
Implementation of the Medicaid Pediatric Hospice Waiver Program

**Department of
Health Care Policy and Financing**

**Performance Audit
May 2011**



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May 17, 2011

Members of the Legislative Audit Committee:

This report contains the results of a performance audit of the Department of Health Care Policy and Financing's implementation of the Medicaid Pediatric Hospice Waiver Program. The audit was conducted pursuant to Section 2-3-103, C.R.S., which authorizes the State Auditor to conduct audits of all departments, institutions, and agencies of state government. The report presents our findings, conclusions, and recommendations, and the responses of the Department of Health Care Policy and Financing.

Sally Symanski



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Glossary of Terms and Abbreviations

CCR - Code of Colorado Regulations. The administrative rules of the executive agencies of the State of Colorado.

CFR - Code of Federal Regulations. The codification of the general and permanent rules published in the Federal Register by the executive departments and agencies of the federal government. These rules govern federally funded programs, such as Medicaid.

CMS - Centers for Medicare and Medicaid Services. The federal agency that regulates Home and Community-Based waiver programs. CMS is authorized to grant program approval, set requirements, and perform compliance assessments.

Department - Department of Health Care Policy and Financing. A principal department in Colorado state government that is responsible for administering the State's Medicaid program.

HCBS - Home and Community-Based Services. Medicaid HCBS waiver programs are authorized under Section 1915(c) of the federal Social Security Act to provide services for persons who require the level of care available in an institution, such as a hospital, but choose instead to receive services in their community.

Life-limiting condition - A medical condition that, in the opinion of the medical specialist involved, has a prognosis of death that is highly probable before the child reaches adulthood.

Palliative care - Care intended to palliate or alleviate an individual's condition through pain relief and symptom management. Does not include care that is intended to heal or cure.

SEP agency - Single Entry Point agency. As authorized in statute, the Department contracts with 23 local SEP agencies around the state to perform operational and administrative functions, such as case management and resource development, for the Pediatric Hospice Waiver program.

SSI - Social Security Income. A federal program that provides monthly assistance to aged, blind, and disabled individuals who have little or no income.

Standard Medicaid program - Colorado's Medicaid program, which is an entitlement program that provides health care services to eligible needy individuals. Colorado's standard Medicaid program offers a wide range of services including physician services, health screenings and exams, access to prescription drugs and medical equipment, inpatient and outpatient hospital care, nursing, medical transportation, and optometric care.

Waiver program - Pediatric Hospice Waiver program. A Medicaid HCBS waiver program established to allow children and families access to palliative, hospice-like services as soon as the child is diagnosed and a physician has certified that the child has a life-limiting condition, regardless of the number of months the child is expected to live at the time of diagnosis. The Waiver program allows enrolled children to continue to receive care intended to heal or cure a life-limiting condition while also receiving palliative, hospice-like care.



**Implementation of the Medicaid Pediatric Hospice Waiver Program
Department of Health Care Policy and Financing
Performance Audit
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Purpose and Scope

This audit was conducted in response to a legislative request voicing concerns that the full implementation of the Medicaid Pediatric Hospice Waiver program (the Waiver program) administered by the Department of Health Care Policy and Financing (the Department) had been delayed and significant portions of the program were not yet in place. Our audit focused on reviewing and evaluating elements of the waiver design and implementation that may prevent enrolled children from being able to access services through the Waiver program as intended. We performed audit work from September 2010 through May 2011. We acknowledge the cooperation and assistance provided by the Department and the local Single Entry Point (SEP) agency management and staff.

We conducted this performance audit in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Overview

In 2004, the General Assembly mandated that the Department establish a specialized hospice care program to better address the needs of children with fatal conditions. The purpose of the hospice program is to allow children access to palliative care—care intended to alleviate the child’s condition through pain relief and symptom management—as soon as a fatal diagnosis is made and without having to forgo care intended to heal or cure the condition. The Department designed and implemented the Pediatric Hospice Waiver program as a Medicaid Home and Community-Based Services (HCBS) waiver program, meaning that it must work in conjunction with the State’s standard Medicaid program, which provides health care services (e.g., physician services, inpatient hospital care) to eligible needy individuals. Children enrolled in the Waiver program may receive services that are curative in nature through the standard Medicaid program while receiving services that are palliative in nature through the Waiver program. Waiver services include those a licensed hospice agency is required to provide (e.g., skilled nursing, home health) as well as additional services that are intended to better address the needs of children (e.g., play therapy). The Department contracts with a network of 23 local SEP agencies to provide case management services for children enrolled in the Waiver program, including assessing the level of care and service needs of each enrolled child. SEP agencies are also responsible for conducting resource development activities.

The Centers for Medicare and Medicaid Services (CMS) is the federal body that governs all state Medicaid programs, including HCBS waiver programs. CMS approved Colorado's Pediatric Hospice Waiver program in July 2007 for an initial three-year period. The Department began enrolling children in the Waiver program in February 2008, and Colorado's renewal waiver application was approved in June 2010. CMS has approved the Waiver program to serve up to 200 children at a time, and as of March 31, 2011, there were 143 children enrolled in the program. The Department had spent, as of March 31, 2011, a total of about \$240,000 on waiver services since the inception of the program.

To be eligible for the Waiver program, a child must be under 19 years of age, have a certified diagnosis from a physician that death is highly probable before the child reaches adulthood (i.e., a "life-limiting" condition), be at risk of hospitalization, and meet financial eligibility requirements. In general, a child is financially eligible for an HCBS waiver program if the *child's* income is less than 300 percent of the Social Security Income (SSI) benefit level (or less than about \$24,000 per year).

Key Findings

There are two indicators that suggest the Department has not fully and effectively implemented the Waiver program to ensure that children with life-limiting conditions receive the services intended by the General Assembly:

- **More than one-quarter of enrolled children have not received any waiver services.** From December 2008 through March 2010 a total of 130 children were enrolled in the Waiver program. We found that 36 children (28 percent) had no record of receiving any waiver services while enrolled during this 16-month period.
- **For children who have received waiver services, utilization has been low.** The Department estimated that the average cost of waiver services for each enrolled child would be \$1,528 per month during the first year of operating the Waiver program. The actual monthly cost for each child that received at least one waiver service between December 2008 and March 2010 was \$76, or about 5 percent of the Department's estimate.

The Department needs to address the following problems to ensure that enrolled children are able to access waiver services.

Care Planning. The Department has allowed a variety of practices in the care planning process which have created a substantial risk that all waiver service needs of enrolled children are not being identified and documented. First, of the 130 children enrolled in the Waiver program between December 2008 and March 2010, only nine children (7 percent) received waiver services within the core *Palliative/Supportive Care* category, which includes the fundamental services (e.g., skilled nursing, home health) intended to help the child manage the physical symptoms of his or her life-limiting condition. The low utilization of this core service category is particularly concerning because enrollment in the Waiver program is dependent on the child having an ongoing need for waiver services to avoid hospitalization. Second, five SEP agencies that served about 87 percent of

enrolled children during this period reported conducting some care planning practices that may not ensure that all of a child's palliative service needs are being identified. These practices included (1) basing the care plan on provider availability rather than the child's needs; (2) not documenting a child's needs when a provider is not available to fill those needs; and (3) fully delegating service need determinations to the child's provider, even though this is the SEP agency's responsibility and individual providers may not have all of the child's medical information.

Access to Providers. The Department has not established a pool of waiver service providers that is sufficient to give enrolled children access to waiver services. Nine of 14 children whose care plans we reviewed did not receive any waiver services because there was not an available waiver service provider. In some instances, a provider was not located within the geographic area; in other instances, a provider was located within the area but had a waitlist and could not accommodate the child. The number of providers has grown from 14 to 17, or about 20 percent, since the inception of the Waiver program while enrollment has more than quadrupled over the same period. Five SEP agencies stated that more providers were needed across all waiver service categories.

Bereavement Counseling for the Family. The Department cannot provide assurance that families are able to access bereavement counseling services through the Waiver program. The Department has not (1) established a tracking mechanism to ensure families are receiving this service when needed; (2) guided SEP agencies on how to identify the need for bereavement services in care plans; or (3) established a payment mechanism to ensure all bereavement services that are provided are paid for, including those provided after the enrolled child has died.

Waiver Service Frequency Requirements. The Department has not enforced its rule that children must receive at least one waiver service each month to remain enrolled in the Waiver program. Of the 130 children enrolled between December 2008 and March 2010, a total of 33 did not appear to receive any waiver services and therefore should have been disenrolled. Of these 33 children, 27 received standard Medicaid program services during the time period, at a total cost of about \$1.37 million. The Department has not monitored the usage of waiver services or evaluated whether the waiver service frequency requirement aligns with the overall purpose of the Waiver program.

Basis for Provider Rates. The Department cannot demonstrate that a valid, comparable basis was used to set some of the waiver service rates. The Department used rates for existing Medicaid services as a basis to set some rates for the new Waiver program. However, the standard Medicaid services the Department used to set waiver rates were not comparable to waiver services because of differences in economies of scale, intensity of service needs, and service bundling discrepancies. Additionally, the Department did not document how rates were established for some waiver services, including *Expressive Therapy* services, which are not available elsewhere in the Medicaid system.

Our recommendations and the responses from the Department can be found in the Recommendation Locator and in the body of this report.

