Report to Congress

Approaches for Identifying, Collecting, and

Evaluating Data on Health Care Disparities in Medicaid and CHIP

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EXECUTIVE SUMMARY

The Department of Health & Human Services (HHS) is committed to collecting data to better understand and direct efforts to reduce health and health care disparities. HHS' efforts have been tested under programs like Medicaid and the Children's Health Insurance Program (CHIP) that face unique challenges in collecting and reporting data on a number of program characteristics. As Medicaid and CHIP are State-Federal partnerships administered by States, State variation in reporting requirements and the lack of current Federal guidance that assure consistent and efficient approaches for identifying, collecting, and evaluating data on health care disparities makes monitoring indicators of performance on disparities a challenge.

Section 4302(a) of the Patient Protection and Affordable Care Act (Affordable Care Act) requires the Secretary of HHS to develop data-collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status, and calls for data for these categories to be consistently collected and reported in all national population health surveys that rely on self reporting.[1] Section 4302(b)(1) of the Affordable Care Act requires the collection of data on these five demographic characteristics in Medicaid and CHIP. This section also requires that the collection and reporting of these data in Medicaid and CHIP adhere to the data-collection standards developed under 4302(a). Additionally, Section 4302(b)(2) requires an evaluation of approaches for collecting data in Medicaid and CHIP that allow for the "ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance" on these five bases. Section 4302(b)(2) also requires the Secretary to report to Congress on the findings of the evaluation.

This report to Congress meets the requirement of Section 4302(b)(2) of the Affordable Care Act. The report includes information on the evaluation conducted, including the methodologies for identifying, collecting, and evaluating data on health care disparities on race, ethnicity, sex, primary language, and disability status; and provides "recommendations on the most effective strategies and approaches to reporting Health Effectiveness Data and Information Set (HEDIS) quality measures…and other nationally-recognized quality performance measures" on such bases in Medicaid and CHIP." The Secretary is required to report to Congress on this evaluation no later than September 23, 2011, and implement the approaches identified in this report by March 23, 2012.

In order to implement the approaches outlined in this report and satisfy the additional requirements of Section 4302 of the Affordable Care Act, HHS, in conjunction with the Centers for Medicare & Medicaid Services (CMS), will:
1. Update the Medicaid Statistical Information System (MSIS) to assure reporting of individual demographic information consistent with the standards developed under section 4302(a) of the Affordable Care Act;
2. Work closely with States to support a gradual transition to collecting and reporting into MSIS the new demographic information as part of a larger effort underway to implement provisions of the Affordable Care Act;
3. Revise the Medicare Current Beneficiary Survey to include 4302 standard demographic information;

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[1] References to "the Secretary" are to the Secretary of HHS.

4. Coordinate work between CMS and the Agency for Healthcare Research and Quality (AHRQ) to revise the Consumer Assessment of Healthcare Providers and Systems survey tools used with Medicaid, CHIP, and Medicare to incorporate the new standards for self-reported demographic information.

Future reports will include recommendations for improving the identification of health care disparities for Medicaid and CHIP enrollees.

I.   INTRODUCTION

Signed into law on March 23, 2010, the Patient Protection and Affordable Care Act (Affordable Care Act) includes multiple strategies to address health and health care disparities, including the expansion of insurance coverage and a focus on improving the quality of care and lowering health care costs. Section 4302 of the Affordable Care Act revises the Public Health Service Act and the Medicaid and CHIP statutes to call for specific attention to collecting, reporting, and analysis of data to better understand and help address health care disparities.

Section 4302(a) of the Affordable Care Act requires the Secretary of Health & Human Services (HHS) to develop data-collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status, and calls for data for these categories to be consistently collected and reported in all national population health surveys that rely on self reporting.[2] The law also gives the Secretary the authority to require that additional demographic data be collected on all Departmental surveys and to develop appropriate data collection standards. At the time of writing this report, the recommended data collection standards for the five demographic categories had been posted for public comment (see Federal Register Notice at: http://www.gpo.gov/fdsys/pkg/FR-2011-06-30/pdf/2011-16435.pdf). The effort to develop the recommended data standards included a workgroup comprised of several HHS agencies.

Section 4302(b) of the Affordable Care Act requires the collection of data on these five demographic characteristics in Medicaid and CHIP. This section also requires that the collection and reporting of these data in Medicaid and CHIP adhere to the data-collection standards developed under 4302(a). Section 4302(b)(2) amends the Social Security Act by adding a new section 1946, which requires an evaluation of approaches for the collection of data in Medicaid and CHIP, to be performed in conjunction with existing quality-reporting requirements and programs, that allow for the "ongoing, accurate, and timely collection and evaluation of data on disparities in health care services and performance on basis of race, ethnicity, sex, primary language, and disability status." This evaluation is to consider the following objectives:
(1) Protecting patient privacy;
(2) Minimizing the administrative burdens of data collection and reporting on States, providers, and health plans participating under Medicaid or CHIP; and
(3) Improving program data under Medicaid and CHIP on race, ethnicity, sex, primary language, and disability status.

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[2] References to "the Secretary" are to the Secretary of HHS.

The Secretary is required to report to Congress on this evaluation no later than September 23, 2011 (18 months after the enactment of this section), and implement data-collection approaches identified in the evaluation by March 23, 2012.

The objective of this report, as required by section 4302(b)(2) of the Affordable Care Act, is to report to Congress on the evaluation conducted, including the methodologies for identifying, collecting, and evaluating data on health care disparities on race, ethnicity, sex, primary language, and disability status; and provide "recommendations on the most effective strategies and approaches to reporting Health Effectiveness Data and Information Set (HEDIS) quality measures as required under section 1852(e)(3) of the Social Security Act and other nationally-recognized quality performance measures" on such bases. This report is organized by the following sections:

II. Defining and Measuring Health Care Disparities
III. Federal Policies Guiding the Collection of Data on Health Care Disparities in Medicaid and CHIP
IV. Data Collection at the State Level: What Data are Collected and How?
V. An Assessment of the Ability of CMS's Data Systems to Collect and Report Demographic Data in Medicaid and CHIP
VI. Selected Approaches for Identifying, Collecting, Reporting, and Evaluating Data on Health Care Disparities in Medicaid and CHIP

Why is it Important to Collect Data on Demographics?

Medicaid and CHIP play important roles in providing health insurance coverage for low-income Americans, many of whom would otherwise be uninsured. Together, these programs facilitate access to health care for nearly 80 million individuals each year, including 44 million children, 18 million adults, 11 million blind and disabled individuals, and 6 million elderly.[3] About sixty percent of Medicaid enrollees are female, and forty percent are male.[4]

Medicaid and CHIP are also critically important for population subgroups, who disproportionately have low-incomes, including racial and ethnic minority groups, the elderly and people with disabilities, individuals with limited English proficiency (LEP), individuals with complex health care needs, or individuals who have historically suffered disparate health care access and health outcomes (e.g. rural population groups). About 50 percent of nonelderly Medicaid enrollees are racial and ethnic minority Americans, and 15 percent of all enrollees have physical or mental disabilities.[5] Currently, about 12 percent of Medicaid and CHIP enrollees have LEP leading to communication barriers that may have a major impact on the quality of health care obtained.[6] When compared with proficient English speakers, LEP patients are less likely to seek care and to receive needed services.[7] In addition, about 15 percent of Medicaid enrollees (9 million) are individuals who are low-income elderly or people with disabilities under

