

115TH CONGRESS 1ST SESSION

S. 428

To amend titles XIX and XXI of the Social Security Act to authorize States to provide coordinated care to children with complex medical conditions through enhanced pediatric health homes, and for other purposes.

IN THE SENATE OF THE UNITED STATES

February 16, 2017

Mr. Grassley (for himself, Mr. Bennet, Mr. Portman, Ms. Harris, Mr. Blunt, Mr. Nelson, Mr. Brown, Mr. Gardner, and Mrs. Murray) introduced the following bill; which was read twice and referred to the Committee on Finance

A BILL

To amend titles XIX and XXI of the Social Security Act to authorize States to provide coordinated care to children with complex medical conditions through enhanced pediatric health homes, 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 of 2017" or the "ACE Kids Act of
- 6 2017".

1	SEC. 2. STATE OPTION TO PROVIDE COORDINATED CARE
2	TO CHILDREN WITH COMPLEX MEDICAL CON-
3	DITIONS THROUGH ENHANCED PEDIATRIC
4	HEALTH HOMES.
5	(a) State Medicaid Plan Amendment.—Title
6	XIX of the Social Security Act (42 U.S.C. 1396 et seq.)
7	is amended by inserting after section 1946 the following
8	new section:
9	"STATE OPTION TO PROVIDE COORDINATED CARE
10	THROUGH ENHANCED PEDIATRIC HEALTH HOMES
11	FOR CHILDREN WITH COMPLEX MEDICAL CONDI-
12	TIONS
13	"Sec. 1947. (a) In General.—Notwithstanding sec-
14	tion 1902(a)(1) (relating to statewideness) and section
15	1902(a)(10)(B) (relating to comparability), beginning
16	January 1, 2018, a State, at its option as a State plan
17	amendment, may establish an EPHH program to provide
18	medical assistance under this title for EPHH services fur-
19	nished to children with complex medical conditions who
20	are enrolled in an enhanced pediatric health home (also
21	referred to in this section as an EPHH) under an EPHH
22	program agreement.
23	"(b) Definitions.—In this section:
24	"(1) CHILD WITH COMPLEX MEDICAL CONDI-
25	TIONS.—The term 'child with complex medical con-
26	ditions' means an individual who—

1	"(A) is enrolled in a State plan under this
2	title or title XXI or under a waiver of such
3	plan;
4	"(B) is under 21 years of age; and
5	"(C) has a chronic medical condition or se-
6	rious injury that—
7	"(i) affects two or more body systems;
8	"(ii) affects cognitive or physical func-
9	tioning (such as reducing the ability to
10	perform the activities of daily living, in-
11	cluding the ability to engage in movement
12	or mobility, eat, drink, communicate, or
13	breathe independently); and
14	"(iii) either—
15	"(I) requires intensive healthcare
16	interventions (such as multiple medi-
17	cations, therapies, or durable medical
18	equipment) and intensive care coordi-
19	nation to optimize health and avoid
20	hospitalizations or emergency depart-
21	ment visits; or
22	"(II) meets the criteria for med-
23	ical complexity under existing risk ad-
24	justment methodologies using a recog-
25	nized, publicly available pediatric

1	grouping system (such as the pedi-
2	atric complex conditions classification
3	system or the Pediatric Medical Com-
4	plexity Algorithm) selected by the Sec-
5	retary in close collaboration with the
6	State agencies responsible for admin-
7	istering State plans under this title
8	and a national panel of pediatric, pe-
9	diatric specialty, and pediatric sub-
10	specialty experts.
11	"(2) Enhanced pediatric health home
12	(EPHH); EPHH SERVICES; EPHH PROGRAM AGREE-
13	MENT.—
14	"(A) IN GENERAL.—The terms 'enhanced
15	pediatric health home' and 'EPHH' mean a
16	provider-sponsored entity qualified to care for
17	children with medically complex conditions
18	that—
19	"(i) satisfies the requirements of sub-
20	paragraph (B);
21	"(ii) has entered into an EPHH pro-
22	gram agreement (as defined in subpara-
23	graph (D)) with a State; and
24	"(iii) provides or arranges for the pro-
25	vision of EPHH services (as defined in

