Federal Stewardship of the Medicaid Program: Strengthening Data Systems for Effective Decision Making

Since it was first enacted in 1965, Medicaid has become an important source of health insurance for millions of people who could not otherwise afford it, including both working age and older adults, children, and persons with disabilities. In 2015, Medicaid and the Children’s Health Insurance Program (CHIP) served over 70 million beneficiaries and paid more than $545 billion for their health care—about 17 percent of the money spent nationally on health care that year. The Congressional Budget Office estimates that, under current law, federal outlays would roughly double over the next decade. By 2026, Medicaid and CHIP may spend about $1 trillion per year for their beneficiaries' health care.

Medicaid’s growth has led to an ever-increasing need for better information about enrollment, covered services, and payments to physicians, hospitals, and other health care providers. Timely, accurate, detailed, and comprehensive data help program administrators and policymakers forecast and manage costs, track access to services, monitor program performance, ensure quality of care, deter fraud, and develop new policy. The need for data and information has driven the development of Medicaid’s data systems since its inception, and this need will only become more pressing as the program keeps evolving.

A primary challenge in developing comprehensive information about Medicaid is intrinsic to the program’s structure. Unlike Medicare, which is operated solely by the federal government, Medicaid is operated by each state under broad federal guidelines. Each state has organized its own Medicaid program and designed its own data systems and definitions, which requires intensive efforts to develop a detailed national picture of enrollment and spending. In addition, as capitated managed care (in which states contract with private health plans to provide all covered services at a fixed monthly rate per beneficiary) has grown to encompass more than three-fourths (77 percent) of Medicaid enrollment in 2014, the need for better information about the services provided through this now-dominant care model continues to grow.

In this issue brief, we examine the history of Medicaid data and identify current opportunities to use emerging data systems to help policymakers guide the program's continued evolution.
Like other information systems designed to track the use of health care, Medicaid data systems have evolved substantially during the last 50 years. We identify six stages, or eras, of this evolution.

Era 1: Modest Reporting Requirements for Aggregate State Data: 1965–1980

Overview
Congress enacted Medicaid in 1965 as a federal-state partnership. States administer the program under broad federal guidelines, and the federal government covers from 50 to 83 percent of states’ expenses for services. In its early years, the program received little attention from Washington and placed only a modest burden on state budgets. States reported their own aggregate statistics on recipients and spending, but broader reporting was often confounded by inconsistencies from one state or one year to the next. Later in this era, the program began to command more federal attention because of its rapid growth—from 7.4 million recipients and $321 million in spending in 1967 to 19.8 million recipients and $1.3 billion in spending in 1980. In response, policymakers asked for more information about the program and the people who were using it. Beginning in the early 1970s, the federal agency responsible for overseeing the Medicaid program, the Health Care Financing Administration (HCFA), required states to report a limited set of summary statistics on a standard reporting form, the HCFA-2082.

Factors Driving Change
- States did not always collect or report their data the same way.
- Medicaid enrollment and spending grew rapidly, but data provided few insights into contributing factors.
- Program administrators could not adequately explain the wide variations in spending from year to year and from state to state.
- Existing data could not be used to examine the effects of key initiatives like the Early and Periodic Screening, Diagnostic, and Treatment program (EPSDT).


Overview
As Medicaid grew and matured, it became more complex. Managed care programs emerged, coverage was expanded to children and pregnant women to improve their health, and Congress increased states’ flexibility to develop special programs using, for example, home- and community-based service (HCBS) waivers as an alternative to institutional care. As a result,
policymakers needed more information about service use (services provided by managed care organizations, for example) to help them balance soaring financial responsibilities with mounting concerns about unmet needs, access to services, and quality of care for Medicaid beneficiaries.

In the 1980s, policymakers, program administrators, and researchers acknowledged that the information collected by the HCFA-2082 form was limited and sometimes inaccurate. HCFA-2082 reporting requirements were expanded, and other data collection forms were instituted—for example, for HCBS waivers and the EPSDT program.

