Social Security Act Title XIX: Grants to states for Medical Assistance Programs (Medicaid)\(^1\)

Enacted in 1965, Title XIX of the Social Security Act established regulations for the Medicaid program, which provides funding for medical and health-related services for persons with limited income. Title XIX contains a number of provisions governing the acquisition, use and disclosure of Medicaid enrollees’ health information.

1. \textit{State Plans for Medical Assistance and Payment to States}

State participation in Medicaid is voluntary; each state designs and administers its own Medicaid program, funded jointly by the state and the federal government. Despite a state’s relative autonomy to develop its own Medicaid program plan, Title XIX predicates federal approval of state plans on the inclusion of certain provisions, and conditions federal financing of the program on the satisfaction of certain requirements. The following is a summary of all the health information provisions that must be included in each plan to earn federal approval and enable the state and providers to receive federal funds and reimbursement for services provided to enrollees.

a. \textit{Collection, Creation and Use of Health Information}

The use and disclosure of health information must be restricted to purposes directly connected with plan administration.\(^2\) Every provider must agree to keep complete records of the services furnished to Medicaid enrollees and to provide such information to the state or Secretary upon request.\(^3\) Every provider must document in the medical record whether an enrollee patient has an advance directive.\(^4\) With regard to the transmission of data, states are required to operate a mechanized claims processing and information retrieval system to electronically transmit data (including individual enrollee encounter data),\(^5\) which must be capable of developing patient and provider profiles that provide information about the use of covered services and items.\(^6\)

There must be a plan to evaluate the quality and appropriateness of the care and services furnished to Medicaid enrollees.\(^7\) The state must implement pre- and post-payment claims review procedures that include review of patient data and the nature of the provided service.\(^8\) The state must establish procedures for preventing unnecessary utilization of services and ensuring that payments are consistent with efficiency, economy and quality of care.\(^9\) These procedures must include a screen and review

\(^3\) Social Security Act § 1902(a)(27), 42 U.S.C. 1396a(27).
process\textsuperscript{10} for every inpatient admission\textsuperscript{11} and a requirement that provider hospitals maintain a utilization program\textsuperscript{12} that evaluates the medical necessity of all admissions, the duration of stays and any professional services provided in the hospital.\textsuperscript{13} If the state covers health home services, the plan must include methods for tracking avoidable hospital readmissions and calculating savings that result from improved care coordination and management.\textsuperscript{14}

b.) Requirements for Mental Hospitals, Institutions for Mental Diseases and Intermediate Care Facilities for the Mentally Retarded (ICF-MRs)

At the time of an enrollee’s admission to an inpatient hospital, an inpatient mental hospital or an ICF-MR (or at the time of a patient’s application for medical assistance), a qualified medical professional must certify that the enrollee needs (or needed) services provided at the facility.\textsuperscript{15} Inpatient mental hospitals and ICF-MRs must maintain a program of regular medical review\textsuperscript{16} and periodic recertification\textsuperscript{17} of each patient’s continued need for services in the facility.\textsuperscript{18} The state must establish a medical review program where an independent team evaluates the professional management of the care and services provided to patients in mental hospitals and ICF-MRs.\textsuperscript{19} The state must develop individual plans for enrollee patients in institutions for mental diseases who are age 65 and older.\textsuperscript{20} These plans must include assurances that there will be initial and regular review of the patient’s needs and a periodic determination of his continued need for treatment in the institution.\textsuperscript{21} The plans must also provide for agreements with mental disease authorities arranging for access to patients and facilities, joint planning and development of alternative methods of care, furnishing information and making reports.\textsuperscript{22}