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[3] Centers for Medicare & Medicaid Services. Medicaid and CHIP enrollment. Table I.16. 2011 CMS Statistics, Office of the Actuary. U.S. Department of Health & Human Services.
[4] Ibid,Table I.17.
[5] Centers for Medicare & Medicaid Services. Medicaid and CHIP enrollment. Table I.16. 2010 CMS Statistics, Office of the Actuary. U.S. Department of Health & Human Services.
[6] Agency for Healthcare Research and Quality. Unpublished estimates.
[7] Brach, C, Fraser, I, and K Paez. 2005. Crossing the Language Chasm. *Health Affairs*. 24(2): 424-434.

age 65 and are enrolled in both the Medicare and Medicaid programs.[8] Many of these beneficiaries live with multiple chronic conditions and have functional and chronic impairments. Individuals enrolled in both Medicare and Medicaid are also more likely than other Medicare beneficiaries to have a mentally disabling condition and be from a community of color.[9]

Disparities in health care access and quality on the basis of race, ethnicity, sex, primary language, and disability status have been well documented.[10] Collecting and monitoring data on health care disparities is a critical first step in monitoring and eliminating these disparities, as these data can be used to inform HHS where to focus efforts, target interventions, and support innovation. For example, collecting and analyzing data on primary language can help us better understand whether some racial and ethnic disparities are largely related to factors specific to race and ethnicity or language. In a study on the effect of access barriers on racial and ethnic disparities in health care among Medicaid-enrolled adults, the authors found that Hispanics and non-Hispanic whites who spoke English as their primary language did not differ in their health care use patterns, but Spanish-speaking Hispanics were significantly less likely than non-Hispanic whites to have had a physician visit, mental health visit, or flu vaccine.[11]

Enrollment in Medicaid is expected to increase in 2014 when the Affordable Care Act expands eligibility to low-income individuals previously ineligible for the program, including adults without dependent children. The Congressional Budget Office estimates that 16 million new individuals will receive coverage through Medicaid and CHIP over the next 10 years as a result of expanding Medicaid eligibility under the Affordable Care Act.[12] Combined with the ever-changing demographics of our country, it will be particularly important for CMS and States to better collect and analyze data to understand the health care needs, experiences, and outcomes of the groups that Medicaid and CHIP currently serve, as well as the populations that these programs will begin to serve.

What HHS Can Do

The HHS has an opportunity to address health care disparities in Medicaid and CHIP by documenting where problems persist, working with States to intervene, and tracking progress in eliminating them. As Medicaid and CHIP serve 80 million Americans, efforts to improve care and reduce and eliminate health disparities in these programs also present major opportunities to reduce overall health care expenditures. A recent report estimated that racial and ethnic health disparities result in excess costs of $17 billion in Medicare and Medicaid.[13]

HHS' commitment to collecting data and undertaking interventions to reduce health and health care disparities is evident through a number of initiatives, including those by the Offices of

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[8] Kaiser Commission on Medicaid and the Uninsured. May 2011. *Dual Eligibles: Medicaid's Role for Low-Income Medicare Beneficiaries*. Menlo Park, CA: The Henry J. Kaiser Family Foundation.
[9] Kaiser Family Foundation. 2010. *Medicare Chartbook, 2010.* Menlo Park, CA: The Henry J. Kaiser Family Foundation.
[10] See, for example, the Agency for Healthcare Research and Quality's 2010 *National Healthcare Quality and Disparities Reports*, available at: http://www.ahrq.gov/qual/qrdr10.htm.
[11] Fiscella, K, et al. 2002. Disparities in Health Care by Race, Ethnicity, and Language Among the Insured: Findings from a National Sample. *Medical Care*. 40(1): 52-59.
[12] Congressional Budget Office. December 2010. Selected CBO Publications Related to Health Care Legislation, 2009-2010. Page 11. http://www.cbo.gov/ftpdocs/120xx/doc12033/12-23-SelectedHealthcarePublications.pdf.
[13] Waidmann, T. September 2009. *Estimating the Cost of Racial and Ethnic Health Disparities*. Washington, DC: The Urban Institute.

Minority Health, Office of Women's Health, the Office of Disability, and the Indian Health Service. These efforts, however, have been tested under programs like Medicaid and CHIP that face unique challenges in collecting and reporting data on a number of program characteristics. Data reporting challenges have hindered HHS's ability to adequately identify and track measures of performance on these factors. While States, providers, and health plans currently collect a variety of information on the demographic characteristics of Medicaid and CHIP enrollees, the lack of Federal guidance about consistent approaches for identifying, collecting, and evaluating data on health care disparities makes monitoring indicators of performance on disparities a challenge.

II. DEFINING AND MEASURING HEALTH CARE DISPARITIES

A discussion of how to define a disparity is germane to the discussion of evaluating approaches for identifying, collecting, and evaluating data on health care disparities. While there is no consensus on the definition of a health care disparity, it can be defined for the purposes of this report as "a meaningful (not merely statistical) difference between population groups in health care coverage, access, or quality of care that is unrelated to the need for health services."[14] It is important to recognize that others may have different definitions.[15]

There are several generally accepted methods for measuring a disparity. One method is to measure a disparity by quantifying the difference on a particular performance measure between the population group with the "best" performance and a comparison group(s). The approach taken in the Agency for Healthcare Research and Quality's (AHRQ) *National Healthcare Disparities Report*, which has reported on the nation's progress and opportunities for reducing health care disparities since 2003, and defines disparities as "any differences among populations," is to measure the relative difference between each population group's performance on a measure relative to a reference group.[16, 17] The reference group is often a group that typically or historically has better health care outcomes relative to other populations, even though this population may not always have the "best" heath care outcomes for each measure. Another method is to measure the difference between each group's performance on a measure relative to an accepted standard of performance for the measure, such as a national standard or goal. Either of these methods, or alternative approaches, can be used to track the magnitude of a disparity over time and document progress in reducing or eliminating disparities.

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[14] Lillie-Blanton, M, et al. 2008. Reducing Racial, Ethnic, and Socioeconomic Disparities in Health Care: Opportunities in National Health Reform. *Journal of Law, Medicine, and Ethics*. 36(4): 693-702.
[15] Swift, EK, Ed. Guidance for the National Healthcare Disparities Report. Institute of Medicine: The National Academies Press, 2002; Smedley, B, Ed. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Institute of Medicine: The National Academies Press, 2002; Kaiser Family Foundation. March 2005. *Policy Challenges and Opportunities in Closing Racial/Ethnic Divide in Health Care*. Menlo Park, CA: The Henry J. Kaiser Family Foundation.
[16] Moy, E, Dayton, E, and C Clancy. 2005. Compiling the Evidence: The National Healthcare Disparities Reports. *Health Affairs*, 24(2): 376-387.
[17] Agency for Healthcare Research and Quality. *2010 National Healthcare Disparities Report*. U.S. Department of Health and Human Services.

III. FEDERAL POLICIES GUIDING THE COLLECTION OF DATA ON HEALTH CARE DISPARITIES IN MEDICAID AND CHIP

As the Federal agency responsible for protecting the health of all Americans, HHS has played a key role in the development and implementation of policies and initiatives to eliminate health care disparities. To assess approaches for identifying, collecting, and evaluating data on health care disparities, and before recommending future courses of action for strengthening these data, it is important to understand the policies already in place that guide the collection of these data in Medicaid and CHIP. The policies below represent some of the major Federal efforts that have guided the collection of data on health care disparities on the basis of race, ethnicity, and sex in Medicaid and CHIP. There are no Federal policies that have required the collection of data on primary language or data on disability status that would be useful for comparing disparities in Medicaid and CHIP prior to the Affordable Care Act. This does not suggest, however, that there are not other important health disparities data-collection efforts and activities happening at the national level that are relevant to Medicaid and CHIP.

