

Guide to Person-Centered Communication – 2024

Disclaimer

The Guide to Person-Centered Communication (*sponsored by the Robert Wood Johnson Foundation*) serves as a valuable tool for fostering relationships built on mutual respect, acknowledgment, and appreciation for the diverse differences within our society. In our pursuit of advancing health equity, the importance of inclusive language cannot be overstated, and this guide aims to be a helpful resource for individuals at any stage of their journey.

Originally developed by the National Association of Community Health Centers (NACHC) in collaboration with the Association of Asian Pacific Community Health Organizations (AAPCHO), the guide has been refined with input from numerous community health professionals. Recognizing the ever-evolving nature of norms and preferences, we present this guide as a living document, understanding that it is a work in progress rather than a rigid doctrine or policy.

Your feedback and suggestions are welcomed and will help inform future editions of the Guide. The Guide will be annually reviewed and updated by the Social Drivers of Health (SDOH) Team at NACHC, email your comments, suggestions, and questions to Cydnee Parsley CParsley@nachc.org.

Background

Advancing health equity requires a shift in how professionals talk about health inequities and how we describe individuals and communities most impacted by negative health outcomes. Language reflects our thoughts and attitudes and has a profound impact on efforts to advance health equity. This guide was born with the acknowledgement that the field has learned hard lessons about the negative impact of language used. The guide is a starting point to invite readers to understand key concepts and explore language that is affirming to communities that are marginalized by thoughts, language, and policies.

Fostering equitable workspaces, partnerships, research, programming, and policy are part of achieving an inclusive environment; using person-centered language when disseminating information and findings on diverse communities is also critical. Person-centered language focuses on the individual and their experiences, emphasizing that we are all unique people who may experience oppression and/or illness and that we are not defined by those experiences (e.g., slaves v. enslaved persons, diabetics v. persons living with diabetes). This guide aims to ensure that all forms of organizational communication (e.g., reports, emails, presentations, etc.) acknowledge cultural humility, the impact of structural racism and discrimination, and the marginalization of communities, while demonstrating the complexities of the care, needs, preferences, and circumstances of all.

Key Principles

The overarching principles which have informed the development of this guide have been adapted from the *Centers for Disease Control and Prevention Health Equity Guiding Principles for Inclusive Communication*¹ and are as follows:

1. Avoid use of adjectives such as “vulnerable,” “marginalized,” and “high-risk.”
 - These terms are not only vague but also suggest that the condition is inherent to the group rather than being linked to specific causal factors.
2. Avoid dehumanizing language. Use person-centered language instead.
 - Describe people as having a condition or circumstance, not being a condition.
3. Remember that there are many types of subpopulations.
 - Be as specific as possible about the group you are referring to.
4. Avoid unintentional blaming.
 - Consider the context and audience to determine if language used could potentially lead to negative assumptions, stereotyping, stigmatization, or blame.

Cultural Humility is defined by the National Institutes of Health as “a lifelong process of self-reflection and critique whereby the individual not only learns about another’s culture, but one starts with an examination of [their] own beliefs and cultural identities.”² **When communicating about oppressed populations, it is important not to assign feelings based on assumptions of one’s own experiences or beliefs.** Microaggressions are a common form of privileged language wherein accidental or purposeful biased statements are made towards or about a structurally marginalized population (e.g., telling someone who is a person of color that they are “very articulate” or a person living with a physical disability that they “move well for their situation”). During the 2022 Listening Sessions facilitated by the SDOH Team at NACHC, a participant shared the concept of cultural safety³, which moves beyond cultural competency and cultural humility. Please reference this resource that reviews key terms and definitions within the project, “**Investing in Health Center Pathways for Equitable Health and Well-being**”.

Racism presents itself through various levels, as listed below.

1. **Structural racism:** oppression founded in systems-based inequalities that isolate, penalize, or harm a person or persons based on their cultural identify and/or beliefs.
2. **Institutional racism:** discrimination formed by following the dictated prejudice and biases of another and/or society. This can result in discriminatory treatment, unfair policies and practices, and inequitable opportunities and impacts within organizations and institutions.
3. **Interpersonal racism:** interactions between individuals that are rooted in bias and prejudice.

