Data collection

Sensitive practices when gathering demographic information.

Why do we collect demographic data?

- Council's collect data to meet regulatory requirements and build a foundation for monitoring racial and ethnic disparities (CMS, 2021).

- We also use the data to help understand the causes of disparities and monitor the reduction of disparities over time.

- We use the information to help make sure we are reaching people from different groups (racial, ethnic, gender, geographic and people with DD and family members).

Questions we hear from Council staff

- Why does gender only reflect male, female and other?

- The categories on race and ethnicity in the PPR does not reflect the race and ethnicities of people who participate in our activities.

- Can we require people give us the information?

- Can Council staff or grantees observe participants to get the answers?

Other concerns Council staff have reported

- Some of the response options are not sensitive (e.g., Female/Male/Other for gender).

- The action of asking for demographic information could be offensive to certain cultures.

- The immigrant population might not want to report their information because they fear they might lose services.

- Some people from other cultures may not self-identify as having a disability. This could be due to different cultural views of disability.

What data do we collect and report?

Council's report demographic information for:
Activities
Council member rosters
Staff member rosters

Minimum standards - OMB

Categories for ethnicity
• Hispanic or Latino • Not Hispanic or Latino

Categories for race
• American Indian or Alaska Native • Asian • Black or African American • Native Hawaiian or Other Pacific Islander • White

PPR required data – minimum standards

- Gender
  - Male
  - Female
  - Other

- Category of participant
  - Individual with DD
  - Family member

- Urban or Rural

These items must be reported on the PPR.

These items represent the minimum standard.

You are encouraged to collect more specific information using categories that can be aggregated back to the minimum categories

Collecting demographic data

Five Best Practices

#1 - Ask for help!

- Ask people from a wide range of demographic groups to help you develop your questions or review your questions.

- Things to consider:
  - Pay attention to feedback from groups that have been historically marginalized.
  - Trouble-shoot for solutions that address all concerns (even when the feedback seems contradictory).

#2 - Explain yourself!

- Tell people why you are collecting the information
- Here are some reasons DD Councils collect data:
    - Grant reporting
    - This helps us see inequities across our projects and activities.

- Tell people **what you will do with the information and who will see it.**
    - Tell them if you are going to share their information with other organizations or companies.
    - Share details about your privacy policy.
    - Tell them when it will be made available for others to see.
- You may want to consider providing an explanation next to each demographic question.

#3 - Make multiple selections possible, rather than limiting users to one choice

- Because most people's identities cannot be summed up by one category, providing multiple options is the best way to accurately capture the demographic information you need—plus, it allows users to identify in the ways that best represent them.

#4 - Leave a blank box at the end of every demographic question

- This would allow people to write in their identity if the categories provided do not accurately reflect them.

- Be sure to track the responses users type in. If you notice a recurring identification, you can modify your forms to include this as one of your main categories.

#5 - Re-examine the order of options you present in each category

- The ordering and phrasing of the options you provide can create a default "norm" or hierarchy.
  - For example, on a question about gender, "male" usually comes first, followed by "female" and then "nonbinary." Reordering the categories so that "male" is not the default gender helps to signal inclusivity.

- One possible solution is to alphabetize all categories in every question.

Cultural Awareness and responsiveness

Use data collection and analysis methods that are sensitive to cultural differences in how knowledge is constructed and communicated.

For participants who might be limited by language, abilities, or factors such as familiarity or trust, use intermediaries to help collect data.

