

ACGC DEIJ Language Guide

Foreword

The Accreditation Council for Genetic Counseling (ACGC) Diversity, Equity, Inclusion, and Justice (DEIJ) Committee has created a guide to help ACGC, and others involved in training, use language that is more inclusive and does not perpetuate harm against individuals who are part of historically excluded and marginalized communities. We are taking this step in response to existing research describing the difficulties genetic counseling students can face during their training, as well as documented gaps in knowledge around DEIJ-related language. This document was created as a general guideline, as language use is ever evolving. Context and individual preferences of those in the community you are communicating about, and with, should be prioritized.

We acknowledge the immense privilege we have as committee members and the limitations of our own lived experiences to understand the profound historical context of the words discussed below. We implore everyone reading this guide to center empathy and humility in their approach to language use. We encourage those using this document to share it freely with others who interact with genetic counseling students. Inclusive communication is one of many important steps in moving towards the goal of a more inclusive organization and profession. Changing how we speak, changes how we think.

Why Does It Matter?

Multiple researchers have found that genetic counselors are less familiar or comfortable with social considerations for diverse populations, some of which is highlighted below. Review of socially-informed language use in genetic counselor education is critical for creating inclusive, equitable, and just interactions with genetic counselors' patients and peers.

- Per Huser, et al. (2022), genetic counselor knowledge of factors affecting gender-diverse individuals is lowest in components of gender affirmation (61% knowledge score in “Potential Aspects of the Gender Affirmation Process” vs. 93% in “Terminology, Population Disparities, and Communication”).
- Per Douglas, et al. (2023), patients with disabilities and their genetic counselors felt that the genetic counselors demonstrated less comfort discussing social aspects compared to medical aspects of disability. Both groups called for educational emphasis on the medical, social, lived experience, and historical considerations of disability.
- Per O'Sullivan, et al. (2023), although genetic counselor training program interviews were not reported to include overt discrimination, cisheteronormative discussion prompts and conversations discouraged the disclosure of LGBTQIA+ identity. Provision of DEIJ support resources and demonstration of an inclusive environment proactively, regardless of whether LGBTQIA+ identity was disclosed, were recommended.
- Carmichael, et al. (2021) found that recent graduates of racial or ethnic minority groups had negative genetic counseling training program experiences, including negative comments about their belonging in the United States, being confused with other non-white classmates, and intrusive questioning about their backgrounds. These interactions occurred in the classroom, clinical rotations, and professional events. Participants felt that racial/ethnic minority program faculty provided guidance for students facing these challenges, whereas non-minority faculty support took the form of listening or action.
- Carmichael, et al. (2022) found that bicultural individuals felt particularly competent in interacting with racial and ethnic minority patients, with heightened cultural awareness. They felt that frame-

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switching - a recognized behavioral pattern in which bicultural individuals demonstrate one part of their identity or another depending on the cultural context - sometimes placed their professional identity at odds with their cultural identities.

- Carmichael, et al. (2020) identified a conscripted curriculum in genetic counseling training programs. The term "conscripted curriculum" is used to describe the use of student diversity to demonstrate lessons in cultural competency (Olsen, 2019). In genetic counseling training programs, minority students have reported feeling pressured to share personal information and to represent the minority groups with which they identify.

General Considerations

Suggestions for Alternative Words:

Instead of using:	Consider using:
Admits, denies 'The patient denies consanguinity.'	Reports, does not report 'The patient does not report consanguinity.'
Broken, bad, atypical, abnormal gene, mutant 'If someone passes down the abnormal copy of the gene, their child would have the condition.'	Not working, non-working, different, unique, variant, affected 'If someone passes down the non-working copy of the gene, their child would have the condition.'
Elderly 'Some elderly patients experience these symptoms.'	Specific age range 'Some patients in their 70s and 80s experience these symptoms.'
Foster kid 'This patient is a foster kid, so we have limited family history information.'	Child in foster care 'This patient is in foster care, so we have limited family history information.'
Genetic anomaly, mutation 'The following genetic anomalies are associated with connective tissue conditions.'	Genetic variant 'The following genetic variants are associated with connective tissue conditions.'
Homeless 'The patient is homeless and has minimal resources.'	Without housing, experiencing homelessness, unhoused 'The patient is currently without housing and has minimal resources.'
Incestuous, inbred 'The child is inbred.'	Consanguinity, identical by descent, be specific 'The child's parents are consanguineous (first-cousins).'
Incest (a legal term) 'The patient was conceived via incest.'	Be specific 'The patient's parents are first-degree relatives (brother-sister).'
Noncompliant 'The patient has a history of noncompliance.'	Describe barriers in access to care 'The patient has a history of transportation issues, which prevent them from regularly attending appointments.'
Normal 'If someone has two normal copies of the gene.'	Common, often, usual, expected, unaffected 'If someone has two unaffected copies of the gene.'
Professional/unprofessional 'Professional attire is required for clinical rotations.' 'Their communication was not professional.'	Be specific 'Closed toed shoes are required for clinical rotations.' 'They did not reply to my emails in a timely manner.'
Obese 'A 40-year-old obese patient.'	Individual with obesity, specific height and weight 'A 40-year-old patient with obesity.'
Risk 'The risk of having a child with Down syndrome is 1/10.'	Chance, likelihood 'The chance of having a child with Down syndrome is 1/10.'

Additional Information:

Regarding the term "professionalism:" This was removed from the ACGC Standards in 2023 due to the Eurocentric history of this word and its use in medical, educational, and workplace environments to perpetuate discrimination against historically excluded groups. In place of the words professional or

professionalism, we encourage the description of specific expectations and/or criteria. You can learn more about this here:

- [The Bias of 'Professionalism' Standards](#)
- [White "Professionalism" Limits Diverse Employees' Belonging](#)

Sex and Gender

Suggestions for Alternative Words:

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Instead of using:	Consider using:
Husband/wife 'Have you discussed testing with your husband/wife?'	Partner, spouse, non-gestational parent 'Have you discussed testing with your partner?'
Father/mother 'Does the father of the baby have a family history?'	Parent, egg or sperm, grandparent 'Does the other parent of the baby have a family history?'
Male/female 'A 4-year-old male presents to the clinic.'	Individual, person, patient 'A 4-year-old patient presents to the clinic.'
Brother/sister 'How many brothers and sisters do you have?' 'Has your sister had genetic testing?'	Sibling 'How many siblings do you have?' 'Has your sibling had genetic testing?'
Pregnant woman 'This medication is considered safe for pregnant women to take.'	Pregnant patient, individuals who are pregnant 'This medication is considered safe for individuals who are pregnant to take.'
Father of the pregnancy ('FOP'), father of the baby ('FOB') 'The father of the pregnancy has sickle cell anemia.'	Reproductive partner, sperm source, sperm donor, be specific 'The patient's reproductive partner for this pregnancy has sickle cell anemia.'
Advanced maternal age (AMA), advanced paternal age (APA) 'The patient was referred for advanced maternal age.'	Age related risk, egg age, sperm age, provide specific age & applicable information 'The patient will be 37 years old at delivery and was referred to review aneuploidy screening options.'
Son/daughter 'There is a 50% chance the patient's sons and daughters will inherit this genetic change.'	Child 'There is a 50% chance the patient's children will inherit this genetic change.'
Men, biological male, chromosomally male 'Men with this condition typically have more severe symptoms.' 'Avery is a 3-year-old male with developmental delay.'	Individuals with an X and Y chromosome, assigned male at birth (AMAB), individual with testes, presumed male at birth 'Individuals with XY chromosomes typically have more severe symptoms.' 'Avery is a 3-year-old who was assigned male at birth and has developmental delays.'
Women, biological female, chromosomally female 'Women who have a high risk for breast cancer could qualify for breast MRIs.' 'Avery is a 7-year-old biological female with short stature.'	Individuals with two X chromosomes, assigned female at birth (AFAB), individual with uterus/ovaries, presumed female at birth 'Individuals with two X chromosomes may qualify for breast MRIs if they have a high chance for breast cancer.' 'Avery is a 7-year-old who was assigned female at birth and has short stature.'
Female reproductive organs, female cancers/organs 'BRCA variants increase the chances for female cancers.'	Uterus/uterine cancer, ovaries/ovarian cancer, and fallopian tubes, be specific 'BRCA variants increase the chance to develop breast and ovarian cancer.'
Male cancers/organs 'BRCA variants increase the chances for male cancers too.'	Prostate and testicular cancer, be specific 'BRCA variants increase the chances for prostate cancer.'
Male and female hormones 'Boys with Klinefelters have decreased male hormone levels.'	Testosterone and estrogen 'Individuals with Klinefelters have decreased testosterone levels.'
Affected men/carrier women 'Carrier women are less likely to show symptoms of X-linked ALD'	People with one X chromosome/people with 2 X chromosomes

