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HOUSE OF REPRESENTATIVES
REPORT
116–546

TRIBAL HEALTH DATA IMPROVEMENT ACT OF 2020

SEPTEMBER 29, 2020.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mr. PALLONE, from the Committee on Energy and Commerce, submitted the following

R E P O R T

[To accompany H.R. 7948]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 7948) to amend the Public Health Service Act with respect to the collection and availability of health data with respect to Indian Tribes, and for other purposes, having considered the same, reports favorably thereon with an amendment and recommends that the bill as amended do pass.

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The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "Tribal Health Data Improvement Act of 2020".

SEC. 2. COLLECTION AND AVAILABILITY OF HEALTH DATA WITH RESPECT TO INDIAN TRIBES.

(a) DATA COLLECTION.—Section 3101(a)(1) of the Public Health Service Act (42 U.S.C. 300kk(a)(1)) is amended—

(1) by striking ", by not later than 2 years after the date of enactment of this title,"; and

(2) in subparagraph (B), by inserting "Tribal," after "State,".

(b) DATA REPORTING AND DISSEMINATION.—Section 3101(c) of the Public Health Service Act (42 U.S.C. 300kk(c)) is amended—

(1) by amending subparagraph (F) of paragraph (1) to read as follows:

"(F) the Indian Health Service, Indian Tribes, Tribal organizations, and epidemiology centers authorized under the Indian Health Care Improvement Act;"; and

(2) in paragraph (3), by inserting "Indian Tribes, Tribal organizations, and epidemiology centers," after "Federal agencies,".

(c) PROTECTION AND SHARING OF DATA.—Section 3101(e) of the Public Health Service Act (42 U.S.C. 300kk(e)) is amended by adding at the end the following new paragraphs:

"(3) DATA SHARING STRATEGY.—With respect to data access for Tribal epidemiology centers and Tribes, the Secretary shall create a data sharing strategy that takes into consideration recommendations by the Secretary's Tribal Advisory Committee for—

"(A) ensuring that Tribal epidemiology centers and Indian Tribes have access to the data sources necessary to accomplish their public health responsibilities; and

"(B) protecting the privacy and security of such data.

"(4) TRIBAL PUBLIC HEALTH AUTHORITY.—

"(A) AVAILABILITY.—Beginning not later than 180 days after the date of the enactment of the Tribal Health Data Improvement Act of 2020, the Secretary shall make available to the entities listed in subparagraph (B) all data that is collected pursuant to this title with respect to health care and public health surveillance programs and activities, including such programs and activities that are federally supported or conducted, so long as—

"(i) such entities request the data pursuant to statute; and

"(ii) the data is requested for use—

"(I) consistent with Federal law and obligations; and

"(II) to satisfy a particular purpose or carry out a specific function consistent with the purpose for which the data was collected.

"(B) ENTITIES.—The entities listed in this subparagraph are—

"(i) the Indian Health Service;

"(ii) Indian Tribes and Tribal organizations; and

"(iii) epidemiology centers.".

(d) TECHNICAL UPDATES.—Section 3101 of the Public Health Service Act (42 U.S.C. 300kk) is amended—

(1) by striking subsections (g) and (h); and

(2) by redesignating subsection (i) as subsection (h).

(e) DEFINITIONS.—After executing the amendments made by subsection (d), section 3101 of the Public Health Service Act (42 U.S.C. 300kk) is amended by inserting after subsection (f) the following new subsection:

"(g) DEFINITIONS.—In this section:

"(1) The term 'epidemiology center' means an epidemiology center established under section 214 of the Indian Health Care Improvement Act, including such Tribal epidemiology centers serving Indian Tribes regionally and any Tribal epidemiology center serving Urban Indian organizations nationally.

"(2) The term 'Indian Tribe' has the meaning given to the term 'Indian tribe' in section 4 of the Indian Self-Determination and Education Assistance Act.

"(3) The term 'Tribal organization' has the meaning given to the term 'tribal organization' in section 4 of the of the Indian Self-Determination and Education Assistance Act.

"(4) The term 'Urban Indian organization' has the meaning given to that term in section 4 of the Indian Health Care Improvement Act.".

(f) TECHNICAL CORRECTION.—Section 3101(b) of the Public Health Service Act (42 U.S.C. 300kk(b)) is amended by striking "DATA ANALYSIS.—" and all that follows through "For each federally" and inserting "DATA ANALYSIS.—For each federally".

SEC. 3. IMPROVING HEALTH STATISTICS REPORTING WITH RESPECT TO INDIAN TRIBES.

(a) TECHNICAL AID TO STATES AND LOCALITIES.—Section 306(d) of the Public Health Service Act (42 U.S.C. 242k(d)) is amended by inserting ", Indian Tribes, Tribal organizations, and epidemiology centers" after "jurisdictions".

(b) COOPERATIVE HEALTH STATISTICS SYSTEM.—Section 306(e)(3) of the Public Health Service Act (42 U.S.C. 242k(e)(3)) is amended by inserting ", Indian Tribes, Tribal organizations, and epidemiology centers" after "health agencies".

(c) FEDERAL-STATE-TRIBAL COOPERATION.—Section 306(f) of the Public Health Service Act (42 U.S.C. 242k(f)) is amended—

(1) by inserting "the Indian Health Service," before "the Departments of Commerce";

(2) by inserting a comma after "the Departments of Commerce and Labor";

(3) by inserting ", Indian Tribes, Tribal organizations, and epidemiology centers" after "State and local health departments and agencies"; and

(4) by striking "he shall" and inserting "the Secretary shall".

