

USING EVIDENCE-BASED PRACTICES with People Who Are DEAF OR HARD OF HEARING

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When we speak about “cultural diversity” in the United States, typically the diversity in question refers to ethnic or racial diversity. However, there are many ways to be diverse, including diversity that is not immediately visible to the eye because it is not based on human physiognomy. In recent years, clinicians and researchers have called for a broader definition of culture to include more than that which is based on ethnicity or race (Henwood & Pope-Davis, 1994; Pedersen, 1991). Like visible diversity, invisible or less obvious diversity has a rich cultural background.

Take for instance individuals who are Deaf.¹ They belong to a distinct cultural community with its own norms, values, traditions, history and language—American Sign Language (ASL). Like diverse groups based on race or ethnicity, they also have a history of oppression and legal protections against discrimination.

Questions about the cultural adaptability of structured evidence-based practice (EBP) protocols have triggered clinician reluctance about the practice’s usefulness with diverse clients. While there are no “one size fits all” practices, many can be adapted for greater cultural sensitivity and thus enhance their overall effectiveness and utility without compromising the scientific aspects of the protocol.

The question of how to maximize cultural sensitivity and minimize cultural bias with evidence-based practices was brought to subject experts, trainers, and treatment providers from diverse backgrounds who came together for a three-day summit to share and discuss cultural adaptations and implications when using the GAIN (Global Appraisal



of Individual Needs). The GAIN is an evidence-based family of assessments used widely in the substance abuse treatment field in both the United States and Canada. Participants in the GAIN Cultural Sensitivity Summit, sponsored by the Substance Abuse and Mental Health Services Administration’s Center for Substance Abuse Treatment and Chestnut Health Systems, worked together to answer the following question: “How can an evidence-based assessment like the GAIN most effectively address the various dimensions of diversity of clients with substance use disorders?”

In the next installment of this series on lessons learned from the GAIN Cultural Sensitivity Summit, we focus on clinical service provision with individuals living in the United States with substance use or mental health disorders whose diversity is related to a hearing loss. Before we begin, it is necessary to provide some context for the discussion by presenting facts and definitions pertinent to the topic.

Similar to the other communities of people discussed in this series, people with hearing loss are not a monolithic group. Diversity within the group is substantial, and arguably the greatest sources of

internal diversity are related to the degree of loss and age of the individual when the loss occurs. These factors, along with the hearing status of the family, have a strong influence on the development of communication.

- Individuals born with a profound hearing loss—or a similar loss that occurs prior to acquisition of oral/aural language (approximately by ages 2 to 3)—are audiologically referred to as “deaf” and are more likely to depend on visual means of communication such as ASL or a related signing system. It is less likely that an oral/aural language (such as English) will be their first language, and they will experience difficulty accessing the larger culture’s oral/aural language via reading, writing, or speaking.
- Individuals with a mild, moderate or severe hearing loss are referred to as “hard of hearing” rather than deaf. Although they may depend on hearing aids, they have more access to aural/oral language than their deaf peers and are thus more likely to have greater facility learning and using aural/oral language.
- “Deafened” refers to people who lose their hearing, often as adults due to

1 The word “deaf” (lowercase “d”) describes people with a hearing loss of severe to profound magnitude. The word “Deaf” (uppercase “D”) refers to the community of people who subscribe to the norms, values, traditions and visual language of Deaf culture, most of whom are deaf. The capital “D” signals cultural affiliation in the same way that people from ethnic cultures (e.g., “Japanese”) capitalize the first letter of their cultural affiliations. Uppercase-D Deaf people are often referred to as “culturally Deaf.”

advancing age or illness. Although they are faced with many challenges, their facility with oral/aural language enables them to function more easily in a hearing world.

Several additional facts about deaf and hard of hearing people will help inform the discussion of cultural sensitivity and evidence-based practices to follow.