- Office of Management and Budget's Standards for Federal Data on Race and Ethnicity

The Office of Management and Budget's (OMB) 1977 Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting, specified a minimum set of categories for data on race and ethnicity to be used in data collection by Federal agencies.[18] These standards were developed to provide consistent data on race and ethnicity throughout the Federal Government. Directive No. 15 also allowed for additional granularity beyond these standards as long as any additional categories could be aggregated into the minimum standard set of categories. Revised standards put forth in 2003 further specified these standards. The OMB standards also encourage self-identification of race and ethnicity, and the use of a two-question format when self-reporting is used – with the question about ethnicity preceding that of race.

The current standards have five minimum categories for data on race and two categories for data on ethnicity:

Race
- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander

NOTE: The standards require that respondents be explicitly instructed and permitted to select more than one racial category when self-identification is used.

Ethnicity
- Hispanic or Latino
- Not Hispanic or Latino

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[18] *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*. (January 1, 2003). Office of Management and Budget. <http://www.census.gov/population/www/socdemo/race/Ombdir15.html>

It is important to note that the OMB standards do not require the collection of racial and ethnic data; they only set the standards to which these data should be collected by Federal agencies.[19] Additionally, while States and the private industry are not required to follow the OMB standards, some States and industries collect and present racial and ethnic data according to these standards.

- HHS Inclusion Policy for Improving Race and Ethnicity Data

With few exceptions, the 1997 HHS Inclusion Policy for Improving Race and Ethnicity Data sets the OMB standard as the minimum standard categories of racial and ethnic groups collected and reported in all HHS data-collection and reporting activities and data systems.[20] As a result of the Inclusion Policy, the minimum OMB standard is already included in most HHS data-collection initiatives.

- Medicare Improvements for Patients and Providers Act of 2008, Section 185

Similar to what section 4302 of the Affordable Care Act requires in Medicaid and CHIP, section 185 of the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA), Addressing Health Care Disparities, directs the Secretary to evaluate and report to Congress on the approaches for ongoing data collection, measurement, and evaluation of disparities in health services and performance by race, ethnicity, and gender in Medicare. The approaches identified in the report must later be implemented. As approximately 9 million Medicaid enrollees are also enrolled in Medicare, this provision applies to data collection in the Medicaid program as well.

- Additional Efforts and Ongoing Activities

There are also a number of HHS activities that affect the collection of data on health care disparities in Medicaid and CHIP, including the activities of the HHS Data Council, which coordinates all Health and Human Services data collection and analysis activities. As part of the CMS Strategic Language Access Plan, which outlines the goals for improving language access for beneficiaries who receive services from CMS, CMS will continuously gather data on the number and/or proportion of limited English proficient (LEP) persons served by CMS programs.[21] Also, as required under the Affordable Care Act, Offices of Minority Health focused on improving the health of racial and ethnic populations have been established within six HHS agencies: AHRQ, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and CMS.

Though data collection is not the primary focus, there are several other HHS efforts focused on health disparities reduction, including the HHS Action Plan to Reduce Racial and Ethnic Disparities, Healthy People 2020, the National Partnership for Action to End Health Disparities, the National Stakeholder Strategy for Achieving Health Equity, the National Prevention Strategy, and the National Quality Strategy.

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[19] Perot, RT and M Youdelman. September 2001. *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices*. New York, NY: The Commonwealth Fund.
[20] *HHS Policy for Improving Race and Ethnicity Data: Memorandum* (October 24, 1997). U.S. Department of Health & Human Services < http://aspe.hhs.gov/datacncl/inclusn.htm>.
[21] Centers for Medicare & Medicaid Services. November 2010. *CMS Strategic Language Access Plan: FY 2010 Outcome Report*. U.S. Department of Health & Human Services.

IV. DATA COLLECTION AT THE STATE LEVEL: WHAT DATA ARE COLLECTED AND HOW?

Federal policies over the years have mandated the collection of many of the data elements identified in section 4302. However, the absence of data standards until the recent posting or guidance about *how* these data should be collected and reported has hindered the quality of the data collected and HHS' ability to evaluate health disparities data. Understanding the methods and mechanisms currently used to collect health disparities data is part of a comprehensive evaluation of the approaches for identifying, collecting, and evaluating data on health disparities in Medicaid and CHIP.

What Data are Collected and How?

Much of the demographic data on Medicaid and CHIP enrollees is collected through a paper or online application during the eligibility determination and enrollment processes. An environmental scan of Medicaid applications revealed that of the 50 States, District of Columbia, and 4 territories with available applications, 93 percent collect information about race, 89 percent collect information about ethnicity, 91 percent collect information about sex or gender, 56 percent collect information about primary language, and 73 percent collect information about disability status.[22] A summary of the findings is available in Table 1. Additional data are also collected during the renewal or redetermination processes, the point at which a Medicaid or CHIP enrollee renews their eligibility. States, health plans, and providers often use different mechanisms to collect this information. Massachusetts, for example, collects racial and ethnic data at several points in order to improve data accuracy.[23] In addition, a 2001 survey found that six of the eight Medicaid agencies responding to the survey asked Medicaid applicants to verbally report their or their children's race or ethnicity to an intake specialist, three of the eight agencies asked potential enrollees to complete a questionnaire about their race or ethnicity, and in three of the eight States, an intake specialist helped in determining the applicant's race and ethnicity.[24]

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[22] Environmental scan conducted by CMS between July 15 and September 20, 2011.

[23] LLanos, K., and L. Palmer. 2006. *Using Data on Race and Ethnicity to Improve Health Care Quality for Medicaid Beneficiaries*. Hamilton, NJ: Center for Health Care Strategies.

[24] *A Primer on Collaborating with Medicaid Agencies and Using Medicaid Data in Efforts to Eliminate Racial and Ethnic Disparities in Health*. January 2002. Center for Health Program Development and Management, University of Maryland Baltimore County.

Table 1: Health disparities data on Medicaid applications

Application asks for information about:

State	Race	Ethnicity	Sex	Primary Language	Disability Status
AL	X	X	X	X	
AK	X	X	X		
AZ	X	X	X	*	X
AR	X	X		*	X
CA	X	X	X	X	X
CO	X	X	X	X	X
CT	X	X	X	X	X
DE	X	X	X		X
DC	X	X	X	*	X
FL	X	X	X	X	X
GA	X		X	*	
HI	X	X	X	X	X
ID	X	X	X	X	X
IL	X	X		X	X
IN	X	X	X	*	X
IA	X	X	X	*	X
KS	X	X	X	X	
KY	X		X	X	X
LA	X	X	X	X	X
ME			X	X	X
MD	X	X	X	X	X
MA	X	X	X	X	X
MI	X	X	X	X	‡
MN	X	X	X	X	X
MS	X	X	X	X	
MO	X	X	X	*	^
MT	X	X	X	*	X
NE	X	X	X	*	X
NV	X	X	X	X	X
NH	X	X		X	X
NJ	X	X	X	X	
NM	X	X	X	*	X
NY	X	X	X	X	X
NC	X	X	X	X	X
ND	X	X	X		X
OH	X	X	X	X	X
OK	X	X	X	*	
OR	X	X	X	*	X
PA	X	X	X	X	X
RI	X	X	X	X	
SC	X	X	X	X	X
SD	X	X	X	X	
TN	X	X	X	*	X
TX	X	X	X	X	X
UT	X	X	X	*	X