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RECOMMENDATION LOCATOR
Agency Addressed: Department of Health Care Policy and Financing

Rec. No.	Page No.	Recommendation Summary	Agency Response	Implementation Date
1	23	Strengthen care planning for the Pediatric Hospice Waiver program to ensure that case managers are identifying and documenting all waiver service needs. This should include (a) providing comprehensive definitions of how <i>Palliative/Supportive Care</i> services are different from similar services under the standard Medicaid program and requiring input from service providers to determine a child's service needs; (b) providing training on what specific services may be offered under the <i>Palliative/Supportive Care</i> category; and (c) enforcing federal and state care planning requirements to ensure services are based on need and coordinated among resource options to avoid gaps or overlaps in service provision.	a. Agree b. Agree c. Agree	a. July 2012 b. July 2012 c. July 2012
2	29	Increase resource development efforts to help ensure there is an adequate pool of providers for the Pediatric Hospice Waiver program by (a) enforcing requirements that Single Entry Point (SEP) agencies identify and recruit providers to address unmet needs and resource gaps in the program; and (b) reevaluating and changing, if warranted, the current limitations on who can become a waiver service provider.	a. Agree b. Agree	a. July 2012 b. July 2012
3	33	Ensure that families receive bereavement counseling through the Pediatric Hospice Waiver program that can continue after the enrolled child has died, by (a) establishing a tracking mechanism for bereavement counseling services; (b) providing guidance to SEP agencies on how to identify the need for bereavement services in care plans; and (c) establishing a payment mechanism for all bereavement services provided, including those provided after the enrolled child has died.	a. Agree b. Agree c. Agree	a. July 2012 b. July 2012 c. January 2012

RECOMMENDATION LOCATOR

Agency Addressed: Department of Health Care Policy and Financing

Rec. No.	Page No.	Recommendation Summary	Agency Response	Implementation Date
4	37	Evaluate whether revising the Pediatric Hospice Waiver program's design is warranted to improve the program and ensure enrolled children are able to access needed services. Address the problems identified in this report with respect to care planning and access to providers, and use utilization data to determine whether changes should be made to the frequency requirement or waiver service categories. If changes are made, submit a waiver application amendment to the federal Centers for Medicare and Medicaid Services for approval. Enforce requirements regarding the frequency of service provision and disenrollment of children who are no longer eligible for the program.	Agree	July 2012
5	41	Reevaluate the rate structure for the Pediatric Hospice Waiver program and adjust as needed to ensure that all rates have a sound basis, including (a) ensuring that rates for the program account for any discrepancies in economies of scale, intensity of service needs, and service bundling; and (b) maintaining complete documentation of the method and rationale used for calculating all program rates.	a. Agree b. Agree	a. January 2012 b. January 2012

Overview of the Medicaid Pediatric Hospice Waiver Program

Chapter 1

The diagnosis and death of a terminally ill child has a devastating and enduring impact. Traditional hospice care provides palliative care—care intended to palliate or alleviate an individual’s condition through pain relief and symptom management—when an individual has been diagnosed with six months or less to live and has elected to forgo further care intended to heal or cure their condition. However, traditional hospice care was not designed to account for the distinct circumstances of a child diagnosed with a fatal condition who may need both curative and hospice-like care over an extended period of months or years and a family who needs support to help cope with the diagnosis.

In 2004, the General Assembly recognized that the standard hospice care system was limited in its ability to provide appropriate care for children and their families. The General Assembly declared it was in the best interest of the State to develop a pediatric hospice care system to better address the needs of children with fatal conditions [Section 25.5-5-305(1), C.R.S.]. Specifically, the General Assembly mandated the establishment of a hospice care program for children and families to allow them access to palliative, hospice-like services as soon as the child is diagnosed with a fatal condition, regardless of the number of months the child is expected to live at the time of diagnosis. Further, the General Assembly mandated that children and families be allowed to continue to receive care intended to heal or cure the child’s condition while also receiving palliative, hospice-like care [Section 25.5-5-305(3)(a)(I)(C) and (3)(b)(III), C.R.S.]. The Department of Health Care Policy and Financing (the Department), which is the state agency responsible for developing policies and financing plans for publicly funded health care programs, was given the responsibility of designing, implementing, and administering this pediatric hospice care program [Section 25.5-5-305(3) and (5), C.R.S.].

Administration

State law designates the Department as the Medicaid Single State Agency that is ultimately responsible for administering Colorado’s standard Medicaid program, which is an entitlement program that provides health care services to eligible needy individuals. The standard Medicaid program offers a wide range of services, including physician services, health screenings and exams, access to

prescription drugs and medical equipment, inpatient and outpatient hospital care, nursing, medical transportation, and optometric care. In large part, the services are intended to cure a condition or preserve health. Individuals enrolled in the standard Medicaid program can also elect to receive hospice services if they have been given a 6-month terminal prognosis and agree to forgo further curative treatments. Additionally, the standard Medicaid program offers long-term care services to individuals who need ongoing medical supports, generally through institutional settings such as nursing facilities and hospitals.

States may also offer long-term care services through Medicaid Home and Community-Based Services (HCBS) waiver programs. Operating a program of services under an HCBS waiver program permits a state to furnish an array of services that are provided in the home and community so that the HCBS waiver enrollee can remain living in the community and avoid institutionalization. HCBS waiver programs “waive” certain provisions in Title XIX of the federal Social Security Act, thereby allowing states flexibility in areas such as:

- Targeting specific populations to be served. This waives the requirement that states provide comparable services to all eligible individuals.
- Establishing specific income and resource thresholds for the target population. This waives the standard medically needy income and resource requirements.
- Providing services not usually covered by the standard Medicaid benefit package.

The Department designed and implemented pediatric hospice care as a Medicaid HCBS waiver program. As the Single State Agency, the Department is responsible for administering all Medicaid HCBS waiver programs, including the Pediatric Hospice Waiver program (the Waiver program).

Medicaid HCBS Waiver Programs

HCBS waiver programs must work in conjunction with the State’s standard Medicaid program. Anyone enrolled in a Medicaid HCBS waiver program is eligible to receive both services under the HCBS waiver program and services available under the State’s standard Medicaid program. Congress authorized the use of HCBS waiver programs as a means for states to provide care to eligible individuals in the home and community rather than in an institutional setting such as a nursing home or hospital. To be eligible for an HCBS waiver program, an individual must be (1) at risk of institutionalization in the near future (i.e., a month or less) and (2) willing and able to receive care in his or her home and community rather than in an institution. The average cost of serving waiver

enrollees cannot be more, in aggregate, than the cost of serving enrollees in an institution.

The Centers for Medicare and Medicaid Services (CMS) is the federal body that governs all state Medicaid programs, including HCBS waiver programs. CMS sets HCBS waiver program requirements and periodically assesses a state's compliance with the requirements. States have significant flexibility in designing HCBS waiver programs. For example, states can target specific populations, control the number of individuals served, and provide customized services not covered by the standard Medicaid program. As is the case for all Medicaid programs, services offered through a Medicaid HCBS waiver program must be used only as a last resort when no other resources are available. Further, services offered through an HCBS waiver program must complement and/or supplement standard Medicaid program services and other federal, state, and local public programs as well as the supports that families and communities can provide. Colorado currently administers a total of 11 Medicaid HCBS waiver programs; the Pediatric Hospice Waiver program is the newest.

The Pediatric Hospice Waiver Program

The Waiver program, like Colorado's 10 other Medicaid HCBS waiver programs, was designed to address the needs of a targeted group—in this case, children diagnosed with a “life-limiting” condition who are at risk of hospitalization. A life-limiting condition is a medical condition for which a physician has certified that death is highly probable before the child reaches adulthood [10 C.C.R. 2505-10, Section 8.504.1]. Two core differences between the Waiver program and the standard hospice care system available to Medicaid-eligible individuals are that:

- Under the standard Medicaid hospice care system, hospice patients must have a 6-month terminal prognosis. Under the Waiver program, enrolled children must have a diagnosis of a life-limiting condition, meaning the child is not expected to live to adulthood. Therefore, under the Waiver program, children can receive care for an extended period—from the time they are diagnosed with a life-limiting condition through age 18.
- Under the standard Medicaid hospice care system, any individual electing hospice care is required to forgo further curative treatments for his or her terminal condition. Under the Waiver program, children do not have to forgo curative medical treatments in order to access palliative, hospice-like care. Rather, children can receive palliative care through the Waiver program and curative care through the standard Medicaid program concurrently.

Pediatric Hospice Waiver Eligibility and Services

To be eligible for the Waiver program, a child must be under 19 years of age, have a certified diagnosis from a physician of a life-limiting condition that has put the child at risk of hospitalization, and meet financial eligibility requirements. In general a child is financially eligible for the Waiver program if the *child* earns less than 300 percent of the Social Security Income (SSI) benefit level (or less than about \$24,000 per year). For all children enrolled in HCBS waiver programs in Colorado, including the Pediatric Hospice Waiver program, parent income is not considered when determining the child's financial eligibility.

All services provided through the Waiver program are palliative in nature, meaning they are intended to alleviate and manage pain and other symptoms but not cure the child's condition. As mentioned above, one of the key design elements and purposes of the Waiver program is to allow children and their families access to palliative services as soon as the child is diagnosed with a life-limiting condition without requiring that the child forgo any further curative treatments. This means that while children are enrolled in the Waiver program, they can receive services that are curative in nature through other resources, such as the standard Medicaid program, while receiving services that are palliative in nature through the Waiver program. Waiver services include those a licensed hospice agency is required to provide, as well as additional services that are intended to better address the needs of children and are not available elsewhere in the Medicaid system. The Department created four categories of waiver services offered to enrolled children and families through the Waiver program:

- **Palliative/Supportive Care** – Includes the variety of services that standard Medicaid hospice care also includes (e.g., skilled nursing, physical therapy, and dietary counseling), as well as alternative therapies (e.g., acupuncture) that are not standard in hospice care and are not available elsewhere in the Medicaid system. All *Palliative/Supportive Care* waiver services are provided to manage, control, and alleviate symptoms such as pain, nausea, discomfort, and anxiety related to a life-limiting diagnosis. All services are non-curative in nature but may be provided at the same time the child receives curative treatments through other resources. The total *Palliative/Supportive Care* waiver services a child can receive annually are not limited.
- **Respite Care** – Services provided to an enrolled child to grant short-term relief to the person who normally cares for the child, such as a parent or other primary caregiver. Total *Respite Care* waiver services are limited to 30 days per year.
- **Counseling** – Grief and bereavement counseling that help the child and family/caregiver cope with the child's life-limiting diagnosis. *Counseling*

waiver services may be provided in either a group or individual setting. This service category includes bereavement counseling services for the family/caregiver after an enrolled child has died, for up to one year after the child's death. Total *Counseling* waiver services are limited to 98 hours per year.

