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Gathering Perceptions about Current Mental Health Services and Collecting Ideas for Improved Service Delivery for Persons who are Deaf, DeafBlind and Hard of Hearing

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Abstract

The authors present a model for obtaining feedback from consumers and therapists about mental health services and outreach strategies from persons who are Deaf, DeafBlind and Hard of hearing. Program planners from Western Pennsylvania used the focus group as a research tool to generate valid information to advance program development. Nine focus groups were conducted which were comprised of consumers, therapists or family members. Feedback from the focus group has led to the implementation of new services in Western Pennsylvania. Group members reported that the focus group format fostered a spirit of collaboration and community problem-solving.

Keywords: focus groups, deaf, deafblind, hard of hearing

Hearing loss is the sixth most common condition in the non-institutionalized United States population, with a prevalence of 9.35% (Iezzoni, O'Day, Killeen & Harker, 2004). Many consumers with hearing loss have limited access to the public mental health system. Deaf leaders, consumers and professional organizations have advocated for specialized mental health services for consumers who are Deaf. In a position statement from the National Association of the Deaf (2003) "accessible" treatment is defined as providing reasonable accommodations to consumers who are Deaf, DeafBlind or Hard of hearing. Culturally affirmative treatment is understood as receiving services from ASL fluent clinicians who are trained specifically to work with persons who are Deaf. Various lawsuits have spurred program development of specialized services for the Deaf in states such as Minnesota, Alabama and South Carolina (Gournaris, Hammerdinger & Williams, 2010).

For a variety of reasons, the prevalence of mental health problems is greater among those with hearing loss (McEntee, 1993). However, only about one-fifth of persons with hearing loss are able to access services when they seek

treatment (Pollard, 1994). Few studies have been published that address why consumers who are Deaf do not access services more frequently. Best practices for raising awareness about existing behavioral health services, and community opinions about current services or necessary service improvements which may be more recovery oriented, are little known.

Only a limited number of studies articles exist where consumer opinion has been obtained directly (from persons who self identify as being Deaf) about health services and health care access (Steinberg, Loew & Sullivan, 1999; Steinberg, Barnett, Meador, Wiggins & Zazove, 2006). There are even fewer articles in the literature where the specific needs of persons who self identify as being hard of hearing or DeafBlind are analyzed. (Trychin, 2003; Bailey & Miner, 2010).

We knew that specialized behavioral health services for the deaf are underutilized in our community by all persons who are Deaf, DeafBlind or hard of hearing. In 2005, county behavioral health administrators and service providers who served the Deaf community began to work together with community leaders and consumers on a task force. This task force aimed to begin to address issues related to observed disparities in behavioral health care services that exist for all persons with hearing loss in Western Pennsylvania. Program planners thought that by conducting focus groups with consumers who utilized services in our region, that the task force would be able to gather information to better direct service development and outreach efforts.

In the process of forming focus groups for research purposes, it has been suggested that it is best to compose focus groups of approximately 10 participants. Groups should not be highly different in power, language, status, income, or personal characteristics. It is felt that individuals will tend to censor their ideas if the group is too diverse (Creswell, 1998). To understand the perspectives of different groups of people, Creswell suggests composing multiple focus groups on the same topic.

We aimed to gather consumer input from individuals with hearing loss who utilized either English or American Sign Language. Groups were conducted in whatever language was primary. In this manner, Consumers and therapists could express their ideas and problem solve with others in their native language. We separated the consumer groups based on preferred language choice and accommodations requested. We viewed that these primary choices would translate into distinct issues that would affect health care access.

We created probes (see appendix) that would create a framework for information about best practices for community outreach and generate ideas for improvements on existing services which were needed in our community. A summary of topics include:

1. Access to Health Information
2. Resource Awareness
3. Barriers to Current Treatment
4. Preferred New Services

Methods

Nine focus groups were conducted which were approximately 90 minutes in length. These focus groups were all conducted in a large, Pennsylvania metropolitan area. We recruited participants from outpatient counseling centers, area support groups and community organizations for persons who are Deaf, DeafBlind or hard of hearing. Six focus groups were comprised exclusively of consumers, one group was comprised of therapists who served the population, and two groups were comprised of family members of consumers who received services at area mental health agencies.

