

DEPARTMENT OF HEALTH CARE FINANCE

NOTICE OF PROPOSED RULEMAKING

The Director of the Department of Health Care Finance, pursuant to the authority set forth in An Act to enable the District of Columbia to receive federal financial assistance under Title XIX of the Social Security Act for a medical assistance program, and for other purposes, approved December 27, 1967 (81 Stat. 744; D.C. Official Code § 1-307.02 (2006 Repl. & 2012 Supp.)) and Section 6(6) of the Department of Health Care Finance Establishment Act of 2007, effective February 27, 2008 (D.C. Law 17-109; D.C. Official Code § 7-771.05(6) (2008 Repl.)), hereby gives notice of the intent to adopt a new Section 940 (Medicaid Pediatric Palliative Care and Hospice Care) to Chapter 9, Title 29 (Public Welfare) of the District of Columbia Municipal Regulations (DCMR). This rule establishes standards for reimbursement by the District of Columbia Medicaid program for pediatric palliative care and hospice services, and reflects recently enacted federal legislation that allows provision of concurrent hospice and curative care for children.

Pediatric palliative care and hospice (PPCH) services for children with life-threatening conditions focuses on enhancing the child’s quality of life, minimizing suffering, optimizing functionality, and providing opportunities for personal and spiritual growth. These services are planned and delivered through the collaborative efforts of an interdisciplinary team with the child, family, and caregivers at its center. These rules also authorize PPCH services to be provided concurrently with ongoing treatment services for the condition by which the child became terminally ill.

PPCH is achieved through a combination of active and compassionate therapies intended to comfort and support the child as well as family members and caregivers. Core services include various therapies, child life services provided by a Child Life Specialist, home health aide services, nutritional counseling, pain/symptom management, pharmacy services and respite care. The Council of the District of Columbia approved the corresponding State Plan Amendment (SPA) on June 15, 2012 (PR-0693), and the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, has approved the corresponding SPA with an effective date of August 1, 2012.

The Director also gives notice of the intent to take final rulemaking action to adopt these proposed rules not less than thirty (30) days after the date of publication of this notice in the *DC Register*.

A new Section 940 of Chapter 9 of Title 29 DCMR is added to read as follows:

940 Pediatric Palliative Care and Hospice Care

940.1 These rules establish the standards and conditions of participation for pediatric palliative care and hospice (PPCH) providers providing pediatric hospice services under the District of Columbia Medicaid Program.

- 940.2 Pediatric palliative and hospice care is an organized program for delivering care to children with life-threatening conditions. This care focuses on enhancing quality of life for the child and family, minimizing suffering, optimizing functions, and providing opportunities for personal growth.
- 940.3 An individual shall be eligible to receive PPCH services when he/she is:
- (a) Under the age of twenty one (21);
  - (c) Eligible for Medicaid; and
  - (d) Certified as terminally ill in accordance with this section.
- 940.4 The hospice shall obtain the certification that a beneficiary is terminally ill in accordance with the following procedures:
- (a) For the initial ninety (90) day period of hospice coverage, the hospice shall obtain, no later than two (2) calendar days after hospice care is initiated, written certification statements signed by:
    - (1) The hospice medical director or the physician member of the hospice interdisciplinary team; and
    - (2) The individual's attending physician, specialty care, or primary care physician.
  - (b) For the second ninety (90) day period, the hospice shall obtain, no later than two (2) calendar days after the beginning of the second election period, written certification prepared by the hospice medical director or the beneficiary's attending physician, specialty care, or primary care physician.
  - (c) For any subsequent election period of sixty (60) days or one or more thirty (30) day extended election periods, the hospice shall obtain, no later than two (2) calendar days after the beginning of any subsequent election period, written certification prepared by the hospice medical director or the beneficiary's attending physician, specialty care, or primary care physician.
- 940.5 The certification required in § 940.4 shall include:
- (a) A statement that the beneficiary's life expectancy is six (6) months or less; and

