Regulations Subcommittee Meeting
March 23, 2016
Demographic Reporting Requirements

Demographic Reporting Categories: Why They Matter

Major reports and initiatives, at both the federal and state level, have helped underscore the prevalence and impact of behavioral health disparities across a variety of ethnic/racial, cultural and sexual minority groups. Historically, health disparities research has focused on relatively broad racial/ethnic categories, such as "Asian-American". Over time, however, researchers and policy makers have drawn increasing attention to disparities and differences in access and care that affect more specific groups, for example, different racial/ethnic groups falling under the Asian umbrella.

The primary goal of the expanded racial/ethnic/cultural and sexual/gender minority identity categories included in the Prevention and Early Intervention (PEI) and Innovation (INN) regulations is to provide better and more reliable information to stakeholders, counties and the State with respect to differences in access, penetration and outcomes across a number of groups that were not previously captured. For example, collection of demographic data at all PEI Outreach for Increasing Recognition of Early Signs Programs will allow the State to understand the extent to which these programs are reaching individuals from cultural/racial/ethnic and sexual/gender minority communities both within individual counties and across the State.

What Are the Standards for Collecting and Reporting Demographic Information for PEI and INN Funded Programs and Strategies?

Contained within the approved regulations are specific standards to ensure consistency in the collection and reporting of demographic information on all individuals served through PEI and INN. Counties will be required to collect demographic information in a number of areas including age, sexual orientation, gender, race and ethnicity. To support the identification of potential barriers counties may encounter when implementing the regulations, and develop viable solutions to those barriers, each of the required demographic areas and the related elements are detailed for review and discussion in the tables below.

AGE GROUPS
Children/youth (0-15)
Transition age youth (16-25)
Adult (26-59)
Older adults (60+)
Declined to answer

SEXUAL ORIENTATION
Gay or Lesbian*
Heterosexual or Straight*
Bisexual*
Questioning or unsure of sexual orientation *
Queer
Another sexual orientation
Declined to answer

**currently collected in CalOMS*

GENDER	
ASSIGNED AT BIRTH	CURRENT IDENTITY
Male	Male
Female	Female
Declined to answer	Transgender
	Genderqueer
	Questioning or unsure of gender identity
	Another gender identity
	Declined to answer

Race & Ethnicity

Despite significant effort at the state and national level to develop consensus methods, differences remain among various data sets with respect to how race and ethnicity are classified. Federal guidelines provide a minimum set of classifications or categories that includes five races ("American Indian or Alaska Native", "Asian", "Black or African American", "Native Hawaiian or Other Pacific Islander", "White") and two ethnicities ("Hispanic or Latino" or "Not Hispanic or Latino"). These categories are considered to be social-political constructs rather than based on any scientific or anthropological factors.[1]

Over the years, these standards have been the subject of increasing criticism from those who believe that they do not reflect the increasing diversity of the Nation's population.[2] Generally the approach taken by state and federal agencies to address these limitations has been to add additional granularity within each of the five racial categories and two ethnicities. This allows for the collection of more detailed information, particularly for traditionally underserved populations while also maintaining the ability to "roll up" data to the standard categories. Maintaining consistent data collection and reporting standards across federal, state and local agencies supports research and evaluation that must rely on multiple data sources. This consistency also facilitates the comparison of demographic services data in relation to individual groups representation within the larger population.

As the two Pew Research Center Issue Briefs contained in meeting packets note, "race" and "ethnicity" are not fixed ("natural" categories) and their distinction and public perception varies cross-sectionally and has also shifted over time. The current regulations largely map on to the core distinctions embedded in the 2010 US Census and other federal data reporting mandates, specifically the distinction between Hispanic/Latino as a marker of ethnicity rather than race. Until federal requirements change, counties and the State must disagreggate an individual's Hispanic/Latino "ethnicity" from his or her designated "race."

[1] *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, Office of Management and Budgets
[2] *Standards for the Classification of Federal Data on Race and Ethnicity*, Office of Management and Budget.

Both the PEI and INN regulations identify the categories and elements detailed in Appendix A for collecting and reporting the number of individuals served by race and ethnicity. Appendix A also provides a quick reference to the race and ethnicity categories and elements currently in use by other state and federal agencies.

Which PEI component Programs and Strategies require demographic reporting and which do not?

The expanded demographic reporting categories listed in Section 3560.010 (5) of the PEI regulations must be reported for Prevention Programs, Early Intervention Programs, Outreach for Increasing Recognition of Early Signs of Mental Illness Programs, Access and Linkage to Treatment Programs & Strategies, and Improving Timely Access to Services for Underserved Programs & Strategies. Demographic reporting for both Stigma & Discrimination Reduction (SDR) Programs and Suicide Prevention (SP) Programs is optional.

How much flexibility do providers have with respect to demographic data collection? In particular, for non-clinical and/or outreach programs?

The regulations assume a "common sense" approach to demographic data collection and reporting. This holds for non-clinical PEI programs, outreach programs, and any instance in which such data collection would be clinically contra-indicated. For example, if a warmline caller phones in in a state of crisis, the State does not expect warmline staff to request that the caller provide demographic information. In other programs and settings, it may make more sense to include only open-ended demographic questions (e.g. "what race/ethnicity do you identity with? What gender or sexual identity (if any)?"). In other situations it might make more sense to first ask participants or clients if they are willing to answer demographic questions and, if they decline, to simply mark "decline to answer" for reporting purposes.

