

**IN OUR OWN VOICE: THE USE OF FOCUS GROUPS TO DESCRIBE MENTAL  
HEALTH CARE EXPERIENCES OF PERSONS WITH HEARING LOSS IN  
ALLEGHENY COUNTY**

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**ABSTRACT**

Disparities in access to mental health care for persons with hearing loss are significant public health problems. Despite federal mandates such as the Americans with Disabilities Act, the Deaf, Deafblind and hard-of hearing populations remain largely underserved. There is limited data available that define the obstacles that account for these differences. There is a great need for formative research to advance a better understanding of these issues.

In Allegheny County persons with hearing loss receive mental health services at a rate far less than the hearing population. A series of focus groups were convened to gather qualitative data to explore perceptions of mental health services and identify barriers to care and ideas for expansion of existing services. The results of the groups suggest that while there are some differences among the three populations in regard to specific barriers to care, all three populations expressed a lack of knowledge regarding where services exist and how to acquire mental health related information.

Many opportunities exist to advance the mental health needs of persons with hearing loss in Allegheny County. One is to develop a standardized protocol for both assessment and treatment of persons with hearing loss within all county mental health centers and physician private practices, including any social supports which exist outside the mental health system. This

protocol would make information available regarding where mental health services can be obtained, how they can be accessed, and what kind of accommodations are necessary.

Much needs to be done to begin to address the disparities that exist within the mental health system for all persons with hearing loss. Understanding what must be done is only the first step. It will take a commitment from many agencies within Allegheny County to realize a service delivery system that meets the needs of persons with hearing loss that is truly recovery-oriented.

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## **PREFACE**

I want to acknowledge the assistance of Dr. Wesley M. Rohrer and Dr. Christopher R. Keane in this study. I want to thank Dr. Martha Ann Terry for her continued support over the last few years and for her guidance in this study.

I want to thank my wife, Kim, for introducing me to the Deaf Community that means so much to her.

## 1.0 INTRODUCTION

In a presentation in 1998 at the First World Conference on Mental Health and Deafness, Bernard Arons, then director of the Center for Mental Health Services at the U.S. Department of Health and Human Services, declared: “America is decades behind where it should be in providing public mental health services to Deaf people; some states have no such services for them at all” (Arons, 1998, p. 3).

One in five people in the United States lives with a mental illness (National Alliance on Mental Illness, 2006). The United States Department of Health and Human Services estimates that 15% of the general population receives mental health services in a given year.

Persons with hearing loss are far less likely to seek mental health services than the general population. Research suggests that the prevalence of mental health disorders is at least equal for persons with hearing loss, yet they seek mental health care at rates that are less than 20% the rate of hearing persons (Critchfield, 2002; McEntee, 1993; Pollard, 1994).

The Pennsylvania Office of the Deaf and Hard of Hearing estimates that of the 1,281,666 people residing in Allegheny County, Pennsylvania, 12,613 people have moderate to profound hearing loss. Local mental health providers estimate that only 2.8% of this population receives mental health services (PAODHH, 2006). Little is known regarding the reasons for this disparity or effective practices that might address this issue.

Persons with hearing loss historically have had little opportunity to advise program planners about their unique needs and the barriers they have faced in meeting their mental health care needs. Officials of the Allegheny County Office of Behavioral Health and Substance Abuse Services sought advice from the Allegheny County Behavioral Health Task Force for Persons who are Deaf, Deafblind, and Hard of Hearing on how best to address the mental health needs of persons with hearing loss. This author has worked in the mental health field for over 30 years and is familiar with the workings of the Task Force since its inception in spring of 2005. In the fall of 2006 meetings were convened to discuss ways to gather information from persons with hearing loss regarding their mental health needs. Together we decided that a series of focus groups would best gather the kind of rich, qualitative information that could provide insight into why persons with hearing loss decide to seek mental health services and to help identify barriers to receiving these services in Allegheny County. Grants were obtained to budget for a series of 11 focus groups that would meet between December, 2006 and July 2007.

The primary purpose of this thesis is to describe the development and implementation of these focus groups and to discuss the analysis of data from the first four discussions. The objectives of the focus groups are to understand how better to provide recovery-oriented services, to identify barriers to mental health care, and to identify ways to improve outreach services to persons with hearing loss.

This information, and the information gathered in the remaining seven groups, will be used to inform the Allegheny County Office of Behavioral Health and Substance Abuse Services around developing programs and necessary services for persons with hearing loss in Allegheny County. These recovery-oriented services should be provided in a culturally competent manner and accessible to the same degree that services are accessible to the general population. Long

range use for the information gathered in the focus groups will be to improve assessment tools used by providers working with this population and to develop a case management support team in Allegheny County to assist persons with hearing loss.

## 2.0 BACKGROUND

In July, 2003, the President's New Freedom Commission on Mental Health issued a final report, "Achieving the Promise: Transforming Mental Health Care in America." This study found the nation's mental health care system beyond simple repair and that the current system is unintentionally focused on *managing disabilities* associated with mental illness rather than promoting the process of *recovery*. The capacity of the system to deliver quality services and treatment has been severely compromised. The report suggests that transformation can occur by designing treatment and services that are both person-centered and family-centered, and by focusing care on increasing a person's ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience (President's New Freedom Commission on Mental Health, 2003).

Such a transformation that is person centered with a focus on developing coping skills and building resilience may be achieved through a 'recovery' vision of service. A recovery vision of service is grounded in the idea that people can and do recover from mental illness and that the service delivery system must be constructed based on this philosophy (Anthony, 1999). A key component of a recovery oriented service system is moving beyond the medical model and its custodial mindset to embrace a system that promotes dialogue between consumer and provider. In this way persons with mental health problems can have a stronger voice in their own treatment and develop a sense of self-efficacy.

In 2004, the Pennsylvania Office of Mental Health and Substance Abuse Services (OMHSAS) issued to all counties guidelines based on federal courses of action concerning recovery-oriented services outlined in the “New Freedom Initiative: State Coalitions to Promote Community-Based Care.” Each county is responsible to assess its population’s health needs and resources and develop appropriate programming that meet those needs. OMHSAS includes in its guiding principles the following statement:

Every individual served by the Mental Health and Substance Abuse Service system will have the opportunity for growth, recovery and inclusion in their community, have access to culturally competent services and supports of their choice, and enjoy a quality of life that includes families and friends (PA OMHSAS, 2004, p.7)

There are few services in Allegheny County that address the mental health needs of persons with hearing loss. For example, there is no mental health inpatient unit that is dedicated solely to the unique needs of persons with hearing loss in Allegheny County. Only two agencies and four private practitioners within Allegheny County provide adult mental health outpatient services for persons with hearing loss (Allegheny County Resource Guide, 2006). The lack of available culturally competent services makes recovery for persons with hearing loss who are suffering from mental illness difficult.

Improving access to and quality of services for vulnerable populations including deaf, deafblind, and hard of hearing persons is a challenging issue that requires serious examination of the shortcomings and successes of the current treatment system.

## 2.1 POPULATIONS

For the purpose of this thesis, the population defined as “persons with hearing loss” includes those who are deaf, deafblind, and hard of hearing. The lower-case “deaf” is used when describing non-cultural matters in this population, such as the audiologic condition of deafness, while the upper-case “Deaf” is used when describing cultural issues, such as Deaf Culture, Deaf Community, or the population that uses American Sign Language (ASL). Similarly, uppercase Deafblind will refer to the Deafblind Community and lower-case deaf blind to refer to the combination of the dual disability of deaf and blind.