1	subparagraph (C)) to children with com-
2	plex medical conditions.
3	"(B) REQUIREMENTS.—The requirements
4	of this subparagraph are that the entity dem-
5	onstrates to the State with which the entity de-
6	sires to enter into an EPHH program agree-
7	ment that it—
8	"(i) has expertise in providing, inte-
9	grating, or coordinating prompt care for
10	children with complex medical conditions,
11	including access to pediatric emergency
12	services at all times;
13	"(ii) shall design an individualized
14	comprehensive pediatric family-centered
15	care plan for each child with complex med-
16	ical conditions assigned to the entity, and
17	provide seamless pediatric care coordina-
18	tion by a customized care team with a des-
19	ignated team lead for each such child and
20	the child's family;
21	"(iii) shall work with the family of
22	each child with complex medical conditions
23	assigned to the entity to develop and incor-
24	porate ongoing home care, community-
25	based pediatric primary care, care from the

1	most medically appropriate or family-pre-
2	ferred children's hospital, social support
3	services, and local hospital pediatric emer-
4	gency care into the child's care plan con-
5	sistent with family choice and the needs of
6	the child;
7	"(iv) shall include the families of chil-
8	dren with complex medical conditions in
9	the delivery of care and the development,
10	operation, and evaluation of its services;
11	"(v) shall interact with children with
12	complex medical conditions and their fami-
13	lies in a culturally and linguistically appro-
14	priate manner;
15	"(vi) shall provide integration and ac-
16	cess to sub-specialized pediatric services
17	and programs for children with complex
18	medical conditions, including the most in-
19	tensive diagnostic, treatment, and critical
20	care levels as medically necessary, includ-
21	ing appropriate out-of-State care;
22	"(vii) can coordinate and integrate the
23	full range of pediatric medical, surgical,
24	and behavioral specialists and subspecial-
25	ists needed, based on clinical qualifications

1	(such as board certification) and patient
2	preference, on the care team to care for
3	children with complex medical conditions,
4	as well as providers offering specialized
5	services, such as rehabilitative and
6	habilitative health care and private-duty
7	nursing, if needed;
8	"(viii) can coordinate the provision of
9	outpatient care needs, including durable
10	medical equipment, medical supplies, and
11	medical foods, if needed;
12	"(ix) can arrange and coordinate care
13	for children with complex medical condi-
14	tions from out-of-State providers to the
15	maximum extent practicable for the fami-
16	lies of such children and where medically
17	necessary in accordance with the guidance
18	provided under subsection (d)(1);
19	"(x) can coordinate and collect pay-
20	ments by liable third parties (including
21	parties described in section
22	1902(a)(25)(A)) for care and services pro-
23	vided or arranged for by the entity; and
24	"(xi) can collect and report on pedi-
25	atric quality measures appropriate for chil-

1	dren with medically complex conditions as
2	described in subsection $(f)(1)$.
3	"(C) EPHH SERVICES.—
4	"(i) In general.—The term 'EPHH
5	services' means timely, high-quality pedi-
6	atric services that are provided to children
7	with complex medical conditions by an en-
8	hanced pediatric health home under an
9	EPHH program agreement, including all
10	services for which medical assistance is
11	available under the State plan under this
12	title of the State that is a party to the
13	agreement (or an amendment to such plan)
14	and the services described in clause (ii).
15	"(ii) Services described.—The
16	services described in this subparagraph are
17	the following:
18	"(I) Comprehensive pediatric
19	care management, including inpatient
20	and outpatient hospital services, oral
21	health, behavioral health, and, where
22	necessary, hospice care or other long-
23	term services and supports as defined
24	by the State.

