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# E-therapy as a Means for Addressing Barriers to Substance Use Disorder Treatment for Persons who are Deaf

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*Persons who are deaf face a number of challenges with regard to vulnerability for substance use disorders. Moreover, accessible treatment for this condition can be difficult to establish and maintain. The Deaf community may be one of the most disenfranchised groups in America in regard to appropriate access to substance use disorder (SUD) prevention and treatment services. This article reviews findings related to substance use disorder and treatment for this condition among persons who are deaf. It also reviews a promising approach for addressing treatment needs via e-therapy, and it highlights the challenges and concerns regarding e-therapy for this population. E-therapy services demonstrate promise in reaching a larger and therefore more economically viable treatment population of deaf individuals while providing culturally appropriate and comprehensible recovery support options. Demographic and intermediate treatment outcome data are presented on a state-wide*

*program established to serve persons who are deaf in the mid-west.*

*Key words: deaf, substance use disorders, treatment, e-therapy, culturally appropriate*

Research since the 1980s has indicated that persons who are deaf face a number of challenges with regard to alcoholism and/or drug abuse (Boros, 1981). The concerns focus on two factors: the risks for substance use disorders (SUD) are appreciable (Guthmann & Moore, 2007), and access to traditional SUD treatment is very limited. The Deaf community may be one of the most disenfranchised groups in America in regard to appropriate access to SUD prevention and treatment services. This article outlines the substance abuse risks and previous efforts to address this need. It also reviews a promising approach for addressing these needs via e-therapy, and highlights the challenges and concerns regarding e-therapy for this population.

Based on estimates taken from the National Health Interview Survey, the United States has an estimated 500,000 persons who are deaf and nearly double that number who "at best, can hear & understand words shouted at the better ear" (Holt, Hotto, & Cole, 1994; NCHS, 1994). This source, although dated, is likely a better determinant of the percentage of the Deaf population, as more recent nationally representative surveys group "deaf" with "hearing impaired," thereby artificially inflating the probable percentage of persons who are deaf (Mitchell, 2004). Severely and profoundly deaf individuals require accommodations beyond hearing aids in order to access their communities and workplaces. The numbers above are rough estimates, as people who are deaf do not use telephones, which is the standard method for obtaining census-based data.

Establishing an estimate on the number of persons who are deaf and experience SUD also is tenuous. The most methodologically rigorous study to date utilized a regional survey of substance use by deaf individuals by means of an interactive ASL-based kiosk in New York City and the upstate New York area. The researchers concluded that alcohol and drug use in this population is similar to patterns reported for the general

population (Lipton & Goldstein, 1997). However, this survey was conducted in public places, such as libraries and deaf clubs. Some researchers contend that deaf individuals at greatest risk for SUD are those who are socially isolated and less connected with the Deaf or hearing communities, as well as being less fluent in ASL (Guthmann & Blozis, 2001). Therefore the actual percentage of deaf persons with SUD may be higher. This is reflected by the majority of articles on SUD among the Deaf, as it is generally assumed that SUD rates are higher than the general population.

A number of barriers exist when trying to provide substance abuse treatment services for deaf individuals (Heavyrunner, 1992; Guthmann, 1999; Titus, Schiller, & Guthmann, 2009). Concern about accessibility for the Deaf to SUD treatment programs have been repeatedly documented (Berman, 1990; Boros, 1980; Guthmann & Graham, 2004; Lane, 1985; Miller, 1990; Moore & Polsgrove, 1991). Contributing to problems linking with services, SUD treatment providers do not fully understand their responsibilities for serving the Deaf, or they encounter difficulty in paying for sign language interpreters. Researchers and advocates maintain that the majority of substance abuse treatment programs are not culturally or linguistically accessible (Ferreyra, Rousso, & deMiranda, 2002). Specifically, few programs have counselors who are deaf and/or fluent in ASL, or they do not use interpreters or technology to provide access (video phone, video relay, equipped with flashing alarms, etc.).

