



PALLIATIVE CARE FOR CHILDREN

Report to:

**Senate Appropriations Committee
Senate Health and Welfare Committee
House Appropriations Committee
House Human Services Committee**

**Office of Vermont Health Access
Agency of Human Services**

November 16, 2009

Executive Summary

Act 25 (H.435), passed by the Vermont legislature in 2009, requires the Agency of Human Services to submit a report to the House Appropriations and Human Services Committees and the Senate Appropriations and Health and Welfare Committees on the programmatic and cost implications of a Medicaid and State Children's Health Insurance Program (SCHIP) waiver amendment allowing Vermont to provide concurrent palliative and curative care to Medicaid- and SCHIP-eligible children who have life-limiting illnesses. The full text of Section 7 of Act 25 is included as Attachment 1.

The Office of Vermont Health Access (OVHA), which is submitting this report on behalf of the Agency, estimates that Vermont could provide additional palliative care services to 29 to 170 Medicaid children with life-limiting illnesses for a cost of between \$160,000 and \$1 million per year in state funds. Based on the number of children served in other states' palliative care programs, the cost would likely be closer to \$160,000 than to \$1 million.

Introduction

Over the last decade there has been growing concern that children with life-limiting illnesses do not always receive the care they need to alleviate physical and psychosocial pain. Under Centers for Medicare and Medicaid (CMS) rules, hospice services, which were originally designed for adults, are available to children only if they have a life expectancy of six months or less and their parents agree to forego any potentially curative treatments. Children and their families often need hospice-like services at an earlier stage of their illness, and many parents are reluctant to terminate curative treatments. Nationally, child health organizations, providers, and advocates are attempting to define a pediatric palliative care model that will enhance the quality of life for both the terminally ill child and the family.

Palliative vs. Curative Care

Hospice is a model of care that focuses on relieving symptoms and supporting patients with a life expectancy of six months or less. Medicare and Medicaid pay for hospice services for children, but federal regulations allow hospice services to be reimbursed only when there is an expectation that the patient will die within the next six months, and only if the child's parents have signed a statement agreeing to forego further curative treatment. Typically adults with a terminal illness experience a precipitous decline just before the end of life, whereas many children with life-limiting illnesses experience a gradual but inevitable decline, thus making it very difficult, if not impossible, to determine whether they are within six months of death.

Palliative care is patient- and family-centered care that seeks to enhance quality of life by providing treatments that focus on the relief of symptoms, such as pain, and conditions, such as loneliness or fear, that cause distress and detract from the child's quality of life. It also seeks to ensure that bereaved families are able to remain functional and intact.

Curative care is intended to eliminate the disease and promote recovery or prolong the life of the patient. However, the term "curative care" is not accurate for many children with severe malignancies or developmental or genetic diseases where survival to adulthood is often unlikely. The continuation of disease-modifying efforts for children with life-limiting diseases is usually life-prolonging rather than curative and may, in fact, provide palliative care rather than curative treatment. In adults, the election of hospice accompanies the medical decision that further disease-treating efforts will not substantially alter the natural course of the disease. In children, the continuation of disease-treating efforts may be seen as providing the child and family with additional improved quality of life.

Services currently available to Medicaid and SCHIP children in Vermont

"Dr. Dynasaur" is the name that most Vermonters recognize as Vermont's Medicaid and SCHIP program. Dr. Dynasaur children currently have access to many types of curative and palliative care services, such as

- physician visits
- inpatient and outpatient care
- medications for pain and symptom control
- medical equipment and supplies
- rehabilitative therapies (PT, OT, speech, inhalation)
- counseling and group therapy
- nurse practitioner services
- home health services, and
- personal care services.

Children also have access to hospice services. However, federal Medicare and Medicaid regulations require that children's life expectancy be six months or less in order to qualify for hospice services. The parents of the child must sign a statement that waives all other Medicaid services, except the services of a designated family physician, ambulance service, and services unrelated to the terminal illness. Hospice services are reimbursed on a per diem basis and are available for a maximum of 210 days.

Additional services under a waiver amendment

If Vermont requested an amendment to its Global Commitment waiver, and the amendment was approved by the Centers for Medicare and Medicaid (CMS), to allow concurrent curative and palliative care for children, children with life-limiting illnesses would be eligible to receive some services that they can receive now only if they are in hospice.

