National Association of the Deaf

Position Statement on Preservation of Mental Health Services for Deaf People in an Integrated Health Care

1. Introduction

It is well documented that communication disparities are connected to poorer health care and mental health access, lower quality care and increased mortality (McKee & Paasche-Orlow, 2012). There are liability considerations for health care providers when disparate outcomes are the result of not providing appropriate language access in health care settings (Quan & Lynch, 2010). As the diversity and size of the population of people with limited English proficiency grow, hospitals and clinics are encountering more patients needing better access. This population includes deaf and hard of hearing people,[1] especially those whose primary language is American Sign Language.

Language access and strong commitment to best practices of serving individuals who are deaf and hard of hearing can have significant impact on overcoming the communication disparities in the integrated health care systems. It is the position of the National Association of the Deaf (NAD) that individuals who are deaf and hard of hearing are members of a cultural and linguistic minority group, many who use American Sign Language as their preferred language. It is their human right to obtain barrier-free access to health care and mental health services.[2]

While direct health care communication – meaning provided by clinicians fluent in the preferred language of the consumer - in integrated health care and mental health services are optimal and always preferred, such services are not always available.[3] Each health care organization must commit that services are provided directly to each deaf or hard of hearing individual using the individual's communication preferences rather than using sign language interpreters as the first solution.

Direct communication and services have long been the preferred approach in mental health care. The NAD urges the preservation and continuation of existing programs that provide direct communication and services, and urges that such programs be the models for replication. Several landmark court cases[4] have found that utilizing interpreters as first solution did not provide "equal access" as did direct services provided by signing mental health professionals. These precedents resulted in several states setting up statewide mental health delivery systems to individuals who are deaf and hard of hearing with mental health needs (Gournaris, Hamerdinger & Williams, 2013). These systems are founded on the principle that deaf people are more appropriately served by clinicians who are fluent in ASL, the very standard established by the above referenced cases.

The Office of Minority Health in the Federal Department of Health and Human Services (2013) has created the Enhanced National Standards for Culturally and Linguistically Appropriate Services (CLAS)[5] in Health Care to ensure that health care organizations provide effective, equitable, comprehensible, and respectful quality care and services that are responsive to the linguistic and communication needs of diverse populations. These standards are built on work pursuant to Executive Order 13166, which in turn expands protections provided for in Title VI of the Civil Rights Act of 1964.[6] The Joint Commission on Accreditation of Healthcare Organizations, from which most hospitals and large medical practices seek

accreditation, revised their Standards to reflect CLAS.[7] No longer is mere accommodation to health care considered to be sufficient. These bodies strongly believe that effective communication in the patients' preferred language is a crucial component of quality health care and patient safety and in a basic human right.

Unfortunately, the current trend is towards a heavy emphasis on cost containment. Health care costs continue to escalate in excess of the rate of inflation, with little end to that trend in sight (Patton, 2015). The increase is most visible through skyrocketing insurance premiums and rising Medicaid expenditures (Rudowitz, Snyder, Smith, 2015). States are responding to this increase by shifting from traditional fee for service arrangements to some form of managed care in which payment is made for "outcome" rather than on how much service is provided. Currently, at least 30 states have some form of 1115b demonstration waiver in which all or part of the risks of costs for care is shifted from Medicaid to providers.

The NAD recognizes the reality of escalating health care costs and the need to control that rise. Our concern is that managed care organizations are looking to reduce cost by reducing essential supports like language access. (Rice. S., 2014).

As existing behavioral health services, including those programs which have demonstrated competence in serving deaf consumers[8] are rolled into larger managed care organizations, the very things that make those programs effective, specifically services delivered directly by clinicians and staff who are fluent in sign language, tend to be lost in the process of "cutting costs". Managed care organizations need to recognize that dismantling effective programs and replacing them with minimal "accommodations", such as interpreters, are not cost-effective in the long run. Managed care organizations should encourage the development of regionalized specialized services for people who are deaf and have mental illness and work together to make those services viable.

The purpose of this paper, which focuses primarily on deaf people who use American Sign Language as their primary language, is to highlight the gains made to date, especially in mental health, and to provide a framework for health care systems to develop and employ best practices for meeting diverse patient needs in the deaf and hard of hearing communities. There is no "one size fits all" approach and the organizational cultural and linguistic competence requirements are unique for each hospital or clinic. Nonetheless, establishing a foundation of policies and procedures that systematically support cultural and linguistic competence within a health care organization is a paramount of importance in order to meet and respond to the needs of individuals who are deaf and hard of hearing to reduce communication disparities in integrated health care and mental health services. Not only that, it is the NAD's position that improved practice and standards developed by integrated health care organizations across country will improve patient satisfaction, reduce in medical errors/risks, improve staff competence, improve access to services, and facilitate the continuity of care in the deaf and hard of hearing communities.

