

NASMHPD Recommendations for Effective Communication Planning and Response with Deaf Communities for 988

The recommendations and background that follow focus on a specific subset of people with hearing loss – those whose preferred language is American Sign Language (ASL).

The hope with 988 is that call centers will stabilize the vast majority of callers but also that the momentum pushes communities to scaffold comprehensive services in line with SAMHSA's [National Guidelines](#) regional or statewide crisis call centers that coordinate in real-time, centrally deployed 24/7 mobile crisis services, 23-hour crisis receiving and stabilization programs, and essential crisis care principles and practices like “no wrong door,” a no-refusal drop-off policy for patients in need. Communities must develop each, points out Hamerdinger, with marginalized, underserved populations in mind, including deaf people. “At the moment, only a handful of states can address the deaf community,” he says. “Most depend on ad hoc arrangements.”

–February 22, 2022 #CrisisTalk article “988 and Deaf Services” (Hepburn, S.)

The societal bias towards hearing both increases the stress a deaf person in crisis experiences and makes it more difficult to find ways to communicate the distress they feel. The literature suggests that the effect of poor communication and cultural insensitivity will continue to increase emotional vulnerability, thus leading to feelings of hopelessness, which in turn, are associated with suicidal ideation. Research and experience suggest that direct services in ASL is most effective for people who are deaf and primary users of ASL to ensure trust and clear communication particularly when an individual who is deaf is in crisis.

NASMHPD recognizes the unique needs of people who are deaf and hard of hearing and has consulted with the Deaf Community to develop the following recommendations for accessing 988 for people who are Deaf/deaf and primary users of ASL.

- (1) NASMHPD recommends that one National Call Center be established for people who are deaf and hard of hearing who are primary users of American Sign Language (ASL). A critical component for services for deaf people is the experience of language and addressing issues related to language acquisition, language deprivation, and information deprivation.**
 - NASMHPD recommends that this call center be modeled after the Disaster Behavioral Health Helpline for people who are Deaf and Hard of Hearing. The Disaster Distress Helpline, administered through Vibrant, is a single platform already in use for people who are deaf and hard of hearing. This Helpline uses ASL fluent counselors. See: <https://www.samhsa.gov/find-help/disaster-distress-helpline>

- The 988 crisis call center for people who are deaf and hard of hearing should be staffed by ASL fluent crisis counselors and utilize video technology.
- Chat and text would be most useful for those who are hard of hearing and English is their primary first language.

Why One Centralized Call Center?

- Most states are unable to provide ASL fluent counselors 24/7. A centralized call center would provide this 24/7 coverage.
- A dedicated line for ASL users would allow other call centers to have higher answer rates and fewer dropped calls by staff unfamiliar with video relay systems utilized by deaf people.
- Vibrant administers specialized hotlines for Veterans, Spanish-speaking individuals, and Tribes. While the Deaf and Hard of Hearing Communities are small in number, these communities are significantly underserved and current crisis response often involves law enforcement and tragic misunderstandings. A centralized call center for this specific population would help provide an appropriate culturally linguistic response 24/7.
- Having one call center would provide a more central approach for data collection

Why Direct Services with ASL Fluent Counselors?

- Critical interactions where comprehension is essential – especially issues of life and death – are best negotiated in a person’s strongest language. For many deaf people, this language means ASL. (<https://talk.crisisnow.com/988-and-deaf-services/>; <https://talk.crisisnow.com/988-and-improving-language-and-cultural-competency/>)
- The shared experience, if both the provider and the person they are assisting are deaf, helps foster trust. A well-trained ASL-trained counselor will know that some deaf callers have grown up in an impoverished language environment, which is a unique experience of people who are deaf. The person might have gaps in vocabulary or grammar, resulting in informational deficits that can appear to look like psychosis ([February 22, 2022, #CrisisTalk article “988 and Deaf Services”](#) Hepburn, S.)
- An ASL fluent counselor will be able to have direct communication and assess the complex interplay of language dysfluency and clinical symptomology. Interpreters are typically trained to “clean up” the communication, possibly guessing what is trying to be communicated, causing misunderstandings and potential misdiagnosis.

Why not interpreters?

