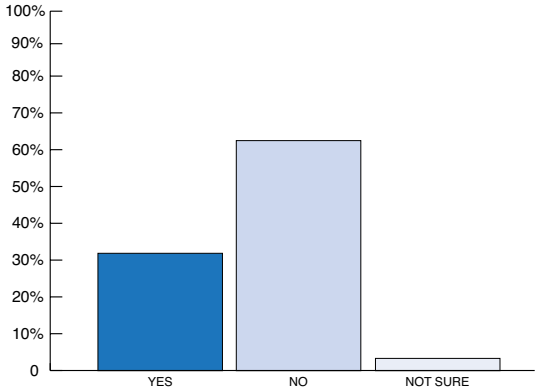
# County Snapshot: San Franscisco

## What type of provider are you?

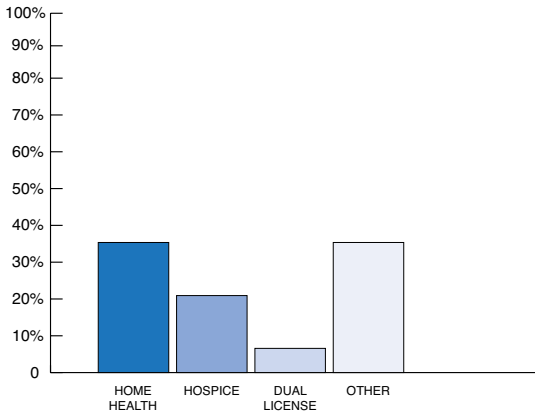
| | | |
|---|---|---|
| Home Health | 18 | 42.9% |
| Hospice | 3 | 7.1% |
| Dual License | 7 | 16.7% |
| Other | 14 | 33.3% |
| Total Responses | 42 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 5 | 3 | 1 | 5 | 14 | 33.3% |
| No | 13 | 0 | 5 | 9 | 27 | 64.3% |
| Not Sure | 0 | 0 | 1 | 0 | 1 | 2.4% |
| Total Responses | 18 | 3 | 7 | 14 | 42 | 100% |

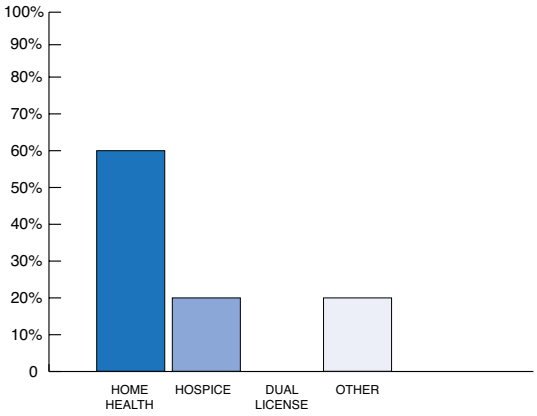
## Which of the following pediatric services does your agency provide?

registered nursing ..... 64.3%
care coordination ..... 78.6%
family counseling ..... 57.1%
bereavement/anticipatory grief support ..... 57.1%
art therapy ..... 50.0%
play therapy ..... 50.0%
respite ..... 42.9%
massage therapy ..... 35.7%
family education ..... 64.3%
24/7 on-call nursing support ..... 64.3%
chaplaincy ..... 50.0%
child life specialists ..... 35.7%
social work ..... 64.3%
other ..... 35.7%

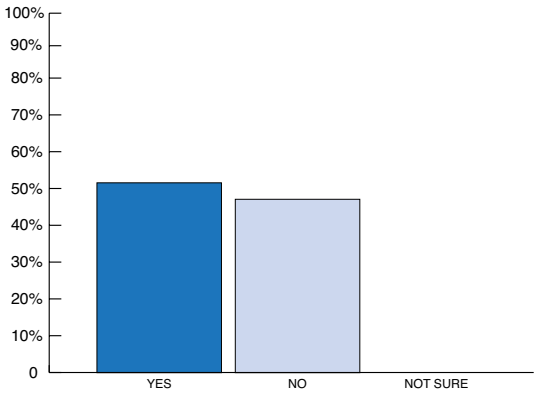
# County Snapshot: Sonoma

## What type of provider are you?

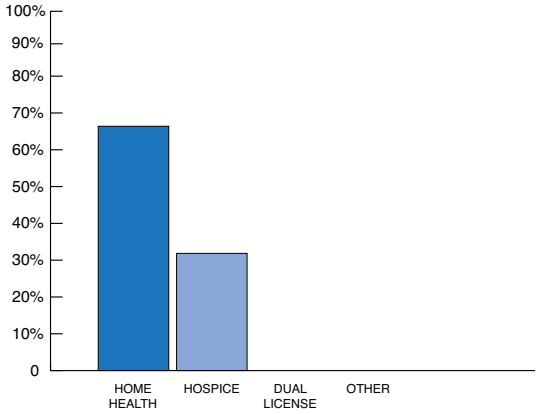
| | | |
|---|---|---|
| Home Health | 9 | 60.0% |
| Hospice | 3 | 20.0% |
| Dual License | 0 | 0.0% |
| Other | 3 | 20.0% |
| Total Responses | 15 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 4 | 2 | 0 | 2 | 8 | 53.3% |
| No | 5 | 1 | 0 | 1 | 7 | 46.7% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 0.0% |
| Total Responses | 9 | 3 | 0 | 3 | 15 | 100% |

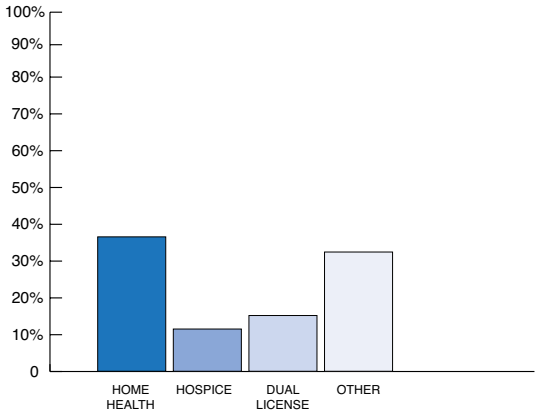
## Which of the following pediatric services does your agency provide?

