NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATION SPECIFIC ISSUES

MEDICAID MANAGED CARE DATA COLLECTION AND REPORTING

FINAL REPORT

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EXECUTIVE SUMMARY

Introduction

This report focuses on a specific area of data collection and program administrative activities for Medicaid, that of data gathering and reporting under managed care. Since its inception, the Medicaid program has actively collected and analyzed information relating to Medicaid recipients and their use of health care services. These activities have been authorized under a series of legislative mandates at the federal and state level.

The Subcommittee on Populations (the Subcommittee) of the National Committee on Vital and Health Statistics focuses on the range of issues raised by obtaining accurate, timely, and relevant information about the health of American people. The Subcommittee specifically focuses on population-based data and data about specific vulnerable groups that are disadvantaged by virtue of their special health needs, economic status, race ethnicity, disability, age or area of residence. In 1997, the Subcommittee put Medicaid managed care at the top of its agenda because reforms of Medicaid increasingly involve moving beneficiaries into managed care programs, but little information is available on the impact of managed care on the health of enrollees and their access to and use of health care services.

It is the expectation of the Committee that the Department will find the conclusions and recommendations useful for developing and improving information, analysis and reporting on the impact of managed care on the health of Medicaid enrollees and their access to and use of health care services.

Background

The report is a synthesis of information collected through public hearings in Washington, DC, Arizona, and Massachusetts, a focused study of Medicaid managed care contracts and a series of interviews with state Medicaid officials involved in Medicaid managed care contracting. Specifically this report: considers the importance of data collection and use in Medicaid managed care and examines the legal and operational framework for data collection and existing federal and state approaches to Medicaid managed care data collection and use.

This report presents recommendations for strengthening and improving the collection and use of data. To implement their managed care programs, many Medicaid agencies contract with Managed Care Organizations (MCOs), which agree to bear the full risk of providing a comprehensive set of services (i.e., three or more Medicaid services) to their enrollees. Contracting has significantly changed the role of the Medicaid agency, from a payer of bills under fee-for-service to a purchaser of services under managed care. But, regardless of the delegation of insurance and delivery duties to plans, the agency retains ultimate legal responsibility for the provision of care and carrying out other statutory duties. This allows the agency to set not only data collection and reporting standards, but also standards for the use of information to monitor and improve the health of the Medicaid population. Medicaid agencies

need information before the contract is signed to enable them to choose among potential contractors based on plan characteristics and performance; information on costs, utilization, and diagnoses to set capitation rates; information once the contract is signed to monitor MCO compliance and hold them accountable for their results, ensure that Medicaid enrollees have access to quality care, and measure health outcomes, and information to support planning activities.

The establishment of managed care programs for Medicaid had some secondary consequences for privacy, as well as for Medicaid oversight. Less information about patients is shared, and that is an advantage from a privacy perspective. The lack of information, however, also has some undesirable effects for oversight. These effects are the main subject of this report.

This report was not designed to focus on the privacy consequences of data collection and sharing for Medicaid. That is a much broader issue. It would have required more time and resources than were available to review all Medicaid information policies in the context of this effort. Reviewing and adjusting information practices focusing on privacy for the managed care part of Medicaid alone will be challenging. Nevertheless, this is a critically important area that the Committee did not address. This is a limitation of the report.

Findings

Several issues, such as ensuring and measuring quality of care, creating baseline data and improving the analytical capacity of staff were mentioned in the hearings, in the focused study and as part of the interviews with State Medicaid officials. Overall, the findings from the Subcommittee's different activities showed that, despite states' considerable efforts, the collection, reporting and analysis of Medicaid managed care data still needed improvement. Additionally, while most states address data collection and reporting in their contracts with participating MCOs, they do so with little uniformity. More specifically, the Subcommittee found that:

- State Medicaid agencies do not use a standardized set of data elements enabling them to track the experiences of Medicaid enrollees with managed care.
- State Medicaid agencies use different definitions of what constitutes an encounter, a barrier to the collection of standardized data.
- State Medicaid agencies do not collect uniform enrollment data, including race and ethnicity data along with data on language, reason for enrollment (e.g., disability), and other demographic information as part of the enrollment process, which would allow them to determine barriers to care and track patterns of discrimination.
- State Medicaid agencies are limited in their ability to monitor the experiences of Medicaid managed care enrollees with access and quality of care due to the poor quality of the encounter data they receive from MCOs, their own inability to analyze encounter data, and the cost of collecting data and performing audits. In addition, the Subcommittee found that the degree to which states collected information on enrollee satisfaction, an important aspect of an enrollee's experience with managed care, varied from state to state.

- State Medicaid agencies do not necessarily collect information on all services provided to Medicaid managed care enrollees under the state Medicaid plan, which is essential to the quality improvement strategies state Medicaid agencies and MCOs are required to implement as a result of the Balanced Budget Act.
- State Medicaid agencies are generally reluctant to provide researchers with access to data, which limits the use of the data.
- State Medicaid agencies and state public health agencies rarely coordinate their data collection and analysis efforts, when they could benefit from sharing utilization and outcomes data to track the experiences of Medicaid patients and other patients living in the state.
- State Medicaid agencies usually lack the financial and human resources to use and analyze all the data they collect, particularly encounter data.
- State Medicaid agencies generally do not mandate, in their contracts, that MCOs report notifiable diseases to the state public health agency, or require in their contracts that MCOs enforce their participating providers' obligation to report notifiable diseases to the state public health agency.

Recommendations to the Department

The Committee recommends that HHS use its authority to be more specific about the manner and the format in which Medicaid managed care data should be collected and reported in order to foster uniformity and comparability of the information, while recognizing that HHS may be bound by statutes and regulations requiring demonstration of the utility of collecting these data relative to the cost of collecting them. The Committee also wishes to underscore that any new data collection and reporting requirements must be consistent with HIPAA-related decisions on privacy, confidentiality and security of data transactions. In addition, HHS should be more specific about the purpose for which the data are collected and define the priority questions about quality, cost, and access that require an answer. The following is a summary of recommendations about specific areas of data collection and reporting:

1. The Committee supports the adoption of a standardized core data set, and recommends consistent data elements across all states. Specifically, the Committee recommends that HCFA adopt a standardized set of data elements in a format consistent with the ASC X12 837. The Committee further recommends:

   -Creation of a common definition of an encounter, and
   -Collection of uniform enrollment data, including race and ethnicity data along with data on language, the reason for eligibility and other demographic information obtained as part of the enrollment process.

2. The Committee recommends that HCFA encourage states to use standardized surveys of member experiences with managed care. State Medicaid agencies could administer, or require MCOs to administer, standardized population-based experience surveys measuring member events, including satisfaction with access to and quality of care.

3. The Committee recommends that HCFA encourage state Medicaid agencies to ensure that providers of services, with whom states directly contract to provide services covered under the state Medicaid plan but not under the MCO contract (e.g., mental health and substance abuse, prescription drug, and dental services), collect and report data to the state on the services they provide using the same standards as required for data on services provided under the MCO contract.

4. The Committee strongly encourages state Medicaid agencies to collaborate on and coordinate their data collection and analysis efforts with those of state public health agencies, in a manner that is consistent with confidentiality and privacy practices and procedures.

5. The Committee recommends that the federal government, in partnership with the private sector, invest in training programs to increase state-level staff capacity to analyze and use Medicaid data.

6. The Committee recommends that HCFA, encourage MCOs to remind and encourage their providers to support the public health surveillance and disease tracking system.

Introduction and purpose

This report focuses on a specific area of data collection and program administrative activities for Medicaid, that of data gathering and reporting under managed care. Since its inception, the Medicaid program has actively collected and analyzed information relating to Medicaid recipients and their use of health care services. These activities have been authorized under a series of legislative mandates at the federal and state level. This extensive history of collecting and analyzing information is specified in Section II, and Table D in the appendix.

This report builds upon this extensive legislative framework, focusing on Medicaid Managed Care Organizations. Recommendations are presented for developing and improving information, analysis and reporting on the impact of managed care on the health of Medicaid enrollees and their access to and use of health services.

The Subcommittee on Populations (the Subcommittee) of the National Committee on Vital and Health Statistics focuses on the range of issues raised by obtaining accurate, timely, and relevant information about the health of American people. Basic information is needed in three main areas: (1) the actual health of people; (2) the health care services provided to people; and (3) the barriers faced by people in achieving optimal health and health care. This information enables the identification of health problems, including those affecting specific vulnerable groups, and the design and the evaluation of programs to address these problems. The Subcommittee specifically focuses on population-based data and data about specific vulnerable groups that are disadvantaged by virtue of their special health needs, economic status, race and ethnicity, disability, age, or area of residence.

In 1997, the Subcommittee put Medicaid managed care at the top of its agenda because—as the Subcommittee's workplan-charge statement indicates—

> "[r]eforms of Medicaid increasingly involve moving beneficiaries into managed care programs, but little information is available on the impact of managed care on the health of enrollees and their access to and use of health care services."

Since then, the Subcommittee has examined the impact of Medicaid managed care on data collection, reporting, and analysis, holding hearings in Washington, DC, Arizona, and Massachusetts. This final report documents the Subcommittee's extended investigation into the issue and

- Considers the importance of data collection and use in Medicaid managed care;
- Examines the legal and operational framework for data collection and existing federal and state approaches to Medicaid managed care data collection and use;
- Synthesizes the results of the Subcommittee meetings and hearings on data collection and use in Medicaid managed care; and

- Presents recommendations for strengthening and improving the collection and use of Medicaid managed care data.

The report has three parts. The first part provides an overview of Medicaid managed care data gathering and the federal legal framework within which it operates. The second part reports Subcommittee findings resulting from three activities—Subcommittee hearings and site visits, a focused study of Medicaid managed care contracts, and interviews with state Medicaid officials involved in Medicaid managed care contracting. While the findings from these three activities are presented in separate sections for the purpose of clarity, the Subcommittee found a significant overlap among them. Several areas, such as ensuring and measuring quality of care, creating baseline data, and improving staff analytical capacity were mentioned throughout. The third part presents the recommendations of the Subcommittee regarding Medicaid managed care data collection, reporting, and analysis.

The establishment of managed care programs for Medicaid had some secondary consequences for privacy, as well as for Medicaid oversight. Less information about patients is shared, and that is an advantage from a privacy perspective. The lack of information, however, also has some undesirable effects for oversight. These effects are the main subject of this report.

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Part One. Background and overview

I. Introduction

Following trends in the private health insurance sector, the Medicaid program has undergone a transformation over the past two decades from fee-for-service to managed care. Because a sizable proportion of Medicaid managed care involves the payment of bundled premiums to private companies in exchange for the provision of medical and administrative services, the shift to managed care has significant implications for data collection and reporting. The chief implication is the loss of the "traditional" claims data that are directly available to Medicaid agencies in a fee-for-service system. While the provision of encounter data by managed care organizations (MCOs) participating in Medicaid can mitigate the loss of claims data, the evidence suggests that most managed care systems cannot currently generate comprehensive, detailed, and timely data.

Although states have had the authority since Medicaid's enactment to use managed care as an alternative to fee-for-service, the more widespread use of managed care, particularly full-risk managed care, only began in the 1980's and emerged in full force in the 1990's. *[See Table A for a summary of Medicaid managed care legislation.]*

Since Medicaid's inception in 1965, the statute allowed states to use "voluntary" managed care to deliver services to individuals who freely choose to enroll in MCOs to receive those services as an alternative to fee-for-service care. While states' interest in managed care increased in the 1970's, it quickly subsided because of the poor quality of services and other problems faced by the program.[1] As a remedy, Section 1903(m) was added to the Medicaid statute in 1976 to set federal standards, including data collection and reporting standards, for health maintenance organizations (renamed managed care organizations or MCOs by the Balanced Budget Act of 1997).

In 1981, the Omnibus Budget Reconciliation Act created Section 1915(b), which authorizes states to request waivers from the Medicaid statute's freedom-of-choice provision so that they can enroll their Medicaid population into "mandatory" managed care programs, i.e., programs requiring eligible individuals to enroll. These programs enroll some or all individuals in some or all portions of a state; almost all states have used this option.