- Trust is difficult to establish between a deaf person and an unknown interpreter. This dynamic adds to the difficulty of establishing trust between the deaf person and the crisis counselor.
- Critical interactions where comprehension is essential – especially issues of life and death – are best negotiated in a person’s strongest language. For many Deaf people, this language means ASL. (<https://talk.crisisnow.com/988-and-deaf-services/> and <https://talk.crisisnow.com/988-and-improving-language-and-cultural-competency/>)
- It is important to have counselors and clinicians understand the unique trauma of a deaf or hard of hearing individual. While a deaf person is in crisis it is not the time to provide a non-ASL fluent clinician in this context.

- Non-specialized crisis counselors must first recognize that they are working through an interpreter. If aware, they must then constantly evaluate whether they are assessing the deaf person or the interpreter. When working through a Video Relay Service, only the interpreter would have access to visual information critical to understanding the deaf individual. Few hearing crisis counselors would understand the dangers of miscommunication and misunderstandings inherent in that process. Direct communication in one's first language is best, especially when an individual is in crisis. (<https://talk.crisisnow.com/988-and-deaf-services/> and <https://talk.crisisnow.com/988-and-improving-language-and-cultural-competency/>)
- The literature suggests that the effect of poor communication and cultural insensitivity of services designed for hearing people will continue to increase emotional vulnerability of the deaf individual reaching out for help, thus leading to feelings of hopelessness, which in turn, are associated with suicidal ideation.
- The interpreter, as a third party, may make the deaf person uncomfortable when in crisis due to linguistic and cultural components that will be lost in translation no matter how skilled the interpreter. The deaf individual in crisis does not know what is being conveyed and therefore cannot easily correct misinterpreted information and self-advocate in this setting, which could worsen the crisis.
- Information may be missing from the interpretation and may not have the richness and feeling of what the individual is trying to convey.
- Most interpreters are not trained in behavioral health or crisis counseling and can be greatly affected emotionally by crisis interaction.
- Well-intentioned efforts to make various programs "accessible" by means of interpreters and other accommodations fall short if they do not also address differences in how the world is viewed and experienced from the deaf cultural standpoint.
- It is difficult to express feelings and distress through an interpreter. This difficulty can exacerbate the crisis.

(2) The Centralized 988 Call Center should have a mechanism to provide follow-up calls for deaf and hard of hearing callers

- Research suggests that well-being increases, and hospitalization decreases for the caller if there is a follow-up call.
- A continually updated resource guide with culturally affirmative and linguistically accessible resources should be maintained by Vibrant, States, and the Centralized 988 ASL / Deaf 988 Call Center. Review of data as well as a landscape analysis will likely reveal further gaps in resources for the population and allow the national networks to collaborate on addressing them.

(3) Each state should have a state coordinator of deaf mental health care to provide updated local resources to the national 988 call center for people who are Deaf/deaf and hard of hearing

- Many callers may need additional services beyond the call and the National Call Center should be prepared to link with local entities if the caller needs immediate services or referrals.

Background

“Promising and Emerging Approaches and Innovations for Crisis Interventions for People Who are Deaf, Hard of Hearing, and Deafblind” (NASMHPD; Hamerdinger; Schaefer, 2016) provides an introduction regarding the experience of people who are deaf who encounter crisis. Research in suicide and suicide prevention in the Deaf Community is scant.¹ As a result of this limited research, it is generally unknown that deaf people are at significant risk for depression, and they do attempt or consider suicide at a significant rate. Black and Glickman² found that, among the patients at the Westborough (Massachusetts) State Hospital Deaf Program, 30% attempted and another 30% seriously considered suicide. Among deaf people with substance use disorders or co-occurring mental illness and SUD, the numbers are even more troubling. According to Embree,³ more than 4 out of every 10 people who are deaf will attempt suicide at one point in their life and more than half will consider it. Among deaf women, the rate is 65.1% for suicidal ideation.

For a hearing person, help is as close as a phone call. For deaf people, there are fewer appropriate resources available to intervene and the same opportunities do not currently exist.

When Mere “Accommodation” Is Not Enough

NASMHPD has a long history of interest in serving the Deaf Community. Throughout this corpus of work, a recurring theme has been that Deaf people should be seen as a cultural and linguistic minority, first, and disabled second. Well-intentioned efforts to make various programs “accessible” by means of interpreters and other accommodations fall short if they do not also address differences in how the world is viewed and experienced from this cultural standpoint.

