

Addressing the Black Hole in Substance Abuse Treatment for Deaf and Hard of Hearing Individuals: Technology to the Rescue

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Abstract

Progress in providing appropriate substance abuse treatment for Deaf and hard of hearing individuals has been slow over the past 30 years. Moving forward in a meaningful way will require investing in technology as a way to deliver specialized treatment, provide recovery support, improve access to professional training, and develop appropriate assessments. Current efforts to advance the field of substance abuse treatment for Deaf and hard of hearing individuals through technology are described.

Keywords: substance abuse treatment, behavioral telehealth, technology

Nearly 30 years ago, the issue of substance abuse within the Deaf and hard of hearing community and the need for appropriate treatment surfaced in the literature. Although there were no epidemiological studies to provide evidence, it was becoming clear to some providers that Deaf and hard of hearing individuals struggled with alcoholism and drug addiction just as their hearing peers. At that time few culturally appropriate resources existed, including providers, programs, materials, and publications. Recognition of the issue resulted in a monograph published by ADARA summarizing the proceedings of the first national conference of mental health, substance abuse, and deafness held in 1981 (Watson, Steitler, Peterson, & Fulton, 1983).

The Past Thirty Years

What has happened in the past 30 years? Despite the initial interest, the past 30 years have witnessed very little progress in addressing substance abuse and treatment for Deaf and hard of hearing people. Current recommendations for reducing barriers to access and improving the state of substance abuse treatment are nearly identical to those written decades ago (Boros, 1981; Guthmann, 1998; McCrone, 1982). Indeed, there remains a serious vacuum in the space where appropriate treatment options should

exist for Deaf and hard of hearing people. Although a handful of advances have been made over 30 years, they do not adequately address the scope of the need.

What advances *have* been made? The past 30 years have brought about improvements in access to services for people with disabilities. During this time we have seen the passage of the Americans with Disabilities Act, the Individuals with Disabilities Educational Act, and other legislation that has made positive contributions to the lives of all people with disabilities, including those who are Deaf and hard of hearing.

Prior to the opening of some specialized treatment programs, the only option for Deaf and hard of hearing individuals was to attend treatment with limited (if any) interpreter access. When provided interpreters, some Deaf and hard of hearing individuals are able to participate in mainstream treatment programs. However, the provision of an interpreter alone does not address the needs of all. In the case of residential treatment - if an interpreter is provided - he/she is typically only available for a portion of formal programming; thus the Deaf client misses out on communication with other patients during the day or evening, such as during free time or meals. Such interactions are a key part of the treatment process. In many regions there is a shortage of available and qualified interpreters, so appropriate communication services may not be provided to the client at all. Although access to interpreters is a step in the right direction, it does not close the gap in access for everyone.

Many Deaf and hard of hearing individuals - especially the segment of the population who relies primarily on American Sign Language (ASL) - do not experience effective treatment in programs that are designed for hearing people. Therapists are not typically trained in Deaf culture and do not understand the unique issues that are faced by this population. Fellow hearing clients who do not experience the day-to-day challenges of living as a Deaf person in a hearing world cannot fathom the range of communication difficulties - at home, among peers, at school, at work, and in the world at large. In short, unless they have Deaf friends or family or some kind of professional training in deafness, they don't "get it" - and can't - through no error of their own.

The last 30 years have seen the advent of a handful of specialized treatment programs for Deaf people. These programs employ Deaf and hearing

clinicians and other staff members who are fluent in ASL and sensitive to Deaf culture. Although very few programs have been developed, they have provided Deaf-centric treatment along the continuum of care for a small subset of Deaf substance abusers who are lucky enough to have access to them. One such program is the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals (MCDPDHHI). This specialized program, one of the first of its kind, is designed to meet the communication and cultural needs of Deaf and hard of hearing individuals in alcohol and drug abuse treatment. The MCDPDHHI opened in 1989 and since that time has treated over 1200 Deaf individuals. All program staff are Deaf or hearing and fluent in ASL. The program serves clients on a national basis and is part of the Fairview-University Medical Center in Minneapolis. Programs such as the MCDPDHHI allow Deaf substance abusers access to Deaf role models as well as counselors or psychologists who are either Deaf or hearing and fluent in sign language. They also allow Deaf people to be placed with other Deaf or hard of hearing clients who share common experiences and can identify with each other. Providing treatment in a specialized setting can eliminate some of the enabling which occurs from professionals who are not experienced in working with this population (Guthmann & Graham, 2004).

