

**AMENDMENT TO THE
SENATE AMENDMENT TO H.R. 1
OFFERED BY MS. STRICKLAND OF WASHINGTON**

At the end of chapter 1 of subtitle B of title VII,
add the following:

1 **SEC. _____. FMAP INCENTIVE FOR STATES IMPLE-**
2 **MENTING NEW RARE DISEASE OUTREACH**
3 **AND TRAINING PROGRAMS.**

4 Section 1905 of the Social Security Act (42 U.S.C.
5 1396d), as amended by section 71110, is further amend-
6 ed—

7 (1) in subsection (b), by striking “and (ii)” and
8 inserting “(ii), and (ll)”;

9 (2) by adding at the end the following new sub-
10 section:

11 “(ll) FMAP FOR IMPLEMENTING NEW RARE DIS-
12 EASE OUTREACH AND TRAINING PROGRAMS.—

13 “(1) IN GENERAL.—Subject to paragraph (2),
14 notwithstanding any other provision of this title, the
15 Federal medical assistance percentage for a State
16 that awards grants to or otherwise supports a quali-
17 fying outreach program or a qualifying training pro-
18 gram shall be 85 percent.

1 “(2) REPORT TO CONGRESS.—To be eligible for
2 the Federal medical assistance percentage under
3 paragraph (1), a State must submit to Congress, on
4 an annual basis (beginning not later than 2 years
5 after the date of the enactment of this paragraph),
6 a report describing the activities carried out under
7 each qualifying outreach program or qualifying
8 training program.

9 “(3) DEFINITIONS.—In this subsection:

10 “(A) MINORITY.—The term ‘minority’ has
11 the meaning given such term in section 464z–
12 3 of the Public Health Service Act.

13 “(B) QUALIFYING OUTREACH PROGRAM.—
14 The term ‘qualifying outreach program’ means
15 a program that—

16 “(i) collects, analyzes, and reports
17 data on rare diseases and conditions in mi-
18 nority populations, including on epidemio-
19 logical data with respect to incidence of
20 such diseases and conditions in such popu-
21 lations;

22 “(ii) conducts outreach and engage-
23 ment activities with the minority popu-
24 lations impacted by such rare diseases and
25 conditions by—

1 “(I) improving health literacy
2 with respect to rare diseases and con-
3 ditions;

4 “(II) disseminating information
5 on health and community services re-
6 lated to rare diseases and conditions;
7 and

8 “(III) providing information re-
9 garding the maintenance of rare dis-
10 eases and conditions; or

11 “(iii) conducts research and aware-
12 ness campaigns with respect to rare dis-
13 eases and conditions in minority popu-
14 lations in cooperation with existing na-
15 tional public awareness campaigns to in-
16 crease awareness about rare diseases and
17 conditions in minority populations through
18 culturally and linguistically appropriate in-
19 formation campaigns about prevention and
20 management of rare diseases and condi-
21 tions.

22 “(C) QUALIFYING TRAINING PROGRAM.—
23 The term ‘qualifying training program’ means a
24 program that—

1 “(i) awards grants to accredited
2 schools of allopathic medicine, osteopathic
3 medicine, and nursing, and other health
4 professional training programs for the
5 training of health care professionals—

6 “(I) to improve the provision of
7 care to individuals who have rare dis-
8 eases or conditions (as defined in sec-
9 tion 526 of the Federal Food, Drug,
10 and Cosmetic Act);

11 “(II) to improve the provision of
12 care to such individuals via telehealth;
13 and

14 “(III) to conduct research rel-
15 evant to rare diseases and conditions;

16 “(ii) awards grants, cooperative agree-
17 ments, and contracts to accredited schools
18 of medicine and nursing, and other health
19 professional training programs, for the de-
20 velopment and implementation of programs
21 to provide education and training to health
22 care professionals on the causes and effects
23 of rare diseases and conditions in minority
24 populations;

1 “(iii) awards grants, contracts, or co-
2 operative agreements to public and non-
3 profit private entities (including Tribal en-
4 tities) for the establishment of a mentoring
5 program for health care professionals seek-
6 ing to treat patients with rare diseases and
7 conditions; or

8 “(iv) awards grants to accredited
9 schools of allopathic medicine, osteopathic
10 medicine, and nursing, or other health pro-
11 fessional training programs (in this clause
12 referred to as ‘eligible entities’) involved in
13 research on rare diseases and minority
14 health to establish programs to increase
15 the recruitment and retention of members
16 of minority groups to conduct research in
17 matters relating to the cause, diagnosis,
18 prevention, and treatment of rare diseases
19 or conditions, including by expanding the
20 number of internships, scholarship, and
21 mentoring opportunities.

22 “(D) RARE DISEASE OR CONDITION.—The
23 term ‘rare disease or condition’ has the mean-

1 ing given such term in section 526 of the Fed-
2 eral Food, Drug, and Cosmetic Act.”.