Trychin (2005) describes two classifications of persons with hearing loss. The first is an audiological classification and the second is a functional classification. In audiological classification, an audiologist uses a unit of measure to determine thresholds of hearing for tones of varying frequencies. These tones are measured in hertz (Hz) to describe pitch, and in decibels (db) to describe loudness. The following categories are derived from assessing hearing in this manner:

- normal hearing--tone thresholds between zero and 15 decibels (db)
- minimal hearing loss--tone thresholds between 16 and 25 decibels (db)
- mild hearing loss--tone thresholds between 25 and 40 db
- moderate hearing loss--tone thresholds between 41 and 55 db
- moderate to severe hearing loss--tone thresholds between 56 and 80 db
- severe hearing loss--tone thresholds between 81 and 90 db
- profound hearing loss--tone thresholds above 90 db

Functional classification concerns the issues of culture and identity that surround persons with hearing loss. These issues are related to how persons with hearing loss choose to communicate given their level of hearing loss and language choice.

*Deaf* is defined as a condition in which sounds, including speech, have no meaning for ordinary life purposes. Most people who are in this category have severe to profound hearing loss and are often born with this condition or acquire it early in life. They derive little or no benefit from hearing aids or other assistive listening devices. Visual means such as sign language, writing, text reading or speech reading are necessary to communicate effectively with and by persons who are Deaf (Allegheny County Resource Guide, 2005). Deaf persons often prefer to socialize with others who share their language, but often have co-workers who have normal hearing (Trychin, 2005).

Rather than viewing themselves as hearing-impaired, the Deaf Community takes pride in being deaf. Witness the recent events at Gallaudet University in which charges of “not deaf enough” were leveled at selected president Jane K. Fernandes by students and faculty at the school. The accusation meant that she was not a native user of ASL, but rather she used Pidgin Signed English (PSE), a blend of English and ASL.

*Deafblind* is a generic term that refers to people who are both deaf and blind. The main etiology of deaf blindness in the United States is Usher Syndrome, which accounts for about half of all cases. Usher Syndrome is a genetic condition consisting of deafness and Retinosis Pigmentosa, a visual impairment that causes both a narrowing of the visual field and a decrease in the ability of the eye to adapt to changes in lighting (night blindness) (Brennan, 1997; Steinberg, 1991). At what age and in what order of occurrence each individual is affected by deafness and blindness may impact the culture with which that person most identifies. For



example, Deafblind individuals who self-identify as being culturally Deaf are usually fluent in American Sign Language (ASL) and then gradually make the transition to tactile signing, or signing in the hand, as their vision deteriorates. Similarly, those who learned ASL at an early age may maintain their identity with the Deaf Culture. Deafblind individuals have mental health care needs that may be vastly different from the deaf and hard of hearing populations (Brennan, 1997).

*Hard of hearing* is defined as a condition in which there is some degree of hearing loss varying in severity from mild to moderately severe. A hard of hearing person may prefer either auditory or visual forms of communication, or sometimes prefer both modes of communication. Many hard of hearing persons function primarily within the “hearing world” in terms of social networks (Trychin, 2005).

Not everyone fits neatly into these functional categories, as many people share characteristics from more than one group. For example, some hard of hearing persons communicate by using ASL.

### **3.0 LITERATURE REVIEW**

Hearing loss has a prevalence of 9.3%, affecting about 28 million people in the United States (Barnett & Franks, 2002; Healthy People 2010). The prevalence of hearing loss increases with age and for persons over age 65 it is 30%. Persons with hearing loss use health care services, including mental health care services, differently than the general population and have reported difficulties accessing all types of health care services. There is little information available concerning why these disparities in care exist (Steinberg, 1991).

While the relevant literature consists of a small number of studies, a review nonetheless suggests that disparities that exist regarding access to mental health care for persons with hearing loss fall into three broad categories. The first of these categories involve a mental health system that is unfamiliar to persons with hearing loss and difficult for them to access. A second category surrounds issues related to language and communication. A third category describes attitudes and beliefs held by Deaf and Deafblind persons regarding mental health care.

### **3.1 MENTAL HEALTH SERVICES**

Lack of access to appropriate mental health services is seen as a significant barrier to treatment for persons with hearing loss. Some studies describe services to consumers of the mental health

system who have hearing loss as generally “user-unfriendly” (Munro-Ludders, 2004; Myers, 1993). Persons with hearing loss are often unaware of the mental health services that are currently available (Myers, 1993; Steinberg, 1998). Furthermore, staff in some mental health centers that have the equipment necessary to improve access to services for persons with hearing loss are poorly trained or ill equipped to use it. In a study to assess 131 community mental health centers in Illinois, Munro-Ludders (2004) found that even though 50% of the facilities reported having teletypewriting equipment (TTY) that allows persons who are deaf to communicate by typing using a standard phone line, only 8% had staff who knew how to use it. Only 9% of staff was familiar with resources and procedures for securing interpreter services for persons who use American Sign Language. In a study to assess accessibility of mental health services and crisis intervention for deaf consumers in Rhode Island, McEntee (1993) found that although more than 70% of respondents indicated that they had served deaf persons that past year, only 25% provided certified interpreters and only 39% were accessible to the Deaf community via a TTY. In addition, of the 28 agencies that responded to this survey, none employed a deaf staff member.

One program that showed success in increasing access to the mental health system for persons with hearing loss is Illinois Deaf Services 2000 (IDS 2000). A public/private partnership, IDS 2000 established service accessibility standards, a technical support and adherence monitoring system and a statewide telepsychiatry service. More importantly, IDS 2000 provided for mental health services for persons with hearing loss that was “mainstreamed” and accessible through the “front door” of all state-funded mental health agencies. In two years the total number of Deaf, Deafblind and hard of hearing persons treated by mental health agencies increased 60% from baseline (Munro-Ludders, 2004).

### 3.2 LANGUAGE AND COMMUNICATION

The impact of hearing loss and subsequent difficulties communicating regarding health care issues is hard to quantify, yet appears to be substantial. The National Association of the Deaf reported in 1993 that in one study of deaf hospital patients, 36.9% of those surveyed understood “some” or “very little” of the information medical staff presented to them, and 16.1% reported that they “did not understand” the information at all (NAD Hospital Guide, 1993).

The lack of a common language between persons with hearing loss and mental health care providers is a huge obstacle when clinically treating this population. American Sign Language, the primary language of the Deaf Community, is a linguistically rich and complex system with its own grammatical and syntactical rules. It is described as a “visual and gestural language, inextricably bound to the development and the very fabric of Deaf Culture” (Critchfield, 2002, p. 7). American Sign Language is the third most commonly used language in the U.S. after English and Spanish, yet few health care providers know much about ASL. Often professionals mistakenly view ASL as a manual version of English (Trychin, 2005). Furthermore, some terms commonly used in the health care lexicon do not even exist in the Deaf Culture or in ASL. For example, Ebert and Heckerling (1995) report poor recognition of the term “psychiatrist” among Deaf consumers and Steinberg (1999) reports varied, and for the most part powerfully negative, interpretations and associations of the phrase “mental health” among Deaf consumers.

Haskins (2004) suggests that health professionals often believe that lip reading is an effective means of communication, yet only 30-45% of English sounds are detected by lip reading. Clinicians also view note writing as an effective means of communication, yet the median English literacy level for deaf high school graduates is between the fourth and fifth grade level (Haskins, 2004; Healthy People 2010).

Little information exists regarding available mental health services designed specifically to meet the needs of persons with hearing loss. Deaf, Deafblind, and hard of hearing persons seem to have different requirements of the mental health system that are based primarily upon their unique needs that come from their chosen mode of communication, whether visually or orally based. Persons who prefer an oral mode of communication choose to seek services at the same sites frequented by the hearing population. They propose that staff be trained and services provided to meet their preferred individual communication needs. Deaf and Deafblind individuals in general prefer services that are more separate from mainstream health systems and that include staff that is fluent in ASL or tactile signing (Steinberg, 1991; Steinberg, 1998).