1	"(II) Care coordination and
2	health promotion.
3	"(III) Comprehensive transitional
4	care, including appropriate follow-up,
5	from inpatient to other settings.
6	"(IV) Patient and family support
7	(including authorized representatives).
8	"(V) Referral to community and
9	social support services, if relevant.
10	"(VI) Use of health information
11	technology to link services, as feasible
12	and appropriate.
13	"(VII) Coordinating access to the
14	full range of pediatric specialty and
15	subspecialty medical services, includ-
16	ing services from out-of-State pro-
17	viders, as medically necessary.
18	"(D) EPHH PROGRAM AGREEMENT.—The
19	term 'EPHH program agreement' means an
20	agreement between a State and an EPHH
21	that—
22	"(i) requires the EPHH to provide, or
23	arrange for or coordinate the provision of,
24	at a minimum, the services described in
25	clause (ii) of subparagraph (C);

1	"(ii) requires the EPHH to carry out
2	the requirements described in subpara-
3	graph (B) and comply with the data collec-
4	tion requirements of subsection (f);
5	"(iii) provides that the State, with re-
6	spect to children with complex medical con-
7	ditions who are residents of the State and
8	are assigned to the EPHH, shall establish
9	policies and procedures for making pay-
10	ments to the EPHH for providing, arrang-
11	ing for, or coordinating EPHH services
12	furnished to such children in another
13	State;
14	"(iv) is subject to all relevant require-
15	ments imposed by Federal, State, and local
16	law; and
17	"(v) contains such additional terms
18	and conditions, not inconsistent with this
19	section, as the parties may agree to.
20	"(3) State administering agency.—The
21	term 'State administering agency' means the State
22	agency (which shall be the State agency responsible
23	for administering the State plan under this title or
24	the State agency responsible for administering the
25	State program under title V) responsible for admin-

1	istering EPHH program agreements under this sec-
2	tion.
3	"(c) Family Preference for an Enhanced Pe-
4	DIATRIC HEALTH HOME.—
5	"(1) In general.—
6	"(A) OPTION TO REQUEST ENROLL-
7	MENT.—Each child with complex medical condi-
8	tions who is eligible to receive EPHH services
9	under a State plan amendment under this sec-
10	tion shall have the option of requesting to be
11	enrolled with an EPHH of the child's choice in
12	accordance with a process established by the
13	State.
14	"(B) Enrollment requirement.—An
15	EPHH shall enroll any child with complex med-
16	ical conditions who requests enrollment with the
17	EPHH under subparagraph (A) unless the
18	terms of the EPHH program agreement be-
19	tween the EPHH and the State allow the
20	EPHH to decline the child's request on the
21	basis of pre-established criteria specified in the
22	agreement.
23	"(2) Outreach and Education.—Each State
24	with a State plan amendment under this section

shall conduct outreach and education activities to

1	raise awareness among children with complex med-
2	ical conditions and their families of the option to en-
3	roll in an EPHH and may provide assistance to such
4	children and their families in making decisions with
5	respect to such enrollment. The activities and assist-
6	ance described in this paragraph may include activi-
7	ties and assistance carried out by—
8	"(A) family-to-family information centers
9	under section 501(c);
10	"(B) family navigators;
11	"(C) nonprofit organizations; and
12	"(D) faith-based organizations.
13	"(3) Option to withdraw from Program.—
14	"(A) IN GENERAL.—Any child with com-
15	plex medical conditions that opts into an en-
16	hanced pediatric health home under this sub-
17	section shall have the option to disenroll from
18	the home and to receive covered services under
19	the State plan under this title or the State child
20	health plan under title XXI.
21	"(B) EFFECTIVE DATE OF
22	DISENROLLMENT.—The disenrollment of a child
23	with complex medical conditions from an
24	enhanced pediatric health home shall take effect
25	not later than 30 days after the child notifies

the health home of the child's desire to disenroll.

"(4) Transition assistance.—In the case of an individual who is enrolled in an enhanced pediatric health home under this section and whose enrollment ceases for any reason (including that the individual no longer qualifies as a child with complex medical conditions, the termination of an EPHH program agreement, or otherwise), the enhanced pediatric health home shall continue to provide EPHH services to the individual during a transition period to ensure that the individual's care is not compromised, help the individual and the individual's family self-manage the individual's medical conditions to the maximum extent practicable, and provide assistance to the individual and the individual's family in obtaining necessary transitional care through appropriate referrals and making the individual's medical records available to new providers. "(d) Coordinating Care From Out-of-State

21 Providers.—

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22 "(1) Guidance.—

23 "(A) IN GENERAL.—Not later than 2 years 24 after the date of the enactment of this section, 25 the Secretary shall issue guidance to State