Inclusion criteria for the six consumer groups included having moderate to profound hearing loss, a history of receiving mental health care, and a willingness to share prior experiences with the mental health care system. Inclusion criteria for the family groups included having a relative with hearing loss, experience with the mental health system, and a willingness to share those service experiences. Lastly, the inclusion criterion for the specialized service provider focus group was being a mental health counselor who currently provided therapy services to persons with hearing loss.

Thus, focus group participants were separated first by self-identification as consumer, family member or therapist. After these initial separations were made, four of the six consumer groups were constituted based on language preference and preferred accommodations. Because it was presumed that accommodation preference would divide the issues expressed in each focus group and the way that information access and service delivery occurred, groups were organized so that members had similar accommodation requests and language preference.

Two consumer groups were organized where members expressed a language preference for American Sign Language (ASL). Two other consumer groups

were organized where members who are hard of hearing expressed a preference for utilizing spoken English with FM amplification and Communication Access Real-time Translation (CART). CART was performed by an expert stenographer who typed the proceedings of the meetings into phonetic output in real-time English that is displayed on a screen. The FM system used by some group participants is a device that amplifies spoken language for a person who uses an oral mode of communication.

Three groups, including the remaining two consumer groups, were mixed as to the member's native language. These linguistically mixed groups included the group defined as DeafBlind, the transition age group and the therapist group. These groups were not subdivided by preferred language modality because group members participated regularly in multilingual settings. Two family groups were conducted utilizing spoken English.

Many authors have written about the unique needs of the transition age population. In clinical practice, in our region, there are many young people who are graduating from area schools and have hearing loss or deafness who present with unmet mental health and social service needs. Hence, the authors felt that it was important to conduct at least one transition age group. This population is defined as youths who are not yet self-sufficient, who may be completing high school or aging out of child behavioral health service (Clark & Uhrich, 2009).

For the groups where members requested ASL, the focus groups were conducted by mental health practitioners who were fluent in ASL. A Pennsylvania registered/certified interpreter was used as well for the purposes of recording the group proceedings.

The focus group that was comprised of individuals who identified themselves as being DeafBlind was the most varied in the accommodations that were requested, which by their description were related to the age of onset and severity of their hearing loss. Tactile sign was utilized by about a third of the group; others in the group used FM systems or communicated in ASL.

We collected basic sociodemographic information from focus group participants (see Table I). Focus group facilitators developed a series of probes (see appendix). There were two focus group facilitators, who regularly worked within the Deaf community and with persons who are hard of hearing or DeafBlind. Certified interpreters voiced the ASL discussions into a tape

recorder. CART transcripts were also collected. The focus group facilitators reviewed audiotapes and transcripts of all nine focus groups, and identified common themes of discussion across the groups. After reviewing the materials, two researchers generated coding categories to facilitate analysis.

The study was approved by the Institutional Review Board of the University of Pittsburgh Medical Center. All participants were volunteers for the focus group and consented to participate. Participant names and characteristics are fictionalized in this report to preserve anonymity.

Results

Despite differences in culture and language across the nine groups, some general themes of discussion emerged. Nonetheless, notable differences between ideas for outreach, information access and needed services were evident between the groups. The succeeding sections describe these similarities and differences within major thematic categories.

Communication

Both Deaf and hard of hearing interviewees reported that language fluency with their provider was of paramount importance for learning about their illness. Consumers wanted to learn about all aspects of their illness so that they could make informed choices about their recovery. All interviewees also felt that their hearing loss or “Deafness” had a negative impact on their potential for recovery. Hearing peers were perceived by group participants to have access to community support programs, housing and supportive living arrangements, peer support groups and supportive employment opportunities to which the group participants did not. Furthermore, interviewees universally described that their communication needs dramatically affected their capability to use existing services effectively.

The process of giving and receiving information and other communication-related issues were discussed extensively in all groups. Often it was reported that the consumer could not find health care professionals who were Deaf or fluent in ASL, nor professionals who were aware of how hearing loss affected mental health. Furthermore, it was reported that interpreters were not available at provider visits, for a variety of reasons. These communication and information gaps led to strong feelings about limited access to the mental health system.

