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Mental Health Services for the Deaf: A Focus Group Study in New York's Capital Region

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Abstract

Improved functioning is typical when deaf mental health consumers are removed from inaccessible programming and placed in accessible environments. Observed gains have long-provided convincing evidence that social interaction (in sign language) is essential to recovery from mental illness. Still, many deaf people reside in psychiatric settings alongside others with whom they cannot communicate. A focus group was convened to investigate services in New York's Capital Region. Identified barriers included lack of deaf clinicians, scarcity of qualified mental health interpreters, and funding restrictions. Grass-root efforts are needed to advocate for increased accessibility and a fuller range of treatment options for deaf consumers.

Keywords: Deaf culture, mental health, incidence, prevalence, accessibility, interpreters, serious mental illness.

Introduction

The development of effective mental health services for non-English speaking populations in the US requires flexible and creative planning. For the deaf, there exist finely tuned service streams in several geographic pockets. Intensive networking and sharing clientele creates sets of interconnected services—some dependent upon one another—that promote healthy living and help prevent unnecessary hospitalization. A small group of experts (nationally) from wide-ranging disciplines are important sources of knowledge regarding deaf psychology, the manifestation of psychosis, and typical responses to medication, as well as developments regarding treatment.

The present endeavor describes an effort to uncover current wisdom from experts regarding mental health services for the deaf in New York's Capital Region. We were interested in eliciting from stakeholders the influences that challenge efforts to achieve psychological well-being for the population. Stakeholders targeted for inclusion in a topic-based focus group were deaf and hearing practitioners and advocates, as well as consumers of mental health services.

Background

Incidence and Prevalence of Deafness

The National Institute on Deafness and other Communication Disorders (NIDCD) estimated that newborn hearing loss occurs 1.11 times per 1,000 live births, or 4,385 U.S. births per year (NIDCD, 2005). Despite the fact that 90% of all newborns are screened for hearing loss before they leave the hospital, as many as 20% of those with permanent hearing loss at 9 months of age are missed by current technology available for the early detection of hearing impairment (Johnson et al., 2005). Furthermore, CDC data revealed that in 2007, state programs for the early detection of hearing impairment were unable to document whether diagnostic evaluations were actually completed for 44.8% of the infants who failed the initial screening (White, Forsman, Eichwald, & Munoz, 2010). As a result, a significant percentage of children with hearing loss are not identified until the second year of life or later.

The National Center for Health Statistics (NCHS) Centers for Disease Control and Prevention has collected hearing status data continuously since 1962 via the National Health Interview Survey (NHIS). Using NHIS data (averaged across 2000-2006), Schoenborn and Heyman (2008) determined that the prevalence of hearing impairment in the adult population (18 years and over) was 15.1%. Thus, approximately 34 million deaf adults resided in the U.S. in 2006. When older adults were removed (i.e., those most likely to have age-related hearing losses) and rates were based on Americans between the ages of 18 and 64, the prevalence of significant hearing loss was 4% or 7.5 million people (Schoenborn & Heyman, 2008; U.S. Census Bureau, 2009).

Publications derived from the NCHS/NHIS data do not discern between people born deaf (i.e., prenatal deafness) and those with acquired losses (e.g., adventitious or genetic postnatal deafness), and this data remains important data to collect. The number of Americans who use sign language—another issue of relevance to the Deaf community—also cannot be discerned from the national data sets currently available. In a treatise related to the issue, Mitchell, Young, Bachleda, & Karchmer (2006) describe the persistent need for information regarding the use of American Sign Language (ASL) that is separate from data regarding deafness per se (e.g., information regarding hearing ASL users).

One of the studies highlighted by Mitchell et al. (2006) served as a potential model for future studies focusing on the prevalence of deafness in the US. In 1971, Schein and Delk conducted the National Census of the Deaf Population (Schein & Delk, 1974) and estimated that 410,522 deaf Americans used sign language in their home (i.e., about 238 signers per 100,000 people). Similar investigations of the American deaf population have not been conducted since.

The term pre-vocationally deafened (i.e., deafened prior to the age of 20 years) reflects the population of interest herein and includes a substantial number of people who identify with deaf culture. In all, the deaf population is exceedingly heterogeneous with regard to sign language use and level of engagement with other deaf people.

