



**Memorandum:
Recommendations Related to
Data Collection Requirements in Section 4302**

Section 4302 of the Patient Protection and Affordable Care Act (ACA), adding new section 3101 to the Public Health Service Act, requires the Department of Health and Human Services (HHS) to ensure that certain data is collected throughout all HHS programs, activities and surveys. In particular, it requires that data be collected on race, ethnicity, primary language, sex, and disability status. It also permits the Secretary to extend this requirement to any other demographic data regarding health disparities. To implement this section, HHS must determine the scope of this provision (specifically to what and whom the new data collection requirements apply), what standards should be used to collect this data, and what, if any, other demographic categories should be required for collection.

Below are the collective recommendations related to implementing this provision from organizations representing communities and populations who will be most affected by the effective implementation of this new requirement.

Overarching Recommendations

The following recommendations are critical to any data collection initiative, across demographic categories:

- ***Ensure community input and engagement in the design, planning, implementation and dissemination of data.*** HHS should ensure that community stakeholders are included in the decision-making process and testing of the Secretary's data collection, reporting and analysis protocol under section 4302. We recommend that HHS also create an expert advisory committee, similar to the U.S. Census Advisory Committees, to ensure that all federal surveys have a process of including non-governmental partners from all Office of Management and Budget (OMB) racial communities to participate in the design, planning, implementation and dissemination of survey data. The inclusion of non-governmental partners will help address the unique cultural, linguistic, and social barriers that deter certain populations from survey participation. The Secretary should build partnerships with local community organizations and trusted groups within these hard-to-count communities to develop data collection protocols that are culturally respectful, and ensures confidentiality for the survey participants.

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- ***Utilize community-based outreach strategies to ensure robust participation of respondents from targeted communities, including racial, ethnic and limited English proficient populations.*** HHS should form community partnerships to ensure sufficient geographic and population-specific representation in any data collected, reported or analyzed pursuant to section 4302. National survey projects such as the U.S. Census have benefitted from high participation rates due to the investments in community outreach that were built into the research design.
- ***Train staff in collecting demographic data, including explaining why this data is being collected.*** The Health Research and Educational Trust (HRET) developed a toolkit for collecting race, ethnicity and language data after testing different rationales for collecting this data.ⁱ Similar training toolkits should be developed and made available for the other demographic categories.
- ***Adopt clear privacy and nondiscrimination protections.*** For this requirement to be impactful, individuals must feel comfortable disclosing personal information that can help to improve the care they receive and foster a broader understanding of health care disparities. We support the language in section 4302(e)(1)(A)(i) regarding the application of the Health Insurance Portability and Accountability Act (HIPAA) of 1996, and encourage HHS to ensure that the privacy protections applied to demographic data should be not only as broad as HIPAA, but as stringent. Patients should be made aware of their privacy protections and rights – including those granted under applicable state laws as well as HIPAA – and have a clear understanding of why this information is being collected and who will have access to what forms of information.
- ***Safeguard that patient/enrollee reporting of demographic data be voluntary.*** While health care systems and providers should be required to ask for data of patients/enrollees, the responses to data collection requests are (and should be) voluntary for patients/enrollees to report and should be self-reported to ensure accuracy.
- ***Support analyses based on multiple demographic variables.*** While this section lists several specific demographic variables for data collection to better understand and address health disparities,ⁱⁱ it should be emphasized that these variables are neither mutually exclusive nor unrelated. As individuals, each person has a sex, race, ethnicity, primary language, and disability status, and all these demographic identities interact in relevant ways for understanding and addressing health disparities. At the community and population level, these variables, both individually and in combination, can be explanatory for both risk and protective factors. Racial and ethnic minority women receive poorer quality care than racial and ethnic minority men, who receive poorer care than white men.ⁱⁱⁱ Spanish-speaking Hispanics experience poorer quality care than English-speaking Hispanics, who experience poorer care than non-Hispanic whites.^{iv} Compared to women without disabilities, women with disabilities are more likely not to have regular mammograms or Pap tests.^v Racial and ethnic minorities with disabilities experience greater disparities in diagnoses and utilization of assistive technology.^{vi} When

additional variables such as socioeconomic status, sexual orientation, and gender identity also are considered, there is evidence that these multiple variables may have a cumulative or compounding impact on health disparities.^{vii} While health disparities research and analyses often focuses on variations based on a single demographic variable, in our increasingly multicultural society, it is vital that HHS's future data collection support these types of analyses based on multiple demographic variables. This requires standardized categories and definitions for all these demographic variables as well as inclusion of all these variables in as many data collection opportunities as possible. Finally, given the smaller population sizes of some of these variables, it is critical that oversampling and other small population data collection methods continue to be used by HHS, especially when seeking data based on multiple demographic variables.

Scope

As the Department of Health and Human Services (HHS) develops regulations and policies implementing section 4302, it will not only define standards for the collection of different categories of data but also determine to what and whom the new data collection requirements apply. How narrowly or broadly HHS interprets the scope of this provision will ultimately determine how effective this requirement will be in combating health and health care disparities.

The collection of high quality data in quantities sufficient for study is a critical first step in understanding and eliminating disparities in health outcomes and access. While the existence of health disparities in the U.S. has been well documented, the reasons for these disparities still are not fully understood. In part, this is due to a lack of high quality, easily available data. For example, data on smaller racial and ethnic groups is often not robust enough to lend itself to meaningful analysis. Similarly, data is often not available for intersecting subpopulations that might experience multiple barriers to access, such as Latinas who have disabilities or transgender individuals with limited English proficiency.

The need for better data is clearly articulated by a variety of researchers studying health disparities. For example, a recent report on health disparities in the U.S. by the Centers for Disease Control and Prevention (CDC) cites a lack of sufficient data, especially with respect to disability status and sexual orientation, as a limitation of the report^{viii}. The need for better data collection was also the subject of a 2004 publication of the Committee on National Statistics entitled *Eliminating Health Disparities: Measurement and Data Needs*.^{ix}

In addition to identifying disparities, high quality data is critical to addressing these disparities. Data can help researchers, policy makers, public health workers, and health care practitioners target interventions to the populations that need them most and tailor interventions to the specific needs of a community. Further, health disparities data collection is crucial for measuring quality. Such information is integral to understanding if a particular program is improving the health outcomes of all groups. Without this data, average improvement in the health outcomes could mask a lack of improvement or even worsening in outcomes for a specific population.

Therefore, it is crucial for demographic data to be collected in sufficient quantities, in a variety of health care settings, and at multiple levels of geographic detail.

At a minimum, we strongly encourage HHS to apply the new data collection requirements to federally-supported health care providers (at the point of care), publicly administered or financially assisted health programs (at enrollment), and federally supported national surveys and research. We also believe the requirements should be included in any federal reporting requirements imposed for purposes of measuring quality.

Statutory Basis

The statutory language of section 4302 applies data collection requirements to *any* “federally conducted or supported health care or public health program, activity or survey . . . to the extent practicable.” This includes not only the listed national surveys (the Current Population Surveys and American Community Surveys conducted by the Bureau of Labor Statistics and the Bureau of the Census) but also any health care or public health program or activity that is conducted by the federal government or that receives federal financial support. Federal support is typically defined as “the U.S. Government providing any funding or other support.”^x Health care surveys that collect data on specific health services such as the Medical Expenditure Panel Survey should also fall under this category.

The plain language of the statute indicates that section 4302 is not limited to large federally supported national surveys. Section 4302 specifically includes “*any* health care or public health program, activity or survey” (emphasis added). The inclusion of the word “any” makes clear that all health care and public health programs or activities are subject to section 4302 and must collect data in accordance with the rules and regulations that will be promulgated by the Secretary. This includes federally-supported health care providers. The plain language is unambiguous on this point. Section 4302 specifically includes **health care** programs or activities. By definition, the provision of medical care by a health care provider is a health care program. For example, the Merriam-Webster dictionary defines health care as, “efforts made to maintain or restore health especially by trained and licensed professionals.”^{xi} Similarly, publicly administered health programs, such as Medicare, Medicaid, and the Children’s Health Insurance Program (CHIP), as well as new programs established by the ACA, like the Pre-Existing Insurance Plan Program and Health Insurance Exchanges (which are supported by federal funds assisting states to set-up Exchanges as well as subsidies to insurers and health plans participating in the Exchanges to enroll low-income individuals), also clearly fall within the purview of section 4302 and must comply with the data collection provisions.