(d) REGISTRATION AREA RECORDS.—Section 306(h)(1) of the Public Health Service Act (42 U.S.C. 242k(h)(1)) is amended—

(1) by striking "in his discretion" and inserting "in the discretion of the Secretary"; and

(2) by striking "Hispanics, Asian Americans, and Pacific Islanders" and inserting "American Indians and Alaska Natives, Hispanics, Asian Americans, and Native Hawaiian and other Pacific Islanders".

(e) NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS.—Section 306(k) of the Public Health Service Act (42 U.S.C. 242k(k)) is amended—

(1) in paragraph (3), by striking ", not later than 60 days after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996," each place it appears; and

(2) in paragraph (7), by striking "Not later than 1 year after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996, and annually thereafter, the Committee shall" and inserting "The Committee shall, on an biennial basis,".

(f) GRANTS FOR ASSEMBLY AND ANALYSIS OF DATA ON ETHNIC AND RACIAL POPULATIONS.—Section 306(m)(4) of the Public Health Service Act (42 U.S.C. 242k(m)(4)) is amended—

(1) in subparagraph (A)—

(A) by striking "Subject to subparagraph (B), the" and inserting "The"; and

(B) by striking "and major Hispanic subpopulation groups and American Indians" and inserting ", major Hispanic subgroups, and American Indians and Alaska Natives"; and

(2) by amending subparagraph (B) to read as follows:

"(B) In carrying out subparagraph (A), with respect to American Indians and Alaska Natives, the Secretary shall—

"(i) consult with Indian Tribes, Tribal organizations, the Tribal Technical Advisory Group of the Centers for Medicare & Medicaid Services maintained under section 5006(e) of the American Recovery and Reinvestment Act of 2009, and the Tribal Advisory Committee established by the Centers for Disease Control and Prevention, in coordination with epidemiology centers, to develop guidelines for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

"(ii) confer with Urban Indian organizations to develop guidelines for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

"(iii) enter into cooperative agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and epidemiology centers to address misclassification and undersampling of American Indians and Alaska Natives with respect to—

"(I) birth and death records; and

"(II) health care and public health surveillance systems, including, but not limited to, data with respect to chronic and infectious diseases, unintentional injuries, environmental health, child and adolescent health, maternal health and mortality, foodborne and waterborne illness, reproductive health, and any other notifiable disease or condition;

"(iv) encourage States to enter into data sharing agreements with Indian Tribes, Tribal organizations, and epidemiology centers to improve the quality and accuracy of public health data; and

"(v) not later than 180 days after the date of enactment of the Tribal Health Data Improvement Act of 2020, and biennially thereafter, issue a report on the following:

"(I) Which States have data sharing agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers to improve the quality and accuracy of health data.

"(II) What the Centers for Disease Control and Prevention is doing to encourage States to enter into data sharing agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers to improve the quality and accuracy of health data.

"(III) Best practices and guidance for States, Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers that wish to enter into data sharing agreements.

"(IV) Best practices and guidance for local, State, Tribal, and Federal uniform standards for the collection of data on race and ethnicity.".

(g) DEFINITIONS.—Section 306 of the Public Health Service Act (42 U.S.C. 242k) is amended—

(1) by redesignating subsection (n) as subsection (o); and

(2) by inserting after subsection (m) the following:

"(n) In this section:

"(1) The term 'epidemiology center' means an epidemiology center established under section 214 of the Indian Health Care Improvement Act, including such Tribal epidemiology centers serving Indian Tribes regionally and any Tribal epidemiology center serving Urban Indian organizations nationally.

"(2) The term 'Indian Tribe' has the meaning given to the term 'Indian tribe' in section 4 of the Indian Self-Determination and Education Assistance Act.

"(3) The term 'Tribal organization' has the meaning given to the term 'tribal organization' in section 4 of the Indian Self-Determination and Education Assistance Act.

"(4) The term 'Urban Indian organization' has the meaning given to that term in section 4 of the Indian Health Care Improvement Act.".

(h) AUTHORIZATION OF APPROPRIATIONS.—Section 306(o) of the Public Health Service Act, as redesignated by subsection (g), is amended to read as follows:

"(o)(1) To carry out this section, there is authorized to be appropriated $185,000,000 for each of the fiscal years 2021 through 2025.

"(2) Of the amount authorized to be appropriated to carry out this section for a fiscal year, the Secretary shall not use more than 10 percent for the combined costs of—

"(A) administration of this section; and

"(B) carrying out subsection (m)(2).".

I. PURPOSE AND SUMMARY

H.R. 7948, the "Tribal Health Data Improvement Act of 2020", was introduced on August 7, 2020, by Representatives Greg Gianforte (R–MT), Ben Ray Luján (D–NM), Cathy McMorris Rodgers (R–WA), Markwayne Mullin (R–OK), Tom O'Halleran (D–AZ), and Raul Ruiz (D–CA).

H.R. 7948 addresses longstanding disparities in the collection and availability of public health data with respect to Indian Tribes by amending the Public Health Service Act to strengthen the ability of the Centers for Disease Control and Prevention (CDC) to address and improve public health data sharing to Indian Tribes, Tribal organizations, and Tribal epidemiology centers (TECs). The legislation also requires the Secretary of Health and Human Services (the Secretary) to report on existing data sharing agreements between States, the CDC, and Tribal communities and identify best practices. The legislation also reauthorizes CDC's National Center for Health Statistics.

II. BACKGROUND AND NEED FOR LEGISLATION

The health of American Indian and Alaskan Native (AI/AN) populations lag behind all other races in the United States.[1] [2] Economic adversity and poor social conditions have contributed to disproportionate disease burden, lower life expectancies, and other

[1] https://www.cdc.gov/nchs/fastats/american-indian-health.htm.

