

## Clients who Identify as Deaf: Providing Culturally Competent Care

### What We Know

- › This Evidence-Based Care Sheet will explore cultural competence in working with Deaf and hard of hearing persons from the viewpoint that this population is a sociocultural minority. Deaf individuals are part of a cultural and linguistic group that possesses a collective name, culture, language, and history, along with shared values, customs, and behavioral norms. For this paper, Deaf is capitalized, just as the name of any ethnic or religious group would be spelled with a capital letter. The capitalization indicates a sociolinguistic affiliation in conjunction with the audiological status of the individual. A lowercase “d” is more commonly used in the medical model and refers to the audiological status of the individual, not his or her cultural identification<sup>(18,21,22)</sup>
- › Deaf culture does not always include all persons who have a hearing loss, since they all may not identify as Deaf<sup>(7)</sup>. Several factors, including age at onset of hearing loss, degree of hearing loss, and communication mode, have an impact on whether or not an individual with a hearing loss identifies as Deaf. Typically, persons who develop a hearing loss after acquiring language (i.e., postlingually) are less likely to self-identify as Deaf. Adults with progressive hearing loss, most commonly due to age, also rarely self-identify as Deaf. Most commonly, individuals who identify as Deaf are audiotically deaf or hard of hearing, use sign language, and identify with the larger cultural group<sup>(8,22)</sup>
- › Deaf adults often feel that the Deaf community provides protection, understanding, a sense of belonging, and a chance to feel normal. Many Deaf adults feel that the hearing world sees them as defective or broken<sup>(20)</sup>
- › To provide culturally competent care, social workers must be able to understand their own personal worldviews while understanding the client. The social worker has to be able to integrate the attitudes, beliefs, and practices of Deaf culture into rapport-building<sup>(22)</sup>
- › **Historic and Current Cultural Values**
  - The majority of persons in the Deaf community do not like to use the phrase “hearing impaired”<sup>(21,22)</sup>. Instead clients who identify as deaf prefer to be labeled “Deaf”<sup>(21)</sup>
  - Deafness is not considered to be a disability by those individuals who culturally identify as Deaf, but instead is considered to be a difference in their human experience<sup>(7,17,21,22)</sup>
  - Individuals with major hearing loss may self-identify in one of four ways. Social workers need to recognize, however, that identity can be fluid and complex, and may change over time<sup>(8)</sup>
    - Marginal identity defines individuals who are deaf but do not feel that they belong in either the hearing world or the Deaf community<sup>(2,8)</sup>
    - Dual or bicultural identity defines individuals who feel comfortable in both the Deaf community and hearing society<sup>(2,8)</sup>
    - Deaf-dominant bicultural identity defines individuals who feel comfortable in both environments but have a strong preference for the Deaf community<sup>(8)</sup>
    - Hearing identity defines individuals who relate most strongly to the hearing community. Often these are individuals who have received cochlear implants and

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do not use sign language. They may also view deafness as pathological or a medical problem to be fixed<sup>(2,8)</sup>

### › **Current Demographic Information**

- Various definitions for deafness are used in the United States and globally, which results in different estimates of the size of the population<sup>(7,14,23)</sup>
  - Federal surveys in the United States related to hearing status do not typically include questions about American Sign Language (ASL) use, other sign language, or how the individual identifies socially. This makes it hard to get accurate estimates, since many people who have hearing loss but do not consider themselves Deaf are included in statistics<sup>(14)</sup>
    - For example, anywhere from 37 to 140 of every 1,000 persons in the United States report some type of hearing loss, but this is much higher than the number that are Deaf<sup>(14)</sup>
- Five percent of the world's population has disabling hearing loss (i.e., a loss greater than 40 decibels in their better ear if an adult and 30 decibels if a child), with the majority of these individuals living in low- or middle-income countries<sup>(23)</sup>
- Fewer than 1 in every 1,000 persons in the United States is deaf before the age of 18<sup>(14)</sup>
- More than 90% of Deaf children in the United States are born to parents who are hearing<sup>(16)</sup>
- Of every 1,000 children in the United States, 2 or 3 are born deaf<sup>(16)</sup>