In addition, the statutory language requires that “*any* reporting requirement imposed for purposes of measuring quality under any ongoing or federally conducted or supported health care or public health program, activity, or survey” (emphasis added) include a data collection requirement for individuals receiving health care items or services under the program. Thus, any federally conducted or supported health care or public health program that is subject to quality reporting requirements must, at a minimum, also collect data on the race, ethnicity, sex, primary language,

and disability status of the individuals who receive health care items or services under that program. We would hope that, while not explicitly required in the statute, this particular requirement would also be extended to include any additional demographic categories specified by the Secretary per section 4302(a)(1)(D).

Implementation

We recognize that while the statute allows for broad application of the data collection requirements, it is limited to what is *practicable*. We do not expect nor do we request that HHS apply data collection requirements to every single health care program, activity, or survey conducted. For instance, it would be impracticable to require the graduate student researching a small study to collect comprehensive demographic data. But, we do ask that HHS avoid interpreting the “practicable” limitation in such a strict way that it would severely limit the effectiveness of the provision. To achieve the goals of this provision efficiently and effectively, we recommend that HHS prioritize application of data collection requirements in three key areas that will result in the greatest impact:

- federally-supported health care providers (at the point of care);
- publicly administered health programs (at enrollment); and
- large federally-supported national surveys.

Application of section 4302 to these three areas is necessary if the federal government is truly committed to identifying and addressing disparities. Demographic data collection will be especially important as we move towards a health care payment system that rewards quality rather than quantity. The ACA recognizes the central role of data in quality care, and appropriately includes a condition that demographic data be collected as a component of any federal quality reporting requirements. In addition to reporting requirements such as the Physician Quality Reporting System (formerly *PQRI*) and Hospital Inpatient Quality Reporting Program (formerly *RHQDAPU*), this provision should apply to any new models of care delivery and payment models and demonstration programs that incorporate quality metrics, like Accountable Care Organizations (ACOs), medical homes, etc. Providers in these new models of care should not solely be held responsible for quality at the population level and should be required to stratify quality metrics by the categories required under this provision to demonstrate that they are reducing and not exacerbating disparities.

Additionally, data collection by federally-supported health care providers as well as health care programs like Medicare, Medicaid, CHIP and the Health Insurance Exchanges will also be critical to ensuring entities comply with civil rights laws, including section 1557 of the ACA, which forbids discrimination on the grounds of race, national origin, gender, age, or disability in health programs or activities that are receiving federal financial assistance, or by programs administered by an executive agency, or any entity established under Title I of the ACA. In implementing section 4302 of the ACA, the Secretary should be cognizant of the interrelationship between sections 4302 and 1557 of the ACA and other civil rights statutes.

Thus, section 4302 should be implemented in a way that will enable the enforcement of the civil rights laws that prohibit discriminatory actions by health programs or activities.

While some providers may raise concerns about the practicability of collecting demographic data collection at the point of care, we believe this is a reasonable requirement. Indeed, many practitioners are already collecting several key forms of data, either voluntarily or because of existing laws and regulations at both the state and federal level. Nationally, 82 percent of hospitals already collect race and ethnicity data and 67 percent collect data on primary language.^{xii} Twenty-two states have passed regulations requiring hospitals to collect race, ethnicity, and language data.^{xiii} Grantees of the Health Resources and Services Administration's (HRSA's) primary care programs, like community health centers, also are required to collect and report patient demographic data.

In addition, the federal government has recently taken an initial step to ensure more uniform data collection requirements at the point of care. Stage 1 of the Medicare and Medicaid Electronic Health Record Incentive Program requires participating Medicare and Medicaid providers and hospitals to record patient demographic data, including race, ethnicity, preferred language, and gender. Survey data recently released by the Office of the National Coordinator for Health Information Technology (ONC) shows that about two-thirds of hospitals and one-third of office-based physicians intend to participate in Stage 1 between 2011 and 2012,^{xiv} demonstrating that providers are ready and willing to take on the responsibility of collecting standardized demographic data. Furthermore, as indicated by a recent Request for Comments from the Health Information Technology Policy Committee, the data collection requirements will get more comprehensive in later stages.^{xv} For Stage 3 – which all Medicare providers must comply with by 2015 or else face financial penalties – providers should expect to collect demographic data (using the categories defined in the Institute of Medicine's (IOM's) 2009 report *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*) from 90 percent of their patients and use this data to produce stratified quality reports.

We also believe that requiring data collection at enrollment in publicly administered health programs, like Medicare, is not only practicable but critical to ensuring equal care is provided to all participants. Medicare does not currently collect language data and relies on data from the Social Security Administration for race and ethnicity, data which is significantly flawed. Yet 94 percent of Medicare/Medicaid enrollees are in plans that collect data on race and ethnicity, and 89 percent are in plans that collect data on primary language. Unfortunately, more often than not these plans rely on indirect sources for race and ethnicity information,^{xvi} while information self-reported at enrollment is generally of a higher quality. The Centers for Medicare & Medicaid Services (CMS) should ensure that this data is gathered from the plans in CMS's databases to allow for analysis and planning purposes. In addition, any data collected during enrollment in the individual and small business exchanges should also be reported to HHS and made publically available.

Specific Data Collection Issues

The next sections of this memorandum will provide detailed recommendations related to the collection of specific demographic data.

A. Race and Ethnicity

Problem

Section 4302(a)(2) directs the Secretary to comply with the 1997 Revised OMB Standards, at a minimum, for race and ethnicity. Currently there are five categories for race based on the OMB Standards—American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White; and two categories for ethnicity—“Hispanic or Latino” and “Not Hispanic or Latino.”

These categories have changed over time and there has been precedence for these changes at the Executive level. For example, OMB’s original Statistical Directive No. 15 classified “Asian and Pacific Islander” as one category, and was separated into two groups as “Asian American” and “Native Hawaiian and other Pacific Islander” pursuant to OMB’s 1997 revised directive. Since then, there have been improvements in the collection, reporting and analysis of data by the federal government, however there continue to be problems with reporting data on smaller populations. For racial/ethnic groups with a relatively small number of members, such as Asian American subgroups, Native Hawaiians, and Pacific Islanders, and American Indians/Alaskan Natives, data collected in national health surveys have often been inadequate to identify salient health issues and inform appropriate policy or other interventions. Such data is often not collected, collected but not analyzed, or not reported due to small sample sizes. Finally, because of a broad array of administrative, cultural, language, social, and other barriers, collecting this data is often problematic. Communities of color, generally, may be reluctant to report their race or ethnicity due to fear of discrimination. Yet much important work has been undertaken to identify the most effective methods of asking for and collecting this data. As one example, HHS could utilize the HRET toolkit to improve data collection throughout its programs and activities.

Recommendations

Implement the IOM’s recommendations on the standardization of race and ethnicity data

The Secretary should adopt all of the recommendations from the 2009 IOM Report on Race, Ethnicity and Language Data, which was commissioned by the Agency for Healthcare Research and Quality (AHRQ) to develop standards for the collection of race, ethnicity and language data. The report, [*Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*](#), recommended variables for standardized collection of race, ethnicity, and language need. The report highlighted the need for granular ethnicity data, and recommended that HHS develop and make available nationally standardized lists for granular ethnicity categories, and proposed strategies for aggregating granular ethnicity categories to the broader OMB race and Hispanic ethnicity categories.

Specifically, the IOM Report proposed the following order of questioning in the collection of race and ethnicity data: Hispanic ethnicity first, followed by OMB race categories, and then granular ethnicity. The granular ethnicity categories should be locally relevant response categories selected from a national standard list with appropriate coding, such as the CDC/Health Level 7 (HL7) Race and Ethnicity Code Set 1.0. In addition, an open-ended option of “Other, please specify: ___” should be provided for persons whose granular ethnicity is not listed as a response option.

Avoid prioritization schemes or other preference categories for multiracial respondents

HHS should follow the recommendations of the IOM Report regarding multiracial respondents which states that “where possible, information on specific combinations of races and ethnicities should be preserved so the data can be aggregated over enough reporting units or periods to provide more informative analyses and the basis for targeted interventions.” In addition, HHS should not use a single category labeled “multiracial” or “more than one race” because it masks detailed information that could be used in analyses.