2. Developing Culturally and Linguistically Appropriate Integrated Healthcare

It is the position of the National Association for the Deaf (NAD) that culturally and linguistically appropriate team-based care is essential to ensure linguistically appropriate mental health services for deaf individuals in an integrated health care environment. NAD's position paper on "Health Care Access on Deaf Patients" demonstrated that the Deaf Community[9] struggles with significant linguistic and communication barriers that render health care largely inaccessible and contributes to existing health disparities.

The Deaf Community consists of individuals who identify themselves as a minority community, with their own language, American Sign Language, and culture. Unfortunately, this community is considered a marginalized cultural community with reduced access to health information and health care, especially behavioral health (Fellinger, Holzinger, & Pollard, 2012). There is an estimated 1 million deaf signers in the USA (Mitchell, Young, Bachleda & Karchmer, 2006). Researchers have demonstrated that the Deaf community struggles with higher rates of mental health issues. For example, Kvam et al., 2007

demonstrated that 33.8% of deaf individuals had either depression or anxiety versus only 6.8% for hearing individuals. Fellinger, Holzinger, & Pollard, 2012, demonstrated further evidence that mental health disorders for deaf signers, including depression and anxiety occur at a much higher rate, usually in the magnitude of two times higher than what is typically seen in the hearing population (Kvam, Loeb, & Tambs, 2007; Fellinger, Holzinger, & Pollard, 2012). This occurs due to congenital, environmental and educational factors. (Black & Glickman, 2006). As a result, deaf individuals may be at a higher risk for a host of adverse outcomes including social isolation and poor physical health.

Reduced access to behavioral health is likely due to multiple factors. The language barrier is likely a primary factor that also may lead misdiagnoses of deaf individuals by health care providers. Language discordance in health care reduces health care satisfaction, diagnosis abilities, and treatment adherence. (McKee, Paasche-Orlow, Winters, Fiscella, Zazove, Sen, & Pearson, 2015). The lack of accessible health information further marginalizes the deaf population and places them at high risk for inadequate health literacy. Members of the deaf community may have limited medical and mental health knowledge because they do not have direct health access to health information during their primary and secondary education. This may result in less help-seeking behavior as a contributing factor (Pollard et al, 2014).

At the provider level, two major legal mandates, the Americans with Disabilities Act (ADA) and Title VI of the Civil Rights Act, mandate provision of effective health communication, but many health care settings do not provide certified and qualified medical & mental health interpreters. Furthermore, deaf people who prefer ASL embody a unique culture that is unfamiliar to most health care providers. This lack of cultural & linguistic competency on the part of the professionals, combined with the lack of interpreters who are trained and qualified to work in health care settings, often results in higher rates of inaccurate evaluations, misdiagnoses and inappropriate treatments. Complicating this already challenging situation is the huge variability in the language skills and opportunity for education and health learning. Providers are simply not aware of how little they really understand the Deaf Community.

At the health care system and insurer level, providers often do not know or fully comprehend that it is their obligation to hire and pay for an interpreter based on the ADA mandate. Few mental health facilities or insurance networks provide direct outreach specifically to the Deaf Community.

At a minimum, providers need to embrace the spirit of the national Culturally & Linguistically Appropriate Services Standards in Health & Healthcare. These standards have specifically included sign language as one of the languages covered under the standards (**United States Department of Health and Human Services, Office of Minority Health**). The CLAS addresses inequities at every point of patient contact with the health care system.

CLAS has three themes:

1) Governance, Leadership, & Workforce;

2) Communication & Language Assistance;

3) Engagement, Continuous Improvement, & Accountability.

Under each theme there are several standards. Of particular interest are standards under theme 2, Communication & Language Assistance (standards 5 – 8):

5) Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services,

6) Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing,

7) Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided, and

8) Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area. (Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.)

Inadequate health literacy is a significant issue with the Deaf Community. McKee et al. (2015) demonstrated that deaf individuals were nearly 7 times more likely to have inadequate health literacy when compared to their hearing peers. Furthermore, the Current State of Health Care for People with Disabilities by National Council on Disability from Washington, DC also added that deaf adults were found to have lower health literacy as compared to their hearing counterparts. Limitations on funds and knowledge significantly contribute to health care illiteracy. (McKee, M. M., et al, 2015).