### › **Prominent Health Conditions/Risk of Health Conditions**

#### • **Health Beliefs**

##### – **Attitude Toward Health**

- Cochlear implants remain controversial in the Deaf community. By December 2012, about 324,200 cochlear implants had been implanted worldwide, with approximately 58,000 being implanted in adults and 38,000 in children in the United States<sup>(16)</sup>
- From June 2012 to June 2013 approximately 50,000 cochlear implants were sold worldwide, with nearly 30,000 implants being received by children. The goal in the medical community is to provide children under 5 with implants to improve their ability to develop listening and speaking skills through the aid of an implant<sup>(9)</sup>
  - Speech commonly is forced on deaf children, despite not speaking being valued in this culture<sup>(7,21)</sup>
- There frequently are health disparities between Deaf adults and hearing adults, especially in the areas of health promotion and health education<sup>(19)</sup>
- Smoking rates among the Deaf differed in one study depending on whether the hearing loss was prelingual or postlingual. Adults who lost hearing before development of language had lower smoking prevalence than the general population, whereas adults who lost hearing after knowing how to speak had the same smoking prevalence as the general population<sup>(1)</sup>
- Deaf individuals may be at a higher cardiovascular risk than the general population due to a lack of appropriate preventive information<sup>(12,13)</sup>
- Deaf adults have reported that when prescribed medications by their physicians, they often have not understood the drugs' uses or side effects<sup>(19)</sup>
- Genetic testing is another area of controversy in the Deaf population, with fears that it may lead to discrimination and devaluing and that it could be used to “cure” or eliminate Deaf persons<sup>(2)</sup>
  - Researchers found that, regardless of whether or not they identified as Deaf, the most common reasons given by deaf adults for genetic testing were wanting to learn why they were deaf, to learn whether the deafness was genetic, and a desire to help with research<sup>(2)</sup>

##### – **Attitude Toward Health Professionals**

- Deaf adults frequently report that dealing with the healthcare system and healthcare professionals is frustrating and embarrassing<sup>(12,19)</sup>
- Deaf adults often feel as though medical staff are impatient with them, which can trigger withdrawal and isolation on the part of the Deaf adult<sup>(19)</sup>

## • Family Participation

### – Family Needs

- Social work services should be family-centered in their focus and be strengths-focused while at the same time respecting any decisions the family has made on communication choices. This will help reduce any feelings of isolation by the deaf individual and strengthen connections<sup>(8)</sup>
- If appropriate, social workers should use an ASL interpreter versus having the parents code-switch between ASL and speech<sup>(8)</sup>

### – Family Support System

- Family members need to be aware of the emotional and social needs of their Deaf family member. Deaf persons residing in a hearing family need to be encouraged to include their deaf family member in conversation. “Dinner table syndrome” is the informal term used by many Deaf individuals to describe a common experience of growing up in a hearing family: at the family dinner table, family members would freely talk about their day while the Deaf person would miss all of these conversational exchanges.<sup>(22)</sup> Family members need to understand that talking through and talking around their deaf family member can have a negative impact on his or her emotional health
- Only about 15% of hearing parents with a Deaf child develop skills in sign language. This can negatively impact bonding, attachment, and healthy psychological development<sup>(17)</sup>

## › Prominent Mental Health Conditions/Risk of Mental Health Conditions

### • Challenges in Mental Health

- Deaf children who are having trouble communicating with the hearing world (e.g., parents, family, peers, teachers) may have behavioral problems that result in diagnoses of conduct disorder, oppositional defiant disorder, or attention-deficit/hyperactivity disorder (ADHD)<sup>(17)</sup>
- There are very few studies on prevalence rates for mental health disorders in the Deaf population<sup>(6)</sup>
  - Investigators conducting a systematic review of European studies found that Deaf individuals reported higher rates of anxiety and depressive symptoms than individuals who were not Deaf<sup>(6)</sup>
  - One study in 2013 was only the second study in two decades to examine prevalence rates of seeking outpatient mental health treatment among Deaf adults<sup>(5)</sup>
    - Investigators for this U.S. study found that Deaf outpatients had the same rates of depressive, psychotic, adjustment, eating, cognitive, and personality disorders as hearing adults. Impulse control disorders, ADHD, pervasive development disorder, and intellectual disabilities were diagnosed more frequently<sup>(5)</sup>
    - Fluent ASL signers were used as the clinicians in this study, except for the psychiatrist, who used an interpreter to improve the accuracy of results<sup>(5)</sup>