Utilize multiple sampling strategies to improve the collection and reporting of smaller populations

The Secretary should direct all federally conducted and supported health programs to utilize sampling strategies appropriate to the target populations in the collection, reporting and analysis of race and ethnicity data. Innovative design strategies such as oversampling and targeted sampling can capture data on hard-to-reach populations and have been successfully used to collect granular ethnicity data in the California Health Interview Survey and the National Latino and Asian American Study. Given the flexibility of the statute, the Secretary can make transformative system-wide changes to ensure that small populations like Asian Americans, Native Hawaiians and Pacific Islanders and American Indians/Alaska Natives are represented at the national level with alternative data collection models.

B. Primary Language

Problem

Collecting data on primary language use remains a challenge for HHS. Although English is spoken by a large majority of those living in the United States, portions of the population cannot effectively communicate or understand English. According to Census data, the population of those who are English language learners or non-English proficient has grown significantly within the last decade. Members of these communities are often linguistically isolated and continue to encounter significant health and health care disparities. This is particularly the case for Asian Americans and Latinos, who, at 71 percent and 76 percent respectively, speak languages other than English in their home. Since those with limited English proficiency may experience significantly greater barriers in accessing health care and information and may thus suffer from poorer health outcomes, it is vitally important to collect data at the federal level on language-

related barriers to inform appropriate interventions and, ultimately, to ensure access to quality care for all.

Recommendations

Implement the IOM's recommendations on the standardization of spoken language need

The Secretary should follow the recommendations from the aforementioned 2009 IOM Report regarding language need. Although the statute requires the collection of “primary language” data, it is silent on the meaning and application of primary language. We suggest HHS adopt the recommendation of the IOM report which prioritizes spoken language need for individuals with limited English proficiency (LEP), defined as able to speak English as “less than very well.” Specifically, the report proposes two questions to assess spoken language need: one assessing the respondent’s ability to speak English, and the second to determine the spoken language preferred in a health care setting using a list of locally relevant response categories from a national standard list, which should include sign language. In addition, an open-ended option of “Other, please specify: ___” should be provided to capture spoken languages not listed as a response option. Where possible, surveys should also collect information on the language spoken at home by the respondent.

Encourage the collection of written language need

While there is evidence that supports a high correlation between English-language proficiency in speaking, reading, and writing ability, differences in education level and health literacy can have an impact on an individual’s reading comprehension. As such, HHS should support the recommendations of the 2009 IOM Report and encourage the collection and reporting of written language preference, including Braille.

Ensure compliance with Title VI and Sec. 1557 non-discrimination requirements by providing translated health surveys and increasing HHS’ language assistance capacity

To ensure participation of LEP individuals and adequate sampling, the Secretary should ensure the proper allocation of resources for written translation and spoken interpretation assistance in its federally conducted programs, activities, and surveys and support funding in federally assisted activities. National survey projects should increase language access by hiring bilingual interviewers or utilize interpreters to assist interviewers to administer surveys in multiple languages. HHS should also trans-create^{xvii} surveys or develop surveys initially in non-English languages. For example, the Census Bureau hires bilingual enumerators to ensure meaningful participation, and the California Health Interview Survey reaches linguistically isolated communities through English simplification and linguistic translation (into Chinese, Korean, and Vietnamese) of its materials. Health surveys and other data collection tools should also be tested for appropriate health literacy levels.

Providing language assistance helps address privacy and confidentiality concerns of respondents by ensuring LEP individuals do not have to rely on friends or family to whom they may not otherwise disclose health information for informal language assistance, and also ensures HHS’ compliance with Title VI of the Civil Rights Act of 1964, which prohibits any federally-funded

program or activity from race or national origin discrimination; Title VI was extended to apply to HHS by Executive Order 13166. Section 1557 of the ACA reinforces this prohibition against discrimination by forbidding any federal program or entity that receives federal funding or assistance from discriminating on the grounds of race, color, national origin, gender, and disability.

C. Disability Status

Section 4302 of the ACA mandates the collection of data on “disability status for applicants, recipients, or participants” by “any federally conducted or supported health care or public health program, activity or survey.” In addition, section 4302 also requires the collection of additional information related to specific, known barriers to healthcare that affect individuals with disabilities and that contribute to the health and health care disparities they experience, and sets forth the following specific data collection standards:

“[S]urvey health care providers and establish other procedures in order to assess access to care and treatment for individuals with disabilities and to identify—

- “(i) locations where individuals with disabilities access primary, acute (including intensive), and long- term care;
- “(ii) the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria
- “(iii) the number of employees of health care providers trained in disability and patient care of individuals with disabilities.”

Problem

Disability is not simply the impact of impairment on, or its implications for, the individual, but also results from the interaction between an individual’s impairment and the social, economic, and built environment. This current understanding of disability recognizes the impact of prejudice, discrimination, inaccessible architectural surroundings, and lack of accommodations such as Sign Language interpreters and accessible medical examination and diagnostic equipment. It replaces the long-held belief that disability equates inevitably with biologic dysfunction, disease and poor health.^{xviii}

In its *International Classification of Functioning, Disability and Health (ICF)*, the World Health Organization (WHO) recognizes that factors outside the individual contribute to the experience of disability. The ICF calls disability an “umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person’s functioning and disability... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors” including environmental and personal attributes. The ICF aims to shift the disability paradigm to universality, encompassing everyone:

Heretofore, disability has been construed as an all or none phenomenon: a distinct category to which an individual either belonged or not. The ICF, on the other hand, presents disability as a continuum, relevant to the lives of all people to different degrees and at different times in their lives.

Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition....^{xix}

Reflecting the new understanding of disability, the 1990 Americans with Disabilities Act^{xx} and Section 504 of the 1973 Rehabilitation Act^{xxi} require that covered entities, including health care programs and facilities, remove physical barriers and provide needed accommodations and equipment, as well as prohibit disability discrimination in order to ensure equality of opportunity to participate in and benefit from care and services.

Disability rights laws such as the ADA, along with evolving public health research methods and the nomenclature of the ICF, have provided the foundation for a growing body of research on the type and prevalence of health disparities among people with disabilities when compared with the general population. For example, the Surgeon General of the United States, IOM, the National Council on Disability (NCD), CDC, the AHRQ, the National Institute for Disability Rehabilitation Research (NIDRR), and certain agencies of the National Institutes of Health have supported research and released seminal reports documenting what is currently known about access to health care and health disparities among people with disabilities.^{xxii} Moreover, Healthy People 2010 for the first time called for promoting the health of people with disabilities, preventing secondary conditions and eliminating disparities between people with and without disabilities in the US population.^{xxiii} In spite of this progress, little data is available about key factors that affect access to health care and health care outcomes for people with disabilities.

The ACA, for the first time in federal law, acknowledged both the prevalence of health disparities among people with disabilities and that health disparities are not the inevitable outcome of disability or disease, but are the result of complex factors including lack of disability awareness on the part of health care providers, and architectural and programmatic barriers to care. Thus, the ACA calls for identifying disability status through population surveys and among applicants, recipients, or participants in federally conducted or supported health care or public health programs. Moreover, the ACA also calls for data to be collected that will reveal where people with disabilities obtain health care, the availability of accessible facilities and equipment, and the extent to which providers have received training on disability awareness and competency.

The ACA acknowledges disability status as a bona fide demographic characteristic. Moreover, there is a substantial body of work that addresses the identification in surveys of people with disabilities. However, survey methods thus far have not adequately revealed healthcare quality and the healthcare experience of those identified as having disabilities, nor have they pinpointed the barriers to healthcare for people with disabilities. The following discussion of national population surveys and recommendations is presented against this backdrop.

There are a number of national population surveys conducted or supported by the federal government that collect data on disability status and on health services use and expenditures. These include the National Health Interview Survey (NHIS), Medical Expenditures Panel Survey (MEPS), National Health and Nutrition Examination Survey (NHANES), the Survey of Income and Program Participation (SIPP), and the Behavioral Risk Factor Surveillance Survey (BRFSS) (see Table). Although not a population-based survey, the Medicare Current Beneficiary Survey (MCBS) also collects extensive information on the disability status and healthcare experiences of Medicare recipients. The American Community Survey (ACS) and Current Population Survey (CPS) also ask questions that identify who have a disability; however, they do not collect detailed information on health services use, expenditures, or experience. All the surveys with an explicit health information focus use the patient as the unit of analysis and, with the exception of the BRFSS, ask six or more questions about functional or activity limitation to identify respondents with disabilities. The BRFSS asks two questions that are not as well validated as the measures used in other surveys. The MEPS (which is a sub-sample of NHIS respondents), NHANES, and the MCBS also collect information about the services received that includes location of care and type of provider.