Effective health education programs for deaf people are largely lacking. Teaching linguistically accessible health, mental health and addiction information should be implemented at all levels of education including mainstream settings, public and private schools and schools for the deaf at the elementary level & high school levels. Utilizing health care navigators who are deaf or fluent in ASL would be an effective way to increase health literacy and improve deaf people's ability to navigate the health care system.**[10]**

A few resources currently exist consumers can use websites such as Deafhealth.org, which provides videos with voice & ASL for interpreting in health care settings, and **www.healthbridges.info**, which provides helpful insight into communication needs & rights pertaining to health care for people who are deaf or hard of hearing. The NAD strongly urges the Federal Department of Health and Human Services to make available grants targeting the development of such information channels to ensure accessible health information, outreach, and media programs for the Deaf Community, which are critical to reduce health disparities and ensure health equity.

The University of California, San Diego (UCSD) School of Medicine, found that deaf patients reported they were more likely to follow recommended health maintenance behaviors, visit their physicians regularly, and feel greater satisfaction with the clinical experience if the clinician signs or has some basic knowledge of the deaf community. This suggests that an effective way to address health care needs, is to provide training to medical students and residents in deaf cultural competency.

An effective and more immediately attainable strategy is to include Deaf Community Health Workers (CHWs) (NASMHPD, 2016) to facilitate deaf patients' care or discharge planning to increase their participation on making informed decisions about their health and to increase their health knowledge. This parallels the remarkable effectiveness of deaf peer support specialists in behavioral health described by Gournaris (2015).

In a handful of states, specialized services have evolved to serve deaf community members on a regional level (Gournaris, Hamerdinger & Williams, 2013). In other states, private practitioners and small hubs of linguistically and culturally accessible services have evolved. However nationally there is a dearth of providers who serve deaf persons (Nolan, 2015). As the behavioral health field moves toward a comprehensive and recovery oriented treatment model, deaf consumers who are often unemployed, underinsured, alone, and ill experience an even more striking level of inequity in service access. In some states, a team approach is beginning to evolve to address the comprehensive needs of deaf behavioral health consumers. Some of these teams are associated with academic facilities and some are not.

A potential tool for encouraging the development of such programs is using the provisions of Part 5 of Chapter 1 of Title 42 of the Code of Federal Regulations**[11]** to declare the Deaf Community a “medically Underserved Population.” This is used when "unusual local conditions which are a barrier to access to or the availability of personal health services" exist and are documented, and if such a designation is recommended by the chief executive officer and local officials of the State where the requested population resides (**http://www.hrsa.gov/shortage/mua/index.html**). Such designation applies to “those who have trouble accessing health care for any reason. They are people who have illnesses or disabilities that have extended their need for care beyond their coverage, or people who live in remote areas where health services are scarce.” (**Colorado Coalition for the Medically Underserved**)

This designation will allow for the use of regional resources in a more effective manner. Programs such as PAHrtners, for example, can then be considered a statewide solution, in this case in Pennsylvania. These programs bring together ASL – fluent clinicians and support specialists and are better able to address the linguistic and cultural needs of deaf people in both mental health and medical settings. Another example is the emerging work being done by Dr. Michael McKee in Ann Arbor, Michigan through the University of Michigan and the Dexter Health Center (McKee, 2016). The demonstration project has effectively become a regional program serving southeastern Michigan, incorporating the use of both in-person and/or telemedicine based visits to expand access to integrated health services for Deaf patients in need of ASL fluent providers.

The NAD has created several position statements, cited elsewhere in this paper, to address on the following: guidelines for the health care providers on caring for deaf patients in health care settings, including mental health providers and medical interpreters. The engagement of certified sign language interpreters and language concordant mental health providers in deaf health care are critical elements to ensure effective and accessible mental health care for deaf patients.

3. Increasing the Number of ASL-Fluent Clinicians across the Health Care Spectrum

Deaf people are underrepresented among counselors, psychologists, psychiatrists and primary care physicians. In the United States there are known to be only a handful of practicing deaf or hard of hearing psychiatrists and primary care physicians (McKee, 2013). Deaf and hard of hearing counselors and psychotherapists are scarce as well. There exists a large mismatch between the health care needs of deaf and hard of hearing individuals in our nation and the numbers of practitioners who are prepared to serve deaf consumers (Nolan et al, 2015).

A large majority of deaf or ASL fluent clinicians currently pursue a path of private practice or employment at schools for the deaf (Nolan, et al. 2015). Employment opportunities in the broader health care system are limited by perceptions of people running those systems. In many, if not most, non – deaf specific health care systems, a deaf clinician is viewed as a liability. Case by case litigation is slowly breaking down this barrier, (see **here**). The Association of Medical Professionals with Hearing Losses (AMPHL) exists specifically to address this widespread bias.