### • Beliefs about Mental Health

#### – Issues for the Deaf Population in Mental Health

- To avoid misdiagnoses, social workers need to correctly assess Deaf clients on their use of language, communication behavior, and level of cognitive functioning<sup>(6)</sup>
- Anxiety and paranoia frequently are misdiagnosed in Deaf clients for situations that are actually based in reality. If a Deaf client says that his family is talking about him, and his family is hearing, this could very well be taking place. If a client reports hearing sounds, this may not be hallucinations but actual tinnitus (i.e., ringing in the ears)<sup>(22)</sup>
- A Deaf person who is experiencing a period of psychosis may report auditory hallucinations even if he or she has been deaf from birth<sup>(17)</sup>
- In all Deaf inpatients in a psychiatric hospital setting, psychotic disorder not otherwise specified was more likely to be diagnosed compared with hearing inpatients (17% versus 2%). Researchers determined that this indicated that clinicians were not trained in Deaf culture or were not fluent in ASL<sup>(11)</sup>
- A Deaf client may express a preference to work with a Deaf social worker or a hearing social worker who can sign; social workers should assist with the appropriate referral<sup>(22)</sup>
- Use of an ASL interpreter may be necessary or may be the best choice in certain situations. The social worker needs to ensure that the interpreter is nationally certified, trained, and experienced<sup>(22)</sup>
- Deaf individuals may work with various interpreters and be familiar enough with those interpreters to feel uncomfortable utilizing them in a mental health situation (e.g., disclosing suicidal thoughts)<sup>(22)</sup>

- Language development that is constricted in children who are deaf can increase the risk for behavioral issues<sup>(6)</sup>
- Childhood adversities of any type have been shown to increase the risk for future mental health disorders. Children with any type of difference or perceived disability can be at risk for increased abuse, whether verbal, physical, sexual, or emotional<sup>(6)</sup>
- Early childhood losses, traumas, and emotional distress frequently are reported by Deaf adults who report depression<sup>(20)</sup>
- Clinicians need to recognize that many mental health assessment tools and standard tests have been found to be invalid with the Deaf population<sup>(6)</sup>

#### – **Attitude Toward Mental Health Professionals**

- Being deaf can be stigmatizing on its own, and as a result Deaf clients will often be mistrustful of mental healthcare providers due to concerns about the communication process in therapy and how they will be viewed by the provider<sup>(17)</sup>
- Stigma or feelings of shame may be magnified if the client is using an interpreter, especially an interpreter with whom the client has a history<sup>(22)</sup>
- In the past, the facial expressions and strong movements that are part of sign language have been misdiagnosed as tics, mania, hypomania, or personality disorders<sup>(17)</sup>
- Deaf clients may want a referral to a counseling agency that can provide videophone counseling, which can allow the client access to Deaf counselors who would otherwise be geographically unavailable. This also affords Deaf clients the opportunity to go beyond their local social and professional environments, which can help with confidentiality<sup>(22)</sup>

#### › **Barriers to Care**

##### • **Communication Challenges**

- For someone who is culturally Deaf, English is effectively a second language and ASL or the relevant sign language in her or her country is the primary language<sup>(18,22)</sup>
- ASL is the language for Deaf persons in North America; it is not universal. There are, instead, various sign languages used for various countries. ASL is the most frequently used sign language in the United States<sup>(8,22)</sup>
- ASL frequently uses nodding as an indication that the person is listening, not necessarily agreeing with what is being said<sup>(22)</sup>
- The frequent use of visual communication modes (e.g., gestures, facial expressions) can result in a client being labeled as agitated when that is not the case<sup>(4,6)</sup>
- Deaf clients may be considered rude when they stare; however, in the Deaf culture to break eye contact while someone is signing is comparable to plugging one's ears when someone is speaking<sup>(21)</sup>
- A client may be mislabeled as withdrawn or anxious when, instead, he or she is simply unable to communicate with the staff or provider<sup>(6)</sup>
- The same sign in ASL may be used for different words that are related (e.g., *mad*, *angry*, *furious*, *enraged*); it is the facial expression that provides the nuance or differentiation<sup>(21,22)</sup>
- A client can be fluent in ASL but not as fluent in verbal or written English, so with some Deaf clients the use of written communication and written scales or assessment tools may not provide adequate information<sup>(17,18)</sup>
- Mini-mental status examinations (MMSE) have been shown to be invalid for Deaf clients, with higher rates of false positives than with hearing clients. This means the MMSE is likely not a good indicator of cognitive functioning if the individual is Deaf<sup>(17)</sup>
- While symptoms of a disorder such as depression are not different for the individual who is deaf, whether he or she identifies as Deaf or is just hard of hearing the communication barriers that exist make it more difficult for these individuals to discuss their symptoms with providers<sup>(20)</sup>