State	Race	Ethnicity	Sex	Primary Language	Disability Status
VT			X	*	X
VA	X	X	X	X	
WA	X	X	X	*	X
WV	X	X	X	X	X[§]
WI	X	X	X	*	X
WY	X	X	X	X	X
AS	NA	NA	NA	NA	NA
GU	X	X	X		X
MP	X	X			
PR					
VI			X		
Total	51	49	50	31	40
Percent	93%	89%	91%	56%	73%

Notes: NA= Not available. American Samoa utilizes a system of 'presumed eligibility,' and does not have a Medicaid application.
MP= The Commonwealth of the Northern Mariana Islands.
Race: Includes applications that allow applicants to report their race.
Ethnicity: Includes applications that allow applicants to report their ethnicity.
Primary Language: Includes applications that ask explicit questions about the primary or preferred language of the applicant. Excludes applications that are available in more than one language and/or ask information for purposes of language assistance unless they also meet the above criteria.
Disability Status: Includes applications that allow applicants to report whether they have a disability or allow applicants to discuss a disability.
Not all States that ask for racial and ethnic information do so in a way that aligns with the OMB standards.

State-Specific Comments:
* Applications do not include explicit questions about the primary language of the applicant, but language information asked for purposes of language assistance, and/or applications are available in more than one language.
[‡]MI: Asks if applicant requires day care due to mental or physical limitations only for those 15-17 years of age.
[^]MO: Only asks if children have a medical condition that if left untreated would result in death or serious injury of the child.
[§]WV: Web-based application asks about disability status on screening application that applicant completes prior to Medicaid application.

Health plans, provider claims, and encounter data from managed care organizations (MCOs) are other rich sources of enrollee information that can be used to monitor and evaluate health disparities. For example, Maryland uses encounter data to set or adjust MCOs rates, evaluate the performance of its managed care program, and assess service use by racial and ethnic groups.[25] South Carolina mandates their MCOs to collect, evaluate, and report data on the race of their Medicaid beneficiaries annually.[26] Additionally, while most Medicaid managed care plans require health plans to collect performance measures, some States use these measures to identify health disparities. From 2002-2004, Michigan, Montana, Oregon, Texas, Virginia, and Washington were part of a demonstration project in which 12 participating managed care plans in these States linked racial and ethnic data from the Medicaid program with data from a nationally-recognized performance measure sets.[27] The States used the data to produce quality-

[25] LLanos, K., and L. Palmer. 2006. *Using Data on Race and Ethnicity to Improve Health Care Quality for Medicaid Beneficiaries*. Hamilton, NJ: Center for Health Care Strategies.
[26] Ibid.
[27] Nerenz, D.R. and D. Darling. November 2004. *Addressing Racial and Ethnic Disparities in the Context of Medicaid Managed Care: A Six-State Demonstration Project*. Rockville, MD: Health Resources and Services Administration.

of-care reports to identify health disparities, implement quality-improvement (QI) projects to address these disparities, and assess the impact of interventions. These QI initiatives focused on topics including diabetes care, well-child care, and smoking cessation.

What are some of the Challenges?

While there are many sources of data on Medicaid and CHIP enrollees, how and what questions about demographic characteristics are asked – if asked at all – often varies from State to State. The result is that data are not uniformly collected across States, and have varying degrees of quality and accuracy. For example, the environmental scan of Medicaid online applications revealed that ethnic groups are sometimes listed on applications under "race," and the five OMB racial categories are not always included. Additionally, not all applications allow a respondent to select more than one race. For primary language, some States ask questions about the language the enrollee usually speaks, with a line and or checkbox to indicate the primary language. Other States ask questions about the primary language the enrollee tends to read, and/or whether the enrollee or the enrollee's family members speak English. Also, demographic data in Medicaid and CHIP programs are sometimes collected through third-party report, which can be less reliable than self-report and lead to inconsistencies.[28] This variation makes it difficult to compare data on health disparities nationally.

V. AN ASSESSMENT OF THE ABILITY OF CMS'S DATA SYSTEMS TO COLLECT AND REPORT DEMOGRAPHIC DATA IN MEDICAID AND CHIP

While there are various modes of demographic data collection in Medicaid and CHIP, and often varying degrees to which these data are collected, there are two primary databases used to manage this information: the State Medicaid Management Information System (MMIS) and the Federal Medicaid Statistical Information System (MSIS) which is an abstract of the State system. The data in both of these databases are used for a variety of reporting activities at CMS, including activities that capture demographic information on health disparities in Medicaid and CHIP.

Appendix A describes the major Federal-State systems for collecting data on race, ethnicity, sex, primary language, and disability status for Medicaid and CHIP enrollees, and discusses the advantages and limitations of each system for capturing these data.

Of the five demographic categories required to be collected and reported in Medicaid and CHIP as required by section 4302(b) of the Affordable Care Act, primary language is not collected routinely through Medicaid and CHIP data systems, and disability status is typically only collected when used as an eligibility category to qualify a person as disabled. Although information is available on disability status for determining program eligibility, program eligibility applications generally only request information to identify individuals who are severely disabled, and not for purposes to identify the spectrum or level of disabilities an

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[28] *A Primer on Collaborating with Medicaid Agencies and Using Medicaid Data in Efforts to Eliminate Racial and Ethnic Disparities in Health.* January 2002. Center for Health Program Development and Management, University of Maryland Baltimore County.

individual may (or may not) have. The lack of routinely and reliably collected data on these two demographic characteristics has limited States' and the Federal government's ability to identify or track health care disparities on these bases.

At the time of this writing, the data standards developed under section 4302(a) are under review by HHS. Section 4302(b)(1) requires that data collected and reported under Medicaid and CHIP adhere to the data standards developed under section 4302(a). CMS will evaluate the demographic variables currently collected in Medicaid and CHIP against the 4302(a) standards when they become available, and will include the results of this analysis in the next report to Congress focused on implementation. In the meantime, current efforts to streamline Medicaid and CHIP data-collection activities through an expanded MSIS will help ensure that data collected and reported on health care disparities in Medicaid and CHIP are uniformly collected according to the standards developed under section 4302(a), and also ease potential burdens imposed by these new standards and existing reporting requirements. Additionally, section 6504(a) of the Affordable Care Act requires that State claims processing and retrieval systems also submit data elements to CMS deemed as necessary for Medicaid program integrity, program oversight, and administration. This provision also includes language aimed at improving managed care encounter data by requiring that managed care organizations (MCOs) provide encounter data to States at a level of detail and frequency determined by the Secretary.

Given the link between the State and Federal data systems, most changes to the reporting requirements on a Federal level will require commensurate changes in State data-collection systems, including eligibility applications. The varying resources of State Medicaid and CHIP programs to monitor disparities and upgrade data systems, as well as concerns about the burden of reporting requirements, are potential State challenges to improving data collection that are recognized by CMS. CMS will work with States to accomplish these tasks as necessary, while seeking to maintain the State flexibility that is a hallmark of the Medicaid and CHIP programs.

