Availability of Mental Health Services for Individuals who are Deaf-Blind

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Abstract

A survey of state mental health agencies found that a majority have no specific policy or procedure regarding how to provide mental health services to persons who are deaf or who are deaf-blind. Agency representatives report that staff lack knowledge of how to provide mental health services to persons who are deaf-blind and the agencies lack qualified interpreters. They recommend training for social workers and counselors to address best practices in working with people who are deaf-blind concerning communication methods and strategies, physical interaction, cultural issues, everyday life, sensory deprivation, ethics, use of an interpreter, and other general issues.

Key word: mental health, dual sensory loss, deaf, blind, deaf-blind

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Individual-level, practitioner-level, and system or process-level factors complicate access to mental health treatment for everyone (National Collaborating Centre for Mental Health, 2011). Consequently, we continue to have substantial numbers of children and adults who are not receiving the mental health treatment they need (Mental Health America, 2015). Persons who are deaf or hard-of-hearing have unique issues that further impact their access to mental health services. The National Association of State Mental Health Program Directors (2008) documented, among others, these important facts: (a) there is no national census of persons with hearing loss, (b) over 5 million persons who are deaf need mental health services each year and only about 2% receive appropriate treatment, (c) children who are deaf are two to three times more likely to experience physical and sexual abuse, and (d) no national database of service providers skilled in mental health services for persons with hearing loss currently exists.

Persons with deaf-blindness or dual sensory loss (i.e., persons with significant hearing and vision losses) are influenced by the factors impacting persons with hearing loss alone and experience additional complex problems accessing mental health services, many associated with communication issues. For example, imagine a person with a hearing loss enters a community mental health center seeking services. Even an intake worker or therapist who is not skilled in sign language might have some success, using either gestures, written communication, or a combination of both, in getting an idea of what the person needs and conveying that an interpreter will be contacted and utilized. But how would an intake worker or therapist respond and communicate if the person had both a hearing and vision loss?

Deaf-Blindness/Dual Sensory Loss

The terms deaf-blind and dual sensory loss tend to be used interchangeably and refer to persons who have significant impairment in both senses. Estimating the number of persons who are deaf-blind is difficult given that it may include persons with varying degrees of impairment of either disability and that the disability may have occurred at various points in time. The prevalence of concurrent hearing and vision loss is estimated at less than 1% among adults below the age of 70, representing approximately 140,000 individuals, but increases significantly with age (Swenor, Ramulu, Willis, Friedman, & Lin, 2013). The estimated number of children in the U.S. classified as deaf-blind was 9,454 in 2013, which is a slight decrease and is regarded as an underestimate, particularly for very young children (NCDB, 2014).

It is widely recognized that dual sensory loss is distinct from either blindness/vision impairment or deafness/hearing impairment alone and as such, requires unique service delivery strategies. The person’s current age; age of onset, cause, and severity of sensory loss; and educational experiences impact the communication style used, thus there is no standardized method of communication with persons who are deaf-blind. Yet communication is the most important challenge facing this population (Miles, 2008). Methods of communication may include tactile sign language; braille, particularly for persons who experience vision loss early in life; use of amplification systems for persons who retain some hearing; or sign language, particularly for persons who experience hearing loss early in life and retain residual vision.

Mental Health Issues

People who are deaf-blind experience the typical mental health issues of the general population. Addressing these issues, such as substance abuse, domestic violence, or adjustment, can be complicated by communication problems that impede access to treatment. But mental health problems may also arise from or be complicated by sensory loss. Persons who experience sensory loss at an early age may experience developmental problems that negatively influence behavior and mental health and consequently put them at risk for victimization, sometimes at the hands of their caregivers. Combined hearing and vision loss may result in a loss of functional independence that could lead to depression, anxiety, and withdrawal (Bodsworth, Clare, & Simblett, 2011). Additionally, reduced sensory stimulation may negatively impact cognitive functioning (Bodsworth et al., 2011).

