Cultural Competency in Home Care Services for Individuals with Intellectual and/or Developmental Disabilities

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<u>Introduction</u>

We are not supposed to all be the same, feel the same, think the same, and believe the same. The key to continued expansion of our universe lies in diversity. – Anthon St Maarten

  Cultural competency is a set of congruent behaviors, knowledge, attitudes, and policies that enable work in crosscultural situations (CHAMPS, 2021). When working in social services, it is important for you to be able to understand the culture of the family/families that you are providing services for. Individuals of different cultures will have different needs and having an understanding of their culture will allow you to be more beneficial to the family as a caretaker. "Culture and cultural diversity can incorporate a variety of factors, including but not limited to age, disability, ethnicity, gender identity

Figure 3: Cultural diversity and communication as core concepts in global care environments.

  (encompasses gender expression), national origin (encompasses related aspects e.g., ancestry, culture, language, dialect, citizenship, and immigration status), race, religion, sex, sexual orientation, and veteran status. Linguistic diversity can accompany cultural diversity." (ASHA, 2017)

  Cultural competence training for health care professionals can improve the providers knowledge, understanding, and skills for treating patients from culturally, linguistically, and socio-economically diverse backgrounds. Valuing diversity means embracing the uniqueness of all individuals along several dimensions such as race, religious beliefs, ethnicity, age, gender, physical abilities, political beliefs, and socio-economic status (PPRS, 2019).

Why is Cultural Competency so important in home care?

- Reduces Health Disparities and Promotes Health Equity
- Improves Safety of the Person Supported
- Improves Outcome of the Person Supported
- Improves Satisfaction of Person Supported
- Increases Quality of Home Care Services
- Builds Trust with Person Supported and Community (CHAMPS, 2021)

Cultural competence requires organizations and their personnel to do the following:

1. Value Diversity
2. Assess Themselves
3. Manage the Dynamics of Difference
4. Acquire and Institutionalize Cultural Knowledge
5. Adapt to Diversity and the Cultural Contexts of Individuals and Communities Served (Joint Commission, 2011)

In this ever changing social environment, there will always be something new to learn in regard to other cultures. Developing cultural competence is a dynamic and complex process requiring ongoing self-assessment and continuous expansion of one's cultural knowledge. It evolves over time, beginning with an understanding of one's own culture, continuing through interactions with individuals from various cultures, and extending through one's own lifelong learning (ASHA, 2017). It is important to keep an open mind and try to accept others for who they are and how they present. Having this kind of mindset will help you to provide the best possible care for the individual that you are supporting.

Tips for Culturally Informed Communication

- Think Beyond Race and Ethnicity
  - Opportunities to expand our cultural understanding exist everywhere, especially when we consider culture beyond its association with ethnicity. Culture is central to our identity and, as such, may be seen or unseen by others. Culture is shaped by personal experiences that may include ethnic and racial identity; religion; age; educational level; body size; heritage and family tradition; physical and cognitive abilities; sexual orientation; gender identity; and geographic and socioeconomic experiences.

- Experience Culture
  - Consider experiential ways that you can learn about other cultures and endeavor to participate in activities that may not be familiar to you. When possible, take part in social, community and educational activities like viewing films, reading books, and attending faith-based services, festivals, parades, concerts, sporting events, art exhibits, workshops, and lectures.
- Use Language that Evokes Images of People Actively Engaged in Life when Working with People with Disabilities.
  - Avoid phrases that suggest helplessness or tragedy. For example, say "Bob uses a wheelchair" instead of "Bob is in a wheelchair."
- Think Outside Your Own Box
  - We are influenced by our own values, beliefs, biases, and life experiences. We need to carefully consider how our perspectives affect our understanding of other cultures and avoid making assumptions about others based on our own experiences. Becoming culturally aware starts with recognizing the limitations of our own cultural knowledge
- Listen Carefully
  - Hearing is not necessarily listening. Our own perceptions, biases and expectations sometimes make it difficult to really listen to and comprehend both overt and covert messages. Be mindful to focus on and identify the information being conveyed.
- Learn by Asking
  - People feel respected when others are genuinely interested in learning about their views and perspectives. Consider incorporating questions into conversations that demonstrate your desire to learn more about others' cultural experiences. Use simple or open-ended questions that encourage dialogue, such as: "What do you think?" "How can I be of assistance to you?" "What information is important for me to know about you and your culture?" "If I was a member of your community, how would I most likely react to/cope with this situation?"
- Avoid Insensitive Comments
  - In group contexts, individuals sometimes make insensitive and hurtful comments about others (e.g., jokes, slurs, etc.). Do not reinforce this behavior. If you are comfortable doing so, make known your discomfort with what has been said and ask that no more insensitive comments be made.
- Tune in to Non-Verbal Behaviors
  - Sometimes, behaviors can provide more details about how someone is reacting to a situation than what they may be comfortable saying. It is important to recognize welcoming behaviors as well as those that may be defensive so that you can adjust your approach accordingly. Similarly, be aware of your own body language. Does standing while others are sitting demonstrate authority, or aggressiveness?
- Respect Language Preferences