1	Medicaid Directors on best practices for ensur-
2	ing that children with complex medical condi-
3	tions receive prompt care from out-of-State pro-
4	viders when medically necessary, including guid-
5	ance regarding—
6	"(i) arranging access to, and pro-
7	viding payment for, care for such children
8	provided by out-of-State providers;
9	"(ii) reducing barriers for such chil-
10	dren receiving care from such providers in
11	a timely fashion;
12	"(iii) screening and enrolling out-of-
13	State providers, including efforts to
14	streamline the process or reduce the bur-
15	den on out-of-State providers that do not
16	regularly treat children from the State or
17	that only treat a small number of children
18	from the State (which may include pro-
19	viding for payment to such a provider
20	without requiring the provider to enroll in
21	the State plan);
22	"(iv) providing for payment to out-of-
23	State providers that provide care for chil-
24	dren with complex medical conditions in

1	emergency	and	non-emergency	situations;
2	and			

"(v) how the guidance provided under this subparagraph interacts with the requirements of section 431.52 of title 42, Code of Federal Regulations.

"(B) STAKEHOLDER INPUT.—In carrying out subparagraph (A), the Secretary shall issue a Request For Information to seek input from States, patient or family advocates and organizations that represent patients or families, children's health groups, providers (including children's hospitals, hospitals, pediatricians, and other pediatric providers), managed care plans, and other relevant stakeholders.

"(2) Out-of-state policies for ephhs.—A State electing to provide medical assistance pursuant to subsection (a) shall provide information, consistent with guidance from the Secretary, to enhanced pediatric health homes receiving payment under this section, regarding the State's policies and procedures for accessing care for children with complex medical conditions from out-of-State providers. For the purpose of helping facilitate medically necessary care for such children, such information shall

- include information on how out-of-State providers
 who provide services to such children can receive
 payment by such State Medicaid program.
- "(3) BEST PRACTICES.—A State electing to provide medical assistance pursuant to subsection (a) shall consider adopting best practices for providing access to out-of-State providers for children with complex medical conditions consistent with guidance provided by the Secretary under paragraph (1).
- 11 "(e) Payments to Enhanced Pediatric Health 12 Homes.—

13 "(1) IN GENERAL.—A State shall provide an 14 EPHH with payments for the provision of EPHH 15 services to each child enrolled with an EPHH that 16 has an EPHH program agreement with the State. 17 Such payments for such services shall be treated in 18 the same manner as payments under section 19 1945(c)(1), and, with respect to payments for serv-20 ices described in section 1945(h)(4)(B) provided by 21 an EPHH to children with complex medical condi-22 tions enrolled with the EPHH during the first 8 fis-23 cal quarters in which the EPHH program agreement 24 is in effect, the Federal medical assistance percent-25 age applicable to such payments shall be equal to the Federal medical assistance percentage specified
 in section 1945(c)(1).

"(2) ALTERNATIVE PAYMENT MODEL METHOD-OLOGY.—Payment to enhanced pediatric health homes for EPHH services furnished pursuant to a EPHH program agreement shall be made in a manner to be determined by the State using an agreedupon alternative payment methodology developed under paragraph (4).

"(3) CMS GUIDANCE ON ALTERNATIVE PAY-MENT MODEL METHODOLOGIES.—

"(A) IN GENERAL.—Not later than January 1, 2018, the Secretary shall publish guidance describing best practices for States to employ in designing and establishing alternative payment model methodologies which may be used by enhanced pediatric health homes with EPHH program agreements in developing equitable, alternative payment model methodologies for EPHH programs under paragraph (4). The guidance shall include descriptions of best practices related to designing shared savings and performance-based payment models that are risk-adjusted for the population enrolled in EPHH programs, and may include guidance re-

1	lated to other alternative payment models, in-
2	cluding global payments and bundled payments.
3	"(B) Stakeholder input.—In carrying
4	out subparagraph (A), the Secretary shall issue
5	a Request for Information to seek input from
6	States, the Medicaid and CHIP Payment and
7	Access Commission, providers (including chil-
8	dren's hospitals, hospitals, pediatricians, and
9	other pediatric providers), managed care plans,
10	children's health groups, family and beneficiary
11	advocates, the pediatric health care community,
12	and other relevant stakeholders.
13	"(C) Data analysis.—Beginning in the
14	first year of the implementation of enhanced
15	pediatric health homes, the Secretary shall ana-
16	lyze, for purposes of developing the guidance re-
17	quired under this paragraph—
18	"(i) data collected under subsection
19	(f)(1); and
20	"(ii) other data as the Secretary de-
21	termines appropriate.
22	"(4) Development of Alternative Pay-
23	MENT MODEL METHODOLOGY.—
24	"(A) In General.—Each State, in col-
25	laboration with any enhanced pediatric health