c.) Disclosure and Reporting of Health Information; Fraud and Abuse Provisions

\textsuperscript{10} Note: The screen and review process must be based on criteria established by independent medical professionals. Social Security Act § 1902(a)(30)(B)(i), 42 U.S.C. 1396a(a)(30)(B)(i).
\textsuperscript{12} Social Security Act § 1903(i)(4), 42 U.S.C. 1396b(i)(4).
\textsuperscript{17} See Social Security Act § 1903(g)(6)(A) (inpatient hospitals) and § 1903(g)(6)(B) (ICF-MRs) (schedules for review and recertifications).
The state is required to offer and provide child health screening services, and must report to the Secretary the number of children screened, the number referred for corrective treatment and the number that received dental services. If the state covers health home services, each designated provider must report to the state on all applicable quality measures. The state must have a mechanism to receive reports and compile data concerning alleged instances of fraud, waste, and abuse and must establish a Medicaid fraud control unit that investigates and prosecutes violations of all applicable fraud laws and maintains procedures for reviewing complaints of abuse or neglect of patients in health care facilities. Any information obtained from an electronic claims processing system that relates to fraud or abuse must be given to the fraud control unit. The state must comply with provider and supplier screening, oversight and reporting requirements. These requirements include complying with the national system for reporting criminal and civil convictions, sanctions, negative licensure actions and other adverse provider actions and providing information and access to information respecting sanctions taken against health care practitioners and providers by state licensing authorities. The state must also have a system of reporting any adverse action or finding involving a health care practitioner or entity at the conclusion of any formal proceedings, including a loss of a practitioner or entity’s license or a dismissal or closure resulting from the practitioner or entity surrendering its license or leaving the state. The state must provide the Secretary with access to such documents as may be necessary to determine the facts and circumstances concerning the adverse actions and determinations and the Secretary may subsequently provide this information to relevant authorities. Provider facilities may be subject to surveys conducted by the state and the Secretary to evaluate compliance with statutory provisions, and within 90 days of such a survey, the pertinent findings must be made public.

2.) Nursing Facilities

Every state plan for medical assistance is required to provide coverage for nursing home care for categorically eligible participants age 21 and older. States may, at their option, design their plan for

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23 Social Security Act § 1902(a)(43)(B), 42 U.S.C. 1396a(a)(43)(B) (see SCHIP 2108(c) for additional requirements).
28 Social Security Act § 1902(a)(64), 42 U.S.C. 1396a(a)(64).
37 Social Security Act § 1921(b), 42 U.S.C. 1396r-2(b).
the provision of nursing home care to include other Medicaid beneficiaries, including individuals under age 21 or the medically needy. In any case, any individual receiving nursing care must satisfy nursing home eligibility criteria, commonly known as level-of-care criteria. There are a number of nursing facility requirements with respect to the collection, use, and disclosure of health information.

a.) Requirements Related to Provision of Services and Resident Rights

i.) Clinical Records
Nursing facilities must maintain clinical records on all residents, and with the patient’s permission, the facility must permit representatives of the state ombudsman to examine such records. The record must contain an assessment of each patient’s functional capacity and a plan of care for each patient, the results of any screenings, and documentation of the reasons for any discharge or transfer.

ii.) Assessments and Plans of Care
Assessments must be conducted upon admission and at least once every 12 months. The facility must examine each resident at least once every three months and revise the assessment as necessary; if a significant change in the resident’s condition has occurred, a new assessment must be conducted and the appropriate state authority must be notified of the change if that resident is mentally ill or retarded. A registered professional nurse must conduct and coordinate assessments, sign the assessment, and certify its completeness; any other health professional completing a portion of the assessment must sign that portion and certify its accuracy. The assessment must describe the resident’s ability to perform daily life functions and identify any medical problems or significant impairments in the resident’s functional capacity.

A team including the resident’s physician and a registered nurse must prepare the plan of care based on the results of the patient assessment. The plan must identify the medical, nursing, and psychosocial needs of the resident and describe how such needs will be met. In dispensing psychopharmacologic drugs, the

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41 Social Security Act § 1919(b)(6)(C), 42 U.S.C. 1396r(b)(6)(C).
facility must maintain plans written by a physician that indicate the need for and proper administration of such drugs; these plans must be annually reviewed for appropriateness by an external consultant.53

iii.) Transfers and Discharges
When transferring or discharging patients, the facility must notify the resident and an immediate family member or legal representative of the impending occurrence of and reasons for the transfer or discharge at least 30 days prior to the transfer or discharge.54 The state must annually report to the Secretary the number and disposition of residents discharged because they no longer required nursing facility or specialized services.55

iv.) Residents’ Rights
The facility must protect and promote the rights of every resident, which include:

- The right to privacy with regard to medical treatment;56
- The right to confidentiality of personal and clinical records;57
- The right to request and receive access to current clinical records;58
- The right to voice grievances with respect to treatment or care that is (or fails to be) furnished and with respect to the behavior of other residents and the right to have the facility make prompt efforts to resolve these grievances and;59
- The right to examine reports of each survey, certification and complaint investigation made within the preceding three years and any plan of correction in effect.60

b.) Requirements Related to Quality Measures, Notification and Reporting

Every nursing facility must maintain a quality assessment and assurance committee that meets quarterly to identify issues needing quality improvement and to develop and implement appropriate plans of action to correct identified quality deficiencies.61 There must be methods for receiving, reviewing and investigating allegations of neglect and abuse and misappropriation of resident property by any nursing facility employee; if the state makes a finding confirming such allegations, it must notify the offending individual and the appropriate licensure authority.62 A public nurse aide registry must be established that includes all documented findings of resident neglect or abuse or misappropriation of property, and any statement of the aide disputing the findings.63 The state must maintain procedures to investigate violations of all the requirements listed above and must also

62 Social Security Act § 1919(g)(1)(C), 42 U.S.C. 1396r(g)(1)(C).
monitor facilities that are, were or are suspected to be non-compliant with these requirements. The state must notify the long-term care ombudsman of any non-compliance or of adverse actions taken against a nursing facility.

The state will conduct regular surveys of the quality of care furnished by all nursing facilities that includes:

- An audit of resident assessments for accuracy;
- A review of plans of care for adequacy on the basis of resident assessments and;
- A review of compliance with residents’ rights.

Within two months, the Secretary will conduct validation surveys to determine whether the state’s survey was adequate. If the results of either survey show that a facility provided a substandard quality of care, an extended survey will be conducted to identify the policies and procedures that produced the problem and determine whether the facility has otherwise complied with all other nursing facility requirements. The state must also notify each affected resident’s attending physician, and any state board responsible for the licensing of the nursing facility administrator.

All survey and certification information will be provided to the state’s fraud and abuse control unit and be made public. The facility must post the results of its most recent survey in an accessible location, removing any information identifying complainants or residents in any notices or reports. The state must also maintain a consumer-oriented website that includes:

- Inspection reports, complaint investigation reports and plans of correction;
- Resident census data and data on the hours of care provided per resident per day;
- Summary information on the number, type, severity, and outcome of substantiated complaints;
- The number of adjudicated instances of criminal violations committed inside the facility by the employees of a facility and;
- The number of violations or crimes committed outside of the facility that resulted in the serious bodily injury of an elder.

3.) Home and Community-Based Care

In an effort to provide alternatives to nursing home care, states have a variety of options available in the form of home and community-based services. These alternatives to institutionalized care include

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64 Social Security Act § 1919(g)(4), 42 U.S.C. 1396r(g)(4).
65 Social Security Act § 1919(g)(5)(B), 42 U.S.C. 1396r(g)(5)(B).
69 Social Security Act § 1919(g)(5)(C), 42 U.S.C. 1396r(g)(5)(C).
70 Social Security Act § 1919(g)(5), 42 U.S.C. 1396r(g)(5).
71 Social Security Act § 1919(c)(8), 42 U.S.C. 1396r(c)(8).
home and community-based care for functionally disabled elderly individuals, the Program of All-Inclusive Care for the Elderly (PACE), consumer-directed services and home and community-based services provided via waiver and via plan amendment.

Prior to the passage of the Affordable Care Act, the threshold requirement to receive home and community-based services in any form was a need for institutionalized care. The ACA expanded states’ ability to provide services to entitled persons by permitting states to amend their plans and establish needs-based criteria for the receipt of home and community-based services. Such need-based criteria can be broad enough to include individuals whose needs do not meet the level of institutionalized care, but who would still benefit from receiving home and community-based services.

Whether via a waiver, an established program or a plan amendment, the plan for and provision of home and community-based services will necessarily rely on the collection and disclosure of enrollee participants’ health information. The following sections discuss all the health information-related provisions in the statute governing home and community-based care

a.) Home and Community Care for Functionally Disabled Elderly Individuals.\(^75\)

As part of their plans for medical assistance, states must provide coverage for home and community care to functionally disabled elderly individuals. There are a variety of options within this care, such as home health aide services, personal care services, and adult day care.\(^76\) A functionally disabled elderly individual is one who is 65 years or over, qualifies for state medical assistance, and is determined to be functionally disabled.\(^77\)

At the request of an eligible individual, the state must conduct an assessment to determine whether the individual is functionally disabled, which must contain:\(^78\)

- An identification or review of the individual’s functional disabilities and need for home and community care and;
- Information about the individual’s health status, home and community environment, and informal support system.