[2] Indian Health Service, *Indian Health Disparities* (Oct. 2019) (www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/documents/factsheets/Disparities.pdf).

health inequalities in Tribal communities.[3] Tragically, Tribal members are expected to live 5.5 fewer years than other U.S. races.[4] The coronavirus disease of 2019 (COVID–19) pandemic has further highlighted these longstanding health inequalities. According to CDC data, more than one-third of nonelderly American Indians and Alaska Natives are at high-risk of developing a serious illness resulting from a COVID–19 infection compared with one-fifth of White nonelderly adults.[5] [6]

Established in 1992 pursuant to the Indian Health Care Improvement Act (IHCIA),[7] TECs are responsible for managing public health information systems serving American Indian and Alaska Native communities.[8] In 2010, Congress permanently reauthorized IHCIA[9] including a provision designating TECs as public health authorities under the Health Insurance Portability and Accountability Act (HIPAA) and authorizing these entities access to data held by the U.S. Department of Health and Human Services (HHS).[10] In addition, IHCIA specified that the HHS Secretary must grant TECs access to "data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary."[11]

Currently, 12 TECs manage regional public health information systems, disease prevention and control programs, and coordinate with other public health authorities in the collection and study of epidemiological data.[12] TECs perform vital public health surveillance work and assistance in consultation with and on the request of the Indian Tribes, tribal organizations, and Urban Indian Health Programs.[13] This includes monitoring the spread of COVID–19 and studying the underlying health risks that could put American Indians and Alaska Natives at higher risk for the disease. In May 2020, the COVID–19 pandemic drew attention to longstanding deficiencies in the ability for TECs ability to access essential public health data from the CDC and other entities.[14] Without access to the critical data information that the CDC collects, TECs cannot effectively do the work needed to manage epidemiological outbreaks across Indian country, such as COVID–19, or other diseases.[15]

According to the CDC Office for State, Tribal, Local and Territorial Support, "[a]ccess to AI/AN public health data is a continuing issue facing TECs, yet is essential towards the successful perform-

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[3] Indian Health Service, *Indian Health Disparities* (Oct. 2019) (www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/documents/factsheets/Disparities.pdf).

[4] *Id.*

[5] https://www.cdc.gov/coronavirus/2019-ncov/community/tribal/index.html.

[6] Samantha Artiga & Kendal Orgera, *COVID–19 Presents Significant Risks for American Indian and Alaska Native People*, KAISER FAMILY FOUNDATION (May 14, 2020), https://www.kff.org/coronavirus-covid-19/issue-brief/covid-19-presents-significant-risks-for-american-indian-and-alaska-native-people/.

[7] Pub. L. No. 102–573, 106 Stat. 4526 § 214(a)(1).

[8] Tribal Epidemiology Centers, *About.* (https://tribalepicenters.org/about/).

[9] The Patient Protection and Affordable Care Act, Pub. L. No. 111–148 (2010).

[10] 25 U.S.C.A § 1621m(e)(1).

[11] 25 U.S.C. § 1621m(e)(2).

[12] Tribal Epidemiology Centers, *About.* (https://tribalepicenters.org/about/).

[13] https://www.cdc.gov/tribal/documents/tec_overview.pdf.

[14] Darius Tahir & Adam Cancryn, *American Indian Tribes Thwarted in Efforts to Get Coronavirus Data*, Politico (Jun. 11, 2020), www.politico.com/news/2020/06/11/native-american-coronavirus-data-314527.

[15] https://www.cdc.gov/healthytribes/pdf/CDC-indian-country-508.pdf.

ance of these functions." [16] CDC continues by clearly stating that, "[a]n additional issue affecting TECs is their difficulty securing relevant data,[17] fostered by concern from State and local jurisdictions and private entities about release of identifiable health data, as well as by State laws limiting access to certain health data." [18] [19]

H.R. 7948 ensures that Tribal Nations are equipped with the necessary public health data to operate public health programs and improve health outcomes within their communities by clarifying the Secretary of HHS's role in collection and availability of health data with respect to Indian Tribes. It also mandates ways of improving health statistics reporting with respect to Indian Tribes such as requiring the Secretary to release all applicable public health data to TECs within 180 days of enactment and requiring the CDC to expand and improve their assistance to States with respect to sharing data with Tribal entities. Finally, H.R. 7948 reauthorizes the National Center for Health Statistics with additional monies in order to provide funding for the new programs and authorities established in this legislation.

III. COMMITTEE HEARINGS

For the purposes of section 103(i) of H. Res. 6 of the 116th Congress, the following hearing was used to develop or consider H.R. 7948:

The full Committee on Energy and Commerce held a hearing on July 8, 2020, entitled "Addressing the Urgent Needs of Our Tribal Communities." The full committee received testimony from the following witnesses:

- Charles Grim, D.D.S., M.H.S.A., Secretary, Chickasaw Nation Department of Health
- Jonathan Nez, President, Navajo Nation
- The Honorable Christine Sage, Chairman, Southern Ute Indian Tribe
- Fawn Sharp, President, National Congress of American Indians
- Pilar M. Thomas, Partner, Quarles & Brady LLP

IV. COMMITTEE CONSIDERATION

H.R. 7948, the "Tribal Health Data Improvement Act of 2020", was introduced on August 7, 2020, by Representatives Gianforte (R–MT), Luján (D–NM), Rodgers (R–WA), Mullin (R–OK), O'Halleran (D–AZ), and Ruiz (D–CA), and was referred to the Committee on Energy and Commerce. The bill was then referred to the Subcommittee on Health on August 10, 2020. The hearing on legislative issue was held by the full Committee prior to the introduction of H.R. 7948.

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[16] Centers for Disease Control and Prevention, *Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act. (Accessed Sept. 17, 2020)* http://www.cdc.gov/phlp/docs/tec-issuebrief.pdf.

