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Bringing Mental Health Care for Deaf and Hard of  
Hearing Populations into the 21<sup>st</sup> Century

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Report on the 2008 Deaf Expert Meeting  
and  
A Framework for Action:

Shaping a world where deaf and hard of hearing people are  
respected, self-determining, and living well.

July 2008

## Preface

We are pleased to present to you this report on the proceedings of the Expert's Meeting on Deaf and Hard of Hearing Mental Health Systems hosted by the National Association of State Mental Health Program Directors on June 5 and 6 of 2008. This meeting was designed as a first step in the process of developing a technical assistance guide for states to create a clear path toward achieving the development of an adequate and effective mental health system of care for deaf and hard of hearing populations. This is a 'living document' in that it will be continually updated as salient issues and innovative solutions arise. In this spirit, it is hoped that readers will submit their ideas, feedback, and suggestions to increase the comprehensiveness and scope of issues covered.

Candice M. Tate, Ph.D.

Owner and Primary Consultant

Tate Consulting, LLC

303-709-6811

[Candice@purplemonarch.com](mailto:Candice@purplemonarch.com)

Bob Glover

Director

National Association of State Mental Health Program Directors

[Bob.Glover@nasmhpd.com](mailto:Bob.Glover@nasmhpd.com)

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## **Executive Summary**

Across the United States and the world there have been historical difficulties in identifying mental health issues and providing appropriate services for 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 mental health system of care for deaf and hard of hearing populations, the Western Interstate Commission for Higher Education (WICHE) Mental Health Program initiated research on relevant issues facing the deaf and hard of hearing populations. This research is now being continued by Candice M. Tate, Ph.D. of Tate Consulting, LLC, and other members of the deaf and hard of hearing community. What follows is a summary of relevant concerns and data in several areas of deaf and hard of hearing populations, a description of an expert panel convened to discuss those concerns, and a synopsis of the resulting action plan. Please note that all statistics are presented in further detail in the main body of the report with accompanying citations.

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

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- There is currently no national census of deaf and hard of hearing persons.
- It is *estimated* that 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 some kind of hearing loss.

- 8.6 percent of the total U.S. population 3 years and older are reported to have some level of hearing loss.

### **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 plans to collect or track the incidence of violent death or suicide in the deaf population.

### **Number and Availability of Services for Deaf Populations**

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- There is no national database of available competent, technically appropriate services for deaf and hard of hearing populations in the United States.
- There are only 150 programs listed for United States and Canada in the *Mental Health Services for Deaf People: A Resource Directory; 2003 Edition*.
- In 1990, there were just 20 deaf psychologists in the United States compared to 5 in 1979.

## **Deaf and Hard Of Hearing Expert Meeting and Action Plan**

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An expert meeting to begin the process of developing a technical assistance document that would guide states in the developments of effective systems of care for their deaf and hard of hearing populations was convened in Alexandria, VA on June 5 and 6, 2008. The National Association of State Mental Health Program Directors (NASMHPD) sponsored this meeting, which was a critical first step to realizing a common vision among important agencies, facilities, consumers, and advocacy groups. The products of the meeting included a determination of key areas of concern and a preliminary action plan outlined below.

There were five key areas identified by the group as being critical to the future of mental health services. The participants broke into five separate groups and listed the most salient goals expected in each area and thus each section below varies in format and presentation. Due to the overwhelming amount of material covered during the two-day meeting, there was insufficient time to arrange each into a standard strategic goal format with a measurement of success and completion dates. In addition, there are several goals listed without a specific reference to a responsible party. These will be clarified through future discussions to determine the most appropriate organizations to address each goal.

### **Area 1: Access and Early Intervention.**

1. Key Outcomes:
  - a. Research and develop a position paper on the right to language access, i.e.: sign language
  - b. Provide parent and professional community education related to language rights and the effects of language deprivation
  - c. Early identification and treatment of emerging mental health needs and social/behavior needs
2. Key Initiatives:
  - a. Research and Data Collection
    - i. Collate current data
    - ii. Verify the validity and reliability of current data

- iii. Federal Census needs to include information on deaf and hard of hearing citizens
- iv. Develop valid instruments for research and data collections
- v. Complete longitudinal studies of deaf people who received cochlear implants as children/infants
- b. Develop assessment tools and benchmarks based on normal linguistic development
- c. Form family, community, and professional alliances to achieve the mission that deaf and hard of hearing people be respected, self-determining, and living well.
- d. Outreach and non-traditional service delivery, utilizing video and leveraging technologies, e.g. web, Public Broadcasting System, Lending Library, etc.

## **Area 2: Advocacy/Empowerment**

1. Political Action
  - a. Identify House & Senate Representatives to serve as legislative advocates
  - b. Identify State & Local Legislatives with an interest as advocates
  - c. Encourage deaf people to run for offices at all levels
2. Of, for, by & with deaf people: “Nothing about us, without us”
3. Deaf Advocates in criminal justice system:
  - a. bring deaf inmates together
  - b. address isolation
4. Linkages with Existing constituency/advocacy groups
  - a. Deaf Representation on major national and state advisory groups/panels
  - b. Planning Commissions to include broad representation from all constituency groups to formulate legislative actions
5. Children should be taught the 3 Rs:
  - a. Rights
  - b. Roles
  - c. Responsibilities
6. Raise the visibility of the deaf community and not bury them within other minority groups – deafness incorporates all other minority populations
7. Peer support training for people in recovery

## **Area 3: Training and Workforce Development**

1. Identify, develop and implement processes to recruit, train and retain a culturally competent workforce (including language competencies) at the pre-professional, paraprofessional, clinical (professional), and peer levels.
2. Include other national organizations in this work, including but not limited to organizations such as the American Psychiatric Association (APA), the American Psychological Association (APA), American Psychiatric Nurses Association (APNA), National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA), National Association of Social Workers (NASW), National Association of Peer Specialists (NAPS), Western Interstate Commission for Higher Education (WICHE; rural), and the Registry of Interpreters for the Deaf (RID).

