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(Original Signature of Member)

115TH CONGRESS
2D SESSION

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 (1) serious illnesses and health conditions that
2 are potentially life-threatening place significant
3 stress on both the child and family;

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

9 (3) under the existing model under the Med-
10 icaid program under title XIX of the Social Security
11 Act (42 U.S.C. 1396 et seq.), eligible children diag-
12 nosed with potentially life-limiting illnesses are lim-
13 ited to receiving hospice services only after they have
14 been given a prognosis of six months to live. There
15 remain many critical barriers to end-of-life-care
16 under the current healthcare system, including reluc-
17 tance of medical professionals and families to ac-
18 knowledge a limited life expectancy;

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

23 (5) the Children’s Program of All-inclusive Co-
24 ordinated Care (referred to in this Act as
25 “ChiPACC”) provides all-inclusive care for children

1 with life-threatening conditions and their families
2 from the time of diagnosis and—

3 (A) fills a gap in coverage under the Med-
4 icaid program of integrated, multi-disciplinary
5 services that are reasonable and necessary for
6 the palliation and management of seriously ill
7 children;

8 (B) serves a population that includes chil-
9 dren who are not yet hospice eligible; and

10 (C) provides greater coordination of pallia-
11 tive and curative services for children through-
12 out the course of their illness or condition,
13 which may begin at the time of diagnosis;

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

21 (7) since 2005, the Secretary of Health and
22 Human Services has approved home and community-
23 based service waivers under section 1915(c) of such
24 Act (42 U.S.C. 1396n(c)) to operate ChiPACC in
25 five States;

1 (8) in States operating ChiPACC under such a
2 waiver—

3 (A) the respective State's Medicaid pro-
4 gram achieved significant cost savings through
5 a reduction in inpatient care and an increase in
6 less expensive outpatient care;

7 (B) access to such services in such States
8 reduced more costly utilizations of other serv-
9 ices; and

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

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

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

21 (B) give States the flexibility to establish
22 and design its program to fit the needs of the
23 respective State.

1 **SEC. 3. OPTIONAL MEDICAID COVERAGE OF CHILDREN'S**
2 **PROGRAM OF ALL-INCLUSIVE COORDINATED**
3 **CARE.**

4 (a) CHILDREN'S PROGRAM OF ALL-INCLUSIVE CO-
5 ORDINATED CARE.—Title XIX of such Act is further
6 amended by inserting after section 1946 (42 U.S.C.
7 1396w-5) the following new section:

8 **“SEC. 1947. CHILDREN'S PROGRAM OF ALL-INCLUSIVE CO-**
9 **ORDINATED CARE.**

10 “(a) STATE OPTION.—

11 “(1) IN GENERAL.—Beginning on January 1,
12 2019, a State, at its option as a State plan amend-
13 ment, may elect to provide for medical assistance
14 under this title to ChiPACC eligible individuals who
15 choose to enroll in a children's program of all-inclu-
16 sive coordinated care. In the case of an individual
17 who chooses to enroll in such a program pursuant
18 to such an election—

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

22 “(B) the health care providers furnishing
23 services under such program shall receive pay-
24 ment for providing such services in accordance
25 with the terms of the State plan.

1 “(2) NUMERICAL AND GEOGRAPHICAL LIMITA-
2 TIONS PERMITTED.—A State may establish—

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

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

8 “(3) PROCESS FOR DETERMINING ELIGIBLE IN-
9 DIVIDUALS.—If a State elects to establish a limita-
10 tion under paragraph (2), the State shall establish
11 a process for determining criteria for which individ-
12 uals who may be enrolled in the State’s ChiPACC.

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

15 “(1) CHILDREN’S PROGRAM OF ALL-INCLUSIVE
16 COORDINATED CARE; CHIPACC.—The terms ‘chil-
17 dren’s program of all-inclusive coordinated care’ and
18 ‘ChiPACC’ mean a program of coordinated care for
19 ChiPACC eligible children that is established by a
20 State under this section and meets the following re-
21 quirements:

22 “(A) OPERATION.—The State admin-
23 istering agency may provide for the operation of
24 the program through arrangements between one
25 or more other entities that will serve as

1 ChiPACC coordinators (as defined in paragraph
2 (3)).

3 “(B) COMPREHENSIVE BENEFITS.—

4 “(i) IN GENERAL.—The program pro-
5 vides comprehensive health care items and
6 services to ChiPACC eligible individuals
7 (as defined in paragraph (2)) in accord-
8 ance with this section.

