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# Information Gaps on the Deaf and Hard of Hearing Population: A Background Paper

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Prepared by the  
Western Interstate Commission for Higher Education (WICHE)  
Mental Health Program

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## Preface

We are pleased to share with you this background paper on the information needs of deaf and hard of hearing populations, particularly in rural America. This document is being produced in response to the pressing mental health needs of an underserved population.

The Western Interstate Commission for Higher Education (WICHE) Mental Health Department seeks to improve the behavioral health workforce of the rural West in regards to deaf and hard of hearing populations. This paper is only the beginning. The following information will provide you with a description of the current status of deafness and hearing loss in America, the prevalence of mental health issues in deaf populations, and an overview of the behavioral health workforce as it pertains to both rural and deaf/hard of hearing populations.

WICHE has prepared this document to assist administrators and key policy-makers to better understand the unmet needs of deaf and hard of hearing populations in their jurisdictions. We hope it will be useful.

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## Table of Contents

Information Gaps on the Deaf and Hard of Hearing Rural Population: A Background Paper.....	1
Preface.....	2
Table of Contents.....	3
Executive Summary .....	5
National and State Statistics on Deaf and Hard of Hearing Populations.....	6
Prevalence of Mental Health and Substance Abuse Disorders in Deaf Populations .....	6
National Issues for Rural Behavioral Health .....	7
Behavioral Health Services for Deaf and Hard of Hearing Populations .....	8
Definitions: Deaf and Hard of Hearing Populations.....	8
The Impact of Definitions on Treatment .....	10
Deafness in America: Epidemiological Data and Prevalence.....	11
Percentage of Deaf and Hard of Hearing Populations in WICHE States .....	14
Prevalence of Mental Health and Substance Abuse Disorders.....	15
Service System Challenges for Deaf Populations.....	16
Accessibility.....	17
Knowledge .....	17
Transportation.....	18
Rural Economy and Employment.....	18
Implications for Mental Health Care .....	19
Availability .....	19
Mental Health Professionals .....	19
Certified Interpreters.....	19
Acceptability .....	20
Rural stigma surrounding deafness is even more acute due to smaller communities.....	20
Language barriers.....	21
Establishment of Systems of Care for Deaf and Hard of Hearing.....	21
Behavioral Health Workforce Shortages .....	21
Rural Behavioral Health is a Nationwide Concern.....	22
Summary .....	28
Appendix A: Categories of Visual Language.....	29

Appendix B: Cultural Definitions of Deafness .....	30
Appendix C: National Standards for Culturally and Linguistically Appropriate Services in Health Care. ....	32
Appendix D: Listings from <i>Mental Health Services for Deaf People: A Resource Directory (2003 Edition)</i> for WICHE States.....	34
Appendix E: Synopsis of Two Model Mental Health Service Programs .....	36
South Carolina Department of Mental Health, Program of Services to Persons who are Deaf or Heard of Hearing .....	36
Threshold Bridge Program for the Deaf, Chicago, Illinois.....	37

## **Executive Summary**

Across the United States there have been historical difficulties in recruiting and retaining an effective behavioral health workforce that is culturally and linguistically prepared to serve the deaf and hard of hearing communities. In addition, the recent report of the Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities* described in detail the significant challenges faced by persons with disabilities, including deaf and hard of hearing, to access the services needed to maintain good health and wellness. These challenges include significant gaps in public and professional knowledge and training about hearing loss, accessibility to services, availability of providers and programs designed for their needs, acceptability of care based on historical perceptions of mistreatment, and establishment of mental health policy without consideration of the impact on deaf and hard of hearing communities.

In order to create a clear path toward achieving the development of an adequate and effective behavioral health workforce for deaf and hard of hearing populations, the Western Interstate Commission for Higher Education (WICHE) Mental Health Program has been researching relevant issues facing the deaf and hard of hearing populations. What follows is a summary of relevant concerns and data in several areas of deaf and hard of hearing populations, including 1) the lack of a consistent definition of hearing loss and culture in the United States, 2) the lack of accurate and thorough epidemiological data at the state and federal levels, 3) the lack of accessibility, availability and acceptability of behavioral health services and 4) national issues for rural populations.

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## National and State Statistics on Deaf and Hard of Hearing Populations

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- There is currently no national database of deaf and hard of hearing persons.
- Out of every 1,000 people in the United States: 2-4 are “functionally deaf” (do not utilize any hearing for communication) and 7-18 have a severe hearing impairment. If the total numbers are added up, there are approximately 37 – 140 people out of 1,000 reporting *any* kind of hearing loss.
- 8.6 percent of the total U.S. population 3 years and older were reported to have hearing problems.
- Within the 15 WICHE states there are an estimated 6 million deaf and hard of hearing individuals.
- California has the greatest numbers of deaf individuals at 3,086,866, more than five times that of the next largest state estimate of Washington at 533,526.
- Wyoming and North Dakota had the fewest numbers, 43,561 and 54,555 respectively.

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## Prevalence of Mental Health and Substance Abuse Disorders in Deaf Populations

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- We can estimate there are over 5 million deaf individuals in the United States who need mental health treatment every year.
- Only about 2% of these deaf individuals receive appropriate treatment for mental illness due to barriers in the effective diagnosis of mental illness.
- The prevalence of adults with serious mental illnesses (SMI) and children with serious emotional disturbances (SED) is likely greater in the deaf population than in the hearing population, sometimes estimated to be 3 to 5 times greater.
- If deaf people represent almost one percent of the U.S. population, there should be approximately 8,000 deaf people in drug or alcohol treatment on any given day. There appears to be no evidence of this occurring, possibly because of barriers that limit access to such services.

- Deaf children experience physical and sexual abuse two to three times higher than that of their hearing peers.
- There are no current attempts or future plans to collect or track the incidence of violent death or suicide in the deaf population.

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## **National Issues for Rural Behavioral Health**

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- Many of the challenges and difficulties that impede service delivery for general populations in rural areas are also present for deaf populations, rural *and* urban.
- More than 60% of rural Americans live in mental health professional shortage areas.
- More than 90% of all psychologists and psychiatrists, and 80% of MSWs, work exclusively in metropolitan areas.
- More than 65% of rural Americans get mental health care from their primary care provider.
- Rural Americans travel further to provide and receive services.
- Comprehensive services are often not available.
- Few programs train professionals to work competently in rural places.

# Behavioral Health Services for Deaf and Hard of Hearing Populations

Over the past 40 years, there has been a growing awareness of the inability of the current mental health system to adequately meet the needs of the deaf and hard of hearing populations. This awareness has taken the form of several reports, some of which have been produced by federal agencies, which describe current problems and possible solutions to improving responsiveness to individuals who are deaf or hard of hearing. These include, the Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities 2005*, The Centers for Medicare & Medicaid Services' *Identification of Performance Standards for the Deaf and Hard of Hearing*, Randall Meyer's *Standards of Care for the Delivery of Mental Health Services to Deaf and Hard of Hearing Persons*, and the National Technical Assistance Center for State Mental Health Planning's *Cultural Diversity Series: Meeting the Mental Health Needs of Persons Who are Deaf*. This paper will summarize relevant issues and data from the reports indicated, but also approach service system improvement from the aspect of workforce development through training and technical assistance, particularly in rural America.

Indeed, an appropriate context and parallel for understanding many issues that impact the quantity and quality of mental health services for deaf and hard of hearing populations is the area of rural mental health. Many of the challenges and difficulties that impede service delivery for general populations in rural areas are also present for deaf populations, rural *and* urban. Like rural Americans, deaf or hard of hearing individuals face problems with the *availability*, *accessibility*, and *acceptability* of mental health services. Too often, quality care is not available, cannot be reached or paid for, and may be stigmatized. As a subsequent section describes in more detail, a majority of deaf persons live in rural areas, which compounds the problem of limited services based on geography by even more limited services specifically for this population. Thus, this section will demonstrate the parallels between rural and deaf or hard of hearing populations, as well as provide a context for proposing possible solutions to the problems based on efforts in rural mental health workforce development.

## Definitions: Deaf and Hard of Hearing Populations

Just as there are multiple definitions and different kinds of people in rural America<sup>1</sup>, so the same is true for deaf and hard of hearing populations. Defining deafness is the first step in examining mental health services for deaf populations, yet there is no nationally accepted standard definition of deafness within the mental health community. The concepts of "rural" and "deaf" or "hard of hearing" have multiple definitions. Depending on which definition is used by whom, there will be real effects on funding or quality of treatment. More fundamentally, multiple definitions can result in varying estimates of the prevalence of mental health and/or substance use disorders within the deaf population. Answering the question of whether or not there should be a standard definition of deafness within the mental health community is not within the scope of this paper. It may be that the best policy is a definition that is applied on a case-by-case basis

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<sup>1</sup> See the President's New Freedom Commission on Mental Health: Subcommittee on Rural Issues Background Paper, available online at: <http://www.mentalhealthcommission.gov/papers/Rural.pdf>.

as determined by the interaction between the professional and the client. However, this section will simply review definitions that currently exist.

There are a number of different definitions of deafness depending on which entity is queried. These definitions break down into four major areas: medical, functional, linguistic and cultural.

1. Medical – The term hearing-impaired covers the broad spectrum of any individual with a less-than-average hearing level. The term deaf is generally used to describe those who are unable to benefit from a hearing aid due to the severity of their hearing loss. It is important to note that the term hearing-impaired is only appropriate for use within the medical community. Most deaf and hard of hearing persons consider the term to be inappropriate for general use.

