

**[DISCUSSION DRAFT]**114<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION**H. R.** \_\_\_\_\_

To amend title XIX of the Social Security Act to provide States with the option of providing coordinated care for children with complex medical conditions through a health home, and for other purposes.

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**IN THE HOUSE OF REPRESENTATIVES**

Mr. BARTON (for himself and Ms. CASTOR of Florida) introduced the following bill; which was referred to the Committee on

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**A BILL**

To amend title XIX of the Social Security Act to provide States with the option of providing coordinated care for children with complex medical conditions through a health home, 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,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Advancing Care for  
5 Exceptional Kids Act” or the “ACE Kids Act”.

1 **SEC. 2. ESTABLISHMENT OF STATE MEDICAID OPTION TO**  
2 **PROVIDE COORDINATED CARE THROUGH A**  
3 **HEALTH HOME FOR CHILDREN WITH COM-**  
4 **PLEX MEDICAL CONDITIONS.**

5 Title XIX of the Social Security Act (42 U.S.C. 1396  
6 et seq.) is amended by adding at the end the following  
7 new section:

8 “STATE OPTION TO PROVIDE COORDINATED CARE  
9 THROUGH A HEALTH HOME FOR CHILDREN WITH  
10 COMPLEX MEDICAL CONDITIONS

11 “SEC. 1947. (a) IN GENERAL.—Notwithstanding sec-  
12 tion 1902(a)(1) (relating to statewideness), section  
13 1902(a)(10)(B) (relating to comparability), and any other  
14 provision of this title which the Secretary determines it  
15 is necessary to waive in order to implement this section,  
16 beginning **【January 1, 2018】**, a State, at its option as  
17 a State plan amendment, may provide for medical assist-  
18 ance under this title to children with medically complex  
19 conditions for whom a designated provider, or a team of  
20 health care professionals, is selected as the individual’s  
21 health home for purposes of providing the individual with  
22 health home services.

23 “(b) PAYMENTS.—

24 “(1) IN GENERAL.—Under this section, a State  
25 shall provide a designated provider, or a team of  
26 health care professionals, with payments for the pro-

1 vision of health home services to each child with  
2 medically complex conditions for whom there is se-  
3 lected such provider or such team as the individual's  
4 health home. Such payments for such services shall  
5 be treated as medical assistance for purposes of sec-  
6 tion 1903(a), except that, during the first 8 fiscal  
7 year quarters that the State plan amendment is in  
8 effect, the Federal medical assistance percentage ap-  
9 plicable to such payments shall be equal to **90 per-**  
10 **cent**].

11 “(2) METHODOLOGY.—

12 “(A) IN GENERAL.—The State shall speci-  
13 fy in the State plan amendment the method-  
14 ology the State will use for determining pay-  
15 ment under paragraph (1). Such methodology  
16 for determining payment—

17 “(i) may be tiered to reflect, with re-  
18 spect to each child with medically complex  
19 conditions and each designated provider, or  
20 team of health care professionals, the se-  
21 verity or number of such child's chronic  
22 conditions, life-threatening illnesses, or  
23 rare diseases or the specific capabilities of  
24 such provider or such team; and

1                   “(ii) shall be established consistent  
2                   with section 1902(a)(30)(A).

3                   “(B) MODELS OF PAYMENT.—The method-  
4                   ology under subparagraph (A) may include (but  
5                   is not required to include) payments made on a  
6                   per-member per-month basis and may include  
7                   shared savings models, pay-for-performance  
8                   models, contingency awards dependent on re-  
9                   ducing utilization of emergency departments, or  
10                  other incentive-based approaches.

11                  “(c) COORDINATING CARE.—

12                  “(1) HOSPITAL REFERRALS.—A State may in-  
13                  clude in the State plan amendment under this sec-  
14                  tion a requirement for hospitals participating under  
15                  the State plan or a waiver of such plan to establish  
16                  procedures for hospital emergency departments to  
17                  refer children with medically complex conditions to  
18                  designated providers.