Troubling Trend

Although few, advances in the past 30 years have been moving – albeit slowly – in the right direction. However, the past two years have witnessed a disconcerting trend in specialized program options. Rather than increasing, the number of programs appears to be decreasing.

In February 2008, and again in February 2009, an informal survey (Guthmann, 2009) was undertaken among national-level professionals who work within the Deaf community to identify programs providing specialized substance abuse treatment to Deaf individuals. Identified programs included both residential/inpatient and outpatient. Of the nine specialized residential programs identified in 2008, only five remained one year later. Of the four programs that closed or no longer provide substance abuse treatment for Deaf and hard of hearing individuals, three provided adolescent programming, thus leaving an even larger gap in service for this population. Reasons for closure for both adolescent and adult programs include loss of funding, lack of specialized staff, and in one case, low census. A similar trend is noted for specialized outpatient programs. Of the seven programs cited in 2008, six

remained in 2009; loss of funding was behind the closure. It appears we are losing what ground we had.

Unfortunately, this trend makes all too much sense. Providing specialized treatment is expensive, more so than treatment designed for a hearing population. Staff training is also highly specialized and very few training opportunities exist to increase the workforce in this area. Deaf and hard of hearing people compose a low incidence population. In less populated areas there are very few, so it is difficult to aggregate a “critical mass” necessary to justify a program. Although the needs are very real, addressing them appropriately is expensive.

Technology to the Rescue

Depending solely on local treatment options is clearly not working. Addressing the black hole will require investing in technology as a way to deliver specialized treatment and address deficiencies in training and treatment resources.

During the past decade, the Internet has become a treatment platform for a range of mental health and substance abuse disorders (Day & Schneider, 2002; Griffiths, 2005; King et al., 2009; Pull, 2006). Although randomized trials of distance technology delivery of treatment are scarce, existing research indicates therapy via the Internet or videoconferencing (“behavioral telehealth”, “telemental health”, “telepsychiatry”, or “e-therapy”) has equivalent outcomes to therapy delivered via traditional face-to-face interactions (Day & Schneider, 2002; King et al., 2009; O’Reilly, Bishop, Maddox, Hutchinson, Fisman, & Takhar, 2007). In one of the few trials in substance abuse treatment, King et al. (2009) found that partial responders to methadone maintenance treatment randomly assigned to group counseling via videoconferencing showed equivalent treatment response and satisfaction with treatment as those assigned to on-site group counseling. Those in the videoconferencing group expressed a preference for Internet-delivered therapy, citing increased convenience and confidentiality (in this case, group participants did not see each other).

Behavioral telehealth is an ideal platform for the delivery of substance abuse services for Deaf and hard of hearing clients (Wilson & Wells, 2009). Current technology could easily and inexpensively connect the relatively few specialized treatment staff with Deaf and hard of hearing clients at any

number of locations throughout a community, state, or even the country. Services along the entire continuum of care, from intake to aftercare, could be delivered efficiently in group or individual counseling formats. Important issues to address prior to implementation of behavioral telehealth substance abuse treatment include privacy and confidentiality, interstate treatment and licensure, and response to crisis or emergency situations (see Barnett & Scheetz, 2003).

Ongoing recovery support is vital for maintaining a clean and sober lifestyle. Deaf and hard of hearing individuals returning to their home communities post-treatment have historically been at a great disadvantage due to the lack of accessible Twelve Step meetings. This is in contrast to a wide range of services and programs that are accessible to hearing individuals. A current project is making use of technology to fill this gap. The “Deaf Off Drugs and Alcohol” (DODA) program at Wright State University is part of a project focusing on e-therapy and funded by the Center for Substance Abuse Treatment (CSAT). One of the program components includes the provision of web-based Twelve Step meetings run by Deaf facilitators who are in recovery. The web conferencing platform is provided by WiredRed, a California company, and is used for a variety of purposes connected with the DODA program. The licensing agreement permits up to 10 Twelve Step group participants across the U.S. on a first-come, first-served basis. Group participants access the meeting by clicking on a web link invitation sent to interested parties. All participants can see each other in individual boxes on the computer screen, and images are large enough to communicate easily. Currently the program supports three weekly Twelve Step meetings; as more facilitators are recruited and trained, more meeting opportunities will be placed online.