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	'Individuals with two X chromosomes are less likely to show symptoms of X-Linked ALD.'
Puberty 'Girls may notice breast development during puberty.'	Estrogen or testosterone-based puberty 'Children that undergo estrogen-based puberty often notice increased development of their breast tissue.'
Couples 'Some couples may want to have diagnostic testing, while others do not.'	Individuals (in prenatal context) 'Some individuals may want to have diagnostic testing, while others do not.'
Men and women 'The risk of inheriting the variant is the same in men and women.'	People, individuals 'The chance of inheriting the variant is the same for all individuals.'
Women's health 'We plan to refer you to a women's health specialist to discuss preimplantation genetic testing options.'	Reproductive health 'We plan to refer you to a reproductive health specialist to discuss preimplantation genetic testing options.'
Breastfeeding 'Did you breastfeed any of your children?' 'This medication is safe for breastfeeding mothers.'	Nursing 'Did you nurse any of your children?' 'This medication is safe for individuals who are nursing.'
Marital status 'What is your marital status?'	Relationship status 'What is your relationship status?' 'Are you in a relationship?'
Sexual preference 'And tell me, what is your sexual preference?'	Sexual orientation 'Can you tell me your sexual orientation?'
Preferred pronouns/gender 'What are your preferred pronouns?' 'What is your preferred gender?'	Pronouns, gender 'What are your pronouns?' 'What is your gender?'
Hermaphrodite 'This individual is considered a hermaphrodite based on these genetic results.'	Intersex 'This individual is considered intersex based on these genetic results.'
NB ◊ NB	Non-binary or enby ◊ non-binary
Ladies and gentleman 'Ladies and gentlemen, thank you for attending today's workshop.'	People, friends, everyone, folks, 'Thank you for attending today's workshop everyone.'
Gender change, sex change, becoming a man/woman, pre/post-operative, transvestite, transgendered 'The transgendered patient has not undergone a sex change yet.'	Gender-affirming surgery, trans man, trans woman, be specific 'The patient is a trans man who has not undergone gender-affirming surgery at this time.'
Ambiguous genitalia 'The infant had ambiguous genitalia at birth.'	Intersex, non-binary genitalia, be specific 'The infant had an enlarged clitoris at birth.'
Real sex, real gender, genital sex, used to be male, used to be female, male-to-female, female-to-male 'The pregnant man's real sex is female.'	Sex assigned at birth, sex presumed at birth, trans man, trans woman 'The pregnant individual is a trans man.'

Additional Information:

Sex and gender are both medical and social constructs that are very personal in individuals' daily lives. As such, whenever possible we encourage individuals to use non-gendered terms when referencing individuals and groups of people whose pronouns, sex, and/or gender has not been confirmed by the

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individuals in reference. An individual's pronouns, sex, and/or gender should not be assumed based on your perception of their appearance. If you'd like additional information regarding pronoun use, please refer to:

- [LGBT Life Center's Understanding Pronouns](#)
- [What Are Personal Pronouns And Why Do They Matter?](#)
- If you'd like to practice: [Practice with Pronouns](#)

Being trans is not defined by an individual's surgery history, current or past organs, pronouns used, sex-assigned at birth, and/or current medication regime or hormone levels. An individual does not have to have undergone a surgical or hormone transition to be trans. If you'd like more information regarding being an inclusive clinician for trans-patients, please refer to:

- [TransHub - For Clinicians](#)

Additional information regarding inclusive word choice can be found:

- [How to Use Inclusive Language in Healthcare](#)

Disability

Suggestions for Alternative Words:

Instead of using:	Consider using:
Typical, normal 'Normally, children begin to walk around 12 months.'	Common, often, usual, expected, unaffected 'It is common for children to start walking around 12 months.'
Broken, bad, atypical, abnormal, mutant, or defective gene 'The abnormal version of the gene makes defective proteins.'	Not working, non-working, different, unique, variant, affected 'If the gene is not working, the protein is not made correctly.'
Genetic anomaly, chromosomal abnormality 'This lecture will cover the most common chromosomal abnormalities.' 'Karyotype is a test that can detect chromosomal abnormalities.'	Genetic variant, chromosome variant, condition, aneuploidy/specific change tested for 'This lecture will cover the most common chromosomal conditions.' 'Karyotype is a test that can detect variations in the chromosomes.'
Impairment, abnormality, disorder 'Hereditary abnormalities in collagen synthesis can lead to numerous genetic disorders.'	Variation, condition 'Hereditary variations in collagen synthesis can lead to numerous genetic conditions.'
Deformed, malformation, defect 'Individuals with this condition are born with limb deformities.'	Use specific diagnoses instead 'Individuals with this condition are born with clubbed feet.'
Low functioning autism 'The patient with low functioning autism'	Autism with an intellectual disability component, high-support needs 'The patient has a diagnosis of autism spectrum disorder with an intellectual disability.'
High functioning autism, Asperger's syndrome 'The patient with Asperger's syndrome.'	Autism without an intellectual disability or history of delays, autism with a history of social milestones delays, low-support needs, autism spectrum disorder 'The patient has a diagnosis of autism spectrum disorder with low-support needs and no intellectual disability noted.'
Addiction, alcoholic, 'drug user,' addict 'The patient is an addict and battles addiction.'	Substance use disorder/alcohol use disorder 'The patient has a history of a substance use disorder.'
Cripple, crippled 'The patient's daughter was a cripple.'	Disabled, physical disability, be specific if possible, or use examples 'The patient's daughter has a physical disability for which she uses a wheelchair.'
Mental illness/mentally ill, crazy, insane 'The patient has a family history of mental illness, her mother is bipolar.'	Mental health condition, be specific if possible 'The patient has a family history of mental health conditions, with her mother having a diagnosis of bipolar disorder.'
Retardation, cognitively impaired 'The patient has been retarded since birth.'	Intellectual disability, global developmental delays 'The patient has a history of global developmental delays, with a diagnosis of intellectual disability provided at age 5.'
Disability/handicapped bathroom/parking 'Clinic has handicapped bathroom stalls and parking for disabled patients.'	Accessible bathroom/parking 'Clinic has accessible bathroom stalls on each floor, with three accessible parking spots near the front entrance.'

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<p>Mute, nonverbal 'The patient has nonverbal autism.'</p>	<p>Situation-dependent speech, does not verbalize, non-speaking 'The patient does not primarily communicate via speech, with situation dependent speech (example – patient uses speech with parents only in home environment).'</p>
<p>Handicapped, handicapable, dis/ability, disAbility, differently abled 'Patients with this condition are severely handicapped.'</p>	<p>Disabled, with a disability 'Patients with this condition will have significant disabilities.'</p>
<p>Special education, special needs 'They have a special needs child.'</p>	<p>Disabled, has an IEP/504 plan, receives additional supports in XYZ subject areas, support needs for XYZ 'Their child has an IEP plan and is in a high-support needs classroom with a 1-1 aid.'</p>
<p>Wheelchair bound/confined 'The patient is confined to a wheelchair.'</p>	<p>Wheelchair user, uses mobility aids 'The patient utilizes a wheelchair, forearm crutches, and ambulation without mobility aids – depending on the day and situation.'</p>
<p>Midget, dwarf 'The patient's aunt is a midget.'</p>	<p>Short stature, has dwarfism, little person 'The patient's aunt has short stature and is approximately 3' in height.'</p>
<p>Deaf-mute, deaf-blind 'The patient's uncle is deaf-blind'</p>	<p>Has hearing loss and does not use words, has hearing and vision loss 'The patient's uncle was born with bilateral congenital hearing loss with vision loss onsetting in childhood. They use sign language to communicate and do not verbalize.'</p>
<p>Survivor, warrior, inspirational 'For today's presentation, we have a muscular dystrophy warrior here to share their inspirational story.'</p>	<p>Has, is affected by, is diagnosed with 'For today's presentation, we have an individual with muscular dystrophy here to share their experience and story.'</p>
<p>Suffers from, afflicted by 'The patient suffers from sickle cell disease.'</p>	<p>Has, is affected by, is diagnosed with 'The patient has sickle cell disease.'</p>