registered nursing ..... 75.0%
care coordination ..... 87.5%
family counseling ..... 87.5%
bereavement/anticipatory grief support ..... 62.5%
art therapy ..... 50.0%
play therapy ..... 62.5%
respite ..... 62.5%
massage therapy ..... 25.0%
family education ..... 100.0%
24/7 on-call nursing support ..... 75.0%
chaplaincy ..... 50.0%
child life specialists ..... 50.0%
social work ..... 100.0%
other ..... 25.0%

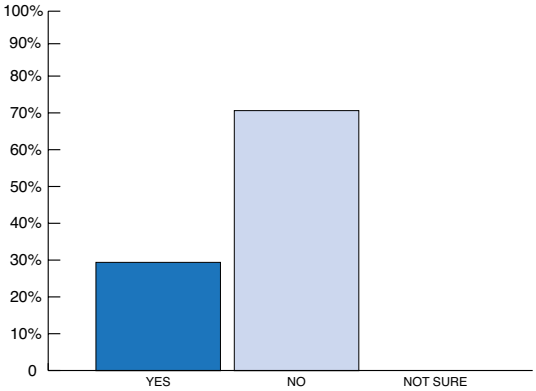
# County Snapshot: Marin

## What type of provider are you?

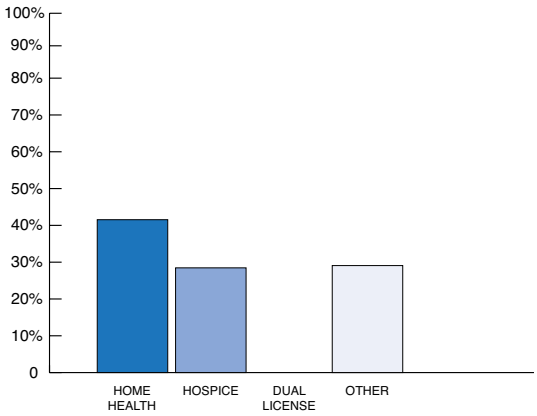
| | | |
|---|---|---|
| Home Health | 9 | 37.5% |
| Hospice | 3 | 12.5% |
| Dual License | 4 | 16.7% |
| Other | 8 | 33.3% |
| Total Responses | 24 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 3 | 2 | 0 | 2 | 7 | 29.2% |
| No | 6 | 1 | 4 | 6 | 17 | 70.8% |
| Not Sure | 0 | 0 | 0 | 0 | 0 | 00% |
| Total Responses | 9 | 3 | 4 | 8 | 24 | 100% |

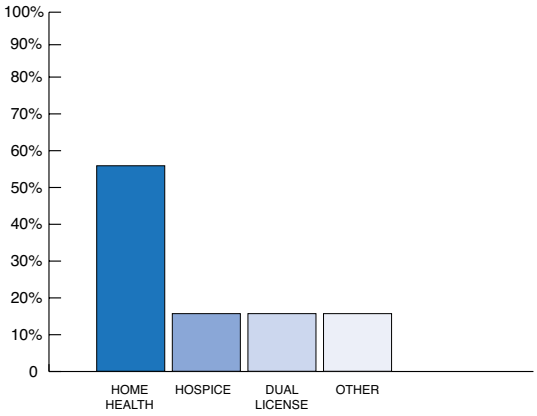
## Which of the following pediatric services does your agency provide?

registered nursing..... 71.4%
care coordination..... 85.7%
family counseling..... 85.7%
bereavement/anticipatory grief support..... 71.4%
art therapy..... 57.1%
play therapy..... 71.4%
respite..... 57.1%
massage therapy..... 28.6%
family education..... 85.7%
24/7 on-call nursing support..... 71.4%
chaplaincy..... 57.1%
child life specialists..... 57.1%
social work..... 85.7%
other..... 28.6%

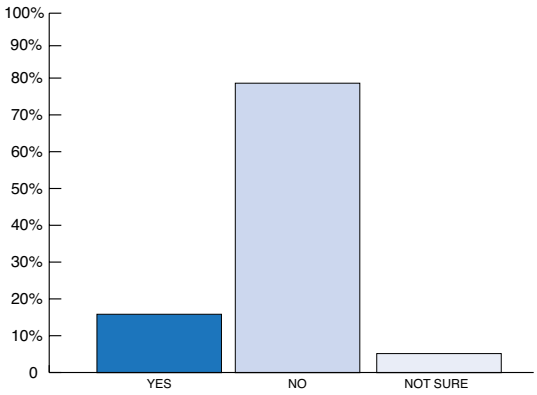
# County Snapshot: Alameda

## What type of provider are you?

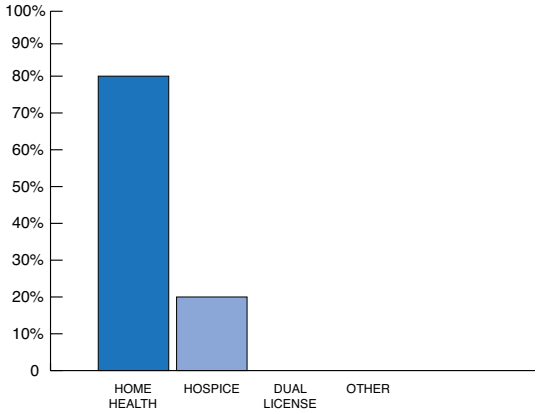
| | | |
|---|---|---|
| Home Health | 19 | 55.9% |
| Hospice | 5 | 14.7% |
| Dual License | 5 | 14.7% |
| Other | 5 | 14.7% |
| Total Responses | 34 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 4 | 1 | 0 | 0 | 5 | 14.7% |
| No | 15 | 3 | 4 | 5 | 27 | 79.4% |
| Not Sure | 0 | 1 | 1 | 0 | 2 | 5.9% |
| Total Responses | 19 | 5 | 5 | 5 | 34 | 100% |

