

113TH CONGRESS
2D SESSION

H. R. 4930

To amend titles XIX and XXI of the Social Security Act to provide States with the option of providing services to children with medically complex conditions under the Medicaid program and Children's Health Insurance Program through a care coordination program focused on improving health outcomes for children with medically complex conditions and lowering costs, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JUNE 20, 2014

Mr. BARTON (for himself, Ms. CASTOR of Florida, Ms. HERRERA BEUTLER, Mr. GENE GREEN of Texas, and Ms. ESHOO) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend titles XIX and XXI of the Social Security Act to provide States with the option of providing services to children with medically complex conditions under the Medicaid program and Children's Health Insurance Program through a care coordination program focused on improving health outcomes for children with medically complex conditions and lowering costs, and for other purposes.

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

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Advancing Care for
3 Exceptional Kids Act of 2014” or the “ACE Kids Act of
4 2014”.

5 **SEC. 2. FINDINGS.**

6 Congress finds the following:

7 (1) Approximately 3,000,000 children in the
8 United States suffer from medically complex condi-
9 tions and approximately 2,000,000 of such children
10 are enrolled in State plans under the Medicaid pro-
11 gram under title XIX of the Social Security Act.

12 (2) Such children account for an estimated 6
13 percent of Medicaid enrollees and approximately 40
14 percent of children’s Medicaid spending is due to the
15 severity of the illnesses of such children.

16 (3) The creation of nationally designated chil-
17 dren’s hospital networks focused upon better coordi-
18 nation and integration of care for such pediatric
19 population will result in improved health outcomes
20 and savings under the Medicaid program and the
21 Children’s Health Insurance Program under title
22 XXI of the Social Security Act.

1 SEC. 3. ESTABLISHMENT OF MEDICAID AND CHIP CARE CO-
2 ORDINATION PROGRAM FOR CHILDREN WITH
3 MEDICALLY COMPLEX CONDITIONS AS MED-
4 ICAID STATE OPTION.

5 (a) MEDICAID.—Title XIX of the Social Security Act
6 (42 U.S.C. 1396 et seq.) is amended—

7 (1) in section 1905(a) (42 U.S.C. 1396d(a))—
8 (A) by striking “and” at the end of para-
9 graph (27);

10 (B) by redesignating paragraph (29) as
11 paragraph (30); and

12 (C) by inserting after paragraph (28) the
13 following new paragraph:

14 “(29) items and services furnished under an
15 MCCC program under section 1947 to eligible chil-
16 dren enrolled in an MCCC program under such sec-
17 tion.”; and

18 (2) by adding at the end the following new sec-
19 tion:

20 "SEC. 1947. MEDICAID CHILDREN'S CARE COORDINATION
21 PROGRAMS FOR CHILDREN WITH COMPLEX
22 MEDICAL CONDITIONS.

23 "(a) ESTABLISHMENT.—

“(1) IN GENERAL.—Beginning January 1, 2015, a State, at its option as a State plan amendment, may elect to provide medical assistance for

1 items and services furnished to eligible children en-
2 rolled in an MCCC program that meets the require-
3 ments of this section. As a condition on an eligible
4 child's receipt of medical assistance under this title,
5 the State shall require, under such an amendment,
6 that the eligible child be enrolled in an MCCC pro-
7 gram that meets the requirements of this section.

8 “(b) MCCC PROGRAM REQUIREMENTS.—An MCCC
9 program meets the requirements of this section if the
10 MCCC program—

11 “(1) coordinates, integrates, and provides for
12 the furnishing of the full range of MCCC program
13 services to eligible children enrolled in the program;

14 “(2) enrolls eligible children in accordance with
15 subsection (c);

16 “(3) is operating under a program agreement
17 that meets the requirements of subsection (d); and

18 “(4) meets the pediatric network adequacy
19 standards developed under subsection (e).

20 “(c) ELIGIBILITY DETERMINATIONS; ASSIGN-
21 MENT.—

22 “(1) ENROLLMENT.—Subject to the assignment
23 requirements of paragraph (2), the enrollment and
24 disenrollment of eligible children in an MCCC pro-
25 gram shall be carried out in accordance with regula-

1 tions issued by the Secretary and the applicable pro-
2 gram agreement.