Feelings

Interviewees often reported a sense of frustration in their pursuit of mental health care and a delay in finding culturally appropriate services. The frustration for some turned to anger and for others a sense of resignation. One Deaf man named Edward had a stroke and was not provided an interpreter for medical or mental health appointments. He stated:

I wanted to know whether I would ever be able to use my arm again. My stroke made it impossible for me to communicate in sign language at all anymore. I wanted to kill myself and I didn't want to write this sort of mindset related stuff back and forth on a note pad. I wanted answers, I wanted to know what was going to happen to me. I wanted to communicate in my language, so that I understood what was happening to me. I quit going for physical therapy too because I was so frustrated and angry by meeting with those people. My depression kept getting worse and worse, and I just wanted to kill myself.

Fear about misdiagnosis and institutionalization was particularly relevant for Deaf and DeafBlind individuals who communicated in ASL. One Deaf consumer named Robert, talked about his recent inpatient hospital experience. He said:

I was recently at a hospital where no Deaf people go. They treated me as if I was some kind of research object. They looked at me like I was some kind of research paper to write up because I was Deaf and I had schizophrenia too. I didn't trust the motives of staff. They didn't pay attention to my background or what I was struggling with. I was very afraid for my life and I was distrusting of them.

Isolation and loneliness were universally reported in the DeafBlind group. One culturally Deaf man who is blind said, "We are the loneliest people on earth...we don't find out information for months even about world events much less about treatment options for depression. No one cares about us. It takes time to communicate with us and no one wants to take the time."

Access to care was also affected by fears. One woman named Loretta from the focus group comprised of people who were DeafBlind stated:

My first focus is safety. I am isolated and lonely because I am afraid to go out....I rarely leave my house. I am afraid to go outside my house unless it is an absolute emergency. So I do not continue to leave my home for weekly therapy to go on a van with a total stranger in order to come to the clinic for counseling. It may take me three hours to get there with those transportation vans.

Language

There were prominent differences between the focus groups as to whether group members valued fluency in ASL, and what peer group they sought as they tried to access services. Deaf interviewees who communicated in ASL, family members of Deaf consumers, and DeafBlind individuals expressed an ideal preference for learning information and seeking assistance from providers or peers who knew ASL. A 25-year-old Deaf woman named Kathy stated:

I think that if someone knows your language and has a general respect for your cultural values or is Deaf themselves, there is less chance for them misdiagnosing or misunderstanding you. If a person communicates in my same language, I can ask questions easily, and I don't feel stupid. I want to learn about new things or things that I am worried about in a one-to-one setting with someone that I can understand...so I can have a dialogue. I want to be with people like me and I want to have professionals who work with me who communicate in my language or at the very least use an interpreter.

Conversely, group members who used English and amplification or CART did not seek to find providers who knew ASL. Neither did members of the focus group who had hearing loss, but who did not communicate in ASL, prefer being with others who used sign language. However, they did want providers and peers to be educated about the nuances of adjustment to hearing loss, understanding amplified speech, possible effective accommodations, and

assistive technology that would facilitate making a diagnosis and help to ameliorate symptoms.

Health Information

There were distinct differences reported between the groups as to where they turned to learn information about mental health and how they found area resources that were accessible to them. Deaf persons who knew ASL tended to learn and trust information that they gathered from others in their community who also knew ASL. Many consumers in the group where ASL was the primary language, were referred to mental health care by a friend, a rehabilitation counselor for the Deaf, or a Deaf friend who had been in counseling themselves. Family members of Deaf individuals stated that they often looked back to trusted professionals in other fields, such as educators whom they had encountered when their child was enrolled in school. Mrs. Glidden from the family group said, "My son is 32 years old, but I found help for him by calling his school...fourteen years after he graduated, but I figured someone there ought to know where to find a counseling place where they would help Deaf people."

Hard of hearing people described that they turned to their primary care physician or audiologist for answers or information about counseling resources. One participant in the hard of hearing group who communicated primarily using spoken English, stated, "We use therapists that are in the same counseling system as hearing people typically, but then these therapists usually don't know anything about how hearing loss affects mental health, and so we have to teach them."

Participants also described less interpersonal methods of acquiring information. One hard of hearing person stated, "We use phone books, the internet and any information we can find with our eyes...brochures in the doctor's office." Similarly, participants from all focus groups regardless of language valued finding information on the internet if it was comprehensible to them.

Considerable differences were noted between the groups as well in their general knowledge base about the role of a therapist and the goals of mental health care. Deaf consumers who communicated in ASL were often not aware of the various types of therapies, the rationale for group therapies, and the roles of an addiction counselor.