These services could include:

- care coordination
- respite care for the child's parents or caregivers
- expressive therapies such as art, music, and play therapies
- training for family members on palliative care principles and care needs, and bereavement counseling for family members.

These additional services could be provided to a child and the child's family as needed, subject to defined limits, for the duration of the child's illness.

There are many other services that families of terminally ill children need that cannot, unfortunately, be provided using Medicaid funds. Based on information received by OVHA from families and community organizations supporting families, these services could include:

- home adaptations and cleaning
- heating and air conditioning
- help with mortgage/rent and utilities
- vehicle repairs
- acupuncture and massage therapy
- help with funeral expenses, and
- travel expenses for families whose children are being treated away from their home community.

OVHA wishes to recognize and commend the excellent work community organizations and private foundations are doing to meet families' needs in these areas in spite of limited resources.

Waiver amendment process

The Social Security Act authorizes multiple waiver and demonstration authorities to allow states flexibility in operating Medicaid programs. Each authority has a distinct purpose, and distinct requirements.

Section 1115 Research & Demonstration Projects: This section provides the Secretary of Health and Human Services broad authority to approve projects that test policy innovations likely to further the objectives of the Medicaid program.

Section 1915(b) Managed Care/Freedom of Choice Waivers: This section provides the Secretary authority to grant waivers that allow states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid.

Section 1915(c) Home and Community-Based Services Waivers: This section provides the Secretary authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings.

Vermont is unique among states in its Section 1115 Global Commitment waiver that encompasses most Medicaid services offered in the state. After consultation with CMS central office staff in Baltimore, OVHA concluded that, were a decision made to move forward on a palliative care program, Vermont would most likely request an amendment to incorporate a pediatric palliative care program as part of its existing 1115 waiver, rather than request a separate waiver.

However, there is a potential problem with children covered by the federal State Children's Health Insurance Program (SCHIP). In Vermont, these are children on Dr. Dynasaur who have family incomes between 225% and 300 % FPL and who have no private insurance. SCHIP children are not covered by the 1115 Global Commitment waiver; rather, they are covered under the SCHIP state plan. Since there is no waiver authority under SCHIP, and since palliative care is not a state plan service under SCHIP, it is possible that palliative care services to SCHIP children would have to be paid for with state funds. However, if the legislature's decision is to move forward on a waiver amendment request, the administration would work with CMS to determine if there is a way to include SCHIP children in the federally-funded palliative care program. SCHIP children have not been included in other states' palliative care programs, except for Washington's program, which is not operating under a waiver.

There was pending federal legislation that, if passed, would have allowed Vermont to implement a palliative care program without a waiver amendment. H.R. 722, the ChiPACC (Children's program of all-inclusive coordinated care) Act of 2009, aka the "Mattie and Melinda bill," was co-sponsored by Representative James Moran of Virginia and Representative C.W. Young of Florida in January of 2009. It was in the House Energy and Commerce Committee when discussion began on the broader health care reform plan. Section 1632 of the Senate health care reform bill would allow states to provide hospice care to a child without requiring the child to give up rights to services related to treatment of the child's condition. There is no comparable provision in the House bills.

Pediatric palliative care programs in other states

Although there have been numerous pediatric palliative care programs in place for many years as collaborations between children's hospitals and hospice agencies, there are only a few states that have implemented programs utilizing federal Medicaid funds.

The Children's Hospice International Program for All-Inclusive Care for Children and Their Families (CHI PACC®) was developed by Children's Hospice International (CHI) in coordination with the Centers for Medicare and Medicaid (CMS). The CHI PACC® model eliminates the requirement that patients decline further curative treatments and have a prognosis of death within six months.

The U.S. Congress appropriated funds for FY 2000-2003 to enable CHI, through the Department of Health and Human Services, to conduct state demonstration model programs of the CHI PACC® model. Organizations (some of which were private hospitals or hospice associations) in six states were included in the demonstration:

Colorado, Florida, Kentucky, New York, Utah, and Virginia. The intent was that states would apply for a CMS waiver to continue the programs. To date, only Florida and Colorado have applied for waivers.