- o Before approaching a new group of people, consider whether the materials you have to offer, or your presentation need to be adapted to ensure that you are understood. In some cases, it might be necessary to translate materials or invite an interpreter to the presentation. Other times, such as when communicating with young children, simply adjusting your vocabulary might suffice.
- Expand Your Comfort Zone
  - o It is likely that there will be individuals or cultural groups with whom you do not have experience working. Acknowledge this challenge and make an effort to learn as much as possible about the individual or group so that you can build your confidence and bolster your outreach. Ask questions to make it clear that you want to learn more and to ensure that you're delivering information in a way that is useful.
- Honor Flexibility in People's Self-Identification
  - o We may make assumptions about people's cultural identity while they may have an entirely different perception of themselves. Listen for information about selfperception. For example, do they consider themselves as having a spouse or a life partner? People may identify with a particular aspect of their diversity at different times (e.g., being a lesbian may be very salient in some circumstances but not in others)
- Make Local Connections
  - o What community-based organizations and venues are respected and trusted by those with whom you work? Organizations like social clubs, advocacy groups, religious institutions, civic groups, unions, colleges, and universities can help you deliver your messages in a forum that is relevant to your audience. In some cases, you may want to partner with leaders from these organizations to help you communicate even more effectively (American Psychological Association, 2013)

<u>Cultural Competency in the use of Disability Language</u>

An essential core-concept of human dignity is that a person is not an object, not a thing. – Beatrice A. Wright

The American Psychological Association (APA) advocates the use of person-first language (e.g., people with disabilities) to refer to individuals with disabilities in daily discourse and to reduce bias in psychological writing (Dunn & Andrews, 2015). Language is very important when working with individuals with disabilities, as certain verbiage could dehumanize the individual by focusing too much on their "impairment". Beatrice A. Wright argued that the emphasis should be placed on the person, who must always come before his or her disability. Person-first language (e.g., person with a disability)—literally emphasizing persons rather than impairments—was believed to preserve disabled people's humanity while promoting their individuality. (Dunn & Andrews, 2015)

It is especially important that you do not refer to anyone with a disability in monolithic terms (e.g., a tetraplegic, a diabetic, an autistic), because doing so effectively objectifies the person by focusing only on the impairment. Such objectifying language promotes essentialism, where people are viewed primarily in terms of their disabilities (Dunn & Andrews, 2015).

Cultural Competency and the LGBTQ+ Community

To be yourself in a world that is constantly trying to make you something else is the greatest accomplishment – Ralph Waldo Emerson

Today's global societal climate is changing. Different cultures across the world have variations on the level of acceptance for the lesbian, gay, bisexual, transgender, and queer (LGBTQ)community. In the United States views about the LGBTQ+ community vary greatly, even just in the state of Colorado, opinions can be vastly different. Regardless of personal views, we are in the people helping business, and that means we help all people. The educational environment is paramount to addressing the issue of stigma and therefore reducing stress initiated by stigma, for LGBTQ populations (Burkey et al., 2021). Stereotypes and stigmas in regard to the LGBTQ+ community can be extremely damaging to the individuals in the community and the community as a whole. Working in the home care field, you might come across individuals who do identify as part of the LGBTQ+ community and being able to understand/respect how they identify could improve the quality of care you are able to provide as well as improve their quality of life.

While the LGBTQ+/ASD population is a small population, it exists, and it is a horribly under researched and misunderstood population that lacks adequate health care services. Focused interviews make a compelling case that American adults with ASD who also identify as LGBTQ+ lack adequate health care services and experience worse health than their straight, cisgender peers with ASD. Despite having higher educational attainment, the ASD/LGBTQ+ group reported greater rates of mental illnesses and smoking and poorer overall health. These findings are in direct contrast to a large body of work demonstrating better health and lower rates of depression and smoking among individuals with more education (Hall et al., 2020).