Numerous laws, regulations and standards of care have all attempted to make services more appropriate for deaf and hard of hearing people. Section 504 of the Rehabilitation Act of 1973 provides that, “No otherwise qualified individual with a disability in the United States, as defined in section 705 (20) of this title, shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.”⁴ The 1990 Americans with Disabilities Act is billed as a comprehensive piece of civil rights legislation that prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life -- to enjoy employment

¹ Turner, O., Windfuhr, K., & Kapur, N. (2007). Suicide in deaf populations: a literature review. *Annals of general psychiatry*, 6(26), 1-9.

² Black, P. A., & Glickman, N. S. (2009). Language and learning challenges in the deaf psychiatric population. *Cognitive-Behavioral Therapy for Deaf and Hearing Persons with Language and Learning Challenges*. New York, Routledge.

³ Embree, J. A. (2012). Prevalence of Suicide Attempts in a Deaf Population with Co-Occurring Substance Use Disorder. *Journal of the American Deafness & Rehabilitation Association (JADARA)*, 45(2).

⁴ <http://www.dol.gov/oasam/regs/statutes/sec504.htm>

opportunities, to purchase goods and services, and to participate in State and local government programs and services.

Both laws, and similar ones that were passed by state legislatures in subsequent years, opened doors to services for people with physical disabilities.

A critical component of opening doors for services for deaf people is the experience of language and addressing issues related to language acquisition, language deprivation, and information deprivation.

Invisible Population – Invisible Trauma

People who are deaf are far from being homogenous. The Deaf Community is diverse, vibrant, and scattered. To understand the population, one must first be able to define it, and this has been a source of confusion over the years.

There are various estimates as to how many deaf and hard of hearing people there are in the United States. Part of the difference is because there is no uniform definition of what it means to be deaf or even hard of hearing. Numbers published range from 37 million people with hearing loss to 670,000 deaf people who use ASL as their primary language.

Unlike other language minorities, deaf people are not necessarily concentrated in particular parts of a city or state. While deaf people do tend to move to where other deaf people are, leading to some skewing of prevalence in some areas, this effect is not as profound as with other linguistic minorities.

John, a counseling intern who is deaf, was called to do a crisis intervention at a rural Junior High School in the Midwest, where a 15-year old deaf boy, Jacob, was threatening to kill himself. Upon arrival, John was led to the classroom where Jacob was and went in. At first there was no sign of the boy, but upon closer examination, it appeared that he was hiding. Soon enough, a slight movement of the doors on one of the cabinets below the long window of the classroom revealed Jacob's hiding place. John sat on the floor trying to engage Jacob who buried his head in his arms, refusing to look at anyone. After a while, though, Jacob started to respond to John's attempts to engage him via ASL. Jacob was skeptical that John was deaf. When asked why, Jacob replied that he had never met a deaf adult before. He assumed all deaf children die before they grew up, thus he would die...

Until Public Law 94-142 caused a revolution in the education of children with disabilities in the late 70s and early 80s, deaf children were largely educated at schools specifically established for them. Deaf children were transported from their home and stayed at a residential school for the Deaf in their respective state. The first of these schools was the American School for the Deaf, established in 1817 in Hartford, Connecticut. Its founding by Thomas Hopkins Gallaudet and Laurent Clerc, a deaf educator from France, provided not only a blueprint for the spread of deaf education over the next 80 years, but also some important lessons for the mental health system to

study. Over the years, schools for the deaf were established in every state. Deaf people founded 24 of them, establishing a cultural and peer-based tradition of deaf people helping other deaf people.⁵

From the middle of 1800s up until the 1980's, it was estimated that perhaps three-quarters of all deaf children attended state residential or large metropolitan center schools. While not all these schools used or use American Sign Language in the classroom, in most cases the children learned it outside of the classroom. Equally important, this shared experience encouraged the development of social skills and the emergence of cultural norms. By the beginning of the 21st century, the ratio of deaf children being educated in the "mainstream" had almost flipped, with nearly 75% of all deaf children being placed in public schools with hearing children.⁶ Most such mainstream programs had few, if any, other deaf children in them, thus the deaf child became isolated in a program that was meant to promote inclusion.

