
DISPARITIES IN MENTAL HEALTH SERVICES FOR PERSONS WHO ARE DEAF: ADVANCING RESEARCH TOWARDS ACTION

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Abstract

Disparities in access and quality of mental health services for persons who are Deaf are a significant public health problem. For the purposes of this article, persons who are Deaf are defined as those who are unable to hear spoken language and who use American Sign Language as their native language. We review the evidence documenting unmet mental health need for this population and review the literature in this area. The primary objective of this article is to apply an existing model of disparities research in delineating current knowledge with respect to mental health services for Deaf persons. We then propose a framework for evaluating and acting on the obstacles that impede quality improvement in this area. We conclude by framing an intervention research agenda for reducing disparities in mental health care for Deaf persons, focusing on the patient and the clinic/systems perspective.

Keywords: mental health services, deaf, disparities research

Introduction

Improving access to and quality of health care for vulnerable populations is a challenging issue that requires serious examination of the shortcomings and successes of current treatment systems. Much literature supports the belief that persons who are culturally Deaf routinely face many serious obstacles to obtaining mental health services (Iezzoni, O'Day, Killeen, & Harker, 2004). These barriers to appropriate mental health care can compound the isolating effect of having an auditory disability, being in a linguistic minority, and of having few persons with whom one can communicate. These problems with realized access to mental health services can lead to suboptimal functioning, increased substance abuse, and mortality from suicide and from non-suicide related causes (Pollard, 1994; World Health Organization [WHO], 1999). The primary objective of this article is to apply

an existing model of disparities research in delineating current knowledge with respect to mental health services for Deaf persons.

Deaf Population and Vulnerability

Hearing loss is the sixth most common condition in the non-institutionalized U.S. population, with a prevalence rate of 9.4 percent (Collins, 1997). About one-fifth of persons with hearing loss have a disability of sufficient severity that they cannot hear spoken language even with amplification (Ries, 1994). These groups of people who are severely or profoundly deaf are a heterogeneous group. They may have been born deaf or they may have developed hearing loss at any time in their life. They may be the only person in their family who is deaf. They may have learned American Sign Language (ASL) to communicate as their primary language. The group of people who use ASL to communicate and who have hearing loss that is generally in the severe to profound range may define themselves as culturally Deaf. When we use the term culturally deaf to describe a person, the "D" is capitalized. Persons who are culturally Deaf constitute about 0.2 percent of the population (<http://gri.gallaudet.edu/Demographics>). In this article, we focus on the group of individuals who are culturally Deaf. Culturally Deaf individuals represent a minority group who may experience many unique barriers to mental health care access. This group typically uses a visual language to communicate, obtain health care information typically from unique sources, have a distinct social support network and a group of trusted informants, have lower English literacy skills as a group, and possess health care beliefs that are unique from hearing people (Pollard, 1994).

Mental Disorders in the Deaf Population

Evidence suggests that the prevalence of mental health problems is at least equal within the culturally Deaf population as compared to the hearing population (McEntee, 1993). However, people who are culturally Deaf obtain mental health services at rates that are one-fifth the rate of hearing persons, according to work done by Pollard (Pollard, 1995). Thus, limited access to mental health services is a serious mental health problem for persons who are Deaf.

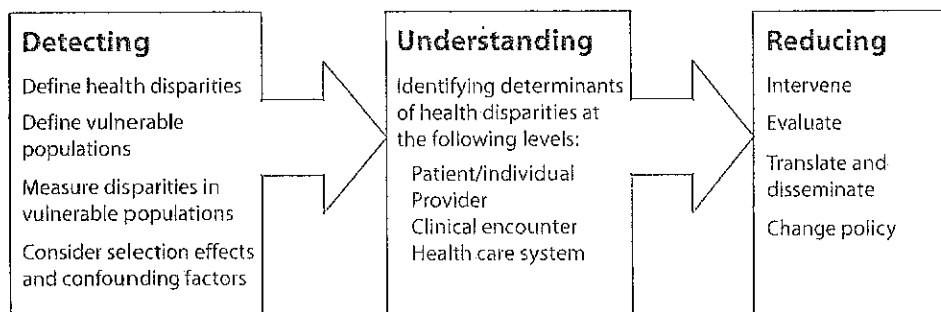
We present in the following sections the context and importance of studying the existing mental health service environment that exists for persons

who are culturally Deaf. We begin by describing a conceptual framework for evaluating and reducing health disparities. In applying this framework to mental health services for persons who are Deaf, we delineate some of the factors that perpetuate these disparities. Finally, we frame an evolving research agenda in which we aim to analyze, understand and intervene on disparities at several levels.