- (b) The signature of any physician required in § 940.4 to certify the terminal illness.
- 940.6 Each beneficiary who elects hospice care shall file an election statement with a participating provider entity.
- 940.7 A parent or legally authorized guardian shall file the election statement for beneficiaries under the age of eighteen (18). Beneficiaries eighteen (18) years of age and over may file the election statement on their own or by a legally authorized representative.
- 940.8 If the beneficiary electing hospice lacks the mental capacity to make an election, the designated representative shall file the election statement pursuant to the requirements set forth in the Health Care Decisions Act of 1988, effective March 16, 1989 (D.C. Law 7-189; D.C. Official Code § 21-2201 *et seq*).
- 940.9 An election statement shall include:
- (a) Identification of the particular PPCH provider that will provide care to the beneficiary;
  - (b) An acknowledgement by the beneficiary or their representative that the beneficiary has been given a full explanation of the palliative rather than curative nature of hospice care as it relates to the beneficiary's terminal illness;
  - (c) An acknowledgement by the beneficiary or their representative that the beneficiary understands that an election to receive hospice care is a waiver of the Medicaid services described in § 940.13;
  - (d) The effective date of the election to receive hospice care; and
  - (e) The signature of the beneficiary or their representative.
- 940.10 The initial election period shall be for ninety (90) days, followed by a second ninety (90) day election period. Subsequent election periods shall be for sixty (60) days or one or more thirty (30) day election periods.
- 940.11 An election to receive PPCH is considered to continue through the initial election period and through any subsequent election periods without a break in care as long as the beneficiary remains in the care of the PPCH provider and does not revoke the election.
- 940.12 A beneficiary or their representative may revoke the hospice election by signing and dating a revocation statement. This shall not prohibit a beneficiary from reelecting PPCH services at a later date.

- 940.13 The beneficiary shall waive all rights to Medicaid coverage for the following services for the duration of the election to receive hospice care:
- (a) Hospice care provided by another provider, other than the PPCH provider designated by the beneficiary; and
  - (b) Any services equivalent to or duplicative of hospice care pursuant to 42 USC 1395(d)(2)(A)).
- 940.14 An election to receive PPCH services shall not constitute a waiver of rights to receive concurrent treatment services for the condition by which the beneficiary became terminally ill.
- 940.15 PPCH services shall be provided in accordance with a written plan of care developed by a pediatric interdisciplinary team in accordance with § 940.20.
- 940.16 The following services, performed by qualified personnel, may qualify as covered PPCH services subject to any requirements or limitations as set forth in § 940.21:
- (a) Physician services;
  - (b) Pediatric nursing services provided by a person who is licensed as a registered nurse pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)), and certified by the National Board of Pediatric Nurse Practitioners or the Pediatric Nursing Certification Board (PNCB);
  - (c) Child life specialist services provided by someone who completed a child life degree program at the bachelor's or master's level and who holds a certified child life specialist accreditation from the Child Life Council;
  - (d) Counseling services (pastoral, spiritual, bereavement, as necessary);
  - (e) Nutritional counseling;
  - (f) Homemaker services, home health aide services as described in Chapter 51 of Title 29 DCMR, and personal care aide services as described in Chapter 50 of Title 29 DCMR;
  - (g) Medical social services provided by a licensed social worker;
  - (h) Durable medical equipment and supplies as described in § 996 of Chapter 9 of Title 29 DCMR;

- (i) Pharmacology and pharmacy services for pain control and symptom management;
- (j) Physical, occupational, and speech therapy services;
- (k) Expressive therapies if necessary;
- (l) Massage therapy if necessary; and
- (m) Respite care for the recipient's family or other persons caring for the beneficiary at home.

940.17 A child life specialist may provide services that utilize play and psychological therapies to facilitate coping and adjustment of the child and to establish therapeutic relationships with beneficiaries and their families to facilitate the family's involvement in the child's care.

