

1 it is necessary to waive in order to implement this section
2 (other than section 1905(a)(4)(B) (relating to early and
3 periodic screening, diagnostic, and treatment services)),
4 beginning on the date that is one year after the date of
5 enactment of this section, a State, at its option as a State
6 plan amendment, may provide for medical assistance
7 under this title to children with medically complex condi-
8 tions who select a designated provider, a team of health
9 care professionals operating with such a provider, or a
10 health team as the child's health home for purposes of pro-
11 viding the child with health home services.

12 “(b) HEALTH HOME QUALIFICATION STANDARDS.—
13 The Secretary shall establish standards for qualification
14 as a health home for purposes of this section. Such stand-
15 ards shall include requiring designated providers, teams
16 of health care professionals operating with such providers,
17 and health teams to demonstrate to the State the ability
18 to do the following:

19 “(1) Coordinate prompt care for children with
20 medically complex conditions, including access to pe-
21 diatric emergency services at all times.

22 “(2) Develop an individualized comprehensive
23 pediatric family-centered care plan for children with
24 medically complex conditions that accommodates pa-
25 tient preferences.

1 “(3) Work in a culturally and linguistically ap-
2 propriate manner with the family of a child with
3 medically complex conditions to develop and incor-
4 porate into such child’s care plan, in a manner con-
5 sistent with the needs of the child and the choices
6 of the child’s family, ongoing home care, community-
7 based pediatric primary care, pediatric inpatient
8 care, social support services, and local hospital pedi-
9 atric emergency care.

10 “(4) Coordinate access to—

11 “(A) subspecialized pediatric services and
12 programs for children with medically complex
13 conditions, including the most intensive diag-
14 nostic, treatment, and critical care levels as
15 medically necessary; and

16 “(B) palliative services if the State pro-
17 vides such services under the State plan (or a
18 waiver of such plan).

19 “(5) Coordinate care for children with medically
20 complex conditions with out-of-State providers fur-
21 nishing care to such children to the maximum extent
22 practicable for the families of such children and
23 where medically necessary, in accordance with guid-
24 ance issued under subsection (e).

1 “(6) Collect and report information under sub-
2 section (g)(1).

3 “(c) PAYMENTS.—

4 “(1) IN GENERAL.—A State shall provide a des-
5 ignated provider, a team of health care professionals
6 operating with such a provider, or a health team
7 with payments for the provision of health home serv-
8 ices to each child with medically complex conditions
9 that selects such provider, team of health care pro-
10 fessionals, or health team as the child’s health home.
11 Payments made to a designated provider, a team of
12 health care professionals operating with such a pro-
13 vider, or a health team for such services shall be
14 treated as medical assistance for purposes of section
15 1903(a), except that, during the [first 8 fiscal year
16 quarters] that the State plan amendment is in ef-
17 fect, the Federal medical assistance percentage ap-
18 plicable to such payments shall be equal to [90 per-
19 cent].

20 “(2) METHODOLOGY.—

21 “(A) IN GENERAL.—The State shall speci-
22 fy in the State plan amendment the method-
23 ology the State will use for determining pay-
24 ment for the provision of health home services.
25 Such methodology for determining payment—

1 “(i) may be tiered to reflect, with re-
2 spect to each child with medically complex
3 conditions provided such services by a des-
4 ignated provider, a team of health care
5 professionals operating with such a pro-
6 vider, or a health team, the severity or
7 number of each such child’s chronic condi-
8 tions, life-threatening illnesses, disabilities,
9 or rare diseases, or the specific capabilities
10 of the provider, team of health care profes-
11 sionals, or health team; and

12 “(ii) shall be established consistent
13 with section 1902(a)(30)(A).

14 “(B) ALTERNATE MODELS OF PAYMENT.—
15 The methodology for determining payment for
16 provision of health home services under this
17 section shall not be limited to a per-member
18 per-month basis and may provide (as proposed
19 by the State and subject to approval by the
20 Secretary) for alternate models of payment.

21 “(3) PLANNING GRANTS.—

22 “(A) IN GENERAL.—Beginning **【**January
23 1, 2019**】**, the Secretary may award planning
24 grants to States for purposes of developing a
25 State plan amendment under this section. A

1 planning grant awarded to a State under this
2 paragraph shall remain available until ex-
3 pended.

