A Primer on Collaborating with Medicaid Agencies and Using Medicaid Data in Efforts to Eliminate Racial and Ethnic Disparities in Health

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Foreword

On behalf of the Office of Minority Health (OMH) of the U.S. Department of Health and Human Services, and in association with the Public Health Foundation (PHF), the Center for Health Program Development and Management at the University of Maryland, Baltimore County (UMBC) is pleased to present "A Primer on Collaborating with Medicaid Agencies and Using Medicaid Data in Efforts to Eliminate Racial and Ethnic Disparities in Health" (the "Primer"). This document is designed as a primer for those who are involved in state efforts to eliminate racial and ethnic disparities in health and who are working with, or could benefit from working with, the Medicaid program and Medicaid data.

There is a growing recognition of the importance of the Medicaid program in planning and implementing initiatives to eliminate disparities in health care and health status. Nationally, the Medicaid program is a health services purchaser for millions of individuals who are economically disadvantaged, institutionalized, or disabled. Racial and ethnic minorities constitute over half of the Medicaid non-elderly population. Success in addressing disparities in health is a significant gauge of the efficacy of the Medicaid program itself. The "Primer" examines some of the key issues and resources associated with Medicaid data and collaborating with Medicaid agencies to eliminate health disparities.

The "Primer" identifies and addresses key Medicaid program data issues that impair or assist states in their efforts to eliminate health disparities. Following discussion of these issues are a series of actions that can be taken and resources that can be used to more effectively utilize Medicaid data to help eliminate health disparities. This document draws on selected literature, a 2001 survey of nine Medicaid and public health agencies, and a series of teleconferences. The teleconferences included Medicaid, public health, and minority health representatives from Massachusetts, Florida, South Carolina, and Maryland and representatives from OMH, PHF, and UMBC (see roster at the end of this document). Also participating in some of the teleconferences were representatives from the Centers for Medicare and Medicaid Services and the Health Resources and Services Administration. The teleconference format was established as a substitute for a four-state workshop scheduled for Washington, D.C., which was cancelled due to the September 11, 2001, tragedy.

In a report published three years ago by PHF titled *Examining Data Sharing Among State Governmental Health Agencies*, the following was noted:

> By linking and sharing data, governmental agencies are able to move beyond historical ways of looking at discrete programs and develop an understanding of how each agency plays an important role in improving and assuring the public's health.

We believe this especially holds true for planning and implementing initiatives focusing on health disparities. The intent of the "Primer" is to contribute to new ways of looking at Medicaid and its important role in eliminating racial and ethnic disparities in health.

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Acronyms

AHCA	Agency for Health Care Administration
AVSS	Automated Vital Statistics System
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CHIP	Children's Health Insurance Program
CLAS	Culturally and Linguistically Appropriate Services
CMS	Centers for Medicare and Medicaid Services
CY	Calendar year
DHEC	Department of Health and Environmental Control
DHMH	Department of Health and Mental Hygiene
DHS	Department of Health Services
DMI	Disease Management Initiative
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
FFS	Fee-for-service
HBCUs	Historically Black Colleges and Universities
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
IT	Information Technology
LEP	Limited English Proficiency
MCO	Managed Care Organization
MDPH	Massachusetts Department of Public Health
MMIS	Medicaid Management Information System
MSIS	Medicaid Statistical Information System
NIH	National Institutes of Health
OMB	Office of Management and Budget
OMH	Office of Minority Health
PHF	Public Health Foundation
SCHIP	State Children's Health Insurance Program
SEER	National Cancer Institute's Surveillance, Epidemiology, and End Results Program
SSI	Supplemental Security Income
UMBC	University of Maryland, Baltimore County
USF	University of South Florida
WIC	Women, Infants and Children

Introduction

Health disparities have been defined as the differences in the incidence, prevalence, mortality, and burden of diseases and other health conditions that exist among specific population groups in the United States (National Institutes of Health [NIH]). Although racial and ethnic groups have experienced substantial improvements in social and economic well-being in the past 50 years, disparities in health between groups persist and, in some cases, have widened (Department of Health and Human Services [HHS] Data Council, 1999).

The federal government's first concerted effort to raise awareness of disparities in health surfaced in 1985 with the issuance of a report from an HHS task force on black and minority health (Mayberry, Mili, & Ofili, 2000). Since that time, the elimination of disparities in health has emerged as a national goal (e.g., *Healthy People 2010)* and a key public health policy issue. Significant and comprehensive federal planning and standards developed for improved data collection and use have been undertaken through the Data Council Working Groups of HHS, the National Committee on Vital and Health Statistics, Centers for Medicare and Medicaid Services (CMS), and Office of Minority Health (OMH). While acknowledging progress to date, a recent report prepared for the Commonwealth Fund concluded that current federal practice does not fully reflect the legal foundation and numerous federal policies supportive of collecting and reporting racial, ethnic, and primary language data. As a result, collection and reporting efforts are often burdened with difficulties under one of the following categories:

- Inconsistent or conflicting policy messages
- Fear of potential misuse or misinterpretation of data
- Lack of enforcement
- Lack of uniform standards for data collection
- Lack of a centralized authority governing data collection
- Technical difficulties with data collection and maintenance

These issues were largely affirmed through a review of selected literature and consultations with state representatives conducted in the preparation of this document, otherwise referred to as the "Primer."

These and other challenges have not impeded the interest and activities of state government. There is considerable participation and data analysis in the development of state 2010 health objectives relating to health disparities and other statewide health issues. However, Medicaid involvement in this planning is episodic and limited (Giordano, Bechamps, & Barry, 1998). The extent to which state (and federal) efforts are successful in eliminating racial and ethnic disparities is, in large part, dependent on the availability of high quality data (accurate, comparable, timely, and complete data). Advances in database

management and technology provide an opportunity for state health and human service agencies to share information from multiple and discrete sources. In considering state Medicaid agencies' participation with state public health agencies, it is clear that these advances do not automatically generate collaborative efforts, guarantee productive data sharing, or universally ensure the quality of data collected and reported. Efforts to address racial and ethnic disparities in health confront the challenges of collaboration and data collection and sharing among a variety of public and private agencies, and insurance and provider systems. The "Primer" focuses on the particular challenges of the Medicaid program and use of Medicaid data in state efforts to eliminate racial and ethnic disparities in health.

An underlying objective of the "Primer" is to increase interests in building collaborations between Medicaid agencies and public health agencies in efforts to eliminate racial and ethnic disparities in health. To this end, examples of efforts made by both the Medicaid and public health agencies are provided.

Section I of the "Primer" provides a brief overview of the Medicaid program and Medicaid data and a broad platform for collaborative efforts.

Section II identifies key issues to consider when collaborating with Medicaid agencies and using Medicaid data. These considerations represent either a particular challenge presented by Medicaid or an important prerequisite for understanding how to work with Medicaid data. Each issue is briefly defined and analyzed. Actions and resources to improve Medicaid data collection, quality, and use are explored.

Section III highlights some of the specific state experiences using Medicaid data to:

- Analyze racial and ethnic health disparities in Medicaid service use
- Generate targeted initiatives to improve health status and reduce disparities
- Broaden state data linkage efforts

References with selected annotations and a section on further readings are provided at the end of this document to guide the reader through seminal studies and reports used as references for the four teleconferences and the preparation of the "Primer."

The "Primer" is intended to expand the understanding of the issues and challenges associated with the involvement of the Medicaid program in eliminating racial and ethnic disparities in health, and to expand the awareness of the potential benefits of using Medicaid data to achieve this goal. Comments, contributions, and critiques are welcome and can be offered at <http://cgi.umbc.edu/~chpdm/healthdisparities/index.html> or <http://listen.to/healthdisparities/>.