- **Expressive Therapy** – Creative art, music, or play therapies that are intended to provide children the ability to creatively and kinesthetically express feelings of isolation due to their medical condition, improve communication skills, decrease emotional suffering, and develop coping skills. These services are not available elsewhere in the Medicaid system. Total *Expressive Therapy* waiver services are limited to 39 hours per year.

The Department is responsible for ensuring that the Waiver program is operated in accordance with applicable state and federal regulations and the provisions of the waiver application approved by CMS. The Department may not delegate its authority over the program to another entity but may allow other entities to perform administrative functions or deliver services; however, CMS holds the Department ultimately responsible for the Waiver program.

Single Entry Point Agencies

For the Waiver program, the Department contracts with 23 local Single Entry Point (SEP) agencies around the state to perform operational and administrative functions. Through the contracts and statutes, SEP agencies are responsible for conducting case management services and resource development activities for HCBS waiver programs as well as for other long-term care programs, such as home health under the standard Medicaid program and institution-based care for Medicaid enrollees residing in nursing facilities. In addition, SEP case managers are responsible for assessing the level of care and service needs of each child enrolled in the Waiver program at least once every six months, developing and managing a comprehensive care plan based on those needs, and monitoring service provision to ensure that each enrolled child is receiving the services outlined in his or her care plan. SEP agencies are also responsible for identifying any unmet needs or resource gaps in their communities, such as a lack of service providers, and conducting resource development activities to address those gaps. SEP agencies are required to submit all care plans and an annual resource development plan to the Department for review.

The SEP agency's role is critical for this HCBS waiver program because of the specialized eligibility requirements and services children enrolled in the Pediatric Hospice Waiver program may receive. Children may remain enrolled in the Waiver program for extended periods, from the time they are diagnosed with a life-limiting condition through age 18 while they meet the level of care criteria (i.e., the child is at risk of hospitalization). During this time, children may receive

both palliative services through the Waiver program and curative services through non-waiver resources such as the standard Medicaid program. As such, children enrolled in the Waiver program are expected to receive a variety of services both regularly and intermittently, depending on their needs, for a few months or over the course of years. During this time, these services may change as the child's life-limiting condition and service needs change. The SEP agency case manager is responsible for ensuring that over the course of the child's enrollment, the child is able to access needed services through the appropriate resources.

Pediatric Hospice Enrollment and Expenditures

CMS approved Colorado's Pediatric Hospice Waiver program in July 2007 for an initial three-year period. The Department began enrolling children in the Waiver program in February 2008, and Colorado's renewal waiver application was approved in June 2010. After an initial three-year approval, all HCBS waiver programs must apply for waiver renewal every five years.

Unlike the standard Medicaid program under which a state must serve all individuals who meet the eligibility criteria, Medicaid HCBS waiver programs cap the number of individuals served. CMS has approved the Waiver program to serve up to 200 children at a time. Annual enrollment in the Waiver program has grown each year, as shown in the table below. As of March 31, 2011, enrollment in the Waiver program had reached 143 children, or 72 percent of the maximum capacity of 200 children.

Pediatric Hospice Waiver Total Enrollments and Expenditures per Fiscal Year		
Fiscal Year	Total Enrolled Children¹	Total Expenditures^{2,3}
2008 (<i>Jan - June</i>)	32	<i>not available</i> ⁴
2009	93	\$29,300
2010	130	\$90,900
2011 (<i>July - Mar</i>)	143	\$119,600 ⁵
Source: Office of the State Auditor's analysis of waiver enrollment and claims data provided by the Department of Health Care Policy and Financing.		
¹ Reflects the total number of children enrolled as of June 30 each year except for 2011, when the number reflects children enrolled as of March 31. Children may be served in multiple years.		
² Reflects spending within the fiscal year. These figures are presented on a cash basis, meaning they do not directly align with the services provided within that fiscal year.		
³ Reflects spending for Pediatric Hospice Waiver program services. These figures do not include administrative costs or spending on non-waiver Medicaid services.		
⁴ The Department did not pay any claims for Pediatric Hospice Waiver services during Fiscal Year 2008 due to billing problems. The Department paid for all waiver services that were provided in Fiscal Year 2008 in Fiscal Year 2009.		
⁵ Reflects claims paid in Fiscal Year 2011 as of March 31, 2011.		

Like other Medicaid HCBS waiver programs, the Pediatric Hospice Waiver program is funded by about 50 percent federal funds and 50 percent state general funds. However, in Fiscal Years 2009, 2010, and 2011 Colorado received additional federal funding through the American Recovery and Reinvestment Act, which temporarily increased the federal share of funding to between about 57 percent and 62 percent for all HCBS waiver programs. For example, in Fiscal Year 2010 the federal share was about 62 percent; the State's share was 38 percent. Federal American Recovery and Reinvestment Act funds will no longer be available as of July 2011.

Audit Scope & Methodology

We conducted this performance audit in response to a legislative request voicing concerns that the full implementation of the Waiver program had been delayed and significant portions of the program were not yet in place. To address this request, our audit focused on reviewing and evaluating elements of the waiver design and implementation that may prevent enrolled children from being able to access services through the Waiver program as intended. We reviewed federal requirements and state statutes and regulations governing the Waiver program and standard hospice care in Colorado. We reviewed Colorado's approved Pediatric Hospice Waiver program applications, client enrollment data, a sample of care plans, and aggregate paid claims data for all services provided to enrolled children. We also spoke to Department staff, Colorado's liaison at CMS, staff at five SEP agencies, a sample of 10 providers for the Waiver program, and other parties who assisted in developing the waiver applications. Our audit scope did not include a review or evaluation of program components that do not directly relate to enrolled children being able to access waiver services, such as processes and controls over eligibility determination, medical assessment accuracy, provider licensure and/or certification, payments for the standard Medicaid program services that children enrolled in the Waiver program received, or waiver claims payment and billing practices.

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Medicaid Waiver Implementation

Chapter 2

When the General Assembly enacted legislation in 2004 to establish pediatric hospice care in Colorado, it recognized the need for a new program to provide compassionate and consistent care to meet the physical, emotional, and spiritual needs of children with fatal conditions and their families. The statutes state that the purpose of establishing a pediatric hospice care program is to (1) allow children and families to receive palliative care as soon as a child is diagnosed with a life-limiting condition, and (2) allow children to continue receiving curative care for the condition while also receiving palliative care [Section 25.5-5-305(3)(a)(I)(C) and (3)(b)(III), C.R.S.]. In accordance with statute, the Department of Health Care Policy and Financing (the Department) developed and implemented the Pediatric Hospice Waiver program (the Waiver program) to allow children who have a life-limiting condition access to palliative care for their condition through the Waiver program and curative care through the standard Medicaid program.

We evaluated the Department's implementation of the Waiver program to determine the extent to which the program is serving enrolled children and meeting the purpose established by the General Assembly. Our focus was on whether key components of the Waiver program have been put in place to ensure that enrolled children have access to care as intended by the statutes. We identified two indicators that suggest the Department has not fully and effectively implemented the Waiver program to ensure that children with life-limiting conditions and their families receive the services intended by the General Assembly:

- **More than one-quarter of enrolled children have not received any waiver services.** We reviewed waiver enrollment and claims data for the period of December 2008 through March 2010. During this 16-month period a total of 130 children were enrolled in the Waiver program. However, we found that 36 children (28 percent) had no record, according to the paid claims data, of receiving any waiver services. For three of these 36 children, the Department could not provide us with the child's waiver enrollment period because of problems in the Department's enrollment database. For the remaining 33 children, enrollment periods ranged from 38 to 480 days, with an average enrollment period of 256 days. Of these 33 enrolled children, 27 did receive services through the standard Medicaid program at a total cost of about \$1.37 million while they were enrolled in the Waiver program during the period reviewed. As noted

above, the Waiver program is intended to allow all enrolled children access to both palliative care through the Waiver program and curative treatments through the standard Medicaid program.

- **For children who have received waiver services, utilization has been low.** As shown in the table below, for children who did receive at least one waiver service during the 16-month period we reviewed, utilization was low—particularly within the core *Palliative/Supportive Care* service category, which includes palliative services that are intended to help the child manage the physical symptoms of his or her life-limiting condition.

Pediatric Hospice Waiver Service Utilization Enrolled Children Receiving Waiver Services December 2008 Through March 2010		
Waiver Service Categories	Total Children Served	Total Expenditures
Palliative/Supportive Care (<i>no limit</i>)	9	\$1,100
Other Waiver Service Categories:		
Counseling (<i>up to 98 hrs/yr</i>)	57	\$39,900
Expressive Therapy (<i>up to 39 hrs/yr</i>)	46	\$33,100
Respite Care (<i>up to 30 days/yr</i>)	25	\$27,300
Source: Office of the State Auditor’s analysis of waiver enrollment and claims data provided by the Department of Health Care Policy and Financing for the 130 children enrolled during the time period.		

Further, when the Department submitted a waiver application to the federal Centers for Medicare and Medicaid Services (CMS) to request approval for the new Pediatric Hospice Waiver program, the Department estimated that the average cost of waiver services per each enrolled child would be \$1,528 per month during the first year of operating the program. In contrast, the actual monthly cost for each enrolled child who received at least one waiver service between December 2008 and March 2010 was \$76, or about 5 percent of what the Department estimated. The Department indicated that because this was a new program, there was no comparable information available to assist in estimating the costs of waiver services. However, the significant discrepancy between the estimated and actual costs indicates that, overall, waiver services have been utilized at a significantly lower rate than the Department anticipated. This is especially concerning because according to federal regulations, in order to be eligible for the Waiver program each enrolled child must require *waiver* services to avoid hospitalization. We discuss the frequency of waiver service utilization in more detail later in this chapter.