- More than 90% of children born with a hearing loss are born to parents who can both hear (Mitchell & Karchmer, 2004); few hearing families with a deaf-signing child learn to sign or sign well.
- Most children with a hearing loss in the United States today are educated in mainstream schools where they participate in at least some regular education classes with the help of accommodations, such as a sign language interpreter, assistive listening devices or preferential seating. They are often only one of a few deaf or hard of hearing students—if not the only one—in the school. Interaction with hearing peers can be difficult and many deaf or hard of hearing students end up feeling isolated and lonely (Oliva, 2004).
- “Deaf culture” describes the collection of values, behaviors, social beliefs, history, art and literary traditions, and institutions of the community of people who have a hearing loss and communicate through sign language. Members of the culturally Deaf community view deafness as a difference, not a pathological condition or disability. Not all members of the Deaf community are deaf (they could be hard of hearing or even hearing, such as family members, interpreters or allies) and not all deaf people belong to the Deaf community. A person belongs to the Deaf community through their identification with and acceptance of the tenants of the culture and through acceptance by others in the community.
- Terms like “hearing impaired” and “handicapped” are offensive

because they cast deafness as a pathological condition and, by extension, imply that those who are deaf must be broken. The terms “deaf” and “hard of hearing” are preferred.

- Available research shows high rates of substance abuse and mental illness among adults and children with a hearing loss (Fellinger, Holzinger, & Pollard, 2012; Leigh & Pollard, 2003; Titus, Schiller, & Guthmann, 2008) and access to effective treatment is low.

How Can EBP Be Used Effectively with Clients Who Are Deaf or Hard of Hearing?

Many (though not all) hard of hearing or deafened clients may prefer a regular mainstream treatment program with accommodations, which could include the provision of a sign language interpreter or a CART (Communication Access Realtime Translation) specialist. (CART specialists type what they hear on stenotype equipment, which prints out on a laptop screen and allows the individual with hearing loss to read what is going on in the auditory environment.) For those who are deaf, participation in mainstream programs may not be the best option for many reasons to be mentioned. However, given the lack of specialized services—programs where all communication barriers are removed through signing staff and clients, Deaf cultural norms are the norm, and materials and procedures are adapted to fit the needs and learning styles of deaf people—it is likely that to receive any treatment, many deaf and hard of hearing individuals may find themselves in mainstream programs with hearing therapists who may have never known a person with a hearing loss before. How can a hearing therapist provide culturally appropriate assessment and counseling for a client with a hearing loss and offer the many benefits associated with evidence-based practices such as the GAIN?

As described in the earlier articles in this series, the GAIN Cultural Sensitivity Summit participants identified five competencies for treatment professionals who want to use evidence-based practices with diverse populations:

- Recognize the power of historical perspective
- Appreciate the impact of cultural explanations and stigmas
- Respect cultural variations, expectations and communication
- Create an atmosphere of cultural safety
- Show adaptability and flexibility

Using these five competencies as discussion points, we present some implications for using evidence-based practices with deaf or hard of hearing clients.

Recognize the Power of Historical Perspective

For thousands of years people with hearing loss have struggled with discrimination and denial of human rights. Beginning in ancient times, deafness was believed to be a punishment from God, and through the ages this belief has spawned pity, ill treatment, paternalism and outright discrimination. At different times throughout history deaf people were not allowed an education or to inherit or own land. Because they could not speak, they could not pray and thus were deemed to be faithless, unsaved and denied entry to church. They were shut up in asylums and believed to be possessed by the devil. During the late 19th and early 20th centuries, as part of the United States’ eugenics movement, there were efforts to prevent deaf people from marrying and to force sterilization on them.

Deaf schools sprang up across the United States beginning in the 1800s, largely in rural areas to keep the deaf hidden from hearing people. In the 1880s, manual methods of education (using sign language) fell from favor and strict oralism (using speech) was instituted for more than 80 years. Students were harshly punished for communicating in sign language, which was not considered a true language until the 1960s following a publication on the linguistics of ASL. The need for bilingual education was not recognized until the 1990s. Although today the situation for deaf and hard of hearing people in the United States is much better than in times past—largely due to

technology and legislation—the struggle for self-determination, equal access and respect continues.

