



**National Association of State Mental Health Program Directors  
66 Canal Center Plaza, Suite 302  
Alexandria, Virginia 22314**

## **Assessment #8**

# **Promising and Emerging Approaches and Innovations for Crisis Interventions for People Who are Deaf, Hard of Hearing, and Deafblind**

**September 2016**

**Alexandria, Virginia**

*Eighth in a Series of Eight Briefs on the Use of Technology in Behavioral  
Health*

*This work was developed under Task 2.1.1 of NASMHPD's Technical Assistance Coalition contract/task order, HHSS28342001T and funded by the Center for Mental Health Services/Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services through the National Association of State Mental Health Program Directors.*

# Promising and Emerging Approaches and Innovations for Crisis Intervention for People Who Are Deaf, Hard Of Hearing, And Deafblind

## **Technical Writers:**

Steve Hamerdinger, MA, Director  
Kent Schafer, MA, MSE, NCSP, Staff Psychologist  
Office of Deaf Services, Alabama Department of Mental Health  
100 North Union Street  
Montgomery, AL 36117

## **Contributor:**

Meighan B. Haupt, M.S., Chief of Staff, NASMHPD

## **National Association of State Mental Health Program Directors**

66 Canal Center Plaza, Suite 302, Alexandria, VA 22314  
703-739-9333 FAX: 703-548-9517

[www.nasmhpd.org](http://www.nasmhpd.org)

**September 2016**

*This working paper was supported by the Center for Mental Health  
Services/Substance Abuse and Mental Health Services Administration of the  
Department of Health and Human Services.*

## Table of Contents

Executive Summary.....	3
When Mere “Accommodation” Is Not Enough .....	4
Invisible Population – Invisible Trauma.....	5
Approaches and Technology.....	9
I. Text-Based Technology.....	10
II. Video-Based Technology .....	14
III. Emerging Innovations.....	16
Privacy and Informed Consent .....	17
When Help Is Sought.....	18
Recommendations.....	19
Conclusion .....	20

## Executive Summary

This paper addresses the need for linguistically and culturally appropriate crisis interventions for people who are deaf<sup>1</sup>, Deaf<sup>2</sup>, late-deafened, deafblind, and, to some degree, hard of hearing. These interventions often include the use of technology.

Throughout this paper, the term “deaf” will be used as shorthand for all groups for whom the discussed technologies would apply. This paper, due to its relative brevity, paints in broad strokes, and focuses on a specific subset of people with hearing loss – those whose preferred language is American Sign Language (ASL).

Research in suicide and suicide prevention in the Deaf Community is scant.<sup>3</sup> 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 Glickman<sup>4</sup> 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,<sup>5</sup> 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, 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.

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<sup>1</sup> As used in this report, a person who is “deaf” is one who has a significant hearing loss and who, with or without amplification, cannot understand speech. A deaf person relies principally on visual, rather than auditory, cues for communication. A person who is “hard of hearing” has a hearing loss that, with or without amplification, can understand speech in some settings. A person who is hard of hearing relies significantly on auditory cues for communication, but many also depend on visual cues. They generally communicate through speech or some version of a spoken language, although they may also know some form of signing.

<sup>2</sup> As used in previous NASMHPD reports, this paper will adopt the custom described by Padden and Humphries (1988) of using the capitalized word “Deaf” to refer to cultural experience or identity, and the lower-case word “deaf” in other contexts, such as clinical references, in reference to people with hearing loss who do not generally associate themselves with Deaf Culture, or in reference to the broad population of people who rely principally on visual, rather than auditory, signals for communication. Padden, C. A., & Humphries, T. (1988). *Deaf in America*. Harvard University Press.

<sup>3</sup> Turner, O., Windfuhr, K., & Kapur, N. (2007). Suicide in deaf populations: a literature review. *Annals of general psychiatry*, 6(26), 1-9.

<sup>4</sup> 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.

<sup>5</sup> 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).

This paper provides background on the use of technology in communication for deaf people; highlights technological approaches that work and show promise; and provides recommendations for establishing linguistically and culturally appropriate crisis services for people who are deaf. Further, it underscores the need to understand the lived experience of deaf people to effectively implement crisis service response for this population. Implementation of the recommendations in this paper will require creativity, leadership, and commitment, but are achievable.