As deaf education became increasingly decentralized, opportunities for social skill development were often lost. School systems imposed a hodge-podge of manually coded English systems on students, often with inconsistent standards of fidelity to the chosen system. Children learned idiosyncratic signs unique to that particular school, classroom or communication aid. Increasingly mental health providers are encountering deaf people who have never been exposed to other deaf people or even to effective language. This lack of exposure creates a subset of people who are both language and learning deprived.⁷

Language and learning deprivation among deaf people is a unique phenomenon that does not indicate the level of cognitive potential. Rarely do clinicians encounter anything similar among non-deaf people. Poor language development among people who hear is almost always an indication of either a neurological or cognitive problem. This is not necessarily the case with deaf people. A fuller treatment of this issue can be found in the 2012 NASMHPD publication, *Trauma in the Deaf Population: Definition, Experiences, and Services*.

A scan of the literature informs us that deaf people are more vulnerable to trauma in general^{8, 9} and that they experience a higher rate of interpersonal trauma than their hearing counterparts.^{10 11} This trauma becomes apparent in the rates of emotional and social maladjustment reported in the

⁵ Gannon, J. R., Butler, J., & Gilbert, L. J. (1981). Deaf heritage: A narrative history of deaf America. Natl Assn of the Deaf.

⁶ Government Accountability Office. (2011). Deaf and hard of hearing children: Federal support for developing language and literacy. (GAO Publication No. 11-357). Washington, DC.: U.S. Government Printing Office

⁷ Glickman, N. (2007). Do you hear voices? Problems in assessment of mental status in deaf persons with severe language deprivation. *Journal of Deaf Studies and Deaf Education*.

⁸ Gallaudet Research Institute. (2001). Regional and national summary report of data from the 1999-2000 annual survey of deaf and hard of hearing children & youth. Washington, DC: GRI, Gallaudet University.

⁹ Gulati, S. (2003). Psychiatric care of culturally deaf people. In N.S. Glickman & Gulati (Eds.), *Mental health care of deaf people* (pp. 33-107). Mahwah, NJ: Erlbaum.

¹⁰ Sullivan, P. M., & Knutson, J. F. (1998). Maltreatment and behavioral characteristics of youth who are deaf and hard-of-hearing. *Sexuality and Disability*, 16(4), 295-319.

¹¹ Vernon, M., & Miller, K. R. (2002). Issues in the sexual molestation of deaf youth. *American annals of the deaf*, 147(5), 28-36.

literature.¹² Schild & Dalenberg¹³ call this information deprivation trauma. The lack of information, also known in the literature as fund of information deficits,¹⁴ is a direct result of language deprivation and not being exposed to incidental learning that is taken for granted by society as a whole.¹⁵ When confronted with new situations, people with language and learning deprivation lack valuable coping strategies and become further traumatized. Tate has found increased levels of trauma among deaf people with severe mental illness who have faced increased communication barriers related to deafness.¹⁶

Often, society places the burden of communication on the deaf person. “It’s a hearing world out there,” is a common statement encountered by deaf people. This societal bias both increases the stress a deaf person in crisis experiences and makes it more difficult to find ways to communicate the distress they feel. The situation can appear hopeless.

LaShonn was being beaten in her apartment by an acquaintance who was staying there. She managed to break away and call 911 by a video relay service. The police were dispatched and LaShonn was instructed to meet them in front of the apartment building. LaShonn complied and when the police drove up she walked toward the officer. She was anxious, scared and hurt, and began signing to the officer, explaining what was happening. The officer, gave her verbal commands to stop, but she did not understand. The officer then tasered her and placed her under arrest. She spent three days in jail without an interpreter being called.¹⁷ When LaShonn tried to seek redress, the court awarded her merely \$1 for the violation of her Fourth Amendment Rights.

Because avenues for successful verbal negotiation and resolution of traumatic experiences for deaf people are lacking, dissociation becomes more common. Schild and Dalenberg, have pointed out that post traumatic reactions manifest differently with deaf people. Characteristics of disassociation in deaf people may be different than in hearing people and may not be recognized by clinicians inexperienced with deaf consumers and they may overlook important indicators of risk.¹⁸ The literature suggests that the effect of poor communication and cultural insensitivity will continue to increase emotional vulnerability, thus leading to feelings of hopelessness, which in turn, are associated with suicidal ideation.

Although research is limited in establishing the prevalence of suicide and deafness, there is some information about incidences associated with suicidal ideation and attempts. A literature review

¹² Glickman, N. S. (Ed.). (2013). Deaf mental health care. Routledge.