Additional Information:

There is no one “right” way to discuss disability, however a common language choice regards person first/identify first language choices. Different communities may prefer either of these, and members within the same community may have different preferences as well. You can learn more about this from author and disability scholar Lydia Brown.

- [The Significance of Semantics: Person-First Language: Why It Matters](#)
- [Identity and Hypocrisy: A Second Argument Against Person-First Language](#)

Beyond simple language use, it can be helpful to consider the narratives of disability that we present in our discussion of the disability community, including the narratives primarily used by resources we present to students and patients. There are many models of disability that extend beyond the, often described, medical and social model. You can learn more about these various models of disability:

- [Medical and Social Models of Disability](#)
- [Models of Disability: Types and Definitions](#)
- [What is Neurodiversity?](#)

As the diagnosis “Asperger’s syndrome” is no longer in the DSM and based on recent acknowledgements of Dr. Asperger’s connections to the Nazi party, we recommend individuals stop using this term. You can learn more about this history here:

- [New Evidence Ties Hans Asperger to Nazi Eugenics Program](#)
- [The Truth About Hans Asperger’s Nazi Collusion](#)

If you’d like to learn more about language considerations specific to certain communities (Deaf, Little People of America) and some specific terms that are considered ableist, you can learn more about at:

*The autism community is discussed in links above so has not been included here:

- [Ableism/Language Words and Terms to Avoid](#)
- [Disability Language Style Guide](#)
- [National Deaf Center - Deaf Awareness](#)
- [Little People of America - The "M" Word](#)

Providing image descriptions (“Alt Text”) is a key element of accessibility for images and graphics. Without accurate descriptions, many resources end up inadvertently defaulting to white, able bodied, heteronormative assumptions. Below are some resources discussing how to help guide accurate, alternative image descriptions:

- [The Case for Describing Race in Alternative Text Attributes](#)
- [Alternative Text: Race, Gender, and Physical Descriptions](#)
- [Identity and Inclusion in Alt Text](#)

Race and Ethnicity

Suggestions for Alternative Words:

Instead of using:	Consider using:
Arab, Middle Eastern 'The Arab patient.'	Specific regions/countries 'The patient is of Iranian ancestry.'
Asian 'The Asian patient.'	Specific regions/countries 'The patient is of Chinese ancestry.'
Black, Blacks 'The Black patient.'	Specific regions/countries 'The patient is of Haitian ancestry.'
Caucasian 'The Caucasian patient.'	Specific regions/countries, European ancestry 'The patient is of German ancestry.'
Hispanic, Latino/a, Spanish (unless from Spain) 'The Spanish patient.'	Specific regions/countries 'The patient is of Mexican ancestry.'
Jewish 'The Jewish patient.'	Specific ancestral groups 'The patient is of mixed Ashkenazi and Sephardic Jewish ancestry.'
Mixed ancestry/race 'The mixed race patient.'	Specific regions/countries 'The patient is of Korean and Guatemalan ancestry.'
Native, Indian, American Indian 'The Native Canadian patient.'	Specific nation/peoples, if unknown can use Indigenous ancestry 'The patient is of Inuit ancestry.'
Minority group 'Patients from minority groups may face bias accessing medical care.'	Underrepresented group, historically marginalized community, historically excluded group, global majority 'Patients from historically underrepresented groups may face bias accessing medical care.'
Harelip 'The baby was born with a harelip.'	Cleft lip 'The baby was born with a unilateral cleft lip.'
Mongolian spot, mongoloid features, mongolian eyes 'The baby was born with a mongolian spot on their back.'	Slate gray nevus, congenital dermal melanosis 'The baby was born with a slate gray nevus on their back.'
Simian crease 'The baby was born with a simian crease.'	Singular palmar crease 'The baby was born with a single palmar crease.'
Moon face 'The patient presented with a moon face.'	Swelling or puffing of the face 'The patient presented with swelling of the face.'