## **When Mere “Accommodation” Is Not Enough**

NASMHPD has a long history of interest in serving the Deaf Community, beginning in 1995 with a national conference of state deaf services coordinators held in Washington, D.C. This meeting led to the publication of a model “Standards of Care” for deaf people<sup>6</sup>. This was followed in 2002 with a report for the Cultural Diversity Series by Dr. Barry Critchfield, “Meeting the Mental Health Needs of Person Who Are Deaf.”<sup>7</sup> This was quickly followed by “Reducing Seclusion and Restraint Part III: Lessons from the Deaf and Hard of Hearing Communities” that same year.<sup>8</sup> More recently, “Trauma in the Deaf Population: Definition, Experience, and Services” (2012)<sup>9</sup> and “Being Seen!: Establishing Deaf to Deaf Peer Support Services and Training” (2015)<sup>10</sup>, which is part of this series of papers, joined the growing list.

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

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<sup>6</sup> Myers, R. R. (Ed.). (1995). Standards of care for the delivery of mental health services to deaf and hard of hearing persons. RR Myers.

<sup>7</sup> Critchfield, A. B. (2002). Cultural diversity series: Meeting the mental health needs of persons who are deaf. National Technical Assistance Center for State Mental Health Planning (NTAC).

<sup>8</sup> NASMHPD. (2002). Reducing Seclusion and Restraint Part III: Lessons from the Deaf and Hard of Hearing Communities. Arlington, VA: National Association of State Mental Health Program Directors.

<sup>9</sup> NASMHPD. 2012. Trauma in the Deaf Population: Definition, Experience, and Services: Definition, Experience, And Services. Arlington, VA: National Association of State Mental Health Program Directors.

<sup>10</sup> NASMHPD. 2015. Being Seen! : Establishing Deaf to Deaf Peer Support Services and Training. Arlington, VA: National Association of State Mental Health Program Directors.

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.”<sup>11</sup> 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 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*

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<sup>11</sup> <http://www.dol.gov/oasam/regs/statutes/sec504.htm>

*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.<sup>12</sup>

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 21<sup>st</sup> 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.<sup>13</sup> Most such mainstream programs had few, if any other deaf children in them, thus the deaf child become 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 aide. Increasingly mental health providers are encountering deaf people who have never been exposed to other deaf people or to even to effective language. This lack of exposure creates a subset of people who are both language and learning deprived.<sup>14</sup>

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

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<sup>12</sup> Gannon, J. R., Butler, J., & Gilbert, L. J. (1981). *Deaf heritage: A narrative history of deaf America*. Natl Assn of the Deaf.

<sup>13</sup> 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

<sup>14</sup> 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*.

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<sup>15, 16</sup> and that they experience a higher rate of interpersonal trauma than their hearing counterparts.<sup>17 18</sup> This trauma becomes apparent in the rates of emotional and social maladjustment reported in the literature.<sup>19</sup> Schild & Dalenberg<sup>20</sup> call this information deprivation trauma. The lack of information, also known in the literature as fund of information deficits,<sup>21</sup> is a direct result of language deprivation and not being exposed to incidental learning that is taken for granted by society as a whole.<sup>22</sup> 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.<sup>23</sup>

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 services. 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*

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<sup>15</sup> 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.

<sup>16</sup> 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.

<sup>17</sup> 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.

<sup>18</sup> Vernon, M., & Miller, K. R. (2002). Issues in the sexual molestation of deaf youth. *American annals of the deaf*, 147(5), 28-36.

<sup>19</sup> Glickman, N. S. (Ed.). (2013). *Deaf mental health care*. Routledge.

<sup>20</sup> Schild, S., & Dalenberg, C. J. (2012). Trauma exposure and traumatic symptoms in deaf adults. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(1), 117.

<sup>21</sup> Pollard Jr, R. Q., & Barnett, S. (2009). Health-related vocabulary knowledge among deaf adults. *Rehabilitation Psychology*, 54(2), 182.

<sup>22</sup> 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.

<sup>23</sup> Tate, Candice. (2012). *Trauma in the deaf population: Definition, experience, and services*. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD)

*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.<sup>24</sup> 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.<sup>25</sup> 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 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.<sup>26</sup> Both Black and Glickman<sup>27</sup> and Embree<sup>28</sup> report numbers on the higher end - 30% and 40% respectively. Black and Glickman<sup>29</sup> found that, among the patients at the Westborough (Massachusetts) State Hospital Deaf Program, 30% attempted and another 30% seriously considered suicide. According to Embree,<sup>30</sup> more than 4 out of every 10 people who are deaf will attempt suicide a one point in their life

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<sup>24</sup> <http://www.kiro7.com/news/crime-law/police-use-taser-deaf-crime-victim/246931400>

<sup>25</sup> Schild, S., & Dalenberg, C. J. (2012). Trauma exposure and traumatic symptoms in deaf adults. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(1), 117.

<sup>26</sup> 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.

<sup>27</sup> 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.

<sup>28</sup> 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).

<sup>29</sup> 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.

<sup>30</sup> 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).