[17] James G. Hodge, Jr., Torrey Kaufman, and Craig Jacques, Legal Issues Concerning Identifiable Health Data Sharing Between State/Local Public Health Authorities and Tribal Epidemiology Centers in Selected US Jurisdictions, COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS, 1 (Nov. 8, 2011), http://c.ymcdn.com/sites/www.cste.org/resource/resmgr/PDFs/LegalIssuesTribalJuris.pdf.

[18] *Id.*

[19] Centers for Disease Control and Prevention, *Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act. (Accessed Sept. 17, 2020)* http://www.cdc.gov/phlp/docs/tec-issuebrief.pdf.

On September 9, 2020, H.R. 7948 was discharged from further consideration by the Subcommittee on Health as the bill was called up for markup by the full Committee on Energy and Commerce. The full Committee met in virtual open markup session, pursuant to notice, on September 9, 2020, to consider H.R. 7948. An amendment in the nature of a substitute (AINS) was offered by Mr. Mullin. The Mullin AINS was agreed to by a voice vote. At the conclusion of consideration, Mr. Pallone, Chairman of the committee, offered a motion to order H.R. 7948 reported favorably to the House, amended, which was agreed to by a voice vote, a quorum being present.

V. Committee Votes

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list each record vote on the motion to report legislation and amendments thereto. The Committee advises that there was no record vote taken on H.R. 7948, including the motion on final passage of the bill.

VI. Oversight Findings

Pursuant to clause 3(c)(1) of rule XIII and clause 2(b)(1) of rule X of the Rules of the House of Representatives, the oversight findings and recommendations of the Committee are reflected in the descriptive portion of the report.

VII. New Budget Authority, Entitlement Authority, and Tax Expenditures

Pursuant to 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee adopts as its own the estimate of new budget authority, entitlement authority, or tax expenditures or revenues contained in the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

The Committee has requested but not received from the Director of the Congressional Budget Office a statement as to whether this bill contains any new budget authority, spending authority, credit authority, or an increase or decrease in revenues or tax expenditures.

VIII. Federal Mandates Statement

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

IX. Statement of General Performance Goals and Objectives

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to enhance the collection and availability of public health data with respect to Indian Tribes.

X. Duplication of Federal Programs

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 7948 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant

to section 21 of Public Law 111–139 or the most recent Catalog of Federal Domestic Assistance.

XI. Committee Cost Estimate

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

XII. Earmarks, Limited Tax Benefits, and Limited Tariff Benefits

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 7948 contains no earmarks, limited tax benefits, or limited tariff benefits.

XIII. Advisory Committee Statement

No advisory committee within the meaning of section 5(b) of the Federal Advisory Committee Act was created by this legislation.

XIV. Applicability to Legislative Branch

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

XV. Section-by-Section Analysis of the Legislation

Section 1. Short title

Section 1 designates that the short title for this Act may be cited as the "Tribal Health Data Improvement Act of 2020".

Sec. 2. Collection and availability of health data with respect to Indian Tribes

Section 2 amends section 3101 of the Public Health Service Act to clarify the Secretary's responsibility to report and disseminate such data collected pursuant to section 3010(a) to the Indian Health Service, Indian Tribes, Tribal organizations, and TECs authorized under the IHCIA. These data include race, ethnicity, sex, preferred language, and disability status Section 2 requires the Secretary to create a data sharing strategy that takes into consideration recommendations by the Secretary's Tribal Advisory Committee to ensure that TECs and Indian Tribes have access to the data sources necessary to accomplish their public health responsibilities while protecting the privacy and security of such data.

Section 2 also requires the Secretary to, within 180 days of enactment of this legislation, make health care and public health surveillance data available to the Indian Health Service, Indian Tribes, Tribal organizations, and TECs so long as the data requested for use is consistent with Federal law and obligations.

Sec. 3. Improving health statistics reporting with respect to Indian Tribes

Section 3 amends section 306 of the Public Health Service Act to require the Secretary to consult with Indian Tribes, Tribal organi-

zations, the Tribal Health Advisory Group of the Centers for Medicare and Medicaid Services, and Urban Indian organizations, in order to develop guidelines for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives. The Secretary must enter into cooperative agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and TECs to address misclassification and undersampling of American Indians and Alaska Natives with respect to birth and death records and health care and public health surveillance systems data.

Section 3 requires that the Secretary to issue a report—not later than 180 days after the date of enactment of this legislation and biennially thereafter—regarding data sharing agreements between States and Indian Tribes, Tribal organizations, Urban Indian organizations, and TECs. The report must outline what the CDC is doing to encourage States to work with Tribal communities and must identify best practices and guidance for Tribes, Tribal organizations, Urban Indian organizations, and TECs that wish to enter into data sharing agreements. The report must also include best practices and guidance for local, State, Tribal, and Federal uniform standards for the collection of data on race and ethnicity.

Section 3 also increases the amount authorized to be appropriated for the National Center for Health Statistics to $185,000,000 for each of the fiscal years 2021 through 2025.

XVI. Changes in Existing Law Made by the Bill, as Reported

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, and existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

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TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

Part A—Research and Investigation

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NATIONAL CENTER FOR HEALTH STATISTICS

Sec. 306. (a) There is established in the Department of Health and Human Services the National Center for Health Statistics (hereinafter in this section referred to as the "Center") which shall be under the direction of a Director who shall be appointed by the Secretary. The Secretary, acting through the Center, shall conduct and support statistical and epidemiological activities for the purpose of improving the effectiveness, efficiency, and quality of health services in the United States.