Factors Driving Change

- As policymakers worked with the rudimentary federal data systems in this era, they realized the value that accurate, person-level information could have in achieving Medicaid’s goals.

- The federal prototype for obtaining person-level state data, the Medicaid Tape-to-Tape project, began collecting data for calendar year 1980 with data that were voluntarily provided by five states (California, Georgia, Michigan, New York, and Tennessee) with large Medicaid programs.

- The Tape-to-Tape project yielded early insights into patterns of service use for specific groups of beneficiaries. For example, analysis revealed that 20 percent of Medicaid beneficiaries never used services in a given year, raising questions about unmet needs and barriers to care.

- As Congress passed new Medicaid initiatives—such as HCBS waivers—to address the lack of flexibility in Medicaid programs, the complexity and reporting needs of the program snowballed.

ERA 3


Overview

The 1991 recession and the full effect of federally mandated eligibility expansions led to rapid growth in Medicaid enrollment and spending. As budget pressures grew, states tried to control spending by mandating managed care enrollment and implementing various types of waivers; for example, eligibility expansions were designed to provide services to designated groups of beneficiaries while controlling costs.

Although Medicaid policymakers had always been concerned about high-need populations, such as people with severe disabilities who need considerable assistance in the activities of daily living and receiving care via HCBS waivers, these concerns grew rapidly as spending trended sharply upward. In addition, the advent of CHIP generated considerable interest in examining how Medicaid and CHIP could work together to meet the needs of children whose families had limited incomes.

A new data system—the Medicaid Statistical Information System (MSIS)—encouraged states to report person-level enrollment and service data quarterly in a uniform format. Many states were slow to submit MSIS data, and key information was not collected. The number of states reporting MSIS data grew during this era; however, by 1998, 13 states were still reporting only HCFA-2082 summary statistics.

Factors Driving Change

- Many states struggled to provide accurate and timely MSIS data because their own data systems were difficult to use or lacked important data elements.

- MSIS included little information on providers and managed care plans, thus constraining program administrators’ ability to understand how program dollars were being spent.

- MSIS data were not configured to support research and policy analysis.

- HCFA generated State Medicaid Research Files (SMRFs) from MSIS to make the data easier to use and to support the production of information and analysis that policymakers increasingly needed. For example, SMRF data were organized by calendar year and date of service, and multiple claims for a single service were combined to create a “final action” service event record.

ERA 4: Mandatory Person-Level Data Reporting: 1999–2004

Overview

As a consequence of a Supreme Court decision and new legislation, Medicaid expanded coverage to new services and new populations. The Supreme Court ruling in Olmstead v. L.C.
required states, under certain circumstances, to provide community-based services as an alternative to institutional care for people with disabilities. The Ticket to Work and Work Incentives Improvement Act of 1999 allowed states to extend Medicaid coverage to certain working individuals with disabilities. The Breast and Cervical Cancer Treatment and Prevention Act of 2000 extended limited Medicaid coverage to women with these cancers.

HCFA, renamed the Centers for Medicare & Medicaid Services (CMS) in 2001, worked to keep up with the rapidly increasing demands for information about these new provisions, and with the continued uptick in Medicaid spending. Beginning in 1999, the Balanced Budget Act required all states to report MSIS person-level data for an expanded list of data elements covering eligibility, services, and spending. CMS also used its experience with the SMRFs and MSIS to develop the Medicaid Analytic eXtract (MAX) data, a research-ready version of MSIS, to support more extensive analysis of program operations and effects. For example, Medicaid data were used to estimate costs associated with Medicare Part D prescription drug coverage.

Factors Driving Change

- Policymakers needed comprehensive, detailed data to examine policy, coverage, and access issues for specific services and groups of beneficiaries (for example, those who used mental health services).
- Despite new requirements, the range of MSIS data elements on eligibility and spending was limited, and data quality varied across states.
- Reporting on managed care encounters, which mirror FFS claims by providing records of each service used by managed care enrollees, was incomplete—an especially vexing problem in light of growing enrollment in managed care.