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.<sup>31</sup> 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.<sup>32</sup>

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.

## Approaches and Technology

This section highlights past, present, and emerging technologies for people who are deaf within a cultural and linguistic context. Understanding the strengths and weaknesses of these approaches and technologies within the context of the lived experience of deaf people is fundamental in developing appropriate crisis services for this population.

ASL is not English and has no written form, thus, until fairly recently, deaf people traditionally relied on face-to-face interactions for most communications in ASL. Many deaf people are, to varying degrees, bi-lingual (ASL and English). English literacy varies widely in the deaf population, from fluent in both languages, to being effectively illiterate in both.<sup>33</sup> Written interactions are based in a language with a written form. In the United States, this generally means English. Unfortunately, there persists the misperception that ASL is simply "English on the hands" rather than a distinct language with its own

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<sup>31</sup> 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.

<sup>32</sup> 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.

<sup>33</sup> Illiteracy in ASL is better understood as language dysfluent or deprived.

grammatical structure and syntax.<sup>34</sup>For numerous reasons, many deaf people are not highly literate in written English. The more technical and clinical the writing becomes, the less likely it is that writing is an effective communication strategy, especially in stressful situations.

## I. Text-Based Technology

From the advent of the telephone until the mid-1960s, non-face-to-face interactions between deaf people generally meant letter writing. Even some face-to-face interactions, especially with those who did not use ASL, and especially with hearing people, involved writing. Often, such writing took the form of cryptic notes that are in some ways analogous to “instant messages,” which has become a popular form of communicating electronically in present times. However, there were, and are, several critical things of which non-deaf, non-ASL fluent providers usually are not aware and need to consider.

The first is the fact that English is the “second language” of many deaf people who prefer ASL.<sup>35</sup> Most people with limited English proficiency, and even people whose native language is not English but who are conversationally fluent in English have a harder time processing critical information presented in English. Simply put, critical interactions where comprehension is essential – even an issue of life and death – are best negotiated in their strongest language. For many deaf people, this language means ASL.

Nevertheless, deaf people have been very creative at finding ways to communicate with each other when they cannot do so face-to-face. One of the earliest efforts involved making it possible for deaf people to use the telephone. In the mid-1960s, two deaf men, Robert Weibrecht, a physicist, and James Marsters, a dentist and private aircraft pilot, teamed up to invent an acoustic coupler, which made it possible to send typed text over telephone lines. Early Teletypewriters (TTYs) were large, cumbersome, and expensive, but for a certain subset of the deaf people who were English-literate, TTYs provided a certain sense of liberation in the latter half of the 60s and through the 70s.

In the 1980s, technology had advanced to the point where TTYs were all electronic and self-contained. Gone were the enormous teletypewriters of Western Union vintage. The new devices, dubbed Telecommunication Device for the Deaf, or TDD, shrunk to the size of a hardback book. In time, the term TDD fell out of favor and TTY became the accepted term once again.

Because TTYs operate in half duplex mode, meaning only one message person at a time could be typing, certain protocols were developed to ensure that conversations went

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<sup>34</sup> Manually Coded English systems exist and are frequently used in educational settings. These systems introduce their own problems, not the least being inconsistency in application and, all too often, language delay.

<sup>35</sup> Outside the scope of this paper, but important to understand, is that with improvement in medical care, how people become deaf has changed dramatically over the last 50 years.

smoothly. Those protocols became common knowledge among deaf people, but were often considered mysterious to people who did not regularly use TTYs. The following is an example of TTY communication that includes some of the protocols used, such as the message people signing off at the end of each communication.

*HELLO DEAF SERVICES, MAY I HELP U Q GA  
HELLO THIS ALEX SMITH WANT TY FOR MAIL N MSG U SENT ME TH BOUT APT  
MON GA  
HD PLS, NUMBERS. CANT RD YOU. OK RPT GA  
WANT TY FOR MAIL N MSG U SENT ME TH BOUT APT MON GA or SK,  
SURE CAN YOU COME AT 10 Q GA  
OK SK  
SKSK*

It was not unusual in the 90s to find TTY numbers listed for service providers. Many of them, however, did not have enough calls for the operators of the TTYs to become comfortable with the technology or protocols, which in turn made for awkward conversations. Even more important, people forgot that deaf people who were not fluent in English typed a pidgin form of English that made little sense to a person who was not ASL fluent.<sup>36</sup>

In the mid-80s, many areas were setting up relay services. These services were essentially a hearing person with two phone lines, one of which was dedicated to a TTY and the other was used to make voice phone calls. These services were the forerunners of telecommunication relay systems (TRS) which were mandated by Title IV of the Americans with Disabilities Act (1990).