Below are descriptions of operating programs in states using federal Medicaid funds:

Florida's Partners in Care: Together for Kids

In 2005 Florida amended an existing 1915(b) waiver to create the first publicly financed program in the nation to support concurrent pediatric palliative and curative care. Partners in Care: Together for Kids (PIC) is administered by Florida's Title V program for children with special health needs (CSHN). To be eligible, children must be under age 21 and enrolled in CSHN, have an illness that puts them at risk of death before age 21, and be certified by a nurse case manager. The program began in seven pilot sites, and as of January 2008 there were nine sites serving a total of 468 children. Any hospice program approved by the state may participate if staff completes modules in a nationally-recognized palliative care curriculum within 24 months from start-up. According to a 2008 report produced by the University of Florida's Institute for Child Health Policy, 85% of parents were satisfied with the program.

Colorado's Hopeful Program

Colorado implemented its palliative care program in January of 2008 after approval of its 1915(c) waiver request by CMS in 2007. The Hopeful program, administered by Colorado's Medicaid agency, operates statewide and serves a maximum of 200 children under the age of 19 each year. To participate, children must be Medicaid eligible, have an illness that will result in probable death before adulthood, be at risk of hospitalization within one month, and be certified by a case manager. As of September of 2009 there were 85 children in the program. An additional 24 children were served prior to leaving the program for various reasons, such as death, reaching the age of 19, moving to traditional hospice services, moving to a group home, or moving out of state.

California's Pediatric Palliative Care Program

California's 1915(c) waiver, which was approved in December of 2008, will result in the implementation of pilot programs in five counties in its first year (beginning April 2009) and 11 counties in year two. They are expecting 300 children to be served in the first year and 800 in the second year. To be eligible, children must be from families with income below 100% of the federal poverty level, be under age 21, have been diagnosed with specific life-limiting conditions, be at risk of hospitalization, and certified by a nurse case manager or physician.

Washington State's Pediatric Palliative Care Program

Washington State did not request a waiver, but rather broadly interpreted the federal Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program to include certain palliative care benefits. To be eligible, children must be eligible for Medicaid, under the age of 21, and have a life-limiting medical condition with complex needs that requires case management and coordination of medical services. A limitation of the EPSDT approach is that services are not available to the child's family.

Although not programs that use federal Medicaid funds, a description of other New England programs is included here:

Massachusetts' Pediatric Initiative

Massachusetts' Health Care Reform Law included a pediatric initiative with a one-time appropriation of \$800,000 in state funds to pay for hospice services for children. Grants of \$55,000 each were awarded by the Department of Public Health to 10 hospice agencies for training, development, and implementation of an integrated pediatric palliative care program. The state sees itself as the "payer of last resort." Any costs for services not underwritten by the appropriation or reimbursed by private insurance become the responsibility of the hospice. Children under the age of 19 are eligible if they are determined by a physician to have a life-limiting illness.

Maine's Jason Program

The Jason Program, which began operation in November 2007, operates as a medical practice with an independent physician, full-time nurse and social worker, and part-time child life specialist and spiritual counselor. The program approaches care using a chronic care model along with palliative care. The Jason Program is a private enterprise, but obtained initial funding through Maine Medicaid program grant carved out of state-only funds and a gift from a local philanthropist.

A side-by-side comparison of programs in Colorado, Florida, and California is included as Attachment 2.

Analysis of Vermont Claims Data for Children with Life-limiting Illnesses

OVHA had hoped to obtain cost/savings data from other states that have pediatric palliative care programs already in place. In submitting their waiver requests, Florida, Colorado, and California predicted that new costs for palliative services would be more than offset by savings in acute services. For example, better coordination of treatment and good case management should reduce the number of emergency room visits, shorten hospital stays, or avoid hospital stays by providing services in the child's home. In fact, Colorado's and California's 1915(c) waiver requests are based on the assumption that children eligible for waiver services would be hospitalized were it not for the availability of the services provided under the waiver.

At the time this report was developed, however, there were no cost/savings data available based on actual program experience in these three programs. Because Florida's pediatric palliative care program is only one component of its 1915(b) waiver, it cannot stratify cost/savings data by program. Colorado will begin working on its first evaluative report to CMS later this fall, and California's program has been up and running for only a few months.