As a Child and Youth Mentor, you will need to try to empathize with the experiences that the person that you are supporting has. We can all empathize with the difficulties of high school and puberty and trying to determine your identity and how you want to express yourself. LGBTQ adolescents and young adults face additional challenges related to sexual orientation, evolving gender roles, peer pressure, bullying, and progression through developmental stages. Sexual minorities including the LGBTQ community are understudied with respect to health and health care inequalities (Walia et al., 2019). Being patient, supportive, and ensuring that the person that you are supporting has equal healthcare opportunities could be what brings their experience as an Individual with Intellectual and Developmental Difficulties who is part of the LGBTQ+ community into a positive light. LGBTQ+ individuals must have access to competent, nondiscriminatory healthcare. This can only be accomplished when healthcare workers are adequately trained to address the health needs and experiences of this population. Without widespread education and training for clinicians and their staff, disparate health outcomes will continue to occur and further marginalize this population (Rhoten et al., 2021)

An important part of being culturally competent regarding this community is understanding the verbiage that individuals use to identify themselves within the community. The LGBTQ+ acronym has expanded to become more inclusive and give more individuals the opportunity and ability to express themselves outside of a five letter acronym. The acronym is now LGBTQQIAAP, which stands for Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, Allies, Asexual and Pansexual.

Term	Definition
Lesbian	A person that identifies as a woman and is primarily attracted to other people who identify as women
Gay	A person who identifies as a man and is primarily attracted to other people who identify as men.
Bisexual	A person who is primarily attracted to both men and women
Transgender	An all-inclusive term to define people who have gender identities, expressions, or behaviors not associated with their birth sex
Queer	Used in the past as a slur to target people that do not follow the "norm" of sexual orientation and/or gender identity. More recently the term is used to identify trans, bisexual, lesbian, gay, intersex, and heterosexuals who do not follow the "norm."
Questioning	A person who is still exploring their sexuality or sexual identity

Intersex	A person whose body is not definitively male or female. This may be because they have chromosomes which are not XX or XY or because their genitals or reproductive organs are not considered "standard".
Allies	A person who identifies as straight but supports people in the LGBTQQIAAP community.
Asexual	A person who is not attracted in a sexual way to people of any gender
Pansexual	A person whose sexual attraction is not based on gender and may themselves be fluid when it comes to gender or sexual identity

(Burkey et al., 2021; BBC, 2015)

It is also important to understand the terms used by individuals within this community, as some of these terms are sometimes confused with others incorrectly interchanged. This includes terms such as Gender Expression, Sexual Orientation, and Gender Identity.

Understanding these terms will help you to better understand the individual that you are serving. It will create a trusting and positive relationship that could greatly benefit the person that you are supporting by increasing their confidence and helping them to feel more comfortable with who they are and how they identify. In addition, if you are supporting a member of the LGBTQ+ community, knowing their pronouns and using their preferred pronouns could increase their mental health and overall outcome.

Term	Definition
Gender Expression	A person's outward expression of gender or how they present themselves to the world
Sexual Orientation	A pattern of emotional, romantic, and/or sexual attractions to men, women, both, neither, or other genders.
Sex	An individual's sex assignment at birth
Gender Identity	A personal conception of oneself as male, female, both, or neither.
Cultural Competency	The ability to understand, appreciate, and interact with persons with diverse values, beliefs, and behaviors.

(Walia et al., 2019)

PRONOUNS
A Helpful Resource
Pronouns are words that substitute for nouns. Gender pronouns are used in place of a person's name. This list is not exhaustive but is a good place to start!

Binary and Gender Neutral Pronouns

	Nominative (Subject)	Objective (Object)	Possessive Adjective	Possessive Pronoun	Reflexive
She	She	Her	Her	Hers	Herself
He	He	Him	His	His	Himself
They	They	Them	Their	Theirs	Themself
Ze	Ze	Hir	Hir	Hirs	Hirself
Ey	Ey	Em	Eir	Eirs	Eirself

LGBTQ+ individuals have a long history of being disrespected not only by the general public, but by care providers as well. Lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals and families experience many barriers to receiving respectful, nondiscriminatory, and adequate health care. LGBTQ people seeking health care services frequently encounter unwelcoming and disrespectful attitudes as well as outright refusals of care. Inadequate health care for individuals in this population may result not only from outright refusals of care or overt hostility, but also from provider discomfort and lack of understanding of these patients' lives and healthcare needs (Rhoten et al., 2021). If you are assigned to an LGBTQ+ individual and you do not feel as though you can provide adequate and unbiased care, please inform your supervisor so that they can be assigned to a different provider.