9 “(ii) SCOPE AND PLAN FOR SERV-
10 ICES.—Such items and services shall—

11 “(I) include items and services
12 described in subsection (c)(1)(A) to
13 the extent such items and services are
14 reasonable and necessary, as deter-
15 mined by the state, for the palliation
16 and management of the CHIPACC el-
17 ible individual’s serious illness or
18 condition; and

19 “(II) be provided consistent with
20 a comprehensive care plan developed
21 by an interdisciplinary health profes-
22 sional team (as defined in paragraph
23 (4)).

1 “(iii) QUALIFICATIONS OF PRO-
2 VIDERS.—Such items and services are pro-
3 vided through health care providers that—

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

10 “(II) maintain records on
11 ChiPACC eligible individuals enrolled
12 in the program and to whom the pro-
13 vider furnishes services, reflecting
14 both the specific care and services fur-
15 nished by the provider and the rela-
16 tionship of those services to the com-
17 prehensive plan of care for that indi-
18 vidual and to the delivery of other
19 services.

20 “(2) CHIPACC ELIGIBLE INDIVIDUAL.—The
21 term ‘ChiPACC eligible individual’ means, with re-
22 spect to a ChiPACC, an individual—

23 “(A) who, at the time of enrollment in the
24 ChiPACC, is under 21 years of age

1 “(B) who resides in the service area of a
2 ChiPACC, as defined by the State admin-
3 istering agency;

4 “(C) who is eligible for medical assistance
5 under the State plan without regard to this sec-
6 tion;

7 “(D) who suffers from a serious illness or
8 health condition and for whom there is a rea-
9 sonable likelihood that the individual’s life will
10 be threatened by such illness or condition; and

11 “(E) whose health status is expected to de-
12 cline because of such illness or condition before
13 attaining the age of 21.

14 “(3) CHIPACC COORDINATOR.—The term
15 ‘ChiPACC coordinator’ means, with respect to a
16 ChiPACC, an entity (which may be the State admin-
17 istering agency or another entity under an arrange-
18 ment with such an agency) that, through the assign-
19 ment of one or more case managers—

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

24 “(B) assures the direct and continuous in-
25 volvement of an interdisciplinary health profes-

1 sional team in managing and coordinating the
2 provision of care and services within the coordi-
3 nator’s responsibility to each such enrolled indi-
4 vidual.

5 “(4) INTERDISCIPLINARY HEALTH PROFES-
6 SIONAL TEAM.—The term ‘interdisciplinary health
7 professional team’ means, with respect to a
8 ChiPACC, a group of health professionals that—

9 “(A) includes at least—

10 “(i) one physician (as defined in sec-
11 tion 1861(r));

12 “(ii) one registered professional nurse;

13 “(iii) one social worker, pastoral coun-
14 selor, or other counselor; and

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

18 “(B) develops a comprehensive plan of care
19 for ChiPACC eligible individuals enrolled with
20 the ChiPACC and furnishes, or supervises the
21 provision of care and services described in sub-
22 section (c)(1) to an individual enrolled in the
23 ChiPACC in a manner that takes into account
24 the best interests of such individual and such
25 individual’s family; and

1 “(C) through direct action and communica-
2 tion with health care providers furnishing serv-
3 ices under the ChiPACC, on behalf of or under
4 the direction or supervision of, a State admin-
5 istering agency or a ChiPACC coordinator, co-
6 ordinates the care and services furnished to
7 such enrollees.

8 “(5) PALLIATIVE SERVICES.—The term ‘pallia-
9 tive services’ means patient and family-centered care
10 that optimizes quality of life for an individual with
11 a serious illness or condition by—

12 “(A) anticipating, preventing, and treating
13 the individual’s suffering throughout the con-
14 tinuum of illness;

15 “(B) addressing the physical, intellectual,
16 emotional, social and spiritual needs of the indi-
17 vidual; and

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

20 “(6) STATE ADMINISTERING AGENCY.—The
21 term ‘State administering agency’ means the State
22 agency administering the State plan under this title
23 (or a waiver of such plan).