There has been some research on the cost savings associated with hospice and palliative care. Some studies have found that hospice care reduced Medicare spending by

significant amounts; however, these studies primarily involved adults who were in their last few months of life and so may or may not have relevance to a pediatric palliative care program that provides services to children at earlier stages of illness.

To analyze the potential costs of pediatric palliative care waiver services in Vermont, OVHA obtained a list from Children’s Hospice International of diagnosis codes for life-limiting illnesses and matched the list against its claims database for the period of SFY 2008 (July 1, 2007, through June 30, 2008). This match revealed 170 children on Medicaid and SCHIP with claims with one or more of these diagnosis codes.

The following chart shows the age and gender of these children:

Children with life-limiting illnesses			
	M	F	Total
Age			
0 to 5	8	7	15
6 to 12	39	25	64
13 to 17	29	16	45
18 to 20	16	13	29
21+ *	11	6	17
Total	103	67	170
*These children were included because they were under 21 on the date of service for the claims included in this analysis.			

Leukemia and other forms of cancer accounted for the majority of the illnesses diagnosed. The following is a chart showing the illnesses diagnosed and the number of children diagnosed with each one:

Diseases and Conditions by Number Of Children	
Disease	Number of children
Leukemia	43
Other cancers	65
Muscular Dystrophy	23
Chronic liver disease	14
Other*	25
Total	170
*Includes cerebral palsy, Werdnig-Hoffmann disease, Patau's Syndrome, congenital heart disease, aplastic anemia, Fragile X Syndrome	

Total Vermont Medicaid expenditures on claims for these 170 children were \$4,551,636.99 for SFY08, a total of 18,968 individual services. Per-child expenditures averaged \$26,774.34; however, per-child expenditures varied widely from a low of \$83.58 to a high of \$355,822.63, with approximately half of the children having claims of less than \$10,000. Forty-three of the 170 children had at least some claims paid by private insurance or Medicare.

The following table shows the number of children in various Medicaid claims expenditure ranges:

Claims Cost Ranges				
Cost range	Number children	Total Amt Paid	% of Children	% of Costs
\$0 to \$1000	17	\$8,247.31	10.00%	0.18%
\$1001 to \$10,000	69	\$302,270.51	40.59%	6.64%
\$10,001 to \$20,000	20	\$291,551.21	11.76%	6.41%
\$20,001 to \$30,000	18	\$431,074.58	10.59%	9.47%
\$30,001 to \$40,000	11	\$386,937.56	6.47%	8.50%
\$40,001 to \$50,000	7	\$313,315.82	4.12%	6.88%
\$50,001 to \$100,000	19	\$1,281,955.48	11.18%	28.16%
\$100,000+	9	\$1,536,284.52	5.29%	33.75%
Total	170	\$4,551,636.99	100%	100%

The 170 children live in towns across the state. The following table shows the percentage of children in each region of the state:

Region	Percentage of children
Northeast	10%
Northwest	33%
Central	20%
Southeast	17%
Southwest	20%
Total	100%

The children were receiving Medicaid through a variety of program components, including Reach Up, disabled child, Dr. Dynasaur, foster child, Katie Beckett, and VHAP. The largest categories were children receiving SSI disability benefits, Dr. Dynasaur, and Katie Beckett (Katie Beckett is a Medicaid component that allows the parents' income to be disregarded if the child meets certain disability criteria).

Financial impact of a waiver amendment

The provision of concurrent palliative care and curative care to Medicaid children could cost as much as \$1 million per year in state dollars, or as little as \$160,000 per year based on current rates for services (this cost may be approximately 4.2% higher for each subsequent year based on the Bureau of Labor Statistics Consumer Price Index five-year average for the Medical Care category). Attachments 3 and 4 show how the high- and low-cost estimates were derived. The high-cost estimate was based on an assumption that all 170 children with life-limiting illnesses would receive palliative care services during a given year, whereas the low-cost estimate assumes that only the highest-need children would receive services. The actual cost of the program would probably be closer to the lower-cost estimate for a number of reasons:

