

117TH CONGRESS
1ST SESSION

H. R. 4952

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

AUGUST 6, 2021

Ms. DEGETTE (for herself and Mr. McCAUL) introduced the following bill;
which was referred to the Committee on Energy and Commerce

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 2021”.

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) many critical barriers to end-of-life care for
10 children exist under the current health care system,
11 including the limitation of hospice care under the
12 Medicaid program to children expected to live six
13 months or less, a prognosis that medical profes-
14 sionals and families are reluctant to make;

15 (4) the Children’s Program of All-inclusive Co-
16 ordinated Care (referred to in this Act as
17 “ChiPACC”) provides all-inclusive care for children
18 with life-threatening conditions and their families
19 from the time of diagnosis and—

20 (A) fills a gap in coverage under the Med-
21 icaid program of integrated, multi-disciplinary
22 services that are reasonable and necessary for
23 the palliation and management of seriously ill
24 children;

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

3 (C) provides greater coordination of pallia-
4 tive and curative services for children through-
5 out the course of their illness or condition,
6 which may begin at the time of diagnosis;

7 (5) some States have opted to provide services
8 targeted to this population through waivers under
9 subsections (b) and (c) of section 1915 of the Social
10 Security Act (42 U.S.C. 1396n), each of which re-
11 quires the approval of the Centers for Medicare &
12 Medicaid Services of the initial waiver application
13 and any subsequent renewal of such waiver;

14 (6) since 2005, the Secretary of Health and
15 Human Services has approved home and community-
16 based service waivers under section 1915(c) of such
17 Act (42 U.S.C. 1396n(c)) to operate ChiPACC in
18 five States;

19 (7) in States operating ChiPACC under such a
20 waiver—

21 (A) the respective State's Medicaid pro-
22 gram achieved significant cost savings through
23 a reduction in inpatient care and an increase in
24 less expensive outpatient care;

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

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

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

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

15 (B) give States the flexibility to establish
 16 and design its program to fit the needs of the
 17 respective State.

18 **SEC. 3. OPTIONAL MEDICAID COVERAGE OF CHILDREN’S**
 19 **PROGRAM OF ALL-INCLUSIVE COORDINATED**
 20 **CARE.**

21 (a) CHILDREN’S PROGRAM OF ALL-INCLUSIVE CO-
 22 ORDINATED CARE.—Title XIX of the Social Security Act
 23 (42 U.S.C. 1396a et seq.), as amended by section 9813
 24 of the American Rescue Plan Act of 2021, is further

1 amended by inserting after section 1947 the following new
2 section:

3 **“SEC. 1948. CHILDREN’S PROGRAM OF ALL-INCLUSIVE CO-**
4 **ORDINATED CARE.**

5 “(a) STATE OPTION.—

6 “(1) IN GENERAL.—Beginning on January 1,
7 2022, a State, at its option as a State plan amend-
8 ment, may elect to provide for ChiPACC services
9 under this title to ChiPACC eligible individuals who
10 choose to enroll in a children’s program of all-inclu-
11 sive coordinated care. In the case of an individual
12 who chooses to enroll in such a program—

13 “(A) the individual shall receive ChiPACC
14 services (as described in subsection (c)), includ-
15 ing but not limited to services under the State
16 plan; and

17 “(B) the health care providers furnishing
18 services under such program shall receive pay-
19 ment for providing such services in accordance
20 with the terms of the State plan.

21 “(2) PROCESS FOR DETERMINING ELIGIBLE IN-
22 DIVIDUALS.—If a State elects to establish a limita-
23 tion under paragraph (2), the State shall establish
24 a process, as described in subsection (e), for deter-

1 mining criteria for which individuals who may be en-
2 rolled in the State's ChiPACC.

3 “(3) STATE ADMINISTRATION.—The ChiPACC
4 shall be administered by the single State agency as
5 described in section 1904(a)(5).

6 “(4) MATCHING RATE.—The Federal medical
7 assistance percentage for ChiPACC coordination,
8 and services shall be that otherwise applicable to
9 medical assistance for the State.

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

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

19 “(A) OPERATION.—The State shall provide
20 for the operation of the program directly, serv-
21 ing as ChiPACC coordinator (as defined in
22 paragraph 3), or through arrangements with
23 one or more other entities that will serve as
24 ChiPACC coordinators.