Incidence and Prevalence of Serious Mental Illness

Incidence of serious mental illness. Contrary to widespread belief, the incidence of serious mental illness (namely, schizophrenia) has prominent variation over several criteria. For example, the incidence is significantly higher in males, migrants, and those living in urban areas (McGrath & Scott, 2006). In the U.S., estimates of the incidence of schizophrenia in the general population (per year) range from 7 to 14 people per 100,000 (McGrath, Saha, Chant, & Wellman, 2006).

Incidence of deafness and serious mental illness. Throughout much of the 20th century, the belief was maintained that the incidence of schizophrenia was higher among deaf people relative to hearing people. The idea may have arisen from the disproportionate number of deaf people who were institutionalized in psychiatric hospitals in the early 1900s (often evaluated and diagnosed with schizophrenia by hearing people who did not know sign language). Over time, the erroneous conclusion that higher prevalence rates reflected an underlying higher incidence of mental illness was evident in the literature (Critchfield, 2002; Freeman, 1989; National Association of the Deaf, 2003). At this writing, the true incidence of serious mental illness in the deaf remains unknown.

Prevalence of serious mental illness. Narrow and colleagues (2002) determined a revised one-year prevalence rate of 20.9% for all psychiatric disorders in the general adult population (18 to 54 years). The revised estimate was derived from data collected by the National Institute of Mental Health

Epidemiologic Catchment Area Program study ([ECA] Robins & Regier, 1991) and the National Comorbidity Survey ([NCS] Kessler et al., 1994). The revised estimate falls well-below original estimates of 37% [ECA] and 53% [NCS]. When all ages are included (18 and over), Narrow, Rae, Robins, & Regier (2002) estimate that the one-year prevalence rate of any mental disorder is 18.5%.

The prevalence of schizophrenia is approximately 1.1% of the population over the age of 18 (National Institutes of Mental Health [NIMH], 2011). At any one time, 2.2 million people in U.S. suffer from schizophrenia (i.e., approximately 7.2 Americans per 1,000) (McGrath et al., 2008; NIMH, 2011). Based on a population of nearly one million in New York's Capital Region, approximately 9,217 residents had schizophrenia in 2010 (U.S. Census, 2010a).

Prevalence of deafness and serious mental illness. Prevalence rates of serious mental illness (e.g., schizophrenia) in the general population may not be appropriate for extrapolation to the deaf because of potential differences in illness onset and trajectory. Though the total number of deaf people who use sign language as their primary mode of communication is relatively small, inadequate treatment in the early stages of mental illness may lead to service dependency for the most ill. Thus, as others have discussed, the number of deaf people receiving costly mental health services may be disproportionately high relative to the general population (Freeman, 1989; Fusick, 2008; Gentili & Holwell, 2011).

The true prevalence of schizophrenia in the deaf remains unknown; however, investigations of deaf people with mental illness continue. Across studies, cognitive, social cognitive, and symptom indicators of schizophrenia are generally similar to those found among hearing people, with a few notable exceptions (Atkinson, 2006; Black & Glickman, 2006; Haskins, 2004; Horton, 2010; Horton & Silverstein, 2007; 2008; 2011). For example, in a sample of 544 deaf and hard-of-hearing patients in upstate New York, Pollard (1994) found prevalence rates of schizophrenia, anxiety, mood, adjustment, and personality disorders (save antisocial personality disorder) similar to a large hearing comparison sample (n=84,437). Earlier work also found comparable prevalence rates of symptoms among hearing samples (Grinker et al., 1969; Rainer, Altshuler, Kallman, & Deming, 1963; Robinson, 1978).

The addition of survey questions to the Census and the National Health Survey are on the horizon because of efforts by advocates within the deaf community. In the meantime an epidemiological study like Schien and Delk's (1974), conducted by advocates from within the deaf community, would be of benefit. Only then can we determine the true number of deaf community members and the prevalence of mental illness within that community. The number of ASL users (by age and hearing status) would be another helpful by-product of ascertaining accurate population parameters.