The specific barriers to SUD treatment for persons who are deaf include the following:

1. Deafness is a low incidence condition, and most SUD providers rarely receive referrals concerning deaf individuals. As such, they are generally unprepared to provide ready access to treatment. Historically, the array of treatment services available to hearing individuals has not been accessible for deaf people.
2. Deaf individuals, their families or professionals serving them may struggle for lengthy periods of time attempting to locate and access appropriate programming (Guthmann & Sandberg, 1998).
3. Specialized programming to meet the needs of deaf

individuals is costly due to the need for specially trained staff and/or interpreters, travel costs, and the depth and breadth of consumer needs. For example, aftercare and sobriety support needs are thought to be a greater need within the Deaf community (Waltzer, 1992).

4. Group therapy, the most common method for SUD treatment, is very difficult to comprehend for persons who are deaf, even when certified interpreters are present and the consumer is fluent in sign language. Concepts such as "sobriety" or "higher power" are largely absent from the Deaf lexicon (Guthmann & Sandberg, 1998), and language idioms do not translate (e.g., "Denial is not a river in Egypt" makes no sense for a culturally Deaf person). ASL is a separate and distinct language with its own set of rules and the syntax and grammar are totally different from spoken and written English. The average reading level of persons who are Deaf with a high school diploma is reported to be somewhere between 4th-6th grade (Holt, Traxler, & Allen, 1997).

5. Self-help and peer support are critically important elements of recovery, but this is largely missing for someone who is deaf.

6. Sign language interpreter skills vary widely, and few interpreters are trained in substance abuse and treatment terminologies. Paying for interpreter services can be a challenge in many cases, as this service is not budgeted by providers, although it is required by the Americans with Disabilities Acts (1990) and its amendments (2008).

7. Interpreters cannot always be on site, so the Deaf consumer misses many conversations and encounters. When interpreters are secured, they may not be hired to provide services for all treatment services available. For example, a treatment provider in Ohio arranged for group therapy interpreting in 90 minute blocks, although the group therapy was conducted for two hours. This was explained as a financial decision, as the hired agency required a second interpreter for any job beyond 90 minutes given the physical and mental intensity involved in ASL translation. After 20 minutes of bilingual translation, an interpreter's accuracy may be significantly reduced, and many agencies require two interpreters for any engagement beyond one hour and mandate that the two trade off duties every 20

minutes to insure accurate communication (NIH, 1996; SignOn, n.d.).

8. Persons who are deaf experience confidentiality problems associated with attending substance abuse treatment. The relatively small size of the Deaf community means that many others in that immediate community will be aware of the individual's SUD status. A lack of confidentiality contributes to the reluctance within the Deaf community to admit to an SUD problem or seek services (Boros, 1989).

9. Persons who are deaf feel the need to fit in and not "make waves." This can mean that persons who are deaf do not understand aspects of what is going on in therapy or in taking prescribed medications, but they will not ask for clarification (Guthmann & Blozis, 2001).

### Background on National SUD treatment for the Deaf

In 1998, the National Association for Alcohol, Drugs, and Disability, Inc. (NAADD) released *Access Limited—Substance Abuse Services for People with Disabilities: A National Perspective* (NAADD, 1998). This report detailed the needs of persons with disabilities regarding access to SUD treatment. Utilizing survey data from 30 California SUD treatment providers, NAADD reported that only 13% of the programs made sign language interpreters available to Deaf clients, no programs had visual emergency alarms for persons who are deaf, and only two programs maintained active TTY devices for communicating with the Deaf.

One of the longest standing programs to serve the SUD treatment needs of deaf individuals is the Minnesota Chemical Dependency Program for the Deaf and Hard of Hearing Individuals (MCDPDHII). The program was established as part of the Fairview Health Services–University Medical Center in Minneapolis in 1989 and has served as a model for 20 years. One characteristic of the program that speaks to the need is that in any given year up to 60% of program consumers come from somewhere outside Minnesota. MCDPDHII is a specialized program designed to meet the communication and cultural needs of deaf and hard of hearing persons in alcohol and drug abuse treatment. The program has treated