(b) In carrying out subsection (a), the Secretary, acting through the Center—

(1) shall collect statistics on—

(A) the extent and nature of illness and disability of the population of the United States (or of any groupings of the people included in the population), including life expectancy, the incidence of various acute and chronic illnesses, and infant and maternal morbidity and mortality,

(B) the impact of illness and disability of the population on the economy of the United States and on other aspects of the well-being of its population (or of such groupings),

(C) environmental, social, and other health hazards,

(D) determinants of health,

(E) health resources, including physicians, dentists, nurses, and other health professionals by specialty and type of practice and the supply of services by hospitals, extended care facilities, home health agencies, and other health institutions,

(F) utilization of health care, including utilization of (i) ambulatory health services by specialties and types of practice of the health professionals providing such services, and (ii) services of hospitals, extended care facilities, home health agencies, and other institutions,

(G) health care costs and financing, including the trends in health care prices and cost, the sources of payments for health care services, and Federal, State, and local governmental expenditures for health care services, and

(H) family formation, growth, and dissolution;

(2) shall undertake and support (by grant or contract) research, demonstrations, and evaluations respecting new or improved methods for obtaining current data on the matters referred to in paragraph (1);

(3) may undertake and support (by grant or contract) epidemiological research, demonstrations, and evaluations on the matters referred to in paragraph (1); and

(4) may collect, furnish, tabulate, and analyze statistics, and prepare studies, on matters referred to in paragraph (1) upon request of public and nonprofit private entities under arrangements under which the entities will pay the cost of the service provided.

Amounts appropriated to the Secretary from payments made under arrangements made under paragraph (4) shall be available to the Secretary for obligation until expended.

(c) The Center shall furnish such special statistical and epidemiological compilations and surveys as the Committee on Labor and Human Resources and the Committee on Appropriations of the Senate and the Committee on Energy and Commerce and the Committee on Appropriations of the House of Representatives may request. Such statistical and epidemiological compilations and surveys shall not be made subject to the payment of the actual or estimated cost of the preparation of such compilations and surveys.

(d) To insure comparability and reliability of health statistics, the Secretary shall, through the Center, provide adequate technical assistance to assist State and local jurisdictions*, Indian Tribes, Tribal organizations, and epidemiology centers* in the development of model laws dealing with issues of confidentiality and comparability of data.

(e) For the purpose of producing comparable and uniform health information and statistics, there is established the Cooperative Health Statistics System. The Secretary, acting through the Center, shall—

(1) coordinate the activities of Federal agencies involved in the design and implementation of the System;

(2) undertake and support (by grant or contract) research, development, demonstrations, and evaluations respecting the System;

(3) make grants to and enter into contracts with State and local health agencies*, Indian Tribes, Tribal organizations, and epidemiology centers* to assist them in meeting the costs of data collection and other activities carried out under the System; and

(4) review the statistical activities of the Department of Health and Human Services to assure that they are consistent with the System.

States participating in the System shall designate a State agency to administer or be responsible for the administration of the statistical activities within the State under the System. The Secretary, acting through the Center, shall prescribe guidelines to assure that statistical activities within States participating in the system produce uniform and timely data and assure appropriate access to such data.

(f) To assist in carrying out this section, the Secretary, acting through the Center, shall cooperate and consult with *the Indian Health Service,* the Departments of Commerce and Labor*,* and any other interested Federal departments or agencies and with State and local health departments and agencies*, Indian Tribes, Tribal organizations, and epidemiology centers*. For such purpose ⟦he shall⟧ *the Secretary shall* utilize insofar as possible the services or facilities of any agency of the Federal Government and, without regard to section 3709 of the Revised Statutes (41 U.S.C. 5), of any appropriate State or other public agency, and may, without regard to such section, utilize the services or facilities of any private agency, organization, group, or individual, in accordance with written agreements between the head of such agency, organization, or group and the Secretary or between such individual and the Secretary. Payment, if any, for such services or facilities shall be made in such amounts as may be provided in such agreement.

(g) To secure uniformity in the registration and collection of mortality, morbidity, and other health data, the Secretary shall prepare and distribute suitable and necessary forms for the collection and compilation of such data.

(h)(1) There shall be an annual collection of data from the records of births, deaths, marriages, and divorces in registration areas. The data shall be obtained only from and restricted to such records of the States and municipalities which the Secretary, ⟦in his discretion⟧ *in the discretion of the Secretary*, determines possess records affording satisfactory data in necessary detail and form. The Secretary shall encourage States and registration areas to obtain detailed data on ethnic and racial populations, including subpopulations of ⟦Hispanics, Asian Americans, and Pacific Islanders⟧ *American Indians and Alaska Natives, Hispanics, Asian Americans, and Native Hawaiian and other Pacific Islanders* with significant

representation in the State or registration area. Each State or registration area shall be paid by the Secretary the Federal share of its reasonable costs (as determined by the Secretary) for collecting and transcribing (at the request of the Secretary and by whatever method authorized by him) its records for such data.

(2) There shall be an annual collection of data from a statistically valid sample concerning the general health, illness, and disability status of the civilian noninstitutionalized population. Specific topics to be addressed under this paragraph, on an annual or periodic basis, shall include the incidence of illness and accidental injuries, prevalence of chronic diseases and impairments, disability, physician visits, hospitalizations, and the relationship between demographic and socioeconomic characteristics and health characteristics.

(i) The Center may provide to public and nonprofit private entities technical assistance in the effective use in such activities of statistics collected or compiled by the Center.