Communication problems associated with sensory loss tend to result in social isolation, a risk factor for both physical and mental health. Difficulty in communication has been identified as a strong predictor of depression among older persons with hearing and vision loss (McDonnall, 2009). People with dual sensory loss may also have visual disturbances or auditory misinterpretations and it is important that mental health providers are able to distinguish between psychotic symptoms and what might be communication problems (du Feu & Fergusson, 2003).

Mental health providers and policy makers are aware that cultural competence, or the ability to work with people from various cultures, is an important factor in effective service delivery. The Substance Abuse and Mental Health Services Administration (SAMHSA) website has a plethora of information about cultural awareness and competency yet there is scant mention of issues surrounding deaf culture or deaf-blindness. Persons who are deaf and their advocates maintain that persons who are deaf should be served by therapists who are fluent in sign language but there is a shortage of mental health professionals able to sign (Critchfield, 2002). There are presumably even fewer mental health professionals skilled in communicating with persons who are deaf-blind.

Purpose of the Study

This study investigated the availability of state mental health services for persons with deaf-blindness via a survey of state mental health agency directors or their designees. We attempted to learn the following: (a) whether policies or procedures exist to provide mental health services to persons with deaf-blindness, (b) if a plan or system is in place to provide interpreters skilled in communicating with persons with deaf-blindness, (c) if states engage in outreach services for people with deaf-blindness, (d) challenges to mental health service delivery for person who are deaf-blind, and (e) what would improve mental health service delivery to persons who are deaf-blind. This research was approved by a university Institutional Review Board for the protection of human subjects.

Method

Survey Description

Although the primary focus of the study was on the availability of mental health services for individuals who are deaf-blind, the first portion of the survey included questions about providing services to individuals who are deaf and use sign language as a way to broach the topic of services to deaf-blind individuals (also with a focus on those who use sign language). The survey consisted of 14 multiple choice questions and 6 open-ended items. An opportunity to comment on all of the multiple choice questions was provided, and most respondents did provide comments to explain their answers in more detail. Questions focused on procedures and policies for serving the two populations, plans or systems to provide interpreters for the populations, other providers in the state with expertise on the populations, challenges and needs for serving the deaf-blind population, and training needs of agency staff.

Procedure

An initial email invitation was distributed by the National Association of State Mental Health Program Directors (NASMHPD) to 51 state mental health agency directors that encouraged agencies to participate in the study. Follow up emails and calls were made by the research team to encourage participation. If no response was received from the agency after multiple attempts, secondary sources were identified by contacting regional representatives from the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC). When someone from the agency or a secondary source was identified, they were contacted and a time was scheduled to complete the survey. Surveys were administered via a telephone interview and all responses were recorded and stored in an electronic database. The interviews took approximately 30 minutes to complete. Each participant was offered a $50 gift card for their participation.

Participants

Of the 51 state agencies contacted, 39 (76.4%) agreed to participate and an additional 5 (9.8%) secondary sources participated, providing a total of 44 (86.3%) responses. Of the 39 individuals from the state mental health agencies, a variety of personnel within the agencies participated in the interviews. Positions included agency directors; assistant commissioner; assistant division chief; directors and coordinators of deaf services; clinical manager; office and bureau chief of cultural competency; quality assurance manager; directors of adult services, special programs, bureau of community based services, and consumer recovery and membership services; and legislative liaisons. The secondary sources were persons not associated with the state mental health agency and included state-federal vocational rehabilitation deaf-blind specialists, executive directors of commissions for the deaf and hard of hearing, a director of a program for older persons who are blind, and a program coordinator of deaf services.