Conceptual Framework

Targeting and intervening in areas of suboptimal health system performance often requires a staged approach, especially with little information on the extent to which disparities exist and the reasons for disparities. Efforts to solve problems with access and quality of mental health care for persons who are Deaf can be informed by the conceptual framework of disparities research delineated by Kilbourne and colleagues (Kilbourne et al., 2004; Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006).

Figure 1. The three phases of the disparities research agenda.



From Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006.

Figure 1 describes the phases of the disparities research agenda. The model strongly emphasizes the importance of identifying barriers at multiple levels. These levels include provider and system-level as well as patient-level barriers. We include a figure from Kilbourne et al (2006). We will describe potential disparities and barriers as they affect persons who are Deaf (Kilbourne et al., 2006). The model explicitly recognizes that designing, testing and implementing improved service models requires a series of progressive steps, beginning with research on the underlying structural problems as a prerequisite to meaningful action. Thus, activities progress from a focus on detecting problems to understanding their determinants and

subsequently, to reducing disparities through intervention, evaluation and dissemination.

Observed Disparities in Mental Health for People who are Deaf

There are limited population-based data on access to and quality of mental health care received by Deaf persons. Nonetheless, the limited evidence suggests that while Deaf persons experience many life stressors and may in fact be more inclined to experience mental health problems, they are far less inclined to receive mental health treatment than comparable hearing populations (McEntee, 1993; Pollard, 1995). Notably, in a medical record review of Deaf patients, only 12% of Deaf persons in need of treatment received mental health services (Pollard, 1995). Hence, the available evidence suggests the need to understand more completely barriers to mental health care for this population.

Understanding Disparities: Unique Factors Experienced by the Deaf Community

Persons who are Deaf have reported numerous issues that could potentially explain disparities in identification and treatment of mental disorders. These include factors that are common across many vulnerable populations, such as low income and strained social resources. Critchfield describes additional barriers that exist at the patient level: many Deaf people are underemployed and uninsured, which presents a distinct barrier to service access (Critchfield, 2002). There are also unique factors that might explain disparities in mental health care and outcomes for persons who are Deaf, including community, patient, clinical encounter, and provider factors (e.g., communication).

Community Factors

For community factors, it is important to realize that most hearing health professionals who do not regularly treat Deaf individuals are unfamiliar with the network of people with whom the culturally Deaf person may regularly interface and with whom they may seek advice. Deaf persons often value the opinions of professionals who have taken time to learn their language, like career counselors for Deaf people, pastors who have church services for the Deaf community or respected Deaf persons in positions of authority. Nonetheless, there is little opportunity for these trusted people to get accurate

information about what constitutes a mental health problem and what treatment options exist for that condition (Munro-Ludders, Simpatico, & Zvetina, 2004; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006; Steinberg, Sullivan, & Loew, 1998).

Clinical Encounter

Clinical encounter factors, such as differences in language and meaning attributed to psychiatric symptoms, as well as the stigma of mental illness, might potentially explain disparities in care. According to Steinberg and colleagues, there is evidence to support that individuals who are Deaf use different labels to describe their symptoms that do not equate with English terminology (Steinberg, 1991; Steinberg et al., 1998). There also is a fear that exists in the Deaf community at large that hearing mental health professionals lack fundamental knowledge of Deaf culture, existing social support networks within that culture and the true implications of linguistic differences on family relationships, employment status and capacity to access mental health care (DeVinney & Murphy, 2002). Stigma surrounding mental health conditions, which might be based in anecdotal cases of long-term institutionalization and therapeutic misadventures, have fostered a rampant distrust of the mental health system among many Deaf people (Steinberg et al., 2006).