Will demographic information be linked to names or protected health information (PHI)?

For clinical programs (e.g. early intervention), demographic information will most likely be linked to PHI, although the regulations do not require this. For non-clinical and outreach-oriented programs, it likely will be easier to collect demographic data anonymously. Even for programs that want to link demographics to program outcomes, anonymous data collection should be feasible in many cases. For example, participants in a two-hour PEI funded Outreach for Increasing Recognition workshop could be given a packet with demographic questions as well as pre-and post-workshop measures, all of which could be filled out anonymously and submitted as a single linked packet.

How were the race/ethnicity categories generated?

The race categories follow standard federal reporting including the US census. The expanded ethnic categories were selected using the following criteria: (1) Population equal to or greater than 100,000 across the State of California as per the 2010 US Census; and (2) already included in at least one federal reporting requirement.

How were the sexual orientation/gender identity categories generated?

Finer-grained questions about sexual and gender identity, including differences between gender/sexual identity at birth and later in life, are relatively new to governmental research and data collection efforts and were not captured in the 2010 US Census. The sexual orientation and gender identity categories were therefore developed in consultation with, and strongly shaped by, stakeholder perspectives communicated during the regulatory process and through written public comment.

Might these expanded demographic categories expose or disclose particular individuals, particularly in small counties and/or small programs?

A relative downside of finer-grained demographics reporting is the greater risk of inadvertently identifying groups or individuals. For this reason, the regulations ask that counties not publicly report any potentially identifying data but instead report such data directly to the State as a private (protected and confidential) supplement.

In Counties (or Programs) with minimal racial/ethnic/cultural and gender/sexual diversity, does it still make sense to require expanded demographic data reporting?

The MHSOAC recognizes that in some counties and programs, representation from the array of groups included in the new regulations may be minimal or non-existent. In telling a statewide story, however, it remains important to collect parallel information across county and program lines and be able to communicate how particular programs and services, both across the state and in specific programs and counties, are or aren't reaching specific groups.

Appendix A: Sample Federal and State Data Collection Standards for Race and Ethnicity

State and National Standards for Maintaining, Collecting, and Presenting Data on Race and Ethnicity	Prevention and Early Intervention/ Innovations Regulations	US Health and Human Services Agency-Affordable Care Act (ACA)	Substance Abuse and Mental Health Services Agency (SAMHSA)	California Outcomes Measurement System (CalOMS)	Client and Services Information (CSI) System
RACE & ETHNICITY					
American Indian or Alaska Native	⊗	⊗	⊗	⊗	⊗
Asian or Asian Indian/South Asian	⊗	⊗	⊗	⊗	⊗
Black or African American	⊗	⊗	⊗	⊗	⊗
Native Hawaiin or Other Pacific Islander	⊗	⊗	⊗	⊗	⊗
White	⊗	⊗	⊗	⊗	⊗
Other Race	⊗			⊗	⊗
Two or More Races	⊗	⊗	⊗	⊗	⊗
Unknown/Declined to Answer (Race)	⊗		⊗		⊗
Hispanic or Latino	⊗	⊗	⊗		⊗
Non-Hispanic or Non-Latino	⊗	⊗	⊗	⊗	⊗
More than one ethnicity	⊗				
Unknown/Declined to answer (Ethnicity)	⊗				⊗
African	⊗				
Cambodian	⊗			⊗	⊗
Caribbean	⊗				
Central American	⊗				
Chinese	⊗	⊗		⊗	⊗
Cuban/Cuban-American		⊗	⊗	⊗	
Eastern European	⊗				
European	⊗				
Filipino	⊗	⊗		⊗	⊗
Guamanian or Chamorro		⊗		⊗	⊗
Hmong					⊗
Japanese	⊗	⊗		⊗	⊗
Korean	⊗	⊗		⊗	⊗
Laotian				⊗	⊗
Mexican, Mexican-American, Chicano	⊗	⊗	⊗	⊗	
Middle Eastern	⊗				
Mien					⊗
Other Asian		⊗		⊗	⊗
Other Hispanic or Latino	⊗	⊗	⊗	⊗	
Other Non-Hispanic or Non-Latino	⊗				
Other Pacific Islander		⊗			⊗
Puerto Rican	⊗	⊗	⊗	⊗	
Samoan/American Samoan		⊗		⊗	⊗
South American	⊗				
Vietnamese	⊗	⊗		⊗	⊗

http://minorityhealth.hhs.gov/templates/content.aspx?ID=9227&lvl=2&lvlID=208
http://www.cdc.gov/nchs/nhis/quest_data_related_1997_forward.htm#2014_NHIS
http://www.dhcs.ca.gov/provgovpart/Documents/CalOMS_Tx_Data_Collection_Guide_JAN%202014.pdf
http://www.cdc.gov/brfss/questionnaires/pdf-ques/2013%20BRFSS_English.pdf
http://www.dhcs.ca.gov/services/MH/Documents/CSI_DataElements2.pdf