Definitions

One goal of the study was to determine whether each agency had a procedure or policy about providing services to persons who are deaf and deaf-blind. For deaf clients, we defined this as having a procedure or policy specific to people who are deaf, not a generic policy that indicated they would serve all people who presented for services or that generically covered the Americans with Disabilities Act (ADA). If the agency only provided interpreters when needed, this was also not considered a clear policy or procedure (as providing interpreters is required by law). To be considered as having a procedure or policy for people who are deaf-blind, the procedure/policy had to have a specific reference to deaf-blind. Two items inquired about a plan or system to provide sign language interpreters for deaf and deaf-blind consumers. To be considered to have a plan or system in place only required that the agency representative described some process regarding how interpreters would be identified; the quality of the plan was not evaluated and some agencies had much more extensive plans/systems than others. Agencies with a plan or system that was not statewide were still classified as having one.

Data Analysis

Responses to open-ended items were transcribed from audio recordings and independently coded by two researchers. Any inconsistencies in codes were reviewed by the research team until agreement was reached. Codes were grouped by theme or category and when appropriate, frequency data generated for responses. Descriptive statistics were used to analyze all data.

Results

Services for Deaf Consumers

A list of survey items about services to persons who are deaf and participant responses are provided in Table 1. Many state mental health agencies do not provide services directly to consumers and provide all mental health services through community mental health centers. Some of these state agencies had specific policies that their contractors (community providers) must follow that include serving the deaf population, some required the contractors to have their own policies or procedures, and still others did not have any requirements for their contractors and did not know what the contractors were doing. Overall, only 43.2% of the agencies had specific procedures or policies in place to provide mental health services to persons who are deaf. Several respondents reported that they collaborate with the state agency that serves persons who are deaf (e.g., Commission for the Deaf) to provide mental health treatment to persons who are deaf. Agencies with a strong policy or procedure for serving those who are deaf tended to be states that had a lawsuit over this issue and were required by court order to improve services to this population.

Most agencies (76.7%) did have therapists fluent in American Sign Language (ASL) in their state and had plans for providing interpreters (68.2%). The question about a plan or system to provide sign language interpreters was not applicable for two agencies because their own staff are fluent in sign language and provide services directly (i.e., they do not use interpreters). The plans or systems that respondents described varied substantially, from providing an approved list of available interpreters to community providers, to having a contract with a private agency for ASL interpreters, to covering the cost of the interpreters for community providers.

Services for Persons who are Deaf-Blind

Agencies with a procedure/policy in place to serve people who are deaf were asked if they had a procedure or policy to provide mental health services to people who are deaf-blind. See Table 2 for responses to this item and other items specific to persons who are deaf-blind. Several respondents indicated that their policy was the same for those who are deaf-blind as for those who are deaf, or that people who are deaf-blind would be covered under their policy for those who are deaf. Only if the agency acknowledged people who are deaf-blind in their policy or had something specific for persons who are deaf-blind was their response categorized as "Yes" and 15.9% of the respondents met that criteria. If the agency did not have a procedure or policy in place to serve people who are deaf, they were not asked about a procedure or policy in place to serve people who are deaf-blind. Note that the percentages in the table include all respondents, as those who were not asked the question were categorized as having a "No" response.

The twenty agencies that did not have a procedure/policy for to serve persons who are deaf were instead asked what their agency would do if someone in their state who was deaf-blind needed mental health services. Some respondents' answers involved more than one theme, therefore percentages total more than 100%. The most common response (70%) was that the agency would refer the person elsewhere. As interviews were with state mental health agencies, many indicated that the person would be referred to the local community mental health agency or that the local agency would handle the case however they could. Others reported that they would refer the person to the state vocational rehabilitation agency or to a center for the deaf. One respondent said the person would be referred to HKNC. Another common response (35%) was that the agency would provide services to the person. Three respondents said they would refer the person to state vocational rehabilitation and jointly provide services. Other respondents were not sure how the agency would provide services but indicated they would try: "We would do our level best to work through our sign language interpreters to find people who are capable of working with deaf-blind." Some respondents said they did not know how they would handle the situation, and an equal percentage said they would provide an interpreter for the person (15% for each).