Section I:

The Importance of the Medicaid Program and Medicaid Data in Addressing Disparities in Health

A. The Medicaid Program

The Medicaid program, established in 1965 as Title XIX of the Social Security Act, currently provides health and long-term care coverage to 44 million Americans, including low-income families, the aged, blind, and disabled. Approximately half of Medicaid beneficiaries are children, and the State Children's Health Insurance Program (SCHIP) has extended coverage to an additional two million children since its enactment in 1997. Racial and ethnic minorities constitute approximately 50 percent of Medicaid's nonelderly beneficiaries (The Kaiser Commission, 2000).

Medicaid is a means-tested entitlement program and is jointly funded by the federal and state governments. It is the largest purchaser of health services for low-income families. Since Medicaid is a state-administered program, covered services can vary considerably from state to state. All states provide core services (e.g., pharmacy) required by the federal government, but each state establishes its own coverage limitations (e.g., number of prescriptions per individual). States can also provide certain "optional" services under the Medicaid program.

In the past several years, state Medicaid agencies have widely embraced "managed care" as a means of purchasing and providing health services to its beneficiaries. Almost half of Medicaid beneficiaries are currently under managed care systems, and all states except Alaska and Wyoming have adopted some form of managed care for at least some of their Medicaid beneficiaries (The Kaiser Commission, 2001).

B. Medicaid Data

State Medicaid agencies collect and maintain data from a variety of sources and through a variety of data collection and reporting mechanisms, including claims and payment data, beneficiary satisfaction and complaint data, clinical data from medical record reviews, service authorization data, provider related data, and beneficiary eligibility data (usually including race and ethnicity information).

With the advent of managed care, Medicaid also collects service utilization data furnished by managed care organizations (MCOs). These data are used in a variety of ways to properly monitor program performance and calibrate payments to contracted providers. Managed care reporting in the form of "encounter" data incorporates many of the data elements of standard claim/billing forms, like the CMS-1500 (formerly HCFA-1500) outpatient billing form. The poor quality of

encounter data received from MCOs and the inability of state Medicaid agencies to process and analyze these encounter data have been key factors in the limited ability of states to adequately monitor the experience of Medicaid managed care enrollees (National Committee, 1999).

C. Disparities in Health Status and Service Use

The health disparities that exist between minorities and whites in the United States have been well established through numerous studies since the publication of the *Report of the Secretary's Task Force on Black and Minority Health* in 1985. The causes of disparities in health status have not been easy to determine, but have been consistently attributed to many variables, including the following:

- Socioeconomic status (income, education, and employment)
- Lifestyle choices and behavioral risks
- Occupational and environmental hazards
- Poor nutrition
- Cultural beliefs regarding health and illness
- Biological or genetic predisposition

The disparities in minority/racial and ethnic groups compared to white service use have also been studied extensively (Williams & Rucker, 2000; Mayberry, et al., 2000). Disparities in service use have been attributed to many of the above causes.

D. Medicaid Collaboration Opportunities

State Medicaid data provide an opportunity for the following:

- The identification of disparities in both health status and service use
- An examination of the causes or factors contributing to the disparities
- The development and implementation of intervention programs through Medicaid's role as service purchaser

Medicaid claims and encounter data, as well as broader aggregate utilization data, have been a significant resource in identifying disparities in service use (see Maryland case example, Section III A of this document). The detailed demographic and diagnostic information captured in Medicaid enrollment data and claims and encounter data provides an opportunity to control for various geographical, socioeconomic, and morbidity factors in examining the causes of health disparities among the enrollee populations. Finally, with the emergence of managed care contracting, state Medicaid agencies are honing their

management and data analysis skills to reflect their increased responsibility as purchasers of services in addition to their historical role as payers.

Although the opportunities associated with using Medicaid data are plentiful, collaborative efforts in the use and sharing of those data are challenging. The following section describes some of these challenges and identifies resources and case examples where available.

Section II:

Key Issues and Resources in Developing Collaborative Efforts with Medicaid Agencies and Using Medicaid Data

A. Collecting Medicaid Data

The collection of Medicaid data in efforts to eliminate racial and ethnic disparities in health involves collecting race and ethnicity data, subpopulation data, and primary language data. The Office of Management and Budget (OMB) Directive 15[1] (as revised) specifies and standardizes the racial and ethnic categories that should be used in data collection by federal agencies (OMB, 1997). This suggests that states should use these standards for reporting their data to the Centers for Medicare and Medicaid Services (CMS). However, state Medicaid agencies do not uniformly adhere to these standards. In addition to OBM defined racial and ethnicity information, subpopulation and primary language data are often collected by state Medicaid agencies. Key issues, actions, and resources are highlighted below as they relate to collecting Medicaid data to eliminate racial and ethnic disparities in health.

1. Race and Ethnicity Data

Issues:

> - The need to transition to self-reported from observer determined/assisted data
> - Inconsistent and deficient data collection and categories (language and ethnicity)
> - Data collection agents external to Medicaid

Data collection methods greatly determine the quality and utility of racial and ethnic data used in the Medicaid program. These data are generally collected during the Medicaid eligibility and enrollment process, a process often administered by non-Medicaid agencies. For example, Medicaid eligibility determinations are frequently performed by the state or local agency responsible for determining eligibility for public assistance (e.g., state Departments of Human Resources, local Departments of Social Services, etc.). Similarly, the federal Social Security Administration makes determinations on applications for SSI (Supplemental Security Income) benefits based on disability; which indirectly determines Medicaid eligibility based on the applicant's "SSI-disabled" status.

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[1] The revised standards have five minimum categories for data on race: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. There will be two categories for data on ethnicity: "Hispanic or Latino" and "Not Hispanic or Latino."

In the 2001 survey conducted by the Public Health Foundation (PHF) to determine what selected states are doing to eliminate disparities in health, Medicaid agencies were asked how data related to race or ethnicity were collected. The survey results showed the following:

- Six of the eight Medicaid agencies ask Medicaid applicants to verbally report their own or their children's race or ethnicity to an intake specialist
- Three of the eight Medicaid agencies ask potential enrollees to complete a questionnaire regarding their race or ethnicity
- In three states, an intake specialist assists in the determination of the applicant's race and ethnicity (PHF, 2001)

The consensus among experts is that self-reported data are preferred, and the use of third parties to determine race, ethnicity, or primary language is less reliable and leads to inconsistencies (Perot & Youdelman, 2001). However, self-reporting procedures generate new challenges, such as missing data. According to California's Medicaid representatives, for example, the mailing of enrollment applications has led to an increase in the percentage of missing racial or ethnic data (PHF, 2001).

There are no standardized data elements used by all states for racial, ethnic, language, or country of origin information. CMS does not uniformly stipulate these data elements in the state reporting system. The absence of common data elements makes it difficult to link and share data between Medicaid and public health agencies and to conduct multi-state Medicaid analysis. Results of the PHF 2001 survey reflect varied levels of racial and ethnic data collection, ranging from detailed subpopulation elements (e.g., in Massachusetts) to standard general racial categories.

Actions and Resources for Improving the Collection of Medicaid Race and Ethnicity Data:

The HHS Inclusion Policy for Improving Race and Ethnicity Data (1997) requires the collection and reporting of racial and ethnic groups in all HHS data collection activities. The Inclusion Policy clearly states that the minimum standard categories of racial and ethnic groups specified in the OMB Directive 15 and future revisions thereof should be collected and reported in all HHS data systems except those exempted by this policy (HHS Data Council, 1999).

The revised OMB Directive 15 specifies and standardizes the categories that should be used in data collection by federal agencies. CMS uses these categories in the collection of Medicaid data from states (see Section II, B, 2). Uniform implementation of these standards by the 2003 target date will address some of the current Medicaid data collection issues. The revised OMB classification standards do the following: introduce the reporting of more than one race for multiracial persons; separate the Asian or Pacific Islander category into

two categories-one labeled Asian and the other Native Hawaiian or Other Pacific Islander; change the term Hispanic to Hispanic or Latino; change the term black to black or African American; strongly encourage that self-identification be used; and maintain the two-question format for race and Hispanic ethnicity when self-identification is used, specifying that the Hispanic origin question should precede the race question (OMB, 1997). Uniform implementation of these standards is expected to alter the counts of racial and ethnic populations derived from the various federal data collection systems, as well as from those non-federal systems that implement them (HHS Data Council, 1999).