VI. SELECTED APPROACHES FOR IDENTIFYING, COLLECTING, REPORTING, AND EVALUATING DATA ON HEALTH CARE DISPARITIES IN MEDICAID AND CHIP

As required by the Affordable Care Act, CMS undertook several steps to evaluate approaches for the identification, collection, and evaluation of data on health care disparities basis of race, ethnicity, sex, primary language, and disability status, including:

- Assessing the ability of current Federal-State data systems to collect data on race, ethnicity, sex, primary language, and disability status in Medicaid and CHIP;
- Discussing possible changes to data systems that may facilitate the collection of Medicaid and CHIP data on these bases; and
- Conducting a literature review for studies and research on best practices and effective strategies for identifying, collecting, reporting, and evaluating data on health care disparities in Medicaid and CHIP.

Out of a number of approaches identified, HHS is considering the following activities presented below to improve collection and evaluation of data on health care disparities in Medicaid and CHIP programs.

- Require States to Collect and Report Demographic Data by the Standards Established Under Section 4302

Although the vast majority of States collect data on the five demographic characteristics identified under section 4302, few report and use that information to evaluate health disparities. As such, it will be important for CMS to require States to collect and report, and encourage them to use, data on race, ethnicity, sex, primary language, and disability status in Medicaid and CHIP by the standards established under this provision.

- Ensure that CMS Data-Collection Systems and Tools are Prepared to Capture All Necessary Demographic Data

CMS will ensure that the systems used to collect and maintain demographic data on Medicaid and CHIP enrollees at the Federal level, its population health surveys (e.g. MCBS), and national population health surveys used by CMS (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS®] survey tool), are prepared and adapted to enable the collection of such information. Some data systems will require minimal retooling, while others will be collecting demographic data for the first time.

- Issue Guidance to States around the Collection of Race, Ethnicity, Sex, Primary Language, and Disability Status Data in Medicaid and CHIP

Once standards are finalized, CMS can issue guidance to States regarding collection of data by race, ethnicity, sex, primary language, and disability status in Medicaid and CHIP. Such guidance might note that self-report is the preferred mechanism for collection of demographic data, and encourage the continual collection of data on patients to ensure accuracy and completeness.

It is important to note, however, that encouraging self-reporting of demographic data is not without challenges. For example, of the one million members who received a questionnaire asking for information about race, ethnicity and primary language from Highmark, Inc. – one of the members of the National Health Plan Collaborative (NHPC) to Reduce Disparities and Improve Quality, a partnership between nine health plans and public and private-sector entities to address racial/ethnic disparities in care – only 30 percent responded to it.[29] Ongoing HHS discussions seek to resolve the issue of low response rates for self-reporting of demographic data while encouraging and achieving higher reporting and collection goals.

The need to upgrade or reprogram data-collection systems may be a primary barrier to improving data collection by States. CMS can also provide technical assistance to States to help them capture demographic data through CMS data systems.

- Require Managed Care Organizations to Collect Data to Track Health Disparities

As of June 2009, about 70 percent of Medicaid enrollees received benefits through some form of

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[29] Lurie, N, et al. May 2008. The National Health Plan Collaborative to Reduce Disparities and Improve Quality. *The Joint Commission Journal on Quality and Patient Safety*. 34(5): 256-265.

Medicaid managed care.[30] Of these beneficiaries, about 80 percent are in capitated plans that are accountable for providing a full range of services to enrollees and are generally required to submit encounter data to States on the services, payment, providers, and diagnosis codes provided under MCO arrangements.[31] However, limited data are often reported to States from Medicaid MCOs, which is then reported to CMS. Under section 6504(a) of the Affordable Care Act, managed care organizations will be required to provide encounter data to States at a level of detail and frequency determined by the HHS. This data can be used to track health disparities.

Current Experience: Due in part to their purchasing power, States have an opportunity to encourage or require their Medicaid managed care organizations (MCOs) to identify and address health disparities among their members. While most States use encounter data to manage MCOs, at the present, South Carolina is the only State that mandates the collection, evaluation, and reporting of data on the race of enrollees by MCOs.[32] Starting in 2005, Florida's Medicaid program required its MCOs to implement at least one quality assessment performance improvement (QAPI) project that addresses health disparities in the area of language and culture; clinical health care disparities; or culturally or linguistically appropriate services.[33] States can also consider implementing financial penalties or other disincentives to encourage MCOs to submit health disparities data. Many States already do this, though not necessarily for purposes of health disparities data collection.

- Stratify Performance Measures by Demographic Characteristics

The Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) required CMS to identify a core set of children's health care quality measures that "can be used…to perform comparative analyses of pediatric health care quality and racial, ethnic, and socioeconomic disparities in child health and health care for children."[34] In December 2009, the Secretary released an initial core set of 24 child quality measures for voluntary reporting by States.[35] The initial core set of adult measures will be released in January 2012.

CMS and States can promote the use of quality-measurement activities to identify and evaluate health and health care disparities through the child and adult quality measures that are required by Congress.   Such activities can be used to improve the evaluation of health disparities in Medicaid and CHIP, by stratifying measures by demographic characteristics to analyze gaps in health care.

Current Experience: Some States are already involved in efforts to use nationally-recognized performance measures, like the Healthcare Effectiveness Information and Data Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS®), to identify health

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[30] Centers for Medicare & Medicaid. Medicaid Managed Care Enrollment as of June 30, 2009. 2009 Medicaid Managed Care Enrollment Report. U.S. Department of Health & Human Services.
[31] CMS analysis using 2009 Medicaid Managed Care Enrollment Report, p. 1. Centers for Medicare & Medicaid Service. U.S. Department of Health & Human Services.
[32] Office of Inspector General. Medicaid Managed Care Encounter Data: Collection and Use. May 2009. U.S. Department of Health & Human Services; LLanos, K., and L. Palmer. 2006. *Using Data on Race and Ethnicity to Improve Health Care Quality for Medicaid Beneficiaries*. Hamilton, NJ: Center for Health Care Strategies.
[33] LLanos, K., and L. Palmer. 2006. *Using Data on Race and Ethnicity to Improve Health Care Quality for Medicaid Beneficiaries*. Hamilton, NJ: Center for Health Care Strategies.
[34] Social Security Act 1139A(a)(3)(D)
[35] For more information about the core quality measures, see: http://www.cms.gov/smdl/downloads/SHO11001.pdf.

disparities among their Medicaid and CHIP members. In an effort funded by the Commonwealth Fund and the Health Resources and Services Administration (HRSA), for example, 12 Medicaid managed care plans in Michigan, Montana, Oregon, Texas, Virginia, and Washington linked racial and ethnic Medicaid program data to HEDIS data to develop reports stratified by race and ethnicity. The reports were used to identify racial and ethnic disparities and implement quality-improvement (QI) projects to address these disparities.[36] Oregon's HEDIS data showed disparities in diabetes management and smoking cessation, and the State focused its project in these areas.   Michigan matched racial and ethnic data from the State's enrollment files with the data of three health plans or HEDIS files to stratify their HEDIS reports by race and ethnicity. The data revealed a high proportion of African Americans in these health plans, and the State focused on this population for their QI project.[37]

CMS considered the option to require States to collect and stratify the CHIPRA and adult quality measures by the demographic categories under 4302, but decided the burden was greater than the benefit, given the potential to obtain this information from other CMS data systems. CMS does, however, encourage States to use quality-measurement activities to identify and evaluate health disparities, to the extent practicable.