For the hearing counselor, one of the most important takeaway points from this history lesson is the understanding that deaf and hard of hearing clients will most likely have experienced and endured a fair amount of ignorance and ill treatment from a hearing world. Lack of trust in a hearing counselor is to be expected, and early on in the relationship the issue of trust and differences in hearing status may need to be broached. The hearing counselor is well-advised to invest time to learn about the lived realities of being deaf. Even a casual perusal of the Web will yield many valuable resources to assist the counselor's deepening understanding of where a deaf or hard of hearing client is coming from. This understanding will aid the counselor in delivering an evidence-based practice with cultural sensitivity.

Appreciate the Impact of Cultural Explanations and Stigmas Associated with Substance Abuse and Mental Illness

Alcohol has a solid place in the social fabric of the Deaf community. In days past, Deaf clubs provided an important outlet for socializing and bonding with other people. Alcohol was sold to raise money to buy buildings to house the clubs, and, once housed, Deaf clubs typically maintained a bar. Although over time the number of actual Deaf clubhouses has dwindled, alcohol remains an important part of community gatherings, such as at Deaf softball games, bowling and golf tournaments or picnics. Alcohol and drug use among deaf and hard of hearing adolescents is a means of social integration with hearing peers, as many youngsters with hearing loss are introduced to substances through hearing siblings or friends.

Having a substance abuse or mental health problem potentially draws negative attention to the community and one's family. The need to protect the image of the Deaf community by hiding or denying an issue could lead to underreporting or minimization of problems. This possibility should be taken into consideration when interpreting an

evidence-based assessment like the GAIN to avoid errors in diagnosis, severity or treatment planning.

The hearing community at large also participates in the denial of substance abuse problems among deaf individuals through enabling and not holding individuals accountable for their actions. For example, several years ago a group of Deaf school students were caught transporting drugs through the mail to sell to students at another school for the Deaf. The local police were contacted and the students were taken to the police station, only to be brought back to school later that evening. When asked why the students weren't held at juvenile hall, school officials were informed that the students seemed to be "good kids." Rather than facing consequences related to using, selling and transporting drugs over state lines, they had been brought to the police station and provided lunch from McDonalds. The students told the police they would not repeat the behavior, so the police decided to release them back to the school. No legal consequences were given, other than the school suspending them for the behavior.

The stigma, denial and enabling associated with substance abuse or mental health disorders are only a few of the barriers that prevent deaf and hard of hearing people from accessing treatment. Mistrust of providers, concern about communication difficulties, fears about losing confidentiality and lack of information about available services also dissuade deaf and hard of hearing people from accessing treatment (Steinberg, Sullivan, & Loew, 1998).

Respect Cultural Variations in Communication, Expectations, and Norms and Values

Deaf culture has a collectivist orientation. It is characterized by a cohesive "in group," strong loyalty, interdependence and priority for group goals over individual goals. Communication is relational and dialogic. When two deaf people meet for the first time, they typically try to figure out how they are related through mutual acquaintances. The Deaf community is small and close-knit, so even if deaf individuals live far from each other, they may know many people in

common. Individuals in the Deaf community also know a lot about each other. This same "small community, big family" feeling can get in the way when someone is struggling with a substance use or mental health disorder. Individuals typically do not want their private, intensely personal information shared on the Deaf grapevine. A Deaf client will need assurances about the confidentiality of their information, even more so than what is typically done for hearing clients.

The substance abuse, mental health and evidence-based practice fields contain language and concepts that may not be familiar to many deaf individuals. Without full access to oral/aural language, it is highly likely a deaf individual's English language proficiency will be limited. Traxler (2000) found that the median reading comprehension scores of Deaf and hard of hearing high school students educated in a variety of settings did not surpass the 4th grade level. Lack of access to aural information in the environment, such as from television, radio and ambient sources such as overheard conversations, adds to the "fund of information" deficit many deaf individuals experience (Guthmann & Graham, 2004; Pollard, 1998). While delivering an evidence-based treatment or assessment like the GAIN, the hearing counselor may need to define or explain terms. For example, on the GAIN instruments, one of the items pertaining to substance abuse problems asks when the individual last experienced withdrawal, followed by a list of illustrative withdrawal symptoms. In an ongoing ASL translation project of a GAIN instrument, we found it necessary to expand upon the meaning of withdrawal in ASL by explaining the time relationship between using alcohol or drugs and later experiencing symptoms of withdrawal. Other possible GAIN terms or concepts that may need explaining or examples include treatment-related terms such as outpatient, inpatient and residential; language related to Twelve-Step programs; abstinence; names of diseases; legal and financial terms. The GAIN has some common American English language idioms that may not make sense to a client with a hearing loss without explanation (e.g., feeling blue, running