3. Strategize to identify funding mechanisms to support this work including fellowship programs, loan forgiveness, federal support, scholarships (in part provider supported).
4. Deliver all workforce and training activities in the following formats, replicating Vocational Rehabilitation and/or substance abuse certification:
  - a. classroom instruction;
  - b. online education/web seminars;
  - c. self-study;
  - d. internships (with strategies to support interpretation for interns).

#### **Area 4: Service Continuum**

1. To develop regional programs which provide for the delivery of services to low-incidence populations needing institutional care. Encourage the Substance Abuse and Mental Health Service Administration (SAMHSA) and the National Association of State Mental Health Program Directors (NASMHPD) to fund and support multi-state agreements which would allow this coalition to have specialized programs serving:
  - a. Forensic populations – Not competent to stand trial (NCST)<sup>1</sup>
  - b. Trauma, Post-traumatic stress disorder (PTSD)
  - c. Substance abuse and co-occurring disorders – inpatient treatment programs
  - d. Children – inpatient and residential treatment
  - e. Housing
2. Programs which receive federal finding for dual diagnosis must show evidence of inclusion of deaf and hard of hearing consumers in service delivery
  - a. Demonstrate service specific to deaf and hard of hearing consumers in their programs and:
  - b. Include service provision by deaf professionals and staff and/or individuals fluent in American Sign Language.

#### **Area 5: Policy Development and Leadership**

1. Establish an overarching National Advisory/Steering Group, staffed by NASMHPD that:
  - a. networks with other federal agencies, e.g., National Institute of Health (NIH), National Institute of Mental Health (NIMH), National Institute on Deafness and other Communication Disorders (NIDCD), National Institute on Disability and Rehabilitation Research (NIDRR), Rehabilitation Services Administration (RSA), etc.;
  - b. coordinates with the Deaf and Hard of Hearing Consumer Action Network (CAN):
  - c. and coordinates with NASMHPD to offer an annual or biennial conference with State Mental Health Authorities (SMHAs).
2. Key Initiatives to bring before the National Advisory/Steering Group:
  - a. Establish a Research Agenda

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<sup>1</sup> Different jurisdictions utilize various terms including but not limited to: Not criminally responsible (NCR); Not guilty by reason of insanity (NGRI); Not guilty by reason of Mental Disease or Defect (NGRMDD). Here and throughout the report we will use NCST to refer to all terms.

- i. Consider the development of a national research database to promote research and networking (e.g., akin to the Interactive Autism Network)
  - ii. Trauma and the Deaf Community
  - iii. Establish a definition of deafness and hard of hearing
- b. Modify existing Centers for Medicare & Medicaid Services (CMS) regulations regarding waivers to directly address language dysfluency and language deprivation
- c. State Incentive Grants to establish infrastructure (including tele-health) and services, and the training that supports them, on both a state-wide basis (for community based services) or multi-state basis (for inpatient, forensic or other niche services), to include a focus on the development of promising practices and Model State Guidelines
- d. Establish a legislative agenda to:
  - i. Address language dysfluency and the effects of language deprivation, and the need for early identification and exposure to ASL
  - ii. Examine federal legislation on disability and their impact on the deaf community, e.g., U.S. Department of Housing and Urban Development (HUD), Individuals with Disabilities Education Act (IDEA)
- e. Establish a staff position at SAMHSA to:
  - i. Address the lack of attention to deaf mental health in all programs and publications,
  - ii. Provide coordination across SAMHSA programs to advance deaf services and work with NASMHPD Office of Technical Assistance and the above mentioned National Steering Group.

### Concrete Next Steps

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- ❖ NASMHPD/Office of Technical Assistance (OTA)/Center for Mental Health Services (CMHS)
  - Assign dedicated Office of Technical Assistance staff person as liaison to the future deaf association.
  - Support monthly conference calls and set up a “memberclicks” list serve
  - “Hold” one experts meeting slot for FY08/09
  - Add Technical Assistance Deaf Experts Consultation Team to offer Technical Assistance “Technical Assistance Roster”. The future deaf association would determine “who” is best suited to provide Technical Assistance, depending on the state and the request.
  - Petition Dr. Glover to include a presentation on Deaf Issues and future activities, including available Technical Assistance, at winter Commissioner’s meeting
  - Include a specific training module on Deaf and Hard of Hearing mental health issues in NASMHPD Adult Direct Care Training Curriculum (in process), targeting adult direct care staff. OTA could provide some dollars for the future deaf association to write the curriculum, including American Sign Language (ASL) versions of the existing modules
- ❖ Expert Meeting Participants

- Develop and follow-through with the above offers from NASMHPD
- Produce a document summarizing the issues and meeting agenda
- Create a national non-profit organization to consolidate and support the action plan
- Follow-through with specific actions in the goal plan

In closing, the meeting provided concrete next steps, commitments from various participants to further the process and most importantly a sense of group motivation and responsibility to make a true difference in the status quo of mental health services for deaf and hard of hearing populations.

## Introduction

Over the past 40 years, there has been a growing awareness of the inability of the current mental health<sup>2</sup> 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*. The following section will briefly summarize relevant issues and data from the reports indicated.

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<sup>2</sup> In this document, the term mental health includes both mental and substance abuse issues. We chose not to use the term 'behavioral health' as it has negative connotations in the deaf and hard of hearing communities.

## **Background: Definitions, Epidemiology, and Prevalence**

### *Definitions: 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. There are four major definitions of deafness: medical, functional, linguistic, and cultural. Please refer to Appendix A for descriptions of each definition. 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.

As a comparable example, 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>3</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. 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 document. *However, this is a critical area in need of research and funding.*

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 refer to Appendix B for a list of the five standards.

Furthermore, according to OMH's *Standards*:

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<sup>3</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.

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 (i.e. English as opposed to American Sign Language) 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.

<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.

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 census 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>4</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. Another GRI publication by Holt, Hotto, and Cole (1994) provides older but more specific

<sup>4</sup> <http://gri.gallaudet.edu/Demographics/deaf-US.php>

data on the demographic profile of deafness in America. 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. 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.

### *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>5</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>6</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>7</sup>. Whether these statistics indicate a true prevalence rate or a

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<sup>5</sup> 1996. Professional psychology and Deaf people: The emergence of a discipline. *American Psychologist*, vol. 51, no. 4, April, pp 389-396.