25 “(B) COMPREHENSIVE BENEFITS.—

1 “(i) IN GENERAL.—The program pro-
 2 vides or coordinates the provision of com-
 3 prehensive items and services to ChiPACC
 4 eligible individuals (as defined in para-
 5 graph (2)) in accordance with this section.

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

8 “(I) include items and services
 9 described in subsections (c)(1) and
 10 (c)(2), to the extent such items and
 11 services are medically necessary as de-
 12 termined by the State; and

13 “(II) be provided consistent with
 14 a comprehensive care plan developed
 15 by an interdisciplinary health profes-
 16 sional team (as defined in paragraph
 17 (4)).

18 “(C) QUALIFICATIONS OF PROVIDERS.—
 19 Such items and services are provided through—

20 “(i) health care providers that meet
 21 such certification or other Federal or State
 22 requirements as may be necessary to par-
 23 ticipate in the program of medical assist-
 24 ance under this title or in the program
 25 under title XVIII; or

1 “(ii) in the case of counselors as de-
2 scribed in (4)(iii), individuals who are le-
3 gally authorized to provide counseling serv-
4 ices under State law or a regulatory mech-
5 anism provided by State law or, if no law
6 or regulatory mechanism is applicable, by
7 determination of the State.

8 “(D) STANDARDS AND GUIDELINES.—The
9 ChiPACC is operated and the services to en-
10 rolled individuals are furnished in a manner
11 that is informed by generally recognized profes-
12 sional guidelines, the Secretary may substitute
13 the revision through sub-regulatory guidance.
14 The Secretary may adopt other standards and
15 guidelines consistent with the purposes of this
16 section.

17 “(2) ChiPACC ELIGIBLE INDIVIDUAL.—The
18 term ‘ChiPACC eligible individual’ means, with re-
19 spect to a ChiPACC, an individual—

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

22 “(B) who resides in the service area of a
23 ChiPACC as determined by the State;

1 “(C) who is eligible for medical assistance
2 under the State plan without regard to this sec-
3 tion;

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

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

11 “(3) CHIPACC COORDINATOR.—The term
12 ‘ChiPACC coordinator’ means, with respect to a
13 ChiPACC, an entity that, through the assignment of
14 one or more case managers—

15 “(A) directs, supervises, and ensures the
16 coordination of services to ChiPACC eligible in-
17 dividuals enrolled in the ChiPACC; and

18 “(B) ensures the direct and continuous in-
19 volvement of an interdisciplinary health profes-
20 sional team (as described in paragraph (4)) in
21 managing and coordinating the provision of
22 care and services within the coordinator’s re-
23 sponsibility, as determined by the State, to each
24 such enrolled individual.

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

5 “(A) includes at least—

6 “(i) one physician (as described in
7 section 1861(r));

8 “(ii) one registered nurse;

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

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

14 “(B) develops a comprehensive care plan
15 for each ChiPACC eligible individual enrolled
16 with the ChiPACC that takes into account the
17 best interests of such individual and such indi-
18 vidual’s family; and

19 “(C) coordinates the provision of services
20 described in subsections (c)(1) and (c)(2), as
21 determined by the state, to an individual en-
22 rolled in the ChiPACC by members of the team
23 or by other providers of services.

24 “(5) PALLIATIVE SERVICES.—The term ‘pallia-
25 tive services’ means, for the purposes of this section,

1 patient and family-centered care that optimizes qual-
2 ity of life for an individual with a serious illness or
3 condition by—

4 “(A) anticipating, preventing, and treating
5 the individual’s suffering throughout the con-
6 tinuum of illness;

7 “(B) addressing the physical, intellectual,
8 emotional, social and spiritual needs of the indi-
9 vidual; and

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

12 “(c) SCOPE OF BENEFITS.—

13 “(1) IN GENERAL.—Under a ChiPACC of a
14 State, the State shall ensure that an individual en-
15 rolled in the ChiPACC is covered for necessary serv-
16 ices including—

17 “(A) any early and periodic screening diag-
18 nostic and treatment service, as described in
19 section 1905(r); and

20 “(B) any additional services that may be
21 necessary to ensure that such coverage includes
22 at least the elements described in paragraph
23 (2).

