

# Riding *the* Waiver

## California's Medi-Cal Benefit Keeping Families Afloat

BY STEPHANIE STEPHENS

California's Medi-Cal Pediatric Palliative Care Benefit, also known as "the waiver," is surging ahead, transforming the lives of families that previously faced insurmountable challenges in caring for children with life-threatening conditions.

Thanks to the waiver, Partners for Children was launched in October 2009 and will continue through April 2012. It is a comprehensive, federally approved demonstration project with 13 pilot counties originally designated as implementation sites.

Supporters anticipate a five-year renewal. The California Department of Health Care Services (DHCS) submitted an application to the Centers for Medicare and Medicaid Services in January of 2012.

No interruption of service is expected.

Partners for Children allows children age 20 or younger, who qualify for full-scope Medi-Cal benefits, to receive home-based palliative care in addition to curative and/or life-prolonging

treatment regardless of their life expectancy. Parents no longer are forced to make the impossible choice between comfort and cure for a seriously ill child.

Referrals can come from a child's primary care physician, hospital medical team, California Children's Services (CCS) nurse liaison, or the family itself. Once a child is determined eligible and enrolled, the CCS nurse liaison helps the family choose a community-based hospice or home health provider. The provider's care coordinator then develops a comprehensive care plan, and arranges for services through a team of local specialists. Proponents say that such a plan rightfully addresses more than physiological issues, and considers the "whole person": physical, spiritual, emotional, and social needs, as well.

Partners for Children services include medical care coordination with an interdisciplinary team approach: pain and symptom management; 24/7 on-call nursing support; expressive





therapies like art, music, massage and play; respite; training on palliative care issues; plus support counseling—all under one very “beneficial” umbrella.

From a fiscal perspective, initial data suggests that Partners for Children saves significant dollars, with some estimates as high as \$4,000 per month, per child, in crisis-driven healthcare costs. While it will be at least another year before a thorough financial analysis is available, a preliminary review is expected by June 2012.

“It makes things go a lot smoother, and helps us all be happier and healthier. I don’t know what I would do without it,” says single mother of three, Gina Barnett of El Cajon. Her 16-year-old son, Tyler Leone, was diagnosed with spinal muscular atrophy Type II at six months. The disease causes progressive muscular degeneration and weakness.

Through the program, a nurse comes to the house, and when requested, accompanies Tyler to doctor’s appointments, “writing everything down, and asking the right questions when I can’t because I’m nervous or frustrated,” says Gina. A social worker is also available to advocate for Tyler at school, making sure that any issues are addressed in a timely

manner and his educational needs are met.

Tyler is prone to pneumonia, a constant threat, and regular nursing visits help to identify and address symptoms early before a full-blown infection develops. Twice weekly, at-home massage therapy helps the wheelchair-using high achiever sleep better, says Gina. “It’s wonderful. He’s not getting sick so much.” There’s art therapy for Tyler’s siblings and a psychotherapist available so the family can assuage their tangled emotions.

“We’re all living this,” Gina says. “It’s good to have a second ear.”

Early data indicates that utilization of the program services reduces hospitalizations and length of stay, emergency transport, and exhausting emergency room visits—all costly, both financially and emotionally.

“Tyler always gets better at home, where I have all the necessary equipment,” his mom says.

### Moving Forward Amid Cutbacks

“Partners for Children has made a big difference in the lives of families,” says Devon Dabbs, co-founder and executive director of Children’s Hospice and Palliative Care Coalition (CHPCC), acknowledged as the *force majeure*

behind the passing of the waiver.

“CHPCC is made up of a lot of strong-willed, yet compassionate individuals. This organization has forever changed the way children receive healthcare in California,” says Leslie Adams, former pediatric palliative care program coordinator for Trinity KidsCare Hospice, the only dedicated pediatric hospice service in Los Angeles and Orange counties.

Despite the number of lives it has improved, establishing Partners for Children in the current topsy-turvy economic climate has proven to be more challenging than expected. “The number of enrollees is growing weekly, sometimes daily, but we’re not moving forward at the pace we would like,” admits Dabbs.

Partners for Children would really be “on a roll” supporters say, if the economic stars were

Though slated to roll out in 13 counties, eight counties are engaged in “various levels of activity,” says Dabbs, citing detrimental provider attrition due to circumstances beyond their control.

Los Angeles, San Diego, Monterey, Santa Cruz, Orange, Sonoma, Fresno and portions of Santa Clara counties are currently enrolling and caring for children. Alameda remains off line due to lack of a provider, as does Humboldt, San Francisco and Marin. The Sacramento CCS office has declined to participate.

