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April 30, 2015

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The Honorable Orrin G. Hatch
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The Honorable Fred Upton
Chairman, Committee on Energy
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The Honorable Ron Wyden
Ranking Member, Committee on Finance
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The Honorable Frank Pallone Jr.
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Re: Report to Congress on Identifying, Collecting, and Evaluating Data on Health Care Disparities in Medicaid and CHIP

The Medicaid and CHIP Payment and Access Commission (MACPAC) appreciates the opportunity to comment on the U.S. Department of Health and Human Services (HHS) report to Congress released in November 2014: *Improving the Identification of Health Care Disparities in Medicaid and CHIP*. MACPAC is required by statute to review and comment on reports to Congress submitted by the Secretary of HHS within six months of the submission date and provide written comments to the Secretary and appropriate committees of Congress.

The ability to identify health care disparities in Medicaid and the State Children's Health Insurance Program (CHIP) is important to efforts to ensure access to and quality of health care for many Medicaid and CHIP enrollees. The Commission commends HHS on its efforts, and offers comments in the following areas:

- survey data;
- administrative data;
- core quality measures; and



- all data sources.

Report Summary

Section 4302(a) of the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) requires the Secretary of HHS to develop data collection standards for five demographic categories: race, ethnicity, sex, primary language, and disability status. Section 4302(b) requires the collection of data on these five demographic characteristics in Medicaid and CHIP and an evaluation of approaches for the collection of 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 the basis of these five demographic categories.

The new data collection standards apply to survey and administrative data, as well as the core quality measures in Medicaid and CHIP. HHS published the final standards for surveys in October 2011, which include the following categories to be applied to surveys conducted or sponsored by HHS to the extent practicable (ASPE 2011):

- **Race:** white, black or African American, American Indian or Alaska Native, Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, other Asian, Native Hawaiian, Guamanian or Chamorro, Samoan, and other Pacific Islander;
- **Ethnicity (Hispanic, Latino/a, or Spanish origin):** Mexican, Mexican American, Chicano/a, Puerto Rican, Cuban, and other;
- **Sex:** male or female;
- **Primary language:** a question asking how well the respondent speaks English (very well, well, not well, not at all), and two optional questions about spoken language (does the respondent speak a language other than English at home and if so, what is the language);
- **Disability:** deaf or serious difficulty hearing; blind or serious difficulty seeing; serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition; serious difficulty walking or climbing stairs; difficulty dressing or bathing; difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition.

To improve data collection, the Centers for Medicare & Medicaid Services (CMS) has made efforts to modernize the Medicaid and CHIP data infrastructure, including launching the Transformed Medicaid Statistical Information System (T-MSIS); incorporating new data standards into all new patient experience surveys as well as existing surveys at the time of major revision; and incorporating new data elements into the single, streamlined application that the Secretary of HHS developed and provider to each state for coverage in qualified health plans, exchange subsidies, Medicaid, and CHIP.

To improve data analysis and reporting, including reporting of core quality measures, CMS has promoted the use of core quality measures to help identify and evaluate health care disparities in Medicaid and CHIP; and promoted data sharing and analyses in collaboration with other HHS agencies such as the Agency for Healthcare Research & Quality.



In the report, HHS provides two recommendations for its own future work in the report: to improve the quality of federal health care disparities data, including the accuracy and completeness of data, across health care payers; and to improve the completeness of health care disparities data collection in managed care.

MACPAC Comments

Improving the identification of health care disparities in Medicaid and CHIP allows policymakers and implementers to monitor the needs of specific populations that may be at increased risk for certain health conditions or have trouble accessing the care that they need. MACPAC acknowledges and appreciates the work that HHS has already completed in its efforts to identify, collect, and evaluate data on health care disparities in Medicaid and CHIP. Such a task requires extensive resources, including time, and expertise.

MACPAC offers the following comments to HHS and Congress about opportunities to build on HHS's progress in identifying health care disparities in Medicaid and CHIP:

1. **Survey data.** The Commission stresses the importance of timely implementation of the new data collection standards into all relevant surveys. In particular, the Commission notes the importance of including primary language and disability variables, which have historically been left out of many surveys.
2. **Administrative data.** MACPAC notes, as it has on several other occasions, that the timeliness, quality, and availability of federal administrative data on Medicaid and CHIP must be improved. T-MSIS should improve the completeness and consistency of administrative data and the Commission urges CMS to continue its efforts to ensure that all states will contribute to T-MSIS. CMS should act to ensure that states are capturing information on race and ethnicity—including information gathered using the model application developed by the federal government for QHP, Medicaid, and CHIP coverage—in their eligibility systems and reporting these data to the federal government at the level of detail specified in the T-MSIS dictionary.
3. **Quality measures.** All Medicaid and CHIP enrollees should have access to appropriate, high quality care. The Commission wishes to reiterate its support for the quality measures identified by CMS, but also notes concern about the voluntary nature of data collection and provision by the states to CMS. To the extent possible, the Commission supports expanding the number of demographic categories required for identification and evaluation within the core sets, such as the requirement that states participating in the Adult Medicaid Quality Grant Program must report at least three of four select measures but only for at least two demographic categories.
4. **All data sources.** MACPAC has previously commented on the significance of collecting data for federal and state officials. Even so, the Commission recognizes the resource limitations affecting all parties. Therefore, data should be collected to the extent they will be utilized for program management and policy development. While there are many important demographic characteristics that might be useful in examining different aspects of Medicaid and CHIP, the five elements currently being introduced into survey and administrative data sources should be the focus of HHS's efforts to identify health care disparities in Medicaid and CHIP. Additionally, HHS should ensure that data collection efforts are tailored to reflect the fact that some races and ethnicities can be identified in multiple ways. For example, data that identify a



person as being Native American can come from self-identified eligibility information or claims data from providers such as the Indian Health Service, which is only permitted to serve Native Americans.

The Commission recognizes the importance of investing in data improvements to both administer and evaluate Medicaid and CHIP and ultimately improve the value of services provided to beneficiaries. We appreciate the opportunity to provide comments on the important data collection and policy issues raised in this report.

Sincerely,



Diane Rowland, ScD
Chair

Reference

Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. 2011. *U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. October 28, 2011: <http://aspe.hhs.gov/datacncl/standards/ACA/4302/index.shtml>.