For many years, the federal health-focused surveys have included questions that allow the identification of disability using a set of questions based either on activity limitation or functional limitation. With a few important exceptions,^{xxiv} the standard reporting of data from the surveys has often not reported out health services use or health outcomes and disparities by disability status. Analyses of the current data collection efforts have concluded that more, better, and *consistent* data are needed; however, there exists a base upon which to build a data collection strategy. For a chart outlining Federal Surveys with Disability Status and Health Services Characteristics Data, see Appendix A.

Recommendations

Standardize questions about functional limitations using ACS questions as a starting point.

Six questions asking about functional limitations have now been incorporated into the ACS following cognitive testing and non-response assessment. These six questions are used to identify respondents with disabilities in the ACS and several other federal surveys. Thus, there is increasing consistency in the use of a set of questions to identify the population of persons with disability. The six questions in the American Community Survey (2008 version and subsequent) are:^{xxv}

- 1) Is this person deaf or does he/she have serious difficulty hearing? (17a: Hearing Disability, asked of all ages)
- 2) Is this person or does he/she have serious difficulty seeing even when wearing glasses? (17b: Visual Disability, asked of all ages):

- 3) Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? (18a: Cognitive Disability, asked of persons ages 5 or older)
- 4) Does this person have serious difficulty walking or climbing stairs? (18b: Ambulatory Disability, asked of persons ages 5 or older)
- 5) Does this person have difficulty dressing or bathing? (18c: Self-Care Disability, asked of persons ages 5 or older)
- 6) Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (19: Independent Living Disability, asked of persons ages 15 or older)

Ensure that standardized disability questions identify people with functional limitations associated with certain cognitive, emotional, or learning impairments.

We support the use of the ACS questions as a starting point, but they are insufficient because they fail to identify people with limitations associated with certain cognitive, emotional, or learning impairments. We strongly recommend that additional questions that ask about these functions be added to the standard 6 for use in identifying disability status. These questions will need to be developed, but they can be built upon the experience with such questions in the health surveys. These additional questions are necessary because otherwise persons who experience health disparities and healthcare access barriers associated with their functional limitations are likely to be missed.

Collect activity limitation information at enrollment and point of care (in the electronic health record) and information about accommodations a patient needs to access services and to improve the quality of care.

The same activity limitation questions (the six-plus) should be used by health plans at enrollment. While the wording in the illustration above is in the third person, the questions are already used in the other surveys to ask the individual directly. In other words, they are self-reports of functional limitation. Where needed, a proxy (e.g. a parent or adult child) has answered these questions. Beyond this broad measure, a way to identify persons with specific risks of barriers to health care and health services is needed. Both at enrollment and point of care, information about what a patient needs to enable access would meet the data collection requirements and at the same time prepare providers with information that can improve the quality of care.

It is important to recognize that identification of individuals with disabilities in health care settings is a dynamic process. People need to be able to identify multiple functional limitations for themselves, and there needs to be a means to update this over time. With the establishment of electronic medical records, it will be feasible to incorporate the functional limitation questions into the record, completed by the patient (or proxy) as a part of the assessment information routinely collected when patients appear for care. The inclusion of these questions in the record

will enable the patient characteristics to be connected to provider characteristics and in this manner provide data on the location where patients with disabilities receive care.

Other possibilities include working with the Systematized Nomenclature of Medicine Clinical Terms (known as SNOMED CT®) to extract functional status information. This is something that is being worked on within NCHS. The Institute of Medicine in its 2007 report recommended that health care settings and providers adopt the nomenclature of the *International Classification of Functioning, Disability and Health*, which is being used internationally. While it has its detractors because the full ICF classification is cumbersome, there should be consideration of using it in U.S. settings because condition specific identifiers of disability appropriately related to ICF domains are being developed. Thus the complete classification would not have to be used.^{xxvi}

Explore with CMS the possibility of retrieving information on locations where people with disabilities receive care who are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries.

There are no known sources of information on the locations where people with disabilities receive health care. However, approximately 20 million children, adults, and seniors^{xxvii} with disabilities rely on Medicaid or Medicare for health insurance. We recommend that the Department of Health and Human Services (HHS) explore with the Centers for Medicare and Medicaid Services (CMS) the potential to retrieve information from CMS databases on the locations where people with disabilities who receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits receive care. As the payer for services, CMS may have access to information that could assist in meeting the requirements of Section 4302. CMS should also obtain such information from states that collect it in relation to Medicaid funding. If such information is not readily available, as a condition of Medicaid payments to states, or Medicaid or Medicare payments to health care providers, CMS should require that providers develop methods to acquire the information called for in Section 4302 and report that information annually.

Require identification of the number of providers with accessible facilities and equipment, including medical diagnostic and treatment equipment, as a condition of federal approval of state Medicaid plans and Medicaid waivers.

Limited information is currently available about the extent to which health care facilities and equipment are accessible and meet the needs of individuals with disabilities. Researchers have found that it is difficult to obtain data from healthcare providers, thus it has been difficult to obtain a quantitative estimate of access barriers, and no federal survey of accessibility of health care facilities yet exists. A recent research review reveals only a few studies that have collected information about healthcare provider accessibility. The studies involved small numbers of providers ranging from 10 to 68, with the exception of the California study of 2389 sites using the methodology that California will now use statewide described below.^{xxviii} In light of the fact that lack of physical accessibility and accessible diagnostic equipment is cited as a reason why certain people with disabilities experience problems obtaining healthcare, it is especially important that steps be taken to begin to systematically collect this information.

In November 2010, California obtained an 1115 Medicaid waiver from the US Centers for Medicare and Medicaid Services (CMS) that permits mandatory enrollment in a managed care health plan of Medicaid beneficiaries who are people with disabilities and seniors residing in specific counties. As a term and condition of the waiver, California must require that Medicaid Managed Care Health Plans conduct accessibility surveys of the primary care practitioners who participate in their service networks. Data collected by the plans using an 86-question survey will be entered into a database managed by the individual Plan and relevant information on accessibility of provider facilities and services provided to member beneficiaries as needed.^{xxix}

Prior to this mandate, five Plans voluntarily conducted accessibility surveys with their networks of primary care providers between 2006 and 2010 using a 55-question research instrument. Research conducted using the outcomes of the combined data from these plans revealed levels of accessibility for 2,389 primary care provider facilities. The survey also evaluated availability of height-adjustable examination tables and wheelchair accessible weight scales in these facilities. Analysis of the combined data revealed significant access deficiencies in restrooms and certain parking facilities. However, the most notable outcome was the absence of accessible equipment: only 8.4percent had height-adjustable exam tables and 3.6percent had accessible weight scales.^{xxx}

California's requirement that accessibility data be collected for network providers in Medicaid Managed Care Plans offers a unique, yet tested model for other states to collect such information. CMS should require that, as a condition of approval of the state Medicaid plan or any Medicaid waiver that permits mandatory enrollment of Medicaid beneficiaries into managed care, that Medicaid Health Plans with which the states contract for service be required to conduct either the same or a similar survey with their provider networks. Plans should provide outcomes to their respective states and, in turn, states should be required to provide the data to CMS as a method to meet the accessibility data requirement of Section 4302 of the ACA.

Other than those relatively few cases where a managed care organization directly hires and employs health care providers, providers who work individually or within group practices are free to engage in any number of managed care as well as fee for service contracts. In many cases, the provider who contracts to take Medicaid patients for a managed care plan is the same provider who also takes Medicare patients and private fee-for-service patients. The accessibility information obtained by plans through network surveys should therefore be widely applicable to all provider and provider offices. Thus, information about provider accessibility and availability of accessible exam, diagnostic and treatment equipment can be extrapolated for patients who are not part of a Medicaid program.

Condition the receipt of federal funds for the Affordable Choices of Health Benefits Plans, the Medicare Shared Savings Program, and the Community-based Collaborative Care Networks mandated by the ACA on both assurance of accessibility for people with disabilities and on the regular reporting of data to meet requirements of Section 4302.