Additionally, OMB has issued draft guidelines for tabulating multiple race responses for use by federal agencies. The guidelines address complications involving historical and trend analysis, population denominators, bridging between the old and new standards, and summary data categories. In addition to the data considerations surrounding the new standards, there will be social implications, as individuals now have the option of choosing more than one race (HHS Data Council, 1999).

An example of a state public health agency using multiple race responses is the California Department of Health Services (DHS). On January 1, 2000, the California DHS revised the collection of race and ethnic data by incorporating changes contained in OMB Directive 15. In accordance with DHS policy, the California Office of Vital Records changed the Certificate of Live Birth to allow the selection of up to three multiple races for an individual. The Automated Vital Statistics System (AVSS), an electronic birth registration system, was therefore modified to allow the collection, storage, and reporting of multiple race data. Because AVSS is an online system with race textual strings automatically coded into numeric values, it is possible to produce tabulations with a minimal delay (within weeks of the birth). Further, since California was one of the few states to implement the new OMB directive in 2000, there is a keen interest in the preliminary results of broadened race reporting. Additional information concerning AVSS and multiple race reporting can be found at <http://www.avss.ucsb.edu/ovr/race2kb.htm>.

Wherever possible, racial and ethnic data regarding populations served by HHS-funded programs (including Medicaid) should either be collected and reported at the providing organizational level and program beneficiary level or be available at that level through use of existing data systems (e.g., matching of enrollment and claims data) so as to be useful in assessing compliance with Title VI of the Civil Rights Act of 1964.[2] Such information would be collected either directly from such entities or through use and/or matching of existing administrative data sets,

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[2] Title VI of the Civil Rights Act of 1964, which prohibits intentional discrimination on the basis of race or national origin in the provision of any services that are supported with federal funds, is considered the broadest mandate the federal government has to require collection and/or reporting of data on race, ethnicity, and primary language. Title VI provides a legal foundation for the collection of racial and ethnic data from recipients of federal assistance (Perot & Youdelman, 2001).

including upgrading of such data sets as appropriate to contain information consistent with Directive 15 reporting categories (HHS Data Council, 1999).

In addition to the revised OMB standards, CMS has proposed regulatory requirements at 42 CFR §438.406, 66 Fed. Reg. 43614, 43672 (August 20, 2001) for state Medicaid agencies to collect and transmit to MCOs racial, ethnic, and primary language information at the time of enrollment. The requirement for reporting racial and ethnic data to MCOs should not present major burdens for Medicaid agencies. The reporting of primary language data, however, may present new challenges to Medicaid agencies that do not routinely collect these data.

2. Racial and Ethnic Subpopulation Data

Issues:

- Lack of racial and ethnic subpopulation data collected by states
- Lack of federal and state classification standards for subpopulations
- Diverse categories and instruments for collecting subpopulation data within states

Racial and ethnic data collection has progressed significantly beyond the "White/Black/Other" categories once used (Williams & Rucker, 2000). However, uneven collection of data regarding subpopulations (e.g., Mexican American, Puerto Rican, Cuban, and Haitian) continues to hinder the analysis of health disparities. It is clear that the larger racial and ethnic groupings can mask significant health disparities among specific racial and ethnic subgroups (HHS Data Council, 1999). Diagnostic, treatment, and preventive service resources could be appropriately targeted by Medicaid and state public health agencies if subpopulation information were available. Additionally, there are inconsistencies in data elements relating to subpopulations.

Actions and Resources for Improving the Collection of Racial and Ethnic Subpopulation Data:

HHS recognizes the diversity of the populations within each of the minimum standard OMB Directive 15 racial and ethnic categories and encourages the inclusion of subgroups when such inclusion improves the usefulness of the data (HHS Data Council, 1999).

The OMB Directive 15 specifies a minimum level for presenting data by race and ethnicity. The Directive also encourages the presentation of data for racial and ethnic subgroups when and where possible, as long as the results can be collapsed back into the minimum categories. Where data currently exist for key subgroups, publication should be encouraged and, if possible, made available as

public use data sets. For example, data for racial and ethnic subgroups for the six HHS health disparities focus areas are contained on the Race and Health website (<http://raceandhealth.hhs.gov/>), and cancer incidence and mortality rates from the National Cancer Institute's Surveillance, Epidemiology, and End Results Program (SEER) (<http://seer.cancer.gov/>) have been published for both the OMB standard/minimum groups and for racial and ethnic subgroups.

See Section III C, discussion of Massachusetts' subpopulation initiatives.

3. Primary Language and Other Data

Issues:

- Lack of sociocultural data collected by states
- Inconsistent sociocultural and socioeconomic data elements used among programs
- No consistent federal requirements for reporting primary language data

Sociocultural data elements, such as primary language, foreign birthplace, U.S. citizenship, year entered U.S., and years of formal education, expand the range of relevant data collected. Sociocultural data elements assist in the understanding of underlying causes of disparities in health. Socioeconomic data can be used to determine the magnitude of the impact that poverty has on health disparities. However, socioeconomic status should be used independent of race and ethnicity since there are differences in rates of poverty among minority populations (Zambrana & Carter-Pokras, 2001).

The PHF 2001 survey indicated that most of the responding eight Medicaid agencies collect information on beneficiaries' first or preferred language. Texas requires health maintenance organizations to collect primary language data for outreach. However, such data are not required for the Medicaid eligibility database, and the Medicaid Management Information System (MMIS) in Texas does not contain such a field. The PHF survey also indicated that the following sociocultural and primary language data elements are collected by the responding Medicaid agencies at time of enrollment:

- Two states collect data on beneficiaries' educational attainment
- Two states collect data on foreign birthplace
- Five states collect information regarding date of entry into the U.S.
- Two states collect data on first language spoken at time of enrollment
- Five of the eight Medicaid agencies collected data on preferred language at time of enrollment

Under the Balanced Budget Act of 1997, CMS published in January 2001 two packages of regulations governing Medicaid managed care and SCHIP, including the requirement to collect and report racial, ethnicity, and primary language data. State Medicaid managed care programs would have to report this information to the MCO of each enrollee, at the time of enrollment. SCHIP programs would have to report racial and ethnic information quarterly and primary language data annually, to CMS. However, the regulations were placed on hold for further review after the change in federal administration. In June 2001, an interim final rule was published by CMS (66 Fed. Reg. 33810) requiring states participating in SCHIP to provide quarterly reports on race and ethnicity but dropping the original requirement for annual reporting of primary language data. Regarding Medicaid managed care requirements, CMS has published new proposed regulations that included requirements for reporting racial, ethnic, and primary language data.

Currently, no federal statutes require collection and reporting of primary language data by Medicaid or public health agencies. However, data elements relevant to primary language (e.g., first language spoken or preferred language) assist in monitoring compliance with Title VI of the Civil Rights Act of 1964 and the identification of specific needs for language assistance (Perot & Youdelman, 2001).

Actions and Resources for Improving the Collection of Primary Language and Other Data:

HHS encourages the collection of data on variables other than race and ethnicity that may be useful in assessing and improving the health and well-being of minority populations and the provision of needed health and social services. Additionally, HHS (HHS Data Council, 1999) recommends encouraging analysts to use additional information collected in their data set on sociocultural items (such as socioeconomic status, behavioral risk factors, occupation, language proficiency, and birthplace) to assist in attempting to understand the factors underlying racial and ethnic disparities in health and health care access.

In recognition of the unique problems individuals with limited proficiency in the English language face when participating in federal programs, President Clinton issued Executive Order 13166, "Improving Access to Services for Persons with Limited English Proficiency," in 2000. Executive Order 13166 requires each federal agency to develop a plan for improving these individuals' access to and participation in its programs and activities. The executive order and subsequent guidance provided by the Department of Justice and HHS do not explicitly discuss data collection. However, to monitor compliance effectively, agencies can require recipients of federal funds (e.g., state Medicaid agencies) to collect primary language data under the same rationale of Title VI,[3] which provides for

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[3] The Title VI regulations do not specifically address collection of primary language data, but collection can be justified by the need to monitor compliance with the national origin nondiscrimination requirements.

the collection of racial and ethnic data. HHS guidance suggests, for example, that program staff enrolling clients or patients should record an individual's primary language in his or her record so that staff can identify specific needs for language assistance (Perot & Youdelman, 2001).