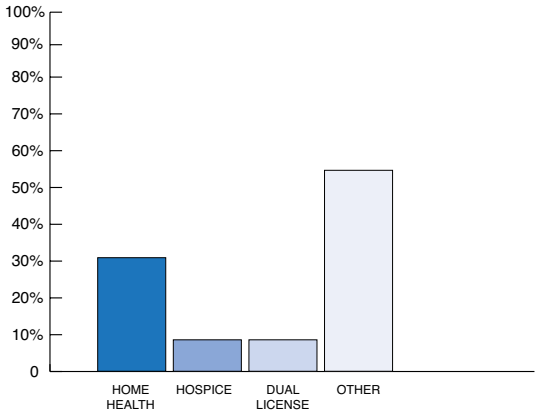
## Which of the following pediatric services does your agency provide?

| | |
|---|---|
| registered nursing | 80.0% |
| care coordination | 80.0% |
| family counseling | 0.0% |
| bereavement/anticipatory grief support | 20.0% |
| art therapy | 0.0% |
| play therapy | 0.0% |
| respite | 20.0% |
| massage therapy | 20.0% |
| family education | 60.0% |
| 24/7 on-call nursing support | 80.0% |
| chaplaincy | 20.0% |
| child life specialists | 0.0% |
| social work | 60.0% |
| other | 40.0% |

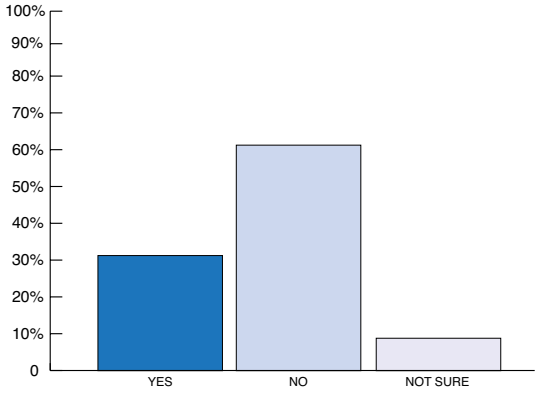
# County Snapshot: Humboldt

## What type of provider are you?

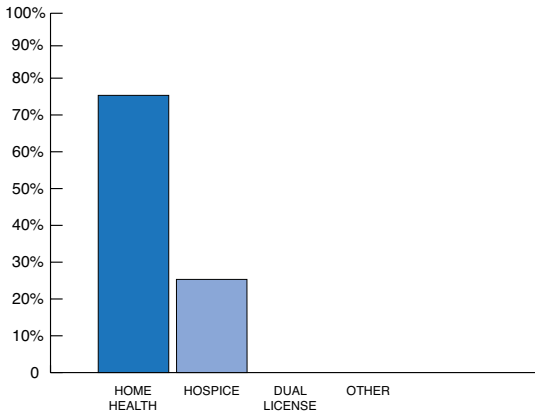
| | | |
|---|---|---|
| Home Health | 4 | 30.8% |
| Hospice | 1 | 7.7% |
| Dual License | 1 | 7.7% |
| Other | 7 | 53.8% |
| Total Responses | 13 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 3 | 1 | 0 | 0 | 4 | 30.8% |
| No | 1 | 0 | 0 | 7 | 8 | 61.5% |
| Not Sure | 0 | 0 | 1 | 0 | 1 | 7.7% |
| Total Responses | 4 | 1 | 1 | 7 | 13 | 100% |

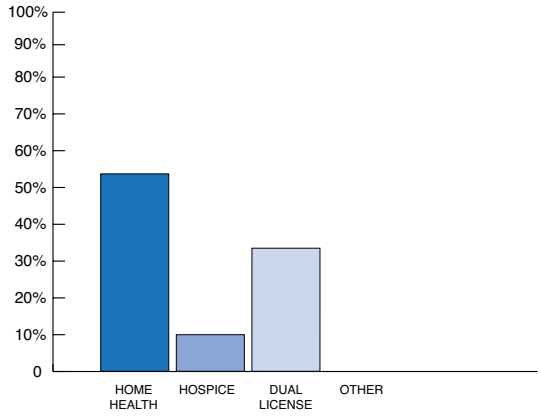
## Which of the following pediatric services does your agency provide?

| | |
|---|---|
| registered nursing | 50.0% |
| care coordination | 50.0% |
| family counseling | 50.0% |
| bereavement/anticipatory grief support | 50.0% |
| art therapy | 25.0% |
| play therapy | 25.0% |
| respite | 25.0% |
| massage therapy | 25.0% |
| family education | 75.0% |
| 24/7 on-call nursing support | 50.0% |
| chaplaincy | 50.0% |
| child life specialists | 0.0% |
| social work | 75.0% |
| other | 0.0% |

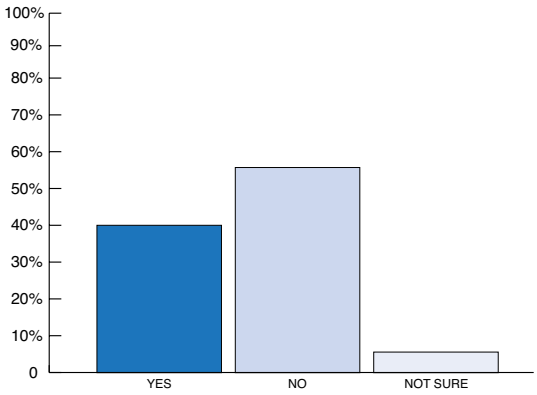
# County Snapshot: Sacramento

## What type of provider are you?

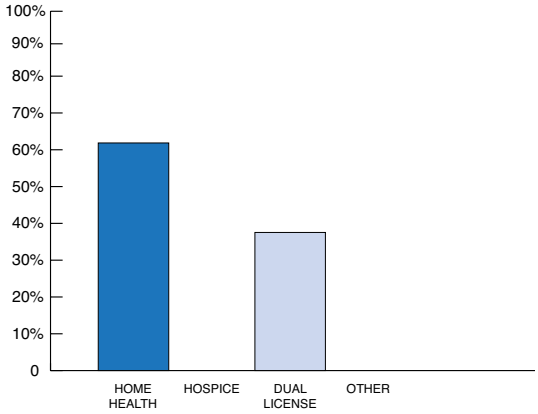
| | | |
|---|---|---|
| Home Health | 11 | 55.0% |
| Hospice | 2 | 10.0% |
| Dual License | 7 | 35.0% |
| Other | 0 | 0.0% |
| Total Responses | 20 | 100.0% |