The ACA contains several provisions that provide opportunities to collect data on provider facility and equipment accessibility. Several provisions, for example, encourage states and

providers to form consortia and collaboratives to improve coordination, quality, and cost-efficiencies. HHS should condition the receipt of federal funds for these initiatives on both assurance of accessibility for people with disabilities and on the regular reporting of data to meet the requirements of Section 4302. States, plans, providers and others involved with these consortia should be required to make this information available to consumers, as well as to HHS.

ACA Title I, Subtitle D, Sec. 1311 - Affordable Choices of Health Benefits Plans, provides grants to states to establish American Health Benefit Exchanges to facilitate purchase of qualified health plans. The Secretary of HHS is required to establish criteria for certification of qualified health plans, which must include, among other things, assurances of sufficient choice of providers, and include in the networks, providers that serve predominantly low income, medically underserved individuals. The health exchanges must, among other things, maintain a toll-free hotline to respond for requests for assistance and maintain an Internet website where enrollees and prospective enrollees can obtain standardized information on the plans. People with disabilities can only be adequately served if health exchanges include information about provider facility and equipment accessibility, and making this information available to consumers should be required for certification as a qualified health plan.

ACA Title III, Subtitle A, Sec. 3022 Medicare Shared Savings Program, provides incentives for physicians, group practices, and hospitals to join together to form "Accountable Care Organizations." The forming of these groups is intended to enable providers to better coordinate patient care, improve quality, help prevent disease and illness and reduce unnecessary hospital admissions. The Secretary of HHS is to establish criteria for how these providers work together and establish quality performance standards ACOs must meet to be eligible for payments for shared savings. The ACOs must provide the Secretary with "such information regarding ACO professionals participating in the ACO as the Secretary determines necessary to support the assignment of Medicare fee-for-service beneficiaries to an ACO ... and to evaluate the quality of care furnished by the ACO." The Secretary should require that ACOs provide information on their facility and equipment accessibility if the Secretary is to make appropriate assignment of Medicare beneficiaries with disabilities, and properly evaluate the quality of care provided to beneficiaries with disabilities.

ACA Title X, Subtitle C, Sec. 10333 - Community-Based Collaborative Care Networks authorizes the Secretary to award grants to support community-based collaborative care networks - a consortium of health care providers with a joint governance structure that provide comprehensive, coordinated and integrated health care for low income populations. In awarding these grants, the Secretary is required to give priority to networks that, among other things, have "the capability to provide the broadest range of services to low-income individuals." According to a recent report, "People with disabilities account for a larger share of those experiencing income poverty than people in any single minority or ethnic group (or, in fact, all minority ethnic and racial groups combined)..."^{xxxii} Thus, grantees should be evaluated for their capability to provide services accessible to people with disabilities. Grant applications for these funds should be required to include information about facility and equipment accessibility.

Collect health care practitioner training data available through the University Centers for Excellence in Developmental Disabilities (UCEDDs) as a starting point.

According to the National Council on Disability, “The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective health care.”^{xxxii} Moreover, disability competency is generally not a requirement for medical practitioner licensing, educational institution accreditation, or medical education loan forgiveness. There is no standard definition of what it means to be trained in disability or patient care of individuals with disabilities.

Faculty members working with certain medical and other professional health educational institutions that have an interest in promoting disability literacy and competency have worked to embed such courses in the curricula of their institutions, but no organized, combined measurement exists of the number of students who participate.^{xxxiii} Some physicians and others concerned with disability and health have created self-paced on-line trainings for medical practitioners while disability and health advocates in California have developed training for health plans so their master trainers can increase disability competency among staff working in primary care facilities.^{xxxiv} Perhaps the most robust health care practitioner training currently available is provided through the University Centers for Excellence in Developmental Disabilities (UCEDDs) funded through the Developmental Disabilities Assistance and Bill of Rights Act. “The UCEDDs provide community services such as training or technical assistance to people with disabilities, their families, professional and paraprofessional service providers, students, and other community members, and may provide services, supports, and assistance through demonstration and model activities.”^{xxxv} HHS should collect any training data that is available through the UCEDDs as a starting point for assessing health care provider training and awareness.

Identify performance standards and monitoring measures related to disability competency as a condition of receiving Federal financial assistance for health care and related services.

Each of the recommendations set forth above for collecting data about health care providers' accessibility should also be considered for building in questions about provider disability competency. HHS should identify performance standards and monitoring measures that must be included as a condition of receiving Federal financial assistance to ensure that states, health plans, managed care organizations, and health care providers who receive Federal health care funds under Medicaid, the State Children's Health Insurance Program (SCHIP), and other Federal programs that pay for health care for people with disabilities meet the minimum requirements of the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, and that they demonstrate sufficient cultural competency to provide effective health care to people with disabilities.

Mount a targeted research project to assess the availability, content, and quality of disability competency training being offered through professional healthcare education and training programs

In light of the lack of established methods to collect information on the number of health care

practitioners who have received disability training, HHS should mount a targeted project to collect such information. One method would be to generate a request for proposals from qualified research organizations that have the capacity to identify and assess the extent and content of training being offered through the various domains previously identified. Methods for regularly collecting this information should be established within an appropriate agency such as AHRQ or HRSA.

Include development of mechanisms for collecting and reporting information about healthcare provider cultural competency in serving people with disabilities under section 5307 of the ACA

Section 5307 of the Affordable Care Act^{xxxvi} authorizes the Secretary of HHS to enter into contracts or cooperative agreements to develop, evaluate, and disseminate research, demonstration projects, and model curricula for cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities training for use in health professions schools and continuing education programs. Any such project should include the development of mechanisms for collecting and reporting information about provider cultural competency in serving people with disabilities.

Add a query about disability cultural competency training to the existing queries about staff training to state-mandated healthcare provider facility site reviews required for Medicaid funding.

Another method to collect information about the extent of practitioner disability cultural awareness training is to add a line or lines to the existing queries about staff training to the site facility review required by the California Department of Health Care Services of Medicaid Managed Care Health Plans. (Other states may have similar requirements.) The California full review already asks if there is evidence that staff have received training in a number of areas (e.g., infection control/universal precautions, informed consent, and child/elder/domestic abuse). Asking about evidence of training for disability awareness and patient care of individuals with disabilities could be an added inquiry.

Require FQHCs to collect data on disability and functional status.

Federally Qualified Health Centers should be required to engage in the data collection and provider site reviews described above as a condition of their federal funding. This should include the collection and federal reporting of data on provider staff training in disability awareness and patient care of individuals with disabilities. FQHCs also should be required to report on and provide the public with information about the availability of accessible facilities and medical equipment. Information collected about patients should indicate not only their functional limitations, but the kinds of accommodations they require and have been provided in the course of receiving health services.

HRSA and HHS should assist the FQHCs by providing basic training about use of a standardized survey that evaluates physical access as well as medical, diagnostic and treatment equipment accessibility (see above). Such training could either be arranged through contract with qualified community organizations, provided by regional HHS offices or through some other effective

means.

D. Sex

Problem

Behavioral, biological, environmental, and social factors, including biases among health care providers, all contribute to sex disparities in health. For example, numerous studies have shown that a patient's sex affects the amount and type of medical care received. Sex disparities have been identified in areas ranging from who receives kidney transplants, whether a patient receives aggressive HIV treatment, the type of cardiac care received, and the diagnosis of lung cancer. For example, a 2002 study of the medical care received by Medicare patients in their last year of life found that women were less likely to receive expensive high-technology services, such as dialysis and transplantation, timely diagnosis of lung cancer, and specific diagnostic and therapeutic interventions for heart disease.^{xxxvii} A 2006 study found that despite being seen more often by health professionals, female HIV patients receive less aggressive treatment.^{xxxviii} In addition, women's health needs differ from men's in important ways, making data collection by sex necessary to address women's and men's specific health needs. For example, although women are more than twice as likely as men to suffer from a major depressive episode,^{xxxix} men are more likely than women to die from suicide.^{xl} Accurate data collection is necessary to identify these differences and appropriately target resources to address men's and women's different health needs.