2. Functional – The US government defines deafness in terms of eligibility for disability benefits based on ability to function within society. Section 504 of the Rehabilitation Act of 1973 is a national law that protects qualified individuals from discrimination based on their disability. The following definition is taken directly from the Act:

*Individuals with disabilities* are defined as persons with a physical or mental impairment which substantially limits one or more major life activities. People who have a history of, or who are regarded as having a physical or mental impairment that substantially limits one or more major life activities, are also covered. Major life activities include caring for one's self, walking, seeing, hearing, speaking, breathing, working, performing manual tasks, and learning<sup>2</sup>.

This definition ‘works’ for providing benefits to those who have difficulty functioning regardless of the level of hearing loss, linguistic utilization or cultural identification.

3. Linguistic – In terms of mental health services, linguistic utilization is the most important to look at when considering services for deaf populations. Those with hearing loss communicate in a variety of ways. Some may use only lip-reading and speech; others will use some form of manual communication: American Sign Language (ASL), Cued Speech, Pidgin Signed English, Signed English and Signing Exact English (SEE). By far, the most widespread of these manual forms is ASL, being the third most commonly used language in the United States behind English and Spanish. Modes of signing are not completely isolated from one another. The different types of signing follow more of a continuum rather than isolated modalities. The less "English" structure the signing contains, the closer it falls to ASL on the continuum. The more "English" structure the signing contains the closer it falls to SEE.<sup>3</sup> For a more in-depth definition of each of these manual modes of communication, please see Appendix A.

4. Cultural – This final definition is tied closely to the linguistic definition but is not completely matched. In the deaf community, there is a distinction between *deaf* and *Deaf*. Lowercase deaf is more indicative of the medical condition and those who are not associated with the Deaf community. The Deaf community (with a capital D) is comprised specifically of those who identify themselves with Deaf culture, which was formed around the use of ASL as the primary means of communication. Only persons who are self-identified as belonging to Deaf culture are

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<sup>2</sup> <http://www.hhs.gov/ocr/504.html>

<sup>3</sup> <http://www.motion.com/deaf/perspective.html>

appropriately referred to as *Deaf*.<sup>4</sup> There are deaf individuals who use ASL but do not self-identify with the Deaf community, as well as individuals who self-identify with the Deaf community but either do not use ASL or have no hearing loss. For a more in-depth discussion of the Deaf culture identity, please see Appendix B.<sup>5</sup>

## The Impact of Definitions on Treatment

The Department of Health and Human Services (HHS) Rural Task Force's One Department Serving Rural America observed the significance of having multiple definitions of rural.<sup>6</sup> The task force noted that the result makes it "difficult to target grants, evaluate services, develop policy, and quantify HHS investment in rural and frontier communities" (p. ii). Undoubtedly, these same issues apply to deaf and hard of hearing populations.

Nevertheless, efforts have been made to address clinical aspects of these issues for deaf or hard of hearing populations. In 2001, the Office of Minority Health (OMH) published the *National Standards for Culturally and Linguistically Appropriate Services in Health Care*, which established 14 national standards for health care delivery to populations that are culturally and linguistically different from mainstream America. No less than five of these standards relate directly to the importance of providing health care in the client's preferred language and culture. (Please see Appendix C for a complete list of the relevant standards.)

These standards include (italics added for emphasis):

- **Standard 1.** Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their *cultural health beliefs and practices and preferred language*.
- **Standard 4.** Health care organizations must offer and provide *language assistance services*, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.
- **Standard 6.** Health care organizations must assure the *competence of language assistance* provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).
- **Standard 9.** Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to *integrate cultural and linguistic competence-related measures* into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations.
- **Standard 10.** Health care organizations should ensure that *data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected* in health records, integrated into the organization's management information systems, and periodically updated.

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<sup>4</sup> The American Heritage® Dictionary of the English Language, Fourth Edition

<sup>5</sup> It is general knowledge that in the United States and across the world there is an on-going debate about the most appropriate method and language in which to educate and raise deaf children. WICHE supports all clients with any degree of hearing loss, whether they are profoundly deaf, hard of hearing in one ear or both, late-deafened, or deaf-blind individuals. It does not endorse which communication methods are appropriate such as sign language, oral method, American Sign Language (ASL), Signed Exact English (SEE), or written English, etc.

<sup>6</sup> U.S. Health and Human Services Rural Task Force. (2002). *One department serving rural America* (Report to the Secretary). Washington, DC: U.S. Department of Health and Human Services.

Furthermore, according to OMH’s *Standards*:

In order for health services to have a chance of being effective in a patient, the clinician must accurately diagnose the illness, discern the correct treatment for that individual, and negotiate the treatment regimen successfully with the patient. These steps can all be affected by linguistically and culturally mediated factors that have an impact on trust, open communication, and adherence to treatment plans.

In other words, if the client does not understand the clinician and/or vice versa, then there is only a slim chance that diagnoses and interventions will be accurate and effective. Serving a client in a language they struggle to understand is potentially worse than not serving them at all. Given the vast cultural and linguistic diversity in the deaf population, the ability to be adequately trained and prepared to serve all of them is nigh impossible. However, development of local, state, or regional technical assistance and training centers that can provide specific consultation to practitioners will enable individualized treatments and high quality care.

## Deafness in America: Epidemiological Data and Prevalence

The preceding section described how deafness can be defined in four different ways, depending on the intended use of the definition. Creating a national survey that incorporates all definitions to meet everyone’s epidemiological needs would likely be cost-prohibitive and unwieldy. As such, the statistics on deafness in America currently need to be painstakingly pieced together to create a tentative picture. The Graduate Research Institute (GRI) has lead the initiative in attempting to compile the most accurate national statistics on deafness from the five surveys listed in the table below gathered between 1990 and 2003.

Survey Name	Limitations
<b>Survey of Income and Program Participation (SIPP)</b>	<ul style="list-style-type: none"> <li>• Uses the self-definition of hearing difficulty even <i>with</i> a hearing aid.</li> <li>• Only queries ages 5 and older.†</li> <li>• Last updated in 2001.</li> </ul>
<b>National Health Interview Survey (NHIS)</b>	<ul style="list-style-type: none"> <li>• Uses the self-definition of amount of hearing trouble <i>without</i> a hearing aid.</li> <li>• Lumps hard of hearing and deaf.</li> <li>• Only queries ages 3 and older.*</li> <li>• Last updated in 1994.</li> </ul>
<b>National Health and Nutrition Examination Survey (NHANES)</b>	<ul style="list-style-type: none"> <li>• Defines hearing loss audiometrically.</li> <li>• Current survey only queries 20-69 year olds.</li> </ul>
<b>U.S. Census</b>	<ul style="list-style-type: none"> <li>• Lumps deaf and blind in a ‘Severe Sensory Disability’ category.</li> <li>• Only queried ages 5 and older.†</li> <li>• Last updated in 2000.</li> </ul>
<b>IDEA Child Count</b>	<ul style="list-style-type: none"> <li>• Only queried youth aged 6 to 21.</li> </ul>

† Children ages newborn to 5 were not included.

\* Children ages newborn to 3 are not included.

For the purposes of this paper, we will only focus on the SIPP, the NHANES, and the NHIS surveys, as the US Census data is too broad (including blindness and other disabilities) and the IDEA survey is too narrow (including only children ages 6 to 21).

The NHIS, the SIPP, and the NHANES national surveys on deafness each use a different operational definition of deafness.<sup>7</sup> In the SIPP survey, respondents are asked to rate whether they have difficulty hearing what is said in a normal conversation with another person *even when wearing a hearing aid*. This is a yes/no question and if answered affirmatively a follow-up question is asked: whether or not the individual is able to hear what is said in a normal conversation at all. Based on these two subjective questions, the survey subdivides respondents into “hearing,” “hard of hearing,” and “deaf” populations.

In the NHIS, respondents are asked to describe their (or their child’s) hearing *without a hearing aid*. They are given four answer choices: good, a little trouble, a lot of trouble, or deaf. Because of the small number of respondents, the last two answer categories (a lot of trouble or deaf) were lumped together in the statistical report, making it difficult to separate the hard of hearing and deaf respondents and thus rendering the survey incomparable to other surveys or to the general population.

NHANES is different from the other two national surveys in that it gathers audiometric information on the spot from the respondent, which eliminates the self-report variable as well as the self-categorization debate. The serious limitation to using this data is that it utilizes only the medical definition of deafness and ignores the functional and cultural self-categorization that is essential to providing appropriate mental health diagnoses and treatments.

## **National Statistics**

The U.S. Department of Education, Interagency Committee on Disability Research (ICDR) noted in their 2003 Annual Report to the President and Congress that there is currently no national database of deaf and hard of hearing persons. In their research recommendations to Congress, they propose to develop a plan for the design and implementation of an improved periodic national disability data collection effort. However, in the absence of a national dataset, other data has been used to obtain an estimate of the number of deaf and hard of hearing persons in the country.

The following population statistics are derived from a GRI untitled website publication based in the SIPP and NHIS datasets<sup>8</sup>. Out of 1,000 people: 2-4 are “functionally deaf” (do not utilize any hearing for communication) and 7-18 have a severe hearing impairment. If the total numbers are added up, there are approximately 37 – 140 people out of 1,000 reporting *any* kind of hearing loss.