## Do you provide palliative and/or hospice services for children?




## Provider composition of "Yes" responders.




| | Home Health | Hospice | Dual License | Other | Total | |
|---|---|---|---|---|---|---|
| Yes | 5 | 0 | 3 | 0 | 8 | 40.0% |
| No | 6 | 2 | 3 | 0 | 11 | 55.0% |
| Not Sure | 0 | 0 | 1 | 0 | 1 | 5.0% |
| Total Responses | 11 | 2 | 7 | 1 | 20 | 100% |

## Which of the following pediatric services does your agency provide?

registered nursing ..... 75.0%
care coordination ..... 87.5%
family counseling ..... 50.0%
bereavement/anticipatory grief support ..... 37.5%
art therapy ..... 12.5%
play therapy ..... 12.5%
respite ..... 37.5%
massage therapy ..... 25.0%
family education ..... 87.5%
24/7 on-call nursing support ..... 87.5%
chaplaincy ..... 37.5%
child life specialists ..... 12.5%
social work ..... 87.5%
other ..... 37.5%

# Medi-Cal Benefit Heroes

In its infancy, the new Benefit found welcoming arms among California's meager population of pediatric palliative care providers. These organizations declared a resounding "Yes" when initially queried by DHCS three years ago and they continue to honor their commitment as providers under the Benefit.

In order to understand the underlying institutional values which govern these successful forerunners, PACE conducted one-on-one interviews with executive staff from several of these key agencies. In their own words, compassionate leaders share their organizational and personal commitment to caring for children.

## **MARGY MAYFIELD,** RN, Administrator Coastal Kids Home Care, Salinas, CA

**Organizational mission:**

***Coastal Kids Home Care provides specialized pediatric medical, therapeutic and social services to any child living with a medical condition, in Monterey, Santa Cruz and San Benito Counties. Our services improve the quality of life for children and families during medical illness and provide support and education throughout treatment and rehabilitation from illness, as well as palliative care through a terminal diagnosis of children under the age of 21 years.***

### *Is there an underlying rationale that drives your organization's philosophy of care?*

I've experienced the difference between living and working in an urban area with a children's hospital in close proximity, and then living in a rural area where a tertiary care facility is hours and hours away. The quality of life that a pediatric home care agency can bring to families that are so far away from their specialty doctors is incredible. That's what drives me to keep Coastal Kids running. Here, the need is so unbelievably great. Something had to be done.

### *How has caring for children made a difference in your life and work?*

Caring for children affects every aspect of my life. I love children. I love that children just want to feel good enough to play again. They don't like being sick. They don't "poor me." They just say, "Fix me so I can be better." And in the midst of horrible surgeries and unimaginable pain, children find a way to smile, to be innocent, and lovely.

### *How do you manage the fiscal challenges of caring for children?*

At Coastal Kids, we earn enough to support the nurses' salaries and we keep administrative costs to a minimum. Pediatrics cannot share the burden of a large organizational overhead and be financially successful. Pediatrics needs to be structured as its own program, and we need to seek the philanthropic dollars to fill the gap when needed. Let's be honest, sick children pull heartstrings. But the real reason we care for them has nothing to do with dollars and cents. It's the right thing to do.

### *How does the Benefit impact this challenge?*

I am really seeing where the Benefit is leading to significant cost savings. Persistent negotiation with CCS is resulting in reimbursement of care coordination time, some administrative hours, and for grief and sibling support in special cases. This opens the door for my staff to think more creatively and assertively about how we manage and bill for our time, while making sure our families are getting as much support as we can give them. In the bigger picture,

we are definitely keeping a lot of kids out of the emergency room, the ICU, and just out of the hospital in general. That's really what this is about. Saving dollars and providing care that is much more appropriate, timely, and less stress on the children and their parents.

### *What was your organization's impetus for joining the Medi-Cal Benefit program?*

I don't believe that most people even know that there is no hospice agency in Monterey County willing or able to care for children. This is a real problem. Once you care for a terminal child, you realize the lack of services that are available for a pediatric patient versus an adult patient. The fact that children don't fit into the adult hospice model doesn't mean they should be left out. It's just so wrong. In this day and age, it just shouldn't be happening…children should not be excluded. There needs to be something else for them. An ICU death is not what we want for our children. I've seen the ripple effect of that experience on families and it's brutal. From day one, it was my goal to be a pilot site, because I believe we have a moral and ethical obligation to change this.

### *Is it working?*

I love what is happening with the Medi-Cal Benefit here on the Central Coast. We are now providing services like pain and symptom management and expressive therapies. Our partners are willing to do this work because they also agree that this is treatment our children need. It's just the right way to take care of a child with a serious illness.

We have found collaborating partners in this community who I never thought we could find to support families. And then to watch and hear about the response of the families receiving these services, of having a care coordinator, and having nurses come to them on a regular basis…they are just blown away.

My disappointment is that we are not able to enroll all of our children in the Benefit right now. We are having some challenges with the state relative to understanding diagnosis. We've had five kids die since we became a functioning pilot site and not one of them has been approved for the Benefit. The enrollment criteria are much too strict.

However, the families we have been able to help are overwhelmingly appreciative. They have children who have been living with devastating neurological conditions for a long time. The kids are older, 15, 18 years of age, and their parents have been their sole caretakers. They are completely amazed by the difference that consistent support is making. That is the beauty and the tragedy of it…they've had to go without for so long.

### *What would you say to a provider who is considering joining the program?*

There is a calling to take care of an adult and there is a calling to take care of a child. I truly believe that. I think you can take care of a lot of children with one or two pediatric nurses. You don't have to have pediatric supervisors or medical directors. Pediatric nurses know how to take care of children…that's what they've devoted their lives to. Just like the program at St. Joseph's Hospital in Marin County, they have one part-time supervisor and one nurse and they take care of a lot of kids. In home care, you can see a lot of children with one, maybe two nurses. It's not great, but it's a start. I think that people need to get brave and add a pediatric nurse onto their staff, even if the position is part-time to begin with.