Most interviewees reported a general problem with finding resources and counselors who provided services to persons who are Deaf, DeafBlind or hard of hearing. In all nine groups there was unanimous reporting that there is no unified place to find resources about mental health for persons who are either hard of hearing, Deaf or DeafBlind. One woman stated, “You know you can call Area Agency on Aging and this great lady there knows everything there is to know to help seniors...what about us? We need a directory to find services for Deaf, DeafBlind and hard of hearing folks and their families or a resource line for us.”

In all the groups, participants often did not self-advocate. The details of the Americans with Disabilities Act (ADA) were not well known. Deaf and DeafBlind consumers did not know how the law applied to them. Group members often did not know that the health care provider was responsible for paying for an interpreter during their office visit or hospital stay. No one in any culturally Deaf group knew where to find effective advocacy support if an interpreter was not hired for them. They did not know about various advocacy organizations in the state that could help them.

Group participants had many practical ideas about how to raise awareness about resources and ways to spread information about mental health-related topics. Focus group members universally reported that professional education (in-services) and talks to social clubs and area support groups would be helpful. Topics to include, they thought, would be about area resources, the Americans with Disabilities Act, advocacy-related information and mental health-related topics .

The groups differed, however, as to which specific audiences these in-service trainings should be prioritized. Hard of hearing group members suggested that presentations could be given to such organizations as Hearing Loss Association chapters, audiologist conferences, assistive device clinics and family practitioners’ grand rounds. For groups where ASL was the primary language, group members expressed a desire for trainings to be directed to their support system, such as area Deaf clubs; and furthermore, expressed a desire to personally learn more about their insurance, the ADA law, mental health and area resources and social service and advocacy organizations that could help them. Transition age consumers and parents of consumers suggested the idea of periodic seminars or a fair where they could learn more about area resources and services that were available. Finally, all nine groups suggested a website where information could be posted would be helpful to their communities.

Priorities for Mental Health Service Development

Deaf and DeafBlind consumer groups where members utilized ASL had a strong preference that, for any new services that are developed, staff who are employed should be Deaf or absolutely fluent in ASL. Consumer and therapist group members expressed a concern that despite laws such as the ADA, Deaf persons who need an interpreter are rarely admitted to extended day programs. These include partial hospital programs, behavioral health skills training program, psycho-educational training programs or drug and alcohol programs. They described a perception that this was because providers are reluctant to hire an interpreter due to cost concerns. This financial consideration was felt to limit treatment options dramatically. All groups concurred that there are no clear solutions emerging to solve this problem. Ultimately, the groups viewed dedicated monies to underwrite the cost of interpreters as necessary to avoid discrimination that they report commonly occurs when they are referred for long- term partial hospital programs, housing facilities or addiction-related counseling or rehabilitation services.

Regarding new services that should be further developed in the community, Deaf consumers and their family members cited as a top priority the need for personal assistance services.

Our loved ones historically miss information that is important to them. They may not be able to read or understand their mail and such things as insurance information. They may sign up for a scam or be taken advantage of easily. Mistakes are made because loved ones do not have enough information, can't read or can't easily talk to others to find out the 'real truth'.

Deaf consumers and their family members suggested the idea of a place to drop in to get personal assistance with bills, medical decisions and phone calls.

DeafBlind group members were adamant about the need for consideration of the development of a Support Service Provider (SSP program) in western Pennsylvania as a means to increase autonomy and encourage independent living capacity. Members described a system of specially trained support personnel who work with individuals with both hearing and vision losses, similar to what is available in some cities. Helen Keller National Center has created a service description for SSPs. "SSPs provide visual and environmental information, sighted guide services and information accessibility to empower

DeafBlind individuals so they can make informed decisions and would make it easier for persons who are DeafBlind to access behavioral health care too.”

All groups discussed the idea of developing peer support services to be provided by a person “like them”. For example, the idea of a culturally Deaf person in recovery could mentor a Deaf person; a hard of hearing person could mentor a fellow hard of hearing person and the same for a DeafBlind person as well.

Support and training for independent living skills were identified in all groups as a sorely needed service. Interviewees in each focus group also mentioned specifically the need for life skills training, advocacy training, maintaining personal safety in the community, budgeting, employment supports, mobility training, environmental awareness, and assistive devices.