In a study to understand perceptions of health care experiences and suggestions for improving care among deaf and hard of hearing individuals, Iezzoni (2004) conducted semi-structured group interviews to identify concerns in six broad areas. Five of the six areas directly involved communication difficulties and the ramifications of these difficulties including possible medication errors, misdiagnosis and privacy issues.

In the national Public Health Survey hearing loss appears under the category “Communication Disorders” as hearing loss primarily affects language and communication (National Health Survey, 2006, p. 11). All persons with hearing loss are at a disadvantage regarding effective communication within the mental health care system and have expressed difficulties obtaining services, scheduling appointments, and exchanging information (McEntee, 1993; Steinberg, 1991). Consumers of the system feel frustrated, distrustful of the system and eventually abandon seeking care. A large portion of the miscommunication between consumers and providers is due to failure to address consumers in their preferred language. Subsequently,

information is not always presented in a culturally competent manner that allows for an exchange of dialogue (Steinberg, 2006; Steinberg, 1999).

There is much written regarding the lack of clinicians who communicate in ASL and the lack of interpreters as barriers to health care for persons in the Deaf Community. Interpreters transform the traditional dyadic relationship between provider and consumer of health services into a triadic relationship in which the interpreter strives to maintain a “blank slate” and not affect the therapeutic process (Brunson, 2002). Certified interpreters abide by a strict code of ethics and are trained in areas regarding confidentiality and impartiality. Many Deaf consumers of mental health services express concern regarding therapeutic discussions in the presence of interpreters, much preferring to deal with a clinician that is fluent in ASL (Steinberg, 2001). This situation also raises issues related to privacy and confidentiality of the consumer (Steinberg, 1998; Vernon, 2001). Even more difficult is when a hearing family member or a friend is asked to interpret for a consumer. Even a well meaning person may bring a bias to the conversation that could affect diagnosis or treatment issues

### **3.3 SOCIAL AND CULTURAL ISSUES**

The degree to which a person with hearing loss identifies with a particular culture is important to consider when assessing how mental health services are accessed. Persons who identify with the hearing culture and use spoken English, and who may have attended the public school system are likely to have different attitudes and beliefs than a person who self- identifies with the Deaf Community and communicates via ASL (Trychin, 2003). For example, within the Deaf Community there exists a distrust of the mental health care system and a general lack of

knowledge regarding understanding the symptoms and treatment of mental illness. Psychiatric hospitals are seen as places to be feared, where persons are taken and abandoned (Steinberg, 1999).

Steinberg (1999) reports that the avenues by which deaf consumers of mental health services find out about these services are almost exclusively through the Deaf Community. This underscores the significance within the Deaf Culture of the bond between deaf peers and the structure and values of the Deaf Community. It also contributes to ignorance about existing resources and mistrust of providers of services.

In a study to investigate knowledge, attitudes, and beliefs regarding mental illness among a group of deaf adults, Steinberg (1998) found a prevailing attitude that the mental health system is similar to “jail” and that if a deaf person is known to receive mental health services that person is “shunned.”

Little is known about how to effectively increase the number of Deaf, Deafblind, and hard of hearing persons receiving mental health services. Steinberg (1991) reports greater consumer satisfaction when deaf individuals were given a choice of providers. In an open letter to the mental health community and allied service providers, The National Association for the Deaf recommended that all persons with hearing loss be referred to specially trained providers who are culturally and linguistically competent and use appropriate support services (NAD, 2003).

### **3.4 SUMMARY**

Mental health services for persons with hearing loss fall far behind those of the hearing population in both availability and quality. Little information exists regarding how to successfully help this population receive the services they so desperately deserve.



## **4.0 METHODOLOGY**

### **4.1 FOCUS GROUPS**

Few studies reviewed for this thesis gathered qualitative information from consumers of mental health services in an attempt to understand how better to provide quality mental health care. Because of this lack of qualitative information this current study was decided to use focus groups as the primary source of data collection.

Focus groups are considered to be useful when exploring issues about which little is known; in addition, they are valuable when it is important to look at deep-seated beliefs, attitudes and opinions. The format of engaging people in brainstorming and generating ideas through dialogue with each other allows for a creative process that often uncovers barriers to behavior not available with other methods of gathering information (Neuman, 2003).

There is little published regarding the use of focus groups to explore the needs of persons with hearing loss. Yet this format allows for the opportunity to capture a better understanding of the needs, values and beliefs of persons with hearing loss. This methodology is especially consistent with Deaf Culture, as gatherings are considered opportunities for sharing information and topics often considered private to hearing individuals are openly discussed by Deaf individuals in moderately large groups (Steinberg, 2006). Written surveys and other forms of information gathering involving reading and writing are not as effective as direct contact with the Deaf and Deafblind populations since English is not their native language (Steinberg, 1998).

## 4.2 STUDY DESIGN

General inclusion criteria for all of the focus groups consist of: age, hearing loss, communication preference, self-identified level of experience with the mental health system in Allegheny County, and a willingness to share health care experiences.

Nine of the eleven focus groups consist of persons with varying degrees of hearing loss and communication preferences. One group consists of providers of mental health services that are Deaf and hard of hearing. Two other groups include hearing family members of persons with hearing loss that receives mental health services. Three groups include criteria that all members be consumers of the mental health system. The other five groups of persons with hearing loss included some participants that were not consumers. The composition of each of the 11 proposed groups is listed in Table 1.

**Table 1. Composition of Focus Groups**

<u><i>Group Participants</i></u>	<u><i>Age</i></u>
Culturally Deaf	18-25
Hard of Hearing	18-25
Culturally Deaf	25+
Hard of Hearing	25+
Deafblind Consumers of the Mental Health System	18+
Persons with Late-Onset Hearing Loss	65+
Culturally Deaf Consumers of the Mental Health System	25+
Hard of Hearing Consumers of the Mental Health System	25+
Parents of Deaf and Hard of Hearing Consumers age 25+	N/A
Family Members of Deaf and Hard of Hearing Consumers Age 18-25	N/A
Deaf and Hard of Hearing Providers of Mental Health Services	N/A

### 4.3 RECRUITMENT

Participants were recruited primarily by using two message delivery channels. An interpersonal channel was used to enlist participants through family, friends and clinicians at mental health centers that serve persons who are Deaf, Deafblind, and hard of hearing. An organization and community channel was utilized via Deaf, Deafblind and hard of hearing advocacy groups, the Allegheny County Behavioral Health Task Force for Persons who are Deaf, Deafblind, and Hard of Hearing, and newsletters and websites that reach each population. Input from community leaders was also helpful in deciding on the makeup of each group. Face-to-face interactions at community events as well as distribution of flyers were used to increase awareness of the focus groups within the Deaf, Deafblind, and hard of hearing communities. Flyers were designed with large print graphics and were at an appropriate literacy level in order to accommodate persons with low vision and/or low literacy levels (see Appendix A).

Recruitment for the remaining groups is currently taking place and every effort is being made to communicate to each group in a culturally appropriate manner and to use appropriate contact persons whenever possible. For example, the recruitment effort involving adult persons who are Deaf and who self-identify as having mental health problems requires identifying therapists, intensive case managers and the psychiatrist who serves them to function as point persons to assist in the recruitment process. The health care professionals who treat the Deaf consumers are given a brief description of the study. These persons can then answer questions about the study and effectively act as liaisons between consumer and researcher.

#### **4.4 INSTITUTIONAL REVIEW BOARD**

The Institutional Review Board (IRB) of the University of Pittsburgh approved the protocol: Gathering Perceptions About Current Mental Health Services and Collecting Data about Necessary Services for Deaf, Deafblind and Hard of Hearing Consumers on Jan 23, 2007, as “exempt” (see Appendix B).