A qualified case manager must use the results of each functional assessment to establish, review and revise an Individual Community Care Plan (ICCP) after a face-to-face interview with the individual or his primary caregiver.\(^79\) The ICCP must specify what care and services the participant will receive and his preferences for the types and providers of services.\(^80\) The functional assessment must be reviewed

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\(^{76}\) Social Security Act § 1 1929(a), 42 U.S.C. 1396f(a).

\(^{77}\) Social Security Act § 1929(b)(1), 42 U.S.C. 1396t(b)(1).

\(^{78}\) Social Security Act § 1929(c)(2), 42 U.S.C. 1396t(c)(2).


and revised at least annually. All home and community care must be provided in a manner that respects, protects and promotes participant’s rights. These rights include:

- The right to voice grievances regarding services that are furnished with discrimination, and the right to be free from reprisal for voicing such grievances;
- The right to confidentiality of personal and clinical records; and
- The right to privacy and to have one’s property treated with respect.

The state must periodically review providers’ performance in providing care under the ICCP and must conduct regular surveys of community care settings; the Secretary will conduct subsequent validation surveys. The state must provide a process for the receipt, review, and investigation of allegations of neglect and abuse and of misappropriation of individual property by home and community care providers and must disclose any adverse findings upon request. The state must notify any affected individual and an immediate family member if the care provided by a home or community care provider is substandard. All surveys, reviews and certifications must be provided to the state fraud and abuse control unit and be made public.

b.) Program of All-Inclusive Care for the Elderly (PACE)

PACE (Program of All-Inclusive Care for the Elderly) is an alternative to institutional care for persons age 55 and older who require a nursing facility level of care. Determinations of eligibility for PACE must be made and annually re-evaluated on the basis of health status and indicators such as medical diagnosis and measures of activities of daily living. Under a PACE agreement, a provider must:

- Collect data;
- Provide access to the Secretary and the states to the records relating to the program; and
- Submit reports on the operation, cost and effectiveness of the program.

c.) Consumer Directed Services

i.) Personal Assistance Services

States may provide coverage of self-directed personal assistance services for individuals who, without such services, would receive personal care services under the state plan or home and community-based

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81 Social Security Act § 1929(c)(2)(D), 42 U.S.C. 1396t(c)(2)(D).
84 Social Security Act § 1929(i)(2), 42 U.S.C. 1396t(i)(2).
85 Social Security Act § 1929(i)(5), 42 U.S.C. 1396t(i)(5).
87 Social Security Act § 1929(i)(6), 42 U.S.C. 1396t(i)(6).
89 Social Security Act § 1934(c)(3)(B), 42 U.S.C. 1396u-4(c)(3)(B)(Re-evaluation unnecessary if the state determines that there is no reasonable expectation of improvement or significant change in an individual’s condition during this time because of the severity of chronic condition, or degree of impairment of functional capacity of the individual involved).
90 Social Security Act § 1934(c), 42 U.S.C. 1396u-4(c).
services pursuant to a waiver. The state must assess the needs, strengths and preferences of the participant and, on the basis of this assessment, establish a plan for such personal assistance services. Based on this assessment and the plan, the state must establish a budget that is open for public inspection. Utilizing a quality assurance and risk management strategy, the state must establish and implement the plan and budget and assure that each is consistent with the participant’s resources and capabilities.

The state must annually report the number of individuals receiving self-directed personal assistance and every three years, the state must include an evaluation of the overall impact on the health and welfare of participating individuals as compared to non-participants.

ii.) Home and Community-Based Attendant Services
States may amend their plans to include coverage of home and community-based attendant services and supports for individuals who would otherwise be eligible for nursing facility services, without which they would require care in a hospital, nursing facility, ICF-MR, or institution for mental disease. The state must create a plan of services and supports based on an assessment of each individual’s functional needs, agreed upon by each participant (or his representative) in writing. The state must establish and maintain a comprehensive quality assurance system that satisfies the following requirements:

- Incorporates feedback from consumers and their representatives;
- Monitors the health and well-being of each participant; and
- Has a process for reporting, investigating and resolving allegations of neglect, abuse or exploitation.