Method

Rationale

The region where the focus group convened is comprised of four counties (Albany, Rensselaer, Schenectady, and Saratoga) with a total population of 837,967 in 2010 (all ages) (U.S. Census Bureau, 2010b). Extrapolating the census-based estimate of a four-percent prevalence rate of deafness among 18–64-year-olds (Schoenborn & Heymanm, 2008), approximately 6,771 deaf people reside in New York's Capital Region.

The Americans with Disabilities Act ([ADA] Public Law 101-336, 1990) requires equal access to services for people with disabilities yet studies continue to indicate that deaf people experience access difficulties because of linguistic, cultural, and systemic barriers (Ebert & Heckerling, 1995; Fusick, 2008; Gentili & Holwell, 2011; Harmer, 1999; Iezzoni et al, 2004; Thomas, Cromwell, & Miller, 2006). Current levels of health disparity between deaf and hearing people make it reasonable to assume that a significant number require mental health services (Barnett, McKee, Smith, & Pearson, 2011).

Participants

Using the region's deaf community as the sampling frame, we purposively sampled active mental health stakeholders for inclusion in the focus group. Twenty potential participants, deaf and hearing, were identified via local deaf informants. The criteria for inclusion were broadly defined as people interested in deafness and mental health services for the deaf in the Capital Region. Potential participants received an email announcement soliciting participation.

In all, nine people (five deaf and four hearing) attended the focus group: three social service providers, four interpreters, and three mental health consumers (each group was mixed with deaf and hearing participants). The groups of participants were not mutually exclusive; in addition to being service providers for example two of the participants were also family members of a deaf mental health consumer. Several other people were present, but were not focus group participants: two certified interpreters (Registry of Interpreters for the Deaf [RID]); two moderators (first and second author); and one research assistant who videotaped the group for later translation. The institutional review board (IRB) at the University of Albany approved the consent, recruitment, and study procedures.

Procedure

A topic-focused group discussion allowed participants to share their opinions, experiences, and beliefs as freely as possible (Schulze & Angermeyer, 2003). During the focus group, interactions among participants reduced the amount of communication between moderators and group members. Thus, the group dynamic superseded the influence of the researchers over the interview process and allowed a more prominent role to the participants' opinion (Madriz, 2000).

We also considered the idea that focus groups are more appropriate for eliciting responses that reflect the social realities of the interviewees (Kruger, 1994). We also hoped to take advantage of the idea that focus groups can become a forum for change for participants and consumers both during and after the focus group meeting itself (Race et al., 1994). Lastly and importantly, the methodology is especially consistent with deaf culture, as gatherings of moderately large groups of deaf individuals are considered opportunities for sharing information about topics often considered private to hearing individuals (Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006).

The focus group was held on May 19th, 2009, at the University at Albany in Albany, New York. After the study procedures were fully explained, written informed consent was obtained from each participant. One-third of the two-hour meeting was spent on introductions and reaching consensus on a desired mode of communication. Participants agreed that ASL was the best communication method for the group; thus the interpreters sat next to the one moderator (second author) who did not know sign language and

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quietly “voiced” (i.e., interpreted) the proceedings. Participants addressed two primary topics during the focus group, both regarding mental health services for the deaf in the Capital Region: 1) current service opportunities; and, 2) barriers and facilitators to accessing and using services. We were primarily interested in the experience of deaf people requiring at least minimal levels of ongoing mental health support.

Data Analysis

A paid native signer who was a child of deaf adults and an RID-certified interpreter translated the videotaped data from ASL to English. The full transcript was analyzed by means of an inductive formation of categories aimed at understanding mental health service delivery in the region. Data analysis was supported by Atlas-ti software; the program facilitated categorization by grouping the text into passages that corresponded to particular ideas or themes. The second author conducted the initial coding of the transcripts. Inter-rater reliability was garnered by the first author’s re-coding of the data. Differences in interpretation were discussed; themes appeared to capture similar ideas and thus the essential quality of the text.

Results

Three primary themes emerged from the focus group discussion. The first theme regarded several straightforward barriers to effective mental health services; the second theme encompassed facilitators to providing effective services; and the third regarded potential action steps for improving access and delivery of mental health services in the region.