(j) In carrying out the requirements of section 304(c) and paragraph (1) of subsection (e) of this section, the Secretary shall coordinate health statistical and epidemiological activities of the Department of Health and Human Services by—

(1) establishing standardized means for the collection of health information and statistics under laws administered by the Secretary;

(2) developing, in consultation with the National Committee on Vital and Health Statistics, and maintaining the minimum sets of data needed on a continuing basis to fulfill the collection requirements of subsection (b)(1);

(3) after consultation with the National Committee on Vital and Health Statistics, establishing standards to assure the quality of health statistical and epidemiological data collection, processing, and analysis;

(4) in the case of proposed health data collections of the Department which are required to be reviewed by the Director of the Office of Management and Budget under section 3509 of title 44, United States Code, reviewing such proposed collections to determine whether they conform with the minimum sets of data and the standards promulgated pursuant to paragraphs (2) and (3), and if any such proposed collection is found not to be in conformance, by taking such action as may be necessary to assure that it will conform to such sets of data and standards, and

(5) periodically reviewing ongoing health data collections of the Department, subject to review under such section 3509, to determine if the collections are being conducted in accordance with the minimum sets of data and the standards promulgated pursuant to paragraphs (2) and (3) and, if any such collection is found not to be in conformance, by taking such action as may be necessary to assure that the collection will conform to such sets of data and standards not later than the nineteenth day after the date of the completion of the review of the collection.

(k)(1) There is established in the Office of the Secretary a committee to be known as the National Committee on Vital and Health

Statistics (hereinafter in this subsection, referred to as the "Committee") which shall consist of 18 members.

(2) The members of the Committee shall be appointed from among persons who have distinguished themselves in the fields of health statistics, electronic interchange of health care information, privacy and security of electronic information, population-based public health, purchasing or financing health care services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Members of the Committee shall be appointed for terms of 4 years.

(3) Of the members of the Committee—

(A) 1 shall be appointed[, not later than 60 days after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996,] by the Speaker of the House of Representatives after consultation with the Minority Leader of the House of Representatives;

(B) 1 shall be appointed[, not later than 60 days after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996,] by the President pro tempore of the Senate after consultation with the Minority Leader of the Senate; and

(C) 16 shall be appointed by the Secretary.

(4) Members of the Committee shall be compensated in accordance with section 208(c).

(5) The Committee—

(A) shall assist and advise the Secretary—

(i) to delineate statistical problems bearing on health and health services which are of national or international interest;

(ii) to stimulate studies of such problems by other organizations and agencies whenever possible or to make investigations of such problems through subcommittees;

(iii) to determine, approve, and revise the terms, definitions, classifications, and guidelines for assessing health status and health services, their distribution and costs, for use (I) within the Department of Health and Human Services, (II) by all programs administered or funded by the Secretary, including the Federal-State-local cooperative health statistics system referred to in subsection (e), and (III) to the extent possible as determined by the head of the agency involved, by the Department of Veterans Affairs, the Department of Defense, and other Federal agencies concerned with health and health services;

(iv) with respect to the design of and approval of health statistical and health information systems concerned with the collection, processing, and tabulation of health statistics within the Department of Health and Human Services, with respect to the Cooperative Health Statistics System established under subsection (e), and with respect to the standardized means for the collection of health information and statistics to be established by the Secretary under subsection (j)(1);

(v) to review and comment on findings and proposals developed by other organizations and agencies and to make

recommendations for their adoption or implementation by local, State, national, or international agencies;

(vi) to cooperate with national committees of other countries and with the World Health Organization and other national agencies in the studies of problems of mutual interest;

(vii) to issue an annual report on the state of the Nation's health, its health services, their costs and distributions, and to make proposals for improvement of the Nation's health statistics and health information systems; and

(viii) in complying with the requirements imposed on the Secretary under part C of title XI of the Social Security Act;

(B) shall study the issues related to the adoption of uniform data standards for patient medical record information and the electronic exchange of such information;

(C) shall report to the Secretary not later than 4 years after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996 recommendations and legislative proposals for such standards and electronic exchange; and

(D) shall be responsible generally for advising the Secretary and the Congress on the status of the implementation of part C of title XI of the Social Security Act.

(6) In carrying out health statistical activities under this part, the Secretary shall consult with, and seek the advice of, the Committee and other appropriate professional advisory groups.

(7) [Not later than 1 year after the date of the enactment of the Health Insurance Portability and Accountability Act of 1996, and annually thereafter, the Committee shall] *The Committee shall, on an biennial basis,* submit to the Congress, and make public, a report regarding the implementation of part C of title XI of the Social Security Act. Such report shall address the following subjects, to the extent that the Committee determines appropriate:

(A) The extent to which persons required to comply with part C of title XI of the Social Security Act are cooperating in implementing the standards adopted under such part.

(B) The extent to which such entities are meeting the security standards adopted under such part and the types of penalties assessed for noncompliance with such standards.

(C) Whether the Federal and State Governments are receiving information of sufficient quality to meet their responsibilities under such part.

(D) Any problems that exist with respect to implementation of such part.

(E) The extent to which timetables under such part are being met.

(l) In carrying out this section, the Secretary, acting through the Center, shall collect and analyze adequate health data that is specific to particular ethnic and racial populations, including data collected under national health surveys. Activities carried out under this subsection shall be in addition to any activities carried out under subsection (m).

(m)(1) The Secretary, acting through the Center, may make grants to public and nonprofit private entities for—

(A) the conduct of special surveys or studies on the health of ethnic and racial populations or subpopulations;

(B) analysis of data on ethnic and racial populations and subpopulations; and

(C) research on improving methods for developing statistics on ethnic and racial populations and subpopulations.

(2) The Secretary, acting through the Center, may provide technical assistance, standards, and methodologies to grantees supported by this subsection in order to maximize the data quality and comparability with other studies.

(3) Provisions of section 308(d) do not apply to surveys or studies conducted by grantees under this subsection unless the Secretary, in accordance with regulations the Secretary may issue, determines that such provisions are necessary for the conduct of the survey or study and receives adequate assurance that the grantee will enforce such provisions.

(4)(A) [Subject to subparagraph (B), the] *The* Secretary, acting through the Center, shall collect data on Hispanics [and major Hispanic subpopulation groups and American Indians], *major Hispanic subgroups, and American Indians and Alaska Natives*, and for developing special area population studies on major Asian American and Pacific Islander populations.