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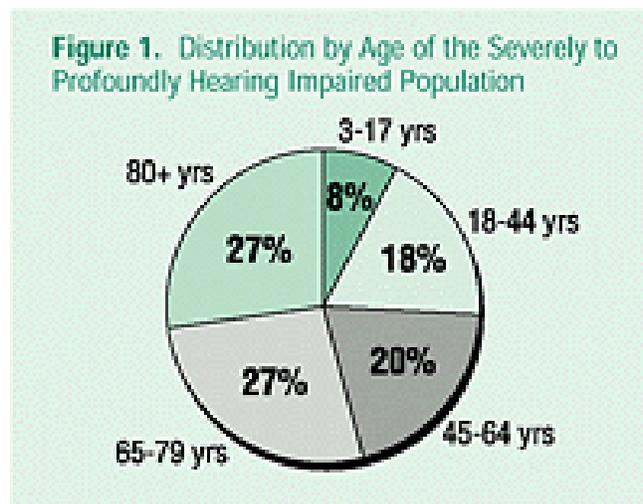
<sup>7</sup> The following definitions are extracted from the untitled webpage: <http://gri.gallaudet.edu/Demographics/deaf-US.php>

<sup>8</sup> <http://gri.gallaudet.edu/Demographics/deaf-US.php>

Another GRI publication by Holt, Hotto and Cole (1994) provides older but more specific data on the demographic profile of deafness in America.<sup>9</sup> Based on their review of the NHIS results, 8.6 percent of the total U.S. population 3 years and older were reported to have hearing problems. This statistic is the most widely used to estimate regional, state, and local population statistics for the deaf population. The table below is from the Holt publication and is based on the NHIS data. In all age groups, there was a greater percentage of the deaf population residing in rural areas than in urban areas. This highlights the urgent need to focus on rural mental health services for the deaf population. Please note that the numbers in each of the presented tables throughout this paper will not match as the deaf and hard of hearing percentages were applied to general population data gathered from different US Census years.

Age Group	Population	Number of Hearing Impaired	Percent of Population	Percent Urban	Percent Rural
TOTAL	235,688,000	20,295,000	8.6%	7.9%	11.1%
3-17 years	53,327,000	968,000	1.8%	1.8%	2.0%
18-34 years	67,414,000	2,309,000	3.4%	4.2%	5.5%*
35-44 years	38,019,000	2,380,000	6.3%		
45-54 years	25,668,000	2,634,000	10.3%	11.8%	15.4%*
55-64 years	21,217,000	3,275,000	15.4%		
65 years & older	30,043,000	8,729,000	29.1%	27.4%	33.7%

\* In computing rural population estimates, the age groups 18-44 years and 45-64 years were not broken down.



<sup>9</sup> Holt, Hotto and Cole (1994). Demographic Aspects of Hearing Impairment: Questions and Answers, 3<sup>rd</sup> Edition.

## Percentage of Deaf and Hard of Hearing Populations in WICHE States

State and local population estimates are not computed by any of the national survey programs because the households sampled are not representative of each state's individual population. According to Holt (1994) this is unfortunate due to the fact that in most states, the allocation of resources and administration of services for deaf populations occur at the state and local level.

The following state estimates were computed at WICHE based on the estimate of 8.6 percent of the population established by NHIS. It is important to note that while these numbers are based on the best information available and can be stated with some confidence, they are still rough estimates based on debatable definitions of deafness as discussed in the previous sections. Individual states will need to take the initiative to reliably determine the numbers of deaf individuals within their borders.

Within the 15 WICHE states there are an estimated 6 million deaf and hard of hearing individuals. California has the greatest numbers of deaf individuals at 3,086,866, more than five times that of the next largest state estimate of Washington at 533,526. Wyoming and North Dakota had the fewest numbers, 43,561 and 54,555 respectively.

WICHE States	Total Population 2004 U.S. Census	Deaf & Hard of Hearing	Deaf	Hard of Hearing
	<b>100%</b>	<b>8.6%</b>	<b>0.9%</b>	<b>7.7%</b>
United States	293,655,404	25,254,364	2,642,898	22,611,466
<u>WICHE States</u>				
Alaska	655,435	56,367	5,899	50,469
Arizona	5,743,834	493,969	51,695	442,274
California	35,893,799	3,086,866	323,044	2,763,822
Colorado	4,601,403	391,359	40,956	350,403
Hawaii	1,262,840	108,604	11,366	97,238
Idaho	1,393,262	119,821	12,539	107,282
Montana	926,865	79,710	8,342	71,368
Nevada	2,334,771	200,790	42,026	158,764
New Mexico	1,903,289	163,683	17,130	146,553
North Dakota	634,366	54,555	5,709	48,846
Oregon	3,594,586	309,134	32,351	276,783
South Dakota	770,883	66,296	6,938	59,358
Utah	2,389,039	205,457	21,501	183,956
Washington	6,203,788	533,526	55,834	477,692
Wyoming	506,529	43,561	4,559	39,002
<b>Total WICHE States</b>	<b>68,814,689</b>	<b>5,913,698</b>	<b>639,889</b>	<b>5,273,810</b>

## Prevalence of Mental Health and Substance Abuse Disorders

The U.S. Department of Health and Human Services (2002) found that the annual prevalence of mental disorders in the general population is 21%. If mental disorders occur at the same rate in the deaf community, based on 2004 US Census report estimate of the total deaf and hard of hearing population (21% of 25,254,364 = 5,303,416) we can estimate there are over 5 million deaf individuals who need mental health treatment every year. Robert Pollard<sup>10</sup> estimates that only about 2% of deaf individuals receive appropriate treatment for mental illness due to barriers in the effective diagnosis of mental illness. These diagnosis and assessment barriers include:

- Language barriers due to lack of interpreters or use of interpreters not trained in mental health issues and diagnoses (e.g., training for recognizing psychotic vs. other types of distortions in ASL use).
- Social and cultural differences between the client and the untrained professional.
- Mental health symptoms may be erroneously attributed to deafness and thus overlooked.
- Mental retardation and learning disabilities are often over-diagnosed.
- Signs of co-occurring disorders are often overlooked or exaggerated.
- Diagnostic tools are often not 'normed' for deaf populations, cannot be administered in American Sign Language and are not sensitive to the nuances of Deaf culture<sup>11</sup>.

The prevalence of adults with serious mental illnesses (SMI) and children with serious emotional disturbances (SED) is greater in the deaf population than in the hearing population, sometimes estimated to be 3 to 5 times greater<sup>12</sup>. Whether these statistics indicate a true prevalence rate or a misdiagnosis based on the cultural misperceptions of hearing professionals is unknown. Aside from misdiagnosis, there are three main theoretical reasons why mental illness is greater in deaf populations<sup>13</sup>:

- Many causes of deafness also cause brain damage
- Communication problems inherent in deafness
- Much greater prevalence of sexual abuse of deaf youth relative to other children.

The deaf and hard of hearing community is also at a greater risk for alcohol and drug abuse than the general population.<sup>14</sup> First, due to isolation from normal information flow, access to information on the prevention of substance abuse is extremely limited. Secondly, deaf individuals may experience greater levels of stress due to strained interactions with the hearing community and isolation from the typical family support network<sup>15</sup>. Furthermore, the circumstances of many deaf people provide environmental pressures that may foster drug abuse:

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<sup>10</sup> 1996. Professional psychology and Deaf people: The emergence of a discipline. *American Psychologist*, vol.1 51, no. 4, April, pp 389-396.

<sup>11</sup> NASMHPD (2002) Reducing the Use of Seclusion and Restraint Part III: Lessons from the Deaf and Hard of Hearing Communities.

<sup>12</sup> Hamerdinger and Murphy (2000).

<sup>13</sup> Willis and Vernon (2002). Residential Psychiatric Treatment of Emotionally Disturbed Youth. *American Annals of the Deaf*. Vol. 147, no. 1.

<sup>14</sup> Substance Abuse and the Deaf/HH Community. Tracy Bell Koster, MSW, MS and Debra Guthmann, Ed.D. [http://www.mncddeaf.org/articles/substance\\_abuse\\_ad.htm](http://www.mncddeaf.org/articles/substance_abuse_ad.htm)

<sup>15</sup> Guthmann, D. Online Article: [http://www.mncddeaf.org/articles/problem\\_ad.htm](http://www.mncddeaf.org/articles/problem_ad.htm)

communication barriers, isolation, unemployment, inadequate support from family and friends, inaccessible meetings and events and namely, insufficient services. These circumstances will be discussed in the following chapter.

More than 800,000 people from the general population are in alcohol and drug abuse treatment at any given time (Robert Wood Johnson Foundation, 1993). If deaf people represent almost one percent of the U.S. population, there should be approximately 8,000 Deaf people in drug or alcohol treatment on any given day (1% of 800,000). There appears to be no evidence of this occurring, possibly because of barriers that limit access to such services.<sup>16</sup>

Another area in mental health that is particularly salient is the abuse of deaf children. Because they are perceived as unable to communicate effectively, often placed in residential settings at an early age, and are likely to have less knowledge about socially unacceptable behaviors, deaf children have significantly higher rates of physical and sexual abuse than those in the general population. Elder (1993) estimates that deaf children experience abuse two to three times higher than that of their hearing peers.

In regards to suicide data, personal queries to the Centers for Disease Control at the state and national levels indicate that there are no current attempts or future plans to collect or track the incidence of violent death or suicide in the deaf population. This lack of data gathering at the national and state levels hinders the establishment of appropriate services for the deaf population in all areas of mental health. Lack of data also hinders the thorough understanding of the causes and catalysts of mental illness on anything other than individual and local levels.