over 1200 deaf individuals over its history, and was one of the first programs established to provide specialized substance abuse treatment services to deaf individuals. All staff that work at the program are fluent in ASL, and many are themselves deaf. The program utilizes a self-help support, cognitive behavioral treatment approach that relies heavily on non-printed materials. This includes a strong focus on consumer-generated drawings and art that depict various aspects of addiction and recovery (Guthmann, Lybarger, & Sandberg, 1993). Since the creation of MCDPDHHI, the Americans with Disabilities Act (1990), the ADA amendments (2008), and the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 were all passed. Consequently, one might assume that SUD services for the Deaf would have become more prevalent in the U.S. during that time. However, the opposite appears to be the case. In 1991, the Substance Abuse Resources and Disability Issues (SARDI) program in the Wright State University School of Medicine compiled a list of all SUD treatment programs in the U.S. that were especially oriented to serving persons with disabilities. Among the list of 22 programs identified nationally, 12 were specialized in deafness (SARDI, 1992). In 2001 only two programs were still in existence, including the MCDPDHHI. In each case of program closure, attrition of specialized programs was attributed to the high unit cost of operation, low census, or inability to find staff with the appropriate training and/or credentials. Low census is especially relevant to programs specialized in deaf SUD treatment, even when the services are established as state-wide entities.

Some treatment programs have attempted to resolve the communication issue by using a sign language interpreter and integrating deaf consumers into the regular treatment process. Programs that provide interpreters for a portion of the treatment programming are considered to be "mainstreamed" programs, which mean that the consumers in the program are predominantly hearing. Staff are typically unable to communicate to the consumer without the use of a sign language interpreter. Although some individuals are successful in this environment, many deaf people do not fully benefit from the treatment experience. Often, the interpreter is provided only

for formal programming and the Deaf person is excluded from communication opportunities with other consumers during activities such as free time and meals. When “deaf” and “hard of hearing” are considered as one group, successful discharges from treatment are comparable to the general treatment population; however, additional research is needed that specifically investigates “deaf” populations (Moore & McAweeney, 2007).

### Current SUD Treatment Programs Specialized For Serving Individuals Who Are Deaf

In February, 2008 and again one year later, an informal survey was sent out via e-mail along with video phone and voice phone contact to a number of professionals who work within the Deaf community on a national basis. The purpose of this contact was to identify programs that serve SUD treatment needs of deaf individuals on an outpatient and inpatient basis, as well as provide other SUD related services. The survey focused on programs identifying themselves as providing specialized treatment to deaf individuals. Programs are considered specialized treatment when staff are able to communicate in ASL, materials are modified to meet the individual needs of the consumer, and program content is culturally sensitive to the needs of the Deaf population. The informal survey was conducted by Debra Guthmann, Ed.D., one of the founders and former Director of MCDPDHII. She has provided state-wide technical assistance throughout the country in SUD treatment specialized for persons with deafness or other disabilities. In addition, respondent agencies were asked if they were aware of any other programs specialized for SUD treatment of the Deaf that were not on the list.

The results of the informal survey indicate that on a national basis programs identified as providing specialized inpatient–residential treatment in 2008 were located in Minnesota, New York, Illinois, New Mexico, Washington, Florida, California, and Michigan. Again in 2009, the information was updated based on the results of the 2008 survey. Within one year, four of the inpatient–residential treatment programs for the Deaf had ceased operation. Survey results indicated that programs identified as providing outpatient, prevention, advocacy or



consultations were located in New York, Maryland, New Jersey, California, and Ohio. The results from 2009 indicate that from 2008-2009 one of these five outpatient programs ceased operations, leaving only four providers in these categories of service (Titus & Guthmann, in press). The results of these surveys are further evidence of the barriers and challenges for providing SUD services to this population.

### Deaf Off Drugs and Alcohol E-therapy Program

In 2007, the Substance Abuse Resources and Disability Issues (SARDI) program in the Wright State University's Boonshoft School of Medicine received a three year SAMHSA targeted capacity expansion grant in the e-therapy category to establish a state-wide program for addressing the SUD treatment needs of persons who are deaf. Established within the Consumer Advocacy Model (CAM), SARDI's substance abuse treatment agency, this e-therapy project is called *Deaf Off Drugs and Alcohol*, (DODA, a word play on "CODA," child of deaf adult). This Dayton, Ohio based program uses clinical approaches developed by MCDPDHHI. Individuals are served in the "least restrictive environment" throughout Ohio in a combination of locally-available treatment and ASL-based e-therapy. Community-based treatment is enhanced through electronic contact that supplements and strengthens the treatment episode, with an emphasis on supporting sobriety and learning about recovery maintenance. Group and individual counseling and support, and case management are offered via video conferencing and video phone technology. Consumer feedback and guidance from a project advisory board guide program content and service delivery. The design of services is provided with consumer input and based on the individual's treatment plan. All DODA clinical staff are fluent in ASL, as well as licensed in Ohio in substance abuse and/or mental health services provision. In the first 19 months of operation DODA provided services to 69 consumers. The DODA program is based on the premise that the unique needs of persons who are deaf are better served by extending services over a larger geographic area. Demographics from the intake questionnaires, approximate numbers of consumer services, and drugs