The reality of what it takes to do a pediatric visit also needs to be taken under consideration. Our visits are longer because we are dealing with the entire family unit, and the distractions of multi-sibling households. The majority of our patients are low-income, Medi-Cal families. We spend a lot of time educating and resource finding for our families. Plus, in rural locations, there's a great deal more travel time. If you go into it with your eyes open, the challenges can be managed.

I really appreciate the adult programs that are considering participation in the Benefit. Marin County, for one. They have a philosophy that says they need to take care of all the people in their community. It doesn't matter if they are young or old. As an organization, they are stepping up and saying, "What can we do?" It's scary to do that. But their leadership understands this isn't a way to make money. It is about serving people.

**TERRI WARREN, MSW**
**Executive Director**
**Providence TrinityCare Hospice, Torrance, CA**

**Organizational mission:**

***We compassionately enter the lives of individuals faced with the realities of suffering, loss, death and grief, to offer expert care and education, while respecting each person's choices, values and beliefs.***

***Is there an underlying rationale that drives your organization's philosophy of care?***

As a mission-based not-for-profit hospice provider, we are fully committed to providing the highest quality end-of-life care to all in our community who need it and choose it. It would actually go against our philosophy in a very material way to not provide care to children. Our opportunity has been to try to figure out a way to operationalize and fund the availability and access to that care, but our philosophy as an organization is inclusive of all in our community.

***How do you manage the fiscal challenges of caring for children?***

We carefully manage revenue and expenses across all of our service and ensure children receive the right care at the right time. We put a lot of effort into philanthropy and raising funds specifically for pediatrics. We apply that same commitment to managing those dollars really carefully. This is critically important because they go very, very quickly. And they go much more easily than they come in.

We need to engage our community in understanding what the needs of these children are. Our job is to tell the story about why our pediatric program is important, whom our service touches, and how they benefit from it. We have an obligation to work with the health care funders and commercial payers, and to continue to advocate for financial resources.

***How does the Benefit impact this challenge?***

Administratively we are working to define the 'break even' point, where the number of children we have on service, and the efficiencies we are able to put into place through our service delivery, will significantly minimize the funding gap. We don't have that formula yet, but I do believe it exists.

***How has caring for children made a difference in your life and work?***

I have absolutely been touched in the past, and currently am, by patients and their families who are on our service at any given time. What they are faced with and living through are truly circumstances that I as a parent find hard to even imagine.

I am personally very passionate about services for children, particularly for children that are seriously ill. And I am committed to making sure that we as an organization provide that service in a really meaningful way. Having the appropriate staff in place is key. The skill set of the clinicians involved with caring for children and their families is really one that is more specific than even the best adult hospice clinicians would provide.

Psychosocially, I believe that a highly competent social worker can bridge the needs of adult and pediatric patients well, but their level of experience and comfort with children really determines if they can be effective at their job.

On the medical side, there is a very clear distinction. Putting an IV into a neonate is dramatically different than doing the same procedure with a 75-year-old. Medical interventions vary dramatically, and dosing for pain and symptom management is extremely different in a sizeable percentage of the children who come onto our service.

From a physician's specialty, pediatrics stands out as well. If I'm having a heart issue, I'm going to go to a cardiologist. I'm not going to go to an oncologist, even though we also consider them a doctor. Pediatric palliative care and hospice fall into that same category. On the nursing end, the gap is a little wider. Not every adult nurse has handled a brain shunt before. There are lots of interventions in pediatric palliative care that don't translate into the adult population on a regular basis, if ever.

### *What was your organization's impetus for joining the Medi-Cal Benefit program?*

Joining the program was an easier decision for TrinityKids Care than for some other organizations because we already had a fairly well established pediatric hospice program. Our clinical team was in place and functioning very effectively. Right from the beginning, our clinicians were very enthusiastic about broadening the scope of our service provision. Organizationally and financially, we went into this with our eyes wide open. At the same time, we did our due diligence and evaluated what funding we could expect as a result of the Benefit and how much of a cash cushion we would need in order to bring children onto our service through this program.

### *Is it working?*

One very positive aspect of the waiver is that all of the organizations involved believe that the program has true value for the families. Providers are getting very creative and partnering to make it work. We at Trinity are fortunate to have the support of San Diego Hospice. They started their service delivery in the first year and they've been really wonderful about candidly sharing their experience with us since our organization is slotted for year two. We've also mutually benefited from dialoguing specific pediatric issues. They ask, "If this were you, what would you do?" It's a positive exchange on both ends. The collaborative development of this program is very refreshing to see. It doesn't happen much anymore.

### *What would you say to a provider who is considering joining the program?*

First and foremost, think through the kind of organizational commitment you are making. Because if your organization's primary motivation is to bring cash in the door very quickly, your service isn't going to do well in the long run. But if you think you really want to get into pediatric palliative care and are going to commit to developing the skills to do it, the more you collaborate with programs already providing this care, the quicker you will be able to get up and get running effectively.

Honestly, it comes down to one critical success factor—you need at least one person in your organization that is going to be committed, who is going to be the cheerleader and the center of building the program.

**JAN WYSS, RN, Program Manager**
**San Diego Hospice and**
**The Institute for Palliative**
**Medicine, San Diego, CA**

**Organizational mission:**

***To prevent and relieve suffering and promote quality of life, at every stage of life, through patient and family care, education, research and advocacy.***

***Is there an underlying rationale that drives your organization's philosophy of care?***

Our mission, *"To prevent and relieve suffering and promote quality of life, at every stage of life, through patient and family care, education, research and advocacy,"* reflects our commitment to provide the highest quality of care for adults and children.

When the new Medi-Cal Benefit Program, Partners for Children, came up, we were very excited about the possibility to participate, as it closely aligned with our mission and expertise. As a not-for-profit organization, promoting quality of life at every stage of life is at the core of our mission and drives our philosophy of care that always asks the question "What is the right thing to do?" Many of the innovative programs at San Diego Hospice and The Institute for Palliative Medicine were created based on the needs of our community. And we are fortunate and grateful for the support from the community that help make these vital programs a reality, such as The Ellen Browning Scripps Foundation and The Billingsley Foundation which support our Partners for Children Program.

