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Brookings National Conference on Health Care Disparities

Mara Youdelman
youdelman@healthlaw.org

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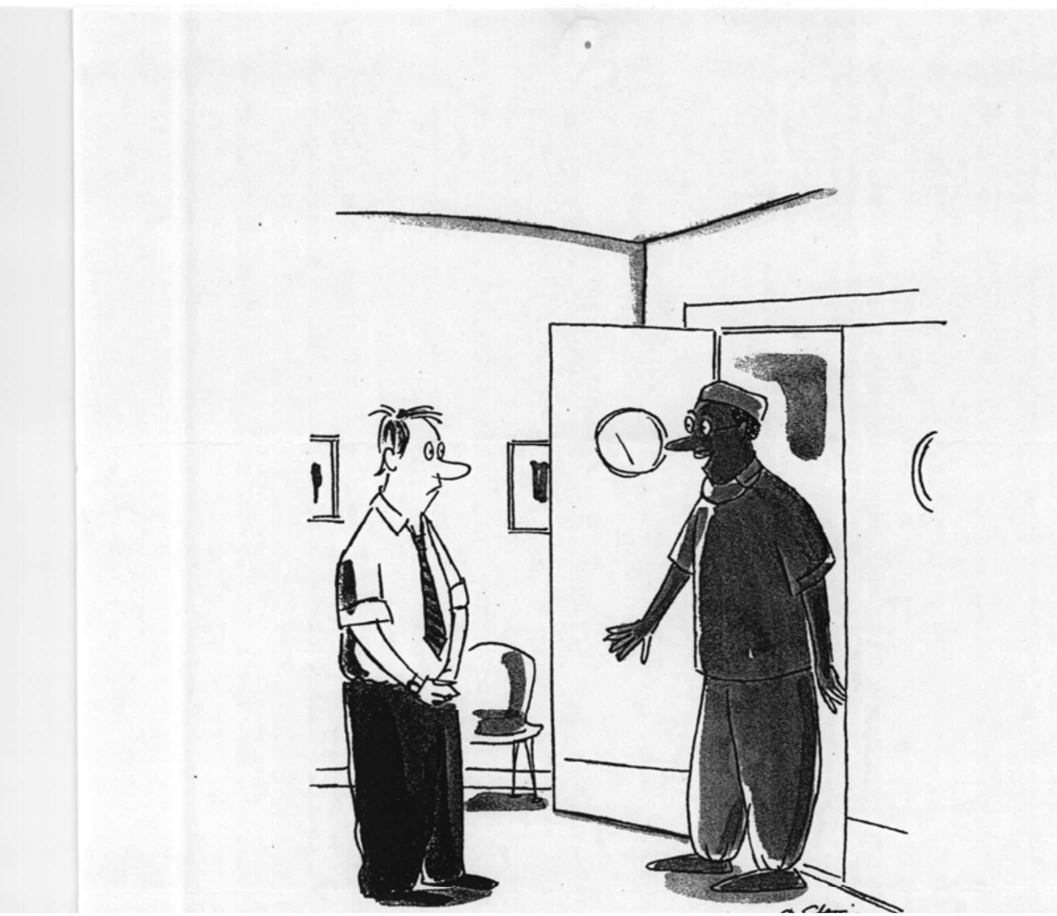
“Securing Health Rights for Those in Need”



"It's a baby. Federal regulations prohibit our mentioning its race, age, or gender."

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Health Disparities Likely Reinforced by a Lack Of Data

- Without data, its difficult to:
  - identify and eliminate any health disparities correlated with race or ethnicity or language
  - develop targeted outreach and quality improvement activities
  - promote culturally and linguistically competent services

Title VI of the Civil Rights Act

- "No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 42 U.S.C. § 2000d
- Provides a legal foundation for the collection of racial and ethnic data even when a specific statutory requirement to collect this data does not exist

Title VI (contd.)

- Title VI protection extends to all programs and activities of any entity receiving federal funds, whether or not the particular program at issue has itself received or benefited from those funds
- Department of Justice Title VI regulations – but not HHS – require data collection sufficient to demonstrate compliance with Title VI
- HHS does <u>not</u> prohibit the routine collection of racial and ethnic data

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HIPAA

- HIPAA required HHS to adopt code sets for electronic transmission of data - each code set is designated as “required,” “situational” or “not used”
- For health care claims (encounters), race & ethnicity code set is currently designated as “not used”
- For benefit enrollment and maintenance, race & ethnicity code set is designated as “situational”
- The result is a missed opportunity to comprehensively collect racial and ethnic data

HITECH Act (2009)

- Requires standards for collecting r/e/l in EHRs
- Proposed regulations released from the Office of the National Coordinator & CMS
- Comment period closed March 15, 2010

Health Reform

- Sec. 4302 – applies to all health care/public health programs, activities, and surveys
  - Collect race, ethnicity, primary language
  - Collect sufficient data to generate statistically reliable estimates for subgroups
  - Medicaid to use OMB standards
  - CHIP to collect language data of enrollees & parents/guardians
  - Medicare will have to start collecting data

Social Security Administration

- SS-5 – Application for Social Security Card
    - Updated 2009
    - Now collects race/ethnicity using OMB standards

- Enumeration at birth
    - Requests forwarded from state vital statistics
    - SSA does not require reporting of r/e

IOM Recommendations

- Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement
  - Released 2009
  - How to collect race/ethnicity/language
  - Offers standardization to allow apples-to-apples comparisons across health programs/plans/surveys
  - Hopefully will be adopted by HHS for Health IT and all data collection

Quality & Accrediting Organizations

- NQF – *National Voluntary Consensus Standards for a Comprehensive Framework and Preferred Practices for Measuring and Reporting Cultural Competency*
  - Endorsed HRET Toolkit for collecting language data
- The Joint Commission –
  - New standards require race/ethnicity and "preferred language for discussing health care"
  - Guide on implementing effective communication, cultural competence and patient-centered care (Spring 2010)
- NCQA –
  - Proposed revisions to HEDIS "Diversity of Membership" measures to align with OMB standards and IOM recommendations (public comment ended)
  - Voluntary Multicultural Health Care Program – includes evaluation of r/e/l data collection (being released on 3/29)

State Laws

- 2002 research – CA, MD, NH, NJ prohibited collection of race & ethnicity data on enrollment

- 2009 update – MD changed law to explicitly allow collection

Maryland

- Insurer may ask about race and ethnicity at enrollment provided the information is used solely for the evaluation of quality of care outcomes and performance measurements
- May not use race or ethnicity data to reject, deny, limit, cancel, refuse to renew, increase the rates of, affect the terms or conditions of, or otherwise affect a health insurance policy or contract
- Requires certain independent agencies within the state’s Department of Health and Mental Hygiene to collect r/e data and report annually

Other States

- MA – regulations require hospitals to collect r/e data
- MI – 2006 law for Medicaid agency to develop and implement a structure to address racial and ethnic health disparities
- MO – FQHCs must report race

Related Data Collection

- Risk Management Issues
  - Lack of effective language services can hinder communication and raise risk of harm/malpractice
- Use of language services
  - Usage of interpreters
  - Provision of translated materials
- Competency of interpreters/translators
  - OCR LEP Guidance – need to ensure competency
  - Efforts to create national standards – Certification Commission for Healthcare Interpreters

Conclusions

- Collecting r/e/l data is legal and supported by federal and state law
  - Very few state restrictions on data collection – only limit collection pre-enrollment
- Collecting r/e/l data can help identify health disparities and methods of eliminating them
- New federal requirements to collect r/e/l will improve data collection