<sup>6</sup> NASMHPD (2002) Reducing the Use of Seclusion and Restraint Part III: Lessons from the Deaf and Hard of Hearing Communities.

<sup>7</sup> Hamerdinger and Murphy (2000).

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 population<sup>8</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>9</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>10</sup>. Furthermore, the circumstances of many deaf people provide environmental pressures that may foster drug abuse: communication barriers, isolation, unemployment, inadequate support from family and friends, inaccessible meetings and events and namely, insufficient services.

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>11</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

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<sup>8</sup> Willis and Vernon (2002). Residential Psychiatric Treatment of Emotionally Disturbed Youth. *American Annals of the Deaf*. Vol. 147, no. 1.

<sup>9</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>10</sup> Guthmann, D. Online Article: [http://www.mncddeaf.org/articles/problem\\_ad.htm](http://www.mncddeaf.org/articles/problem_ad.htm)

<sup>11</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.

population. Elder (1993) estimates that deaf children experience abuse two to three times higher than that of their hearing peers.

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>12</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.*

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.

#### *Availability of Mental Health Services*

Deaf Americans need competent, technically appropriate mental health professionals who have demonstrated knowledge and experience in deaf culture and sign language fluency. However, Pollard<sup>13</sup> 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 only 5 in 1979. The Gallaudet University Graduate Research Institute published the *Mental Health Services for Deaf People, A Resource Directory, 2003 Edition*<sup>14</sup>. They listed only 150 mental health programs for the United States and Canada. In addition, there are numerous mainstream programs that affirm

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<sup>12</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.

<sup>13</sup> Pollard, R. Q (1996). Professional psychology and deaf people: The emergence of a discipline. *American Psychologist*, 51(4), 389-396.

<sup>14</sup> <http://gri.gallaudet.edu/Publications/>

their ability to serve deaf and hard of hearing populations. However, there are no standards for defining competent and technically appropriate services and the range of quality between programs is large. This low availability of competent and appropriate services also presents a severely limited choice of services and a restricted continuum of services. These individuals rarely have a choice of providers and may even have to travel out of state to receive appropriate services. Clearly, this is a serious issue for the 5 million deaf and hard of hearing individuals who need mental health services in their communities *now*.

## **Deaf and Hard Of Hearing Expert Meeting and Action Plan**

### *Background*

An expert meeting to begin the process of developing a technical assistance document that would guide states in the developments of effective systems of care for their deaf and hard of hearing populations was convened in Alexandria, VA on June 5 and 6, 2008. The National Association of State Mental Health Program Directors (NASMHPD) sponsored this meeting, which was a critical first step to realizing a common vision of enhancing the quality of mental health care for individuals with hearing loss. The meeting targeted behavioral health researchers, policy makers, consumers, and other stakeholders in the field of deafness to promote a national dialogue and action planning process to determine the most effective type of service provisions and the necessary supportive actions. The products of the meeting included a determination of the key areas of concern and a preliminary action plan outlined below.

The vision organizes several core values for the mental health system of care:

- 1) It is deaf and hard of hearing centered, with cultural and communication needs dictating the types and mix of services provided,
- 2) It is state-based, with the locus of services as well as decision- making responsibility resting at the state level, and
- 3) It is culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

This meeting was expected to develop consensus about what model mental health systems of care will look like, how they will function, and the path to their achievement. Professionals, consumers, and parents of consumers from many different agencies and disciplines across the United States attended (see Appendix C for a list of attendees) and participated in meeting activities. The meeting was assisted by an experienced facilitator in the Expert Meeting process, Richard Mettler, as well as Candice Tate formerly of the Western Interstate Commission for Higher Education (WICHE) Mental Health Program.

The Expert Meeting began an important dialogue at program, state, and national levels that participants will be encouraged to continue within their own states. As indicated by the core values noted above, an effective system of care must be guided by the needs of the locality in which it exists. Although the Expert Meeting participants and facilitators are committed to supporting states in their efforts to develop an effective system, ultimately they cannot and should not prescribe such a system. Thus, participants were encouraged to consider flexible, adaptable, but integrated systems based on best and evidence-based practices for inclusion in the technical assistance document as model systems.

### *Expert Meeting Process*

The meeting started as planned with the Briefing and Desired Outcome Number 1 (Please see Appendix D for the Agenda). However, during Desired Outcome Number 2, participants became increasingly dissatisfied with the meeting progress. Three main themes emerged: 1) “this process has been done before and nothing has transpired,” 2) “the *salient* issues are not being addressed, namely the language deprivation of deaf children, which prevents appropriate mental health development and treatment,” and 3) “the research and educational institutions are not connected to the ‘real world’ of deafness in the community, especially in non-urban areas where resources and services are scarce.” At the conclusion of the first day, Richard Mettler, Candice Tate, and Bob Glover met to review the meeting progress and after intense discussion decided to abandon the established agenda for the second day in favor of a group-led process. This was tremendously empowering and produced enthusiasm, motivation, and even hope for many of the participants that this process would be fruitful. The following outline demonstrates the astounding amount of material covered in the two day meeting<sup>15</sup>.

#### ❖ Challenges

- Most mental health programs and systems of care do not work for deaf people
  - 1) Compartmentalization of services serves as a huge disincentive
  - 2) Contradictory mandates
    - a) Provide mental health services
    - b) Prevent bad mental health outcomes of suicide and homicide
    - c) Conflict resolved in the direction of serving as an agent of social control, rather than of service provision
  - 3) Limited access to valid assessment – misdiagnosis is the norm

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<sup>15</sup> Much appreciation is due to Felix Vincenz, MD for his willingness to take notes during this intense process!