Provider Communication

Researchers in the field have also described barriers to care that exist at the provider level. Some problems related to access are very basic, but dishearteningly widespread. Deaf persons cannot use traditional telephones, so they may use a specialized phone called a TTY or a video phone in order to call for help or to schedule an appointment. A TTY is a special device that allows people who are deaf or speech impaired to use a telephone line to communicate by allowing them to type a message back and forth instead of talking and listening (Steinberg, 2003). Videophone calls, on the other hand, are placed over a high-speed Internet connection through an appliance connected to a television or through a personal computer equipped with a web camera and specific software. Using video relay services (VRS), the Deaf viewer accesses an ASL interpreter. The ASL interpreter appears on their television screen and the Deaf caller signs to the interpreter who then contacts the hearing user via a standard phone line. Unfortunately, in many

instances, intake personnel in medical settings do not have a dedicated TTY line or do not know how to accept a relay call, so often the phone call is prematurely terminated (Iezzoni et al., 2004).

Lack of effective communication during a patient visit may also be a crucial factor explaining disparities in care for Deaf persons. Focus groups conducted by Steinberg and colleagues (Steinberg et al., 2006) revealed that Deaf persons often described feeling quite constrained in asserting one's communication or language preferences and they often lack knowledge of their legal rights. Nonetheless, they did describe their experiences to be more satisfactory when accommodations were made, and were more inclined to return to the facility where they had a good experience.

Moreover, ASL interpreters may not be available at clinics, especially in more rural areas (Iezzoni et al., 2004). Even when they are available, many Deaf communities across the country welcome interpreters who may regularly socialize with Deaf individuals. Hence, many Deaf individuals might not feel comfortable that confidentiality will be ensured when they seek mental health treatment if they require an interpreter in order to access services. Deaf people frequently express a strong preference to seek out providers who are themselves Deaf or who are fluent in ASL, to be sure that there is not miscommunication or breach of confidentiality (Steinberg, 1991). However, providers who are themselves Deaf or who are fluent in ASL are a rare commodity across the country (Gallaudet University, 2003; Steinberg, 1991). Many states only have a handful of mental health providers who are fluent in ASL, and listed in the "Mental Health Services for Deaf People: A Resource Directory" published by Gallaudet University (Gallaudet University, 2003).

Health System Barriers

Health system barriers include lack of understanding regarding the rights of Deaf persons to interpreter services, and availability of health services in general. Even when an appointment can be made despite communication and access barriers, issues related to the interpreter may arise. Providers often do not understand that it is their responsibility to hire and to pay for the interpreter (McEntee, 1993). Hence, providers frequently do not use an interpreter to communicate with a Deaf client even when the client requests one. Providers are often unfamiliar with the Americans with Disabilities Act

that requires this accommodation for Deaf persons who express a preference to have an interpreter (McEntee, 1993). Cost is often cited as a barrier to hiring an interpreter, especially for intermediate or long-term mental health services. Many providers also report that they do not have familiarity with how to access an interpreter in their community (Steinberg et al., 2006). Persons who are Deaf and who use ASL generally express a strong preference to have an interpreter over using a pen and paper to communicate. This preference is important in a mental health setting when a history based on clear timelines and accurate reporting of symptom expression is crucial for diagnostic purposes, for gauging patient preferences in treatment, and for exchange of information about therapy options or medication trials (Steinberg et al., 2006).

As with hearing clients, Deaf patients often present to their family physicians even before they present to mental health clinicians. Primary care providers who were interviewed by Iezzoni and colleagues also did not routinely use interpreters, even when Deaf clients specifically requested them (Iezzoni et al., 2004). These physicians reported that they felt uncomfortable with the unfamiliar task of communicating with a Deaf person. They acknowledged that they may have missed conditions in their Deaf clients because of being preoccupied with the novelty of this new communication interchange and its inherent challenges.