All groups also raised the issue of developing more self- and family-help groups. For example, parents wanted groups designed for them to learn about resources and about how to best help their loved one with decisions that affected their lives.

The need for supportive housing was another priority that was clearly articulated. Deaf and DeafBlind group members had obviously reflected on this at great length.

It is very difficult for a Deaf person to find any housing. There is a great amount of discrimination even if you are a Deaf person who doesn't have a mental health problem. It becomes even more difficult to find safe housing when we also have a mental health problem. We need supportive housing or modular homes or something like that, where we could all live in the same area if we chose to and still have independence. Then we could move out when we were ready.

Transition age individuals conceptualized a renovated apartment building with a “house parent.” “That way we could all be near to each other who knew our language if we got stressed out or if we needed information about something. We wouldn't have to worry about getting raped or anything.” A DeafBlind woman said, “We need a place to live together, assisted living, personal care, independent or supportive living program or whatever...we don't want to live and die alone. In New York City there are high rises specifically for DeafBlind people so they don't have to live in fear and die alone.”

The idea of in-home therapy services arose frequently. DeafBlind consumers stated,

We know that it is important to meet with other people outside our homes, but it takes hours to get to therapy appointments on public transportation vans. Last week there was a bomb threat in the Parkway tunnels... so I sat in the cab for two hours and no one told me what was going on....These kind of problems make DeafBlind people prefer to not come out of their homes for therapy...so the idea of someone coming to see us is a good one.

Underemployment and unemployment were also a common issue that affected mental health and insurance status as well for all groups. Transition to work and supportive employment programs that were accessible to hearing people were not accessible to group members. One consumer reported, "I have a graphic arts degree and I was recently offered a job putting clothes on hangers. I want to do something in my field, but no one wants to take a chance on me because I am Deaf and mentally ill. We need supportive employment opportunities and an opportunity to learn employment skills. Many of us have never worked or have not worked for a long time."

Discussion

Deaf, DeafBlind and hard of hearing interviewees reported on their experiences, feelings about current services, outreach strategies, and ideas for service development. The use of focus groups allowed us to gather unique insights into important ideas concerning ways to improve outreach and expand on existing mental health services that are culturally appropriate for different groups of persons with hearing loss. The use of focus groups allowed us to learn about participants' perspectives and experiences. The organizing of the groups by language, accommodation preferences and co-occurring visual loss allowed us to explore differences between groups of people with hearing loss.

Some commonalities between the groups emerged. A common feeling of frustration when trying to access the mental health system was reported. Communication breakdowns during clinical encounters made consumers feel that many mental health professionals did not understand the unique needs

of persons with hearing loss or deafness. These general feelings led many to avoid mental health care unless it was an emergency.

Significant differences between groups were notable, even about specific terminology. Differences between the groups about terms commonly used in mental health became apparent. For example, the phrase “social worker” had very negative connotations among some group members who used ASL. For some group members this term “social worker” evoked fears of a children, youth and family agent they believed historically would perceive Deaf parents as incompetent and take their children away.

Differences in preferred methods of learning about mental health services also were quite different between the groups. These differences in preferred ways to learn new information seemed to be related to language.

Interviewees who identified ASL as their language tended to learn about community resources by “word of mouth” at community gatherings, cultural events or on listserves to which they were subscribed. Some learned information on the internet. Deaf and DeafBlind interviewees expressed a desire for outreach talks at their community centers, social gatherings and support groups as a way to learn new information.

Hard of hearing group members typically learned about mental health resources by searching in a phone book or looking on a website. Hard of hearing group members thought that it would be helpful for audiologists and primary care physicians, and in advocacy groups such as Hearing Loss Association chapters to receive information about behavioral health related services in the region.

All groups valued the idea of a resource center or a place to call for help, or a drop-in center or call center for persons “like them.” A website where area resources could be posted was also suggested.

Language and culture played a significant role in ideas about service development. Interviewees who used ASL or were DeafBlind had well-formulated ideas about the need for case management, as well as drop-in services, peer support, and housing where they could be with others who shared their language or their dual sensory condition.

Lastly, interviewees offered sensible solutions for improving mental health informational campaigns to their respective groups. All were thankful about the opportunity to provide input into community service development.