For a modest yearly charge, programs are equipped to provide 24 hour access, use of the WiredRed servers, technical support, and eligibility for any system upgrades without additional charges. The company offers discounts to non-profit organizations and for longer-term contracts. Required equipment for participants includes a computer with a Windows platform, a high-speed internet connection, and a webcam. The web conferencing software is also used for case management and support of Deaf and hard of hearing individuals involved in the DODA program. For instance, DODA currently offers two group counseling sessions per week using the same technology. Topics include relapse prevention and recovery support. Group counseling is currently limited to Ohio residents, but potential expansions

are being investigated on a state-by-state basis as allowable by licensing standards.

Technology has begun to impact the development of substance abuse and mental health assessments for Deaf and hard of hearing individuals. The Drug and Alcohol Assessment for the Deaf (DAAD; Alexander, DiNitto, & Tidblom, 2005) is a 10 item screening tool delivered in ASL. The computer CD is available from the Gulf Coast Addiction Technology Transfer Center (GulfCoast@austin.utexas.edu) and comes with start-up information, an FAQ about the DAAD, answer sheets, and information on the psychometrics of the DAAD. A second screening tool is currently under development and being piloted nationally. The Substance Abuse Screener in ASL (SAS-ASL; Guthmann & Moore, 2007) is an adapted version of the Substance Abuse Subtle Screening Inventory (version 6) (SASSI; Miller & Lazowski, 1999), a widely used substance abuse screening tool. The computer-based interactive assessment is being developed under the Rehabilitation Research and Training Center (RRTC) on Substance Abuse, Disability and Employment at Wright State University in cooperation with the SASSI Institute and the Rehabilitation Institute of Chicago. The National Institute on Disability and Rehabilitation Research (NIDRR) is providing support for the project. Analyses of the adapted instrument are ongoing and a large validation study with 200 participants has been completed. Other than these two screening assessments, no other substance abuse assessments – intake or monitoring – have been adapted to ASL.

The current pool of substance abuse treatment professionals who are Deaf or hearing, fluent in ASL, and knowledgeable about Deaf culture is small. In order to provide a larger workforce, more post secondary training options are needed. In addition, over the past decade, there has been a boom in the development of treatment interventions in the hearing community, especially in adolescent treatment. Many of these methods were developed using government or private foundation dollars and are supported by an evidence base. Professional training opportunities in the hearing world abound. However, these resources are not yet accessible to Deaf counselors or clients. Evidence-based treatments have yet to be adapted for Deaf substance abusers, and there are no trainings available in sign. Technology could also play a role in post secondary training opportunities, including the adaptation and dissemination of training materials. Once developed, trainings could be delivered via real-time Webinars, with materials readily available on the Internet.

The Next 30 Years

Thirty years from now, we don't want to be making the same recycled arguments for appropriate substance abuse treatment for Deaf and hard of hearing people. What can we do to encourage forward mobility?

One of the foundational tasks that needs to be done is to document the problem in a scientifically valid way. It is very difficult to secure funding for specialized treatment when you cannot prove – in numbers – that there is a problem. Several attempts have been made to gather epidemiological data on the rates of substance abuse in the Deaf and hard of hearing population (see Lipton & Goldstein, 1997). One of the major stumbling blocks in this pursuit is the lack of a centralized database of Deaf and hard of hearing individuals from which to sample. The only estimates of substance abuse among Deaf and hard of hearing people in the United States are based on deduction or small convenience samples in geographically limited areas (Issacs, Buckley, & Martin, 1979; Lipton & Goldstein, 1997; McCrone, 1994). It may not be possible to employ the most rigorous standards to sample the Deaf and hard of hearing population, but the lack of a sampling base should not dissuade a more wide-ranging effort. What would be essential is the support of the network of Deaf and hard of hearing communities across the United States who recognize the fundamental importance in collecting information of this nature and desire to partner with research professionals.

For people who are Deaf or hard of hearing, the principles of addiction are the same as they are for hearing people, yet these individuals are currently unable to fully access the resources available to the hearing world. Just as advances in technology have dramatically opened up the array of possibilities for everyday communication for the Deaf and hard of hearing, technology also has the potential to dramatically improve the state of affairs for access to appropriate treatment, ongoing support, workforce development, and assessment. Reigning in the black hole is within reach.

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