To assess why some enrolled children have not received waiver services at all and why service utilization for other children has been significantly lower than the Department anticipated, we evaluated the implementation and operation of key program components, as discussed below.

Waiver Implementation Components

Federal and state laws and regulations guide the Department in designing and implementing Medicaid Home and Community-Based Services (HCBS) waiver programs so that these programs accomplish their intended purposes and comply with applicable requirements. To ensure that enrolled children have access to the care they need, statutes and regulations outline the following key components that the Waiver program should include:

- Planning processes to identify the service needs of each enrolled child [42 C.F.R. Section 441.301(b)(1)]. This should include care planning that provides for coordination of services offered through the Waiver program with those available through other, non-waiver sources like the standard Medicaid program.
- Resource development activities to ensure that waiver services are available and can be accessed by enrollees [Section 25.5-6-106(2)(c)(X), C.R.S.]. This should include identifying and recruiting appropriate service providers.
- Waiver design choices that ensure the program will accomplish the program purpose of allowing children and families to receive palliative care as soon as a child is diagnosed with a life-limiting condition and that allow children to continue receiving curative care for the condition while also receiving palliative care [Section 25.5-5-305(3)(a)(I)(C) and (3)(b)(III), C.R.S.]. This should include thoughtfully defining the types and frequency of waiver services being provided and the rate structure for those services.

Overall, we found that the Department has not fully and effectively implemented these three key program components. Specifically, the Department has not (1) ensured that care planning identifies and documents all of the child's needed waiver services and coordinates waiver services with non-waiver services; (2) recruited a sufficient number of providers with expertise in all the waiver service areas to give enrolled children access to needed waiver services; or (3) ensured that waiver design choices, including the types and frequency of services and the provider reimbursement structure, are accomplishing the intent of the Waiver program. We discuss each of these problems in the following sections.

Care Planning

As noted above, a key component in implementing a Medicaid HCBS waiver program is establishing a process of identifying and planning for the waiver services that enrollees will need. For HCBS waiver programs, federal regulations require that waiver services are documented in a written plan of care for each enrollee and are based on an assessment of the enrollee's needs. For the Pediatric Hospice Waiver program, case managers at Single Entry Point (SEP) agencies are responsible for assessing the waiver service needs of enrolled children and documenting in a care plan how those service needs will be coordinated with all of the other care the child will receive from non-waiver sources. As we discuss in this section, we found that current Department and SEP agency practices create a substantial risk that all waiver service needs of enrolled children are not being identified and documented.

Waiver services must complement and/or supplement services the child will access through non-waiver sources, such as the standard Medicaid program. This requirement is in place to ensure that all of a child's service needs are identified and addressed, and that gaps or duplication in service provision do not occur. For children enrolled in the Waiver program, care planning requirements are particularly important because one of the main purposes of the program is to allow a child access to multiple services and resources to treat his or her life-limiting condition. Children with life-limiting conditions generally have complex service needs and will receive care from multiple sources at the same time for different treatment goals (i.e., care intended to heal or cure from one set of providers and care intended to palliate pain and manage symptoms from another set). The Department has designed the program so that enrolled children may access palliative services through the Waiver program and curative services through the standard Medicaid program. For example, a child enrolled in the Waiver program may receive a curative treatment, such as chemotherapy, from one provider through the standard Medicaid program while receiving palliative services, such as those provided by a Registered Nurse to address the side effects of chemotherapy, from another provider through the Waiver program.

Additionally, children enrolled in the Waiver program can receive care for extended periods—from the time they are diagnosed with a life-limiting condition through age 18. This means children may receive a variety of services both regularly and intermittently, depending on their needs, for a few months or over the course of years. As such, identifying service needs and coordinating care for enrolled children is a complicated but critical and ongoing function in ensuring they receive the care they need. The General Assembly recognized this and mandated that a “continuum of care” be provided to children enrolled in the Waiver program [Section 25.5-5-305(3)(a)(1)(D), C.R.S.]. This means that all of a child's waiver service needs must be effectively identified through careful

coordination of services and resources to enable the child to “move from one level or type of care to another without encountering gaps in or barriers to service” [Section 25.5-6-104(2)(e), C.R.S.].

To determine if waiver service needs of enrolled children are being identified and documented, we reviewed a non-statistical sample of care plans for 14 children enrolled between December 2008 and March 2010. Our sample included children who were initially enrolled in the Waiver program across all three years within the testing period and included both children who had received waiver services and those who had not received waiver services. We also spoke to a sample of five of the 23 SEP agencies that provide case management services and to the Department about care planning practices for the Waiver program. Our sample of five SEP agencies provided case management services to about 87 percent of children enrolled between December 2008 and March 2010. Overall, we found that the Department has allowed a variety of practices in the care planning process that together create a substantial risk that all waiver service needs of enrolled children are not being identified and documented, as described in the following sections.

SEP case managers do not identify *Palliative/Supportive Care* waiver service needs during care planning. Of the care plans we reviewed for 14 enrolled children, care plans for 13 children did not document a need for any waiver services from the broad *Palliative/Supportive Care* service category. Further, when we reviewed claims data for the 130 children enrolled in the Waiver program between December 2008 and March 2010 we found that only nine children (about 7 percent) received services within this category over the 16-month period, at a total cost of about \$1,100. This category includes some of the most fundamental services available through the Waiver program, such as skilled nursing, home health, physical therapy, and speech pathology, which are intended to help the child manage the physical symptoms of his or her life-limiting condition. The Department anticipated in the waiver application for the program that every enrolled child would utilize services within the *Palliative/Supportive Care* waiver service category at an average of 74 days each year per child, costing an average of about \$9,000 per child annually. As noted previously, the Department indicated that because this was a new program, there was no comparable information available to assist the Department in estimating the costs or usage of waiver services. However, enrollment in the Waiver program is dependent upon the ongoing need for waiver services to avoid hospitalization and so it is reasonable to anticipate that most enrolled children would require core *Palliative/Supportive Care* services on a regular basis to manage their physical symptoms. Given the critical health issues faced by these children, the low utilization of core *Palliative/Supportive Care* services may indicate that when SEP case managers are making service determinations, they are not identifying all of a child’s palliative service needs.

SEP agencies report that providers, rather than case managers, sometimes determine waiver service needs. SEP agencies are required by contract to determine which waiver services an enrolled child will need and in what amounts, and develop a care plan for the child based on those needs. Of the five SEP agencies we spoke with, two reported that they are not determining which waiver services an enrolled child will need and in what amounts. Instead, these two SEP agencies require the waiver service provider to make this determination. The SEP agencies then enter the provider's service determinations into the Department's care planning database. This is a problem because the two SEP agencies reported that case managers are not evaluating or questioning how providers determine waiver service needs; rather, case managers defer to the provider. Although it is important for case managers to get input from providers when determining a child's service needs, if the case manager is not actively involved in making service need determinations, there is a risk that all waiver service needs will not be identified or will overlap with care provided by other resources that the provider is not aware of. This risk exists because waiver service providers do not have all of the information needed to develop a comprehensive care plan, such as the case manager's eligibility assessment and data on all other services the child is receiving. Further, having providers develop care plans violates the SEP agencies' contracts with the Department, which require SEP case managers to determine waiver service needs.

SEP agencies report that case managers do not always document service needs if a provider is not available. Of the five SEP agencies we spoke with, three reported conducting care planning practices that do not adhere to the federal requirement that care plans reflect all of the child's service needs, even in instances where the need is not being met. Case managers at one SEP agency reported that they do not document in the care plan needed services if no provider is available. At two other SEP agencies, case managers reported that they encourage families to elect services that may not be needed if a provider is available to provide the service. Case managers reported recommending these services rather than, or in addition to, needed services for which no provider is available, to ensure the child and family receive at least some waiver services on a regular basis.

Because of the issues we identified with respect to care planning, we are concerned that the SEP agencies do not fully understand their responsibilities for identifying and documenting the service needs of children in the Waiver program. We recognize that the reported practices of the five SEP agencies we contacted may not reflect how all 23 agencies manage the care planning process for the Waiver program. However, based on the low utilization of the fundamental *Palliative/Supportive Care* services across the program and the reported practices of three of the five SEP agencies we contacted, we believe SEP agencies are not conducting the care planning process in a way that enables children to access services through the program as intended by state and federal laws.

We identified deficiencies in the Department's guidance on and monitoring of care planning that we believe contribute to the risk that waiver service needs are not being identified. These concerns are discussed in the following two sections.

Direction to SEP Case Managers on Care Planning

We spoke to a sample of five SEP agencies about the guidance they have received from the Department on care planning. We also reviewed all the materials provided by the Department to SEP agencies regarding the Waiver program, including the waiver statutes, regulations, training materials, program fact sheets, provider bulletins, and provider manuals. We identified three specific deficiencies in the guidance provided to the SEP case managers on how to identify and document waiver service needs and determine how those services should be coordinated with non-waiver services.

The Department does not require SEP agencies to work with medical experts during care planning. Although the Department requires SEP case managers to meet and speak with the child's family or primary caregiver during the assessment of the child's waiver service needs, the Department does not require case managers to contact the child's regular physician and waiver service provider(s) during this assessment period. Children enrolled in the Waiver program have complex medical conditions that often include multiple diagnoses that require a combination of medication and treatment needs, which are provided by multiple specialists responsible for different aspects of the child's care. SEP agencies provide case management for enrolled children as an administrative function and, as such, case managers are not required to have a medical background but are required to coordinate all of a child's care. As stated above, two SEP agencies we spoke with reported that they do contact the waiver service provider and ultimately rely on that provider to determine the child's waiver service needs. However, in order to identify and coordinate waiver services that supplement the other care an enrolled child receives for his or her life-limiting condition, the case manager must establish a dialogue among all of the key medical experts responsible for providing the child's care. The care plans we reviewed for our sample of 14 enrolled children included documentation showing that a physician had certified the child had a life-limiting condition and that the case manager had received a medical information form from the physician for the child's file. However, none of the care plans we reviewed included documentation that the case manager had been in contact with the child's service providers in order to assess waiver service needs and coordinate waiver services with the other, non-waiver care the child would receive.