Some states, such as South Carolina, have implemented Limited English Proficiency (LEP) initiatives into their health agency's administrative protocol. The South Carolina Department of Health and Environmental Control (DHEC) Cultural Competence Action Plan provides guidelines for implementing cultural competence in the agency's strategic plan. The underlying premise of this initative is the application of cultural competence at all administrative levels: policy development, program planning and implementation, and service delivery. In addition to these measures, DHEC has established policies, guidelines, and standards to ensure linguistically appropriate services for LEP customers through LEP initiatives, and Hispanic Assistance and Bi-Lingual Access (H.A.B.L.A.) services for Spanish-speaking customers.

Although the HHS Office of Minority Health (OMH) does not independently oversee any data collection activities, it recently published standards for the provision of Culturally and Linguistically Appropriate Services (CLAS) for health care. The CLAS standards include a guideline stating that health care organizations should ensure that data on patients' race, ethnicity, and spoken/written language(s) are collected, integrated into the organization's management information systems, and updated periodically. The standards encourage self-identification by patients and suggest that the primary language of parents or caregivers of minor patients be noted. Although adoption of the standards is not required, CLAS standards have been incorporated in proposed purchasing specifications for Medicaid managed care and have been recommended for adoption by federal, state, and national accrediting agencies (Perot & Youdelman, 2001).

See Section III C, discussion of Massachusetts' primary language initiatives.

B. Quality of Medicaid Race and Ethnicity Data

Key considerations regarding Medicaid racial and ethnic data quality include missing data, reliability, validity, accessibility and confidentiality. The following issues and resources relate to the quality of Medicaid racial and ethnic data.

1. Data Quality

Issues:

- Level of incomplete or missing racial and ethnic data
- Establishing data validation measures

Data quality encompasses all methods used to assure that data are valid, comparable, timely, complete, and reliable. Data quality is, in part, determined by the data collection processes examined earlier.

In the PHF 2001 survey, state Medicaid agencies were asked about the percentage of missing race or ethnicity data in the most recent year. The problem of incomplete data ranged from high to low, as shown in the following examples:

- New York City had the highest rate (75 percent) of missing race or ethnicity data
- In Massachusetts, 29 percent of race or ethnicity data are missing
- California and Florida reported approximately 11 percent of race or ethnicity data missing

- Maryland, Missouri, and South Carolina, reported less than 4 percent missing data

Actions and Resources for Improving the Quality of Medicaid Racial and Ethnic Data:

In states where the completion of race or ethnicity information is not required to successfully complete the application process, there is likely to be a continuing problem with missing data (PHF, 2001). Medicaid agencies that have not expanded their data collection to include ethnicity will have difficulty comparing the race and ethnicity data with other data sources.

It is recognized that the leadership of the HHS should enforce the current collection and reporting of race, ethnicity, and primary language data by state Medicaid and SCHIP programs (Perot & Youdelman, 2001). It has also been recommended that CMS encourage state Medicaid agencies to collect uniform enrollment data relating to race, ethnicity, and language (National Committee, 1999).

One state (Massachusetts) indicated in the PHF 2001 survey that it collects race and ethnicity information throughout the health services delivery process: during intake, enrollment and treatment, and other points of contact in order to confirm the patient's self-identification information.

2. Data Accessibility and Use

Issues:

- State capacity to analyze Medicaid racial and ethnic data
- Timeliness of the MSIS data reports to the states

States are required to report Medicaid eligibility and claims information to CMS through the Medicaid Statistical Information System (MSIS). MSIS serves as a national data reporting system. MSIS does adhere to the OMB prescribed racial and ethnic data categories. The MSIS reporting extract does not limit state data collection to the MSIS categories. However, the teleconferences revealed that some states might not have established the crosswalks between the MSIS elements and the fuller set of eligibility and claims data available to the state. The four-state teleconferences revealed that some states discontinued or curtailed certain analytic activities/report generation, perhaps anticipating that the MSIS reports would provide such data. In addition, there have been delays in accessing the CMS quarterly and annual state-specific reported data. Annual data compilations for state use are currently available through 1999.

Based on interviews conducted during the process of developing its report, the Subcommittee on Population Specific Issues of the National Committee on Vital

and Health Statistics (1999) concluded that, regarding the service purchasing process for Medicaid, "states were experiencing difficulties with their information systems and struggling with the proper allocation of financial and staffing resources." Also revealed in the four-state teleconferences was the fact that participants saw allocation of Medicaid staff and resources as a major obstacle.

It was further revealed during the four-state teleconferences that there is a gap (real or perceived) between agency staff who are responsible for implementing data collection and reporting policies and staff who are responsible for the operations of information technology (IT) and management information systems (MIS). Teleconference participants suggested that in agency efforts to eliminate disparities, IT/MIS staff be included in discussions aimed at improving analytic activities/report generation.

Actions and Resources for Improving the Accessibility and Use of Medicaid Racial and Ethnic Data:

CMS suggested in the four-state teleconferences that states submit to CMS specific data requests relating to the racial and ethnic data submitted by their state. For state data request information, contact Robyn Thomas (CMS) at rthomas@cms.hhs.gov.

CMS has contracted with the Research Triangle Institute to conduct a multi-state analysis of Medicaid racial and ethnic disparities in perinatal care, which is scheduled for completion in December 2002. For more information on this analysis, contact Norma Gavin (Research Triangle Institute) at gavin@rti.org.

CMS has developed collaborations with Historically Black Colleges and Universities (HBCUs) to strengthen their analytic capabilities in efforts to eliminate racial and ethnic disparities in health. These collaborations are beneficial to Medicaid agencies that need analytical and research support. Examples of Medicaid agencies' collaborations with HBCUs include the following studies:

- "Medicaid Managed Care Quality and Costs Among Black and White Adults with Diabetes Mellitus," Morehouse School of Medicine, Atlanta, Georgia, Robert Mayberry, Investigator.
- "Prevalence of Key Health Risk Factors and Barriers to Health Care Seeking Among Medicaid and Medicare Eligible Living in Low-Income Housing Projects," Meharry Medical College, Nashville, Tennessee, Margaret Hargreaves, Investigator.

- "Reducing Hospitalization and Rehabilitation Medicaid Costs in African American Teens with Spinal Cord Injuries Who Survive Teen Violence," Southern University and A&M College, Baton Rouge, Louisiana, Betty Fomby, Investigator.

For additional information regarding CMS and Medicaid agencies' collaborations with HBCUs contact Richard Bragg (CMS), Senior Minority Health Services Research Coordinator, Office of Research, Development, and Information, at Rbragg@cms.hhs.gov.

When describing the difficulties that state agencies experience with their information systems, the National Committee on Vital and Health Statistics Subcommittee on Population Specific Issues (1999) reported that several states responding to their survey indicated that "strengthening collaborative efforts and joint analytic support with academic institutions and among state agencies may begin to address issues of technical assistance." The PHF 2001 survey report recommends that Medicaid agencies develop partnerships with academic centers to assist in analyzing Medicaid data and conducting research on health disparities. These partnerships can assume a variety of forms based on organizational structure, formality and quality of the relationship between the university and state government (Coburn, 1998). The following are three examples of data warehousing and data and policy analysis performed by academic centers through partnership arrangements with state Medicaid agencies:

- Muskie School of Public Service, University of Southern Maine – contact Maureen Booth, maureenb@usm.maine.edu
- Center for Health Program Development and Management, University of Maryland, Baltimore County – contact John Kaelin, Executive Director, jkaelin@chpdm.umbc.edu
- University of Southern Florida – contact Nancy Ross, Administrator, Florida Agency for Health Care Administration, rossn@fdhc.state.fl.us

See Section III B, discussion of Florida's collaboration with academic centers.