Deaf and hard of hearing clinicians are uniquely positioned to understand the unique challenges of fellow community members as it related to values, culture, language and life experience (Steinberg, 1991). Like other ethnic minorities, including Hispanics, Asian Americans, and Southeast Asians (Myers, 2012), there are a limited number of trained professionals to meet the unique needs of the deaf population. The NAD urges providers to welcome deaf clinicians in both academic and community settings. Strategies for increasing the number of deaf and hard of hearing health students and providers, are present in the **final report**.

It is important as well to recognize that there are significant attitudinal barriers for deaf, deaf-blind and hard of hearing applicants to medical schools and training programs. Despite the success of a number of deaf people who have completed medical training, there exists a general attitude that deaf people can’t meet requirements to perform “independently” (Butler, J. 2013).

There continue to be limited opportunities for mentorship and field placements for qualified students. (McKee et al., 2013). The NAD urges the health care provider community to identify, encourage and seek to support training programs and field placement sites that advance the training opportunities of deaf and hard of hearing clinicians.

Deaf or hard of hearing clinicians who successfully do complete their training often find it difficult to identify field placement sites. A few states such as Minnesota, South Carolina and Alabama have regionalized deaf behavioral health services (Gournaris, Hamerdinger & Williams 2013). Some university centers such as the Deaf Wellness Center/ University of Rochester and the University of Michigan/Department of Family Medicine have developed models of services to address the clinical needs of the local Deaf Community. These two programs have established themselves as a training ground for future professionals. Other centers of excellence must be promoted and well-advertised to field placement advisors.

Still another issue of concern is that it continues to be difficult for deaf, hard of hearing or deaf-blind clinicians to find full time employment. It is common practice in some regions of the country for deaf and hard of hearing clinicians to work at a variety of practice sites. For example, clinicians may work part time at the local School for the deaf as well as work as a clinician in a community mental health setting. Underemployment of deaf professionals and of ASL fluent clinicians continues to be an issue of concern.

A high degree of burn out exists among deaf, deaf-blind and hard of hearing behavioral health professionals. We must work to find ways to support them. A list-serve could be established to join professionals together. Behavioral health clinicians often report that such conferences as the ADARA (formerly the American Deafness and Rehabilitation Association) Conference are highly valued. Association of Medical Professionals with Hearing Loss (AMPHL) also provides networking opportunities. Both professional associations are seriously underfunded. The NAD strongly urges that Federal training funding be made available to support more frequent professional networking opportunities.

In order to increase the number of consumers served, some deaf private practitioners have established tele-therapy based caseloads in states that allow payment for these services. deaf consumers often welcome video based services because they are comfortable with this technology when this service delivery option is presented to them. Tele-therapy based services are ideal for many consumers particularly when geography and confidentiality are issues of clinical concern (Gournaris, 2009). Deaf clinicians must be supported to establish tele-therapy practices in states that encourage such service delivery. The NAD urges that national accrediting and licensing bodies examine ways to make it easier to establish such services by encouraging the development of regulations that allow professionals to practice across state lines.

New Partnerships that model the provision of mental health care which is provided at non-traditional community based sites is an important concept to cultivate in order to promote career opportunities for young deaf and hard of hearing professionals. Co-location of advocacy, employment services, medical and mental health and substance abuse services would serve to improve access to behavioral health services for deaf consumers and also would provide potential employment practice sites for young professionals.

Consumers with complicated needs are known to benefit from integration of services (Pollard, American Psychologist, 2014). The new concept of a medical home highlights the need for establishing a team of providers who share the values, culture and language of a specific population. Medical homes could provide a potential opportunity to promote the concept of a specialized deaf mental health care service site and further employment opportunities for qualified professionals. Medical homes could be fostered to develop around hubs of support in each state for deaf citizens in concert with interested academic partners. Funding strategies and billing codes must be modified to encourage such creative programming.

Currently few psychiatry or counseling programs provide training opportunities about mental health risk factors for deaf persons or about existing community supports. Hearing behavioral health care providers and payers must continue to be appraised of the unique behavioral health needs of deaf and hard of hearing persons and the value of specialized services for consumers. To this end specific strategies include increasing training requirements that address the needs of deaf and hard of hearing people by:

a. Making it a requirement to have a criteria (milestone) that is met as part of for the Liaison Committee on Medical Education (LCME) medical student cultural competence education graduation criteria and again as an American College for Graduate Medical Education (ACGME) Disabilities milestone- USF has a module each year on health care disparities among deaf patients,

b. Expanding basic health care disparities LCME module to include information on the national CLAS standards, and

c. Training deaf professionals in services and care coordination of PCMH and Health Home models

4. Recommendations and conclusion

It is the position of the NAD that all previous position papers on health care access apply in an integrated health care environment. The paramount concern here is the preservation of mental health services that are provided through direct communication, and to ensure that such a direct care system is implemented throughout the country. There is concern that as payment reform and practice transformation leads from fee for service payment to pay for value and outcomes, the disparity widens – actually widening the gap of services accessible for deaf as more services happen in less structured environments in the form of care coordination, health promotion, and peer support services.