The Department has not clearly defined some waiver services. For the services that have been identified in the *Palliative/Supportive Care* waiver service category, the Department has not given SEP case managers comprehensive

definitions for each service. Most of the services within this category mirror services that are also provided through the standard Medicaid program. For example, skilled nursing may be accessed through the Waiver program or the standard Medicaid program. The Department has not specified the precise skilled nursing services or other *Palliative/Supportive Care* services that are available under the Waiver program. Neither the Department nor any of the five SEP agencies we spoke with were able to articulate how case managers should determine when a service such as skilled nursing should be provided through the Waiver program, and in what amounts, when the service will also be offered through the standard Medicaid program. All five of these SEP agencies need more direction from the Department on how to make waiver service determinations for *Palliative/Supportive Care*. This is particularly concerning because enrollment in the Waiver program is dependent on the child having an ongoing need for waiver services to avoid hospitalization. The *Palliative/Supportive Care* waiver service category includes all of the fundamental palliative, hospice-like services intended to manage the physical symptoms of a life-limiting condition. Providing specificity on how these waiver services are distinct from services available to enrolled children through the standard Medicaid program is fundamental in communicating to the SEP case managers how to identify all of the appropriate services available to meet a child’s needs and thus avoid hospitalization.

The Department has not provided SEP agencies with adequate training on *Palliative/Supportive Care* services. We asked a sample of five of the 23 SEP agencies to tell us how case managers determine what specific waiver services may be provided under the *Palliative/Supportive Care* waiver service category. Although the Department has provided examples and a written definition of what *Palliative/Supportive Care* may include, all five SEP agencies we contacted reported some confusion about what services this category may include and when these services should be used, indicating a need for further instruction in this area. For example, one SEP agency reported that only “teach and assist” services were included under this category, meaning it is used only in instances when the family needs instruction from a medical professional, such as on how to use a feeding tube. The Department’s definition of *Palliative/Supportive Care* under the Waiver program, which is noted above, does not limit the category to only “teach and assist” services. As such, the SEP agency’s interpretation of this service category appears to be narrower than the Department intended under *Palliative/Supportive Care* services.

Department Monitoring of Care Planning Practices

The Department, as the Medicaid Single State Agency, is ultimately responsible for ensuring that the Waiver program is operated in accordance with applicable state and federal regulations and the provisions of the waiver application approved by CMS. This means that while the Department contracts with SEP

agencies to perform case management services, such as developing care plans, the Department must ensure that SEP agencies are performing these functions as required by their contracts.

We asked the Department for documentation showing how it has ensured that SEP agencies are properly developing care plans for the Waiver program to reflect all of a child's waiver service needs. From the implementation of the Waiver program in 2008 through Fiscal Year 2010, the Department did not have a process in place to review, track, identify, and correct violations of federal and state requirements in care plans developed by SEP agencies for the Waiver program. The Department was not aware of the care planning practices SEP agencies reported to us, such as instances where SEP case managers required that waiver providers determine all of a child's waiver service needs, did not document service needs when a provider was not available, and allowed service provision to be based on provider availability rather than the child's needs.

The Department states that in January 2011 it began implementing a new review process to monitor SEP agency practices and ensure compliance with federal regulations and the provisions of the waiver application approved by CMS. The Department states that this review process, called the Quality Improvement Strategy (QIS), is intended to identify inconsistencies across the SEP agencies and practices that do not comply with state and federal requirements. The Department did not have the results of the QIS process available during this audit and, as such, we were not able to review those results or determine whether the QIS process will address the problems we have identified here. Going forward, the Department should ensure that through the QIS review or other monitoring processes, care planning requirements are enforced so that the services a child receives are based on need and are coordinated among resource options to avoid gaps or overlaps in service provision. Additionally, the Department's review and monitoring processes should ensure that SEP case managers are (1) determining the Waiver service needs of enrolled children rather than fully delegating this responsibility to waiver providers, (2) documenting service needs when a provider is not available, and (3) basing the care plan on the child's needs rather than on provider availability.

Recommendation No. 1:

The Department of Health Care Policy and Financing (the Department) should strengthen care planning for children in the Pediatric Hospice Waiver program (the Waiver program) to ensure that Single Entry Point (SEP) case managers are identifying and documenting all of a child's waiver service needs. This should include:

- a. Providing clear, written direction to SEP agencies on care planning, including comprehensive definitions of how *Palliative/Supportive Care* waiver services are different from similar services under the standard Medicaid program and a requirement that SEP case managers obtain and use the input of both palliative and curative service providers to assess a child’s service needs, plan services to address the needs, and determine the proper source for each service.
- b. Providing training on what specific services may be offered under the *Palliative/Supportive Care* waiver service category. The training should cover the comprehensive definitions of how these waiver services are different from similar services offered through the standard Medicaid program recommended in Part “a,” above.
- c. Enforcing federal and state care planning requirements that are in place to ensure that the services a child receives are based on need and are coordinated among resource options to avoid gaps or overlaps in service provision. This should include using the newly implemented review and monitoring process. The Department’s review and monitoring processes should ensure that SEP case managers are determining the waiver service needs of enrolled children rather than fully delegating this responsibility to waiver providers; documenting service needs when a provider is not available; and basing the care plan on the child’s needs rather than on provider availability.

Department of Health Care Policy and Financing Response:

Agree. Implementation date: July 2012.

- a. The Department agrees to develop clear, precise written direction to SEP agencies on how to create the care plans for the Waiver program. Trainings will be conducted annually on the Home and Community-Based Services (HCBS) waiver services with an emphasis on *Palliative/Supportive Care* as a waiver service. To accomplish this, the Department will research *Palliative/Supportive Care* definitions that are currently in use by other pediatric hospice waiver programs that have been approved by the Centers for Medicare and Medicaid Services (CMS). The comprehensive training plan will also address the use of input of both palliative and curative service providers to assess a child’s service needs, plan services to address the needs, and determine the proper source for each service.

- b. The Department agrees to conduct annual SEP trainings on care planning, to include definitions of *Palliative/Supportive Care*, as well as the similarities and differences between the Medicaid state plan (i.e., the standard Medicaid program) benefits and HCBS waiver services to ensure that the Waiver program recipient receives appropriate services.
- c. The Department agrees that all federal and state requirements should be enforced and that all services needed are received and coordinated to ensure there are no gaps or overlaps in services provided to the recipient. This will be addressed through the annual SEP trainings and monitored through the recently implemented “Program Tool.”

The Department agrees to continue to use the Program Tool, which was implemented in January 2011, to monitor the SEP agencies to ensure the following: recipient receives all services identified in the ULTC 100.2 (i.e., the assessment tool); services are coordinated with providers; service needs are documented when a provider is not available; care plans are based on recipient needs and not provider availability; communication is occurring between providers and SEP agencies; and care plans are regularly reviewed and revised as needed.

Through analysis of the data received from the Program Tool, remediation plans will be put in place to ensure that all care planning requirement efforts are enforced. This process will occur annually.

Access to Providers

A second key component in implementing a Medicaid HCBS waiver program is establishing an adequate provider pool. Service providers must be identified and recruited to ensure that waiver enrollees have access to the services they need. State Medicaid Rules [10 C.C.R. 2505-10, Section 8.393.51] require SEP agencies to assume a leadership role in facilitating the development of local resources to meet the needs of clients who reside in the community. Statute [Section 25.5-6-106(2)(c)(X), C.R.S.] requires SEP agencies to identify resource gaps and conduct resource development activities to fill those gaps; this includes identifying and addressing gaps in the pool of waiver service providers.

While SEP agencies are responsible for identifying and recruiting potential providers for the Waiver program, the Department is responsible for guiding providers through the application process and ultimately determining who is qualified to provide waiver services. To become an approved provider for the

Waiver program, a provider must first be licensed by the State and then go through a two-part application process at the Department. First, the provider must be approved as a provider within the standard Medicaid program and receive a Medicaid Provider ID number so the provider can bill for services under the standard Medicaid program. Then, the provider must apply for a Pediatric Hospice Waiver Provider ID number so that the provider can bill for services within the Waiver program. Before assigning a Waiver Provider ID number, the Department requires providers who have received a Medicaid Provider ID number to submit additional information, including a letter of intent, an employee roster, employee qualifications, and the provider's policies and procedures. Providers cannot be approved to receive a Waiver Provider ID number to bill for waiver services without completing both parts of this application process. Currently, there are a total of 17 approved providers for the Waiver program; 12 of these are hospice agencies and five are home health agencies.

We talked to the Department and five SEP agencies regarding their practices for identifying, recruiting, and approving service providers for the Waiver program, and we reviewed care plans and claims data for 14 enrolled children who did not receive any waiver services. We found that the Department has not established a pool of waiver service providers that can adequately meet current waiver service demands. As a result, some children are not receiving waiver services. Specifically:

- **SEP agencies reported that some children did not receive waiver services due to a lack of providers.** For nine of the 14 children whose care plans we reviewed, the SEP agency indicated that the child did not receive waiver services because there was not an available waiver service provider. In some instances, a provider was not located within the geographic area where the enrolled child resided; in other instances, a service provider was located in the area but had a waitlist in place and could not accommodate the child. All five SEP agencies indicated that more providers were needed across all waiver services.
- **There has been very little growth in the number of providers for the Waiver program.** According to information from the Department, as of August 2010 there was a combined total of 85 licensed hospice and home health agencies in Colorado but of these, only 17 were approved providers for the Waiver program. The number of providers for the Waiver program has grown about 20 percent since the inception of the program, from 14 in January 2008 to 17 as of August 2010. In contrast, enrollment has more than quadrupled since the Waiver program began, growing from 32 children in Fiscal Year 2008 to 143 children who were enrolled as of March 31, 2011.