3. **Data Confidentiality**

Issues:

> - Perceived prohibition regarding Medicaid data sharing
> - Ambiguity of confidentiality laws and inconsistencies between federal and state laws and regulations

Data confidentiality is frequently cited as an obstacle to data sharing and collaborative efforts between Medicaid and public health entities. There is a

confusing array of state and federal statutes, regulations, and policy guidance surrounding the confidentiality of health data in general, and Medicaid data in particular. Section 1092 (a) (7) of the Social Security Act limits the use of individually identifiable Medicaid data to purposes directly connected to the administration of Medicaid.

In the PHF 2001 survey and the four-state teleconferences, several states reported that there is a perceived prohibition regarding data sharing. Legal counsel for the Medicaid agency typically refer to Section 1092 of the Social Security Act as the basis for this response. However, some states have created systematic, ongoing opportunities to share and link data. For instance, South Carolina has initiated data warehousing and integrated information systems (including Medicaid) at the state level to support the evolving role of state government in assuring appropriate, accessible, cost-effective care for vulnerable populations. Additional information concerning South Carolina's data warehouse and integrated information systems can be found at <http://ucdata.berkeley.edu/new_web/inventory/sc.pdf>. For many states, however, restricting data sharing to the agency that generated the data remains the prevailing operational guidance.

Actions and Resources for Improving the Confidentiality of Medicaid Race and Ethnicity Data:

CMS, in cooperation with the Health Resources and Services Administration (HRSA), and the Centers for Disease Control and Prevention (CDC), has created a model data sharing agreement to guide permissible sharing and dissemination of Medicaid data among state Medicaid and public health agencies. The agreement provides a generic framework that includes all federal confidentiality requirements and other restrictions on the use of information regarding Medicaid beneficiaries. The collaboration between these agencies augments efforts to eliminate racial and ethnic disparities in health by encouraging the development of integrated information systems at the state level. This integration will support the evolving role of state government in assuring appropriate, accessible, cost-effective care for vulnerable populations (Health Care Financing Administration, 1999; HRSA News Brief, 1999). The model agreement can be accessed at <http://www.hcfa.gov/medicaid/letters/smd10228.htm>. For more information contact Rachel Block, (CMS) Director, Data and Systems Group, Center for Medicaid and State Operations (Rblock@hcfa.gov); Mike Millman, (HRSA) Research Coordinator, Office of Research, Policy and Legislation (Mmillman@hrsa.gov); or Paul Stange, (CDC) Policy Advisor, Epidemiology Program Office (pvs0@cdc.gov).

For an example of a state data sharing agreement: the Missouri Department of Health and Senior Services (MDHSS) Memorandum of Agreement (See Section II C).

Greater awareness of and success with data warehousing efforts may reduce resistance to data sharing. However, implications of the implementation of the Health Insurance Portability Accountability Act of 1996 (HIPAA) may increase agency anxiety regarding data sharing.

**Recommendations Regarding
the Quality of Medicaid Race and Ethnicity Data**

- States should expand technical training for agencies collecting and reporting data to improve the completeness and reliability of racial and ethnic data.

- State Medicaid agencies could expand their analytical capacity by building and/or enhancing collaborative efforts with academic institutions.

- Representatives from information technology (IT) and management information systems (MIS) should be included in agency efforts to eliminate disparities and improve analytic activities/report generation.

- CMS should continue to improve timeliness of MSIS data availability and promote analysis of MSIS data to address race and ethnicity disparities in health.

C. Sharing and Using Medicaid Data

According to CMS, HRSA and CDC, (HRSA News Brief, 1999), the benefits, which can be derived from sharing data include:

- Encouraging the development of integrated information systems at the state level to support the evolving role of state government in assuring appropriate, accessible, cost-effective care for underserved or vulnerable people.
- Improving the technical capacity of states to analyze data from multiple sources to support policy decision-making and program monitoring.
- Promoting the development and implementation of common performance measures across multiple programs to improve effectiveness.
- Better use of Medicaid encounter data to assist in public health surveillance to ensure appropriate care for those enrolled in the Medicaid program.

Collaboration in sharing, linking and jointly analyzing data between Medicaid agencies and state public health and minority health agencies and programs poses many operational challenges. The following issues and resources address selected communication and data challenges.

1. Interagency Collaboration

Issues:

- Lack of formal communication mechanisms, such as Memorandum of Understanding (MOU) or data sharing agreements
- Lack of informal communication opportunities
- Lack of established disparity concerns in Medicaid program priorities
- Resource allocation for technical efforts required in data linkage initiatives

A major barrier to data sharing is the lack of a common understanding of why data sharing is important. Often Medicaid agencies and public health departments do not believe that there are overlapping missions across their agencies (Giordano et al., 1998). To the extent that this lack of recognition is prevalent, data sharing will face significant barriers.

Communication barriers have sometimes emerged between public health and Medicaid agencies due to a variety of organizational, political, and adversarial issues. These barriers significantly impact data sharing efforts and persist even when public health and Medicaid are housed in the same state agency (Rutherford & Backer, 1999). Despite the availability of the model data sharing agreement developed by CDC, CMS, and HRSA, few states have actually executed formal data sharing agreements. The State Healthy People 2010 Plans, to the extent that they incorporate specific health disparity objectives, provide an opportunity for enhanced Medicaid and public health communication. According to the PHF 2001 survey report, participation of Medicaid in State 2010 planning processes has been limited.

Funding and internal resource allocation also may interfere with an agency's capability and willingness to collaborate. The chronic shortage of well-trained and experienced technical and programming staff is a barrier to data sharing. States reported through the four-state teleconferences that operational pressures connected with the Medicaid program make it difficult to invest in broader public health initiatives unless an immediate benefit to the Medicaid program and its beneficiaries is clearly identified. Agency representatives have also identified the frustration of working with complex data systems with limited technical resources. A recent HRSA sixteen-state survey identified "technical/IT" issues as one of the major barriers to collaborative efforts (Auerbach, 2001).

Actions and Resources for Improving Interagency Collaboration:

The four-state teleconferences conducted in preparation for this document and a sixteen-state survey conducted by HRSA (Auerbach, 2001) facilitated an informal initial communication process among several state public health and Medicaid representatives, and revealed the extent of previous communication gaps.

The HRSA sixteen-state survey was itself an intervention in data sharing and linking since the process of completing the survey required that state public health and Medicaid agency staff work with each other and share information. Results of the survey indicated that 11 jurisdictions had successful data linkages between Medicaid and public health (Auerbach, 2001).

A report published by PHF (Giordano et al., 1998) noted that study respondents regarded informal relationships between staff in different agencies as the most important element and greatest aid to sharing data and information across agencies. Formal linkages between agencies to enable the sharing of data or to meet legal or other guidelines for data use, and high quality data were also commonly cited as essential facilitators to data sharing. According to study respondents, developing and maintaining informal relationships and ongoing communication with staff in other agencies is the key to overcoming global, agency-wide barriers to data sharing. Informal communication can help resolve problems around data sharing by increasing understanding of the questions asked about a particular data set and what information is needed to answer the question.

One example of successful interagency communication can be found in the Massachusetts Medicaid program (MassHealth), which shares its Medicaid data with the state's mental health and substance abuse agencies to allow these agencies to accurately assess the populations they serve. Other examples of interagency communications and data sharing include the California Health Information for Policy Project (CHIPP); Massachusetts Community Health Information Profile (MassCHIP); Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC); and South Carolina's Budget and Control Board Master File (Giordano et al., 1998). The website addresses that follow provide additional information about these examples. It is anticipated that Medicaid agencies will more actively begin to use other organizations' data sources to help them determine what the expanding Medicaid population will look like (Giordano et al., 1998).