of choice are presented in Tables 1 and 2.

*Intermediate Outcomes.* A total of 36 of 38 DODA consumers eligible for the follow-up window have completed six-month follow-up interviews. This represents a follow up rate of 94.7%, an especially robust rate for follow-up based on previous projects within CAM. DODA staff attribute the high follow-up rate to the level of need in the Deaf community for professional support and case management, as well as the culturally sensitive and accessible nature of the DODA program staff. A total of 24 (66.7%) DODA consumers report no alcohol use, and 23 (63.9%) report no illicit drug use over the past 30 days.

Table 1. Selected DODA consumer demographics and services characteristics (first 19 months of operation, through 5/2009; N=69)

N or %	Descriptor	Comment
58%	Male	Recent referrals have included higher % of females
66.7%	Caucasian	26.1% African American
40.6%	35–44 yrs of age	Range: 18–68 years
1,250	Emails transmitted or received from consumers	Includes text messages
35	No show or cancellation	Lower no-show rate than CAM-based program for persons with other disabilities (10% vs 17%); transportation issues minimized with e-therapy
332	Individual counseling or case management sessions	All services intended as adjunct to primary, in-community treatment. Some consumers are pre-contemplation and pre-treatment engagement
168	case management contacts w/ providers and/or social services	Advocacy and problem solving are integral components of program
329	In person or video remote interpreting, or print transcription sessions	Numbers would be higher, but community providers often do not have PC or high speed internet available in treatment rooms; logistic issues take time even with freely loaned equipment from DODA

In contrast to the text-based TTY technology, teleconferencing services for ASL speakers provide a virtual person-to-person live experience. Expressed meaning in sign language is 85% gestures and facial expression, so visual contact between speakers provides more efficient communication than TTY or speaking through hearing interpreters. TTY is English-based, and therefore ASL speakers must translate their primary thoughts into English and type them in through an English alphabet keyboard, a further barrier to efficient and clear communication. For example, DODA counselors have found that resolving issues via teleconferencing takes roughly half the time necessary for similar issues addressed via TTY. In spite of this time savings, counseling and case management services generally take more than twice as long to accomplish as compared to CAM consumers from the hearing population. Staff also note that consumers will make multiple video calls to the office or attempt to engage the staff longer in conversation because of limited communication with people at home and the need to reduce feelings of isolation.

Table 2. Drugs reported as used by DODA consumers at intake interview

Drug	Frequency	% Used
Any alcohol	34	49.3
Marijuana/hashish	21	30.4
Cocaine/crack	13	18.8
Bezodiazepines: Diazepam (Valium), Alprazolam (Xanax); Triazolam (Halcion); and Estazolam (Prosom and Rohypnol, aka roofies, roche, and cope)	3	4.3
Heroin (smack, H, junk, skag)	1	1.4
Percocet	1	1.4
Darvon	1	1.4
Tylenol 2, 3, 4	1	1.4
Oxycontin/Oxycodone	1	1.4
Non-prescription methadone	1	1.4
Methamphetamine or other amphetamines (meth, uppers, speed, ice, chalk, crystal, glass, fire, crank)	1	1.4

Number of intakes used in calculation of the report=69.

Number of intakes is used as the denominator for this report..

Because a number of deaf individuals who were referred to DODA have been unable to successfully engage with local SUD treatment, as the host clinical agency for DODA, CAM will soon offer primary outpatient services in an e-therapy model as a treatment option. Group and individual sessions will be based on electronic communications supported by Nefsis® web and video conferencing software from WiredRed Corporation.