We identified two areas in which the Department can address insufficiencies in the pool of available waiver providers. First, the Department could improve provider recruitment efforts, using care plan documentation of unmet service needs, as discussed in the previous comment. Second, the Department could re-evaluate the current waiver provider application and approval requirements and modify restrictions on provider eligibility. We discuss these areas below.

Ensure that SEP agencies are actively recruiting providers for the Waiver program. Colorado regulations [10 C.C.R. 2505-10, Section 8.393.51] and SEP agency contracts require SEP agencies to identify and develop local resources to meet the needs of their communities. SEP agencies must develop annual resource plans that identify resource gaps for the HCBS waiver programs for which they provide case management services, including the Pediatric Hospice Waiver program, as well as for other long-term care programs such as home health under the standard Medicaid program and institution-based care for Medicaid enrollees residing in nursing facilities. These resource plans must include the strategies and timelines the SEP agency will implement to address any gaps, including gaps in available service providers, identified in any of the programs. The Department did not provide evidence that it or any of the SEP agencies had taken steps to recruit providers for the Waiver program. We spoke to the Department and a sample of five SEP agencies about resource development and provider recruitment, and we reviewed three resource development plans prepared by SEP agencies. We found that while the plans we reviewed contained strategies generally intended to ensure that resources were available to provide services within the SEP agencies' communities, none of the plans made any reference to identifying and recruiting providers specifically for the Waiver program. The Department confirmed that, in fact, none of the SEP agencies' resource development plans contain activities intended to recruit providers for this waiver program. Further, two of the five SEP agencies we contacted stated that provider recruitment is the Department's responsibility, although SEP agencies are contractually required to conduct provider recruitment. The Department should direct all SEP agencies to identify strategies that can be implemented immediately for the Waiver program, particularly for services needed but not being provided for currently enrolled children.

We have previously identified weaknesses in the Department's monitoring of SEP agency activities to ensure that the SEP agencies carry out all required functions under statute and contract. In 2009, our office conducted the performance audit *Access to Medicaid Home and Community-Based Long-Term Care Services*, which included a review of the policies, processes, and practices in place at the Department and at SEP agencies affecting individuals' ability to access Medicaid waiver and other long-term care services. Similar to the issues we noted above, the 2009 audit found that the Department had not done enough to identify unmet needs and coordinate resource development across all SEP agencies. That audit recommended the Department take steps to address deficiencies in documenting

unmet needs in care plans, hold SEP agencies accountable for resource development planning, and actively oversee and coordinate resource development efforts. According to information received from the Department in January 2011, the 2009 recommendations regarding resource development activities had not yet been fully implemented. Implementing the recommendations made in the 2009 audit report would help the Department address provider access issues across all Medicaid waiver programs, including the Waiver program.

Modify restrictions on provider eligibility. The Department designed the Waiver program with certain limitations on the types of organizations and individuals that can become providers. We believe the Department may be able to modify or eliminate some limitations to expand the pool of providers for the Waiver program without sacrificing quality of care. The first limitation is that the Department allows only hospice agencies or home health agencies to provide services within the *Palliative/Supportive Care* waiver service category. As noted previously, this waiver service category includes services such as skilled nursing, nutritional counseling, physical therapy, home health services, and speech/language pathology. Hospice and home health agencies are not the only types of providers that offer these services. Allowing only hospice and home health agencies to provide the services available under the *Palliative/Supportive Care* category may create unnecessary barriers to provider participation and prevent enrolled children from receiving needed services. The Department should consider expanding the pool of available providers by enlisting qualified providers outside of hospice and home health agencies for some specific services within the broad *Palliative/Supportive Care* category. For example, the Department allows licensed counselors who are not employed by a hospice or home health agency to provide *Counseling* services through the waiver. Expanding the option to allow licensed individuals not employed by a hospice or home health agency, such as physical therapists or dieticians, to provide *Palliative/Supportive Care* services may allow the Department to recruit more waiver providers for these services.

Further, expanding the types of providers for *Palliative/Supportive Care* waiver services could be beneficial for children and families who do not want to work with a hospice agency at certain stages of the child’s condition. Department staff, SEP agency staff, and waiver providers reported to us that the term “hospice” can be a barrier because some families may view accepting hospice services as an acknowledgment that death is imminent. The Department may be able to address this barrier, in part, if it allowed families to receive some palliative services from a larger pool of non-hospice providers.

The second limitation on provider recruitment is that the Department requires all waiver providers to undergo the two-part approval process described earlier to obtain both a Medicaid Provider ID number and a Pediatric Hospice Waiver Provider ID number prior to being able to provide and bill for services through the

Waiver program. This two-part process can be time-consuming for providers and may not be necessary for all providers. For example, one waiver provider we spoke with reported that after his agency was approved as a standard Medicaid program provider, the approval process to become a provider for the Waiver program took another eight months to complete. Additionally, there are some waiver services, such as those within the *Expressive Therapy* category (e.g., music therapy, play therapy, and art therapy), that are not available under any other Medicaid program. Because some *Expressive Therapy* providers are not allowed to provide services under other Medicaid programs, it is a disincentive to these providers for the Department to require them to apply first for the general Medicaid Provider ID and then for a second Waiver Provider ID. The Department should evaluate ways to simplify the requirements for providers to become approved providers for the Waiver program. Among the options the Department should assess are (1) combining the approval processes so that providers are required to complete only one streamlined process to become waiver service providers, and (2) eliminating the requirement for all providers to be separately approved to receive a second Provider ID number for the Waiver program.

The Department needs to take proactive steps to increase the pool of providers for the Waiver program. In addition to enforcing the requirement that SEP case managers document all of a child's service needs in the care plan even when those needs are not being met, as discussed in the previous section, the Department needs to enforce the requirement for SEP agencies to recruit providers by ensuring that the SEP agencies are developing and implementing plans to identify and recruit new providers for the Waiver program. In addition, the Department needs to reevaluate the limitations it has established that may prevent qualified providers from delivering services under the Waiver program and find ways to encourage provider participation.

Recommendation No. 2:

The Department of Health Care Policy and Financing (the Department) should increase resource development efforts to help ensure there is an adequate pool of providers for the Pediatric Hospice Waiver program (the Waiver program) by:

- a. Enforcing contractual and regulatory requirements that the Single Entry Point (SEP) agencies identify and recruit providers. This should include ensuring that SEP agencies conduct and document recruitment efforts specific to the Waiver program that address unmet needs and resource gaps identified by case managers.
- b. Reevaluating and changing, if warranted, the current limitations placed on who can become a waiver service provider. This should include an

evaluation of whether qualified providers who are not employed by a hospice or home health agency can be enlisted to provide services within the broad *Palliative/Supportive Care* service category. This should also include assessing whether the requirement that all waiver providers must apply separately for both a Medicaid Provider ID number and a Pediatric Hospice Waiver Provider ID number can be streamlined to require potential providers to go through only one, rather than two, approval processes.

Department of Health Care Policy and Financing Response:

Agree. Implementation date: July 2012.

- a. As required per contract, the Department receives on an annual basis Resource Development activities from all SEP agencies. The Department agrees there is always room for improvement and will develop more concrete expectations concerning provider outreach and monitor efforts related to the identification of resource gaps and necessary targeted recruitment efforts.
- b. The Department agrees to reevaluate the current provider application process to determine if changes are warranted to streamline the process, as well as expand the list of qualified providers for the *Palliative/Supportive Care* service category.

Waiver Program Design Choices

A third key component in implementing a Medicaid HCBS waiver program is choosing effective design elements that will achieve the goals of the program, address the specific needs of the target population, and complement the services available through other resources available to waiver enrollees. States have broad flexibility in designing waiver programs to accomplish these purposes and, as such, final waiver designs can be complex and unique. States receive guidance from CMS throughout the waiver design and implementation process to ensure that new waivers include essential program components. Ultimately, though, the Medicaid Single State Agency is responsible for ensuring the success of each waiver by carefully building a cohesive program and actively monitoring how well the program is operating so that improvements can be made as needed to ensure that the program functions as intended.

We reviewed the original and renewal applications for the Waiver program, service utilization data, and information on how the Department set provider reimbursement rates for the program. We identified three areas in which the Department should reevaluate its design choices and program structure to better meet the statutory goals of the program. Specifically, we found:

- The Department should improve its mechanisms for ensuring that families of children enrolled in the Waiver program are able to receive bereavement counseling both before and after a child has died, as the General Assembly has required.
- The Department should take steps to ensure the waiver service frequency requirements align with the overall purpose and goals of the Waiver program.
- The Department should use a valid, comparable basis for setting waiver service rates.

We discuss these problems in the following three sections.

Bereavement Counseling for the Family

The first area in which the Department should reexamine the Waiver program's design relates to bereavement counseling. An important part of providing palliative and hospice care is extending grief and bereavement services to the family of the person who may die. Bereavement is defined in federal regulations as "emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment" [42 C.F.R. Section 418.3]. The General Assembly mandated that Colorado's pediatric hospice care system include a means of offering bereavement services "to the extent available under federal law" [Section 25.5-5-305(3)(c), C.R.S.]. Federal laws allow bereavement services to be offered to a Medicaid enrollee's family through a Medicaid HCBS waiver program. Consistent with the statutory direction, state regulations specify that bereavement counseling must be made available to the family through the Pediatric Hospice Waiver program for up to one year following an enrolled child's death [10 C.C.R. 2505-10, Section 8.504.2].