Few mental health facilities or insurance networks provide direct outreach specifically to the Deaf community. Insurance care managers often do not have familiarity with where linguistically and culturally specialized services exist in their region. Insurance provider networks may not include providers who are fluent in ASL even when those providers are located in the same geographic area (Critchfield, 2002). Acquisition of these services is generally dependent on county of residence; thus, some services may not be accessible if a client lives outside of the county where that service is provided (Myers, 1993, 1994). Few counties across the country offer case management services by providers who are fluent in ASL. In addition, Deaf citizens often travel a great distance from their home in order to attend a trade school or college in an environment that is accessible to them and where peers and staff are fluent in ASL. This presents frequent reimbursement problems because the insurance provider from their place of full-time residence may know nothing about regional supports that exist outside of their locale (Myers, 1993, 1994).

An Intervention Research Agenda for Reducing Mental Health Disparities

There is good evidence detecting that persons who are Deaf are affected by disparities in access and quality of behavioral health services, and some evidence pointing to unique factors explaining such disparities in overall health care in the Deaf community. However, to move a research agenda forward that focuses on reducing disparities in mental health care for Deaf persons, a better understanding of the mutable determinants of disparities is necessary to improve mental health services for this population and develop effective interventions.

Patient Interventions.

There are important issues to address from a patient perspective. Clearly, heightened awareness about the Americans with Disabilities Act is of critical importance so that mental health consumers can better advocate for their right to an interpreter in the mental health care setting. Additionally, many individuals in the Deaf community rely on computer technologies for access to information. Mental health care providers may be able to enhance patient outreach strategies by including these networking strategies and channels of information access that are familiar to persons who use vision as a primary mode of communication.

Community Linkage.

Another area for interventions that may be effective is for mental health providers to improve linkages to community partners that support Deaf persons. In-service trainings to groups frequented by Deaf citizens, that provide information about mental health disorders and about where appropriate services can be obtained, would be a valuable intervention.

In some cities around the country, agencies have developed where staff is fluent in ASL and well versed in issues related to Deaf culture. Many of these agencies hire staff who are Deaf as well. Some of these agencies are listed in a directory published by Gallaudet University entitled "Mental Health Services for Deaf People: A Resource Directory" (Gallaudet University, 2003). Typically, the agencies that are listed in the directory provide outpatient counseling and medication management. Services such as case management, partial hospitalization programs, drug and alcohol

counseling, inpatient units, in-home services, and behavioral management training are rarely available or offered by ASL-fluent staff.

Nonetheless, it is important to better define the support systems utilized and trusted by Deaf community members. When these agencies are better defined in a given region, then psycho-educational materials and information about mental health issues and available resources that address the unique concerns of Deaf individuals can be made more widely available.

Provider Interventions.

Consumer advocacy agencies and support networks are only beginning to address the disparity in services available for Deaf community members. There have been a few attempts at widespread implementation of specialized mental health services for Deaf persons (Lawler, 1986; Steinberg, 1991). Most have focused on the need for communication accessibility and for the establishment of a network of providers who can meet some of the unique cultural and communication needs of this population. Evidence suggests that when Deaf individuals are given a choice of providers, they report greater consumer satisfaction and greater treatment efficacy when their health care providers are culturally attuned and are careful to make language fluency a priority in treatment (Steinberg, 1991). However, the impetus for developing these services has not been consistent across the U.S. (Lawler, 1986). As such, it is not surprising that work in surveying the extent of behavioral health providers working with Deaf persons suggests substantial regional variation across the country in the prevalence of specialized treatment organizations and ASL-fluent staff (Critchfield, 1992; Mathos & Broussard, 2005). Furthermore, little is known about variation in how these organizations are structured, or about how they function in providing treatment services, interface with governmental and social service agencies to meet consumer needs and attempt to increase the number of consumers who receive needed care (Pollard, 1995).

In addition, given the significant regional variation regarding access to mental health services for all Deaf people, it is crucial for clinicians who are training to work with Deaf persons to learn about the spectrum of services that exists for serving the mental health needs of hearing people (Myers, 1993). Clinicians in training should learn about funding streams that can support service development to expand on outpatient therapy options for Deaf consumers.