Additional Information:

Race and ethnicity are both social constructs that are embedded into most aspects of everyday life. Accordingly, the consequences of racism are significant, particularly within medicine given the downstream effects. There is ample research examining the various ways in which race and ethnicity affect medical teaching, clinical decision-making, and patient treatment and outcomes. You can learn more about this here:

- [Use of Race in Clinical Diagnosis and Decision Making: Overview and Implications](#)

As the medical field comes to terms with the realities of systemic racism and makes efforts to correct course, it is essential that the language and terminology that we use “be accurate, clear, and precise, and ... reflect fairness, equity, and consistency in use and reporting of race and ethnicity.”* Race and ethnicity data should be collected from individuals directly and should never be assumed based on an individual’s appearance, name, or otherwise. Whenever possible, we should refer to specific regions or countries when discussing an individual’s ancestral origin rather than using blanket language. If the specific

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regions/countries are unknown, referring to the larger ancestral group is generally acceptable (e.g. “The patient is of European ancestry”). Be mindful about matching an individual’s use where appropriate, as there can be personal preferences for certain terminology.

Of note, the terms “African American” and “Black” are **not** interchangeable - an individual can be Black but not be African American, as “Black” generally refers to individuals of the African diaspora; the key is to match an individual’s use and preferences. Similarly, when using the term “Jewish,” you should be clear on whether you are referring to Judaism as a religion or Jewish as an ethnic group or specific subgroup/genetic ancestry (e.g. Ashkenazi Jewish, etc). Furthermore, we recommend moving away from the use of the term “Caucasian” to refer to individuals of European ancestry, as it is an outdated term rooted in racism. You can learn more about all of these topics here:

- [*Updated Guidance on the Reporting of Race and Ethnicity in Medical and Science Journals](#)
- [Perspective: Are We Teaching Racial Profiling? The Dangers of Subjective Determinations of Race and Ethnicity in Case Presentations](#)
- [NSGC Perspectives: “Black/African American” - Black Cultural Erasure in Genetic Counseling](#)
- [The population genetics of the Jewish people](#)
- [Rethinking the Use of "Caucasian" in Clinical Language and Curricula: a Trainee's Call to Action](#)
- [The Surprisingly Racist History of "Caucasian" | Decoded | MTV News](#)

Though knowing an individual’s ancestry can be important in the context of data collection and assessment (e.g. calculating genetic risks, demographics in a research or academic setting, etc.), we must be mindful of why we collect this data and how we use it. If mention of a person’s race or ethnicity in a chart note, case presentation, etc., might introduce bias, there is a shift towards excluding this information. Ask yourself “is this information *necessary*?”; you can learn more about this here:

- [Race, Ethnicity, and Culture in the Medical Record: Implicit Bias or Patient Advocacy?](#)
- [First Impressions - Should We Include Race or Ethnicity at the Beginning of Clinical Case Presentations?](#)

If you’d like to learn more about language considerations specific to race, ethnicity, and related social justice movements, here is a great resource created by the genetic counseling student group Genetic Counseling Trainee Platform for Racial Justice. Of note, this resource does include a reference to an article that uses “crippling” in its title, and so we’d like to acknowledge the third party inclusion of a disability slur.

- [GCRJ's Racial Justice Glossary](#)

The above document was created in September 2024 and plans to be updated regularly. If you have suggestions, edits, or concerns with this document, we encourage you to reach out by emailing info@gceducation.org.