3 “(2) NETWORK ASSIGNMENT.—

4 “(A) IN GENERAL.—Eligible children shall
5 be prospectively enrolled in an MCCC program
6 by initially assigning such eligible children to a
7 nationally designated children’s hospital net-
8 work for a period of not less than 90 days be-
9 ginning on the date on which the child is ini-
10 tially assigned to such hospital network.

11 “(B) BASIS FOR INITIAL ASSIGNMENT.—
12 Such an assignment shall be based upon any of
13 the following factors (or a combination thereof):

14 “(i) The prevalence of visits by the
15 child to a pediatrician or other specialist
16 who is participating in the nationally des-
17 gnated children’s hospital network.

18 “(ii) The selection of the child’s fam-
19 ily.

20 “(iii) The location of the primary resi-
21 dence of the child.

22 “(iv) The proximity of the child to re-
23 gional referral networks established by the
24 nationally designated children’s hospital
25 network.

1 “(C) LIMITATION ON CERTAIN ASSIGN-
2 MENTS.—An assignment of a child under clause
3 (iii) or (iv) of subparagraph (B) may only be
4 made in the case of a nationally designated chil-
5 dren’s hospital network that offers medical
6 home access within 30 miles of the primary res-
7 idence of the child.

8 “(D) REASSIGNMENT.—Following the 90-
9 day period referred to in subparagraph (A), the
10 child may elect—

11 “(i) to be assigned to the nationally
12 designated children’s hospital network of
13 their choice that has an MCCC program
14 agreement in effect with respect to an
15 MCCC program in which the child is eligi-
16 ble to enroll; or

17 “(ii) to not participate in any MCCC
18 program and receive care through enroll-
19 ment in the State plan under this title or
20 the State child health plan under title
21 XXI.

22 “(d) PROGRAM AGREEMENTS.—

23 “(1) IN GENERAL.—The Secretary, in close co-
24 operation with the State administering agencies
25 electing to provide the medical assistance described

1 in subsection (a), shall establish procedures for en-
2 tering into, extending, and terminating program
3 agreements under this section.

4 “(2) TERMS.—

5 “(A) IN GENERAL.—A program agreement
6 entered into under this section by the Sec-
7 retary, a State administering agency, and a na-
8 tionally designated children’s hospital network
9 shall provide for each of the following terms:

10 “(i) The agreement shall designate
11 the service area of the MCCC program
12 that is the subject of the agreement.

13 “(ii) The agreement shall be effective
14 for a contract year, but may be extended
15 for additional contract years in the absence
16 of a notice by a party to terminate, and is
17 subject to termination by the Secretary
18 and the State administering agency at any
19 time for cause (as provided under the
20 agreement).

21 “(iii) The agreement shall require
22 that the nationally designated children’s
23 hospital network submit care management
24 network and coverage plans to the Sec-
25 retary that are centered around medical

1 home models and that describe the govern-
2 ance of the network.

3 “(iv) The agreement shall require the
4 hospital network to meet all applicable re-
5 quirements imposed by State and local
6 laws.

7 “(v) The agreement shall require such
8 State, in the case of eligible children who
9 are residents of the State, to make pay-
10 ments to the hospital network, regardless
11 of whether MCCC program services are
12 furnished to such eligible children in an-
13 other State.

14 “(vi) The agreement shall require that
15 the standards and measures developed
16 under subsection (e) be applied to the hos-
17 pital network, including measures requir-
18 ing, with respect to network adequacy
19 standards, that the hospital network estab-
20 lish such provider networks for primary,
21 secondary, and tertiary care as are nec-
22 essary to ensure the adequate furnishing of
23 MCCC program services to eligible children
24 enrolled in the MCCC program that is the
25 subject of the agreement.

1 “(vii) The agreement shall require the
2 hospital network to comply with the data
3 collection and recordkeeping requirements
4 of subparagraph (C).

5 “(viii) The agreement shall require
6 the hospital network to accept as payment
7 any payment made using the risk-based
8 methodology developed under subsection
9 (g).

10 “(ix) The agreement shall contain
11 such additional terms and conditions as
12 the parties may agree to, so long as such
13 terms and conditions are consistent with
14 this section.

15 “(B) SERVICE AREA OVERLAP.—In desig-
16 nating a service area under subparagraph
17 (A)(i), the Secretary (in consultation with the
18 relevant State administering agency) shall con-
19 sider the impacts of designating an area that is
20 already covered under another program agree-
21 ment, for purposes of avoiding the unnecessary
22 duplication of services and the impairment of
23 the financial and service viability of another
24 MCCC program.