1 “(2) ELEMENTS OF A PROGRAM OF ALL-INCLU-
2 SIVE COORDINATED CARE.—The elements referred
3 to in paragraph (1)(A)(ii) are—

4 “(A) medical and long-term care services
5 and supports as described in section 1905 or as
6 may be available to the individual under waiver
7 programs approved under section 1915;

8 “(B) palliative services as described in sub-
9 section (b)(5);

10 “(C) counseling services and expressive
11 therapy;

12 “(D) respite care; and

13 “(E) anticipatory bereavement and be-
14 reavement services to the immediate family
15 members of the ChiPACC eligible individual.

16 “(3) COST-SHARING WAIVERS.—A State may,
17 in the case of a ChiPACC eligible individual enrolled
18 in the State’s ChiPACC, waive deductibles, copay-
19 ments, coinsurance, or other cost-sharing that would
20 otherwise apply under the State plan under this
21 title, as described in sections 1916 and 1916A.

22 “(d) RECORDS.—A provider participating in an inter-
23 disciplinary health professional team shall maintain
24 records on ChiPACC eligible individuals enrolled in the
25 program and to whom the provider furnishes services, re-

1 fleeting both the specific care and services furnished by
2 the provider and the relationship of those services to the
3 comprehensive plan of care for that individual and to the
4 delivery of other services.

5 “(e) ELIGIBILITY DETERMINATIONS.—In deter-
6 mining whether an individual is a ChiPACC eligible indi-
7 vidual, the State shall conduct, directly or under arrange-
8 ment, an assessment based on a determination by a physi-
9 cian and consultation with appropriate treating and con-
10 sulting health and support professionals caring for the in-
11 dividual.

12 “(f) PAYMENTS TO HEALTH CARE PROVIDERS AND
13 CHIPACC COORDINATORS UNDER CHIPACC.—Payments
14 to health care providers, a ChiPACC coordinator, or mem-
15 bers of an interdisciplinary health professional team fur-
16 nishing items and services under a ChiPACC shall be
17 made on a fee-for-service basis, through a Medicaid man-
18 aged care organization (as described in section
19 1903(m)(1)), or as otherwise allowable under the State
20 plan under this title, and determined in a manner to en-
21 sure such payments are sufficient to support the ongoing
22 care provided by such providers, coordinator, and team.

23 “(g) QUALITY ASSURANCE; PATIENT SAFE-
24 GUARDS.—

1 “(1) IN GENERAL.—With respect to a
2 ChiPACC, the State shall adopt quality assurance
3 provisions and patient safeguards, which may be the
4 same as those in existing State systems, applicable
5 to ChiPACC coordinators and interdisciplinary
6 health professional teams.

7 “(2) CONSTRUCTION.—Nothing in this section
8 shall be construed as preventing the Secretary from
9 imposing requirements to ensure the health and
10 safety of individuals enrolled in a ChiPACC under
11 this section that are in addition to those otherwise
12 provided under this section.

13 “(h) APPLICABILITY OF REQUIREMENTS.—With re-
14 spect to a State plan amendment under this section, the
15 following requirements of this title (and regulations relat-
16 ing to such requirements) shall not apply:

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

20 “(2) Section 1902(a)(10), insofar as such sec-
21 tion relates to comparability of services among dif-
22 ferent population groups, and to permit a ChiPACC
23 program operating under this State plan amendment
24 to enroll only individuals under age 21.

1 “(3) Section 1905(o), insofar as it limits eligi-
2 bility for hospice care to individuals with a medical
3 prognosis of a life expectancy of six months or less,
4 as described in section 1861(dd)(3)(A).”.

5 (b) APPLICATION UNDER CHIP.—Section 2107(e)(1)
6 of the Social Security Act (42 U.S.C. 1397gg(e)(1)), as
7 amended by section 9822 of the American Rescue Plan
8 Act of 2021, is further amended by adding at the end the
9 following new subparagraph:

10 “(U) Section 1948 (relating to Medicaid
11 children’s program of all-inclusive coordinated
12 care).”.

13 (c) CONTINUED DEMONSTRATION PROJECT AU-
14 THORITY.—Section 1948 of the Social Security Act, as
15 added by subsection (a), shall not be construed as pre-
16 venting a State from developing, or the Secretary of
17 Health and Human Services from approving, a project
18 similar to or related to ChiPACCs (as described in such
19 section) under alternative authorities, including dem-
20 onstration project and waiver authorities under title XIX
21 of such Act or other provisions of such Act.

○