- The California Health Information for Policy Project (CHIPP)
  <http://www2.umdnj.edu/ishppweb/californ.htm>
- Massachusetts Community Health Information Profile (MassCHIP)
  <http://masschip.state.ma.us/>
- Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC)
  <http://www.ibi.com/applications/missouri.html>
- South Carolina's Budget and Control Board Master File
  <http://ucdata.berkeley.edu/new_web/inventory/sc.pdf>

An example of a state data sharing agreement is the Missouri Department of Health and Senior Services (DHSS) Memorandum of Agreement (MOA). The purpose of the MOA is to identify each party's roles and responsibilities related to

participation in the DHSS MOHSAIC Integrated Information system. The MOA can be accessed at <http://www.health.state.mo.us/Access/moa0700.doc>.

The Iowa Medicaid program is an example of a state Medicaid agency involvement in the states' Healthy People 2010 process. Called *Healthy Iowans 2010*, the program contains Medicaid-specific goals and actions. *Healthy Iowans 2010* Medicaid-specific goals and actions are found in Chapter 11 on Maternal, Infant, and Child Health. California and Maryland are other examples of states that have Healthy People 2000/2010 plans with Medicaid-specific objectives. It was noted in the PHF 2001 survey report that the opportunities for Medicaid data monitoring will most likely occur between agencies when Medicaid-specific objectives and Medicaid data quality objectives are included in the Medicaid state plan and the state Healthy People plan. One strategy for developing and improving interagency communication is to have Medicaid and public health participate in each other's planning processes. Often times all it takes is for one agency to approach the other about participating in these activities. Consult the following websites for additional information.

- *California County Health Status Profiles 2001*
  <http://www.dhs.ca.gov/hisp/chs/phweek/cprofile2001/profile2001.htm>
- *Healthy Iowans 2010*
  <http://www.idph.state.ia.us/sa/h_ia2010/contents.htm>
- Maryland Health Improvement Plan: A Product of Healthy Maryland – Project 2010
  <http://www.mdpublichealth.org/ohp/html/hip.html>

Despite costs and resource availability challenges, some state Medicaid and public health agencies have collaborated successfully. An example of a public health agency using Medicaid data is Missouri, where vital statistics birth data are matched with Medicaid enrollment data to produce measures that match Health Plan Employer Data and Information Set (HEDIS) indicators. The health department applies these measures in assessing MCOs. Recently enacted state law also provides the Missouri Health Department the authority to produce a consumer guide on MCOs. Missouri State law requires all MCOs (Medicaid and commercial) to submit their enrollment data to the health department. Once this occurs, the state's Medicaid and commercial provider enrollment files will be linked with vital statistics, notifiable disease reports, and hospital discharge data for tracking morbidity and other health outcomes (PHF, 2001).

Federal agency interest and support exemplified through the development of model agreements and continuing examination and dialogue will advance collaborative efforts. It is unknown whether state budgetary pressures (especially in Medicaid) may undermine broader collaborative efforts.

2. Medicaid Managed Care and Encounter Data

Issues:

> - Persistent under-reporting of encounter data by MCOs
> - Absence of communication (by the state to the MCO) of racial and ethnic indicators for new and current eligibles
> - Absence of specific racial and ethnic measures for MCOs in state Medicaid purchasing strategies

Nationally, approximately half of Medicaid eligibles are enrolled in managed care programs (CMS, 2001). Because MCOs are paid a fixed capitation rate for a comprehensive set of benefits, the state Medicaid agency does not generally receive or pay individual claims for these Medicaid recipients enrolled in contracted MCOs. Claims data provide the state with the date and category of service, payment information, diagnosis and procedure codes, and specific provider information. In the absence of submitted fee-for-service claims, Medicaid agencies rely on and require contracted MCOs to report services provided for which they have generated payment through encounter data. Technical, payment, and resource factors contribute to the problem of insufficient encounter data reporting from Medicaid MCOs and their contracted service providers.

Proposed federal regulations (66 Fed Reg. 43614) require states to provide racial, ethnic and primary language information to MCOs for each Medicaid enrollee at the time of enrollment. The reporting of racial and ethnic data to MCOs should not present major burdens for Medicaid agencies. The reporting of primary language, however, may present new challenges to Medicaid agencies that do not routinely collect language information.

In addition, Medicaid MCOs are not usually required under standard state purchasing strategies to specify outreach, treatment, and outcome goals associated with racial and ethnic disparities.

Actions and Resources for Improving Medicaid Managed Care and Encounter Data:

States with improved encounter data reporting have relied either on incentives (e.g., using encounter data for future capitation rate-setting activities) or disincentives (e.g., financial sanctions for under-reporting). Maryland MCOs have an incentive for reporting encounter data since these data are used for future rate setting and rate adjustment. Maryland uses these encounter data to evaluate the performance of the managed care program in general and the services used by racial and ethnic groups in particular (see Section III A for more detail). Delaware and Arizona are among state Medicaid agencies that have

achieved some success in capturing Medicaid encounter data from MCOs through the use of incentives and disincentives. For more information about Delaware, contact Kay Holmes (kholmes@state.de.us). For more information about Arizona, contact Brent Ratterree (rbratterree@ahcccs.state.az.us).

There is widespread recognition that state collection and reporting of Medicaid managed care data needs significant improvement (National Committee, 1999). The development of value-based purchasing strategies and support systems by Medicaid agencies will continue to require expansion of data gathering and analysis capacity.

**Recommendations Regarding
Sharing and Using Medicaid Data**

- State Medicaid agencies should transmit race, ethnicity, and primary language data to MCOs.

- State Medicaid agencies should ensure that enrollment data are, at a minimum, linkable to encounter data, and that each state performs this linkage in a manner that is consistent with standards regarding the electronic transfer of data and with confidentiality and privacy practices and procedures (National Committee, 1999).

- State Medicaid agencies should consider incorporating objectives related to racial and ethnic health disparities in their purchasing strategies and agreements.

- State health and Medicaid agencies should collaborate to develop specific guidance or standards for the collection and use of subpopulation, sociocultural, and language data to ensure consistency and comparability among different systems.

- State agencies should consider using the CMS, HRSA, and CDC model data sharing agreement to develop agency data sharing agreements to guide the permissible sharing and dissemination of Medicaid data among state Medicaid and public health agencies.

- State Medicaid agencies should participate in state-level planning activities, such as Healthy People 2010 and state health improvement plans.

- Medicaid waiver applications, such as the 1115 waiver, should include goals or objectives related to the elimination of racial and ethnic disparities in health.

Section III:
State Examples of Medicaid Data Use and Sharing in Addressing Disparities in Health

A. Maryland Medicaid's Use of Encounter Data to Examine Disparities in Service Use

During calendar year (CY) 2001, the Medical Assistance Administration of the Maryland Department of Health and Mental Hygiene (DHMH) initiated a comprehensive evaluation of the HealthChoice Program, Maryland's Medicaid managed care program. The Public Health Division of DHMH was significantly involved in the development of the HealthChoice Program. HealthChoice was initiated in 1997 and currently serves individuals through six MCOs. A major component of the evaluation was the analysis of MCO encounter data and comparison with the pre-HealthChoice fee-for-service (FFS) claims data. Service use was analyzed by a variety of measures, including race. The following descriptions of the encounter data, the utilization measures, and the evaluation findings relating to service utilization by race are excerpted (and edited) from the HealthChoice Evaluation Report (Maryland DHMH, 2002).

Encounter Data

Encounter data offer an array of information, including diagnosis; type and number of ambulatory encounters; types of diagnostic tests and surgical and other therapeutic procedures performed; type of prescription filled; and duration and level of hospitalization. Linking encounter data to beneficiary files allows identification of the demographic characteristics of insured persons. MCO-reported encounter data, as contained in the state's MMIS, were used for the purposes of this evaluation. Although regulations require complete reporting, actual reporting is somewhat lower. Maryland estimated that CY 2000 encounter data used in the analysis were 90 to 95 percent complete. Use of the MMIS data, linked to beneficiary enrollment data, allows for direct examination of the utilization history of all individuals enrolled in the HealthChoice Program. The MMIS file system contains data on enrollee utilization and can be easily linked to beneficiary enrollment data containing a host of demographic information, including age, race, gender, and geographic location by region.