- 4) Inadequate response to mental health crises
  - 5) Absence of appropriate resources for treatment or training
    - a) No interpreters: cost too much and are too few in number
    - b) No deaf staff/clinicians
    - c) Limited interested among mental health providers in “niche” programs
    - d) Guidelines or Best Practices are developed for hearing people and do not work for deaf populations
    - e) Federal funding streams are not supportive of services or attentive to the need
      - Limited knowledge of prevalence of mental health disorders among the deaf population (whether Diagnostic and Statistical Manual-IV or not) – which prevents the issue from getting on the federal agenda (need to know how big the elephant is).
      - Federal Census does not count individuals who are deaf, save for one question on the long form about whether anyone has difficulty hearing
      - Most of the deaf community are not insured under Medicaid or Medicare, which makes it difficult to grow those programs that work
    - f) Budget Cuts and low salary levels in general in the mental health field, compounding the impact on the deaf population
  - 6) Bias: do the bare minimum to avoid litigation
    - As a result, deaf people are unserved and bad outcomes occur
- ❖ “Seeming” Solutions
- Common Response from Mental Health Service Providers/Systems: Provide an interpreter or access to a “deafness expert”
    - 1) Reason: Federal laws do not require “culturally affirmative” practice, only “access”, which generally is a very low bar
    - 2) Access requires only -
      - a) Provision of Interpreters; and/or
      - b) Provision of a “deafness expert”, who becomes all things to all people and must be experts in all disorders and all evidence based practices in order to adopt them and provide them to everyone in need, which is a ludicrous proposition
    - 3) Problem with this approach is that many deaf consumers are unable to benefit from interpretation or do not have access to an expert who can meet their needs
  - Better response is to find individuals who are sensitive to cultural and linguistic realities of the deaf community and who have the skill sets needed to meet their needs
    - 1) Examples include
      - a) Deaf professionals
      - b) Interpreters who are professionally trained
      - c) Adult children of deaf parents
      - d) Deaf consumers serving as peer specialists, who can augment the professional workforce, and who may be interested in future professional training (other examples include: drop-in centers, warm lines)
    - 2) Problem: Many of the above such individuals are in short supply. It’s not just an issue of “finding them, they’re just not there to be found”. Even if you do happen to find one, your agency may not be able to retain them.
      - a) Interpreters are few and far between and make so much money interpreting that they are unwilling to pursue professional training
      - b) The other groups are slow to enter the field or are slowly embraced
        - It is perceived that adult children of deaf parents are often blue-collar and not interested in higher education
        - Glass ceiling for deaf individuals interested in pursuing higher education
          - No options for professional training for deaf individuals/peer specialists interested in certification/higher education, other than Gallaudet
          - Note: Perception in some circles that graduates of Gallaudet University are not part of the “real world” and are not interested in leaving Washington D.C., preferring to work only

with rich consumers, and not with SMI populations. Job fairs do not seem to work to attract Gallaudet graduates

- Qualifying exams and certification processes that are not accessible to deaf population
- Growing willingness to bring people in at the ground level, but a general failure to promote and develop

❖ “Real” Solutions

- Stay Solution Focused to Find Such Solutions
  - 1) Think what opportunities may exist among the weaknesses.
  - 2) Rely on the paradox principle
    - a) Name 3 impossible things
    - b) If you don't think you have solution, identify one anyway
  - 3) Pareto Principal
    - a) Original Formulation: 80% of problems are caused by 20% of the processes in any system
    - b) Corollary: 80% of system change can be achieved by focusing on 20% of the possible solutions
  - 4) Develop a narrow focused list of macro-actionable items at both the federal and state mental health authority level (for psychiatric services, substance abuse and developmental disability services), and develop the mechanisms to sustain action
- General Perception: Things work best in centralized “centers/islands of excellence”, where there is a repository of trained and available staff, with the trade off being that deaf individuals have to travel. But even in such centers, we have problems
  - 1) More “centers of mediocrity” – those states that do it best are providing only basic services, rather than cutting edge technology
  - 2) Mental Health is More than Psychiatric Problems: Absence of programs specific to deaf children, substance abuse
  - 3) Absence of information on HIV/AIDS, specific to prevention and early intervention
- Other Strengths – actual or potential
  - 1) Potential workforce ripe for workforce development (see examples above)
  - 2) Growing awareness of how hiring deaf staff is the preferred approach (e.g., Massachusetts) – with historical biases against this practice disappearing
  - 3) A few states have peer training programs
  - 4) Interagency agreements/interdisciplinary approaches
  - 5) Technology: Video Conferencing/Video Phones/Tele-health
    - a) Provide access to skilled deaf clinicians or culturally and linguistically competent clinicians who can be a good fit for consumers who are shopping around for someone who can address their individual needs
    - b) Able to address the needs of consumers in rural settings
  - 6) Seven Studies leading to greater awareness of psychopathology prevalence/incidence – John Denmark, Ken Altshuler are among the best known
    - a) The studies do not always agree – some say psychosis is higher - others lower; some say more mental retardation - others less
    - b) Some issues are entirely unaddressed: e.g., trauma, depression
    - c) General Consensus among such studies: Psychopathology *is* different
      - Some present with significant behavior disorders, but without a presentation that fits into a nice clean diagnostic classification – it's more psychosocial developmental problems associated with language deprivation
      - Problems include: Limited literacy with significant educational and work deficits; issues around socialization, conflict management and communication
      - Many are found on the back wards of long-term care institutionalizations
  - 7) Program Development among the Hearing Community that has great potential for transfer to the Deaf Community (with the associated challenge to no longer remain 20 – 25 years behind this cutting edge and to ensure that members of the deaf community are included in the training offered to push this agenda, both at the local and federal level)
    - a) Self-Directed Care; Person Centered Planning
    - b) Wellness
    - c) Trauma