Barriers to Effective Mental Health Services for the Deaf

Lack of deaf-friendly mental health services. New York’s Office of Mental Health governs adult, child, forensic and research facilities for the entire state (www.omh.state.ny.us). Capital District Psychiatric Center (CDPC) provides inpatient services (among other services) for those with serious and persistent mental illnesses in the Capital Region. With the exception of the public education system, the region does not include specialized services for the deaf. General social service centers and other mental health and substance abuse agencies offer services that are only marginally accessible (e.g., interpreters present for several hours per day or week). By specialized services for the deaf, we refer to facilities—and mental health programs

in particular—that employ full-time interdisciplinary staff who are fluent signers, knowledgeable about deafness and deaf culture. In all settings where deaf people frequent, communication and information access should be freely available.

In the Capital Region, focus group participants made clear that the first-stop for deaf people with mental health concerns were places other deaf people work or frequent (e.g., independent living centers, Deaf Clubs, churches). Like many ethnic, linguistic, and cultural groups, members of the deaf community obtain information regarding mental health services from friends, family, and other members of the community (Steinberg, 1991). Further complicating access to mental health care is the fact that it is common for deaf people to be unaware of existing local services (Steinberg, Sullivan, & Loew, 1998).

The four-county region, inclusive of approximately two thousand square miles, has a geographically widespread deaf population and several people described this as being a hindrance to improving mental health services:

We must remember that the local deaf community [in this region] is fractured. It is very difficult to get people to band together and support one another, especially for mental health needs.

Qualified mental health interpreters. Most participants, especially the interpreters, described that few working interpreters understand deaf culture and possess mental health knowledge and experience (e.g., “I started out as an interpreter and soon realized that there were not a lot of professionals locally who understood deaf culture”). Similar to Briffa (1999), another participant stated:

[M]any interpreters working in mental health settings do not have enough background in mental health. They are not able to see [the] subtle nuances that are so important in this line of interpreting work. What should be happening is teamwork between the therapist and the interpreter, but what [happens instead] due to budget constraints, is that the cheapest interpreter is hired; this most likely means...[working with] under-qualified individuals.

Above and beyond locating, funding, and retaining qualified interpreters, focus group participants emphasized the need to consider the fit between the interpreter, the client, and the clinician; ideally compatibility should be evaluated on a case-by-case basis (Briffa, 1999; Cornes & Napier, 2005; Critchfield, 2002; Davis, 2005; de Bruinn & Brugmans, 2006; Vernon & Leigh, 2007). Discussants agreed that the most successful clinicians and clinician-interpreter teams, in addition to possessing requisite diagnostic and treatment knowledge, possess specific knowledge regarding the cultural and linguistic characteristics of their clientele (Gutman, 2005; Haskins, 2004; Iezzoni et al., 2004; Sussman & Brauer, 1991; Vernon & Miller, 2001).

Insurance-related barriers. Discussants explained that many agencies in the region do not accept Medicaid as payment for mental health services. Further, because Medicaid does not pay for interpreter services (i.e., ADA is an unfunded mandate) opportunities are further limited for deaf people. First, the cost of interpreter services was considered prohibitive for providers and consumers alike; thus, even for providers accepting both public and private insurance:

Many [still] cannot afford to pay for an interpreter, especially those in private practice. Often, providers will agree to make accommodations until faced with the cost.

Second, rigid geographic boundaries within which one can receive mental health services (described below) are harmful to the deaf primarily because they further limit access to an already scarce pool of deaf-friendly services.

County-based services. The education and mental health systems in New York serve as case examples of the barriers created by limiting service options to one's home county. The Boards of Cooperative Educational Services (BOCES) represents 37 education boards statewide (three in the Capital Region). BOCES funding does not provide specific, deaf-centered mental health services; the primary focus is on special education (e.g., deaf classrooms, interpreter services, social-emotional development). One participant explained, "Deaf students cannot be referred outside of their home county for mental health services with BOCES funding." A deaf social worker from a community-based mental health center (CBMHC) stated:

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[Since] money goes to the schools, we have to refer outside [of BOCES] but the problem is there is no place to which we can refer people. As others have said, this is a problem in each county.