Era 5: Growth of Managed Care: 2005–2009

Overview

Congress passed new initiatives to satisfy states’ needs for flexibility in providing care to high-need beneficiaries living in the community. For example, new legislation permitted states to provide HCBS as a part of the state plan benefit package (Section 1915i) and provide self-directed personal assistant services (Section 1915j) targeting people receiving Section 1915c waiver services. A new demonstration known as Money Follows the Person helped states strike the right balance between providing those services or institutional care.

Enrollment in managed care and CHIP also grew substantially. In light of policymakers’ expectations for comprehensive, high-quality data to help track this growth, CMS took critical steps to support states and fill data gaps. CMS expanded data quality reviews, especially for managed care, and began providing technical assistance to states to improve the information they submitted to MSIS for CHIP and managed care encounters.

In addition, because accurate information on provider characteristics and participation was unavailable, a database of provider characteristics was created under the MAX project. Staff at CMS used this information to examine a wide variety of provider-related issues, such as geographic variation in the cost of hospital care. CMS’s responsibilities for investigating fraud and abuse in Medicaid increased, and some highly visible incidents of fraud and abuse took place, leading to demands for comprehensive, detailed, and timely data on providers.

Factors Driving Change

- New program authorities and the continued growth in managed care enrollment revealed the need for nimble data systems to capture new information.
- Analyses of service use were typically limited to the population using the fee-for-service payment model, an increasingly small share of the Medicaid population.
- As policymakers asked more questions about the availability and cost of community-based services and supports for people on limited incomes, data gaps in these areas became increasingly visible.
behavioral health and long-term services and supports, led to a demand for better encounter data to monitor pricing and performance.

- Data were needed to examine policy, coverage, and access issues for specific populations, such as beneficiaries who used a substantial amount of both physical and mental health services.

**Era 6: Expanded Person-Level Data Collection: 2010–2017**

**Overview**
During this era, CMS recognized the need to build a more robust and comprehensive information strategy for Medicaid and CHIP.

In 2010, CMS decided to replace MSIS with the Transformed Medicaid Statistical Information System (T-MSIS), which (1) expands required data elements on person-level eligibility and services; (2) captures data on providers, managed care plans, and third-party insurance; (3) provides for improved quality of state data; and (4) requires states to submit data monthly instead of quarterly, making the data available sooner. A second system, the Medicaid and CHIP Program (MACPro), was designed to capture, for the first time, standardized information about the characteristics of states’ Medicaid programs, including waivers and state plan options. A third system, the Medicaid Drug Program, was developed to consolidate information from four existing drug monitoring and reporting systems.

The goals of these systems are to make program data more accessible to stakeholders, reduce the reporting burden on states, and eliminate duplicative efforts. CMS and other stakeholders cannot realize their full potential yet. There is still much to be done to fully implement these systems, examine quality, ensure timeliness, and provide access to the data for policymakers, federal and state program staff, and others. As the Medicaid program continues to evolve, accountability to policymakers and the public will remain essential. This era’s developments offer great promise for enhancing access to the high quality information that such accountability demands.

**Factors Driving Change**
- A rising emphasis on implementing payment methods that offer more value than the traditional fee-for-service approach underscored the need for more robust data on providers.
- The Affordable Care Act (ACA) substantially expanded Medicaid by extending coverage to adults between the ages of 21 and 64 who qualified on the basis of income.
- ACA also introduced new Medicaid options (such as the health homes and Community First Choice programs) for beneficiaries with chronic and disabling conditions.
- Detailed information on provider characteristics and spending patterns became even more necessary to ensure adequate financing, develop policy, and assess the risk of fraud.
- Policymakers recognized that health problems often go hand in hand with other problems, such as inadequate housing and aging; as a result, solving health care delivery problems means linking health data to data from social service programs.
- Congress recently requested more information to address concerns about Medicaid’s financial viability going forward.