- d) Recovery/Resilience
  - e) Peer Support/Consumer Operated Services/Family Support: have the potential to bring their cultural and linguistic experience and competence to address workforce shortages
  - f) Greater attention to the integration of health and behavioral health<sup>16</sup>
- ❖ Basic Components of a Model System of Care for Deaf People [Note: The models are already out there, and have been for the past 30 years, but we need to do something different to really move the agenda forward and not continue “to spin our wheels” (the fear is that any real change in states that have made progress has only been in response to successful litigation)]
- General Principles
    - 1) Language is a basic human right, and the decision to honor that right would constitute *the* most significant change that in and of itself would create a model system of care for deaf people. Note: This moves the discussion forward from the traditional focus within the hearing community on the epidemiological distribution of the various DSM IV diagnoses among the deaf community, and how to get the appropriate mental health services to them – which inevitably limits this discussion to the simple addition of interpreters to the traditional mental health system
      - a) Corollary 1: Access to language, both ASL and English, is an entitlement (honor choice of ASL and/or cochlear implant). Intrinsic to that entitlement is the recognition that ASL is the only language that can be acquired naturally and without substantial effort or expense, but is not the only choice available)
      - b) Corollary 2: Language deprivation/dysfluency is entirely curable and is purely a product of social policy (Note: deafness may be a product of disease, neurological defects, etc., but such conditions need not cause language deprivation/dysfluency)
      - c) Corollary 3: Recognize language deprivation/dysfluency as a developmental disability
      - d) Corollary 4: Language deprivation/dysfluency severely exacerbates any other disabling condition or illness, and is the single most powerful contributor to the psychosocial and developmental problems that the deaf community experiences.
      - e) Corollary 5: Appropriate neonatal language screening is essential
    - 2) “Nothing about us, without us” – inclusion is not enough
    - 3) “Cultural Affirmation not Disability Accommodation” – caution: over-emphasis on the word culture can suggest that only interpretation is necessary, as this is the model used for other non-English speaking groups
    - 4) The Mental Health Services and Continuum of Care available to Hearing Consumers in any community are a legal entitlement for deaf individuals in that same community
    - 5) Honoring these principles does not just enable systems to avoid risk and litigation, but enables them to do the right thing
  - Workforce Development
    - 1) Training professionals, para-professionals, and peer-professionals to ensure that providers of mental health services are both culturally and linguistically competent to serve the needs of the deaf community. This has to include training of policy makers and administrator of mental health systems
    - 2) Aggressive Outreach to Individuals who are Culturally and Linguistically Competent to involve them in service provision and to pursue training in Mental Health Service Provision (e.g., outreach to parents of deaf children, to children of deaf parents while they are in high school)
    - 3) Loan Forgiveness (challenge and rewrite rules that ignore deafness for the training and education of deaf individuals)
  - Policy Development/Leadership
    - 1) Provide seed money to operationalize the above via Grant Dollars, to include setting requirements in the Block Grant to address such issues
    - 2) Ensure that deaf individuals serve on all groups/councils at the national and state levels, and continue to do in a sustainable fashion (and not just stay within the deaf community)
- ❖ Two Minute Drill regarding Concrete Suggestions
- Policy Development/Leadership

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<sup>16</sup> There is some concern that health/behavioral health research does not represent an opportunity for the deaf community. It would be helpful to have more clarity within the NIH regarding key areas of responsibility for issues that overlap the focus areas of the multiple institutes.

- 1) SAMHSA should establish a staff position to develop the following:
  - a) A program to support demonstration projects, focusing on Transformation of Mental Health Systems regarding the deaf and hard of hearing community.
  - b) A multi-state demonstration project to establish promising practices.
  - c) A program to offer technical assistance to the states who want to push this agenda. In particular, address states who have nothing, via a national technical assistance center, who can provide on-site assistance and service, either actually or virtually on-line or by video
  - d) National Advisory Group meeting at least once annually, staffed by NASMHPD
- 2) Role of NIMH<sup>17</sup>
  - a) Get this on the agenda at NIMH, which tends to have staff with vast knowledge, but only in very narrow areas. The agency recognizes this and is making efforts to establish linkages
    - Efforts to establish linkages represents an opportunity for the deaf community
    - Start with something NIH already knows, helping them to see connections with initiatives they have already introduced
      - Culture
      - Disparities
      - Under-served
      - Rural
      - Gaps in the literature and the research: which can raise a “score” in and of itself for a given proposal
      - Specific Topics of particular interest
        - i. Post Traumatic Stress Disorder
        - ii. Trauma
        - iii. Suicide
        - iv. Veterans
        - v. Co-Occurring Mental Illness and Physical Disorders
        - vi. HIV/AIDS
        - vii. Recovery, Resiliency, Self-Efficacy/Self-Directed Care, Person Centered Planning
      - Possible Connections?
        - i. Language deprivation as trauma and/or as a possible cause of PTSD?
        - ii. Many veterans coming back with hearing loss – but with limited needs for ASL and integration into the deaf community
        - iii. Self-directed care for deaf community; Person centered planning
  - b) Grants
    - Infrastructure
    - Training
    - NIH Research Project Grant Program
    - Center Grants (large grant composed of multiple RO1 grants – community, research, etc. - for 800K per year for 5 years), particularly if they focus on some of the topics above (e.g., Rochester)
- 3) Ensuring that the Office of Minority Health includes a focus specific to the deaf community
- 4) Look at the Public Health approach, bringing issues specific to the deaf community into the public health agenda, like Healthy People 2010, rather than rely exclusively on lawsuits and confrontation
- 5) State Model Guidelines centered around language deprivation, for dissemination through various national organizations, including the National Association for the Deaf, using web-technology
- Advocacy
  - 1) State Schools for the deaf need to be more proactive with state mental health authorities to ensure early identification and intervention
  - 2) Identify house and senate representatives to serve as an advocate

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<sup>17</sup> Relationship among NIMH, NIH and National Institute on Deafness and Other Communication Disorders (NIDCD): NIH is the parent organization and the others are separate institutes. NIH and NIDCD tend to play hot potato between the two institutes when faced with issues around mental health services for the deaf, seeing the other agency as the responsible party