1 “(C) DATA AND RECORDKEEPING RE-
2 QUIREMENTS.—The data collection and record-
3 keeping requirements under this subparagraph,
4 with respect to a nationally designated chil-
5 dren’s hospital network, are as follows:

6 “(i) The hospital network shall collect
7 claims data on claims submitted with re-
8 spect to eligible children who are furnished
9 MCCC program services under an MCCC
10 program. Such data shall be reported in a
11 standardized format and made available to
12 the public for purposes of establishing a
13 national database on such claims.

14 “(ii) The hospital network shall main-
15 tain, and provide the Secretary and the
16 State administering agency access to, the
17 records relating to the MCCC program op-
18 erated by the hospital network, including
19 pertinent financial, medical, and personnel
20 records.

21 “(iii) The hospital network shall sub-
22 mit to the Secretary and the State admin-
23 istering agency such reports as the Sec-
24 retary finds (in consultation with the State
25 administering agency) necessary to monitor

1 the operation, cost, and effectiveness of the
2 MCCC program operated by the hospital
3 network.

4 “(3) TERMINATION OF AGREEMENTS.—The
5 Secretary shall issue regulations establishing the cir-
6 cumstances under which—

7 “(A) the Secretary or a State admin-
8 istering agency may terminate an MCCC pro-
9 gram agreement for cause; and

10 “(B) a nationally designated children’s
11 hospital network may terminate such an agree-
12 ment after appropriate notice to the Secretary,
13 the State administering agency, and enrollees.

14 “(e) QUALITY ASSURANCE.—

15 “(1) DEVELOPMENT OF STANDARDS AND MEAS-
16 URES.—The Secretary shall, in consultation with na-
17 tionally designated children’s hospital networks and
18 national pediatric policy organizations (such as the
19 Children’s Hospital Association and the American
20 Academy of Pediatrics)—

21 “(A) establish a national set of quality as-
22 surance and improvement protocols and proce-
23 dures to apply under MCCC programs;

24 “(B) develop pediatric quality measures;

1 “(C) develop pediatric network adequacy
2 standards for access by eligible children to
3 MCCC program services; and

4 “(D) develop criteria for national pediatric-
5 focused care coordination for eligible children.

6 “(2) USE OF PQMP MEASURES.—In carrying
7 out subparagraph (A), the Secretary shall apply, to
8 the extent applicable, child health quality measures
9 and measures for centers of excellence for children
10 with complex needs developed under this title, title
11 XXI, and section 1139A and take into account
12 HEDIS quality measures as required under section
13 1852(e)(3) and other quality measures.

14 “(f) STANDARD MEDICAID DATA SET.—

15 “(1) IN GENERAL.—The Secretary, the States,
16 and the nationally designated children’s hospital net-
17 works shall collaborate to obtain consistent and
18 verifiable Medicaid Analytic Extract data or a com-
19 parable data set and shall establish data-sharing
20 agreements to further support collaborative planning
21 and care coordination for medically complex chil-
22 dren.

23 “(2) CLAIMS ANALYSIS.—The Secretary shall—
24 “(A) perform claims analysis on the data
25 set developed under paragraph (1) to determine

1 the utilization of items and services furnished
2 under an MCCC program to eligible children;
3 and

4 “(B) submit to Congress and make pub-
5 licly available on the Internet site of the Cen-
6 ters for Medicare and Medicaid services, a re-
7 port on such claims in a standardized format
8 for purposes of building a national database.

9 “(3) PAYMENT FOR REPORTING INCENTIVES.—
10 The Secretary may provide for pay-for-reporting in-
11 centives during the first two years of any MCCC
12 program agreement entered into under this section
13 to ensure participation and analysis of consistent
14 data under this paragraph to enable the development
15 of an appropriate risk-based payment methodology
16 under subsection (g).

17 “(g) PAYMENTS TO NATIONALLY DESIGNATED CHIL-
18 DREN’S HOSPITAL NETWORKS.—

19 “(1) IN GENERAL.—The State plan shall pro-
20 vide for payment to nationally designated children’s
21 hospital networks pursuant to the terms of an
22 MCCC program agreement using a risk-based pay-
23 ment methodology (or methodologies) established by
24 the Secretary in accordance with this subsection.