In addition to Section 1915(b) freedom-of-choice waiver programs, states also relied on Section 1115 of the Social Security Act (SSA) to mandate enrollment in managed care. Section 1115, which was adopted in 1962 prior to the Medicaid statute, was invoked for the first time by Arizona in the early 1980's, and accelerated in the early 1990's following the failure of comprehensive federal health care reform. Under Section 1115, the Secretary of Health and Human Services (HHS) has the authority to waive requirements of SSA, including the Medicaid statute, for the purpose of research and demonstration as long as the

[1] See, e.g., Schneider A, Stern J. HMOs and the poor: Problems and prospects. 70 Northwestern U.L.Rev.90 (1975) in Rosenbaum S, Darnell J. Medicaid managed care: An analysis of the Health Care Financing Administration's Notice of Proposed Rulemaking. Washington, DC: Center for Health Policy Research, November 1998.

TABLE A
MEDICAID MANAGED CARE LEGISLATIVE HISTORY

Enactment date	**Statutory provisions**
1962	*Section 1115 of the Social Security Act* Grants the Secretary of Health and Human Services the authority to waive program operational requirements of the Social Security Act (SSA) for the purpose of research and demonstration as long as the exemptions further the goal of the program. This authority applies to the Medicaid program, which is codified at Title XIX of SSA. States commonly request to waive the Medicaid requirements of statewideness (to enable them to vary the program by region), comparability (to enable them to vary benefit and eligibility levels among groups of individuals), eligibility (to enable them to modify eligibility standards to, for example, expand coverage), freedom-of-choice (to enable them to mandate enrollment in managed care by limiting the freedom to choose a provider), MCOs' conditions of participation (to enable them to contact with entities that do not meet state and federal standards or to control disenrollment), reimbursement (to enable them to alter payments), and benefits (to enable them to expand benefits).
1965	*Title XIX of the Social Security Act (Medicaid)* Creates the Medicaid program. Allows states to design managed care programs in which individuals voluntarily enroll, though no specific statutory provision addressed the use of managed care by states.
1976	*Section 1903(m), Title XIX of the Social Security Act* Sets federal standards, including data collection and reporting standards for health maintenance organizations, renamed managed care organizations in 1997, participating in Medicaid.
1981	*Section 1915(b), Title XIX of the Social Security Act* Authorizes states to request waivers from the Medicaid statute's freedom-of-choice provision so that they can require individuals to enroll in managed care.
1997	*Section 1932, Title XIX of the Social Security Act* Allows states to require individuals to enroll in managed care by simply amending their Medicaid plan. Although approval of the state plan amendment by the Secretary of Health and Human Services is required, it is generally less cumbersome a process than that of a Section 1915(b) or 1115 waiver.

exemptions further the goals of the program (in this case, the Medicaid program). Thus far, 19 states have implemented Section 1115 research and demonstration waiver programs.[2] *[See Table B for a comparison of Section 1115 and 1915(b) waivers.]*

More recently, the Balanced Budget Act of 1997 created Section 1932, which allows states to implement mandatory managed care programs through an amendment to the state Medicaid plan, a less burdensome process than the waiver application process. As of October 1998, one state had implemented a Section 1932 state plan amendment program, another one had received federal approval to implement one, and four additional states had applications pending with the federal government.

In sum, states have three main options if they wish to use managed care in financing and delivering Medicaid services: (1) voluntary enrollment as allowed by the Medicaid statute; (2) mandatory enrollment without a waiver under Section 1932; and (3) mandatory enrollment under Section 1115 and Section 1915(b) waiver authority.

As a result of these various state efforts to enroll Medicaid-eligible individuals into managed care, enrollment has grown steadily, particularly since the early 1990's. Enrollment data show that 12 percent of the Medicaid population was enrolled in managed care in 1992, 14 percent in 1993, 23 percent in 1994, and 32 percent in 1995.[3] Enrollment in full-risk managed care has also grown steadily to 67 percent of the total managed care enrollment.[4]

To implement their managed care programs, many Medicaid agencies contract with MCOs, which agree to bear the full risk of providing a comprehensive set of services (i.e., three or more Medicaid services) to their enrollees. Contracting has significantly changed the role of the Medicaid agency, from a payer of bills under fee-for-service to a purchaser of services under managed care. But, regardless of the delegation of insurance and delivery duties to plans, the agency retains ultimate legal responsibility for the provision of care and carrying out other statutory duties. This allows the agency to set not only data collection and reporting standards, but also standards for the use of information to monitor and improve the health of the Medicaid population. Medicaid agencies need information before the contract is signed to enable them to choose among potential contractors based on plan characteristics and performance; information on costs, utilization, and diagnoses to set capitation rates; information once the contract is signed to monitor MCO compliance and hold them accountable for their results, ensure that Medicaid enrollees have access to quality care, and measure health outcomes, and information to support planning activities.

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[2] For additional information on Section 1115 waivers, see Rosenbaum S, Darnell J. Statewide Medicaid managed care demonstrations under Section 1115 of the Social Security Act: A review of the waiver applications, letters of approval and special terms and conditions. Prepared for The Kaiser Commission on the Future of Medicaid. Washington, DC: Center for Health Policy Research, May 1997.

[3] Levit K et al. National health expenditures, 1995. Health Care Financing Review 1996;18(1):175-214, Fall.

[4] Health Care Financing Administration. 1997. Medicaid managed care enrollment report. Baltimore, MD: Department of Health and Human Services.

TABLE B
COMPARISON OF MEDICAID MANAGED CARE WAIVER PROGRAMS

Program operational requirements	**Waiver authority**	
	Section 1915(b) of the Social Security Act	*Section 1115 of the Social Security Act*
Eligibility rules	May NOT be waived	MAY be waived; permits program expansion
Minimum benefit requirements	May NOT be waived	MAY be waived
Freedom-of-choice	MAY be waived, except in the case of certain benefits, including emergency services, family planning services, and FQHC (health center) services; requires choice of at least two delivery systems when delivery system is limited to HMOs, otherwise may be limited to one system (Primary Care Case Management)	MAY be waived; permits limitation of choice to one delivery system, when appropriate
No cause disenrollment	MAY be waived; permits beneficiary "lock-in" for up to six months for federally-qualified HMOs (one month only), although retains right to disenroll for good cause	MAY be waived; permits extended "lock-in" for up to one year, although retains right to disenroll for good cause
Federal standards for "full-risk" managed care plans (includes periodic medical audit, financial disclosure, encounter data)	May NOT be waived	MAY be waived in limited circumstances
Provider reimbursement rules	MAY be waived only in limited circumstances	MAY be waived in limited circumstances
State administration requirements (e.g., eligibility determination, quality control)	MAY be waived only in limited circumstances	MAY be waived

Source: Reproduced from Rosenbaum S, Darnell J. Statewide Medicaid managed care demonstrations under Section 1115 of the Social Security Act: A review of the waiver applications, letters of approval and special terms and conditions. Prepared for The Kaiser Commission on the Future of Medicaid. Washington, DC: Center for Health Policy Research, May 1997.

Medicaid agencies obtain the information they need by requiring MCOs to submit data as specified in their contracts, which often duplicate federal data collection and reporting requirements. One major source of information is administrative data provided through claims/encounter forms. To augment administrative data, states rely on other sources of information, such as medical chart reviews and member satisfaction surveys.

II. Relevant legal framework and other statutory authorities governing data

A. General authorities

As a general matter, federal administrative and regulatory agencies that oversee the implementation of federal spending and regulatory laws have the power to establish performance standards as well as data collection and reporting requirements to measure compliance with pre-established performance standards. This general authority is derived from the Administrative Procedure Act of 1946 (APA), through which Congress has formally delegated certain powers to federal agencies. While the legal authority of agencies to collect data is expansive, this power is bounded by formal Congressional checks (e.g., the Paperwork Reduction Act) and by informal considerations, such as administrative burden, autonomy, and federalism, which operate as political checks on the administrative process.

Although formal and informal limitations on agency power are strong, the APA grants federal agencies the basic authority to pursue data collection and reporting efforts deemed necessary to carry out their statutory provisions. These data collection activities may be limited by rules against data disclosure contained in executive orders, other laws, or federal regulations. Data disclosure prohibitions, however, do not prohibit an agency from engaging in ongoing, prospective monitoring of public and private entities for compliance or from issuing general reports on the course of legislative implementation, as long as confidentiality and privacy standards are not breached. *[See Table C, appendix, for more details.]*

In addition to this general authority, the federal government has the specific authority to impose data submission duties on states and MCOs under several federal statutes, including: the Medicaid statute (Title XIX of the Social Security Act)[5] as amended by the Balanced Budget Act of 1997;[6] Section 1115 of the Social Security Act;[7] the Children's Health Insurance Program statute (Title XXI of the Social Security Act);[8] the Health Maintenance Organization Act of 1973;[9] Title VI of the Civil Rights Act of 1964,[10] the Americans with Disabilities Act,[11] Section 504 of the Rehabilitation Act;[12] and the Health Insurance Portability and Accountability Act of 1996.[13] *[See Table D, appendix, for more details.]*

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[5] Sections 1901-1932 of the Social Security Act; 42 U.S.C. §§1396-1396v.
[6] P.L. 105-33; §§4701-4710.
[7] 42 U.S.C. §1315.
[8] Section 2101 of the Social Security Act; 42. U.S.C. §1397aa.
[9] Section 1310 of the Public Health Service Act; 42 U.S.C. §300e *et seq*.
[10] 42 U.S.C. §2000d.
[11] 42 U.S.C. §12101.
[12] 29 U.S.C. §794(a).
[13] Section 1172(f) of the Social Security Act; 42 U.S.C. §1320d-1(f).

While HHS has broad authority under the Medicaid and other statutes to impose data collection and submission duties upon state Medicaid agencies and MCOs, it has done so to a limited extent. Although the federal government has taken a more proactive role since the enactment of the Balanced Budget Act of 1997, existing federal requirements regarding Medicaid managed care data remain broad. The following discussion focuses on federal data collection and reporting requirements under the Medicaid statute and Section 1115 of the Social Security Act before and after the amendments of the Balanced Budget Act of 1997 and the proposed implementing rules issued in September 1998.

The "Summary of Federal Reporting Requirements" under TAB A, discusses the federal legal framework in greater length.

B. Data collection and reporting requirements specific to Medicaid

The Medicaid statute contains a broad, implicit grant of authority to the Secretary of HHS to oversee its implementation and state compliance. Congress, in a number of instances, has also delegated authority to the Secretary to develop enforcement and performance standards related to eligibility, benefits, payments, coverage, or the management of specific aspects of the program, as well as requirements regarding information collection and reporting to verify compliance with those standards.

Through the Section 1915(b) and Section 1115 waiver application process, the Secretary has the authority to establish conditions of approval for federal waivers and the information that is required to measure state and contractor compliance with waiver conditions. As part of the implementation of their waiver programs, states may further impose new or more specific duties on participating MCOs in their contracts.

Section 1932 creates new federal, state, and MCO duties with data implications in the areas of marketing, enrollment, services to be provided, networks and access, quality of care, financial information, and utilization and encounter data. Either implicitly or explicitly, any one of these duties can generate data collection and reporting requirements. In addition, because states electing this option must go through a state plan approval process, the Secretary has the authority to require data submission on each required element prior to granting approval.