## **Service System Challenges for Deaf Populations**

Historical perceptions of the deaf community have not been conducive to their optimal mental health. Deaf people were often viewed as uneducable, and unable to learn the language necessary to function in society. Deaf persons were known to have been institutionalized for many years for no reason other than their lack of hearing and they continue to mistrust the mental health world for this reason<sup>17</sup>. Little research was done to study the effects of hearing loss on individuals and the best ways to assist them in development through the lifespan. Only in the past 35 years has research begun to catch up in response to the imperative established by the American's with Disabilities Act. Even so, it is estimated that deaf mental health services are two to four decades behind that of hearing services.

As indicated in the previous section, prevalence of deaf or hard of hearing adults with SMI and children with SED are significantly higher than that of the hearing community. However, like persons in rural areas, it is the *experience* of having a mental illness that adds to their unique circumstances. For instance, individuals in tight-knit rural communities may find it difficult to seek services with complete anonymity. The same can also be true for an individual who is part of a tight-knit deaf community, even in an urban setting. More deeply, persons who are either

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<sup>16</sup> Guthmann, D., Sandberg, k., & Dickinson, J. Chapter 15 Chemical Dependency: An Application of a Treatment Model for Deaf People. In *Psychotherapy with Deaf Clients from Diverse Groups* (1999). Leigh, I., Ed.

<sup>17</sup> Steinberg, Sullivan and Loew (1998) Cultural and Linguistic Barriers to Mental Health Service Access: The Deaf Consumer's Perspective. *American Journal of Psychiatry*, vol. 155. pp. 982-984.

born deaf or lose their hearing very early in life must grow up without one of the primary means by which people experience and understand the world. Undoubtedly, individuals have made incredible personal adaptations in their lives through their intelligence and resiliency, while advances in technology, early screening, and sign language (to name just a few) have helped as well. Nevertheless, there are service system issues that can make the experience of having a mental illness very difficult for deaf or hard of hearing persons, especially those living in rural areas.

The difficulties that are shared by the deaf and rural communities can be categorized into three overarching factors:

- Accessibility,
- Availability, and
- Acceptability.<sup>18</sup>

These three factors are drawn directly from research related to rural populations. The following sections will discuss these rural issues as they apply to the deaf community.

## **Accessibility**

Accessibility to mental health services generally refers to one's ability to receive needed treatment. Three significant components of accessibility put deaf individuals at significant disadvantage: knowledge, transportation, and financing.

### **Knowledge**

An essential element of access is knowing when one needs care, where to get it, and what care options are available to address that need.

There are often misconceptions within the deaf community of what mental illness symptoms are and how to seek treatment for them. That is, they don't have a great understanding of mental health issues generally and, therefore, are more likely to dismiss, minimize, or simply not see the significance of real problems and symptoms. One main reason for these misconceptions is that, historically, the deaf experience with mental health systems of care has been rocky due to misunderstandings and misdiagnoses based on cultural and linguistic variables.

Another main reason is that the typical avenues of public education are generally inaccessible to deaf individuals. These individuals have historically been unable to access radio and TV education programs on mental health issues. Pamphlets and books on mental illness are written in English and generally require a reading level that is above that of the typical deaf person (4<sup>th</sup> grade is average<sup>19</sup>). Family members, an important source of education in the general

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<sup>18</sup> Larson, M.L., Beeson, P.G., & Mohatt, D.F. (1993). Taking rural into account: A report of the national public hearing on rural mental health. St. Cloud, MN: National Association for Rural Mental Health and the Federal Center for Mental Health Services.

<sup>19</sup> This low reading level is due to a variety of factors, the two main ones being inadequate educational accommodations and that for many deaf individuals English is a second language and ASL has no written equivalent Dolnick, E., (1993). Deafness as Culture. Atlantic Monthly. Thus, poor reading skills do not necessarily indicate low intelligence.

community, often do not use sign language as the primary way of communicating with their deaf family members. It is documented that more than 90% of deaf children are born to hearing parents creating the rare situation where the child is automatically linguistically different from his or her own parents<sup>20</sup>. Only recently have closed captioning, internet access, relay services and ASL video information ‘pamphlets’ begun to narrow the information gap between the deaf and hearing communities. Even so, it will take a number of years to see the effects of greater information access on the general knowledge base of mental health symptoms in the deaf community as a whole.

Another barrier to accessing care is the all too common experience of requesting accommodations and being refused for various reasons, generally financial and stereotypical. Despite the mandate set forth by ADA for ensuring easy accessibility, many business and practices are still unaware of their obligation to provide (and pay for) interpreting services. Furthermore, there is still an all-too-common perception that deaf individuals can communicate fully and effectively using the lip/speech-reading and writing back-and-forth techniques.

### **Transportation**

The ability to travel to services and pay for those services if accessed is a significant barrier to rural deaf Americans. Affordable and accessible transportation services may be unavailable, especially in the more rural areas which lack extensive public transportation. Because of the scarcity of specially trained providers, deaf clients may have to travel hundreds of miles one-way to receive appropriate services rather than utilizing providers in their local community.

Compounding the transportation issue is the issue of mainstreaming. It is not appropriate to assume that deaf individuals want to be 100% immersed into hearing culture along the lines of the ‘least restrictive environment (LRE)’ theory. For some deaf consumers the LRE may be a Deaf community or a program where there are a number of other signing professionals or consumers. Placing a consumer in a mainstreamed environment where they are surrounded by hearing individuals with only an occasional interpreter may be more isolating and detrimental to their mental health than not serving them at all. The experience of wanting to communicate in a complete and meaningful way and being unable to do so can be immensely frustrating.

### **Rural Economy and Employment**

Further information is needed regarding the income levels of deaf and hard-of-hearing individuals. However, rural persons generally have lower incomes and insurance coverage to pay for treatment. Thus, a person who is deaf or hard of hearing living in a rural area likely faces the same situation. Because of their hearing loss most deaf individuals qualify for Medicaid and, as a result, also qualify for a certain amount of mental health services. However, these services may not be fully utilized due to the low number of providers able to serve the population. In addition, Medicaid benefits vary widely from state to state and are complex to understand, even for trained professionals.

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<sup>20</sup> Schein, J.D. (1989). *At home among strangers*. Washington, D.C.: Gallaudet University Press.

## **Implications for Mental Health Care**

The implications of these phenomena can have a significant bearing on deaf rural mental health through limiting the following:

1. The supply pool of skilled individuals to staff mental health programs.
2. The availability of natural supports for d/hoh people with SMI and children with SED.
3. The level of peer support and affiliations.
4. The financial resources available to support a continuum of mental health services.

## **Availability**

The availability of rural mental health services appropriate to serve deaf populations depends on the complex interplay of education, rural and deaf training opportunities, recruitment and retention activities, continuing education, and technical support.

## **Mental Health Professionals**

Deaf Americans need competent, technically appropriate mental health professionals who have demonstrated knowledge and experience in deaf culture and sign language fluency. However, Pollard (1996) asserts that the numbers of professionals trained to work with deaf individuals are woefully lacking and not likely to meet the unmet need anytime soon. He reports that in 1990 there were just 20 deaf psychologists in the United States, compared to just 5 in 1979. However, with the passing of the Americans with Disabilities Act, deaf and hard of hearing students have joined their hearing peers in doctoral level psychology programs across the states. Other programs such as Gallaudet University and the University of Rochester's doctoral programs in clinical psychology have recently begun graduating both deaf and hearing persons who are culturally and linguistically competent to serve the deaf community.

Still, these numbers are woefully lacking for the 5 million deaf and hard of hearing individuals who need mental health services *now*. A system must be established that will serve as a temporary solution until greater numbers of trained professionals can be disseminated across underserved areas.

## **Certified Interpreters**

At present there is no national certification program for training interpreters to work in mental health settings. A few individual states, such as Alabama have established their own certification competencies for mental health interpreters. It is beginning to be recognized that mental health interpreting is vastly different from general interpreting settings. This is due to a variety of reasons:

- The dynamics of the highly sensitive nature of therapy and assessment are inevitably changed with the addition of a third person.
- The establishment of trust that confidentiality will be maintained.
- Remaining neutral in the face of emotionally charged situations.
- The challenge of knowing when to interpret words vs. meanings. Clinicians must be aware that many words, especially the more technical ones, do not have a direct or simple

translation into sign language (i.e. psychosis, self-esteem). The same is true when translating sign language into English. Interpreters are faced with the challenge of deciding when to translate word for word and when to convey meanings in their own words.

- The potential ‘muting’ of the deaf individual’s symptomatology in the process of interpreting, thereby affecting the diagnosis. Interpreters in mental health settings need to be aware that sometimes the information conveyed may make no sense as a result of a thought disorder, flight of ideas or dysphasia. Since interpreters are trained to take what they see and translate it into English, these symptoms may not manifest in translation and thus be overlooked.

Dr. Robert Pollard has developed an innovative training program to train interpreters for mental health settings and to also train providers on how to access remote interpreting services for deaf individuals. He currently has a grant to establish this service in Alaska, which will be a model program for the rest of the states.

The emergence and rapid expansion of telehealth strategies over the past decade has opened a new access point for many deaf consumers, rural and urban. The strategies span from using pagers and text-messengers to communicate instantaneously with providers all the way to very sophisticated video relay to either provide long-distance interpreting services or for qualified professionals to provide services to those clients outside of their geographic area. However, the two main barriers to the implementation of these new technologies are lack of awareness and lack of funding to establish the networks needed.

## **Acceptability**

### **Rural stigma surrounding deafness is even more acute due to smaller communities.**

Stigma is a major barrier to receiving care. In general, most people understandably do not want the “label” of mental illness applied to them. They understand that with acknowledgement of a mental illness comes the possibility of being shunned by others, discriminated against in terms of work or social activities, and perhaps personal beliefs that mental illnesses are signs of weakness. Rural areas, which tend to be composed of smaller, more tightly-knit communities, make privacy a major issue for anyone who has a problem and is considering treatment.