4 “(B) STATE CONTRIBUTION.—A State
5 awarded a planning grant shall contribute an
6 amount equal to the State percentage deter-
7 mined under section 1905(b) (without regard to
8 section 5001 of Public Law 111–5) for each fis-
9 cal year for which the grant is awarded.

10 “(C) LIMITATION.—The total amount of
11 payments made to States under this paragraph
12 shall not exceed \$[25,000,000].

13 “(d) COORDINATING CARE.—

14 “(1) HOSPITAL NOTIFICATION.—A State with a
15 State plan amendment approved under this section
16 shall require each hospital that is a participating
17 provider under the State plan (or a waiver of such
18 plan) to establish procedures for, in the case of a
19 child with medically complex conditions who is en-
20 rolled in a health home pursuant to this section and
21 seeks treatment in the emergency department of
22 such hospital, notifying the health home of such
23 child of such treatment.

24 “(2) EDUCATION WITH RESPECT TO AVAIL-
25 ABILITY OF HEALTH HOME SERVICES.—In order for

1 a State plan amendment to be approved under this
2 section, a State shall include in the State plan
3 amendment a description of the State's process for
4 educating providers participating in the State plan
5 (or a waiver of such plan) on the availability of
6 health home services for children with medically
7 complex conditions, including the process by which
8 such providers can refer such children to a des-
9 ignated provider, team of health care professionals
10 operating such a provider, or health team for the
11 purpose of establishing a health home through which
12 such children may receive such services.

13 “(3) FAMILY EDUCATION.—In order for a State
14 plan amendment to be approved under this section,
15 a State shall include in the State plan amendment
16 a description of the State's process for educating
17 families with children eligible to receive health home
18 services pursuant to this section of the availability of
19 such services. Such process shall include the partici-
20 pation of family-to-family entities or other public or
21 private organizations or entities who provide out-
22 reach and information on the availability of health
23 care items and services to families of individuals eli-
24 gible to receive medical assistance under the State
25 plan (or a waiver of such plan).

1 “(4) MENTAL HEALTH COORDINATION.—A
2 State with a State plan amendment approved under
3 this section shall consult and coordinate, as appro-
4 priate, with the Assistant Secretary for Mental
5 Health and Substance Use in addressing issues re-
6 garding the prevention and treatment of mental ill-
7 ness and substance use among children with medi-
8 cally complex conditions receiving health home serv-
9 ices under this section.

10 “(e) GUIDANCE ON COORDINATING CARE FROM
11 OUT-OF-STATE PROVIDERS.—

12 “(1) IN GENERAL.—Not later than the date
13 that is six months after the date of the enactment
14 of this Act, and every three years thereafter, the
15 Secretary shall, with respect to States with a State
16 plan amendment approved under this section, issue
17 guidance to the State Medicaid directors of such
18 States on—

19 “(A) best practices for using out-of-State
20 providers to provide care to children with medi-
21 cally complex conditions;

22 “(B) coordinating care for such children
23 provided by such out-of-State providers (includ-
24 ing when provided in emergency and non-emer-
25 gency situations);

1 “(C) reducing barriers for such children
2 receiving care from such providers in a timely
3 fashion; and

4 “(D) processes for screening and enrolling
5 such providers in the respective State plan (or
6 a waiver of such plan), including efforts to
7 streamline such processes or reduce the burden
8 of such processes on such providers.

9 “(2) STAKEHOLDER INPUT.—In carrying out
10 paragraph (1), the Secretary shall issue a request
11 for information to seek input from children with
12 medically complex conditions and their families,
13 States, providers (including children’s hospitals, hos-
14 pitals, pediatricians, and other providers), managed
15 care plans, children’s health groups, family and ben-
16 eficiary advocates, and other stakeholders with re-
17 spect to coordinating the care for such children pro-
18 vided by out-of-State providers.