Utilization Measures

To compare service utilization before and after the implementation of HealthChoice, three standard measures were developed for use in the comparative studies. These measures are:

- *Ambulatory visits.* The definition used for an ambulatory visit is the most inclusive "visit" definition used in the evaluation. An ambulatory visit is defined as any time an enrollee had contact with a doctor (or a nurse practitioner) in an ambulatory setting. To address multiple services occurring during a single visit, ambulatory visits are reported as an unduplicated count that may not exceed one per day.

- *Well child visits.* A consideration of well child visits is important since many children are enrolled in HealthChoice. Well child visits are defined by one comprehensive measure, inclusive of well child visits, Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), and preventive services. This measure includes what the state uses to report EPSDT services for federal reports and includes clinic services in an outpatient department that are accompanied by an appropriate diagnosis code. Well child visits are a subset of all ambulatory visits.

- *Emergency room visits.* Emergency room visits that do not result in a hospital admission are counted as ambulatory visits.

Measurement Approaches

The standard measures identified above are examined in two ways, each of which yields different insights and conclusions:

- *Percent of eligible population receiving service.* This measure examines the percent of the population that had contact with a health care provider. As such, it serves as a measure of overall access to care and reveals the relative success HealthChoice has had in bringing people into care.

- *Visits per thousand member months (annualized).* This is a standard method for presenting units of service (e.g., physician visits). This measure supports an assessment of the level of *service* provided, as opposed to simply the access provided.

Findings

The HealthChoice Program encompasses a racially and ethnically diverse population. African Americans account for 58 percent of the HealthChoice population; Caucasians account for 31 percent; and Hispanics, Asians, and others account for the remaining 11 percent. The data show that, under both the previous FFS system and the HealthChoice Program, African Americans received the fewest visits and had the lowest percentage receiving service of all racial and ethnic categories studied. In CY 2000, 56.2 percent of African Americans received an ambulatory visit, compared to 64.8 percent of Caucasians and 60.3 percent of the population as a whole.

In CY 2000, 37 percent of African American and Caucasian children experienced a well child visit. In breaking this down by race, 737 African American children per thousand experienced a well child visit, compared to 832 Caucasian children per thousand.

While the gains observed for the HealthChoice population have occurred across all racial and ethnic groups, the disparities in access and utilization that existed prior to the HealthChoice Program persist. Although these disparities existed across coverage categories and regions, observed trends in access and utilization have indicated that these disparities are narrowing. In critical areas such as the percentage of the population receiving either an ambulatory or a well child visit, the improvement for African Americans has outpaced the improvement for Caucasians.

For more information regarding the HealthChoice Evaluation Report, contact Alice Burton (Department of Health and Mental Hygiene) at burton@dhmh.state.md.us.

For information regarding encounter data analysis of racial utilization contained in the evaluation, contact John O'Brien (University of Maryland, Baltimore County) at jobrien@umbc.edu.

B. Florida's Use of Medicaid Data to Enhance Outreach and Treatment Efforts

The Agency for Health Care Administration (AHCA) administers the Medicaid program in Florida. The AHCA provides examples of how the Medicaid program integrates its data with the Florida Department of Health, community-based organizations, and academic institutions to evaluate and improve birth and disease outcomes.

Disease Management Initiative (DMI)

The AHCA, through the Medicaid program, administers a disease management initiative (DMI) that provides ambulatory care services to diabetic patients and conducts cost-effectiveness analysis for health care services provided to Medicaid recipients with HIV/AIDS, diabetes, or Hemophilia. Race, ethnicity, and primary language data are linked with public health data as part of the evaluation of these health services.

In addition to the DMI, AHCA is collaborating with the University of South Florida (USF) to examine Medicaid claims data in efforts to identify Medicaid recipients with Sickle Cell Anemia.

Healthy Start Coalition

The Medicaid program, in collaboration with the Florida Department of Health's Healthy Start Program, provides data to 31 local Healthy Start Coalitions to be used as part of the Coalition's formal planning process. These data consist of information about Medicaid eligibility and race and ethnicity that is linked with the Florida Department of Health vital statistics, Healthy Start assessment scores for women and infants, and Women, Infants and Children Nutritional Supplement Program (WIC) data. These data allow local coalitions to develop services and target services to those most at risk for poor pregnancy outcomes.

Birth Outcomes Study

In 2000, AHCA supported a study titled "Impact of Medicaid Managed Care on Birth Outcomes." A data committee consisting of maternal and child health experts selected birth outcomes used in the study. The committee comprised representatives from AHCA, the Department of Health, Florida State University, USF, and University of Florida. Birth outcomes analyzed included neonatal mortality; infant mortality; low birth weight; very low birth weight; and Part C participation (an early intervention program for children with disabilities from birth up to age three).

In addition to birth outcomes, the study analyzed sociodemographic and health related factors: infant's sex, maternal education, adequacy of prenatal care (Kotelchuck score), maternal age, mother's race, marital status, previous pregnancy experience, Florida's Healthy Start Prenatal Screen Score, and WIC participation.

The analysis used a birth record data set for 1996, created by the data managers at the Lawton and Rhea Chiles Center for Healthy Mothers and Babies at USF. This data set was compiled from four data sources: Medicaid eligibility files supplied by AHCA; the liveborn birth file for 1996 births and merged with death files from 1996 and 1997 supplied by Vital Statistics; WIC certification files supplied by the Florida WIC office; and the Florida Healthy Start prenatal screen data file supplied by the state of Florida Department of Health.

A total of 178,685 birth records were included in the USF data set. The USF data set was merged twice. The first merge was with the Early Intervention Program (EIP) data file to obtain Part C participation information. A second merge with 1996 Birth Vital Statistics was to obtain the mother's education level and previous pregnancy experience information.

For more information regarding the Florida AHCA and the Medicaid program, contact Nancy Ross (AHCA) at rossn@fdhc.state.fl.us.

C. Massachusetts' Use of Primary Language and Subpopulation Identifiers as a Planning, Outreach, and Care Enhancement Tool

The Division of Medical Assistance is the Commonwealth's single agency that administers Medicaid (Title XIX) and the Children's Health Insurance Program (CHIP) (Title XXI). In Massachusetts, Medicaid and CHIP are combined into one program called MassHealth.

Primary Language Identifiers

In response to the Commonwealth's diverse and multi-lingual population, as well as federal guidelines that address collection, reporting, and use of race, ethnicity, and primary language data (e.g., Title VI, OMB Directive 15, and CLAS), the Division of Medical Assistance instituted initiatives for the collection of primary language data. MassHealth incorporates a *Primary Language Declaration Form* that allows applicants to self-identify their primary language, request interpreter services in their language if needed, and request a MassHealth booklet in their primary language. Users of the *Primary Language Declaration Form* can select their appropriate language from among nine categories to request MassHealth Enrollment Center forms and assistance.

MassHealth eligibility and enrollment forms provide an alternative to traditional race and ethnicity categories by making race and ethnicity optional and requiring applicants to respond to primary language identifiers. These primary language identifiers include preferred spoken language and preferred written language. Using primary language identifiers allows MassHealth to identify the diversity of languages spoken by Medicaid applicants and beneficiaries, address specific language assistance needs, and expand racial and ethnic categories by developing subpopulation identifiers supported by language identifiers.

Although reporting race and ethnicity information is optional on MassHealth eligibility and enrollment forms, MassHealth has the opportunity to collect race and ethnicity data at intake, enrollment, and treatment. Under this system, Medicaid beneficiaries can verify their race, ethnicity, and primary language information at various points of service delivery.

Massachusetts Department of Public Health

The Massachusetts Department of Public Health (MDPH) has several initiatives concerning the collection and reporting of racial and ethnic data and subpopulation identifiers. These initiatives provide an example of public health efforts to eliminate racial and ethnic disparities in health. In some cases, these initiatives either directly or indirectly impact MassHealth.