19                  “(2) EDUCATION WITH RESPECT TO AVAIL-  
20                  ABILITY OF HEALTH HOME SERVICES.—A State  
21                  shall include in the State plan amendment under  
22                  this section a description of the State’s process for  
23                  educating providers participating in the State plan  
24                  or a waiver of such plan about the availability of  
25                  health home services for children with medically

1 complex conditions, including the process by which  
2 such providers can refer such children to designated  
3 providers to receive such services.

4 “(3) COORDINATING CARE FROM OUT-OF-STATE  
5 PROVIDERS.—

6 “(A) IN GENERAL.—A State electing to  
7 provide medical assistance pursuant to sub-  
8 section (a) shall provide guidance, consistent  
9 with guidance from the Administrator of the  
10 Centers for Medicare & Medicaid Services, to  
11 designated providers receiving payment under  
12 this section, regarding the State’s policies and  
13 procedures for accessing care for children with  
14 medically complex conditions from out-of-State  
15 providers. For the purpose of helping facilitate  
16 medically necessary care for such children, such  
17 guidance shall include information on how out-  
18 of-State providers who provide services to such  
19 children can receive payment by such State  
20 Medicaid program.

21 “(B) BEST PRACTICES.—A State electing  
22 to provide medical assistance pursuant to sub-  
23 section (a) shall consider adopting best prac-  
24 tices for providing access to out-of-State pro-  
25 viders for children with medically complex con-

1           ditions consistent with guidance provided by the  
2           Administrator of the Centers for Medicare &  
3           Medicaid Services.

4           “(d) DATA COLLECTION.—

5           “(1) PROVIDER REPORTING REQUIREMENTS.—

6           As a condition of receiving payment under this sec-  
7           tion, a designated provider receiving payment for  
8           health home services under this section shall report  
9           to the State, in accordance with such guidance as  
10          the Administrator of the Centers for Medicare &  
11          Medicaid Services shall specify, on all applicable  
12          measures for determining the quality of such serv-  
13          ices.

14          “(2) STATE REPORTING REQUIREMENTS.—A

15          State electing to provide medical assistance pursuant  
16          to subsection (a) shall collect and provide to the Sec-  
17          retary (and to the Medicaid and CHIP Payment and  
18          Access Commission upon request), in a form and  
19          manner determined by the Secretary, the following  
20          information:

21                  “(A) Information reported under para-  
22                  graph (1).

23                  “(B) The number of children with medi-  
24                  cally complex conditions who have selected a  
25                  health home.

1           “(C) The nature, number, and prevalence  
2 of chronic conditions, life-threatening illnesses,  
3 or rare diseases that such children have.

4           “(D) The type of delivery systems and pay-  
5 ment models used to provide services to such  
6 children under this section.

7           “(E) The number and characteristics of  
8 providers serving as health homes under this  
9 section.

10           “(F) The extent to which such children re-  
11 ceive services under a State plan or a waiver of  
12 such plan from out-of-State providers, and the  
13 extent to which such services were provided on  
14 an emergency or non-emergency basis.

15           “(e) DEFINITIONS.—In this section:

16           【“(1) CHILD WITH MEDICALLY COMPLEX CON-  
17 DITIONS.—】

18           【“(A) IN GENERAL.—Subject to subpara-  
19 graph (B), the term ‘child with medically com-  
20 plex conditions’ means an individual under 21  
21 years of age who—】

22                   【“(i) is eligible for medical assistance  
23 under the State plan or under a waiver of  
24 such plan; and】

25                           【“(ii) has at least—】

1                   【“(I) 2 chronic conditions;】

2                   【“(II) 1 chronic condition that  
3 affects two or more body systems and  
4 reduces cognitive or physical func-  
5 tioning (such as the ability to eat,  
6 drink, or breathe independently); or】

7                   【“(III) 1 life-threatening illness  
8 or rare disease, such as a form of can-  
9 cer or a rare disease (as defined in  
10 section 481(c) of the Public Health  
11 Service Act).】

12                   “(B) RULE OF CONSTRUCTION.—Nothing  
13 in this paragraph shall prevent a State partici-  
14 pating under this section from establishing  
15 higher levels as to the number or severity of  
16 chronic conditions, life-threatening illnesses, or  
17 rare diseases for purposes of determining eligi-  
18 bility for receipt of health home services under  
19 this section.