***How do you manage the fiscal challenges of caring for children?***

As a not-for-profit organization, we understand the importance of being fiscally responsible in operating our programs. My hiring practices are such that I acquire the most qualified candidates. My team understands and reviews operational practices to ensure we are providing quality care, while allowing our staff to find innovative ways in meeting our program goals. Our budget is well managed and monitored, forecasting the program's needs and being fiscally responsible for all costs involved in the program. Again, we cannot underscore the importance of community and donor support and we are extremely fortunate to be recognized as a trusted resource in our community to garner the incredible support we continue to receive, so that we can provide vital programs like Partners for Children.

***How does the Benefit impact this challenge?***

The Benefit has made a positive impact overall, regarding the fiscal challenges of caring for children. Prior to the Benefit, some children who were in need of hospice care and symptom management were unable to qualify for hospice because doing so meant that they would lose other vital home-based services, such as shift nursing, We are committed to caring for children in need, regardless of the family's ability to pay, so often the services we provided were not reimbursed. The main financial impact we have seen is that under the Benefit we are now being reimbursed for providing care for some children who are in need of hospice care but don't currently meet the hospice criteria of having likely less than six months to live or who would lose other vital home-based services, such as shift nursing, if they were to enroll in hospice. In this way, Partners for Children benefits the families we serve as well as our hospice agency. Ultimately, if children can receive the best, most appropriate care for their health care needs, without emergency room and/or ICU visits, it's not only a fiscal benefit, but also an ideal situation for a child and family to receive the best care possible in familiar surroundings.

***Can you tell me a story about a family being served under the Benefit?***

One of the families we are now serving has seven biological children of their own, and has since adopted nine additional children. These people don't just foster kids, they foster fragile kids that have no family ties. That makes it possible for these children to eventually become an adoptive member of their family.

When our art therapist goes out to visit, they've had almost 20 people involved between staff, kids, and parents. It's pretty awesome because the expressive therapies are supportive for all the kids in the family. We're going to provide music therapy on a one-time experimental basis soon.

In addition, they receive care coordination services. We accompany the child to appointments, monitor their care, and provide support to their parents and siblings. This family loves it…absolutely loves it.

### *How has caring for children made a difference in your life and work?*

Taking care of these kids and these families feels really, really good. It gives me a lot more energy, truthfully. It fills my well. We all need to find work in areas that feed us. We need to feel that we are making a difference in the lives of others. This work does that for me.

### *What was your organization's impetus for joining the Medi-Cal Benefit program?*

The decision to move forward with the program was examined very carefully by our management team. As a not-for-profit agency, we understand that programs such as this will not break even in the budget process as it currently stands. Moreover, understanding the economic barriers that our nation has experienced, particularly in health care, we understood the challenges of taking on a new program. Ultimately, it goes back to our mission and in meeting the needs of our community; in this case, in meeting the needs of children in our community who need our help. So that's what we are doing.

We started admitting kids in February of this year. The Benefit program itself started in October; however, state guidelines for the program were not finalized until January. Within a month of receiving the guidelines, we were operational.

### *Is it working?*

Yes, it is working. There are a few challenges that I see but they're all paperwork and administrative issues. It's not the program itself that's the challenge. To be honest, it is a joy to work on this project. I can see what an incredible difference it is making in the lives of the children and their families that we care for. I'm so happy to be a part of it.

## Recommendations

Children's Hospice and Palliative Care Coalition has developed the following recommendations through the analysis of PACE data. These assertions take into consideration the state budget crisis and its impact on the Medi-Cal Benefit and additional potential barriers to the successful implementation of the program in pilot counties. CHPCC has also identified areas for further exploration that are essential to the goal of increasing access to pediatric palliative and hospice care for vulnerable children in California.

1. Focus outreach and educational efforts on Medi-Cal Benefit pilot counties that demonstrate the greatest opportunity for successful implementation. Pilot counties selected for this 'premier' status fulfill the following requirements:
    a) participation of a CCS county office;
    b) high CCS/Medi-Cal population density;
    c) critical mass of existing or potential hospice and/or home health provider base willing or able to care for children;
    d) access to pediatric staff; and,
    e) willingness to collaborate.

2. With consideration for the fact that reimbursement structures under Medi-Cal are more advantageous for agencies that function with a home health or dual hospice/home health licensure, prioritize working with DHCS to augment billing codes under the Benefit to include pain and symptom management, therefore, ensuring efficacy and equal opportunity among the provider pool.

3. Increase access to pediatric palliative education among the provider base in premier pilot counties, while also increasing availability to this learning statewide. Lack of pediatric palliative care knowledge among clinicians was the singular most popular rationale for providers who responded negatively to caring for children. This presents a clear opportunity, not only to bolster the pediatric training of stakeholders in the premier territories but also to fill a knowledge gap that marginalizes children statewide.

4. One hundred percent of the providers currently delivering services under the Medi-Cal Benefit in year-one are not-for-profit entities who have relied on some portion of philanthropic funding to underwrite the unreimbursed costs associated with the program. These agencies have cited the moral obligation of providing care to children as a necessary extension, or in fulfillment of, their mission-based philosophy. Understanding that the care of pediatric patients who are chronically ill requires an ethical and financial commitment, CHPCC suggests that escalated engagement with the not-for-profit sector in premier counties as a key strategy moving forward.

5. Through continued advocacy, seek to ensure state and federal funding for the CCS nurse liaison position, specifically in the designated premier counties. With state budget cuts threatening to minimize funding for this staffing, it is essential that CHPCC encourage sustainability for all pilot locations. Challenges of reduced funding can possibly be mitigated by redirecting resources to premier locations if need be. In addition, explore options for operationalizing the program within CCS regardless of whether funding is available for the CCS nurse liaison position.

6. Continue fundamental support to year-one Medi-Cal Benefit pilot counties such as Monterey, Santa Cruz, and San Diego. Streamline communication systems with providers and ensure data compliance and evaluative protocols remain in place. Continue to collect anecdotal data from these functioning pilot counties, with further exploration needed to ascertain the soft benefits of the concurrent care approach.