1	home that is operating an EPHH program
2	under this section in the State, shall develop
3	the payment methodology or methodologies for
4	payment under the State plan in accordance
5	with this subsection that—
6	"(i) includes—
7	"(I) a risk adjustment method,
8	re-insurance system, or risk-corridor
9	procedure to account for variations in
10	acuity of the children with complex
11	medical conditions enrolled in en-
12	hanced pediatric health homes; and
13	"(II) an alternative payment
14	model, which may include a shared
15	savings approach or performance-
16	based approach, such as a bundled
17	payment or risk-reward payment
18	model;
19	"(ii) may be informed by guidance
20	published by the Secretary under para-
21	graph $(3)(A)$; and
22	"(iii) considers data analyzed under
23	paragraph (3)(C), to the maximum extent
24	practicable.

1	"(B) APPROVAL BY STATE MEDICAID
2	AGENCY REQUIRED.—No payment may be made
3	under a payment methodology developed under
4	this paragraph unless—
5	"(i) the relevant State agency respon-
6	sible for administering the State plan
7	under this title has approved such method-
8	ology; and
9	"(ii) the methodology is described in a
10	State plan amendment that has received
11	approval from the Secretary.
12	"(f) Data and Quality Assurance.—
13	"(1) Data.—The data collection requirements
14	under this paragraph, with respect to an enhanced
15	pediatric health home, are as follows:
16	"(A) The home, in collaboration with the
17	State and the child's health plan if appropriate,
18	shall collect and submit claims data on claims
19	submitted with respect to children who are fur-
20	nished EPHH services. After approval by the
21	State, such data shall be reported in a stand-
22	ardized format in a timely manner and made
23	available to the public for the purposes of estab-
24	lishing a national database on such claims.

1	"(B) The State shall submit to the Sec-
2	retary such reports as the Secretary finds nec-
3	essary to monitor the operation, cost, and effec-
4	tiveness of the EPHH services furnished by the
5	home.
6	"(2) Development of standards and meas-
7	URES.—The Secretary shall, in consultation with
8	States and enhanced pediatric health homes with
9	EPHH program agreements under this section and
10	national pediatric policy organizations—
11	"(A) establish a national set of quality as-
12	surance and improvement protocols and proce-
13	dures to apply under EPHH programs estab-
14	lished under this section;
15	"(B) develop pediatric quality measures
16	that are tailored to the care and treatment of
17	children with complex medical conditions and
18	account for the health and well-being, care co-
19	ordination, child and family experience, and ac-
20	cess to and cost of care for children with com-
21	plex medical conditions;
22	"(C) develop provider accessibility stand-
23	ards for access by children with complex med-
24	ical conditions to EPHH services, and

1	"(D) develop criteria for national pediatric-
2	focused care coordination for children with com-
3	plex medical conditions.
4	"(3) Use of existing quality measures.—
5	In carrying out paragraph (2), the Secretary shall
6	consider incorporating, to the extent applicable, the
7	following measures:
8	"(A) Child health quality measures and
9	measures for centers of excellence for children
10	with complex needs developed under this title,
11	title XXI, and section 1139A.
12	"(B) The Healthcare Effectiveness Data
13	and Information Set (HEDIS).
14	"(C) Other existing quality measures, as
15	considered appropriate by the Secretary.
16	"(4) National pediatric policy organiza-
17	TIONS.—For purposes of paragraph (2), the national
18	pediatric policy organizations that the Secretary
19	shall consult with shall include the following:
20	"(A) Acute care children's hospitals.
21	"(B) Specialty pediatric hospitals.
22	"(C) Subacute, rehabilitative, and long-
23	term care pediatric hospitals.