**EMERGING OPPORTUNITIES**
CMS stands on the doorstep of a substantially enhanced capacity to procure information that will help guide the continued evolution of Medicaid and CHIP. T-MSIS and the other new systems for gathering data will give both state and federal policymakers more and better information about state Medicaid programs—who is eligible to receive services, what services are provided and to whom, and how much it costs—and they will have this information for all states, beneficiary groups, and payment systems.

The continued implementation of T-MSIS is an important foundational element for enhancing access to high quality information and increasing the accountability of these programs to policymakers.

The continued implementation of T-MSIS is an important foundation for this enhanced capacity, because it includes data elements that were never available before. In addition to continuing oft-repeated analyses (such as tracking changes in the Medicaid population and expenditures), state and federal program administrators can use T-MSIS data to conduct new analyses to answer critical questions like the ones that follow.
Questions that can be answered in more detail once T-MSIS is fully implemented

- **What are the services** that different groups of Medicaid beneficiaries—children, people with disabilities and chronic illnesses, dual beneficiaries’ use? How do new programs or waivers affect service use, costs, and quality?
- **How can we better measure the value of the care** that beneficiaries receive, both in fee-for-service and in managed care? How is spending related to quality of care?
- For beneficiaries with complex or chronic illnesses, **how can we efficiently manage expensive episodes of care** and ensure appropriate transitions (such as moving from the hospital to home)?
- **How can we compare the performance** of different managed care organizations beyond the measures reported currently in the Healthcare Effectiveness Data Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS)?

Questions that can be answered by linking T-MSIS to other data systems

- **How can we better track spending** on services for dual Medicare and Medicaid beneficiaries who live in nursing homes, rely on expensive durable medical equipment, or have intellectual disabilities?
- **What other services do Medicaid and CHIP beneficiaries use** (such as housing, food support, and income support), and can Medicaid services help beneficiaries find jobs so they rely less on these services?
- **How can we determine if spending by accountable care organizations** on services they are accountable for is less than projected spending?
- **What are the benefits of alternative payment strategies** (such as episode-based payments, bundled payments, or shared-saving plans) or alternative treatment approaches (as assessed via comparative effectiveness analyses)?

CONCLUSIONS

In the decades since its inception, Medicaid’s enrollment, spending, and administrative complexity have grown enormously (see figure on page 7). Yet the federal and state administrators who are responsible for managing this large and vitally important program have been hampered by information systems that have not kept pace with the need for information. Program growth in one era has typically outpaced the availability of information needed to manage the program well in the next. Data systems now on the verge of implementation promise to mitigate this situation, but much remains to be done. Continued evolution in Medicaid policy means policymakers will continue needing access to reliable data so they can develop new initiatives and determine if current initiatives are achieving their goals.

As we begin a new era that is almost certain to bring substantial changes to the Medicaid program, our historical review of Medicaid data underscores several challenges ahead for all levels of government. These challenges have both policy and technical implications.

For policymakers, the challenges stem from the need for a better understanding of the complex interplay between the health and social factors that influence Medicaid enrollment, access to care, and spending.

for example, food security and health status, or between housing security and use of mental health services. These insights can support new initiatives that improve Medicaid beneficiaries’ health status and reduce costs. Translating these new insights into effective legislation or new program initiatives will provide both opportunities and challenges for policymakers.

New data systems, such as T-MSIS, usually bring unexpected technical problems when they are first implemented. Consequently, both the state and federal technical staff who are responsible for implementing these initiatives will play essential roles in harnessing the power of information technology to overcome these challenges. These roles include ensuring the accuracy and completeness of the data; producing them sooner; identifying unique beneficiaries consistently; improving ease of access for program administrators at all levels of government; developing customized applications such as dashboards and special reports; supporting progress toward dynamic data extraction and reporting capabilities; and facilitating the use of advanced data analytics.