Demographic
Data Collectionon

Some ideas and examples
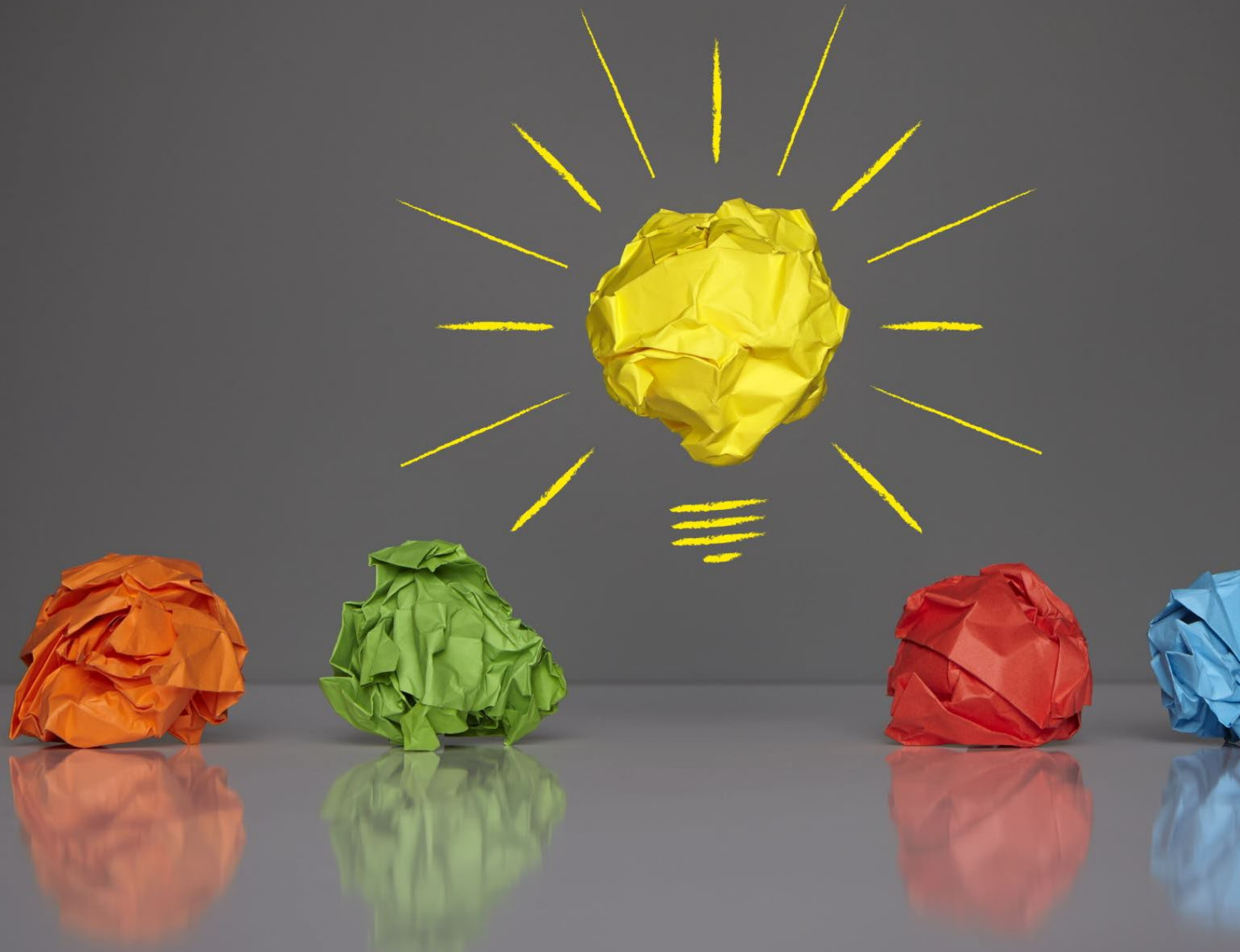
HHS Guidance* for Ethnicity and Race Questions

*Self-identification is the preferred way to get this information, unless observer identification is more practical.

*When using self-identification approaches, people who want to identify their multi-racial heritage may choose "more than one race" (multi-racial is not a category).

*You can gather more specific data if the additional detail can be aggregated back to the standard set of race and ethnicity categories.

• Consider using a general approach when collecting this information such as "which categories best describe you?"

Q. Which categories describe you? Select all that apply to you:

❏ American Indian or Alaska Native—For example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community

❏ Asian—For example, Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese

❏ Black or African American—For example, Jamaican, Haitian, Nigerian, Ethiopian, Somalian

❏ Hispanic, Latino or Spanish Origin—For example, Mexican or Mexican American, Puerto Rican, Cuban, Salvadoran, Dominican, Columbian

❏ Middle Eastern or North African—For example, Lebanese, Iranian, Egyptian, Syrian, Moroccan, Algerian

❏ Native Hawaiian or Other Pacific Islander—For example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshallese

❏ White—For example, German, Irish, English, Italian, Polish, French

❏ Some other race, ethnicity, please specify: _____

❏ I prefer not to answer.

Recommendations for Gender Questions

How do you currently describe your gender identity?

❏ Please specify: _____
❏ I prefer not to answer.