Thus, a piecemeal approach to mental health treatment begins for the most impaired—typically provided by clinicians not familiar with deafness and deaf culture.

Mental health centers are also county-bound in terms of deliverables. However, a hearing social worker stated that one CBMHC located in Rensselaer County did not “serve all parts of Rensselaer County.” In one case, “when I called regarding a deaf consumer, they stated services were dependent on where in the county the consumer resided.” Moreover:

I had a deaf consumer with Medicaid [living] in [a county in the region] and I was unable to find any mental health services for her. I even contacted Medicaid and they sent me two numbers...one for a psychologist who had retired and the other for a pediatric psychologist (and my consumer was in her 40s). The [CBMHC] in [the county] would only see her if she had a severe diagnosis, but would not do an assessment.

The participant conceded that the incident occurred 2-3 years prior to the focus group, and that since then, “things may have changed.”

The following statement revealed the added value of just one deaf psychologist to the Capital Region (psychologist’s name changed):

I was unable to find any mental health services [for some deaf clients] until Dr. Logan came along. [Several CBMHC’s] will accept Medicaid and will provide interpreters [however] Dr. Logan has proven to be a great resource as he accepts Medicaid and is not county-specific.

Receiving services directly from a deaf professional quickly benefitted the deaf community, as Dr. Logan became the person-to-call for providers

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in need of culturally and linguistically sensitive mental health services. Participants agreed that structured funding streams, not bound by county, are needed in order to create high quality, deaf-focused mental health services in the region.

Facilitators to Effective Mental Health Services for the Deaf

Facilitators often reflected the simple inverse of obstacles. However, substantial discussion of several core facilitators reflected issues of high value to the deaf community.

Culturally competent mental health professionals. Participants indicated that ASL-fluent therapists are perhaps best equipped to effect change in their deaf clients. Rather than relying on an interpreter, signing practitioners were preferred. A deaf social worker stated that “[Deaf people] would prefer to see a professional who can communicate with them rather than pulling someone else in.” Another mental health consumer stated:

A third person in the room changes the dynamic. With direct communication there would be more time spent addressing real issues.

Some participants believed that social workers, psychologists, and counselors should be educated about deaf culture and norms. For example, one participant stated “[I]n my experience as an interpreter, I often need to educate the therapist about deaf culture and norms [before therapy can begin].”

Notably, there was one deaf mental health consumer who was “very comfortable” with the use of an interpreter in therapeutic settings. The triad created by a hearing therapist, hearing ASL interpreter, and deaf consumer was perceived as supportive; indeed, the particular deaf participant had never received services (directly) from someone who signed. The focus group’s small sample of deaf community members thus reflected the heterogeneity of the larger deaf community; the use of interpreters is an acceptable, even preferred, way to receive mental health services for at least some portion of the population, while other deaf persons would prefer ASL-fluent mental health practitioners. Notably, most focus group participants were well-aware of legislation arising from *Tugg v. Towey* (1994) stating that services provided

through a sign language interpreter are not equivalent to the services hearing people receive and thus violates ADA.

Technology. Participants considered the use of technology, such as videophones (VP), to be an important part of increasing accessibility in the region. Two family members described a creative solution to a typical barrier: “We prefer not to participate in [counseling] with an interpreter, [so] we would consider [driving 3 hours] to meet a signing therapist and then do all other sessions from the comfort of our home [via] VP.”

Technology as a means to increase mental health literacy among deaf people was also discussed. An on-line community, as a means to share information and provide social support, could be made available via a website with videos in ASL. Linking to web pages originating in near-by cities with large deaf populations would allow members to exchange information and resources related to a variety of cultural and social opportunities, including those related to mental health.

Action Suggestions for New York's Capital Region

The final theme, emerging toward the end of the focus group, centered on potential action steps the group could take to effect change in the region. It is noteworthy that a sense of unity amongst focus group members was apparent during this phase of the meeting and appeared to motivate creative thinking.

Initial action suggestions. Increased funding for interpreters was reiterated as a priority even though relying on interpreters was not the preferred mode of communication for the majority of participants. One participant explained:

My concerns are around accessibility for deaf individuals. Hopefully we can influence systems that address the affordability of interpreting services for mental health providers.