States must annually report:

- The number of individuals estimated to receive home and community-based attendant services; and
- The specific number who received attendant services the preceding fiscal year, organized into groups by disability, age, gender, education level and employment status and the number of individuals who received each service type.

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98 Social Security Act § 1915(k)(1), 42 U.S.C. 1396n(k)(1).
individuals within each group previously served under other home and community-based services provided by the state (or via waiver). 102

The Secretary will evaluate the provision of home and community-based attendant services and supports to determine whether such services allow the participants to lead an independent life and what impact the services have on the physical and emotional health of participants. 103

d.) Waivers

The Secretary may grant a state a waiver to provide services not typically covered by the Medicaid program, such as adult day care and home health aides, if the services are necessary to prevent institutionalizing the participant. Waivers can be used to target specific groups, such as individuals with developmental disabilities or HIV/AIDS or can be used to provide specific programs, such as homemaker and respite care services for eligible enrollees. All states operate multiple waiver programs.

In order to be granted a waiver for home and community-based services, the state must evaluate eligible enrollees’ need for institutionalized services104 and if the enrollee is age 65 or older, his need for SNF or ICF services. 105 If the state determines from these evaluations that the individual should receive home and community-based services, the state must establish a written plan of care for the individual and provide all services pursuant to that plan of care. 106 The Secretary may also grant a waiver to states to provide coverage for community-based care for children under age five who would otherwise require care in a hospital or nursing facility and who have AIDS or were born dependent on heroin, cocaine or phencyclidine and for whom adoption or foster care assistance is or will be made available. 107

For each waiver, the state must annually report to the Secretary on the projected number of individuals to receive services under the waiver, 108 the impact of the waiver on the type and amount of medical assistance provided109 and on the health and welfare of recipients. 110

e.) Plan Amendments Expanding Criteria for Home and Community-Based Care

106 Social Security Act § 1915(c)(1), 42 U.S.C. 1396n(c)(1)(inpatient services); Social Security Act § 1015(d)(1)(individuals age 65 and up).
110 Social Security Act § 1915(c)(2)(E), 42 U.S.C. 1396n(c)(2)(E)
States may amend their plans to include coverage of home and community-based services for individuals who meet objective, needs-based criteria established by the state. The state must conduct an independent assessment of every individual’s support needs and capabilities. The assessment must include:

- A face-to-face evaluation of the individual (including an objective evaluation of the individual’s inability to perform at least two activities of daily living);
- An examination of his history, medical records, care and support needs;
- A consultation with professionals caring for him and, where appropriate, a consultation with his family, guardian or other responsible individual; and
- An evaluation of the individual’s (or his representative’s) ability to self-direct the purchase or control the receipt of such services, if the state provides this option.

On the basis of this independent assessment, the state must establish a written plan of care for the participant, developed in consultation with the participant and his treating health care professional and, where appropriate, his family, caregiver or representative. The plan must identify the necessary home and community-based services to be furnished to or funded for the participant and must be reviewed annually and whenever there is a significant change in his circumstances. The state must annually report the projected number of individuals receiving home and community-based services via plan amendment.

4.) Covered Outpatient Drugs

Each state must maintain a covered outpatient drug use review program. The drug use review program will include:

- Reviews of drug therapy before prescriptions are dispensed, including screening for potential drug therapy problems.

- Establishing standards for pharmacists to use in counseling enrollees, which must include:
  - A reasonable effort to obtain, record, and maintain name, address, telephone number, date of birth (or age), and gender;