940.18 Pharmacology/pharmacy services shall include the following:

- (a) Prescription drug administration used primarily for relief of pain and symptom control related to the child's condition;
- (b) Evaluation of the child's response to medication therapy; and
- (c) Recommendations for appropriate corrective action administered by licensed pharmacists.

940.19 A provider of PPCH services may include:

- (a) A hospital;
- (b) A hospice enrolled in the Medicare program; or
- (c) A home health agency enrolled in the Medicare program that meets the requirements set forth in the Health-Care and Community Residence Facility Act, Hospice and Home-Care Licensure Act of 1983, effective Feb. 24, 1984 (D.C. Law 5-48; D.C. Official Code, §§ 44-501, *et seq.* (2005 Repl.; 2011 Supp.)).

940.20 A provider of PPCH services shall employ or contract with a pediatric interdisciplinary team which should include, at a minimum: a hospice medical director or a pediatrician; nurse or pediatric nurse practitioner; licensed social worker, counselor, child life specialist; and spiritual care provider. All members of the interdisciplinary team shall be able to provide pediatric expertise twenty-four (24) hours per day, seven (7) days a week.

- 940.21 A provider of PPCH services shall be reimbursed on a per diem rate basis at one (1) of the four (4) rates depending on which of the following levels of care is recommended in the plan of care:
- (a) Routine home care for a beneficiary who is not receiving continuous home care or general inpatient care as described in § 940.21 (b) and (c);
  - (b) Continuous home care consisting of care to maintain a beneficiary at home during a brief period of crisis lasting seventy two (72) hours or less consisting of:
    - (1) A minimum of eight (8) hours of care, not necessarily consecutive, provided during a twenty-four (24) hour day which begins and ends at midnight;
    - (2) Nursing care, provided by a registered nurse or licensed practical nurse (LPN) and accounting for more than half of the period of care; and
    - (3) Homemaker, home health aide, and personal care aide services if needed, to supplement nursing care.
  - (c) General inpatient care for purposes of pain control or acute or chronic symptom management provided in an approved freestanding hospice, or hospital consisting of:
    - (1) A minimum of eight (8) hours of care, not necessarily consecutive, provided during a twenty-four (24) hour day which begins and ends at midnight; and
    - (2) Nursing care, provided by a registered nurse or LPN and accounting for more than half of the period of care.
  - (d) Inpatient respite care or short term care to relieve family members caring for the beneficiary at home, when the beneficiary does not meet the requirements for continuous home care or general inpatient care. This service shall consist of:
    - (1) Care limited to five (5) consecutive days at a time not to exceed thirty (30) days per year; and
    - (2) PPCH services pursuant to a written plan of care.
- 940.22 A brief period of crisis shall be a period when care, predominantly consisting of nursing care, may be covered on a continuous basis for as long as twenty four (24)

hours a day or as necessary to maintain an individual in the home during an unexpected or dangerous event lasting seventy two (72) hours or less.

- 940.23 The rates for routine home care, continuous home care, general inpatient care and inpatient respite care shall be those developed by the Centers for Medicare and Medicaid (CMS) Hospice Wage Index guidelines, in accordance with 42 CFR Part 418, Subpart E. The rates shall be posted on the DHCF website at [www.dc-medicaid.gov](http://www.dc-medicaid.gov).
- 940.24 Inpatient respite care shall begin on the date of admission and excludes the date of discharge.
- 940.25 Medicaid-enrolled providers who are furnishing concurrent curative treatment services relating to the treatment of the condition for which a diagnosis of terminal illness has been made, shall be reimbursed by the Department under the authority of the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services benefit subject to any requirements set forth in State Plan and attendant rules.
- 940.26 Providers of PPCH services shall be responsible for the coordination of all services described in these rules to avoid duplication of equivalent services.
- 940.27 All services submitted for the child's ongoing hospice care beyond the initial one hundred and eighty day (180) period during the initial election period described under § 940.10 shall only be reimbursed upon receiving a prior authorization from DHCF's designated quality improvement organization.
- 940.99 **Definitions**

When used in this section, the following terms and phrases shall have the meanings ascribed:

**Beneficiary-** An individual who has been determined eligible to receive services under the D.C. Medicaid program.

**Continuous home care-** A day on which an individual who has elected to receive hospice care is not in an inpatient facility and receives hospice care consisting predominantly of nursing care on a continuous basis at home during a brief period of crisis necessary to maintain the terminally ill patient at home.