around, driven by a motor, spaced out). The definitions of time frames should be carefully reviewed, and when time frames change, it should be specifically pointed out. GAIN instruments' administration allows for this kind of expansion or explanation of items as long as the overall meaning of the item is not changed. This ensures that individuals understand the items as intended and preserves the validity of the information collected. Explanations take time but are necessary to ensure that the client with hearing loss has access to the meaning of items and can thus respond with valid information. Longer or even several assessment sessions may need to be scheduled to complete a GAIN assessment.

Storytelling is an important cultural communication norm in Deaf individuals' everyday discourse. A Deaf client may provide a very full and detailed account of an interchange between people by recreating it—what was said, body language, affect, physical features of the people involved. This style of communication is dialogic, like a dialogue between people, and recreates the exchange in the present rather than retelling it in hindsight. In addition, specific facial expressions and movements have grammatical significance in ASL (e.g., lowering eyebrows to indicate a “Wh” question, shifting body position to indicate shifting roles). Behaviors that may appear to be overly animated to a hearing counselor may, on the contrary, reflect a normative style of communication rather than an agitated state. Steinberg (1991, p. 381) says it well: “Sign language is so animated and affect-laden that signers might be misdiagnosed as having inappropriate affect.” Awareness of the dialogic and seemingly animated nature of communication in ASL will help inform any culturally based adaptations to an evidence-based practice.

The mental health care of deaf individuals is replete with misdiagnosis and misconceptions as a result of hearing clinicians' lack of understanding of deafness (Phillips, 1996). For instance, some deaf people may be language-deprived from an early age and do not have fluency in either visual or oral language. Their language dysfluency may

be mistaken for cognitive impairment or even psychosis. Some hard of hearing people are able to speak intelligibly yet cannot comprehend spoken language. Their oral fluency leads others to question their request for an interpreter and gives the impression they are stubborn, demanding or even feigning their hearing loss. This judgment error is based on the misconception that if you can speak, then you can hear, and thus don't need an interpreter. Another misconception centers around lip-reading. Although some people with hearing loss are better at it, only about 3 out of 10 English words are readable on the lips (Jeffers, 1971). A fair amount of guesswork is needed to fill in the missing words, which makes lip-reading inaccurate at best and mentally exhausting.

Other important norms include those related to attention-getting and personal space. To get the attention of someone at a distance, it is perfectly acceptable to wave exaggeratedly in the visual field, stomp on the floor (thus creating vibrations) or flick the overhead lights on and off. If someone is close by, tapping them on the shoulder or upper arm is acceptable. Finally, personal space in the Deaf world is closer than that in the hearing world. This is something to be aware of to avoid misinterpretation of boundaries.

Create an Atmosphere of Cultural Safety

Given the many day-to-day frustrations encountered by deaf individuals living in a hearing world, it is essential that the counseling office be a respite, a place where those frustrations are minimized. Much of cultural safety for deaf and hard of hearing individuals rests on the communication environment and the therapists' understanding and acceptance of the Deaf experience.

It is important to inquire about the client's communication preferences and accommodate them. For someone who is hard of hearing or deafened but depends on their residual hearing in concert with lip reading, appropriate accommodations include a quiet environment with minimal background noise, good front lighting without backlighting and sitting facing the client to provide a clear, unobstructed view of your face. It is not

necessary to speak any louder or more exaggerated than normally. Eye contact while communicating with deaf individuals should be maintained. This differs from American hearing culture, where eye contact is often fleeting. In Deaf culture, breaking eye contact during communication can be perceived as rude, evasive, dismissive or even hostile.