#### **4.5 FUNDING AND BUDGET**

Funding for the focus groups is provided by a collaboration of The Allegheny County Office of Behavioral Health and Substance Abuse Services with Community Care Behavioral Health (CCBH). CCBH is a managed care company for medical assistance recipients for mental health and drug and alcohol services. Both groups have expressed an interest in how to best gather information regarding the unmet behavioral health needs, including quality of services, of persons who are Deaf, Deafblind, and hard of hearing. A working budget of \$12,000.00 was received through grants from the above agencies (see Appendix C).

## 4.6 FORMAT

A Focus Group Moderator Guide was created (see Appendix D). Coders, transcribers and consultants for the focus groups are from the University Of Pittsburgh Graduate School Of Public Health. Interpreters and assistive devices, when needed, are provided at the focus groups sessions and are listed in the budget in Appendix C.

Some general guidelines are followed to ensure conducting effective focus groups. Open ended questioning is used to elicit more discussion and minimize brief answers. General questions regarding health care are used early in the process and lead into questions regarding more sensitive issues like mental health care or substance abuse services. The guide can be modified based on the particular audience that evening. For example, interpreters can be used when American Sign Language is the preferred mode of communication and computer assisted real time captioning (CART) used for persons who are hard of hearing. Every effort is made to keep everyone informed of the content of the conversation, especially when interpreters are used.

A “greeter” is designated for each focus group site to ensure each participant is met with a welcome and if needed, directed to the correct room. A sign-in list is prepared in advance as are preparations for the room: name cards, paper and pencils, recording equipment, refreshments and gift cards. All participants are treated with the utmost respect and confidentiality is ensured as no identifying information is recorded.

## **4.7 DATA COLLECTION**

When working with the Deaf population, certified interpreters translated ASL into spoken English and voiced the discussion for audio recording. Researchers present at the groups reviewed the taped commentaries for accuracy. For the hard of hearing groups, computer assisted real time captioning (CART) was utilized so that focus group participants could read the transcript as it is being spoken. Note takers that attended the groups were cognizant of not only the content of the conversation but any non-verbal cues that could be used as information for this study. Laughter, blank stares, and body language are all examples of information that is useful to record.

Following each group a debriefing was held by the focus group team to discuss their thoughts regarding the group process. The debriefing helps to begin gathering ideas for coding themes and to allow for each person to present their interpretation of the group while thoughts and impressions are still fresh.

## **4.8 DATA ANALYSIS**

Each group was audio recorded and transcribed. Transcripts were generated and two members of the research team identified key recurring themes. A coding system will be developed based on those themes.

## **5.0 RESULTS**

Four focus groups were conducted between December, 2006 and March 2007. Each group lasted approximately two hours. All were conducted at sites within Allegheny County, Pa. Each participant was given a \$25 gift certificate for a local grocery market. Food and beverages were also provided. Seven additional focus groups will be completed by July, 2007. At that time, the results will be coded, analyzed, and then presented to The Office of Behavioral Health and Substance Abuse Services.

### **5.1 DEMOGRAPHIC INFORMATION**

Demographic information describing the participants of the four completed focus groups is listed in Table 1. Focus group size ranged from 3-9 members. Participants ranged in age from 28-62. Self-identity regarding hearing loss is included for the Deaf and hard of hearing groups. For the family group, hearing status of the non-participating family member is used when identified.

**Table 2. Demographic characteristics of Group Participants**

<b>Characteristics</b>	<b>Number of Subjects</b>	<b>Percent</b>
Gender		
Male	4	14%
Female	22	85%
Race		
Caucasian	25	96%
African-American	1	4%
Other	0	
Age		
18-25	0	0%
25-65	26	100%
65+	0	0%
Self-identity regarding hearing loss		
Deaf	13	50%
deaf and not part of Deaf Culture	0	0%
Deafblind	0	0%
Hard of hearing	9	36%
Hearing family member	4	14%



## **5.2 FOCUS GROUP RESULTS**

Results of each group are presented separately and in the order in which they were completed. Each group includes information sorted into four broad themes: mental health services, language and communication, social and cultural issues, and suggestions. These results are preliminary and will be included into the larger data set when all eleven groups are completed. Direct quotations from participants are in italics.

### **5.2.1 Deaf Focus Group**

The initial focus group was held on December 4, 2006. The group included nine Culturally Deaf participants who communicate using ASL, ages 25 and older, who did not self-identify as consumers of the mental health system and who reside in either Allegheny or Beaver County. Beaver County residents were included because they receive health care in Allegheny County. Recruitment was facilitated by a community leader who was known to group participants in a social context. This community leader notified group participants by email or in person about the group approximately one month in advance. A letter was then sent as a reminder to the homes of potential Deaf group participants (see Appendix E). This community leader served as a point person who could answer questions concerning details of the group process.

This group was moderated by Dr. Martha Ann Terry, University of Pittsburgh Graduate School of Public Health. The questions used in the initial focus group are listed in Appendix F.

### **1.) Mental Health Services**

- Most participants were aware of the term ‘social worker’ within child protective services, but no one understood the role of a social worker in the mental health system.
- While group members were aware of inpatient mental health services that were available, no one knew that outpatient services also exist.
- At some facilities interpreters are not used in every instance where one should be used. Word spread among the community and as a consequence persons who are Deaf no longer seek treatment there.
- No health agencies were viewed as adept at handling TTY calls. One woman stated she was waiting for her hearing daughter to come home for the holidays in order to get a doctor’s appointment.
- No one knew who was responsible for paying for an interpreter.
- No one knew how to find a counselor or clinician within the mental health system. One woman stated, *I don’t know. I have no idea. I don’t know where it is. That’s a problem. We don’t know where these things are. I have no idea.*
- No one knew where to turn to complain about a health care problem or how an insurance provider could offer assistance.
- Group participants heard of the Americans with Disabilities Act (ADA), but did not know how it could apply to them.

## **2.) Language and Communication**

- Language fluency was judged as more important than any specific degree or counseling skill.
- Contact with others who shared their language was important.
- One woman who asked her physician for an interpreter was told that writing back and forth *was good enough*.
- *The doctor said I don't need an interpreter. He said 'you can read what I write to you' because he wanted to save his money. He refused to hire the interpreter. He wouldn't hire the interpreter.*
- Participants suggested that note writing is commonly used by health care professionals. This method of communication is viewed as not allowing for an adequate exchange of health related information.
- If given a choice, group members preferred a physician that used a family member as an interpreter over a physician that passes written notes back and forth. One woman expressed concerns that this practice was a violation of her mother's privacy rights but felt she must comply so her mother would benefit from the appointment.
- The group felt that doctors don't understand how much more information could be conveyed if interpreters are used.
- Physicians informed some of those in the group to bring a family member to use in lieu of an interpreter.

- Only one interpreter was known to the group; she is not certified and her services are not paid for by the physicians in the area.
- No one reported contacting the available interpreter services that exist in Allegheny County because they did not know that interpreters could travel beyond county borders.
- One woman recounted how her husband had a stroke. When he met with a neurologist and rehabilitation staff he had many questions regarding his treatment. He repeatedly asked for an interpreter and one was never hired. He quit going to see the neurologist because *it was not worth it*.

### **3.) Social and Cultural Issues**

- *Avoid the health care or mental health system if you can.*
- When an interpreter was used at a doctor's office the doctor's name was referred to others in the Deaf Community.
- Fear of growing old in isolation was a recurring theme.
- Group members expressed fear of advocating for an interpreter. They felt their physician would stop seeing them if they repeatedly asked for one.
- "Peer support" was universally valued.

### **4.) Suggestions**

- It would be beneficial if someone could help with reading important mail such as Medicare D information in order to access services and assistance with the language used to explain insurance coverage.

- Deaf prefer to live in close proximity of each other in order to provide support. Suggestions included a ‘high-rise’ apartment building.
- Support staff who were Deaf or ASL fluent could be helpful if they were available to visit in the homes of the Deaf.