¹ https://www.cdc.gov/healthcommunication/Key_Principles.html

² Yeager KA, Bauer-Wu S. Cultural humility: essential foundation for clinical researchers. *Appl Nurs Res*. 2013;26(4):251-256. doi:10.1016/j.apnr.2013.06.008

³ First Names Health Authority. <https://www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/cultural-safety-and-humility>

*According to the National Juvenile Justice Network, we must continuously recognize and reflect upon white power structures and privilege and how communications can actively counteract those principles.*⁴ [The People’s Institute for Survival and Beyond](#) has an intensive, facilitated workshop that explores the definition of racism at various levels and its manifestations throughout them.

Marginalized populations are “groups and communities that experience discrimination and exclusion (social, political and economic) because of unequal power relationships across economic, political, social and cultural dimensions” (National Collaborating Centre for Determinants).⁵ This includes notions such as homophobia, ableism, sexism, ageism, xenophobia, anti-Semitism, and anti-Arabism. ***Social Drivers of Health***⁶ (SDOH) ***are not a construct of the client or community but are instead a result of policies and systems of which many are racist and oppressive. As such, SDOH can have either a positive or negative impact on a person’s health.***

⁴ National Juvenile Justice Network. <https://www.njjn.org/our-work/training-and-resources>

⁵ National Collaborating Centre for Determinants of Health. <https://nccdh.ca/glossary/entry/marginalized-populations>

⁶ <https://prapare.org/using-clear-terms-to-advance-health-equity-social-drivers-vs-social-determinants/>

Examples of Biased Language and Adapted Person-Centered Language (Written and Verbal)

**The list below is not meant to be exhaustive, but to promote critical reflection on language and word choice.*

| Biased Language | Person-Centered Language |
|---|--|
| A diabetic patient... | A person living with diabetes... |
| A person afflicted with HIV, HIV-positive, HIV infected | A person living with HIV... |
| People of color are incarcerated more often... | Institutional racism increases the rate of incarceration amongst people of color |
| Crowded housing | It is recommended to be mindful of why certain households have multiple people living in a dwelling unit. In instances where it is a cultural preference, consider using the term “multi-generational housing”. In other instances, there may be a need to understand the health and safety implications of multiple people living in a unit. Be sure to state the definition and the formula used to understand a person’s living situation ⁷ . |
| Drug Addicts/Alcoholics | Individuals living with a substance use disorder |
| Elderly/Geriatric | Older Adults; Elders; Aging Populations; People over the age of... |
| Foreign Language | Preferred Primary Language other than English/Native Language |
| Foreigners/Aliens | Immigrants, Refugees, Persons born outside of the US |
| Handicapped Special Needs | Disability is not a bad word and can be used to describe oneself. Avoid using terms like “afflicted with” or “suffers from” as well as made-up terms like “handicapable.” Some within the disability community prefer identity-first language. This is especially true in the big D “Deaf” community, in which there is a cultural connection and the autistic community. Other terms widely accepted in the disability community include person with a disability, visually impaired, Deaf or hard of hearing, and neurodivergent. ⁸ |
| Homeless | Individuals experiencing unstable housing/without housing |
| Illegal Immigrants/ Illegal Aliens | Undocumented Individuals or Immigrants without papers |
| Indians | Native peoples/ Indigenous peoples/ American Indian and Alaska Native |
| Inmates/Felons/ Prisoners | Individuals currently (or formerly) incarcerated; justice-involved person ⁹ ; returning resident; person with a history of incarceration |
| Insane/Crazy | Individuals living with a mental illness or cognitive impairment |

⁷ U.S. Department of Housing and Urban Development. https://www.huduser.gov/publications/pdf/measuring_overcrowding_in_hsg.pdf

⁸ <https://ncdi.org/style-guide/>

⁹ <https://iincnc.org/language-of-incarceration/>

| Biased Language | Person-Centered Language |
|--|---|
| Minority Populations | Not all groups that are considered “minorities” are in fact minority (e.g., the Hispanic/Latino/Latinx community in Texas); When possible, be specific in the population you are speaking about by asking individuals and communities how they would like to be identified and described or using words such as BIPOC, diverse, or multicultural. |
| Native Americans have some of the highest rates of alcoholism... | Structural Racism has contributed to elevated levels of alcoholism within the Native American community... |
| Poor People | Persons living at or below the federal poverty level; people with low income or limited resources... |
| Uneducated | Those who have completed [specify] grade... |
| Under-resourced/ Under-served | Historically and intentionally excluded; disinvested |
| Weird name | Unique name. Ask how to say a person’s name ¹⁰ and not the “American”, English, or easier version of their name ¹¹ . |
| Vulnerable population | Oppressed or marginalized population. This recognizes that systems, policies, and structures are tools that oppress people, and clarifies that certain populations are <i>not</i> inherently vulnerable ¹² |