Deaf individuals tend to be wary of the mental health service sector due to the historical reasons described above. The deaf community across America is very small and dissemination of information across the community happens very rapidly. Susan Anthony, PhD, Gallaudet University in Washington, D.C., notes the speed with which gossip travels within the deaf community: “It can start on the East Coast and within hours have landed in California. This is much faster than the hearing population, even if you take cyberspace into account.”<sup>21</sup>

Thus a deaf person seeking services is rarely surprised to learn that most of his/her acquaintances are aware of the situation. This is compounded by the fact that, historically, interpreters were not trained on ethics and confidentiality issues. It was not unheard of for interpreters to share

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<sup>21</sup> Westin, R. (1996). The Real Slant on Gossip. Psychology Today, July/August.

sensitive information occurring in the session with other members of the community. While this did not occur in most situations and is definitely not the case with today's well-trained interpreters, it happened enough times in the past to create mistrust of the therapy process, believing that everything shared would become public knowledge.

### **Language barriers.**

Despite the fact that it is the third most common language used in the United States, sign language is not routinely recognized as a legitimate form of communication. Often deaf individuals are encouraged to lip-read and speak for themselves to avoid the "trouble" of obtaining an interpreter. Providers and other service professionals may also lack awareness of the language barriers that deaf individuals face. Professionals that are not trained to work with the deaf population and/or do not have fluency in sign communication are likely to misunderstand the patient in ways that can have a potentially deleterious effect. This miscommunication between patient and provider, especially in inpatient settings, can lead to manipulation, coercion, and victimization of the deaf individual.

## **Establishment of Systems of Care for Deaf and Hard of Hearing**

There have been several movements to establish systems of mental health care for deaf populations on a state level. In 1990, the American Deafness and Rehabilitation Association (ADARA) began work on a document with the intention of creating a 'Model State Plan.' Working with a number of mental health professionals they created the *Standards of Care for the Delivery of Mental Health Services to Deaf or Hard of Hearing Persons* published in 1993.

More recently, Barry Critchfield, Ph.D. director of the South Carolina Department of Mental Health's Program of Services to Deaf and Hard of Hearing People, teamed up with the National Technical Assistance Center for State Mental Health Planning to produce a report entitled *Meeting the Mental Health Needs of Persons who are Deaf* (2002). This report presents a guideline for states to establish a system of care and provides details on two model programs, South Carolina and Chicago, Illinois. Please see Appendix E for a synopsis of these two programs.

## **Behavioral Health Workforce Shortages**

As was briefly indicated in previous sections, another significant similarity between rural and deaf or hard of hearing Americans is the lack of an adequate behavioral health workforce that is prepared to effectively serve the population from a cultural and linguistic level, using appropriate (but currently non-existent) evidence-based treatments. This section will elaborate on these issues by, first, describing the national picture of behavioral health workforce and then focusing more specifically on the 15 western states that compose WICHE and deaf or hard of hearing populations.

## Rural Behavioral Health is a Nationwide Concern

President Bush's New Freedom Commission on Mental Health represents the first federal initiative to evaluate and reform America's behavioral health system since the Carter Administration. The Commission's final report<sup>22</sup> concluded that incremental reform of the behavioral health system is no longer a viable option; a fundamental transformation is needed. As indicated in the "Vision Statement" of the report:

"We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports — essentials for living, working, learning, and participating fully in the community" (p. 1).

Moreover, the Commission's final report included a subcommittee report on unique problems in behavioral health care facing Americans living in rural or frontier regions:

- The federal government lacks a consistently applied definition of rural America.
- There are critical gaps in accessibility to services.
- There are critical shortages in the availability of providers and programs.
- Acceptability of care is often impaired due to urban-based models and strategies.
- A clearly defined plan to address long standing rural mental health disparities does not exist.
- Mental health policy is routinely established without consideration of its rural impact.

Rural America, as the map below indicates, covers the vast majority of geographical space in the country. Rural areas are often defined and viewed by what they lack, which is telling when considering behavioral health services. For example, consider these "cold, hard facts" related to rural areas in America:

- More than 60% of rural Americans live in mental health professional shortage areas.
- More than 90% of all psychologists and psychiatrists, and 80% of MSWs, work exclusively in metropolitan areas.
- More than 65% of rural Americans get mental health care from their primary care provider.
- Finally, rural Americans enter care later in the course of their disorders, with more advanced symptoms, and require more intensive and expensive interventions.

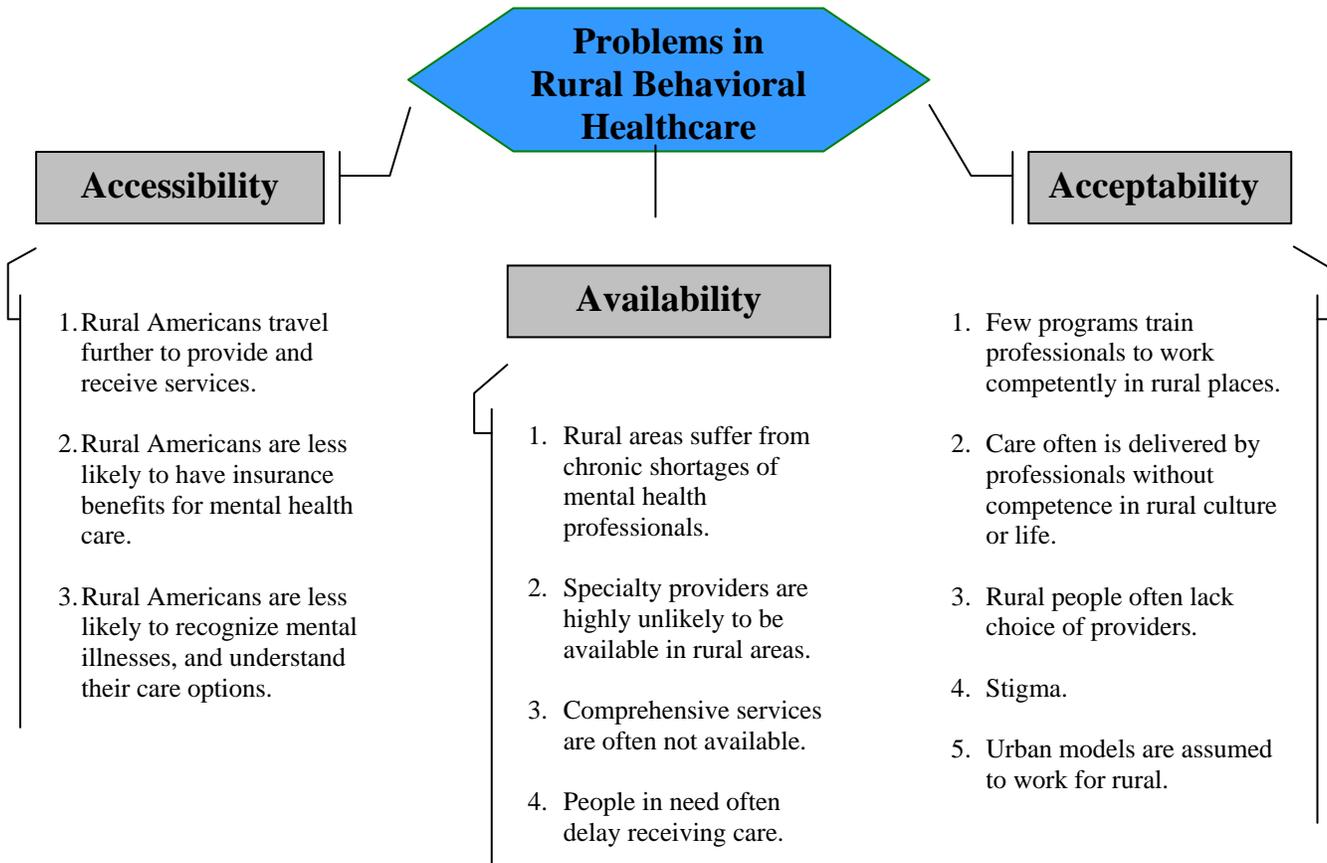
Challenges regarding behavioral health services in rural America can be understood in terms of three general issues: accessibility, availability, and acceptability. Figure 1 below lists some of the major concerns related to these issues. The focus of this project is the availability of rural behavioral health professionals, which is dependent upon several interrelated factors. These include education, rural training opportunities, recruitment and retention activities, and continuing education and support. For instance, existing funding streams and training programs do not mandate a set of skills that lead toward rural competency. Most specialty behavioral health (psychiatry and psychology) care is available locally only via itinerant providers. Furthermore, for rural persons with emergent behavioral health needs, law enforcement is often the only emergency responder and transport out of the community for care<sup>23</sup>.