Regardless of the direction the Medicaid program may take in the years ahead, policymakers and program administrators will still be accountable for explaining the program’s spending, the needs of its beneficiaries, the payment patterns of managed care plans and providers, and the quality and outcomes of the services it supports. As a result, the need to improve and strengthen Medicaid’s data systems will endure as well.
ENDNOTES

1 CHIP was enacted in 1997.


4 In this brief, “states” are the 50 states and the District of Columbia.

5 For most traditional eligibility groups (those eligible before recent expansions), actual rates vary between these statutory limits by state and fiscal year, according to a federally defined formula. The legislation allows as high as 83 percent for traditional eligibility groups, but the highest rate in fiscal 2017 was 74.6 percent for Mississippi. More recent legislation set higher rates for Medicaid and CHIP expansion populations.

6 Initially, the HCFA-2082 contained only a few tables on program recipients and expenditures. Over time, reporting included enrollment and expanded to 48 tables. CMS did not require states to report person-level data during this era.

7 The Deficit Reduction Act of 2005 authorized the Money Follows the Person demonstration.

8 In one incident, leaders of a nonprofit organization that served individuals with developmental disabilities used Medicaid funds to pay exorbitant salaries to their executives, pay college tuition for their children, and buy an apartment.

9 CMS’s Medicaid and CHIP Business and Information Solutions Council launched these initiatives during this era and will retire older, duplicative systems as appropriate.


12 Constant vigilance will be needed to produce consistent and comparable data, given that state programs and their administration may evolve independently from one another. Also, data collection instruments will need to have the flexibility to capture new program features and options as they are implemented.
Examples of expanded analytic opportunities using T-MSIS data

### Enrollment and Cost
- Track the growth in the eligible population, including variation across states and over time for different groups of Medicaid beneficiaries and new Medicaid authorities
- Develop better measures of utilization and spending by different populations
- Improve understanding of the optional eligibility groups and optional services covered by different states
- Provide better spending forecasts
- Improve understanding of dual Medicare and Medicaid beneficiaries, particularly individuals with high combined costs in both programs
- Enhance activities to promote the program’s integrity by monitoring aberrant provider practices and billing
- Compare cost-effectiveness for individual managed care plans to other plans

### Patient Management
- Create new patient status measures for each day of enrollment to manage high-cost episodes of care and ensure appropriate and efficient transitions between types of care
- Promote preventive measures to improve health status and contain cost, while reducing the incidence and prevalence of certain diseases and conditions (including acquired conditions and adverse drug events)
- Determine the health needs of special populations (for example, persons with autism spectrum disorder)
- Improve continuity of care and coordination of services by health homes while reducing the unnecessary use of high-cost services; for example, emergency room services
- Identify specific problems with care coordination and patient management by managed care plans and fee-for-service

### Outcomes and Quality
- Develop and monitor new measures of health care delivery and quality
- Assess models to manage patients with one or more chronic conditions
- Enhance models to increase the coordination and integration of physical and behavioral health services
- Improve prenatal care for pregnant women with risk of adverse outcomes
- Employ predictive modeling of outcomes to incorporate social determinants of health
- Assess access to care for different groups of beneficiaries by measuring actual provider participation based on persons served and services delivered
- Ensure that health plans include enough different kinds of providers to meet the needs of beneficiaries by linking provider and plan data to analyze the number and types of participating providers

### New analytic opportunities made possible by data links and other enhancements
- Link T-MSIS data to other data sets with information on housing, food assistance, income support, and health insurance plans other than Medicaid to determine cross-program policy effects, costs, and outcomes
- Link T-MSIS data to surveys to improve program policy through better understanding of beneficiary demographics, health status, and lifestyle
- Evaluate the performance and cost-effectiveness of special state or new federal Medicaid provisions (for example, health homes and Medicaid accountable care organizations)
- Monitor states in their efforts to identify and address disparities to care (for example, the time and travel distance for a beneficiary to reach providers)
- Assess provider-level effects of different payment methodologies
- Assess the benefit, cost, and effectiveness of alternative prescription drug policies (for example, prescription limits and fail-first policies) and therapies
- Assess program enrollment for special populations, such as American Indians and Alaskan Natives (to preserve limited Indian Health Services funds for individuals who cannot qualify for Medicaid)