1 “(2) TRANSITION FROM FEE-FOR-SERVICE TO
2 RISK-BASED PAYMENT MODEL.—

3 “(A) IN GENERAL.—Payment to nationally
4 designated children’s hospital networks under
5 this subsection shall be based initially on a fee-
6 for-service payment model and shall gradually
7 transition, over a 5-year period, to an equitable,
8 risk-based payment model using a methodology
9 developed under paragraph (3). For the first
10 two years of such period, a nationally des-
11 ignated children’s hospital network may receive,
12 in addition to any fee-for-service payments
13 made to such hospital network, per capita care
14 coordination payments with respect to expendi-
15 tures for items and services furnished to eligible
16 children enrolled in the MCCC program oper-
17 ated by the hospital network through medical
18 home programs and other care coordination ac-
19 tivities for which an all-inclusive payment model
20 is more suitable than fee-for-service reimburse-
21 ment.

22 “(B) DATA ANALYSIS DURING INITIAL PE-
23 RIOD.—During the first two years of the imple-
24 mentation of an MCCC program, the Secretary
25 shall analyze data collected under subsection (f)

1 for purposes of developing a risk-based payment
2 methodology that would be implemented begin-
3 ning with the third year of implementation of
4 the MCCC program.

5 “(3) DEVELOPMENT OF RISK-BASED PAYMENT
6 METHODOLOGY.—The Secretary shall develop pay-
7 ment methodologies under this subsection in coordi-
8 nation with the Medicaid and CHIP Payment and
9 Access Commission and the pediatric health care
10 provider community that—

11 “(A) take into account the data analyzed
12 under paragraph (2)(B);

13 “(B) are actuarially sound, as determined
14 by the Secretary and the relevant State admin-
15 istering agency, in coordination with National
16 Association of Insurance Commissioners, using
17 an actuarial methodology that is adopted using
18 historic pediatric claims data;

19 “(C) include—

20 “(i) a risk adjustment method, re-in-
21 surance system, and risk-corridor proce-
22 dure to account for variations in acuity of
23 the eligible children enrolled in MCCC pro-
24 grams; and

25 “(ii) a shared-savings component; and

1 “(D) may provide for a model for making
2 payments other than payments made on a per-
3 member, per-month basis.

4 “(h) WAIVERS OF REQUIREMENTS.—With respect to
5 carrying out an MCCC program under this section, the
6 following provisions of law shall not apply:

7 “(1) Section 1902(a)(1), relating to
8 statewideness.

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

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

14 “(4) Section 1903(m)(2)(A), insofar as such
15 section would prohibit a nationally designated chil-
16 dren’s hospital network from receiving certain pay-
17 ments.

18 “(5) Such other provisions of this title, title
19 XVIII, sections 1128A and 1128B, and any provi-
20 sions of the Federal antitrust laws as the Secretary
21 determines are inapplicable or the waiver of which
22 are necessary for purposes of carrying out an MCCC
23 program under this section.

24 “(i) PREEMPTION OF STATE LAW.—A State may not
25 impose any requirement on the nationally qualified chil-

1 dren's hospital network's operation of an MCCC program
2 under a program agreement that meets the requirements
3 of this section that is inconsistent with or would otherwise
4 impede the satisfaction by such hospital network of the
5 requirements of this section (including the requirements
6 of such program agreement).

7 “(j) DEFINITIONS.—In this section:

8 “(1) ELIGIBLE CHILD.—The term ‘eligible
9 child’ means, with respect to an MCCC program, an
10 individual who is under the age of 18 and who—

11 “(A) is eligible for medical assistance
12 under the State plan under this title or child
13 health assistance under the State child health
14 plan under title XXI; and

15 “(B) has, or is at a heightened risk of de-
16 veloping, a chronic, physical, developmental, be-
17 havioral, or emotional condition that—

18 “(i) affects two or more body systems;

19 “(ii) requires intensive care coordina-
20 tion to avoid excessive hospitalizations or
21 emergency department visits; or

22 “(iii) meets the criteria for medical
23 complexity using risk adjustment meth-
24 odologies (such as Clinical Risk Groups)
25 agreed upon by the Secretary in coordina-

1 tion with a national panel of pediatric ex-
2 perts.