Despite the lack of a coordinated approach to service development, novel approaches have advanced in a number of states, largely through the efforts of professionals who have dedicated their careers to working with people who are Deaf. For example, some states such as South Carolina have been using tele-psychiatry to meet the outpatient counseling needs of Deaf people who live in rural areas (Gore & Critchfield, 1992). Other states such as Minnesota have developed specialized centers where persons with substance abuse and addiction problems can seek treatment in a setting where staff and peers share a common language and cultural background (Guthmann, Lybarger, & Sandberg, 1993). However, many state agencies for the deaf have not developed strong linkages to mental health resources, despite these agencies' place in the advocacy network that constitutes one of the traditional points of entry to mental health services for Deaf people (Myers, 1993). Unfortunately, states often do not recognize the need to evaluate and address mental health care disparities for Deaf citizens until legal action forces them to do so (Tugg v. Towey, 1994).

Clinic and System Interventions

Given the shortcomings of the current service environment, attention to the clinic/systems perspective is important in understanding the issues and potential solutions to improve services for these populations. Compared to a patient perspective, studying organizations that serve Deaf persons provides a different view of access and quality. Organizations' reporting of outreach efforts and perception of barriers within the local environment may contrast sharply with patients' experiences. However, this clinic/systems approach is necessary regardless of these differing perspectives. Cultural Deafness is a relatively low prevalence disorder and a practical approach to improving treatment requires us to understand, focus and ultimately strengthen and extend the specialized service sector that is currently in place. In this regard, we adopt the premise that understanding the best practices of these organizations nationwide can serve as an appropriate nidus for a model of improved services in this area, and represents an approach consistent with the patient-centered views that Steinberg's focus group sample endorsed toward quality improvement among their health care providers (Steinberg et al., 2006).

Finally, a systems-level strategy for improving quality of mental health care for Deaf persons is needed. Quality improvement, by definition, seeks to

advance the performance of a part of the health care system from its current baseline level. A crucial component of quality improving is measuring the quality of care. Stakeholders interested in improving care for the Deaf community want “bottom-line” information on the quality and adequacy of care for this group in order to advocate for improved services. Thus, a natural point of departure in seeking to improve treatment outcomes for the Deaf population is a serious examination of the quality of care already in place (Critchfield, 1992; DeVinney & Murphy, 2002; Pollard, 1995). However, few if any of the national datasets or performance monitoring systems (e.g., NCQA), collect information on hearing status in order to enable such comparisons of quality to be made at a system level.

We will perform a comprehensive national survey of agencies that define their mission as serving the mental health needs of persons who are Deaf. The survey will analyze similarities and differences between agencies regarding how they strategize outreach efforts to the Deaf community at large, and which types of services are prioritized and considered most cost-effective. We will also study which interagency collaborations are most highly valued and effective to facilitate patient recovery. Information about barriers to care that agencies have faced at multiple levels will be analyzed. Most importantly, we aim to gather information about how these barriers to care have been successfully circumvented.

Conclusion

In summary, addressing mental health services for Deaf persons remains a great challenge. Deaf persons have high rates of unmet need for mental health care and a preference for seeking services where providers understand their linguistic, cultural and acoustic needs. This translates into an imperative for better analysis of the specific mental health services that currently exist to prevent hospitalization and optimize quality of life. However, little systemic knowledge has been gathered on the current service environment. Thus, there is a great need for formative research to develop an evidence base that will translate into development and empiric testing of improved models of care for these vulnerable populations. For example, Steinberg and colleagues point out the importance of research into outreach efforts of current clinical programs (Steinberg et al., 1998). Similarly, Critchfield emphasizes the need for applied research that can and will inform systems change through a better understanding of the organizational barriers and facilitators of service

improvement (Critchfield, 1992). Efforts to better understand the structure and process of the mental health service environment, and effective patient-centered outreach strategies, are instrumental to developing the evidence base that can guide quality improvement strategies for services to the Deaf community.