1. Prior to the Balanced Budget Act of 1997

a. Federal authority

Prior to the Balanced Budget Act of 1997, the Secretary had the authority "to audit and inspect any books and records" of participating HMOs to ensure that they were financially solvent and furnish quality and accessible care to Medicaid enrollees.[14] In addition, under both Section 1915(b) and Section 1115, the Secretary could impose information and data requirements through the application and approval process.

b. State duties

State agencies were required to conduct medical audits at least once a year of HMOs to ensure that they were financially solvent and furnished quality and accessible care to Medicaid enrollees.[15] As part of the audit, states had to "collect management data," including data on "reasons for enrollment and termination and use of services … for use by medical audit personnel."[16] In addition, state agencies had to "use a utilization and quality control peer review

[14] Section 1903(m)(2)(A)(iv) of the Social Security Act; 42 U.S.C. §1396(b)(m) (2)(A)(xi).
[15] Section 1903(m)(2)(A)(xi); 42 U.S.C. §1396b(m) (2)(A)(xi); 42 C.F.R. 434.53.
[16] 42 C.F.R. 434.53.

organization" or "a private accreditation body" to conduct an annual independent, external review of the quality of services furnished by each HMO.[17] The results of the review had to be shared with the state and made available upon request to the Secretary, the Inspector General, and the Comptroller General. All of these requirements applied to Section 1915(b) programs, though they could be waived by the Secretary for Section 1115 programs. Under both types of waivers, states had to abide by additional requirements specified by the Secretary through the application and approval process. States running Section 1915(b) programs in effect, or renewed, prior to 1997 were required to submit summary clinical data on an annual basis and quarterly utilization reports based on their Medicaid Management Information System's payment history file. Under Section 1115, all states, regardless of their plan's specific terms and conditions, had to submit 100 percent encounter data, report utilization data on Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), submit quarterly and annual progress reports, and share with HHS the results of focused studies on four clinical outcomes of their choosing.

c. HMO duties

Medicaid law and regulations required HMOs to have an internal quality assurance plan that, among other requirements, provided for "systematic data collection of performance and patient results" and " interpretation of this data to the practitioners."[18] In addition, HMOs were required to maintain "sufficient patient encounter data to identify the physician who delivers services to patients."[19] HMOs also had to disclose certain financial information[20] and let the Medicaid agency and the Department "inspect and audit any financial records … relating to the HMO's capacity to bear the risk of potential financial losses."[21] All of these requirements applied to Section 1915(b) waivers, though they could be waived under Section 1115. Under both types of waivers, HMOs were to comply with any additional duties specified by the Secretary through the application and approval process.

2. Following enactment of the Balanced Budget Act of 1997

a. Federal authority

The Balanced Budget Act of 1997 gave the federal government an explicit duty to specify minimum standards in the area of quality. In implementing this new mandate, the Health Care Financing Administration (HCFA) redefined the minimum elements of information needed to assist "the Federal government and state agencies in becoming more effective 'value-based' purchasers of health care for vulnerable populations,"[22] bringing consistent reporting requirements to Medicare and Medicaid. In September 1998, HCFA issued a proposed Medicaid managed care rule that integrates the old managed care regulations with the new ones resulting

[17] Section 1902(a)(3)(C); 42 U.S.C. §1396a(a)(3)(C).
[18] 42 C.F.R. 434.34.
[19] Section 1903(m)(2)(A)(xi); 42 U.S.C. §1396(b)(m) (2)(A)(xi).
[20] Section 1903(m)(2)(A)(viii); 42 U.S.C. §1396b(m) (2)(A)(viii).
[21] 42 C.F.R. 434.38.
[22] 63 Fed. Reg. 52022 (September 29, 1998).

from the modifications of the Balanced Budget Act. At the same time, HCFA published interim final standards and guidelines implementing the Quality Improvement System for Managed Care (QISMC),[23, 24] in which HCFA requires MCOs participating in the Medicare program to comply with QISMC and encourages states to consider using QISMIC in monitoring quality in their Medicaid managed care programs. HCFA also includes this state option in the background section accompanying the proposed Medicaid managed care rule, but appears to mandate the use of QISMC through the language (similar to that of the QISMC standards and guidelines) used in the rule to describe MCOs' duty to implement a quality assessment and improvement program.[25]

As before, the Secretary (through HCFA) retains the authority "to audit and inspect any books and records" of participating HMOs, renamed MCOs, to ensure that they are financially solvent and furnish quality and accessible care to Medicaid enrollees.[26] In addition, under both Section 1915(b) and Section 1115, the Secretary retains her authority to impose additional information requirements during the waiver application process. Finally, under Section 1932 created by the Balanced Budget Act of 1997, the Secretary gains new authority to impose data submission duties during the state plan amendment process.

b. State duties

States continue to be subject to Section 1903(m) and HCFA regulations regarding periodic medical audits as they existed prior to the Balanced Budget Act of 1997.[27] While the Balanced Budget Act made some important changes to Section 1903(m), these changes do not affect previous reporting requirements, other than incorporating applicable requirements from Section 1932 by reference. *[See Box A, next page.]*

The periodic medical audit requirement also continues to apply to Section 1915(b) waivers, but may be waived under Section 1115. Existing 1915(b) and 1115 programs are exempt from Section 1932 and other Medicaid-related provisions and implementing regulations to the extent that they already address the issue at hand, even if it differs from Section 1932 and other Medicaid-related provisions. However, existing 1915(b) and 1115 programs that do not address these provisions are required to abide by them.[28] Renewed or extended 1915(b) programs must also meet Section 1932 and other Medicaid-related provisions.[29] New or amended 1115 programs could ask to waive Section 1932 and other Medicaid-related provisions, although HCFA expects quality assurance standards to apply unless states can demonstrate that

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[23] Health Care Financing Administration. Quality Improvement System for Managed Care (QISMC) for organizations contracting with Medicare or Medicaid—Interim QISMC standards. Baltimore, MD: Department of Health and Human Services, September 28, 1998.

[24] Health Care Financing Administration. Quality Improvement System for Managed Care (QISMC) for organizations contracting with Medicare or Medicaid—Guidelines for implementing and monitoring compliance with interim QISMC standards. Baltimore, MD: Department of Health and Human Services, September 28, 1998.

[25] 63 Fed. Reg. 52022 (September 29, 1998).

[26] Section 1903(m)(2)(A)(iv) of the Social Security Act; 42 U.S.C. §1396(b)(m) (2)(A)(xi).

[27] Proposed rule 42 C.F.R. §438.50(b)(1).

[28] Rosenbaum S, Darnell J. Medicaid managed care: An analysis of the Health Care Financing Administration's Notice of Proposed Rulemaking. Washington, DC: Center for Health Policy Research, School of Public Health and Health Services, The George Washington University, Medical Center, November 1998.

[29] Op. Cit.

their standards equal or exceed the federal standards.[30] HHS may impose additional requirements upon states through the waiver application and approval process.

Under Section 1932, the Secretary may impose information requirements upon states through the state plan amendment process, in addition to the periodic medical audit and the requirements of Section 1932. *[See Box A, below.]*

BOX A

SECTION 1932 AND PROPOSED IMPLEMENTING RULES: STATE REQUIREMENTS

Marketing information for prospective enrollees
The statute and proposed rules require states to review and approve marketing materials submitted by MCOs. When states prohibit MCOs from using direct marketing, they must provide member information to prospective enrollees upon request.

Member information for current enrollees
When states prohibit MCOs from directly providing members with enrollee information on benefits, procedures for obtaining services, cost-sharing, and complaint and grievance rights through restrictions on marketing or some other means, states must provide that information themselves.

Information on networks and access
States must review and certify that MCOs have adequate service capacity in accordance with the minimum access standards proposed by HCFA and further defined by states.

Information on solvency
The proposed rules require MCOs to provide assurances to the state that it has adequate protection against insolvency in accordance with state solvency standards.

Information on quality[31]
According to the statute and the proposed regulations, states have a responsibility to implement a quality assessment and improvement strategy, which assesses and improves the quality of care furnished by MCOs, ensures compliance with state standards that are consistent with federal standards, and is periodically reviewed for its effectiveness. The strategy consists of five minimum elements: contract provisions that include the minimum federal standards on access to care, structure and operations, and quality measurement and improvement as further defined by the state; procedures for evaluating quality and appropriateness of care, including monitoring of MCO compliance with standards; annual, external independent reviews of quality and access; use of sanctions; and an information system to support the ongoing operation of the strategy.

[30] Op. Cit.
[31] 63 Fed. Reg. 25272 (May 7, 1998); 63 Fed. Reg. 32784 (June 16, 1998); 63 Fed. Reg. 43242 (August 12, 1998).

This information system must comply with Section 1903(r), which governs the operation of states' Medicaid Management Information Systems, as amended by the Balanced Budget Act of 1997. Under this provision, states are required to use electronic transmission of claims data, including encounter data and other data (e.g., race data), to be specified by HHS and consistent with the Medicaid Statistical Information System (MSIS), which, until 1997, was a voluntary program for states that wished to transmit administrative information electronically to HCFA using data tapes. States will also have to comply with the proposed federal standards on electronic transmission and security that were developed as a result of the Health Insurance Portability and Accountability Act.

c. MCO duties

MCOs participating in Medicaid managed care continue to be subject to Section 1903(m) and implementing HCFA regulations regarding the establishment of an internal quality assurance plan, the collection of encounter data, and the disclosure of financial information as they existed prior to the Balanced Budget Act of 1997.[32] As with states, the Balanced Budget Act amendments to MCOs' conditions of participation do not affect previous reporting requirements, other than incorporating applicable requirements from Section 1932 by reference. *[See Box B, next page.]*

Under Section 1915(b), requirements related to quality assurance, encounter data, and financial disclosure also continue to apply to MCOs, but may be waived under Section 1115. Section 1932 requirements do not apply to MCOs participating in existing 1915(b) and 1115 programs that already address the issue at hand, even if it differs from Section 1932, but do apply if the programs do not address it or when 1915(b) programs are renewed or extended. New or amended 1115 programs could waive Section 1932 and other Medicaid-related provisions, although HCFA expects quality assurance standards to apply unless states can demonstrate that their standards equal or exceed the federal standards. Again, HHS may impose additional requirements through the waiver application and approval process.

MCOs may have to comply with information requirements imposed by the Secretary through the Section 1932 state plan amendment process, in addition to establishing an internal quality assurance plan, collecting encounter data, and disclosing certain financial information, and complying with the requirements of Section 1932. *[See Box B, next page.]*

[32] Proposed rule 42 C.F.R. §438.50(c)(2).

BOX B

SECTION 1932 AND PROPOSED IMPLEMENTING RULES: MCO REQUIREMENTS

Marketing information for prospective enrollees
In compliance with HHS procedures on the provision of information for prospective enrollees, MCOs must submit marketing materials to the state for approval. When authorized, they must provide member information to prospective enrollees upon request.

Member information for current enrollees
As part of the enrollment process and when authorized by the state, MCOs have to provide information to enrollees regarding their structure of care and coverage of services.

Information on networks and access
MCOs must provide assurances to the state and HCFA by documenting that they have adequate service capacity in accordance with the minimum access standards proposed by HCFA to be further defined by states. Following state's review and approval, MCOs must submit copies of the state-certified documents to HCFA.

Information on solvency
The proposed rules require MCOs to provide assurances to the state that it has adequate protection against insolvency in accordance with state solvency standards.

Information on complaints and grievances
The proposed rule requires MCOs to annually analyze complaints and grievances filed over the year and submit a summary report to the state on their number and nature, resolution, and trends.

Information on quality[33]
Proposed HCFA regulations require MCOs to have an ongoing quality assessment and improvement program, which must include the following basic elements that mirror QISMC: MCOs must meet and report minimum performance levels established by the state using standard measures required by the state; MCOs must initiate their own performance improvement projects that focus on clinical and non-clinical areas, as well as performance improvement projects required by the state; and MCOs must have their program reviewed by the state annually. In addition, MCOs are required to maintain an information system that collects, analyzes, integrates, and reports (i) information on utilization, grievances, disenrollment, and solvency, and (ii) encounter data on enrollee and provider characteristics, and services furnished. MCOs are required to make this information available to states and HCFA. When final, they will also have to comply with the federal standards on electronic transmission and security developed as a result of the Health Insurance Portability and Accountability Act.

[33] 63 Fed. Reg. 25272 (May 7, 1998); 63 Fed. Reg. 32784 (June 16, 1998); 63 Fed. Reg. 43242 (August 12, 1998).

