H. R. _____

To amend title XIX of the Social Security Act to provide States an option to cover a children’s program of all-inclusive coordinated care (ChiPACC) under Medicaid program.

IN THE HOUSE OF REPRESENTATIVES

Ms. DeGette introduced the following bill; which was referred to the Committee on ______________________

A BILL

To amend title XIX of the Social Security Act to provide States an option to cover a children’s program of all-inclusive coordinated care (ChiPACC) under Medicaid program.

1 Be it enacted by the Senate and House of Representa-
2 tives of the United States of America in Congress assembled,

3 SECTION 1. SHORT TITLE.

4 This Act may be cited as the “ChiPACC Act of
5 2018”.

6 SEC. 2. FINDINGS.

7 Congress finds that—
(1) serious illnesses and health conditions that are potentially life-threatening place significant stress on both the child and family;

(2) palliative care relieves children’s symptoms such as pain, fatigue, anxiety, nausea, and sleep problems, and may be provided at any age or stage of serious illness, and has been shown to enhance the quality of life for both the child and family;

(3) under the existing model under the Medicaid program under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.), eligible children diagnosed with potentially life-limiting illnesses are limited to receiving hospice services only after they have been given a prognosis of six months to live. There remain many critical barriers to end-of-life-care under the current healthcare system, including reluctance of medical professionals and families to acknowledge a limited life expectancy;

(4) such model offers discrete services, which can be difficult to navigate, while the qualifications for coverage under the Medicaid program can block access to critical care;

(5) the Children’s Program of All-inclusive Coordinated Care (referred to in this Act as “ChiPACC”) provides all-inclusive care for children
with life-threatening conditions and their families
from the time of diagnosis and—

(A) fills a gap in coverage under the Medicaid program of integrated, multi-disciplinary services that are reasonable and necessary for the palliation and management of seriously ill children;

(B) serves a population that includes children who are not yet hospice eligible; and

(C) provides greater coordination of palliative and curative services for children throughout the course of their illness or condition, which may begin at the time of diagnosis;

(6) some States have opted to provide services targeted to this population through waivers under subsections (b) and (c) of section 1915 of the Social Security Act (42 U.S.C. 1396n), each of which requires the approval of the Centers for Medicare & Medicaid Services of the initial waiver application and any subsequent renewal of such waiver;

(7) since 2005, the Secretary of Health and Human Services has approved home and community-based service waivers under section 1915(e) of such Act (42 U.S.C. 1396n(c)) to operate ChiPACC in five States;
(8) in States operating ChiPACC under such a waiver—

(A) the respective State’s Medicaid program achieved significant cost savings through a reduction in inpatient care and an increase in less expensive outpatient care;

(B) access to such services in such States reduced more costly utilizations of other services; and

(C) services provided through ChiPACC are less costly to the State’s Medicaid program because ChiPACC facilitates children receiving palliative care at home rather than receiving such services in an inpatient hospital setting; and

(9) allowing States the option to implement ChiPACC through a State plan amendment would—

(A) give States the ability to make such program a part of a State’s Medicaid program while avoiding the lengthy waiver process; and

(B) give States the flexibility to establish and design its program to fit the needs of the respective State.
SEC. 3. OPTIONAL MEDICAID COVERAGE OF CHILDREN’S PROGRAM OF ALL-INCLUSIVE COORDINATED CARE.

(a) Children’s Program of All-Inclusive Coordinated Care.—Title XIX of such Act is further amended by inserting after section 1946 (42 U.S.C. 1396w–5) the following new section:

“SEC. 1947. CHILDREN'S PROGRAM OF ALL-INCLUSIVE COORDINATED CARE.

“(a) State Option.—

“(1) In general.—Beginning on January 1, 2019, a State, at its option as a State plan amendment, may elect to provide for medical assistance under this title to ChiPACC eligible individuals who choose to enroll in a children’s program of all-inclusive coordinated care. In the case of an individual who chooses to enroll in such a program pursuant to such an election—

“(A) the individual shall receive ChiPACC benefits in addition to other services under the State plan; and

“(B) the health care providers furnishing services under such program shall receive payment for providing such services in accordance with the terms of the State plan.”
“(2) NUMERICAL AND GEOGRAPHICAL LIMITATIONS PERMITTED.—A State may establish—

“(A) a numerical limit on the number of individuals who may be enrolled in the State’s ChiPACC; or

“(B) geographic limitations on the service areas for a ChiPACC.