- Although all of the 170 children had at least one life-limiting diagnosis, many of the children had very few claims submitted under that diagnosis code, indicating that the illness was probably in an early stage or in remission, in which case palliative services may not yet be necessary.
- It is likely that there would not be an expectation of death before age 21 for at least some of the 170 children, in which case they would not qualify for hospice-like services under this program.
- Other states that have implemented similar programs are serving a relatively small number of children. For example, Florida has 468 children in its palliative care program out of a population of Medicaid children of 1,095,400 (as of 2008), or .04%. Colorado has 85 children out of a population of 232,500, or .037%. The 29 children in the low-cost estimate would represent .05% of Vermont's Medicaid children enrolled in 2008.
- Some of the children are receiving services through other state programs, such as Developmental Disability Services and Children's Personal Care Services, both programs administered by the Department of Disabilities, Aging, and Independent Living (DAIL). To the extent that other programs are providing case management, care coordination, home supports, respite care, crisis services, and other types of services, these same services would not be add-ons to the palliative care program. Both the high- and low-cost estimates do subtract personal care services from the additional costs, since the provision of personal care services would reduce the added cost for respite care.

Based on the advice of clinicians, OVHA has included in its cost analysis an estimate of inpatient and outpatient savings based on an assumption that some emergency room and hospital readmissions could be avoided through effective case management.

Conclusions

Although other states have projected cost neutrality for their palliative care programs, no state has yet been able to prove cost neutrality using actual program experience. Based on actual claims data for SFY 08 for children with life-limiting illnesses, OVHA estimates that a palliative care program in Vermont could cost as little as \$160,000 per year in state funds, provided that additional palliative care services are provided only to children in advanced stages of illness.

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Attachment 1

Section 7 of Act 25, An Act Relating to Palliative Care

- (a) No later than October 1, 2009, the secretary of human services shall submit to the house committees on appropriations and on human services and the senate committees on appropriations and on health and welfare a report on the programmatic and cost implications of a Medicaid and a State Children's Health Insurance Program (SCHIP) waiver amendment allowing Vermont to provide its Medicaid- and SCHIP-eligible children who have life-limiting illnesses with concurrent palliative services and curative care.
- (b) For purposes of this section:
 - (1) "Life-limiting illness" means a medical condition that, in the opinion of the child's treating health care provider, has a prognosis of death that is highly probable before the child reaches adulthood.
 - (2) "Palliative services" means personal care, respite care, hospice-like services, and counseling.

Attachment 2

COMPARISON OF PEDIATRIC PALLIATIVE CARE PROGRAM IN THREE STATES

	Colorado	Florida	California
Implementation date	January 1, 2008	January 1, 2005	April 1, 2009
Name of program	Hopeful (Pediatric Hospice waiver)	FL Partners in Care: Together for Kids	CA Pediatric Palliative Care
Waiver type	1915c HCBS	1915b managed care	1915c HCBS
Regions	Statewide	7 sites to start, 9 sites in 2008	5 counties in Yr 1, 11 in Yr 2
Age	Up to age 19	Up to age 21	Up to age 21
Number served	Up to 200 per year, currently 85	Up to 1000/yr, 251 in 2007, 468 in 2008	300 Yr 1, 801 Yr 2, 1802 Yr 3
Agency	Dept. of HC Policy & Financing (Medicaid agency)	Children's Medical Services Network Title V - CSHN	Medi-Cal (Medicaid agency) CA Children's Services
Eligibility criteria	Medicaid-eligible Probable death before adulthood At risk of hospitalization within 1 mo. Certification by case manager At least one benefit per month	Enrolled in CSHN At risk of death prior to age 21 Certification by nurse case manager	100% FPL (Medi-Cal eligible) Diagnosed with specified conditions At risk of hospitalization Certification by nurse case mgr or phys
Covered services	In-home respite care (30 days/year) Personal care Nursing or home health aide Individual/family counseling (98 hrs/yr) Expressive therapies (39 hrs/yr) Palliative/supportive care (per diem) Hospice-like services such as: PT/OT Speech pathology Alternative therapies Dietary counseling Case management (admin, not benefit)	Provided by 7 hospice agencies: Art, music, play therapies Pain and symptom control In-home nursing In-home personal care (up to 6 hrs/day) Respite care (7 days/yr) Individual/group counseling	Care coordination (fixed fee 4-12 hrs/mo) Respite care (in and out of home) (30 days/yr) Family counseling (52 hrs/yr) Expressive therapies (30 hrs/90 days) Family training on palliative care (100 hrs/yr)