Part Two. Findings

I. Introduction

Given existing legal obligations of the federal government, states, and MCOs to collect and report data on care furnished under Medicaid managed care programs, the Subcommittee assessed gaps between current practices and data collection and reporting duties, and examined the extent to which state Medicaid agencies had addressed these gaps. The Subcommittee conducted several hearings in Washington, DC, inviting representatives from the federal government, state legislatures, state Medicaid agencies, advocacy organizations, and academia, among others, to testify about their perspectives on data issues for Medicaid managed care. In order to be sure that issues were consistently addressed, the Subcommittee provided a series of questions to the participants before the hearings. These questions included types of data collected, analytic framework, collaboration efforts as well as, areas of privacy and confidentiality. The specific questions are contained in the Appendix. These testimonies provided the Subcommittee with a national perspective on the problems regarding data collection and reporting in the context of Medicaid managed care. The Subcommittee also traveled to Massachusetts and Arizona to hear information specific to these two states. The information gathered during these site visits complemented the national perspective, while bringing to light local concerns.

In order to determine current state practices on Medicaid managed care data collection and use, the Subcommittee built on testimony collected during hearings and site visits to design both an analysis of Medicaid managed care contract provisions and a series of interviews with state Medicaid officials. The basic aim of this research was to describe the types of data duties states impose on participating MCOs and gauge how states decide which data duties to include in their contracts. In addition this report explores how they use the data they require, and what their analytic needs might be.

Overall, the findings from the Subcommittee's two main activities showed that, despite states' considerable efforts, the collection and reporting of Medicaid managed care data needs improvement. Based on the discrepancy observed between existing gaps and current practices, the Subcommittee articulated recommendations to improve the collection and reporting of information needed to evaluate "the impact of managed care on the health of [Medicaid] enrollees and their access to and use of health care services." The report presents the Subcommittee's findings following by the Subcommittee's recommendations. Note, that while the term Subcommittee is used in selected sections of this report, this report was approved by the full Committee on November 3, 1999.

II. Data needs and gaps: Subcommittee hearings and site visits

Over the past two years, the Subcommittee heard stakeholders[34] interested in Medicaid managed care describe their data needs, delineate data gaps, and provide recommendations and suggestions to the Subcommittee for a national strategy around data collection, reporting, and analysis for the program. The discussion below summarizes pages of minutes from a number of hearings held in Washington, DC and in two states, Arizona and Massachusetts, and presents the findings from these hearings. These minutes are included under TAB B.

While different stakeholders tended to emphasize different aspects of data collection and reporting, a synthesis of their statements reveals consistent themes:

- need for useful information on access, cost, and quality;
- desirability for standardization of a core encounter data set, enrollment/eligibility files, survey instruments, and measures, as well as the collection process itself; and
- access to, dissemination, or sharing of results or access to results obtained from analyzing the data.

A. Federal agencies

Testimony from representatives of the Substance Abuse and Mental Health Administration, Centers for Disease Control and Prevention, and the Bureau of Primary Health Care shows agreement among these agencies on the main questions that they would like answered with Medicaid managed care data:

1. What services are available to Medicaid enrollees? Do they have access to the full spectrum of services, including preventive services?
2. What are the appropriateness and the quality of the services received by Medicaid enrollees?
3. What are the health outcomes of Medicaid enrollees?

[34] For the purpose of this paper, stakeholders include: federal, state, and local government agencies, plans, providers, beneficiaries and their representatives, researchers and other policy analysts.

For each question, those who testified stressed the importance of comparing results between Medicaid fee-for-service and Medicaid managed care, Medicaid enrollees and commercial enrollees, and the Medicaid population and the population at large.

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> *"We are concerned about the access to care of this population. We are concerned that they get access to good preventive services. We are concerned that they get the information, so that they can utilize those services in an accurate and appropriate way. We are also very concerned that public health be an active partner in determining what those services are going to be in, and interacting with Medicaid in drawing up the contracts, in collecting, and sharing the data."*
>
> (January 12,1998 testimony of Gail Janes, CDC; pp.41.-42)

Agency representatives called for accurate, standardized individual level encounter and eligibility data collected at the plan level. The CDC, in particular, recommended that population-based data be linked to Medicaid data to supplement the program's encounter and enrollment data. HCFA pointed to the option of considering an "enhanced" encounter data form, which would include "basic" billing information to which "standardized information on some key risk factors" would be added.[35]

HCFA also emphasized the need for standardized measures, while respecting state flexibility in other domains. Since HEDIS has become the industry standard, and has clearly influenced the selection by states of measures and measurement methods for Medicaid, HFCA recommended that the Subcommittee consider what besides HEDIS would be useful to evaluate managed care, including early warning systems, supplemental clinical or outcome data, and information system capabilities.

B. State legislatures

While state legislators have similar concerns as those expressed by federal agencies, their primary concern is financial. State legislators testified that they are interested in knowing whether "health care results compare to what we used to get in fee-for- service for the clients."[36] Then, the interesting question is how the results of the Medicaid population compare to the results of other insured populations, including privately insured populations, in the areas of access and quality.

To answer these questions, representatives from several state legislatures stated that they rely on external sources, particularly on state agencies, including Medicaid and public health agencies, to provide them with useful information on which to base policy choices.

These representatives reported large gaps in available information. As one legislator pointed out, "we don't really know anything about the quality of the value of the dollars that we

[35] January 13, 1998 testimony of Rachel Block, HCFA; p. 44.
[36] January 12, 1998 testimony of Rep. Lee Greenfield, MN; pp. 113-114 .

are spending."[37] In addition, as another legislator underscored, there is a clear need to link Medicaid to public health goals by "integrating those goals into your contract requirements with your health plans, and then that, in turn, is the kind of information that you make them report…"[38]

Suggestions from state legislators:

- State agencies need to collect encounter data, satisfaction surveys, and outcome measures, and produce outcomes studies (e.g., on whether services provided by Medicaid kept enrollees healthy, enabled children to stay in school and adults to work and stay off of welfare, deterred them from using emergency rooms, and avoided hospitalizations), which legislators would then use to assess the general performance of the Medicaid managed care programs.[39]

- The federal government should rely more on the federal financial participation mechanism to support Medicaid information systems, which state legislatures are reluctant to fund, or rely more on the private sector, which may be ahead in developing systems that are operational.

C. State Medicaid agencies

Testimonies from state Medicaid officials, consultants, and researchers delineated the data needs of state Medicaid agencies. They need information to support three main goals:

1. Purchase health care for a good price;

2. Pay health plans fairly; and

3. Monitor and assure quality.[40]

Testimonies also described the sources of information used by Medicaid agencies to support these goals, including encounter data, member satisfaction surveys, eligibility and enrollment data, provider data, grievance data, and financial data.

> *"Clearly, there is a great interest in terms of health outcomes and quality assessment to identify any of the health status or outcome variables and how they might differ in terms of populations of different race and ethnic categories. I believe that states that have elected to look at that measure have often tried to differentiate their rates, not only by gender, but also by race and ethnicity. There is concern about whether and to what degree different kinds of counselling strategies and materials might be appropriate for different groups so that they have an impact on the effectiveness of the services delivered."*
>
> (January 13, 1998 testimony of Rachel Block, HCFA, pp. 43 and 90)

State officials participating in the hearings and site visits and other speakers identified several gaps

[37] February 10, 1998 testimony of Rep. Susan Gerard, AZ; pp. 23-24.
[38] Ibid.
[39] April 15, 1998 testimony of Rep. Harriette Chandler, MA; p.73.
[40] April 15, 1998 testimony of Richard Frank, MA; p.5.

and problems in existing data, including: underuse of information on pharmacy and laboratory encounters; missing data on dual eligibles, birth weight, race and ethnicity, and people with special health care needs; poor quality of encounter data; and lack of national and regional benchmarks for performance measurement that would allow a fair comparison among states.

Suggestions from Medicaid officials and other speakers:

- "Purchasers[41], those that request the data, must be very clear before they make the request how they intend to use the data."[42]

- Standardization of core data elements and fields for encounters, including procedure codes, consistent with Medicare, survey instruments, and enrollment files.

- Medicaid agencies should define data requirements and be specific about how information should be reported in the contract agreement, stick to the requirements, and sanction plans for noncompliance when necessary.

- Uniformity of the collection process, development of protocols to produce quality data, and increased use of the data because "use makes perfect."

- Measurement of health outcomes of the Medicaid population that is comparable to those of the state population.

- Effective data pooling, through, among other things, a common identifier and increased cooperation across state agencies.

- Establishment of data warehouses and information systems that allow people to pull down and manipulate the data.

- Medicaid agencies should perform readiness reviews for new bidders to check whether they have a claims system and other features necessary for data collection and reporting.

- Keep communication channels open with participating MCOs and encourage cooperation.

- Increase resources devoted to data issues.

D. State public health agencies

Representatives from state public health agencies stated that they must address the following main questions about Medicaid managed care:

[41] The term refers to state Medicaid agencies.
[42] April 14, 1998 testimony of Brian Burwell, MA; pp.49-50

1. Is Medicaid managed care cost-effective compared to Medicaid fee-for-service?

2. "Do people in our state have access to medical care, especially disadvantaged populations?"[43] In other words, "are they getting the care they need, particularly from a prevention standpoint, and are they getting the care that is comparable to commercially insured managed care?"[44]

3. "Has managed care improved the quality of care for Medicaid enrollees?"[45]

4. "How can we use our managed care organizations as a lever to improve the provision of preventive care to all …?"[46]

In order to answer these questions, state public health agencies' representatives indicated that their agencies conduct routine population telephone surveys on insurance and health status, collect satisfaction survey data using instruments such as the Consumer Assessment of Health Plans Study (CAHPS), and analyze eligibility and enrollment data to design interventions. Several indicated that some states link Medicaid eligibility and enrollment data to diagnostic information recorded on the claims and encounter forms and/or on the birth certificates. These data are used to conduct clinical and performance studies.

However, collection of encounter data poses problems. Examples are presented in the box at right.

> *"Our naivete, combined with this notion that we could take a 12-year old MMIS system and just tweak a little bit and we would be able to answer managed care questions, was wrong. When you change the incentives for submission of data, you need a totally new quality process. […] The data is submitted differently, the quality is different, and so you need a whole new system for that."*
>
> (January 12, 1998 testimony of Nancy Clark, OR; 154)
>
> *"But other than that, the arrangement between the providers and the managed care plans is fee for services, and I think that that has some real implications for data collection. So in essence then, the plans get the claims forms from the providers, and then they package that as encounter data, which in turn is sent on to the state.*
>
> (January 12, 1998 testimony of Bob Brewer, NE; pp. 181-182)

Specifically, achieving compliance by health plans with encounter data collection and reporting requirements has been difficult because plans do not assign them a high priority. Presentors suggested that collecting and reporting those data can be difficult in the Medicaid program because of shorter enrollment periods. In addition, the health officials' testimony indicated that public health and Medicaid agencies in general have not worked closely together. As some speakers have pointed out, an executive and legislative commitment to improving health for the citizens may be a factor in promoting the link between public health and Medicaid.

[43] January 12, 1998 testimony of Nancy Clark, OR; p. 148
[44] Ibid.
[45] January 12, 1998 testimony of Bob Brewer, NE; p. 179
[46] Ibid.

Suggestions from state public health officials and other speakers:

- Development of consensus standards for a core encounter data set, with state flexibility to add specific data elements.
- National review of the ICD-9 and CPT-4 coding system to enhance the ability to measure delivery system performance.
- Review of the state of the art managed care plan administrative and clinical data systems for the purpose of creating a system of certification.
- Development of a common electronic format for health care transactions, e.g., use of a common provider identification number.
- Development of administrative mechanisms and methods promoting linkage of public health and Medicaid managed care data.
- Guidance on methods to assess data quality.
- Use of common Medicaid contract specifications as a tool to foster collaboration.

E. Consumers

Consumer representatives and patient advocates who testified identified the following areas of inquiry:

1. Are people with special needs receiving the services they need?

> *"We would like to know about continuity of care."*
> *"We would like to know about typical voluntary disenrollment rates."*
> *"We would like to see standard instruments for assessing consumer satisfaction with additional questions specific to state programs."*
> *"We would like to know about treatment outcomes for health problems typical among TANF related beneficiaries."*
> *"We would like to see best practice monitoring instruments for chronically ill people."*
> (January 12, 1998 testimony of Cheryl Fish-Parcham, Families USA; pp. 132-133)

2. Are those services quality services, using measures such as continuity of care, referrals to specialists, provider-patient communication, and health status?