- 3) Establish linkages with Traditional mental health advocacy groups. Need to reach outside internal constituencies to penetrate to other groups and establish national and regional venues to push the agenda forward, and join with the existing national and regional. Examples include -
    - a) National Council of State Directors of Deaf Services
    - b) State Directors need to be able to gain entry into other national and regional groups
    - c) Alternatives Conference
  - 4) Planning Commission to include broad representation from all constituency groups to formulate legislative action
  - 5) Raise the visibility of the deaf community and not bury them within other minority groups
  - 6) Bring diversity into the mix
- Legislation
    - 1) To prevent language deprivation
    - 2) To mandate exposure to ASL
    - 3) Redefine developmental disability in include language deprivation
    - 4) American with Disabilities Act needs to include mention of the deaf community
  - Training/Workforce Development
    - 1) Recruit more deaf clinicians by getting them into the existing programs
    - 2) Funding for training for professionals, para-professionals and peer-professionals, using on-line and video technology, to enable us to fill needed positions, targeting some of the baby-boomers nearing retirement
    - 3) Grow the pool of mental health interpreters
      - a) Grow the number who are certified,
      - b) Include deaf people themselves who are qualified to serve as interpreters in the mental health fields (CDIs)
      - c) Grow the numbers who support deaf professionals
    - 4) Specialty Topics
      - a) Peer and Family Support
      - b) Trauma and its connection to the deaf community
      - c) Standards of training for interpreters on mental health, especially regarding confidentiality
      - d) Distinctions between interpreters and language specialists to ensure role clarification
      - e) Cultural competency training with all existing professional groups
      - f) Develop state leadership academies that include addressing this as an issue
  - Access and Early Intervention
    - 1) Aggressive grass-roots outreach to parents and family to ensure early identification and intervention, to include education service centers run by individuals who are deaf and hard of hearing
    - 2) Partnership with Existing Social Service Infrastructure to ensure that the needs of the Deaf Community are incorporated in that infrastructure: e.g., Department of Education, Centers for Medicare & Medicaid Services (CMS), Parents as Teachers, Infant Toddler Program, Head Start, etc.
    - 3) Interagency collaboration with Vocational Rehabilitation, Department of Elementary and Secondary Education (DESE), and the Southeastern Mental Health Authority (SMHA) with a focus of wellness and care to facilitate transition to the world of work or college
    - 4) Support for Independent Living Centers to identify at risk groups
    - 5) Children's services
    - 6) Rural communities
  - Epidemiology and Research
    - 1) Need to define the population to establish prevalence and incidence
    - 2) Have to answer the question regarding the size of the problem to address those who hold the purse strings as to why already scarce dollars should be spent on this group
    - 3) Develop a national research database, affiliated with a research institution
  - Funding
    - 1) Expansion of waivers beyond the elderly and individuals with developmental disabilities to include individuals with the deaf community, allowing a focus based on "need", rather than have us chase what is currently funded
    - 2) Medicaid reimbursement
      - a) For psychiatric rehabilitation services provided to the deaf community
      - b) Cover part of the bill for interpreting

- 3) Multi-state approaches to make efficient usage of resources and serve the broadest available groups that are otherwise too small to justify the expense Economy of scale associated with multi-state initiatives suddenly makes it palatable to devote scarce resources to what is otherwise seen as too small a group
- 4) Video-Relay Interpreting needs to be more available in mental health settings and work across state lines
- 5) Substance abuse treatment needs to be included
  - a) Co-occurring treatment for MICA (?) deaf community, to include 12 step programs, that are inviting of the deaf community and have access to interpreters
- 6) Need residential options for the deaf community and the deaf-blind community
- Forensics
  - 1) Strategies for addressing dangerous, even criminal acts, that are an outgrowth of linguistic deprivation
  - 2) Limited inpatient resources for forensic, sexual offenders
  - 3) Outreach to deaf communities in correctional settings
- ❖ Strategic Planning
  - Hopes for the deaf community: Happy, Competent, Productive, Respected, Self-Actualized/Self-Determined, Have Goals, To be Understood
  - Possible Goals Statements
    - 1) Comparable behavioral health services for deaf and hard of hearing people
      - a) Lot of concerns with the word “comparable”
      - b) Other suggestions include “functionally equivalent”, “culturally affirmative or aligned”, “clinically attuned or relevant”, “respectful”, “better”
    - 2) Direct services in a respectful environment
    - 3) Best practices in mental health care of deaf people
    - 4) Deaf and Hard of Hearing people deserve culturally appropriate behavioral health care (more of a mission statement than a goal)
    - 5) Deaf and Hard of Hearing People want to Live Like Everyone Else
    - 6) Communication Access for Deaf People in Mental Health Settings
    - 7) Deaf and Hard of Hearing People are Living Well in the World
    - 8) Deaf and Hard of Hearing People have Choices and are Treated Like Human Beings
    - 9) Deaf and Hard of Hearing People Want to be Understood
    - 10) Deaf and Hard of Hearing People want Lives without Limitations
    - 11) Deaf and Hard of Hearing People are Heard/Seen
    - 12) Deaf and Hard of Hearing People are Living Well and Participating Fully in the World
    - 13) Deaf and Hard of Hearing People are Seen, Heard and Respected
    - 14) Deaf and Hard of Hearing People are Seen, Heard and Living Well
    - 15) Deaf and Hard of Hearing People are Recognized, Respected and Living Well in the World
    - 16) Deaf and Hard of Hearing People are Self-Determined, Respected, and Living Well
  - Provisional Goal/Mission Statement: Deaf and Hard of Hearing People are Respected, Self-Determining, and Living Well
 

Associated Values

    - 1) Happy
    - 2) Successful
    - 3) Respected
    - 4) Understood
  - Strategy Areas
    - 1) Policy Development and Leadership (Felix, Steve, Carole, Candice, and Neil)
      - a) Establish an overarching National Advisory/Steering Group, staffed by NASMHPD, that networks with other federal agencies (e.g., NIH, NIMH, NIDCD, NIDRR, Rehabilitation Services Administration (RSA), etc.)
        - That coordinates with the Deaf and Hard of Hearing Consumer Action Network (CAN)
        - That coordinates with NASMHPD to offer an annual or biennial conference with State Mental Health Authorities (SMHAs)
      - b) Key Initiatives to bring before the National Advisory/Steering Group
        - Establish a Research Agenda