OR

Gender:
❏ Female
❏ Male
❏ Nonbinary (A person whose gender identity cannot be described as exclusively woman or man).
❏ Prefer not to say
❏ Self identify: _____

Recommendations for where people live

A short question "where do you live"? Followed by choices

❑ A big city (for example: Birmingham, Montgomery, Mobile, Huntsville)

❑ A medium sized city (for example: Dothan, Tuscaloosa, Florence)

❑ A smaller, rural area (for example: Cottonwood, Banks, Troy)

❑ Some other area, please specify: _____

❑ Zip code:_____ (Some Councils use the USDA Rural-Urban Continuum Codes to classify urban and rural counties).

❑ I do not know

❑ I prefer not to answer.

Disability data – one example

Please answer the following questions: (Your answers will help make sure we are reaching a broad group)

Question: I am a (Select the answers that best describes you)
- ❏ Person with a developmental disability (DD)
- ❏ Person with a physical or sensory disability
- ❏ Person with a mental health disability
- ❏ Family/caregiver of a person with a disability
- ❏ Professional of an agency or organization working on disability issues
- ❏ Community representative/advocate
- ❏ I prefer not to answer
- ❏ Other

Disability data – another example

Question: What is your (or your family member's) disability?(check all that apply)

❏ Intellectual disability

❏ Cerebral Palsy

❏ Autism

❏ Deaf

❏ Blind

❏ Multiple disabilities (more than one)

❏ Mental/emotional

❏ Physical

❏ Self-identify: _____

❏ I prefer not to answer

More to consider!

When is it best to ask people for the data?

- Trust (in a new community) may not have been developed early on – asking the questions later in a project (if applicable) and providing the questionnaire at the end of a project is more fruitful rather than asking for demographic info up-front.

If people do not want to give the information – report it. Then explore what needs to be done differently.

- If people do not want to provide information about ethnicity/race, report it as race unknown. If people choose not to answer that is the answer.

How do I use the data I collected?

You may need to do some work to transfer the data you collected to the PPR

The PPR categories are:

Race/Ethnicity
White, alone
Black or African American alone
American Indian and Alaska Native alone
Hispanic/Latino
Asian alone
Native Hawaiian & Other Pacific Islander alone
Two or more races
Race unknown

Remember the OMB Race Data Standard? From the HHS Office of Minority Health

What is your race? (One or more categories may be selected)

- White
- Black or African American
- American Indian or Alaska Native

These categories are part of current OMB standards

- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian

These categories roll-up to the Asian category of the OMB standard.

- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander

These categories roll-up to the Native Hawaiian or Other Pacific Islander category of the OMB standard.

Remember the OMB Ethnicity data standard?

Question: Are you Hispanic, Latino/a, or Spanish origin (one or more can be selected)

- No, not of Hispanic, Latino/a or Spanish origin
- Yes, Mexican, Mexican American, Chicano/a
- Yes, Puerto Rican
- Yes, Cuban
- Yes, Another Hispanic, Latino/a or Spanish Origin

These categories roll-up to the Hispanic or Latino category of the OMB standard (PPR Demographic section)

Statements that explain

Some examples

Information for a "survey statement"

Survey introduction: We need some information from you for the DD Council to improve their programs.

Items you may want to tell people about:

- We use the information you provide about yourself to help us make sure we are reaching people from different ethnic and racial groups that live in [state/territory/community/county].

- We use your information to help the Council develop and make programs and activities for people with developmental disabilities stronger.

- We do not collect your name, address or phone number.

Check out the New York State Council survey statements!

- Statement for Grantees: STARTING IN 2016, THE NYS DEVELOPMENTAL DISABILITIES PLANNING COUNCIL (DDPC) BEGAN REQUIRING ALL GRANTEES TO COLLECT DEMOGRAPHIC DATA AS PART OF OUR FEDERAL REPORTING REQUIREMENTS.

- Statement of purpose: THE DDPC IS COMMITTED TO THIS EFFORT BECAUSE THIS DATA HELPS US DETERMINE IF OUR GRANT DOLLARS ARE REACHING THE DIVERSITY OF NEW YORK STATE, INCLUDING UNSERVED AND UNDERSERVED COMMUNITIES.

How are you using this data?

To prepare for our ongoing conversations during the June Peer-toPeer meeting, we would like to know:

How Councils are using demographic data.

How the Council assessment of data has led to meaningful changes in how Council efforts are implemented.

How grant level data has been used to inform the grantee's work and the Councils goals.

Final thoughts

- Routinely evaluate your demographic questions to make sure they do not include outdated or inappropriate terms.

- Review to determine if your questions are brief, relevant, and have meaningful use.

- Annually, review your questions to see if revisions need to be made.

Information

Information and Technical Assistance Center (ITACC) for Councils on Developmental Disabilities

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