Comprehensive and accurate data collection is necessary to identify, understand, and eventually eliminate sex disparities in health. Such data will help researchers, policy makers, and public health workers understand where sex disparities exist, target interventions to the populations that need them most and tailor those interventions to the specific needs of the community. Accurate data collection for sex also makes it possible to understand and address intersectional health disparities. For example, African-American women have a higher prevalence of diabetes than either white women or African-American men.^{xli} Without accurate data on race and sex, important health disparity information would be lost. The higher prevalence of diabetes in African-American women would be masked if data were collected and reported on sex or race alone. Data on sex must therefore be collected throughout the health care system in a way that allows for meaningful analysis of sex disparities in health and that aids in the analysis of intersectional health disparities.

Recommendations

Biological sex, unlike some of the other more complicated categories, is rather straight forward and would only consist of one question on a form. Ensuring, however, that this data is collected at varying points throughout the health care process, in sufficient quantities for useful analysis, and alongside other data, is vital.

It is particularly important that data on sex be collected alongside other data categories. We know that sex intersects with other identities in a variety of ways that might affect health care. For example, while both race and sex disparities were found in a study examining heart attack treatments, it was black women who were the most at risk for not receiving the most aggressive treatments.^{xlii} This is just one example of the ways that sex can intersect with race, ethnicity, primary language, disability, or sexual orientation to affect the health outcomes. Being able to analyze subcategories such as black women or non-English speaking men, while still having sufficient quantities of data for good analysis, is necessary to adequately understand health disparities.

E. Sexual Orientation and Gender Identity

Problem

A significant body of literature attests to the disparities that impact the health and wellbeing of lesbian, gay, bisexual, and transgender (LGBT) individuals and families. These disparities include less access to insurance and healthcare services, including preventive care such as cancer screenings; lower overall health status; and higher rates of chronic conditions, mental health concerns, substance use, sexual health concerns, and violence.^{xliii xliiv xliv} All of these disparities are compounded by wide gaps in state and federal protections for LGBT people and their families against discrimination in areas such as health care, insurance, employment, relationship recognition, and housing.^{xlvi} A small sample of statistics clearly illustrates the disparities that many LGBT people experience, particularly those who are also members of other disparity groups, such as LGBT people of color:

- LGBT people smoke at rates up to 200 percent of the general population,^{xlvii}
- Gay and bisexual men comprise more than half of new HIV infections in the U.S. each year,^{xlviii} and research indicates that HIV prevalence among transgender women exceeds 25 percent nationwide;^{xlix}
- Black and Latina lesbian and bisexual women are much more likely to be overweight than their heterosexual peers;¹ and
- Approximately 30 percent of LGBT youth report having been physically abused by family members because of their sexual orientation or gender identity or expression.^{li}

A lack of standardized data collection on gender identity and sexual orientation, including same-sex relationship status, same-sex sexual behavior, and self-identification as lesbian, gay, or bisexual, severely hampers both government and community-based efforts to identify, track, and address these health disparities. As Healthy People 2020, the federal blueprint of a healthier nation over the decade from 2010 to 2020, notes, “sexual orientation and gender identity questions are not asked on most national or State surveys, making it difficult to estimate the number of LGBT individuals and their health needs.” The *Strategic Plan on Addressing Health Disparities Related to Sexual Orientation* released by HHS in April 2001 stated bluntly that “unless [sexual orientation and gender identity] health concerns are included broadly in

Department-sponsored health surveys, research, and surveillance systems, it will not be possible to document, understand, or address health disparities in this population.”^{liii} This conclusion is decisively echoed by the March 2011 report from the IOM, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, which emphasizes the need for collection of gender identity and sexual orientation data on federally supported surveys and in electronic health records.^{liiii}

LGBT health disparities are recognized by many divisions of HHS, including HRSA, CDC, NIH, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Administration on Aging (AoA), and the Office of Minority Health (OMH). However, recognition remains piecemeal, and researchers, advocates, and service providers remain disadvantaged in seeking funding for health research and interventions to ameliorate these disparities. For example, Philadelphia’s Mazzoni Center is the only community health center in Pennsylvania that explicitly serves the LGBT population. In addition to serving a majority low-income population, Mazzoni provides the same services as an FQHC, but they have been unable to apply for FQHC designation due to a lack of federal and state data on the income level and health of the LGBT population. This prevents Mazzoni and the people it serves from qualifying for a range of support from the federal government, including higher reimbursement rates from Medicare and Medicaid, access to the National Health Service Corps, and lower prices on prescription drugs.^{liv}

A recent publication by the Center for American Progress (CAP), “The Power of the President: Recommendations to Advance Progressive Change,” echoes these concerns and further notes that, “in the absence of accurate data, policymakers are often unable to assess the effectiveness of current policies in meeting the needs of lesbian, gay, bisexual, and transgender people...[and] the lack of good data in policy debates and decisions increases the likelihood that stereotypes and myths will guide policies that impact LGBT Americans.” Likewise, professional bodies such as the American Medical Association, the American Public Health Association, and the American Psychological Association have issued statements in support of standardized data collection on sexual orientation and gender identity. Congress has also spoken in favor of LGBT data collection: in fact, the House of Representatives’ parallel provision to ACA Section 4302 specifically directed HHS to collect data on sexual orientation and gender identity, among other disparity factors.^{lv}

As is the case for other disparity populations, including racial and ethnic minority groups, sexual orientation and gender identity data collection on a nationwide scale must be buttressed with routine program-level data collection. Intake forms, exit surveys, and other program documents are unique sources of valuable population-specific health data for the LGBT population, which has too often been disenfranchised and overlooked by health and medical institutions. Sexual orientation and gender identity demographic data, when abstracted and aggregated for analysis with other participant data, facilitates program design, monitoring, and evaluation and allows for tracking of trends in participant satisfaction and experience and the program’s effectiveness in reaching priority populations.

Evidence of Practicability

While sexual orientation and gender identity are frequently omitted from health surveys and often ignored by healthcare providers, this data has been successfully collected in a range of settings. A number of federal surveys collect some form of data regarding sexual orientation, including the National Health and Nutrition Examination Survey (NHANES), National Survey of Family Growth (NSFG), the National Epidemiologic Survey on Alcohol and Related Conditions, the National Household Survey on Drug Abuse and the National Comorbidity Study-R,^{lvi} and several CDC HIV surveillance instruments collect data on gender identity. HRSA-funded providers offering services under the Ryan White Care Act also collect and report data on gender identity. The decennial Census reports data on the number of same-sex couples.

Many states, including North Dakota, Massachusetts, California, Wisconsin, and New Mexico, also recognize the challenges posed by a lack of LGBT health and demographic data and have added questions on sexual orientation and/or gender identity to their health surveys. In administering the BRFSS and YRBSS questionnaires, at least eight and thirteen states, respectively, currently include questions on sexual orientation, behavior, and attraction. In addition, several BRFSS and YRBSS questionnaires have included or currently include a question about gender identity.^{lvii} Since its inception in 2001, the California Health Interview Survey (CHIS), a biennial, statewide telephone survey and the largest state health survey conducted in the United States, has asked questions on sexual orientation and is considering asking gender identity as well.^{lviii}

A number of healthcare facilities, in an effort to provide culturally competent care and track health outcomes, independently collect LGBT health data. A 2010 national survey of over 175 healthcare facilities conducted by the Human Rights Campaign Foundation, the Healthcare Equality Index (HEI), asked whether participating facilities requested data on patients' sexual orientation and/or gender identity through intake forms or other data collection systems.^{lix} According to the survey, 17.4 percent of respondent facilities have data collection systems that allow people to self-identify as lesbian, gay, or bisexual. In addition, 24.2 percent of respondent facilities allow for designation of transgender status on intake forms and 5.6 percent have data collections systems that allow people to self-identify as transgender.^{lx}

In addition, 53.4 percent of respondent facilities also provide LGBT cultural competency training for staff.^{lxi} Such training helps to ensure that LGBT people feel comfortable providing information about their sexual orientation and gender identity. As a representative of the University of California San Francisco (UCSF) Medical Center noted in an HEI testimonial, as part of cultural competency training, "registration staff learn about various ways that LGBT patients identify themselves, so that they can respond knowledgeably and record information accurately."^{lxii}

Addressing Challenges to Obtaining Data

Some have expressed concerns that individuals would be unwilling to volunteer information about their sexual orientation and gender identity, or even that the presence of such questions would dissuade survey respondents from participating altogether. Research has shown such concerns to be unfounded. For example, the Epidemiological Survey on Alcohol and Related Conditions and the Nurses Health Study II, both large-scale surveys with a combined sample size of 120,000, showed no drop-off in participation with a question about sexual orientation.^{lxiii} Another study indicated that respondents who were unwilling to answer a question about being lesbian, gay, or bisexual were much more likely to refuse to answer questions about other personal characteristics, such as race.^{lxiv} Of course, the mode of data collection, question placement and other factors can impact how successfully surveys solicit data on LGBT respondents. The SMART Report mentioned below demonstrates that these issues can be addressed successfully.