Challenges to Providing Services to Persons who are Deaf-Blind

When asked their agency's biggest challenge to providing mental health services to people who are deaf-blind most respondents identified multiple challenges. A list of the themes identified and the percentages reporting them are in Table 3. The most common challenge (43.2%) was not having any, or a limited number of, professionals with the knowledge necessary to work with the population. Limited/lack of awareness by mental health providers of cultural differences for those who are deaf-blind was identified as a challenge by 25% of respondents. Some added that providers may not be aware that they do not have the necessary knowledge and skills to work effectively with this population. Another challenge mentioned by 34.1% was the rural nature of their state. The high cost associated with serving the population, as well as limited resources of the agency, was another major challenge (29.5%). The low incidence of deaf-blindness was identified as a challenge by 20.5% of respondents. Some (13.6%) also indicated a lack of awareness of this population's need for mental health services in their state, or being unaware of the extent of the need. A lack of qualified interpreters to work with people who are deaf-blind to receive mental health services was an issue for some agencies and a few people mentioned problems with outreach, or lack of awareness by the deaf-blind population that mental health services are available.

Assistance and Training Needed to Serve Persons who are Deaf-Blind

When asked what would help their agency serve the mental health needs of people who are deaf-blind in their state respondents typically identified more than one thing that would be helpful. Three agencies did not respond to this item, and three (6.8%) said they did not need anything.

Training was the most commonly identified issue (36.4%) that would help agencies serve the mental health needs of people who are deaf-blind. An increased awareness of the needs of the population was mentioned by 29.5% of participants. This included things like knowing how many in this population are in the state, greater awareness of deaf-blind culture, and awareness of private practice professionals within the state who could provide services to the population. An equal percentage indicated that additional funding and resources are needed (29.5% for each category). Resources mentioned included a good knowledge source for information about deaf-blindness, information about resources to serve the population (e.g., other agencies that can provide services in local communities), and assistance with developing policies and procedures regarding this population. An additional two people (4.5%) mentioned the need for more community support, which could be considered a resource. As one participant said, “The biggest frustration is lack of support for independent living and employment. The mental health system is only one piece of the puzzle and we have a lack of active community partners.”

Another thing that would help agencies serve people who are deaf-blind is qualified personnel, mentioned by 29.5%. Respondents discussed the need for interpreters, clinicians, and more staff in general who are aware of this population’s needs, and several people mentioned the need for someone within the agency to coordinate services for this population. Building partnerships with other agencies who could help the state mental health agency serve this population was mentioned by 9.1% of participants. For example, one respondent said the agency “would like to build stronger partnerships with advocates and others who provide services to this population so they know the service is available.”

To identify training needs of agency staff, a list of potential training topics was presented and participants asked about their need for each. As seen in Table 4, respondents thought all of the topics were important. When asked to choose from a list of titles who within the agency could most benefit from training about working with people who are deaf-blind many respondents did not name only one group and instead identified two or more. A common response was that social workers and counselors perform the same job, so the two could not be separated. The percentages that identified each group are displayed in Table 5. (Percentages sum to more than 100% as multiple groups were identified by some respondents.) The most common "other" response was administrators of the agency, with 11.9% of the respondents identifying that group.

Discussion

Results indicate that there is considerable variety between, and in some cases within, states regarding the mental health service delivery system for persons who are deaf-blind. State agency administrators were sometimes unable to articulate how their various contractors were providing services to this population, though they must require those contractors to do so. While respondents were not asked directly about the factors impacting the variation in service delivery, their comments indicate that in addition to agency structure, the financial resources available, population density (with more populous areas tending to have more and better developed services), demand for services, whether lawsuits have been filed in that state, and administrator awareness of the need for services impact service delivery. A potential concern is that some states that appeared to have functional policies/procedures in place relied on a small number of persons to keep that policy/procedure operational and were susceptible to major disruption by turnover in key personnel.