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<sup>22</sup> see <http://www.mentalhealthcommission.gov/>

<sup>23</sup> Larson et al., 1993

Figure 1

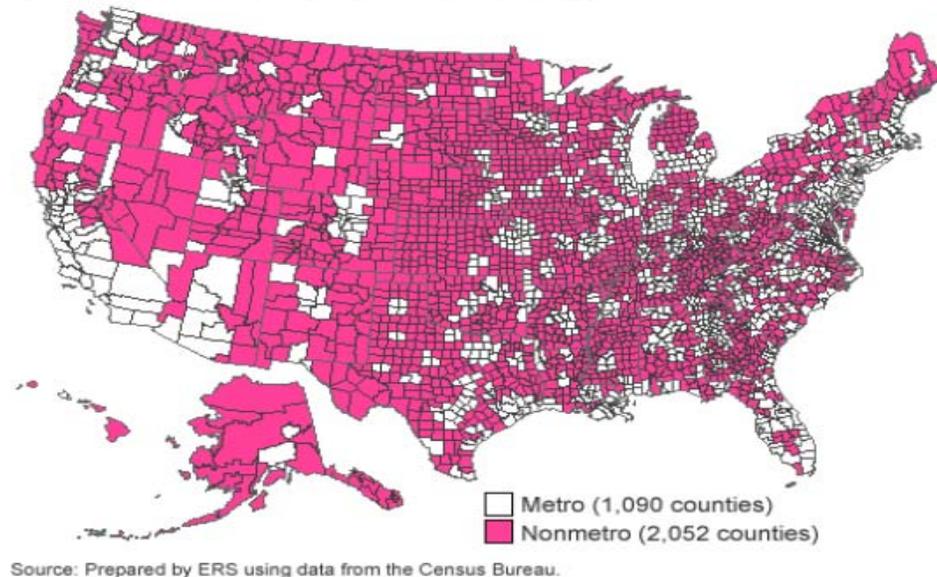


Data regarding workforce shortages portrays a critical disparity in the availability of behavioral health professionals in rural areas, over 85% of 1,669 federally designated mental health professional shortage areas are rural. The National Advisory Committee on Rural Health (1993) noted that across the 3,075 counties in the United States, 55% had no practicing psychiatrists, psychologists, or social workers, and all of these counties were rural.

The ratio of these providers to the population worsens as rurality increases. For instance, Holzer and colleagues studied the availability of health and mental health providers by population density. They found that only about 10% of frontier counties had psychiatrists and less than 1% of very frontier counties had any psychiatrists. These rates of psychiatrists per 100,000 people for frontier and very frontier counties are 1.3 and 0.1, respectively. Additionally, only 13.3% of very frontier counties had psychologists (13 per 100,000), although frontier counties had 43.1% (18.1 per 100,000). For very frontier counties, 18.5% had social workers (12.8 per 100,000), while 23.4% exist in frontier counties (9.1 per 100,000). In summary, rural America needs, but does not have, an appropriate supply of competent, technically skilled professionals who have demonstrated knowledge and experience in rural/remote practice.

## Map 1

Nonmetropolitan and metropolitan counties, 2003



The New Freedom Commission’s final report contains several recommendations specific or applicable to rural behavioral health. These include:

1.1: Advance and implement a national campaign to reduce the stigma of seeking care and a national strategy for suicide prevention.

3.2: Improve access to quality care in rural and geographically remote areas.

5.3: Improve and expand the workforce providing evidence-based mental health services and supports.

6.1: Use health technology and telehealth to improve access and coordination of mental health care, especially for Americans in remote areas or in underserved populations.

While each of these recommendations is important for improving rural behavioral health services, the proposed project presented here is largely focused with 6.1, which is viewed as a means to achieving the goals in recommendations 3.2 and 5.3. Subsequent sections will expand on how the project will accomplish this, but several more aspects of the context of this proposal need to be discussed first.

### ***National, Regional and State Activities on Behavioral Health Workforce Development***

Efforts to address behavioral health workforce shortages have been underway for several years. At present, there is a national endeavor to increase the workforce for all Americans, which

includes rural as one of its primary focuses, as well as regional and state-level activities that have also primarily focused on rural workforce. These efforts will be briefly discussed here.

### **National Initiatives**

At the national level, the Annapolis Coalition on Behavioral Health Workforce has engaged in a multi-phase process to create a national strategic plan for behavioral health workforce development. The plan is sponsored by all SAMHSA Centers (i.e., CMHS, CSAT, CSAP) and encompasses workforce issues for a comprehensive range of specialty areas (e.g., rural, co-occurring disorders). A major goal was to focus on common issues, while respecting the unique needs of each specialty area.

The desired results from the multi-phase process included: 1) broad national consensus on mission, vision, and strategic directions; 2) a proposed plan of action for SAMHSA and its federal partners; 3) a set of high priority interventions; 4) new or strengthened partnerships to implement the interventions; 5) focused action at federal level; 6) focused action at the state and local levels; 7) focused action at the organizational level (providers, associations, educational); and 8) stimulate collective and individual action.

This national movement on the rural front has important ramifications for professionals and agencies serving the deaf community. Not only is there a significant overlap of the two populations (the majority of deaf individuals live in rural areas), there are also a number of parallels that can be drawn between the two communities. Historically, both of these populations have been overlooked and underserved. Little is known about how to effectively apply current evidence-based practices to these specialized populations. They have been overlooked due to a number of factors including but not limited to: myths and stereotypes that prevent the acknowledgement of service needs; an ‘out-of-sight, out-of-mind’ philosophy; lower numbers of individuals compared to their ‘hearing’ and urban counterparts; and lack of accessibility, availability and acceptability of services and training.

### **Regional Initiatives**

The behavioral health workforce, especially in rural and frontier WICHE states, faces many of the problems in its rural behavioral health systems identified in previous sections. However, unique issues can arise for a given area due to state-specific characteristics, which may include economics and state budgets, reimbursement systems, natural disasters, or other factors. WCRSWE was created to help improve behavioral health services to families and individuals living in rural and remote areas of the West – as about 20 percent [?] of all Westerners do. That’s essential, because the fallout for untreated mental illness can be extreme: [say what it leads to, specifically, e.g.: Those with untreated depression have a suicide/alcoholism/unemployment/poverty rate of x%, compared the y% for the general population]. Many of these problems are especially acute in remote rural areas, which see higher rates of [whatever -- if this is true, name those problems that are also associated w/untreated mental illness: e.g.: ... which see higher rates of alcoholism and suicide – 5 and 10 percent, respectively, compared to 2 and 3 percent for urban/suburban populations].

On a regional level, the call for western states to engage in formal efforts to develop a strong and able behavioral health workforce occurred in September, 2003, during a regional meeting in Reno, Nevada. The Health Resources and Services Administration (HRSA) provided funding for a WICHE Mental Health facilitated roundtable on rural behavioral health workforce issues. The basic premise of the meeting was that behavioral health and higher education can collaborate to develop effective workforce development strategies. This required a discussion of the multilevel contexts in which workforce shortages exist, the implications of these shortages, and possible solutions.

Following the Reno Meeting the WICHE Mental Health Program received funding from SAMHSA to sponsor a second conference to bring together public behavioral health systems and higher education stakeholders to continue the efforts of the Reno Meeting. "Building Partnerships in Rural Mental Health Workforce Development Meeting" was held in Mesa, Arizona in March 2005. Four specific recommendations for rural behavioral health initiatives were produced by the attendees to be included in the National Strategy for Workforce Development:

1. Distance Learning: Use Distance Education as a strategy to deliver seamless training across the rural behavioral health care career ladder. (Each State will identify their unique needs.)
2. Community-Specific Needs: Consult communities about their specific needs as defined by the community itself.
3. Include "Rural" in Cultural Competence: Determine ways to introduce "rural" and "cultural humility" into cultural competence (i.e., unique aspects of rural; no one "rural;" values of individual and community, spirituality, and linguistics).
4. Training in Model Rural Treatment Programs: Promote the adoption of rural training programs by identifying model programs and replicating and tailoring them to other rural communities.

### **State Initiatives**

At the state level, the WICHE Mental Health Program has worked or is working with four of its member states on projects specifically focused on developing the rural behavioral health workforce. The first project occurred in Alaska shortly after the Reno meeting. Key components of all projects are collaboration among behavioral health and higher education programs using distance learning via technology.

In December, 2003, faculty in behavioral health disciplines from the University of Alaska Fairbanks and Anchorage campuses met to discuss important issues and goals related to developing the workforce. The WICHE Mental Health Program conducted key informant surveys of faculty and facilitated the December meeting, then helped organize and facilitate the Alyeska summit in May, 2004, which resulted in the identification of specific workforce development goals and support of 1.178 million dollars for these efforts.

A particular strength of the Alaska approach was using a data-driven decision making process. University faculty involved in the partnership, with the help of WICHE, synthesized data regarding behavioral health professional shortage areas, workforce projections, student totals in each of the behavioral health programs and projected graduates, as well as macro-level trends

such as the number of people projected to enter versus leave the workforce by 2025. The use of data helped clarify areas of need, present and future workforce trends, and focused decision-making.

Beginning in April, 2004, the State of Arizona has been working to integrate higher education behavioral health training curricula with state practice models and the reality of practice in the public behavioral health system. This partnership has involved a number of meetings of faculty, CMHC staff, consumers and consumer advocates, as well as state personnel. The meetings were facilitated by the WICHE Mental Health Program and have focused on developing mission statements and specific, concrete, and achievable goals. In addition to the goal of integrating clinical practice models with higher education curricula, Arizona is ultimately trying to develop and recruit a workforce that is representative of the local communities, using a “grow your own” approach. Although the project continues, a major event was a one-day conference held in April, 2005 to disseminate the project to university faculty and enlist their help in making it a reality.

Nevada is working with WICHE to develop their workforce, using the same approach as that of Alaska. Specifically, they are using a data-driven model to demonstrate the significant lack of behavioral health providers, unmet need for treatment, and ways in which higher education programs can work with the state to better prepare graduates of behavioral health programs for the kinds of environments and issues they will face. WICHE is at the beginning phase of a similar plan with the State of Montana, and expects to follow a similar process.