- Develop New Measures Specific to Populations of Interest

Planned quality-measures programs and other initiatives present unique opportunities to develop or tailor quality measures specific to populations of interest, or with the intent of evaluating health and health care disparities.

Current Experience: For example, as part of a new HHS initiative to improve care for individuals with sickle cell disease – which is prevalent among African Americans – CMS will work with AHRQ to develop quality-of-care metrics for individuals with sickle cell disease and incorporate these metrics into existing Medicaid and CHIP quality-reporting activities.

Also as required by CHIPRA, the Secretary created a Pediatric Quality Measures Program (PQMP) that will test and refine the initial core set of measures to make them more broadly applicable to Medicaid and CHIP enrollees, and develop additional quality measures that address dimensions of care where standardized measures do not currently exist. Through the PQMP, AHRQ issued grant awards to Centers of Excellence – cooperative agreement grants – that will work to improve and enhance the initial core set of children's health measures, and to develop new quality measures meaningful to State Medicaid and CHIP programs, and applicable to all payer systems.[38] One of the first priorities for the PQMP is to, at a minimum, develop measures designed to identify and eliminate racial and ethnic disparities in child health and health care. The Secretary will incorporate these improved measures into the core set by January 1, 2013, and annually thereafter.

- Promote Data Sharing, Collaboration, and Analyses

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[36] Nerenz, D.R. and D. Darling. November 2004. *Addressing Racial and Ethnic Disparities in the Context of Medicaid Managed Care: A Six-State Demonstration Project*. Rockville, MD: Health Resources and Services Administration.

[37] LLanos, K., and L. Palmer. 2006. *Using Data on Race and Ethnicity to Improve Health Care Quality for Medicaid Beneficiaries*. Hamilton, NJ: Center for Health Care Strategies.

[38] Pediatric Quality Measures Program (PQMP) Center for Excellence Grant Awards fact sheet <http://www.ahrq.gov/chipra/pqmpfact.htm>

Creating partnerships with other Medicaid programs, State agencies, academic centers, or institutions can aid States in the evaluation of health disparities, and can also help overcome many of the staff, IT system, and resource challenges that hinder the evaluation of these data.

Current Experience: Massachusetts, for example, shares its Medicaid data with the State's mental health and substance abuse agencies in order to better assess their populations.[39] In Missouri, Medicaid enrollment data are matched with birth data from the public health department to produce HEDIS-like measures used to assess MCOs.[40] The Agency for Health Care Administration in Florida, which administers the State's Medicaid program, is involved in multiple collaborations. The State works with academic institutions, the department of health, and community-based organizations to evaluate disease management and birth and outcomes using racial, ethnic, gender and other Medicaid data.[41]

Similar efforts can be promoted at the Federal level. CMS's Historically Black Colleges and University (HBCU) Grant Program, for example, supports HBCU researchers in carrying out health services research activities to meet the needs of CMS beneficiary populations, including Medicaid enrollees. Some of the goals of the program are to assist CMS improve health care and health care quality for enrollees, and assist in fostering inter-university communication and collaboration regarding African American health disparities issues.[42] CMS's Hispanic Grant Program has similar goals with an eye toward Hispanic health care issues. CMS also collaborates with and leverages the work of other HHS agencies to evaluate health disparities data in Medicaid and CHIP, including AHRQ, which adapted the *National Healthcare Quality and Disparity Reports* for CMS in 2008 to present data on quality and racial and ethnic disparity measures by payer.[43]

Data sharing is another key approach. CMS, for example, makes MSIS data publically available through the MSIS State Summary Datamart, where users can create statistical tables covering a range of Medicaid program data. Topics can be viewed by demographic categories, including race, ethnicity, and sex. Similarly, AHRQ's CAHPS® Database allows those administering the CAHPS® survey to participate in the CAHPS® Database, and those submitting data to view their own results compared to benchmarks. The CAHPS® Comparative Database makes select data available to the public for a variety of data activities, including running frequencies of data on or by race, ethnicity, and gender.

In States with offices of minority health, women's health, and disability, Medicaid and CHIP agencies are encouraged to engage these offices in their efforts, as there are likely opportunities for synergy.

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[39] "*A Primer on Collaborating with Medicaid Agencies and Using Medicaid Data in Efforts to Eliminate Racial and Ethnic Disparities in Health*," Center for Health Program Development and Management, University of Maryland Baltimore County, January 2002.

[40] Ibid.

[41] Ibid.

[42] *Historically Black Colleges and Universities (HBCUs) Grant Program*. (2011). Centers for Medicare & Medicaid Services. U.S. Department of Health & Human Services. <http://www.cms.gov/ResearchDemoGrantsOpt/02_Historically_Black_Colleges_and_Universities.asp#TopOfPage>

[43] Agency for Healthcare Research and Quality. December 2008. *Health Care Coverage Analyses of the 2006 National Healthcare Quality and Disparities Reports*. U.S. Department of Health & Human Services, Centers for Medicare & Medicaid Services. Baltimore: MD.

With any collaborative approach, protecting the privacy of Medicaid and CHIP must remain a chief objective. A number of policies, such as The Privacy Act of 1974, help protect the privacy of data that can be retrieved by personal identifiers.

VII. CONCLUSION

Implementation of section 4302 of the Affordable Care Act will make great strides in efforts to reduce health care disparities in Medicaid and CHIP. By standardizing data collected on demographic characteristics associated with health care disparities, and by requiring collection and evaluation of this data, Medicaid and CHIP are in a better position to track progress and work with States to intervene to address disparities in health care. While States already collect data on many of the five demographic characteristics identified in section 4302, it is not collected uniformly from State to State. Similarly, the Federal government currently has some efforts underway to collect and evaluate data by race, ethnicity, and sex, however, collection of data on primary language and disability status rarely occurs in Medicaid and CHIP. While data alone will not solve the problem of health and health care disparities, it does allow for a deeper understanding and monitoring of progress.

In order to implement the approaches outlined in this report and satisfy the additional requirements of Section 4302 of the Affordable Care Act, HHS will:
1. Update the Medicaid Statistical Information System (MSIS) to assure reporting of individual demographic information consistent with the standards developed under section 4302(a) of the Affordable Care Act;
2. Work closely with States to support a gradual transition to collecting and reporting into MSIS the new demographic information as part of a larger effort underway to implement provisions of the Affordable Care Act;
3. Revise the Medicare Current Beneficiary Survey to include 4302 standard demographic information;
4. Coordinate work between CMS and the Agency for Healthcare Research and Quality (AHRQ) to revise the Consumer Assessment of Healthcare Providers and Systems survey tools used with Medicaid, CHIP, and Medicare to incorporate the new standards for self-reported demographic information.

Of critical importance in implementing the approaches identified in this report will be the participation of States. HHS will need to work with States to understand their concerns about the implementation of these approaches, the challenges they may encounter, and understand how we can work together to achieve desired goals. Since Medicaid and CHIP are State-Federal programs administered by States, the challenges that may exist in one program may not exist in others. States also will be at different points in their efforts to collect data and address health disparities; some States have been at the forefront of health disparities data collection and analysis for years, while this effort will represent a beginning for others. Future reports will include recommendations for improving the identification of health care disparities for Medicaid and CHIP enrollees.