A seasoned interpreter stated: “[I]t may help to provide public education for mental health professionals [regarding the idea] that a deaf person is not just a hearing person who doesn’t hear.” A sub-theme of this discussion was the participants’ desire to attract more culturally competent mental health practitioners and deaf professionals to the region.

When distilled, mental health funding issues revolved around two related state of affairs. First, ADA legislation does not apply to agencies or businesses for which accommodations would prove a financial burden (e.g., employers with less than 100 employees). Therefore ADA compliance is not required of many CBMHCs in the region. Second, agencies willing to hire interpreters are limited to serving those who reside in the same county as the agency—further restricting access to a full menu of services. It was clear, at least to the group of deaf community members interviewed herein, that there is little recourse when faced with a county with few signing clinicians and/or providers who are excused from ADA compliance. In general, the participants felt that the cost of being accessible dictates level of compliance with ADA legislation.

Task force development. A deaf participant described the core action suggestion, as follows:

I think that this group here is a great start for a task force or an advisory board of sorts. We [could] formally set up a group and meet on a regular basis with goals and timelines... along with someone to chair the group. As of now, it is too loose and may fall apart. That is my recommendation; establish a task force with an official name and a mission. This way you will get the recognition needed.

The idea was supported and related actions were elaborated. For example, data collection efforts that determine the prevalence of deaf people with mental illness in the Albany area and attendance would be useful, as would sending representation to local meetings administered by New York's Office of Mental Health and the Albany County Department of Mental Health. Developing potential allies was considered an important part of improving access to services.

Finally, it was re-emphasized that the full set of treatment options for the deaf were lacking in the region. At the minimum, stakeholders will need to advocate for the most basic of mental health services: Assessment, individualized treatment plans, individual/group/family therapy, medication therapy, symptom management, crisis intervention, case management, and ongoing clinical support. Ideally, services would be delivered by fluently signing psychiatrists, therapists, nurses, and case managers (deaf and hearing).

Study Limitations

There are several limitations to the study that may be outweighed by mental health disparities influencing the deaf. The use of a convenient sample means that results can only be generalized to a limited segment of the general population. Namely, deaf people residing in mid-sized cities in the U.S. However, even people residing in cities with similar concentrations of deaf and hearing people may differ from the study sample because of factors unique to New York or the Northeast. While generalizability is limited, it is likely that deaf mental health consumers in other U.S. regions face some of the same challenges as those reported herein. A summary of the major findings is presented in Figure 1.

Figure 1. Major Themes Derived from Focus Group.

Barriers to effective mental health services for the deaf

- Lack of deaf-friendly mental health services
- Qualified mental health interpreters
- Insurance-related barriers
- County-based services

Facilitators to effective mental health services for the deaf

- Culturally competent mental health professionals
- Technology

Action suggestions

- Increased funding for interpreters
- Task force development

Conclusion

We investigated mental health services for the deaf in the Capital Region of New York. Placed between two of the largest deaf centers in the world (Rochester and New York City), the Albany area deaf community it is not only much smaller, but is geographically widespread relative to the larger cities. Specialists in deafness and mental health reside in the Capital Region yet coordinated efforts are needed to advance the cause of gaining levels of accessibility the general (hearing) population enjoys.

The data replicated several previous findings: a) there exist inequalities in terms of access to mental health services for the deaf; b) deaf people generally prefer direct communication with culturally sensitive, signing mental health professionals; and c) interpreters are highly valued by the deaf community

Horton et al.: Mental Health Services for the Deaf: A Focus Group Study in New York and are seen as necessary to improving accessibility in the region. Preparing the manuscript for publication has contributed to post-focus group activities including soliciting feedback from participants on the initial report and planning development of a task force (underway at this writing).

The data collected reflected socially relevant and empirically valid information about mental health services for the deaf. The desire for specialized care is based on a century of research, from various empirical perspectives, describing the population's unique cultural and linguistic heritage. Deaf-centered treatment is based on the straightforward notion that communicating freely, 24 hours per day with clinicians, receptionists, support staff, and perhaps most importantly other consumers, is invaluable to basic mental health.

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