19 “(f) MONITORING.—A State shall include in the State
20 plan amendment—

21 “(1) a methodology for tracking avoidable hos-
22 pital readmissions and calculating savings that re-
23 sult from improved care coordination and manage-
24 ment under this section;

1 “(2) a proposal for use of health information
2 technology in providing health home services under
3 this section and improving service delivery and co-
4 ordination across the care continuum (including the
5 use of wireless patient technology to improve coordi-
6 nation and management of care and patient adher-
7 ence to recommendations made by their provider);
8 and

9 “(3) a methodology for tracking prompt and
10 timely access to medically necessary care for children
11 with medically complex conditions from out-of-State
12 providers.

13 “(g) DATA COLLECTION.—

14 “(1) PROVIDER REPORTING REQUIREMENTS.—
15 In order to receive payments from a State under
16 subsection (c), a designated provider, a team of
17 health care professionals operating with such a pro-
18 vider, or a health team shall report to the State, at
19 such time and in such form and manner as may be
20 required by the State, the following information:

21 “(A) With respect to each such provider,
22 team of health care professionals, or health
23 team, the name, National Provider Identifica-
24 tion number, address, and specific health care
25 services offered to be provided to children with

1 medically complex conditions who have selected
2 such provider, team of health care profes-
3 sionals, or health team as the health home of
4 such children.

5 “(B) Information on all applicable meas-
6 ures for determining the quality of health home
7 services provided by such provider, team of
8 health care professionals, or health team, in-
9 cluding, to the extent applicable, child health
10 quality measures and measures for centers of
11 excellence for children with complex needs de-
12 veloped under this title, title XXI, and section
13 1139A.

14 “(C) Such other information as the Sec-
15 retary shall specify in guidance.

16 When appropriate and feasible, such provider, team
17 of health care professionals, or health team, as the
18 case may be, shall use health information technology
19 in providing the State with such information.

20 “(2) STATE REPORTING REQUIREMENTS.—

21 “(A) COMPREHENSIVE REPORT.—A State
22 with a State plan amendment approved under
23 this section shall report to the Secretary (and,
24 upon request, to the Medicaid and CHIP Pay-
25 ment and Access Commission), at such time

1 and in such form and manner determined by
2 the Secretary to be reasonable and minimally
3 burdensome, the following information:

4 “(i) Information reported under para-
5 graph (1).

6 “(ii) The number of children with
7 medically complex conditions who have se-
8 lected a health home pursuant to this sec-
9 tion.

10 “(iii) The nature, number, and preva-
11 lence of chronic conditions, life-threatening
12 illnesses, disabilities, or rare diseases that
13 such children have.

14 “(iv) The type of delivery systems and
15 payment models used to provide services to
16 such children under this section.

17 “(v) The number and characteristics
18 of designated providers, teams of health
19 care professionals operating with such pro-
20 viders, and health teams selected as health
21 homes pursuant to this section, including
22 the number and characteristics of out-of-
23 State providers, teams of health care pro-
24 fessionals operating with such providers,

1 and health teams who have provided health
2 care items and services to such children.

3 “(vi) The extent to which such chil-
4 dren receive health care items and services
5 under the State plan.

6 “(vii) Quality measures developed spe-
7 cifically with respect to health care items
8 and services provided to children with
9 medically complex conditions.

10 “(B) REPORT ON BEST PRACTICES.—Not
11 later than 90 days after the date on which ini-
12 tial guidance is issued under subsection (e)(1),
13 a State with a State plan amendment approved
14 under this section shall submit to the Secretary,
15 and make publicly available on the appropriate
16 State website, a report on how the State is im-
17 plementing such guidance, including through
18 any best practices adopted by the State.

19 “(h) RULE OF CONSTRUCTION RELATING TO FREE-
20 DOM OF CHOICE.—Nothing in this section may be con-
21 strued to limit the choice of a child with medically complex
22 conditions in selecting a designated provider, team of
23 health care professionals operating with such a provider,
24 or health team under this section as the child’s health

1 home for purposes of providing the child with health home
2 services.