Under Federal Communication Commission (FCC) rules, these centers were required to operate 24 hours a day, 365 days a year. By the beginning of the new millennium, such services were in place in all 50 states and were typically overseen by the states' telecommunication regulatory bodies.<sup>37</sup>

Yet, relay services created new and different challenges. Telephone etiquette used by hearing people was as strange and unfamiliar to deaf people as TTY etiquette was to hearing people. TTYs could handle only one data stream at a time, while telephones allowed both people to talk and hear at the same time. The TTY technology created a pause while the Communication Assistant (CA) was typing and waiting on the deaf person to type back a response. For a hearing person using a telephone, this pause was sometimes mistaken for a prank call. Another misunderstanding arose from how the call

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The first author received many such calls in his early days as a clinician. Usually what was needed was to stop trying to read English and start transliterating into ASL what he saw. This essentially meant signing, either literally or mentally, what was on the read out. It usually made sense then.  
<sup>37</sup> (FCC) (2015-01-28). "Telecommunication Relay Service (TRS)". Telecommunications Relay Service (TRS) Guide. Federal Communications Commission. p. 1. Archived from the original on 2014-10-15. Retrieved 2015-02-01.

was introduced to the hearing person. “Hello, this is (XYZ) Relay, Communication Assistant 97 with a call from a deaf person...” was sometimes assumed to be a solicitation or even a scam call.

The platform was quickly abused by con artists who realized the anonymity of using a TTY and FCC rules regarding strict confidentiality of the calls made it easy to scam unsuspecting people.<sup>38</sup> This abuse led businesses to reject legitimate calls from deaf people. A legitimate call from a deaf person would often take several attempts, sometimes requiring the communication assistant to try to explain what was happening. Even after repeated attempts to explain to the hearing person what a relay call was and that the hearing person was in fact communicating with the deaf person, hang ups continued to be a common occurrence. The frustration of trying to get through for help likely stopped many deaf people from reaching out for help at all.

TTYs were not the only means deaf people used to communicate with each other. As fax machines became affordable, deaf people realized fax technology could be used to communicate with other people. Because fax could support graphics, it was used to communicate information that would not have been possible by TTY. Even deaf people with limited English were able to make use of it.

Some agencies, particularly in areas with large deaf populations, established *ad hoc* crisis lines that were run by volunteers. Early examples in the 90’s included Deafline Missouri, operated in Columbia, Missouri by a deaf-run social services program, L.E.A.D. This organization was originally named Leadership through Empowerment and Advocacy for the Deaf and later became the L.E.A.D. Institute.<sup>39</sup> Because these programs were generally operated by volunteers, consistency was often an issue. Further, the expansion of dual-party relay services provided a ready excuse for programs to not establish more specialized social services for deaf people. Dedicated TTY lines faded out as deaf people became more comfortable with the relays.

Alphanumeric pagers started to come into general use in the mid-90s and some deaf people created code systems which could transmit simple information. By 2010, full text pagers, exemplified by the Sidekick by Danger and Blackberry became popular as a method of communication. Concurrently, the development of instant message services by various providers also increased options. The primary disadvantage of all these technologies was that they were not truly real-time. This disadvantage remains with various forms of short message service (SMS) formats.

Nevertheless, it created opportunities for more efficient crisis response. In some areas, local public safety authorities created special text only numbers dedicated for use by the

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<sup>38</sup>[https://en.wikipedia.org/wiki/Telecommunications\\_relay\\_service#Fraudulent\\_uses\\_in\\_the\\_United\\_States](https://en.wikipedia.org/wiki/Telecommunications_relay_service#Fraudulent_uses_in_the_United_States)

<sup>39</sup> <http://www.deaflead.com/victim-services>

deaf community.<sup>40</sup> Within the past few years, crisis intervention services solely based on SMS text systems have emerged. For example, Crisis Text Line has recruited and trained deaf people to serve as crisis counselors.<sup>41</sup>

*“In 2014, one of our crisis counselors received a message that read, ‘I can’t call suicide hotlines because I can’t hear, so I was hoping I could use this service.’”  
Jared Wolf, Crisis Text Line.*

In recent years, speech-to-text software has taken over a large portion of the telecommunication relay service (TRS) workload. This software can reduce costs, but introduces errors in transcription that can change the meaning, context, and nuances of the conversation. These errors are familiar to anyone who uses speech-to-text software or even, watches real-time captioning at meetings or on television. For a quick insight to the issue, the reader is invited to watch any of the 1,000s of videos on YouTube which have auto-generated captions. While real life CAs monitor the transcription, those errors must be kept in mind.