REPORT TO CONGRESS

Approaches for Identifying, Collecting, and
Evaluating Data on Health Care Disparities in Medicaid and CHIP

APPENDICES

APPENDIX A
CMS STATE-FEDERAL SYSTEMS FOR COLLECTING AND REPORTING DEMOGRAPHIC DATA IN
MEDICAID AND CHIP

Data Source	Description	Advantages	Limitations
Medicaid Management Information System (MMIS)	MMIS is the primary system States use to store information on Medicaid and CHIP enrollees and submit to CMS. It is a mechanized claims processing and information system that States are required to have, unless waived by the Secretary. The objectives of the system include Medicaid program control and administrative costs; service to recipients; providers and inquiries; operations of claims control and computer capabilities; and management reporting for planning and control. States use their MMIS data to allow payers and purchasers to track a variety of Medicaid and CHIP data on health care expenditures and utilization patterns, and also to report to CMS for a variety of reporting activities, including the CMS Form-416 (the reporting tool that is used to assess the effectiveness of States' Early and Periodic Screening, Diagnostic and Treatment [EPSDT] programs) and Medicaid Statistical Information System (MSIS).	• Collects and reports to CMS data on race, ethnicity, sex, and disability (determined by basis of eligibility)	• Does not currently report information about primary language to CMS
Medicaid Statistical Information System (MSIS)	MSIS is an electronic system through which States submit eligibility and claims program data to CMS. MSIS data originate from the MMIS. MSIS collects, manages, analyzes and disseminates information on beneficiaries and utilization and payment for services covered by State Medicaid programs. States provide CMS with five quarterly computer files; one file contains eligibility and demographic characteristics for each person enrolled in Medicaid at any time during the quarter, and four separate files contain claims adjudicated for payment during the quarter for long-term care services, drugs, inpatient hospital stays and all other types of services. The state-submitted data include over 60 million eligibility records and over 3 billion claims records per year.	• Collects sex and disability data (determined by basis of eligibility), and race and ethnicity data in accordance with OMB standards • Staff have indicated that the system could likely be adapted to collect data on primary language	• Does not currently collect primary language data • The system is currently unable to detail the severity or category of the disability • Data can be difficult to use for various analytic purposes such as statistics and

	Each State compiles information regarding enrollment, service utilization, and payment in their MMIS, and CMS provides States with a data dictionary to map their MMIS data elements into the MSIS.[44] Each State provides final, reconciled MSIS data files to CMS in the MSIS format. A flow chart of the process is available in Appendix B. The information below provides detail on the race, ethnicity, sex, and disability status data currently captured in MSIS, as specified in the MSIS Data Dictionary (Release 3.1). The Data Dictionary is available at: http://www.cms.gov/MSIS/Downloads/msisdd2010.pdf. • Race: White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander. Beneficiaries are also able to indicate more than one race. The definitions of each race group are available in Appendix C. • Ethnicity: Hispanic or Latino and Not Hispanic or Latino. The definitions of each ethnic group are available in Appendix C. • Sex: Female, Male, and Unknown. Disability Status: Because MSIS is a claims-based system, most of the information on disability in MSIS is based on medical claims. Disability status can currently be captured in MSIS either through specific diagnosis or service codes if the codes are submitted on a claim, or by the individual's category of eligibility: aged, blind/disabled, children, adults, children (unemployed parent), unemployed adult, unknown, and women who are eligible by virtue of the Breast and Cervical Cancer and Treatment Act of 2000 (BCCA women).	• As part of the process for implementing section 6504 of the Affordable Care Act, MSIS is under review by an internal CMS workgroup considering options for an expanded system that would improve data-collection activities at CMS, including collection of managed care encounter data	forecasting and health care disparities[45]

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[44] Chronic Condition Data Warehouse. *Medicaid Analytic eXtract Files (MAX) User Guide*. Version 1.0. April 2011.

[45] Baugh, D and S Radke. (May 6, 2008). *An Introduction to Medicaid Analytic eXtract (MAX) Data* [PowerPoint slides]. Retrieved from Centers for Medicare & Medicaid website: https://www.cms.gov/MedicaidDataSourcesGenInfo/07_MAXGeneralInformation.asp.

CHIP Statistical Enrollment Data System (SEDS)	SEDS allows States to report data on children enrolled in CHIP and Medicaid (and some adults) on a quarterly and aggregate annual basis. The system is a web-based application that has the capacity to capture enrollment data across different service delivery systems, stratified by a number of socio-demographic categories including age, income, race, ethnicity, and gender. States are required to report each enrollee's race, ethnicity, and gender on a "Race, Ethnicity, and Gender" form (see Appendix D). The "Race, Ethnicity, and Gender" form has one section each for gender, race, and ethnicity, and five columns, one for each program type (children enrolled in a Medicaid Expansion CHIP, Separate CHIP, Total CHIP, and Medicaid, and low-income pregnant women enrolled in CHIP through the State Plan option). The information below provides detail on the race, ethnicity, and gender data currently captured in SEDS, as detailed in SEDS Instruction for Data Entry manual. SEDS captures sex data using a variable named gender. • Race: White, Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islander, More than One Race (regardless of ethnicity). If a child's race is not reported or is unknown, States report that the enrollee is an 'Unspecified Race.' Definitions of each self-reported category are available in Appendix E. • Ethnicity: Hispanic or Latino, Not Hispanic or Latino, and 'Unspecified Ethnicity.'[46] The definitions of each self-reported category are available in Appendix E. • Gender: Female, Male, and Unspecified Gender. Reporting of 'Unspecified Race,' 'Unspecified Ethnicity,' an 'Unspecified Gender' began on January 1, 2011. Prior to this	• Collects data on gender, and on race and ethnicity in accordance with the OMB standards • Unique at CMS for its ability to provide timely, point-in-time Medicaid and CHIP enrollment data for children • Under the Affordable Care Act, a companion data system to SEDS, the CHIP Annual Reporting Template System (CARTS) will be required to collect data on CHIP enrollees in accordance with section 4302. This includes primary language data	• Does not currently collect primary language or disability status data • Race, ethnicity, gender data often not reported by States • SEDS is in need of system upgrades to improve functionality and data verification

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[46] Though the ethnicity categories in the SEDS instruction manual conform to the OMB standards, due to a programming error, the current ethnicity field in the SEDS system does not. This field is scheduled to be updated in accordance with the OMB standards in fall 2011, and States will begin reporting data accordingly on January 1, 2012.

	point, Unspecified Race, Ethnicity, or Gender included only those children for whom no data were reported.		
Electronic Health Record (EHR)	An EHR is an electronic version of a patient's medical history that is maintained by the provider over time and may include all of the key administrative clinical data relevant to that person's care under a particular provider, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology reports. The Health Information Technology for Economic and Clinical Health (HITECH) Act, enacted as part of the American Recovery and Reinvestment Act of 2009 (Recovery Act), promotes and provides support for the adoption and "meaningful use" of health information technology. "Meaningful use" means providers need to show that they use certified EHR technology in ways that can be measured significantly in quality and in quantity. The Medicaid EHR Incentive Program provides incentive payments to eligible professionals, eligible hospitals and critical access hospitals as they adopt, implement, upgrade, or demonstrate meaningful use of certified EHR technology. Meaningful use criteria for EHRs require that providers capture preferred language, gender, race, and ethnicity information. Also included within the HITECH Act are several provisions that underscore the importance of applying HIT to help eliminate health disparities, as recent data has indicated a lack of HIT use among providers of the underserved.	• All certified EHR systems will have the capacity for meaningful use and require that providers capture patient demographics, including race, ethnicity, gender, and preferred language. • Data can be shared with healthcare systems, providers, and patients	• Disability is not currently a required variable for meaningful use • EHR data is not easily accessible to CMS and is not available for research, analysis, and reporting on health disparities within Medicaid and CHIP programs
Medicare Modernization Act file (MMA file)	The MMA file provides monthly identification of beneficiaries who are dually eligible for both Medicare and Medicaid. The file, which all 50 States and DC are required to submit to CMS monthly, identifies the beneficiaries, their level (full vs. partial Medicaid benefits) and specific category, along with other information for that State.	• Collects sex data • Can be linked with MSIS files to acquire additional demographic data on Medicaid enrollees	• There is limited demographic information in the MMA file; the file does not capture race, ethnicity, primary language, or disability status data