24 “(c) SCOPE OF BENEFITS.—

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

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

6 “(i) comprehensive, integrated pallia-
7 tive and curative services;

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

11 “(iii) counseling services and expres-
12 sive therapy;

13 “(iv) respite care; and

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

17 “(B) the ChiPACC is operated, and the
18 services to enrolled individuals are furnished, in
19 a manner that is consistent with Standards of
20 Care and Practice Guidelines developed by Chil-
21 dren’s Hospice International for a Program of
22 All-Inclusive Care for Children (as in effect as
23 of the date of the enactment of this section or
24 such later date as the Secretary may specify) or

1 such other standards as the Secretary may pro-
2 vide.

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

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

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

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

23 “(4) COST-SHARING WAIVER.—A State admin-
24 istering agency may, in the case of a ChiPACC eligi-
25 ble individual enrolled in the State’s ChiPACC,

1 waive deductibles, copayments, coinsurance, or other
2 cost-sharing that would otherwise apply under the
3 State plan under this title.

4 “(d) ELIGIBILITY DETERMINATIONS.—

5 “(1) IN GENERAL.—In determining whether an
6 individual is a ChiPACC eligible individual, the
7 State administering agency shall conduct an inde-
8 pendent evaluation and assessment, which shall in-
9 clude at least the following:

10 “(A) Consultation with appropriate treat-
11 ing and consulting health and support profes-
12 sionals caring for the individual.

13 “(B) An examination of the individual’s
14 relevant history, medical records, and care and
15 support needs, guided by best practices and re-
16 search on effective strategies that result in im-
17 proved health and quality of life outcomes.

18 “(C) To the extent appropriate, consulta-
19 tion with the individual, individual’s family,
20 guardian, or other responsible individual.

21 “(2) RECORDKEEPING; APPEALS.—Any entity
22 making the eligibility determination under para-
23 graph (1) under contract with the State admin-
24 istering agency shall be subject to the recordkeeping

1 and appeals processes requirements specified in sec-
2 tion 1902(a)(3).

3 “(e) PAYMENTS TO HEALTH CARE PROVIDERS AND
4 CHIPACC COORDINATORS UNDER CHIPACC.—Payments to
5 health care providers, a ChiPACC coordinator, or an inter-
6 disciplinary health professional team furnishing items and
7 services under a ChiPACC shall be paid on a capitated
8 or fee-for-service basis (or as otherwise allowable under
9 the State plan under this title).

10 “(f) APPLICABILITY OF REQUIREMENTS.—With re-
11 spect to carrying out a ChiPACC under this section, the
12 following requirements of this title (and regulations relat-
13 ing to such requirements) shall not apply:

14 “(1) Section 1902(a)(1), relating to any re-
15 quirement that ChiPACCs or ChiPACC services be
16 provided in all areas of a State.

17 “(2) Section 1902(a)(10), insofar as such sec-
18 tion relates to comparability of services among dif-
19 ferent population groups.

20 “(3) Sections 1902(a)(23) and 1915(b)(4), re-
21 lating to freedom of choice of providers.

22 “(4) Section 1903(m)(2)(A), insofar as it re-
23 stricts a ChiPACC provider from receiving prepaid
24 capitation payments.

1 “(5) Section 1905(o), limiting the scope of hos-
2 pice care.

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

5 (b) APPLICATION UNDER CHIP.—Section
6 2107(e)(1) of the Social Security Act (42 U.S.C.
7 1397gg(e)(1)) is amended by adding at the end the fol-
8 lowing new subparagraph:

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

12 (c) CONTINUED DEMONSTRATION PROJECT AU-
13 THORITY.—Section 1947 of the Social Security Act, as
14 added by subsection (a), shall not be construed as pre-
15 venting a State from developing, or the Secretary of
16 Health and Human Services from approving, a project
17 similar to or related to ChiPACCs (as described in such
18 section) under alternative authorities, including dem-
19 onstration project and waiver authorities under title XIX
20 of such Act or other provisions of such Act.