### **5.2.2 Hard of Hearing Focus Group**

The second focus group was held on February 23, 2007. The group consisted of nine persons who were hard of hearing, ages 25 and older, who did not self-identify as consumers of the mental health system. Some identified as members of The Pennsylvania Hearing Loss Association (HLA-PA), a support group for persons who are hard of hearing.

Recruitment was facilitated through a community leader. The person who assisted in recruitment for this group is the assistant director of The Pennsylvania Hearing Loss Association. This woman offered a list of interested persons and these people were contacted by email or TTY or amplified phone. The contact method was dependent on their preferred communication modality or which assistive listening device they typically used.

During the group process, five members of the group admitted experiencing depression or anxiety in the past and three members reported being diagnosed with mental health problems. Participants discussed their experiences with mental health or drug and alcohol services and all shared their stories very openly with the group.

#### **1.) Mental Health Services**

- People who are hard of hearing often first try to approach the same mental health providers that serve hearing people.

- Participants stressed the importance of quality of services.
- No one knew of any drug and alcohol groups that cater to or specifically welcome hard of hearing people.
- *It would be nice to have providers who were savvy with serving persons who are hard of hearing; drug and alcohol providers, as well as physical and mental health providers.*
- Assistive devices and hearing aids are indeed very helpful to allay anxiety and enhance self-esteem, but typically mental health providers know nothing about these. Also, insurance never covers these services.
- The Office of Vocational Rehabilitation personnel and audiologists lack pamphlets that direct people where to get assistive devices, where to turn for emotional help, or what constitutes a mental health or drug and alcohol problem.

## **2.) Language and Communication**

- One-on-one interactions and explanations in a quiet room are very valued.
- Relief, but surprise, if a provider remembers to always face towards the client, and not use the phone to convey information.
- Hard of hearing people often would like to have their diagnoses written down so that they can peruse their records or look things up on the web.
- *Captioning is not a good way to get information on any issue. There are too many inaccuracies.*
- *Insurance companies and the medical assistance office are used to doing business over the phone, which is not always best for us.*

- A common misconception by both consumers and audiologists is that getting a hearing aid will fix all the emotional related problems.
- Drug and alcohol groups are typically difficult settings in which to communicate due to background noise and uneven sound sources.

### **3.) Social and Cultural Issues**

- Most persons in the room described frustration that often accompanies hearing loss. They stated that persons with hearing loss initially don't realize how hearing loss affects their emotional state. One woman described how her hearing loss lead to her divorce.
- Many group members commented that interactions with the health system remind them that they are powerless and they comment that health care visits often causes them to revisit the grief and loss associated with the hearing loss. *It was a most horrendous experience.*
- Many participants commented that hearing loss is a big blow to self esteem and hard of hearing persons do not feel empowered enough to make requests of their service provider due to a perceived "power differential."
- Most have to often change insurance or get medical assistance because it is difficult for them to keep a job.
- Hard of hearing persons often spend much of their time describing how hearing loss affects their lives and the health care provider does more listening than helping. When describing a therapy session with a mental health counselor, one woman stated that she was focusing too much on her hearing loss and not discussing her mental health problems with the clinician. The clinician knew little regarding hearing loss. *If persons who are*

*hard of hearing themselves have not accepted their hearing loss and the ramifications that that the hearing loss has on their lives, this kind of therapy can be wasted time.*

#### **4.) Suggestions**

- A videotape could be generated for providers that would explain about hearing loss, which may simulate different levels of hearing loss and how it impacts lives.
- Providers could get a certification for undertaking this “sensitivity training.”
- *Hearing support specialists exist in other cities. This person functions as a ‘big brother.’ This person has hearing loss too. They can provide advice and help people get connected with the appropriate services that they need. They often have knowledge of where behavioral health services are available, where drug and alcohol services can be accessed, how to get assistive devices, and how to get signed up for Medical Assistance.*
- Many hard of hearing people are connected with Pittsburgh Hearing Loss Association (HLA) and read the newsletter “Hearsay.” Information could be placed there.
- A brochure should be generated that explains the signs and symptoms of anxiety and depression and where to turn for help.
- *Advocacy brochures should be generated that list accommodations that people often request.*
- *Most hard of hearing people are avid readers, constantly looking with their eyes for information, since their ears fail them usually in most health care settings. Therefore a brochure that guided people put in places where hard of hearing people go would be welcome.*



- *Richard Meritzer and the Disability Task force will be using Public TV to get information out in an awareness raising spot. Perhaps information relevant for persons with hearing loss can be put on that spot.*
- *Because Allegheny County has the second largest population of persons with hearing loss in the country we should work to improve how health providers deal with this population in order to decrease the anxiety of persons with hearing loss as a sort of preventative mental health strategy.*
- One woman cited her experiences in Atlanta. She described how she was asked by staff how they could make her situation easier for her to understand what is going on.
- One suggestion was that our task force should generate a protocol for local hospitals to use that helps to outline what to ask a consumer when a provider encounters a person who can't hear. The protocol would be similar to the familiar angina protocol in hospital emergency rooms. This would help the person who is anxious and unable to hear to understand what is happening to them.

### **5.2.3 Family Members of Persons with Hearing Loss Focus Group**

The third focus group was held on March 19, 2007. The group was comprised of three hearing parents of adult consumers of mental health services that have hearing loss. Two parents each have a child that is Deaf and one parent has a child that is Deafblind.

The family members were identified by a psychiatrist who treats Deaf and hard of hearing persons in the Pittsburgh area. All of the family members had normal hearing. They were

informed of the focus group by telephone three weeks in advance of the focus group. A follow-up letter was sent to their home one week in advance as a reminder of the group.

### **1.) Mental Health System**

- There was a general lack of knowledge about where community supports and services existed for mental health and drug and alcohol services for Deaf, Deafblind or hard of hearing family members.
- Inpatient experiences for family members were terrifying because hospital staff rarely spoke with their loved one and did not include the hearing family member in treatment.
- One participant recounted how ambulance drivers did not try to gather any background information surrounding the involuntary commitment of a Deaf consumer while transporting him to the hospital.
- Family members feared misdiagnosis and overmedication happened because medical information is not always gathered using the persons preferred mode of communication.
- When questioned following complaints from family members, hospital staff frequently cited HIPAA as a reason for not contacting family members. Family members were certain that their Deaf loved one had no clue what HIPAA was and that their loved one would have welcomed family input.
- In addition to perceived errors that were made in diagnosis about major mental health phenomena, family members feared that hospital staff gathered no information about learning disabilities or possible mental retardation. Family members thought that this information would be relevant for discharge planning.

## **2.) Language and Communication**

- Language barriers in the workplace make employment unlikely, particularly when a loved one has mental health issues in addition to hearing loss.
- Language barriers lead to self esteem issues and rejection in the workplace. These issues make the recovery process of the Deaf family member from mental illness very difficult.
- Lack of reading skills is a huge stressor. Deaf persons frequently miss deadlines and don't pay bills in a timely fashion which increases their stress.

## **3.) Social and Cultural Issues**

- It is difficult for a Deaf person to find housing. This is exacerbated when they also have mental health problems.
- Family members felt that professionals that they encountered were unprepared to guide them about the decisions that they had made about educational choice, amplification and intervention for mental health and drug and alcohol services.
- Family members stressed that because loved ones have hearing loss and have historically missed relevant information in their lives, they often make poor life choices which add to the stress in their own lives as well as add to the stress of their family members.

## **4.) Suggestions**

- There should be one hospital were Deaf people could go where family members could be certain that their loved one could get help and that their loved one's rights would not be violated. Family members did not seem to care where this hospital was located within our region.