**Counseling services-** Services provided by a person who is licensed or authorized to practice as a licensed professional counselor pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

**Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services Benefit -** Comprehensive and preventive health care services as described in

Section 1905(r) of the Social Security Act, including necessary health care services for treatment of all physical and mental illnesses or conditions discovered by any screening or diagnostic procedures, for children under twenty one (21) who are enrolled in the Medicaid program.

**Expressive therapies** -Art therapy and/or music therapy provided by appropriately licensed professionals.

**General inpatient care day** -A day on which an individual who has elected hospice care receives general inpatient care in an inpatient facility for pain control or acute or chronic symptom management which cannot be managed in a home or other settings.

**Homemaker services** - Services consisting of general household activities provided by a trained homemaker, when the individual regularly responsible for these activities is unable to manage the home and care for themselves.

**Hospice** - A public agency or private organization or a subdivision of either that is primarily engaged in providing care to terminally ill individuals that meets the licensure requirements set forth in the Health-Care and Community Residence Facility Act, Hospice and Home-Care Licensure Act of 1983, effective Feb. 24, 1984 (D.C. Law 5-48; D.C. Official Code, §§ 44-501, *et seq.* (2005 Repl.; 2011 Supp.)) or the laws, and regulations of the particular jurisdiction where the facility is located.

**Hospice care** - A comprehensive set of services described in §1861(dd)(1) of the Social Security Act, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care.

**Hospice medical director** – A person who is hired by the Hospice as a medical director and licensed or authorized to practice as a physician pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

**Massage therapy** - Services provided by a person who is licensed or authorized to practice as a massage therapist pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

**Nutrition counseling**- Services provided by a person who is licensed or authorized to practice as a nutrition counselor pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).



**Occupational therapy services** – Services provided by a person who is licensed or authorized to practice occupational therapy services pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

**Pain and symptom management**- The use of pharmacologic and non-pharmacologic methods in compliance with nationally developed standards for pediatric palliative care pain and symptom management by the National Hospice and Palliative Care Organization.

**Physician services**- Services provided by a person who is licensed or authorized to practice as a physician pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

**Physical therapy services** – Services provided by a person who is licensed or authorized to practice as a physical therapist pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

**Plan of Care**- A written document developed by the patient's pediatric interdisciplinary team describing the scope of services and levels of care to be provided.

**Respite care** -Short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons caring for the individual.

**Routine home care**- A day on which an individual who has elected to receive hospice care is at home because he/she is not receiving continuous care or general inpatient care and may receive homemaker, home health aide or personal care services, if necessary to supplement regular at-home care.

**Speech therapy services** – Services provided by a person who is licensed or authorized to practice as a speech therapist pursuant to the District of Columbia Health Occupations Revisions Act of 1985, effective March 25, 1986 (D.C. Law 6-99; D.C. Official Code §§ 3-1201 *et seq.* (2007 Repl.; 2012 Supp.)).

Comments on these rules should be submitted in writing to Linda Elam, Ph.D., Medicaid Director, Department of Health Care Finance, Government of the District of Columbia, 899 North Capitol Street, NE, 6<sup>th</sup> Floor, Washington DC 20002; via telephone at (202) 442-9115; via email at [DHCFPublicComments@dc.gov](mailto:DHCFPublicComments@dc.gov); or online at [www.dcregs.dc.gov](http://www.dcregs.dc.gov), within thirty (30) days of the date of publication of this notice in the *D.C. Register*. Additional copies of these rules are available from the above address.