We spoke to the Department about how it included bereavement counseling as a service within the Waiver program and found, overall, the Department cannot provide assurance that families are receiving this service. We identified the following areas in which the Department should improve its system for ensuring that families receive bereavement counseling services:

The Department did not establish bereavement counseling as a separate waiver service. Instead, bereavement is included within the general *Counseling* waiver service category. The Department offers children and their families up to 98 hours of counseling services each year, but there is no distinction within this limit between bereavement and general grief counseling or between bereavement counseling to be provided before the child’s death and after. Without a separate service category, it is not possible for the SEP agencies or the Department to track whether families are receiving bereavement counseling or in what amounts. We asked the Department for data on the utilization of bereavement counseling, but the Department was unable to provide any evidence that any family had received this service through the Waiver program. The Department stated it can identify utilization of waiver counseling services only in general. The Department attested to CMS in its 2010 waiver renewal application that bereavement counseling has been utilized by families of enrolled children who have died.

The Department has not provided guidance to SEP agencies on planning for bereavement counseling. Generally, Medicaid services cannot be provided to the Medicaid enrollee’s family after the enrollee has died. However, federal regulations do allow states to provide bereavement services to a family after an HCBS waiver program enrollee has died. We reviewed all the materials available to the SEP agencies regarding the Waiver program, including the waiver application, statutes, regulations, training materials, program fact sheets, provider bulletins, and provider manuals. We found that none of the materials contains any guidance to the SEP agencies about how to reflect, in the care plans, the need for a family to receive bereavement services after the enrolled child has died. This lack of guidance is particularly concerning because bereavement is not a separate waiver service—it is part of the broader *Counseling* service category. As such, when case managers review the waiver services that are available they may not readily think about addressing the need for families to receive bereavement counseling after a child’s death. We reviewed a sample of care plans for 14 children enrolled in the Waiver program and found that none of the care plans identified a need for bereavement counseling. The Department should require that SEP case managers consider the need for bereavement services during care planning and require case managers to specifically reflect the need for any bereavement services in the written plan of care.

The Department has not established a separate reimbursement rate for bereavement services. Because the Department bundled bereavement counseling within the general *Counseling* waiver service category, it did not establish a separate rate for bereavement services. The Department attested to CMS in its waiver application that payment for bereavement services had been built into the rates for all *Counseling* waiver services provided prior to the child’s death; we found no evidence to support this attestation. Establishing a rate for bereavement counseling that will cover services both before and after the enrolled child has died is challenging because federal Medicaid laws do not allow payment for

services that occur after the Medicaid enrollee has died. However, CMS has allowed HCBS waiver programs to implement mechanisms to pay providers in advance (i.e., before the enrollee dies) for bereavement services that occur after an enrollee's death as long as the bereavement services are *initiated* prior to the enrollee's death.

Two other states with approved HCBS waiver programs and the standard Medicaid hospice care system currently have mechanisms in place to plan and pay for bereavement services after death. These programs could serve as models for Colorado. First, California and North Dakota have established HCBS waiver programs for pediatric hospice care that include the requirement that families request bereavement care prior to the child's death. This allows payment for service to be made before the child's death. California also specifies the total number of hours of bereavement counseling that can be provided rather than the total number of all types of counseling hours that can be provided. Second, under the standard hospice care system, federal law [42 C.F.R. Section 418.64(d)(1)(ii)] requires all licensed hospice agencies to offer bereavement services for up to one year following the death of the hospice patient. The law requires the hospice agency and family to establish a "bereavement plan of care" separate from the patient's general care plan that specifies who will receive bereavement services, what the services will consist of, and what the frequency will be.

The Department needs to improve its system of offering bereavement counseling services to the families of children enrolled in the Waiver program, as intended by statute. This effort should include establishing a tracking mechanism to ensure that the Department can clearly identify bereavement counseling services from other waiver services, providing guidance to the SEP agencies regarding planning for bereavement counseling, and establishing limitations and payment mechanisms for bereavement services.

Recommendation No. 3:

The Department of Health Care Policy and Financing (the Department) should make improvements to the Pediatric Hospice Waiver program (the Waiver program) to ensure that families receive bereavement counseling that can continue after the enrolled child has died by:

- a. Establishing a tracking mechanism to ensure that the Department can differentiate bereavement counseling services from other waiver services, including other counseling services. To accomplish this, the Department should consider making bereavement counseling a separate waiver service category with separate service limitations from the general *Counseling* waiver service category.

- b. Providing guidance to Single Entry Point (SEP) agencies on how to identify the need for bereavement services in care plans. This guidance should include the requirement that a bereavement plan of care be initiated prior to an enrolled child's death.
- c. Establishing a payment mechanism so the Department can ensure that payment is made for all bereavement services provided, including those services provided after the enrolled child has died. To accomplish this, the Department should consider bereavement service payment models currently in use by other pediatric hospice waiver programs that have been approved by the Centers for Medicare and Medicaid Services (CMS).

Department of Health Care Policy and Financing Response:

- a. Agree. Implementation date: July 2012.

The Department agrees to establish a tracking mechanism in order to differentiate bereavement services from the counseling services. The Department also agrees to explore options around the possibility of separating bereavement services from the general *Counseling* service category, including reaching out to other states with similar Home and Community-Based Services (HCBS) waiver services, as well as evaluating the possible financial implications.

- b. Agree. Implementation date: July 2012.

The Department agrees to conduct annual SEP care plan training to include bereavement services. Training will include how to address and document bereavement services, as well as how to initiate the service needs when requested by a parent, prior to the death of the enrolled recipient.

- c. Agree. Implementation date: January 2012.

The methodology of bundling bereavement counseling into other rates to ensure payment after death is a precedent set by the Medicare hospice benefit. However, this methodology may not directly apply in a waiver program due to some differences in the way the service is billed. By January 1, 2012, the Department will review other pediatric hospice waiver programs that have been approved by CMS, specifically mechanisms for making payments for bereavement counseling and other family services delivered after the client's death. Once the methodologies have been reviewed, the Department will

evaluate the effectiveness of the current model and will incorporate any changes that the Department deems necessary.

Waiver Service Frequency Requirements

The second design area the Department needs to reevaluate relates to the required frequency of waiver services. Under both state and federal laws, the Waiver program is intended to be only one source for providing needed services to an enrolled child. Statutes require that waiver services be coordinated with other services, including curative treatments, and be available over a lengthy time span—from the time of diagnosis of a life-limiting condition until the child reaches 19 years of age. Federal laws require that waiver services complement or supplement other services and be used only after all other sources of care have been accessed. These state and federal requirements for the Waiver program clearly indicate that waiver services are intended to be part of a larger spectrum of care for a child. As such, the waiver services and service frequency requirements the Department establishes for the Waiver program must account for the range of services and providers available to enrolled children.

The Department currently has a rule requiring children enrolled in the Waiver program to receive at least one waiver service every month to maintain enrollment in the program [10 C.C.R. 2505-10, Section 8.504.4]. We found the Department has not enforced this requirement. We reviewed waiver enrollment and claims data for the period between December 2008 and March 2010 and identified 33 children who remained enrolled in the Waiver program for more than a month (i.e., 30 days) even though it appears they had not received any waiver services. Enrollment periods for these 33 children ranged from 38 to 480 days. Of these 33 children, 27 did receive standard Medicaid program services while they were enrolled in the Waiver program at a total cost of about \$1.37 million during the 16-month period we reviewed. Because these 27 children did not receive waiver services and therefore should have been disenrolled from the Waiver program in accordance with the Department's rule, they may not have been eligible to receive the \$1.37 million in services through the standard Medicaid program.

As discussed in a previous section, in some instances children did not receive waiver services because a waiver service provider was not available. Four of the five SEP agencies we spoke with reported they were aware the Department requires enrolled children to be disenrolled if the child does not receive a waiver service each month. However, these SEP agencies stated that despite the rule requiring disenrollment, they have been unwilling to penalize children and families when there is a "no fault" reason the child did not receive a waiver service once every month, such as when a provider is not available for the service the child needs. These same SEP agencies stated that enrolled children were

receiving at least some of the services they needed through the standard Medicaid program, as intended, and disenrollment would disrupt the care they were getting. The Department stated it was not aware that some enrolled children were not receiving services through the Waiver program.

The Department needs to take steps to make the Waiver program more consistent with the intent of the General Assembly. First, the Department should increase efforts to ensure that enrolled children have access to at least one waiver service each month. As we have noted in previous sections of the report, there are problems with respect to care planning and access to providers that the Department needs to address. Making improvements in these areas could help the Department ensure that enrolled children are able to access needed waiver services. In addition, the Department now has program utilization data that it can use to determine if other problems in program implementation may be keeping enrolled children from accessing needed waiver services.

Second, the Department should evaluate whether revising the waiver’s design is warranted. If the Department determines that the needs of enrolled children may be met in instances where a waiver service is not provided every month, the Department should consider requiring monitoring of the child every month as an alternative to requiring a waiver service, in months when a waiver service is not provided. According to CMS staff, federal regulations would allow the SEP case manager to contact the family to ensure the child’s condition does not deteriorate to the point of needing hospitalization, in months where a waiver service is not provided. This waiver design option would allow the Department to maintain case management as an administrative function but would require the Department to submit a waiver amendment to CMS for approval.

Finally, the Department may need to consider making case management or another service one of the waiver services that is required every month to maintain enrollment in the Waiver program. Currently, case management is conducted under SEP agency contracts and is not a waiver service that may be used to meet the Department’s frequency rule. Federal regulations allow case management to be a waiver service. For the Children’s HCBS waiver program, which also grants children access to the standard Medicaid program, the Department included case management as a waiver service. Further, California’s pediatric hospice waiver program was designed to include “Care Coordination” as a waiver service, which is defined as case management that “includes development and implementation of the Comprehensive Care Plan, home visits for regular monitoring of the health and safety of the waiver participant and central coordination of medical and psychological services.”