- Supportive housing is sorely needed. Intensive Case Management and Resource Support Team staff who are fluent in ASL could be used to assess status and monitor for needs.
- Modular homes could be purchased so that Deaf people could live in the same area and yet still have some level of independence.
- Supportive housing staff should be ASL fluent. They should be paid more so that they are tempted to stay in the field of mental health. This group cited many relatives of Deaf people who were ASL fluent and became interpreters or even maids because the pay was better.
- Parent support groups are desperately needed in the area. Most parents report having experienced depression themselves related to the condition of their loved one.
- The National Alliance for Mental Illness has been a good resource for some parents. Parents of Deaf consumers should be informed of this available support.
- Staff at schools where Deaf, hard of hearing and Deafblind children go should all know where mental health resources are available. Participants stated that parents often return to the school system for information even 20 years or more after their child has graduated as they are perceived to be trusted and knowledgeable professionals.
- Parents should all be informed about community and behavioral health supports, even before their child needs them because behavioral health and drug and alcohol problems are so rampant.
- Preventative talks about drug and alcohol abuse, rape, abuse and sexually transmitted disease should be given by Deaf adults to children, so that Deaf children can be aware of these problems.

- Schools, audiologists at Children’s Hospital and Eye and Ear should get updated resource directories.
- There should be one commonly know phone number/video number where questions relevant to services for Deaf persons can be answered.
- A resource support team should offer:
  - Mentors
  - Daily living skill training
  - Budgeting skills staining
  - Mobility training
  - Relationship training
  - Employment supports
  - Safety training
  - Environmental awareness
  - Assistive device awareness
- *It is great to help with program planning. We should have the opportunity to meet with program planners again. You don’t need to pay us!! We can pay you!!*

#### **5.2.4 Deaf Consumers of Mental Health Services Focus Group**

The group was comprised of four Deaf adult consumers of the mental health system who communicated in ASL and one hearing family member. The group was held in the community

room at Pittsburgh Hearing and Deaf Services (HDS). Two certified interpreters were used to assist with communication.

### **1) Mental Health System**

- *In instances when Deaf people go for mental health treatment it is very important to have a certified interpreter. This is because if the interpreter is not skilled and misinterprets what the Deaf person says, then a person could get a wrong diagnosis and get the wrong medicines and maybe get sicker or maybe get locked up.*
- *Therapy helps Deaf people but people don't know what therapy is for.*
- *Deaf people suffer when a hospital or clinic doesn't get interpreters when a Deaf person comes for treatment.*
- *I used to go to a place where no Deaf people go. A big university place here. They treated me as if I was some kind of research object. They looked at me like I was some kind of paper to write up because I was Deaf and had schizophrenia. They didn't pay attention to my background or what I was struggling with. I feel much more comfortable going to a place where I can relax where people understand my culture and my language.*
- *If a doctor values and respects a client, they should listen to what the client needs in order to get help.*
- *I met a lot of interpreters when I was an inpatient recently. That gave me a chance to tell people about the things that I was thinking about and the people who helped me at the hospital could make better decisions about medicines that I needed because they could understand what was wrong with me more clearly.*

- *I found out about where to go for mental health services from a WPSD (Western Pennsylvania School for the Deaf) counselor.*
- *I found out about mental health services for the Deaf from my OVR (Office of Vocational Rehabilitation) counselor.*
- *In one other state where I lived, they had a place where you could drop in for help if you didn't understand a letter. They also housed OVR services for the Deaf there, interpreters, drug and alcohol counselors and mental health counselors. People could get info about pretty much anything there. There were Deaf people who could let other Deaf people know about different places to go for help.*
- Every county in Pennsylvania should have a center where Deaf people could drop in for help.
- *I know people who need help with drug and alcohol problems.*
- *I never heard of any place where Deaf people were welcome for help with drug or alcohol problems. In fact, Deaf people I know have been refused admittance to some programs because of the fact that they would need an interpreter for a long period of time.*
- All generally agreed it would be good if there was a drug and alcohol program that accepted Deaf people.
- Deaf people usually learn about where to go for help from other Deaf people. Sometimes family members help too.

- *I found out about my family doctor from someone in my family. That doctor doesn't use an interpreter, but if something was really wrong with me I guess that they would tell someone else in my family.*

## **2) Language and Communication**

- *In other states where I have lived, people would ask me if I needed an interpreter. Here doctors have actually asked me if I brought my own interpreter. I am the client and I am Deaf. I guess doctors don't know the law about equal access to services for everyone.*
- *Sometimes I learn about new information on the internet or from co-workers.*
- *I would not understand anything that is happening to me at a doctor's office if I didn't have an interpreter. Often I don't get an interpreter at my appointment so I might as well not have gone. I need to know about high blood pressure and things like that and I like to learn that information from my doctor. They have more training and should be the people who tell you about what they think are wrong with you.*
- *Video relay has made it easier to schedule an appointment for myself.*

## **3) Social and Cultural Issues**

- *We want equality and respect and then we would be happier. That disrespect affects our mental health too you know.*
- *Deaf people like to learn information from other people who are Deaf or who know American Sign Language. I think that this is because if someone knows your same language there is no chance to misunderstand something. You get the concept clearly. You feel more comfortable asking questions. You don't feel stupid or anything.*



- *I would like to learn about new things in a 1:1 situation where I can use my native language freely.*
- *I prefer to go to a doctor or therapist who is fluent in ASL and knows about Deaf culture.*
- *At HDS (Pittsburgh Hearing and Deaf Services) people understand my language and my culture. I wish more people knew about this place. Doctors don't know about it either.*
- *I wish doctors at different places knew about my culture and my language.*
- *I used to work in Washington DC. There, Deaf people were better understood. OVR would work to put Deaf people in jobs for which they were qualified and trained for. So hearing people saw Deaf people in prominent jobs and there was more respect for Deaf people.*

#### **4) Suggestions**

- *We need a person who knows ASL. Maybe they would be able to be Deaf too who can explain where we should go for things. You know, like where to go for different services; a support person who has had the same experiences before.*
- *I did something like that when I lived in California. I did that service for free so that I felt good about myself and could help other Deaf people who were less fortunate even than me.*
- *Most agreed that there should be a Deaf newsletter or a flyer or website where Deaf people could read information regarding health care that is written in their language. This could also contain job listings and housing information. Deaf people in Pittsburgh are passive you know. There is a lack of information and a lack of a good way to get*

*information. A newsletter would be great!! Maybe WPSD, OVR and HDS or other people could work on that together. I would help!*

- *OVR counselors for the Deaf are not informed about very good jobs for us. I have a graphic arts degree and they offered me a job at Goodwill putting clothes on hangers for minimum wage. That is DEPRESSIING!*
- *All the services that we have are outpatient counseling now. Hearing people have emergency services if they need help. Could we get that?*
- Requests were made for more skills training opportunities in order to get better jobs.
- Most agreed that there needs to be more education regarding the Americans with Disabilities Act. One person suggested a workshop that included both consumers and providers.

## 6.0 DISCUSSION

Focus groups provide a unique opportunity to gather input from consumers of mental health services about barriers to care and information about unmet service needs in their community and to gather information about services that have been most helpful. The process of organizing these focus groups has allowed individuals, organizations, policy makers and service providers with an opportunity to come together to share ideas that may bring about effective system change. The process of effective participation in focus groups allow for the shaping of individual self-efficacy and the belief that each person has the power to effect change by his own actions as well as observational learning (Webb, 2001). Participants learn from one another and experience the positive feeling that people typically get when others validate what they say. The evidence of perceived empowerment emerged as many persons with hearing loss expressed gratitude toward the researchers in allowing them to “make a difference.”

The focus groups suggest that there are distinct health care needs as well as barriers to care that exist for each of the Deaf, Deafblind , and hard of hearing populations. Understanding these differences is an important first step to develop therapeutic relationships and to develop services that are culturally competent. Effective mental health services may be enhanced by a successful therapeutic relationship between the therapist and the consumer of the services.