Sexual Orientation, Gender Identity, Pronouns, and Gender-Neutral Neologisms

Like other structurally marginalized populations, it is critical not to assume or guess individuals’ sex, gender, preferred pronouns, or physical/behavioral health needs or wishes. For example, not every person who identifies as a man has the same medical needs (e.g., transgender men may still need to receive critical screenings like cervical and breast cancer) and regardless of their physical appearance not every woman identifies as feminine or desires to have a baby. It is also important to remember that ***the concepts of sexual orientation and gender identity (often referred to as SOGI) are social constructs, like race, and should be communicated about as non-binary ideologies (i.e., not just male/female).***

¹⁰ <https://hbr.org/2020/01/if-you-dont-know-how-to-say-someones-name-just-ask>

¹¹ https://www.huffingtonpost.co.uk/entry/difficult-names_uk_5e286f0ec5b67d8874aabe67

¹² “Roots of Health Inequity” from the National Association of County and City Health Officials

Examples of Affirmative Sexual Orientation and Gender Identity Language

**The list below is not meant to be exhaustive, but to promote critical reflection on language and word choice.*

| Topic | Affirmative Language |
|-----------------|--|
| Gender Identity | <p><u>Agender</u>: An individual who does not identify as a specific gender (aka. Gender-Neutral or Genderless)</p> <p><u>Cisgender</u>: An individual who identifies as the biological sex they were born as (e.g., I was born as a male and identify as a man)</p> <p><u>Gender Fluid</u>: An individual who moves between genders.</p> <p><u>Intersex</u>: Someone born with sex characteristics that do not fit typical binary notions of male or female</p> <p><u>Non-Binary</u>: Not identifying as simply a man or a woman; Gender is multifaceted and can be fluid.</p> <p><u>Queer/Genderqueer</u>: An umbrella term used to describe individuals who may be gender non-conforming or non-binary.</p> <p><u>Transgender</u>: An individual who self-identifies as a gender they were not biologically born as [e.g., FTM (Female to Male) AFAB (assigned female at birth) or MTF (Male to Female) AMAB (assigned male at birth)]; Transgender also includes non-binary as well where an individual does not conform to any specific gender.</p> <p><u>Two-spirit</u>: Direct translation of the Ojibwe term, Niizh manidoowag. “Two-Spirited” or “Two- Spirit” is usually used to indicate a person whose body simultaneously houses a masculine spirit and a feminine spirit. This pan-Indigenous term can also be used more abstractly, to indicate the presence of two contrasting human spirits (such as Warrior and Clan Mother), challenging the colonial gender binary. Two-Spirit People (also Two Spirit or Twospirit), an English term that emerged in 1990 out of the third annual inter-tribal Native American/First Nations gay/lesbian American conference in Winnipeg, describes Indigenous North Americans who fulfill mixed gender roles in their respective community. The mixed gender roles encompassed by the term, historically included wearing the clothing and performing work associated with both men and women. It’s important to know that the traditional term for Two- Spirit identity varies between Indigenous groups. It is also not a term that can be used by a non-Indigenous person.¹³</p> |

¹³ <https://gender.fandom.com/wiki/Two-Spirit>

| Topic | Affirmative Language |
|--------------------------|---|
| Gender-Neutral Neologism | Removing the gender or sex from words (e.g., Latinx instead of Latino/Latina, Womxn instead of Woman, Mx. Instead of Mr./Ms./Mrs.) ^{14,15} Also consider this idea when writing about individuals’ occupations (e.g., firefighter, not fireman; mail carrier, not mailman, etc.) |
| Pronouns | He/Him/His; She/Her/Hers; They/Them/Theirs; Ze [“Zee”] /Hir [“Here”] (non-binary, alternative gender-neutral pronouns and neopronouns); People are including their pronouns when they introduce themselves or on written documents in order to be more inclusive and welcoming. ¹⁶ People may use more than one set of pronouns when identifying (For example She/They). |
| Sexual Orientation | Lesbian, Gay, Bisexual, Queer, Asexual, Pansexual, Straight/Heterosexual, Questioning, Demisexual, Omnisexual, etc. ¹⁷ |