3 “(i) DEFINITIONS.—In this section:

4 “(1) CHILD WITH MEDICALLY COMPLEX CONDI-
5 TIONS.—

6 “(A) IN GENERAL.—Subject to subpara-
7 graph (B), the term ‘child with medically com-
8 plex conditions’ means an individual under 21
9 years of age who—

10 “(i) is eligible for medical assistance
11 under the State plan (or under a waiver of
12 such plan); and

13 “(ii) has at least—

14 “(I) one chronic condition that
15 affects three or more organ systems
16 and severely reduces cognitive or
17 physical functioning (such as the abil-
18 ity to eat, drink, or breathe independ-
19 ently) and that also requires the use
20 of medication, durable medical equip-
21 ment, therapy, surgery, or other treat-
22 ments; or

23 “(II) one life-limiting illness or
24 rare pediatric disease (as defined in
25 section 529(a)(3) of the Federal

1 Food, Drug, and Cosmetic Act (21
2 U.S.C. 360ff(a)(3))), such as a form
3 of cancer.

4 “(B) RULE OF CONSTRUCTION.—Nothing
5 in this paragraph shall prevent the Secretary
6 from establishing higher levels as to the number
7 or severity of chronic, life threatening illnesses,
8 disabilities, rare diseases or mental health con-
9 ditions for purposes of determining eligibility
10 for receipt of health home services under this
11 section.

12 “(2) CHRONIC CONDITION.—The term ‘chronic
13 condition’ means a serious, long-term physical, men-
14 tal, or developmental disability or disease, including
15 the following:

16 “(A) Cerebral palsy.

17 “(B) Cystic fibrosis.

18 “(C) HIV/AIDS.

19 “(D) Blood diseases, such as anemia or
20 sickle cell disease.

21 “(E) Muscular dystrophy.

22 “(F) Spina bifida.

23 “(G) Epilepsy.

24 “(H) Severe autism spectrum disorder.

1 “(I) Serious emotional disturbance or seri-
2 ous mental health illness.

3 “(3) HEALTH HOME.—The term ‘health home’
4 means a designated provider (including a provider
5 that operates in coordination with a team of health
6 care professionals) or a health team selected by a
7 child with medically complex conditions (or the fam-
8 ily of such child) to provide health home services.

9 “(4) HEALTH HOME SERVICES.—

10 “(A) IN GENERAL.—The term ‘health
11 home services’ means comprehensive and timely
12 high-quality services described in subparagraph
13 (B) that are provided by a designated provider,
14 a team of health care professionals operating
15 with such a provider, or a health team.

16 “(B) SERVICES DESCRIBED.—The services
17 described in this subparagraph shall include—

18 “(i) comprehensive care management;

19 “(ii) care coordination, health pro-
20 motion, and providing access to the full
21 range of pediatric specialty and sub-
22 specialty medical services, including serv-
23 ices from out-of-State providers, as medi-
24 cally necessary;

1 “(iii) comprehensive transitional care,
2 including appropriate follow-up, from inpa-
3 tient to other settings;

4 “(iv) patient and family support (in-
5 cluding authorized representatives);

6 “(v) referrals to community and social
7 support services, if relevant; and

8 “(vi) use of health information tech-
9 nology to link services, as feasible and ap-
10 propriate.

11 “(5) DESIGNATED PROVIDER.—The term ‘des-
12 ignated provider’ means a physician (including a pe-
13 diatrician or a pediatric specialty or subspecialty
14 provider), children’s hospital, clinical practice or
15 clinical group practice, prepaid inpatient health plan
16 or prepaid ambulatory health plan (as defined by the
17 Secretary), rural clinic, community health center,
18 community mental health center, home health agen-
19 cy, or any other entity or provider that is deter-
20 mined by the State and approved by the Secretary
21 to be qualified to be a health home for children with
22 medically complex conditions on the basis of docu-
23 mentation evidencing that the entity has the sys-
24 tems, expertise, and infrastructure in place to pro-
25 vide health home services. Such term may include

1 providers who are employed by, or affiliated with, a
2 children's hospital.