[(B) The provisions of subparagraph (A) shall be effective with respect to a fiscal year only to the extent that funds are appropriated pursuant to paragraph (3) of subsection (n), and only if the amounts appropriated for such fiscal year pursuant to each of paragraphs (1) and (2) of subsection (n) equal or exceed the amounts so appropriated for fiscal year 1997.]

(B) In carrying out subparagraph (A), with respect to American Indians and Alaska Natives, the Secretary shall—

(i) consult with Indian Tribes, Tribal organizations, the Tribal Technical Advisory Group of the Centers for Medicare & Medicaid Services maintained under section 5006(e) of the American Recovery and Reinvestment Act of 2009, and the Tribal Advisory Committee established by the Centers for Disease Control and Prevention, in coordination with epidemiology centers, to develop guidelines for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

(ii) confer with Urban Indian organizations to develop guidelines for State and local health agencies to improve the quality and accuracy of data with respect to the birth and death records of American Indians and Alaska Natives;

(iii) enter into cooperative agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and epidemiology centers to address misclassification and undersampling of American Indians and Alaska Natives with respect to—

(I) birth and death records; and

(II) health care and public health surveillance systems, including, but not limited to, data with respect to chronic and infectious diseases, unintentional injuries, environmental health, child and adolescent health, maternal health and mortality, foodborne and waterborne illness, re-

productive health, and any other notifiable disease or condition;

(iv) encourage States to enter into data sharing agreements with Indian Tribes, Tribal organizations, and epidemiology centers to improve the quality and accuracy of public health data; and

(v) not later than 180 days after the date of enactment of the Tribal Health Data Improvement Act of 2020, and biennially thereafter, issue a report on the following:

(I) Which States have data sharing agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers to improve the quality and accuracy of health data.

(II) What the Centers for Disease Control and Prevention is doing to encourage States to enter into data sharing agreements with Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers to improve the quality and accuracy of health data.

(III) Best practices and guidance for States, Indian Tribes, Tribal organizations, Urban Indian organizations, and Tribal epidemiology centers that wish to enter into data sharing agreements.

(IV) Best practices and guidance for local, State, Tribal, and Federal uniform standards for the collection of data on race and ethnicity.

(n) In this section:

(1) The term "epidemiology center" means an epidemiology center established under section 214 of the Indian Health Care Improvement Act, including such Tribal epidemiology centers serving Indian Tribes regionally and any Tribal epidemiology center serving Urban Indian organizations nationally.

(2) The term "Indian Tribe" has the meaning given to the term "Indian tribe" in section 4 of the Indian Self-Determination and Education Assistance Act.

(3) The term "Tribal organization" has the meaning given to the term "tribal organization" in section 4 of the Indian Self-Determination and Education Assistance Act.

(4) The term "Urban Indian organization" has the meaning given to that term in section 4 of the Indian Health Care Improvement Act.

[(n)(1) For health statistical and epidemiological activities undertaken or supported under subsections (a) through (l), there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 1991 through 2003.

[(2) For activities authorized in paragraphs (1) through (3) of subsection (m), there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 1999 through 2003. Of such amounts, the Secretary shall use not more than 10 percent for administration and for activities described in subsection (m)(2).

[(3) For activities authorized in subsection (m)(4), there are authorized to be appropriated $1,000,000 for fiscal year 1998, and such sums as may be necessary for each of the fiscal years 1999 through 2002.]

(o)(1) To carry out this section, there is authorized to be appropriated $185,000,000 for each of the fiscal years 2021 through 2025.

(2) Of the amount authorized to be appropriated to carry out this section for a fiscal year, the Secretary shall not use more than 10 percent for the combined costs of—

(A) administration of this section; and

(B) carrying out subsection (m)(2).

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TITLE XXXI—DATA COLLECTION, ANALYSIS, AND QUALITY

SEC. 3101. DATA COLLECTION, ANALYSIS, AND QUALITY.

(a) DATA COLLECTION.—

(1) IN GENERAL.—The Secretary shall ensure that**[**, by not later than 2 years after the date of enactment of this title,**]** any federally conducted or supported health care or public health program, activity or survey (including Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) collects and reports, to the extent practicable—

(A) data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants;

(B) data at the smallest geographic level such as State, *Tribal,* local, or institutional levels if such data can be aggregated;

(C) sufficient data to generate statistically reliable estimates by racial, ethnic, sex, primary language, and disability status subgroups for applicants, recipients or participants using, if needed, statistical oversamples of these subpopulations; and

(D) any other demographic data as deemed appropriate by the Secretary regarding health disparities.

(2) COLLECTION STANDARDS.—In collecting data described in paragraph (1), the Secretary or designee shall—

(A) use Office of Management and Budget standards, at a minimum, for race and ethnicity measures;

(B) develop standards for the measurement of sex, primary language, and disability status;

(C) develop standards for the collection of data described in paragraph (1) that, at a minimum—

(i) collects self-reported data by the applicant, recipient, or participant; and

(ii) collects data from a parent or legal guardian if the applicant, recipient, or participant is a minor or legally incapacitated;

(D) survey health care providers and establish other procedures in order to assess access to care and treatment for individuals with disabilities and to identify—

(i) locations where individuals with disabilities access primary, acute (including intensive), and long-term care;

(ii) the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equip-

ment that meets the minimum technical criteria set forth in section 510 of the Rehabilitation Act of 1973; and

(iii) the number of employees of health care providers trained in disability awareness and patient care of individuals with disabilities; and

(E) require that any reporting requirement imposed for purposes of measuring quality under any ongoing or federally conducted or supported health care or public health program, activity, or survey includes requirements for the collection of data on individuals receiving health care items or services under such programs activities by race, ethnicity, sex, primary language, and disability status.