The four focus groups examined a variety of experiences with mental health services within Allegheny County, Pennsylvania. A preliminary comparison of the results among the groups

showed that all persons with hearing loss report difficulties in knowing where to turn for mental health services. Similarly, most participants did not know where to turn to find information on these services. Family members reported similar experiences. Directories of services that exist do not reach enough of the target population.

Most surprising is the lack of understanding among participants of the role of social workers and the purpose of counseling within the mental health system. In a study that examined cultural and linguistic barriers to mental health service access among Deaf consumers, Steinberg (1998) refers to 'recognition of terms in English' as a measure of knowledge. She found the term "social worker" recognized by 80% of the study participants (N=43) and "counselor" by 87% (N=47). These were two of the highest scores in her study. This issue needs to be more closely examined in our future groups.

Participants reported many negative experiences with the mental health system. Most negative experiences centered on reports of communication difficulties. Hearing loss is one of the disabilities covered by the provisions of the Americans with Disabilities Act (ADA). With passage of the ADA, persons with hearing loss were guaranteed equal access to all services. The ADA was signed into law in 1990 with provisions that mandate equal communication access for persons with hearing loss. Simply stated, health care providers must have a way to communicate with persons that have hearing loss. It is a broadly written document and many aspects of the law are still being interpreted by the court system. The ADA states that all physician offices are public accommodations and therefore are subject to the provisions of the ADA. For example, the office must ensure "effective communication" with deaf patients and deaf family members of patients. However, the cost of adhering to the ADA cannot be passed on to the patient, and insurers are not required to cover the cost of interpreters. Interpreter fees can exceed

reimbursement dollars, adding a financial burden to the already existing barriers to service (Iezzoni, 2004).

Deaf participants acknowledged as barriers a lack of clinicians that are fluent in ASL and that few interpreters are available upon request at both hospital settings and physician offices. Hard of hearing participants spoke of not having their preferred language asked of them or that staff assumes that it is appropriate to write notes back and forth. Hearing family members of both Deaf and Deafblind consumers of mental health services had similar experiences and reported much frustration with a system that Steinberg (1991) noted is difficult to navigate. The benefits of improved communication not only enhance diagnosis and treatment, but consumer satisfaction which is associated with treatment compliance.

Ideas about how mobile personnel can be used to provide services to persons with hearing loss in the community were discussed, as well as how to assist persons with hearing loss interface with the existing mental health services more effectively. Mobile personnel teams are an interesting concept that is based on Community Treatment Teams that already exist in some areas in Allegheny County and travel to the homes of consumers.

Participants reported a perception that mental health clinicians did not understand much regarding hearing loss and added that this view is a barrier to seeking services. “No one wants to go where they don’t know much about you,” stated one participant. Suggestions to educate providers was a frequent topic of discussion. Providers need to be informed of these perceptions among persons with hearing loss in order to be able to provide appropriate services that are accessible in the consumers preferred method of communication.

Differences between the group responses sometimes correlated to which culture a person most identifies. Deaf respondents referred to a “pride” in being Deaf and comfort within a

culture that identifies less with the hearing culture than their hard of hearing counterparts. They prefer “Deaf sites” for mental health services that are separate from where the hearing community receives services. These sites would be staffed by clinicians that understand the Deaf Culture and are fluent in ASL.

Hard of hearing persons responded that their hearing loss resulted in “grief and loss” and is a blow to their self-esteem. Feelings of a power differential with hearing health care providers are strongly associated with consumers not asking for services they should have. They prefer to be seen at sites frequented by the hearing community but need the provider to understand their communication needs and have appropriate services available.

Preliminary results from the four focus groups have already had an impact with The Allegheny County Behavioral Health Task Force for Persons who are Deaf, Deafblind, and Hard of Hearing. In response to the information gathered at the focus groups, the Task Force is looking at ways to address how to better educate both providers and consumers regarding the Americans with Disabilities Act. Also, a conference titled *Healing Partnerships: Understanding and Solving Communication Challenges with Persons Who are Deaf, Hard of Hearing, and Deafblind* is planned for May 18, 2007. The conference is designed specifically to present information about the ADA law, to raise awareness about what outpatient counseling services are available in our region, and to discuss among health care providers in attendance at the conference about the impact of hearing loss on health care accessibility.

## **7.0 CONCLUSIONS AND RECOMMENDATIONS**

This study is limited in the small number of groups convened and its limited inclusion of persons receiving services in a single urban county in Western Pennsylvania. Participants in the focus groups were not chosen randomly and are not representative of the entire population of persons with hearing loss in Allegheny County. Persons who agreed to participate in the focus groups may have a different set of experiences with the health care system than those that chose not to participate or who were not aware of our study. For these reasons, the results do not generalize beyond the focus groups we conducted. More research in larger, more representative populations is necessary to understand how to better provide effective and culturally competent mental health services for persons with hearing loss.

While the composition of the subsequent focus groups has been largely determined, the challenge is to make this study more available to African-Americans. Similarly, due to the small turnout of parents of adult persons with hearing loss, more information is needed from parents and another parent group may be included in the study. Other future groups for consideration are members of the school system, including school nurses, administrators, counselors and social workers.

There were methodological implications that arose from conducting focus groups with this population. Smaller groups were used for the Deaf population in order to keep within the allotted time frame of the programs. The use of two interpreters and the process of using ASL

seemed to add to the length of some discussions. Similarly, the use of CART, in which a court reporter operated a stenotype machine linked to a computer that projects spoken words onto a projector screen is also more time consuming than a spoken conversation. Based on these challenges, our experience suggests to have smaller groups of around 6-8 persons when participants are using ASL to communicate. It was our experience when using CART that eight was an appropriate number of participants. It is also necessary to have a room large enough to accommodate the equipment and stenographer, and also to have the participants seated on the same side of the room so they can all view the screen.

Participants of the focus groups took advantage of an infrequent opportunity to speak freely describing their thoughts regarding mental health services. The challenge for providers of these services is how best to use these results to improve resource utilization, expand on existing services, and provide feedback to the appropriate agencies that can act on these issues.

Disparities exist in service acquisition and in the number and kinds of services that are available for persons with hearing loss. The information gathered in the focus groups indicates that existing services designed to meet the needs of this population are underutilized. Furthermore, few in this population know where to turn for direction or availability of services.

Opportunities exist to advance the mental health needs of persons with hearing loss in Allegheny County. The first is to increase awareness of existing mental health programs in Allegheny County. More brochures and printed materials similar to the Allegheny County Resource Guide need to be designed and distributed widely among providers of services, organizations, advocacy and support groups, schools, and hospitals. Similar information needs to be available via links to popular consumer and advocacy web sites.



Peer-support services and self-advocacy training regarding mental health issues need to be made available for persons with hearing loss just as they are available for the hearing population. The Director of The Allegheny County Office of Behavioral Health and Substance Abuse Service is currently in discussions with local agencies regarding the feasibility of developing such services.

More education sessions need to be designed that train providers regarding the needs of persons with hearing loss. Providers need to be made aware of cultural and social issues so they can better understand the health values and beliefs that may influence behaviors of persons with hearing loss. Above all, persons with hearing loss who are consumers of mental health services need to be assessed as early as possible, and with each subsequent contact, on how best to meet their language and communication needs. These issues must be addressed in order to improve therapeutic relationships with consumers in a recovery-oriented model of mental health services.

## APPENDIX A

### RECRUITMENT FLYER

Join us to discuss the Mental Health Project for Deaf, Deafblind and Hard of Hearing people.

We hope to gather your opinions about what new services are needed in our region and how to make current services easier to get.

Small group discussions will be organized to give feedback to program planners and to brainstorm for the future.

Where: Center for Hearing and Deaf Services

When: February 28th at 6:00

Light refreshments will be provided

Contact: Kimberly K. Mathos D.O., M.P.H.