While these questions are clearly a priority for consumers and patients, testimony indicated that access to the answers is also important. Consumer representatives and patient advocates expressed concern that they do not have enough information about the "basics" of a plan, including how to file a complaint and how to use the system in general. They also indicated that Medicaid agencies should provide them with an explanation of benefits and

information on billing. Finally, consumer representatives testified that providing consumers with information on referrals to specialty care and other non plan specific services (e.g., special education plan provided through the schools).

Suggestions from consumer representatives and other speakers:

- Focus of managed care performance ought to be on "high-risk" individuals, i.e. persons with special health care needs.

- Mechanisms should be available involving families and consumers in setting standards for types of data collection and in the quality measurement process.

- Develop a coordinated collection process by state agencies to avoid duplication and intrusion into families' lives.

- Available information should be shared more with families and with organizations that can interpret it for them.

- A mechanism to publicly report measures, e.g., creation of a report card. In the area of mental health and substance abuse, a panelist suggested that a basic report card would contain claims-based information on who received services by population characteristics (assessment of access with utilization or "penetration" rates). Additional report card items could include services enrollees obtained, stratified by type of service, and whether there is a correlation between what enrollees received and their well-being.

F. Health plans

Most of the testimony indicated that health plans are primarily concerned with overall utilization and total costs. In addition to utilization and costs, health plan representatives stated that plans focus on access and quality. Specific questions related to access and quality include: Are there differences in utilization rates between patients who have managed care coverage vs. those who have fee-for-service coverage? Is managed care reducing utilization rates compared to fee-for-service? Are there differences between Medicaid and commercial enrollees, and if so, are they due to provider or patient behavior? Are there differences between primary care and specialty care visit length? Are there differences in initiation rates between different types of specialty care? Are outcomes different between Medicaid and commercial enrollees, among conditions, or across MCOs or providers?

Presenters indicated that health plans currently use a mixture of data to answer these questions. Plans collect prior authorization data, encounter and claims data, provider data, membership data, member satisfaction survey data, focus group data, complaint data, chart review data, EPSDT data, and HEDIS data. Speakers also reported that health plans collect data from health or functional risk assessments or screenings administered at the enrollment stage.

Gaps and problems identified by health plan representatives include: data on race and ethnicity, and literacy level or years of education; difficulty in obtaining information on pharmacy services and laboratory results; and lack of accurate diagnostic reporting.

Suggestions from health plans representatives and other speakers:

- Purchasers should determine use for the data before requesting specific variables, especially those that protect and improve the health of the population (as opposed to those that ensure and monitor accountability and compliance), while being selective about the amount of data to collect.

- States initiating Medicaid managed care data collection should equally emphasize indicators and data on quality of care and utilization.

- Comparable and consistent reporting should be required across plans.

- Additional reporting requirements should build on existing data structures of health plans. Guidance should be provided to plans and providers to implement these enhanced structures.

- Contracting provisions with providers should include information and requirements on data quality.

- The collection by health plans of race and ethnicity data should be federally mandated.

G. Evaluators

Evaluators and researchers described the same concerns about access and quality as those expressed by other stakeholders. They pointed to the same gaps in information, particularly those on outcomes, health status, and current management of health conditions.

Suggestions from evaluators and other speakers:

- HCFA should take a leadership role in developing data set standards.

- There should be standardization of a core encounter data set and a reporting format, promoting standardization of results across states, programs, plans, and providers.

- Development of data standards building upon existing information systems, which should be recognized by all payers.

- Encourage better access to clinical data to measure quality from a process and outcome standpoint.

- Develop a unique identifier to promote linkages among data sets, while maintaining individual privacy and confidentiality requirements.

- Use of an on-line relational database should be considered.

III. Current state practices: Study of Medicaid managed care contract provisions

Within the federal statutory and regulatory framework governing the Medicaid program, states retain the primary responsibility for delineating data submission duties for MCOs participating in the Medicaid program. States usually define these duties in both their regulations and contracts with MCOs. The following discussion summarizes the results from a focused study of state contract provisions on data collection and reporting, entitled "An Overview of Data Submission Requirements Applicable to Managed Care Organizations Under State Medicaid Managed Care Contracts," which can be found in its entirety under TAB C following this report.

A. Purpose

This study examined whether a state contract included language requiring MCOs to provide data that demonstrate their compliance with one or more contract specifications. In addition, this study examined contract specifications related to state access to certain types of data deemed by the state to be relevant to performance measurement. In either case, the focus was on plan data submission. Regardless of the inclusion of a data submission duty in the contract, plans remain accountable for complying with the contract and performing according to specified standards, and often have a general duty to provide access to data beyond what is indicated in their contracts.

A typology of terms related to data collection and reporting (e.g., "submit," "encounter," "clinical study," etc.) was used to search Medicaid managed care contract provisions[47] from a total of 54 requests for proposals and final standard contract agreements in use in 41 states and the District of Columbia as of the beginning of 1997. This search resulted in the extraction of a variety of language referring to data requirements, which were analyzed to determine whether it explicitly mandated MCOs to directly submit data to the state in the areas outlined by the Balanced Budget Act: marketing; enrollment and disenrollment; networks and access; financial information; quality; services to be furnished; and utilization or encounter data. Additional areas studied in the focus study include communicable diseases and disease prevention services, which are reportable under state public health laws to an agency other than the Medicaid agency, and sanctions, which are directly tied to noncompliance of data submission duties.

[47] These provisions are stored in a database, which is the main source of information for CHSRP's annual study of Medicaid managed care contracts. Latest edition: Rosenbaum S, et al. Negotiating the new health system: A nationwide study of Medicaid managed care contracts. Third Edition. Washington, DC: The George Washington University Medical Center, Center for Health Services Research and Policy, June 1999.

B. MCO data reporting requirements

Based on a review of Medicaid managed care contracts, this study found that most states imposed data submission duties upon MCOs in their 1997 contracts. However, the type and extent of these duties varied considerably among states. Sample contract language is provided for each topical area as an illustration.

1. Marketing

States generally include provisions regulating marketing practices. These provisions parallel the marketing provisions of the Balanced Budget Act and HCFA's proposed rule. For example:

> AThe Contractor shall submit proposed marketing plans and materials to AHCCCSA for prior approval in accordance with *AHCCCS Health Plan Marketing Policy*, a copy of which is available in the Bidders' Library."

(**Arizona Contract Amendment**, page 36)

2. Enrollment and disenrollment

Many state contracts include provisions related to enrollment, auto-enrollment, and disenrollment procedures. However, few states were found to explicitly require MCOs to submit enrollment data to the state, presumably because states maintain these databases themselves. States that requested enrollment information tended to ask for information by age, gender and premium category. Race and ethnicity data are usually not required though states often record that information separately in the eligibility files. For example:

> AContractor shall provide the * * * enrollment information, using Report * * * A6 attached to this EXHIBIT on a quarterly basis within 60 calendar days of the end of the quarter."
>
> **Report A6. CURRENT MEMBER ENROLLMENT**
>
> Contractor _____
>
> Report Period _____through_____
>
> Provide general membership information for your corporate business.

		Number
1.	Members with Group Policies	
2.	Members with Medicare Policies	
3.	OMAP Members	
4.	Medicaid Members other than OMAP Members	
5.	Members with Individual Policies	
6.	Other Members	
7.	TOTAL MEMBERS	

(**Oregon Contract**, pages A-4 and A-28)

States are more likely to require information on voluntary disenrollment than enrollment as a red flag indicator of potential problems with an MCO. For example:

> "Provide studies done on HMO voluntary disenrollment during the prior Contract Year or the first six months of the current Contract Year and describe actions taken in the last year to address opportunities for improvement identified through the analysis of voluntary disenrollments."

(**Massachusetts Contract**, Appendix A, page 14)

3. Networks and access

Most states request information on the plan's network composition and geographic distribution. States seeking data on networks typically ask MCOs to submit periodic reports that list the providers in their network with geographic indicators (e.g., addresses, counties, zip codes) and changes in the network as they occur. Examinations of these data, in turn, can be used as a simple measure of beneficiary access. For example:

> "The CONTRACTOR shall furnish to TENNCARE at the beginning of the Agreement period a listing of all providers enrolled in the TennCare plan * * *. The minimum data elements required for this listing may be found in Attachment II, Exhibit B of this Agreement. This listing shall be updated monthly with all additions, changes or deletions to the listing appropriately noted."

(**Tennessee Contract**, page 45)

A limited number of states go beyond periodic submission of descriptive information of participating providers to require submission of data that would allow them to measure access along a number of indicators. For example:

> "The plan shall provide the following reports and information:
>
> - Descriptive Information on Availability and Access—Plans are to provide descriptive information on physician availability, health plan standards for assuring access, results of access monitoring activities, and actions taken to improve access.
> - Percent of Recipients Aged 42 Through 64 With a Plan Visit in the Previous Two Years—This measure shall be applied to recipients who have been enrolled in the plan for a minimum of two years during the previous calendar year."

(**Hawaii RFP**, page 50)

4. Solvency and expenditures

Most states require submission of financial information, from documents demonstrating fiscal solvency (often submitted to the Department of Insurance) to reports containing expenditure and cost data. For example:

> "Contractor shall comply with all financial reporting requirements contained in the *Reporting Guide for Acute Health Care Contractors with the Arizona Health Care Cost Containment System*. The Guide, which may be found in the Bidders' Library, contains a complete listing of all monthly, quarterly and annual reporting requirements including due dates for each report."

(**Arizona Contract Amendment**, page 24)

5. Complaints and grievances

Prior to the Balanced Budget Act, federal regulations required contractors to have an internal grievance procedure that is approved by the agency, provides for prompt resolution of grievances and complaints, and "assures the participation of individuals with authority to require collective action." About one-half of the contracts studied contain fairly extensive procedural provisions to be followed by MCOs in dealing with or filing grievances. Most states require that MCOs maintain a record keeping system or document complaints and grievances, and submit regular reports to the state. For example:

> "B. Grievance Reports: The Contractor shall provide to DMAHS quarterly reports of all grievances in accordance with Article 13 and Appendices D[48] and J of this contract."

(**New Jersey Contract**, page 64)

6. Quality

Almost all states reiterate in their contracts the federal obligation of MCOs to develop an internal quality assurance plan, and also require a written plan to be submitted to the state for approval. Similarly, the majority of states refer explicitly to the federal requirement that MCOs subject themselves to periodic medical audits and participate in an annual external review by an independent entity. Many states also require MCOs to perform focused clinical studies. As an example:

> "Annually, for the priority areas specified by the Department and listed below, the HMO must monitor and evaluate the quality of care and services through studies for at least two of the listed areas. An executive summary for the first two studies must be submitted by September 1, 1997, and for the second two studies by September 1, 1998, for the preceding contract year (i.e., from July to June). The annual report must include the following general areas: project topic, time frame, study question(s), reason for selection of topic, study goals and indicators, criteria for determining if performance met the indicators, sample selection, sample size, data sources and collection methodology, data analysis plan, data analysis, presentation and interpretation, improvement plan, reevaluation, and distribution of results to providers * * *"

(**Wisconsin Contract**, page 32)

7. Communicable diseases and disease prevention services

Several state contracts require MCOs to report communicable diseases and other notifiable events directly to the public health agency in support of its surveillance activities, perhaps in an effort to use the MCOs' leverage to improve private provider reporting, which has traditionally been poor, or in an attempt to fill a legislative void. Only a few states (e.g., Vermont[49]) include HMOs and MCOs in their legal definition of who has an obligation to report communicable diseases to the state public health agency under their public health laws and/or provider licensure and regulatory statutes. Thus, unless states mandate reporting of communicable diseases by MCOs in their contracts, MCOs have no obligation to do so. In requiring MCOs to notify the public health agency of reportable diseases and events, contracts have adopted two basic approaches: they either require the plan to remind their providers of their

[48] Appendix D contains the grievance process/problem resolution policy provided by the HMO.
[49] 18 V.S.A. § 1000.

obligation to report notifiable diseases to the state; or they impose a duty to report all reportable diseases in the state directly on the plan itself, regardless of the site of service. For example:

> "State law requires that health professionals comply with specified reporting requirements for communicable disease and other health indicators. The health plan must assure through its contracts that providers within their network comply with all such reporting requirements."