A service provided by TRS that we must mention is Voice Carry Over (VCO). VCO provides people who are deaf or hard of hearing and prefer to speak for themselves the option to have what is said to them transcribed on a monitor, often built into the telephone.<sup>42</sup> For many people, VCO is a useful option that provides much more “transparency” and direct communication than is possible when the CA must handle both sides of the communication. Devices like CapTel<sup>43</sup>, which are captioned telephones, provide the ability for the person with hearing loss to both hear the person on the other end and to speak directly with that person all while waiting watching a near real-time transcription of what the other person is saying. It is a TRS service, so issues related to the accuracy of the captioning apply here as well.

At the end of the day, all of these approaches are, essentially, English based. For the most part, the platforms are ones that most people are familiar with, thus no special training is necessary. (TTYs are the exception, which requires training and familiarization with codes and protocols. TTYs are, however, not in common use now.) There are some drawbacks, however.

Because these systems, as used in the United States, are English based, they require the deaf person to have some competence in English, which can be problematic given that

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<sup>40</sup> Jefferson City News Tribune February 8, 2007. Sheriff hears deaf concern. Retrieved from <https://fookembug.wordpress.com/2007/02/08/sheriff-hears-deaf-concern/>.

<sup>41</sup> <http://www.crisistextline.org/> and [http://www.huffingtonpost.com/crisis-text-line/finally-a-crisis-hotline- b\\_8136694.html](http://www.huffingtonpost.com/crisis-text-line/finally-a-crisis-hotline- b_8136694.html)

<sup>42</sup> Simpson, J. (2009). Inclusive information and communication technologies for people with disabilities. *Disability Studies Quarterly*, 29(1).

<sup>43</sup> <http://www.captel.com/>

the average reading level of deaf people in the US is not quite 4<sup>th</sup> grade.<sup>44</sup> Further, showing emotion in text is difficult for anyone, and especially so when someone's English vocabulary is limited.

On the other hand, text-based systems can be significantly helpful to people who are hard of hearing or late-deafened. Additionally, they are very helpful for DeafBlind people who are skilled with Braille, using refreshable Braille display<sup>45</sup> technology that allows for nearly real-time two-way communication.<sup>46</sup>

## II. Video-Based Technology

Videotelephony, a more fitting solution for signing deaf people, did not become widespread until the latter half of the first decade of the 21<sup>st</sup> century since it required bandwidth that was simply not available or affordable until then. As broadband internet service became commonplace, so did the use of videophones – to the point that TTYs fell out of favor. Further, the FCC created a special fund to pay for and promote video relay interpreting services (VRS), which, unlike TRS systems, were not operated by the various states, but rather contracted by the FCC and operated on a nationwide basis. Where TRS does not require Communication Assistants to have knowledge of ASL, VRS requires fully trained interpreters. Initially, all providers required interpreters to be certified, though at the time of publication of this paper, that standard is not as rigidly enforced as it once was. The competence and experience of the interpreter has important implications for crisis intervention providers.

Response time standards and work force availability created an incentive for VRS providers to decentralize their workforce. Unlike TRS, which are funded at the state level by surcharges on telephone lines, VRS is funded at the national level and paid by the FCC. For these reasons, most VRS providers maintain call centers around the country, thus the interpreter handling the call might be based anywhere in the United States. This decentralization means that caller ID, often used to get a geographical fix on where the caller is located in case the crisis center must dispatch first responders, likely will not indicate where the caller is, but rather where the VRS call center is located.<sup>47</sup>

*During the winter of 2012-1013, staff members of the Alabama Department of Mental Health, Office of Deaf Services, called a number of national crisis intervention hotlines, including hotlines related to suicide prevention, tobacco*

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<sup>44</sup> Qi, S., & Mitchell, R. E. (2012). Large-scale academic achievement testing of deaf and hard-of-hearing students: Past, present, and future. *Journal of Deaf Studies and Deaf Education*, 17(1), 1-18.

<sup>45</sup> <http://www.afb.org/info/living-with-vision-loss/for-job-seekers/careerconnect-virtual-worksites/retail-worksite-for-blind-users/refreshable-braille-display-3652/12345>

<sup>46</sup> <http://globalaccessibilitynews.com/2012/02/13/krown-developed-vtouch-braille-tty-for-deafblind-people/>

<sup>47</sup> It should be noted that with the proliferation of cell phones, this is not limited to deaf people. Many people have cell phones with area codes that do not match their geographic location.

*quit support, and domestic violence, to see whether they would be responsive to VRS calls. In most cases referrals were made to services in the state where the VRS call center was located, and not in the state where the consumer was located.*

These VRS services now made it possible for deaf people who were not fluent in English to have equal access to telecommunications. Most deaf people and many hearing people consider this technology to be a huge improvement. And it is, albeit one with certain tradeoffs that should be considered.