3 “(6) TEAM OF HEALTH CARE PROFES-
4 SIONALS.—The term ‘team of health care profes-
5 sionals’ means a team of health care professionals
6 (as described in the State plan amendment under
7 this section) that may—

8 “(A) include—

9 “(i) physicians and other profes-
10 sionals, such as pediatricians or pediatric
11 specialty or subspecialty providers, nurse
12 care coordinators, dietitians, nutritionists,
13 social workers, behavioral health profes-
14 sionals, physical therapists, occupational
15 therapists, speech pathologists, nurses, in-
16 dividuals with experience in medical sup-
17 portive technologies, or any professionals
18 determined to be appropriate by the State
19 and approved by the Secretary;

20 “(ii) an entity or individual who is
21 designated to coordinate such a team; and

22 “(iii) community health workers,
23 translators, and other individuals with cul-
24 turally-appropriate expertise; and

1 “(B) be freestanding, virtual, or based at
2 a children’s hospital, hospital, community
3 health center, community mental health center,
4 rural clinic, clinical practice or clinical group
5 practice, academic health center, or any entity
6 determined to be appropriate by the State and
7 approved by the Secretary.

8 “(7) HEALTH TEAM.—The term ‘health team’
9 has the meaning given such term for purposes of
10 section 3502 of Public Law 111–148.”.

11 **SEC. 3. MACPAC REPORT.**

12 (a) IN GENERAL.—Not later than 24 months after
13 the date of the enactment of this Act, the Medicaid and
14 CHIP Payment and Access Commission established under
15 section 1900 of the Social Security Act (42 U.S.C. 1396)
16 shall submit to Congress and the Secretary of Health and
17 Human Services a report on children with medically com-
18 plex conditions (as defined in section 1945A of the Social
19 Security Act (as added by section 2)) that—

20 (1) describes options for defining the character-
21 istics of such children;

22 (2) includes the information described in sub-
23 section (b); and

24 (3) includes such recommendations as the Com-
25 mission determines appropriate.

1 (b) INFORMATION TO BE INCLUDED.—The informa-
2 tion described in this subsection is, to the extent practical
3 and available, the following information:

4 (1) With respect to the characteristics of chil-
5 dren with medically complex conditions—

6 (A) a literature review examining—

7 (i) research on such children;

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

11 (iii) demographic characteristics, in-
12 cluding primary language, based on avail-
13 able data; and

14 (B) information gathered from consulta-
15 tion with medical and academic experts engaged
16 in research about, or the treatment of, such
17 children.

18 (2) Information relating to children with medi-
19 cally complex conditions who are receiving medical
20 assistance under a State plan under title XIX of the
21 Social Security Act (42 U.S.C. 1396 et seq.) (or a
22 waiver of such plan), including—

23 (A) the number of such children;

1 (B) the chronic conditions, life-threatening
2 illnesses, disabilities, injuries, or rare diseases
3 that such children have;

4 (C) the number of such children receiving
5 services under each delivery system or payment
6 model, including health homes (as defined in
7 section 1945A of the Social Security Act (as
8 added by section 2)), fee-for-service systems,
9 primary care case managers, or managed care
10 plans; and

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

13 (3) Information on the providers who provide
14 health care items and services to children with medi-
15 cally complex conditions, such as physicians (includ-
16 ing pediatricians and pediatric specialty or sub-
17 specialty providers), children's hospitals, clinical
18 practices or clinical group practices, rural clinics,
19 community health centers, community mental health
20 centers, or home health agencies.

21 (4) The extent to which children with medically
22 complex conditions receive (or are denied) health
23 care items and services from out-of-State providers
24 that receive payment under a State plan under title
25 XIX of the Social Security Act (42 U.S.C. 1396 et

1 seq.) (or a waiver of such plan) and any barriers to
2 receiving such services from such providers in a
3 timely fashion, including any variation in access to
4 such services provided by such providers,
5 disaggregated by delivery system.

6 (5) The amount and nature of the total re-
7 sources used to provide care to individual children
8 with medically complex conditions during the period
9 in which such a child is enrolled in a health home,
10 including—

11 (A) the amount of capital spent in pro-
12 viding such care;

13 (B) the resources used to provide such care
14 during any waiting period with respect to the
15 enrollment of the child in a State plan under
16 title XIX of the Social Security Act (42 U.S.C.
17 1396 et seq.) (or a waiver of such plan) or any
18 necessary approval under the State plan for the
19 provision of such services (such as inpatient
20 costs awaiting discharge);

21 (C) the cost of the coordination of such
22 child's care;

23 (D) the cost of providing to such child any
24 non-medical benefits (such as transportation
25 and home services); and

1 (E) the clinical costs of providing such
2 care.