A related concern has been expressed regarding healthcare settings. It is an unfortunate reality that LGBT people continue to experience widespread discrimination and harassment, including in seeking and receiving healthcare services. As such, they may be reluctant to disclose their sexual orientation and gender identity on an intake form or through other means to a provider, when that information could conceivably be the basis for differential treatment. However, as noted above, numerous healthcare facilities already collect such data, suggesting that such reticence is not an insurmountable problem. Clear nondiscrimination protections and proper staff training can ensure that LGBT patients feel comfortable disclosing personal information that can help to improve the care they receive and foster a broader understanding of health issues facing the LGBT population.

Both of these concerns are directly a result of societal discrimination against LGBT people. It is also due to such discrimination that, to date, there is very little data available about this population. Permitting the perception that LGBT people would be too fearful to disclose this information and/or the possibility that disclosure might result in continued discrimination by providers to stymie the collection of this critical data only perpetuates discrimination based on sexual orientation and gender identity. The evidence strongly suggests that these concerns are unfounded, and, most importantly, they are substantially outweighed by the need to better understand the health needs of the LGBT population.

Recommendations

Establish standard specifications for collecting sexual orientation and gender identity data utilizing best practices.

In describing the health disparities affecting the LGBT population, it is important to consider both sexual orientation and gender identity in tandem. Just as the non-transgender population contains a diversity of sexual orientations, transgender people may identify as any sexual orientation. Moreover, people of diverse sexual orientations may face discrimination and adverse health effects on the basis of nonstandard gender identity or expression even if they do not

identify as transgender, and those who do identify as transgender often face some of the largest health disparities, particularly around access to health insurance and vital healthcare services.^{lxv}

As described in more detail below, a number of options currently exist for asking about sexual orientation and gender identity both on surveys and in health services settings. Standardization of these metrics is a key aspect of building an internally consistent evidence base with wide applicability to the variety of challenges in LGBT health services and research.

i. Survey Data

Between 2004 and 2009, the Williams Institute at UCLA convened a multidisciplinary and multi-institutional group of experts on sexual orientation and gender identity data collection. The resulting report, *Best Practices for Asking Questions about Sexual Orientation on Surveys* (the “SMART Report”), provides detailed background on question design for measures of sexual orientation and gender identity, as well as a consideration of best practices for asking about both sexual orientation and gender identity.

Survey metrics for sexual orientation and gender identity that have been used on instruments such as the BRFSS, the YRBSS, and the NSFG, and several private studies include the following:

Gender Identity:

“Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman. Do you consider yourself to be transgender?”

Yes, No, Don’t know/not sure, Refused

“When a person’s sex and gender do not match, they might think of themselves as transgender. Sex is what a person is born. Gender is how a person feels. Do you think of yourself as transgender?”

Yes, No, Not sure

Sexual Orientation:

- **Sexual identity:**

Do you consider yourself to be:

- a) Heterosexual or straight;
- b) Gay or lesbian; or
- c) Bisexual.

- **Sexual behavior:**

In the past (time period e.g. year) who have you had sex with?

- a) Men only;
 - b) Women only;
 - c) Both men and women;
 - d) I have not had sex.
- **Sexual attraction:**
People are different in their sexual attraction to other people. Which best describes your feelings? Are you:
 - a) Only attracted to females;
 - b) Mostly attracted to females;
 - c) Equally attracted to females and males;
 - d) Mostly attracted to males;
 - e) Only attracted to males;
 - f) Not sure.

Gender Identity and Sexual Orientation:

“Do you consider yourself to be (**check all that apply**):”

- a) Heterosexual or straight;
- b) Gay or lesbian;
- c) Bisexual;
- d) Transgender.

[If pause or refusal/none of above, also say:]

“You can name a different category if that fits you better: _____.”

This question has passed cognitive testing to the level appropriate for inclusion on nationwide surveys such as the National Health Interview Survey.^{lxvi}

ii. Program Data

The recommended metrics for sexual orientation and gender identity data collection program level data range from providing space for respondents to check “domestic partner” or to identify their transgender status on intake forms to including sexual orientation and transgender status input fields in forms and electronic records. The following suggested preamble for program-level data collection on sexual orientation and gender identity/transgender status is adapted from the Health Research and Education Trust Toolkit for collecting race, ethnicity, and primary language data.^{lxvii}

“We want to make sure that all our participants get the best service possible. We would like you to ask you some questions about your background and identity so that we can review the experiences of all participants and make sure that everyone gets the highest quality of services. The only people who see this information are registration staff, administrators, and the people involved in quality improvement and oversight, and the confidentiality of what you tell us about yourself is protected by law.”

F. Standardization of Non-Mandatory Data Collection Regarding Immigrants

In addition to the recommendations regarding standardization of data for mandatory collection and reporting, we also advise HHS to establish standardized categories for certain health disparities data that will be important for many health surveys and researchers to collect and analyze. These data should not be designated as an additional mandatory category as there are some instances, such as enrollment in health coverage programs, in which requesting this data may deter respondents from program participation.

Promoting a standardized measure for these categories, however, will allow researchers to monitor how successfully vulnerable populations are able to maximize access to health coverage and care under health care reform implementation. In particular, HHS should develop standardized categories for immigrants and their families.

Problem

Approximately 12 percent of the nation's population is foreign born, representing more than 37 million people in the U.S., including nearly three million children.^{lxviii} Moreover, many immigrants live in "mixed-status" households where members of the same family hold different citizenship or immigration statuses; the most common configuration is a U.S. citizen child living with at least one immigrant parent. Millions of citizens live in mixed-status families, including approximately four million citizen children with at least one undocumented immigrant parent.^{lxix}

Immigrant and mixed-status families often face challenges accessing both health insurance coverage and health care services in the U.S. Structural barriers, such as a federal five year waiting period for many qualified legal immigrants, prevent many noncitizens from accessing health coverage and care. Other barriers, such as fear of unintended immigration consequences, confusion about complex eligibility requirements, or lack of language access, also impede immigrant households from accessing programs for eligible children or other family members. As a result, immigrant and mixed-status families are more vulnerable to uninsurance than citizen families. For example, in 2008, just 8percent of citizen children with citizen parents were uninsured, compared to 14 percent of citizen children with at least one legal immigrant parent and 25 percent of citizen children with at least one undocumented parent.^{lxx} Immigrant children fared even worse; nearly half (45 percent) of all immigrant children with at least one undocumented parent were uninsured.^{lxxi}

Although the ACA will provide opportunities to promote health equity for diverse populations, many of the barriers that immigrants and children of immigrants face will remain. It is possible for an undocumented immigrant, legal immigrant and U.S. citizen to be members of the same low-income family, and all will have differing eligibility for new health coverage pathways under the ACA. For example, an undocumented head of household is prohibited from buying a family or individual health plan in the health insurance exchanges, but may apply for coverage and affordability tax credits on behalf of eligible legal immigrant or citizen members. By

collecting data on how immigrant and mixed-status families interact with the health system, policymakers will be able to monitor progress and target outreach to this population.

Recommendations

Adopt Citizenship and Mixed-Status Family Categories utilized by CHIS

It is important that questions about citizenship or immigration status be standardized not only to provide the best analysis, but also to ensure that questions are formulated in a way that removes any threat respondents may perceive. In this regard, we encourage HHS to adopt the citizenship and mixed-status family categories developed by the UCLA Center for Health Policy Research, in collaboration with the California Department of Public Health and the Department of Health Care Services, in the California Health Interview Survey (CHIS).

CHIS is a survey of approximately 50,000 Californians, including adults, teenagers, and children, that is recognized for collecting data on hard-to-reach populations, including ethnic subgroups and immigrant families. In particular, CHIS has integrated questions in its instruments regarding respondents' citizenship, possession of green card, country of birth, and length of time residing in the U.S. From these questions, the UCLA Center for Health Policy Research researchers to construct variables that reflect the configurations of mixed-status and immigrant families and several important factors affecting their health care access. The Center has shared a constructed variable that we urge the HHS to consider adopting as a standard for collecting such data (see below).