Survey of MDPH Client-Based Databases

In 1997, the MDPH Bureau of Health Statistics, Research and Evaluation, Division of Research and Epidemiology developed an overview of minority health data at MDPH. The Information Technology Steering Committee engaged a consulting firm to survey MDPH client-based databases to ascertain information about core variables on data sets. Practical concerns about race and ethnicity data collection included the following:

- Distinction between race and ethnicity was unclear
- Existing racial categories were too broad for meaningful analysis
- Existing categories varied too much among data collection systems
- Concepts change over time
- Source and mode of data collection affect completeness and quality of data

Additionally, limitations in data collection source and modality affect accuracy, completeness, and interpretation. There are also limitations in data collection category requirements. For example, different agency/funding requirements reduce comparability of categories, and differences in coding schemes reduce comparability.

The survey of MDPH client-based databases identified 64 data sets with usable information in three types of databases:

- General population, disease, or event surveillance population based data systems that collect information on persons regardless of health status (e.g., BRFSS, births, and deaths)
- Specific disease or event surveillance systems that collect information on persons with specific diagnosis or events (e.g., AIDS surveillance)
- Programs to collect information on clients to whom services are provided (e.g., WIC)

A summary of race and ethnicity data indicated that 69 percent (44 out of 64) of the MDPH client-based databases had a variable for race; 44 percent (28 out of 64) had a variable for ethnicity; and 70 percent (45 out of 64) had a variable either for race or for ethnicity. Eight percent (5 out of 64) had a variable for multi- or bi-racial.

A summary of Hispanic data indicated that 66 percent (42 out of 64) of the databases had a Hispanic identifier; 93 percent (42 out of 45) of the databases with race information had a Hispanic identifier; and 27 percent (17 out of 64) of the databases had Hispanic subgroups. Of the databases with a Hispanic identifier, 36 percent included race; 26 percent included ethnicity; and 36 percent included both race and ethnicity.

A summary of Asian data indicated that 70 percent (45 out of 64) of the databases had an Asian identifier, and 30 percent (19 out of 64) of the databases had Asian subgroups.

Overall, program databases had the most race and ethnicity data; surveillance databases had the least ethnicity detail; and little information is collected for multi or bi-racial categories in any of the three types of databases.

The final report of the survey discusses information concerning minority health status (black, Hispanic, and Asian rates compared to white rates) with a description of health and disease risk factors for each of the minority racial and ethnic groups categorized as "doing well" or "not doing well." Gaps and issues relating to data and quality, as well as potential next steps, are discussed in the final report. A final element of the survey was a table ("Summary of the Availability of Race and Ethnicity Data from the Massachusetts Department of Public Health Client Database") that listed core variables on data sets for each of the 64 databases. Some of the databases included Medicaid data collected by MDPH.

MDPH Initiative on Racial and Ethnic Minority Health Surveillance

In January 2001, the MDPH Bureau of Health Statistics, Research and Evaluation, Division of Research and Epidemiology distributed an updated listing of statistical and surveillance reports and activities relevant to racial and ethnic minority groups. Some of the reports emphasize the collection of subgroup data. Selected reports and activities include the following:

- Expansion of detailed ethnicity categories in the Advance Data Birth annual surveillance publication (on-going since March 1999)
- Perinatal report focusing on subgroups of Asians (Asian Births in Massachusetts, released May 2001)
- Perinatal report focusing on subgroups of Hispanics (Hispanic Births in Massachusetts, released Summer 2001)
- Perinatal report focusing on subgroups of Blacks (scheduled for release December 2002)
- BRFSS data for racial subgroups by aggregating multiple years of data (on-going)

Massachusetts Community Health Information Profile (MassCHIP)

In January 2001, a new series of five reports on minority health in Massachusetts was made available in MassCHIP, the MDPH electronic on-line data warehouse. These reports provide a variety of demographic and health information about Massachusetts' residents grouped by race and Hispanic ethnicity.

The five reports are divided into the following topics:

- Population and Demographics
- Births and Perinatal Health
- Health Risk Factors
- Health Care Access and Screening
- Mortality

Data sources used for the reports include Massachusetts Vital Records (births and deaths); U.S. Census; MISER (Massachusetts Institute for Social and Economic Research); and the Massachusetts Behavioral Risk Factor Survey. Each of the five reports provides the most recent three-year aggregate of data available.

For more information about MassHealth, primary language identifiers, and collection and reporting of racial and ethnic data identifiers, contact Iris Garcia-Caban (Division of Medical Assistance) at Igarcia@nt.dma.state.ma.us.

For information regarding the MDPH and initiatives regarding Survey of MDPH Client-Based Databases, Racial and Ethnic Minority Health Surveillance, and the Massachusetts Community Health Information Profile (MassCHIP), contact Christine Judge (MDPH) at Christine.Judge@state.ma.us.

Section IV:

Conclusion

The topics considered in the "Primer" were drawn from the discussions and materials shared by several states. During September, October, and November of 2001, representatives of public health, minority health, and Medicaid from four states explored the challenges of working with one another and accessing and using data in efforts to eliminate racial and ethnic disparities in health. This process involved review of selected literature, teleconferences, and the collection and sharing of information gathered through multi-state surveys of Medicaid and public health agencies. The teleconferences were organized around the topics of data collection, data quality, data sharing, and model development. The following themes emerged from these discussions and survey findings:

Need for Improved Communication

There is little doubt that the "Primer" would differ significantly in tone and content if the participants were only Medicaid representatives or only public health or minority health leaders. It is often stated (and clearly evident) that even when Medicaid and Public Health are housed in the same agency or building, communication and collaboration do not automatically happen.

Need for Shared Vision

"Vision" provides the reason to communicate beyond one's organizational boundaries. Leadership and commitment to the issues are needed at all levels of government if collaborative efforts are to be expanded.

Need for Tools and Resources

Vision that chronically lacks resources and skills engenders cynicism rather than collaborative efforts. Analytic capacity in state agencies seems too often to be outstripped by demands and new data requirements.

Need for Defined Boundaries and Supports

Statutory and regulatory uncertainty, misunderstandings, and ambiguity have resulted in a certain paralysis and atrophy. Data sharing and linkage and developing subpopulation data collection systems, for example, are difficult challenges requiring the integration of informal relationships between individual staffs, formal linkages between agencies, high quality data, and an understanding of why specific data elements should be collected and shared (Giordano et al., 1998).

These needs (gleaned from the teleconferences) sometimes directly articulated but more often underpinning the deliberations of those involved, formed the basis for the actions, resources, and recommendations listed in Section II of this document.

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Department of Health and Human Services. (1997). "Policy on the Inclusion of Racial and Ethnic Categories in HHS Funded and Sponsored Data Collection and Reporting Systems." <http://aspe.hhs.gov/datacncl/inclusn.htm>.

Executive Order No. 13166, "Improving Access to Services for Persons with Limited English Proficiency" (August 11, 2000).

> Executive Order No. 13166 requires federal agencies to develop a system by which individuals with limited English proficiency can meaningfully access their services. However, this guidance does not require collection and reporting of primary language data. This is the first time that the mandates of Title VI have been extended to the federal agencies themselves.

Giordano, L., Bechamps, M., & Barry, M. (December 1998). "Examining Data Sharing Among State Governmental Health Agencies." Public Health Foundation. <http://www.phf.org/Reports/Data1/datashar.pdf>

> This report examines data use and sharing by state governmental health agencies (health departments, mental health, substance abuse, and Medicaid agencies) in six states (California, Massachusetts, Missouri, South Carolina, Utah, and Washington). The report documents these states' current status of data access, sharing, and use; potential effects of health systems changes on data sharing; examples of successfully acquiring and using data sets; and root problems with and missed opportunities for data access and sharing. The report also discusses facilitators of sharing data, barriers to data sharing, lessons learned, and policy recommendations. The report indicates that data sharing among state health governmental agencies is not occurring on a routine basis.

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