7. Pursue alteration of the Benefit's medical eligibility criteria with the goal of expanding support to all CCS children enrolled as full-scope Medi-Cal who are living with life-threatening conditions. While this may be considered an expansive goal, it is important to consider the pediatric waiver programs in Washington and Florida; programs that boast an open enrollment and that do not employ rigid eligibility guidelines. During the development phase of the Benefit, it was originally determined that restrictive eligibility criteria was necessary to prohibit the program from being overrun with cases of chronic, but not necessarily life-threatening illness. However, as enrollment has progressed, it has become clear that children and families for whom Benefit services were intended, are being rejected; a fundamental flaw in the implementation process that must be addressed.

8. Promote collaboration among pilot site providers as an effective strategy for bundling Benefit services. Utilize the Monterey County pilot as a successful example of how collaboration can yield improved service delivery and ease the financial burden of providing community-based pediatric palliative care.

## Issues for Further Exploration

***Cost Neutrality.*** Explore financial models that demonstrate the Benefit's efficacy in both the for-profit and not-for-profit sectors. Take into consideration the impact of reimbursement structures as they relate to each unique provider type.

***Pediatric Expertise.*** The lack of pediatric expertise has been identified as a significant barrier to sustaining, expanding, and/or establishing a pediatric program. Further research should be considered as a means for exploring the actual levels of pediatric expertise present in the pilot counties and the underlying reasons behind this shortage such as lack of interest or opportunity.

***Philosophical Barrier.*** Explore the philosophical notion that home health agencies are not 'qualified' to provide pediatric palliative care.  Conduct research to understand whether there is any material evidence to support this claim.

***Reimbursement Opportunity.*** In order to augment opportunities for the reimbursement of pediatric home-based services, explore strategies for engaging commercial payers.

## Sampling Method

The primary aim of PACE was to create a comprehensive "snapshot" of what the situation is like on the ground in the 13 pilot counties. CHPCC set out to perform an extensive electronic and phone survey of all providers in these regions. The initial sampling frame was based on the 2009 California Office of Statewide Health Planning and Development utilization report, an official government document that lists all legitimate hospice and home health providers in the state. The roster was augmented with web-based provider research conducted by CHPCC for each of the counties and surrounding territories.

Every provider named in the roster was contacted by telephone individually, and responses were gathered from senior level staff, if possible. Unfortunately, a great number of providers were unable to participate or, at times, refused to cooperate entirely. Overall, 486 surveys were completed, 43% of the initial provider population segment. Given the short time frame for completing PACE, and the challenges inherent in conducting phone-based outreach to a broad contingent of health care professionals, CHPCC firmly believes that the final sample is as representative as humanly possible of the general population of interest.

## Survey Development

The survey was designed in collaboration with Betty Ferrell, Ph.D., FAAN, City of Hope Professor, Nursing Research and Education. Its overall structure can be viewed in Appendix 1. In general, the survey branches into two different tracks depending on whether or not the agency in question cares for children. If the agency does not care for pediatric patients, the respondent is asked to rank their willingness and current ability to expand services to children on a six-point scale. They also are queried regarding institutional requirements for extending care to children.

For those agencies that do serve pediatric patients, the respondents are asked numerous detailed questions, such as: what type of services are provided, the number of qualified pediatric nurses on staff, current capacity, if and why they have declined children, the percentage of children currently covered under Medi-Cal, and others. Regardless of whether the agency cares for children, all respondents are asked if they refer pediatric patients to other agencies and for what services, and are ranked by CHPCC in terms of overall likelihood for future participation in the pilot program.

The survey is designed to be both quantitative and qualitative. For example, each area of the survey form that allows for multiple choices also allows for open-ended responses to help supplement the information provided. Furthermore, the survey also includes a "comments" section which was completed by CHPCC's researchers and was used specifically to capture additional information, such as poignant quotes or testimonials.

Survey data was tabulated in Excel and results were re-segmented to reflect global and county-level results. Taking into consideration that many of the organizations surveyed extend their service delivery beyond their county of residence, county-level statistics were tabulated based on the number of facilities that reported serving a county regardless of their origin.

Lisa Simonson Maiuro, MSPH, PhD, Researcher, Health Management Associates, facilitated the capture of PACE data in pivot tables, and provided evaluative support.

# Children's Hospice and Palliative Care Coalition: PACE Survey

**Two separate survey tracks were prompted based upon provider's response to question #2, "Does your agency provide palliative and/or hospice services to children?"**

## Survey Track for Respondents who answered **YES** to Question #2

Contact Name*
Title
Organization
Phone
Email*

To ensure accurate results please answer all questions in the order given.

1. *Are you
- ☐ Home health & hospice
- ☐ Home health
- ☐ Hospice
- ☐ Other

2. *Does your agency provide palliative and/or hospice services for children?
- ☑ Yes
- ☐ No
- ☐ Not sure

3. *Did you decline a child in 2009?
- ☐ Yes
- ☐ No
- ☐ Not sure

If answer to #3 is Yes, these additional answers are requested:

3.a How many children did you decline in 2009?

3.b Why did your organization decline a child? (Please check all that apply.)
- ☐ Agency at capacity
- ☐ Childs lack of medical coverage
- ☐ Child had medical coverage but reimbursement insufficient
- ☐ Lack of pediatric clinical expertise in staff
- ☐ Staff uncomfortable caring for a child
- ☐ Lack of weekend or night coverage with pediatric expertise
- ☐ Lack of a medical director/MD with pediatric expertise
- ☐ Other (explain)

4. How many children do you estimate your agency served last year?

5. How interested is your agency in increasing the number of children they serve?

0 1 2 3 4 5
Not at all Very Interested

6. How many adults do you estimate your agency served last year?

7. How many nurses on your team have 3 years or more of pediatric experience?

8. How many nurses do you have?

9. How many social workers on your team have 3 years or more of pediatric experience?

10. How many social workers do you have?

11. Are any of the children your agency served full-scope Medi-Cal?
- ☐ Yes
- ☐ No
- ☐ Not sure

If answer to #11 is Yes, this additional answer is requested:

11.a What percentage of the children your agency care for are full-scope Medi-Cal?