Attachment 3: ADDITIONAL PALLIATIVE CARE COSTS--HIGH ESTIMATE

COSTS						
Type of service	Max units/child	# Children ⁴	Units/child	Cost/unit ⁵	Gross cost/year	
Family training/counseling	98 hours ¹					
High need		35	98	\$70.56		\$242,020.80
Medium need		49	49	\$70.56		\$169,414.56
Low need		86	24	\$70.56		\$145,635.84
In-home respite care	720 hours ¹					
Skilled	High need	35	720	\$40.68		\$1,025,136.00
Unskilled	Medium need	49	360	\$23.08		\$407,131.20
	Low need	86	180	\$23.08		\$357,278.40
Expressive therapy	39 hours ¹					
	High need	35	39	\$46.96		\$64,100.40
	Medium need	49	20	\$46.96		\$46,020.80
	Low need	86	10	\$46.96		\$40,385.60
Bereavement counseling	26 hours ²	5	26	\$70.56		\$9,172.80
Care coordination/case mgt.	2 positions ³		2	\$77,625.00		\$155,250.00
GROSS COSTS						\$2,661,546.40
Minus personal care⁶						\$473,314.83
ADJUSTED COSTS						\$2,188,231.57
SAVINGS⁷						
Type of service	Claims cost	Reduction		Gross savings		
Inpatient claims	\$942,920.53	20%		\$188,584.11		
Outpatient claims	\$387,319.55	10%		\$38,731.96		
GROSS SAVINGS						\$227,316.06
NET COSTS						\$2,434,230.34
STATE SHARE⁸						\$1,005,093.71

¹Maximum units are based on Colorado's program.

²Payment would occur at time of child's death; sessions could be spread over a 12-month period following child's death.

³Estimate of # positions is based on a ratio of 1:25, with assumption that not all 170 children would need CM, and some were already receiving CM services.

⁴High/medium/low need categories are based on cost; if program became operational, a clinical evaluation would determine each child's needs.

High need = \$40,000+, medium need = \$10,000-\$40,000, low need = less than \$10,000.

⁵Cost per unit is based on current allowable Medicaid reimbursement rates for same or similar services.

⁶46 of the 170 children were receiving personal care services equivalent to respite care, so these would not be additional costs.

⁷Savings estimates are based on the assumption that some inpatient and emergency room claims can be avoided with effective case management.

Attachment 4
ADDITIONAL PALLIATIVE CARE COSTS--LOW ESTIMATE

COSTS						
Type of service	Max units/child	# Children	Units/child	Cost/unit⁴	Gross cost/year	
Family training/counseling	98 hours ¹	29	98	\$70.56	\$200,531.52	
In-home respite care ⁵	720 hours ¹	5	720	\$40.68	\$146,448.00	
Expressive therapy	39 hours ¹	29	39	\$46.96	\$53,111.76	
Bereavement counseling	26 hours ²	3	26	\$70.56	\$5,503.68	
Care coordination/case mgt.	1 positions ³		1	\$77,625.00	\$77,625.00	
GROSS COSTS					\$483,219.96	
SAVINGS⁶						
Type of service	Claims cost	Reduction	Gross savings			
Inpatient claims	\$708,726.49	20%	\$141,745.30			
Outpatient claims	\$191,233.88	10%	\$19,123.39			
GROSS SAVINGS					\$160,868.69	
NET COSTS					\$322,351.27	
STATE SHARE					\$133,098.84	

¹Maximum units are based on Colorado's program.

²Payment would occur at time of child's death; sessions could be spread over a 12-month period following child's death.

³Estimate of # positions is based on a ratio of 1:25, with the assumption that not all 170 children will need CM, and some children were already receiving CM.

⁴Cost per unit is based on current allowable Medicaid reimbursement rates for same or similar services.

⁵Only 5 of the 29 children were not receiving personal care.

⁶Savings estimates are based on the assumption that some inpatient and emergency room claims can be avoided with effective case management.

Costs and savings have not been adjusted for medical inflation, assuming a potential program implementation date of SFY11.