Center for Hearing and Deaf Services/ University of Pittsburgh

Phone: 412-281-1375 (V/TTY)



\*\*\*\*\* Realtime Captions or interpreters provided as needed

## APPENDIX B

### IRB LETTER



## University of Pittsburgh Institutional Review Board

Exempt and Expedited Reviews

University of Pittsburgh FWA: 00006790  
University of Pittsburgh Medical Center: FWA 00006735  
Children's Hospital of Pittsburgh: FWA 00000600

3500 Fifth Avenue  
Suite 100  
Pittsburgh, PA 15213  
Phone: 412.383.1480  
Fax: 412.383.1508

TO: Dr. Kimberly Mathos

FROM: Christopher M. Ryan, PhD, Vice Chair *Chris*

DATE: January 23, 2007

PROTOCOL: Gathering Perceptions About Current Mental Health Services and Collecting Data about Necessary Services for Services for Deaf, Deafblind and Hard of Hearing Consumers

IRB Number: 0611052

The above-referenced protocol has been reviewed by the University of Pittsburgh Institutional Review Board. Based on the information provided in the IRB protocol, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section 45 CFR 46.101(b)(2).

- If any modifications are made to this project, please submit an 'exempt modification' form to the IRB.
- Please advise the IRB when your project has been completed so that it may be officially terminated in the IRB database.
- This research study may be audited by the University of Pittsburgh Research Conduct and Compliance Office.

Approval Date: January 23, 2007

CR:kh

## APPENDIX C

### BUDGET DETAILS

<b>Expense</b>	<b>Amount requested</b>
<i><u>Personnel</u></i>	
Kimberly K. Mathos D.O., M.P.H.	5500
Martha Terry Ph.D.	
Francis Lokar R.N.	1000
Edward Post M.D., Ph.D.	
Melinda Litzinger, transcription service	550
<i><u>Other Expenses</u></i>	
Incentives for focus group participants	2000
Refreshments for focus group participants	475
Photocopying	50
Interpreters	600
CART	1800

## **APPENDIX D**

### **MODERATOR GUIDE**

*Perceptions of Health Services and Barriers to Care Among Persons With Hearing Loss*

#### **A. Introduction** (5 minutes)

Good evening/afternoon, my name is Fran Lokar and I will be moderating this focus group. I am a nurse and a graduate student at the University of Pittsburgh, Graduate School of Public Health. I do not work for any agency or service provider of mental health services in Allegheny County.

Tonight/this evening we will be discussing various issues related to receiving behavioral health/mental health services in Allegheny County. You have been chosen to give your opinion on health issues important to persons with hearing loss in Allegheny County.

Focus groups are designed to allow you to present your ideas and thoughts on these issues. There are no right or wrong answers, but your opinions are very important to us. I would like to hear from all of you equally. It is extremely important that you speak one at a time. Please feel free to disagree if you do not share someone's opinion. We are not here to agree on issues, but to discuss them. I am also interested in hearing any questions you have as we go along. We agreed to meet for 2 hours. That may seem like a lot of time, but we have many

points to discuss and to keep on schedule I may have to move the conversation along to get to all of the points.

We are audio taping our discussion. This is done so we don't miss any of your important comments. We will use the tape to make a written copy of your comments. A report will be generated to the Allegheny County Office of Behavioral Health and Substance Abuse Services.

All of your comments will be confidential and are used only for the purpose of this research. Nothing you say will be connected with your name and if you are uncomfortable with a particular question it is ok to not answer. There is research staff sitting in the back of the room. They are interested in your comments and will help us put together the written copy I spoke about earlier. There also is an interpreter (for groups of persons who are Deaf and use ASL) that will be interpreting our conversation. Her/his name is \_\_\_\_\_ and he/she is a certified interpreter in ASL.

### **B. Warm Up** (10 minutes)

I would like to begin by having everyone write the name they would like to be called on the card in front of you. This will be used to allow others to identify you by the name you prefer to be called.

At this time I would like you each to introduce yourself to the group and tell us a little about yourself, perhaps why you agreed to come here this evening.

We will now begin the discussion questions.

**C. Health Care Services (20 minutes)**

1. Where do (persons who are Deaf, Deafblind or hard of hearing) go to receive health care?

2. How did you find out about this place?

3. What made you decide to use/not use this place?

**D. Mental Health Services (20 minutes)**

1. Where do (persons who are Deaf, Deafblind or hard of hearing) go to receive mental health care?

2. How did you find out about this place?

3. Why do you think people go/don't go there?

**E. Drug and Alcohol Services (10 minutes)**

1. What drug and alcohol services are available for persons who are Deaf, Deafblind, or hard of hearing?

2. How do people find out about that place?

3. Why do/don't people go there?

**F. Health Care Information Needs (15 minutes)**

1. How do (persons who are Deaf, Deafblind or hard of hearing) learn about or get information about what types of health care services are available?

2. Where do they get this information?

3. What type of information works best?

4. What do you think would be a good way to get this information to you in the future?

4. How do (persons who are Deaf, Deafblind or hard of hearing) get information on different types of health conditions like heart disease or mental illness?

5. Where do they get the information?

6. What type of information works best?

7. What do you think is a good way to get this information to you in the future?



**G. Health Care Service Needs (20 minutes)**

1. What would make it easier for people like you to access the services that currently exist?
2. What other services do we need in our area to help (people who are Deaf, Deafblind, or hard of hearing)?
3. What would make you be more confident in seeking health services?
4. What would help you to have a higher quality of life?
5. Who pays for the health care services?
6. What are the laws regarding services/interpreters?

**H. Close (10 minutes)**

Does anyone have any additional comments they would like to make regarding any of tonight's topics?

We would like to give each of you a copy of the Allegheny County Resource Guide of Behavioral Health Providers for Persons Who Are Deaf or Hard of Hearing. It will allow you to

better choose a provider of services based on your needs. We have come to the end of our discussion. The sponsors of these focus groups are the Allegheny County Behavioral Health and Substance Abuse Services and Community Care Behavioral Health. On behalf of these organizations I want to thank you for your participation. Your opinions tonight will be very helpful as we continue to gather information regarding the health care system in Allegheny County. Please accept these gift vouchers as a token of our appreciation for your help.

## **APPENDIX E**

### **RECRUITMENT LETTER**

Dear Participant,

The purpose of this focus group is to gather information from people who are Deaf, Deafblind and hard of hearing who reside in Southwestern Pennsylvania about current mental health services and barriers to care. Ideas will be collected about necessary social supports and new behavioral health services which are needed to benefit each community.

We are asking you to participate in a two-hour discussion, which will be moderated by a professor from the University of Pittsburgh. Members of the project staff will document the feedback of group participants but no names will be recorded.

There are no foreseeable risks associated with these activities, nor are there any direct benefits to you. All responses are confidential and results will be kept under lock and key. Your participation is voluntary and you may withdraw at any time.

The study is being conducted by Dr. Kimberly Mathos and Dr. Martha Terry. If you have any questions, you may call Dr. Mathos at 412-281-1375 (V/TTY)

Thank you!!

## **APPENDIX F.**

### **QUESTIONS FOR INITIAL FOCUS GROUP DEC 4, 2006**

**1.) Where do persons who are Deaf, Deafblind or hard of hearing turn when you need emotional support?**

Probes: What kinds of services work best?

How do the services help?

**2.) How do persons who are Deaf, Deafblind or hard of hearing receive help with drug or alcohol addictions?**

**3.) What prevents people from getting these needed services?**

**4.) What makes it easier to get these services?**

**5.) How do persons that are Deaf, Deafblind and hard of hearing find out about social services?**

**6.) If a “social work” type of position were created to go into communities and help people with their emotional needs what sort of jobs should they be prepared to do? Probe:**

What skills should they have?

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