Persons receiving full outpatient services through CAM must be Medicaid eligible and have access to computers that are equipped with cameras and high speed internet access. CAM was primarily designed to serve persons with any co-existing disabilities from its beginning, and as such it is a somewhat unusual model that includes concepts of “less intensity—longer duration” and an emphasis on strong case management support (Heinemann, Corrigan, & Moore, 2004; Moore & Lorber, 2004). CAM was originally based on the “TBI Network” case management model developed by John Corrigan at Ohio State University in Columbus, Ohio (Corrigan, 1995).

DODA has established Deaf, ASL-based 12-step meetings through video conferencing. This technology allows up to ten locations to be online at the same time. The individuals can see each other and are able to interact in real time. This is a critical component of Deaf recovery, as it is culturally specific, non-threatening, and is based on peer assisted recovery principles. Since July, 2008, DODA has recruited individuals with long term sobriety willing to facilitate 12-step meetings. Individuals who are deaf and in recovery serve as sponsors and coordinators for these meetings after they receive a 90-minute technical training. The software is highly intuitive, and there have been few problems that have occurred to date over the nearly 150 meetings. Average attendance per meeting is six, but some meetings have been at full capacity of ten participants. There is a group and/or 12-step video meeting every day of the week, and staff are establishing specialized groups like the women’s group. Because the meetings are not governed by Ohio state laws regarding professional competency, persons in other states also may participate. A total of 17 states have been represented in e-mails or video phone calls regarding DODA to date.

DODA counselors note that the benefits of deaf-specific treatment extend beyond the simple receipt of services for deaf and hard of hearing consumers to a sense of community and interconnectedness. Many DODA consumers are isolated from the hearing community by their reliance on ASL, and the addition of substance use disorder adds to this sense of singularity. Meeting with other non-hearing consumers in the 12-step setting teaches them that others experience similar issues and barriers. Further, these consumers can support one another, share experiences, and air grievances to people who truly understand their perspective. For many, this is a new and liberating experience.

By using certified substance abuse counselors and case managers, the DODA program allows consumers and counselors to develop a stronger relationship than is possible in other situations that require an interpreter. When an ASL interpreter is used between a non-signing counselor and a deaf consumer, some of the attention necessarily focuses on the interpreter. Using ASL in direct communication fosters a more personal connection between the counselor and consumer, which seems to provide greater engagement in treatment and a richer therapeutic experience.

### Addressing Barriers and Challenges to E-therapy

There are several reports of success using e-therapy models in SUD treatment (King, et al., 2009), including use of e-therapy for addressing the SUD treatment needs of the Deaf (Wilson & Wells, 2009). However, there continue to be several challenges in provision of this type of service (Castelnuovo, Gaggioli, Mantovani, & Riva, 2003), including certifications, jurisdiction, client protection, obtaining informed consent, confidentiality, duty to protect, and maintaining appropriate boundaries (Kanani & Regehr, 2003). Below, we describe ways that DODA has addressed each of these issues.

*Certifications and Jurisdiction*—A waiver was obtained from the Ohio Department of Alcoholism and Drug Addiction Services (ODADAS) so that e-therapy utilizing live picture technology constitutes the same level of service as “in person” services. The Ohio Department of Mental Health also

established a similar policy in regard to services for the Deaf.

*Client Protection*—A “lethality-criticality” assessment is built into the initial assessment so that persons at risk for harm to themselves or others are seen immediately in person. If a local treatment provider cannot meet this need, DODA staff travel to the site and meet with the individual. One recent case of a deaf individual showing up in an emergency room requesting detoxification services was addressed via 4 hours of text messaging with the person and a DODA counselor. The person was then admitted in the same day to a local detoxification program.

*Obtaining Informed Consent*—When time permits, potential DODA consumers are overnight mailed an informed consent with a self-addressed and stamped return envelope. In the next video phone or Nefsis® session, the consumer is informed about the content of the informed consent, any questions are answered, and the consumer signs the informed consent while on line. The paper form is then mailed back to DODA. Future variances with ODADAS may address creation of a video file showing the consumer covering the informed consent and signing it. In unusual cases, DODA clinical staff drive to meet the potential consumer and obtain informed consent in person. This situation is reserved for special circumstances due to the amount of time involved with the process.