(**Michigan RFP**, page 32)

> "The Contractor will implement and maintain a procedure for reporting infectious diseases to public health authorities as required by State law."

(**California Contract**, page 76)

8. Utilization or encounter data

Nearly every state requires the submission of aggregate utilization data, individual encounter data, or both. In 1997, eight states collected encounter data and three states reported collecting aggregate utilization data, respectively. The majority (29 states) collected both.[50] States usually use aggregate utilization data to validate encounter data and to perform a quick check on amounts of services furnished and rates to ensure that they are reasonable. Frequently, contract provisions simply spell out the data submission requirement and refer to appendices or attachments, which become part of the contract by reference. Unlike the more general contract provisions, the appendices or attachments are extremely detailed. For example:

> "7.2 Periodic Reports
> Upon reasonable request, the HMO, inclusive of its subcontractors and providers, agree to furnish information, which the DEPARTMENT may require to administer this contract, from its records to the DEPARTMENT or the DEPARTMENT's authorized agents within 30 days.
> The following periodic reports (outlined within this contract) shall be submitted to the Department within 30 days from the end of the time period for which the report is to cover:
>
> (3) Service encounter data for enrollees under this contract shall be submitted monthly, by the fifth working day of the next month, in the format specified in Addendum V. Additional specific submission requirements for encounter data and penalties for failure to meet submission timeframes are noted in Addendum V. Additionally, should the HMO contract be canceled for any reason, the submission of encounter data will be required for up to one year subsequent to the effective date of cancellation to reflect services paid for covered HMO months of eligibility."

[50] Rosenbaum S, et al. Negotiating the new health system: A nationwide study of Medicaid managed care contracts. Third Edition. Washington, DC: Center for Health Policy Research, School of Public Health and Health Services, The George Washington University Medical Center, Center for Health Services Research and Policy, June 1999.

"ADDENDUM V – ENCOUNTER DATA * * *
Encounter data will routinely be expected to be received by the DEPARTMENT by the 5th working day of the month subsequent to the month for which data is reflected. Corrections to the encounter data submission shall be finalized within 45 days from the date of notification for which data is reflected. The HMO shall not exceed these timelines more than 3 months of any contract year. In the event that the HMO does exceed the timeframes more than three months of the contract year, the issue shall be subject to the provisions outlined in Article X- PERFORMANCE REVIEW, DISPUTES, AND REMEDIES FOR VIOLATION, BREACH OR NON-PERFORMANCE OF CONTRACT. For the Contract for State Fiscal Year 1997, this provision shall apply as of the submission for October 1996 dates of service * * *

HMO ENCOUNTER DATA SPECIFICATIONS INDEX
Data Element Name
Admission Date
Amount Charged
Begin Date of Service
Claim Receipt Date
Date of Birth
Date of Payment
Diagnosis Code
Discharge Status
Drug Code
End Date of Service
Gender Code
Medicaid Covered Inpatient Days
Medicaid HMO Amount Paid
Medicare Coinsurance Payment
Medicare Deductible Payment
Other Third Party Payment
Place of Service
Principal Procedure Code
Principal Procedure Date
Principal Procedure Flag
Quantity of Service
Recipient ID Number
Rendering Provider ID Number
Rendering Provider Type
Secondary Diagnosis Code
Secondary Procedure Code
Secondary Procedure Flag
Service Procedure Code
Service Procedure Code Modifier
Service Procedure Flag
Submitting HMO/PHP Medicaid Provider Number
Type Claim
Type Coverage
Type Service."

(**Iowa 1997 Contract**, pages 34 and 72)

IV. State purchasing of Medicaid managed care data: Interviews with Medicaid agency officials

States determine their data needs based in large part on federal requirements. Interviews with state Medicaid officials revealed that these are translated into contractual specifications with MCOs. A synthesis of the findings from these interviews is presented below. A more complete analysis, called "State Data Purchasing Under Medicaid Managed Care," is attached under TAB D.

A. Methodology

The purpose of the interviews was threefold: (1) to describe how state Medicaid agencies select the data they require full-risk MCOs to collect and report to the state as part of their contract to serve the Medicaid population enrolled in managed care, and the bases for their choices; (2) to describe the types of data submitted to the state as a result of these choices; and (3) to describe the state's ability to analyze the information to inform the purchasing process.

The study design was a qualitative design, using inductive inquiry. Ten states, including two pilot states, were selected based on two criteria—i.e., they enrolled a high proportion of their own Medicaid population in full-risk MCOs, and, in the aggregate, they covered almost half of the total Medicaid enrollment in full-risk MCOs nationwide.[51] An interview guide was developed and tested in the two pilot states. The same researcher then used the guide to conduct eight semi-structured telephone interviews with Medicaid officials (one to four individuals on a given call) who oversee the managed care contracting process. Interviews started in June 1998 and ended in September 1998. Data collected through the ten interviews were content analyzed, looking for emerging patterns, if any. Results were aggregated across all of the states interviewed, including the pilots, for the purpose of summarizing the findings.

B. Summary of findings

Most states have developed, as a result of managed care purchasing, a multi-faceted operational and financial data collection plan to monitor actual program performance with

[51] In these ten states, a total of 3,748,235 Medicaid recipients were enrolled in full-risk MCOs, representing 26 percent of the total Medicaid managed care enrollment and 12 percent of the total Medicaid population (calculations based on HCFA's "1997 Medicaid Managed Care Enrollment Report"). Because of the qualitative nature of the inquiry, these states are not representative of all states in a statistical sense, despite the fact that, together, they cover almost half of all full-risk enrollees.

respect to service access and health outcomes, most of which is translated into contractual health plan reporting requirements.

1. Determination of data needs

The majority of states had a process to make decisions about specific data to require from participating MCOs. Half of those states indicated that their process is not restricted to data. It encompasses all aspects of managed care purchasing, of which data are a part. The majority of states involve health plans in their discussions about data collection and reporting, both in the pre- and post-contract phase."

The top three rationales for state choices regarding data requirements are compliance with federal requirements, compliance with state requirements as laid out in contract specifications, and measurement of access to care, quality of care, or outcomes. The most frequently cited selection criteria include federal requirements, NSF HCFA 1500 and UB 92, and the general direction of HEDIS.

2. Types of data collected and required in the contract

Based on these various rationales and selection criteria, all states currently require MCOs to collect and report encounter data, and most states also collect directly from health plans aggregate utilization information, summary enrollment statistics, and varied access, quality, and financial data (states are broken down in more detail in the accompanying report under TAB D). These data submission requirements are generally written into the contract.

a. Encounter data

States collect complete individual-level encounter data on all services provided, including data on laboratory and pharmaceutical services, though a few states do not collect information on prescription drugs. The data elements reported are similar to fee-for-service elements found on any billing (e.g., procedure code, diagnosis code, place of service, type of service, provider, etc); states either use the UB 92 and HCFA 1500 forms or a state-designed form.

Interviewees stated that they currently use encounter data for the following purposes: limited measurement of quality; calculation of capitation rates; measurement of plan compliance with performance standards; and comparison of utilization rates among plans. In the future, states plan to use encounter data to report HEDIS measures and other quality indicators, calculate capitation rates adjusted by diagnosis, and measure plan compliance with financial incentive-based performance standards.

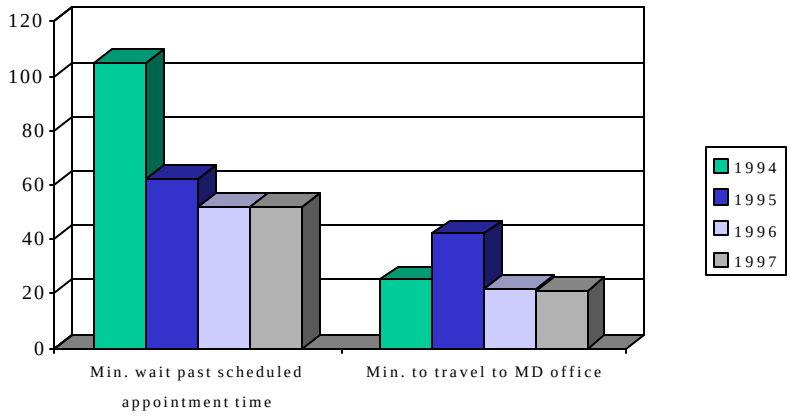
While they saw the potential of encounter data to serve many purposes, interviewees also expressed concern about the quality of the data, including the timeliness, completeness, and accuracy of these data. Concerns about the lack of analytic capability, and the impact of

HCFA's requirements on agency costs, particularly in the view of the uncertainty surrounding use of encounter data for quality measurement were also expressed.

b. Data on access to care

The majority of states measure access in two ways. First, they use provider network capacity as one indicator of access. To that end, they usually require plans to submit provider data on the type of provider participating in the network, panel size, and number of patients each provider is willing to see. Second, they measure compliance with access standards on waiting times, travel distances, and other dimensions (e.g., utilization rates), which may be state or plan defined. States may collect that information from plans indirectly through the annual medical audit, medical chart reviews, member satisfaction surveys, and grievances, or directly through the submission of encounter data. Below is an example of a state using a survey to measure access indicators and satisfaction with quality.[52]

Time for Appointments



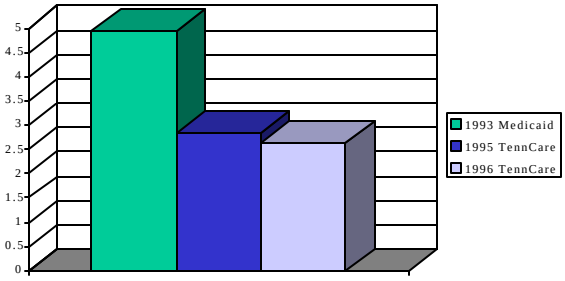
c. Data on quality of care

The main sources of data on quality are the annual medical audit or external review, encounter data, and focused clinical studies. Other sources of information include grievances, financial data, and member satisfaction surveys. Those that use HEDIS measures to assess quality collect data on these measures either through medical chart reviews performed during the

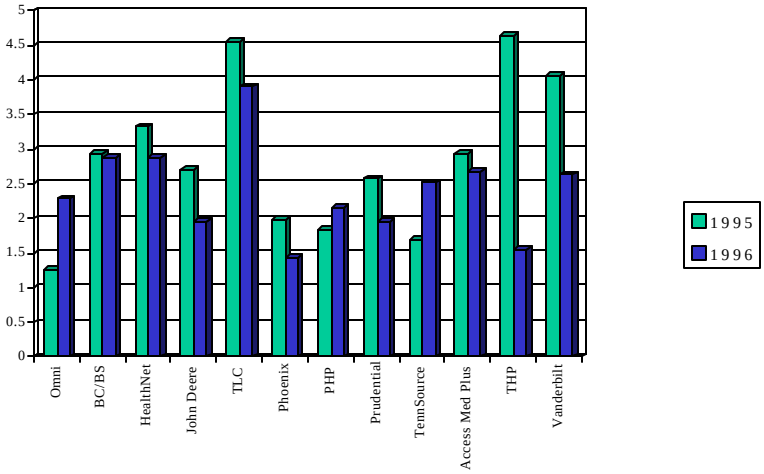
[52] Fox W and Lyons W. The impact of TennCare: A survey of recipients. Knoxville, TN: The University of Tennessee, March 1998.

periodic medical audit, or encounter data, or both. Below is an example of a state using Medicaid eligibility and encounter data for a focused study performed by the state's External Quality Review Organization to measure the rate of hospitalization of diabetic patients in Medicaid fee-for-service and in Medicaid managed care, as well as to compare it across participating plans.[53]

Inpatient admissions due to diabetes per 1000 member years



Diabetes Inpatient Admissions per 1000 member years by MCO



d. Data supporting public health activities

Although data supporting public health activities, including surveillance, control, and prevention of communicable and other notifiable diseases, are one useful source of information for Medicaid managed care purchasing (e.g., utilization rate of preventive services), states do not

[53] Bureau of TennCare. TennCare inpatient admissions due to diabetes: A report of regional and managed care organization variation. On-line at http: //www.state.tn.us/health/tenncare/diabetes.htm

yet see them as a priority. Very few states specifically require plans to report data related to public health to the Medicaid agency or the appropriate public health agency. Even though states collect information on laboratories and pharmacies as part of their encounter data, few focus on them as the main sources of "public health" data. Finally, Medicaid agencies' ability to integrate these data with Medicaid data remains limited to such activities as encounter data validation or discontinuation of payment for deceased individuals.