- Consider the development of a national research database to promote research and networking (e.g., akin to the Interactive Autism Network)
    - Trauma and the Deaf Community
    - Establish a definition of deafness and hard of hearing
  - Modify existing CMS regulations regarding waivers to directly address language dysfluency and language deprivation
  - State Incentive Grants to establish infrastructure (including tele-health) and services, and the training that supports them, on both a state-wide basis (for community based services) or multi-state basis (for inpatient, forensic or other niche services), to include a focus on the development of promising practices and Model State Guidelines
  - Establish a legislative agenda to
    - Address language dysfluency and the effects of language deprivation, and the need for early identification and exposure to ASL
    - Examine federal legislation on disability and their impact on the deaf community (e.g., Housing and Urban Development, Individuals with Disabilities Education Act (IDEA))
- 2) Training/Workforce Development
  - a) Overarching Statement: Training/Workforce Development subcommittee/workgroup will:
    - Identify, develop and implement processes to recruit, train and retrain culturally competent (including language competencies) at the pre-professional, para-professional, clinical, and peer levels
    - Include other national organizations in this work, including but not limited to organizations such as the American Psychiatric Association, American Psychological Association, APNA, NAC/SMHA, NASW, NAPSP, WICHE, Registry of Interpreters for the Deaf (RID)
    - Strategize to identify funding mechanisms to support this work, including fellowship programs, loan forgiveness, federal support, scholarships (in part provider supported)
  - b) Deliver all workforce and training activities in the following formats, replicating Voc Rehab and/or substance abuse certification
    - Classroom instruction
    - On-line education/webinars
    - Self-Study
    - Internship (with strategies to support interpretation for interns)
- 3) Advocacy/Empowerment
  - a) Political Action
    - Identify representatives and senators to serve as legislative advocates
    - Identify state and local legislators with an interest as advocates
    - Encourage deaf people to run for office at all levels
  - b) Of, for, by and with Deaf People: “Nothing about us without us”
  - c) Deaf advocates in the criminal justice system
    - Bring deaf inmates together
    - Address isolation
  - d) Linkages with Existing Constituency/Advocacy Groups
    - Deaf representation on major national and state advisory groups/panels
    - Planning Commissions to include broad representation from all constituency groups to formulate legislative actions
  - e) Children should be taught the 3 Rs
    - Rights
    - Roles
    - Responsibilities
  - f) Raise the visibility of the deaf community and not bury them within other minority groups – deafness incorporates all other minority populations

- g) Peer support training for people in recovery
  - 4) Access and Early Intervention
    - a) Key Outcomes
      - Position Paper on the right to language access, i.e., ASL
      - Parent and professional community education (physicians, teachers and social workers, etc.) related to language right and the effects of language deprivation
      - Early identification and treatment of emerging mental health needs and social/behavioral needs
    - b) Key Initiatives
      - Research and Data Collection
        - Collate current data
        - Verify the validity and reliability of current data
        - Federal Census needs to include information on deaf and hard of hearing citizens
        - Develop valid instruments for research and data collections
        - Complete longitudinal studies of deaf people who received cochlear implants as children/infants
      - Develop assessment tools and benchmarks based on normal linguistic development
      - Form Family, Community and Professional Alliances to achieve the mission that deaf and hard of hearing people be respected, self-determining and living well
      - Outreach and Non-Traditional Service Delivery, utilizing video and leveraging technologies, e.g., web, PBS, Lending Library, etc.
  - 5) Service Continuum
    - a) To develop regional programs which provide for the delivery of services to low-incidence populations needing institutional care. Encourage SAMSHA and NASHMPD to fund and support multi-state agreements which would allow this coalition to have specialized programs serving:
      - Forensic population – not competent to stand trial (NCST)
      - Substance Abuse – inpatient treatment programs
      - Children – inpatient and residential treatment
    - b) To require that all programs receiving Federal funding/support for dual diagnosis services
      - Demonstrate services specific to Deaf and Hard of Hearing consumers in their programs; and
      - Include service provision by deaf professionals and staff and/or individuals fluent in ASL
- ❖ This Entity of which we are a part
    - Options for Names
      - 1) NASMHPD Committee on Deafness and Mental Health
      - 2) National Coalition on Mental Health and Deafness/the Deaf Community
      - 3) Roundtable ....
      - 4) Experts on Mental Health and the Deaf Community
    - Structure (Subcommittees)
      - 1) Policy Development and Leadership
      - 2) Training/Workforce Development
      - 3) Advocacy/Empowerment
      - 4) Access and Early Intervention
      - 5) Service Continuum
        - a) Forensics
        - b) Trauma
        - c) Substance Abuse
        - d) Housing
  - ❖ NASMHPD/Office of Technical Assistance/CMHS – Ideas to Support Going Forward
    - Assign dedicated Office of Technical Assistance staff person as liaison to the future deaf association
    - Support monthly conference calls and set up a “memberclicks” list serve
    - “Hold” one experts meeting slot for FY08/09

- Add Technical Assistance Deaf Experts Consultation Team to offer Technical Assistance “Technical Assistance Roster”. The future deaf association would determine “who” is best suited to provide Technical Assistance, depending on the state and the request.
  - Petition Dr. Glover to include a presentation on Deaf Issues and future activities, including available Technical Assistance, at winter Commissioner’s meeting
  - Include a specific training module on Deaf and Hard of Hearing mental health issues in NASMHPD Adult Direct Care Training Curriculum (in process), targeting adult direct care staff. OTA could provide some dollars for some of you to write the curriculum, including ASL versions of the existing modules
- ❖ Closing Thoughts from Candice
- Very impressive
  - Lot of work ahead of us

### *Summary*

In closing, the meeting provided concrete next steps, commitments from various participants to further the process and most importantly a sense of group motivation and responsibility to make a true difference in the status quo of mental health services for deaf and hard of hearing populations.

## Appendix A

### Four Areas of Hearing Loss Definitions

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.

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 appropriately referred to as *Deaf*. 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.

## Appendix B

### Selected Standards from the *National Standards for Culturally and Linguistically Appropriate Services in Health Care*

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.