The Department needs to address the problems we have identified with respect to care planning, access to providers, and the design of the Waiver program—specifically bereavement counseling services and frequency requirements under

the program—to improve the program and ensure that enrolled children are able to access needed services. If the Department determines a change in waiver service frequency or classification of case management is warranted, the Department will need to submit a waiver application amendment to CMS for approval of any waiver design modifications.

Recommendation No. 4:

The Department of Health Care Policy and Financing (the Department) should evaluate whether revising the design of the Pediatric Hospice Waiver program (the Waiver program) is warranted to improve the program and ensure enrolled children are able to access needed services. Specifically, the Department should address the problems identified in this report with respect to care planning and access to providers, and use utilization data to determine whether changes should be made to the current frequency requirement or waiver service categories. If the Department chooses to change the frequency requirement or include case management or another service as a waiver service, the Department should submit a waiver application amendment reflecting these changes to the federal Centers for Medicare and Medicaid Services (CMS) for approval. Regardless of changes to the frequency requirement or waiver services, the Department should enforce the requirements it establishes regarding the frequency of service provision and disenrollment of children who are no longer eligible for the program.

Department of Health Care Policy and Financing Response:

Agree. Implementation date: July 2012.

The Department agrees that the requirements regarding the frequency of service provision and disenrollment of children who are no longer eligible for the program should be enforced and will do so through annual Single Entry Point (SEP) agency trainings, to include clearly defined service definitions, as well as coordination of available services. The Department agrees to develop a process to monitor frequency of service utilization.

The Department also agrees to reevaluate the frequency requirement for this waiver and explore available options. If it is determined that changes in frequency requirements are warranted, a waiver amendment will need to be submitted to CMS for approval.

The Department has already evaluated the option of using case management as a waiver service and will not pursue this option. Case

management can be received through state plan services. Because waiver services are intended to be an adjunct to state plan services and not intended to replace state plan services, the Department would not want to set up a new service which would replace a state plan service.

The Department does agree to conduct annual SEP trainings on the Waiver program to include detailed explanation of services available through this Home and Community-Based Services (HCBS) waiver program to ensure that eligible recipients receive the waiver services, as appropriate, in a timely manner. It is the Department's belief that training specific to services offered through the Waiver program will address Recommendation No. 4.

Basis for Provider Rates

The third area of waiver design that should be addressed by the Department relates to the establishment of provider payment rates for waiver services. The Department established four main service categories under the Waiver program, with sub-categories for further payment rate distinctions as listed in the table below, to account for the array of waiver services available to enrolled children and their families. Waiver services within these categories include those that are similar to hospice care under the standard Medicaid program as well as additional services that are not available elsewhere in the Medicaid system, such as *Expressive Therapy*, designed to address the unique needs of children.

Pediatric Hospice Waiver Service Payment Rate Table Rates Effective as of July 2010		
Description	July 2010 Rate / Unit	Maximum Allowed
Expressive Therapy	\$54.88 / hr	39 hrs/yr
Individual Counseling	\$13.72 / 15 min	98 hrs/yr
Family Counseling	\$13.72 / 15 min	
Group Counseling	\$7.69 / 15 min	
Unskilled Respite (<i>up to 4 hrs/visit</i>)	\$3.49 / 15 min	30 unique days/yr
Unskilled Respite	\$69.96 / day	
RN/LPN Respite (<i>up to 4 hrs/visit</i>)	\$8.99 / 15 min	
RN/LPN Respite	\$144.16 / day	
RN/LPN Palliative Care (<i>up to 4 hrs/visit</i>)	\$32.21 / hr	n/a
RN/LPN Palliative Care	\$132.57 / day	
Source: Provider Bulletin published by the Department of Health Care Policy and Financing in June 2010.		

The rate structure for a public service program should have a sound basis, and the rationales underlying how rates were established should be documented. This is important to ensure that the State does not pay too much or too little for public services and to identify whether these rates have an impact on recruiting service providers. We reviewed the waiver application and waiver service rates published in the Department's provider bulletins to determine how the Department established the rate structure for the array of waiver services available through the Waiver program. We also asked the Department for documented evidence to support the methods and calculations that were used to determine rates for waiver services. We found two problems related to the Department's processes for setting rates for the Waiver program, as discussed below.

The Department did not use a valid, comparable basis for setting some waiver service rates. The Department states that it used existing Medicaid services as a basis for establishing rates for services under the Waiver program when an existing Medicaid service was comparable to a waiver service. For example, the Department stated it used standard hospice rates paid through the standard Medicaid program as a basis for determining the rates it would pay for similar waiver services within the *Palliative/Supportive Care* service category. However, we found that the services the Department used as a basis were not comparable to the waiver services in the following ways:

- **One-on-one care.** Waiver services are designed to be offered as one-on-one services in the child's home or community, but the Department set some of the rates for waiver services using Medicaid services that may be provided in a group setting within an inpatient facility. There are economies of scale when a provider cares for a group of patients in an inpatient facility rather than caring for a single patient in the patient's home. However, the payment rate for the Waiver program does not appear to recognize that these economies of scale are not available when providing services to a single patient in his or her home. For example, the Department set the Waiver program's *Respite* service rates based on respite rates for standard hospice care, where the hospice patient is required to be served in the hospice agency's inpatient facility.
- **Intensity of service needs.** Waiver services within the *Palliative/Supportive Care* category can be provided to address acute needs that require round-the-clock care, or to address less intensive needs for shorter periods. The Department used existing hourly and daily rates for standard hospice care to set hourly and daily rates, respectively, for the Waiver program. However, under standard hospice care, the hourly and daily rates are applied differently than under the Waiver program, making the standard hospice rates not relevant for setting waiver rates. Specifically, under standard hospice care, hourly rates are charged when a client is

receiving constant bedside monitoring (from 8 up to 24 hours) for acute cases; daily rates are charged when a client is receiving routine, short-term care (less than 8 hours) for less acute cases. In contrast, under the Waiver program, hourly rates are charged when a client is receiving short-term, less intensive services, and daily rates are charged when the client receives continuous services to address more acute needs.

- **Service bundling.** The Department used the standard Medicaid program hospice care rates as a basis for the Waiver program’s *Palliative/Supportive Care* rates, although the range of services offered under the two programs is different. Under the standard Medicaid program, the hospice rates cover a “bundle” of services that includes grief and bereavement counseling as part of the palliative care offered. Under the Waiver program, the *Palliative/Supportive Care* service category does not include any counseling services; *Counseling* is a separate service category with a separate rate for the Waiver program. Because of the differences in the range of services covered, the standard Medicaid program’s hospice care rates do not serve as a sound basis for the Waiver program’s *Palliative/Supportive Care* rates. In addition, as mentioned previously, the Department established a single rate for *Counseling* that was intended to include bereavement services provided after the death of an enrolled child. We found no evidence that the *Counseling* rate was developed to incorporate payment for such bereavement services.

The Department did not document how the rate structure was established for some waiver services. Specifically, the Department did not document how it set rates for services within the *Expressive Therapy* category, which includes services such as music therapy, play therapy, and art therapy. The services within this category are not available elsewhere in the Medicaid system but have been included in the waiver to address the unique needs of children diagnosed with a life-limiting condition. Because these services are unique to the Waiver program, the Department could not use established rates for other Medicaid services as a basis for the *Expressive Therapy* services. The Department stated that it did not have documentation to show how *Expressive Therapy* rates were set but that salary information for therapists and counselors working for The Children’s Hospital was used. The Department did not have the data it used from The Children’s Hospital available for us to review.

Ensuring that the waiver service payment rates have a sound basis is an important element in designing this specialized program that serves some of Colorado’s most vulnerable citizens. Without establishing a sound basis for provider payment rates, the Department cannot ensure that the rates are not serving as a disincentive to provider recruitment or that the State is not paying too much or too little for waiver services.

Recommendation No. 5:

The Department of Health Care Policy and Financing (the Department) should reevaluate the rate structure established for the Pediatric Hospice Waiver program (the Waiver program) services and adjust the rates as needed to ensure that all rates have a sound basis. Specifically, the Department should:

- a. Ensure that rates for the program account for any discrepancies in economies of scale, intensity of service needs, and service bundling between the Waiver program services and other similar services referenced for rate setting.
- b. Fully document the method and rationale used for calculating all Waiver program service rates and maintain the documentation for future reference.

Department of Health Care Policy and Financing Response:

Agree. Implementation date: January 2012.

- a. By January 2012, the Department will evaluate the current rate structure established for Pediatric Hospice Waiver program services. If the Department determines that modification to the rate structure and adjustment to the rates are necessary, the Department will prioritize the required changes within budget and staffing constraints. The development of a new rate structure would require substantial staff time, and any rate change resulting in higher payments or new staff would require a budget action and additional appropriations from the General Assembly.

The Department asserts that the development of a comprehensive initial rate structure is only the first step in assuring adequate payment rates for services. The Department is concerned that factors that are used to set rates are only evaluated once, and after that point updates to the rates are based solely on appropriations from the General Assembly. When additional funding is not made available, the Department cannot ensure adequate reimbursement.

This problem is not unique to Colorado; the Centers for Medicare and Medicaid Services (CMS) recently published draft rules with a similar objective; that is, to clarify which factors should be considered when setting new rates in order to ensure appropriate payment and access to

providers. These proposed rules require several standard factors that must be considered when setting rates and evaluating rates on an ongoing basis. While it is not known at this time what the final rules will be, the Department will incorporate any new requirements from CMS into this evaluation. However, because the new regulations may require additional budgetary or statutory authority, the Department will be required to work within the existing budget and legislative process to ensure that it complies with this recommendation.

- b. By January 1, 2012 the Department will establish a standard operating procedure for documenting decisions made during the rate-setting process. Upon completion of the rate review as discussed in response to Recommendation No. 5a, the Department will follow the new procedure to create a comprehensive document outlining the rationale for rates for the Waiver program for future reference.
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