¹³ Schild, S., & Dalenberg, C. J. (2012). Trauma exposure and traumatic symptoms in deaf adults. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(1), 117.

¹⁴ Pollard Jr, R. Q., & Barnett, S. (2009). Health-related vocabulary knowledge among deaf adults. *Rehabilitation Psychology*, 54(2), 182.

¹⁵ As early as 1981, the issue of the lack of incidental learning in “mainstream” schools became a concern for deaf leaders. See Garretson, M.D. (1981) the deaf child and the unwritten curriculum. *Directions*, (2)1.

¹⁶ Tate, Candice. (2012). Trauma in the deaf population: Definition, experience, and services. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD)

¹⁷ <http://www.kiro7.com/news/crime-law/police-use-taser-deaf-crime-victim/246931400>

¹⁸ Schild, S., & Dalenberg, C. J. (2012). Trauma exposure and traumatic symptoms in deaf adults. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(1), 117.

by Landsberger et al found widely varying results. Landsberger reported that depending on the study, between 6.2% and 30% of the deaf community report suicidal ideation.¹⁹ Both Black and Glickman²⁰ and Embree²¹ report numbers on the higher end - 30% and 40% respectively. Black and Glickman²² found that, among the patients at the Westborough (Massachusetts) State Hospital Deaf Program, 30% attempted and another 30% seriously considered suicide. According to Embree,²³ more than 4 out of every 10 people who are deaf will attempt suicide a one point in their life and more than half will consider it. Among deaf women, Embree's research suggests that the rate is higher with 65.1% for suicidal ideation.

Embree's research used a health-based survey explicitly conducted in ASL. The results from this ASL conducted survey suggested 14.6% of the deaf sample reported suicide attempts. The previous year, the same health survey, which was not conducted in ASL, reported only 2.2% of the deaf sample reported suicide attempts.

In a study of deaf college students, it was found that deaf college freshmen women were more at risk for suicide attempts than their hearing counterparts.²⁴ Further, there appears to be a significant correlation between anxiety and self-reported attempts for the deaf community. Among deaf consumers with co-occurring disorders, a sample was gathered through *Deaf Off Drugs and Alcohol* (DODA) substance abuse services that found that Deaf consumers were 42.1% more likely to report suicide attempts when compared to the hearing control groups.²⁵

It is likely that deaf people are, in fact at higher risk for suicide, however there are fewer appropriate resources available to intervene. For a hearing person, help is as close as a phone call. For deaf people, it is much more complicated and the same opportunities do not currently exist.

¹⁹ Landsberger, S. A., Sajid, A., Schmelkin, L., Diaz, D. R., & Weiler, C. (2013). Assessment and treatment of deaf adults with psychiatric disorders: A review of the literature for practitioners. *Journal of Psychiatric Practice*, 19(2), 87-97.

²⁰ Black, P. A., & Glickman, N. S. (2009). Language and learning challenges in the deaf psychiatric population. *Cognitive-Behavioral Therapy for Deaf and Hearing Persons with Language and Learning Challenges*. New York, Routledge.

²¹ Embree, J. A. (2012). Prevalence of Suicide Attempts in a Deaf Population with Co-Occurring Substance Use Disorder. *Journal of the American Deafness & Rehabilitation Association (JADARA)*, 45(2).

²² Black, P. A., & Glickman, N. S. (2009). Language and learning challenges in the deaf psychiatric population. *Cognitive-Behavioral Therapy for Deaf and Hearing Persons with Language and Learning Challenges*. New York, Routledge.

²³ Embree, J. A. (2012). Prevalence of Suicide Attempts in a Deaf Population with Co-Occurring Substance Use Disorder. *Journal of the American Deafness & Rehabilitation Association (JADARA)*, 45(2).

²⁴ Samar, V. J., Pollard, R., Sutter, E., O'Hearn, A., Lalley, P., & Barnett, S. (2007). Deaf young adults' self-reported suicide attempt rate: role of reading and gender. In meeting of the Pacific Rim Disability Conference, Honolulu, Hawaii.

²⁵ Embree, J. A. (2012). Prevalence of Suicide Attempts in a Deaf Population with Co-Occurring Substance Use Disorder. *Journal of the American Deafness & Rehabilitation Association (JADARA)*, 45(2), 258-272.