Due to the feedback from these focus groups, several community interventions and actions have recently been undertaken. First, a grant from a local community organization led to the development of a mobile mental health team. This team includes a Deaf staff member and a therapist who can provide community outreach talks to raise awareness about mental health, social services, advocacy-related information and area resources. Other members of this new team now provide counseling and living skills assistance to consumers in their home.

Second, a new website at www.healthbridges.info was created to provide advocacy-related information and mental health education, in both English and ASL. Third, a committee was convened to generate a self-advocacy or "Accommodation Card" to raise awareness about patient communication rights. This card can be individualized and downloaded from the newly created website.

Finally, community leaders, mental health providers, consumers, and program planners recently applied for a grant for an eight-bed independent housing facility in which consumers could reside.

This study gathered ideas to aid in outreach campaigns and service development for persons with hearing loss who reside in Western Pennsylvania. The study does have limitations. The views of the participants may not represent the state or the U.S. Deaf, DeafBlind or hard of hearing populations at large. Nearly three-fourths of the participants in our study were involved in mental health treatment or in a support group. This makes our sample atypical, because few people with hearing loss successfully engage in therapy.

We did not seek the opinions of consumers from a diverse geographic region, or who lived in exclusively rural areas. We focused only on the recruitment of adult consumers who resided in Western Pennsylvania who were geographically near to services in a select metropolitan area. We did not specifically recruit persons in this study who had co-occurring intellectual disabilities, senior citizens or children.

Conclusion

These focus groups represented a unique way to gather information to examine differences and similarities between groups of people with hearing loss about service development and ways to raise awareness about mental health. Further research in larger, more representative populations of Deaf, DeafBlind and hard of hearing groups is needed to provide information amenable to quantitative analysis and to assure generalizable results. Consumers in this study did report that significant differences existed in preferred ways to acquire information about mental health related topics. In addition, significant differences emerged in what services were valued by consumers in the different groups. Thus, a “one size fits all” model will not work to meet the diversity of needs that face persons with hearing loss who seek mental health services.

There appear to be many unique needs and preferences related to housing, group therapies and acquisition of independent living skills for persons with hearing loss or multi-sensory disability that may be unique to them. It is evident that language, culture and accommodation needs are important variables to consider in planning for the development of a true continuum of recovery-oriented services to benefit consumers with hearing loss or deafness.

In summary, information gleaned from consumers in these focus groups informed recent advances in programming throughout Western Pennsylvania. The focus group process fostered a spirit of collaboration and community problem solving between community members and helped to set a stage for future work together.

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Table I. Focus Group Participants

Group	Size	Language	Ages	Race	Gender
ASL/Deaf	8	8 ASL	40 -65	8 C	2 M 6 F
ASL/Deaf	5	5 ASL	26-50	2 AA 3 C	2 M 3 F
Hard of Hearing	3	3 English	35-45	1 AA 2 C	3 F
Hard of Hearing	9	9 English	35-74	9 C	2 M 7 F
Therapist	10	1 ASL 9 English / ASL	25-60	1 AA 9 C	10 F
Family	3	3 English	55-65	3 C	3 F
Family	6	6 English	40-55	1 AA 5 C	6 M
DeafBlind	12	7 ASL 5 English	35-65	1 AA 11 C	5 M 7 F
Transition age	6	4 ASL (1 DeafBlind) 2 English	18-21	2 AA 4 C	3 M 3 F

Legend:

AA: African American; C: Caucasian; F: Female; M: Male

Appendix

Informational Probes for the Focus Groups

- How do you first learn about health topics and where to turn for help?
- Where do you learn new information about health care topics? (cholesterol, depression, etc.)
- How do people who are Deaf/DeafBlind or hard of hearing find out about where to go for help with such things as depression and drug or alcohol use?
- What aspects of behavioral health care work well in our region and what aspects need improvement?
- What type of information is needed by your community (or among people who have hearing/vision loss like yourselves)?
- What would make it easier for people to go for services like counseling or treatment for emotional or drug problems?
- What kind of mental health supports or programs would help Deaf people/hard of hearing/DeafBlind people have an opportunity for improved mental health outcomes, once they get depression, schizophrenia or bipolar illness for example?
- If there was a resource or support person who could go into the community to help people get connected to services, what kind of help should that person be able to provide?

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