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111 Social Security Act § 1915(i)(1), 42 U.S.C. 1396n(i)(1) (In this circumstance, the state need not determine whether the individual would require the level of care provided in a hospital, nursing facility or ICF-MR).
Individual history; and
  • Comments relevant to the individual’s drug therapy.
  • Periodic examination of data to identify patterns of fraud, abuse, gross overuse, or
    inappropriate or medically unnecessary care among physicians, pharmacists, and enrollees, or
    associated with specific drugs or groups of drugs.121
  • Assessing data on drug use against explicit predetermined standards.122
  • Establishing a Drug Use Review Board (DUR),123 which will, among other duties:
    • Conduct interventions with physicians and pharmacists, including providing reminders
      about patient- and/or drug-specific information and suggesting changes in prescribing or
      dispensing practices, communicated in a manner designed to ensure the privacy of
      patient-related information.124
    • Re-evaluate interventions after an appropriate period of time to determine if the
      intervention improved the quality of drug therapy, to evaluate the success of the
      interventions and to make modifications to interventions as necessary.125

Based on data collected by the activities of the drug use review board and other surveillance and
utilization review programs, the Secretary shall periodically update the list of drugs or classes or
medical uses that are determined to be subject to clinical abuse or inappropriate use.126

5.) Medicaid Managed Care Organizations

If the state contracts with Medicaid managed care organizations to provide services to enrollees, the
state must develop and implement a quality assessment and improvement strategy127 that includes:128
  • Procedures for monitoring and evaluating the quality and appropriateness of care and services
    and;
  • Requirements for the provision of quality assurance data.

Managed care contracts must provide for an annual external independent review of the quality
outcomes and timeliness of and access to the items and services for which the organization is
responsible. The results of each review will be available to providers, potential and current enrollees
of the organization; the identity of any individual patient must not be disclosed in these results.129 The
state must establish intermediate sanctions that may be imposed if the managed care organization:130

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122 Social Security Act § 1927(g)(2)(C), 42 U.S.C. 1396r-8(g)(2)(C) (Standards must include monitoring for therapeutic
    appropriateness, overutilization and underutilization, appropriate use of generic products, therapeutic duplication, drug-
    disease contraindications, drug-drug interactions, incorrect drug dosage or duration of drug treatment, and clinical
    abuse/misuse).
126 Social Security Act § 1927(d)(3); 42 U.S.C. 1396r-8(d)(3).
127 Social Security Act § 1903(m), 42 U.S.C. 1396b(m).
• Substantially fails to provide required and medically necessary items and services;
• Acts to discriminate among enrollees on the basis of their health status or requirements for health care services;
• Engages in any practice that would reasonably be expected to deny or discourage eligible individuals who, on the basis of their medical record or history, will need substantial medical services from enrolling with the organization; and/or
• Misrepresents or falsifies information to an enrollee, a potential enrollee, or the state.

6.) Medicaid Program Improvement Strategies

a.) Electronic Health Records\(^{131}\)

In an effort to improve the use, collection and disclosure of health information, states can receive funding for the adoption and use of certified EHR technology.\(^{132}\) In order to qualify for funding, the state must track meaningful use by Medicaid providers and conduct program oversight.\(^{133}\) The Secretary shall periodically submit reports to Congress that include a description of any improvements in health outcomes, clinical quality, or efficiency resulting from EHR adoption.\(^{134}\)

b.) Medicaid Integrity Program\(^{135}\)

This program\(^{136}\) will include an audit of claims and a review of entities furnishing items or services to determine whether fraud, waste, or abuse has or is likely to occur.\(^{137}\)

c.) Health Care Disparities\(^{138}\)

As of September 2011, the Secretary has identified approaches for identifying, collecting and evaluating data on disparities in health care services and performance on the basis of race, ethnicity, sex, primary language and disability status\(^{139}\) and, in considering the objectives of protecting patient privacy\(^{140}\) and improving program data,\(^{141}\) has made recommendations to Congress on the most effective strategies and approaches for reporting quality performance measures.\(^{142}\) The Secretary shall implement these approaches by March 2012\(^{143}\) and submit a report to Congress by March 2014 that

\(^{133}\) Social Security Act § 1903(t)(9), 42 U.S.C. 1396b(t)(9).
\(^{134}\) Social Security Act § 1903(t)(10), 42 U.S.C. 1396b(t)(10).
\(^{136}\) Social Security Act § 1936(a), 42 U.S.C. 1396u-6(a).
\(^{137}\) Social Security Act § 1936(b), 42 U.S.C. 1396u-6(b).
\(^{143}\) Social Security Act § 1946(c), 42 U.S.C. 1396w-5(c).
includes recommendations for improving the identification of disparities based on analyses of collected data.¹⁴⁴