As with any interpreted interaction, there is the possibility of important information being “lost in the translation.”<sup>48</sup> A crisis situation where a deaf person is highly at risk and stressed is extremely difficult to interpret in any circumstance. With VRS, the hearing person is using their telephone and does not see the deaf person or interpreter. The interpreter sees and reads what is signed and speaks the interpretation to the hearing person. A hearing person trying to assess risk to a person they cannot see, solely by listening to what the interpreter has adjudged the deaf person to mean can make the assessment much more difficult. Crisis counselors must constantly evaluate whether what they are assessing is the deaf person or the interpreter.<sup>49 50</sup>

Currently, there are several VRS providers that make dedicated videophones available for deaf people who use that service. The FCC pays the VRS provider per minute of a connected call. Over time, as with TRS, the unscrupulous found ways to abuse the system. In this case, the abuse involved some VRS companies paying kickbacks to individuals – sometimes hearing - to make calls to such things as reading services for the blind, news reader services, webinars, and other such things, for the sole purpose of allowing the VRS provider to log a connected call and run up the number of minutes billed to the FCC. The individual involved in the scam would not need to pay attention to the call, and indeed, may actually tell the relay interpreter not to bother interpreting, because no attention would be paid anyway. In a relatively new twist, the person involved in the scam would engage VRS by making a call to a number that was knowingly out of service, and then ask to be connected to another number, which would be routed through a second VRS. Thus, VRS providers would rack up minutes by billing the FCC twice for the same call.

In response to this abuse, the FCC has established rules that require the VRS providers to verify that people to whom videophones are distributed are, in fact, deaf, or that the VRS

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<sup>48</sup> Hamerdinger, S., & Karlin, B. (2003). Therapy using interpreters: Questions on the use of interpreters in therapeutic settings for monolingual therapists. *Journal of American Deafness and Rehabilitation Association*, 36(3), pp. 12-30.

<sup>49</sup> Brunson, J. G., & Lawrence, P. S. (2002). Impact of sign language interpreter and therapist moods on deaf recipient mood. *Professional Psychology: Research and Practice*, 33(6), 576

<sup>50</sup> Hamerdinger, S., & Karlin, B. (2003). Therapy using interpreters: Questions on the use of interpreters in therapeutic settings for monolingual therapists. *Journal of American Deafness and Rehabilitation Association*, 36(3), pp. 12-30.

capability has been removed from the device or software if distributed to a person who is hearing but knows ASL. Unlike TTYs, which were available to purchase by anyone, hearing or deaf, the availability of videophones remains tightly regulated. At the time of this writing, ZVRS is the only company that offers any videophone option for hearing people.<sup>51</sup>

Availability and quality of the video is an issue in some locations. A considerable percentage of deaf people with mental illness are without broadband internet service, which is required for videophones. For some, it is a geographical issue, but for many, access to broadband services is too expensive for them. To address this concern, one VRS provider contracted with the National Telecommunications and Information Administration through the American Recovery and Reinvestment Act to fund broadband cellular service using discounted or paid-up internet service plans to allow deaf people the opportunity to connect with the community using their primary language through the use of videophones installed on smartphones. This project was sustainable for only two years and has since expired but should be reconsidered.<sup>52</sup>

### III. Emerging Innovations

In recent years, the quality of web-based videoconferencing has improved dramatically and the price has become less prohibitive. Several platforms are exciting for potential application to mental health work. Several of these sites emphasize security, which is a concern for providers. OmniJoin, for example, touts its application to telehealth and telepsychiatry, and is used by several organizations connected with deafness for training.

Wright State University conducts an intriguing grant-funded project using videoconferencing to run 12-Step meetings for deaf people. *Deaf Off Drugs and Alcohol (DODA)*<sup>53</sup> allows for people who are deaf and in recovery to participate in Alcoholics Anonymous/Narcotics Anonymous (AA/NA) type meetings that are made up of deaf people from around the country. In most parts of the country, there are not enough deaf people in any location to successfully run a 12-Step program. Concerns about anonymity and the fact that AA is not obligated by law to provide interpreters (although many groups do) make attending meetings unattractive for deaf people to participate. By using multipoint videoconferencing, which allows for up to 12 different locations to join at a given time, DODA is able to conduct meetings seven days a week.

Similar projects could be used for any self-help initiative and to develop peer support networks in areas where the number of deaf people is too small to support developing stand-alone projects.