3 “(2) MCCC PROGRAM.—The term ‘MCCC pro-
4 gram’ means a Medicaid coordinated care program
5 that provides eligible children with MCCC program
6 services through a nationally designated children’s
7 hospital network in accordance with a program
8 agreement that meets the requirements of subsection
9 (d).

10 “(3) MCCC PROGRAM SERVICES.—The term
11 ‘MCCC program services’ means the full range of
12 items and services for which medical assistance is
13 available under a State plan for children, including
14 pediatric care management services and pediatric-fo-
15 cused care coordination and health promotion, as
16 specified in the program agreement.

17 “(4) QUALIFIED CHILDREN’S HOSPITAL.—The
18 term ‘qualified children’s hospital’ means a chil-
19 dren’s hospital that—

20 “(A) qualifies to receive payment under
21 section 340E of the Public Health Service Act
22 (relating to children’s hospitals that operate
23 graduate medical education programs); or

24 “(B) meets 3 or more of the following cri-
25 teria:

1 “(i) MINIMUM PEDIATRIC DIS-
2 CHARGES.—The hospital has at least 5,000
3 annual pediatric discharges (including neo-
4 nates, but excluding obstetrics and normal
5 newborns) for the most recent cost report-
6 ing period for which data are available.

7 “(ii) MINIMUM NUMBER OF BEDS.—
8 The hospital has 100 licensed pediatric
9 beds, not including beds in neonatal inten-
10 sive care units but including beds in pedi-
11 atric intensive care units and other acute
12 care beds.

13 “(iii) ACCESS TO PEDIATRIC EMER-
14 GENCY SERVICES.—The hospital has access
15 (through ownership or otherwise) to pedi-
16 atric emergency services.

17 “(iv) MEDICAID RELIANT.—At least
18 30 percent of the pediatric discharges or
19 inpatient days (excluding observation days)
20 in the hospital for the most recent cost re-
21 porting period for which data are available
22 were children eligible for medical assist-
23 ance under this title or for children’s
24 health assistance under title XXI.

1 “(v) AFFILIATION WITH ACCREDITED
2 PEDIATRIC RESIDENCY TRAINING PRO-
3 GRAM.—The hospital sponsors or is affili-
4 ated with a pediatric residency program
5 that is accredited by the Accreditation
6 Council for Graduate Medical Education.

7 “(vi) PEDIATRIC MEDICAL HOME PRO-
8 GRAMS.—The hospital has established and
9 implemented demonstrable pediatric med-
10 ical home programs dedicated to medically
11 complex children.

12 “(5) NATIONALLY DESIGNATED CHILDREN’S
13 HOSPITAL NETWORK.—The term ‘nationally des-
14 gnated children’s hospital network’ means a net-
15 work of hospitals and health care providers—

16 “(A) anchored by a qualified children’s
17 hospital or hospitals with principal governance
18 responsibility over the hospital network;

19 “(B) in which the full complement of
20 health care providers needed to provide the best
21 care for children in the network participate; and

22 “(C) that represents the interests of physi-
23 cians, other health care providers, parents of
24 medically complex children, and other relatives
25 of such children.

1 “(6) PROGRAM AGREEMENT.—The term ‘pro-
2 gram agreement’ means, with respect to a nationally
3 designated children’s hospital network, an agree-
4 ment, between the hospital network, the Secretary,
5 and a State administering agency for the operation
6 of an MCCC program by the hospital network in the
7 State that meets the requirements of this section.

8 “(7) STATE ADMINISTERING AGENCY.—The
9 term ‘State administering agency’ means, with re-
10 spect to the operation of an MCCC program in a
11 State, the agency of that State (which may be the
12 single agency responsible for administration of the
13 State plan under this title in the State) responsible
14 for administering program agreements under this
15 section.”.

16 (b) APPLICATION UNDER CHIP.—Section
17 2107(e)(1) of the Social Security Act (42 U.S.C.
18 1397gg(e)(1)) is amended by adding at the end the fol-
19 lowing new subparagraph:

20 “(P) Section 1947 (relating to Medicaid
21 children’s care coordination programs for chil-
22 dren with complex medical conditions).”.

23 (c) REGULATIONS.—Not later than 120 days after
24 the date of the enactment of this Act, the Secretary of
25 Health and Human Services shall make rules on the

1 record, after opportunity for an agency hearing to carry
2 out the amendments made by this section in accordance
3 with sections 556 and 557 of title 5, United States Code.