Current enrollment in the majority of participating counties is below 10. Notable exceptions include San Diego County, which was on track to enroll more than 50 children in 2012 even with paperwork and administrative obstacles. Dabbs calls it, “Our most robust pilot site.” Los Angeles County, which launched

### ELIGIBLE DIAGNOSES

- Neoplasms
- Immune
- Cardiac
- GI
- Pulmonary
- Renal

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For more detailed information on diagnoses, see page 39

aligned differently, and hadn’t impacted an already marginalized system.

At the launch of the Partners for Children pilot project, organizers estimated that more than 7,000 CCS Medi-Cal children living in pilot counties would benefit from the services, according to Dabbs. Instead the program has serviced 65 children since its inception—six have died and three were discharged.

The current economy has forced many hospices and home health agencies to cut back on pediatric programs or shut their doors entirely. “Fewer agencies are providing community-based palliative care for children,” says Dabbs regretfully.

in October 2011, is quickly gaining ground with more than 50 children identified as eligible candidates for the program.

“We have a lot of eligible kids and we’re the only pilot provider in San Diego and the first in California,” says Jan Wyss, program manager for San Diego Hospice and the Institute for Palliative Medicine. “We were already participating with the AIDS medical waiver program, and we have a big children’s hospice program. Our physicians and social workers underwent a lot of education. We were ready.”

Families see the program as their safety net, Wyss says. “They really depend on it and upon the support of staff, and they are tak-

ing advantage of therapies offered.”

One can always dream. “It would be nice if Medi-Cal could pay more to provide these vital services for children in need,” says Wyss, adding that only limited provisions exist to pay the hospice’s medical team, including her and her colleagues.

“Our organization provides services at a loss. Any small hospice would struggle to do this. Fortunately, our community supports our hospice,” she says. At San Diego Hospice, 75 percent of funds come from insurance and Medicare/Medi-Cal payments, while the rest is donated.

At Hospice of the Valley, located in San Jose, president and CEO Sally Adelus, a fervent supporter of the Partners for Children pilot program, acknowledges, “The challenge hospices have in general is that they’re now operating in an environment of change and turmoil, in a very different landscape. Reimbursement cuts, increased government scrutiny, regulatory changes, and the advent of healthcare reform have changed the landscape radically.

For example, hospices must report on quality measures in 2012 and it is predicted that a complete overhaul of the hospice Medicare payment system will be implemented as early as 2013—the hospice benefit was enacted in 1982.

Presently, hospices are reimbursed on a daily rate, no matter how long a patient is on service. The new system, Adelus predicts, will likely alter that structure.

“Potentially, hospices may get higher reimbursement when a patient is admitted, but as the stay gets longer, the payment will decline,” she says.

In a reactive mode, hospices are starting to consolidate programs, “With any disruption, at first you tend to have a reaction of tightening down, less risk-taking,” says Adelus.

## California’s Partners for Children Stacks up Against Affordable Care Act Provision 2302

Provision 2302 of the Affordable Care Act (ACA) allows hospices to care for children who have six months or less to live, as determined by a physician and parent, but who still choose to pursue potentially curative treatment.

By contrast, children enrolled in California’s Partners for Children, funded by the Medi-Cal Pediatric Palliative Care Benefit, need not meet the six-month provision. Thus far, a survey of enrollees confirms that none would be eligible for concurrent care under Provision 2302.

“We’re identifying children earlier in treatment,” says Dabbs. “It’s the ultimate in pediatric palliative care to address the needs of children as close to diagnosis as possible.”

With the federal provision on the books, more agencies may be forced into building a pediatric program to provide for children who are hospice eligible. That bodes well for the “still recruiting” Partners for Children, says Dabbs, who calls the two programs “complementary.”