Having a Child and Youth Mentor who is accepting and respectful has the potential to provide a more positive mental health outcome for the individual. LGBTQ+ individuals are more likely to suffer from depression, anxiety, and other mental health challenges, report poor health, use tobacco, abuse drugs, consume excessive alcohol, fare more poorly than others when undergoing cancer treatment; and suffer from eating disorders (Rhoten et al., 2021). Being part of the LGBTQ+ community can be difficult on its own and identifying outside of the "norm" as an Individual with an Intellectual and/or Developmental Disability can add an entirely new set of challenges both in terms of mental health and societal support.

One suggested best practice for serving YYA (youth and young adults) who are LGBTQ is to enable YYA to self-identify their sexual orientation and gender identity. Asking these questions can be one way to identify and refer YYA who are LGBTQ to appropriate and competent supportive services that will address their unique needs, to ensure that transgender and gender expansive youth are referred to using accurate names and pronouns (Shelton et al., 2018). If you intentionally refer to the person that you are supporting by their "dead" name (if they have

chosen to go by a different name) and their incorrect pronoun, you could be setting them up for a negative outcome, and their mental health may deteriorate. Respecting the individuals name and pronouns and looking for care/resources that are in line with their chosen identity can help youth and young adults to gain further self-confidence and independence.

You might start working with an individual while are socially transitioning, and your help and support could make that transition significantly easier. Social transitioning may include changing names and pronouns; using particular toilets and changing rooms; dressing more in accordance with societal expectations of their gender; performing mannerisms in line with their gender; using binders or, for some, seeking medical measures such as hormone therapy (McGlashan & Fitzpatrick, 2018). If you do end up supporting a transgender individual, you need to remember that the identity that they have chosen might make them feel stronger and more self-assured. Even implying that their identity is not valid or that they are wrong to identify as a sex that that were not born as can be extremely damaging and should be avoided at all costs. It is important to note that being trans is by no means necessarily a singular or even shared experience. Like all identity positions, trans is one articulation among many (including those connected with ethnicity, social class, place, age, ability and so on) (McGlashan & Fitzpatrick, 2018)

Transgender people who live with a social gender identity that differs from the gender they were assigned at birth-can successfully do masculinity or femininity without having the genitalia that are presumed to follow from their outward appearance (McGlashan & Fitzpatrick, 2018).

- Jenkins et al. (2022) demonstrated that bias-reduction workshops for home care staff resulted in measurable increases in client satisfaction and decreased healthcare disparities among minority populations. (Jenkins et al., 2022)

Is implicit bias training effective?

Raising awareness	Evidence that training can raise awareness is strong, but more research into how meaningful and long-lasting this awareness is is needed.
Reducing implicit bias	The most commonly used metric in studies on the effectiveness of training. The results are unpromising – large-scale studies find effects to be small or not distinguishable from zero.
Reducing explicit bias	This is often measured using self-reported attitudes, so accuracy is questionable and results are hard to interpret. There is no reliable evidence that implicit-bias training reduces explicit bias.
Changing behavior	This is the "gold standard" metric when it comes to implicit-bias training. There is no significant evidence that it can trigger behavioral change.

TestGorilla   *Information taken from Herbert, Frederick, "Is unconscious bias training still worthwhile?" for LSE business review (2021)

Figure 1: Visual summary of research findings on the effectiveness of implicit bias training.
- Nguyen and Patel (2024) highlight the importance of culturally responsive language development strategies, emphasizing the use of inclusive, non-pathologizing terminology in home care services. (Nguyen & Patel, 2024)

Figure 2: Examples of inclusive language in written agreements and communication.
- Mason et al. (2023) found that cultural competency interventions that include immersive training significantly improve service outcomes among caregivers supporting neurodivergent youth across diverse cultural contexts. (Mason et al., 2023)
Recent Research and Updates (2022–2025)

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