(3) DATA MANAGEMENT.—In collecting data described in paragraph (1), the Secretary, acting through the National Coordinator for Health Information Technology shall—

(A) develop national standards for the management of data collected; and

(B) develop interoperability and security systems for data management.

(b) [DATA ANALYSIS.—

[(1) IN GENERAL.—For each federally] *DATA ANALYSIS.—For each federally* conducted or supported health care or public health program or activity, the Secretary shall analyze data collected under paragraph (a) to detect and monitor trends in health disparities (as defined for purposes of section 485E) at the Federal and State levels.

(c) DATA REPORTING AND DISSEMINATION.—

(1) IN GENERAL.—The Secretary shall make the analyses described in (b) available to—

(A) the Office of Minority Health;

(B) the National Center on Minority Health and Health Disparities;

(C) the Agency for Healthcare Research and Quality;

(D) the Centers for Disease Control and Prevention;

(E) the Centers for Medicare & Medicaid Services;

[(F) the Indian Health Service and epidemiology centers funded under the Indian Health Care Improvement Act;]

(F) the Indian Health Service, Indian Tribes, Tribal organizations, and epidemiology centers authorized under the Indian Health Care Improvement Act;

(G) the Office of Rural health;

(H) other agencies within the Department of Health and Human Services; and

(I) other entities as determined appropriate by the Secretary.

(2) REPORTING OF DATA.—The Secretary shall report data and analyses described in (a) and (b) through—

(A) public postings on the Internet websites of the Department of Health and Human Services; and

(B) any other reporting or dissemination mechanisms determined appropriate by the Secretary.

(3) AVAILABILITY OF DATA.—The Secretary may make data described in (a) and (b) available for additional research, analyses, and dissemination to other Federal agencies, *Indian*

Tribes, Tribal organizations, and epidemiology centers, non-governmental entities, and the public, in accordance with any Federal agency's data user agreements.

(d) LIMITATIONS ON USE OF DATA.—Nothing in this section shall be construed to permit the use of information collected under this section in a manner that would adversely affect any individual.

(e) PROTECTION AND SHARING OF DATA.—

(1) PRIVACY AND OTHER SAFEGUARDS.—The Secretary shall ensure (through the promulgation of regulations or otherwise) that—

(A) all data collected pursuant to subsection (a) is protected—

(i) under privacy protections that are at least as broad as those that the Secretary applies to other health data under the regulations promulgated under section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (Public Law 104–191; 110 Stat. 2033); and

(ii) from all inappropriate internal use by any entity that collects, stores, or receives the data, including use of such data in determinations of eligibility (or continued eligibility) in health plans, and from other inappropriate uses, as defined by the Secretary; and

(B) all appropriate information security safeguards are used in the collection, analysis, and sharing of data collected pursuant to subsection (a).

(2) DATA SHARING.—The Secretary shall establish procedures for sharing data collected pursuant to subsection (a), measures relating to such data, and analyses of such data, with other relevant Federal and State agencies including the agencies, centers, and entities within the Department of Health and Human Services specified in subsection (c)(1)..

(3) DATA SHARING STRATEGY.—With respect to data access for Tribal epidemiology centers and Tribes, the Secretary shall create a data sharing strategy that takes into consideration recommendations by the Secretary's Tribal Advisory Committee for—

(A) ensuring that Tribal epidemiology centers and Indian Tribes have access to the data sources necessary to accomplish their public health responsibilities; and

(B) protecting the privacy and security of such data.

(4) TRIBAL PUBLIC HEALTH AUTHORITY.—

(A) AVAILABILITY.—Beginning not later than 180 days after the date of the enactment of the Tribal Health Data Improvement Act of 2020, the Secretary shall make available to the entities listed in subparagraph (B) all data that is collected pursuant to this title with respect to health care and public health surveillance programs and activities, including such programs and activities that are federally supported or conducted, so long as—

(i) such entities request the data pursuant to statute; and

(ii) the data is requested for use—

(I) consistent with Federal law and obligations; and

(II) to satisfy a particular purpose or carry out a specific function consistent with the purpose for which the data was collected.

(B) ENTITIES.—The entities listed in this subparagraph are—

(i) the Indian Health Service;

(ii) Indian Tribes and Tribal organizations; and

(iii) epidemiology centers.

(f) DATA ON RURAL UNDERSERVED POPULATIONS.—The Secretary shall ensure that any data collected in accordance with this section regarding racial and ethnic minority groups are also collected regarding underserved rural and frontier populations.

[(g) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for each of fiscal years 2010 through 2014.

[(h) REQUIREMENT FOR IMPLEMENTATION.—Notwithstanding any other provision of this section, data may not be collected under this section unless funds are directly appropriated for such purpose in an appropriations Act.]

(g) DEFINITIONS.—In this section:

(1) The term "epidemiology center" means an epidemiology center established under section 214 of the Indian Health Care Improvement Act, including such Tribal epidemiology centers serving Indian Tribes regionally and any Tribal epidemiology center serving Urban Indian organizations nationally.

(2) The term "Indian Tribe" has the meaning given to the term "Indian tribe" in section 4 of the Indian Self-Determination and Education Assistance Act.

(3) The term "Tribal organization" has the meaning given to the term "tribal organization" in section 4 of the of the Indian Self-Determination and Education Assistance Act.

(4) The term "Urban Indian organization" has the meaning given to that term in section 4 of the Indian Health Care Improvement Act.

[(i)] *(h)* CONSULTATION.—The Secretary shall consult with the Director of the Office of Personnel Management, the Secretary of Defense, the Secretary of Veterans Affairs, the Director of the Bureau of the Census, the Commissioner of Social Security, and the head of other appropriate Federal agencies in carrying out this section.

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