1	"(D) Pediatric providers, including pri-
2	mary care providers, specialists, and subspecial-
3	ists.
4	"(E) Pediatric home, community, and fam-
5	ily care organizations, including organizations
6	representing families or children with special
7	needs.
8	"(F) National pediatric policy organiza-
9	tions with specific expertise relating to children
10	with complex medical conditions.
11	"(G) Such other entities as the Secretary
12	shall determine appropriate.
13	"(5) Standard medicaid data set.—
14	"(A) In General.—The Secretary, the
15	States, and the enhanced pediatric health
16	homes with EPHH program agreements under
17	this section shall collaborate to obtain con-
18	sistent and verifiable Medicaid Analytic Extract
19	data or a comparable data set and shall estab-
20	lish data-sharing agreements to further support
21	collaborative planning and care coordination for
22	children with complex medical conditions.
23	"(B) Claims analysis.—
24	"(i) Analysis by independent
25	THIRD PARTY.—The Secretary shall com-

mission an independent third party to per-1 2 form claims analysis on the data set devel-3 oped under subparagraph (A) to determine 4 the utilization of items and services furnished under EPHH programs to children 6 with complex medical conditions, and the 7 overall effectiveness of EPHH programs. "(ii) REPORT.—For purposes of build-8 9 ing a national database, the Secretary shall 10 submit to Congress, and make publicly 11 available on the Internet site of the Cen-12 ters for Medicare & Medicaid Services, a 13 report on the analysis carried out under 14 clause (i).". 15 (b) APPLICATION Under CHIP.—Section 2107(e)(1) of the Social Security Act (42) 16 U.S.C. 1397gg(e)(1)) is amended by adding at the end the fol-17 18 lowing new subparagraph: 19 "(P) Section 1947 (relating to the Med-20 icaid EPHH program for children with complex 21 medical conditions).". 22 SEC. 3. MACPAC REPORT. 23 (a) IN GENERAL.—Not later than 24 months after the date of the enactment of this Act, the Medicaid and

CHIP Payment and Access Commission established under

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1	section 1900 of the Social Security Act (42 U.S.C. 1396)
2	shall submit a report to Congress and the Secretary of
3	Health and Human Services on children with complex
4	medical conditions which includes the information de-
5	scribed in subsection (b) and such recommendations as the
6	Commission deems appropriate.
7	(b) Information To Be Included.—The informa-
8	tion described in this subsection is the following informa-
9	tion:
10	(1) The characteristics of children with complex
11	medical conditions, including—
12	(A) a literature review examining—
13	(i) research on such children; and
14	(ii) clinical measures or other group-
15	ings which enable comparison among such
16	children; and
17	(B) information gathered from consulta-
18	tion with medical and academic experts engaged
19	in research about or treatment of such children.
20	(2) Children with complex medical conditions
21	who are enrolled in a State Medicaid plan under title
22	XIX of the Social Security Act (or a waiver of such
23	plan), including—
24	(A) the number of such children;

- 1 (B) the chronic conditions, serious injuries,
 2 life-threatening illnesses, or rare diseases that
 3 such children have;
 4 (C) the number of such children receiving
 - (C) the number of such children receiving services under each delivery system or payment model and the type of payment model being used; and
 - (D) the extent to which such children receive care coordination services.
 - (3) The pediatric providers who serve children with complex medical conditions.
 - (4) The extent to which children with complex medical conditions receive or are denied services from out-of-State providers that receive payment under the State Medicaid plan under title XIX of the Social Security Act (or a waiver of such plan) and any barriers to receiving such services in a timely fashion, including any variation in access to such services by delivery system.

20 SEC. 4. REPORT TO CONGRESS.

Not later than 5 years after the date of the enactment of this Act, the Secretary of Health and Human Services shall submit Congress, and make publicly available on the Internet site of the Centers for Medicare & Medicaid Services, a report evaluating and assessing the

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- 1 enhanced pediatric health home program established
- 2 under section 1947 of the Social Security Act (as added
- 3 by section 2), for the purposes of determining—
- 4 (1) how the program might be improved; and
- 5 (2) whether the program should be expanded to 6 include pediatric populations that are not children 7 with complex medical conditions (as such term is de-8 fined for purposes of the program) but who would 9 still benefit from the type of care coordination pro-

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vided by an enhanced pediatric health home.