*Confidentiality*—All counselor and case manager space in the DODA office is partitioned so that others cannot see the sign language interaction with consumers. Although a consumer has the choice to interact with DODA staff from home (thereby potentially informing other family members of the conversation), the default policy is for the consumer to access equipment where both parties are assured of privacy. Deaf consumers are assured that they may choose or not choose their interpreters based on local situations or other involvement the interpreter may have with them or other family members. Rules for involvement in electronic 12-step meetings are reviewed at each session, and this includes not sharing personal information with other group attendees.

*Duty to Protect*—As in the normal treatment setting, consumers are made aware that DODA staff have a legal responsibility to protect the health and well-being of the consumer as

well as others who may have contact with the consumer. Since the majority of consumers enrolled in the DODA program to date have the dual disorder of mental illness issues, local mental health providers for the Deaf also are enlisted and included in the treatment plan. This is particularly important for emergency plans, which include identifying and linking with local providers who can intervene in crisis situations, especially for consumers who are geographically inaccessible to DODA staff. On a related topic, all video content of the DODA website involves actors or treatment professionals, not consumers enrolled in the program.

*Maintaining Appropriate Boundaries*—As in other areas involving services to the Deaf community, there can be boundary issues when addressing consumer needs. For this reason, consumers are continually educated about the appropriate roles for staff and consumers, as well as the roles for interpreters. It is not unusual for a deaf individual to turn to interpreters for clinical guidance, and this practice is discouraged by all DODA staff. Contract interpreters associated with DODA are trained in professional ethics and the specific applications that apply to SUD treatment, and receive advanced training in SUD-related terminology.

### Program Sustainability

One challenge for the DODA program to date has been a policy of the federal funding source. The Center for Substance Abuse Treatment (CSAT/SAMHSA) maintains a “cost band” policy, where their targeted capacity expansion projects must serve a minimum number of persons per year in order to fall within program compliance. “Under-performing” programs that serve less than this number are in jeopardy of receiving reduced funding in continuing years of the grant, or in being de-funded altogether. The DODA program was identified as under-performing by not serving 80 persons per year, and the program was informed that the third of three years of funding would be reduced, or the program would be de-funded altogether, unless this target could be reached. This was in spite of the program serving more individuals than proposed and approved in the original grant application

(25-50-75 individuals per year, respectively). Historically, the authors are aware of no program serving the Deaf in the U.S. that has been able to identify, recruit, and serve 80 persons per year, regardless of the geographic catchment area. In order to comply with this CSAT policy, the DODA program has had to divert staff resources into recruiting and serving additional hard of hearing individuals for what amounts to a different type of program service.

The other challenge imposed by the federal funding is that it is only a three year grant, rather than the usual five for a targeted capacity expansion project. It is very difficult to establish infrastructure, recruitment channels, sustainable funding, specialized treatment protocols, and obtain needed waivers and variances for e-therapy within such a short time. However, strong support for the program has been provided by the Ohio Department of Alcohol and Drug Addictions Services (ODADAS), and plans are on-going to establish funding mechanisms for this statewide project following the end of the funding cycle. In a recent 20<sup>th</sup> anniversary event, ODADAS recognized DODA as being one of the "Top 10" programs to ever serve Ohioans with SUD (OACBHA, 2009).

Additional grant funding is being investigated, along with the possibility of providing direct service that would qualify for Medicaid billing. Expanding the geographic scope of service would provide more consumers, but drug counselor certifications are state-specific, meaning that the Ohio-based DODA program cannot provide services outside the state. Further, the logistical limitations of statewide services above would be magnified for a national service. In the case of direct service, the difficulties of regular urinalysis via distance is one issue that has been suggested as a difficulty representative of others of a similar nature.

The challenges to providing appropriate and accessible SUD treatment for the Deaf are appreciable, but utilizing models that incorporate e-therapy may have promise for at least partially addressing the need. Future efforts in this area will need to investigate creative methods for underwriting the high costs for interpreters, as well as addressing capacity-building activities so that SUD counselors, case managers, and interpreters are better prepared to meet the unique needs of this population.



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