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<sup>51</sup> <https://www.zvrs.com/products/videophones/z5h---z5-for-hearing>

<sup>52</sup> <http://www.csd.org/news/project-endeavor/>

<sup>53</sup> <http://medicine.wright.edu/citar/sardi/deaf-off-drugs-and-alcohol>

Not all videoconferencing sites are equal. Some seem to prioritize video quality over audio quality, an advantage for people using ASL. Some offer more features for sharing content; others allow more connections. A major disadvantage to web-based videoconferencing lies in the need for relative up-to-date hardware – usually a webcam equipped laptop or desktop – and stable broadband. These equipment needs can be beyond the means for some consumers. Nevertheless, videoconferencing is worth considering, especially when serving a geographically dispersed group of people. Videoconferencing technology is rapidly improving. It would be important to research what is available at the time of implementation.

Video quality of consumer level platforms remain such that speechreading is even more difficult than it is in “real-world”. People who prefer speechreading will likely need higher resolution video with integrated sound or text-based options, like CapTel.

Technology improves faster than implementation and the formulation of regulations. This difference creates challenges for adopting new ideas, since the level of tolerance for change varies greatly. In some areas, technological change is welcomed and embraced. In others, it is viewed with trepidation.

An important system intervention would be to encourage innovation by making regulations less cumbersome. Areas of particular concern relate to the restriction of cross-state practice of clinical mental health services, such as counseling, psychiatry, and psychology. Current rules require that the clinician be licensed in the state where the consumer is located, not just where the clinician is based. This regulation can discourage efficient use of scarce resources for deaf people who, without this rule, could use video technology to access ASL-fluent clinicians located in other states.

## **Privacy and Informed Consent**

Since consumer level platforms generally used by VRS companies do not encrypt the data, concerns have been raised about Health Insurance Portability and Accountability Act (HIPAA) compliance. The authors are not aware of any legal precedent one way or the other. However, the FCC has determined that using VRS does not violate (HIPAA) or the Family Educational Rights and Privacy Act (FERPA).<sup>54</sup> The Deaf and Hard of Hearing Services Division Mental Health Program in Minnesota has developed a protocol to ensure informed consent is given, which is intended to warn of risks<sup>55</sup> as well as to forestall possible HIPAA or liability/malpractice complaints.

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<sup>54</sup> <https://federalregister.gov/a/04-15539>

<sup>55</sup> Gournaris, M. J. (2009). Preparation for the delivery of telemental health service with individuals who are deaf: informed consent and provider procedure guidelines. *Journal of the American Deafness & Rehabilitation Association (JADARA)*, 43(1).

## When Help Is Sought

Various crisis hotlines are not insensitive to deaf people. Indeed, a cursory survey shows most of them at least reference a method for deaf people to contact them. Listing a TTY number is common. Some list texting options. A few use live chat via internet in their webpages. Unfortunately, these text-based options disadvantage deaf people with limited English proficiency. It would be helpful if crisis hotlines mentioned that VRS or TRS can be used. However, crisis counselors who field calls coming through the relay need training to understand the impact of an interpreter in a highly charged encounter. They must use care to ensure that they are not responding to the interpreter rather than the deaf person. \

Programs like Nation Deaf Domestic Violence Hotline makes use of multiple ways to connect with counselors. Their videophone hotline is answered by ASL-fluent staff based at the Abused Deaf Women's Advocacy Services (ADWAS) in Seattle, Washington.<sup>56</sup> Providing direct services removes the interpreter from the process, leading to more accurate assessment than would be possible if going through a TRS or VRS. A possible reason for the paucity of videophone-based crisis lines may be an unintended consequence of FCC rules meant to reduce fraudulent use of VRS. The FCC currently requires that VRS companies, which provide consumer-level equipment, verify that the recipient of that equipment is, in fact deaf. This rule means that relay companies cannot provide this equipment to hearing people, regardless of whether they use it to communicate with deaf people or not. Unfortunately, those devices cannot interface with web-based videoconferencing programs and applications like OoVoo, Skype, GoToMeetings, and so on.

*"It is extraordinarily difficult to find enough qualified individuals who are fluent in American Sign Language and other various signed systems who are available to volunteer to cover crisis line services 24 hours a day, 7 days a week. We have been working on this for the last several months. Currently, we are planning to establish the crisis videophone services in phases...in the first phase, we'll be providing the services for a few hours per day and only on one videophone line. We hope to begin that by this fall." Stephanie Logan, Ph.D., M.B.A., Executive Director, The L.E.A.D. Institute*

Perhaps the most pressing concern is simply the shortage of qualified people who are ASL-fluent and qualified to provide crisis services. While nearly every state mental health system can identify some providers who are both qualified to provide clinical services and who are ASL-fluent, only a few locations have the population density to support a system of care that includes crisis response.