Some states reported having little demand for services from people who are deaf-blind. In some cases, providers associated the lack of demand for services with the lack of availability. Individuals who are deaf-blind tend to know where services are not available and/or accessible and consequently either do not pursue services or go to other sources for mental health treatment. In other cases, survey participants appeared to believe that there were no people who were deaf-blind in that state who needed services.

Mental health service delivery methods included providers that have therapists who sign, those who use interpreters with agency therapists, those who pay a third party who signs to provide mental health services, and those who did not have a clear plan for what they would do or what is being done. Even when there was a plan to provide an interpreter, well over half of the state agencies have no plan or system in place to assure that interpreters are qualified to work with someone who is both deaf and blind. In some agencies there did not appear to be a recognition that working with someone who is deaf-blind would be different than working with someone who is deaf.

Some providers indicated that they would refer the person who is deaf-blind to another agency, but sometimes it was not clear exactly how that would be operationalized. For example, several states reported coordinating services with their state vocational rehabilitation agencies but were then vague about how vocational rehabilitation might be involved in providing mental health services or what would happen if the consumer was not eligible for vocational rehabilitation services. Similarly, some mentioned referring consumers to the state school for the deaf but were unclear about how that might be helpful, particularly if the person was not school age. Of the 44 states represented, nine identified HKNC as a resource and four have referred persons who are deaf-blind to HKNC for services. On a positive note, more than half of the respondents said that there are mental health professionals in their state with expertise or awareness about the needs/experiences of people who are deaf-blind.

Respondents identified lack of qualified personnel as the most significant challenge to providing mental health services to persons who are deaf-blind and also said that training was the thing that would most help their agencies provide these services. Related to this, respondents reported that having more qualified personnel and having increased awareness of the needs of the population were important to improve mental health services to persons who are deaf-blind. All these responses speak to the critical need for making mental health providers aware of the numbers of persons who are deaf-blind in their state and estimates about how many need services, providing training to the appropriate persons about best practices in mental health service delivery to persons who are deaf-blind, and maintaining qualified mental health providers who can develop their skills and expertise with this population.

Another commonly identified biggest challenge to providing services to persons who are deaf-blind was budget concerns. Approximately one-third mentioned the rural nature of their state as a challenge, which could be an indirect reference to budget as presumably expenses associated with either transporting professionals or maintaining their offices in rural areas can be high. When asked what would help them provide services to persons who are deaf-blind, 29.5% said additional funding and 29.5% said more resources. There appears to be the perception by some mental health providers that service delivery to persons who are deaf-blind will require considerable investment of agency funds.

The variety of answers about who most needs training is reflective of the many professions involved in mental health service delivery. The two most frequently mentioned professions were counselors and social workers, both fields that typically require graduate training as well as some state or national licensure or certification to provide mental health treatment. It appears that these are the professionals, along with psychologists and substance abuse therapists, who conduct much of the direct clinical work with consumers and their training needs may be different from other parties in the mental health service delivery system. Of those respondents who named administrators as most in need of training, several said that until agency administrators are made aware of the extent of the need there will be no substantive changes in their service delivery system. The increased awareness of and availability of services in states where lawsuits have been filed tend to support this assertion. Still other respondents stressed the need for the first point of contact at the agency to be positive, so wanted intake workers or clerical staff to have training about how to work with someone who is deaf-blind.

Implications

Mental health service providers may lack clear direction from their agencies regarding how to handle requests for services from persons who are deaf-blind. Further, many service providers do not appear well informed about where to get support and assistance regarding provision of mental health services for this population. Contact with state vocational rehabilitation agencies may be helpful in locating interpreters or other resources but those agencies are not designated mental health providers and many do not have the appropriate clinical staff available to address mental health concerns. Consequently, those contacts should typically not be regarded as an appropriate venue for mental health service delivery. Other resources that might be helpful in locating interpreters or providing support, if the mental health agency does not have staff trained to work with people who are deaf-blind, are HKNC regional representatives or, when it exists, a local agency for persons who are deaf. However, when seeking services outside of the mental health agency providers should be aware that persons qualified in providing mental health services to persons who are deaf are not always qualified to serve persons who are deaf-blind.