### **Summary of Workforce Initiatives**

The national, regional, and state efforts currently underway indicate significant momentum behind behavioral health workforce development, particularly in rural areas. These activities provide a context in which the proposed project has arisen. Furthermore, it will be helpful to understand components of workforce development that must be considered when undertaking any project. While it is beyond the scope of this proposal to describe all possible factors that impact workforce development, there are four key areas that have arisen in similar work in Western states that bear most directly on behavioral health workforce. We are now also focusing particularly on workforce development for deaf and hard of hearing populations.

### **Current Status of D/HOH Behavioral Health Workforce**

Given the data and information regarding behavioral health workforce shortages in rural areas, one gets a clearer idea of the very limited specialized services for deaf and hard of hearing persons who need mental health and/or substance abuse treatment. The *2003 Edition of the Mental Health Services for Deaf People: A Resources Directory* only lists 35 mental health providers for the 15 WICHE states. California claimed the most at 18. Seven of the states did not have any services listed at all; most have only one service for the entire state. All of the listed services are located in urban settings. (See Appendix D for a listing of these services.) While all of the 15 states list that they have a government department, generally in the health and human services division, many of these programs are extremely limited in scope and application.

## **Summary**

Across the United States there have been historical difficulties in recruiting and retaining an effective behavioral health workforce that is culturally and linguistically prepared to serve the deaf and hard of hearing communities. These challenges include significant gaps in public and professional knowledge and training about hearing loss, accessibility to services, availability of providers and programs designed for their needs, acceptability of care based on historical perceptions of mistreatment, and establishment of mental health policy without consideration of the impact on deaf and hard of hearing communities. The Western Interstate Commission for Higher Education (WICHE) Mental Health Department is undertaking a project to address these issues. A successful workforce development project will increase the number of professionals available to provide services, thereby reducing the significant unmet need in the western region.

## Appendix A: Categories of Visual Language

The following definitions were extracted from <http://www.motion.com/deaf/perspective.html>

### American Sign Language (ASL)

ASL is the natural language of the Deaf and also the most used form of communication among the Deaf. However, if a signing module is included in a program, it must be understood that ASL signs will not match the speaker word for word. ASL has its own grammatical structure (different than English). ASL tends to be a visual or concept based way of communication. Users who are only familiar with SEE signs may have a difficult time understanding a pure ASL model.

### Pidgin Signed English (PSE)

PSE is not a specific form of signing. The term PSE is used to refer to signing that is in the middle of the continuum of signing. PSE is often some form of combination of ASL and manually-coded English. PSE is a likely choice for the signing module. A decision will need to be made as to if the PSE signer will use ASL signs in an English word order (Conceptually Accurate Signed English, CASE) or use more of a manually-coded English like SE. It is likely that most users who sign will be able to follow a signer using a form of PSE. It can be matched closely to the current spoken English audio on a program.

### Signed English (SE)

SE is similar to SEE sign. It follows closely to English grammar and structure. However, it has fewer supplementary signs for endings of verbs and other words.

### Signing Exact English (SEE)

SEE, like ASL, is probably not the ideal choice to include in a program unless all other forms of signing are also included as options. SEE has a smaller audience of users and educational programs as compared to PSE /ASL based users and educational institutions. SEE is a form of manually-coded English. It tends not to be as visually conceptual as other modes of signing. SEE follows English grammar exactly by using supplementary signs for endings such as -ing or -ed. It would be difficult for ASL signers to follow SEE signing.

## **Appendix B: Cultural Definitions of Deafness**

Deaf community and Deaf culture are two phrases used to refer to persons who are culturally Deaf as opposed to those who are deaf from the medical/audiological/pathological perspective. When used in the cultural sense, the word deaf is very often capitalized.

Being unable to hear is only a part of being Deaf. In fact, when the word is used in the cultural sense, hearing is one of the least important criteria used to delineate group membership. Many persons that are labeled hearing or hard-of-hearing from the medical perspective are labeled or would label themselves as Deaf from the cultural perspective. Similarly, a person who self-identifies as Deaf may in fact have much more hearing than one who self-identifies as either hearing or hard-of-hearing. The use of the cultural label is a declaration of personal identity much more than an explanation of hearing ability.

For the above reason, culturally Deaf people do not look on deafness as a disability. Deaf people view deafness as an asset in much the same way it is an asset to be a Navajo within the Navajo tribe or to be a Korean within the community of Koreans in Los Angeles. It is a manner of viewing the world and a matter of semantics. Most Deaf see deafness as the norm and thus do not see hearing as something they lack, even though the significant majority of the population has hearing. One would not define Navajos or Koreans as lacking the ability to be something other than Navajo or Korean. They, and the culturally Deaf, define themselves by what they are instead of what they are not. They consider what they are to be a positive trait, because it is tightly connected to their culture.

As an example of how thoroughly deafness is seen as a positive attribute, many Deaf individuals wish for their children to be born deaf. This can be hard or even impossible for hearing people to understand, but there is also a simple explanation for this when one considers how difficult it can be for hearing parents to raise deaf children. It can be equally difficult for deaf parents to raise hearing children. Both hearing and deaf parents who have children unlike them understand how much simpler life is when they fully understand the needs of their children and can easily communicate with and relate to their child's experience in the world. As hearing parents seek out resources to help them in the nurturing and education of their deaf children so too must deaf parents take extraordinary steps to ensure their hearing children, whose mother tongue might be a sign language, are exposed to hearing people and culture. Furthermore, Deaf parents know firsthand that Deaf people are able to live productive, fulfilling, and rewarding lives. So, taking all this into consideration, it comes as no surprise that as with hearing parents, some deaf parents see their abilities and skills best utilized on children who cannot hear.

Those who view deafness as a disability -- known as a pathological perspective of deafness -- can be met with hostility by individuals in the Deaf community. Such hostility probably represents a reaction to the suspicion and hostility that many deaf people encounter during their lives.

People without hearing loss can and do participate in the Deaf community. For example, hearing children of deaf adults (commonly called "CODAs") can experience full acceptance within the Deaf-World, a term some deaf Americans use to describe their social network. Acceptance into

this world extends to anyone who appreciates the easy flow of communication within the group and upholds the hard-earned values, history, mores, and dignity of deaf people.

As with any other culture, there exists a set of shared experiences, attitudes and cultural norms that serve to identify and bring together members of the Deaf community while simultaneously excluding outsiders from entering the core group. To be fully included in the Deaf community, one must at least have the following attributes and possibly others not mentioned.

Fluency in a sign language and a positive attitude toward the language. Sign language is the central-most valued aspect of Deaf culture and having a shared language sets up a powerful affinity among the Deaf as it does in hearing cultures. Language is often a central, indeed required, component of a culture. In hearing cultures foreigners are expected to learn the language of the land of their residence in order to successfully assimilate into the culture. Use of the majority language is desirable, but the grave difficulty of acquiring spoken language for the prelingually deaf has been balanced by the community's genius in creating original, indigenous sign languages that are truly "of" the nation that nurtures the signing deaf as citizens, embodying both their national culture and the culture of the deaf community itself.

Knowledge and respect for the cultural norms of the Deaf community. For example, the Deaf community has attention-getting behaviors: waving a hand or creating a vibration with an object to gain attention; pointing at people is not considered rude behavior. Direct eye contact is insisted on to glean meaning. There are Deaf culture norms for introductions and leave-taking, which are prolonged and physical with much contact. Many other cultural norms are different from those of the hearing culture within which Deaf culture is embedded.

Adaptations to deafness. Deafness may present both liabilities and assets in the interaction of the Deaf with the surrounding world. While one cannot attract the attention of a deaf person by calling their name, deaf people can communicate freely where ambient noise prohibits communication, or even comfort, among the hearing. This is one reason deaf people are highly sought after as employees in large-scale manufacturing and publishing where the noise of machinery is a serious concern. Two deaf people can converse through a closed window or glass office wall, or across a space too large for a voice to carry, so long as they can see one another. Many Deaf do not see themselves as disabled. A hearing person may not understand why some deaf people express no sense of loss over being unable to experience sound. Since experiencing sound is something some deaf people never had, there may be no loss or associated emotions with not having it. Deaf people are aware of the things they cannot succeed in and may be adept at ferreting out the range of activities in which they can occupy or create an established niche. This may seem unusual to some hearing people because they are aware of the abundance of opportunities afforded to people who hear sounds. Hearing persons who are members of the Deaf community are aware of and share this Deaf-World view not so much because they are expected to, but because they have witnessed the common-sense practicality of deaf methods of problem solving.

## **Appendix C: National Standards for Culturally and Linguistically Appropriate Services in Health Care.**

- **Standard 1.** Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.
- **Standard 2.** Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.
- **Standard 3.** Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.
- **Standard 4.** Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.
- **Standard 5.** Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.
- **Standard 6.** Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).
- **Standard 7.** Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.
- **Standard 8.** Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.
- **Standard 9.** Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations.
- **Standard 10.** Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.
- **Standard 11.** Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.
- **Standard 12.** Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.