State licensure laws, especially in states that do not have reciprocity, make it difficult for deaf people to seek ASL-fluent clinicians out of state, even when the other state is nearby. Since a large percentage of mental health services is paid by a third party, rules

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<sup>56</sup> <http://www.adwas.org/hotline/national/> and <http://www.thehotline.org/help/deaf-services/>

related to catchment areas, in-network providers and so on, make it difficult for deaf people to access services with ASL-fluent clinicians.

*Jonah, a licensed social worker working for a mental health program operated by the state mental health authority, requested assistance from the Employee Assistance Program. His preferred language is ASL, and he requested permission to receive counseling for a domestic situation from an out of state provider that has ASL-fluent therapists. The EAP initially denied the request, stating that interpreters were adequate. It was pointed out that because Jonah worked for the state mental health agency, he worked professionally with most of the mental health interpreters in the area and he would not be comfortable using any of the interpreters in state. After several months of discussions and intervention of the state mental health commissioner, permission was granted to use the out of state counselor.*

## Recommendations

*Jane, a female client who is deaf, was considering suicide. She was encouraged to go to her local mental health center. The center, which was located in a rural area of the state, had no experience with deaf consumers. When she asked for a female counselor that could communicate directly in sign language, the center first was perplexed at the request, believing that their clinicians would be able to address her needs. An interpreter from the local church was engaged in helping with Jane's intake. It became obvious that this well-intentioned person was not qualified to do mental health interpreting and the nearest qualified interpreter was more than 30 minutes away and was in very high demand. Jane insisted that she wanted an ASL-fluent clinician. One was located about 45 minutes away from the center, but in the adjoining state. This clinician was not licensed to practice in Jane's state, which had no reciprocity. The mental health center would not cover the cost for dual licensing nor could they contract with an out of state provider due to insurance requiring the clinician be "in network."*

1. **Consider a national crisis center hotline for deaf people where professionals are ASL fluent and respond to emergency calls.** The crisis center hotline should be equipped and prepared to respond to contacts for help that come by text, videophone, TRS or any other communication method. Since such a program will likely need to use responders nationwide, it should follow the model established by the Crisis Text Line, which recruited and trained deaf people to serve as crisis counselors. This crisis center hotline should use the existing technology to make it possible for the crisis center to connect consumers with clinicians regardless of where the consumers might physically be located.
2. **Crisis hotlines should consider adding the option of videophones, and train counselors in how to handle VRS and TRS calls.** It would be helpful if crisis hotlines indicated that VRS or TRS could be used to call. An additional

- consideration would be to ensure the counselor asks where the caller is physically located.
3. **Encourage the use of technology, particularly in rural areas where resources for low incident populations likely do not exist.** State mental health authorities should consider partnering with other state agencies, such as Vocational Rehabilitation, to develop Broadband internet capability in rural areas. With technology rapidly improving, it would be important to research what is available at the time of implementation.
  4. **Utilize videoconferencing to run self-help initiatives and to develop peer support networks in areas where the number of deaf people is too small to support developing stand-alone projects.** The use of videoconferencing would allow for people who are deaf and in recovery to participate from around the country.
  5. **State mental health authorities should consider multi-state compacts to share the pool of ASL-fluent clinical specialists on a regional basis.** One of the daunting barriers to deaf people seeking services has been political boundaries in the form of catchment areas and licensure laws, which make it difficult for a clinician who is ASL-fluent to provide care outside the clinician's state of licensure. The authors encourage the investigation of ways to address licensure issues across state lines to increase the scarce clinical resources for deaf people.
  6. **Consider re-establishing a funding mechanism for providing broadband cellular service at discounted or paid-up internet service plans for the purpose of allowing deaf people the opportunity to connect with the community using their primary language through the use of videophones installed on smartphones.**

## Conclusion

Despite the great strides made over the past decade in access to crisis response and suicide prevention, particularly utilizing various forms of text-based communication, the need for culturally and linguistically appropriate access for deaf individuals who are not English-fluent and use ASL persists. Barriers are surmountable with the willingness to use creative approaches. It requires an understanding that simply adopting an approach or utilizing a technology without understanding the lived experience of deaf people, will miss the mark. Cultural and linguistic competence is critical and without knowing something of the “deaf world” providers will not be as trusted or effective as they would like. This trust is important to establish in order for deaf people to know they can reach out for help in crisis and be responded to appropriately.

The approaches identified in this paper would also benefit other low-incident populations, if they were generalized. While providing crisis services and suicide prevention for deaf people is the example used in this paper, the technological principles to improve access can be applied to other mental health activities for deaf people and low incident populations. Anti-smoking, drug prevention, early intervention, assertive community treatment activities, all could benefit from application of recommendations in this report.