FAMCIT3 (2010)

- 1 Citizen child with citizen parents
- 2 Citizen child with noncitizen with green card parents
- 3 Citizen child with noncitizen without green card parents*
- 4 Noncitizen child in U.S. less than 5 years**
- 5 Noncitizen child in U.S. 5 years or more

* "Noncitizens without green cards" are used as a proxy for unauthorized immigrants; this category will also capture some legal immigrants.

** This variable allows researchers to estimate those who may be subject to the federal five year bar for Medicaid and other programs.

Ensure privacy protections are in place and ensure data provided is confidential and will not be shared with immigration officials

CHIS researchers take several crucial precautions to protect the privacy of respondents. Survey administrators make clear that answers to these questions are confidential and will not be shared with immigration officials. Additionally, because of privacy concerns, CHIS data on mixed-status families is confidential; researchers who wish to access this data must submit an application for committee review. We recommend that HHS consult with the UCLA Center for Health Policy Research to develop standardized questions and variables as well as practices to

secure and protect the privacy of respondents.

Provide clear direction on circumstances in which asking questions regarding citizenship or immigration status is inappropriate.

Finally, while collection of this data is important for researchers to assess whether health and health care disparities continue to persist for immigrant and mixed-status families, it should not create access barriers for eligible individuals' participation in health programs. Issuance of data standards should be paired with clear direction on circumstances in which asking questions regarding citizenship or immigration status is inappropriate. The "Tri-Agency Guidance," issued by U.S. Department of Agriculture Food and Nutrition Service and U.S. Department of Health and Human Services Health Care Financing Administration, Administration for Children and Families, and Office for Civil Rights, provides such direction and reinforces to states the circumstances under which states may or may not inquire about program applicants' citizenship or immigration status.^{lxxii} HHS should reinforce this guidance when issuing a standard for collection of immigrant and mixed-status family data.

G. Conclusion

Section 4302 of the Patient Protection and Affordable Care Act (ACA) requires Department of Health and Human Services (HHS) to ensure that certain data is collected throughout all HHS programs, activities and surveys. This authority offers significant opportunities to expand the comprehensive data collection of a variety of demographic data essential to identify and address health and healthcare disparities.

We urge HHS to undertake a full evaluation of its data collection activities and work towards effective implementation of section 4302. We look forward to working with you on this endeavor.

Appendix A

Federal Surveys with Disability Status and Health Services Characteristics Data

Survey	Agency	Disability measures	Health & healthcare measures
National Health Interview Survey: NHIS	National Center for Health Statistics (NCHS)	<ul style="list-style-type: none"> • Activity limitation • Activities of daily living (ADL) & Instrumental Activities of Daily Living (IADL) • Mobility impairment scale • Cognitive impairment • Deafness, hard of hearing • Blindness, low vision • Mental health disability 	<ul style="list-style-type: none"> • Cancer screenings (breast, cervical, colon) • Immunization and health behaviors (smoking, drinking, obesity) • Delayed or missed healthcare due to cost • Didn't get needed mental healthcare/cost • Usual source of care • Additional questions on specific unmet needs or delayed care in sample adult & child sections
Medical Expenditure Panel Survey: MEPS	Agency for Healthcare Research & Quality (AHRQ)	<ul style="list-style-type: none"> • Activity limitation • ADL/ IADL limitation • Mobility impairment scale • Cognitive impairment • Blindness, low vision • Deafness, hard of hearing 	<ul style="list-style-type: none"> • Cancer screenings (breast, cervical, colon) • Delayed or missed healthcare or meds • Usual source of care • Provider characteristics
Behavioral Risk Factor Surveillance System: BRFSS	Centers for Disease Control & Prevention	<ul style="list-style-type: none"> • Use of Assistive Devices • Activity limitation • 	<ul style="list-style-type: none"> • Regular doctor • Didn't get care because of cost • Time since last checkup
National Health And Nutrition Examination Survey: NHANES	National Center for Health Statistics (NCHS)	<ul style="list-style-type: none"> • Activity limitation • ADL/ IADL limitation • Mobility impairment scale • Cognitive impairment 	<ul style="list-style-type: none"> • Usual source of care
Survey of Income and Program Participation: SIPP	Census Bureau	<ul style="list-style-type: none"> • Activity limitation • ADL/IADL limitation • Mobility aids • Mental health disability • Vision and hearing impairments 	<ul style="list-style-type: none"> • Hospital stays, doctor visits • Usual source of care • Home health care

<p>Medicare Current Beneficiary Survey: MCBS</p>	<p>Centers for Medicare and Medicaid Services (CMS)</p>	<ul style="list-style-type: none"> • Speech difficulties • Visual & hearing impairment • Mobility impairment scale • ADL/IADL • Cognitive limitation 	<ul style="list-style-type: none"> • Cancer and other screenings • Difficulty obtaining healthcare • Delayed healthcare due to cost • Usual source of care • Reasons for changing/not having provider • Provider quality • Healthcare satisfaction • Reasons for not seeking care • Unmet need for medication
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Author: Steve Kaye, University of California San Francisco, 2011.

ⁱ See <http://www.hret disparities.org>.

ⁱⁱ Several frameworks and reports recently issued by HHS have recognized a broad, inclusive list of the demographic variables that should be considered when examining health disparities. See, e.g. Healthy People 2020 (“Although the term “disparities” often is interpreted to mean racial or ethnic disparities, many dimensions of disparity exist in the United States, particularly in health. If a health outcome is seen in a greater or lesser extent between populations, there is disparity. Race and ethnicity, primary language, sex, sexual identity, age, disability, socioeconomic status, and geographic location all contribute to an individual’s ability to achieve good health. It is important to recognize the impact that social determinants have on health outcomes of specific populations. Healthy People 2020 strives to improve the health of all groups.” and Healthy People 2020 defines a *health disparity* as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”

<http://www.healthypeople.gov/2020/about/DisparitiesAbout.aspx>); HHS Strategic Framework for Multiple Chronic Conditions (“It is likely that as racial and ethnic, gender, gender identity, disability, sexual orientation, age, geographic, and socioeconomic disparities of access to care and health outcomes exist in the total population, those disparities also exist in the MCC population. Additional research directed toward understanding the roles of disparities in the MCC population would assist in focusing interventions.” http://www.hhs.gov/ash/initiatives/mcc/mcc_framework.pdf); and Centers for Disease Control and Prevention Health Disparities and Inequalities Report (“Health disparities are differences in health outcomes and their determinants between segments of the population, as defined by social, demographic, environmental, and geographic attributes.” with the report examining health disparities by age, sex, race, ethnicity, education, income, geography, disability, and sexual orientation; cross-

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<http://www.nap.edu/openbook.php?isbn=0309092310>.

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^{xxiv} US Department of Health and Human Services, Agency for Healthcare Research and Quality, *2008 National Healthcare Quality and Disparities Reports*, No. 09-0001, March 2009

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The Women with Disabilities Education Program concept emanated from a special task force consisting of practicing physicians and other healthcare professionals who have a strong commitment to providing high-quality medical care for women with disabilities. Principals include Lisa Iezzoni, MD, Medical Director, Harvard Medical School, Carol J. Gill, PhD, Associate Professor, Department of Disability & Human Development, University of Illinois at Chicago, and Jennifer E. Potter, MD, Associate Professor of Medicine, Harvard Medical School. The Program pursues two parallel tracts: a web-based self-management curriculum for patients and a training curriculum for health professionals. When completed, each curriculum will address a wide range of topics, from how to build better patient-provider relationships to how to diagnosis and treat acute medical problems in women with disabilities. *Topical Webinar Series on Disability and Health: Integrating Disability Awareness and Women's Reproductive Health* by the Association of University Centers on Disabilities (AUCD). This webinar introduces participants to a newly-developed online resource devoted to promoting reproductive health care for women with disabilities. This interactive recorded program, "Reproductive Health Care for Women with Disabilities," was developed through a partnership between the American College of Obstetricians and Gynecologists and the Centers for Disease Control and Prevention, and is designed to be an easily navigable source of information to assist clinicians providing care to women with physical, developmental, and sensory disabilities.

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