Given that in many areas, particularly rural ones, incidence of deaf-blindness is low, it may be more cost effective for some mental health agencies to subcontract with skilled private providers for mental health services for this population. But regardless of who provides the actual service, community mental health providers need some awareness of best practices in working with persons who are deaf-blind to address immediate concerns and negotiate referral arrangements. Most mental health providers are required to engage in continuing education to maintain their licensure or certification for professional practice and these continuing education activities would provide an ideal opportunity to learn about working with people who are deaf-blind.

Although the numbers of persons who are deaf-blind are low, they do have mental health needs. Prevalence increases with age and depression is associated with communication difficulties so mental health providers should be alert that depression among seniors could be associated with sensory loss. Additionally, the deaf-blind population is particularly vulnerable to exploitation and abuse. Community outreach to identify persons who are deaf-blind and offer mental health services to them, both as prevention and treatment, is an important part of comprehensive community mental health service delivery.

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Table 1

Services for Persons who are Deaf

Item	**N**	**Yes (%)**	**Don't Know (%)**
Does your agency have a procedure or policy in place to provide mental health services to deaf people in your state?	44	43.2	--
Does your agency have a plan or system in place to provide sign language interpreters for mental health services as needed?	44	68.2	--
Are there any therapists in the state who are fluent in American Sign Language (could be deaf or hearing)?	43	76.7	--
Does your agency have a formal method to measure sign language fluency of mental health providers?	33	30.3	--
Are there any private mental health providers in your state who have expertise working with people who are deaf?	42	57.1	35.7
Does your agency employ a mental health coordinator for the deaf?	43	37.2	4.7

Table 2

Services for Persons who are Deaf-Blind

Item	**N**	**Yes (%)**	**Don't Know (%)**
Do you have a procedure or policy in place to provide mental health services to people in your state who are deaf-blind?	44	15.9	--
Is there an effort in your state to provide outreach regarding mental health services for people who are deaf-blind?	22	40.9	--
Do you have a plan or system in place to provide interpreters who have experience working with people who are deaf-blind for mental health services when needed?	44	36.4	--
Are there any mental health professionals in your state, employed by your agency or otherwise, who have expertise in or awareness about the needs/experiences of people who are deaf-blind?	44	56.8	29.6

Table 3

Challenges to Providing Mental Health Services to Persons who are Deaf-Blind

Item	**Percent**
Lack of professionals with knowledge	43.2
Rural nature of state	34.1
High cost/Limited agency resources	29.5
Lack of/Limited awareness of cultural differences	25.0
Low incidence of deaf-blindness	20.5
Lack of qualified interpreters	20.5
Not aware of/Don’t know extent of need in the state	13.6
Outreach/Lack of awareness of DB about services	9.1

Table 4

Information/Training Topics Needed

Item	**Percent**
Communication methods and strategies	100.0
How to physically interact with people who are deaf-blind	97.7
Information about deaf-blind culture and cultural idiosyncrasies	95.4
How everyday life experiences impact the individual and may require counseling intervention	95.4
The impact of sensory deprivation on mental health	95.4
Ethical issues specific to working with people who are deaf-blind	95.4
General information about deaf-blindness	86.1
The role of and how to use an interpreter during a therapy session	83.7

Table 5

Group That Would Most Benefit from Training

Item	**Percent**
Counselors	38.1
Social workers	35.7
Other	19.1
Case managers	16.7
Intake staff	11.9
Administrators[a]	11.9
Interpreters	7.1
Psychologists	7.1
Diversity coordinator	4.8
Psychiatrists	4.8
Substance abuse therapists	2.4

[a] This group was not on the original list, but was identified by people who selected the “Other” category.