Language and Health Literacy

While many individuals may speak the English language, it may not be the primary language spoken at home and/or the language in which individuals would like to receive information or medical care. Over 60 million Americans speak more than one language, and it is not always one that can be assumed (e.g., not all individuals who identify as Hispanic/Latino/Latinx speak Spanish). Additionally, the United States does not have an official language.¹⁸ Identifying a person’s “preferred” primary and/or secondary language is necessary. This becomes critically important when sharing health-related information such as medication directions or consent forms. ***A person may be completely literate in their language(s) yet find it difficult to understand medical jargon and technical research terms – also known as health literacy.*** Age, education, and other factors may affect individuals’ health literacy comprehension.

The History and Use of “Hispanic”, “Latino”, “Latin@”, “Latine”, and “Latinx”

There has been an increase in discussion on the history and use of terms used to describe people from Central America, South America, and the Caribbean. The history is complex and nuanced, with people from different regions having different opinions and preferences on which terms resonate most for them¹⁹. The current discussion, and in some cases debate, exemplifies how critical it is to ask people – individuals, families, and communities – to describe how **they** identify. There will likely never be a definitive answer or conclusion on which terms(s) will be best given the vastness and complexity of how people identify within the social constructs of race, ethnicity, and gender. What may work for one person or community may not work for someone else... and that is ok. Inclusion is not a pie that can be sliced and taken from another person. Be open and

¹⁴ <https://young.scot/get-informed/national/gender-identity-terms>

¹⁵ <https://www.nytimes.com/2019/03/14/style/womxn.html>

¹⁶ <https://igbt.ucsf.edu/pronounsmatter>

¹⁷ <https://www.thehealthsite.com/sexual-health/whats-your-sexual-orientation-p915-325062/>

¹⁸ <https://www.usa.gov/official-language-of-us>

¹⁹ <https://remezcla.com/features/culture/latino-vs-hispanic-vs-latinx-how-these-words-originated/>

aware of the nuances within the Hispanic, Latino, and Latinx communities²⁰. There are plenty of other options for self-identification beside Latino, Latinx, and Hispanic. There's Latin@, popular in the 1990s as a gender-expansive precursor to Latinx. There's Latine, a gender-neutral term championed by detractors of Latinx, primarily for its better adherence to Spanish grammar.²¹

The History and Use of “black” and “Caucasian” and the Preferred Use of “Black” and “white”

The term Caucasian originated in the 18th century, with the work of the German anatomist Johann Blumembach. He developed a system of racial classification after visiting the Caucasus Mountains, by the Caspian and Black seas.²² The commonly used lowercase “black” denotes a color not a person. The equity focused capitalized “Black” aligns with the long-standing capitalization of other racial and ethnic identifiers such as Latino and Asian American. The term “white” is not capitalized, recognizing that “white people generally do not share the same history and culture, or the experience of being discriminated against because of skin color.”²³

The use of “people of color” in the Black Community

There are mixed views of the term “people of color” or “POC” in the Black Community. During the Black Lives Matter protests, many Black people called for people to stop referring to Black people as “people of color.” Many feel as though when they are grouped as a “person of color,” it is sidestepping the truth in terms of the effects of racism on different groups. Things such as mass incarceration, police violence, and health disparities disproportionately affect Black people at different levels. Many also feel as though the term “people of color” evokes a racist past and is close to the term “colored” which was widely used in the Jim Crow era.^{24,25}

Bias in Big Data

Large research study datasets and outcomes are often referenced in policy narratives as highly rigorous due to the many hundreds or thousands of human subjects that may have participated in the study. ***Being aware of biases in data and research are essential when disseminating outcomes and/or citing findings, as haphazard framing of data may imply blame or causation.*** For example, when reporting higher rates of COVID-19 incidence and prevalence in BIPOC communities failing to provide adequate context as to ***why*** these communities have experienced higher rates of COVID-19 insinuated damaging causal linkages between race and ethnicity and infection.