## Appendix C

### Expert's Meeting Participant List

**Beth Bowers, MDiv, MSW**

Community Engagement  
Office of the Deputy Director  
National Institute of Mental Health  
6001 Executive Boulevard  
Room 7217 MSC 9634  
Bethesda, Maryland 20892  
301-443-3776  
301-443-1424 (Fax)  
bbowers@mail.nih.gov

**Tec Chapman, PhD**

Deputy Director, Division of MRDD  
Missouri Department of Mental Health  
1706 East Elm Street  
Jefferson City, MO 65102  
573-751-8667  
573-751-9207 (Fax)  
tec.chapman@dmh.mo.gov

**Amber Christensen**

Consumer  
307 Miller Road  
Mauldin, SC 29662  
864-297-5044 (Voice)  
864-297-5130 (TTY)  
ctlady172@yahoo.com

**A. Barry Critchfield, PhD**

Private Consultant  
Deafness and Behavioral Health  
601 E. Capitol Ave, Apt 101  
Jefferson City, MO 65109  
573-462-0792 (Voice)  
abcritchfield@gmail.com

**Suzanne Dennis, LMSW**

Kansas Statewide Coordinator  
Mental Health Services to Deaf  
and Hard of Hearing  
Johnson County Mental Health Center  
1125 West Spruce Street  
Olathe, KS 66061  
913-782-2100  
913-782-1186 (Fax)  
suzanne.dennis@jocogov.org

**Neil S. Glickman, PhD**

Deaf Unit Director  
Westborough State Hospital  
P.O. Box 288, Lyman Street  
Westborough, MA 01581  
508-616-2327  
508-616-2343 (Fax)  
neilglickman@rcn.com

**Denise Handon**

Special Loans Analyst  
Special Loans Group  
RBC Builder Finance  
4300 Glenwood Ave.  
Raleigh, NC 27612  
866-254-2850  
919-788-5505 (Fax)  
denise.handon@rbc.com

**Steve Hamerdinger, MA**

Director, Office of Deaf Services  
Alabama Department of Mental Health  
and Mental Retardation  
P.O. Box 301410  
Montgomery, Alabama 36117  
334-353-4701  
334-242-3024 (Fax)  
steve.hamerdinger@mh.alabama.gov

**Richard E. Mettler**  
System Consultant  
Nebraska Department  
of Health & Human Services  
5842 South 52<sup>nd</sup> Street  
Lincoln, NE 68516  
402-420-1139  
remettler@aol.com

**Sallie Mae Pauley**  
230 North New Ave  
Highland Springs, VA 23075  
804-328-0126/VP/tty  
smap19541@yahoo.com

**Dr. Roz Rosen**  
Director, National Center on Deafness  
California State University  
18111 Nordhoff Street  
818-677-2611  
818-677-4899 (Fax)  
roz.rosen@csun.edu

**Carole Schauer, MS, RN**  
Senior Consumer Affairs Specialist  
Center for Mental Health Services  
Administration  
Substance Abuse and Mental Health  
Services Administration  
1 Choke Cherry Road  
Rockville, MD 20857  
carole.schauer@samhsa.hhs.gov

**Patricia M. Sullivan, PhD – did not attend**  
Professor of Psychiatry  
Creighton University School of Medicine  
11111 Mill Valley Road  
Omaha, Nebraska 68154  
402-280-3912  
tsullivan@creighton.edu

**Candice M. Tate, PhD**  
Tate Consulting, LLC  
Purple Monarch, LLC  
201 East Simpson Street  
Lafayette, Colorado 80026  
303-709-6811  
Candice@purplemonarch.com

**Brad Trotter**  
Program Director  
Services for Deaf, Hard of Hearing  
and Deaf-Blind Consumers  
North Carolina Division of Mental Health,  
Developmental Disabilities and  
Substance Abuse Services  
3005 MSC  
Raleigh, NC 27699  
919-715-2774 (Voice)  
919-715-1233 (VP/TTY)  
919-508-0962 (Fax)  
brad.trotter@ncmail.net

**Felix T. Vincenz, PhD**  
Chief Operating Officer  
Division of Comprehensive  
Psychiatric Services  
1706 East Elm, P.O. BOX 687  
Jefferson City, MO 65102  
573-752-9482  
felix.vincenz@dmh.mo.gov

**Roger Williams, LMSW, CT**  
Director, Deaf Services  
South Carolina Department of Mental  
Health  
2414 Bull Street  
P.O. Box 485  
Columbia, SC 29202  
803-898-8301 (V-TTY)  
803-898-8347 (Fax)  
rcw53@scdmh.org

## Appendix D

### *Deaf and Hard of Hearing Behavioral Health Systems of Care Expert Meeting Agenda*

June 5 & 6, 2008

Alexandria, VA

**Day 1—Thursday, June 5, 2008—10:00 a.m.-6:00 p.m.**

- **10:00-12:00—Registration & Check-in**
- **12:00-1:00—Lunch**
- **1:00-2:00—Welcome by the Director & Preview Roundtable Proceedings**
- **2:00-3:00—Briefing: Setting the Roundtable Context**—The need for strategic planning with data presented from each state to answer why current state behavioral health systems of care are not working
- **3:00-3:15—Break**
- **3:15-4:15—Desired Outcome #1**: Lists of *strengths & weaknesses* of current behavioral health systems of care, and a list of *lessons learned*—what works and what doesn't work as revealed in the literature and past experience
- **4:15-4:30—Break**
- **4:30-5:30—Desired Outcome #2**: A shared understanding of the options available—Model behavioral health systems of care and a first pass at basic components identified
- **5:30-6:00—Wrap Up & Preview Day 2 Agenda**
- **6:00—Adjourn Day 1**

**Day 2—Friday, June 6, 2008—8:00 a.m.-5:00 p.m.**

- **8:00-8:15—Start Up: Group Reaction to Day 1 Proceedings**
- **8:15-9:15—Desired Outcome #3:** Agreement on a refined list of key components to a behavioral health system of care
- **9:15-9:30—Break**
- **9:30-10:45—Desired Outcome #4:** Agreement on state structure, organization, & funding
- **10:45-11:00—Break**
- **11:00-12:00—Desired Outcome #5:** Agreement on the roles of leadership & advocacy
- **12:00-1:00—Lunch**
- **1:00-2:30—Desired Outcome #6:** An understanding of issues surrounding interpreting, telehealth, and service access
- **2:30-2:45—Break**
- **2:45-3:45—Desired Outcome #7:** Agreement on a model macro plan for workforce development
- **3:45-4:00—Break**
- **4:00-4:45—Desired Outcome #8:** Agreement on Next Steps—How to move forward with the work of this roundtable
- **4:45-5:00—Roundtable Evaluation**
- **5:00—Adjourn Day 2**