##### • **Logistical Challenges**

- For Deaf clients in rural areas, mental health services that are culturally competent may be harder to find. There is an increased likelihood that such individuals will be more isolated from the Deaf community and have decreased access to interpreters<sup>(17)</sup>
- Access is an issue for many Deaf individuals, whether it is trying to obtain referrals for specialists or being able to find a primary care doctor who will accept a Deaf patient<sup>(19)</sup>

## What We Can Do

- › Learn about cultural competence in working with Deaf individuals so you can accurately assess your clients' personal characteristics and health information needs; share this information with your colleagues
- › Develop an awareness of your own cultural values, beliefs, and biases and develop knowledge about the histories, traditions, and values of your clients. Adopt treatment methodologies that reflect the cultural needs of your clients<sup>(3,10,15)</sup>
- › Social workers should practice with awareness of and adherence to the National Association of Social Workers (NASW) Code of Ethics core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence; and become knowledgeable of the NASW ethical standards as they apply to clients who identify as Deaf and practice accordingly<sup>(15)</sup>
- › Recognize that Deaf clients may benefit from a counseling approach that is visual, tactile, or expressive<sup>(22)</sup>
- › Encourage parents of Deaf children to learn ASL or other appropriate sign language to improve attachment and inclusion<sup>(22)</sup>
- › Advocate for clients' communication needs in both health and mental health settings
- › Avoid any assumption that the Deaf client views his or her deafness as a disability<sup>(22)</sup>

## Coding Matrix

References are rated using the following codes, listed in order of strength:

<b>M</b> Published meta-analysis	<b>RV</b> Published review of the literature	<b>PP</b> Policies, procedures, protocols
<b>SR</b> Published systematic or integrative literature review	<b>RU</b> Published research utilization report	<b>X</b> Practice exemplars, stories, opinions
<b>RCT</b> Published research (randomized controlled trial)	<b>QI</b> Published quality improvement report	<b>GI</b> General or background information/texts/reports
<b>R</b> Published research (not randomized controlled trial)	<b>L</b> Legislation	<b>U</b> Unpublished research, reviews, poster presentations or other such materials
<b>C</b> Case histories, case studies	<b>PGR</b> Published government report	<b>CP</b> Conference proceedings, abstracts, presentation
<b>G</b> Published guidelines	<b>PFR</b> Published funded report	