Concerns over technological redlining (creating and perpetuating inequities for marginalized groups in technological access, literacy, and inclusion) and weighted data analyses (multiplying results by an over or under rate based on the assumed total to more accurately reflect a population) have real consequences when focusing on person-centered language (Noble, Safiya Umoja).²⁶ ***If participants including diverse racial and ethnic groups, people with disabilities, and***

²⁰ <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/>

²¹ <https://www.bu.edu/articles/2022/why-is-latinx-still-used-if-hispanics-hate-the-term/>

²² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2151154/>

²³ <https://apnews.com/article/entertainment-cultures-race-and-ethnicity-us-news-ap-top-news-7e36c00c5af0436abc09e051261fff1f>

²⁴ <https://www.npr.org/2020/09/29/918418825/is-it-time-to-say-r-i-p-to-p-o-c>

²⁵ <https://www.npr.org/sections/codeswitch/2014/03/30/295931070/the-journey-from-colored-to-minorities-to-people-of-color>

²⁶ Noble, Safiya Umoja. *Algorithms of Oppression: How Search Engines Reinforce Racism*. New York University Press, 2018.

other marginalized populations have not been included in, informed about, or equitably provided the opportunity to participate in social behavioral or clinical research studies due to structural racism, discrimination, and the effects of social drivers of health, making statements about these populations is not practicing cultural humility or inclusivity. Data algorithms, medical guidelines, and other large health and policy outcomes do not instinctively recognize discrimination.²⁷ Thus, it is important that when writing about data and research, these limitations should be included as a part of the narrative, or a different study be considered altogether.

Furthermore, current federal reporting guidelines only include the following standardized variables when discussing individual demographics.

Federal Reporting Demographic Variables²⁸

| Demographic Category | Standardized Responses |
|----------------------|---|
| Age | Children; Adults; Older Adults |
| Ethnicity | Hispanic or Latino/a; Non-Hispanic or Latino/a |
| Gender Identity | Male; Female; Transgender Man/Male; Transgender Woman/Female; Other; Choose not to disclose; Unknown |
| Language | Best Served in a Language Other than English |
| Race | White; Black or African American; Asian; Native Hawaiian or Other Pacific Islander; American Indian or Alaskan Native; More than one race |
| Sexual Orientation | Lesbian or Gay; Heterosexual or Straight; Bisexual; Something else; Don't Know; Choose not to disclose; Unknown |

These limitations often result in the generalization of communities (e.g., Asian instead of Indian, Japanese, Chinese, etc.). ***Adding a disclosure to publications acknowledging that these variables do not represent the breadth of communities' uniqueness is encouraged.***

Example of Data Bias Disclosure

“The data variables described in this [paper, article, brief] were developed by and disseminated in alignment with Federal reporting guidelines. [Organization] recognizes that these variables are not 100% inclusive and may result in unintended biases. Whenever possible, [Organization] believes in the equitable inclusion and dissemination of data on all communities.”

²⁷ Williams, Betsy Anne, et al. “How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications.” *Journal of Information Policy*, vol. 8, 2018, pp. 78–115. *JSTOR*, www.jstor.org/stable/10.5325/jinfopoli.8.2018.0078. Accessed 19 Oct. 2020.

²⁸ <https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/2020-uds-manual.pdf>

Key take-aways

1. We are all on a journey towards a more equitable and just society and each of us are learning more about how we as individuals, teams, organizations, and communities can make changes in our thoughts, attitudes, and language to advance health equity. This guide is a starting point and is meant to invite conversation and discussion. There are organizations that are subject matter experts that have developed comprehensive tools and resources for those looking to take a deeper dive within their respective areas of focus. We encourage you to explore the following resources and tools related to the use of person-centered communication:
 - [A Progressive’s Style Guide](#) – Sum of Us
 - [Applying Racial Equity Awareness in Data Visualization](#) - Urban Institute
 - [Roots of Health Inequity](#) – National Association of County and City Health Officials
2. It is widely recommended that we ask individuals and communities about how they would like to be identified and described since preferences will vary, especially across different geographic areas (using Black or African American in the north vs. the south). For example, it is encouraged to ask individuals if they identify as Latino, Hispanic, or Latinx or if there is another term they prefer to use to describe their identity. Another example would be people in the disability community. Some people prefer person-first language, “I have a disability” while others prefer identity-first language, “I am disabled”. Both can be person-centered language so long as the individual’s preference is being recognized and affirmed.
3. Have grace for yourself and others on this journey. When we make a mistake and someone corrects us, thank them for doing so and grow from the experience. Likewise, if someone’s language or words cause harm, don’t be afraid to have an open conversation and let them know your preferences. An example would be to include your pronouns when introducing yourself or on email signatures to encourage a welcoming and inclusive environment.

For more information or to provide feedback, please contact CydneeParsley@nachc.org.

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