### Two sides of the same coin? Not really. A nuts and bolts comparison reveals benefits and inequities.

	ACA Provision 2302	California’s Partners for Children
<b>What are the geographic limitations?</b>	Nationwide, in theory. Only a handful of states are authorizing concurrent care services and nearly half of the 50 states have filed lawsuits claiming the ACA is unconstitutional	Eight California counties including: Santa Cruz, Monterey, Fresno, Santa Clara, Sonoma, Orange, Los Angeles, and San Diego
<b>How many children can enroll?</b>	Unlimited	Maximum of 1,802 in total (calculated on a revolving basis)
<b>Is there a life expectancy requirement?</b>	Fewer than six months (must meet federal hospice requirements)	No life expectancy requirements
<b>How is eligibility defined?</b>	Must be under 21 years of age and eligible for Medicaid	<ul style="list-style-type: none"> <li>■ Must be under 21 years of age and receive “full-scope” no cost Medi-Cal (California’s Medicaid)</li> <li>■ Reside in a participating county</li> <li>■ Be diagnosed with an eligible medical condition (see page 39 for eligible diagnoses)</li> <li>■ At risk for hospitalization unless able to access home-based medical care</li> </ul>
<b>Where can care be accessed?</b>	Licensed hospices only	California state approved Partners for Children home health or hospice providers
<b>Who will provide the hands-on care?</b>	An interdisciplinary hospice team including a physician, nurse, social worker, chaplain, home health aide, and trained volunteer	Nurse, social worker, expressive therapists and other medical consultants as needed
<b>What services are available?</b>	Comprehensive hospice care provided in-home or in a community-based setting, including case management, 24/7 on-call nursing, pain and symptom management, psychosocial support, personal care, spiritual care, pre- and post-death bereavement support, practical assistance, and respite	Palliative care services provided in home and in community-based setting including: care coordination, 24/7 on-call nursing, pain and symptom management, expressive therapies (including art, music, and massage), family education, pre- and post-death bereavement support, and respite <i>*Personal care is under consideration for inclusion in 2012.</i>

Continued on page 39

## WHAT'S IN THE BAG?

### Delicious Mix:

- ✓ ChiPPS Newsletter
- ✓ Virtual Courses
- ✓ Toolkit



ChiPPS, a pediatric-focused subset of the National Hospice and Palliative Care Organization (NHPCO), is serving up practical strategies that advance care for children and families coping with life-threatening conditions, dying and bereavement. Educational offerings include a bi-monthly free electronic newsletter, and a Pediatric Palliative Care Online Training Series, which offers 10 online educational modules written by leading pediatric palliative/hospice care experts across the country and is available through NHPCO's E-Online.

In response to the Affordable Care Act's new Provision 2302, NHPCO published *The Concurrent Care for Children Implementation Toolkit*, which details options for states interested in putting 2302 into practice.

For information about tools and resources available: [www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics) or 800-646-6460.

## HARVARD TAKES AIM

The Harvard Medical School Program in Palliative Care Education and Practice (PCEP) now includes a special pediatric track, says Joanne Wolfe, MD, MPH, Director of Pediatric Palliative Care at Children's Hospital Boston and one of the curriculum's esteemed authors. "Our program is designed to help interested clinicians fully explore the field of pediatric palliative care through a combination of large group lectures by internationally recognized experts and intensive small group

experiential learning. We are aiming to train clinicians committed to leading efforts to integrate pediatric palliative care into the care of children with serious illness within their institutional settings."

The course is a savvy combination of intensive learning and project-based application that meets core competencies. Upcoming Dates: April 17-24 and November 7-13, 2012.

Learn more at: [www.hms.harvard.edu/pallcare](http://www.hms.harvard.edu/pallcare) or 866-408-3324 •

# Grandfather Clause All the Rage at CAPC

## *The Clock is Ticking on Physician Certification in Palliative Care*

It's no rumor. After 2012, any physician interested in becoming board certified in palliative care will have to complete an Accreditation Council for Graduate Medical Education (ACGME) fellowship training program. 2012 is the last year when physicians with adequate clinical experience in the field can be "grandfathered" into board eligibility. Dr. Diane Meier, Director of The Center to Advance Palliative Care (CAPC), a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness, says the workforce issue is considerable. "There's a huge demand for palliative care physicians but only about 100 fellowship slots available every year. Physicians working in the field who want to take the boards without doing fellowship training should apply now for the 2012 exam." According to Dr. Meier, the challenge is even greater for pediatrics as there are only three ACGME-accredited pediatric fellowship training programs available in the U.S. today. "Pediatricians working in palliative care are scarce but the demand for their skills is growing rapidly." As the nation's leading resource for palliative care program development, CAPC offers comprehensive training for palliative care



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programs at every stage—from strategic planning and funding to operations and sustainability. CAPC provides seminars, audio conferences, tools, reference materials, and a robust website. Last fall, CAPC's annual conference included a pediatric track for the first time, and the move appears permanent. Palliative Care Leadership Centers™ (PCLC), established by CAPC, now provide intensive operational training and year-long mentoring for programs at every stage of development and growth. Akron Children's Hospital and Children's Hospitals and Clinics of Minnesota offer the PCLC pediatrics curriculum. 2012 training dates for pediatric palliative care programs are now available at [www.capc.org/pclc](http://www.capc.org/pclc) or for more information call 210-201-2673. •