“(3) PROCESS FOR DETERMINING ELIGIBLE INDIVIDUALS.—If a State elects to establish a limitation under paragraph (2), the State shall establish a process for determining criteria for which individuals who may be enrolled in the State’s ChiPACC.

“(b) CHIPACC AND OTHER TERMS DEFINED.—In this section:

“(1) CHILDREN’S PROGRAM OF ALL-INCLUSIVE COORDINATED CARE; CHIPACC.—The terms ‘children’s program of all-inclusive coordinated care’ and ‘ChiPACC’ mean a program of coordinated care for ChiPACC eligible children that is established by a State under this section and meets the following requirements:

“(A) OPERATION.—The State administering agency may provide for the operation of the program through arrangements between one or more other entities that will serve as
ChiPACC coordinators (as defined in paragraph (3)).

“(B) COMPREHENSIVE BENEFITS.—

“(i) IN GENERAL.—The program provides comprehensive health care items and services to ChiPACC eligible individuals (as defined in paragraph (2)) in accordance with this section.

“(ii) SCOPE AND PLAN FOR SERVICES.—Such items and services shall—

“(I) include items and services described in subsection (c)(1)(A) to the extent such items and services are reasonable and necessary, as determined by the state, for the palliation and management of the CHiPACC eligible individual’s serious illness or condition; and

“(II) be provided consistent with a comprehensive care plan developed by an interdisciplinary health professional team (as defined in paragraph (4)).
“(iii) Qualifications of Providers.—Such items and services are provided through health care providers that—

“(I) meet such certification or other federal or state requirements as may be necessary to participate in the program of medical assistance under this title or in the program under title XVIII; and

“(II) maintain records on ChiPACC eligible individuals enrolled in the program and to whom the provider furnishes services, reflecting both the specific care and services furnished by the provider and the relationship of those services to the comprehensive plan of care for that individual and to the delivery of other services.

“(2) ChiPACC Eligible Individual.—The term ‘ChiPACC eligible individual’ means, with respect to a ChiPACC, an individual—

“(A) who, at the time of enrollment in the ChiPACC, is under 21 years of age
“(B) who resides in the service area of a ChiPACC, as defined by the State administering agency;

“(C) who is eligible for medical assistance under the State plan without regard to this section;

“(D) who suffers from a serious illness or health condition and for whom there is a reasonable likelihood that the individual’s life will be threatened by such illness or condition; and

“(E) whose health status is expected to decline because of such illness or condition before attaining the age of 21.

“(3) ChiPACC coordinator.—The term ‘ChiPACC coordinator’ means, with respect to a ChiPACC, an entity (which may be the State administering agency or another entity under an arrangement with such an agency) that, through the assignment of one or more case managers—

“(A) directs, supervises, and assures the coordination of comprehensive services to ChiPACC eligible individuals enrolled in the ChiPACC; and

“(B) assures the direct and continuous involvement of an interdisciplinary health profes-
sional team in managing and coordinating the
provision of care and services within the coordi-
nator’s responsibility to each such enrolled indi-
vidual.

“(4) INTERDISCIPLINARY HEALTH PROFESSIONAL TEAM.—The term ‘interdisciplinary health professional team’ means, with respect to a ChiPACC, a group of health professionals that—

“(A) includes at least—

“(i) one physician (as defined in section 1861(r));

“(ii) one registered professional nurse;

“(iii) one social worker, pastoral counselor, or other counselor; and

“(iv) one case manager who may be one of the individuals described in clauses (i) through (iii);

“(B) develops a comprehensive plan of care for ChiPACC eligible individuals enrolled with the ChiPACC and furnishes, or supervises the provision of care and services described in subsection (c)(1) to an individual enrolled in the ChiPACC in a manner that takes into account the best interests of such individual and such individual’s family; and
“(C) through direct action and communication with health care providers furnishing services under the ChiPACC, on behalf of or under the direction or supervision of, a State administering agency or a ChiPACC coordinator, coordinates the care and services furnished to such enrollees.

“(5) Palliative services.—The term ‘palliative services’ means patient and family-centered care that optimizes quality of life for an individual with a serious illness or condition by—

“(A) anticipating, preventing, and treating the individual’s suffering throughout the continuum of illness;

“(B) addressing the physical, intellectual, emotional, social and spiritual needs of the individual; and

“(C) facilitating the individual’s autonomy, access to information, and choice.

“(6) State administering agency.—The term ‘State administering agency’ means the State agency administering the State plan under this title (or a waiver of such plan).