The U.S. Department of Health and Human Services outlined a comprehensive guide to provide appropriate services for patients with health care disparities. This culminated in the National Culturally and Linguistically Appropriate Services (CLAS)**[12]** standards and its applications for impacting care to deaf/hard of hearing individuals is paramount.

The following things are recommended to move integrated health care closer to what is seen as best practices in deaf behavioral health care.

1. The U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) should encourage each state to declare the Deaf Community a Medically Underserved Population (MUP). Each state should appoint a State Coordinator for Behavioral Health that can effectively steer state health care policy (NAD 2013).

2. Deaf and ASL-Fluent professionals should be included as team members at all levels of Integrated Behavioral Health organizations (from peer support team members to being trained as mental health providers). The National Associations of State Mental Health Program Directors should encourage the state behavioral health authorities to integrate deaf support specialists and peer support specialists into Medical Homes to serve as advocates and navigators of the mental health system.

3. SAMHSA should encourage the reduction of barriers to cross-catchment area, cross network, and even cross-state use of professionals who are fluent in ASL. This includes increasing use of telehealth technologies to utilize existing medical and mental health professionals. (NAD 2008a).

4. Promote the use of specialized programs such as **PAHrtners**, **Deaf Community Advocacy Network**, and **Deaf Community Services of San Diego**. This will require changes to state and federal regulations which currently discourage out of state options.

5. States should establish minimum training requirements for interpreters in medical and behavioral health settings.**[13]** These rules should be established through either the state behavioral health authorities, the state commissions for deaf and hard of hearing persons or jointly if applicable.

6. Through the process of approving block grant and waiver applications, CMS should encourage the states to adopt policies which covering the provision of sign language interpreters and CART services as "medically necessary services," and allow for billing for interpreter and CART services.

7. Encourage the development of interpreter consortiums to increase availability of qualified medical and mental health interpreters.

8. Video Remote Interpreter should be used judiciously and should comply with training standards for specialized settings.**[14]**

Progress in the development of direct mental health services by ASL-fluent professionals over the last several decades has proven the effectiveness of such services. There exists now an expectation, even a demand that professionals providing theses will be linguistically and culturally competent. This progress must not be lost due to the shift to integrated health care, which potentially threatens those programs. Acting on the steps outlined above will mitigate that danger.

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[1] The use of “deaf and hard of hearing” is intended to represent the entirety of the community including those who are deaf, hard of hearing, DeafBlind, late-deafened, have other types of hearing losses, or have additional disabilities.

[2] NAD, 2003; 2008a; 2008b; 2012a; 2012b; 2013; 2014a; 2014b

[3] NAD, 2012b

[4] Tugg v. Towey, 1994, Bailey v. Sawyer, 1999, and Belton v. State of Georgia, 2013) (need full cites)

[5] https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedCLASStandardsBluepr...

[6] Title VI of Civil Rights Act of 1964, 42 U.S. Code § 2000d *et seq.*; Executive Order 13166; see: **http://www.lep.gov/13166/eo13166.html**

[7] Joint Commission, see: **https://www.jointcommission.org/assets/1/6/Crosswalk_CLAS_AHC_20141110.pdf**

[8] This paper primarily addresses deaf people who American Sign Language as their preferred mode of communication. The NAD recognizes that other deaf people benefit from other forms of accommodation, such as CART.

[9] The NAD generally does not capitalize “deaf” when referring to the entire community of deaf and hard of hearing individuals. However, when referring to those who identify as a cultural and linguistic minority, the phrase “Deaf Community” is used in this position statement to refer to this distinct segment of the population.

[10] NAD, 2003; 2008a; 2008b; 2012a; 2012b; 2013; 2014a; 2014b

[11] Under the provisions of Public law 99-280, enacted in 1986, a population group which does not meet the established criteria of an [MUP] can nevertheless be considered for designation if "unusual local conditions which are a barrier to access to or the availability of personal health services" exist and are documented, and if such a designation is recommended by the chief executive officer and local officials of the State where the requested population resides (**http://www.hrsa.gov/shortage/mua/index.html**).

[13] NAD 2012b

[14] NAD 2008c