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References

- Collins, J. G. (1997). Prevalence of selected chronic conditions: United States, 1990-1992. National Center for Health Statistics *Vital Health Stat*, 10(194).
- Critchfield, A. B. (1992). Improving training approaches. *Journal of the American Deafness & Rehabilitation Association*, 25(4), 15-20.
- Critchfield, A. B. (2002). *Meeting the Mental Health Needs of Persons Who are Deaf*: National Technical Assistance Center for State Mental Health Planning (NTAC).
- DeVinney, J., & Murphy, S. (2002). Mental health experiences and deafness: personal and legal perspectives. *Psychiatric Rehabilitation Journal*, 25(3), 304-309.
- Gallaudet University (2003). *Mental Health Services for Deaf People: A Resource Directory - 2003 Edition*. Washington, D.C.: Department of Counseling, Graduate School and Professional Programs, Gallaudet Research Institute, Gallaudet University.
- Gore, T. A., & Critchfield, A. B. (1992). The development of a state-wide mental health system for deaf and hard of hearing persons. *Journal of the American Deafness & Rehabilitation Association*, 26(2), 1-8.
- Guthmann, D., Lybarger, R., & Sandberg, K. (1993). Providing chemical dependency treatment to the deaf or hard of hearing mentally ill client. *J Am Deaf Rehabil Assoc*, 27(1), 1-15.
- Iezzoni, L. I., O'Day, B. L., Killeen, M., & Harker, H. (2004). Communicating about health care: observations from persons who are deaf or hard of hearing. *Annals of Internal Medicine*, 140(5), 356-362.
- Kilbourne, A. M., Schulberg, H. C., Post, E. P., Rollman, B. L., Belnap, B. H., & Pincus, H. A. (2004). Translating evidence-based depression management services to community-based primary care practices. *Milbank Quarterly*, 82(4), 631-659.

- Kilbourne, A. M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M. J. (2006). Advancing health disparities research within the health care system: a conceptual framework. *Am J Public Health, 96*(12), 2113-2121.
- Lawler, D. M. (1986). Mental health service planning for deaf persons: A beginning. *Journal of Rehabilitation of the Deaf, 19*(3-4), 1-4.
- Mathos, K. K., & Broussard, E. R. (2005). Outlining the concerns of children who have hearing loss and their families. *Journal of the American Academy of Child & Adolescent Psychiatry, 44*(1), 96-100.
- McEntee, M. K. (1993). Accessibility of mental health services and crisis intervention to the deaf. *American Annals of the Deaf, 138*(1), 26-30.
- Munro-Ludders, B., Simpatico, T., & Zvetina, D. (2004). Making public mental-health services accessible to deaf consumers: Illinois Deaf Services 2000. *American Annals of the Deaf, 148*(5), 396-402.
- Myers, R. R. (1993). Model Mental Health State Plan (MMHSP) of services for persons who are deaf or hard-of-hearing. *Journal of the American Deafness & Rehabilitation Association, 26*(4), 19-28.
- Myers, R. R. (1994). *Standards of care for the delivery of mental health services to deaf and hard of hearing persons*. Paper presented at the State Coordinator Conference, Arlington, VA.
- Pollard, R. Q. (1994). Public mental health service and diagnostic trends regarding individuals who are deaf or hard of hearing. *Rehabilitation Psychology, 39*(3), 147-160.
- Pollard, R. Q. (1995). Mental health services and the deaf population: A regional consensus planning approach. *Journal of the American Deafness & Rehabilitation Association, 28*(3), 1-47.
- Ries, P. W. (1994). Prevalence and characteristics of persons with hearing trouble: United States, 1990-91. National Center for Health Statistics. *Vital Health Stat, 10*(188).

- Steinberg, A. (1991). Issues in providing mental health services to hearing-impaired persons. *Hospital & Community Psychiatry, 42*(4), 380-389.
- Steinberg, A. G., Barnett, S., Meador, H. E., Wiggins, E. A., & Zazove, P. (2006). Health Care System Accessibility. Experiences and Perceptions of Deaf People. *Journal of General Internal Medicine, 21*(3), 260-266.
- Steinberg, A. G., Sullivan, V. J., & Loew, R. C. (1998). Cultural and linguistic barriers to mental health service access: the deaf consumer's perspective. *American Journal of Psychiatry, 155*(7), 982-984.
- Steinberg, E. P. (2003). Improving the quality of care--can we practice what we preach? *New England Journal of Medicine, 348*(26), 2681-2683.
- World Health Organization [WHO] (1999). Mental Health Fact Sheet, 2005, from <http://www.who.int/inf-fs/en/fact217.html>.