“(c) Scope of Benefits.—
“(1) IN GENERAL.—Under a ChiPACC of a State, the State administering agency shall assure that—

“(A) an individual enrolled in the ChiPACC is covered for, at least—

“(i) comprehensive, integrated palliative and curative services;

“(ii) any long-term care services and supports provided under the State plan under this title (or waiver of such plan);

“(iii) counseling services and expressive therapy;

“(iv) respite care; and

“(v) anticipatory bereavement services to the immediate family members of the ChiPACC eligible individual; and

“(B) the ChiPACC is operated, and the services to enrolled individuals are furnished, in a manner that is consistent with Standards of Care and Practice Guidelines developed by Children’s Hospice International for a Program of All-Inclusive Care for Children (as in effect as of the date of the enactment of this section or such later date as the Secretary may specify).
such other standards as the Secretary may pro-
vide.

“(2) CONSTRUCTION.—Nothing in this sub-
section shall be construed to preclude a ChiPACC el-
igible individual’s eligibility to receive other services
under the State plan (or a waiver of such plan), in-
cluding early and periodic screening, diagnostic, and
treatment services under section 1905(a)(4)(B).

“(3) QUALITY ASSURANCE; PATIENT SAFE-
GUARDS.—

“(A) IN GENERAL.—With respect to a
ChiPACC, quality assurance and patient safeguards
shall be established by the State admin-
istering agency or shall be consistent with exist-
ing State systems.

“(B) CONSTRUCTION.—Nothing in this
subsection shall be construed as preventing the
Secretary from imposing requirements to ensure
the health and safety of individuals enrolled in
a ChiPACC under this section that are in addi-
tion to those otherwise provided under this sec-
tion.

“(4) COST-SHARING WAIVER.—A State admin-
istering agency may, in the case of a ChiPACC eligi-
ble individual enrolled in the State’s ChiPACC,
waive deductibles, copayments, coinsurance, or other cost-sharing that would otherwise apply under the State plan under this title.

“(d) ELIGIBILITY DETERMINATIONS.—

“(1) IN GENERAL.—In determining whether an individual is a ChiPACC eligible individual, the State administering agency shall conduct an independent evaluation and assessment, which shall include at least the following:

“(A) Consultation with appropriate treating and consulting health and support professionals caring for the individual.

“(B) An examination of the individual’s relevant history, medical records, and care and support needs, guided by best practices and research on effective strategies that result in improved health and quality of life outcomes.

“(C) To the extent appropriate, consultation with the individual, individual’s family, guardian, or other responsible individual.

“(2) RECORDKEEPING; APPEALS.—Any entity making the eligibility determination under paragraph (1) under contract with the State administering agency shall be subject to the recordkeeping
and appeals processes requirements specified in section 1902(a)(3).

“(e) Payments to Health Care Providers and CHIPACC Coordinators Under CHIPACC.—Payments to health care providers, a CHIPACC coordinator, or an interdisciplinary health professional team furnishing items and services under a CHIPACC shall be paid on a capitated or fee-for-service basis (or as otherwise allowable under the State plan under this title).

“(f) Applicability of Requirements.—With respect to carrying out a CHIPACC under this section, the following requirements of this title (and regulations relating to such requirements) shall not apply:

“(1) Section 1902(a)(1), relating to any requirement that CHIPACCs or CHIPACC services be provided in all areas of a State.

“(2) Section 1902(a)(10), insofar as such section relates to comparability of services among different population groups.

“(3) Sections 1902(a)(23) and 1915(b)(4), relating to freedom of choice of providers.

“(4) Section 1903(m)(2)(A), insofar as it restricts a CHIPACC provider from receiving prepaid capitation payments.
“(5) Section 1905(o), limiting the scope of hospice care.

“(6) Such other provisions of this title that the Secretary determines are inapplicable.”.

(b) Application Under CHIP.—Section 2107(e)(1) of the Social Security Act (42 U.S.C. 1397gg(e)(1)) is amended by adding at the end the following new subparagraph:

“(S) Section 1947 (relating to Medicaid children’s program of all-inclusive coordinated care).”.

(c) Continued Demonstration Project Authority.—Section 1947 of the Social Security Act, as added by subsection (a), shall not be construed as preventing a State from developing, or the Secretary of Health and Human Services from approving, a project similar to or related to ChiPACCs (as described in such section) under alternative authorities, including demonstration project and waiver authorities under title XIX of such Act or other provisions of such Act.