States that benefit from a legislative and executive commitment to public health or are able to build a relation of trust between the Medicaid and public health agencies tend to emphasize public health within Medicaid. For example, one state has focused on comparing the progress made by the Medicaid population and the general population toward reaching the Year 2000 national and state public health goals; another has been linking birth certificates and Medicaid eligibility files to evaluate infant death and prenatal care.

3. Capacity to analyze data to inform the purchasing process

In order to use the information collected to inform the purchasing process, states need to be able to link the various data files stored on their MMIS, including files on eligibility, enrollment, providers, expenditures, and use of services, all of which are linkable in theory. To turn a theoretical possibility into practice, states need to have at their disposition appropriate resources, including information systems, financing, and staffing. The overall impression gathered from the interviews was that states were experiencing difficulties with their information systems and struggling with the proper allocation of financial and staffing resources. Several respondents indicated that strengthening collaborative efforts and joint analytic support with academic institutions and among state agencies may begin to address the issues of technical assistance. They recommended that consideration be given to the federal government making resources available for states to purchase needed technical assistance to train staff in specific methodological areas (e.g., use of statistical packages, analysis of encounter data, and integration of public health and Medicaid data).

V. Summary of findings

Overall, the findings from the Subcommittee's two main activities showed that, despite states' considerable efforts, the collection, reporting and analysis of Medicaid managed care data still needed improvement. Additionally, while most states address data collection and reporting in their contracts with participating MCOs, they do so with little uniformity. More specifically, the Subcommittee found that:

- State Medicaid agencies do not use a standardized set of data elements enabling them to track the experiences of Medicaid enrollees with managed care.
- State Medicaid agencies use different definitions of what constitutes an encounter, a barrier to the collection of standardized data.
- State Medicaid agencies do not collect uniform enrollment data, including race and ethnicity data along with data on language, reason for enrollment (e.g., disability), and other demographic information as part of the enrollment process, which would allow them to determine barriers to care and track patterns of discrimination.
- State Medicaid agencies are limited in their ability to monitor the experiences of Medicaid managed care enrollees with access and quality of care due to the poor quality of the encounter data they receive from MCOs, their own inability to analyze encounter data, and the cost of collecting data and performing audits. In addition, the Subcommittee found that the degree to which states collected information on enrollee satisfaction, an important aspect of an enrollee's experience with managed care, varied from state to state.
- State Medicaid agencies do not necessarily collect information on all services provided to Medicaid managed care enrollees under the state Medicaid plan, which is essential to the quality improvement strategies state Medicaid agencies and MCOs are required to implement as a result of the Balanced Budget Act.
- State Medicaid agencies are generally reluctant to provide researchers with access to data, which limits the use of the data.
- State Medicaid agencies and state public health agencies rarely coordinate their data collection and analysis efforts, when they could benefit from sharing utilization and outcomes data to track the experiences of Medicaid patients and other patients living in the state.
- State Medicaid agencies usually lack the financial and human resources to use and analyze all the data they collect, particularly encounter data.
- State Medicaid agencies generally do not mandate, in their contracts, that MCOs report notifiable diseases to the state public health agency, or require in their contracts that MCOs enforce their participating providers' obligation to report notifiable diseases to the state public health agency.

Based on these findings, the Subcommittee articulated a set of recommendations to improve the collection and reporting of information needed to evaluate "the impact of managed care on the health of [Medicaid] enrollees and their access to and use of health care services." The recommendations address the following areas: adoption of a standardized set of data elements, including use of a common definition of an encounter and collection of uniform enrollment data. Recommendations also focus on: description of patient experiences with access to quality care, including patient satisfaction and or report/rating of care; collection of data on services covered under the state Medicaid plan, not under the MCO contract and dissemination, availability and sharing of data. The development of training opportunities for state staff to increase their analytical capacity; and submission of data on notifiable diseases are also areas addressed by recommendations from the Subcommittee.

Recommendations

Since the inception of the Medicaid program, state Medicaid agencies have had direct access to data through claims that were submitted by providers for payment of each service furnished. However, as the program increasingly relies on managed care rather than fee-for-service reimbursement to pay for and deliver services, concerns arise that agencies may lose access to the data they need to perform their oversight and enforcement functions, which includes maintaining quality care for the most vulnerable populations. Under managed care, loss of access to data occurs because MCOs are paid prospectively with bundled premiums for the provision of medical and administrative services, without requiring the submission of individual claims. The provision of encounter data by MCOs to state Medicaid agencies can mitigate the loss of claims data.

As noted in Part One of this report, HHS has broad authority under the Medicaid statute to require state Medicaid agencies and MCOs to collect and report data to verify compliance with federal requirements and performance standards. Until the passage of the Balanced Budget Act, HHS had made limited use of this authority, due in part to the need to balance the utility of the information with the burden of collecting it. Even as HHS takes the opportunity offered by the Balanced Budget Act to standardize federal data collection and reporting requirements across Medicare and Medicaid, these requirements remain broad, lacking specification regarding, for example, the format in which the data should be collected.

At the state level, Medicaid agencies enforce applicable federal reporting requirements as well as relevant state laws and regulations pertaining to data. As the study of Medicaid managed care contracts presented in Part Two of this report indicated, states often replicate these requirements in the service agreements they sign with MCOs. In some cases, they also impose additional data collection and reporting duties on MCOs regarding the type and format of data they want MCOs to collect or the information systems they want MCOs to use. However, the specificity of these contract provisions and MCO compliance with contractual requirements vary across states.

The Subcommittee, with subsequent approval from the full Committee, recommends that HHS use its authority to be more specific about the manner and the format in which Medicaid managed care data should be collected and reported in order to foster uniformity and comparability of the information, while recognizing that HHS may be bound by statutes and regulations requiring demonstration of the utility of collecting these data relative to the cost of collecting them.[54] The Subcommittee/Committee also wishes to underscore that any new data collection and reporting requirements must be consistent with HIPAA-related decisions on privacy, confidentiality and security of data transactions. In addition, HHS should be more specific about the purpose for which the data are collected and define the priority questions about quality, cost, and access that require an answer.

[54] See Table C in the Appendix.

The Subcommittee/Committee acknowledges that one possible vehicle for delineating data collection and reporting duties is the contract signed between Medicaid agencies and participating MCOs.

Finally, the Subcommittee/Committee has six recommendations about specific areas of data collection and reporting.

Specific recommendations related to data

1. Standardized set of data elements

Ideally, HHS and state Medicaid agencies would want to be able to collect data on every aspect of the services delivered to the Medicaid population. However, due to financial and administrative constraints, such a comprehensive approach to data collection is unrealistic. Several state representatives suggested in interviews and at Subcommittee hearings that 20 to 30 data elements would be sufficient to track the experiences of Medicaid managed care enrollees. The Subcommittee/Committee supports the adoption of a standardized core data set and recommends that data elements be consistent across states, manageable for states when collecting and analyzing the data, and uniform for health plans when doing business in more than one state.

Specifically, the Subcommittee/Committee recommends that HCFA adopt a standardized set of data elements in a format consistent with ASC X12 837. HCFA could use the 1996 recommendations of the National Committee on Vital and Health Statistics as a guide in selecting a consistent data set. The Subcommittee/Committee strongly encourages state Medicaid agencies to adopt the standardized set of data elements as defined by HCFA to ensure comparability of the information collected for enrollment and encounters. The Subcommittee/Committee also recommends that MCOs implement information systems that are compatible with these elements and consistent with existing privacy and confidentiality practices.

1a. Common definition of an encounter

A standardized set of data elements cannot be implemented without standard definitions. Common definitions also help improve the validity and reliability of the data collected. For these reasons, the Subcommittee/Committee recommends that HCFA, when defining a standardized set of data elements, also adopt a common definition of what constitutes an encounter. The Subcommittee/Committee strongly encourages states to use this common definition in their contacts with MCOs. While the unit of reporting is a service furnished, as is the case in fee-for-service, the definition should enable states and MCOs to record which services were rendered as a result of a contact between a patient and her provider.

1b. Enrollment data

When linked to utilization of services and health outcomes, enrollment data are particularly useful in determining barriers to care and tracking patterns of discrimination. The Subcommittee found that states varied in the type of enrollment data they collect. Subcommittee/Committee members also heard from the field that collecting race and ethnicity data is essential in assessing access and quality of care received by minorities. In many cases, state Medicaid agencies collect but do not use this information, due in part to the poor quality of the data. Additionally, MCOs do not collect these data because of the appearance of discrimination it might create.

The Subcommittee/Committee recommends that HCFA encourage state Medicaid agencies to collect uniform enrollment data, including race and ethnicity data along with data on language, reason for eligibility (e.g., disability), and other demographic information as part of the enrollment process. The Subcommittee/Committee recommends that the format and content of race and ethnicity data be consistent with the Office of Management and Budget's Standards for Maintaining, Collecting and Presenting Federal Data on Race and Ethnicity. The Subcommittee/Committee strongly encourages states to explicitly collect race and ethnicity data on the enrollment form, and to share that information with MCOs to enable them to produce state-required reports along these dimensions. The Subcommittee/Committee also recommends that HCFA encourage state Medicaid agencies to ensure that enrollment data are, at a minimum, linkable to encounter data, and encourages each state to perform this linkage in a manner that is consistent with standards regarding the electronic transfer of data and with confidentiality and privacy practices and procedures.

2. Patient experiences with access to quality care

Through regular reports and periodic audits, HCFA reviews state Medicaid agency compliance with federal standards, including statutory and regulatory requirements regarding the proper and efficient administration of the program, benefits and coverage, comparability of services and coverage among eligible groups, and management and oversight of managed care. Under the law, state Medicaid agencies are required to monitor Medicaid managed care enrollees' access to quality care. In order to further their monitoring activities, state Medicaid agencies generally require MCOs to provide encounter data to the state on an ongoing basis and to undergo periodic audits, during which state Medicaid agencies or their independent contractor collect data on access and quality. The data are then analyzed to describe patient experiences with access to and quality of care.

The Subcommittee/Committee found, however, that in many instances states are limited in their ability to monitor these experiences due to the poor quality of the encounter data they receive from MCOs, their own inability to analyze encounter data, and the cost of collecting data and performing audits. In addition, the Subcommittee/Committee found that the degree to which states collected information on enrollee experiences with managed care varied from state to state.

In addition to recommending the adoption of a standardized set of data elements as described in the first recommendation, the Subcommittee/Committee recommends that HCFA encourage states to use standardized surveys of member experiences with managed care. The Subcommittee recommends that state Medicaid agencies administer, or require MCOs to administer, standardized population-based experience surveys measuring member events, including satisfaction with access to and quality of care. The Subcommittee/Committeee recommends that states use standard satisfaction and or rating instruments that are widely and consistently applied across populations (e.g. instruments consistent to those developed such as CAHPS or Consumer Assessment of Health Plan Study) and translated in languages other than English.

3. Services covered under the state Medicaid plan, but not under the MCO contract

Collecting information on all services provided to Medicaid managed care enrollees under the state Medicaid plan is essential to the quality improvement strategies state Medicaid agencies and MCOs are required to implement as a result of the Balanced Budget Act. For example, without pharmacy encounter data, states and MCOs alike have difficulty in analyzing the quality of care provided to members.