20                   【“(2) CHRONIC CONDITION.—The term ‘chronic  
21 ic condition’ shall include, at a minimum, each of  
22 the following:】

23                   【“(A) Cerebral palsy.】

24                   【“(B) Cystic fibrosis.】

25                   【“(C) HIV/AIDS.】

1           【“(D) A congenital heart condition that  
2 impedes proper function of the heart.”】

3           【“(E) Blood problems such as anemia or  
4 sickle cell disease.”】

5           【“(F) Muscular dystrophy.”】

6           【“(G) Spina bifida.”】

7           【“(H) Epilepsy.”】

8           【“(I) Severe autism spectrum disorder.”】

9           【“(J) Serious emotional disturbance or se-  
10 rious mental health condition.”】

11           “(3) HEALTH HOME.—The term ‘health home’  
12 means a designated provider or a team of health  
13 care professionals (who may employed by or affili-  
14 ated with a children’s hospital) selected to provide  
15 health home services to a child with medically com-  
16 plex conditions.

17           “(4) HEALTH HOME SERVICES.—

18           “(A) IN GENERAL.—The term ‘health  
19 home services’ means comprehensive and time-  
20 ly, high-quality services described in subpara-  
21 graph (B) that are provided by a designated  
22 provider, or a team of health care professionals.

23           “(B) SERVICES DESCRIBED.—The services  
24 described in this subparagraph shall, at a min-  
25 imum, include—

1 “(i) comprehensive care management;

2 “(ii) care coordination and health pro-  
3 motion;

4 “(iii) comprehensive transitional care,  
5 including appropriate follow-up, from inpa-  
6 tient to other settings;

7 “(iv) patient and family support (in-  
8 cluding authorized representatives);

9 “(v) referral to community and social  
10 support services, if relevant;

11 “(vi) use of health information tech-  
12 nology to link services, as feasible and ap-  
13 propriate; and

14 “(vii) coordinating access to the full  
15 range of pediatric specialty and sub-  
16 specialty medical services, including serv-  
17 ices from out-of-State providers, as medi-  
18 cally necessary.

19 “(5) DESIGNATED PROVIDER.—The term ‘des-  
20 ignated provider’ means a physician (including a pe-  
21 diatrician or a pediatric specialty or subspecialty  
22 provider), children’s hospital, clinical practice or  
23 clinical group practice, rural clinic, community  
24 health center, community mental health center,  
25 home health agency, or any other entity or provider

1 that is determined by the State [and approved by  
2 Administrator of the Centers for Medicare & Med-  
3 icaid Services] to be qualified to be a health home  
4 for children with medically complex conditions on  
5 the basis of documentation evidencing that the phy-  
6 sician, practice, or clinic has the systems and infra-  
7 structure in place to provide health home services.

8 “(6) TEAM OF HEALTH CARE PROFES-  
9 SIONALS.—The term ‘team of health care profes-  
10 sionals’ means a team of health professionals (as de-  
11 scribed in the State plan amendment under this sec-  
12 tion) that may—

13 “(A) include physicians and other profes-  
14 sionals, such as a pediatrician or pediatric spe-  
15 cialty or subspecialty provider, nurse care coor-  
16 dinator, nutritionist, social worker, behavioral  
17 health professional, or any professionals deemed  
18 appropriate by the State [and approved by the  
19 Administrator of the Centers for Medicare &  
20 Medicaid Services]; and

21 “(B) be free standing, virtual, or based at  
22 a children’s hospital, hospital, community  
23 health center, community mental health center,  
24 rural clinic, clinical practice or clinical group  
25 practice, academic health center, or any entity

1           deemed appropriate by the State [and approved  
2           by the Administrator of the Centers for Medi-  
3           care & Medicaid Services].”.