Medicare Current Beneficiary Survey (MCBS)	CMS's MCBS is a nationally representative survey that is a comprehensive source of information on the health status, health care use and expenditures, health insurance coverage, and socioeconomic and demographic characteristics of Medicare beneficiaries.	• Asks questions about race, ethnicity, sex, and disability	• Contains a question about the language of interview, but no explicit questions about the primary language of the beneficiary

Race

Data Element Name: RACE-CODE-1
Definition: Quarterly Field - A code indicating if the eligible has indicated a race of White.
Coding Requirements: Use this code to indicate if the eligible's race demographics include a race of White. This determination is independent of indications of other races. That is, for RACE-CODE-1 through RACE-CODE-5, any combination of race codes is possible. If there is no available race information for the eligible, code all five RACE-CODE(s) as 0, and the race for the eligible will be deemed to be unknown.
Valid Values   Code Definition 0   Non-White or Race Unknown 1   White
Data Element Name: RACE-CODE-2
Definition: Quarterly Field - A code indicating if the eligible has indicated a race of Black or African-American.
Coding Requirements: Use this code to indicate if the eligible's race demographics include a race of Black or African-American. This determination is independent of indications of other races. That is, for RACE-CODE-1 through RACE-CODE-5, any combination of race codes is possible. If there is no available race information for the eligible, code all five RACE-CODE(s) as 0, and the race for the eligible will be deemed to be unknown.
Valid Values   Code Definition 0   Non-Black or African American or Race Unknown 1   Black or African American
Data Element Name: RACE-CODE-3
Definition: Quarterly Field - A code indicating if the eligible has indicated a race of American Indian or Alaska Native.
Coding Requirements: Use this code to indicate if the eligible's race demographics include a race of American Indian or Alaska Native. This determination is independent of indications of other races. That is, for RACE-CODE-1 through RACE-CODE-5, any combination of race codes is possible. If there is no available race information for the eligible, code all five RACE-CODE(s) as 0, and the race for the eligible will be deemed to be unknown.
Valid Values   Code Definition 0   Non-American Indian or Alaska Native or Race Unknown 1   American Indian or Alaska Native
Data Element Name: RACE-CODE-4
Definition: Quarterly Field - A code indicating if the eligible has indicated a race of Asian.
Coding Requirements: Use this code to indicate if the eligible's race demographics include a race of Asian. This determination is independent of indications of other races. That is, for RACE-CODE-1 through RACE-CODE-5, any combination of race codes is possible. If there is no available race information for the eligible, code all five RACE-CODE(s) as 0, and the race for the eligible will be deemed to be unknown.
Valid Values   Code Definition 0   Non-Asian or Race Unknown 1   Asian

Data Element Name: RACE-CODE-5
Definition: Quarterly Field - A code indicating if the eligible has indicated a race of Native Hawaiian or Other Pacific Islander.
Coding Requirements: Use this code to indicate if the eligible's race demographics include a race of Native Hawaiian or Other Pacific Islander. This determination is independent of indications of other races. That is, for RACE-CODE-1 through RACE-CODE-5, any combination of race codes is possible. If there is no available race information for the eligible, code all five RACE-CODE(s) as 0, and the race for the eligible will be deemed to be unknown.

Valid Values	Code Definition
0	Non-Native Hawaiian or Other Pacific Islander or Race Unknown
1	Native Hawaiian or Other Pacific Islander

Ethnicity

Data Element Name: ETHNICITY-CODE
Definition: Quarterly Field - A code indicating if the eligible has indicated an ethnicity of Hispanic or Latino.
Coding Requirements: Use this code to indicate if the eligible's demographics include an ethnicity of Hispanic or Latino. This determination is independent of indication of RACE-CODE (1-5).

Valid Values	Code Definition
0	Not Hispanic or Latino
1	Hispanic or Latino
9	Ethnicity Unknown

Sex

Data Element Name: SEX-CODE
Definition: Quarterly Field – The eligible's gender.
Coding Requirements:

Valid Values	Code Definition
F	Female
M	Male
U	Unknown

CHIP STATISTICAL ENROLLMENT DATA SYSTEM (SEDS) FORM RACE, ETHNICITY, GENDER

CHIP Statistical Enrollment Data Reports

Gender, Race, Ethnicity

| RACE | AL | 3/01/2011 | 6EA8E4EF-3AA0 |

Gender, Race, Ethnicity	State:					
				Quarter:		
		21E Enrolled	64.21E Enrolled	Total CHIP Enrolled	64.EC Enrolled	21PW Enrolled
Gender						
1 Female						
2 Male						
3 Unspecified Gender						
Race						
1 American Indian/Alaska Native						
2 Asian						
3 Black or African American						
4 Native Hawaiian or Other Pacific Islander						
5 White						
6 More than one race (regardless of ethnicity)						
7 Unspecified Race						
Ethnicity						
1 Hispanic or Latino						
2 Hispanic or Latino and one or more race						
3 Unspecified Ethnicity						

Form Race/Ethn./Gndr

Note: Though the ethnicity categories in the SEDS instruction manual conform to the OMB standards, due to a programming error, the current ethnicity field in the SEDS system does not. This field is scheduled to be updated in accordance with the OMB standards in fall 2011, and States will begin reporting data accordingly on January 1, 2012.

Source: Form "Race, Ethnicity, Gender." CHIP Statistical Enrollment Data System (SEDS). Centers for Medicare & Medicaid Services.

CHIP STATISTICAL ENROLLMENT DATA SYSTEM (SEDS) DATA DEFINITIONS

Race

White. A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.
Black or African American. A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."
American Indian or Alaska Native. A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.
Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, The Philippine Island, Thailand, and Vietnam.
Native Hawaiian or Other Pacific Islander. A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
More Than One Race (regardless of ethnicity). If a person self reports more than one of the above racial categories, report this count for those persons selecting more than one race, as well as the counts for the individual races selected. States shall offer respondents the option of selecting one or more racial designations. (Recommended forms for the instruction accompanying the multiple response question are "Mark one or more" and "Select one or more.")
Unspecified Race. If Race is not reported or Race is unknown, States shall report that the enrollee is an Unspecified Race.

Ethnicity

Hispanic or Latino. A person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race. The term, "Spanish origin," can be used in addition to "Hispanic or Latino."
Not Hispanic or Latino. Respondents who self report that they are not of Hispanic or Latino cultural origin shall be counted in this category.
Unspecified Ethnicity. If Ethnicity is not reported or Ethnicity is unknown, States shall report that the enrollee is an Unspecified Ethnicity.

Gender

Gender. This section has three (3) categories, Female, Male, and Unspecified Gender. States submit the number of enrollees who self report that they are Female, or Male, and if not reported or Gender is unknown, States shall report that the enrollee is an Unspecified Gender.

 Bottom of Form