- **Standard 13.** Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.
- **Standard 14.** Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

**Appendix D: Listings from *Mental Health Services for Deaf People: A Resource Directory (2003 Edition)* for WICHE States**

<b>State</b>	<b>City</b>	<b>Program</b>	<b>Program Type</b>	<b>Organization Type</b>	<b># of deaf clients served in 2002</b>
AK	Anchorage	Anne B. Norton, AK Mental Health Services for Deaf	Private Practice	Ind. For Profit	25
AZ	Tucson	Community Outreach Program for Deaf	CMHC	Other Nonprofit	253
CA	Alhambra	Alhambra School District	School/Univ.	City	100
	Berkeley	Center for Independent Living – Deaf Services Peggy Kelly, Ph.D.	Voc/Rehab/ILS	Corp. Not-for-profit	0
	Fremont	California School for the Deaf	Private Practice	Ind. For Profit	5
	Hayward	Fred Morrison, MFT	School/Univ.	State	300
	Napa	Napa State Hospital	Private Practice	Ind. For Profit	3
			Psychiatric Hospital	State & County	15
	Riverside	Counseling Services, CA School for the Deaf	School/Univ.	State	0
	San Diego	Cindi Cassady, Ph.D.	Private Practice	Ind. For Profit	200
		Kristen Cole, Ph.D.	Private Practice	Ind. For Profit	50
		Signs of Life	Outpatient MHC	County	
				Corp. Not-for-profit	130
	San Francisco	Daniel J. Langhotz, LCSW	Private Practice	Private Practice	80
		Hank Berman, MFT	Private Practice	Private Practice	26
	Hearing Society for the Bay Area, INC.	Ind., Family & Child Therapy	Corp. Not-for-profit	0	
	UCSF Center on Deafness, Langley Porter Psychiatric Inst.	Outpatient MHC	Corp. Not-for-profit	16	
	William I. Perry, Ph.D.	Private Practice	Ind. For Profit	0	
San Jose	Deaf/Hard of Hearing Program, Family and Children Services	Outpatient MHC	Corp. Not-for-profit	0	
Santa Monica	Mental Health Services for Deaf and Hard of Hearing People, Saint John's Health Center – Child & Family Development Center	Outpatient MHC	Private Church-related	250	
Santa Rosa	Willow Creek Treatment Center/ North Valley School	Residential Treatment Center	Corp. Not-for-profit	16	
CO	Denver	Mental Health Corporation of Denver, Deaf Counseling Services	Outpatient MHC	Corp. Not-for-profit	100

HI	No Services Listed				
ID	No Services Listed				
MT	No Services Listed				
NV	No Services Listed				
NM	Albuquerque	Desert Hills of New Mexico	Psychiatric Hospital	Corp. For Profit	15
		Southwest Services for the Deaf	Outpatient MHC	Corp. For Profit	60
		The Deaf Group Home	MH Day/ Night Facility	Corp. Not-for-profit	0
ND	No Services Listed				
OR	Salem	Connection Program	Other	Other Nonprofit	56
		Irmgard Friedman, Ph.D.	Private Practice	Ind. For Profit	0
SD	No Services Listed				
UT	Murray	Kristylynne Brady, The Counseling Center	Outpatient MHC	Outpatient Treatment	50
		Salt Lake City	Sego Lily Center for the Abused Deaf	Domestic Violence Advocacy	Corp. Not-for-profit
	Taylorsville	Utah Community Center for the Deaf – Mental Health Program	CMHC	Outpatient Treatment	80
		Utah State Office of Rehabilitation, UT Community Center for the Deaf and Hard of Hearing	Voc/Rehab/ILS	Day/Voc	270
WA	Seattle	Melissa Wood Brewster	Private Practice	Ind. For Profit	0
		Psychiatric Services for Deaf and Hard of Hearing Children, Children’s Hospital and Regional Medical Center	Outpatient MHC	Outpatient Treatment	45
		Wendy B. Marlowe, Ph.D., ABPP	Private Practice	Ind. For Profit	15
	Spokane	Karen Lyden, M.S., Spokane Mental Health	CMHC	Corp. Not-for-profit	40
	Yakima	Suzanne Noble, M.A., Central Washington Comprehensive Mental Health	CMHC	Corp. Not-for-profit	30
WY	No Services Listed				

## **Appendix E: Synopsis of Two Model Mental Health Service Programs**

### **South Carolina Department of Mental Health, Program of Services to Persons who are Deaf or Heard of Hearing<sup>24</sup>**

#### ***Program Overview***

Since 1989, the South Carolina Department of Mental Health has funded a unique program of services for persons with mental illness who are deaf or hard of hearing. Key components of the program include mobile, community-based counselors who are responsive to consumer needs, residential alternatives that affirm the values of Deaf Culture by enabling recipients of public mental health services to live in close proximity to other persons who are deaf, and a small inpatient treatment unit that complements and supports the community-based programs.

Regional services include a traditional continuum of mental health care enhanced by the use of state-of-the-art technology that affords greater efficiency in the delivery of services. These technical innovations include the use of video conferencing, a statewide crisis-line, and laptop computers that enable regional counselors to have access to central databases and supervision assistance through modems and directline connections to the larger mental health computer network. Two-way pagers assist professionals in the field who are deaf in the same way that cellular telephones benefit field personnel who can hear.

#### ***Collaborative Efforts***

In South Carolina, a significant level of collaboration exists between the state mental health agency and numerous other entities, including educational programs for children who are deaf, the state vocational rehabilitation agency, the South Carolina Association of the Deaf, the Commission for the Blind, the state agency serving people with Developmental Disabilities and Cultural Diversity Series: Meeting the Mental Health Needs of Persons Who Are Deaf Page 38 Special Needs, the state Department on Alcohol and Other Drug Abuse Services, and the Governor's Offices of Children's Services.

In addition, state mental health administrators frequently receive requests for consultation in developing services for consumers who are deaf from other state mental health systems. To date, South Carolina mental health system staff have provided direct consultation to 16 states and made more than 100 presentations at national, state, and regional conferences regarding its model for providing public mental health services to people who are deaf or hard of hearing. In cooperation with South Carolina Educational Television, the state deaf services program developed a videotape explaining how its services operate. Indeed, at least three states have implemented mental health services for persons who are deaf based on the South Carolina model, which can be replicated, with modifications, in any statewide or regional public mental health system.

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<sup>24</sup> Information in this section excerpted directly from Critchfield, B., Cultural Diversity Series: Meeting the Mental Health Needs of Persons Who are Deaf. (2002).

### ***Evaluation Efforts and Results***

In South Carolina, the average daily inpatient census of consumers who are deaf has dropped from a peak of 22 in 1993 to the current average of 1.2. The average length of stay for persons who are deaf with mental illnesses in inpatient settings decreased from more than 20 years to approximately 15 days during that same period. Simultaneously, the number of consumers that the state mental health system serves has steadily increased. The significant reduction in inpatient census and length of stay combined with substantial growth in the number of consumers served provides a clear indication that the program is meeting its goal of providing appropriate, community-based mental health services to members of the Deaf Community. In addition, fewer state funds are spent today to serve a far larger population of consumers who are deaf than were spent in past years to place a relatively small number of consumers who are deaf in inappropriate and expensive inpatient settings. In 1991, the South Carolina Department of Mental Health spent more than \$1.7 million to provide mental health services for fewer than 30 consumers who are deaf (primarily in inpatient settings); today, the state mental health system serves more than 400 persons who are deaf in community settings at a much lower overall cost, when factoring in Medicaid revenue as well as block grant funds. These consumers receive significantly better services in far less restrictive settings. Some of the persons once confined to inpatient facilities now hold competitive jobs, live independently, and function as productive and contributing members of society.

### **Threshold Bridge Program for the Deaf, Chicago, Illinois<sup>25</sup>**

#### ***Program Overview***

Thresholds Bridge Program for the Deaf, established in 1984, serves consumers who are deaf with a broad range of psychiatric disabilities in the Chicago metropolitan area. The program provides comprehensive mental health services for adults who are deaf, including residential, outreach, and vocational rehabilitation programs. The Bridge Program has been successful in integrating inpatient, outpatient, residential, and advocacy services in a manner tailored to address the special needs of persons who are deaf. The program, which serves 150 to 200 consumers who are deaf each year, is one of several specialty programs operated by its parent agency, Thresholds, whose mission includes developing and expanding services to help meet the mental health needs of consumers and to improve the quality of life of a wide range of persons with serious mental illness.

Thresholds' specialty programs also include the Mother's Program, the Young Adult Program, the Older Adult Program, and, most recently, the Jail Program. Each of these programs serves populations that often are neglected by other mental health systems. The Thresholds Jail Program recently received the American Psychiatric Association's highest honor, the Gold Achievement Award for innovative service provision and excellence in service delivery. The Bridge Program received a significant achievement award from the American Psychiatric Association in 1991 for its rehabilitative services to adults who are deaf and who have a mental illness. Altogether, Thresholds serves more than 5,000 consumers each year and employs 1,000 staff with an annual budget of more than \$40 million.

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<sup>25</sup> Information in this section excerpted directly from Critchfield, B., Cultural Diversity Series: Meeting the Mental Health Needs of Persons Who are Deaf. (2002).

### ***Evaluation Efforts***

Thresholds consistently evaluates its programs and activities, and it disseminates the findings through training, consultations, publications, and conference presentations. Upon entering the program, a typical Cultural Diversity Series: Meeting the Mental Health Needs of Persons Who Are Deaf Page 44 consumer has been hospitalized an average of six times and has spent more than three years in an outpatient setting. Many members lived with relatives before entering the program (42 percent) or in sheltered settings (38 percent), and 90 percent were unemployed. During their tenure in the program (average 2.9 years), 43 percent avoid re-hospitalization altogether, 63 percent are employed, and 45 percent live in independent apartments. Among members who have spent at least 12 months in the program, Global Assessment Scale scores have improved significantly between intake and follow-up, moving members to the next higher category of functioning. Many members also experience a significant decrease in symptoms as measured by the Brief Psychiatric Rating Scale and demonstrate significantly improved independent living skills.