## References

1. Barnett, S., & Franks, P. (1999). Smoking and deaf adults: Associations with age at onset of deafness. *American Annals of the Deaf*, 144(1), 44-50. doi:10.1353/aad.2012.0120 (R)
2. Boudreaux, P., Baldwin, E. E., Fox, M., Dutton, L., Tullis, L., Linden, J., ... Palmer, C. G. S. (2010). Deaf adults' reasons for genetic testing depend on cultural affiliation: Results from a prospective, longitudinal genetic counseling and testing study. *Journal of Deaf Studies and Deaf Education*, 15(3), 209-227. doi:10.1093/deafed/enq012 (R)
3. The British Association of Social Workers. (2012, January). The code of ethics for social work: Statement of principles. Retrieved September 22, 2016, from [http://cdn.basw.co.uk/upload/basw\\_112315-7.pdf](http://cdn.basw.co.uk/upload/basw_112315-7.pdf) (PP)
4. Deafculture.com. (n.d.). Comparative chart: Deaf and ethnic cultures. Retrieved September 22, 2016, from [http://www.deafculture.com/ethnic\\_culture/](http://www.deafculture.com/ethnic_culture/) (GI)
5. Diaz, D. R., Landsberger, S. A., Povlinski, J., Sheward, J., & Sculley, C. (2013). Psychiatric disorder prevalence among deaf and hard-of-hearing outpatients. *Comprehensive Psychiatry*, 54(7), 991-995. doi:10.1016/j.comppsy.2013.04.004 (R)
6. Fellingner, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *Lancet*, 379(9820), 1037-1044. doi:10.1016/S0140-6736(11)61143-4 (R)
7. Filippová, E., & Hudáková, A. (2016). Czech Sign Language in contemporary Czech society. *Journal of the Sociology of Language*, 2016(238), 85-103. doi:10.1515/jisl-2015-0046 (GI)
8. Hardin, B. J., Blanchard, S. B., Kemmerly, M. A., Appenzeller, M., & Parker, S. D. (2014). Family-centered practices and American Sign Language: Challenges and recommendations. *Exceptional Children*, 81(1), 107-123. doi:10.1177/0014402914532229 (R)
9. Hochmair, I. (2013). Cochlear implants: Facts. Medel.com. Retrieved September 22, 2016, from <http://www.medel.com/cochlear-implants-facts/> (GI)
10. International Federation of Social Workers. (2012, March 3). Statement of Ethical Principles. Retrieved September 22, 2016, from <http://ifsw.org/policies/statement-of-ethical-principles/> (PP)
11. Landsberger, S. A., & Diaz, D. R. (2010). Inpatient psychiatric treatment of Deaf adults: Demographic and diagnostic comparisons with hearing inpatients. *Psychiatric Services*, 61(2), 196-199. doi:10.1176/appi.ps.61.2.196 (R)
12. Lapinski, J., Clonna, C., Sexton, P., & Richard, M. (2015). American Sign Language and Deaf culture competency of osteopathic medical students. *American Annals of the Deaf*, 160(1), 36-47. doi:10.1353/aad.2015.0014 (R)
13. McKee, M., Schlehofer, D., Cuculick, J., Starr, M., Smith, S., & Chin, N. P. (2011). Perceptions of cardiovascular health in an underserved community of deaf adults using American Sign Language. *Disability Health*, 4(3), 192-197. doi:10.1016/j.dhjo.2011.04.001 (R)
14. Mitchell, R. E. (2004). Current estimates (2004): How many deaf people are there in the United States? Retrieved September 22, 2016, from <https://research.gallaudet.edu/Demographics/deaf-US.php> (GI)
15. National Association of Social Workers. (2015). Standards and indicators for cultural competence in social work practice. Retrieved June 4, 2016, from <http://www.socialworkers.org/practice/standards/PRA-BRO-253150-CC-Standards.pdf> (PP)
16. National Institute on Deafness and Other Communication Disorders (NIDCD). (2016). Quick statistics about hearing. Retrieved September 22, 2016, from <http://www.nidcd.nih.gov/health/statistics/pages/quick.aspx> (GI)
17. New York State Office of Mental Health—Nathan Kline Institute Center of Excellence in Culturally Competent Mental Health. (2010). Cultural profile: Deaf Americans. Retrieved September 22, 2016, from <http://ssrdqst.rfmh.org/cecc/index.php?q=node/259> (PGR)
18. O'Brien, C., Kroner, C., & Placier, P. (2015). Deaf culture and academic culture: Cultivating understanding across cultural and linguistic boundaries. *Journal of Diversity in Higher Education*, 8(2), 104-119. (R)
19. Sheppard, K. (2014). Deaf adults and health care: Giving voice to their stories. *Journal of the American Association of Nurse Practitioners*, 26(9), 504-510. doi:10.1002/2327-6924.12087 (R)
20. Sheppard, K., & Badger, T. (2010). The lived experience of depression among culturally Deaf adults. *Journal of Psychiatric and Mental Health Nursing*, 17, 9. doi:10.1111/j.1365-2850.2010.01606.x (R)
21. Start ASL. (n.d.). Deaf culture. Retrieved September 22, 2016, from <https://www.start-american-sign-language.com/deaf-culture.html> (GI)

22. Whyte, A. K., Aubrecht, A. L., McCullough, C. A., Lewis, J. W., & Thompson-Ochoa, D. (2013, October). Understanding Deaf people in counseling contexts. Retrieved September 22, 2015, from <http://ct.counseling.org/2013/10/understanding-deaf-people-in-counseling-contexts> **(GI)**
23. World Health Organization (WHO). (2015, March). Deafness and hearing loss – Fact sheet N300. Retrieved September 22, 2016, from <http://www.who.int/mediacentre/factsheets/fs300/en> **(GI)**