4 **SEC. 3. RULE OF CONSTRUCTION ON FREEDOM OF CHOICE.**

5           Nothing in section 1947 of the Social Security Act  
6 (as added by this Act) may be construed, with respect to  
7 children with medically complex conditions (as defined in  
8 such section 1947), to limit the choice of providers by such  
9 children under section 1902(a)(23) of the Social Security  
10 Act (42 U.S.C. 1396a(a)(23)).

11 **SEC. 4. GUIDANCE ON COORDINATING CARE FROM OUT-OF-**  
12 **STATE PROVIDERS.**

13           (a) IN GENERAL.—Not later than one year after the  
14 date of the enactment of this section, the Administrator  
15 of the Centers for Medicare & Medicaid Services shall  
16 issue guidance to State Medicaid Directors on best prac-  
17 tices for using out-of-State providers to provide care to  
18 children with medically complex conditions (as defined in  
19 section 1947 of the Social Security Act, as added by this  
20 Act), including guidance regarding—

21           (1) arranging access to, and providing payment  
22           for, care for such children provided by such pro-  
23           viders;

24           (2) reducing barriers for such children receiving  
25           care from such providers in a timely fashion;

1 (3) screening and enrolling such providers, in-  
2 cluding efforts to streamline the process or reduce  
3 the burden on providers; and

4 (4) providing for payment to such providers  
5 who provide care for children with medically complex  
6 conditions in emergency and non-emergency situa-  
7 tions.

8 (b) **STAKEHOLDER INPUT.**—In carrying out sub-  
9 section (a), the Administrator of the Centers for Medicare  
10 & Medicaid Services shall issue a Request For Information  
11 to seek input from States, providers (including children’s  
12 hospitals, hospitals, pediatricians and other providers),  
13 managed care plans, children’s health groups, beneficiary  
14 advocates, and other stakeholders.

15 **SEC. 5. MACPAC REPORT.**

16 (a) **IN GENERAL.**—Not later than 18 months after  
17 the date of the enactment of this Act, the Medicaid and  
18 CHIP Payment and Access Commission established under  
19 section 1900 of the Social Security Act (42 U.S.C. 1396)  
20 shall submit a report to Congress and the Secretary of  
21 Health and Human Services on children with medically  
22 complex conditions which describes options for defining  
23 the characteristics of such children and which includes the  
24 information described in subsection (b) and such rec-  
25 ommendations as the Commission deems appropriate.

1 (b) INFORMATION TO BE INCLUDED.—The informa-  
2 tion described in this subsection is the following informa-  
3 tion:

4 (1) The characteristics of children with medi-  
5 cally complex conditions, including—

6 (A) a literature review examining—

7 (i) research on such children; and

8 (ii) clinical measures or other  
9 groupings which enable comparison among  
10 such children; and

11 (B) information gathered from consulta-  
12 tion with medical and academic experts engaged  
13 in research about or treatment of such children.

14 (2) Children with medically complex conditions  
15 who are enrolled in a State Medicaid plan under title  
16 XIX of the Social Security Act (or a waiver of such  
17 plan), including—

18 (A) the number of such children;

19 (B) the chronic conditions, life-threatening  
20 illnesses, or rare diseases that such children  
21 have;

22 (C) the number of such children receiving  
23 services under each delivery system or payment  
24 model, including health homes, fee-for-service,

1 primary care case managers, or managed care  
2 plans; and

3 (D) the extent to which such children re-  
4 ceive care coordination services.

5 (3) The providers who serve children with medi-  
6 cally complex conditions, such as physicians (includ-  
7 ing pediatricians and pediatric specialty or sub-  
8 specialty providers), children's hospitals, clinical  
9 practices or clinical group practices, rural clinics,  
10 community health centers, community mental health  
11 centers, or home health agencies.

12 (4) The extent to which children with medically  
13 complex conditions receive services from out-of-State  
14 providers that receive payment under the State Med-  
15 icaid plan under title XIX of the Social Security Act  
16 (or a waiver of such plan) and any barriers to re-  
17 ceiving such services in a timely fashion, including  
18 any variation in access to such services by delivery  
19 system.