

which was set out in the Appendix to Title 5, Government Organization and Employees, and was repealed and restated as section 406 of Title 5 by Pub. L. 117-286, §§3(b), 7, Dec. 27, 2022, 136 Stat. 4218, 4361.

AMENDMENTS

2021—Subsec. (b)(4). Pub. L. 116-321 added par. (4).

**Statutory Notes and Related Subsidiaries**

EFFECTIVE DATE OF 2021 AMENDMENT

Pub. L. 116-321, §2(b), Jan. 5, 2021, 134 Stat. 5073, provided that: “The amendment made by subsection (a) [amending this section] shall take effect as if included in the enactment of the 21st Century Cures Act (Public Law 114-255).”

SUBCHAPTER XXIX—DATA COLLECTION,  
ANALYSIS, AND QUALITY

**§ 300kk. Data collection, analysis, and quality**

**(a) Data collection**

**(1) In general**

The Secretary shall ensure that, by not later than 2 years after March 23, 2010, 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, 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 equipment that meets the minimum technical criteria set forth in section 794f of title 29; 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<sup>1</sup> 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)<sup>2</sup> In general**

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 285t<sup>3</sup> of this title) at the Federal and State levels.

**(c) Data reporting and dissemination**

**(1) In general**

The Secretary shall make the analyses described in (b)<sup>4</sup> 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 [25 U.S.C. 1601 et seq.];

(G) the Office of Rural health;<sup>5</sup>

(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)<sup>6</sup> and (b) through—

<sup>1</sup> So in original.

<sup>2</sup> So in original. No par. (2) has been enacted.

<sup>3</sup> See References in Text note below.

<sup>4</sup> So in original. Probably should be preceded by “subsection”.

<sup>5</sup> So in original. Probably should be “Health;”.

<sup>6</sup> So in original. Probably should be preceded by “subsections”.

(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, 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).<sup>1</sup>

**(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.

**(i) 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.

(July 1, 1944, ch. 373, title XXXI, § 3101, as added Pub. L. 111-148, title IV, § 4302(a), Mar. 23, 2010, 124 Stat. 578.)

**Editorial Notes**

REFERENCES IN TEXT

Section 285t of this title, referred to in subsec. (b)(1), was in the original "section 485E", meaning section 485E of act July 1, 1944, which was renumbered section 464z-3 by Pub. L. 111-148, title X, § 10334(c)(1)(D)(i), Mar. 23, 2010, 124 Stat. 973, and is classified to section 285t of this title. The act of July 1, 1944, no longer contains a section 485E.

The Indian Health Care Improvement Act, referred to in subsec. (c)(1)(F), is Pub. L. 94-437, Sept. 30, 1976, 90 Stat. 1400, which is classified principally to chapter 18 (§ 1601 et seq.) of Title 25, Indians. For complete classification of this Act to the Code, see Short Title note set out under section 1601 of Title 25 and Tables.

Section 264(c) of the Health Insurance Portability and Accountability Act of 1996 (Public Law 104-191; 110 Stat. 2033), referred to in subsec. (e)(1)(A)(i), is set out as a note under section 1320d-2 of this title.

SUBCHAPTER XXX—COMMUNITY LIVING ASSISTANCE SERVICES AND SUPPORTS

**§§ 300*ll* to 300*ll*-9. Repealed. Pub. L. 112-240, title VI, § 642(a), Jan. 2, 2013, 126 Stat. 2358**

Section 300*ll*, act July 1, 1944, ch. 373, title XXXII, § 3201, as added Pub. L. 111-148, title VIII, § 8002(a)(1), Mar. 23, 2010, 124 Stat. 828, established the purpose of this subchapter.

Section 300*ll*-1, act July 1, 1944, ch. 373, title XXXII, § 3202, as added Pub. L. 111-148, title VIII, § 8002(a)(1), Mar. 23, 2010, 124 Stat. 828, set out definitions.

Section 300*ll*-2, act July 1, 1944, ch. 373, title XXXII, § 3203, as added and amended Pub. L. 111-148, title VIII, § 8002(a)(1), title X, § 10801(a)(1), Mar. 23, 2010, 124 Stat. 830, 1015, required the Secretary to develop at least 3 actuarially sound benefit plans as alternatives for consideration for designation by the Secretary as the CLASS Independence Benefit Plan.

Section 300*ll*-3, act July 1, 1944, ch. 373, title XXXII, § 3204, as added and amended Pub. L. 111-148, title VIII, § 8002(a)(1), title X, § 10801(a)(2), Mar. 23, 2010, 124 Stat. 834, 1015, related to enrollment and disenrollment requirements.

Section 300*ll*-4, act July 1, 1944, ch. 373, title XXXII, § 3205, as added Pub. L. 111-148, title VIII, § 8002(a)(1), Mar. 23, 2010, 124 Stat. 836, related to benefits and determination of eligibility.

Section 300*ll*-5, act July 1, 1944, ch. 373, title XXXII, § 3206, as added Pub. L. 111-148, title VIII, § 8002(a)(1), Mar. 23, 2010, 124 Stat. 842, related to the CLASS Independence Fund.

Section 300*ll*-6, act July 1, 1944, ch. 373, title XXXII, § 3207, as added Pub. L. 111-148, title VIII, § 8002(a)(1), Mar. 23, 2010, 124 Stat. 844, created the CLASS Independence Advisory Council.

Section 300*ll*-7, act July 1, 1944, ch. 373, title XXXII, § 3208, as added Pub. L. 111-148, title VIII, § 8002(a)(1), Mar. 23, 2010, 124 Stat. 845, related to solvency and fiscal independence of the CLASS program and required regulations and annual reports.

Section 300*ll*-8, act July 1, 1944, ch. 373, title XXXII, § 3209, as added Pub. L. 111-148, title VIII, § 8002(a)(1),