The Subcommittee/Committee recommends that HCFA encourage state Medicaid agencies to ensure that providers of services, with whom states directly contract to provide services covered under the state Medicaid plan but not under the MCO contract (e.g., mental health and substance abuse, prescription drug, and dental services), collect and report data to the state on the services they provide. The Subcommittee/Committee encourages states to subject such data to the same standards as required for data on services provided under the MCO contract. In addition, the Subcommittee/Committee encourages states to share relevant data needed by MCOs in order to comply with the Quality Improvement System for Managed Care (QISMC). Similarly, when MCOs are responsible for delivering all services under the state Medicaid plan but contract them out, the Subcommittee encourages states to require MCOs to enforce the same reporting requirements on their subcontractors as are imposed on them.

4. Availability of data and sharing of information among state agencies

To generate the reports and studies required by HCFA and state Medicaid agencies, HCFA, state Medicaid agencies, or their designated contractors need to access MCOs' data, while strictly respecting privacy protections. Similarly, approved research projects by academic centers or other independent research entities often depend on the availability of data collected by HCFA, state Medicaid agencies, and MCOs subject to full adherence to confidentiality requirements. State officials interviewed for the Subcommittee/Committee noted that "use makes perfect" when it comes to the data they collect.

In addition, because of the situation described in the last recommendation, it is all the more important for public health agencies to collaborate with other agencies to gain access to

utilization or encounter data so that they can continue to track diseases in communities increasingly served by managed care. Therefore, the Subcommittee/Committee strongly encourages state Medicaid agencies to collaborate on and coordinate their data collection and analysis efforts with those of state public health agencies, in a manner that is consistent with confidentiality and privacy practices and procedures.

5. Training to increase staff analytic capacity

Throughout the hearings and interviews with state officials, the Subcommittee/Committee found that states needed to promote capacity building and expand analytic staff. Some interviewees indicated the need for decision support systems, and others indicated the need to enhance and expand basic analytic skills beginning with the types of research questions analysts should ask. There is a common need across state Medicaid agencies to share research methods, data collection, and analytic skills from other agencies, develop a collaboration among state agencies and the academic community, and train the workforce.

The Subcommittee/Committee recommends that the federal government, in partnership with the private sector, invest in training programs to increase state-level staff capacity to analyze and use Medicaid data. This investment should involve both financial and human resources. The Subcommittee/Committee suggests that a "menu of technical assistance options" be developed, using existing resources to the extent possible. The menu would include such strategies as: public health traineeship grants in public health techniques; tuition programs; training similar to that of the Applied Statistics Training Institute (ASTI); personnel sharing between Departments and Agencies, Agency for Health Care Policy Research (AHCPR) fellowships; funding of HHS fellowships and scholarships; learning collaboratives for analytic techniques; evaluation templates for analysis (which could take the form of a toolbox similar to Healthy People 2010); a website for technology transfer; and videoconferencing. Finally, the Subcommittee encourages a closer collaboration among state agencies to expand analytic capability.

6. Data on notifiable diseases

State public health agencies have relied on available data to support the management of public health surveillance and disease tracking. Providers of health care services have submitted these data on both a formal and informal manner. The advent of managed care, as well as structural modifications to the fee-for-service world, have increased tensions between providers, recipients, and payers to provide these data. Clinical laboratory data are an example of this. As MCOs increasingly contract with private, out-of-state laboratories to conduct test rather than using state public health laboratories as was previously the case, state public health agencies may lose an important source of information due to the lack of a legal framework requiring the reporting of that information. The federal Clinical Laboratories Improvement Amendments (CLIA) do not require state public health agency reporting as a condition of CLIA certification.

States, however, may wish to exercise one of two main options to ensure laboratory reporting of test results: like New York, they may require licensure of any laboratory conducting business in the state (i.e., out-of-state laboratories that test laboratory specimens drawn in the state) and test result reporting as a condition of licensure; or like Vermont, they may specify in the contract that MCOs' subcontracting laboratories report test results to the state public health agency, consistent with applicable confidentiality protections. In addition, the Subcommittee found that MCOs may be in a better position to improve the reporting of these data. Thus, the Subcommittee /Committee recommends that HCFA, in working with state agencies, encourage MCOs to remind and encourage their providers to support the public health surveillance and disease tracking system.

APPENDIX

TAB A

SUMMARY OF FEDERAL REPORTING REQUIREMENTS

General legal framework	
1946	*The Administrative Procedure Act (APA)* Enacted by Congress in 1946, the APA represented an effort to curb the expansion of administrative authority and standardize administrative decisionmaking, by prescribing minimum procedures that all federal agencies must use when adopting rules. All proposed rules or changes to rules (with certain exemptions) must be posted in the Federal Register to allow interested parties the opportunity to provide comments. Some agencies (including HHS in certain respects) are exempt, but they tend to follow the procedures as a matter of agency policy. The law further lays out the rights of individual people in agency adjudication proceedings when a hearing is required as a matter of law, and establishes standards for judicial review of agency actions. Congress may impose additional requirements on agencies by statute and may legislate agency-specific procedures that differ from those in the APA. The APA is interpreted and enforced by the courts.
1966	*The Freedom of Information Act (FOIA)* In an effort to limit administrative agencies' collection, use, and disclosure of information, Congress passed the FOIA, which establishes certain public access rights.
1974	*The Privacy Act* In an effort to limit administrative agencies' collection, use, and disclosure of information, Congress passed the Privacy Act, which establishes protection standards for individuals.
1976	*The Government in the Sunshine Act* In an effort to limit administrative agencies' collection, use, and disclosure of information, Congress passed the Government in the Sunshine Act, which establishes standards to ensure public access to certain internal agency deliberative processes. More recently, the Administrative Dispute Resolution Act and the Negotiated Rulemaking Act amended the Act.
1980	*The Paperwork Reduction Act* Under the Paperwork Reduction Act, the Office of Management and Budget (OMB) must approve any new information demand that an agency wishes to impose on the private sector. Most recently amended in 1995, the Act now requires agencies to seek public comment through a 60 day notice before submitting a proposal to collect information to OMB for clearance. Agencies also have to show that the collection efforts would not create an undue burden on small businesses, local governments, and other small entities.

Source: Rosenbaum S, Markus A, Repasch L. An overview of data submission requirements applicable to managed care organizations under federal law. Prepared for the National Committee on Vital and Health Statistics Subcommittee on Population Specific Issues. Washington, DC: Center for Health Policy Research, July 1998.

Specific statutory authority	
1965	*Medicaid (Title XIX of the Social Security Act)* The Medicaid program, established in 1965 and codified at Title XIX of the Social Security Act, is a federal grant-in-aid program jointly administered by the federal government and the states, which provides medical assistance to certain low income persons who satisfy the law's eligibility requirements. For persons who qualify, coverage is extensive; indeed, Medicaid benefits reach well beyond the level of coverage typically available to privately insured persons. However, the statute's eligibility restrictions limit its reach to only about half the nation's poor, although coverage of children and pregnant women is now quite broad. The program is governed by numerous standards regarding eligibility, services, and provider reimbursement, with which participating states and providers of "medical assistance benefits" (including managed care providers) must comply. The Health Care Financing Administration (HCFA) is the agency within Health and Human Services (HHS), which has the express delegation of authority to oversee the implementation of Medicaid. HCFA reviews state agency compliance with federal standards mainly through regular reports from, and periodic audits or inspections of, state plans and operations as well as those of contractors, which, under the law, include MCOs.
1997	*Children's Health Insurance Program (CHIP, Title XXI of the Social Security Act)* The Children's Health Insurance Program (CHIP), codified at Title XXI of the Social Security Act, was enacted as part of the Balanced Budget Act of 1997. CHIP is a federal grant-in-aid program that entitles participating states to enhanced federal funds (compared to the current matching formula used for Medicaid) to expand coverage to "targeted low-income" children who do not qualify for other coverage, including Medicaid. Despite Medicaid expansions undertaken in the late 1980's, approximately 14 percent of all children remain uninsured. Most uninsured children live in working families with incomes below 200 percent of the federal poverty level ($32,000 for a family of four in 1997). In general, CHIP imposes new data collection and analysis requirements on states, but does not specify either conditions of participation or federal reporting requirements for CHIP MCOs, other than those found in other laws (such as HIPAA, see below, as long as the CHIP plans are considered health insurance issuers). HCFA, which administers CHIP jointly with the Health Resources and Services Administration within HHS, has the authority to set conditions of participation and reporting requirements for CHIP MCOs, as a general exercise of its administrative powers.
1973	*The Health Maintenance Organization Act (The HMO Act)* A portion of all Medicaid managed care enrollees are members of federally-qualified health maintenance organizations (HMOs). In order to become federally-qualified, HMOs have to abide by the HMO Act of 1973 (the Act) and its implementing regulations, which define federally-qualified HMOs as entities that provide basic and supplemental services and operate according to the Act's specifications, including those related to service accessibility and organization. Under the Act, federally-qualified HMOs are required to report and disclose certain data. To the extent that requirements conflict with Medicaid requirements, HMOs have to comply with the latter. In addition,

Specific statutory authority	
	they are required to follow Medicaid rules regarding deductibles and coinsurance, enrollment practices, state plan rules on copayment options, and grievance procedures. Since the mid-1980's, HCFA has been responsible for the administration of the Act. HMOs that seek federal qualification must complete an application form provided by HCFA, which then makes a determination based on the information reported in the form and on-site visits, hearings or other methods, if needed.
1996	*The Health Insurance Portability and Accountability Act (HIPAA)* Subtitle F of HIPAA subjects health plans (including the Medicaid program, participating MCOs, and HMOs), health clearinghouses, and health care providers to new standardized data elements and code sets (e.g., medical procedure codes) as specified by the Secretary when transmitting health information electronically. Subtitle F also calls for the protection of confidential health care information through the adoption of security standards and federal privacy legislation. Finally, HIPAA also prohibits discrimination in the enrollment phase of coverage against persons with preexisting conditions.
1964	*Title VI of the Civil Rights Act* Title VI of the Civil Rights Act of 1954 (the Act) prohibits discrimination based on race, color, or national origin by recipients of federal financial assistance. Medicaid is considered to be federal financial assistance, and thus the provisions of the Act bind HMOs and other MCOs that participate in Medicaid. Federal agencies are charged with the enforcement of Title VI under their federally-assisted programs; within HHS the Office for Civil Rights has lead responsibility for Title VI enforcement. HHS has the authority to require MCOs and states to report race data to verify compliance of managed care with the Civil Rights Act.
1973	*Section 504 of The Rehabilitation Act* Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability against qualified individuals with disabilities. In the context of health care, the term "qualified individuals" signifies a person who meets the eligibility requirement for the program from which assistance is obtained. Like Title VI, Section 504 applies to federally-assisted programs. As with Title VI, HHS has the authority to require the ongoing collection of data by recipients of federal financial assistance that would allow inspection of patterns of health care access and utilization. However, the Department does not impose such ongoing data collection responsibilities, electing instead to limit data collection to the investigation of particular alleged incidents.
1990	*The Americans with Disabilities Act (ADA)* Like Section 504, the ADA prohibits discrimination on the basis of disability against qualified individuals with disabilities. The ADA applies to employers, federally-assisted programs, and places of public accommodation, which have been held to include managed care plans. As with Title VI, HHS has the authority to require the ongoing collection of data by places of public accommodation that would allow inspection of patterns of health care access and utilization. However, the Department does not impose such ongoing data collection responsibilities, electing instead to limit data collection to the investigation of particular alleged incidents.

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TAB B

See Meeting Minutes at:

http://www.ncvhs.hhs.gov/970721ag.htm

http://www.ncvhs.hhs.gov/970929ag.htm

http://www.ncvhs.hhs.gov/980209az.htm

http://www.ncvhs.hhs.gov/980414ag.htm

TAB C

Focused Study of Medicaid Managed Care Contracts

(Not available electronically. Please request copy from NCVHS)

TAB D

Interviews with Medicaid Officials

(Not available electronically. Please request copy from NCVHS)