For deaf and hard of hearing clients who communicate through sign language, a hearing counselor who does not sign will need to work with a certified interpreter, preferably one who has further qualifications such as training and experience in mental health or substance abuse settings. Although the interpreter is a third person in the room, their role is purely that of a communication conduit: they are essentially invisible. The interpreter should sit in a place that provides clear visual access to the client, for example, to the side and a little behind the counselor while the counselor talks directly to and maintains eye contact with the deaf individual. The interpreter will make sure the information is appropriately conveyed. The counselor should never address the interpreter as in “Tell him” or ask “What did she mean?” as doing so breaks direct communication with the client and acknowledges the interpreter over the individual. It is recommended that the counselor and interpreter communicate ahead of time to identify possible “lingo” or concepts used in the evidence-based treatment or assessment that could arise during the session. This pre-meeting also helps to clarify roles and responsibilities. Finally, although the interpreter is “invisible,” a third person in the room can change the dynamics of the session and may negatively impact therapeutic alliance. The Deaf world is a small world, so there may be situations where the client and interpreter know each other from



other appointments or activities in the community. Interpreters are bound by a code of ethics including those that address confidentiality, but this may not provide the level of assurance needed by some clients to feel safe and could thus impact the content or breadth of information the client shares.

In some parts of the country, there are shortages of qualified interpreters. Through the use of technology, there are now more options available where the interpreter is remotely located and the counselor and client are in the same space. This is called video remote interpreting (VRI). VRI uses videoconferencing technology, equipment and a high-speed Internet connection with sufficient band width to provide the services of a qualified interpreter, usually located at a call center, to people at a distant location. Organizations may contract for VRI services to be provided by appointment or to be available "on demand" 24 hours a day, 7 days per week. Using this kind of video remote interpreting service is another option to ensure confidentiality during evidence-based treatment and may help if the deaf client's comfort and level of disclosure is impacted by a known interpreter.

The best option for many deaf individuals in need of substance abuse or mental health services is to attend a program with deaf or hearing professionals who sign fluently. Even better is to attend programs tailored specifically for deaf individuals, where the treatment curriculum is adapted to include issues related to deafness, and the physical environment hosts communication devices and other technology used by deaf individuals. Unfortunately, this situation is rarely available. One such program is the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals (MCDPDHDI), a specialized program designed to meet the communication and cultural needs of deaf and hard of hearing persons. The program is

comprised of staff who sign fluently and are knowledgeable about and sensitive to Deaf culture. The program operates on a Twelve-Step philosophy using treatment approaches that are modified to respect the linguistic and cultural needs of the clients. For example, as opposed to relying on reading and writing, clients are encouraged to use a variety of communication and learning methods including drawing, role play and a variety of sign language systems. Written material used in the program is modified and video materials are developed and presented using sign language, voice and captioning. The use of technology such as video phones, assistive listening devices, flashing light signals and decoders helps to make the treatment setting accessible to deaf and hard of hearing clients. The MCDPDHDI is one of only a few substance abuse treatment programs in the United States completely tailored for deaf individuals.

Show Adaptability and Flexibility

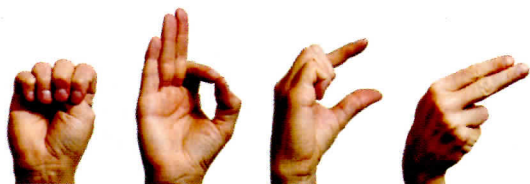
None of the myriad of evidence-based treatments for substance abuse that are available for hearing individuals have been adapted and disseminated for use with deaf individuals or for training deaf counselors. Two evidence-based screening assessments used in substance abuse have been translated into ASL, including the Substance Abuse Screener in ASL (SAS-ASL; Guthmann, Lazowski, Moore, Heineman, & Embree, 2012), which is based on the SASSI version 3 (Lazowski, Miller, Boye, & Miller, 1998), and the GAIN Coordinating Center's SS-ASL (Titus, 2012), a signed version of the Global Appraisal of Individual Needs Short Screener (GAIN-SS; Dennis, Chan, & Funk, 2006) currently under development. Both of these instruments use video clips to communicate the items; the SS-ASL will allow for Web-based administration and create a narrative report of the results once completed. However, neither of these instruments provides diagnoses, but are limited to screening.