12. Which of the following pediatric services does your agency provide? (please check all that apply)
- ☐ registered nursing
- ☐ care coordination (defined as coordination of services across clinical settings)
- ☐ family counseling
- ☐ bereavement including anticipatory grief support
- ☐ art therapy
- ☐ play therapy
- ☐ respite
- ☐ massage therapy
- ☐ family education
- ☐ 24/7 on-call nursing support
- ☐ chaplaincy
- ☐ child life specialists
- ☐ social work
- ☐ Other (explain)

13. Does your agency work collaboratively with any other community-based agencies to provide care for children?
- ☐ Yes
- ☐ No
- ☐ Not sure

If answer to #13 is Yes, these additional answers are requested:

13.a Which of the following pediatric services do your collaborating partners provide? (please check all that apply)
- ☐ registered nursing
- ☐ care coordination (defined as coordination of services across clinical settings)
- ☐ family counseling
- ☐ bereavement including anticipatory grief support
- ☐ art therapy
- ☐ play therapy
- ☐ child life
- ☐ respite
- ☐ massage therapy
- ☐ family education
- ☐ 24/7 on-call nursing support
- ☐ chaplaincy
- ☐ child life specialists
- ☐ social work
- ☐ Other (explain)

13.b Will you share with us the names of the collaborating agencies and the primary contacts?

13.c Please include Organization's Name, Primary Contact & Phone Number

What county(s) does your agency serve?*

*Are you a not-for-profit agency?

Respondee's potential for future participation ?

0 1 2 3 4 5
not able to participate eager to participate

Comments

# Children's Hospice and Palliative Care Coalition: PACE Survey

**Two separate survey tracks were prompted based upon provider's response to question #2, "Does your agency provide palliative and/or hospice services to children?"**

## Survey Track for Respondents who answered **NO** to Question #2

Contact Name*

Title

Organization

Phone

Email*

To ensure accurate results please answer all questions in the order given.

1. *Are you
- ☐ Home health & hospice
- ☐ Home health
- ☐ Hospice
- ☐ Other

2. *Does your agency provide palliative and/or hospice services for children?
- ☐ Yes
- ☑ No
- ☐ Not sure

3. *Did you decline a child in 2009?
- ☐ Yes
- ☐ No
- ☐ Not sure

If answer to #3 is Yes, these additional answers are requested:

3.a How many children did you decline in 2009?

3.b Why did your organization decline a child? (Please check all that apply.)
- ☐ Agency at capacity
- ☐ Childs lack of medical coverage
- ☐ Child had medical coverage but reimbursement insufficient
- ☐ Lack of pediatric clinical expertise in staff
- ☐ Staff uncomfortable caring for a child
- ☐ Lack of weekend or night coverage with pediatric expertise
- ☐ Lack of a medical director/MD with pediatric expertise
- ☐ Other (explain)

4. How interested is your agency in expanding services to children?

0 1 2 3 4 5

Not at all — Very Interested

5. What do you estimate is your agency's ability to expand services to children?

0 1 2 3 4 5

Not able — Very Capable

6. What systems/tools would need to be in place in order for your organization to care for children? (Please check all that apply.)
- ☐ Staff education
- ☐ Pediatric medical consultants
- ☐ Pediatric protocols
- ☐ Higher level of reimbursement
- ☐ Support from agency administration
- ☐ Support from Board of Directors
- ☐ Other (explain)

7. Do you refer children to another agency in your community?

If yes, what is the name of the agency?

What county(s) does your agency serve?*

*Are you a not-for-profit agency?

Respondee's potential for future participation ?

0 1 2 3 4 5

not able to participate — eager to participate

Comments

# Definitions

**Medi-Cal Pediatric Palliative Care Benefit** – California demonstration project for children with life-threatening conditions who have full-scope Medi-Cal. Facilitated through a 1915(c) Home and Community-based waiver, the project enables medically-eligible children to receive home-based palliative care services concurrent with curative and/or life-prolonging treatment. Benefit services include care coordination, expressive therapies (art, music, massage and play), family education and training on palliative care issues, respite care and support counseling including bereavement if needed. The objective of the Benefit is to improve the quality of life for the child and family and aid in the reduction of unnecessary hospitalizations, medical transports and emergency room visits. The project does not require children to meet current hospice eligibility criteria. Launched in October of 2009, the project, entitled Partners for Children, will be piloted in a maximum of 13 California counties through April 2012.

**Palliative Care** – The medical specialty focused on improving overall quality of life for patients and families facing serious illness. Emphasis is placed on communication that clarifies the disease process, pain and symptom management, and coordination of care. Palliative care may be offered at any time during an individual's illness from diagnosis throughout treatment and can be provided in tandem with curative treatment.

**The Nick Snow Children's Hospice and Palliative Care Act of 2006/Assembly Bill 1745** – legislative bill requiring the California Department of Health Care Services to submit a federal waiver that allows children with life-threatening conditions to receive concurrent curative treatment and community-based palliative care. The Children's Medical Services Branch (CMS) worked in collaboration Children's Hospice and Palliative Care Coalition and other stakeholders to develop the waiver. It was approved in December of 2008 and implemented in October of 2009.

**Care Coordination** – fundamental, ongoing component of an effective system of care for children with life-threatening conditions and their families. Care coordination engages families in the development of a care plan and links them to health and other services that address the full range of their needs and concerns across settings.

**Eligible Medical Conditions** – one qualifying provision for the Medi-Cal Pediatric Palliative Care Benefit is that children meet certain medical requirements. Eligible conditions include cancer, cystic fibrosis, brain or head injuries, leukodystrophies, and disorders of the musculoskeletal system and connective tissues.

**CCS Nurse Liaison** – staff position housed within the county CCS office charged with administrative case management for Benefit participants. The nurse liaison is responsible for identifying and enrolling eligible children, evaluating needs and authorizing all state plan and waiver services, and tracking all services provided.

# Acronyms

CHCF – California HealthCare Foundation
CHPCC – Children's Hospice and Palliative Care Coalition
CCS – California Children's Services
DHCS – Department of Health Care Services
DNR – Do not resuscitate
LTC – Life-threatening conditions
PACE – Palliative Assessment and Capacity Evaluation

CHILDREN'S HOSPICE
AND PALLIATIVE CARE COALITION

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