In the mental health arena, there are no video-based assessments available outside those used for research. However, materials and methods of dialectical

behavior therapy for treating suicidality among individuals with borderline personality disorder have been adapted for use with deaf clients (O'Hearn & Pollard, 2008), as have cognitive-behavioral therapy techniques (Glickman, 2009), constructionist therapy (Munro, Know, & Lowe, 2008), and solution-focused therapy (Estrada & Beyeback, 2007). Although a few of these adaptations are primarily for use by deaf or hearing signing professionals in their work with deaf individuals, some of the materials can be used by hearing therapists who work with deaf individuals individually or with mixed groups of hearing and deaf individuals.

Neil Glickman, a psychologist who has worked with deaf individuals for more than 25 years, has done much to promote the philosophy and need for "culturally affirmative treatment" for deaf individuals. He defines culturally affirmative treatment as therapy that is socioculturally informed, that utilizes culturally relevant tools, and that seeks to empower clients and their communities (Glickman, 1996). He and his colleagues have provided a wide variety of examples of culturally affirmative programs tailored for deaf people (Glickman, 2012; Glickman & Gulati, 2003; Glickman & Harvey, 1996). Unfortunately, given the small number of such programs, most deaf people in need would not have access to them. However, Glickman also describes culturally affirmative treatment as a set of principles and strategies that can work within the broad spectrum of existing psychotherapies. Some of the elements of Deaf-friendly counseling that could be applied to evidence-based practices include (Glickman, 2009):

1. *The use of a dialogic as opposed to a didactic teaching style (i.e., teaching information through dialogue rather than lecture)*
2. *Paying close attention to whether or not clients are understanding*
3. *Using stories to illustrate the main points*
4. *Using practical examples first, and then building definitions, abstractions and theory from these examples (specific to general)*



5. *Implification of English language-based materials and inclusion of more visual aids*

Even with the services of a qualified interpreter, the counselor should pay attention to his or her own use of language, remembering that communication goes far beyond language used. Incorporating nonverbal communication through drawing or using visually based metaphors to illustrate points will broaden the communication base. Special attention should be focused on avoiding the use of English idioms. Some therapy-related resources such as DVDs and videos are available in sign language, thus providing information in a deaf-signing individual's first language. Given the dearth of evidence-based assessments that have been translated into sign language, English language assessments should be used cautiously and their interpretation should be attentive to the language and cultural factors that can influence results. Although a hard of hearing individual may wish to complete a written English assessment on their own, a deaf individual may not. In that case, interviewer-administration with an interpreter will be necessary, and explanation and expansion of unclear language will be needed.

Probably the best accommodation for deaf clients would be to have deaf or hearing-signing staff with knowledge of Deaf culture on the evidence-based treatment team. Most deaf individuals in a study by Steinberg and colleagues (1998) said they would prefer a deaf or hard of hearing therapist as well as group therapy with all deaf or hard of hearing participants. Although the number of deaf or hearing-signing therapists has increased over time, it is not close to meeting the need.

In Conclusion

Language and communication are the conduits of healing in therapy. Like any other language group, people with hearing loss heal best in their own language. Evidence-based practices hold a great deal of promise for deaf and hard of hearing people in need of substance abuse or mental health intervention, though not without making culturally appropriate

adjustments. Investing time and effort to become knowledgeable about deafness, Deaf culture and the history of the community provides therapists the grounding to begin to understand where their deaf client is coming from. Appreciating the impact of cultural stigmas and other barriers to treatment provide clinicians insight on the shame that deaf and hard of hearing individuals may feel when they struggle with substance abuse or mental health issues. Being knowledgeable of and showing respect for cultural variations in communication, expectations, norms and values communicates acceptance. Being flexible and adapting practices to better fit the deaf or hard of hearing client's need will allow them to also benefit from a wide array of evidence-based practices previously accessible only to hearing clients.

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